



Curtin University

The support needs of terminally ill people living alone at home: A narrative review

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Introduction

- Home-based palliative care services face increasing challenges in supporting home alone clients

In Europe, 28% of palliative clients live alone (Kaasa et al., 2007)

In Australia, 7-12% are 'home alone' (Aoun et al., 2007)

- Likely to increase:

Ageing population

Declining fertility rate

Rising employment of women

- Reduction in the number and availability of informal carers and an increasing demand for formal care



Introduction

- However, there is limited evidence upon which services may draw in order to inform service planning for this growing population
- The objectives of the review were to:
 - Highlight the unmet support needs of terminally ill people who live alone at home and have no primary carer; and
 - Identify specific models of care that have been used to address these gaps.



Methods

- Searched peer-reviewed studies

English language

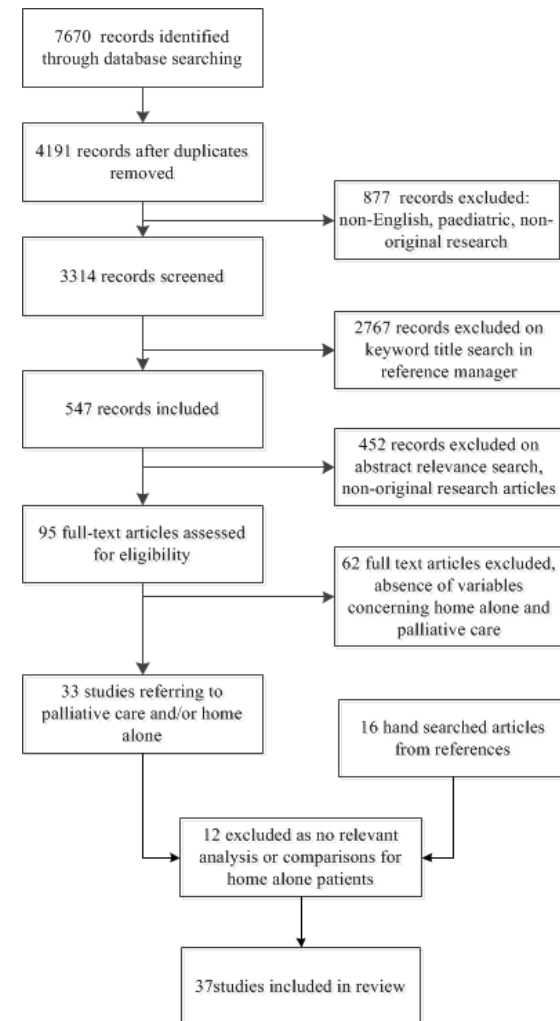
Published 2002-2013

Keywords – palliative care, hospice care, end of life, supportive care, life-limiting and/or terminal illness, models of care, interventions, home alone, living alone, no carer/caregiver, home care, place of care, place of death

- 547 abstracts as being potentially relevant

- 95 were retrieved and assessed

- 37 studies included in the review



Results

- The unmet needs of terminally ill people living alone

Thirty-five (95%) studies described the unmet needs of terminally ill people who live alone, centred on places of care and death and physical and psychosocial wellbeing

- Models of care for terminally ill people living alone

2 studies (5%) explored models of care for terminally ill people who live alone



Places of care and death

- 28 studies (76%) demonstrated that people were less likely to die at home when they lived alone

In determining variables associated with home death, several studies overlooked this group by sampling carers or did not report home alone status and/or inferred it from the absence of a carer or being single

- People living alone are:

Less likely to die at home (Aabom et al., 2005; Alonso-Barbarro et al., 2011; Brink & Smith, 2008; Brogaard et al., 2013; Cohen et al., 2010; Gao et al., 2013; Goodridge et al., 2010; Houttekier et al., 2009; Lee et al., 2013; Masucci et al., 2010)

More likely to be in hospital for longer (Aoun et al., 2007)

More likely to feel unable to be cared for and die at home (Tang, 2003; Tang & McCorkle, 2003)

Places of care and death



- Only one study focussed on place of death outcomes for ‘home alones’
compared to patients with a carer, those without were less likely to die at home (35% compared to 57%), twice as likely to die in a hospice, and 2.5 times as likely to die in a hospital (Aoun et al., 2007)

Physical and psychosocial wellbeing

- 9 studies (24%) included comparative data in relation to physical and psychosocial wellbeing
- People living alone report:
 - More distress (Chibnall et al., 2002)
 - More problems with mood, memory, vision, diet, alcohol use, falls (Kharicha et al., 2007)
 - Greater social isolation and depressed mood (Iliffe et al., 2007)
 - Challenges in addressing their physical, social, emotional and existential needs (Aoun et al., 2008)
 - Being disadvantaged in terms of access support and real choice in directing their care (Hanratty et al., 2013)

Physical and psychosocial wellbeing

- Despite these additional struggles, people without a family carer receive half as many home visits and less equipment, even when enrolled in a service for longer, and were more likely to be admitted to hospital (Aoun et al., 2007; Currow et al., 2008; Goodridge et al, 2010; Johnson et al., 2004)



Models of care for terminally ill people living alone

- 2 studies (5%) explored models of care for terminally ill people who live alone

A pilot intervention using a randomised trial design to test personal alarms and additional care-aide support compared to standard care; care aides reduced appetite problems and fatigue (Aoun et al., 2013)

In-depth feedback from these participants on these interventions showed that care aides eased the burden of everyday living, supported wellbeing, preserved a sense of dignity, and reduced loneliness and isolation while personal alarms imparted a sense of security, provided peace of mind, and helped clients manage feelings of isolation (Aoun et al., 2012)

Discussion

- The majority of studies highlighted the reduced likelihood of this group to be cared for and die at home and the increased likelihood of more psychosocial distress and more hospital admissions than people with a primary carer
- Few studies reported on the development of models of care but showed that the challenges faced by this group may be mitigated by interventions tailored to meet their specific needs



Conclusions

- This is the first review to highlight the growing challenges facing community palliative care services in supporting the increasing number of people living alone who require care
- There is a need for more studies to examine the effectiveness of informal support networks and suitable models of care that will inform service planning for this growing, challenging, and vulnerable group



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- Journal article

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