



Shortlisted 2016

Cities and Community

**Living Well with Dementia at Home:
Understanding the Role of the Home
Environment**

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This was a timely piece of research that has been methodologically investigated and articulately written up and has the potential to make a valuable contribution to the existing body of research into dementia and the built environment.

2016 Judging Panel

Living Well with Dementia at Home: Understanding the Role of the Home Environment

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This project aimed to explore the role of the home environment in dementia care and support, and it consists of two parts. The research starts with a systematic synthesis of international qualitative studies exploring the role of the home environment, architectural elements and strategies. From 11824 citations found in 12 databases, 40 qualitative studies representing nine countries, 653 informal carers, 372 people with dementia and 120 professionals were analysed using thematic synthesis. Findings indicated that: (a) Home, although an important place, can also be a place of tensions. (b) Home needs to remain individualised and flexible to accommodate life and health challenges and changes. (c) Adapting the physical space, objects and behaviour is necessary to facilitate quality of life. These findings offer evidence on a number of important architectural and design aspects that need to be taken into consideration to support community dementia care. The second part involved walking interviews with thirteen co-resident family carers to explore (a) the subjective and (b) the objective impact of their home, and were analysed thematically. Findings revealed that 'home is everything' for carers and has different meanings ('home as a secure haven', 'home as a prison') and great impact on carers (relocation versus staying in place but redefining their home). Data also revealed the impact of home as a site of care provision and highlighted important aspects of the architectural and interior environment, that when adapted can encourage independence and comfort at home. The unique challenges of dementia and the important home components (e.g. size, layout and accessibility) need to be taken under consideration to ensure future housing is dementia and caring friendly to correspond to the needs of our ageing society. Future carers will clearly benefit from the adaptability and hybridity of their homes.

Introduction

The rapid growth of the elderly population has increased the number of people who are diagnosed with dementia, with over 46 million people globally living with dementia (Prince et al., 2015) and over 850,000 people in the UK (Alzheimer's Society, 2014). The majority of people with dementia are cared for in their own home, making informal caregiving a significant proportion of dementia care provision (WHO, 2012). One of the most challenging aspects for carers is dealing with the neuropsychiatric symptoms of dementia, such

as agitation, wandering, restlessness, and apathy, and several reviews have examined non pharmacological interventions to support people with dementia and their carers and delay institutionalisation (Brodsky, Green, & Koschera, 2003; Cooke et al., 2001; Moniz Cook et al., 2012; Torti, Gwyther, Reed, Friedman, & Schulman, 2004). Until a cure is found, it has been argued that examining the suitability of the home environment (e.g. design, adaptations, interventions) and manipulating the physical environment can play a significant role in the management of dementia and the quality of

life of both the patient and carer (Garcia, Kartolo, & Méthot-Curtis, 2012; Gitlin, Liebman, & Winter, 2003; Robinson et al., 2006; van Hoof, Kort, van Waarde, & Blom, 2010).

Researching the home environment and ageing in place has increasingly become the focus of dementia care and is crucial for a number of reasons. Firstly, it is a consistent wish of older people to remain at home (van der Roest et al., 2007; WHO, 2012) as they feel attached to it; it is a central, meaningful and important place for them (Petersson, Lilja, & Borell, 2012). Older people are attached to their homes and more committed to remaining in place as “for the young, the home is a point on housing career trajectory; for the old, it is the end point of such a trajectory” (Saunders, 1989; p. 183). Especially for family carers of people with dementia who spend a lot of time indoors, the interior home space is significant as it becomes their ‘primary restorative context’ (Betrabet Gulwadi, 2009). A number of researchers developed approaches to capture the enduring and evolving meaning of home and its multi-dimensional nature (Oswald & Wahl, 2004; Saunders, 1989; Sixsmith, 1986; Somerville, 1992), mostly including two principle dimensions of the meanings of home: (a) a socio-cognitive- psychological dimension, associated with family, happiness, identity and privacy, and (b) a physical/spatial dimension, associated with shelter, security, comfort and relaxation. The meaningful relationship that people form between all dimensions (social, physical, psychological, personal) of their ‘house’ to create a ‘home’ develops and intensifies throughout the life span (Gillsjö, Schwartz-Barcott, & von Post, 2011;

Swenson, 2010), is closely associated with life stability, healthy ageing, and quality of life (Boström, Bravell, Lundgren, & Björklund, 2013), enables older people to feel safe (Petersson et al., 2012), and results in the ‘feeling at home’, as a perfect state of being (Zingmark et al., 1995). Disruptions of this feeling at home, for example, relocation, may result in changes to people’s wellbeing (Chaudhury & Rowles, 2005).

The person-environment fit (or press) model is the pivotal framework in person-environment research (Kahana, Lovegreen, Kahana, & Kahana, 2003; Lawton, 1990) that has been used in many intervention studies to explore the usefulness of environmental modifications (Wahl & Weisman, 2003) and residential satisfaction (Kahana et al., 2003). Several reviews, including Cochrane reviews, have examined the effectiveness of different environments and/or environmental strategies in dementia care, such as lighting (Forbes, Blake, Thiessen, Peacock, & Hawranik, 2014; Torrington & Tregenza, 2007), special care units (Lai, Yeung, Mok, & Chi, 2009), Snoezelen (Chung & Lai, 2009), music (Vink, Bruinsma, & Scholten, 2011), built environment (Soril et al., 2014), aromatherapy (Holt et al., 2009; Nguyen & Paton, 2008), subjective barriers (Price, Hermans, & Grimley Evans, 2009), or a variety of strategies (Day, Carreon, & Stump, 2000; Gitlin et al., 2003). All these reviews focused mainly on residential care settings apart from one (Gitlin et al., 2003) that also included private homes. To our knowledge, there has not been any updated nor qualitative review that examined aspects of home environment together with environmental strategies.

However, qualitative studies exploring the experiences and perceptions of the role of home environment and helpful (or not) interventions have been undertaken. Qualitative studies are useful in bringing light on to people's experiences, acceptance and satisfaction with interventions, especially in domestic settings which is a largely ignored territory (van Hoof & Kort, 2009). To our knowledge, there are only limited studies that explore carers perceptions around the role of home design and modifications for dementia carers. This study aims to (a) explore and synthesise international qualitative evidence on the experiences of people with dementia and their carers of their home environment, and home design and strategies perceived as helpful and acceptable, and (b) explore carers' views on all aspects of their home environment and available environmental strategies in order to enhance our understanding of how the home environment can best support people with dementia and their carers at home. This thesis starts with a systematic review and continues with an empirical study.

Systematic Review of Qualitative Research on the Role of the Home Environment in Dementia Care and Support

The aim of this review is to explore and synthesise qualitative evidence on the experiences of people with dementia and their carers of their home environment, and environmental strategies perceived as helpful and acceptable. The research question is 'What is the role of the home environment in dementia care?'. Ultimately the goal is to identify barriers and facilitators that impact in effective

dementia care at home and identify research gaps. Systematic reviews allow transferability, prevent unnecessary duplication of research, and are invaluable for busy practitioners as they combine results from many studies, provide up-to-date summarised evidence and disseminate them in an unbiased and rigorous manner (Dixon-Woods, Agarwal, Young, Jones, & Sutton, 2004; Mackenzie et al., 2012; Pope & Mays, 2006). This review is intended to inform health and social care professionals, as well as professionals working in environmental design, and provide some evidence-based guidance to policy makers and general public to better understand environmental considerations in dementia care. A protocol (Soilemezi, Drahota, Stores, & Crossland, 2013) was published setting out all aspects of the review plan.

Methods

Inclusion criteria

I adopted the term 'sensory environment' (Drahota et al., 2012) to refer to any aspects of the home surroundings that can be seen, touched, smelt, or heard. This included: (a) the built environment (walls, flooring, windows, size, lay-out), (b) ambient and interior environment (design, music, art, photographs, decor, furniture and furnishings, aromas / odours, lighting and noises/sounds), and (c) technologies, equipment and devices. In addition, we included the 'lived' experience of home, as a personal dimension of home experience. Qualitative studies that looked at any aspect of these as well as the manipulation or

strategies involving these aspects, were relevant for inclusion.

Publications were screened as to whether they met the following criteria:

- Primary qualitative studies, or qualitative studies that were part of a mixed methods project, from any geographical location published from 1970-onwards.
- Studies published in English, German and Greek were included as members of the research team were fluent.
- The study population had to include either people with dementia (of any type, stage and age who live at home), informal carers or healthcare professionals who work and support people with dementia and their carers in the community.
- The study had to examine either experiences, attitudes and/or beliefs around the impact of the home environment, acceptability and preferences of environmental components, barriers and facilitators to managing dementia at home and/or perceptions of what is helpful (or not) and why.
- Any type of private dwelling (house, flat, apartment, maisonette, bungalow, cottage) was included. We also included supported accommodation (e.g. retirement housing), as it is a self-contained accommodation that allows people to live independently with available help if needed.
- Studies that used any qualitative methods (including grounded theory, ethnography, narrative analysis, and phenomenology) were included.

Search strategy

An initial search was performed in MEDLINE and CINAHL that indicated key terms and text words, after testing and exploding the main terms in order to achieve the best sensitivity (Wilczynski, Marks, & Haynes, 2007). This exercise informed the second extensive search (May 2013) on 12 databases (from 1970-2013): MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Art and Architecture Complete (AAC), SocIndex, PsycINFO, British Architectural Library Catalogue (BALC), Joanna Briggs Institute (JBI), Social Care Online, Social Sciences Citation Index (SSCI), Science Direct, Campbell Library and Center for International Rehabilitation Research Information and Exchange (CIRRIE). Five sets of search terms were used to capture the key research question components: people with dementia, carers, professionals, environmental terms and qualitative research. Duplicates were deleted and final results were saved on EndNote software (Figure 1).

Data screening

Papers were doubled screened independently by the author (DS) and a second member of the supervision team (AD, RS, JC). Screening was done in three stages: initially on titles, then abstracts, and finally on full papers. Disagreements were resolved by consensus or by discussion with a third reviewer from the research team.

Data extraction

The author extracted data from all included publications, which included: type of study design, year when study was conducted, theoretical framework,

study aims, methods, type and demographics of participants, setting, method of analysis of the primary data and outcomes (Appendix).

Quality assessment

The Critical Appraisal Skills Programme (CASP) checklist consists of ten questions and was used to evaluate the included papers methodologically. The author evaluated all studies independently,

The research supervision team checked a quarter of the studies ($n=10$), discussed and resolved any disagreements. Afterwards, the author also conducted a sensitivity analysis. This involved reanalysing the data without the studies considered being of low quality (scoring <8 out of 10) to examine whether the final themes were affected significantly after removing those studies from the synthesis.

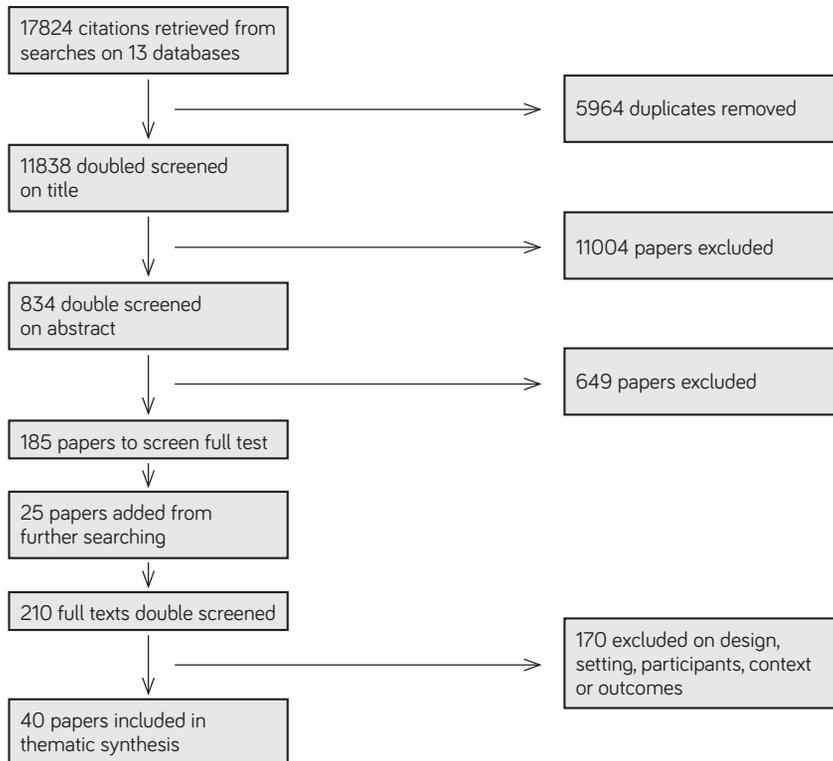


Figure 1
Flowchart of the Screening Process and Search Results

Data synthesis

This synthesis aimed to identify barriers and facilitators and answer a predefined question. For this reason, thematic synthesis was used that involved three stages. Firstly, each study was read repeatedly and relevant text was highlighted and coded in QSR International's NVivo 10 Software. Data included were all the text labelled as 'results' or 'findings' and in few cases even the discussion section (Thomas and Harden, 2008). Secondly, the coded data was read again to identify any patterns, similarities and differences, while preserving the context of the original studies. The codes from the inductive analysis were revisited and grouped together into a hierarchical structure in several layers to produce descriptive themes and topics. When necessary, new codes were created to represent the meaning and association between codes, ensuring that the reviewer remained very close to the findings. Finally, the reviewer used the descriptive themes to 'go beyond' the original studies and answer the review questions (Thomas and Harden, 2008), which enabled the generation of final themes. When the themes were finalised, they were discussed with the other reviewers to refine and rename (when appropriate) the final themes and subthemes.

Results

Description of included studies

Overall, forty two papers reporting forty studies met all criteria and were included in the review (Appendix). They involved studies from nine countries: USA ($n=12$), UK ($n=11$), Sweden ($n=7$), Turkey

($n=1$), Australia ($n=1$), Canada ($n=4$), Netherlands ($n=2$), Colombia ($n=1$), and Hong Kong ($n=1$). Studies were published between 1995 and 2013. The studies included 1,145 participants, the majority of them informal carers ($n=653$) across 33 studies, followed by people with dementia ($n=372$) across 18 studies, and professionals ($n=120$) across eight studies.

Quality of included studies

In terms of quality, three studies provided information to answer all 10 criteria on the CASP checklist and hence were considered of good quality; the majority of studies ($n=37$) lacked or missed some methodological information (Appendix). There were six studies (Dodds, 1994; Dröes, 2006; Forbat, 2003; Nochajski, 2013; Olsen, 1996; van Hoof, 2009) that did not address all three above-mentioned elements and could be considered of low quality. The sensitivity analysis showed that their contribution was minor to formation of the three main themes, as the main themes did not change after removing these studies. However, when the subthemes were examined, it was noted that one study (Olsen, 1996) made a considerable contribution to the formation of a subtheme ('layout and accessibility'), part of the second subtheme (2.2 'useful home components').

Thematic synthesis

The thematic synthesis enabled the generation of three final themes and a number of subthemes (Table 1). Some themes and their subthemes derived from a number of studies with few data to report and other derived from a substantial number

of data reported in included studies. Direct quotations from included studies were taken to represent the key themes and are presented in Appendix.

Home as a paradox

Home, sweet home

Home is a very important place with profound significance for people with dementia (Aminzadeh, 2010; Sixsmith, 2007). Home is associated with positive feelings for people with dementia and is the centre of their lives (de Witt, 2009). Home is a (a) centre of socialisation, (b) locus of autonomy and control, (c) locus of familiarity and constancy, (d) place of retreat, (e) repository of memories of life history, (f) site of the expression of personal interests and values, (g) site of the expression of functional competence and engagement in meaningful activities (Aminzadeh, 2010). Cherished personal possessions reveal a strong attachment to people's home, displaying their interests, values and life achievements (Aminzadeh, 2010). Leaving their home was perceived by people with dementia as a death sentence (de Witt, 2009).

Home experience disrupted

Dementia changed the way people with dementia and co-resident carers experienced their home and provoked a series of tensions and discontinuity (Kinney, 2003). Home became a paradox due to the disruptions caused by the adaptations and the psychological tensions, as home was experienced not only as a place of strong attachment but also a burden (Aminzadeh, 2010) and carers' needs are weighed against their relatives'

needs (Olsson, 2011). Studies pointed to the disruption of the sense of homeliness (Aminzadeh, 2010); home was changing its homely character and gaining more of an institutional look, gradually becoming a place of negative experiences and a medicalised space, for example, bedrooms resembling a hospital room (de la Cuesta, 2005). From the carers' perspective, findings highlighted the lack of privacy and personal space (physical and emotional) as a contributing factor to the home experience being disrupted (Dröes, 2006; Spring, 2009; Olsen, 1996), smells and disposal of waste as distressing and embarrassing (Drennan, 2011), and feeling like a prisoner at home (Taşci, 2012). Homes were transformed into hybrid places, 'almost-homes', where family life is combined with clinical care and identities were merged (de la Cuesta, 2005).

Home tensions

There were three main tensions experienced at home that carers and/or people with dementia faced and tried to overcome:

Tension between safety versus comfort

Maintaining safety was paramount (Kinney, 2003; Olsen, 1996; Richter, 1995) but also was the reason for constant supervision and why adaptations were made (Kinney, 2003; Nochajski, 2013), including to avoid falls and accidents (Dickson, 2012; Kinney, 2003; Olsen, 1996; Spring, 2009; Toot, 2013). Homes that provided the opportunities for privacy were considered easier to provide care (Olsen, 1996) as carers needed to find a balance between monitoring and the need for

Table 1.
Key Themes, Subthemes
And Contribution of
Included Studies

Key themes and subthemes	Contribution of included studies
1. Home as a paradox	Aminzadeh, 2010; Askham, 2007; Buri, 2000; Chung, 1997; Cott, 2013; de la Cuesta, 2005; de Witt, 2009; Dickson, 2012; Dodds, 1994; Dröes, 2006; Drennan, 2011; Kinney, 2003; Nochajski, 2013; Nygård, 2008; Nygård, 2002; Olsen, 1996; Olsson, 2011; Powell, 2010; Redfern, 2002; Richter, 1995; Spring, 2009; Sixsmith, 2007; Taşci, 2012; Toot, 2013
1.1 Home, sweet home	
1.2 Home experience disrupted	
1.3 Home tensions	
2. There is no magic formula	Askham, 2007; Buri, 2000; Chung, 2013; Chung, 1997; de la Cuesta, 2005; Dröes, 2006; Forbat, 2004; Kinney, 2003; Lach, 2007; Nygård, 2008; Olsen, 1996; Olsson, 2011; O'Donnell, 2000; Richter, 1995; Redfern, 2002; Smith, 2001
2.1 The ongoing changing nature of home	
2.2 Useful home components	
2.3 Individualised strategies	
2.4 Improvising strategies	
3. Adapting the physical space, objects & behaviour	Aminzadeh, 2010; Askham, 2007; Baker, 2012; Boger, 2013; Buri, 2000; Chung, 2013; Chung, 1997; Cott, 2013; de la Cuesta, 2005; de Witt, 2009; Dickson, 2012; Dodds, 1994; Drennan, 2011; Dröes, 2006; Forbat, 2004; Harris, 2006; Hogan, 2003; Kinney, 2003; Lach, 2007; Nochajski, 2013; Nygård, 2008; Nygård, 2003; Nygård, 2002; O'Donnell, 2000; Olsen, 1996; Olsson, 2011; Olsson, 1998; Powell, 2010; Richter, 1995; Redfern, 2002; Rosenberg, 2012; Sixsmith, 2007; Smith, 2001; Taşci, 2012; Toot, 2013; Wherton, 2008; van Hoof, 2009; Vikström, 2005; Yang, 1997
3.1 Transformative strategies	
3.2 Behavioural strategies	
3.3 Subtractive strategies	
3.4 Additive strategies	

some personal space and time. Use of different technologies was perceived with mixed feelings: some were considered as very valuable, providing freedom, reassurance and continuity at home (Kinney, 2003; Toot, 2013); some were viewed as a threat to privacy (Powell, 2010), or non-significant (Nygård, 2008).

Tension between familiarity versus adaptations

Studies reported fear of causing confusion to their relative if they were to implement changes at home (de la Cuesta, 2005; Toot, 2013). The home environment could be enabling in the sense that it could encourage independence and engage the person with dementia in meaningful activities, but

at the same time remain familiar and comfortable (Olsen, 1996). Some people with dementia saw simplifying and downsizing as a relief, as keeping the home as it used to be, became increasingly difficult to manage (Aminzadeh, 2010).

Tension between risks versus independence

Concerns over the safety of the person with dementia were the main reason that carers implemented risk strategies, although people with dementia living alone did not always recognise risk (Cott, 2013). Some carers, concerned with their relative's safety, decided to use controlling strategies (e.g. blocking, restricting access, and locking). The use of technologies was considered to promote safety and ensure continuity of daily activities in a less restrictive environment (e.g. alarms), but in some cases restrict the independence (Kinney, 2003; Nygård, 2008). Another strategy highlighted was to create safety zones within the home that the person with dementia could use safely (Olsen, 1996).

There is no magic formula.

The ongoing changing nature of home

The home environment becomes more challenging as the dementia progresses. The timing, way and extent that the home needs adapting depends largely on individual cases, influenced by the type of dementia, progress, type of housing, and finances. As a result, there is no unique solution or strategy (Olsen, 1996); rather adapting the home requires an ongoing and personalised procedure, and home needs to be a hybrid space to accommodate changes (de la Cuesta, 2005; Forbat, 2004; Olsen, 1996).

Useful home components

The included studies highlighted some general components in the home environment that would make life with dementia at home much easier. For example, the layout was perceived as important to make home totally accessible and adaptable to accommodate changes over time, especially at the later stages of dementia when both mobility and cognition is severely affected (Olsen, 1996). This means enabling access to and within the house, for example accessing the entrance of the home or access to outdoors (Olsen, 1996). The bathroom needs to be accessible and spacious to accommodate adaptations, such as entering the bath/shower via aids or on wheelchair (Olsen, 1996). Accessible and adaptable design reduces emotional and physical demands for the carer, while encouraging comfort and independence for the person with dementia (Olsen, 1996). For people with dementia windows became focal points and provided company and access to the outside world (de Witt, 2009).

A useful layout was perceived as one that includes a toilet and shower located on the same level/floor (Forbat, 2004; Olsen, 1996), a ground floor laundry (Olsen, 1996), compact, easy and one level layout without stairs (Olsen, 1996). Multi-level design was perceived as unhelpful as it did not support easy surveillance (Askham, 2007) and stairs were perceived as a potential falls risk (Chung, 2013). Small and divided rooms were also perceived as unsupportive of supervision at home whereas an open layout was perceived as helpful because it enhances visibility and hence makes monitoring and interaction for the carer easier, and

fosters reassurance for the person with dementia (Olsen, 1996; Askham, 2007). However, in terms of safety, one study reported that closed off rooms (especially kitchen) is ideal (Olsen, 1996).

Another crucial home element was to have adequate space. This was perceived to be important and therapeutic to: serve changing needs (de la Cuesta, 2005; Olsen, 1996), support caring by providing space for wandering safely (Olsen, 1996), afford retreat space for the person with dementia to sustain personhood (de la Cuesta, 2005), and provide an extra bedroom for carers to sleep if necessary as well as providing some privacy (Olsen, 1996). Caring in a small apartment or small house was perceived as difficult, whereas bigger space extended the duration of care in the home (de la Cuesta, 2005). However, a single study highlighted that some carers considered moving to a smaller accommodation as a better caring option (Lach, 2007).

Individualised strategies

In order to be effective, adaptive strategies need to be individualised (Richter, 1995) and responsive to specific situations (Redfern, 2002). Professionals reported that strategies needed to be geared to the changing needs of the person with dementia (Dröes, 2006).

Improvising strategies

Studies highlighted that carers had implemented various improvisations and tricks to tackle particular challenges at home related to safety, communication, and convenience. Often carers and people with dementia became inventive

via trial and error and without professional input (Chung, 2013; de la Cuesta, 2005; Kinney, 2003; Olsen, 1996; Richter, 1995; Nygård, 2008).

Adapting the physical space, objects and behaviour

Transformative strategies

Examples are: creating wider doorways, extending landings, repositioning objects and furniture, adjusting the light (especially night lights for orientation), changing the functions of rooms (for example to create retreat areas, secure outdoor decks, screen porches, relocate to another room), and adjusting the mirror to assist with monitoring.

Behavioural strategies

Maintaining familiarity, habits, regulated and simple routines, setting up systems, and keeping the aesthetic aspects and order in the environment (items and favourite furniture in specific locations) was important to carers and people with dementia. In maintaining the home's aesthetics, religious objects and ornaments were considered to add a more home-like atmosphere (de la Cuesta, 2005) and compensate for the institutionalised look. Apart from maintaining familiarity, a number of other controlling and monitoring strategies were reported in the included studies.

Subtractive strategies

These types of strategies included: removing items and replacing items (e.g. rugs, flooring), de-cluttering and house cleaning, hiding and disguising objects and spaces, reducing

distractions and avoiding exposure to irrelevant or multiple (visual and/or auditory) stimuli (Nygård, 2002; Richter, 1995; van Hoof, 2009; Vikström, 2005). A home environment which is too noisy or too busy was considered negative (Dröes, 2006).

Additive strategies

This subtheme involves two main additive strategies: (1) compensating using senses and (2) the introduction of assistive devices and equipment. Compensating via senses included using auditory, tactile and visual cues as reminders (Nygård, 2002; Nygård, 2003) to support the person with dementia with memory problems and engaging in tasks. Everyday technologies, for example micro-waves, torch, washing-machines and a variety of alerting devices and reminding devices (such as medication dispensers, timers, time orientation devices and computers) were a useful resource for people with dementia and their carers. However, studies highlighted mixed perceptions over the usefulness of technologies depending on context and need.

Empirical research: Exploring the Meaning of Home and the Impact of the Physical Home Environment for Carers of People with Dementia

Design and Methods

This is cross-sectional qualitative study that explored carers' perspectives on (a) subjective (personal, social, psychological, existential) and (b) objective (physical, structural, sensory and functional) aspects of housing. The findings of each aspect are reported separately below.

Phenomenological sedentary and walking interviews were used to explore the carers' lived experience. Walking interviews, also known as "go-along" interviews, are traditionally used in geographical and urban planning, and are a novel approach in dementia research. In comparison with the traditional (static) interviews, walking interviews encourage participants' connections with surrounding environment and elicit detailed, context-sensitive perceptions of spatial practices and their impact (Carpiano, 2009; Evans & Jones, 2011; Van Cauwenberg et al., 2012). Walking interviews combine field observation and interviewing and allow the researcher to observe the participants interactions directly in their natural setting (Carpiano, 2009). The environment acts as a prompt and offers stimuli for further discussion and questioning. According to Keady et al. (2012) walking with the participants "can illuminate the practical and subjective experience of moving around a familiar zone of experience and the biographical connections it holds" (p.160).

Initially a purposive and convenience sampling approach was used, followed by snowball sampling and word-of-mouth referrals. Recruitment was carried out using community gatekeepers (Alzheimer's Society, Care UK, and local community groups). Because this study was aiming to gather different perspectives, diversity in terms of types of accommodation, gender, age, years of caring, and location was desirable.

After a pilot phase (December 2012) with two carers, eleven more carers were interviewed ($n=13$). Family co-habiting carers, living in Portsmouth and the surrounding area in the county of Hampshire

Table 2.
Demographic
Characteristics of
Participants (N=13)

Characteristic	N
Sex	
Male	4
Female	9
Age	
50-59	1
60-69	8
70-79	3
80-89	1
Years of caring	
0-5	10
6-10	3
Type of property	
Flat	3
House	7
Maisonette	2
Bungalow	1
Duration of residence	
0-10	6
11-20	2
21-30	1
31+	4

(UK), who had mental capacity to consent at the time of the study, were eligible. The recorded interviews lasted 39 – 79 minutes (average 60 minutes). Participants were informed of confidentiality, anonymity issues and how data would be managed. All participants were allocated a number and names were removed from all written reports. The Faculty of Science Ethics Committee, Portsmouth City Council, members of the Engage (our public involvement panel) and informal carers reviewed the recruitment leaflets before distribution.

The data were analysed using Thematic Analysis in six phases (Braun & Clarke, 2006), using QSR International's NVivo 10 Software. All transcripts and notes were repeatedly read and initial interesting points were written. Then each line of each transcript was carefully read and coded to capture an interesting feature related to the research questions. Following that an extensive number of initial codes were created that were grouped together to reveal a similar interesting point. These grouped codes (initial themes) were checked back against each transcript to review the meaning and redefine it if necessary. The revised themes were then checked against all transcripts to ensure they relate back to the original text in a systematic and clear way. The final themes were then formed and written making final refinements to keep the participants' story as clear and vivid as possible. Original text extracts were chosen from across participants to emphasise an important point and enrich the reported story. The author designed the study and materials, conducted all interviews, data coding, analysis and write-up. She

had previous experience of interviewing participants and also supporting people with dementia.

Results

All 13 participants (9 female, 4 male) were White British and living with a person with dementia. One carer was an adult child; the rest were spouses (Table 2). They had been carers for an average of 3.5 years (ranging from 1 to 6 years). Carers had been living in their current residence for an average of 18 years (ranging from <1 to 45 years). Six carers had lived long-term in the same property; six carers had moved and one couple was looking to move to a more suitable accommodation.

Results PART 1: Exploring the Meaning of Home for Family Carers of People with Dementia

The interviewees made clear that the home was a place with significant personal meanings. The experiences of the cohabiting carers are described in two main themes: 1. the different meanings of home and 2. the perceived impact of the home environment: to move or not to move? (Table 3).

The different meanings of home

Home as a secure haven

In general, home was strongly associated with security, safety, familiarity, comfort, and happiness. It was also considered the hub of their lives, their nest and a place they spent the majority of their time since starting to care for a person with dementia. Carers felt safe to be at home and also reassured when their relative was at home, "I always feel safe when I'm in my house...

because it's easier to care for my husband here... I worry about him in other places" (CA06). It is precisely that sense of safety that allowed them the freedom of action. As such, home was perceived as a place of retreat and a place of control, where they can discard the social mask and be themselves. Carers considered their home to reflect their personality and link strongly to their identity. Home was full of memories, decorations reflecting their life journey, their family formation, their personal interests, which infused strong positive feelings and emotional support.

You got all your memories in your home as well, haven't you?... I think that's home; somewhere that I can nest that has my personality showing (CA02).

Home looks like a hospital, feels like a prison

Carers talked about compromises to their daily routine and physical surroundings of their home. In some cases carers had to relocate; others remained in place but their home had become increasingly hard to maintain due to both the additional responsibilities and inconvenience caused by the added equipment and adaptations. Although perceived as very helpful to safeguard against possible risks, equipment had changed the ambience, especially in the bedroom and living room. For those carers home ceased to be a place of comfort and self-expression and turned into a place of stress and inconvenience, resembling a hospital.

There's been a lot of disabled equipment coming in, which has taken up space, like a commode, toilet aids, bed aids, wheel chair so your home

Table 3.
Main Themes
And Subthemes

Main Themes	Subthemes
1. The different meanings of home	1.1 Home as a secure haven 1.2 Home looks like a hospital, feels like a prison
2. Perceived impact of home: to move or not to move?	2.1 Need for relocation 2.2 Staying in place but redefine the home environment

has taken-been like a hospital sometimes; I have to hide the commodes because it's not very nice when people come in (CA10).

Care at home led to compromises in space, in aesthetics, and/or in sensory environment. Some carers had to decide whether to keep or replace appliances (e.g. sacrificing the bath for a walk-in shower) and furniture, "we don't have a coffee table in the middle of the room, which I would love to have because of, you know, problems" (CA10). Additionally, the home ceased to be a place of freedom and gradually became a locus of confinement, even a prison.

I could say [home is] like a prison now really... because you are trapped in here a lot... [before home was] somewhere to relax I think and feel free and that, but home... you are all trapped in now (CA03).

Similarly, carers had to restrict or change their social life and hobbies (mainly to indoor) to remain at home looking after their relative. The home as a place of family gatherings and social life was gradually shrinking.

Perceived impact of home: to move or not to move?

Need for relocation

Carers who moved to a new home with fewer hazards reported that this transition was necessary to regain control, prevent institutional placement and ease the impact of supporting their relatives. Carers mentioned two different strategies to assist them settling in: maintaining the familiarity and detachment. Carers, who employed the first strategy, brought along familiar objects and furniture, positioning them in familiar places and layout to simulate the routes from their older residence to make the transition smoother for the person with dementia and recreate the meaning of home for the carer.

On the other hand, in order to detach themselves from the old house, some carers decided to leave their old possessions and previous cherished objects and bought new furniture and appliances. Their new home had fewer hazards and that the transition made carers more relaxed, confident and 'in control' compared to the previous residence.

Since we've moved here I, I've been a lot more calm... I think it's helped me to be more calm and be able to, to care really... if we had had to stay in the flat, I think I probably would have had a breakdown (CA13).

A few carers that moved to a more supportive accommodation felt safer, "peace of mind" (CA11) knowing there were alarms, cameras and support if needed. Opportunities for social interaction were regarded important to smooth their transition and acquire new networks.

Staying in place but redefine the home environment

All carers strongly opposed the idea of moving their relative to another care setting as an unsuitable option; home was the preferred place to care for their relatives until the end. Some carers admittedly struggled with aspects of their home (e.g. stairs), but they clearly underplayed that because leaving their home was unthinkable. Carers who remained in place discussed their need to refresh and redefine their environment possibly stemming from their need to be more comfortable at home. The scale of changes varied, depending largely on personal circumstances. Some carers reported that the process of refreshing their home was therapeutic and empowering: "It [decoration] helps to take my mind off things... it's the one thing I can control" (CA02).

In redefining space, some carers relocated to another bedroom, permanently or temporary, to cope and get much needed sleep. Others created a hide-away, an 'escape room', where they created

a personalised environment, the aesthetics and use of which they could control. It was a room, physically and emotionally, just for the carer, not associated with caring, disability, or illness. It was regarded a necessary strategy to restore normalcy and, most importantly, maintain their identity, "I feel like a carer now and not a wife" (CA05). Escape spaces were seen as a symbol of their self-identity more so than the rest of their houses.

I am going to make a couple of rooms here very much my own and the room upstairs is going to be quite important... I think you need space... in the bad days, you need them [separate rooms] so you can comfort yourself (CA02).

Results PART 2: Exploring the Impact of the Physical Home Environment for Carers of People with Dementia

Three main themes each with subthemes (Table 4) were developed: (1) Important environmental aspects, (2) adapting the home space, objects and behaviours, and (3) barriers to implementing environmental strategies.

Important environmental aspects

These can be categorised under two types: (1) important architectural elements, such as size, layout and access, natural light and views, physical condition, and (2) important interior design aspects, such as decoration and furnishing, brightness and colour, materials and finishes, and the internal sensory (acoustic- thermal- olfactory) environment.

Architectural elements

Size: The majority of carers believed that dwelling size adds to safety. A large property (at least two bedrooms) was considered helpful as it can offer choices and space to accommodate equipment, modifications (or even conversions), and implement various environmental strategies. Most carers agreed that having space makes life easier, functional and practical, and enables safe care delivery and accessibility. Lack of enough space meant less room for storage, equipment and appliances and possible (undesirable) conversion of rooms. Lack of space was the reason that two carers decided to move to a more spacious property.

if you got someone looking at having new accommodation for the future is finding space (CA02).

Carers believed that a spacious property allows for extra rooms, for example a separate bedroom

for the carer (or family members or paid carer) to sleep, space for ideally a second bathroom and availability for an ‘escape room’. The latter was thought as paramount to enable them to comfort themselves, relax and restore their identity.

if we were stuck together in a little flat, I think I'd go mental [laughs]... the small room I've turned into my office, which is one of my escape rooms [laughs] (CA05).

On the other hand, a carer, who moved from a 4-bed house to a 1-bed flat regarded it as more handy and manageable, as a compact size property made them feel more in control, requiring less attention and housework.

It's a help to me because it's small, and convenient... most of my time, really, is taken up looking after my husband... It's enough to do without having a big house to look after (CA01).

Table 4.
Main Themes And
Subthemes

Main Themes	Subthemes
1. Important environmental aspects	1.1 Architectural elements 1.2 Interior design aspects
2. Adapting and improvising	2.1 Additive and supplementing strategies 2.2 Transformative strategies 2.3 Subtractive and simplifying strategies 2.4 Behavioural and structuring strategies
3. Barriers to implementing environmental strategies	3.1 Carer's scepticism 3.2 Professionals' involvement 3.3 Property characteristics 3.4 Financial reasons 3.5 Timing

Layout and access: One level accommodation, open living space, big windows, flooring and proximity of rooms were discussed as helpful home elements. Carers who lived on one level, with no stairs to tackle, explained that it was beneficial and less stressful in terms of accessibility, "Everything's on this level and I know my wife's in a matter of three rooms" (CA08). Carers who lived in houses considered the stairs to be a risk for falls, incontinence accidents, and a reason for constant vigilance and future relocation to a property that will not need further modifications.

I feel now that the house is not fit for what we need... They [stairs] are very steep and they do worry me... I just feel that with no steps and everything, that it would make it, in a way I suppose, it might be easier for me because I won't have to be following him everywhere (CA07).

On the other hand, one carer living in a three-storey house, perceived stairs as a positive element for two reasons. Firstly, stairs limited access to lower level to exit the house and as a result they might prevent wandering and secondly stairs offered an opportunity to keep active.

The majority of carers thought it was easier and more practical to supervise their relatives in open plan layout as it offers visual and acoustic access. One carer altered the design to allow for direct observation by knocking down the wall between the kitchen and living room. However, some carers favoured closed rooms, especially the kitchen, where often they did not allow the person with dementia. In general, participants considered a helpful layout to have a toilet on each level, an

outside space and easy access for wheelchair users: "probably thinking about it, we've had less accidents since that [toilet]s been there [downstairs] because it's not so far to go" (CA05).

Carers reported that the location and proximity of the rooms was also important. Ideally they would like the bedroom next to the bathroom, "he's going to the toilet 3-4 times in the night, so to have the bathroom right next to him is beneficial" (CA10), the spare room next to the bedroom for closer supervision and the spare bedroom next to stairs to alert the carer in the night.

Natural light and views: A home with large windows that could afford sensory enrichment and pleasing views to the outside world was considered important for the person with dementia, as they offered stimulation and spontaneous communication, as well as comfort and escape for the carer, "to be able to see out; even if it's raining or snowing, anything, I don't mind. I can see out and I'm not sort of enclosed too much" (CA12).

Physical condition: The condition of the property was another factor regarded both as a problematic when old and requiring a lot of work and facilitative when there was no need for any improvements or alterations.

Interior design aspects

Decoration and furnishing

Maintaining familiarity in the domestic surroundings (old furniture and familiar objects), maintaining environmental order and avoiding unnecessary changes and re-arrangements were considered crucial in promoting the relative's well

being and minimising confusion. Even for those carers, who moved to a new home, keeping familiarity was perceived as important to make the transition more smoothly.

Brightness and colour: Brightness, including natural lighting from windows, was considered important to uplift the carers' mood: "Lots of light makes me feel better" (CA05). The same was reported with the use of colour as important to improve the home aesthetics and subsequently improve the carers' mood.

Materials and finishes: Most carers commented on qualities of their flooring and favoured carpets as they were perceived to add comfort and warmth. Some carers favoured the hard type of flooring, such as tiles or wooden floor, as they perceived them as more practical and easier to clean, "sometimes there is an accident... it's a lot handier when you can wipe a floor" (CA04). However, one carer removed the existing lino floor because her mother thought it was cold: "She wouldn't go in on the floor because it was white and she thought it as marble and cold" (CA02).

Acoustic, olfactory and thermal environment: For most carers a positive (not noisy) environment was important to ensure they can relax and get enough sleep. Some carers mentioned that listening to music, having the radio or music on was helpful for company and as a way to improve their mood, "I do like the music, I can't bear it so silent... I always, always have my music on" (CA04).

Most carers also explained that they were concerned about the thermal comfort and worried whether the temperature was appropriate and

comfortable for their relative, and in some cases the heating was kept constantly on. Elements, such as unpleasant smells from incontinence, were also identified as problematic for carers. Good ventilation and fresh air were important but sometimes not possible or practical.

Adapting and improvising

The bathroom was considered most problematic and where most modifications were done. Other areas of high-risk concern were the stairs and, in a few cases, the kitchen. The bedroom and living room (and/or conservatory if available) were considered the most favourable rooms in the house. Carers installed adaptations and equipment in all rooms but less so in the living room. Notably, carers adapted their home space, objects and their behaviours both proactively, following professionals' advice and reactively by improvising solutions, mostly following a risk event or crisis.

Additive and supplementing strategies

Carers used a number of technologies and equipment. These included: everyday technologies (television, appliances, computers, lamps), assistive devices (alarms, baby monitors, reminders, walkers), prosthetic devices (e.g. glasses) and equipment (rails, commodes). Overall carers reported finding everyday technologies very helpful and some wished they had more appliances, specifically a dishwasher and a tumble dryer. Although assistive devices were exclusively used by carers, the equipment (such as bed guard, commode, hospital bed, raised toilet seat, stair gates, ramp, stair lift, shower seat, handrails

and stair lift) was put in place for the relatives' safety and independence. Positive opinions were expressed regarding the use of equipment as a means to increased quality of life for both the carer and the person with dementia.

Very helpful; I just wouldn't be able to cope. Because I'd be forever sort of, glued to my wife, all the time... I don't have to give her so much, so much [help] because like, before I was having to come in and lift her up and get her on her feet again; whereas now she can do; And it gives her more independence... which I think makes, helps her dignity as well (CA12).

Leaving visual cues and use of colour was another supplementing strategy and reminder to assist the person with dementia with initiation or completion of a task. It included leaving notes, using calendars, leaving the door ajar, putting up labels and messages on boards. One carer used colour to highlight objects, to attract the attention of the person with dementia and assist with personal care.

Carers also commented on the importance of personal items and photographs as a means to enrich the environment and support familiarity. Family objects and pictures were considered important for the person with dementia to provide sensory enrichment and reminisce, but also for the carers, "makes me feel like I'm still part of a family even if I don't see them very much" (CA05).

Transformative strategies

Rearranging objects and space (e.g. covering mirrors, shortening cords, repositioning the bed,

reversing doors and relocating hazardous items to top shelves) were perceived as easy and useful modifications to monitor and prevent confusion and risks: "I've reversed a couple of doors, because the downstairs toilet door used to open inwards, whereas if you collapsed behind there, we'd never get the door open" (CA12).

The most common room transformation reported was the installation of a walk-in shower with nonslip flooring, "The shower's made an awful lot easier... that's more practical... it's brilliant... you got the whole length of it, so it's a lot safer" (CA03).

Subtractive and simplifying strategies

De-cluttering, making the environment minimalist and simplifying the space and choices, was considered a way to make a house more practical and safe. Organising and simplifying was also used by carers to prepare or re-arrange the space for a task (for example shaving, dressing, making a drink). Removing physical barriers was sometimes considered as a strategy to add more safety around the house, but this meant that sometimes carers had to balance or compromise between safety and privacy or comfort in their own home.

Actually, I was very close of taking the bathroom door off, cause she fell inside with the door shut and the compromise was... if I take the door off, I lose privacy as well (CA02).

Behavioural and structuring strategies

Maintaining a structured routine and familiarity was considered an effective strategy to a

predictable and simplified way of life and care. Some carers used controlling strategies in order to prevent harmful behaviour or wandering. These techniques included blocking and locking (doors, cupboards, and cabinets) to control behaviours, access to rooms or objects. Additionally, some carers controlled the thermal, olfactory and acoustic environment at home.

Barriers to implementing environmental strategies

Carers' scepticism

Scepticism was the main reason carers did not implement environmental solutions. If carers perceived that the environment was not influential on the behaviour of their relative, then they did not consider it worth exploring further. Some carers believed that their relative would not be able to use any environmental strategy due to functional deterioration, or thought that using many adaptations and devices would make the environment more complicated for the person with dementia.

Professionals' involvement

Carers expressed some scepticism around the involvement of health and social care professionals, believing that they will not offer adequate support, or finance any changes. Some carers were reluctant or did not think to involve professionals and had implemented modifications without consulting professionals, just via trial and error.

Property characteristics

Home ownership and size were reported as two

limitations that prevented them from implementing environmental strategies. In the first case, carers perceived that rental accommodation is a restriction criterion to modifying the environment, "This isn't our flat, so... I don't want to spend money on somebody else's property... I may not be here much longer" (CA01). In the second case, a small space meant that they had no room for adaptations. A bigger space would allow them to add, remove or convert rooms: "Things I would like [to change] but there, but I can't do it because there's no room so" (CA03).

Financial reasons

Another barrier identified was the financial costs involved in implementing adaptations. This was mentioned both by carers who owned their property and those who did not.

Timing

The last limitation was the timing of adaptations in relation to the progress of the dementia. Some carers thought that introducing changes and equipment is best early on to prevent further confusion. On the other hand, other carers thought that adaptations and devices are needed in a later stage.

Discussion

Contributions

This submission presents research findings from two approaches (systematic review of literature and primary qualitative data) that enhance our understanding of the importance and impact of the home environment in dementia care and identifies barriers

and facilitators in creating dementia friendly homes. The systematic review examined the impact of the home environment in a holistic way, examining various housing aspects (e.g. layout, size), environmental strategies (e.g. use of lighting, assistive technologies), as well as the personal experiences of how the home environment might change for people with dementia and carers.

The analysis suggests moving to a new home gave the opportunity to have an ideal home, with no modifications. This is an important finding for two reasons. Firstly, it confirms previous studies that the environmental incongruities (e.g. a home environment not suitable to the residents' abilities and values) can compromise their well being (Gitlin & Corcoran, 2000) and provoke relocation (Kahana et al., 2003). Secondly, relocation was sometimes preferred to familiarity, which contradicts previous research suggesting that changes are a potential threat for people with dementia and their family carers (Norman, Redfern, Briggs, & Askham, 2004). Although attachment to home and familiarity is important, it may limit people's choice of suitable housing (Wiles, Leibing, Guberman, Reeve, & Allen, 2011). Conversely, voluntary relocation may be more appropriate rather than staying in place, as some people oppose moving to nursing facilities and prefer moving to a more suitable residence.

Building on suggestions from previous studies that carers are in need of a clear division between caring and non-caring household space (Olsen, Hutchings, & Ehrenkrantz, 1999), carers in this study also indicated a need to redefine their home environment. Carers with some degree of

environmental competence, created an escape room to have a 'home' within their house, a comfortable, relaxing and private space away from their caring tasks to support them in caring for longer. A place has to be comfortable and offer opportunities for control and privacy to become home (Calkins, 2001; Rubinstein, 1989). Experts in dementia friendly dwellings (Gitlin, 2007; van Hoof & Kort, 2009) recommend that carers set up a quiet and comfortable room or a private area in the bedroom for rest and this study adds empirical evidence to these recommendations. Heywood (2005) also emphasises the importance of 'away' private space as a human need for both the sake of carers and their relatives. This is a key finding considering that carers' stress is likely to be exacerbated by lack of privacy and space (Betrabet Gulwadi, 2009) and that self-image and relationships are threatened by home adaptations and the reduction of usable home space for other family members (Heywood, 2005).

Another contribution of this study is that it identified various reasons why carers did not implement environmental solutions, namely the carers' perceptions and expectations around the usability and need, the involvement of professionals and mistrust in the support from professionals, timing (too late and the adaptations may be ineffective, whereas too early they might get rejected), cost and property characteristics: space and ownership.

Implications

The findings of this thesis can be valuable to people with dementia, their family carers, health and social

care professionals, architects and designers, policy makers, housing developers, as well as researchers interested in environmental gerontology. Our findings are unlikely to be applicable to all people with dementia and their families but could provide guidance and ideas for acceptable ways to promote dementia- and caring- friendly homes.

Implications for architects and home designers

It is also important to sensitise architects and home designers to the potential role of the home environment and consider opportunities for privacy and temporary escape (Betrabet Gulwadi, 2009; Heywood, 2005), while incorporating the unique personal meanings and social-cultural practices within the home space to enhance the feeling 'at home'. There is an interesting paradox that dementia care facilities are focusing on promoting homely environments, whereas private homes are increasingly transformed into hospital-like spaces (de la Cuesta & Sandelowski, 2005). Architects need to take into consideration the unique challenges of dementia and consider important home components, such as adequate size, layout and accessibility. By considering these aspects, future housing should be more ageing and caring friendly to correspond to the needs of our ageing society. Future carers will clearly benefit from the adaptability and hybridity of their homes and people with dementia could enjoy a better quality of life at home.

Furthermore, when building sustainable housing one ought to have a holistic approach and take under consideration the illness, the environment and the inhabitants. Housing developers need to

understand the dynamic relationship between people and their homes and the need to live in flexible living spaces to accommodate changes over their lifetime with minimal possible cost, modifications and stress involved (Hawkins & Stewart, 2002; Pierce, Cahill, Grey, & Dyer, 2015). It is advisable to focus on incorporating permanent safety elements into the interior design of homes, so the next generation of people affected by dementia will already be exposed to them (Nygård, 2009). Architects have the great challenge to marry together several aspects that are perceived as important for carers, such as adequate size, accessibility and layout, and proximity of rooms, as well as natural light, but also to understand the unique personal meanings and experiences of living at home (Aminzadeh et al., 2010).

When designing future accommodation, availability of natural light is important and hence the positioning of a dwelling and availability of large windows can have a great impact. Especially in the UK, due to weather conditions and climate this is particularly crucial. It is also advisable that planners should provide opportunities for privacy, temporary escape via positive distractions (views outside the windows, artwork), flexible use of space and incorporate permanent safety elements into interior designing (e.g. flood or gas detectors). Recent reports on developing dementia friendly housing suggest that that future dwellings should be 'future proofed' and 'care ready' to support the needs of both the person with dementia and family members and address both safety and comfort until the end of life (Andrews & Molyneux, 2012; Pierce et al., 2015).

Although evidence suggests that environmental condition and design is crucial for people's health and wellbeing, it is doubtful that the existing UK housing stock meets dementia-friendly standards. It is assumed that the majority of people with dementia live in unsuitable homes (Pierce et al., 2015). In the face of the increasingly ageing population, architects and designers should build with old age in mind and address ageing needs when designing future housing or adapting existing dwellings. Therefore, it is advisable to have a holistic approach, taking into consideration the illness, the environment and the inhabitants. Housing developers need to understand the dynamic relationship between people and their homes and the need to live in flexible living spaces with home features to accommodate changes over a person's lifetime at minimal cost and stress (Hawkins & Stewart, 2002; Pierce et al., 2015). Universal design and Lifetime Homes are suggested by experts (Pierce et al., 2015) as two examples of housing concepts that provide a list of criteria on how to ensure accessible and sustainable housing for ageing population.

Currently, there are some guides and checklists on home dementia-friendly design (Alzheimer's Society, 2015; Dementia Services Development Centre, 2013; The King's Fund, 2014; Thomas Pocklington Trust, 2014), but no official set of guidelines and standards to assist housing developers and commissioners on how to ensure that future housing addresses the diverse needs of people with dementia and their families. Improving health through the home requires raising public and professional awareness and partnerships. The findings of this thesis offer evidence on crucial

home elements and a number of environmental strategies to manage behavioural symptoms of dementia and ensure living well with dementia at home. Considering these aspects, future housing should focus on adaptability so that people with dementia and carers can enjoy a better quality of life. As it stands, housing provision is largely driven by the market and existing regulations and not person-centred. The timely assessment and support of people with dementia and their carers is paramount.

Because housing underpins health and wellbeing it is considered fundamental to the health and social care system and national economy, especially for an ageing population (Housing and Ageing Summit, 2015). Previous research indicated that modifications and compensatory strategies at home by community occupational therapists (Graff et al., 2008) and dementia friendly home design (Andrews & Molyneux, 2012; Pierce et al., 2015) are cost effective and could prevent hospital admissions and delay the need for admission to long-term care that has detrimental effects on the person with dementia. Already in some Scandinavian municipalities, some assistive technologies (e.g. stove timers) are offered free of cost to support safety and ageing in place for people with dementia and their carers (Nygård, 2009). As Shaw (2004) argues, "investment in housing can be more than an investment in bricks and mortar: it can also form a foundation for the future health and wellbeing of the population" (p. 397). Based on these findings and evidence from previous research, local and national guidelines need reform to address dementia specific housing needs.

Appendix – Characteristics of Included Studies (N=40)

No	Study ID	Year study conducted	Country	Participants	Age	Gender	Ethnicity	Stage of dementia	Type of carer	Main focus	Research method	Type of analysis
1	Aminzadeh, 2010	not reported	Canada	16 people with dementia	76 to 93 (M=85.3)	11 female, 5 male	12 Canadian, 3 Europeans & 1 Asian	2/3 in mild, the rest moderate	n/a	meanings and significance of home for people with dementia	in-depth face-to-face home interviews	grounded theory
2	Askham, 2007	not reported	UK	20 couples of people with dementia and their carers	people with dementia: 74 to 96 (M=85); spouse carers: 75 to 87 (M=79), children or other: 50-68 (M=57)	people with dementia: 15 women, 5 men; carers: 14 women, 6 men	not reported	mild to severe	9 spouses, 4 children, 1 friend, 1 neighbour, 1 daughter-in-law, 1 nephew, 1 niece	care at home for people with dementia	depth interviews & non-participant observation	constant comparison
3	Baker, 2012	not reported	Australia	5 couples of people with dementia and their carers	carers: 59 to 81; people with dementia: 59 to 88	carers: 3 female, 2 male; people with dementia: 2 female, 3 male	not reported	not reported	all spouses	evaluate music intervention in relation to couple's relationship	scales, diaries & interviews	thematic analysis
4	Boger, 2013	2010	Canada	3 family carers, 10 occupational therapists	carers: 2 between 50-59, 1 over 80	carers & occupational therapists: females	not reported	not reported	2 spouses, 1 adult child	use of assistive technologies to support daily occupations	semi-structure interviews	visually analysed with frequencies
5	Buri, 2000	1996	UK	6 family carers	not reported	carers: 3 male, 3 female	not reported	moderate to severe	1 spouse, 3 daughters, 2 sons-in-law	meanings of falls risk in elderly persons with dementia	focus group, individual unstructured home interviews	content analysis
6	Chung, 1997	not reported	Hong Kong	15 family carers	28 to 79	4 male, 11 female	not reported	n/a	8 spouses, 6 daughter, 1 granddaughter	meanings of caring	2 semi-structured focus groups	content analysis
7	Chung, 2013	not reported	UK	stage 1: 15 family carers; stage 2: 21 co-resident carers	not reported	stage 1: 11 female, 4 male; stage 2: not reported	not reported	n/a	stage 1: 12 spouses, 2 children, 1 partner; stage 2: not reported	how carers engage people with dementia with activities	stage 1: interviews; stage 2: focus groups	constant comparison
8	Cott, 2013	2005-2007	Canada	20 family members & 20 people with dementia living alone	People with dementia: 67 to 95, Carers: middle-aged	people with dementia: 15 women, 5 men, carers: not reported clearly	not reported	very mild to moderate	12 children, 4 friends, 1 niece, 1 nephew, 1 cousin, 1 sister	how family and friends balance risk with people with dementia who live alone	in-depth semi-structured, home / phone interviews & field notes	constant comparison
9	de la Cuesta, 2005	2000-2002	Colombia	18 caregivers & 2 healthcare professionals	10: 51 to 75, 5: 25 to 50, 3: younger than 25	15 female, 3 male	Colombian	advanced	10 daughters, 5: wives, sisters, or nieces, 2 husbands, 1 son.	strategies used by Colombian family caregivers to manage the demands of care	interviews & home observations	constant comparison

No	Study ID	Year study conducted	Country	Participants	Age	Gender	Ethnicity	Stage of dementia	Type of carer	Main focus	Research method	Type of analysis
10	De Witt, 2009	2004-2005	Canada	8 women with dementia living alone	58 to 87	8 female	7 Canadians, 1 not reported	mild to moderate	n/a	meaning of living alone for older people with dementia	11 open-ended interviews, journal notes & one participant letter	van Manen's method
11	Dickson, 2012	2011-2012	USA	22 family carers	50 to 82 (M=66)	not reported	18 Caucasians, 3 African-American, 1 Hispanic	all stages	majority spouses, then daughters, mother, friend	caregivers' perceptions of wandering	open-ended, semi-structured interviews & questionnaire	grounded theory
12	Dodds, 1994	not reported	UK	6 family carers	late 40s to late 80s	not reported	not reported	not reported	3 spouses, 2 daughters, 1 sister;	how carers deal with wandering behaviour	interviews	not reported
13	Drennan, 2011	not reported	UK	32 family carers	not reported	19 female, 13 male	12 White, 9 other: Afro-Caribbean, Asian, European, 11 missing	not reported	21 spouses, 10 adult child, 1 daughter-in-law;	carers' perceptions of incontinence problems and strategies employed	face-to-face & telephone interviews	thematic analysis
14	Dröes, 2006	2002-2003	Netherlands	106 people with dementia & 10 healthcare professionals	people with dementia: 65-80; professionals: 34 to 51	People with dementia: not reported; Professionals: 9 female, 1 male	not reported	mild to moderate	n/a	what people with dementia consider important for their quality of life	interviews & focus groups	constant comparison
15	Forbat, 2004	not reported	UK	11 family carers from BME	not reported	not reported	South-Asian or Afro-Caribbean	n/a	not reported	difficulties in continence and toileting	interviews	not reported
16	Harris, 2006	not reported	USA	15 people with dementia & 10 family carers	people with dementia: M=75.4 (62 to 87); Carers: M=51 (38 to 60)	13 female, 2 males	3 African-Americans, 12 White	12 early dementia or 3 mild MCI	8 children, 1 cousin, 1 sister	concerns, needs and coping strategies of people with dementia living alone	in-depth interviews	constant comparison
17	Hogan, 2003	not reported	USA	8 family carers	49 to 81	2 male, 6 female	not reported	early, middle, late and unknown	4 spouses, 3 adult children, 1 daughter-in-law	explore the role change by family carers	interviews	thematic analysis
18	Kinney, 2004	2001	USA	26 family carers	Phase 1: M=63.2 (SD=11.83)	Phase 1: majority females	Phase 1: 1 African, 25 White,	beyond early stages	one half cared for parent, step parent or parent-in-law, 2/5 for a spouse & rest for grandparent and child	challenges in caregiving and how technology assists caregivers	focus groups	Strauss and Corbin, table narrative
19	Lach, 2007	not reported	USA	39 co-resident carers	M=71.6 (SD=10.3)	28 women, 11 men	not reported	very mild, mild and moderate	34 spouses, 5 children	experiences of carers in managing safety at home	focus groups	Dilorio method, coding book, contingency matrix

No	Study ID	Year study conducted	Country	Participants	Age	Gender	Ethnicity	Stage of dementia	Type of carer	Main focus	Research method	Type of analysis
20	Nochajski, 2013	not reported	USA	20 people with cognitive impairments and 17 carers	people with dementia: M= 79; carers: 61.8, 39 to 80	10 female, 10 male	90% White	not reported	8 spouses, 6 children, 1 sibling, 1 cousin, 1 nephew	use and satisfaction of assistive devices	questionnaires & interviews	not reported
21	Nygård, 2002	not reported	Sweden	7 people with dementia	62 to 78	4 male, 3 female	not reported	mild to moderate	n/a	how people with dementia manage their everyday occupations	repeated interviews, observations & field notes	Empirical Phenomenological Psychological analysis
22	Nygård, 2003	not reported	Sweden	10 people with dementia	75 to 87	7 female, 3 male	not reported	mild to moderate	n/a	difficulties and strategies in telephone use	interviews, observations & field notes	constant comparison
23	Nygård, 2008	not reported	Sweden	8 people with dementia	57 to 82	3 male, 5 female	not reported	mild to moderate	n/a	how people with dementia experience and use everyday technology	repeated interviews & observations	Empirical Phenomenological Psychological analysis
24	O'Donnell, 2000	not reported	USA	12 spousal carers	Carers: 49 to 78 (M=68); People with dementia: 60-96 (M=73)	10 female, 2 male	11 Caucasian, 1 Black	pass very mild stage	all spouses	experience of spouse carers of their day-to-day life	interviews, observations & field notes	Colaizzi's method
25	Olsen, 1996	not reported	USA	90 family carers of people with dementia	not reported	60 female, 30 male	not reported	not reported	46 spouses, 41 children, 3 other	impact of physical environment and strategies used	in-depth home interviews & scales	not reported
26	Olsson, 1998	not reported	Sweden	36 home care staff	not reported	1 male, 34 female	not reported	not reported	n/a	staff's reflections on caring for people with dementia	interviews	constant comparison
27	Olsson, 2011	2007-2008	Sweden	14 spousal carers	62 to 89	8 female, 6 male	not reported	mean time of diagnosis: 6 years	all spouses	reflections of family carers on use of ICT	individual interviews	content analysis
28	Powell, 2010	not reported	UK	34 informal carers	23 to 91 (M=57)	12 male, 22 female	27 White British, 7 other	different stages, some with early-onset dementia	15 spouses, 15 adult children, 3 grandchildren, 1 friend	carers' perceptions on networked ICT	semi-structured interviews & group discussion	framework approach
29	Redfern, 2002	not reported	UK	20 couples of people with dementia and their carers	people with dementia: M=85, spouses: M=79, children: M=50	people with dementia: 15 female, 5 male; carers: 14 female, 6 male	not reported	moderate to severe	7 children, 9 spouses, 4 unrelated	care at home focusing on routines, control and care goals	repeated home interviews & observation	content analysis, constant comparison
30	Richter, 1995	not reported	USA	23 family carers & 22 paid carers	former carers: not reported; paid carers: M=24	majority females	all Caucasian	not reported	either spouses or adult children	communicative processes used by family and paid carers	focus groups	three-phase analysis
31	Rosenberg, 2012	not reported	Sweden	16 informal carers	45 to 78	11 female, 5 male	not reported	not reported	5 children, 1 neighbour, 9 spouses, 1 son-in-law	attitudes to technologies	interviews & focus groups	constant comparison

No	Study ID	Year study conducted	Country	Participants	Age	Gender	Ethnicity	Stage of dementia	Type of carer	Main focus	Research method	Type of analysis
32	Sixsmith, 2007	not reported	UK	26 people with dementia and their carers	62 to 96	18 female, 8 male	not reported	not reported	not reported	meaning and role of music	in-depth interviews (some repeated)	thematic analysis
33	Smith, 2001	not reported	USA	45 family carers	36-75 or older	39 female, 6 male	not reported	mild to severe	23 spouses, 16 adult children	different types of needs for carers	semi-structured intensive interviews	not reported
34	Spring, 2009	not reported	USA	14 family carers	38 to 86 (M=64)	13 female, 1 male	11 White, 2 African-American, 1 Hispanic	not reported	8 spouses, 5 daughters, 1 grand-daughter;	problems associated with night time supervision	semi-structured home interviews	grounded theory
35	Taşcı, 2012	not reported	Turkey	8 family carers	M=48,87	not reported	not reported	not reported	3 spouses, 4 adult children, 1 daughter-in-law	problems experienced by family Turkish carers	focus groups & questionnaires	not reported
36	Toot, 2013	not reported	UK	18 people with dementia, 15 family carers, 19 healthcare professionals	people with dementia: >65yrs: 1 <65: 17; carers: 6 >65yrs, 9 >65yrs; Professionals: not reported	people with dementia: 10 females 8 male; carers: 6 male, 9 female; Profs: 11 female, 8 male	people with dementia & Professionals: not reported; carers: range of ethnicities	mild-moderate stage	9 spouses, 5 child, 1 friend, staff: 11 females, 8 males	factors precipitating crises and interventions used in dementia care	focus groups	thematic and long-table approach
37	Van Hoof, 2009	sample 1: not reported; sample 2: 2006-2007	Netherlands	sample 1: 10 carers and people with dementia; sample 2: 18 older people (some with dementia)	sample 2: 63-87yrs	sample 1: carers: 2 male, 8 female; people with dementia: 4 male, 6 female/ sample 2: 14 female, 4 male	not reported	not reported	sample 1: often relatives / sample 2: n/a	experiences of technology at home and thermal environment	interviews & questionnaires	theoretical framework
38	Vikström , 2005	not reported	Sweden	30 co-habiting couples of people with dementia and their carers	carers: 58 to 84 (M=74); people with dementia: 68 to 85 (M=78)	carers: 14 male, 16 female; people with dementia: 16 male, 14 female	not reported	mild to moderate	30 spouses	family carers' self-initiated support to partners with dementia	video recording, observation & field notes	constant comparison
39	Wherton, 2008	not reported	UK	study 1: 20 healthcare professionals; study 2: 10 family carers and 8 people with dementia	not reported	not reported	not reported	mild to moderate	not reported	difficulties and opportunities for technological solutions	interviews & focus group	grounded approach
40	Yang, 1997	not reported	USA	7 people with dementia 8 family carers, 1 paid carer	people with dementia: 72 to 92 (M= 81.6); carers: 47 to 80 (M=62)	people with dementia: 3 male, 4 female; carers: 6 female, 2 male	6 White Caucasian, 1 African-American	MMSE: 10-23	3 spouses, four children, 1 nephew	perceptions on the use of assistive devices	open-ended questionnaire	descriptive analysis

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