



## End-of-Life care in a community garden: Findings from a Participatory Action Research project in regional Australia



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### ABSTRACT

This article presents findings from research that explored how a community garden might function as a place of end-of-life and bereavement support. Adopting Participatory Action Research (PAR) methods, and informed by Third Place theory and notions of therapeutic landscape, creative consultations were held in the Garden and people's homes. The findings provide insights into the nature of informal care as it is played out in the liminal garden space, between home and institution. The results illuminate the therapeutic landscape of community gardens, and contribute new understandings to the fields of PAR, health geography and end-of-life care.

### 1. Introduction

An established confidence in the health benefits of human contact with nature and the natural environment underpins health geography scholarship (Burls, 2007; George et al., 2015; Johnsen et al., 2013; Maller et al., 2005; Wang and Macmillan, 2013). Physical, psychological and emotional improvements arising from an individual's contact with plants, nature and with various natural environments have been documented, including positive outcomes in post-surgery recovery times (Ulrich, 1984), reduced stress and lowered blood pressure (Berto, 2014), improved mood states (Hayashi et al., 2008), and improved balance and gait (Chen and Janke, 2012). With roots in Wilson's 1980s biophilia hypothesis (Howell et al., 2011), a space is defined as therapeutic when a positive interrelationship is generated between a location, health, and human subjective experience (Williams, 2002). Causal factors are not limited to an individual's contact with a natural environment, but also encompass the social and cultural determinants of health and/or restoration (Gesler, 1992; Korpela and Ylen, 2009). A "holistic concern for the quality of local environments" (Kearns and Collins, 2010, p. 17) underscores an understanding that collectively the environmental, cultural, social and individual constituents of a space form a complex landscape of health and healing – a therapeutic landscape.

Palliative care research demonstrates an interest in the concept of the therapeutic landscape, principally for restorative purposes. Studies are predominantly concerned with the influence of environments (built

or otherwise) for patients with a life-limiting illness and their loved ones on wellbeing and quality of life (English et al., 2008; Marsh and Spinaze, 2016). Many cancer centres and palliative care wards within hospitals and hospices, for example, incorporate a garden. The Health Promoting Palliative Care (HPPC) arm of palliation also employs the principles of therapeutic landscape: as Allison Williams (2010) notes, the health promotion movement has embraced the concept. The basis of HPPC is an understanding that healthcare for a person with a life-limiting illness should aim to improve overall quality of life (Kellehear, 2013) and includes the influence of home and community spaces (Mills et al., 2015). It is in the field of quality of life research that we most commonly find literature on the type of space occupying the central focus of this paper, the community garden.

The literature on community gardens is vast, and foci cover mainly environmental and social impacts such as sustainable food production, food security, urbanisation, climate change, healthy eating, community resilience and the benefits of gardens in low socio-economic areas (Milburn and Vail, 2010; Guitart, 2013). Community gardens are often founded on community development principles (Glover et al., 2005), and they represent the importance of the socio-cultural aspects of food and food production—nourishing both the body and also a relationship between people through contact with nature. Indeed, community garden literature "enthuses about their communal benefits, for reasons ranging from social inclusion to health" (Turner, 2011, p. 514). Christine Milligan et al. (2004) applied a therapeutic landscape lens to their study of the benefits of communal gardening for older people

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on allotments in the UK. Despite this encouraging early research, and an abundance of scholarship on the socio-environmental impacts of community gardens, the nature and extent of the therapeutic landscapes of community gardens remain largely underexplored in the end-of-life sphere.

In 2015, the Okines Community Garden (Okines) in southern Tasmania, Australia, collaborated with the University of Tasmania's Centre for Rural Health (CRH) to explore how the garden community might provide better support for people at the end-of-life and in bereavement. The garden coordinators and volunteers prompted this partnership when they noticed increasing numbers of people coming to the garden during times of grief, seeking company, physical activity and solace. In Australia, community gardens function primarily to produce food in affordable and sustainable ways and to enable social interactions, and in this regard Okines is largely typical. Taking a purposeful role in the provision of end-of-life and bereavement care therefore required extending the everyday community garden activities. A participatory action research (PAR) project, 'Walking Each Other Home', designed and lead by a group of local garden members, including the CRH researcher, aimed to help the Okines Garden coordinators and volunteers to navigate this new therapeutic territory. The team (the authors) comprised a fibre artist, garden coordinator, grief counsellor and social researcher, and they worked together to explore what a garden organisation could contribute to community-based palliative care.

In Australia, community gardens are generally open spaces managed by a local community, volunteers and/or paid coordinators. They are part of a worldwide movement of gardening in communal spaces, including city farms and 'allotments' in the United Kingdom. Community gardens are generally located on public land, sometimes established in school grounds, church yards and, as is the case with Okines, in the yards of neighbourhood (or community) houses. Some gardens share the space and produce, usually by donation of money or labour. In other gardens, individuals take responsibility for plots and grow produce for their own use; and in some community gardens it is a combination of both.

Community gardens meet Ray Oldenburg's (1989) definition of a Third Place—as neither home nor work—and satisfy his key criteria as informal, relaxed places that are conducive to gathering. Through the Walking Each Other Home project, we introduced a new dimension to this Third Place by inviting people to come to the garden with the specific intent of talking with each other about death and dying. The overarching aims of Walking Each Other Home were to expand and strengthen informal supports for people with a life-limiting illness, their carers and people in bereavement, and to have a positive influence on future practice in community-based palliative care. Specifically, the research aimed to investigate if and how a community garden, largely run by volunteers and located in a small rural location, might play a useful and sustainable role in palliative and grief support.

### 1.1. Policy context

Our interest in end-of-life care in the Okines Garden coincided with a shift in policy for palliative care. At both federal and state levels of government in Australia, a public health approach to end-of-life care has been gradually strengthening. An important component of a public health approach is an emphasis on facilitating support to die at home. However, the capacity to endure the end-of-life at home depends greatly upon the amount and quality of support that the dying person's family and community can provide. The report by an Australian Government Senate review of palliative care (Australian Government, 2012) made several recommendations designed to improve home and community-based services and support for people who wish to die at home. Similarly, the Australian National Palliative Care Standards (2005), which aim to assist services to provide an equitable and high standard of care, foregrounds in Standard 9 the importance of

community capacity in palliation. Standard 9 focuses on aspects of community education, normalising death, the importance of community input into palliative care systems and services, and the value of collaborative partnerships. The approach to community capacity taken in the Standards is less redolent of community development principles, and more like a call to primary care givers and clinical services to increase awareness of the importance of involving communities in the provision of care (Mills et al., 2015, p. 221).

The findings of a report by the Grattan Institute, an Australian public policy think tank, authored by Swerissen and Duckett (2014) strongly support the move by policy makers to strengthen home-based palliative care. They concluded that despite most Australians wanting to "die comfortably at home supported by family and friends if they can," only a small proportion of health spending had been allocated for community-based end-of-life care. The report presents an economic imperative for community-based palliative care and states that the savings gained from the decreased demand on hospital and residential aged care services offset the significant investment required (p. 28). The explicit link Swerissen and Duckett (2014) make, between the economic imperative for community-based care and the savings gained, bespeaks the large reliance on the volunteer workforce in the informal care sector; a reliance held in common with the community garden movement.

Additional funding for Tasmania matched the shift seen toward a public health approach to palliative care. Three years prior to the Walking Each Other Home project, Tasmania received a \$325 million Health Assistance Package from the Federal Government. Of this, \$54.95 million was set aside to expand the capacity of the health system to deliver multi-disciplinary, home-based palliative care services. Named the Better Access to Palliative Care in Tasmania Program, the funding enabled a not-for-profit hospice organisation to establish a grant scheme. The Tasmanian Association for Hospice and Palliative Care<sup>2</sup> biannual "Networking End of Life Care" seed funding rounds supported community projects that encouraged conversations about death and dying, including the Walking Each Other Home project.

### 1.2. Theoretical framework

Two theoretical concepts are key to the design of this research. The first is therapeutic landscape, as articulated by Gesler in 1992: environmental, individual, and societal factors coming together in the healing process (p. 735). In the context of a life-limiting illness, the 'healing process' relates to improving the quality of life for people and their carers; that is, people may not necessarily be well, but they feel well (Kearns and Collins, 2010). Williams (2010, p. 210) summarises three areas of research in which the therapeutic landscape idea is usually applied: physical areas associated with health benefits; health care sites; and places that are of particular interest for various population groups. In this research we deploy the idea in a site that encompasses all three of these areas as a means of understanding the existing therapeutic qualities of the community garden, as both a natural environment and a social space. It also serves as a framework for investigating the capacity to broaden and extend the community garden community's healthcare activities, as the space shifts to become a site where formal and informal caregiving merge.

Third Place theory provides a framework for articulating the nature of this place of importance, and the site of our research. Oldenburg (1989), one of the first to publish on this topic, calls this the study of "happy gathering places" located on neutral, accessible ground. The definition of a Third Place is dynamic, but generally denotes a public place that is neither home nor work and examples include libraries, shopping centres, public squares, public parks, local businesses and community organisations. They are places people gravitate toward, or

<sup>2</sup> Now called Palliative Care Tasmania.

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