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**Extra Care: Viable for Couples Living with Dementia?**

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## **Extra Care: Viable for Couples Living with Dementia?**

### **Abstract**

#### ***Purpose***

The perspectives of people with dementia and their care partners regarding 'extra care' housing are currently unknown. This paper will report findings of a consultation study exploring the perceived barriers and facilitators of a relocation to extra care housing, from the perspective of people living with dementia, and their care partners.

#### ***Design/methodology/approach***

Fieldwork consisted of paired or 1-1 interviews and small focus groups with potential users of an alternative model of extra care support for people living with dementia in the South of England. The consultation took place between June and August 2013. The interviews and focus groups were audio recorded and transcribed verbatim. The transcripts were analysed thematically.

#### ***Findings***

Benefits of extra care were identified as the opportunity for couples to remain living together for longer and the creation of a supportive, dementia-friendly community. Barriers centred on a sense of loss, stress and uncertainty. Living and caring at home was perceived as preferable to shared care.

#### ***Research limitations/implications***

The *shared care model* consulted on was very specific. Participants form a purposive sample and as such are unlikely to be representative of the wider population. Despite best intentions the voice of people with dementia are underreported in this consultation.

#### ***Social and Practical implications***

The findings cast doubt on the viability of extra care facilities, designed for couples living with dementia, whilst highlighting the need for better welfare support for people living in the community with dementia.

#### ***Originality/value***

This paper contributes to the body of literature, exploring the feasibility of new and innovative alternative care with housing options, for people with dementia. This paper is one of the first to explore extra care as a housing with care option for couples with dementia.

#### ***Keywords***

Dementia care, carer perspectives, extra care, housing with care, shared care, consultation

## Introduction

It is estimated that 850,000 people are living with dementia in the UK (Alzheimer's Society, 2014). This figure is expected to rise to over one million by 2021 (Department of Health, 2009). The economic cost associated with dementia is higher than that of stroke, cancer and heart disease combined (Luengo-Fernandez et al., 2012). In 2013 the estimated annual cost of dementia in the UK, when taking into consideration factors such as unpaid care, health and social services and dementia research, was £26.3 billion (Alzheimer's Society, 2014). The global economic impact is estimated to be \$818 Billion (Alzheimer's Association, 2015).

Approximately 70% of people living in care homes have a form of dementia, representing 29% of all people with dementia; the remaining 71% live in a community setting (Alzheimer's Society, 2014). Despite guidelines on best practice being freely available, poor care practice is still a commonly reported occurrence in care homes (Care Quality Commission, 2014). Care in the community is largely provided by unpaid care partners (Hollander et al., 2009) and care partners of people with dementia have reported a decline in their physical health, a feeling of social isolation, depression and an increase in stress levels (Huang et al., 2009; Brodaty et al., 2014). Respite and educational interventions do not significantly reduce the impact that caring for a person with dementia in community settings has on mental and physical well-being (Pinquart and Sorensen, 2006; Jensen et al., 2015). An economic and social incentive therefore exists to review, evaluate and revolutionise models of housing and long term care options for people living with dementia.

## *Extra Care*

Extra care has been defined as purpose built private apartments or homes, for people over the age of 65, coupled with a supplementary care package that helps people maintain their independence (Darton et al., 2012), typically models are idiosyncratic (Wright et al., 2010). There are 72 different phrases used to describe social housing models akin to extra care. They include Sheltered Accommodation, Housing with Care, Assisted Living, Retirement Villages and Senior Housing (Howe et al., 2012). **Research exists on the influence living in extra care type social housing can have on various outcomes for people with dementia. Extra care facilities more likely to be occupied by a healthier demographic of people, with less care needs than those living in care homes (Kopetz et al., 2000; Darton et al., 2011). People with dementia in assisted living are more likely to have received a diagnosis of dementia less than one year prior to a move, than those living in nursing facilities (Carlson et al., 2005). It is possible to infer therefore, that older people are more likely to seek extra care accommodation as a lifestyle choice, rather than a reaction to a crisis, as is often the case with moves to care homes. This inference is supported by evidence suggesting determinants of care home placement include vulnerability, poor health outcomes and depression within family caregivers (Gallagher et al., 2011).**

Recent government policy has prioritised the design and building of innovative extra care housing solutions for people with dementia across the UK (Department of Health, 2015), leading to heavy investment in such projects (Evans et al., 2007; Barnes et al., 2011; Atkinson et al., 2014). For example, the Department of Health Care and Support Fund 2013-2017 has made £160 Million of funding available for specialist housing to be built for people with dementia, people with mental health problems or physical and sensory disabilities

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3 outside of London (Department of Health, 2013).

4  
5 Research has been conducted on the experience and outcomes of living in a form of social  
6 housing akin to extra care for older people with dementia (Vallelly et al., 2006; Smith,  
7 Buckwalter et al., 2008; Brooker et al., 2011; Abbott et al., 2015). Moreover, care partner  
8 perspectives on assisted living facilities have been explored (Kelsey et al., 2010). Despite  
9 this, reviews of the research literature have not identified any research evidence investigating  
10 the perspectives of couples living with dementia surrounding extra care environment, prior to  
11 them deciding to move in (O'Malley and Croucher, 2005; Atkinson et al., 2014). This paper  
12 contributes to improving this gap in the literature, through a discussion of the findings of a  
13 consultation study into one model of extra care, coined as *Shared Care*.  
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17 *Shared Care* was proposed as a dementia specialist extra care facility for couples where one  
18 person has dementia. It is within this context that the term 'couples living with dementia' is  
19 used throughout this paper. The concept was devised by a care provider in the south of  
20 England. The principle behind *Shared Care* was to 'share' the care between a person with  
21 dementia, their family care partner and care staff members. The aim of *Shared Care* was to  
22 enable people with dementia to retain independence and control of their lives whilst  
23 providing care partners with support and respite services as and when they are required. Once  
24 people moved to *Shared Care* every possible effort was to be made to ensure the couple  
25 could age in place, should they choose. Therefore, a future move to a care home could be  
26 avoided, enabling the person with dementia and the care partner to live together until the end  
27 of their lives.  
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32 *Shared Care* was planned as a 52 apartment build with each apartment consisting of two  
33 bedrooms (including a master bedroom with an en suite bathroom), a kitchen and dining area,  
34 lounge area and a private garden or balcony area. 24-hour domiciliary care was planned to be  
35 available from an onsite team. Moreover, a CCTV system was to be installed in each  
36 apartment, should the owner wish to incorporate it into their care package. Onsite nursing  
37 wing to the build was seen as being able to provide respite and rehabilitation. The person  
38 with dementia could move to the nursing wing permanently if necessary, although this was to  
39 be avoided if possible. A community hub was designed, including a hair dressing salon, local  
40 shop, library and coffee shop. The idea and promotion of a supportive community was a  
41 principle central to the conceptualisation of *Shared Care*. ***Shared Care is still in the***  
42 **proposal stage at the time of writing.**  
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## 47 **Methods**

48  
49 **This qualitative study utilises a cross-sectional research design. A purposive sample was**  
50 **utilised consisting of people with memory problems and those who care, or have cared**  
51 **for, people with dementia. A diagnosis of dementia was not sought or confirmed as part**  
52 **of the consultation. A diagnosis of dementia was not an inclusion criteria to avoid**  
53 **excluding people from taking part. People may experience dementia without being**  
54 **diagnosed by a medical professional.**  
55

56 Consulting with people with dementia is vital to ensuring their perspective has an impact on  
57 relevant local and national policy initiatives. Giving voice to people with dementia on any  
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3 issue they hold a vested interest in should be prioritised (Litherland and Williamson, 2013).  
4 The perspective of people with dementia should not be assumed, this can only exacerbate the  
5 marginalisation people with dementia face in the community today (Swaffer, 2014). Despite  
6 this, opportunities for people with dementia to participate in the development of dementia  
7 care and housing policy are limited (Batsch et al., 2012).  
8  
9

10 All participants lived locally to the proposed build. Participants were recruited through  
11 voluntary sector organisations at events such as memory cafes and community support  
12 groups. **Family carers were also accessed, whose partners now live in a special care unit**  
13 **(SCU) run by the care provider. Although person-caregiver dyads were recruited, the**  
14 **recruitment of individuals with dementia was challenging, with only one person with**  
15 **early on-set dementia being recruited. This highlights the marginalisation of people**  
16 **living on their own with dementia, and the lack of community based resources available**  
17 **to them, given the main recruitment strategy used for this consultation study targeted**  
18 **community support groups and events. People living in care homes with dementia were**  
19 **not included in the sample due to ethical concerns.**  
20  
21

22 **17 people were consulted. Fieldwork consisted of eight 1-1 interviews, one with a person**  
23 **with early on-set dementia, 7 with care partners; 3 paired interviews with person-**  
24 **caregiver dyads and one focus group consisting of 3 care partners. One dyad consisted**  
25 **of two friends living together in the community. The remaining dyads consisted of**  
26 **married couples living in the community. Of the 7 caregivers interviewed, 6 were in a**  
27 **relationship and 1 caregiver was a friend of the person they cared for. All caregivers**  
28 **interviewed, lived with the person in the community during the time they cared for**  
29 **them. The 3 focus group participants were all married to the person with dementia**  
30 **whom they cared for, living with them in the community prior to SCU placement. In**  
31 **total, 3 male and 10 female caregivers were interviewed. 1 male and 3 female people**  
32 **with dementia were interviewed.**  
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39 The consultation took place between June and August 2013 in the South of England. All  
40 interviews took place at the home of participants at their request. **The focus group took**  
41 **place at a SCU, run and owned by the care provider proposing the *Shared Care* model.**  
42 Each consultation was audio recorded and transcribed verbatim. **The lead author of this**  
43 **paper (CP) collected all data.** The fieldwork was conducted as part of a wider consultation  
44 including the views of other stakeholders about the *Shared Care* model (Poyner and Innes,  
45 2013).  
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### 53 ***Ethics***

54 Full ethical approval was given by the author's University ethics board prior to the study  
55 commencing. Permission to conduct interviews and focus groups at the special care unit and  
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extra care facility was granted by the relevant care provider. All participants were given the choice of a convenient location to participate.

### *Analysis*

Data was transcribed verbatim and an inductive thematic approach was adopted (Braun and Clarke, 2006). Two cycles of coding were completed manually within the Nvivo data management software tool using an inductive 'bottom up' approach to data analysis. Codes interpreted as having common meaning across the entire data set were grouped together to form categories. 6 overarching themes, with several sub themes subsumed underneath, were interpreted as being present within the data set. For example, the overarching theme of 'obstacles to apartment purchase' included the sub theme of 'loss' which in turn was produced with the categories of 'space' 'familiarity' 'home' and 'local community'. The main criterion for the creation of a theme was the frequency of reoccurrence across the data set and the number of relatable categories and subthemes. The rationale behind this analytic strategy was to achieve a rich and detailed description of the data set due to the exploratory nature of the study. All analysis was conducted by the lead author (CP) and checked for accuracy by AI.

Nvivo was used to organise and manage the data. All data was analysed within Nvivo.

### **Results**

The findings are presented thematically below.

#### *Facilitators of a move to Shared Care*

##### *Creation of a supportive community*

The community aspect of *Shared Care* was reported as an enticing element and something lacking in alternative local models of extra care.

Care Partner: (P1) '*...when I first read about it I thought this is fantastic and I think along the line there might have been stages [in journey] when I would have thought we'll go for this, because when I went to [extra care provider] when that opened up...but that is just a big hotel really whereas this is more a little community isn't it?*'

##### *Staying together*

Carers who had to make the decision to place their partner into permanent nursing care disclosed the guilt and anxiety they felt and the pain of having to be apart from their partner:

Family caregiver (P14): '*When he went off to that nursing home...well care home, I couldn't describe the feelings we'd separated with a big wrench.*'

Care partners have reported feeling guilty and struggling to adapt with their new lives post seeking care home placements for people with dementia that they have cared for (Garity, 2006; Graneheim et al., 2014). For example, Graneheim et al found care partners experience a process that starts with feeling responsible for their partner's admission, adjusting to their

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3 new role and getting used to their new relationship with their loved one. This process was  
4 reported to be accompanied by feelings of guilt, loss and shame (Graneheim et al., 2014).  
5 Such findings are reinforced by research investigating why couples living with dementia  
6 remain together (Loboprabhu et al., 2005; Davies, 2011).  
7

### 8 ***Barriers of a move to Shared Care***

#### 9 ***Uncertainly around when to move and mortality***

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11 Despite recognising benefits of a move to *Shared Care*, carers described not knowing when  
12 would be the right time to move into the setting. This seemed to be due to a concern around  
13 the right time to move to achieve the maximum benefit out of *Shared Care*. The perceived  
14 unpredictability of dementia was seen as adding to this dilemma:  
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19 Care partner (P15): *'I think it is a tricky one to know how you work, whether you're*  
20 *going to kind of get the benefit or not, because it's such an unpredictable illness.'*  
21

22  
23 Care partner (P1): *'... it would be far, far too soon...now we've got to a stage where it's*  
24 *getting really, really difficult to care for [person with dementia] and I think I would be*  
25 *reluctant to give my home up.'*  
26

27 Care partners shared their worries about their own mortality as well as the remaining lifespan  
28 of their partner as reasons why they would dismiss *Shared Care* as an option. If the person  
29 with dementia died there was a concern apartments would be 'blocked' by the care partner  
30 when another person with dementia may require the support. Moreover, respondents did not  
31 know whether care partners would want to leave the shared care environment due to the idea  
32 of 'resettling'.  
33

34  
35 Care Partner (P14): *'Also, if they die and you decide you like it there, you're blocking it*  
36 *for someone that needs it. I don't know how that bit would work.'*  
37

38  
39 Care Partner (P7): *'...when your relative has died then what do you do? You've got to*  
40 *sell up again and then go resettle yourself and you can never go back to where you*  
41 *were.'*  
42

43 A person with dementia also questioned their ability to live on her own should their care  
44 partner die:  
45

46  
47 Care Partner (P2): *'I was saying it wasn't suitable in looking to some distant future of*  
48 *time when it might happen if I'm no longer here. Do I think [person with dementia]*  
49 *could live in that situation? My answer to that is, I honestly think, no not on her own.'*  
50

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52 Person with dementia (P3): *'No, not on my own.'*  
53

### 54 ***Loss of home, moving home and adjusting to a new home***

55  
56 Couples living with dementia were anxious about 'losing' or 'giving up' their home.  
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Care Partner (P1): *'Well I think as I've got this far I would be very reluctant to sell the house because I would lose it as well because I would feel I've lost everything.'*

Care partner (P6): *'...we thought, no, we'll be living here all our lives, so suddenly if I decide to move out, that would be very, very painful for both of us, really.'*

This finding reflects the large body of literature reporting the significance and importance of home to older people in general and people with dementia specifically (Aminzadeh et al., 2010).

Respondents reported key benefits of their home. Key benefits included the location, the familiarity of the house and the local community their home is situated in. Respondents suggested skills such as navigation and personal care tasks could become difficult to retain in an unfamiliar setting:

Care Partner (P2): *'If I died, and [person with dementia] was left there on her own, I think she'd be losing too much. I really do. Yes, this house is everything. This location means so much. Even if [person with dementia] gets separated from me in the town she's made it back home....'*

Care Partner (P12): *'Well, you think you can tolerate the situation better in familiar surroundings; because if you move somewhere else ...there's additional concerns to adapt to the new...whereas you haven't got that here, you're so used to it, it's all routine.'*

The perspectives of the participants on this issue finds supporting evidence from research that suggests the more familiar people with dementia are with their environment the more likely they are to retain skills and act independently (Brittain et al., 2010; Provencher et al., 2012; Boger et al., 2013.) For example, Provencher et al (2012) found older people with 'poor and preserved executive functions' to perform cooking tasks more effectively at home than in unfamiliar surroundings.

A perceived disadvantage of moving into *Shared Care* would be the loss of community services, local health professionals and lay support such as neighbours and friends. Respondents also felt moving further away from family would impact on their lack of desire to move, indicating people living with dementia would only consider *Shared Care* as a last resort. The following two extracts from a two-to-one interview with a couple living with dementia exemplify this point:

Care Partner (P2): *'What would be the advantages of selling this place and moving into a two-bedroom flat? We would be moving away from all our friends, our medical support teams. My GP knows more about me than I know about me.'*

Person with dementia (P3): *'Well, we've got two daughters, they come in and do things, don't they?'*

Care Partner (P12): *'Yeah, I say, it's just the fact that you're set up, you know, we've*

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3 *got all the connections, the [laugh] plumbers and...you're familiar with everything... I*  
4 *suppose we're quite well placed here, and we don't want to move unless it's absolutely*  
5 *essential.'*  
6

7 Care partners perceived moving into a new environment as a stressful thought for themselves  
8 and their partner with dementia.  
9

10  
11 Care Partner (P15): *'Also, selling a house is very stressful, if people are stressing out*  
12 *with dementia, will they also be able to take on the pressure of selling the house and*  
13 *making that decision? I don't know.'*  
14

15  
16 Care partner (P7): *'I think it would have been such a massive thing to do in the middle*  
17 *of everything else that was going on I just wouldn't have contemplated it.'*  
18

19 Downsizing to a two-bedroom apartment was perceived as undesirable. Downsizing was  
20 associated with having a negative impact effect on their well-being and quality of life as a  
21 couple. One respondent indicated their opinion on this could change if they get 'some  
22 horrible disease' again indicating *Shared Care* may be perceived as a last resort option and  
23 would be tolerated if physical health needs dictated the need for a move from their own  
24 homes.  
25  
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27  
28 Care partner (P12): *'Well, I suppose views might change [re downsizing], you see, as I*  
29 *might get some horrible disease, or something, and the view might change; but all the*  
30 *time I am still capable of doing things I'd rather carry on.'*  
31

32 One care partner emphasised the importance of community living given the effect downsizing  
33 may have on their well-being. This extract is another example of the value respondents  
34 placed on community provision:  
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36  
37 Care Partner (P6): *'...when you said it's a two-bedroomed flat I thought, oh dear.*  
38 *Would I be able to live there? I [would] have to go out and talk to other people because*  
39 *I would be claustrophobic in two bedroomed house...he might be claustrophobic...he*  
40 *would definitely feeling like a prisoner there.'*  
41

### 42 **Care at home**

43  
44 In home care services were a recurring theme in the data set. The *Shared Care* model was  
45 directly compared to existing models of support provided at home. *Shared Care* was  
46 perceived by some to not offer any service that would entice a move, as care support  
47 packages provided in the home were seen to deliver the support required, such as personal  
48 care and periods of respite. Care at home services were reported to have the added benefit of  
49 enabling people to age in place in their home and within their local community. Aging in  
50 place has been reported by older people to be desired due to the feeling of security,  
51 attachment and familiarity they have with a specific home environment (Wiles et al., 2011).  
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Care partner (P7): *'What's the difference [between Shared Care and care at home services]? The difference is you've got to sell your house...I was able to have help from [care at home services] ...Yes, we paid for it, but they would take him out a couple of times a week...we had got him staying [at home] a bit longer, bit longer.'*

As well as receiving support with personal care, respondents reported receiving help with cleaning and gardening to reduce the workload of the care partner:

Person with dementia (P12): *'Mm. We have a cleaner come in as well, don't we?'*

Care partner (P13): *'Yes, and the cleaner comes in. So, yeah, I think we'd miss all that. And I certainly would, you know, I'd – not resent it – but I've got all these facilities here.'*

### ***Inadequate support at home***

Despite generally positive feedback about support provided at home there was a recognition that services were not always enough to relieve the burden experienced by the care partner.

Care Partner: (P7) *'I used to have [care at home services] in for a couple of hours... they'd say to me, this is your time go and relax, but I didn't, I did all the things that I couldn't do when my husband was there.'*

A care at home service was perceived as inadequate when the needs of the person with dementia and the care partner were more complex.

Care Partner (P5): *'The [care at home services] was fine except for one occasion when she had a really bad infection... I'd try and walk her to the bathroom and her legs would just go underneath her, I'd have to catch her. It was a really bad day...It was an hour and a half visit I think from [care at home service provider], by the time they'd gone I was feeling shattered...So having somebody on site would take care of those situations.'*

### ***Cost***

Cost was perceived as a barrier especially in terms of couples deciding to make a move to *Shared Care* early on in their journey with dementia. One family caregiver discussed the low cost of living in their current home. Another expressed concern about their money running out whilst another questioned whether *Shared Care* would be socially funded to any extent.

Care Partner (P12): *'...you probably wouldn't get away with much cheaper [than current home] if you moved to a smaller place. So there's no real financial incentive to move.'*

Care partner (P14): *'That's why I say, I think the costing, the people would want to look and see what the bottom line is... I think the concept is super, it's just, in my opinion, for me, costing would be quite an important issue.'*

## Discussion

The majority of barriers to considering *Shared Care* as a viable alternative model of housing centre around the unwillingness of potential residents to move, due to perceptions of losing what they defined as 'their home', and the stress of moving whilst trying to cope with caregiving responsibilities. This finding is representative of the literature on the significance and importance of home to older people in general and people with dementia specifically (e.g. Aminzadeh et al., 2010). A 'home' represents what people have achieved in their working life, it is inherently reflective of a person's individuality, whilst being perceived as a deeply familiar space (Gould and Basta, 2013). People with dementia and their care partners reported a desire to remain in place for as long as possible during their journey with dementia, thus demonstrating a commitment to each other, their home and community. Staying in place in the community is however, deeply reliant on the unpaid labour of care partners (Pickard, 2010; Vreugdanhil, 2014). The lack of welfare support for care partners, coupled with the strain of being a full-time care partner, frequently results in poor health outcomes in care partners of a person with dementia (Huang et al., 2009; Brodaty et al., 2014). The implication for policy and practice is more needs to be done to support the welfare of people living in the community with dementia and the intermediate care services, providing care to those with dementia, living in the community.

Care spouses of people with dementia have reported wanting to stay together, despite the negative mental and physical impact caring for someone with dementia can have (Loboprabhu et al., 2005; Davies, 2011). For example, Davies found that the concepts of partnership for life, reciprocity, resilience and forgiveness were all factors that ensured couples remained committed to each other during their journey with dementia (Davies, 2011). These findings were reflected in the anecdotes of the care partner's experience of the caregiver role. Several instances of depression, loneliness and poor physical health were recorded in the data set that contextualised people's responses to questioning. Despite this, couples maintained their desire to be together for as long as they possibly can. The conceptualisation of extra care for couples living with dementia, as a desirable positive life choice was therefore not supported by the views of care partners and people living with dementia in this consultation.

Care at home services were perceived as an attractive option to those with access and a key reason why *Shared Care* was seen an unsuitable model of housing with care. There is a paucity of literature evaluating the impact of models of at home care services on people living with dementia in the community (Low and Fletcher, 2015). Findings from the literature have previously suggested carer partners in the community are resistant to taking up care at

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3 home services (Markle-Reid and Brown, 2001; Morgan et al., 2002; Brodaty et al., 2005),  
4 contradicting the findings of this study, thus indicting progress in terms of people being more  
5 open about living with dementia and accepting support when available. Care partners  
6 reported using both private and public care at home support services, with high levels of  
7 satisfaction, due to the advantage of being able to age in place. Previous research has  
8 suggested care at home services score highly on care partner satisfaction only when they are  
9 consumer focused or person-centred (Low et al., 2011; Low et al., 2013). Such research  
10 however, has compared community care services in isolation from alternative long term care  
11 options.  
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15 Extra care as a positive lifestyle choice early in people's journey with dementia was not  
16 supported by those we consulted. However, participants reported that the respite provided by  
17 services, such as care at home, was not always adequate and this is one area where a *Shared*  
18 *Care* approach was seen as advantageous. As people progress through their journey with  
19 dementia the positive impact of support, provided by care at home services, was perceived to  
20 have lessened as the care needs of people with dementia increased. This finding supports  
21 previous research indicating care at home services meet basic and general need, but fail to  
22 provide person-centred care, or meet specific or complex needs (Vreuhdenhil, 2014; Bökberg  
23 et al., 2015).  
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27  
28 The dual stresses of caring for someone with dementia, and coping with the process of selling  
29 and moving house, was perceived as an addition major barrier preventing people from  
30 viewing *Shared Care* as a viable housing with care option.  
31

32  
33 The findings presented here have limited generalizability. The *Shared Care* model consulted  
34 on was very specific. Moreover, our participants form a purposive sample and as such are not  
35 representative of wider populations. For example, the majority of participants in our sample  
36 reported an emotional attachment and relationship to their local community and home that  
37 may not be as prevalent in the overall population, as living in a place does not necessarily  
38 equate to attachment (Rubinstein and Parmelee, 1992). Despite best intentions the voice of  
39 people with dementia are underreported in this consultation. One person with early on-set  
40 dementia was interviewed and the remaining two people with dementia were interviewed  
41 alongside their care partner. In these instances, the care partner would typically speak on  
42 behalf on the person with dementia themselves. In future studies, researchers should be aware  
43 of this issue and make every effort to ensure they engage creatively with people with  
44 dementia, allowing them the space to air their views.  
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49 **Further research is needed given the limited scope of this consultation study. The**  
50 **research should include a representative sample of couples living with dementia,**  
51 **informal caregivers, and people with dementia. Multiple extra care facilities designed**  
52 **for couples with dementia should be included due to the specific nature of such facilities.**  
53 **Given the rarity of extra care housing, designed for couples living with dementia,**  
54 **multiple examples may be unfeasible at present. Researchers however, could still design**  
55 **a pilot study exploring the perspectives of couples living with dementia, on the**  
56 **suitability of models of extra care for couples with physical health needs. It would then**  
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3 **be possible to explore how to adapt these housing with care options for couples living**  
4 **with dementia.**

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6 **Given the emphasis on loss of community, home, dying and cost as major obstacles**  
7 **within the data set, alternative means of 'buy in' to services offered by extra care**  
8 **facilities for couples living with dementia are recommended i.e. rental or equality based**  
9 **options. The main recommendation for policy is to better fund and support the welfare**  
10 **of people living in the community with dementia and the intermediate care services,**  
11 **providing care to those with dementia living in the community.**

## 14 15 16 17 **Conclusion**

18 Findings suggest extra care models of housing and care, for couples living with dementia, are  
19 not perceived as a viable alternative care solution or lifestyle choice by those who  
20 participated in this consultation. The initial satisfaction with care services provided at home,  
21 an emotional attachment to home and local community, cost, a lack of a coherent strategy for  
22 when either person dies, and the stress associated with moving home, renders extra care an  
23 unviable housing with care choice for couples living with dementia.

## 24 25 26 27 28 29 30 **References**

31  
32  
33 Abbott, K. M., Bettger, J. P., Hampton, K. N. and Kohler, H.-P., 2015. The feasibility of  
34 measuring social networks among older adults in assisted living and dementia special care  
35 units. *Dementia: The International Journal of Social Research and Practice*, 14  
36 (2), 199-219.

37  
38  
39 Alzheimer's Association, 2015. 2015 Alzheimer's disease facts and figures. *Alzheimer's and*  
40 *Dementia*, 11 (3), 332-384.

41  
42 Alzheimer's Society, 2014. Dementia UK Update. London: Alzheimer's Society

43  
44 Aminzadeh, F., Dalziel, W. B., Molnar, F. J. and Garcia, L. J., 2010. Meanings, functions,  
45 and experiences of living at home for individuals with dementia at the critical point of  
46 relocation. *Journal Of Gerontological Nursing*, 36 (6), 28-35.

47  
48  
49 Atkinson, T. J., Evans, S., Darton, R., Cameron, A., Porteus, J. and Smith, R., 2014. Creating  
50 the asset base -- a review of literature and policy on housing with care. *Housing, Care*  
51 *& Support*, 17 (1), 16-25.

52  
53  
54 Barnes, S., Torrington, J., Darton, R., Holder, J., Lewis, A., McKee, K., ... Orrell, A., 2012.  
55 Does the design of extra-care housing meet the needs of the residents? A focus group  
56 study. *Ageing & Society*, 32 (7), 1193-1214.

- 1  
2  
3 Batsch, N. and Mittelman, M., 2012. World Alzheimer Report 2012. *Overcoming the Stigma*  
4 *of Dementia*. Alzheimer's Disease International (ADI): London.  
5  
6 Boger, J., Craig, T. and Mihailidis, A., 2013. Examining the impact of familiarity on faucet  
7 usability for older adults with dementia. *BMC Geriatrics*, 13, 63-63.  
8  
9  
10 Bökberg, C., Ahlstorm, G., Leino-Kilpi, H., Soto-Marin, M., Caberera, E., Verbeek, H., ...  
11 C., Karlsson, S., 2015. Care and Service at Home for Persons with Dementia in  
12 Europe. *Journal of Nursing Scholarship*, 47 (5), 407-416.  
13  
14  
15 Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research*  
16 *in Psychology*, 3 (2), 77-101.  
17  
18  
19  
20 Brittain, K., Corner, L., Robinson, L. and Bond, J., 2010. Ageing in place and technologies of  
21 place: the lived experience of people with dementia in changing social, physical and  
22 technological environments. *Sociology of Health & Illness*, 32 (2), 272-287.  
23  
24 Brodaty, H., Thomson, C., Thompson, C. and Fine, M., 2005. Why caregivers of people with  
25 dementia and memory loss don't use services. *International Journal Of Geriatric*  
26 *Psychiatry*, 20 (6), 537-546.  
27  
28  
29  
30 Brodaty, H., Woodward, M., Boundy, K., Ames, D. and Balshaw, R., 2014. Regular Research  
31 Article: Prevalence and Predictors of Burden in Caregivers of People with Dementia.  
32 *The American Journal of Geriatric Psychiatry*, 22, 756-765.  
33  
34 Brooker, D. J., Argyle, E., Scally, A. J. and Clancy, D., 2011. The enriched opportunities  
35 programme for people with dementia: a cluster-randomised controlled trial in 10 extra  
36 care housing schemes. *Aging & Mental Health*, 15 (8), 1008-1017.  
37  
38  
39  
40 Care Quality Commission, 2014. *Cracks in the pathway: People's experience of dementia*  
41 *care as they move between care homes and hospitals*. Care Quality Commission:  
42 London.  
43  
44 Carlson, J. M., Gerding, G. and Estoup, M. W. (2005) 'Evaluation of demographics and  
45 medication use in patients with dementia in assisted living and skilled nursing  
46 facilities', *Consultant Pharmacist*, 20(7), pp. 584-591.  
47  
48  
49  
50 Darton, R., Bäumker, T., Callaghan, L. and Netten, A., 2011. Improving housing with care  
51 choices for older people: the PSSRU evaluation of extra care housing. *Housing, Care*  
52 *& Support*, 14 (3), 77.  
53  
54  
55 Darton, R., Bäumker, T., Callaghan, L., Holder, J., Netten, A. and Towers, A.-M., 2012. The  
56 characteristics of residents in extra care housing and care homes in England. *Health &*  
57 *Social Care In The Community*, 20 (1), 87-96.  
58  
59  
60

- 1  
2  
3  
4 Davies, J. C., 2011. Preserving the "us identity" through marriage commitment while living  
5 with early-stage dementia. *Dementia*, 10 (2), 217-234.  
6  
7  
8  
9 Department of Health., 2009. *Living Well With Dementia: a national dementia strategy*.  
10 London: Department of Health.  
11  
12 Department of Health, 2015. *Care and Support Specialised Housing Fund: Phase 2*. London:  
13 Department of Health.  
14  
15  
16 Evans, S., Fear, T., Means, R. and Vallely, S., 2007. Supporting independence for people  
17 with dementia in extra care housing. *Dementia: The International Journal of Social*  
18 *Research and Practice*, 6 (1), 144-145.  
19  
20  
21 Gallagher, D., Ni Mhaolain, A., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., Walsh, C.,  
22 Coakley, D., Walsh, J. B., Cunningham, C. and Lawlor, B. A. (2011) 'Determinants of  
23 the Desire to Institutionalize in Alzheimer's Caregivers', *American Journal of*  
24 *Alzheimer's Disease & Other Dementias*, 26(3), pp. 205-211.  
25  
26  
27 Garity, J., 2006. Caring for a family member with Alzheimer's disease - Coping with  
28 caregiver burden post-nursing home placement. *JOURNAL OF GERONTOLOGICAL*  
29 *NURSING*, 32 (6), 39-48.  
30  
31  
32 Gould, E. and Basta, P., 2013. Home Is Where the Heart Is-for People in All Stages of  
33 Dementia. *Generations*, 37 (3), 74-78 75p.  
34  
35  
36 Graneheim, U. H., Johansson, A. and Lindgren, B.-M., 2014. Family caregivers' experiences  
37 of relinquishing the care of a person with dementia to a nursing home: insights from a  
38 meta-ethnographic study. *Scandinavian Journal of Caring Sciences*, 28 (2), 215-224  
39 210p.  
40  
41  
42 Hollander, M. J., Liu, G. and Chappell, N. L., 2009. Who cares and how much? The imputed  
43 economic contribution to the Canadian healthcare system of middle-aged and older  
44 unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12 (2), 42-49.  
45  
46  
47 Howe, A. L., Jones, A. E. and Tilse, C., 2013. What's in a name? Similarities and differences  
48 in international terms and meanings for older peoples' housing with services.  
49 *AGEING & SOCIETY*, 33, 547-578.  
50  
51  
52 Huang, C., Souza, V.D., Perng, S., Hwang, M., Tsai, C., Huang, M., Yao, S., 2009. Stressors,  
53 social support, depressive symptoms and general health of Taiwanese caregivers pf  
54 persons with stroke or Alzheimer's disease. *Journal of Clinical Nursing*, 18 (4), 502-  
55 511.  
56  
57  
58 Jensen, M., Agbata, I. N., Canavan, M. and McCarthy, G., 2015. Effectiveness of educational  
59 interventions for informal caregivers of individuals with dementia residing in the  
60



- 1  
2  
3 community: Systematic review and meta-analysis of randomised controlled trials.  
4 *International Journal of Geriatric Psychiatry*, 30 (2), 130-143.  
5  
6 Kelsey, S. G., Laditka, S. B. and Laditka, J. N., 2010. Caregiver perspectives on transitions to  
7 assisted living and memory care. *American Journal of Alzheimer's Disease and Other*  
8 *Dementias*, 25 (3), 255-264.  
9  
10  
11 Kopetz, S., Steele, C. D., Brandt, J., Baker, A., Kronberg, M., Galik, E., Steinberg, M.,  
12 Warren, A. and Lyketsos, C. G. (2000) 'Characteristics and outcomes of dementia  
13 residents in an assisted living facility', *International Journal of Geriatric Psychiatry*,  
14 15(7), pp. 586-593.  
15  
16  
17 Litherland, R and Williamson, T., 2013. DEEP: the engagement, involvement and  
18 empowerment of people with dementia in collective influencing. *Working with older*  
19 *people; Community Care Policy and Practice*, 17 (2), 66-73.  
20  
21  
22 Loboprabhu, S., Molinari, V., Arlinghaus, K., Barr, E., Lomax, L., 2005. Spouses of patients  
23 with dementia: How Do They Stay Together 'Til death do us part? *Journal of*  
24 *Gerontological Social Work*, 44 (3-4), 161-174.  
25  
26  
27 Low, L-F., Yap, M., Brodaty, H., 2011. A systematic review of different models of home and  
28 community care services for older persons. *BMC Health Services Research*, 11, 93-  
29 93.  
30  
31  
32 Low, L-F., White, F., Jeon, Y-H., Gresham, M., Brodaty, H., 2013. Desired characteristics  
33 and outcomes of community care services for persons with dementia: what is  
34 important according to clients, service providers and policy? *Australasian Journal On*  
35 *Ageing*, 32 (2), 91-96.  
36  
37  
38 Low, L.-F. and Fletcher, J., 2015. Models of home care services for persons with dementia: A  
39 narrative review. *International Psychogeriatrics*, 27 (10), 1593-1600.  
40  
41  
42 Luengo-Fernandez, R., Leal, J. and Gray, A. M., 2012. UK research expenditure on dementia,  
43 heart disease, stroke and cancer: are levels of spending related to disease burden?  
44 *European Journal Of Neurology: The Official Journal Of The European Federation*  
45 *Of Neurological Societies*, 19 (1), 149-154.  
46  
47  
48 Markle-Reid, M. and Browne, G., 2001. Explaining the use and non-use of community-based  
49 long-term care services by caregivers of persons with dementia. *Journal Of*  
50 *Evaluation In Clinical Practice*, 7 (3), 271-287.  
51  
52  
53 Morgan, D. G., Semchuk, K. M., Stewart, N. J. and D'Arcy, C., 2002. Rural families caring  
54 for a relative with dementia: barriers to use of formal services. *Social Science &*  
55 *Medicine*, 55, 1129-1142.  
56  
57  
58 O'Malley, L. and Croucher, K., 2005. Housing and dementia care – a scoping review of the  
59 literature. *Health & Social Care in the Community*, 13 (6), 570-577.  
60  
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4 Pinquart, M. and Sorensen, S., 2006. Helping caregivers of persons with dementia: which  
5 interventions work and how large are their effects? *INTERNATIONAL*  
6 *PSYCHOGERIATRICS*, 18 (4), 577-595.  
7
- 8 Poyner, C. and Innes, A., 2013. Consultation study with formal dementia care staff,  
9 family carers and people with dementia into the Shared Care concept. Unpublished report.  
10
- 11 Provencher, V., Demers, L., Gagnon, L. and Gelinas, I., 2012. Impact of familiar and  
12 unfamiliar settings on cooking task assessments in frail older adults with poor and  
13 preserved executive functions. *INTERNATIONAL PSYCHOGERIATRICS*, 24 (5),  
14 775-783.  
15  
16
- 17 Rubinstein, R. L. and Parmelee, P. A., 1992. Attachment to place and the representation of  
18 the life course by the elderly. *Human Behavior & Environment: Advances in Theory*  
19 *& Research*, 12, 139-163.  
20
- 21 Smith, M., Buckwalter, K. C., Kang, H., Ellingrod, V. and Schultz, S. K., 2008. Dementia-  
22 specific assisted living: Clinical factors and psychotropic medication use. *Journal of*  
23 *the American Psychiatric Nurses Association*, 14 (1), 39-49.  
24  
25
- 26 Vallely, S., Evans, S., Fear, T., Means, R., 2006. Opening doors to independence: A  
27 longitudinal study exploring the contribution of extra care housing to the care and support of  
28 older people with dementia. London: Housing 21, Housing Corporation  
29
- 30 Vreugdenhil, A., 2014. 'Ageing-in-place': Frontline experiences of intergenerational family  
31 carers of people with dementia. *Health Sociology Review*, 23 (1), 43-52.  
32  
33
- 34 Wiles, J. L., Leibing, A., Guberman, N., Reeve, J. and Allen, R., The Meaning of 'Ageing in  
35 Place' to Older People: Oxford University Press.  
36
- 37 Wright, F., Tinker, A., Mayagoitia, R., Hanson, J., Wojgani, H. and Holmans, A., 2010. What  
38 is the 'Extra' in Extra Care Housing? *British Journal of Social Work*, 40 (7), 2239-2254.  
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## **Extra Care: Viable for Couples Living with Dementia?**

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## **Extra Care: Viable for Couples Living with Dementia?**

### **Abstract**

#### ***Purpose***

The perspectives of people with dementia and their care partners regarding 'extra care' housing are currently unknown. This paper will report findings of a consultation study exploring the perceived barriers and facilitators of a relocation to extra care housing, from the perspective of people living with dementia, and their care partners.

#### ***Design/methodology/approach***

Fieldwork consisted of paired or 1-1 interviews and small focus groups with potential users of an alternative model of extra care support for people living with dementia in the South of England. The consultation took place between June and August 2013. The interviews and focus groups were audio recorded and transcribed verbatim. The transcripts were analysed thematically.

#### ***Findings***

Benefits of extra care were identified as the opportunity for couples to remain living together for longer and the creation of a supportive, dementia-friendly community. Barriers centred on a sense of loss, stress and uncertainty. Living and caring at home was perceived as preferable to shared care.

#### ***Research limitations/implications***

The *shared care model* consulted on was very specific. Participants form a purposive sample and as such are unlikely to be representative of the wider population. Despite best intentions the voice of people with dementia are underreported in this consultation.

#### ***Social and Practical implications***

The findings cast doubt on the viability of extra care facilities, designed for couples living with dementia, whilst highlighting the need for better welfare support for people living in the community with dementia.

#### ***Originality/value***

This paper contributes to the body of literature, exploring the feasibility of new and innovative alternative care with housing options, for people with dementia. This paper is one of the first to explore extra care as a housing with care option for couples with dementia.

#### ***Keywords***

Dementia care, carer perspectives, extra care, housing with care, shared care, consultation

## Introduction

It is estimated that 850,000 people are living with dementia in the UK (Alzheimer's Society, 2014). This figure is expected to rise to over one million by 2021 (Department of Health, 2009). The economic cost associated with dementia is higher than that of stroke, cancer and heart disease combined (Luengo-Fernandez et al., 2012). In 2013 the estimated annual cost of dementia in the UK, when taking into consideration factors such as unpaid care, health and social services and dementia research, was £26.3 billion (Alzheimer's Society, 2014). The global economic impact is estimated to be \$818 Billion (Alzheimer's Association, 2015).

Approximately 70% of people living in care homes have a form of dementia, representing 29% of all people with dementia; the remaining 71% live in a community setting (Alzheimer's Society, 2014). Despite guidelines on best practice being freely available, poor care practice is still a commonly reported occurrence in care homes (Care Quality Commission, 2014). Care in the community is largely provided by unpaid care partners (Hollander et al., 2009) and care partners of people with dementia have reported a decline in their physical health, a feeling of social isolation, depression and an increase in stress levels (Huang et al., 2009; Brodaty et al., 2014). Respite and educational interventions do not significantly reduce the impact that caring for a person with dementia in community settings has on mental and physical well-being (Pinquart and Sorensen, 2006; Jensen et al., 2015). An economic and social incentive therefore exists to review, evaluate and revolutionise models of housing and long term care options for people living with dementia.

## *Extra Care*

Extra care has been defined as purpose built private apartments or homes, for people over the age of 65, coupled with a supplementary care package that helps people maintain their independence (Darton et al., 2012), typically models are idiosyncratic (Wright et al., 2010). There are 72 different phrases used to describe social housing models akin to extra care. They include Sheltered Accommodation, Housing with Care, Assisted Living, Retirement Villages and Senior Housing (Howe et al., 2012). **Research exists on the influence living in extra care type social housing can have on various outcomes for people with dementia. Extra care facilities more likely to be occupied by a healthier demographic of people, with less care needs than those living in care homes (Kopetz et al., 2000; Darton et al., 2011). People with dementia in assisted living are more likely to have received a diagnosis of dementia less than one year prior to a move, than those living in nursing facilities (Carlson et al., 2005). It is possible to infer therefore, that older people are more likely to seek extra care accommodation as a lifestyle choice, rather than a reaction to a crisis, as is often the case with moves to care homes. This inference is supported by evidence suggesting determinants of care home placement include vulnerability, poor health outcomes and depression within family caregivers (Gallagher et al., 2011).**

Recent government policy has prioritised the design and building of innovative extra care housing solutions for people with dementia across the UK (Department of Health, 2015), leading to heavy investment in such projects (Evans et al., 2007; Barnes et al., 2011; Atkinson et al., 2014). For example, the Department of Health Care and Support Fund 2013-2017 has made £160 Million of funding available for specialist housing to be built for people with dementia, people with mental health problems or physical and sensory disabilities

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3 outside of London (Department of Health, 2013).

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5 Research has been conducted on the experience and outcomes of living in a form of social  
6 housing akin to extra care for older people with dementia (Vallelly et al., 2006; Smith,  
7 Buckwalter et al., 2008; Brooker et al., 2011; Abbott et al., 2015). Moreover, care partner  
8 perspectives on assisted living facilities have been explored (Kelsey et al., 2010). Despite  
9 this, reviews of the research literature have not identified any research evidence investigating  
10 the perspectives of couples living with dementia surrounding extra care environment, prior to  
11 them deciding to move in (O'Malley and Croucher, 2005; Atkinson et al., 2014). This paper  
12 contributes to improving this gap in the literature, through a discussion of the findings of a  
13 consultation study into one model of extra care, coined as *Shared Care*.  
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17 *Shared Care* was proposed as a dementia specialist extra care facility for couples where one  
18 person has dementia. It is within this context that the term 'couples living with dementia' is  
19 used throughout this paper. The concept was devised by a care provider in the south of  
20 England. The principle behind *Shared Care* was to 'share' the care between a person with  
21 dementia, their family care partner and care staff members. The aim of *Shared Care* was to  
22 enable people with dementia to retain independence and control of their lives whilst  
23 providing care partners with support and respite services as and when they are required. Once  
24 people moved to *Shared Care* every possible effort was to be made to ensure the couple  
25 could age in place, should they choose. Therefore, a future move to a care home could be  
26 avoided, enabling the person with dementia and the care partner to live together until the end  
27 of their lives.  
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32 *Shared Care* was planned as a 52 apartment build with each apartment consisting of two  
33 bedrooms (including a master bedroom with an en suite bathroom), a kitchen and dining area,  
34 lounge area and a private garden or balcony area. 24-hour domiciliary care was planned to be  
35 available from an onsite team. Moreover, a CCTV system was to be installed in each  
36 apartment, should the owner wish to incorporate it into their care package. Onsite nursing  
37 wing to the build was seen as being able to provide respite and rehabilitation. The person  
38 with dementia could move to the nursing wing permanently if necessary, although this was to  
39 be avoided if possible. A community hub was designed, including a hair dressing salon, local  
40 shop, library and coffee shop. The idea and promotion of a supportive community was a  
41 principle central to the conceptualisation of *Shared Care*. ***Shared Care is still in the***  
42 **proposal stage at the time of writing.**  
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## 47 **Methods**

48  
49 **This qualitative study utilises a cross-sectional research design. A purposive sample was**  
50 **utilised consisting of people with memory problems and those who care, or have cared**  
51 **for, people with dementia. A diagnosis of dementia was not sought or confirmed as part**  
52 **of the consultation. A diagnosis of dementia was not an inclusion criteria to avoid**  
53 **excluding people from taking part. People may experience dementia without being**  
54 **diagnosed by a medical professional.**  
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56 Consulting with people with dementia is vital to ensuring their perspective has an impact on  
57 relevant local and national policy initiatives. Giving voice to people with dementia on any  
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3 issue they hold a vested interest in should be prioritised (Litherland and Williamson, 2013).  
4 The perspective of people with dementia should not be assumed, this can only exacerbate the  
5 marginalisation people with dementia face in the community today (Swaffer, 2014). Despite  
6 this, opportunities for people with dementia to participate in the development of dementia  
7 care and housing policy are limited (Batsch et al., 2012).  
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10 All participants lived locally to the proposed build. Participants were recruited through  
11 voluntary sector organisations at events such as memory cafes and community support  
12 groups. **Family carers were also accessed, whose partners now live in a special care unit**  
13 **(SCU) run by the care provider. Although person-caregiver dyads were recruited, the**  
14 **recruitment of individuals with dementia was challenging, with only one person with**  
15 **early on-set dementia being recruited. This highlights the marginalisation of people**  
16 **living on their own with dementia, and the lack of community based resources available**  
17 **to them, given the main recruitment strategy used for this consultation study targeted**  
18 **community support groups and events. People living in care homes with dementia were**  
19 **not included in the sample due to ethical concerns.**  
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22 **17 people were consulted. Fieldwork consisted of eight 1-1 interviews, one with a person**  
23 **with early on-set dementia, 7 with care partners; 3 paired interviews with person-**  
24 **caregiver dyads and one focus group consisting of 3 care partners. One dyad consisted**  
25 **of two friends living together in the community. The remaining dyads consisted of**  
26 **married couples living in the community. Of the 7 caregivers interviewed, 6 were in a**  
27 **relationship and 1 caregiver was a friend of the person they cared for. All caregivers**  
28 **interviewed, lived with the person in the community during the time they cared for**  
29 **them. The 3 focus group participants were all married to the person with dementia**  
30 **whom they cared for, living with them in the community prior to SCU placement. In**  
31 **total, 3 male and 10 female caregivers were interviewed. 1 male and 3 female people**  
32 **with dementia were interviewed.**  
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39 The consultation took place between June and August 2013 in the South of England. All  
40 interviews took place at the home of participants at their request. **The focus group took**  
41 **place at a SCU, run and owned by the care provider proposing the *Shared Care* model.**  
42 Each consultation was audio recorded and transcribed verbatim. **The lead author of this**  
43 **paper (CP) collected all data.** The fieldwork was conducted as part of a wider consultation  
44 including the views of other stakeholders about the *Shared Care* model (Poyner and Innes,  
45 2013).  
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### 53 ***Ethics***

54 Full ethical approval was given by the author's University ethics board prior to the study  
55 commencing. Permission to conduct interviews and focus groups at the special care unit and  
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extra care facility was granted by the relevant care provider. All participants were given the choice of a convenient location to participate.

### *Analysis*

Data was transcribed verbatim and an inductive thematic approach was adopted (Braun and Clarke, 2006). Two cycles of coding were completed manually within the Nvivo data management software tool using an inductive 'bottom up' approach to data analysis. Codes interpreted as having common meaning across the entire data set were grouped together to form categories. 6 overarching themes, with several sub themes subsumed underneath, were interpreted as being present within the data set. For example, the overarching theme of 'obstacles to apartment purchase' included the sub theme of 'loss' which in turn was produced with the categories of 'space' 'familiarity' 'home' and 'local community'. The main criterion for the creation of a theme was the frequency of reoccurrence across the data set and the number of relatable categories and subthemes. The rationale behind this analytic strategy was to achieve a rich and detailed description of the data set due to the exploratory nature of the study. All analysis was conducted by the lead author (CP) and checked for accuracy by AI.

Nvivo was used to organise and manage the data. All data was analysed within Nvivo.

### **Results**

The findings are presented thematically below.

#### *Facilitators of a move to Shared Care*

##### *Creation of a supportive community*

The community aspect of *Shared Care* was reported as an enticing element and something lacking in alternative local models of extra care.

Care Partner: (P1) *'...when I first read about it I thought this is fantastic and I think along the line there might have been stages [in journey] when I would have thought we'll go for this, because when I went to [extra care provider] when that opened up...but that is just a big hotel really whereas this is more a little community isn't it?'*

##### *Staying together*

Carers who had to make the decision to place their partner into permanent nursing care disclosed the guilt and anxiety they felt and the pain of having to be apart from their partner:

Family caregiver (P14): *'When he went off to that nursing home...well care home, I couldn't describe the feelings we'd separated with a big wrench.'*

Care partners have reported feeling guilty and struggling to adapt with their new lives post seeking care home placements for people with dementia that they have cared for (Garity, 2006; Graneheim et al., 2014). For example, Graneheim et al found care partners experience a process that starts with feeling responsible for their partner's admission, adjusting to their



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3 new role and getting used to their new relationship with their loved one. This process was  
4 reported to be accompanied by feelings of guilt, loss and shame (Graneheim et al., 2014).  
5 Such findings are reinforced by research investigating why couples living with dementia  
6 remain together (Loboprabhu et al., 2005; Davies, 2011).  
7

### 8 ***Barriers of a move to Shared Care***

#### 9 ***Uncertainly around when to move and mortality***

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11 Despite recognising benefits of a move to *Shared Care*, carers described not knowing when  
12 would be the right time to move into the setting. This seemed to be due to a concern around  
13 the right time to move to achieve the maximum benefit out of *Shared Care*. The perceived  
14 unpredictability of dementia was seen as adding to this dilemma:  
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19 Care partner (P15): *'I think it is a tricky one to know how you work, whether you're*  
20 *going to kind of get the benefit or not, because it's such an unpredictable illness.'*  
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23 Care partner (P1): *'... it would be far, far too soon...now we've got to a stage where it's*  
24 *getting really, really difficult to care for [person with dementia] and I think I would be*  
25 *reluctant to give my home up.'*  
26

27  
28 Care partners shared their worries about their own mortality as well as the remaining lifespan  
29 of their partner as reasons why they would dismiss *Shared Care* as an option. If the person  
30 with dementia died there was a concern apartments would be 'blocked' by the care partner  
31 when another person with dementia may require the support. Moreover, respondents did not  
32 know whether care partners would want to leave the shared care environment due to the idea  
33 of 'resettling'.  
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35  
36 Care Partner (P14): *'Also, if they die and you decide you like it there, you're blocking it*  
37 *for someone that needs it. I don't know how that bit would work.'*  
38

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40 Care Partner (P7): *'...when your relative has died then what do you do? You've got to*  
41 *sell up again and then go resettle yourself and you can never go back to where you*  
42 *were.'*  
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45 A person with dementia also questioned their ability to live on her own should their care  
46 partner die:

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48 Care Partner (P2): *'I was saying it wasn't suitable in looking to some distant future of*  
49 *time when it might happen if I'm no longer here. Do I think [person with dementia]*  
50 *could live in that situation? My answer to that is, I honestly think, no not on her own.'*  
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53 Person with dementia (P3): *'No, not on my own.'*

### 54 ***Loss of home, moving home and adjusting to a new home***

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56 Couples living with dementia were anxious about 'losing' or 'giving up' their home.  
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Care Partner (P1): *'Well I think as I've got this far I would be very reluctant to sell the house because I would lose it as well because I would feel I've lost everything.'*

Care partner (P6): *'...we thought, no, we'll be living here all our lives, so suddenly if I decide to move out, that would be very, very painful for both of us, really.'*

This finding reflects the large body of literature reporting the significance and importance of home to older people in general and people with dementia specifically (Aminzadeh et al., 2010).

Respondents reported key benefits of their home. Key benefits included the location, the familiarity of the house and the local community their home is situated in. Respondents suggested skills such as navigation and personal care tasks could become difficult to retain in an unfamiliar setting:

Care Partner (P2): *'If I died, and [person with dementia] was left there on her own, I think she'd be losing too much. I really do. Yes, this house is everything. This location means so much. Even if [person with dementia] gets separated from me in the town she's made it back home....'*

Care Partner (P12): *'Well, you think you can tolerate the situation better in familiar surroundings; because if you move somewhere else ...there's additional concerns to adapt to the new...whereas you haven't got that here, you're so used to it, it's all routine.'*

The perspectives of the participants on this issue finds supporting evidence from research that suggests the more familiar people with dementia are with their environment the more likely they are to retain skills and act independently (Brittain et al., 2010; Provencher et al., 2012; Boger et al., 2013.) For example, Provencher et al (2012) found older people with 'poor and preserved executive functions' to perform cooking tasks more effectively at home than in unfamiliar surroundings.

A perceived disadvantage of moving into *Shared Care* would be the loss of community services, local health professionals and lay support such as neighbours and friends. Respondents also felt moving further away from family would impact on their lack of desire to move, indicating people living with dementia would only consider *Shared Care* as a last resort. The following two extracts from a two-to-one interview with a couple living with dementia exemplify this point:

Care Partner (P2): *'What would be the advantages of selling this place and moving into a two-bedroom flat? We would be moving away from all our friends, our medical support teams. My GP knows more about me than I know about me.'*

Person with dementia (P3): *'Well, we've got two daughters, they come in and do things, don't they?'*

Care Partner (P12): *'Yeah, I say, it's just the fact that you're set up, you know, we've*

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3 *got all the connections, the [laugh] plumbers and...you're familiar with everything... I*  
4 *suppose we're quite well placed here, and we don't want to move unless it's absolutely*  
5 *essential.'*  
6

7 Care partners perceived moving into a new environment as a stressful thought for themselves  
8 and their partner with dementia.  
9

10  
11 Care Partner (P15): *'Also, selling a house is very stressful, if people are stressing out*  
12 *with dementia, will they also be able to take on the pressure of selling the house and*  
13 *making that decision? I don't know.'*  
14

15 Care partner (P7): *'I think it would have been such a massive thing to do in the middle*  
16 *of everything else that was going on I just wouldn't have contemplated it.'*  
17  
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19 Downsizing to a two-bedroom apartment was perceived as undesirable. Downsizing was  
20 associated with having a negative impact effect on their well-being and quality of life as a  
21 couple. One respondent indicated their opinion on this could change if they get 'some  
22 horrible disease' again indicating *Shared Care* may be perceived as a last resort option and  
23 would be tolerated if physical health needs dictated the need for a move from their own  
24 homes.  
25  
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27 Care partner (P12): *'Well, I suppose views might change [re downsizing], you see, as I*  
28 *might get some horrible disease, or something, and the view might change; but all the*  
29 *time I am still capable of doing things I'd rather carry on.'*  
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32 One care partner emphasised the importance of community living given the effect downsizing  
33 may have on their well-being. This extract is another example of the value respondents  
34 placed on community provision:  
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37 Care Partner (P6): *'...when you said it's a two-bedroomed flat I thought, oh dear.*  
38 *Would I be able to live there? I [would] have to go out and talk to other people because*  
39 *I would be claustrophobic in two bedroomed house...he might be claustrophobic...he*  
40 *would definitely feeling like a prisoner there.'*  
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### 43 **Care at home**

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45 In home care services were a recurring theme in the data set. The *Shared Care* model was  
46 directly compared to existing models of support provided at home. *Shared Care* was  
47 perceived by some to not offer any service that would entice a move, as care support  
48 packages provided in the home were seen to deliver the support required, such as personal  
49 care and periods of respite. Care at home services were reported to have the added benefit of  
50 enabling people to age in place in their home and within their local community. Aging in  
51 place has been reported by older people to be desired due to the feeling of security,  
52 attachment and familiarity they have with a specific home environment (Wiles et al., 2011).  
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Care partner (P7): *'What's the difference [between Shared Care and care at home services]? The difference is you've got to sell your house...I was able to have help from [care at home services] ...Yes, we paid for it, but they would take him out a couple of times a week...we had got him staying [at home] a bit longer, bit longer.'*

As well as receiving support with personal care, respondents reported receiving help with cleaning and gardening to reduce the workload of the care partner:

Person with dementia (P12): *'Mm. We have a cleaner come in as well, don't we?'*

Care partner (P13): *'Yes, and the cleaner comes in. So, yeah, I think we'd miss all that. And I certainly would, you know, I'd – not resent it – but I've got all these facilities here.'*

### ***Inadequate support at home***

Despite generally positive feedback about support provided at home there was a recognition that services were not always enough to relieve the burden experienced by the care partner.

Care Partner: (P7) *'I used to have [care at home services] in for a couple of hours... they'd say to me, this is your time go and relax, but I didn't, I did all the things that I couldn't do when my husband was there.'*

A care at home service was perceived as inadequate when the needs of the person with dementia and the care partner were more complex.

Care Partner (P5): *'The [care at home services] was fine except for one occasion when she had a really bad infection... I'd try and walk her to the bathroom and her legs would just go underneath her, I'd have to catch her. It was a really bad day...It was an hour and a half visit I think from [care at home service provider], by the time they'd gone I was feeling shattered...So having somebody on site would take care of those situations.'*

### ***Cost***

Cost was perceived as a barrier especially in terms of couples deciding to make a move to *Shared Care* early on in their journey with dementia. One family caregiver discussed the low cost of living in their current home. Another expressed concern about their money running out whilst another questioned whether *Shared Care* would be socially funded to any extent.

Care Partner (P12): *'...you probably wouldn't get away with much cheaper [than current home] if you moved to a smaller place. So there's no real financial incentive to move.'*

Care partner (P14): *'That's why I say, I think the costing, the people would want to look and see what the bottom line is... I think the concept is super, it's just, in my opinion, for me, costing would be quite an important issue.'*

## Discussion

The majority of barriers to considering *Shared Care* as a viable alternative model of housing centre around the unwillingness of potential residents to move, due to perceptions of losing what they defined as 'their home', and the stress of moving whilst trying to cope with caregiving responsibilities. This finding is representative of the literature on the significance and importance of home to older people in general and people with dementia specifically (e.g. Aminzadeh et al., 2010). A 'home' represents what people have achieved in their working life, it is inherently reflective of a person's individuality, whilst being perceived as a deeply familiar space (Gould and Basta, 2013). People with dementia and their care partners reported a desire to remain in place for as long as possible during their journey with dementia, thus demonstrating a commitment to each other, their home and community. Staying in place in the community is however, deeply reliant on the unpaid labour of care partners (Pickard, 2010; Vreugdanhil, 2014). The lack of welfare support for care partners, coupled with the strain of being a full-time care partner, frequently results in poor health outcomes in care partners of a person with dementia (Huang et al., 2009; Brodaty et al., 2014). The implication for policy and practice is more needs to be done to support the welfare of people living in the community with dementia and the intermediate care services, providing care to those with dementia, living in the community.

Care spouses of people with dementia have reported wanting to stay together, despite the negative mental and physical impact caring for someone with dementia can have (Loboprabhu et al., 2005; Davies, 2011). For example, Davies found that the concepts of partnership for life, reciprocity, resilience and forgiveness were all factors that ensured couples remained committed to each other during their journey with dementia (Davies, 2011). These findings were reflected in the anecdotes of the care partner's experience of the caregiver role. Several instances of depression, loneliness and poor physical health were recorded in the data set that contextualised people's responses to questioning. Despite this, couples maintained their desire to be together for as long as they possibly can. The conceptualisation of extra care for couples living with dementia, as a desirable positive life choice was therefore not supported by the views of care partners and people living with dementia in this consultation.

Care at home services were perceived as an attractive option to those with access and a key reason why *Shared Care* was seen an unsuitable model of housing with care. There is a paucity of literature evaluating the impact of models of at home care services on people living with dementia in the community (Low and Fletcher, 2015). Findings from the literature have previously suggested carer partners in the community are resistant to taking up care at

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3 home services (Markle-Reid and Brown, 2001; Morgan et al., 2002; Brodaty et al., 2005),  
4 contradicting the findings of this study, thus indicting progress in terms of people being more  
5 open about living with dementia and accepting support when available. Care partners  
6 reported using both private and public care at home support services, with high levels of  
7 satisfaction, due to the advantage of being able to age in place. Previous research has  
8 suggested care at home services score highly on care partner satisfaction only when they are  
9 consumer focused or person-centred (Low et al., 2011; Low et al., 2013). Such research  
10 however, has compared community care services in isolation from alternative long term care  
11 options.  
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15 Extra care as a positive lifestyle choice early in people's journey with dementia was not  
16 supported by those we consulted. However, participants reported that the respite provided by  
17 services, such as care at home, was not always adequate and this is one area where a *Shared*  
18 *Care* approach was seen as advantageous. As people progress through their journey with  
19 dementia the positive impact of support, provided by care at home services, was perceived to  
20 have lessened as the care needs of people with dementia increased. This finding supports  
21 previous research indicating care at home services meet basic and general need, but fail to  
22 provide person-centred care, or meet specific or complex needs (Vreuhdenhil, 2014; Bökberg  
23 et al., 2015).  
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28 The dual stresses of caring for someone with dementia, and coping with the process of selling  
29 and moving house, was perceived as an addition major barrier preventing people from  
30 viewing *Shared Care* as a viable housing with care option.  
31

32  
33 The findings presented here have limited generalizability. The *Shared Care* model consulted  
34 on was very specific. Moreover, our participants form a purposive sample and as such are not  
35 representative of wider populations. For example, the majority of participants in our sample  
36 reported an emotional attachment and relationship to their local community and home that  
37 may not be as prevalent in the overall population, as living in a place does not necessarily  
38 equate to attachment (Rubinstein and Parmelee, 1992). Despite best intentions the voice of  
39 people with dementia are underreported in this consultation. One person with early on-set  
40 dementia was interviewed and the remaining two people with dementia were interviewed  
41 alongside their care partner. In these instances, the care partner would typically speak on  
42 behalf on the person with dementia themselves. In future studies, researchers should be aware  
43 of this issue and make every effort to ensure they engage creatively with people with  
44 dementia, allowing them the space to air their views.  
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49 **Further research is needed given the limited scope of this consultation study. The**  
50 **research should include a representative sample of couples living with dementia,**  
51 **informal caregivers, and people with dementia. Multiple extra care facilities designed**  
52 **for couples with dementia should be included due to the specific nature of such facilities.**  
53 **Given the rarity of extra care housing, designed for couples living with dementia,**  
54 **multiple examples may be unfeasible at present. Researchers however, could still design**  
55 **a pilot study exploring the perspectives of couples living with dementia, on the**  
56 **suitability of models of extra care for couples with physical health needs. It would then**  
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3 **be possible to explore how to adapt these housing with care options for couples living**  
4 **with dementia.**

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6 **Given the emphasis on loss of community, home, dying and cost as major obstacles**  
7 **within the data set, alternative means of 'buy in' to services offered by extra care**  
8 **facilities for couples living with dementia are recommended i.e. rental or equality based**  
9 **options. The main recommendation for policy is to better fund and support the welfare**  
10 **of people living in the community with dementia and the intermediate care services,**  
11 **providing care to those with dementia living in the community.**  
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## 15 16 17 **Conclusion**

18 Findings suggest extra care models of housing and care, for couples living with dementia, are  
19 not perceived as a viable alternative care solution or lifestyle choice by those who  
20 participated in this consultation. The initial satisfaction with care services provided at home,  
21 an emotional attachment to home and local community, cost, a lack of a coherent strategy for  
22 when either person dies, and the stress associated with moving home, renders extra care an  
23 unviable housing with care choice for couples living with dementia.  
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## 30 **References**

- 31  
32  
33  
34 Abbott, K. M., Bettger, J. P., Hampton, K. N. and Kohler, H.-P., 2015. The feasibility of  
35 measuring social networks among older adults in assisted living and dementia special care  
36 units. *Dementia: The International Journal of Social Research and Practice*, 14  
37 (2), 199-219.  
38  
39 Alzheimer's Association, 2015. 2015 Alzheimer's disease facts and figures. *Alzheimer's and*  
40 *Dementia*, 11 (3), 332-384.  
41  
42 Alzheimer's Society, 2014. Dementia UK Update. London: Alzheimer's Society  
43  
44 Aminzadeh, F., Dalziel, W. B., Molnar, F. J. and Garcia, L. J., 2010. Meanings, functions,  
45 and experiences of living at home for individuals with dementia at the critical point of  
46 relocation. *Journal Of Gerontological Nursing*, 36 (6), 28-35.  
47  
48 Atkinson, T. J., Evans, S., Darton, R., Cameron, A., Porteus, J. and Smith, R., 2014. Creating  
49 the asset base -- a review of literature and policy on housing with care. *Housing, Care*  
50 *& Support*, 17 (1), 16-25.  
51  
52  
53 Barnes, S., Torrington, J., Darton, R., Holder, J., Lewis, A., McKee, K., ... Orrell, A., 2012.  
54 Does the design of extra-care housing meet the needs of the residents? A focus group  
55 study. *Ageing & Society*, 32 (7), 1193-1214.  
56  
57  
58  
59  
60

- 1  
2  
3 Batsch, N. and Mittelman, M., 2012. World Alzheimer Report 2012. *Overcoming the Stigma*  
4 *of Dementia*. Alzheimer's Disease International (ADI): London.  
5  
6 Boger, J., Craig, T. and Mihailidis, A., 2013. Examining the impact of familiarity on faucet  
7 usability for older adults with dementia. *BMC Geriatrics*, 13, 63-63.  
8  
9  
10 Bökberg, C., Ahlstorm, G., Leino-Kilpi, H., Soto-Marin, M., Caberera, E., Verbeek, H., ...  
11 C., Karlsson, S., 2015. Care and Service at Home for Persons with Dementia in  
12 Europe. *Journal of Nursing Scholarship*, 47 (5), 407-416.  
13  
14  
15 Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative Research*  
16 *in Psychology*, 3 (2), 77-101.  
17  
18  
19  
20 Brittain, K., Corner, L., Robinson, L. and Bond, J., 2010. Ageing in place and technologies of  
21 place: the lived experience of people with dementia in changing social, physical and  
22 technological environments. *Sociology of Health & Illness*, 32 (2), 272-287.  
23  
24 Brodaty, H., Thomson, C., Thompson, C. and Fine, M., 2005. Why caregivers of people with  
25 dementia and memory loss don't use services. *International Journal Of Geriatric*  
26 *Psychiatry*, 20 (6), 537-546.  
27  
28  
29  
30 Brodaty, H., Woodward, M., Boundy, K., Ames, D. and Balshaw, R., 2014. Regular Research  
31 Article: Prevalence and Predictors of Burden in Caregivers of People with Dementia.  
32 *The American Journal of Geriatric Psychiatry*, 22, 756-765.  
33  
34 Brooker, D. J., Argyle, E., Scally, A. J. and Clancy, D., 2011. The enriched opportunities  
35 programme for people with dementia: a cluster-randomised controlled trial in 10 extra  
36 care housing schemes. *Aging & Mental Health*, 15 (8), 1008-1017.  
37  
38  
39  
40 Care Quality Commission, 2014. *Cracks in the pathway: People's experience of dementia*  
41 *care as they move between care homes and hospitals*. Care Quality Commission:  
42 London.  
43  
44 Carlson, J. M., Gerding, G. and Estoup, M. W. (2005) 'Evaluation of demographics and  
45 medication use in patients with dementia in assisted living and skilled nursing  
46 facilities', *Consultant Pharmacist*, 20(7), pp. 584-591.  
47  
48  
49  
50 Darton, R., Bäumker, T., Callaghan, L. and Netten, A., 2011. Improving housing with care  
51 choices for older people: the PSSRU evaluation of extra care housing. *Housing, Care*  
52 *& Support*, 14 (3), 77.  
53  
54  
55 Darton, R., Bäumker, T., Callaghan, L., Holder, J., Netten, A. and Towers, A.-M., 2012. The  
56 characteristics of residents in extra care housing and care homes in England. *Health &*  
57 *Social Care In The Community*, 20 (1), 87-96.  
58  
59  
60



- 1  
2  
3  
4 Davies, J. C., 2011. Preserving the "us identity" through marriage commitment while living  
5 with early-stage dementia. *Dementia*, 10 (2), 217-234.  
6  
7  
8  
9 Department of Health., 2009. *Living Well With Dementia: a national dementia strategy*.  
10 London: Department of Health.  
11  
12 Department of Health, 2015. *Care and Support Specialised Housing Fund: Phase 2*. London:  
13 Department of Health.  
14  
15  
16 Evans, S., Fear, T., Means, R. and Valletly, S., 2007. Supporting independence for people  
17 with dementia in extra care housing. *Dementia: The International Journal of Social*  
18 *Research and Practice*, 6 (1), 144-145.  
19  
20  
21 Gallagher, D., Ni Mhaolain, A., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., Walsh, C.,  
22 Coakley, D., Walsh, J. B., Cunningham, C. and Lawlor, B. A. (2011) 'Determinants of  
23 the Desire to Institutionalize in Alzheimer's Caregivers', *American Journal of*  
24 *Alzheimer's Disease & Other Dementias*, 26(3), pp. 205-211.  
25  
26 Garity, J., 2006. Caring for a family member with Alzheimer's disease - Coping with  
27 caregiver burden post-nursing home placement. *JOURNAL OF GERONTOLOGICAL*  
28 *NURSING*, 32 (6), 39-48.  
29  
30  
31 Gould, E. and Basta, P., 2013. Home Is Where the Heart Is-for People in All Stages of  
32 Dementia. *Generations*, 37 (3), 74-78 75p.  
33  
34  
35 Graneheim, U. H., Johansson, A. and Lindgren, B.-M., 2014. Family caregivers' experiences  
36 of relinquishing the care of a person with dementia to a nursing home: insights from a  
37 meta-ethnographic study. *Scandinavian Journal of Caring Sciences*, 28 (2), 215-224  
38 210p.  
39  
40  
41 Hollander, M. J., Liu, G. and Chappell, N. L., 2009. Who cares and how much? The imputed  
42 economic contribution to the Canadian healthcare system of middle-aged and older  
43 unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12 (2), 42-49.  
44  
45  
46 Howe, A. L., Jones, A. E. and Tilse, C., 2013. What's in a name? Similarities and differences  
47 in international terms and meanings for older peoples' housing with services.  
48 *AGEING & SOCIETY*, 33, 547-578.  
49  
50  
51 Huang, C., Souza, V.D., Perng, S., Hwang, M., Tsai, C., Huang, M., Yao, S., 2009. Stressors,  
52 social support, depressive symptoms and general health of Taiwanese caregivers pf  
53 persons with stroke or Alzheimer's disease. *Journal of Clinical Nursing*, 18 (4), 502-  
54 511.  
55  
56  
57 Jensen, M., Agbata, I. N., Canavan, M. and McCarthy, G., 2015. Effectiveness of educational  
58 interventions for informal caregivers of individuals with dementia residing in the  
59  
60

- 1  
2  
3 community: Systematic review and meta-analysis of randomised controlled trials.  
4 *International Journal of Geriatric Psychiatry*, 30 (2), 130-143.  
5  
6 Kelsey, S. G., Laditka, S. B. and Laditka, J. N., 2010. Caregiver perspectives on transitions to  
7 assisted living and memory care. *American Journal of Alzheimer's Disease and Other*  
8 *Dementias*, 25 (3), 255-264.  
9  
10  
11 Kopetz, S., Steele, C. D., Brandt, J., Baker, A., Kronberg, M., Galik, E., Steinberg, M.,  
12 Warren, A. and Lyketsos, C. G. (2000) 'Characteristics and outcomes of dementia  
13 residents in an assisted living facility', *International Journal of Geriatric Psychiatry*,  
14 15(7), pp. 586-593.  
15  
16  
17 Litherland, R and Williamson, T., 2013. DEEP: the engagement, involvement and  
18 empowerment of people with dementia in collective influencing. *Working with older*  
19 *people; Community Care Policy and Practice*, 17 (2), 66-73.  
20  
21  
22 Loboprabhu, S., Molinari, V., Arlinghaus, K., Barr, E., Lomax, L., 2005. Spouses of patients  
23 with dementia: How Do They Stay Together 'Til death do us part? *Journal of*  
24 *Gerontological Social Work*, 44 (3-4), 161-174.  
25  
26  
27 Low, L-F., Yap, M., Brodaty, H., 2011. A systematic review of different models of home and  
28 community care services for older persons. *BMC Health Services Research*, 11, 93-  
29 93.  
30  
31 Low, L-F., White, F., Jeon, Y-H., Gresham, M., Brodaty, H., 2013. Desired characteristics  
32 and outcomes of community care services for persons with dementia: what is  
33 important according to clients, service providers and policy? *Australasian Journal On*  
34 *Ageing*, 32 (2), 91-96.  
35  
36  
37 Low, L.-F. and Fletcher, J., 2015. Models of home care services for persons with dementia: A  
38 narrative review. *International Psychogeriatrics*, 27 (10), 1593-1600.  
39  
40  
41 Luengo-Fernandez, R., Leal, J. and Gray, A. M., 2012. UK research expenditure on dementia,  
42 heart disease, stroke and cancer: are levels of spending related to disease burden?  
43 *European Journal Of Neurology: The Official Journal Of The European Federation*  
44 *Of Neurological Societies*, 19 (1), 149-154.  
45  
46  
47 Markle-Reid, M. and Browne, G., 2001. Explaining the use and non-use of community-based  
48 long-term care services by caregivers of persons with dementia. *Journal Of*  
49 *Evaluation In Clinical Practice*, 7 (3), 271-287.  
50  
51  
52 Morgan, D. G., Semchuk, K. M., Stewart, N. J. and D'Arcy, C., 2002. Rural families caring  
53 for a relative with dementia: barriers to use of formal services. *Social Science &*  
54 *Medicine*, 55, 1129-1142.  
55  
56  
57 O'Malley, L. and Croucher, K., 2005. Housing and dementia care – a scoping review of the  
58 literature. *Health & Social Care in the Community*, 13 (6), 570-577.  
59  
60  
61  
62  
63  
64  
65  
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67  
68  
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157  
158  
159  
160

- 1  
2  
3  
4 Pinquart, M. and Sorensen, S., 2006. Helping caregivers of persons with dementia: which  
5 interventions work and how large are their effects? *INTERNATIONAL*  
6 *PSYCHOGERIATRICS*, 18 (4), 577-595.  
7
- 8 Poyner, C. and Innes, A., 2013. Consultation study with formal dementia care staff,  
9 family carers and people with dementia into the Shared Care concept. Unpublished report.  
10
- 11 Provencher, V., Demers, L., Gagnon, L. and Gelinas, I., 2012. Impact of familiar and  
12 unfamiliar settings on cooking task assessments in frail older adults with poor and  
13 preserved executive functions. *INTERNATIONAL PSYCHOGERIATRICS*, 24 (5),  
14 775-783.  
15  
16
- 17 Rubinstein, R. L. and Parmelee, P. A., 1992. Attachment to place and the representation of  
18 the life course by the elderly. *Human Behavior & Environment: Advances in Theory*  
19 *& Research*, 12, 139-163.  
20
- 21 Smith, M., Buckwalter, K. C., Kang, H., Ellingrod, V. and Schultz, S. K., 2008. Dementia-  
22 specific assisted living: Clinical factors and psychotropic medication use. *Journal of*  
23 *the American Psychiatric Nurses Association*, 14 (1), 39-49.  
24  
25
- 26 Vallely, S., Evans, S., Fear, T., Means, R., 2006. Opening doors to independence: A  
27 longitudinal study exploring the contribution of extra care housing to the care and support of  
28 older people with dementia. London: Housing 21, Housing Corporation  
29
- 30 Vreugdenhil, A., 2014. 'Ageing-in-place': Frontline experiences of intergenerational family  
31 carers of people with dementia. *Health Sociology Review*, 23 (1), 43-52.  
32  
33
- 34 Wiles, J. L., Leibing, A., Guberman, N., Reeve, J. and Allen, R., The Meaning of 'Ageing in  
35 Place' to Older People: Oxford University Press.  
36
- 37 Wright, F., Tinker, A., Mayagoitia, R., Hanson, J., Wojgani, H. and Holmans, A., 2010. What  
38 is the 'Extra' in Extra Care Housing? *British Journal of Social Work*, 40 (7), 2239-2254.  
39  
40  
41  
42  
43  
44  
45  
46  
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