



‘It sort of has the feel of being at home’: Mixed-methods evaluation of a pilot community-based palliative end-of-life service in a regional setting

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Abstract

Objective: To evaluate the acceptability and effectiveness of a small community-based hospice on the end-of-life experiences of patients and families.

Methods: Mixed-methods study.

Design: Patient admission data were used to assess utilisation of the hospice. Open-ended interviews with hospice patients and their families/carers were used to understand the emotional effects of the service.

Setting: A small palliative end-of-life hospice in a rural town in NSW, Australia, during a 12-month trial period that began in March 2019. Data were collected in October–November 2019.

Participants: Patients, families and carers who used the hospice during the trial period, as well as staff working at the hospice.

Main outcome measure(s): Quantitative measures included the number of patients admitted to the hospice, the average length of stay and the overall occupancy rate of the hospice. Quantitative interviews were used to explore the experiences of patients and families who used the hospice, and whether the hospice met their end-of-life needs.

Results: During the trial, 58 patients were admitted to the hospice. The majority of admissions were less than 7 days. Two patients and nine family members were interviewed about their experiences, and six staff completed interviews. Experiences were consistently positive, with the community setting of the hospice contributing to a peaceful and home-like end-of-life experience. Interviewees described meaningful relationships with staff, a pleasant physical environment and the comprehensive care provided were key elements of this experience.

Conclusion: This model, embedding end-of-life care within a residential aged care facility, facilitated a positive end-of-life experience for residents of this regional community. The development of local models to meet local needs is

essential to enabling people nearing the end of life to remain in their location of choice, and ensure that their needs are met at this vulnerable time.

KEYWORDS

community-based, hospice, nurse-led, palliative care, rural

1 | INTRODUCTION

Quality End of Life Care (EoLC) is where the dying person can: (1) be cared for and die in their place of choice; (2) have access to care and services; and (3) maintain connection to family and meaning.^{1,2} In Australia, approximately one-third of people reside in rural or remote areas. Rural areas are typically characterised by an older age profile and poorer health outcomes, including higher rates of chronic illness, higher death rates, and a lower life expectancy, which are typically exacerbated by poorer access to services.³

There are recognised gaps in the provision of EoLC to rural and remote residents. While approximately 30% of those who die in Australia receive specialist palliative care at some point in their journey, those from regional, rural and Indigenous populations undergo worse end-of-life care, characterised by 'poor access, relocation and hardship'⁴ and barriers to specialised support services.⁵⁻⁸ More patients overall would choose to die at or near home than do, and fewer rural than urban patients die at (or near) home.⁹⁻¹⁴

When family members are engaged as informal providers of palliative care this responsibility can result in negative consequences to their well-being.¹⁵ Approximately half of informal carers report that caring for a loved one nearing the end of life was worse, or much worse, than they expected.¹⁶ A systematic review of rural EoLC found that family members take on a disproportionate amount of care-giving due to less access to services and to information.⁴

While all agree that a range of support is necessary, and the State Plan prescribes coordinated, responsive care,¹⁷ many rural and remote areas of NSW have no access to specialist palliative care physicians or services.^{18,19} The rate per 100 000 of Medicare-subsidised palliative medicine services in outer regional areas is only half that in major cities, with even lower rates of provision in remote and very remote areas.²⁰ Most people who die will be cared for by non-specialists,²¹ with community-based professionals and families taking the burden of care.²² Australian rural GPs have a central role in EoLC and despite the challenges they face, some rural/regional communities report closer doctor-patient relationships and better care integration.²³ However, the availability of

What is already known on the subject:

- Research consistently shows that a majority of people would like to die at home while only 14% currently do so
- The process of dying is institutionalised and medicalised
- Families particularly in rural and remote areas feel unsupported in realising the final wishes of their loved one

What this paper adds:

- A trial of a small hospice in a rural town was effective in creating a homelike, calm end-of-life environment which gave patients autonomy and relieved carer burden
- This model provides an opportunity for patients at the end of life, and their families, to be supported in a homelike setting without having to leave their community or remain in a sometimes stressful home environment
- Challenges were related to fluctuating admission rates and difficulties predicting the final days of life

designated beds with dedicated staff to support the dying person in rural regions of Australia is limited. Admission to a formally designated hospice will usually mean the rural patient has to leave their region, community and family.²⁴

Perceptions about the desired place for death though can differ between patient and carer and do differ over time.²⁵ The Australian Productivity Commission cautioned about death at home as a performance measure, a better goal being 'helping people to stay at home for longer' regardless of where 'people spend the last few days of life, when pain and care needs can be greatest'.²⁶ A study of place of death in the Snowy Monaro region of NSW concluded: 'While there may be a need to support an increase in home deaths, local rural hospitals and residential aged-care facilities must not be overlooked as a substitute for inpatient hospices'.²⁴

Rural end-of-life care has been identified as a priority for research²⁷ and systematic reviews^{28,29} have revealed a focus on identifying problems with the delivery of care, rather than evaluating strategies to improve services. Recently, a community-based Victorian palliative and end-of-life service *were* comprehensively assessed for sustainability—defined as acceptability, affordability and adaptability—with serious challenges identified.^{30,31} Thus, building on the identified need to study models of end-of-life care for rural patients, this paper examines an implementation trial of a new Palliative End of Life Care service, providing a residential facility with four dedicated beds (attached to but separate from an established residential aged care facility), in a regional town in NSW, Australia.

2 | METHODS

2.1 | Setting

Members of this NSW inland regional community of approximately 40 000 people lobbied for a ‘hospice’. The Local Health District (LHD) implemented The Palliative End of Life Service (PELS) in March 2019 and provided funding to the residential aged care facility to implement and evaluate a 12-month trial of PELS that began in March 2019. Data were collected in October–November 2019. There was no cost to the patient under this model. In the LHD, end-of-life and palliative care are primarily provided by patients’ own local GPs. There is also a small community palliative care service of nurses, medical officers, etc., operating out of the local base hospital. This team supports patients within the immediate community and neighbouring townships, the furthest of which is located approximately 130 kilometres from the base hospital. The team can provide equipment to support home palliative care, syringe drivers for morphine, etc., but these services are limited to homes within the immediate region.

2.2 | Characteristics of the end-of-life service trialled

A residential aged care provider was selected to establish and run the PELS (after a competitive tender process). The four-bed service is housed within an established residential aged care facility. Rooms are fully furnished and include a patient bed, wardrobe, bedside table and lamp and multiple comfortable chairs for family members, including a chair that reclines into a single bed for family members who wish to sleep in the patient’s room. These rooms

are also fully equipped with necessary medical equipment and supplies. Each has a private bathroom with handrails and an accessible shower. Many of the furnishings and artwork in the patient rooms were donated by the local community, reflecting the strong community support for the service. Each of the rooms has direct views and access to outdoor areas, which include a garden developed through fundraising by local community groups.

The service includes several communal areas for the families of patients. There is a fully equipped kitchen and dining area, a sofa bed for family members who may wish to sleep at the facility, and a communal lounge room, with multiple comfortable lounges and occasional chairs, and a large flat-screen television for family members to use. Families also have access to other facilities including laundry services and a hairdresser.

2.3 | Service provision

Patients are able to be referred to the service by their GP, the community palliative care service, or a member of their inpatient team, when they are clinically assessed as being in their final 14 days of life and deemed by a member of their clinical team to be suitable for the services offered by the facility. Once the referral has been made, patients can then be admitted to the service directly from the community, or inpatients may be transferred from the local hospital.

Palliative End of Life Service is funded to have a registered nurse on-site 24 h a day, as well as support staff during the day and is supported by the local community palliative care service. The patient’s GP is responsible for day-to-day medical management, including charting and administering medications, medical reviews and on-call availability. Where a patient is admitted without a nominated GP able to manage their admission, support is provided by the Palliative Care Service Medical Officer from the community palliative care service who acts as the ‘GP of last resort’. The model also specifies that, where required, the local hospital will provide expert medical and nursing consultation advice including face-to-face visits if needed.

2.4 | Post-service implementation evaluation

2.4.1 | Ethics

Approval for all components of this mixed-methods post-service implementation study was obtained from the Greater Western Human Research Ethics Committee (Ref

ETH12484). All participants were provided with an information sheet and gave written informed consent.

2.4.2 | Participants and data collection

This study took a mixed-methods approach. The data collection period was from October to November 2019, 6 months' post-service implementation.

Qualitative data were collected from convenience sampling, with PELS service staff approaching patients and family members to determine their interest in participating in the study. Patients or families who were considered too physically unwell or emotionally distressed were not approached. The qualitative interviews were conducted by two female social workers employed by the LHD, who had extensive experience talking to vulnerable families. The social workers were independent of both the PELS and the research team, however expressed an interest in the topic as a reason for taking part. They were involved in data collection only; data analysis was undertaken by the research team. They phoned the service weekly to inquire whether there were any patients or families interested in taking part in an interview, and if so, arranged a time suitable for participants to complete an interview. Patients were fully informed about the purpose of the study, and provided written consent before commencing their interview. Interviews were undertaken with all appropriate and interested patients and families during the data collection period. As patients were admitted to the PELS for a short period before their death, and interviews were brief, it was not possible for interviewers to establish a relationship with participants prior to or during their interview.

Palliative End of Life Service staff were informed about the evaluation by their manager, and staff who indicated interest in participating met with a member of the research team (TH) to learn more about the study, read the information sheet, provide consent and complete an interview.

Interviews with families and staff were audio-recorded, with the exception of one family interview (two family members) where the family did not consent to audio recording; in this case, extensive notes were taken. To maintain rapport, patient interviews were not recorded, but extensive notes including direct quotes were taken by the interviewers. Nobody other than the interviewer and participants was present for the interviews. Recorded interviews were transcribed verbatim by a member of the research team (TH).

Quantitative data for the evaluation were provided by electronic health records within the LHD and the

TABLE 1 Interview schedules for patients, families and staff

Patient and family interview guide
How did you/your family member come to be staying at the hospice?
What did you expect staying in a hospice would be like and has this experience fitted with your initial expectations? <i>If further prompts are needed for this question: is there anything you were worried about, or surprised by, either pleasantly or unpleasantly?</i>
What kind of environment were you/your family member being cared in for prior to entering the hospice; and in what ways, positive or negative, does the experience of being in the hospice vary from the environment you were in previously?
Is there anything that would improve your hospice experience?
Have you noticed any benefits or drawbacks to you/your family members arising from you/your family member being cared for in the hospice?
What do you think about the physical environment of the hospice; how does it make you feel and is there anything you would change about it?
Staff interview guide
What, if any, benefits have you observed for patients and their families who use this service?
What, if any, drawbacks have you observed for patients and their families who use this service?
Do you have any suggestions for improvements that would improve the patient/family experience?

palliative care team. Descriptive data included admissions, occupancy rates and average length of stay at the service.

2.5 | Data analysis

Quantitative data for this study were categorised as follows:

1. Demographics (age and sex)
2. Occupancy rates (proportion of available beds that were occupied)
3. Length of stay (number of days patients remained in the service)

The interview transcripts and notes were deductively coded guided by the interview schedule (Table 1). Data were analysed using thematic analysis. The two researchers who undertook the analysis firstly strengthened their familiarity with the data through re-reading, listening to audio-recordings and reviewing notes made during or following the interviews. The researchers conducted an initial independent coding exercise to identify recurring themes. Themes were consolidated through discussion between the two researchers.

3 | RESULTS

3.1 | End-of-life care service demographics

There were 58 admissions to the service during the trial period (March–November), representing 51 patients. Several patients had two admissions as they became well enough to go home for a short period before returning. During this period, 59% of patients were male and 41% were female, with an overall average age of 76 years. Due to privacy considerations, no more detail can be provided.

3.2 | Occupancy rates

Occupancy rates fluctuated during the trial period, with the lowest rate of 15% in August and the highest rate of 73% in October, and an overall average occupancy rate of 43% for the period of study. However, the occupancy data were affected by two patients who had extended lengths of stay at the service in October–November. When those months are excluded, the overall occupancy rate was 35%.

3.3 | Length of stay

The average length of stay at the service during the trial period was 9.3 days, including five admissions that exceeded 21 days. This is similar to the average length of stay in inpatient palliative care services across NSW (10.3 days) and nationally (10.2 days) (Australian Institute of Health and Welfare, 2019). Table 2 shows the patient length of stay at the service for the trial period.

3.4 | PELS impacts on patients, families and staff

3.4.1 | Patient and family interview outcomes

In total, two patients, and nine family members of patients were interviewed while they were residing at the service. The nine family members represented five families; there were one to two family members present at each interview, and they were generally children or partners of the patient. The majority of patients who were interviewed (or whose families were interviewed) had been primarily cared for at home, with increasing hospital admissions prior to their transfer to PELS; in most cases, patients had been transferred to PELS directly from the hospital following an admission.

TABLE 2 Length of stay at the palliative end-of-life service, $n = 58$

Length of stay (days)	Number of patient admissions	Percentage of admissions
1–7	36	62%
8–14	13	22%
15–21	4	7%
Greater than 21	5	9%

The duration of interviews ranged from 7 to 18 min. The key themes from the interviews with patients and family members are described in further details below. While the number of participants interviewed was based on those who were eligible during the data collection period, analysis of transcripts indicated that data saturation was reached.

Patients and family members contrasted PELs with previous experiences

Patient and family experiences were largely positive, with one patient (P2) stating that they had ‘not one complaint’ about the service, that they ‘wouldn’t change anything’, and that they were ‘pleasantly surprised’ with the service. This patient also reported that the service provided ‘everything you could ask for’. One family member (F6) said that ‘it’s only been 2 days, but so far I don’t think any of us could think of anything we would change’. Another family member (F3) stated that “I would recommend it to anyone who is in the same situation.”

The period of home care was described as demanding due to the relentless nature of providing care and over an uncertain timeframe and its effects on family relationships:

I’ve actually taken leave from work to be mum’s primary carer. We’re getting into the fifth month, which has been very stressful to a degree on myself and my brother...

[F2]

Additionally, some families were providing these views on a background of considerable previous lived experience:

We did go through the palliative system 18 months ago with my mother, and it was a problem... mum was in hospital for 6 weeks ... and they basically said ‘you need to find her an old aged home because she can’t stay here any longer at the hospital’ ... And we’ve had some bad run-ins with old aged homes

in the past with grandfathers and stuff like that...

[F3]

18 months ago when we were looking [for services for another palliative family member], there wasn't a facility. So we're just super grateful that there is now, and it's only new but it's wonderful.

[F4]

Overall impacts on patients and families

The perceived atmosphere of the service was associated with multiple benefits for both patients and family members. In some circumstances these were noted as broad improvements in well-being for the family as a result of short-term respite provided and flexibility, whereas in other instances participants highlighted specific improvements to the patient's previous situation. For example one family member expressed the relief of having his wife admitted to the service as she had previously been residing at home with her young children. The patient and her husband did not want the children becoming distressed watching their mother in pain and being admitted to the service had alleviated this concern.

A beneficial effect on some patients' general well-being was noted by one family member:

Mum actually likes it here, she's found it quite uplifting to talk to other people, other than us. You've got other people to talk to when you have your meals.

[F2]

I think she [the patient] has picked up a little bit [since being admitted to the service], because at home she was becoming a bit stressed. It takes that family pressure aspect away from it.

[F2]

Similarly, patients also spoke about the benefits that the service had offered to their family members, with one patient saying that it had eased their family's distress because "they know I'm being cared for." [P1] Another patient described how "it has given them respite...gave them a break." [P2].

Multiple family members mentioned the comprehensive care and social support provided:

It's an isolating experience with someone going through something like this at home, for both that person and the carer. So when

you come to somewhere like this, there's people going through the same process. So, I think really it's well set up.

[F2]

With the level of care here, if [a family member] had to leave to just have a break, he knew that his dad was in good care here with the staff. Whereas in other cases, he's hesitated to have a break and go home because he's worried about the care that will be given while he's away only for a brief moment, whereas that hasn't been an issue here.

[F3]

This has been a godsend because it's unrealistic to think that you can do it all the time [care for a family member full-time at home].

[F2]

The flexibility for families provided by PELS was greatly appreciated:

Just the flexibility here to be able to come and go as you please for family members. Like with hospitals, obviously you have to be within the visiting hours and stuff like that. And if you've got a family member who is very restless, which happens towards the end of their life, and visiting hours are up, and you're basically told you've got to leave, that's very hard to deal with.

[F3]

The access is very easy, the staff are very friendly. Even when they do have the lockout at the front door after 6pm, it's not an issue for you to buzz the bell, and they come and welcome you in.

[F5]

You can come and go as you can fit into work, before or after work. You can visit any time.

[F2]

Relationship with staff

Many family members spoke about the positive relationship that they had built with the staff at the service, and the positive effect that this had had on their experience.

As soon as we came to [the service], all the staff were very welcoming and you could tell that they were very caring. The 6 days or

so that we've been here, I can't fault them. They're absolutely perfect, I would recommend them to anyone that is going through the same situation.

[F3]

The nursing staff is incredible, they're so attentive, and they're very caring. Which is what a family wants to see when they've got a loved one at the end of their life.

[F3]

I was pleasantly surprised by just by how attentive the staff are, not only to my father but to me and my brother, and other family members. It's not just a matter of coming in and going "how's your dad?" and having a bit of a once-over and walking out. They're then "how are you?" And they want to know how the family is and how the family are coping with it.

[F3]

Several families mentioned their appreciation that their regular GP could continue to provide care, particularly in cases where families had an ongoing, positive relationship with their GP. One family described that their family member (the patient) had been 'greatly relieved' that his own GP could continue to provide his care in the service, and that the family felt more comfortable with a doctor who knew the patient's history and could identify changes in the patient's wellbeing.

Physical environment of the service

Both patients and families highlighted the positive physical environment at the service, and the benefits that this has provided. One family member stated: 'the facilities are excellent', while another said 'I didn't imagine it would be this good'.

Several patients and family members spoke about the autonomy allowed and encouragement to voice personal wishes, stating:

I wouldn't change anything, I'm pleasantly surprised with it. It's good to be able to go outside to have a cigarette. The fresh air in the room from the opening door. There is everything in the room that I need.

[P2]

We can bring the little dog to visit

[F8]

Anything you want is in the room already. The people working here are always asking me if there's anything we want. Everything you need is already here.

[F5]

Other family members spoke of the facility more broadly, and the resources and atmosphere outside of the patient rooms in the broader building and surrounds:

It's great when the kids come, they're young and after about 10 min they're pulling their hair out. So they can come out and hang in here [the communal room] which is a nice touch to have somewhere else to go.

[F4]

I think the facilities they have here for families, that make families feel very comfortable and welcome to be here, are fantastic.

[F7]

I like the way the facility is set up in here with the large windows and the sliding doors so they can look out into a bit of a garden scene. It's less clinical, a bit more homely and very calming.

[F3]

Like home

The final theme is an integrating one. The comprehensive care provided, the flexibility, the caring staff and the physical environment created, made patients and families describe it as 'an extension of home'. [P1] Patients and families shared perceptions of feeling settled and contented: 'I think it has a settling effect. What you thought you had as a problem wasn't really a problem'. [P1].

Families described a positive and welcoming environment, and that this had settled their anxieties about having their family member admitted.

As soon as we got here, I thought 'we've made the right decision.'

[F6]

It was a pleasant surprise. Simply a pleasant surprise to know that something like this existed. It immediately created a better sense of calmness under the circumstances, immediately.

[F7]

My experience here has been like being treated like family, not like a patient.

[F5]

It's nice. This place is like a familiar place, and all the people working are very helpful. It looks like your own house. On the first day, they said to me 'anything you want, just tell me, and we'll provide it for you.' I wasn't expecting it to be like that.

[F5]

The décor is really nice, it sort of has the feel of being at home. Not quite, but a much less clinical environment. All of that creates a more relaxing and comfortable atmosphere to go through something like this.

[F7]

I think the homely atmosphere of the place is really good.

[F2]

Suggestions for improvement

No negative experiences were reported from participating patients or families. Many suggested there was a need for more information about and promotion of the service. The majority of patients had received information about the service from their doctors or nurse managers, but had not been aware that the service existed until they were asked if they would like to transfer. One family member stated: 'I didn't know about it prior to a few weeks ago', [F3] while another said 'the doctor came up 2 days ago and explained to me all about this... I didn't know it existed'. [F6]. Another family member described how he was initially hesitant to admit his father into the service, and changed his mind only when provided with more detailed information from his family GP:

I said 'I'm not putting Dad in some old aged facility that's rundown and the staff aren't caring, I'm not having a part of that.' And he [the GP] said 'no, this is a different show. This is actually trialling four palliative beds.' Once we had that sort of information we were happy to move Dad here.

[F3]

3.4.2 | Staff interview outcomes

Six members of staff from the service completed interviews, with staff professions including care service employee, registered nurse, kitchen staff and homemaker. Staff discussed their understanding of how the service has affected the experiences of patients and families. Two

central themes emerged from the data, which are described in detail below.

Perceived patient experience

Staff reported that the perceived experience of patients and families at the service was consistently positive.

All the families... they tell us 'you're marvellous. We don't know how you do it.' And they're happy because the rooms are beautiful. And they're comfortable and they feel like they're at home.

[S1]

Most of the families are 100% over the moon with the service provided, the facility, all that.

[S3]

It is good for the family. We're support for the family, we listen to them. It's much more appropriate and kind; it's personal.

[S4]

Furthermore, staff also indicated that patients and families seemed comfortable in the service, as evidenced by the fact that patients did not hesitate to tell staff their needs.

If something is an issue then they're very vocal about that, nothing goes on (that they don't tell staff about)

[S2]

The palliative care RNs ... they come regularly and interview the patients and the families, and they're always very well voiced. Communication is very good.

[S4]

Need for more awareness about end-of-life services

Similar to the family members, the staff mentioned that more promotion might be needed to increase occupancy rates, as awareness of the service is low both among staff at the hospital, and among members of the community:

We need more exposure of what the service is. More public awareness. The average person, you tell them where you work and I say the front bit (of the building) is the end of life and they'll say 'oh I didn't know that was here.'

[S3]

I feel like we need more exposure... At the hospital they were admitting someone from the ward to here, and the guys on the ward didn't even know the process. So I feel like on the hospital side of things we're a little bit unknown because they're not sure how to get to here. But then on the community side of things, they're not really aware... I think there's a couple of gaps on both sides.

[S2]

4 | DISCUSSION

The aim of this evaluation was to examine the impact of a community-based end-of-life facility in a regional town, where the majority of end-of-life care had previously been provided in a hospital setting. The final days of life have been previously reported as a time when patients' symptoms are often uncontrolled and the support needs of families may not be met,³² suggesting that the introduction of this service will have considerable benefits for the community.

Although the service was well received by patients and families, the occupancy rates for the duration of the trial were overall low, which may be a result of the perception expressed by both families and staff that greater promotion of the service was needed. It is not uncommon for occupancy rates to fluctuate in end-of-life services, and therefore the lower rates observed in some months were not unexpected. It is possible that occupancy rates for the PELS will improve over time as local awareness of the service increases. However, this does reflect a challenge for ongoing resourcing for this type of service in smaller regional areas. It has been suggested that an average occupancy rate for a hospice in Australia is 85%,³³ although it is important to consider that this will vary greatly due to the demographic and remoteness profiles of communities, levels of demand and different approaches to planning and delivering services between states and territories.³⁴ The use of residential aged care staff and the co-location and support provide an example of an 'adaptable model' as advocated by Spelten for sustainability of quality EOLC in rural regions.³¹

Interviews with patients, families and staff reflect the value of the service in contributing to a positive end-of-life experience. Families spoke about advantages of the PELS over caring at home, in that it relieved some of their stress and isolation. Previous research has reported that caring for a patient in a home-based setting is often very stressful for family members, resulting in both physical and emotional burdens associated with the responsibility

of providing physical care.³⁵⁻³⁷ PELS alleviated this, and patients and families were, therefore, able to spend their final days together without concern about the physical aspects of the patient's care.

Themes emerging from staff interviews largely reflected the findings from patient and family interviews. Similarly to patients and families, staff reported that patient experiences at the service appeared to be positive, and that where possible all patient needs were met to contribute to a positive end-of-life experience. They also echoed the findings from the quantitative analysis that the service was underutilised, expressing that this may be because awareness of the service was poor. Staff suggested from their interactions with both patients and families and employees of the local health service, that there is room to improve promotion of the service, which might increase referrals. It has been noted in previous research that an underuse of end-of-life services in rural areas is not uncommon, with strategies such as education for local health workers on available end-of-life care options and the use of palliative care case managers being suggested as potential options to improve uptake.³⁸

This study has several limitations. Patients were initially informed about the study by PELS staff, who used their clinical judgement to assess whether patients were in a sufficient physical and emotional state to participate. This meant that patient participant numbers were small, and it is also possible that the full scope of patient views was not represented. Second, we did not interview patients, families, or staff from the area's other end-of-life services (which include the local hospital and supported at-home care), and therefore cannot conclude whether the positive views expressed towards the PELS are unique to this model of care. Lastly, our evaluation was conducted reasonably early within a relatively short-term trial; it is possible that some issues raised, such as low occupancy rates, may have changed over time as awareness of the PELS increased within the community.

This small new residential rural unit dedicated to end-of-life care managed physically and socially to create the feel of home, and was greatly valued by residents and their families. Promotion with community and practitioners is needed to ensure reasonable occupancy levels and that dying patients and their families were aware of this option available to support end-of-life care. Evaluations such as this will assist decision makers in determining how best to invest to improve end-of-life care in rural regions, being mindful that approaches should be tailored to the needs and existing resources of communities (such as residential aged care facilities). This evaluation demonstrates the value to a rural setting of the addition of a hospice model of care.

AUTHOR CONTRIBUTIONS

TEH: conceptualization; data curation; formal analysis; methodology; writing – original draft. CJ: data curation; methodology; writing – review and editing. CS: data curation; methodology; writing – review and editing. LC: data curation; methodology; writing – review and editing. EF: writing – review and editing. AM: writing – review and editing. RC: writing – review and editing.

ACKNOWLEDGEMENT

This study was funded by the Western NSW Local Health District. Open access publishing facilitated by The University of Newcastle, as part of the Wiley - The University of Newcastle agreement via the Council of Australian University Librarians.

CONFLICT OF INTEREST

No conflicts to report.

ETHICAL APPROVAL

This study has received approval from the Greater Western Human Research Ethics Committee (GWHREC) (2019/ETH12484).

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How to cite this article: Handley T, Jorm C, Symington C, Christie L, Forbes E, Munro A, ‘It sort of has the feel of being at home’: Mixed-methods evaluation of a pilot community-based palliative end-of-life service in a regional setting. *Aust J Rural Health.* 2022;30:582–592. doi:[10.1111/ajr.12897](https://doi.org/10.1111/ajr.12897)