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Article Title:

'My father is a gardener...': a systematic narrative review on access and use of the garden by people living with dementia.

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ABSTRACT

Access to the outdoors impacts positively on people living with dementia. In this narrative review we explored existing evidence about people living with dementia accessing and using their garden in both the domestic home and care home settings. This review revealed that gardens enabled people living with dementia to maintain a sense of life continuity and identity by connecting to nature, and to the moment, whilst managing everyday risks. However, the subjective experience of people living with dementia is significantly under-represented and under-reported in the literature, as are studies conducted in the garden and outside spaces of the domestic home.

Keywords

Dementia, garden, gardening, home, outdoors, narrative review.

1.0 INTRODUCTION

Brief overview of dementia

Dementia is one of the greatest global challenges for health and social care in the 21st century (Livingston et al 2017) and for those in mid-life, it is reported as being one of the most feared conditions of older age (Birt et al 2017). Across the world, the World Health Organisation (2017) estimate that 47 million people currently live with a dementia and this number is set to increase to 75 million by 2030. In the United Kingdom (UK) there are approximately 850,000 people living with dementia and of this total, there are an estimated 25,000 people from black, Asian and minority ethnic communities and 42,000 people living with dementia under the age of 65 (Alzheimer's Society 2014a). Currently, almost two-thirds of people living with dementia live in their own homes with up to 90% of care provided by family and/or friends and the remaining one third live in supported accommodation, such as a care home (Alzheimer's Society 2014b). With the absence of disease modifying treatments, such prevalence rates will continue to present a challenge for a wide-range of stakeholders, from those who live with the diagnosis through to service providers and society as a whole (Livingston et al 2020).

Living with dementia

Living with dementia comprises a loss of physical and cognitive abilities (Kenigsberg et al 2016). In turn, this leads to challenges for the person living with dementia him or herself in undertaking everyday activities of daily living (Giebel et al 2015; Han et al 2016; Patterson et al 2018). A systematic meta-analysis about the experience of living with dementia by Forsund et al (2018) concluded that living with dementia is like living 'in a space where the walls keep closing in' (p.1). The World Health Organisation (2019) also suggested that dementia is not only overwhelming for the person living with the diagnosis, but also for family carers. Given this negative positioning, it is perhaps unsurprising that the inclusivity and social citizenship of people living with dementia is regularly called into question (Bartlett & O'Connor 2010). Therefore, understanding how to best support people living with dementia to age well with their condition is of key importance, especially in the person's attempts to engage with the world outside their front door (Bartlett 2014; Duggan et al 2008; Author et al 2012; Marsh et al 2018; Woodbridge et al 2018).

Why is getting outdoors important?

It is well documented that for all human beings, being outdoors and engaging in the natural world has both a restorative and relaxing effect (Kaplan 1992; Kaplan 1995; Kaplan & Kaplan 1989). Similarly, research has consistently shown that access to nature, and to the outdoors, can have a positive impact on people living with dementia (Calkins et al 2007; Clarke et al 2013; Lakhani et al 2019; Mapes 2012; Mapes et al 2016; Rappe & Topo 2007). For example, it allows for: i) exercise, fresh air, social encounters and appreciation of the countryside (Duggan et al 2008; Phinney et al 2016); ii) improvements in circadian rhythm (the body's internal biological clock), which is important for sleep and energy levels (McNair et al 2010); iii) a positive increase in mood in people living with mid- to advanced stage dementia (White et al 2018); iv) a lowering of stress levels for care staff and families (Connell et al 2007, Edwards et al 2012); and v) the feelings of 'being home' through reconnecting with familiar outdoor space (Tsai et al 2020). Moreover, Mapes (2012) has also suggested that being outdoors helps a person living with dementia to orientate to the changing seasons.

For people living with dementia therefore, the home environment, both as a place of memories (Chaudhury 2008) and as a physical entity (Soilemezi et al 2017), is important. Most literature on the domestic home environment for people living with dementia fails to consider the garden/outside space within its remit and the focus of attention is placed on inside spaces, particularly housing adaptations/modifications (see for example: Mackintosh et al 2018; Powell et al 2017). When the literature does address outdoor spaces, emphasis is placed upon the impact of a broad range of 'away-from-home' outdoor-based activities, including horticultural therapy (Blake & Mitchell 2016; Gonzalez & Kirkevold 2014) and visiting green spaces such as parks and woodlands (Mmako et al 2020). A similar picture is found for people living with dementia in accessing and using a care home garden where the greatest emphasis is placed upon the therapeutic impact of the garden (Whear et al 2014) and/or creating a dementia-friendly garden design (Motealleh et al 2019). So far, there has been no review that considers the everyday use of, and access to, the domestic garden and this is where this review is located.

Review Aim

The primary aim of this narrative review is to explore the everyday experiences of people living with dementia in using and accessing their garden in both the domestic home and care home settings.

2.0 METHOD

A narrative review was chosen to address the review aim as the approach seeks to provide a more interpretive and discursive synthesis of the literature in comparison to other methods of review (Grant & Booth 2009, Greenhalgh et al 2018). The review protocol described below was first registered on the PROSPERO database (<https://www.crd.york.ac.uk/prospero/>) under registration number CRD42020165839. The review methodology and findings are reported according to the PRISMA reporting guidelines (Moher et al 2009).

2.1 Eligibility criteria

Using the 'PCC' mnemonic - Population, Concept, Context which is recommended for qualitative reviews (Lockwood et al 2017) studies were included in the review if they met the following criteria:

Population: People living with dementia who may/may not have a formal diagnosis, or people speaking on behalf of a person living with dementia (for example family/professional carers, voluntary organisations).

Concept: Access to, and use of, the garden including active use (such as gardening, putting out the washing, feeding the birds) and passive use (such as sitting), and including restrictions to access.

Context: The garden/outdoor space which is integral to the home environment and is within the curtilage of the home, including both private and shared/communal gardens. The type of residence was mainstream (everyday) or specialised housing and care homes as categorised by Housing our Ageing Population Panel for Innovation (HAPPI2; 2012:12).

Types of studies: Studies that meet the inclusion criteria including qualitative, quantitative and mixed methods. Limits were applied to studies published in English (due to lack of translation capacity) and studies published from 1990 providing a more contemporaneous understanding of the review aim. Research protocols, conference abstracts, editorials, and grey literature including garden design were excluded.

2.2 Search strategy

Using CINAHL, Google Scholar and Web of Science Core Collection (Bramer et al 2017) three sets of search terms were developed on the basis of Participant/Concept/Context. These search terms

were then applied in the relevant databases: dementia* OR alzheimer* OR neurodegeneration AND garden* OR horticultur* OR outdoor* OR “outside space” or “greenspace” AND home* OR dwelling* OR housing OR residen*. Published studies were identified through the electronic search of 9 databases recognising the need to include specialist databases (Bramer et al 2017) relevant to housing in addition to health and social care whilst carefully avoiding overlap: Allied and Complimentary Medicine (AMED), Applied Social Science Index and Abstracts (ASSIA), Cumulative Index to Nursing and Allied Health Literature (CINAHL PLUS), Design and Applied Arts Index, EMBASE, GreenFILE, Health Management Information Consortium (HMIC), MEDLINE, Social Policy and Practice (which includes Age Info).

It is possible that relevant studies may still be missed, therefore the accepted practice of using complementary search methods was important in compensating for such deficiencies (Papaioannou et al 2010) and this comprised three approaches. Firstly, reference list checking of the included studies was utilised because it is suggested that this is ‘simply good practice’ (Booth 2016 p.16). Second, Web of Science citation index was additionally used for citation reference searching to see where included studies had later been cited in case this identified any additional studies. Third, hand searches were undertaken of a number of salient journals to ensure that no articles were missed (Britten & Pope 2012), namely *Dementia: the international journal of social research and practice*, *Environment and Behaviour*, *Journal of Home and Consumer Horticulture*, *Journal of Housing for the Elderly*, *Journal of Therapeutic Horticulture*, *Landscape Journal*, *Landscape and Urban Planning*, and *Landscape Research*. The final list of studies from each database was imported into Endnote bibliographic software. Automated removal of duplicates was only partly successful, so this was supplemented with manual removal (Rathbone et al 2015).

2.3 Data extraction

For each included study, one reviewer extracted the characteristics of the included studies using an adapted version of the Joanna Briggs JBI QARI Data Extraction Tool for Qualitative Research (Lockwood et al 2017). The completed form was then checked for accuracy by two members of the authorship [author initials withheld for peer review] and any implications for the review, such as the planned approach to analysis including potential sub group analysis, were discussed by the review team, i.e. all members of the authorship.

2.4 Risk of bias (quality) assessment

For each included study, one reviewer assessed the methodological quality to determine the extent to which a study had addressed the possibility of bias in its design, conduct and analysis. The Critical Appraisal Skills Programme (CASP) (2018) Qualitative Checklist was used for this purpose due to the wide diversity in both character and content of the included studies. The completed form was then checked for accuracy by a second reviewer [author initials withheld for peer review].

2.5 Strategy for data synthesis

Thematic analysis was undertaken using the six-phase approach proposed by Braun & Clarke (2006). Each of the included studies was an individual dataset, with a finding being defined as 'a verbatim extract of the author's analytic interpretation of their results or data' (Lockwood et al 2017 p.29). Where possible, each finding was accompanied by an illustration defined as 'a direct quotation of a participant's voice, field-work observation or other supporting data from the paper' (Lockwood et al 2017 p.29). The aim of the coding and theme development was to provide a coherent and compelling interpretation of the data, grounded in the data through a reflexive thematic approach (Braun & Clarke 2019).

3.0 FINDINGS

Figure 1 outlines the review process undertaken according to PRISMA 2009 Flow Diagram Guidelines (Moher et al 2009). Here, 1174 records were identified from both database and hand searches and after removal of duplicates, 439 records were screened by title and/or abstract for relevance by one reviewer (the first author), with a random sample of 10% independently checked by a second reviewer. Any disagreements on whether a record should be included were resolved through discussion. By following this process, 130 full texts of potentially relevant records were screened for relevance against the inclusion criteria by one reviewer and 108 records were excluded at this stage. Again, a random sample of 10% were independently checked by a second reviewer and any disagreements were resolved through discussion. The final number of included studies was 22.

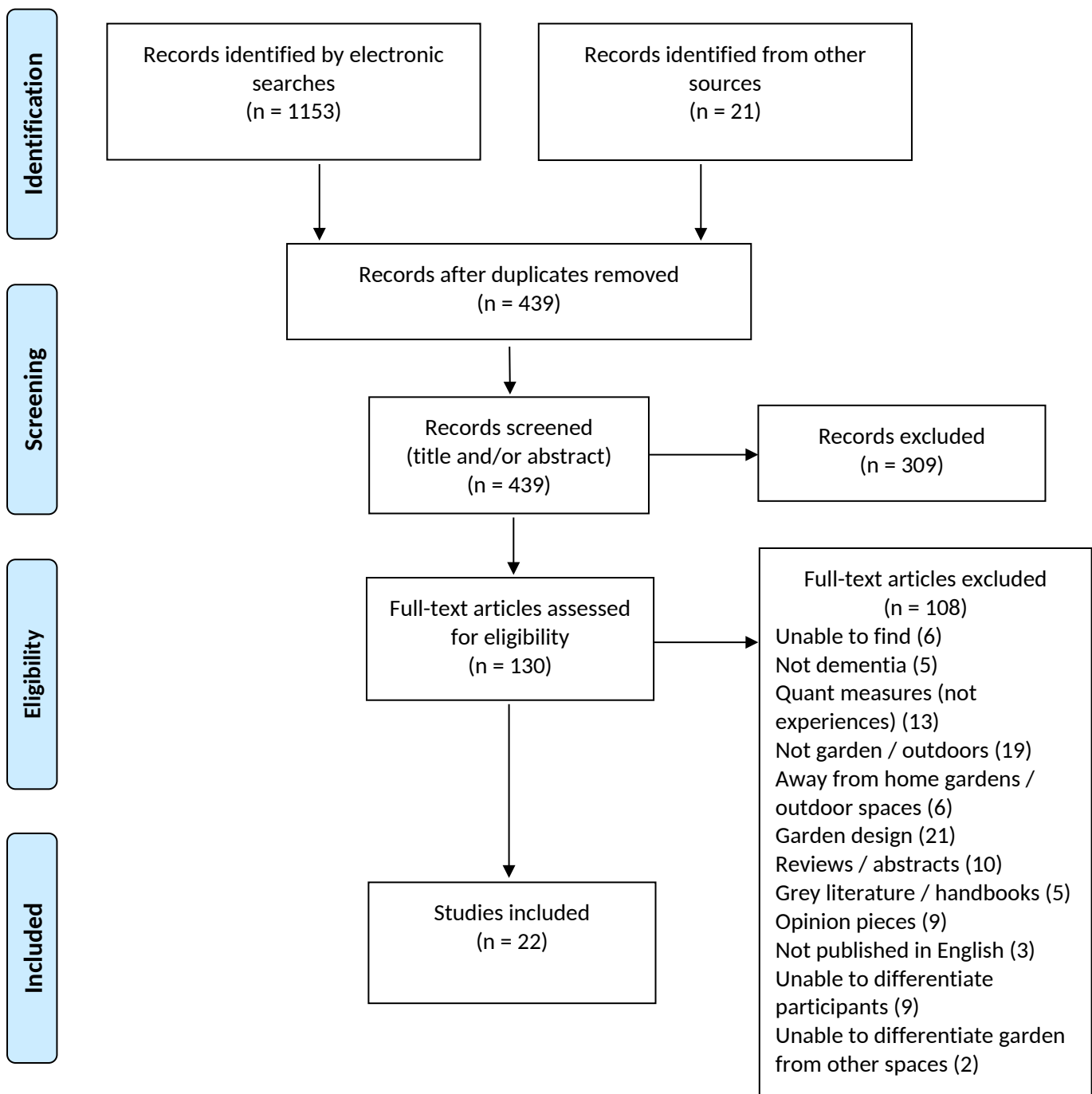


Figure 1 PRISMA Flow Diagram (Moher et al 2009)

Of the 22 included studies published between 1990 and 2019, nine were conducted in the UK, seven in USA/Canada, three in Netherlands/Belgium, two in Sweden/Norway, and one in Australia. Consistent with the aim of the review, six studies focussed on own home, 14 studies on care homes, and two studies on a combination of own home/specialised extra care housing/care home.

Predominantly, the garden was just one element of a study with only four studies having the garden as the main focus, and each of these four studies was in the context of care homes. Further details of study characteristics are summarised in Table 1. The risk of bias (quality) assessment for each individual study are reported in Table 2. No studies were excluded on the basis of this quality assessment, but the information was used to highlight potential issues within a study's methodology where appropriate.

Author	Location	Publication	Setting (context)	Participants (population)	Phenomena of interest (concept)	Methodology (overall approach)	Method of data collection	Data analysis	Extent of garden / outdoor discussion
Allen et al 2019	UK	Dementia	Own home	10 people with dementia and their informal carer	Adapting the home	Interpretive phenomenological analysis	Semi structured interviews + researcher reflexive diary	Thematic analysis	Garden is just one element
Barrett et al 2018	UK	U of Worcester Report	Residential care & extra care housing	Not stated	Green or nature based opportunities	Case study	Interviews with residents & staff across 3 residential care environments and 3 extra care housing schemes	Not stated	All sorts of green including pets etc
Buist et al 2018	Netherlands	Int Psychogeriatrics	Green care farms	23 professionals from GCF's	Characteristics of GCF	Survey	Interviews with professionals	Framework analysis	Garden / outdoors is just one element (but a main element)
Chalfont 2013	UK	J of Dementia Care	Care home	Not stated	Re-design of outdoor space	Case study	Narrative of design changes at 1 care home	Not stated	Garden / outdoors is the main focus
Chung et al 2017	UK	Int J Qualitative Studies on Health and Well-being	Own home	15 resident carers of people with dementia (interviews); 21 carers (focus groups)	Family carers experiences of engaging their relatives in daily activities	Grounded theory	Interviews of carers of people with dementia; focus groups	Grounded theory	Garden is just one element
Duggan et al 2008	UK	Dementia	Own home	22 people with dementia & 14 of their carers	Use of the outdoor environment	Grounded theory	Interviews	Grounded theory	Outdoors (away from home)
Edwards et al 2012	Australia	Dementia	Special care unit (dementia)	10 residents with dementia; Number of staff & carers not stated	Evaluation of a new therapeutic garden	Case study	Quant measures; Interviews with staff, carers & residents at 1 SCU	Quant instruments described; approach to analysis of interviews not stated	Garden / outdoors is the main focus
Evans et al 2018	UK	Aging & Mental Health	Care home	18 care home staff each from a different care home	Balancing risk and autonomy	Survey	Interviews with care home managers	Thematic analysis	Garden is just one element
Evans et al 2019	UK	Working with older people	Extra care housing & residential care	144 staff / managers (online survey); interviews 19 residents (7 extra care, 12 care home), 5 managers (3 extra care, 2 care home), 11 other staff members (4 extra care, 7 care home) (interview)	Integration with nature within extra care, and residential care	Survey	Online survey with staff / managers from both types of care; subsequent case studies involving interviews with staff, residents & family carers	Thematic analysis	Green dementia care main focus
Heggestad et al 2013	Norway	Nursing Ethics	Nursing home	5 residents with dementia	Life in a nursing home with an emphasis on dignity	A phenomenological and interpretive hermeneutical approach	Participant observation and interviews with 5 residents (total) in 2 nursing homes	Thematic analysis	Garden is just one element
Hernandez 2007	USA	J Housing for the Elderly	Special care unit	28 staff members, 12 family members, 5 architects / designers	Therapeutic garden	Qualitative inquiry	Post occupancy evaluation in 2 units	Not stated	Garden is the main focus
Innes et al 2011	UK	Aging and Mental Health	Care home	29 people with dementia, 11 family carers	What do residents and carers value in care home design?	Survey	2 focus groups	Thematic analysis	Garden is just one element
Jaffe & Wellin 2008	USA	Care Management Journals	Residential care	1 person with dementia	Transition into res care	Narrative gerontology	Single case study of female with dementia; largely a narrative	Narrative analysis	Garden is just one element
Li et al 2019	UK	Ageing & Society	Own home	5 couples (one partner with a diagnosis of dementia)	The meaning, construction and place of neighbourhood	Narrative inquiry within a longitudinal participatory approach	Interviews, neighbourhood maps, photographs, diaries & observations	Narrative analysis	Garden is just one element

McAllister & Silverman 1999	USA	Qualitative Health Research	Residential care	93 residents with dementia; Number of staff & carers not stated	Traditional nursing home v residential alz facility	Ethnography	2 case study sites; participant observation and open ended interviews; quant data measures	Patterns	Garden is just one element
Morgan & Stewart 1999	Canada	Qualitative Health Research	Special Care Unit	9 staff, 9 family carers	Needs of residents from the perspectives of staff and family carers	Qualitative methods	Interviews with staff and family carers	Grounded theory	Garden is just one element
Olsson et al 2013	Sweden	Aging & Mental Health	Own home	11 people with dementia	Being outdoors	Qualitative inquiry	Repeated interviews	Content analysis	Outdoors (away from home) and garden
Raske 2010	USA	J of Gerontological Social Work	Nursing home	16 residents (4 of whom had dementia), 6 family members, 15 staff members, 6 garden club volunteers	Planning of a garden and post occupancy evaluation	Qualitative exploratory study	Interviews	Content analysis	Garden / outdoors is the main focus
Silverman 2018	Canada	International Journal of Care and Caring	Own home	10 carers	Carer respite	Qualitative inquiry	Repeated interviews	Thematic analysis	Garden is just one element
Van Hecke et al 2019	Belgium	Health Environments and Research Journal	Residential care	4 residents with dementia, 3 close relatives, 4 care staff members, the director, client, & architect	Effect of enclosure and spatial organisation (design) on residents experience	Case study	Single care study, post occupancy evaluation - participant observation & interviews	Grounded theory	Garden is just one element
Van Hoof et al 2016	Netherlands	BMC Geriatrics	Nursing home	24 residents, 18 relatives, 26 care professionals	Sense of home	Qualitative methodology	4 nursing homes - photography & interviews (residents), focus groups (professionals and carers)	Thematic analysis	Garden is just one element
Wood et al 2009	USA	American J of Occupational Therapy	Special Care Unit (dementia) (2)	14 residents with dementia	The daily occupational lives of older adults with dementia	Instrumental case study design	Observations across 2 case study sites (mainly quant data)	A range of statistical measures	Garden is just one element

Table 1: Characteristics of included studies

Included Study	Critical Appraisal Skills Programme (CASP 21018) Question									
	Q1 Was there a clear statement of the aims of the research?	Q2 Was a qualitative methodology appropriate?	Q3 Was the research design appropriate to address the aims of the research?	Q4 Was the recruitment strategy appropriate to the aims of the research?	Q5 Was the data collected in a way that addressed the research issue?	Q6 Has the relationship between the researcher and participants been adequately considered?	Q7 Have ethical issues been taken into consideration?	Q8 Was the data analysis sufficiently rigorous?	Q9 Was there a clear statement of findings?	Q10 Was there a statement on how valuable is the research?
Allen et al (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Barrett et al (2018)	Y	Y	Y	Y	Y	?	N	Y	Y	Y
Buist et al (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Chalfont 2013	Y	Y	Y	Y	Y	Y	N	N	Y	Y
Chung et al (2017)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Duggan et al (2008)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Edwards et al (2012)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Evans et al (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Evans et al (2019)	Y	Y	Y	Y	Y	?	Y	?	Y	Y
Heggstad et al (2013)	Y	Y	Y	Y	Y	Y	?	Y	Y	Y
Hernandez 2007	Y	Y	Y	Y	Y	Y	?	Y	Y	Y
Innes et al (2011)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Jaffe & Wellin (2008)	Y	Y	Y	Y	Y	Y	?	?	Y	Y
Li et al (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
McAllister & Silverman (1999)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Morgan & Stewart (1999)	Y	Y	Y	Y	Y	Y	?	Y	Y	Y
Olsson et al (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Raske (2010)	Y	Y	Y	Y	Y	Y	?	?	Y	Y
Silverman (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Van Hecke et al (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Van Hoof et al (2016)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wood et al (2009)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Table 2: Risk of bias (quality) assessment (CASP 2018)

Data analysis revealed three main themes for describing the experiences of people living with dementia in accessing and using their garden: i) Enabling a sense of life continuity and identity; ii) Connecting to nature and to the moment; iii) Managing everyday risks. There is some overlap between the themes due to the reliance on a small number of papers which had the garden as a main focus (discussed previously). Further details about each of the themes are now outlined below.

3.1 Theme 1: Enabling a sense of life continuity and identity

This first theme reflects the importance of the garden and outside space integral to the home to enable a sense of life continuity and identity for people living with dementia. In particular, the theme represents the importance of 'meaningful doing' and that the garden and outside space continued to represent a sense of enjoyment and happiness that impacted upon the person living with dementia's overall well-being (Chung et al 2017). Developing this point further, in a study by Barrett et al (2018), an outside activity was described by staff as having a positive outcome 'if the resident had engaged in meaningful activity, experienced pleasure while doing so, and was happy and calm that day as a result' (p.10). Knowing the person living with dementia well, particularly their capabilities and potential, was seen to be important. For example, Buist et al (2018) shared an example of a gentleman living with dementia who loved animals and for him, the ability to tend to his pet brought more fulfilment than 'shovelling in the garden' (p.1061). Similar examples of meaningful activities undertaken by people living with dementia were seen in the literature, such as: keeping busy by tidying up (Barrett et al 2018), watering the garden (Edwards et al 2012), putting animals to bed (Evans et al 2019), taking the (care home) resident dog for a walk (Innes et al 2011), listening to the birdsong (Barrett et al 2018), planting and weeding (Innes et al 2011, Raske 2010), harvesting produce (Edwards et al 2012), and simply going into the garden to admire it and take in the sensory experience (Raske 2010). In turn, these activities impacted upon a person living with dementia's everyday well-being by giving the individual a conversational reservoir that could be drawn upon to tell and share stories (Hernandez 2007).

Furthermore, being outside and doing meaningful things enhanced a sense of agency and personhood for people living with dementia (Chung et al 2017; Olsson et al 2013). Often, family carers would support a gardening activity being undertaken by a person living with dementia, even if it was not seen as being 'successful', as they felt it upheld the person's biographical identity. The following slice of data from the work of Chung et al. (2017) best illustrates this point:

‘On five separate occasions I observed two gentlemen [with dementia] walking to a bench and sitting together. They had this ritual of walking quietly together and sitting on the same bench each morning. No talking occurred, but they would sit for fifteen minutes or so, look up at the sky or down at the ground for a few moments, bask in the sun a little, then get up and walk back inside to the common area’ (p.137).

Passive sitting, whether indoors or outdoors, will often contain an element of ‘social walking’ which is a phrase coined by McAllister & Silverman (1999) to describe an activity involving several residents walking around inside (and sometimes outside) in small groups, often linking arms. In their study, McAllister & Silverman (1999) provided an example of connecting to the moment ‘when they [the social walking group] encountered another such group or passed by residents sitting along the public pathways, numerous greetings were exchanged’ (p.74).

Similarly, gardens were described as extensions to the home and as places of relaxation which were integral to well-being (Silverman 2018). Within the context of a person’s own home, having a view from a window and being able to look into the garden helped family carers to bring the outside world into the home and to draw on it as a source of support (Silverman 2018). Family carers with relatives in care homes recognised the difference that accessing a garden had had on their relatives, which in turn improved the quality of their visit (Barrett et al 2018; Edwards et al 2012). This access to a garden also enabled a sense of intergenerational family connection to continue, especially when a care home pet(s) may also be outside in the garden. In such circumstances, opportunities for human to pet interaction often rekindled family memories and provided an ‘in the moment’ frame of reference for shared fun and enjoyment (Evans et al 2019). This everyday enjoyment was further elaborated upon by Edwards et al (2012) who shared a family carers’ experience in a care home setting:

‘I can’t say how much a difference the garden has made for [names his wife]. Today I have taken her up on the viewing platform and we wrote a letter, she talked about the birds, she loves animals. It’s relaxing for us both to be out here. It has definitely improved her quality of life and I enjoy coming more too’ (p.505).

A sense of freedom (Evans et al 2019) and a sense of enjoyment from being present in the garden was experienced by people living with dementia (Barrett et al 2018; Li et al 2019; Raske 2010; Van Hoof et al 2016). Similarly, ‘feeling good’ from having been outside in the garden was identified in a number of studies (Barrett et al 2018; Chalfont 2013; Duggan et al 2008; Hernandez 2007; Raske

2010) with a recurrent message that 'It's a change to get out you know. Well fresh air makes you feel better. If I've been walking around the garden, then I come back, and I feel great' (Duggan et al 2008 p.195). Similarly, being outdoors was found to help prevent isolation and withdrawal (Evans et al 2019) and support social interaction (Edwards et al 2012; Wood et al 2009). This extract from the study data by Li et al (2019) helps to illustrate this experience:

'For Mary and Steve (couple 1), by simply sitting in the garden they could clearly see the local secondary school where school children sometimes played sports on the playing field opposite to their home. It was the importance of the sounds of life and visual impression that enabled the couple to feel connected to the neighbourhood' (p.18).

Furthermore, personalised spaces within the garden provided a sense of 'being in place in the moment' and provided a sense of connection from inside the home to the connections outside the front door (Li et al 2019; Silverman 2018).

Interestingly, the threshold space between indoors and outdoors also provided an opportunity for people living with dementia in care homes to nurture close relationships with other residents (McAllister & Silverman 1999). Moreover, people living with dementia could connect to nature and to the moment by staying indoors, such as by looking through a window and watching the birds outside (Evans et al 2019). However it was experienced, such moments with nature were a creative spark for conversation and shared stories.

3.3 Managing everyday risks

This third theme reflects the challenges in facilitating and assisting people living with dementia to engage with the garden whilst managing the risks associated with conducting everyday life in such spaces and places. In particular, the theme draws attention to the effect on well-being and quality of life when risk is managed positively, as opposed to the potential detrimental effect on people living with the dementia when restrictions to go outdoors are imposed and basic freedoms restricted.

As seen in the literature, quick and easy access into the garden, coupled with accessible, attractive and safe garden spaces, enabled people living with dementia to move around freely and safely either independently or with support (Evans et al 2018; Evans et al 2019; Innes et al 2011; Raske 2010). Such access was seen to increase people living with dementia's mood (Chalfont 2013; Edwards et al 2012; Evans et al 2018) and to help a person become more calm and relaxed as a

consequence. A study by Hernandez (2007) found that the simple act of going from an indoor space to outdoors helped a person living with dementia to forget why they were upset. Similarly, a study by Chalfont (2013) found that when a person living with dementia once again returned indoors they continued to be much calmer and relaxed, as this rather lengthy extract from the data reveals:

'We have one resident and he can be quite challenging: quite loud, outspoken. So we'll take him outside, and we'll go walk around the garden. He acts like he doesn't like the outside, but you can tell he secretly does, he just wants to be a bit cheeky. So we'll walk around and come back in and I'll ask 'Did you really enjoy that?' and he'll say, 'Yeah, yeah, yeah'. Then I'll ask 'Do you want a cup of tea?' and he'll sit and drink a full cup of tea. Now if we hadn't taken him outside and took him for a walk, then he probably wouldn't want to sit down for long in order to have that cup of tea. He wouldn't be so calm to have a cup of tea. Something so small, and then the rest of the day it's quite nice.' (p.33)

Whilst relatives of people living with dementia felt that safety, cleanliness and security were important elements of care home settings, in contrast residents at times articulated feelings that they were being controlled and needed to ask to use outdoor spaces (Innes et al 2011). In other studies, this feeling of being controlled and lacking autonomy (Van Hoof et al 2016) manifested itself as feeling imprisoned: 'You know, it's like a prison without bars ... I feel like a prisoner. I have no freedom' (Heggestad et al 2013 p.887). Consequently, people living with dementia reported a sense of captivity either because they were unable to access internal rooms, such as the kitchen within a care home due to locked doors, or because they were unable to access the garden on their own and when they wanted to. In turn, this led to people living with dementia feeling trapped (Heggestad et al 2013; Jaffe & Wellin 2008; Olsson et al 2013) and believing that they were 'living in an institution' (Olsson et al 2013). This experience was emotively captured in the study by Jaffe & Wellin (2008) when sharing data from 'Jane', a resident living with dementia:

'Coming here was the worst decision I've made in my life...I'm not allowed to feed the birds here...They don't let you just sit out there by yourself; one of them [staff members] has to be out there with you. Maybe they think I've got a motorcycle out there, and I'll hop on.'

(p132)

In another study conducted by Buist et al (2018), the manager of a larger scale care facility gave an example of the frustrations of residents in being restricted to go outdoors:

'A while ago we had a bench in front of the door. And when the sun was shining staff members would go out to smoke a cigarette there. But then we noticed that they [people living with dementia] become agitated and they want to go outside. They started tapping on the window, and pounding the doors because they wanted to go outdoors to sit on the bench. So we removed the bench, since it only caused agitation. We concluded that the bench did not work because residents became agitated, and wanted to go outdoors, so we removed it.' (p.1064).

The physical layout of a care home was often an obstacle to spontaneous, independent access. In particular, facilities/rooms located on an upper floor reinforced the barrier to going outside when the garden was located on the ground floor (Buist et al 2018; Evans et al 2018; Evans et al 2019; Raske 2010; Van Hecke et al 2019). A study by Evans et al (2018) described how people living with dementia were purposefully allocated an upstairs room to restrict freedom of movement because of the challenge in providing a safe environment. Similarly, Van Hecke et al (2019) found that where there was an outside space at first floor level, concerns were expressed by staff and family carers about the appropriateness of the space in terms of safety and risk.

Concerns for personal safety of the person living with dementia, such as a risk of falling or the possibility of an altercation with another resident, often prompted care home staff to supervise and accompany the person outdoors (Evans et al 2018; Evans et al 2019; Morgan & Stewart 1999). This risk-adverse behaviour was further heightened when care home staff were simply unable to observe the use of the garden from inside the care home (Van Hecke et al 2019). In the care home literature, access to outside spaces was often controlled by locking doors, using doors with keypads, fitting door alarms or disguising doors (Evans 2018). Building code regulations were also frequently cited as a reason for this restriction (Hernandez 2007). At times, it was found that gardens in care homes were little used despite doors opening directly onto them (Chalfont 2013; Hernandez 2007) and where doors were not locked during the day, both Van Hoof et al (2016) and Wood et al (2009) reported that care home staff restricted resident access to the garden from late afternoon. In such circumstances, risks and the denial of access to garden spaces are intersecting with the fundamental human rights of people living with dementia. Put simply, it is difficult to interact with a garden and obtain the benefits of the outside and the natural world when a person living with dementia is denied access to it.

4.0 DISCUSSION

This systematic narrative review of the literature has explored the experiences of people living with dementia (including family/carers as appropriate) in accessing and using their garden in both the domestic home and care home settings. Evidence from 22 studies was thematically analysed using the six-phase approach proposed by Braun & Clarke (2006). The review findings identified three independent but at times intersecting themes the explored and described this process: enabling a sense of life continuity and identity; connecting to nature and to the moment; and managing everyday risks.

Theme 1 reflected the importance of the garden in enabling a sense of life continuity and identity in the selfhood of people living with dementia and these findings are consistent with the wider literature. For older people in general, looking after the garden, including watering, planting, decorating and beautifying, is important (Tsai et al 2020), and in turn, these meaningful activities prompt a person to orientate towards the present (Sudmann & Borsheim 2017). Specifically, within the context of the lived experience of dementia, sensory stimulation, such as light, smells, sounds and touch, trigger the process of remembering (Cook 2019). This connection enables a person living with dementia to reconnect to special memories (Cloke & Pawson 2008), past skills (Gibson et al 2017), and to feel at 'home' (Kitwood 1997). In turn, this supports selfhood and subjective well-being (Smith-Carrier et al 2019). Recognising that quality of life is diminished when a person living with dementia is disengaged from familiar outdoor spaces (O'Rourke et al 2015) can be overcome by taking a biographical and person-centred approach to care (Ballard et al 2018; Edvardsson et al 2014; Kaufman & Engel 2016; Kim & Park 2017). Here, the role of life story can capture and map a person's 'garden story', for example, and continue a sense of biographical identity for a person living with dementia (Gridley et al 2016).

Theme 2 revealed that connecting to nature, and to the moment, could be achieved by the person living with dementia in a number of ways. For example, looking at nature either from the window (Burton & Sheehan 2010; Gibson et al 2007; Kaplan 2001) or actively seeking to connect with nature (Milligan et al 2004), provides people living with dementia with 'both instant and long lasting pleasure' (Tilley 2006 p.326). Similarly, sensory experiences help with feeling connected and to being a part of the 'ordinary life' and belonging to the wider world (Orr et al 2016 p.12). Being active in the garden is an important element of home-making particularly for care home residents

(Cooney 2012). By investing physical, social and emotional labour into the garden (Eijkelenboom et al 2017) roles as passive consumers are transformed, and thus 'garden making' becomes a part of 'home making' which is central to having a concept of home (Tsai et al 2020 p.6). Indeed, the opportunity to create the moment for people living with dementia to engage and interact with garden and outdoor spaces would seem an important future development (Author 2020).

Theme 3 confirmed the challenges in facilitating and assisting a person with dementia to engage with the garden whilst managing the associated risks. Within the wider literature, little is known about risk-taking within the context of the domestic home garden. No studies were found on the management of risk in this specific area, and only one of the included studies (Olsson et al 2013) touched upon this, but within the context of getting outdoors in general. Within the context of care homes, a systematic review by Whear et al (2014) found two principle barriers to accessing and using the garden, first the perception of the garden as a hazard and then the limited (if any) time staff had to accompany residents outside regularly, and this is consistent with our findings. Whilst outside spaces can be naturally hazardous for anyone because they typically comprise 'a complex, multi-faceted collection of elements' (Marsh et al 2018 p.178), denying the person living with dementia a right to take risks on the basis of their diagnosis is a threat to personhood and to living well (Mapes et al 2016; Potter et al 2017). Overall, within the context of care homes, the literature suggests that people living with dementia are generally restricted in accessing the garden and that this has a potentially detrimental effect on personal well-being.

Across the whole review data set, living in the domestic home setting as opposed to a care home posed diverse challenges for people living with dementia (Forsund et al 2018). It is clear from the underpinning evidence collected for this review that people living with dementia at home in the community were more in control of their environment, including the garden, than those living in a care home. This is consistent with findings from other reviews about older people more generally (see for example: Orr et al 2016). Whilst access to, and use of, the garden within both settings can give a sense of freedom and independence, there is a particular challenge in supporting people living with dementia to do this in the context of care home settings. The potential implications of this dichotomy reinforces the direct relationship between feeling purposeful and having a positive quality of life within the domestic home setting, as opposed to feeling aimless and having a diminished quality of life in a care home setting (O'Rourke et al 2015).

Whilst there is increasing attention on the garden/outdoor environment (Cooper-Marcus & Sachs 2014), the literature is presently 'awash' with recommendations for garden design (Orr et al 2016 p.13), particularly within the context of care homes and at the expense of the domestic garden setting. Arguably, there is a need to even-up this gap and develop a greater understanding about the link between garden design and garden use by people living with dementia within the everyday domestic garden setting. Similarly, there is also a common assumption that older people no longer garden (Tsai et al 2020). However, there is robust evidence for the positive effect of gardening on health in general (Soga et al 2017) and despite dementia being a complex nuanced condition (McParland et al 2017), community gardening has been shown to have multiple benefits for people who live with the diagnosis (see for example: Marsh et al 2018; Mmako et al 2020, Noone et al 2017; Noone & Jenkins 2018). It would therefore seem important to determine whether these 'outside' benefits are mutually transferable to the domestic garden given the prevalence of the number of people with dementia who live at home in the community.

Finally, the contribution of people living with dementia was significantly under-represented within the included studies for the reported review. If the presence of people living with dementia is largely absent from the research process, or they are included as a homogenous group within a broader sample of older people, then this impacts upon an authentic representation of experiences (Marsh et al 2018). Without more participatory study designs, and ones that values the outside space of a home as much as the inside, then the picture will remain static and undeveloped. And that would be an inauthentic representation of the reality of human life and experience.

5.0 STUDY LIMITATIONS

The studies included in this narrative review used largely standard qualitative data collection methods yet the evidence generally lacked depth, particularly in how data were recorded, reported and analysed. Rich descriptions of data were often absent and this has meant an over-reliance on a small number of papers for these descriptions. The review was also limited by including studies only published in English, which may, in part, have accounted for the lack of representation of studies from non-Western countries.

6.0 CONCLUSION

This systematic narrative review confirmed that relatively little is known about the domestic garden and the everyday lived experience of dementia. Moving forwards, there is a pressing need to better understand how the domestic home garden contributes to the overall well-being of people living with dementia and how this links to the continuity of everyday life. Moreover, issues of denial of access to the garden and outside spaces of the home, be that the domestic home and/or a care home, or other form of sheltered living, is in need of urgent attention and study.

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