



The landscape of dementia inclusivity

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ABSTRACT

A supported community gardening program became appealing and therapeutically beneficial to people living with the impacts of dementia and their carers, despite not targeting either cohort specifically. This paper discusses how this program provides insights into the landscape of dementia inclusivity. The gardens involved were spaces that allowed positive risk-taking opportunities, respectful intersubjectivity and active citizenship. Our research findings indicate that a meaningful response to the rising incidence of dementia may be to build upon social and geographical attributes of community gardens. Understanding the multifaceted nature of a dementia inclusive landscape will enable authentic engagement and rights-based support for people living with the impacts of dementia.

1. Introduction

The health and wellbeing benefits of community gardening are well documented, and encompass positive physical, mental and social impacts for individuals and whole communities (Marsh and Spinaze, 2016; Milligan et al., 2004; Pitt, 2014; Winterbottom and Wagenfeld, 2015). Drawing upon Williams's (2007) definition of therapeutic landscape, there is an intertwining of cultural, social, emotional, relational and physical constituents that enable the overall therapeutic functions of community gardens. DIGnity Supported Gardening is a wellbeing project that has been running in three community gardens in South Eastern Tasmania, Australia, since 2016. The project aims to facilitate inclusion of people, otherwise excluded, into the activities of community gardens. The target population groups include any people who do not participate due to physical, mental and/or cognitive constraints: both actual or perceived. The community gardens in which DIGnity operates are open shared spaces, located within the grounds of the auspice organisations, two Neighbourhood Houses. The gardens are open at all times, staffed by a garden coordinator 1–2 days per week and supported by 10–15 regular volunteers. Adopting community development principles, they aim to improve the overall wellbeing of their resident communities through a range of activities that include all aspects of gardening and sustainable horticulture, as well as promoting healthy eating, hosting social functions and educational activities (Reference withheld for review).

Harnessing and complementing existing therapeutic attributes, the DIGnity project aims to expand the therapeutic reach of the community gardens through the addition of a team of professional and creative

support personnel who are in the garden at regular days and times. The team includes an occupational therapist, mental health social worker and fibre artist (weaving and textiles), each of whom live and work in the region, and had collaborated on an earlier pilot project. They work closely with the garden volunteers and coordinators. There is no process of referral or assessment, rather the team integrate themselves into the everyday activities of the gardens, while working to ensure that people are assisted to participate. They liaise with local Aged Care providers and health and welfare organisations to generate interest and attendance. DIGnity does not provide dementia-specific therapy, nor is it intentionally therapeutic in the ways of horticultural therapy programs; the objective is to provide unobtrusive additional supports that enable people to take part in the everyday activities of their communities. Nonetheless, over time the program became particularly appealing to people living with the impacts of dementia and their carers.

Dementia is an umbrella term for a condition characterised by cognitive decline and decreasing capacity to undertake everyday physical and cognitive activities. In line with ageing demographics, particularly in developed countries, greater longevity will result in increased numbers of people living with dementia as there is currently no cure and age is a contributing risk factor (Orrell and Brayne, 2015). Globally, there are an estimated 46.8 million people living with dementia (Prince et al., 2015) which presents a significant and ongoing challenge for health and social care providers, individuals and families alike (Brown and Hansnata, 2017). In Australia, Dementia has become the second leading cause of death. The potential impact on communities is exacerbated by little prospect of successful pharmaceutical or medical interventions to address the condition in the near future (Orrell and

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Brayne, 2015). Multimodal lifestyle modifications, such as those recommended for chronic diseases, hold some potential to decrease risk and impact of the disease after diagnosis (Olanrewaju et al., 2015), however overall the therapeutic landscape of dementia care is still emerging (McLean, 2007).

Currently, the key focus of responses to people living with the impacts of dementia is informed by a public health approach that aims to maintain quality of life through the different stages experienced during the progression of the condition. Such an approach involves family and carers of people living with the impacts of dementia, who are at increased risk of depression, isolation, and poorer health (Joling et al., 2015) and whole communities, for example the dementia-friendly communities initiatives (Hebert and Scales, 2017). Nevertheless, to date, there has been little research about the impacts of community-based initiatives to improve the quality of life for people living with the impacts of dementia. For example, the number of 'dementia friends' has been cited as a positive outcome measure – dementia friends is a program that aims to engage individuals to learn about the experience of dementia and act on that knowledge (Dementia Friends, 2017). While it can be argued more people are now educated about the condition, there is no evidence to demonstrate how this has translated to community-wide or individual improvements for those living with the impact of dementia (Hebert and Scales, 2017).

An ethical concern permeates discourses about people living with the impacts of dementia participating as active citizens in community spaces, articulated in a concept coined the "Dignity of Risk" (DofR) (Perske, 1972). Proponents of the DofR concept argue that risk-taking is a means of enabling autonomy, a vehicle for personal growth and success (Robertson and Collinson, 2011) and a fundamental part of human life: "Life is a risk. It is through struggling and overcoming challenges and taking risks that we become fully human" (Nay, 2002). First used in the disability sector, the concept is now common in dementia discourses to articulate the dilemma faced by people working alongside or caring for people living with dementia for whom the capacity to make rational choices may be compromised by severe cognitive impairment (Bailey et al., 2013; Behrman et al., 2017; Tarzia et al., 2012). Fears of negative consequences from risk-taking in these instances are heightened. Nevertheless, to deny people the right to take risks on the basis of cognitive impairment threatens the personhood of those people.

The aim of our research was to explore and understand the elements of DIGnity that engendered dementia inclusivity.¹ In this paper we present our research findings, which suggest a useful and achievable public health dementia management strategy may be to focus on the attributes and strengths of community spaces that make them more inclusive for all community members, including people living with the impacts of dementia. Utilising the insights of the participants in the DIGnity program, this paper illuminates the multi-layered landscape of dementia inclusivity. The findings reveal key landscape elements include positive risk-taking opportunities, respectful intersubjectivity, and active citizenship. We argue that recognising and accommodating the complexities of dementia inclusivity will enable communities to authentically engage with understanding, including and supporting those living with the impact of dementia.

2. Method

The overarching methodological framework for this research is Participatory Research (PR), chosen as an appropriate approach to achieve the project aims and for its compatibility with the community development principles of the DIGnity Project. A key PR criterion is that the research approach incorporates lived experience of participants as

well as theoretical and academic knowledge to construct new knowledges and understandings (Higginbottom and Liamputtong, 2016). In addition, the DIGnity project adheres to other key PR principles, articulated by Higginbottom and Liamputtong (2016), including a long-term commitment between the researcher and the community, the research 'subjects' function as co-researchers, and the learnings are beneficial to both researchers and participants and bring about positive change. PR is a methodology within which a number of different methods may be used. In this study we employed qualitative methods of participant observation, videography and semi-structured interviews. This paper focuses on specific components of the DIGnity program and research that are relevant to the participation of people living with the impacts of dementia.

The purpose of the study was explained to all participants, a written information sheet provided and consent obtained. Consent from participants who were noticeably living with the impacts of dementia followed the same process, plus an additional step in which the researchers confirmed they had capacity to give informed consent with the accompanying employees from Residential Aged Care facilities with whom the participants were familiar. All were confirmed as having capacity to provide informed consent.

Face-to-face interviews were conducted by both participant co-researchers and the authors over six months (summarised in Table 1). Four participants who attended DIGnity in their capacity as residents of a Residential Aged Care Facility (m = 2, f = 2) participated at two sites. DIGnity team members interviewed these participants on camera, using an open approach that started with a single lead question based on established rapport and observation of their active engagement in the program: "Why do you like coming to the garden?" The ensuing conversation was then only minimally prompted to facilitate discussion about the participants' experiences of being in the gardens and involved with DIGnity.

Other participants included members of the DIGnity Team (garden coordinators, occupational therapist, fibre artist and mental health social worker) as well as a local social worker regularly attending the project (n = 7, m = 1, f = 6). Interview prompts were designed to elicit team members' understandings of their role on the project and their reflections on the benefits and challenges faced during the first four months of operation. A further eight participants were those who worked closely in the garden with people living with the impacts of dementia. The research team, in pairs or individually, interviewed staff and volunteers from the Residential Aged Care Facility who accompanied residents to DIGnity (n = 3, m = 1, f = 2), volunteers who attended specifically for the DIGnity program (n = 3, f = 3), and garden volunteers who attend the gardens during DIGnity as well as at other times (n = 2, m = 2). The interviews followed a modified version of the original prompts, which were altered to target the specific research aims more directly, that is, to understand the impacts of an integrated supported community garden on dementia inclusivity.

All interviews took place in the community gardens, apart from two which were held in the nearby Residential Aged Care facility. They lasted between 20 min (videography) and 90 min (audio-recorded), and were transcribed verbatim. Informed by Braun and Clarke (2006) all transcripts were reviewed and coded independently by the three researchers, using an inductive approach to identify, analyse and report emerging themes in the data. Themes were then reviewed and discussed collaboratively, and dominant themes identified. Through a process of further discussion and review, consensus was obtained as to the three major themes, and additional multiple sub-themes.

Ethics approval was granted by the Social Sciences Human Research Ethics Committee (Reference H0015133).

3. Findings

Three key themes emerged from the data, and the findings are organised under these domains: Place, People, and Balance. Participants

¹ We use the term dementia inclusivity to mean the active practice of including people who might otherwise be excluded due to the isolating impacts of living with dementia.

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