

RESEARCH ARTICLE

Managers' experiences of providing end-of-life care under the Home Care Package Program

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Abstract

Objective: The study explored the experiences of Australian aged care providers in supporting clients on a home care package to die at home.

Methods: Semistructured interviews were conducted with 13 aged care managers responsible for delivering services under the Home Care Package Program. Interviews were analysed thematically.

Results: Four themes emerged that illuminated managers' experiences: struggling to meet a preference to die at home; lack of opportunities to build workforce capacity in end-of-life care; challenges in negotiating fragmented funding arrangements between health and aged care providers; and mixed success in collaborating across sectors.

Conclusions: Aged care providers want to support older Australians who prefer to stay at home at the end of life. However, most clients are admitted to a residential facility when their care needs exceed a home care budget long before a specialist palliative care team will intervene. Budgets for health and aged care providers must be sufficient and flexible to support timely access to end-of-life care, to reward collaboration across sectors and to invest in building palliative care skills in the nursing and personal care workforce.

KEYWORDS

elderly, end-of-life-care, home care, home health agencies, palliative care

1 | INTRODUCTION

Recent Australian Government policy has increased funding to support older adults to live independently at home for as long as possible.¹ Older adults' preferences to remain at home are aligned with government interests in fiscal sustainability since the provision of aged care services at home requires less public funding than residential care.² The Home Care Package Program³ subsidises a structured, comprehensive package of daily living, personal care and

clinical care; tailored to meet the needs of older people living at home with more complex needs than are supported by the Commonwealth Home Support Program. There are four package levels depending on individuals' assessed needs from basic (Level 1) to high care (Level 4).³

The goal of home care packages is to delay or prevent admission into residential care. Indeed, many older Australians near the end of life (that is, those who are likely to die within the next 12 months⁴) report that they prefer to remain at home until death.⁵ Place of death is

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one of many factors influencing preferences for end-of-life care.⁶ However, Australia has the second lowest proportion of home deaths compared to institutional deaths (in hospital or residential care) in the Organisation for Economic Co-operation and Development (OECD).⁷ The majority of people who exited the Home Care Package Program in 2019–2020 entered residential care, while 34% died while still receiving care at home (11,289 people).⁸

Little is known about the capacity of aged care providers to support people to die at home, or their access to, and coordination with healthcare services able to deliver the clinical care needed at the end of life.⁹ Drawing on interviews with home care managers, this paper explores the experiences of providers trying to support clients on a home care package to die at home.

2 | METHODS

Given the lack of existing research, qualitative interviews were selected as the most appropriate method to explore home care managers' experiences of delivering end-of-life care for clients on a home care package.

2.1 | Participant recruitment and consent

Eligible participants were responsible for the front-line management of services delivered under the Home Care Package Program. Participants were recruited via convenience sampling through an advertisement in the newsletter of aged care peak bodies, and an online presentation to the home care manager groups of those peak bodies. Fourteen volunteers, unknown to the researchers, expressed an interest in participation via email. One researcher [SS] provided volunteers with an information sheet identifying the research team, funding, research aims, risks and explaining confidentiality, consent and withdrawal. Once [SS] confirmed a volunteer's eligibility, she obtained signed and informed consent. One participant withdrew due to time constraints.

2.2 | Data collection

A semistructured interview guide was developed in consultation with aged care peak bodies and explored all aspects of home care service provision including funding, staffing, training, models of care, perceptions of client preferences and experiences of delivering end-of-life care. End-of-life care was defined as caring for clients likely to be in the last 12 months of life.⁴ Interviewees were asked

Policy impact

As the Australian Government designs the new home support program, it should consider how the end-of-life needs of recipients will be met.

about their interactions with general practitioners (GPs) and specialist palliative care services. Palliative care was defined as a holistic approach to maintaining clients' quality of life who have life-limiting illnesses, through the prevention and relief of suffering.⁴

Data were collected through telephone interviews conducted between August and September 2020. [SS] (female, PhD), a project officer with 7 years of applied research experience, conducted the interviews under the guidance of an experienced senior research fellow ([SW], female, PhD) with over 20 years of applied research and qualitative expertise in health and aged care. Interviews lasted 30–45 min and were audio-recorded, transcribed and de-identified.

2.3 | Data analysis

Interview transcripts were thematically analysed using NVivo v12.¹⁰ Open codes were created by noting frequently recurring and evocative phrases, ideas and perceptions, which were then grouped into meaningful themes in an iterative process by one researcher [SS].¹¹ A random selection of four transcripts was re-coded by a second researcher [SW] to test for consistency. Where there was disagreement in coding, the themes were discussed and refined. To ensure the study conformed to best practice guidelines, we used the COnsolidated criteria for REporting Qualitative (COREQ) research checklist and met 28 of 32 items.¹²

Ethics approval was granted by the University of Technology Sydney Human Research Ethics Committee (Reference ETH19-4515) and Flinders University of South Australia Social and Behavioural Research Ethics Committee (Reference OH-00241).

3 | RESULTS

Thirteen interviews were conducted from a range of services across Australia (Table 1). Seven interviewees estimated that their service had <100 home care package clients. Managers were asked to estimate the number of their clients likely to be in their last year of life. Seven managers estimated that less than five of the clients were in their last year, while four were not able to provide a number.

TABLE 1 Profile of participating home care services

	<i>n</i> (%)
Ownership type	
Not-for-profit	7 (54)
For-profit	6 (46)
State/Territory	
QLD	4 (31)
VIC	3 (23)
WA	3 (23)
ACT	1 (8)
NSW	1 (8)
SA	1 (8)
Area served ^a	
Metropolitan	10 (77)
Inner regional	4 (31)
Outer regional	3 (23)
Remote or very remote	2 (15)
Number of clients on a home care package	
<50	4 (31)
50–99	3 (23)
100–199	2 (15)
200+	3 (23)
Do not know	1 (8)
Number of home care clients likely to be in the last year of life	
<5	7 (54)
5–9	1 (8)
10–19	0
20+	1 (8)
Do not know	4 (31)

^aSum > total *n* and 100% as some services served more than one type of area.

Most interviewees described their role as care or case manager and had extensive experience in the aged care sector. Eight had clinical experience as a health professional (Table 2). On average, interviewees reported that they had worked in their current role for 4 years and in aged care for approximately 18 years.

Four themes emerged from the interview data that illuminate managers' experiences of delivering end-of-life care for clients on a home care package: struggling to meet a preference to die at home; lack of opportunities to build workforce capacity; negotiating fragmented funding arrangements; and collaboration across sectors.

3.1 | Struggling to meet a preference to die at home

Managers perceived that most of their clients would prefer to die at home, but reported that they, and clients' families, struggled to accommodate this preference. There was

TABLE 2 Manager characteristics

	Number of managers (%)
Years in current role	
<2	3 (23)
2–5	5 (38)
6–10	2 (15)
11–15	3 (23)
Years in aged care	
2–5	3 (23)
6–10	1 (8)
11–15	1 (8)
16–20	3 (23)
21+	5 (38)
Healthcare profession	
Nurse practitioner	1 (8)
Registered nurse	7 (54)
None	5 (38)

a unanimous view that home care funding did not cover the cost of more intense personal and nursing care needed towards the end of life, or the equipment and consumables to support this care. Many remarked that the clinical care delivered by registered nurses was beyond the capacity of a home care package:

We need the [registered] nurses to go in AM and PM, and even if someone is on a level four package, there just is not enough money to cover that service. Our big goal with the packages is to keep clients at home, but they have to go into residential care because you cannot get the support.

(Manager 6)

Two managers commented that only clients who had accumulated a large amount of unspent funds could die at home from their budget, and only when combined with a short end-of-life phase. Such cases were rare. Consequently, the majority of clients are transferred to a residential facility before death. Indeed, two managers commented that this pattern was so entrenched that there was no demand from clients to be supported to die at home. Others worked hard to source equipment (appropriate beds were frequently mentioned) and alternative funds (from government and charities) to supplement a home care package. Manager 8 noted they spent 'a lot of effort and energy chasing grants and special funding'. Many proposed that an end-of-life supplement should be added to the home care program.

In the meantime, it was deemed almost impossible to accommodate a preference to die at home without significant family input. However, family carers were often overwhelmed by the financial, physical and emotional toll of providing this care.

[The client's] wishes caused heartache to the family. He was adamant he was going to stay home, but it was costing the family money... they didn't want to disobey his wishes, they just couldn't live with the guilt, so they went into debt.

(Manager 7)

I think the families really want them at home... but I think many of them are unprepared for the amount of time and care that's required in that final time.

(Manager 9)

The struggle to accommodate a client's preference to die in their own home and a consequent norm of transferring to a residential facility meant many organisations in the study had little experience in end-of-life care.

3.2 | Lack of opportunities to build workforce capacity

With home care funding insufficient to deliver end-of-life care, providers have lacked opportunities to build their workforce capacity. One manager commented that their organisation was keen to expand its personal care and nursing workforce capacity, but there were limited opportunities to gain the experience in delivering care to develop those skills.

We do all these online trainings but then [the specialist palliative care team] do it ...We're not empowered to do anything and although the [organisation] want us to be leaders in palliative care, we're not necessarily getting that opportunity.

(Manager 2)

Reflecting the Australian home care workforce more broadly, the skill mix in the participating organisations was heavily weighted towards personal care workers. There were mixed views on whether this workforce had the skills to provide personal care at the end of life. Some felt Certificate III training was adequate. Others recognised the need for specific training, but few provided

it. Crucially, two managers (both registered nurses) commented that timely identification of end of life is difficult for personal care workers.

I think there's still a long way to go for care staff [but they] are learning to recognise changes in the clients and to acknowledge when that end phase is approaching... When I came on board I went to a reassessment of a client. It was very clear to me that this lady was in a terminal phase and immediately did the referral to [a nursing agency]. Within days the lady passed away.

(Manager 11)

It is notable that five managers do not have a clinical background and therefore are not able to provide such oversight. Indeed, most organisations employed few or no registered nurses and therefore relied on agency nurses, who did not provide ongoing supervision of care. Manager 4 described this task-driven model as '[Personal care] is provided by our staff and then [the agency] come in and do the morphine'. Some managers valued the flexibility of agency arrangements since demand for palliative nursing services was sporadic. However, most home care budgets could not bear the cost of high hourly rates for agency staff at the intensity of nursing care required. Others commented it was difficult to secure agency nurses with palliative care skills at all, especially in rural locations.

With limited capacity within the aged care sector to deliver end-of-life care, managers advocated on behalf of clients to access the higher level clinical care provided by health services.

3.3 | Negotiating fragmented funding arrangements

Managers were asked whether, and how, they worked with specialist palliative care teams (typically based in local hospitals) and/or general practitioners (GPs) to support people to die in their own home. Two reported they did not work with such health services, both from smaller organisations who perceived there was no demand from their clients to die at home. The remaining managers reported a key challenge was negotiating the fragmented funding arrangements between the health and aged care sectors: who was funded to deliver what care, and when.

Managers' experience of securing palliative care services for their clients was highly variable. Many reported that palliative care services were themselves 'stretched',

especially outside metropolitan areas. Uncertainty around the timing and duration of the end-of-life phase created a gap between the clients' care needs exceeding their home care budget, and when the palliative care team considered them to be eligible for more intensive services (typically in the last month of life).

It's quite awful now that we have to really keep pushing to get their intervention and get them to help and sometimes it doesn't come until even maybe the last week – they are going in there and just doing that final bit.

(Manager 10)

Once palliative care services did become involved in a client's care, managers provided many examples where a simple division of responsibilities between them providing clinical, home and personal care worked successfully. One manager commented that the domestic services they provided were valued by the family carers involved in end-of-life care. However, where personal care needs exceeded the home care budget, disagreements could arise with palliative care teams over who was funded to provide what type of care.

Mostly, if you say [the client's] on a package, they offer limited palliative care. They might say, you have to offer personal care, and we'll offer this, or we won't pay for this, but you've got to pay for that.

(Manager 7)

Similar barriers to access were noted in arranging medical care at home from a GP. Managers perceived that GPs should be central to planning end-of-life care and symptom management. However, some clients did not have a regular GP, especially in rural areas. Managers also reported that many GPs were reluctant to make home visits on a regular or ad hoc basis, though some acknowledged that GPs were not properly remunerated for this. As Manager 11 highlights, this created another gap in care that led people to be moved to an institution to die.

When you need pain management or symptom control and you need a GP to be involved, it's often very hard to get that immediate response. I guess that's one of the reasons then that people are more likely to have to go to hospital.

(Manager 11)

Limitations in the level and model of funding often made it difficult to negotiate access to, and agree on a division of

responsibilities with health services. The fragmentation between the two sectors was sometimes evident in the quality of collaboration between services.

3.4 | Collaboration across sectors

Collaboration across sectors to deliver end-of-life care at home was variable. A small number of managers felt specialist palliative care teams did not work collaboratively with aged care providers and that their staff were 'shut out' of client care once palliative services intervened. However, most managers appraised the quality of collaboration between their service and the palliative care service positively. They described the team as responsive and easy to work with (even during the COVID-19 crisis). There were examples of successful partnerships working, palliative care teams providing training in end-of-life care, and in one case, of cross-sector clinical meetings.

We have regular clinical meetings with the palliative care team. The clinicians meet once a week. The managers meet once a month.

(Manager 3)

Overall, managers appraised the quality of collaboration with GPs more negatively. Many perceived that GPs were difficult to engage, unresponsive to emails and phone calls, and did not keep home care providers 'in the loop' about clients' care. This manager, a registered nurse new to the aged care sector, was frustrated with the difficulties of engaging GPs in clients' care planning.

There are seven doctors I've sent client reports to, two and a half months ago, and they haven't bothered to respond. So that system needs to change drastically because the partnerships are sitting there waiting to be made ... but if they won't engage with us, our hands are tied.

(Manager 1)

4 | DISCUSSION

Aged care providers want to support older Australians who prefer to stay at home at the end of life, but even the highest-level funding available under the Home Care Package Program does not support the level of personal and nursing care required. Managers overwhelmingly reported that in the absence of a family able to invest significant time, financial and emotional resources, older people are likely to be moved to a residential facility

or hospital. These findings are in line with those of the Royal Commission into Aged Care Quality and Safety (Royal Commission)¹³ and Gill et al.'s¹⁴ study of older people's experiences of managing their home care budgets. Managers' calls for an end-of-life care supplement appear warranted, though any additional funding would have to be flexible, consider unspent funds, and not be subject to lengthy waiting times. At the time of writing, such specific funding is not included in proposed reforms. However, a proposal to improve service responsiveness by allowing a temporary funding increase (up to 25% of a client's annual budget) could contribute to the cost of end-of-life care.¹⁵

A consequence of the Home Care Package Program not being set up to support people to die at home is that providers have not built workforce capacity to deliver end-of-life care. This has further entrenched the norm of older people being moved to institutional care. As for the sector more broadly,¹⁶ few of the providers in this study had specific end-of-life training for their personal care or nursing staff. However, training does not overcome the problem of the low numbers of registered nurses employed in the home care sector and the subsequent limited opportunity to oversee care. An analysis of HCP spending in 2018/2019 found 2% of Level 4 budgets were spent on nursing care services.¹⁷ Some providers in the study did not employ registered nursing staff at all, which means that personal care staff undertake unsupervised care and assessments,¹⁸ and the end-of-life phase is identified too late. In response to the challenges, the Australian Government has accepted the Royal Commission¹³ recommendation that providers must ensure that staff working in palliative care are appropriately trained,¹⁹ and steps are being taken in training, growing and skilling the aged care workforce.²⁰⁻²²

Low levels of nursing staff and limited budgets in the home care sector make access to specialist palliative and GP care essential. Most managers appraised their local palliative care team positively with examples of successful partnerships. However, there was often a gap when care needs exceeded the home care budget, but the palliative care team considered the client not near enough to the end of life to warrant their intensive services. This, combined with the late identification of the end-of-life phase, perhaps explains why older people underutilise palliative care services.^{23,24} Managers' experiences of working with GPs were less positive. As the Royal Commission¹³ identified, Medicare funding is a significant barrier to older people receiving timely medical care at home (or in residential facilities), because it does not adequately compensate GPs for travel to patients' homes or the communication needed for successful collaboration with aged care providers.

Providers' challenges in accessing and collaborating with health services are symptomatic of the divide between an aged care sector model of social care and health services which are not funded to provide longer term care. The health/social care divide is a challenge internationally, but complex state and federal funding arrangements make Australia more fragmented than most.²⁵ Fragmentation in the funding (and therefore delivery) of the essential components of end-of-life care has produced a patchwork of siloed services that is a barrier to coordinated care.^{26,27} Previous research has shown that in a fragmented system, the onus of integrating the array of different services falls on family carers, which is both frustrating and burdensome.²⁸ This study expands that experience to home care managers who advocate for their clients and are often well-placed to understand their needs.

The Australian Government has introduced the Greater Choice for At Home Palliative Care²⁹ measure that will fund Primary Health Networks to coordinate aged care providers, specialist palliative care teams and GPs. This may improve collaboration and facilitate earlier referrals to palliative care services. However, ultimately, health and social care for older people should be integrated under a single funding stream to reduce system complexity, and facilitate the holistic care needed to support older people wishing to die in their own home.²⁸ In the absence of a systemic funding solution, budgets and staffing on both sides must be sufficient to support timely, quality end-of-life care for those who cannot afford to pay, and to reward collaboration across sectors.³⁰

4.1 | Limitations

Recruitment occurred during the second wave of the COVID-19 pandemic in Australia. New South Wales was particularly affected, which impacted recruitment from that State. Nonetheless, rich qualitative data were gained from managers across a wide range of services and were broadly representative of the sector by ownership-type and geographical location. Further research could explore the factors which influence the variable experiences identified by specialist palliative care teams and GPs in supporting people on a home care package.

5 | CONCLUSIONS

Our study highlights that aged care providers want to support older Australians who prefer to stay at home at the end of life. However, most clients are admitted to a residential facility since their care needs exceed a home care budget long before specialist palliative care teams are able

to intervene. Budgets for health and aged care providers must be sufficient and flexible to support timely access to end-of-life care, to reward collaboration across sectors and to invest in building palliative care skills in the nursing and personal care workforce.

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CONFLICTS OF INTEREST

No conflicts of interest declared.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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