



# Integrating specialist palliative care into residential care for older

# people: a stepped wedge randomised control trial (INSPIRED trial)

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# **Executive summary**

#### Background

Residential facilities for older persons (hereafter "facilities") are increasingly involved in supporting older people at end of life; consequently, the provision of palliative care is required to improve outcomes for residents.

The national palliative care strategy sets a vision which aims to (i) improve awareness and understanding, (ii) be appropriate and effective, (iii) has high quality leadership and governance and (iv) builds capacity and capability. The national palliative care standards re-assert the need for palliative care to be available to all people living with progressive or advanced disease.

In 2014-2015, we developed and tested a new approach to integrating specialist palliative care into residential care to meet the objectives of the national strategy and improve the delivery of high quality appropriate care to older Australians. The study was funded by ACT Health.

### Intervention

The new model of care involved monthly triage meetings called 'Palliative Care Needs Rounds' (hereafter 'Needs Rounds'). These hour-long meetings focus on discussing residents who are at risk of dying and who may not have an adequate plan in place. The intervention was delivered by specialist palliative care staff (two nurse practitioners and a clinical nurse consultant). The model is provided on the basis of risk stratification and specialist need.

### Subjects and methods

A stepped wedge randomised control trial was adopted, with 1700 people from 12 facilities across the Australian Capital Territory (ACT). A qualitative process evaluation of interviews with facility staff was conducted with 21 interviewees.

### **Main findings**

The new model of care:

- Reduced length of stay in hospital (p=0.048), and substantially reduced the overall number of hospital admissions. A conservative estimate of annual net cost saving from reducing admissions is: \$1,759,011.
- If the costs are scaled across the length of the trial (17 months of intervention), then the cost saving is estimated at \$2.5m.
- Staff at most facilities had learnt more about the risks and burdens of hospitalisations and felt that they were more able to support residents in the facility preventing unnecessary admissions. Needs Rounds had led to better anticipatory care planning, for example, accessing appropriate medicines for end of life care, and understanding disease trajectory.
- Improved residents' ability to die in their preferred place (p=0.016).

- Improved care staff understanding of death and dying, and staff confidence. As the trial progressed, there was an incremental improvement in staff outcomes (p<0.001).
- Staff felt more confident in providing nursing and psychosocial care to residents and
  relatives. Staff changed their care practices as a consequence of the Needs Rounds, notably
  in improved pain management. Needs Rounds also precipitated changes in information
  sharing between staff; those who did not attend Needs Rounds were updated through
  email, verbal handovers, and electronic resident notes.
- Improved quality of death and dying (p=0.019) in facilities that complied to the intervention protocol. Staff reported a shift in people's quality of life and death being improved by the new model of care.

Fidelity to the model was variable. Five sites were deemed to have high fidelity, five moderate and two low. One of the low adherence sites withdrew from the study. Barriers to implementation were pragmatic, for example flexibly planning Needs Rounds to fit with facility workloads and reducing the number of residents discussed in Needs Rounds.

#### Recommendations

- 1. The Needs Rounds model of care should be implemented without delay.
- Flexibility regarding the frequency of Needs Rounds and numbers of residents discussed in Needs Rounds may increase buy-in from sites. Such measures would reduce perceived pressure on facilities with fewer residents, or lower turn-over of residents.
- Engagement from facilities is needed to effectively implement the model of care, including level of buy in from management and staff and willingness to change.

- 4. Feedback from residents and relatives would helpfully bolster the evidence base on the impact of the model of care.
- 5. Developing positive working relationships with GPs will facilitate better uptake of the actions emanating from the Needs Rounds. GPs often inform whether hospital transfers occur, and their attitudes affect their engagement to provide palliative care and comfort with anticipatory prescribing.
- 6. This model of care could also be adapted to use teleconferencing to allow uptake in remote and rural settings without easy access to face-to-face specialist palliative care.

# **1** Introduction

Australia's national palliative care strategy seeks to drive the delivery of high quality care to support people at the end of life (Commonwealth of Australia 2010). The four primary goals of the strategy are:

- *i.* To significantly improve the appreciation of dying and death as a normal part of the life continuum.
- *ii.* To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services.
- iii. To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.
- *iv.* To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

The review of the strategy identified a number of areas pertinent to providing support to older Australians living in residential care. Specifically, consistency of access and quality, and addressing the needs of an ageing population.

Residential facilities for older persons (hereafter "residential facilities") are increasingly involved in supporting older people at end of life; consequently, adopting a palliative approach is required (Miller 2015, Teno 2003), and indeed is considered a basic human right (Ahmedzai *et al.*). In Australia, improving the quality of life for residents approaching end of life has focused on staff providing primary palliative care. The Government funded Palliative Approach Toolkit, rolled out in October 2013, provides resource materials designed specifically for the residential facility setting to support staff in a number of key end-of-life processes including advance care planning, and palliative care case conferencing (Parker & Hughes 2010).

Despite this appropriate focus on supporting a palliative approach to care, some residents will require specialist support (Quill & Abernathy 2013). How to access such support is complicated by a lack of clear data on the appropriateness of different models of specialist palliative care provision. A recent rapid review found that specialist palliative care models broadly lacked uniformity (Luckett *et al.* 2014). Although models varied, frequently cited elements included case management, shared care, specialist outreach services, managed clinical networks, integrated care and volunteers. Luckett's review suggests that models integrating specialist palliative care into primary and community care should be needs-led, with a particular focus on transitions across care settings, and adopting dynamic approaches flexible to the changing needs of patients.

However, there is an absence of clear and tested models of how to provide efficient quality specialist palliative care services to residential facilities and significant variation in practice exists both within Australia and internationally (Kaasalainen *et al.* 2013, Luckett *et al.* 2014).

The elements and outcomes of specialist palliative care integration into residential facilities remain unknown. The importance of staff education in improving palliative care in residential facilities suggests its utility as a component of any proposed model (Miller 2015). Increasing death literacy is an important component, in supporting staff, relatives and residents to engage in conversations about death and dying in order to develop informed plans for end of life care (Noonan *et al.* 2016). This is underpinned by a public health approach to palliative care (Kellehear 1999, Kellehear & Sallnow 2012), whereby there is provision of education and information for death/dying to 'promote optimal health even in the presence of incurable disease' (Rosenberg & Yates 2010 p206).

A recent systematic review identified a range of positive impacts from specialist palliative care involvement in residential facilities including an increased incidence of advance care planning,

decreasing hospital admissions and improved symptom management (Cimino & McPherson 2014). Specialist palliative care services are also demonstrated to increase in-facility deaths for residential facility residents (Rosenwax 2006). Although models involving a nurse practitioner providing palliative care consultation support within residential care have reported sustained benefits (Finucane *et al.* 2013), in practice the professional mix of clinicians varies.

#### 1.1 Pilot work

Developing models of care that provide effective and sustainable access to specialist palliative care for residents whose needs require them is therefore a matter of urgent clinical need. In 2014-2015, we developed and tested a new approach to integrating specialist palliative care into residential care. The approach led to decreased length of hospitalizations and increases in residents dying in their preferred place (Chapman *et al.* 2016 early online). The approach was found to also assist staff in normalizing death and dying, while providing essential anticipatory prescribing and better decision-making leading to planned care for residents (Johnston *et al.* 2016 early online). However, this study focused only on four facilities, and applied a quasi-experimental design with decedents from the previous year acting as the control group. The current study seeks to expand the provision of the model and produce an evidence base for its impact.

# 2 Aim

This study sought to establish evidence for the effectiveness of the model of integrating specialist palliative care into residential facilities, using a prospective stepped wedge design.

# **Research questions:**

- 1. Does integrating specialist palliative care into residential care reduce hospital length of stay?
- Does integrating specialist palliative care into residential care increase residents dying in their documented preferred place of death?
- 3. What is the impact of integrating specialist palliative care in residential care have on residents' quality of dying?
- 4. What impact does the integration of specialist palliative care in residential care have on staff death literacy?
- 5. What impact does the integration of specialist palliative care in residential care have on complaints?
- 6. What impact does the integration of specialist palliative care in residential care have on relatives' self-reported distress?

# 2.1 Context and setting

The intervention was delivered in the Australian Capital Territory (ACT). Specialist palliative care staff included two nurse practitioners and a clinical nurse consultant. These clinicians received supervision from a palliative care medical specialist, who was not directly involved in the trial. Two team members were employed by local government health funding, one was employed through the trial's funding. All staff were based in the specialist palliative care unit. At commencement of the study, facilities in the territory ranged in size, from 20-120 residents (mean: 94) with a total of 2,247 beds. Based on 2015 data, the number of deaths of residents referred to specialist palliative care anticipated per 12 months was 205 and number of admissions to specialist palliative care per 12 months was 277.

#### 2.2 Theoretical framework

The model is provided on the basis of risk stratification and specialist need. Following service organisation and delivery models in other disciplines, we adopted a case-finding (Lewis et al. 2011) stepped-care model (Richards et al. 2012). Residents with more complex needs receive higher levels of specialist input. Complex needs in this context are defined as residents with a high degree of uncontrolled symptoms, risk of unmanaged symptoms, risk of unnecessary hospital admissions in the last six months of life due to a lack of planning conversations about goals of care, and relatives who are highly distressed. With approximately 2,200 residents, identification of those most in need of specialist care is essential in the equitable and efficient distribution of their time and skills. As illustrated in Figure 1, the majority of residents' care needs will be met by the registered nursing staff and carers with certified accreditation in aged care (vocational Certificate 3 or 4) in aged care, team leaders, enrolled nurses within the facilities, with input from general practitioners. A smaller number will require non-specialist palliative care which can be provided by general practitioners and facility nurses focusing on life-limiting illnesses and the frail elderly. The smallest cohort will require input from specialist palliative care, involving nurse practitioners, clinical nurse consultants and medical consultants with expertise in palliative care. Risk prediction is built into the model being trialled in this study (see section 'description of the intervention' for further details).



Figure 1: Stratified model of clinical need for residents

# **3** Intervention components

The intervention model has three components.

 Palliative Care Needs Rounds. Needs Rounds are monthly 60 minute triage (and risk stratification) meetings, where up to ten residents with a short prognosis and high symptom burden are presented by facility staff to the specialist palliative care clinician. The Palliative Care Needs Rounds Checklist was used to inform the running of these meetings (Forbat *et al.* 2017).

The markers for a prognosis of six month or less, taken from the Palliative Approach toolkit (Parker & Hughes 2010), are used to identify residents to be discussed in Needs Rounds. Discussion includes the residents' treatment plans, symptom management, medicines and support system. Case-based education is integrated into the Needs Rounds, with each resident's bio-psycho-social status discussed to promote symptom management and identify opportunities to extend and reinforce staff knowledge. Residents discussed at Needs Rounds frequently lead to initiating the other elements of the model.

- 2. Case conferences. Case conferences between facility staff, resident, relatives and relevant health care providers (including, but not limited to the GP, geriatrician, dementia services) are facilitated by either the SPC clinician or facility staff. Case conferences are attended and facilitated by specialist palliative care staff at the beginning of the intervention to model how to conduct the meetings. As the facility staff gain confidence, they take over the chair function, and specialist palliative care are involved only when resident/family have complex physical, psychological or social needs. The agenda focuses on resident and/or family concerns, moving to discussion of how quality of life could be improved, goals of care (including discussion about hospitalization), and completion of an advance care plan. Medications and cares plan may be changed as a consequence of these discussions. The facility staff explain their capacity to achieve the goals which have been described.
- 3. Clinical work with relevant residents. Both Needs Rounds and case-conferences may lead to referrals for direct specialist palliative care clinical work with residents. Clinical referrals may also arise from other residents who have not been discussed in Needs rounds or case conferences. Direct clinical work involves: symptom assessment, diagnosis, symptom management.

# 4 Methods and analysis

#### 4.1 Design

This is a stepped wedge trial with an embedded inductive process evaluation. Stepped wedges are recognised as a beneficial design for trials involving a palliative population, where there are no clinical equipoise considerations, and where sequential roll-out of the intervention is beneficial. An integrated qualitative process evaluation was also conducted, to elicit perceptions of the model from the point of view of residents and relatives.

The study compared the new model of care (described in section 3) with usual care. Usual care involves access to the specialist palliative care nurses who work in residential aged care and case conferencing but critically does not involve component 1, the Needs Rounds. Essentially, usual care is reactive, whereas the trial intervention is proactive and anticipatory.

The trial was conducted with five steps, with a cluster size of two or three facilities in each step. The staggered commencement timings and intervention length (8–60 weeks), supports feasibility while maintaining the rigour of the study. This design allowed research staff to collect robust data in all sites, and the clinicians to change over from usual care to the new model with facilities. This maximised consistency of implementation of the model and avoiding managing change at 12 sites across the ACT simultaneously. This design also avoided having control facilities that received no intervention, thereby ensuring equity.

Participant timelines and flow through the trial component of the study are illustrated in Figure 2.

No changes were made to the trial design were made after commencement of the study.

#### 4.1.1 Blinding and randomisation

This trial was not blinded to facilities and clinicians, and consequently this should be considered an open-label trial. Simple randomisation was used, with facilities allocated a unique code at the outset of the project. Sequence generation was managed through an internet-based programme which randomly selected facilities for each step. Once randomisation was conducted, facilities were informed of the timing of their facility's migration from control to intervention condition. Clinicians were also randomly assigned to clusters (by way of an internet based programme), however, the clinicians had several periods of extended leave resulting in all three clinicians having involvement in all clusters.

## 4.1.2 Qualitative process evaluation

A process evaluation was conducted to understand the impact of the trial on usual care, management and internal processes. The qualitative process evaluation was conducted toward the end of the trial.



Figure 2: Participant flow

# 4.2 Setting, sample and recruitment

Recruitment proceeded through residential aged care facilities in the Australian Capital Territory. Four of the 26 facilities were excluded as pilot work had been conducted there and were therefore considered contaminated. A further facility was excluded, as it was used as a training site, where clinicians not currently using the model were trained to apply it (e.g. through modelling Needs Rounds, being observed running Needs Rounds and engaging in case-based education). The remaining 21 facilities were invited via letter (with accompanying information sheet) to participate. Sites requesting a briefing meeting were met with by the Chief Investigator and/or one of the specialist palliative care clinicians who would deliver the intervention.

# Inclusion criteria for facilities in the trial

- Residential facility operating in the Australian Capital Territory from January 2017-December 2018.
- Senior management agreement to access residents' records.
- Staff working at the collaborating facilities who are registered nurses or assistants in nursing (notwithstanding the important role of the whole multi-disciplinary team, these are the staff groups who provide most direct care).
- Residents whose data is collected must have the facility as their main residence (thereby excluding those on respite stay).

# Inclusion criteria for staff completing outcome measures

- Staff who by virtue of their role, are invited to Needs Rounds meetings, for example team leaders, registered nurses, enrolled nurses, site managers, and carers.
- Over 18 and willing/able to give informed consent.

# Inclusion criteria for relatives completing outcome measures

- Relative of a resident in one of the participating facilities.
- Over 18 and willing/able to give informed consent.

# Inclusion criteria for the process evaluation

Recruitment for the process evaluation proceeded through sampling of residents or relatives whose care was considerably shaped and changed by the palliative care team. Up to five staff, residents or relatives were recruited per site. Inclusion criteria were:

- Resident able to provide informed consent, as assessed by the clinician, using the minimental state examination, cut-off score of ≥20 (Pachet *et al.* 2010) to inform eligibility.
- Relative or enduring power of attorney of a resident, able to provide informed consent.
- The resident must have had their clinical care discussed at Needs Rounds.
- Care of the resident was considerably shaped and changed, operationalised as the provision of staff education (for example on death, dying, setting goals of care), or providing advice on symptom management.

Purposive sampling was used, whereby a list of potential interviewees was generated by the research and clinical team, to reflect a range of views of the Needs Rounds. Senior and junior staff within the facility were invited to interviews to identify the impact of the intervention on their staff and working practices. Inclusion criteria were:

- Care managers, carers, nurse educators or general managers who have attended Needs Rounds.
- Willing and able to give informed consent.
- Aged 18 or over.

#### 4.3 Sample size calculation

The sample size was estimated taking into consideration of the study design as a stepped-wedge randomised trial and the primary outcome of the study being length of hospitalisation when participants are admitted to acute care. Results obtained from the pilot study suggested that the intervention could achieve a moderate effect size of 0.6 with a means difference in length of stay of 1.8 days (pooled S.D. =2.9). The calculation was also based on the conventional two-arm RCT for estimating the unadjusted sample size. The calculation indicated that the study requires an unadjusted sample of about 41 residents in each arm to provide 80% power at a 2-tail significance level of 5% with an intervention effect size of 0.6 and the ratio between the intervention and control groups is 1 to 1. It is further assumed that there will be an attrition of 10%, thus to total unadjusted sample size required for the study is about 90.

Taking into consideration that this is a stepped-wedge randomised trial, the sample size calculated above will be adjusted with the stepped-wedge design effect (DEsw) as proposed by Woertman et al. (2013).

The design effect (*DEsw*) = 
$$\frac{1 + \rho (ktn + bn - 1)}{1 + \rho (1/2ktn + bn - 1)}$$
 •  $\frac{3(1 - \rho)}{2t (k - 1/k)}$ 

Where, k = 6 (number of steps) n = 20 (the average number of residents within each cluster)  $\rho = 0.05$  (Intra-Class Correlation within cluster) b = 1 (number of baseline assessment) t = 1 (number of treatment measurement after each step)

Hence, the design effect is calculated as 4.55, thus the total sample required for the study is about410, but a greater number offers greater power for the statistical analysis.

Recruitment estimates are show in table 1, indicating an anticipated minimum of 720 potential

residents for recruitment and thus providing more than sufficient individuals in the pool. The overall

sample size is higher to account for relatives' responses to a questionnaire and staff completing

education outcome measures.

	Population (all facilities)	Likely minimum total for the trial <sup>1</sup> (% of all facilities)
Facilities	22	<b>10</b> (45%)
Residents within facilities	2500	<b>920</b> (37%)
Range of residents per facility	20-160	60-140
Deaths/annum	205	<b>78</b> (38%)
Number of Needs Rounds being conducted/month	22 (one per facility)	<b>10</b> (one per facility) (45%)
Number of residents discussed at Needs Rounds monthly	150	<b>60</b> (40%)
Number of residents discussed at Needs Rounds across all sites annually	1800	<b>720</b> (40%)

# Table 1: Sample size estimates for the trial and total resident population

With no pilot data for the relatives' involvement in completing outcome measures, there was no data from which to estimate completion rates (see item 5 in Section 4.4 for further details on this data collection).

Sample size for the process evaluation (qualitative interviews) was 24 staff members, 15 relatives and 15 residents across all participating facilities. This sample size allows for theoretical sufficiency and is adequate to identify and saturate core themes and findings (Baker & Edwards 2012).

<sup>&</sup>lt;sup>1</sup> This sample size was based on 12 sites commencing the trial, and 10 completing, and hence overrecruited to allow for withdrawals.

#### 4.4 Outcome measures

Primary outcome measure:

- Length of hospitalisation for residents. This was measured in days. Length of stay in hospital applied the following definitions:
  - *Hospitalisation*: a resident *admitted* to hospital for 24 hours or longer.
  - Presentation: a resident sent to the hospital who then stayed there for less than 24 hours.

Secondary outcome measures:

- Preferred place of death was measured by recording recorded preference and actual place of death. Data was recorded as a binary of yes/no, regarding whether preferred place of death was achieved.
- 2. A 9-item questionnaire measuring staff death literacy and knowledge was used. This validated scale is used routinely in PEPA (Progam of Experience in the Palliative Approach) with participants from varied disciplines, including considerable use in residential care settings. The tool is formally known as the Capability of Adopting Palliative Approach. Preliminary analyses of psychometrics were conducted, identifying it as a uni-dimensional scale. Internal consistency reliability is very high with a Cronbach's alpha of 0.95, and Splithalf reliability, via Spearman-Brown splithalf coefficient at 0.93 (He 2016).
- 3. Based on the original 31-item version of QODD (Curtis *et al.* 2013, Curtis *et al.* 2002), the revised short-form version was used (Downey *et al.* 2010). The 18 item QODD is a questionnaire examining four correlated but distinct domains: symptom control, preparation, connectedness and transcendence. The decedent's experience is rated on a 0 to 10 scale, where higher scores indicate a better experience. Following correspondence with the scale's originator, one item has been excluded as it asks about access to assisted-suicide.

QODDI measures were grouped as QODDI 1 – questions that applied to all deaths e.g. how often did the resident appear to have pain under control, and QODDI 2- questions that applied in specific circumstances, e.g. visits from a religious or spiritual advisor, of the use of mechanical ventilator or kidney dialysis to prolong resident's life.

- 4. Family views on care was collected using the Brief Assessment Scale for Caregivers (BASC) of the Medically III. This is a 14-item measure, where items on the impact of caring and caregiver distress are rated on a 5-point Likert scale. The scale has good psychometric properties with a Cronbach's alpha of 0.70, and 0.8 for the negative personal impact subscale.
- 5. A further bespoke measure captured core demographic data on facilities and residents.

## 4.5 Data collection

Outcome measures were gathered monthly, hence at the start of each step in the roll-out. Figure 3 illustrates these steps.

Month	Cluster 1 Site 1&2	Cluster 2 Site 3&4	Cluster 3 Site 5,6,7*	Cluster 4 Site 8,9, 10	Cluster 5 Site 11&12
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
16					
17					
Months in intervention (control)	30(4)	26(8)	27(18)	27(24)	14(20)

Shaded cells represent time in intervention (124 months). Unshaded cells represent time in control (74 months). \*Site 7 withdrew in month 12.

### **Figure 3: Data collection points**

Data were collected for 17months in total. As Table 2 depicts, clusters varied with their length of

exposure to the intervention.

Cluster	Site/Facility	Time in control (months)	Time in intervention (months)
1	1	2	15
1	2	2	15
2	3	4	13
2	4	4	13
3	5	6	11
3	6	6	11
3	7	6	5*
4	8	8	9
4	9	8	9
4	10	8	9
5	11	10	7
5	12	10	7
Total		74	124

Table 2: Time in control and intervention phase by cluster

\*Site 7 withdrew mid-study

Stepped wedge designs place greater burden on data collection (Kotz *et al.* 2012). Consequently, the measures have been selected to reduce participant burden, by capping the length and number of measures used. We generously estimated that measures may take a total of 30 minutes to complete, based on the pilot work (Chapman *et al.* 2016 early online, Johnston *et al.* 2016 early online).

- i. The primary outcome measure (hospitalisation length of stay) was collected on all residents throughout the course of the trial, as well preferred place of death.
- ii. The 9-item PEPA measure was completed by staff attending Needs Rounds. At the outset of each Needs Round staff were asked to complete the tool. Paper copies were provided to staff and returned to the clinician attending the Needs Rounds.

- iii. The Quality of Death tool (QODD) was collected on all residents who died during the course of the trial. Though the tool is designed for relatives to complete, the burden which this places on relatives (who may not have been involved and aware of the resident's end of life experience) was considered too great for this study. Registered nurses and experienced team leaders in each facility were provided with training on completing the tool from the research or clinical team. Having the same staff complete the QODD is a strategy to reduce variability (and increase reliability) in use of the measure. Approximately four staff per facility were trained, to account for absences due to annual leave, sick leave and staff turnover. Training on the tool involved discussion of the items and then completing the QODD for three case-studies devised by the specialist palliative care team of recent deaths, to provide reassurance on reliability of completion. Further training was provided to staff where necessary.
- iv. Family views on care were collected within facilities on a paper-based survey. Families were invited to complete the survey by reception staff; the information sheet was provided next to the survey. A secure locked-response box was provided in the reception area for the collection of completed surveys.
- v. Resident data was collected from participating facilities' records. This data was collected by the study research team.
- vi. Fidelity to the model was monitored. Data was collected on each clinician's Needs Rounds, randomly sampling 20% of Needs Rounds, which were scrutinised for covering core elements. Needs Rounds were audio-recorded for this purpose. Written consent of all staff participating was gained. The central elements of the Needs Rounds have been identified in a recent ethnographic study of Needs Rounds and constitute the core active ingredients (Forbat *et al.* 2017). This data was collected by the study research team.

- vii. Process evaluation data was collected via face-to-face interviews. Interviews focused on: views and experiences of the quality of care provided, symptom management, impact of the intervention on death literacy, working practices, staff morale, quality of care, access to specialist input and quality of death.
- viii. Impact on conflict was measured with reference to the number of complaints received, and staff perspectives (as per data collection method above integrated into the process evaluation). The pilot work indicates that the package of work around anticipatory care (triaging, staff education and case conferences) reduces friction between staff and relatives. Complaints are a proxy measure for conflict. Staff were asked on the first of each month how many complaints were received in the previous month. The definition of 'complaints' was operationalised as a letter/email to the Facility about concerns relating to palliative/end of life care received within the site. Verbal or written statements made to staff indicating that a family has written to a Minister about care received will also be included in this definition of complaint.
- **ix.** Process evaluation data was collected through one-off audio-recorded qualitative interviews in aged care facilities. The questions were generated by the research team and built on questions used in the pilot work. The interview topic guide was not piloted. Interviews were conducted by a female experienced qualitative health care researcher, via phone or face-to-face interviews. About a third of participants had had previous contact with the interviewer, through collection of monthly data from facilities. The prior relationship was unlikely to have impacted the qualitative accounts generated. Interview questions prior to the interview and generated transcripts were not shared with interviewees. Data checking was not used.

Quantitative data entry and coding was conducted by four researchers, with samples regularly checked for accuracy by another researcher. Qualitative data were coded by two researchers.

#### 4.6 Analysis

The analyses of data for the primary outcome, namely length of stay in hospital, were based on the study design being a Stepped-Wedge Trial. The approach involved analysis of the overall sample taking into consideration of all participants in the pre-step phase (control) and stepped phase (intervention) as a whole. It was also conducted on the level of individual site or sub-groups of the total sample. Descriptive statistics on the main outcome variables, such as length of stay, preferred place of death, QODDIs, and PEPA, were obtained as means, standard deviations, or frequencies and percentages, depending on the nature of the variables. Simple comparisons of continuous variables by groups were conducted using either the Student t-tests or Oneway Analysis of Variances (ANOVA). For categorical variables, Pearson Chi-squared tests were employed to examine the association between groups. For the length of stay, owing to the fact that residents could have been hospitalised multiple times in both the control and intervention phases of the trial, data were clustered by residential sites and were analysed using the mixed effect linear regression approach. For other outcome variables, based on the nature of the variable being continuous or categorical, multiple linear regression model of logistic regression techniques were applied. Data analyses were also conducted at the site level whenever the sample size of the site could allow. To elucidate the precision of the results obtained and to determine whether different results could be obtained in different sites with various levels of the compliance to the intervention protocol, sub-group analyses were also conducted on most of the outcome variables. For the test of statistical hypotheses, a Type I error rate of 5% was adopted in all analyses.

Generalised Linear and Latent Mixed Model (GLLAMM) was used to analyse length of stay, to manage the fact that patients could have been hospitalised multiple times in the control and intervention phases, as well as being distributed across sites. This approach is able to incorporate the clustering effect of repeated measures from individual patients nested in different sites, as well

as the variabilities among patients across various sites. For other outcome variables, based on the variable being continuous or categorical, multiple linear regression model of logistic regression techniques were applied.

The cost analysis was calculated by comparing the difference in total overnight stays in hospital (The Canberra Hospital and Calvary Hospital, Bruce) between control and intervention phase. Adjustment is also made to accommodate the difference of time spent in the control phase as opposed to the intervention phase; specifically, the average length of stay per month per facility across two phases was calculated.

The hospital bed cost is calculated based on the most recent National Hospital Cost Data Collection Cost Report 2015-2016 (IHPA 2018). The total bed day cost saving is calculated based on the subacute bed day cost for geriatric evaluation and management (GEM), which is \$1,286. This cost was chosen as it offers the most conservative estimate (compared with acute bed costs of \$2,200), in the absence of prospective linked data for individual admissions.

Qualitative data were analysed adopting a five-stage process of familiarisation: identifying a thematic framework, indexing the data, synthesising across respondents and data interpretation to form key themes (Braun & Clarke 2006). Qualitative analysis was led by a female experienced health services researcher with a PhD in qualitative research. Nvivo version 11 was used to store and organise the data.

#### 4.7 Ethical parameters

Ethical permission was gained from Calvary Public Hospital Bruce's HREC, National Capital Private Hospital and Australian Catholic University's research ethics committee (ACU). ACT Health (for Canberra Hospital records) declined to give approval for access to their records.

Consent was gained at a facility level for resident-level data. This involved signing a memorandum of understanding with the Australian Catholic University. Individual staff provided consent to complete the PEPA outcome measure, and interviews. Where relative interviews were conducted, individual written consent was gained.

No protocol amendments were required. The trial was registered with the Australian New Zealand Clinical Trials Group. Data are held in locked cabinets and password protected electronic files. All identifying details were removed and replaced with alpha-numeric identifiers. Security and storage of data was managed by the principal investigator.

Criteria for discontinuing the trial were informed by Stallard (2001) whereby data were monitored on an ongoing basis, and the trial would be ceased if there was evidence of adverse events or of a lack of efficacy.

An independent data monitoring committee was not convened as the primary outcomes are related to quality of death and staff education rather than reducing risk of major adverse events (FDA. 2016).

The trial was registered on the Australian and New Zealand Clinical Trials Registry (ref: ACTRN12617000080325). The full protocol is available from the first author.

# 5 Findings

#### 5.1 Description of the sample

This stepped wedge trial consisted of two phases, namely the control and intervention phases. The overall sample consisted of residents recruited from 12 sites with a total sample size of 1700. Residents were recruited in the control phase and then "crossed-over" to the intervention phase, until the end census date (a pre-set date), or their date of death if that occurred before the end of the trial.

A small number of residents migrated from one site to another during the study period. Only one resident moved between sites that were in different phases of the trial (i.e. moved from control to intervention). Consequently, the impact of such migration across sites on the analyses was negligible.

The overall distribution of residents by site are summarised in Table 3. The distribution of the intervention group within sites are also shown. In total, there were 537 deaths, with 71 (13%) and 466 (87%) residents dying in the control and intervention phases respectively. Of the 1700 residents in the trial, 31.6% died and 1163 (68.4%) survived to the completion of the study. The number of deaths is an artefact of the morbidity of residents.

Owing to the small sample size of most facilities (with only 4 having a size greater than 150) further breakdowns of each site for comparison would not provide more meaningful insights than the overall sample. Hence, no further analyses on the sample characteristics were conducted at the site or cluster level.

	-	Frequency (%) within site of residents followed to
Site	Frequency (%)	the completion day of the study
1	122 (7.2%)	76 (62.3%)
2	55 (3.2%)	39 (70.9%)
3	217 (12.8%)	149 (68.7%)
4	120 (7.1%)	72 (60.0%)
5	86 (5.1%)	72 (83.7%)
6	243 (14.3%)	162 (66.7%)
7	154 (9.1%)	118 (76.6%)*
8	127 (7.5%)	86 (67.7%)
9	129 (7.6%)	91 (70.5%)
10	140 (8.2%)	97 (69.3%)
11	108 (6.3%)	70 (64.8%)
12	199 (11.7%)	131 (65.8%)
Total	1700 (100.0%)	1163 (68.4%)

Table 3. Distribution of residents by site (n=1700)

\* Site 7 withdrew from the study after 6months, and these data therefore represent the end of involvement in the trial.

Since residents were followed from the control phase into the intervention phase, the demographics and characteristics should, by and large, remained unchanged except all surviving residents aged. However, it is important to understand whether there were any differences in residents' characteristics between those who died during the study period. The results are summarised in Table 4. As shown, there were statistically significant differences between groups in some characteristics. The age of the residents who died was similar in the control phase and intervention phases with the mean age of 86.2 (s.d.=8.7) and 85.9 (s.d.=8.3) years respectively. While a higher percentage of residents who died in the intervention were male (39% vs 34%), had an EPOA/Guardianship order/emergency management order (74% vs 68%), and had an advance care plan (53% vs 41%) when compared to those who died in the control phase, the differences were not statistically significant.

Some differences were also observed in the primary diagnosis with slightly more residents with dementia or Parkinson's disease dying during the intervention phase (Table 4). Thirty-two percent of residents who died in the intervention phase had dementia (149/466). The corresponding

percentage in the control phase was 23% (16/77), which is significantly smaller. The average age-

adjusted Charlson Comorbidity Index of those who died in the control phase was similar to those

who died in the intervention phase with 5.5 (s.d.= 1.6) and 5.6 (s.d.=1.6) respectively.

Patients' Characteristics	Mean (s.d.) o	r Frequency (%)	Results
	Control phase	Intervention phase	
	(n=71)	(n=466)	
Age	86.2 (8.7)	85.9 (8.3)	<i>t</i> <sub>535</sub> = -0.63, p=0.53
Male	24 (34%)	182 (39%)	χ <sup>2</sup> <sub>1</sub> = 0.72, p=0.40
EPOA etc (Yes)*	48 (68%)	346 (74%)	χ <sup>2</sup> <sub>1</sub> =1.50, p=0.22
Health Direction (Yes)*	2 (3%)	24 (5%)	χ <sup>2</sup> 1 =0.80, p=0.37
Advance Care Plan etc			
(Yes)*	29 (41%)	248 (53%)	χ <sup>2</sup> <sub>1</sub> =3.42, p=0.06
Primary Diagnosis			
Dementia/Parkinson	18 (25%)	169 (36%)	χ <sup>2</sup> <sub>5</sub> =8.12, p=0.15
Cancer	7 (10%)	31 (7%)	
Cardiovascular Disease	13 (18%)	61 (13%)	
Frail aged	4 (6%)	39 (8%)	
Organ Failure	6 (8%)	17 (4%)	
Others	23 (32%)	149 (32%)	
Age-adjusted Charlson Comorbidity Index	5.5 (1.6)	5.6 (1.6)	t <sub>436</sub> = -0.50, p=0.62

**Table 4.** Characteristics of patients who died during the study by phases and results on comparison (n=537)

# 5.1.1 Fidelity to the model

The research team monitored all sites for compliance with the intervention, grading them with a 3tier rating system, namely low, moderate, and high compliance. Adherence to the model of care was assessed by two methods. First, a random sample of 20% of all recorded Needs Rounds were assessed for adherence to the published Needs Rounds Checklist (Forbat *et al.* 2017). Discussions were assessed on an 8-point scoring system for core elements of the checklist. Second, feedback from the specialist palliative care clinicians was assessed regarding site buy-in to the model of care, for example engagement in organising case conferences, and take up of actions

following Needs Rounds.

Two of the sites had very poor compliance to the intervention procedures. The ratings are depicted

in Table 5.

Site	Compliance with the intervention protocol
1	High
2	Low
3	High
4	Moderate
5	High
6	High
7	Low
8	Moderate
9	Moderate
10	Moderate
11	High
12	Moderate

Table 5. Rating on	the extent of con	npliance with the	intervention	protocol
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These ratings were incorporated in further analyses of data for the overall sample here forward. Sub-group analyses were also conducted based on the rating of these sites. For the ease of analyses and based on the available number of residents in the sites, sub-group analyses were conducted for the high and the moderate/low compliance groups separately. Whenever the sample sizes allowed, the low level compliance group were collapsed with the moderate group in some analyses.

As noted above, site seven withdrew from the trial after six months. Site managers cited workload burden as a factor in this decision, alongside finding monthly Needs Rounds too frequent to fit with their model of care.

# 5.2 Harms and adverse events

No adverse events were recorded.

#### 5.3 Primary and secondary outcomes

#### 5.3.1 Length of stay in hospitals

In total, there were 1149 hospital encounters, of which 943 were admissions (>24 hours). Of these hospital admissions, 415 (44%) were in the control phase, with 528 in the intervention phase. There were 88 and 123 presentations (<24 hours) in the control and intervention phases respectively. Descriptive information is presented in Table 6. As shown, many of these residents had multiple hospital encounters, as expected in this population.

The number of episodes of hospitalisation per facility-month reduced in the intervention phase by 23%, from 5.6 to 4.3. The total hospital bed days per facility-month was reduced by 31% from 39 to 27. The intervention showed limited impact on hospital presentations (<24 hour stay) per facility-month, but importantly does lead to fewer hospital encounters. That is, the model of care leads to fewer residents using acute care services.

Data were examined to report whether the remaining admissions has changed with regard to length of stay (LOS). LOS was calculated on those who stayed longer than 24 hours, including those who died during the hospitalisation. Residents who presented to the hospital but did not stay longer than 24 hours were excluded from LOS analyses (as their length of stay was considered as 0 days).

Results obtained from the Generalised Linear Latent Mixed Model suggested that there was a significant difference in the mean length of stay in the hospital between the intervention and control phases after adjusting for demographic, resident characteristics, level of compliance, and the time weighting (Table 6). The average of length of stay of residents in the intervention phase was 6.4 days (s.d.=8.3) which was statistically shorter than that of the those in the control phase with an average

of 6.9 days (s.d.=9.1). Thus, of those admitted to hospital, they tended to stay half a day less in the intervention compared to control condition.

The overall impact of this model of care is the marked reduction in hospital encounters, whereby substantially fewer residents were sent to hospital. LOS reduces by half a day, but this is not a clinically meaningful unit of change.

	Control	Intervention	Results
No. of hospital admissions (>24 hours)	415	528	-
No. of presentations to hospital (<24 hours)	83	123	
Minimal number of hospitalisation	1	1	-
Maximum number of hospitalisation	18	14	-
Total bed days	2876	3385	
No. of admissions per facility-month	5.6	4.3	
No. of presentations per facility-month	1.1	1.0	
Total bed days per facility-month	39	27	-
LOS for those patients admitted and discharged (days)	Mean=6.9, s.d.=9.1 95%C.I.=6.1-7.8	Mean=6.4, s.d.=8.3 95%C.I.=5.6-7.1	<b>Z= -1.98, p=0.048</b> ª
	Relative Risk of	Hospitalisation	
	OR <sup>b</sup>	95%C.I.	Results
4 days or more	0.89	0.61-1.32	Z= -0.57, p=0.568
3 days	1.11	0.63-1.963	Z= 0.36, p=0.720
2 days	0.64	0.36-1.13	Z= -1.54, p=0.124
1 day	0.82	0.54-1.27	Z= -0.84, p=0.398
0 day	-	-	-

# Table 6. Descriptive information on the hospitalisation of residents by phases

<sup>a</sup> Adjusted for age, sex, EPOA, health directive, Advance Care Plan, Primary diagnosis, age-adjusted Charlson index, compliance rating.

<sup>b</sup> ORs were calculated using ED admission as the referent group and adjusted for age, sex, and other patients' characteristics.

#### 5.3.1.1 Cost calculation

Bed day costs were calculated at \$1,286 per day. The total number of bed days during the 74 facilitymonths of the control phase was 2,876. The corresponding number during the intervention phase was 3,385 over a period of 124 facility-months of exposure to the new model of care.

Given the total time spent in each phase, the reduction of bed days for each facility-month was: 2,876/74 - 3,385/124 = 11.56. This yields an average monthly cost saving of \$14,866 per facility

This model of care was delivered by senior nurses, employed as nurse practitioners or clinical nurse consultant. To report a net cost saving, maximum staffing during the trial is based on two full time nurse practitioners, where annual salaries (plus on-cost) were approximately \$381,716.

Overall, the annual estimated net cost saving across 12 sites was \$1,759,011 (12 monthly savings of \$14,866  $\times$  12 sites, minus annual staffing of \$381,716). If the costs are scaled across the length of the trial (17 months of intervention), then the cost saving is estimated at \$2.5m.

#### Analyses on site level or by sub-group

Sub-group analyses were conducted by protocol compliance per site (Table 7). As shown, the results were similar to that obtained from the overall sample. Statistically significant differences in the average length of stay were observed between the intervention and control phases for sites with high levels of compliance as well as moderate levels of compliance. The length of stay of residents in the intervention phase however was found to be slightly longer in comparison to that in the control phase for high compliance sites (Table 7). This may reflect the clinical status of residents admitted, with lower-acuity issues managed within the nursing home and only more intractable problems referred to the hospital for management. For sites with moderate level of compliance, the length of
stay for both groups were not statistically different. For sites with lower of compliance, analyses

were not conducted due to small samples.

Table 7. Means (s.d.) of length of stay by treatment status and compliance level with results on comparison

Levels of compliance	Control	Intervention	Results <sup>a</sup>
High	6.2 (8.9)	6.5 (7.3)	z= -2.47, p=0.013ª
Moderate	7.0 (9.2)	6.5 (9.9)	z=-0.30, p=0.768

<sup>a</sup> Adjusted for age, sex, EPOA, health directive, Advance Care Plan, Primary diagnosis, age-adjusted Charlson index, compliance rating and with time weighting.

## 5.3.2 Preferred place of death

Of the 1700 residents in the overall sample, 537 (31.6%) died during the study. Of the 537 deaths, 134 (25%) either did not specify a preferred place or did not record this information. Analysis

excluded those with missing record of the actual place of death. A total of 397 deaths were included

in the analysis of preferred place of death.

Of those who died at their preferred place, the unadjusted results on the between groups comparison indicated that the difference between intervention and control phases was not statistically significant ( $\chi^2_1$ =3.22, p=0.073) with 86% and 75.2% of residents dying at their preferred place respectively (Table 8). After adjusting for compliance ratings, residents' demographic and other characteristics, there was a significant difference in the odds of dying in the preferred place between phases after adjusting for the effect of other potential confounding variables (OR=3.40, 95% C.I.=1.26-9.13). Residents had around three and a half times the odds of dying in their preferred place during the intervention, compared with the control (Table 9).

 Table 8. Died at the preferred places by phases, unadjusted results (n=397)

	Control	Intervention	Results
Died at the preferred place	27 (75%)	311 (86%)	χ <sup>2</sup> 1=3.22, p=0.073

## Table 9. Odds of dying at preferred place, adjusted results

Group	Odds Ratio <sup>a</sup>	95% C.I.	Results
Intervention	3.40	1.26-9.13	z =2.42, p=0.016
Control	1	-	-

<sup>a</sup> Adjusted for age, sex, EPOA, health directive, Advance Care Plan, Primary diagnosis, age-adjusted Charlson index, compliance rating and with time weighting.

## Sub-group analysis

No further analyses on place of death were conducted at the sites level due to the small sample size

in most sites. However, sub-group analyses were conducted based on the extent of protocol

compliance. Results of the sub-group analyses are summarised in Table 10. There is a significant

difference in the preferred place of death between the intervention and control phases for sites with

high or moderate level of compliance. For sites with lower of compliance, analyses were not

conducted due to small samples as well as some zero cell sizes.

Table 10. Adjusted results for a	lying at preferred place,	for facilities with	high/moderate levels of
compliance			

	Intervention		
	Odds Ratio <sup>a</sup>	95%C.I.	Results
Intervention	3.00	1.02-8.78	z =1.99, p=0.046
Control	1		

<sup>a</sup> Adjusted for age, sex, EPOA, health direct, Advance Care Plan, Primary diagnosis, age-adjusted Charlson index and with time weighting.

## 5.3.3 Resident quality of death

Residents' quality of death was assessed by the Quality of Death and Dying (QODD) with main scores, the QODD1 and QODD2, based on the different sets of items on the scale. Of the 537 deceased residents, 471 (87.7%) had complete information for analysis. The unadjusted associations between residents' demographics, other characteristics and both QODD scores were summarised in Table 11 below. As shown, some demographics and residents' characteristics were related to either the QODD1 or QODD2 scores. Hence, these variables were included in the further analyses for controlling their effects on the outcome variables. Table 12 depicts the results on the means and standard deviations of both scores by treatment status. For QODD1 scores, results on the comparison between groups after adjusting for other variables suggested no statistical difference with the average scores of 75.1 (s.d.=14.2) and 75.4 (s.d.=15.9) for the intervention and control groups respectively. Similarly, no statistical difference was found in the QODD2 scores between phases with average scores of 63.4 (s.d.=17.7) and 63.6 (s.d.=16.4) for the intervention and control phases respectively.

Table 11. Unadjusted associations between demographics, resident characteristics, and the qualityof death assessment

Variables	Results on association		
	QODD1	QODD2	
Age	r = 0.04, p=0.407	r = 0.08, p=0.101	
Sex	t <sub>469</sub> = -0.38, p=0.704	t <sub>351</sub> = -0.93, p=0.354	
EPOA	t <sub>469</sub> = -2.70, p=0.007	t <sub>469</sub> = -1.51, p=0.131	
Health Directive	t <sub>459</sub> = -4.15, p<0.001	t <sub>459</sub> = -0.74, p=0.469	
Advance Care Plan	t <sub>450</sub> = -0.52, p=0.600	t <sub>450</sub> = -2.30, p=0.022	
Primary Diagnosis	F <sub>(5,465)</sub> =3.43, p=0.005	F <sub>(5,465)</sub> =2.75, p=0.019	
Charlson Comorbidity Index	r = 0.01, p=0.779	r = 0.10, p=0.034	
Level of compliance	F <sub>(2,468)</sub> =2.43, p=0.089	F <sub>(2,468)</sub> =5.04, p=0.007	

Table 12. Means and standard deviations of Quality of Death and Dying assessments by phases with
results on comparisons

	Control (n=67)	Intervention (n=404)	Results <sup>a</sup>
QODD1	75.1 (14.2)	75.4 (15.9)	t <sub>445</sub> =1.67, p=0.095
QODD2	63.4 (17.7)	63.6 (16.4)	t <sub>445</sub> =1.96, p=0.156

<sup>a</sup> Adjusted for age, sex, EPOA, health direct, Advance Care Plan, Primary diagnosis, Charlson index, level of compliance and with time weighting.

#### Sub-group analysis

Due to small sizes in each site, no further analyses were conducted. Sub-group analyses by the

extent of protocol compliance were carried out. Results obtained on the comparisons of the mean

QODD1 and QODD2 scores between groups for high/moderate compliance are presented in Table

13. After adjusting for demographics and other residents' characteristics, the differences between

intervention and controls phases for both QODD1 and QODD2 were significantly higher in sites with high or moderate level of compliance.

Table 13.	Means and	standard deviation	is of Quality	of Death	and Dying	assessments	by r	phases
adjusted	for facilities v	with high/moderate	e compliance	•				

		Intervention	
	Control (n=57)	(n=372)	Results <sup>a</sup>
QODD1	74.5 (14.9)	76.1 (15.9)	T <sub>429</sub> =2.34, p<0.019
QODD2	62.6 (18.3)	64.6 (16.2)	T <sub>429</sub> =1.97, p=0.049

<sup>a</sup> Adjusted for age, sex, EPOA, health directive, Advance Care Plan, Primary diagnosis, age-adjusted Charlson index, and with time weighting.

## 5.3.4 Staff death literacy and confidence

Staff death literacy began only when each site was moved from the control phase into the intervention phase. As a result, there were no pre-intervention data to be used as the baseline measure for each site. However, once intervention had started, staff death literacy levels were then assessed throughout the entire intervention period. Again, based on the assumption that different individual staff members might have been involved in responding to the death literacy assessment throughout the intervention period, their responses were assumed to be independent. Furthermore, once the intervention had begun, the entire site was exposed to the change in practices and were also involved in an environment in which the change would perpetuate. Hence, it was further assumed that there could be a cumulative effect of the exposure to the intervention on the understanding and perception towards death and dying in staff. In other words, as a whole, the longer the exposure to the intervention, the greater effect on the death literacy in the staff body.

In the analysis, the "duration of exposure" to the intervention was defined as the time-lapse in months from the commencement of the intervention to the date that individual staff responded to the questionnaire. To ascertain the relationship between duration of exposure and death literacy, the PEPA total scores were regressed on the duration of exposure for the overall sample as well as for some larger sites.

Figure 4 depicts the overall relationship between the PEPA total scores and the duration of exposure. As shown, there was a linear and positive association between these two variables. Results obtained from the multiple linear regression analyses confirmed that there was a statistically significant and positive relationship between PEPA total score and the duration of exposure with a regression coefficient of 0.50 (s.e. = 0.09) (Table 14). The analyses were conducted with adjustment the effect of site but no other variables since none of the residents' characteristics were associated with the PEPA total scores. These results suggested that for an increase of 1 month of exposure to the intervention, there was an increase of about 0.5 units in the PEPA total score.

# Table 14. Results obtained from the multiple linear regression analysis with PEPA total scores asthe outcome variable

Variable	Regression Coefficient <sup>a</sup>	S.E.	Results
Duration of exposure	0.50	0.09	t <sub>474</sub> = 5.47, p<0.001

<sup>a</sup> After adjusting for the site.



Figure 4. Scatter plot and fitted linear line of PEPA total scores on the duration of exposure

## Sub-analysis of sites

Analyses on the site level also revealed that the results held true for some sites, particularly sites 3, 6, 9, 10, but not the others.

Results obtained from the multiple linear regression analyses are also summarised in Table 15. As shown, significant and positive relationships between PEPA total score and duration of exposure remained within these sites with estimated regression coefficients ranging from 0.62 to 1.45. It was worth noting that two of these sites were of high level of compliance (3,6) and the other two were of a moderate level of compliance (9, 10).

#### Table 15. Results obtained from the multiple linear regression analysis with PEPA total scores as

Duration of exposure	Regression Coefficient <sup>a</sup>	s.e.	Results
Site 3	0.62	0.11	t <sub>60</sub> = 5.85, p<0.001
Site 6	0.88	0.27	t <sub>60</sub> = 3.31, p=0.002
Site 9	1.45	0.31	t <sub>39</sub> = 4.66, p<0.001
Site 10	1.14	0.40	t <sub>29</sub> = 2.83, p=0.008

#### the outcome variable for selected site

#### 5.3.5 Effect of the intervention on reducing complaints

Sites reported the number of complaints received relating to palliative or end of life care during the course of the study. Very few such complaints were received, and consequently no statistical analyses were conducted on this study outcome.

#### 5.3.6 Effect of the intervention on improving relative's stress

Similar to residents' complaints, limited quantitative data were collected on relative's stress. Data collection on this outcome was ceased after six months, as completion rates were so low as to not warrant continuation. Consequently, no statistical analyses were conducted on this study outcome.

#### **5.4 Process evaluation**

Interviews were conducted with 21 staff members (see Table 16 for demographics). 27 staff were invited to participate but declined or did not respond. The site which withdrew was not approached for a formal interview as they had expressed how burdened their care load was. Consequently, the following data are drawn from the 11 facilities which completed the intervention. All sites had been in the intervention phase for between six and eight months before they were interviewed. Two facilities chose dyadic interviews, whereby two staff were interviewed together. All other interviews were individual. All interviewees had participated in the intervention. Two interviewees were relatively new to the facility and were unable to provide comparison for practice before/after the

introduction of Needs Rounds. Interviewees' roles are not noted by the quotations in order to

preserve anonymity of respondents.

Nine hours and 39 minutes of interview data were transcribed and interviews lasted between 16:01 minutes and 53:36 minutes, with a mean of 52:18 minutes.

Role		
Facility manager (incl. Dir. of Nursing and RNs)	5	
Care manager	7	
Team leader	2	
Carer	1	
RN	1	
EN	2	
Deputy/Assistant facility manager	2	
Clinical nurse specialist	1	
Age		
21-30	7	
31-40	4	
41-40	4	
51-60	2	
61+	4	
Gender		
Female	17	
Male	4	
Length of experience		
1-2 years	2	
3-5 years	3	
5-10 years	6	
11-20 years	5	
20+ year	5	

## Table 16. Interviewee demographics

Note: some interviewees were not employed by the facilities prior to the Needs Rounds commencing, so had little baseline knowledge of how the NRs could have changed practice. E.g. Site 9, interviewee 1.

## 5.4.1 Site environmental analysis

Sites varied considerably. Some were members of national chains, whereas others were individual

privately owned units. At baseline the smallest facility had 42 residents, and the largest 165. Two

sites (5 and 9) expanded their resident sizes considerably during the course of the study. All sites had access to registered nurses, but with varying degrees of cover during days, nights and weekends. As Table 17 illustrates, relationships with GPs varied considerably and consequently access to medicines, medical advice and symptom management varied.

None of the sites had resident GPs, and relationships with GPs varied. Some sites had a few GPs who visited regularly (including one large site with more than 10 GPs visiting regularly), while others had limited ongoing contact. One facility was situated very close to a community pharmacy and reported enjoying easier access to obtaining medicines than other sites after they received a prescription.

Several sites described their staff make-up as being highly international:

[This facility has] only two staff members that were born in Australia out of 25 (Site 1, interviewee 2)

While not unusual in aged care facilities to have a very diverse staff group, the speaker points out that the cultural diversity of staff impacts care at end of life:

It was more the Indian culture that actually don't see someone who's deceased so the fear, they actually had a fear of betraying their culture if they were to see the deceased person. A lot of younger students had never seen someone die, so that's another cultural thing that you just have to teach what's going on (Site 1, interviewee 1)

## Table 17. Nursing and medical provision in study sites

Site	Occupancy	RNs /Overnight	GP access and relationships
	at baseline (n)		
1	88	8 in total/1	"We have regular rounds with Dr GP1 and Dr GP2, so they come every Tuesdays and Thursdays when I'm available and we actually do rounds and we actually assess most residents. Probably 75 per cent of our nursing home is under their care."
2	42	3 per shift /on-call until 10:30pm	"We're a bit lucky in a way too in that we don't have a lot of GPs that come here []We've really only got two at the facility"
3	165	2 per shift (10 total)/1	"We predominantly use three GPs"
4	83	1/unknown	"It's very hard to get hold the doctor to actually start a palliative pathway whereas now [after the trial] it just makes so much easier for us
5	48	8/1	"We've got a GP for the facility but he works at his own practice."
6	178	28/2	"We don't have an in house GP"
7	137	Data not collected due to withdrawal from study prior to interview	
8	115	17 total/1	[We deal with] A lot twenty plus [GPs] more than ten GP are coming on a regular basis, but maybe 3 or 4 they hardly come."
9	82	2 per shift/1	"We have two GPs that visit regularly."
10	114	7/1	"we have [four] regular GPs that come in"
11	98	11 in total/1	"We have GPs who come to the facility, and they come like once in a week so we have at the moment we have three or four GPs and most of the residents are with the same GP"
12	156	20 in total/1	"more than twenty different GPs we're are working withit's quite a difficult to work with us while doing the profile paperwork and keeping all the medication charts signed on time and to especially in the palliative care, to contact some GPs are easier to contact, some of them are not. Some may always their receptionist will take a message and they will never get back to us. So in the case of prescribing medication or doing any review as urgent for example palliative care or end of life care, we always rely on [the specialist palliative care team]"

Prior to the intervention, some facilities had unwritten policies indicating that residents were often transferred to hospital. All sites indicated that hospital transfers occurred after consultation with

family members. Although some sites had palliative care policies prior to the intervention, staff were often unable to articulate what the policy's intent was or how it shaped care practices.

[We would transfer to hospital] if the staff could not manage what the situation was, then they called an ambulance and they just go. (Site 2, interviewee 1)

If the resident becomes unwell, we always contact the family members and it's always up to them whether they send to hospital or not. So that's for non-emergency transfers. For emergencies we'll decide on when to transfer or not, like for example fracture or fall causing a fracture, of course we have to send to hospital straight away and then inform the family afterwards. (Site 4, interviewee 1)

#### 5.4.2 *Reflections on the intervention*

Analysis of the data identified six core themes: (i) preparedness for palliative care, (ii) reflections on adopting the model of care, (iii) how knowledge gained through the trial has changed practice, (iv) the documentation and discussion of end of life wishes, (v) impact on hospital transfers, (vi) core learning about implementation of the model of care. Sub-themes included the impact on quality of life and quality of death for residents, relationships with GPs, staff morale, running case conferences and communication with the specialist palliative care team.

#### 5.4.3 Preparedness for palliative care

Interviewees were asked to talk about how palliative-care ready their facility was prior to the Needs Rounds commencing. Responses varied, with some sites stating they were already performing well in this area, and others indicating only limited understanding of palliative care prior to the trial:

I would say it was ready, however it was not - nobody really understood risks of, you know, potentially recognising someone's dying rather than just recognising a deteriorating patient. (Site 1, interviewee 1)

I would say [the facility was] below average, before the Needs Round. Because the only idea we had about palliative is like when someone's actually like you know, close to being terminal. (Site 10, interviewee 1)

Many sites noted that prior to the trial, their staff had attended the national PEPA program, and had thereby contributed to their confidence and insight into palliative care provision.

One site described themselves as fairly prepared:

I would say we were fairly palliative care ready. Only because we had had a good relationship with palliative care ongoing for the years I've been here anyway. And we've also had the reverse PEPA which we've had four staff through [...] and so and we've had [palliative care educator] come and give us quite a few lectures on palliative care and you know our staff meetings and so forth but the partnership has certainly strengthened since we've been in the trial. (Site 2, interviewee 1)

Other interviewees reflected on the areas where they had not felt adequately prepared:

I don't think very well. We relied a lot on the GP's, or the family's wishes without focusing on the person, and their wishes and what was best for them. We have this sort of culture, nursing to heal and to fix and palliative care is something that you can't fix, it's going to happen. So that was – it was hard and it still is hard to change the mindset particularly of families when we start talking about palliative care that it doesn't mean that death is imminent and we would transfer to hospital a lot. (Site 9, interviewee 2)

Lack of preparation was also linked with limited insight regarding the longevity of residents:

I don't think we thought about how long a person might have to live. (Site 6, interviewee 2)

#### 5.4.4 Adoption of palliative care Needs Rounds

Interviewees were uniform in reporting that the Needs Rounds approach had been beneficial to their facility, staff and residents. The new model of care had led to improved preparedness and better relationships with families who now trusted facilities to better take care of their relatives.

Definitely feel that since having the Needs Rounds we are a lot more prepared, we know what we need to do, we know what's involved, who we need to involve, at what stage, I definitely think we have gained a lot, a lot from having the Needs Rounds. (Site 2, interviewee 2)

[The palliative care team] made time for every one of our residents for every question we've had and I don't know how they've done it. I really don't. But to see families go through a nice peaceful, almost beautiful death, [...] I can't put it into words, I'm going to cry. I feel like I want to cry. Because I you know, we deserve that as human beings, and our families deserve that. (Site 9, interviewee 2)

Staff were directly invited to comment on whether residents' quality of life had been improved by adopting the new model of care. Responses were often focused on management of access to medicines, management of physical symptoms, particularly pain and bowel care.

[Care] seems more peaceful. We're not running around saying 'they're in pain we need to do this.' (Site 9, interviewee 2)

Bowels there's been improvements. With noticing like distended abdomens for someone who hasn't opened their bowels for a long time, yes just identifying thing I guess and then learning how to fix it. (Site 1, interviewee 2)

Involvement of the family had also been cited by a few respondents as improving residents' quality of life:

We can get the family to be more involved and then the residents themselves feel like 'actually my wife, you know my daughters are still here, they're part of this process' and yeah so we can definitely see with the residents that they're satisfactory. More than satisfied with the Needs Rounds. (Site 10, interviewee 1)

Facilitating residents' ability to make informed decisions was also cited as a marker of improved quality of life. This change was instigated by better staff understanding of the benefits and burdens of choices.

The trial showed me that the choice that a resident makes whether it negatively impacts them that they have that right to do that, but if they say for a smoker who's dying if they still want to go out for a cigarette knowing that they will go into acute respiratory distress, that we have the medications on hand to provide the quality so to manage their symptoms. (Site 5, interviewee 2)

Staff in all but one facility reported that the intervention had improved resident quality of care. As with other reflections on the intervention, they cited symptom control are a core component of this improvement. Further, staff also reported that their confidence to care for dying residents and skill in talking about death and dying had improved the care they were able to provide to both the resident and their relatives:

They're [staff] a bit more attentive to what's required as well. Rather than just you know they're dying and we just leave them be, sort of thing, they're a bit more attentive with their care, pressure area care and all that stuff as well and understanding the important that that still needs to occur. (Site 5, interviewee 1)

It gives us a plan as well. As well as the relatives it gives us an outline of where we're heading yes. (Site 1, interviewee 2)

I think we are more aware of signs to look for around pain management and constipation and things, so I feel that we are definitely more aware of the signs and symptoms than we previously were. (Site 2, interviewee 2)

The one site which did not feel that the new model had improved care reported already delivering top quality care, and that after only six months of the new model they did not feel as though there had been sufficient time to assess change. Despite those elements of reservation, the interviewee did feel that the intervention had improved their confidence.

Interviewee: Most of our staff are really good on that, here.

Interviewer: Do you think it's changed?

Interviewee: Not too sure yet again with this discussion. With the staffing I'm not too sure yet, with the Needs Rounds, because it's – not even a year [since] we starting in the area [...]My confidence really building up and I'm so happy with this Needs Rounds, I think it's really great and keeping in the place (Site 10, interviewee 2)

Indeed, the impact on staff confidence was reported by multiple interviewees, relating to talking to relatives/residents about death and dying, communicating with GPs and managing medicines.

I think it's given [staff] more courage I guess to try and do things themselves rather than sort of the head in the sand 'it's too hard'. So they're more hands-on with it. (Site 2, interviewee 1)

The surge in confidence had also meant that staff were taking on more of a leadership role in running case-conferences:

As [staff] knowledge improves they're also able to start doing a little bit more. So less reliant on, you know, having someone come and run the case conference for you, now going, "Oh well, actually, I can do that" (Site 3, interviewee 1)

Morale had therefore been improved within sites as staff increasingly felt able to take on more sophisticated tasks relating to nursing and psychosocial care:

I think we give better care through the knowledge that we've been given. We're actually we're better at giving care to the residents at the end of their life with what's been given to us and then with the whole staff- like the staff are good like they're taking it in, they're actually wanting to know. (Site 3, interviewee 2)

One staff member illustrated how her confidence had improved enabling her to talk to a family openly about their father's prognosis and facilitating him to die in his preferred place:

That was a conversation that I would have struggled with before the palliative care Needs Rounds. (Site 6, interviewee 1)

Staff were asked directly to comment on whether the model of care had impacted residents' quality of death. In keeping with the quantitative data, the majority said it had improved residents' deaths, with only one interviewee saying that they were uncertain as the resident themselves was often unconscious in the period just prior to death. Responses often summarised that better anticipatory care had led to better controlled symptoms for the resident at end of life. These features had also meant that relatives' experiences had improved too.

It has [made a difference to quality of death] if we can give the resident a pain free time at the end. If we can keep them comfortable you know. It's – pain. It's skin integrity you know if we can look after them so they're not in pain, they're comfortable, they're relaxed, they're in their own bed, you know it's all those things that add to their comfort, all these medications. (Site 12, interviewee 2)

I think people now are dying in a – this sounds very odd, in a much better way, like, really – being pre-emptive having those conversations, preparing families, having that medication on hand so when it needs to happen it can straight away. And having people alert to the fact that there's a significant – like there's a deterioration and we need to do something about it and now I think that, that has led to some better outcomes and people dying in a really comfortable way and the families being at terms with it, before it happens, which means that they cope a whole lot better after the death. (Site 3, interviewee 1)

Post-death care had also improved with one site indicating that washing residents after death and preparing their bedding was now 'more personal' (Site 2, interviewee 2), as the fear of death had been removed.

Anticipatory planning was considered key to improving residents' quality of life, particularly through communication with the family and assessment of symptoms that may require medical management. Needs Rounds were also indicated to offer a more holistic approach to anticipatory care planning:

It's provided a more holistic approach to I guess thinking about the future and what could possibly go wrong for a resident and what interventions we need in place in case an acute event was to happen to facilitate appropriate palliative care measure. (Site 5, interviewee 2)

For one interviewee, a strength of the model of care was in helping develop better multidisciplinary care in the facility:

We have gained a lot, a lot from having the Needs Rounds. Involving the care staff has probably been the biggest thing because prior to that you know [RNs] would kind of be the ones that were just dealing with everything, they were just dealing with the one on one care. [...] Carers really appreciate that, they love the fact that they can come in and sit on [Needs Rounds] as well and they learn so much more from it. (Site 2, interviewee 2)

#### 5.4.5 Knowledge changing practice

As indicated in section 5.2.4, staff confidence in supporting people approaching end of life increased with exposure to the Needs Rounds approach.

In the qualitative interviews, staff commented that the Needs Rounds had increased staff confidence in implementing a holistic palliative care approach particular in terms of anticipating end of life, and in managing symptoms.

Like I said we didn't have that much broad knowledge about the whole palliative [approach] and the only idea we had is so they're close to the end so we just had to like check on them simple [things] like oral care but now [we have a] broader understanding definitely, when the Needs Round you know, came into place. (Site 10, Interviewee 1)

Yes it did increase a lot because they [staff] were not confident at all. Now you know ...we can frankly speak during the palliative care Needs Rounds so talking to [Clinician 3] it did help us in increasing our confidence. (Site 11, interviewee 1)

I think especially pain and education really managing well since Needs Rounds because then we're getting built up confidence (Site 10, interviewee 2)

I think they're definitely more aware of telling us and you know us putting something in place a lot earlier than waiting .... I think they [staff] definitely have more understanding that it's not just about when it gets to the last you know couple of days/weeks what not that having something in place prior to that is going to help that resident to help the comfort. (Site 2, interviewee 2)

Education was identified as one of the important benefits from the Needs Rounds. Not all staff at the facilities attended the Needs Rounds and so did not directly benefit from the case-based education offered. However, some sites had built in mechanisms to broaden out the learning and share new insights with the wider care team. Some sites wrote a detailed synopsis of the learning in the resident's file, emailed Needs Rounds discussions to care staff who were not able to attend, while others gave verbal summaries to staff.

Yes yes yes. I think especially pain and education really managing well since Needs Rounds because then we're getting to know more to the palliative nurses and we're getting built up confidence as well like what can be done and we still can discuss any time with them and yes I think it's definitely improving. (Site 10, interviewee 2)

I think education has been the greatest thing about them [Needs Rounds], which is just improving care. We're learning so much more and then we can provide better care which is good. (Site 1, interviewee 1)

Our knowledge base has improved due to the Needs Rounds and the word of mouth. So when we have our AINs that come to - and RNs that come to the Needs Round, they go and spread the word and give you a feedback to the other AINs and RNs and whatnot, and we do like a little teaching thing. (Site 1, interviewee 1)

So I take minutes for that [the Needs Round] and then after we have the meeting I actually disseminate that to all the staff because we had an email address that goes to everyone. So I can impart all of that information and everyone can read it. ...we need to share it with everyone, because it's not always the RN at the bed side that's doing the care, we know that. It's the care worker or the care supervisor. (Site 3, interviewee 1)

Staff felt that the involvement of nurse practitioners in delivering the intervention led to improved benefits for facility staff and residents. Residents were able to have medications put in place faster.

it's been amazing. It's been really good to have [Name of NP] come review, change, be able to change medication immediately rather than waiting for a GP and we've definitely seen an improvement in symptom management from her input. (Site 5, interviewee 1)

The trial had sought to increase the number and utility of case conferences, to aid anticipatory care. At some sites, the number of case conferences has not increased, but at most sites, staff reported a qualitative improvement in how they were run. From a clinical point or view when we first started before the trial, a lot of RNs were a bit hesitant to be involved in the advance care planning and having those discussions but they're definitely become a lot more confident in their knowledge and how they can support someone in going through an advance care directive and goals and what people want, and what they don't want so I think that's a positive. (Site 5 interviewee 2)

Many staff reported that they had learnt a lot about medicines from the Needs Rounds, including side-effects, dosing and contraindications. While management of symptoms and confidence in medicines had improved for many, one interviewee identified the learning around polypharmacy as being one of their most important learnings:

Managing polypharmacy, that's really important in aged care. We want them to be on as less as possible that would create a therapeutic effect and I think with knowledge from the palliative care team is to acknowledge what's not going to make a difference anymore.[...] that was probably one of the most important things that they've really raised at the care Needs Rounds with families as well. (Site 1, interviewee 1)

#### 5.4.6 Documenting and discussing end of life choices

As illustrated in section 5.1, those residents who died during the trial were more likely to have an ACP, health direction and/or EPOA in place. This affirms the idea that overall, Needs Rounds led to better anticipatory planning.

During the qualitative interviews staff indicated that facilities differed in their views on whether the Needs Rounds had led to more or better advance care plans for residents. Site 4, for example, interviewees felt that their practice had already been at high standard, while others identified an improvement: Even the start of this trial we used to include that thing with advance care plan whether they wanted to go to hospital. (Site 8, interviewee 2)

The number of advance care plans we have has just escalated. So it's just fantastic and we've now actually got the majority of our residents on with advance care plans which is really good. We've also introduced a way of showing who's got one and who hasn't so on our list we've got the red dots to show who has got an advance care plan and doesn't want to go to hospital. (Site 6, interviewee 1)

For many staff, the documentation and discussion of choices went hand in hand. Though many sites felt their documentation was strong prior to the trial, they all reported improvements in how they went about discussing end of life choices with residents and relatives. Staff were more confident in explaining the need for advance care plans and discussing the benefits and burdens of choices.

Now that we have a Needs Rounds it's, like I said, we're more confident in actually putting plan in place because we know what to answer now. Before, like I said, it is in place, but when they ask you, "Why you doing this now?" We kind of like get frozen and stop, "Actually, we don't know." Now we're confident that we're. It's been a great help. (Site 10, interviewee 1).

I feel that I'm definitely confident in having all the conversations around those aspects, in giving them you know – going through the advance care plans, explaining what each individual thing means, and what it means for the resident and for the family you know things to expect and what not and so I feel that I'm pretty confident in going through that with them and discussing you know funeral arrangements and things like that, what their wishes are. (Site 2, interviewee 2)

#### 5.4.7 Hospital transfers

Qualitative data revealed complexity with regard to impacting hospitalisations. Some of the data reflected the quantitative findings that the intervention reduced hospitalisations, while other interviewees felt that the intervention had not influenced hospitalisations.

Needs Rounds does not make a dramatic difference, we always minimise that... I think it may have given more confidence to talk to families [about managing in the facility rather than sending to hospital] (Site 8, interviewee 2)

They still seem to transfer too many people I think. (Site 9, interviewee 1)

All but two sites reported reduced hospital transfers, with Site 8 stating that they had always managed transfers well, while another interviewee felt that most residents *want* hospital transfers.

Before the start of the trial, we always aim to minimise the hospital transfer at the end of life. And that is – and still we are following that. [...] Needs Rounds does not make a dramatic difference, we always minimise that. (Site 8, interviewee 1)

*Probably less now because we're able to you know handle symptoms here lots better than we once were. (Site 4, interviewee 2)* 

Staff knowledge about disease trajectories, increased knowledge to manage symptoms in the facility and the likely functional and physical decline of residents transferred to hospital were core pieces of new learning.

I've worked in an aged care facility before and it was "if in doubt send out". That was actually the rule, whereas now that's completely changed and, you know, the theory is we go through the care plan, what do they want. How did they want to die, where did they want to die and that's definitely changed since we've been doing Needs Round. (Site 1, interviewee 1)

I didn't have much knowledge on how badly it can affect the care of a resident when they go to hospital so the prevention of going to hospital I think I learnt a lot about and I think a couple of the RNs did as well, they can deterioration a lot faster. (Site 1, interviewee 2) We are more confident to tell their own family, 'look we can do this thing here rather than sending [them] hospital again, this is their home' (Site 10, interviewee 2)

We have less admissions to hospital well I don't think we have any for palliative care measures ... I guess if the nurses have become more confident if their care directive says 'not for hospital' they still have an obligation and a duty to discuss the risk [of sending residents to hospital]. ...We've learnt to do that. (Site 5, interviewee 1)

Staff articulated that making decisions about transfers was always done in the light of resident and relative preferences, but that facility staff were more confident in caring for people without necessitating a hospital admission. Cultural norms were reported to affect some hospital transfer decisions, whereby some residents would always want to be admitted.

## 5.4.8 Implementation

Implementation was largely reported as easy and worthwhile. Having regular Needs Rounds meant staff recognised a regular time at which they could ask questions and gain feedback and training. Many of the sites had existing relationships with the clinicians delivering the intervention and were comfortable contacting them outside of Needs Rounds. Respondents often used the word 'easy' to describe implementation at their site.

However, some interviewees reported difficulties in the practicalities of the Needs Rounds. One interviewee felt that there was pressure to run the Needs Round on the monthly schedule even if this was pragmatically difficult at the facility. This was explained as an artefact of being in the trial where monthly Need Rounds were expected:

It doesn't make any sense to me, why. You know those sort of thing? So just for the sake of those few to make the number for your trial, why I need to do it and within 20 days in a month so that doesn't make any sense and I'm really not happy with the way how- like you know these discussions should be driven by the patient by the need of the patient, not by the need of your trial. (Site 8, interviewee 1)

Consequently at some sites monthly Needs Rounds were felt to not fit neatly with the flow of work in all sites. Some of the clinicians were more flexible than others in arranging and re-arranging Needs Rounds and case conferences, so the personal style of the palliative care practitioner acted as a moderator of implementation.

One site (with fewest residents) found that they had discussed all residents at Needs Rounds several times, and had no new people to talk about, or worried in the lead up to the Needs Rounds about being able to identify appropriate residents to discuss. Releasing staff from care was also reported by some sites as hard, but not insurmountable.

It wasn't hard to adopt the model but it was hard to get staff off the floor to sit with the educators (Site 1, interviewee 1)

Other challenges, for some but not all sites, involved the additional staff time commitment in attending and running case conferences, and organising GPs to attend.

There's always time constraints. You know it doesn't matter whatever you're doing in aged care, it's always very busy. That's our biggest thing. I think getting the family conferences with the GP and everything has bene difficult. That's been our most difficult thing. (Site 2, interviewee 1)

Many interviewees noted the positive impact that PEPA (a national palliative care education program) and GRACE (a local clinical initiative with care nurses supporting people post-discharge from acute settings) had had on their work.

## 6 **Discussion**

#### 6.1 Generalisability and connections with established evidence

The overall impact of this model of care is the marked reduction in hospital admissions, whereby substantially fewer residents were sent to hospital. The primary outcome, length of stay, was shown to reduce by half a day, which was a statistically significant reduction, but does not represent a clinically meaningful unit of change.

Needs Rounds reduce the number of hospitalisations and length of stay, increase the ability to die in preferred place, improve residents' death and dying and improve staff confidence in looking after people who are receiving palliative care. Process evaluation findings indicate the model improved documentation about end of life choices, such as ACP, directives and EPOA, and involvement of specialist palliative care staff, including nurse practitioners, facilitated preparedness and improved knowledge and management of symptoms through accesses to medications and education.

Many of the National Palliative Care Standards are met by this study. The intervention allows for ongoing assessment of the person's needs (standard 1), the person's needs directly inform the care plan (standard 2), the family's needs are assessed (standard 3), facilities were supported to deliver person centred care (standard 7), the specialist palliative care service and aged care facilities engaged in this research to improve provision (standard 8), the education provided in the Needs Rounds supports facility staff continuing professional development (standard 9) (Commonwealth of Australia 2010).

Further, palliative care Needs Rounds model addresses the four core areas of the national strategy, namely: i) improves awareness and understanding of palliative care among staff in care facilities, (ii)

offers appropriate and effective specialist palliative care, (iii) supports high quality leadership and governance and (iv) builds capacity and capability in care staff (Commonwealth of Australia 2010).

Australia's population is aging rapidly, with 3.8 million people aged 65 and over representing 15% of the population in 2017 expected to increase to 8.8 million over the next 40 years (AIHW 2017). In Australia in 2015-16 there were 235, 100 permanent residents in aged care (AIHW 2018b). The increasing number of older people will result in increased need for residential aged care services, with projections estimating the number of residents in residential aged care to rise by 150% from 1998 to 2031 (Madge 2000). Data analysing where people die in Australia indicate that 46.1% of people who died in 2012 to 2014 were in permanent and respite residential aged care (AIHW 2018a). Hospital use at end of life is high indicating that 47.1% of permanent resident deaths had been hospitalised within 30 days of death, of these 14.1% died in hospital (AIHW 2018a). While data is not available on projected deaths in residential aged care in Australia, studies from the UK and Portugal indicate future projections of decreasing deaths at home, while a study in Belgium indicates an increase in deaths in residential aged care (Gomes & Higginson 2008, Houttekier *et al.* 2011, Sarmento *et al.* 2015). This indicates the need for health care policy and services to meet the needs of the increasing number of people dying in residential aged care.

Of residents who attended hospital, the reduction in length of stay (half a day) is not large enough to have clinical significance, however the overall reduction in number of hospital episodes is of substance and produces a substantial cost saving. Indeed, it is striking that 528/943 (56%) of hospital presentations were in the intervention phase, since the intervention duration was nearly twice as long as the control phase (124 months in intervention compared to 74 in control). In the case that the intervention had no effect, hospitalisations would be expected to be twice as high in the intervention period. Study findings are consistent with other studies which have found that treating

residents in the nursing home as opposed to hospital improved outcomes for residents, including improved mortality and reduced end of life hospitalisations (Caplan *et al.* 2006, Miller *et al.* 2016).

Nursing home staff wish to reduce preventable hospitalisations, yet often lack clear methods of doing so (Cohen *et al.* 2017). Increased ACP improves the confidence of residential care staff to discuss goals of care and leads to a reduction in hospitalisations (Caplan *et al.* 2006). Nursing home nurses who are supported to provide anticipatory medications leads to reduced hospital admissions and faster symptom management (Wilson *et al.* 2015). Provision of support to nursing home staff has been shown to improve end of life care for nursing home residents (Seymour *et al.* 2011). Needs Rounds provide a much-needed structure and outcome for nurses and residents.

This model of care helps people to die in their preferred place, and this is consistent with findings from a systematic review of the determinants of home and nursing home deaths which found that the availability of palliative care services increased the likelihood of dying in a nursing home compared to in hospital (Costa *et al.* 2016). This model therefore acts as a substantial tool to meet this recognised international marker of quality end of life experience (Smith 2000).

Findings indicate the trial was effective in improving staff awareness about end of life symptoms and their management. Late awareness of impending death leads to missed opportunities to manage late stage pain and symptoms. A previous study has found that when nursing home staff identify impending death, care provision incorporating palliative care to manage pain and symptoms are put in place (Cable-Williams & Wilson 2014). This model of care helps enable people to achieve a good death (Swerissen & Duckett 2014) and is consistent with the Effectiveness and Appropriateness goal of the National Palliative Care Strategy which aims to provide interventions which are supported by an evidence base (Commonwealth of Australia 2010).

Facilitating discussions about end of life choices for people leads to improved outcomes for the resident, their family and carers, and staff members looking after them. This finding is consistent with other studies which have found ACP increase the likelihood of residents dying in the nursing facility, rather than an acute hospital (Pekmezaris *et al.* 2004), and being supported in the nursing home for conditions other than fractures (Cohen-Mansfield & Lipson 2006).

The model improved preparedness for palliative care, and knowledge has changed practice, including improved management of symptoms through access to medications and education. This is consistent with other studies which have found palliative care improved symptom management including for pain, and supported staff in building palliative care capacity in residential facilities (Kaasalainen *et al.* 2013, Ziegler *et al.* 2018).

## 6.2 Limitations

A number of limitations should be considered alongside the findings.

The cost calculations may underestimate the total savings as it excludes treatment costs and transfer costs. Data were unavailable to estimate treatment costs. The cost of transfer to hospital varies by mode of transport and who initiates the transfer. The range is from \$247 (patient transport such as discharge from the hospital), \$685 (transfer requiring paramedics and booked through a health service) to \$959 (emergency ambulance through 000)<sup>2</sup>. The cost may be an out-of-pocket expense to residents, or fully funded by the government if the resident has a concession healthcare card.

<sup>&</sup>lt;sup>2</sup> See <u>http://esa.act.gov.au/actas/fees-and-charges/</u>

The dose effect of the intervention and its impact on cost savings has not been calculated. Cost savings may not continue at a linear rate; larger facilities may continue to reduce hospitalisations in residents not discussed in Needs Rounds during the trial, smaller facilities may have plateaued in benefit having already implemented high quality anticipatory planning for all residents.

There is potential that the some hospitalisations were not captured in the data collection, in both control and intervention phases. Consequently, the LoS and cost evaluation should be treated with some caution to account for missing data from both public and private hospitals.

The cost of hospitalisations within the trial are also impacted by the number of deaths. The 537 residents who died during the study (155 whom died in the intervention phase) cannot subsequently access a hospital bed. Consequently, decedents prospectively accrue zero costs, and annual cost savings have not been adjusted to reflect the number of deaths by phase of trial.

The cost savings would be significantly higher if acute bed day cost is used. The most recent published acute bed day cost in 2015/2016 is \$2,200. Hence the total bed day cost saving per month per facility is:  $11.56 \times $2,200 = $25,432$ , and the annual minimum net cost saving would be: \$3,280,492. However, the costs evaluation was based on an average bed cost, and included both private and public hospitalisations. Though the majority of admissions were to public hospitals, the net savings to the public sector may be slightly inflated by not separating out the private admissions.

Staff turnover in the facilities and the specialist palliative care team may have impacted on the implementation of the intervention, and the ability to build working relationships. Consequently, the observed impact of the intervention might have been stronger without such staff changes. Engagement with the facilities was an ongoing component of the clinical work, and in addition to

usual practice in maintaining good working relationships, a one-off celebration of facilities' work in supporting palliative care was held. This celebration event was seen as important in recognising the additional work that the trial had created for staff (notably in providing data and adopting the new structure of Needs Rounds meetings) but no data were collected on whether the celebration impacted fidelity to the study.

Facilities varied in their engagement with the intervention, with consequent impact on outcomes. The implementation challenges reflect real-world working dynamics where facility cultures may ease or hinder the adoption of new models of care.

The study did not assess the quality of ACPs. That is, while the crude number of residents with an ACP increased, it is not possible to report on whether these were useful or high quality documents. Existing facility policies regarding hospital transfers may have impacted on study's ability to reduce hospital admissions – for example, policies such as 'always transfer residents on blood thinners to hospital'. Further work could be conducted with facilities to make these strategic and policy-level changes to further bolster the impact of the work.

The access and availability of medications in facilities may have impacted on study outcomes. Some facilities had easier access to pharmacies, though this did not necessarily mean that residents always had timely and appropriate prescriptions. Data was not collected on whether anticipatory medications were administered.

In October 2017 the Geriatric Rapid Acute Care Evaluation partnership (GRACE service) was implemented in three of the trial facilities. The aim of the GRACE service was to provide a

collaborative care model for acutely unwell residents in retirement and aged care facilities. The GRACE service may have contributed to changes in number and length of hospitalisations.

It was not possible to collect adequate data on relatives' views of the care in the facility. The monthly questionnaire was used at all facilities for a period of six months but yielded very low response rates. Consequently, this data collection was ceased as the burden of completion was thought to outweigh the learning which would come from data that had not achieved a sufficient sample size for analysis.

Only three interviews were conducted with relatives of residents discussed within Needs Rounds. It became apparent during these interviews that relatives often had little insight into how the different elements of care worked together. Further relatives were often unaware of the Needs Rounds and although had attended case conferences, were not clear how this related to specialist palliative care involvement. Consequently, since the interviews were unable to shed light on the intervention, this part of data collection was ceased. Little data on the model of care was therefore collected from relatives or residents. This is a limitation of the data and means that the impact of the approach to care is partial and restricted only to staff views and the quantitative outcome measures from hospital records. There is increasing need for models of care which can appropriately support residents and staff in residential settings. The acuity of resident symptoms, multiple morbidities and demographic shifts mean that implementation is an urgent clinical priority.

## 6.3 Recommendations

- The Needs Rounds model of care should be implemented without delay, which may require additional staffing.
- Flexibility regarding the frequency of Needs Rounds and numbers of residents discussed in Needs Rounds may increase buy-in from sites. Such measures would reduce perceived pressure on facilities with fewer residents, or lower turn-over of residents.
- Engagement from facilities is needed to effectively implement the model of care, including level of buy in from management and staff and willingness to change.
- 4. Adherence to the model directly impacts outcomes, an observation which was demonstrated most starkly on quality of death.
- 5. Feedback from residents and relatives would helpfully bolster the evidence base on the impact of the model of care.
- 6. Developing positive working relationships with GPs will facilitate better uptake of the actions emanating from the Needs Rounds. GPs often inform whether hospital transfers occur, and their attitudes affect their engagement to provide palliative care and comfort with anticipatory prescribing.
- 7. This model of care could also be adapted to use teleconferencing to allow uptake in remote and rural settings without easy access to face-to-face specialist palliative care.

## 7 References

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