EXPERIENCES OF GOVERNMENT-FUNDED AGED HOME CARE IN THE CONTEXT OF LIFE-LIMITING ILLNESS

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KEYWORDS

Carers, caregivers, informal caregivers; home care services/home care; home care package; end of life; older people/older Australians

EXECUTIVE SUMMARY

Despite the growing population of older Australians with life-limiting illnesses, little is known about the experience and effectiveness of government-funded programs of aged home care to support care at home at the end of life. This qualitative study sought to understand the experience of current or bereaved carers caring for a family member in the last year of life, who currently or previously received support through programs of commonwealth aged home care. Findings reveal limitations regarding the features and capacity of these programs to adequately and consistently support a preference for care at home at the end of life.

INTRODUCTION

While the majority of Australians express a preference to die at home, the minority do so; with people in countries such as New Zealand, the United States and France twice as likely to die at home. Facilitation of the care of older Australians within their own homes for as long as possible is an evident priority of Australian Government policy, driven by the growing costs of aged care and reduced costs of care at home in contrast to acute settings and residential aged care. To provide services that support independence and care at home, Older Australians may be eligible to access two key programs of government-subsidised in-home aged care. The Commonwealth Home Support Program (CHSP) delivers a higher volume of lower cost entry-level support services, and the Home Care Packages (HCP) Program provides higher-cost services for more complex needs to a smaller number of people.

The projected demand for these programs of in-home aged care is growing rapidly, and the proportion of older Australians who are living longer and dying with life-limiting illnesses is increasing. For older people, end of life is associated with unique clinical and social challenges that may increase the risk of poor end-of-life care, including multi-comorbidities, frailty and cognitive decline. This critical period is also related to potentially burdensome and multiple transitions between systems and settings of care. Therefore, there is a clear and urgent need to facilitate high-quality and well-integrated end-of-life care for older Australians with a preference to receive this care at home. Yet little is known about the experience and effectiveness of the CHSP and HCP Program in supporting people at home at the end of life. The aim of this study was therefore to understand the experience of current or bereaved carers providing support to a family member in the last year of life, who currently or previously received support through the CHSP or HCP Program.

HIGHLIGHTS

- More older Australians are living longer and dying with life-limiting illnesses
- Programs of Commonwealth-funded aged home care are in increasingly growing demand
- Program features may not consistently and adequately support end of life care

METHODOLOGY/ PROCESS

The study employed a qualitative research design and utilised semi-structured interviews to elicit the experience of current and former (bereaved) carers (n=14). Carers were recruited through an online self-registration service (StepUp for Research) that enables volunteers to register their interest in taking part in dementia and/or ageing related research. Potentially eligible volunteers were contacted to discuss recruitment. To meet eligibility criteria, current carers were providing unpaid care for someone with a life-limiting illness in

the community who was receiving a CHSP or HCP, and bereaved carers had provided unpaid care for someone who received a CHSP or HCP in the last year of life, and were at least two months post-bereavement. Carers were also required to be 18 years or over and possess adequate English proficiency for interview participation. Semi-structured interviews were conducted with an experienced qualitative researcher via zoom or telephone according to the preferences of participants. Interviews explored the experience of receiving a CHSP or HCP in the last year of life, specific barriers and enablers to sustaining care at home, and ways in which CHSP and HCPs might be improved to support end of life care at home. Interviews were audio recorded, transcribed verbatim, and entered into NVIVO 12 for analysis. Analysis employed a reflexive thematic approach.

RESULTS/OUTCOMES

Participants were 11 current and 3 former (bereaved) carers of people who received forms of packaged in-home aged care. Most care recipients were the partner or spouse of the carer (n=8), with the remaining care recipients being parents (n=6), and almost all care recipients had a dementia diagnosis. Care recipients were receiving (or had received) varying levels of aged in-home support, with the largest proportion in receipt or approved for a Level 3 HCP (n=5).

Analysis highlighted varied experiences of package providers, services, and care workers that suggest there are evident limitations regarding the features and capacity of in-home aged care to adequately support a preference to remain at home at the end of life. Approaches to the delivery of care at home that were relationally driven and tailored to the specific and often complex needs of care recipients sat in contrast to experiences of poorly coordinated, inflexible or delayed care and support. The experiences of initially accessing aged in-home care as well as negotiating reassessment for increasing care needs were reported to be often confusing and time-consuming. Additionally, interactions with specialist palliative care services alongside the receipt of in-home aged care were very limited.

CONCLUSION

Carer-defined recommendations possess implications for the facilitation of care at home at the end of life. With the proposed redesign of the program of in-home aged care (as Support at Home) to commence from mid-2025, findings point to considerations for design and implementation related to people with life-limiting illness and their carers. Findings also provoke reflection on strategies that could be considered by providers of health care and specialist palliative care to support the integration of care and capacity building across sectors. While the sample is small and may not be representative this study does raise some important considerations for the increasing number of older Australians who may require end of life care at home.

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