

Normalising and planning for death in residential care: findings from a qualitative focus group study of a specialist palliative care intervention

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ABSTRACT

Background Improving access to palliative care for older adults living in residential care is recognised internationally as a pressing clinical need. The integration of specialist palliative care in residential care for older adults is not yet standard practice.

Objective This study aimed to understand the experience and impact of integrating a specialist palliative care model on residents, relatives and staff.

Methods Focus groups were held with staff (n=40) and relatives (n=17). Thematic analysis was applied to the data.

Results Three major themes were identified. The intervention led to (1) normalising death and dying in these settings, (2) timely access to a palliative care specialist who was able to prescribe anticipatory medications aiding symptom management and unnecessary hospitalisations and (3) better decision-making and planned care for residents, which meant that staff and relatives were better informed about, and prepared for, the resident's likely trajectory.

Conclusions The intervention normalised death and dying and also underlined the important role that specialists play in providing staff education, timely access to medicines and advance care planning. The findings from our study, and the growing wealth of evidence integrating specialist palliative care in residential care for older adults, indicate a number of priorities for care providers, academics and policymakers. Further work on determining the role of primary and specialist palliative care services in residential care settings is needed to inform service delivery models.

INTRODUCTION

An ageing population, improvements in disease management and a reduction in

the nuclear and local family have all contributed to the rise in residential care for older adults¹ providing subacute care. With an often short interval between admission and death, survival is often <6 months.² Consequently, providing care that is conversant with palliative care principles is important.

Improving access to palliative care for older adults living in residential care is recognised internationally as a pressing clinical need.^{3–5} The integration of specialist palliative care in residential care facilities for older adults is not standard practice, although recent studies have provided evidence for the utility of this approach.⁶ In Australia, there has been a drive towards facilities offering a palliative approach⁷ to support residents, with promising results.⁸

Skill mix in clinicians working with older adults is a key consideration, with community nurse practitioners specialising in gerontology and long-term care identified as particularly useful team members.⁹ Access to a specialist palliative care clinicians who are authorised to prescribe, such as nurse practitioners, has benefits within this setting.¹⁰ Additionally, residential care staff with experience and expertise in diseases other than cancer have insight into conditions relevant to this age group, such as dementia and stroke.¹¹

This paper reports findings from an intervention integrating specialist palliative care into residential services (nursing homes) for older adults. The study sought to improve outcomes for residents, including reducing hospitalisation, and increasing achievement of preferred

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place of death. This paper reports the views of staff and relatives on the intervention.

METHODS

This paper reports the qualitative inductive component of a larger study. The wider study applied a quasi-experimental design, examining the impact of a new model of specialist palliative care service delivery.¹² The model involved direct and indirect clinical inputs, and case-based education provided by a palliative care nurse practitioner (PCNP). This paper reports the experiences and impact of integrating specialist palliative care into residential care for older adults on residents, relatives and staff.

The intervention involved education for staff (identifying deteriorating patients, symptom management and communicating with general practitioners (GPs) and relatives) and direct clinical work (symptom assessment, diagnosing, prescribing) with residents. Needs rounds were also held. Needs rounds are triage and education meetings with staff to identify residents likely to die in the subsequent 6 months and start planning to ensure relevant goals of care are met. The intervention was delivered by a PCNP in four sites in an Australian city. The PCNP was employed with local government health funding and was based in the specialist palliative care unit. The PCNP provided in-reach integrated services to a total of 14 facilities in the city (only four of which were involved in the study). Overall input to the four facilities was ~2 days/week. The PCNP time was split: ~60% face-to-face care including symptom management, case conferencing and supporting families, 40% indirect care on triage meetings (educating and mentoring staff), communicating with other health professionals and data collection. The facilities involved in the study ranged in size from 60 to 120 residents (mean: 90) with a total of 360 beds. The intervention was conducted over a 6-month period from November 2014 to May 2015.

The data reported here are based on focus groups that ran separately with staff and relatives of residents at the care facilities. Participants were recruited using a convenience sampling strategy. Staff employed by the facilities who had contact with residents receiving the intervention were invited to a focus group. As most residents had significant communication impairments, the views of relatives rather than residents were sought.

Inclusion criteria for relatives:

1. Resident died at least 3 months ago.¹³
2. The resident had been discussed at a needs round or had direct input from the clinical specialist.
3. Lived in the same city as the study was conducted.

Recruitment

Invitations and information sheets about the study were posted to the 51 eligible relatives of the 104 residents involved in the study. Of them, 20 replied and

17 consented to participate, with the remaining 3 indicating their lack of availability. Staff at the facilities were asked by their managers to participate. Forty attended, representing ~14% of the workforce.

Data collection

Semistructured focus group topic-guides were developed by the researchers based on curiosities developed during the course of the study, on the impact of the intervention on routine care (see online supplementary file). The staff focus groups examined: perspectives on the PCNP's involvement in resident care, the impact on staff, changes in practice, experiences of talking about dying and care needs, knowledge and attitude about caring for people at end of life and recognising dying. Relative focus groups explored interactions with the PCNP and wider care team, symptom management and communication about death and dying. Six staff focus groups and three relatives' focus groups were conducted. With consent, all discussions were audio recorded and transcribed. Data were collected at the local hospice (relatives' focus groups) or in the residential facilities (staff focus groups). Focus groups lasted between 38 and 90 min.

The majority of focus groups were run by a female qualitative health researcher, with 17 years experience in the field, who had no prior relationship with any of the participants. One further focus group was run by a female gerontological nurse practitioner, with a small amount of research experience. She was employed part-time by the residential facilities, with no direct line-management relationship with any of the participants and limited day-to-day interaction with staff.

Data analysis

Recordings were transcribed, anonymised, then subjected to an iterative thematic analysis¹⁴ and informed by a position of theoretical freedom. Analysis, using Nvivo, proceeded through a five-stage process. Stage 1 involved familiarisation with the data set. Stage 2 involved identifying a thematic framework. Stage 3 involved indexing the data with reference to the themes. In Stage 4, responses were synthesised across respondents and themes refined. Stage 5 focused on data interpretation and finalisation of key themes. Staff and relative data were analysed separately to begin and then jointly to identify overlapping issues.

Analytical rigour was enhanced through NJ and LF coding data and team discussion of emerging themes. Thematic sufficiency was achieved within the focus groups, with no new substantial areas arising in the final focus group.¹⁵ Participant checking of the transcripts, findings and interpretation was not used.

RESULTS

Focus groups had a total of 57 participants. Seventeen relatives participated (n=14 women, all adult

Table 1 Study participants

Facility	Total residents	Patients receiving the intervention	Registered nurses/facility (in focus group)	Paid carers and other staff (in focus group)
1	100	45	4 (4)	98 (12)
2	60	30	3 (2)	70 (3)
3	80	15	3 (3)	70 (5)
4	120	14	4 (4)	98 (7)
Total	360	104	14 (13)	336 (27)

children). Forty staff participated (n=35 women), consisting 20 carers, 13 registered nurses, 4 team leaders, 2 managers and 1 geriatrician. Table 1 illustrates the size of facility, residents receiving the intervention and staffing. Data analysis led to considerable homogeneity in themes, indicating that the sample size was adequate.

Three major themes were identified in the analysis: (1) normalising death and dying, (2) access to specialist palliative care and (3) planning. Less dominant themes, not reported in full here, included ideas raised by staff and relatives (communication, support for the family, responsibility for residents' care) and issues raised solely by staff (expertise/authority of the PCNP and specific symptoms such as mouth care and hydration).

Theme 1: normalising death and dying

The intervention normalised the presence of death and the process of dying in care facilities. Through this intervention, staff were supported to recognise that supporting people who are dying was a routine part of their work:

It's a bit tragic it's [death and dying] a medical discussion because it's very obvious that when most of us are born, that we're going to die. It's a given. (Staff: Group 6)

The palliative care [needs] rounds [...] makes you think about people, and there will be possibly three quarters or a half of this building may die in six months. So it's just making it beyond the people who are actually sort of, you know, sort of a day or so away of dying that you can incorporate [palliative care] quite early [...] so everyone is in a better place to deal with it when the resident does start to decline. (Staff: Group 3)

The intervention allowed staff to understand dying better, leading to improved confidence in discussing death and dying with families. Staff also reported identifying their role in such conversations and avoided them less:

[The PCNP] is straight down the line, you know what I mean, and that's good, and that's what we've learnt we've kind of not just beating around the bush you

know, she's straight down the line with the families and it seems to work because the families understand her and they want to go with whatever and the outcomes have been great. The families now do have a lot of confidence. (Staff: Group 2)

The previous quote illustrates that the staff did not feel that they were yet experts in holding discussions about end of life or terminal care. The PCNPs communication style modelled an approach to talking with relatives about the normalcy of preparing for death and dying. Consequently, although death was more normalised, there still appeared to be an implicit request that a palliative care specialist begins those conversations.

Some staff reported their realisation that relatives were open to discussions of planning for death:

The communication part has been quite good, for example there was a couple of residents that, or resident's families that have expressed their desire to have a palliative care approach for their family member, like within the next day a representative came and spoke to the family and the residents about it and they've gotten onto the palliative care approach quite soon after that. They [the family] are very open about it. (Staff: Group 1)

Education was an important part of the intervention, enabling staff to understand symptom management, including administering pain relief before personal care. Education also improved the relationship among staff, families and residents:

Families feel a lot more supported I think going through the end-stage because we sit with them hour after hour after hour but because, well like we've had an education from [the PCNP], we can now like connect with [the family] and give them the support that they need [...] we've established a strong relationship with not only our residents but the families as well in that end stage. (Staff: Group 4)

End of life conversations happened sooner:

I have those conversations two, three days, a week, sometimes we start having that conversation, we start putting in 'I don't think mum's right, have you considered an advance care plan, have you looked at', you know we have those conversations earlier, before, because I used to be a team leader on night shift, it would be like two o'clock in the morning and you'd see something's gone wrong with the resident and you'd be ringing the family like 'oh I think you should come in', 'well why I was there on the weekend and mum was fine' you know so those conversations are happening earlier at more appropriate times than leaving it to the last minute. (Staff: Group 4)

Staff reported that overall, the work led to them feeling like they were providing better care to people who were dying.

Theme 2: involvement of a palliative care specialist

The focus group data demonstrated the inherent value in involving a palliative care specialist to support residents. Awareness of the benefits that such involvement brings was evident, for example providing specialist expertise:

Not just the residents and the family but the staff as well, you know I've noticed a big change in the staff and the fact that they think 'oh we've got someone we can fall back on and rely on' and the PCNP's been really strong like that and awareness, yeah the awareness and the comfort knowing that there's someone there who's professional and can help support the team. (Staff: Group 1)

Symptom management was felt to have improved, with multiple examples of starting syringe drivers and managing agitation. Staff reported that evidence-based tools such as the Abbey Pain Scale¹⁶ made pain management more effective. Educating staff about symptoms and potential treatments was felt to have benefitted residents and family members:

P1: [Pain] is a bit more manageable isn't it, I noticed

P3: With the nurse practitioner being here they're more involving pain control for our residents which is really good and they review it quite regularly or frequently, so if it's not working change it and then

P1: And I think the residents' families are much better with that too and they're not, obviously if they see their family in pain they freak out, where I think now it's been more controlled. (Staff: Group 1).

Feedback specific to the nurse practitioner role was also abundant in the data. Improving timely access to medication was particularly valued by staff and recognised as important to relatives too:

The fact that [the PCNP] has the ability to increase medications and make medication changes is helpful because sometimes you can wait for weeks for a GP to come, so you've got that extra person who can make the changes on the med charts. (Staff: Group 5)

Medication reviews were also strongly valued:

P2: [the PCNP prescribing] was our salvation... mum was on Endone and I wanted her taken off it because it was just sending her nuts and she really didn't need to be on something like that and I kept asking them to take her off it. She was put on it in hospital at one stage and they said for her to be weaned off when she went back to the nursing home. But the doctor said 'oh no, I like to keep the patients on the medication that they come out of hospital with because they've got it right' and I said 'but they said to wean her off' but it wasn't written in the notes...

Interviewer: So did [the PCNP] help remove medications as well?

P2: Yes, and we changed it to a patch, a Fentanyl patch which wasn't as bad for mum. (Daughter: Group 2).

Slow and variable access to GPs was a consistent theme for staff. This model provided a useful conduit to GPs. The model increased confidence of staff talking with GPs, and was reported to improve GP confidence in the care provided by the staff:

P1: [If we didn't have the specialist PCNP] we'd lose effective and prompt management of residents dependent on their lottery of who their GP was.

P3: And whether or not their palliative care and end of life quality of care would be impacted on, I believe it would be, I believe it would be, I think they would have a better death with a palliative care nurse practitioner than without.

P2: I think all that we've been saying is that the GPs are taking more notice of [the nurse practitioner] than they were of us, so she's that intermediary if you like facilitator (Staff: Group 5).

Staff were asked whether and in what ways care had changed since the introduction of the specialist palliative care clinician. Symptom management was identified by all teams as managed proactively rather than reactively, meaning that anticipatory prescriptions could reduce symptom burden considerably:

We were able to get prescriptions and get everything running, we can save at least 12 hours, one day and get [analgesia] started. (Staff: Group 2)

Theme 3: decision-making and planning for life and death

Part of the model was to ensure that conversations about goals of care and developing advance care plans happened in a planned manner, rather than during medical emergencies:

The meetings were sort of, mainly happened on the go actually where [PCNP] was present and the doctor was present, there was [GP] she was there and also perhaps the nurse in charge and so it was directly discussing a particular set of circumstances with mum's health at the time, so whether or not she was responding properly to the medication she was receiving or responding adequately enough for us and [PCNP] to feel that the desired effect was actually happening. (Son, Relatives: Group 3)

Family members reported that hearing in advance what their relative's death was likely to be like was helpful in enabling them to psychologically prepare for the dying phase:

We were basically watching him die, so and that's hard and that's, it's scary too, you think oh my God what's going to happen, but [the PCNP] told us what was going to happen or where he's at and you know and that, that made it a lot easier. (Daughter, Relatives: Group 3)

The needs rounds were reported to be beneficial in planning ahead, checking the status of residents' care plans and starting palliative care earlier:

Because we recognise deterioration in someone [...] who may have given up or decided enough's enough, or you can sort of see the disease process hastening, actually getting onto that palliation earlier, not necessarily doing anything about it, but just being aware, I love that, I love the fact that you can pinpoint [...] and say 'look I really don't think they're going to be here for another 12 months'. Can we start looking at that? And when something happens you're sort of ready for it. (Staff: Group 1)

Unnecessary hospitalisations had been avoided through planning for symptoms and discussions of goals of care:

There's been a lot less hospitalisations because we're prepared whereas before we'd be sending residents off because we couldn't bear to watch them in pain and the doctors weren't really on board and we had no other [option] so we would send them to hospital for pain relief, whereas now we're better prepared. (Staff: Group 4)

Planning around medications was widely regarded as a very positive component of the model:

There's been great improvement in getting the medications on time before it reaches end stage palliation, getting the pain a lot better controlled I think is also an improvement. (Staff: Group 4)

Trust between GPs and the registered nurses at the facilities had flourished, meaning that GPs had confidence to write-up anticipatory medications for end of life, knowing that they would be used appropriately:

The GPs are definitely more on board having dealt with the PCNP [...] there was a hesitance to commence a syringe driver or look at palliative medication and so it was almost like they were worried that we were going to use them when we didn't need to [...] they trust us more with our decisions now. (Staff: Group 4)

DISCUSSION

The data from this study document staff and relatives' views of an intervention integrating specialist palliative care into residential care for older people. The findings echo a recent rapid review endorsing the integration of specialist palliative care and residential care for older adults.¹⁷

The intervention normalised death and dying and also underlined the important role that specialists play in providing staff education, timely access to medicines and advance care planning. The data suggest connections with discourses of creating compassionate communities that normalise death,¹⁸ alongside the necessity of specialist medical advice and interventions. Our model sought to strike a balance between

providing expertise in death and dying (including timely access to palliative medicines, sophisticated understanding of disease process), and supporting staff to become more used to supporting people near end of life. This fits with data suggesting that death is an inevitable and often rapid sequelae of admission to residential care.¹⁹

The data illustrate the complexity inherent in the overlapping roles of the specialist and generalist health practitioners,²⁰ and care facility staff lack of confidence in leading conversations. Specific roles such as medication review were identified as specialist tasks. More universal primary palliative care tasks, such as communicating with residents and relatives about advance care plans, were enabled by access to a specialist. The literature demonstrates growing concern that GP services are unable to meet current need.^{21 22} Staff confidence and skill in discussing end of life decision-making and role expectations require attention to avoid unnecessary hospitalisations.²³ Our study suggests a place for specialists (with expertise in prescribing and prognosticating) and non-specialists (with a growth of confidence in talking about death and dying and planning for end of life care).

The rise in staff confidence evident in the data is linked to staff education. Education has been identified as a core component in other projects integrating palliative care specialists in residential settings.^{24 25} There have been very few longer term follow-ups of how such models are experienced over time,⁶ which indicates a need for longitudinal designs.

The well-received anticipatory 'needs rounds' mirror evidence of the benefits of case conferences, which improve quality of care.²⁶ These needs rounds approximate 'comfort care rounds', piloted in Canada, with promising results indicating an impact on staff knowledge and confidence.²⁷ The needs rounds in our study however differ from comfort care rounds, and case conferences, in identifying residents most likely to require palliation and triaging care requirement.

Anticipatory prescribing, indicated in our data, has been evidenced elsewhere as a clinically useful approach.^{28 29} The data from our study underline the importance of analgesic prescribing and echo a study identifying that the second most commonly prescribed medication by nurse practitioners is analgesia, at 42%.³⁰

In the wider study, cost savings were estimated from the reduced length of stay for hospitalised residents. The data indicate considerable savings in adopting this model.¹² The model appears sustainable, with the input required reducing over time as staff confidence increases and they take on more of the tasks. We aim to roll out the intervention across the city to determine take-up and impact of the model on a wider scale.

This study had a number of limitations. Recruitment to the study may have resulted in a bias sample of staff and relatives with positive accounts of

the intervention. The frequent turnover of staff at these care providers also meant that the cohort recruited to the study were those who had been employed longer and therefore not necessarily representative of employees. Managers were encouraged to invite all staff to focus groups. Two focus groups were populated by staff attending an in-service training day and were consequently not handpicked. However, it is possible that at other sites managers differentially encouraged some staff to participate in focus groups. GPs were not invited to participate in focus groups, and this limits insight into how the model impacted their practice. Further, with only one PCNP employed within this study, the positive results may be an artefact of that individual, rather than the model as described.

The findings from our study and the growing wealth of evidence integrating specialist palliative care in residential care for older adults indicate a number of priorities for care providers, academics and policy-makers. Education and support for care staff that normalise death and dying in residential care through increased exposure to the principles and practices of health-promoting palliative care is a priority, alongside appropriate access to specialist clinicians with palliative care skills. Further work on determining the role of primary and specialist palliative care services in residential care settings is needed to inform service delivery models.³¹ Integrated models of care require an additional longitudinal study focusing on the transferable principles of these complex interventions, in order that this most vulnerable population has equality of access to appropriate care. Further research should evidence the impact of this work when rolled out on a larger scale quantifying, for example, staff death literacy, and quality of life and quality of death of residents.

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