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Supporting palliative care clients who live alone: Nurses' perspectives on improving quality of care



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Summary

Background: Terminally ill people who live alone at home are disadvantaged in terms of their places of care and death and health outcomes. There is a need to trial models of care that can extend the period of care at home for as long as possible for this group. The objective was to explore the experiences of nurses providing care to terminally ill clients who live at home alone and who were receiving either additional care aide support or a personal alarm through an RCT. **Methods:** Nine nurses in a home-based palliative care service in Western Australia completed a questionnaire (82% response rate).

Findings: Client willingness to accept additional support from care aides, development of rapport between the client and care staff, and willingness to use the alarm appropriately all influenced the effectiveness of the models of care. These models of care may negate the need for frequent nurses' visits when nurses feel confident that the care aide can pass on relevant information or that the client will use the alarm when required.

Conclusions: Both models of care assisted in meeting the challenges to care provision; however, further larger trials are needed to test whether these might translate into granting clients their wishes regarding places of terminal care and death. This study is the first account of nurses' perspectives on service provision to support palliative care clients who live alone. It has prompted changes in practice and will inform service planning for this growing and challenging population group.

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1. Introduction

Palliative care services often rely on clients' informal caregivers to provide unpaid help and support in undertaking a range of tasks including assessing and managing symptoms, administering medications, and providing or assisting with personal care (Funk et al., 2010; Stajduhar et al., 2010). The presence of informal caregivers improves the feasibility of home-based care (Hudson, 2003) and in turn reduces the costs of formal care (Aoun, Kristjanson, Currow, & Hudson, 2005; Rolls, Seymour, Froggart, & Hanratty, 2011).

Few studies have explored the issues facing palliative care clients who have no family caregivers and live alone, yet such research is vital to inform service planning for this growing population (Aoun, Wall, Kristjanson, & Shahid, 2013). Research demonstrates that terminally ill people living alone without a caregiver are disadvantaged in terms of places of care and death and physical and psychosocial health outcomes (Aoun, Breen, & Howting, 2014). Compared to clients living with an informal caregiver, clients living alone were significantly less likely to die at home (Aoun et al., 2007; Brink & Smith, 2008; Cohen et al., 2006; Masucci, Guerriere, Cheng, & Coyte, 2010), report challenges in addressing their physical, social, emotional, and existential needs (Aoun, Kristjanson, Oldham, & Currow, 2008), had higher death distress (Chibnall, Videen, Duckro, & Miller, 2002), received fewer home visits, required more assistance with activities of daily living but received less equipment and counselling (Aoun et al., 2007; Currow et al., 2008).

This paper reports on the perspectives of nurses on models of care trialled for palliative care clients living alone in Western Australia. The data were drawn from a larger study, the Home Alone Models of Care Project, for Silver Chain Hospice Care clients who lived alone. The study comprised a pilot randomised controlled trial (RCT) of two models of care (either a personal alarm or extra care aide time) for people living alone at home while receiving palliative care in comparison to standard care (Aoun, O'Connor, Breen, Deas, & Skett, 2013). Interviews with clients and a survey of nurses involved in their care complemented the RCT. Interviews with clients showed that personal alarms provided a sense of security and reduced feelings of isolation while additional care-aide time assisted with activities of daily living, enhanced quality of life, maintained dignity, and decreased feelings of loneliness (Aoun et al., 2012). The nurses' perspectives on the benefits of and barriers to implementing two of the models of care and their suggestions for improvement are the focus of the present paper.

2. Methods

The study was approved by the Human Research Ethics Committees of Curtin University and Silver Chain. In 2011, all nurses who had referred clients to the Home Alone Models of Care Project ($n = 11$), were invited to provide their feedback. When the nurses were given the option between a focus group, face to face interview and completing a questionnaire, they chose the latter so that they could complete the task when they most had the time to think and reflect. A researcher contacted each nurse to explain this component

of the study, seek consent, and arrange for the pack containing the information sheet, the questionnaire and reply paid envelope to be delivered to their workplace. Repeat invitations were issued to all participants to encourage participation. Due to their time limitations, all participants were offered the options to complete the questionnaire in writing and then return it to research team via fax or post in a reply paid envelope provided to them, or electronically via email, or via a telephone call.

The questionnaire comprised three sections of open-ended questions: Section 1 (six questions concerning home alone clients e.g., What issues have you faced with home alone clients in your practice?), Section 2 (four questions pertaining to models of care e.g., Please describe any positive or negative aspects of providing these two models of care?), and Section 3 (three questions asking for suggestions to improve models of care e.g., Please specify any other particular resources that may be useful to help improve the care you provide for home alone clients).

2.1. Analysis

Data were de-identified for analysis and were subjected to a directed content analysis (Hsieh & Shannon, 2005) in order to identify nurses' perspectives on implementing the two models of care. The coding scheme was drawn from the focus of each section of the questionnaire (i.e., experiences with home alone clients, perspectives on models of care, and ideas for improved service delivery). The nurses' responses were each systematically coded inductively and then classified and grouped under each of the three overarching categories. The authors independently blind-coded all responses and there was substantial degree of agreement between coders. The emerging interpretations were refined throughout the analysis processes and aided by the comparison between the data and the existing literature, enabling a data-driven approach to interpretation. Finally, excerpts were chosen to illustrate the themes. The authors are palliative care researchers and one is also employed as a home-based palliative care nurse and therefore brought both theoretical and practical perspectives to interpreting the data, enabling a rigorous approach to reflexivity (Mauthner & Doucet, 2003). All differences were discussed and consensus achieved, indicating the trustworthiness of the coding scheme (Mays & Pope, 2000).

3. Results

Nine nurses completed the questionnaire concerning both models of care (an 82% response rate). The median age was 49 years (range 45–63); the median period of experience in palliative care was 20 years (range 5–26) and these nurses have been working with Silver Chain for a median of 9.5 years (range 5–20). During the intervention period, 14 clients completed the intervention in the personal alarm group and 12 in the care aide group (Aoun, O'Connor, et al., 2013). The findings pertain to the experience of nurses with these 26 clients, their opinion on the benefits or the drawbacks of the two models of care, and suggestions for improvement.

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