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Palliative care needs of terminally ill people living alone: A service provider perspective

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KEYWORDS

Palliative care;
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Summary

Background: Community-based palliative care services face challenges in meeting the needs of terminally ill clients who live alone without a primary caregiver. Yet, there is a dearth of literature on the perceptions of health service providers (HSPs) regarding the care needs and possible management options to assist this growing group to remain at home.

Objective: This paper investigated the support needs of people living alone with a terminal illness from a service provider perspective.

Design: In depth semi-structured interviews were conducted with nine HSPs from community based services in three Australian states.

Results: Four main themes emerged: care challenges, differences in care provision, appropriate approaches to care and essentials for an effective service such as 24 h care, cost-free provision of personal alarm systems, supported and coordinated housekeeping services, funded respite care and financial care packages. HSPs expressed a respect for the autonomy and independence of the clients, yet felt pressured to ensure that safe and attentive care was possible. HSPs recognised the central importance of maintaining the independence and autonomy of palliative care clients living alone.

Conclusions: This study is the first in-depth account of what HSPs perceive they need to effectively look after home alone dying clients. The study provided directions to inform service

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planning for this growing and challenging population group regarding adequate and timely services that will lead to more complying with the clients' wishes, more care being delivered at home, a reduction in hospitalisations, a better quality of life and a capacity to die at home.
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Introduction

Community-based palliative care services face challenges in meeting the needs of clients who live alone without a primary caregiver (Aoun, Kristjanson, Oldham, Currow, & Yates, 2005; Devlin & McIlpatrick, 2009). In Australia, about 29% of older people lived alone in private dwellings in 2006, with the percentage as high as 39% among those aged 85 years and over (Australian Institute of Health and Welfare and Commonwealth Department of Health and Ageing, 2007). Population projections predict an increase in the number and proportion of older adults who are living alone with fewer informal caregivers available (National Centre for Social and Economic Modelling, 2004).

A national Australian scoping study of three community based palliative care services reported that clients who were living alone with no primary caregiver made up between 7% and 12% of the total number of palliative care clients (Aoun et al., 2007). This scoping study further confirmed reports that, compared to those with a caregiver, people living alone with a terminal illness had more hospital admissions (71% vs 57%, $P < 0.001$); and were less likely to die at home (35% vs 56%, $P < 0.001$) (Aoun et al., 2007).

Home-based interdisciplinary palliative care is cheaper than hospice- or hospital-based palliative care, and increases the likelihood for home deaths (Adams, 2005; Aranda & Hayman-White, 2001; Enguidanos, Cherin, & Brumley, 2005). Although more than 50%, and maybe as many as 90%, of people diagnosed with cancer showed a preference to be cared for, and die at home, this figure varied according to the availability of services (Higginson & Sen-Gupta, 2000; Tang, 2003). However, there is a paucity of information about the needs and preferences of people requiring palliative care, whilst living at home alone towards the end-of-life (Jordhøy & Grande, 2006).

'Home alone' clients interviewed in Aoun et al.'s study (2008) stated their preference to be at home at the end of their life and the importance of dying with dignity, which meant for them staying at home for as long as possible.

"I don't want to finish up in some kind of barn waiting for God, so the doctor assured me he will treat me here as long as he can . . . so that's just a bit of dignity".

The notion of maintaining independence was extremely important to these clients and it determined their judgment about whether, how much, and when they allowed individuals or agencies to provide them with support. Participants in the study were unable to describe the types of support required to help them remain at home for as long as possible. Moreover, they were not willing to contemplate the kinds of events that would impact on their ability to stay at home until the end of life.

Some literature has discussed the needs or perspectives of family caregivers in the provision of home-based palliative care (Aranda & Hayman-White, 2001; Zapart, Kenny, Hall, Servis, & Wiley, 2007), as well as the perceived needs and role perceptions of nurses providing palliative care in the community (King, Melvin, Ashby, & Firth, 2010). However, there is a dearth of literature on the perceptions of service providers regarding the needs of the terminally ill who live alone and also literature that has explored possible management options to assist this population to remain at home.

This paper reports on a cross-sectional qualitative study that used content analysis to explore the perspectives of health service providers (HSPs) regarding challenges and service provision needs of palliative care clients living alone in three Australian states: Western Australia (WA), South Australia (SA) and Queensland (QLD). The findings provide directions to inform service planning for a growing and challenging population group.

Methodology

Participants

Following ethical approval of the study by the health research ethics committees of participating health services (Silver Chain in WA, Royal District Nursing Service in SA and Blue Care in QLD) and academic institutions (Edith Cowan University, Flinders University and Queensland University of Technology), nine HSPs were purposively recruited from community nursing services in QLD, SA, and WA. The three Australian states were diverse and were spread out geographically, from the south west to the north east of the country.

The project reference group members situated in each of the three states facilitated the recruitment of the HSPs to the study. Of the nine HSPs recruited, three were located in each state, with two from the metropolitan area and one from a rural area in each state. The HSP group from QLD consisted of a Director of Nursing, a Nurse Manager, and a Clinical Nurse (Palliative Care); the group from SA consisted of two Clinical Nurse Consultants and one Clinical Nurse (Community Palliative Care), and the group from WA consisted of a Clinical Nurse Consultant (Palliative Care), a Clinical Nurse Specialist (Palliative Care), and a Clinical Nurse. None of the participants declined an invitation to participate in the study, and following recruitment none withdrew from the study.

Concerning confidentiality, each HSP's identity, personal information, and data obtained from interviews were protected. Each HSP was given a participant number (e.g. HSP1), used in all transcripts and this paper.

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