FINAL REPORT

Name of Project	**The impact on mental health of frequent deaths that occur in high care in aged care settings, on individuals and the resident community**
Name of Participant	**Monash University** **Palliative Care Research Team** **School of Nursing and Midwifery** **Frankston, Victoria 3199**
Target population and/or geographic area the Project covered	**Mornington-Peninsula Shire, City of Greater Dandenong, City of Latrobe**

Part 1 – Project definition

Purpose of Project	*Please describe the project purpose* *How was the objective achieved? (maximum 250 words)* The original purpose of this project was to investigate the impact of frequent deaths on residents with mild dementia living in aged care facilities, with a view to developing a simple assessment tool to identify those at risk of complicated grief and an intervention. Interviews were conducted with facility staff and residents with mild dementia from three residential aged care facilities located in metropolitan, regional and rural areas. Residents were asked about their experience of the death of fellow residents and loss and its impact personally; whilst staff were interviewed about their perceptions of the impact of deaths on residents. Although depression and grief were observed in residents, it was found that deaths of other residents were not a significant contributing factor. There was little evidence that exposure to frequent death in the aged care facilities was having a significant impact on the mental health of the residents. The most interesting outcome was the mismatch between residents and staff views on the impact of deaths and the less than ideal communication and acknowledgement of those deaths by staff to the residents. This difference may be due to a higher level of death anxiety in the staff. In light of this data the communication differences were further investigated to produce a staff education program and policy recommendations for aged care providers to educate staff and inform managers of resident preferences and feelings about death communication with aged care facilities.

Estimated number of people impacted by the project (if known)	*How many people (e.g. patients, carers, staff, and other health professionals) were directly impacted by the project? How many people do you estimate will benefit indirectly from the project?* Directly impacted: • 23 RACF residents • 25 RACF staff • Managers from the three sites and members of the reference group (7) The data generated by this project has been and will continue to be widely disseminated – Abstracts and Presentations attached (Appendices 11 – 18). • Monash Ageing Research Centre (MONARC) seminar series (March 2011) attended by 30 Southern health staff consisting of nurse, medical students and other allied health professionals (Appendix 11). • Southern health Research Week – May 2011 – attended by nurses, medical students and practitioners and other allied health professionals (Appendix 13) • Australian & New Zealand Society for Geriatric Medicine's Annual Scientific Meeting – May 2011 – attended by 70 healthcare professionals (Appendix 12) • Death Down Under –Sydney University to be held in June 2011 (100 participants registered) [Appendix 14] • Asia Pacific Hospice Conference – Malaysia 2011 (Appendix 15) • Palliative Care Australia Conference August 2011 – Cairns (Appendix 16) • International Psychogeriatric Association conference – September 2011 – The Netherlands (Appendix 17) • Asia/Oceania Congress of Geriatrics and Gerontology – October 2011 – Melbourne (Appendix 18) The research has already been reported in the Australian Nursing Journal, Vol 18, 7, Feb 2011 (a journal distributed to 72,750 nurses with an estimated readership of 120,000) – [Attachment 1]; Palliative Care Research Team Newsletter (sent to approximately 550 nurses, doctors and allied health professionals) [Attachment 2]. The training package will be listed on Caresearch and available to all residential aged care facilities in Australia possible impact to the 162,300 residents currently residing in mainstream residential aged care facilities (RACFs), (Residential Aged Care in Australia 2008-09, AIHWB).

Service infrastructure	*List the resources funded by the project grant i.e. what was needed to make the project happen? (dot points)* • Salary/recruitment resources – allowed high calibre research fellows to conduct the project • Travel expenses enabled travel to diverse sites for interviews and stakeholder engagement; and to reference and working groups • Accommodation costs allowed the incorporation of a necessary rural RACF into the project • Catering – for meetings with non-paid outside participants such as the reference group • Voice recorder required to record interviews • Transcribing costs – allowed a professional touch typist skilled in transcribing to accurately and quickly transcribe interviews • Computer equipment – analysis, communication, dissemination and engagement during project • Printing costs – allowed printing of posters, postcards, pamphlets and other material • Telephone/internet etc – contact, engagement • Multimedia development funds – allowed development of training package, including filming, editing, final production and burning DVDs. • Consumable funds – postage of DVDs and general copying.

Part 2 – Project objectives and outcomes

Notes:

- The sections ***Project objectives*** and ***Key activities*** should contain information based on your grant submission.
- The following sections should contain information that explains **W*hat actually happened***, as well as ***Revised objectives*** and the ***Rationale for any changes*** if applicable.
- ***Outcomes*** and ***Performance indicators*** should describe the actual outcomes (qualitative and quantitative) that the project achieved and how these were measured.

Where applicable, attach any tools, resources and other material produced for this Project, in support of this Report.

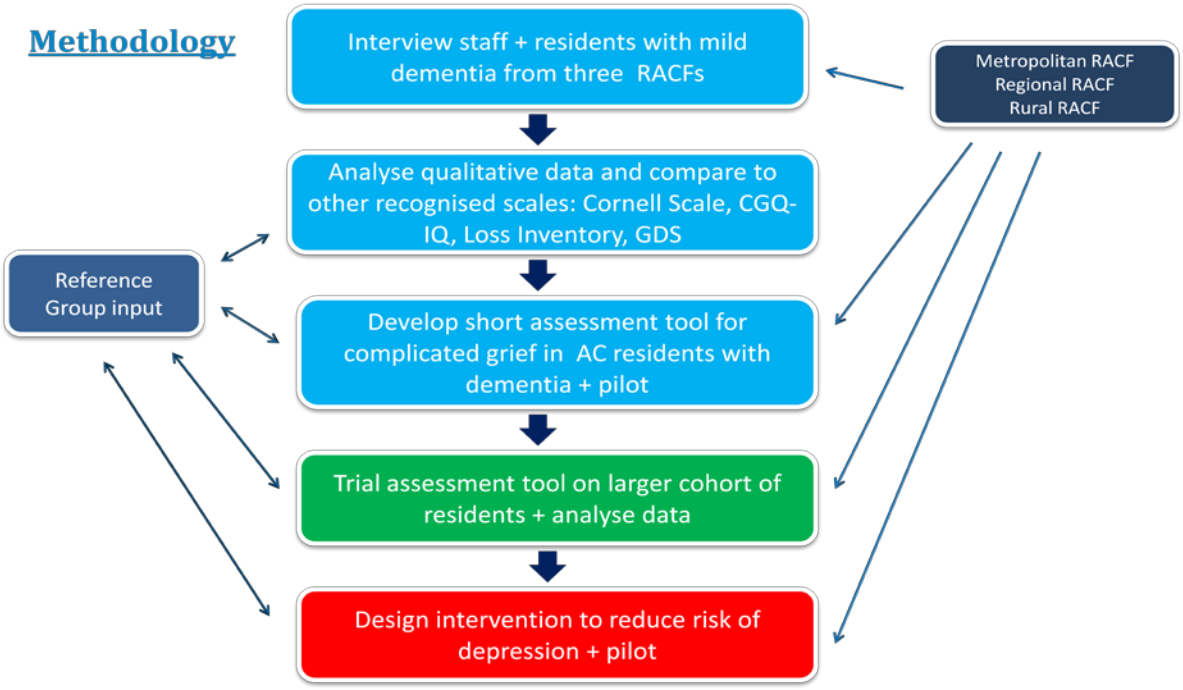
Project objectives:

Original project objectives:

Deaths occur more frequently in residential aged care facilities than in the general community, while the effects on staff are well documented little is known about the mental health/social impacts on the residents.

This project was designed to:

1. Investigate the impact of frequent deaths on individuals and the resident community of aged care residential facilities;
2. Develop a simple assessment tool to identify those at risk of complicated grief in residential aged care facilities;
3. Evaluate this tool on a larger cohort of aged care residents;
4. Formulate an intervention designed to assist those identified as being at risk with the aim of reducing likelihood of progress to depression.

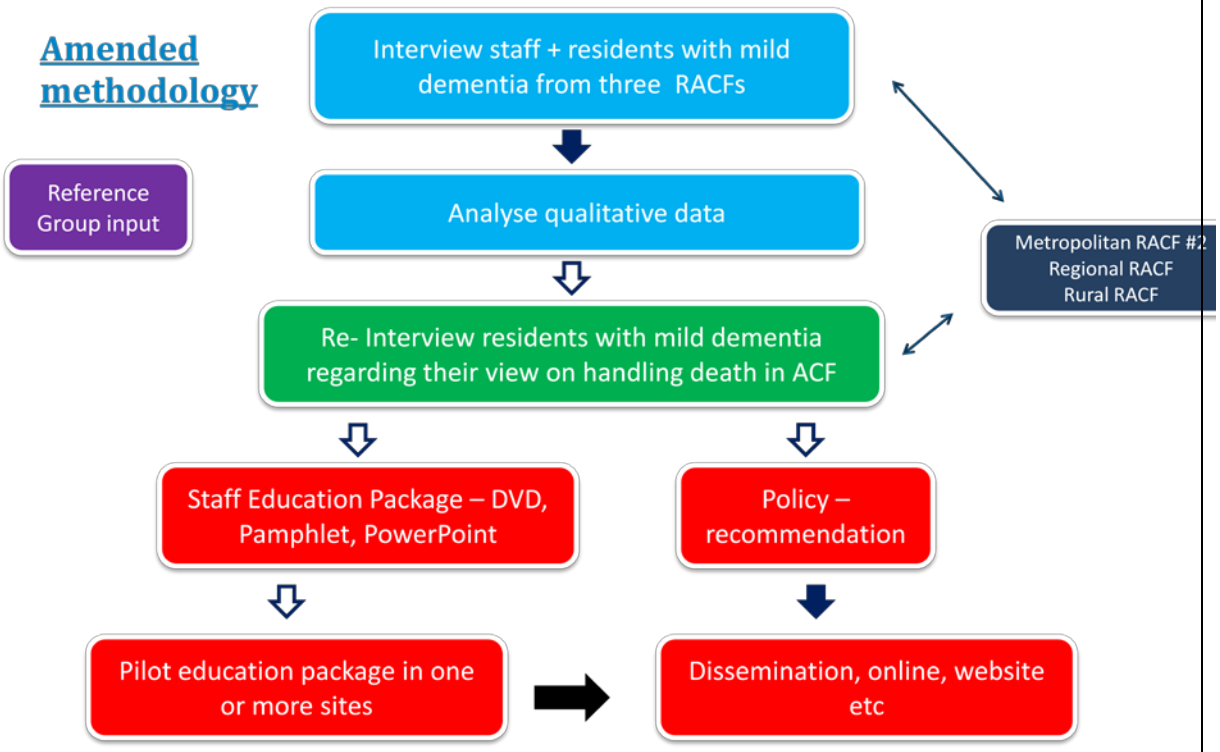


Revised objectives (if applicable):

Revised Project Objectives

Our revised objectives were:

1. To investigate the impact of frequent deaths on individuals and the resident community of aged care residential facilities; Project objectives deviated due to results of this phase of the investigation;
2. Reinterview selected residents with a set of questions that targets the issue around the appropriate communication with residents after the death of another resident, and what they the residents want in regards to that communication;
3. Develop a staff training package (Standalone DVD & pamphlet, and PowerPoint presentation for interactive training) and policy recommendations for management that represent the residents' views on death communication and not our or the facility staff's perceived views;
4. Small pilot of the training package to staff at a participating aged care facility;



What actually happened:

Residents with psycho-geriatric assessment scale scores (PAS) of between 4-9, and facility staff, were recruited from three residential aged care facilities. Interviews were conducted with 23 residents about their experience of (see Appendix 1) the deaths of fellow residents. Twenty five staff were interviewed about their perceptions of the impact of deaths on the residents within the facility and personally (see Appendix 2). Interview responses were thematically analysed using NVivo8 software.

Although depression and grief were observed in the residents there was little evidence that deaths of other residents were having a high impact. The most interesting and unexpected outcome was the mismatch between resident and staff views on the impact of deaths and the less than ideal communication and acknowledgement of those deaths to residents. This outcome may be due to a higher level of death anxiety in the staff compared to the residents.

Originally the development of an assessment tool was considered, however the data collected did not support the continuation of this project pathway. A deviation to the project aims was

discussed with the investigators and reference group, in light of the data, and the need to produce a tangible outcome, within the available timeframe, and in keeping with the original proposal. It was decided to develop a training package to raise staff awareness around dealing with and communicating about death in aged care facilities, as well as developing policy recommendations for RACF management.

Some of the residents who had previously participated in interviews were approached for a second interview designed to obtain more detail about the residents' views on selected points of interest arising from the first round of interviews (see Appendix 3). Those residents involved in first round of interviews who were considered most likely to be able to add more information were approached to participate in round 2. Of the 14 approached 11 agreed to take part again.

Residents generally indicated that they wanted to be told about the death of another resident, preferable personally when it was someone they know. Although the grapevine in the RACF is particularly active when another resident dies, this doesn't seem to be too much of a concern when it was someone they did not know. Dining room announcements were generally supported by the residents. The residents are definitely less concerned about seeing a body removed than the staff think they are, with most indicating they had seen a lot worse and didn't believe that the secrecy was important. It was felt that it would be better to give residents the option of having their door closed or going to their room, but that there was no need to go to extreme measures to avoid someone seeing it. The option of attending a funeral or of having a special afternoon tea were favoured as ways of remembering and celebrating the life on one who had died, although most were open to other possibilities if that is what someone wanted.

The key outcomes of the two rounds of interviews have been incorporated into a training package consisting of four short modules.

- Impact on residents of the death of another resident
- How to tell residents of a death within the home
- Removal of the body
- Remembering/celebrating

The training package has been produced as a standalone DVD as well as being available as a semi-interactive program for placement on in-house websites, Caresearch and the university website. The package will also be accompanied by policy recommendations for RACF management.

A small pilot trial of the above training package has been undertaken at one of the participating RACFs. This was run in two parts (2 modules at each session) as part of the regular in-house staff training program. A short, paired pre and post questionnaire (see Appendices) were utilised to evaluate staff response to the training package. Participant numbers are small (5 in each session, three of whom participated in both sessions). Participant numbers were too low to allow meaningful statistical analysis of data but the following general outcomes were indicted:

- 4/5 changed their views about the impact of a death on other residents understanding that they may not be as strongly affected as they had thought;
- 4/5 became more willing to tell residents about a death and indicated they would be more comfortable doing so;
- 4/5 had a greater understanding that those with dementia may need also to be told (one participant acknowledged that strong personal cultural views would prevent them from changing their ideas about this matter.)
- No change was observed in attitudes to how body is removed with one exception participants preferred to be cautious and maintain the habit of discreet removal.
- Generally it was agreed that it was important to celebrate the life of a resident with some increased awareness that this may also be important to residents.
- Generally the DVD was considered informative but most remained unsure about its impact on their future work practice.
- It was thought that guidelines would be helpful but would need to remain fairly general to accommodate the big range of resident needs and capabilities.

- It was fairly evident that the idea that staff members own ideas and fears may be impacting on the decisions made about what residents want and need was a new idea and one that would take some further thought and consideration.

It will be important for further trials of this package to be undertaken. Although each module is about 15 minutes in length and can be undertaken by an individual in their own time it is likely that group sessions with plenty of time for discussion will result in the best outcomes.

Rationale for change (if applicable):

The original objectives were revised as indicated below

- Interview data did not show that residents with mild dementia were experiencing significant mental health impacts due to the *actual* death of other residents. Past losses and loss associated with the transition to aged care were more evident from the interview data. However the data showed a significant mismatch between the staff and residents in relation to the lack of and often inconsistent communication around the death of other residents that *was* having an impact on the residents.

- Issues around who and how to tell residents about deaths, removing bodies, and celebrating the life of those who have died were raised as important issues by many of the residents, highlighting their significance. Staff interview data identified that many staff were uncomfortable communicating to residents about death generally and deaths occurring within the facility. In addition no consistent policy of informing residents of deaths was evident in any of the participating facilities.

- Although we did not find what we were expecting, the death of residents in aged care facilities is having a different but very important impact on residents' wellbeing and sense of self. Many residents said that they were often unaware of the deaths of other residents or were only told when they asked or had a close connection; with most hearing of other resident deaths on the grapevine which was not always reliable. Some residents said that others had disappeared (most likely to hospital) and replaced by new residents. There were also some issues around the removal of the body with residents reporting that the staff tried to cover up removal– "we know they do it on the quiet".

- Staff too were obviously having issues with communication around death, with many avoiding telling residents about deaths that had occurred in the facility, this may be due to more death anxiety in facility staff, than residents.

- In keeping with the overall aims of the project and in following our findings to a logical conclusion, two main outcomes of the data were considered for further investigation by the project reference group:

  1. Further Investigation of other grief issues impacting on residents with mild dementia, such as past losses and the impact of transition to aged care.
  2. Development of a staff education package to raise staff self awareness around dealing with and communicating about death in aged care facilities; and the development of policy recommendations for RACF management.

- A significant amount of research has already been done around other grief issues and transition to aged care; although much of it has been done internationally it was thought that this area was too broad for the remaining 6 months of the project. Due to this, and the poor likelihood of producing a tangible outcome in the short term, it was decided not to investigate this area further at this time.

- The decision to pursue the development of a training module and policy recommendations was supported by members of the reference committee and considered likely to produce a

tangible outcome. The direction of this project supports recent trends in incorporating the views of the aged (particularly those with mild dementia) in the development and ongoing improvement of the aged care sector.

- The objectives and project methodology was amended to reflect the changes (as per page 6). Selected residents were re-interviewed to discuss their needs in relation to communication; topics not fully covered in the original interview process. The results from these re-interviews were combined with the original staff and resident interviews to provide foundational evidence for a staff training package to emphasise the "resident death communication" needs of those residents with mild dementia as well as those residents with no cognitive impairment.

- The training package has been produced as a standalone DVD as well as being available as a semi-interactive program for placement on in-house websites , Caresearch and the university website. The package will also be accompanied by policy recommendations aimed at aged care facility management and funding bodies.

.

Key activities:

1. Ethical approvals received/Amendments

- Ethics submission to Peninsula Health (PH), submitted 13/5/10, with final approval by the committee on the 19th June 2010. Southern Health Ethics (SH), submitted 17/5/10 with final approval given on 13th July 2010.

- Ethics amendment (1) to PH and SH ethics committees in direct response to the Mini-mental State Examination (MMSE) no longer being used to test cognitive ability, having been replaced by the Psychogeriatric Assessment Score (PAS) being used to test. A new resident selection process was developed to properly recruit consenting residents to the study. Amendment submitted to PH & SH on 20/7/10 and approved by SH on 30/7/10 and PH on 1/9/10. Resident recruitment could not proceed until ethics approval was received, staff recruitment and interview were able o proceed with above approvals.

- Ethics amendment 2 – SH site change to a lower care RACF required due to one site, Chestnut Gardens not having any residents able to consent to be interviewed. Submitted 30/09/10 and approved 11/10/10.

- Ethics amendment 3 – amendment to re-interview residents following the change in direction/objectives of the project was submitted to SH on 21/12/2010 and approved on 11/1/2011, submitted to PH on 22/12/2010 and approved on 2/3/2011.

- Ethics amendment 4 – amendment to Southern Health 20th July 2011 to present pre-training and post-training questionnaires and the explanatory statement and consent form. Approved August 2011.

- Documents submitted and used in the project see Appendices 1 through 10 and 19 - 21.

2. Convene project working and reference group

- A project working group of consisting of the chief investigators and co-investigators was convened on 1/6/2010 and has met 7 times in the period of the project.

- Project reference group was convened on the 16th of August 2010. The reference group consists of representatives from all three clinical partners, Baptcare, Peninsula Health and Southern Health. Other participants represent a cross section of parties selected on their expertise and relevance to the project. This group has met 4 times during the life of the project.

3. Recruit residents from each facility

- Initial site visits were made to the Peninsula Health (PH) site, Rosebud Residential Aged Care Service (RACS) and the SH site Chestnut Gardens in June of 2010. These meetings uncovered the change in cognitive assessment tool from MMSE to PAS that required a change in resident selection criteria and an ethics amendment before proceeding. After ethics approvals were received staff recruitment proceeded at SH on 13/7/10, Baptcare (St Hilary's Nursing Home) on 23/8/10 and PH on 19/7/10. A postcard and poster was printed to assist in recruitment (see Attachments 3 & 4).

4. Interviews – staff & residents

- Staff interviews (25) started on 28/7/10, and continued until late September according to the date of the ethics agreements.
- Resident interviews (23) occurred after staff interviews and after approval of the second amendment.
- There were no residents identified at Chestnut Gardens that fitted the resident selection criteria – resulting in a site change for SH to a lower care facility AG Eastwood Hostel.

5. Analysis of data using NVivo software

- Staff and resident interviews were transcribed, and analysis was assisted with the use of NVivo software package. The volume and quality of the data collected from staff and residents surpassed the investigators expectations. The data generated led to a revised protocol and revised outcome.

6. Re-Interview of Residents

- Following ethics approval (amendment 3) selected residents who had originally participated in the project were reinterviewed to discuss their needs in relation to communication around the death of another resident

7. **Analysis of Resident Re-interview data**

- Resident interviews (11) were transcribed and analysed as above.

8. **Development of Training package**

- Data collected from all interviews were combined to provide foundational evidence for the staff training package.
- Pertinent quotes from both staff and residents were coded to maintain anonymity and then combined to create a number of staff and resident dialogues that represented the main themes of the interview data. Characters were written for each of these dialogues/amalgams of views to be performed by actors in short vignettes designed to be used in the training package.
- The training package has been piloted at one site.
- This package includes recommendations for discussion and development by RACF in relation to:
    - When and how to tell residents about the death of another resident;
    - Processes for removing the body of deceased resident;
    - Celebrating the life of a deceased resident.

Identified outcomes:

- The interview data did not show that residents with mild dementia were experiencing significant mental health impacts due to the *actual* death of other residents.
- Past losses and loss associated with the transition to aged care were more prominent issues impacting the mental health of residents in RACFs.
- A significant mismatch between the staff and residents in relation to the lack of and often inconsistent communication around the death of other residents that *was* having an impact on the residents.
- Issues around telling residents about deaths, removing bodies, and celebrating the life of those who have died were raised as important issues by many of the residents, highlighting their significance.
- Staff interview data identified that many staff were uncomfortable communicating to residents about death generally and deaths occurring within the facility.
- No consistent policy of informing residents of deaths was evident in any of the participating facilities.
- Although we did not find what we were expecting, the death of residents in aged care facilities is having a different but very important impact on residents' wellbeing and sense of self.
- Many residents said that they were often unaware of the deaths of other residents or were only told when they asked or had a close connection; with most hearing of other resident deaths on the grapevine which was not always reliable. Some residents said that others had disappeared (most likely to hospital) and replaced by new residents.
- There were also some issues around the removal of the body with residents reporting that the staff tried to cover up removal instead of being honest – "we know they do it on the quiet".
- Staff too were obviously having issues with communication around death, with many avoiding telling residents about deaths that had occurred in the facility. A significant amount of death anxiety was observed in facility staff, in contrast to residents who did not have the same level of anxiety.
- High levels of social isolation was observed among residents
- Residents would like to be told personally about the death of another resident, especially when it was someone they were close to, but most considered that an announcement in the dining room for example was alright in cases when they did not know the person.
- Most residents said they were not particularly bothered by the public removal of a deceased person's body, with the practise of shutting doors and hiding the removal seen as childish. Overall being told what was happening and given the choice of shutting their door was preferred by most residents interviewed.
- When asked how they would like to remember or celebrate the life of a deceased resident some expressed a desire to go to the funeral of friends although acknowledged it would be difficult to achieve; most felt an afternoon tea was a good

low key way to remember or celebrate the life; memorial services (although favoured by staff at a couple of sites) were not particularly well favoured by residents, nor where memorial corners (or anything written).

- Training package has been produced and a small pilot trial conducted. This package includes recommendations for consideration within RACFs.

Performance indicators:

- A high level of staff and resident engagement in the project indicates the desire of these groups to participate in discussions around the impact of death in RACFs.
- Lots of interest has been shown in the results as indicated by the high number of conference/seminar attendances and/or abstract approvals
  - Monash Ageing Research Centre (MONARC) seminar series (March 2011) attended by 30 Southern health staff (nurses, medical students and other allied health professionals).
  - Southern health Research Week – May 2011 – attended by nurses, medical students and practitioners and other allied health professionals
  - Australian & New Zealand Society for Geriatric Medicine's Annual Scientific Meeting – May 2011 – attended by 70 healthcare professionals
  - Death Down Under –Sydney University to be held in June 2011 (100 participants registered)
  - Asia Pacific Hospice Conference – Malaysia 2011
  - Palliative Care Australia Conference August 2011 - Cairns
  - International Psychogeriatric Association conference – September 2011 – The Netherlands
  - Asia/Oceania Congress of Geriatrics and Gerontology – October 2011 – Melbourne
- A training package has been produced and a small paired pre and post evaluation completed.
- It is hoped to include the training package in at least one service based online training website. In progress.
- The policy recommendations document will be made available to RACF staff and managers.
- Final bound report will be published by Palliative Care Research Team will be lodged with Monash University with an ISBN for wider accessibility.

Part 3 – Evaluation

While there is no provision for an overarching national evaluation of this project, it would be most helpful if you could provide information about the following aspects of your project to aid planning for future funding directions.

Project title ‘	
Keywords	Residential Aged Care Facility (RACF) Psychogeriatric Assessment Scale (PAS) Mini-mental State Examination (MMSE) Clinical Dementia Rating (CDR) Aged Care Funding Instrument (ACFI)
Project organisation	Palliative Care Research Team, School of Nursing and Midwifery, Peninsula Campus, Monash University, Frankston, VIC 3199
Partner organisations	Rosebud Residential Aged Care Services, Peninsula Health (PH), Rosebud, VIC 3939 Chestnut Gardens Nursing Home, Southern Health (SH), Doveton VIC 3177* A.G. Eastwood Hostel, Southern Health (SH), Cheltenham VIC 3192 St Hilary’s Nursing Home, Baptcare, Morwell, VIC 3840 *replaced with AG Eastwood as no residents were considered able to consent using the criteria employed by this study
Project funding	• Project funding does not allow for major changes in direction of the project as they occur that may be beyond the funding for the project as it was originally proposed
Project timeframe	• Need more time to develop and write the grant application. Writing proposals in haste can lead to mistakes that impact both time and cost. In this case it lead to us not knowing that PAS had replaced MMSE as the cognitive impairment tool – ultimately leading to the need for a new resident selection process and an ethics amendment – has we more time to prepare site visits could have been completed and the correct tool would have been identified. • Project was too ambitious within the timeline allowed, before and after the deviation – there is a tendency for researchers to plan grants without allowing time for project development of changes in direction in the hope of obtaining a grant, hence they can be too ambitious for the timeframes allotted • The 4 month wait to commence the project (due to contract issues) negatively impacted the project reducing the timeframe for the project by a couple of months and requiring a deviation to the project. In this project this delayed the hiring of a project manager who started 6 weeks into the project, and also delayed the ethics (although ethics applications were started before official start date). • Major changes in direction of the project can lead to new

	objectives or outcomes that are unable to be completed in time – in this project the change to the project objectives led to the development of a training package that could not be trialled further and refined
Were there any issues in designing the methodology?	• PAS had replaced MMSE as the RACFI preferred tool for the assessment of cognitive impairment. This lead to the development of a new pathway and ultimately the use of 3 tests in the selection pathway instead on one. It also impacted the timeframe due to the development of the pathway and waiting for the ethics approval. • Chestnut Gardens was originally chosen as the SH site of choice however after staff interviews had been conducted it was found that there were not enough residents with the ability to consent. This lead to the inclusion of a replacement site, another amendment and ultimately lost time. More time in the application stage may have avoided this issue. • The availability of more advance planning time would have facilitated the development of a more refined and detailed process plan thus saving time at later stages of the project.
Were there any issues with governance in the course of the project?	• Reference group participation overall was good however there were a few participants who never attended meetings or commented on the project. • One ethics committee was a particular problem taking each minor amendment back to a full committee meeting – this resulted in delays of between 4 – 6 weeks. • Two deviations to the original proposal were completed. One due to revise report and finish times due to the delayed start; the second to amend the objectives and outcome due to unexpected results. Delays between university lawyers and the department occurred.
Comments on what worked	• The working and reference groups for this project were strong, helping the project progress and develop, responding to unexpected results and helping to deliver a tangible outcome from this project for the aged care sector. • The partnerships developed within the three healthcare services (PH, SH and Baptcare) were significant enablers for this project, facilitating access to the sites and in one case promptly finding another site within its service. This project has further cemented our relationship with PH and SH, and developed a whole new partnership with Baptcare that has already lead to collaboration on another project. • The relationship developed by the project officer with the individual sites was a most important facilitator. The project officer spent many days at each site getting to know the staff and residents ultimately leading to a high level of staff and resident engagement in the project. • Partnership with DoHA was a facilitator – Bev Hamming was an excellent project administrator, providing timely and clear advice.

How was the project evaluated?	• High numbers of people have engaged with the project already with the project results being widely disseminated in an industry journal (Australian Nursing Journal) and newsletter (Palliative Care Research Team – Monash University). • Research has been presented at one international conference, one research centre seminar series (MONARC) and one health service research week (SH). • Research is to be presented to two further domestic conferences and three international conferences • Education will be evaluated by a pre and post training survey • Numbers of staff and residents engaging in the interviews was high for this type of research helping to enable more rigorous research • At least 3 peer reviewed publications are planned for this research
Was the project completed on time and within budget?	• Yes
Were there any factors which impacted the cost of the project and its purpose?	• Inhibiting factors were mainly time factors • Cost and time factors determined the direction this project took when the project objectives required revision. Given more time and more funds the training package could have been trailed at a number of sites.
Were there things which, in hindsight, you would have done differently?	• Spent more time in the planning stage if submission time allowed • More consultation with partner sites during proposal and prior to contract being signed to refine project objectives and process.
Were there any unexpected issues or unintended consequences identified in the course of implementing this project? List the positive and negative issues.	**<u>Positive</u>** • Data collected was not anticipated leading to major change in the direction of the project and ultimately the outcomes • Uncovered a mismatch between staff and resident views that impacts the residents sense of self and discourages open communication about death • Identified a number of other issues impacting the residents in RACFs including: social isolation and losses associated with loss of home and transition to aged care. • Staff training package to help “death communication” a more valuable and tangible outcome than the development of a tool for complicated grief • Enhanced/cemented partnerships with SH and PH, and developed strong partnership with Baptcare

	Negative • A few residents had PAS scores that we out of date, and despite being ranked as "mild dementia" on the clinical dementia rating when tested by the MMSE were definitely more cognitively impaired than we had thought.
If the project involved contact with people with dementia or mental illness and their carers/family/friends, was there positive/negative feedback?	• Of thirty residents approached to be interviewed the first time only 6 declined, and one was not interviewed by request of the family. • Of 24 family members informed of their family members consent only one family member declined their support. • Of 14 residents asked to participate in the re-interview process three declined. • These results indicate a willingness of people with mild dementia to talk about death and engage in research – people in aged care want to be heard but need a forum to do so.
Was there any feedback from other groups of people impacted by the project?	• There were high levels of staff engagement, more than we required – unusually high for this type of research – indicating a willingness of staff to talk about these issues • On the whole staff members were highly engaged and passionate about their work and happy to honestly answer questions. • Feedback obtained during the presentation of the results so far has been excellent. • Unexpected number of accepted abstract approvals

Part 4 – Future directions

Please use the following sections to describe:

- the extent to which the project or the outcomes achieved by the project will be sustainable beyond the timeframe for the project funding received under the Local Palliative Care Grant Program Round, including comments on contributing factors or barriers to sustainability
- issues that impacted on the achievement of the intended objectives of the project, overall Program design, and suggestions for improvement to the Program in the future
- any additional comments you would like to make.

Sustainability
• Training package will be made available on Caresearch, on the Monash website and will be available via DVD. • It is hoped that some health services will adapt the training program for their online intranet training programs • Would like to see it incorporated in some way into the Certificate III in aged care.

- Training package uptake will rely on management engagement

Issues and suggested improvements related to Program design

- Longer lead time for application – 2-3 months
- Incorporation of extra time into proposals for ethics and amendments without penalty to the project objectives
- Need for sub-funding rounds to expand on project, especially in relation to those projects with broader applications where value can be added to the original project and result in a higher level of sustainability.
- The Round 5 workshop run in Sydney in April 2011 was a fantastic opportunity to collaborate with other research groups and share our results. It was well run and extremely dynamic. A workshop held early in the round to share ideas and discuss common issues would have been very beneficial and would enable collaboration with other groups and reduce the duplication of effort in some areas.

Additional comments

- The reporting templates are easy to understand and complete

Appendix	Document Description	Page No.
1	Resident Interview Guide (ethics approved – original application)	18
2	Staff Interview Guide (ethics approved – original application)	19
3	Resident Re-interview Guide (ethics approved amendment 3)	20
4	Explanatory Statement & Consent Form – staff interview (ethics approved – original application)	21
5	Letter of invitation to residents (ethics approved – original application)	24
6	Explanatory Statement & Consent Form– resident (ethics approved – original application)	25
7	Letter to Family – resident interview (ethics approved – original application)	28
8	Resident Interview Selection Process (ethics approved- amendment1)	29
9	Explanatory Statement & Consent Form – Resident Re-interview (ethics approved amendment 3)	30
10	Letter to Family – Resident Re-interview (ethics approved amendment 3)	33
11	MONARC Seminar Series Presentation	34
12	ANZGSM Presentation	37
13	Southern Health Research Week Poster	41
14	Abstract – Death Down Under Conference	42
15	Abstract – Asia Pacific Hospice Conference	43
16	Abstract – Palliative Care Australia Conference	44
17	Abstract - International Psycho geriatric Association Conference	45
18	Abstract – Asia/Oceania Congress of geriatrics and Gerontology Conference	46
19	Pre-Training Questionnaire	47
20	Post-training questionnaire	48
21	Explanatory Statement and Consent Form – Staff Training Pilot (ethics approved)	50
22	Death Down Under Presentation	53
23	Asia Pacific Hospice Presentation	56

Report Attachments

1	Australian Nursing Journal PDF
2	Staff Interview Recruitment poster PDF
3	Staff Interview Recruitment postcard PDF