Home as a place of caring and wellbeing? A qualitative study of informal carers and caring networks lived experiences of providing in-home end-of-life care

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ABSTRACT

Although the burden of caring is well described, the value of home as a potential place of wellbeing and support for informal caring networks when providing end-of-life care is not well recognised. Interviews and focus groups with 127 primary carers and members of informal care networks revealed their collaborative stories about caring for a dying person at home. Four themes emerged from the data: home as a place of comfort and belonging; places of social connection and collaborative caring; places of connection to nature and the non-human; places of achievement and triumph. When support is available, nurturing carer wellbeing may be best achieved at home.

1. Introduction

The importance of being at home for a person dying of a terminal illness is receiving increasing attention in the literature. Understandably, the needs and experiences of the dying person are usually the focus (Milligan et al., 2016; Rosenberg, 2011; Williams, 2002) with some attention being given to family caregivers (Turner et al., 2016; Milligan et al., 2016). There is, however, an increasing focus on home as a preferred place to die (Gomes et al., 2013; Palliative Care Australia, 2011) and growing policy imperatives towards dying in place (Swerissen and Duckett, 2015; Gott et al., 2014). In Australia, most of end-of-life (EOL) care takes place at home and certainly hospices and hospitals could not cope if it did not.

People's stated preference for home as place of death and dying can be understood as an attachment to place; an emotional response to the social, physical, emotional and spiritual dimensions of the environment which can engender a sense of identity, security and belonging. Place-attachment is understood as the result of the person/process/place relationship (Scannell and Gifford, 2010), although more attention is given to the social dimensions of place-attachment than the physicality of the place or what actually happens there (Lewicka, 2011). There are many reported benefits of place-attachment, including better health outcomes, increased and improved social relationships, and appreciation of, and satisfaction with, one's environment (Tartaglia, 2012).

Related concepts of place-identity (Proshansky et al., 1983) and place-dependence (Shumaker and Taylor, 1983; Moore and Graefe, 1994; Vaske and Kobrin, 2001) are useful for understanding caring at home; when a place meets a person's needs they become increasingly dependent on that place and choose to stay there. The longer a person stays in a place the more likely that home will become central to their identity, especially if that place also provides feelings of distinctiveness, continuity, self-esteem and self-efficacy (Anton and Lawrence, 2014).

This research explored if and how home-place, which we propose encompasses the social and physical dimensions of place, supports carers' and caring networks' wellbeing, and thus their ability to continue to care. We use the lens of home as a potential therapeutic landscape (Williams, 2002) and ask if home may indeed have health promoting aspects.

2. Home, caring and wellbeing

Home as a preferred place to die is contested in the literature with arguments coalescing around a pragmatist view that hospital will remain the actual place of death for most people (Pollock, 2015) and a view that home is a simplistic notion which is romanticised, idealised and poorly understood (Gott et al., 2014; Randall et al., 2017). Current policy developments toward the deinstitutionalisation of death may result in moving the burden of care to the community with caring and

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home being further reinscribed as gendered and domesticated, resulting in an expectation that more unpaid caring will be provided, often by women who dominate the unpaid caring field (Williams, 2002; Milligan, 2009; Gott et al., 2014). Furthermore, home for some is a site of struggle. This could mean that attention is not paid to those for whom home is a site of difficulty or oppression, or that intensive caregiving in the home changes both the emotional and physical geographies within that space (Milligan, 2009; Gott et al., 2014).

The very word *home* is contested and value laden (Walmsley and Lewis, 1993; Mallett, 2004; Tuan, 1977): is home a place, a feeling, a set of relations, a refuge, somewhere imbued with memory? Is it simply a dwelling or a social construction? Recognising this complexity, we use the term home in this article to refer to non-institutionalised dwelling; meaning where people live, be it an apartment, house, terrace, room or caravan. We do this as the participants in our study speak of home, not dwelling or house. We also move away from what people might mean by home, to people's lived experiences of caring for the dying and how home might support that, whatever the home might mean. We are not debating the meaning of home or home death as equating to a good death. Rather, our position is that home death is a stated preference and it is on that basis alone worthy of attention, without which we risk perpetuating the disenfranchisement of dying people and their carers (Swerissen and Duckett, 2015).

The contested notion of home remains debated in the literature. There is evidence regarding the importance of home for the ontological security of the dying person (Collier et al., 2015; Williams, 2002) and some attention is being paid to making palliative care environments more homely (Collier et al., 2015). There is also growing discussion of home and carers, sometimes at EOL (for example Higginson et al., 2013; Milligan et al., 2016; Morris et al., 2015; Lewis et al., 2013). In a systematic review of the environmental needs of older people with life-limiting illnesses, one of four themes that emerged was that the EOL environment should support caregiving (both formal and informal) (Rigby et al., 2010), and thus to ensure optimal caregiving at EOL, consideration must be given to carers. This focus on caregiving and carers is discussed in this article, as without the support of a network of informal carers the wish to die at home is unlikely to eventuate (Milligan, 2016).

The dominant narratives about caring at EOL have had a narrow focus on the primary carer, usually a family member, and the burden of care. The emotional, physical and psychological costs of such care are well documented (Grande et al., 2009; Australian Bureau of Statistics, 2012; Hagell et al., 2016; Veloso and Tripodoro, 2016) and include stress, poor mental health, sleep disruption, fatigue, and family and social isolation. This focus reflects a medicalised orientation to caring where the carer is one who places themselves at risk of harm, who is in need of assessment, and who needs to be *relieved of the assumed long-term burden of caring* (Sadler and McKevitt, 2013, p. 50). However, people who relinquish caring often still visit every day, perhaps still worry about the care the person is receiving, sit alone or in small family groups with the dying person for long hours, and may have to travel long distances to visit or pay to stay in closer accommodation. Visser et al. (2004) found that carer stress and burden may actually increase when someone is admitted to hospital. There are natural stressors associated when a person dies: it is difficult regardless of place.

It is also recognised that caring for terminally ill people can be rewarding and satisfying, providing meaning, purpose and a sense of belonging for the carer, thus having positive impacts on carers' wellbeing, quality of life and social relations (Ratcliffe et al., 2013; Zapart et al., 2007) with 75% of people who have cared at home saying they would do it again (Currow et al., 2011). Caring can be a burden, but this is not necessarily always so. Indeed it is more likely to be a mixture of complex, perhaps competing, lived experiences.

People's stated preference to die at home turns our attention more sharply on informal carers and their support networks comprising service providers (formal networks) and friends, family, colleagues and neighbours (informal networks). Brown (2003) found that home was not ideal when support from others was lacking, so it is vital that if people are to die in their place of choice, support from others is forthcoming. Those who comprise networks of care have a crucial role in promoting carer wellbeing and avoiding carer burnout (Hudson, 2004; Horsfall et al., 2012, 2013; Leonard et al., 2013). Previous research regarding carers' preferred place of caring for their dying friend or relative supports the view that carers prefer to care at home 'because the home environment facilitated: being there, normalcy, self–direction, sustenance, relationships and reciprocity' (Williams, 2002, p. 144). The present study further explored what is it that carers do as they care for someone at home, what is it they need, how home enables caring and perhaps promotes wellbeing, and what is it that people report about this lived experience.

3. Research design

The present research took place between 2012 and 2015. It was partnership research between Western Sydney University, Cancer Council of NSW, CSIRO, Australian Catholic University/Calvary Health Care ACT, and Queensland University of Technology and was funded by the Australian Research Council. Ethics approvals were obtained prior to commencement of the project. The research reported here is stage 2 of this study where we spoke with 127 primary carers, informal care networks, and outer networks in interviews and focus groups in eight urban, regional and rural locations across NSW and ACT. Each location had a Cancer Council regional office to support and promote the research and was chosen to reflect different levels of service provision and geographic and social distinctness.

Informed by the research principles of appreciative inquiry the research was qualitative, in-depth and strengths-based. Appreciative inquiry departs from a problem-based approach to one which seeks to uncover, understand and document stories of what is working well. The aim is to fan these examples, to show what can be done and how to do it (Liebling et al., 1999; Hennessy and Hughes, 2014; Watkins and Cooperrider, 2000). This approach is well suited to understand the lived experiences (Sadler and McKevitt, 2013) of people who had successfully cared for a terminally ill person at home, and what was supportive of them as they did so. Giving the carers and caring network member's epistemic privilege was also central, with an ethical imperative to be particularly sensitive, given the topic. Creative methods are increasingly used in such situations (Davidson, 2004; Yardley, 2008) to provide conversational spaces for people to speak if and how they want about their experiences, enabling us to understand what is important to them, and why (McCarthy, 1998). We selected photography as our main method as it can help people see familiar everyday things with new eyes (Diamond and Van Halen-Faber, 2002). This was significant because some elements of the caring journey and social relations are often not seen or discussed because they are thought to be common or ordinary aspects of life. The camera can enable participants to tell visual stories, creating opportunities for them to express themselves in their own images, words, and reflections. In turn, these images become points of entry into often unexplored areas of life providing a form of detachment that facilitates critical reflection on people's lived experiences (McIntyre, 2003; Freire, 2003). The research design and methods had been successfully trialled in a previous study (see Horsfall et al., 2012).

4. Recruitment, participants and method

The research was promoted through Cancer Council newsletters and networks, regional and state-based newspapers and radio. Selection criteria included those who: have cared for a person with a terminal illness at home within the last 1−5 years; have been either a primary carer or a member of a caring network; are willing to talk about what was useful, as part of the caring journey. People opted into