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# How people with dementia and their carers adapt their homes: A qualitative study.

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## **Abstract**

The objective was to explore the ways in which people with dementia and their carers adapt their homes, including the barriers and use of available information. Semi-structured interviews were conducted with ten people with dementia and their informal carer. The collected data were analysed using thematic analysis. Three core themes emerged: *Maintaining familiarity and coping with change*, *Having knowledge and finding knowledge* and *Meeting challenges through home adaptation*. The most significant barriers to making home adaptations were lack of knowledge and maintaining familiarity. Having more information and making home modifications earlier might enable individuals with dementia to adjust to their adapted environment.

## **Keywords**

Dementia, home adaptation, information, home modification, qualitative

## Introduction

There are estimated to be over 850,000 people with dementia in the UK, two thirds of which live in their own homes and one third live in residential care settings( Moore, Pritchard-Wilkes, Miles, & Sweeney, 2017; Prince et al., 2014). For individuals with dementia being able live in their own home allows individuals to maintain a sense of control over both their environment and their activities (Fänge & Ivanoff, 2009). Dementia is often typified by a reduction in short term memory which can be mitigated by remaining in a familiar environment. This familiarity and control, in turn, leads to improved wellbeing and independence (Wahl, Schilling, Oswald, & Iwarsson, 2009). This is reflected by figures showing that eighty-three percent of people with dementia and carers of individuals with dementia in the UK rated being able to remain living in their own homes as very important(Quince, 2011). The desire to remain living at home and Age in Place is one way that individuals living with dementia maintain consistency and familiarity in the environment, however, the aging process and ill health creates continually changing levels of ability. The Ecology of Aging proposed by Nahemow & Lawton, (1973) describes three co-existing processes which explain the interaction with the environment as people age:

- *Press-Competence model*: This model hypothesises that decreased function is caused through either a decrease in competence or an increase in the amount of environmental aspects motivating the individual (environmental press) (Nahemow & Lawton, 1973)
- *Environmental Docility Hypothesis*: The less able an individual becomes, the greater the limiting influence of the environment becomes(Lawton & Simon, 1968)
- *Person-environment (P-E) fit*: Level of congruence between the needs of the individual and the ability of the environment to meet these needs (Nahemow & Lawton, 1973)

Modification of the environment aimed at decreasing environmental press can mitigate for changes in personal ability (Lawton, 1985; K. D. Moore, VanHaitsma, Curyto, & Saperstein, 2003; Nahemow & Lawton, 1973). In this way modification of the home to meet changing needs has been shown to be effective in enabling people to remain at home through increasing age and long term illness (Alzheimer's Society, 2014; Marquardt, Bueter, & Motzek, 2014). Evidence shows the risk of falls and some cognitive symptoms (such as impaired memory, agitation and aggression) can be ameliorated through changes within the physical environment (e.g. Algase, Beattie, Antonakos, Beel-Bates, & Lan, 2010; Pollock & Fuggle, 2013; van Hoof, Kort, Hensen, Duijnste, & Rutten, 2010). Indeed, The National Institute for Health and Care Excellence Quality Standards for independence and wellbeing in dementia recommend the use of housing adaptation to reduce feelings of confusion and anxiety (National Institute for Health and Care Excellence, 2013). Despite this evidence, a report by the Alzheimer's Society found that only forty percent of people with dementia had adapted their home in some way (Quince, 2011). Although the report did not specify which adaptations were made or by whom. Adaptions to the home canbe divided into four types (Pynoos, Steinman, Do Nguyen, & Bressette, 2012). First, additive (e.g. adding labels to aid memory). Second, subtractive (e.g. removing clutter to prevent confusion and falls). Third, behavioural/ (e.g. leaving kitchen items out on the counter to prompt their use). Lastly transformative (e.g. changing lighting to reduce agitation or improve sleep patterns); (Pollock & Fuggle, 2013; Pynoos et al., 2012; Torrington & Tregenza, 2007). Each type of adaptation has the potential to change the way in which an individual interacts with their environment

and can improve person-environment fit. However Pynoos et al (2012) also point out that to be effective, home adaptations need to be personalised for the individual.

There have been relatively few studies which investigate attitudes towards home adaptation in dementia (Damme & Ray-Degges, 2016; Kruse et al., 2010; Marquardt et al., 2011). These studies conclude that home adaptations offered by health professionals are often not completed by people with dementia and their carers because they both feel that adaptations are not needed (Brodaty, Thomson, Thompson, & Fine, 2005; Kruse et al., 2010; Marquardt et al., 2011; Silverstein & Hyde, 1997). Additionally, adaptations to assist physical difficulties were more readily accepted than those to aid cognitive or behavioural impairment (Gabriel, Faulkner, & Stirling, 2015). Yet, the reason why some adaptations are more willingly accepted than others remains unclear.

Traditionally, the provision of home adaptations and related advice for older people has been from health and social care professionals (Mountain & Way, 2012). Recently, there has been a growth in the range of accessible health and wellbeing advice particularly from online sources (Lemire, Paré, Sicotte, & Harvey, 2008) which are seen as quick and easily accessible (Kort S.M. & van Hoof, 2014) . For example a variety of charities and advice groups such as the Alzheimer's Society, AgeUK and Home Improvement Agencies produce both downloadable and printed documents on a range of topics regarding dementia care including home adaptation and improvements (Mountain & Way, 2012).

For some the availability of this information may be limited due to a lack of internet access. For example in the UK in 2015, only 59 percent of households containing at least one adult over 65 have access to the internet (Office for National Statistics, 2015) For others there may be concerns over the quality of information offered by the internet (Anderson, Nikzad-Terhune, & Gaugler, 2009)

In summary, the appropriate use of home adaptation has the potential to reduce hospital admission and delay a move to long term care for Persons with dementia. Yet, it remains unclear to what extent people living at home with dementia are utilising home adaptations. Also, there is a lack of clarity as to how people with dementia and their carers access advice on adapting their home environment and what the barriers are to making these changes. Therefore, the aim of this study is to investigate the experiences of Persons with dementia and their carers in making home adaptations by addressing the following research questions:

- How are Persons with dementia and their carers adapting their homes for independent living?
- What are the barriers to the use of home adaptation by Persons with dementia and their carers?
- How do Persons with dementia and their carers find and use information relating to home adaptation for dementia?

## Methods

The study uses semi-structured interviews to examine the experiences of Persons with dementia and their carers in applying changes to their homes. The collected data then underwent a process of thematic analysis.

## *Participants / Recruitment*

Recruitment was via the 'Join Dementia Research' (JDR) recruitment tool, run by the National Institute for Health Research. This service enables individuals with dementia (and their carers) to register their interest in taking part in research (National Institute for Health Research, 2014). The Interpretive Phenomenological Analysis approach outlined by Smith, & Osborn (2007) states that sample size should be kept small to allow for a penetrating depth of analysis of each participant and meaningful contrasts to be made between cases without researchers becoming overwhelmed by data. Therefore ten dyads of participants consisting of a Person with dementia and an informal carer who live at the same residential property were recruited via purposive sampling. All participants were English speaking and had lived in their current home for more than six months.

Not all study partners identify themselves as carers as they perceive that they do not yet perform any traditional caring tasks. For the purposes of clarity, study partners without dementia in this study are referred to as carers to make a clear demarcation between those with dementia and those without.

Following ethical approval, individual JDR records were screened to establish whether individuals met the inclusion criteria above. If it remained unclear from the JDR register whether a volunteer was appropriate, they were contacted for further information via Email, post or phone as per their indicated preference. Once it was established that a participant met the inclusion criteria, they were then sent a copy of the Participant Information Leaflet along with an invitation to participate via email or post.

## *Procedure*

Following informed consent, information including age, gender, dementia type and length of time since diagnosis was collected. Data were collected via semi-structured interviews in the participant's home at one single meeting. An interview schedule (Figure 1) was used to provide cues for the interviewer. However, participants were allowed to talk and guide the interview according to their own experiences. Participant dyads were allowed to choose whether to be interviewed together or separately. Interview questions reflected areas prevalent in the literature including: home adaptations made; those considered or dismissed; and the process of obtaining information about dementia and home adaptation.

Consistent with the approach outlined by Smith and Osborn (2007) interviews were audio recorded and written notes were taken by the researcher at each interview to add observations and insights to the verbal data (Smith, Jonathan & Osborn, 2007). To improve the validity of the research data a reflexive diary was kept throughout the data collection phase to note thoughts and aspects of the interviews not documented on the audio recording.

Figure 1 Summary of Interview Schedule Themes

Demographic data	Advice and information	Feelings of home	Home adaptation	General
<ul style="list-style-type: none"> <li>• Age</li> <li>• Diagnosis</li> <li>• Time since diagnosis</li> <li>• Relationship</li> <li>• Time in current home</li> <li>• Symptoms</li> </ul>	<ul style="list-style-type: none"> <li>• Types of advice</li> <li>• Who is involved</li> <li>• What has been helpful?</li> </ul>	<ul style="list-style-type: none"> <li>• Positives</li> <li>• Negatives</li> <li>• Future</li> <li>• History</li> <li>• Access</li> <li>• Importance of home</li> <li>• Community</li> </ul>	<ul style="list-style-type: none"> <li>• Added anything</li> <li>• Removed anything</li> <li>• Changed anything</li> <li>• Different rooms (list)</li> <li>• Outside space</li> </ul>	<ul style="list-style-type: none"> <li>• Advice for others</li> <li>• Where do you go for advice?</li> </ul>

In order to address issues that may have been raised by the interview process, following the interview all participants were given an information sheet outlining how to access home adaptation advice from online sources and how to arrange for a professional assessment. Each participant was given the opportunity to review the transcript of their interview to confirm its accuracy.

### *Consent*

Written consent was obtained from all participants prior to commencement of the interview and if during the research process a participant lost capacity to consent, they were immediately withdrawn from the study.

### *Data Analysis*

Interviews were transcribed verbatim from the audio recordings. All records were anonymised at the point of transcription. The data were then coded and analysed using Interpretive Phenomenological Analysis; (Smith, Jonathan & Osborn, 2007). This involved repeated reading of the interview transcripts and the abstraction of responses into recurrent themes which were then interpreted, through successive analysis, into meaning.

Two interview transcripts were then examined by a second researcher to review the coding themes. The second researcher also assessed the coding themes for internal homogeneity and external heterogeneity.

## **Results**

### *Study Participants*

Ten pairs of participants were recruited (Table 1). Two participants with dementia were unable to give informed consent on the day of the meeting, so an interview was conducted

with the carer in both instances which enabled the inclusion of experiences of living at home and caring for someone at a more severe stage of the disease. All remaining dyads of participants opted to be interviewed together and all declined the opportunity to review the interview transcript. The interviews lasted between 20-90 minutes in length.

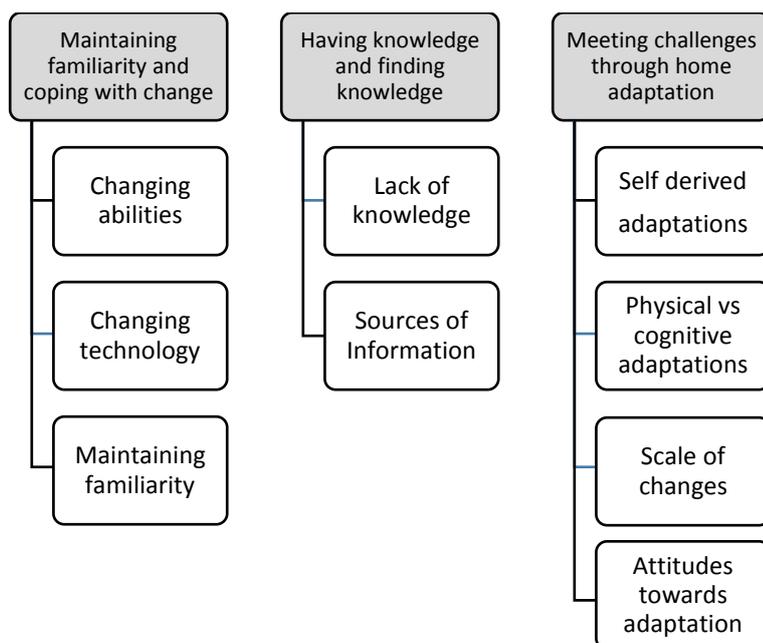
*Table 1 Demographic details of participants with dementia*

Interview	Person with dementia (D) or Carer (C)	Identifier	Age	Gender	Dementia type and time since diagnosis	Relationship
1	D	Unable to interview	77	F	Alzheimer's 4 years	Co-habiting couple
	C	D	63	M		
2	D	E	81	M	Alzheimer's & Vascular 18 months	Married Couple
	C	L	72	F		
3	D	J	75	M	Unknown type 3 years	Married Couple
	C	M	66	F		
4	D	P	75	M	Alzheimer's 3 years	Married Couple
	C	R	71	F		
5	D	F	55	M	Frontotemporal 4 years	Married Couple
	C	W	52	F		
6	D	N	72	F	Alzheimer's 2 months	Married Couple
	C	K	71	M		
7	D	C	76	M	Vascular 14 months	Married Couple
	C	G	68	F		
8	D	Unable to interview	82	M	Vascular & Lewy body 18 months	Father & Son
	C	A	36	M		
9	D	S	55	M	Alzheimer's 9 months	Married Couple
	C	B	50	F		
10	D	T	84	F	Mixed 12 months	Married Couple
	C	H	82	M		

Participants with dementia had a mean age of 73.2 ( $\sigma=10.3$ ) and represented a range of different dementia diagnoses including Alzheimer's disease, Vascular, frontotemporal and dementia with Lewy bodies. Carers had a mean age of 61.3 ( $\sigma=13.4$ ). Participants lived in a variety of housing types, locations and for varying lengths of occupancy see Appendix 1 (supplementary data).

The analysis of data identified three central themes: *Maintaining familiarity and coping with change*, *Having knowledge and finding knowledge* and *Meeting challenges through home adaptation*. Nine sub-themes were then drawn from the central themes as shown in Figure 2.

*Figure 2 Themes drawn from the data*



### *Maintaining familiarity, coping with change*

Participants expressed a variety of ways in which both Persons with dementia and carers respond to changes, some brought about by the changing nature of dementia and others through the changing nature of the world around them.

*Changing abilities.* Due to the progressive nature of dementia, the severity of symptoms experienced by participants is frequently changing and requires Persons with dementia and carers to make adaptations to solve new problems.

*“Up until this week...if I went into the bathroom to have a wash and a shave, I would come down on her own but since this... progression in her unsteadiness she’s not been allowed to come downstairs on her own. I keep the bedroom door locked” (Carer D)*

These adaptations made by participants were predominantly behavioural in nature, involving new ways to use the home or changes to a routine to work around new problems.

*Changing technology:* The majority of dyads had purchased or started to use new technology since the diagnosis of dementia had been given. For some, this adaptation had proved difficult to adapt to.

*“...cos obviously you have to have new phones you know when they go wrong and so we tried that and we've kind of given up on that haven't we, I just have to get used to the stress of knowing that I can't contact him or where he is.” (Carer B)*

Issues such as planned obsolescence mean that home technology and appliances frequently need replacing with new and potentially more complex items. New technology often led to using prompts or reminders in order to use effectively.

*“I did in the car like (use labels) because it's an electric (parking) brake and it's like underneath there's a little catch like that you pull on, push off and I couldn't get used to that. There are 'Pull on', 'Push off' little notes all over it”. (Participant with dementia J)*

In this example, a new technology was introduced that required adaptation of a long established skill (driving) and therefore had the potential to reduce the independence of the individual concerned which then led to an adaptation being made. Those at an earlier stage of dementia found that they were able to use new technology if given time to adapt: *"We had some new phones and he worked out how to use them quicker than me. ...He did it all by himself, I didn't tell him."* (Carer R). Therefore, these participants are able to adapt to some changes or make compromises to allow for difficulties in adapting to new technology.

*Maintaining Familiarity.* Participants stated that keeping familiarity in the home was important to them: *"...generally speaking he knows where the cereal bowls are kept, what bedroom we're in, in fact I feel I would confuse E by changing anything"* (Carer L). In contrast, three couples had completely redecorated their homes since the diagnosis of dementia. Changing décor was completed for aesthetic reasons and not with any consideration of how these changes could impact on dementia symptoms.

### *Having Knowledge and finding knowledge*

The overarching theme expressed by the participants was frustration at a perceived lack of general information about dementia and advice about how to live following diagnosis.

*Lack of knowledge.* Out of the eighteen participants, only one (Carer G) had received information about how adapting the physical environment could alter symptoms of dementia. However, although the topic had been covered in the carers support group that she attended, she was unable to recall specific detail. Over half the participants voiced frustration in trying to access appropriate and timely information about living with dementia.

*"When I got home after that (diagnosis)... I looked it up and I remember a day or two afterwards phoning my son and saying, I've got to tell the DVLA I think. Nobody had told me, it was on the internet... I did tell them at the memory clinic I said I think its appalling that you just send people out, surely it's not beyond your wit to devise some kind of little information book."* (Carer R)

This participant emphasises the need for appropriate signposting of services and information and that people at different stages of dementia have differing needs. This view was also reflected by participants who felt that there lacked a clear source of information that meets their needs;

*"...we went to some of the Alzheimer's dementia cafes and you pick things up from there and you gradually thread your way through to find different things. But what everyone says, there needs to be, when you first start, a leaflet or a book something that says this is where you can go, this is what you can access, this is what you can do. So you don't have to do it yourself"* (Carer G)

Participants were also concerned that when support and advice was offered it did not meet their needs specifically, this was highlighted by both of the couples affected by early onset dementia.

*"...things that are more appropriate to us you know like, benefits, you know cos I've had to stop work to care for S. ... I've only got 30 years of National Insurance Contributions so that's going to affect my pension so things like that... where they just*

*tell you everywhere else 'just to go to Citizens Advice' you know, it's not ideal." (Carer B)*

This shows difficulties experienced when generic rather than individualised information is provided. Carer B then went on to explain their preference for face to face support and information which can be adjusted to answer specific questions.

Interestingly whilst participants expressed frustration at a lack of information about issues that affect them in the now, seven participants expressed a reluctance to access information about the future of living with dementia *"I don't want to know about anything in the future. Cos then you would go mad"* (Carer B).

*Sources of Information.* Participants used a wide variety of sources to collect dementia specific information including; support groups, support workers, healthcare professionals, the internet and mass media. Face to face meetings with dementia support workers were largely praised and a source of good information. There were mixed experiences of support groups with participants from interviews seven and ten valuing the peer support and information as vital. However, the majority of participants had negative feelings towards attending support groups *"They were all doing the conga through the room. I could see his face and it sort of put him off completely"* (Carer W)

In this case the group activities clashed with the expectations of the participant. For others attending a support group would mean mixing with those at a more advanced stage of the disease which they felt they were not yet ready to face. This again represents a reluctance of participants to consider what their future may hold.

In the present study, none of the participants had looked for home adaptation information because they did not recognise that it is something that could affect cognitive or behavioural symptoms. Therefore, in order to be able to actively seek information, there needs to be either an understanding that there is information available on a subject, or the topic needs to be appropriately and clearly signposted from a main hub of information.

Mass media such as newspapers and television were also reported by four participants as a source of information about both managing symptoms of dementia and activities which act as a way of slowing the cognitive decline. They had then sought clarity regarding this from healthcare professionals. This shows that passive information has a role in highlighting areas that can then be actively sought at a later time.

*"I read things in the papers like they reckon cocoa helps so I think ok, have a bit of cocoa on your cereal in the morning and when you tell them at the memory clinic they laugh at you as if... he thinks I'm trying to do his job"* (Carer R)

Although seven of the carers reported using the internet to look for information about dementia, none of the Persons with dementia found information in this way. However, while the internet was used as an information source, it was seen as something which would provide too much information, and a negative outlook. *"I hold back a bit to look on the internet because sometimes a little knowledge is dangerous"* (Carer M). For others the over-reliance on the internet by health and social care workers was not helpful.

*“Cos I said if one more person tells me to go look it up on the internet, I will actually throw my laptop at them. You know, that's how bad it got, that's the only solution we were getting” (Carer B)*

All participants had been in contact with Dementia support workers from either health, social care or charity providers but the overwhelming majority could not recall receiving any information regarding home adaptation. Carer A had completed extensive additive home adaptations and installed a variety living aids to assist with personal care and mobility for his father. As an employee of social services, he was able to contact colleagues to gain advice, but felt that this information would be difficult for others to obtain. He goes on to explain that, even with a working knowledge of the social care system, it was difficult to obtain information and assessment of the home specific to his father's type of dementia:

*“I'm not sure if Alzheimer's Society or the dementia information support service, or the carers hub that we've got here, are clued up with the affects and the practicalities of dealing with a situation like this because they haven't been through it themselves” (Carer A)*

This points to issues regarding the perceived credibility in addition to the availability of the sources that are offering support.

### *Meeting Challenges through home adaptation*

*Self-derived adaptations.* The majority of the adaptations made were needs-driven and self-initiated, rather than as a result of provided information sources or a healthcare assessment.

*“I want to go to the shed to get a, a chisel or something, and by the time I unlock the door I've forgotten what I was looking for and this sort of thing. So to make life a little bit easier I have...different coloured buckets so I put my spanners in one and the other things in that so I sort of set things out.” (Participant with dementia S)*

This participant shows that they have devised their own behavioural adaptation of overcoming problems linked with memory and enabling him to preserve his role in maintaining the home. In many cases, changes to the environment were made as a result of experiences in the home and through trial and error.

*“we realised we need this extra lighting...he steps out at night there's a light that lights up cos we've got a step and he's had a couple of tumbles there. So we've got a light there that comes on as soon as he steps out or if he walks down the garden to the garage” (Carer W)*

Lighting changes are an example of a transformative adaptation, here used as a physical tool to prevent falls.

*Physical vs Cognitive problems.* The most commonly completed adaptations made by participants were additive adaptations which address physical deficits and prevent falls such as grab-rails, and stair-lifts. For some, it was due to physical problems having a more immediate need (such as pain) or to aid moving around the home in order to be able to complete activities of daily living. *“The Occupational Therapist came (and) the level access shower had just been put in. She basically asked for another couple of grab rails for the shower area....” (Carer A).* The use of equipment to assist with cognitive symptoms was less well received. Carer B voiced concerns about the use of labels to assist with her husband's

memory: *"I feel that's demeaning really (putting up signs). Don't get me wrong...I'd love to put signs all over the kitchen cupboards"* (Carer B). This demonstrates the need felt by carers to maintain home and adding labels is seen as detracting from the individuals place within their home.

*Scale of changes.* For participants in the earlier stages of dementia, the adaptations that had been made were small in scale and highlighted the significance of outwardly trivial issues. *"...this carpet, could do with a good vacuum,... with things left on the floor, those dog toys or a pattern ... that can cause me to get confused and then down I go"* (Participant with dementia C). In this example, participant C describes the importance of keeping the floor clean to avoid the perceptual disturbances caused by objects or patterns on the floor. This is an example of a simple subtractive adaptation (Pynoos et al., 2012) which was described by three participants as a method they use to prevent falls.

Small additive adaptations were also made: *"he doesn't remember which toothbrush is his, cos we've got this thing with the three toothbrushes in so on F's toothbrush he has either a piece of ribbon or a sticker so he can see which one is his."*(Carer W). This example of simple colour labelling means that Participant 'F' can continue to clean his teeth independently.

*Attitudes towards adaptations.* Participants in the current study voiced a positive attitude towards equipment that would meet physical needs and that any equipment would be considered if they saw a need:

*"...you have to be practical if there is problems you overcome them, where you can. There's always a solution, and (if) the solution is put the bed down there and that's where it will go"* (Carer D)

Participants voiced a willingness to make appropriate changes to their home in order for it to continue to meet their needs. *"...if one of us is in a wheelchair we'll have to have a ramp I suppose"* (Carer R). One participant also stated that they would consider adaptations as the need arose: *"... think we have things as we need them, you know you think of something that we might need but we're more than likely to go out and get it ourselves"* (Carer G), but here Carer G indicates that they would want to remain autonomous in their choice of equipment.

## Discussion

The results found that there is an absence of the use of home adaptation in the homes of people with dementia interviewed in this study. Although participants described home adaptations which arise from all four classifications of adaptations as described by Pynoos et al., (2012), changes remain small in scale. In agreement with the previous research, the most common group of adaptations were additive with additions of grab rails, furniture and security measures being made. Transformative changes such as moving furniture, were less well used, it is notable that no participants had changed flooring, wall colour or daytime lighting for example. Carers had not opted to use concepts which could reduce carer burden and improve the independence of those they care for (Pollock & Fuggle, 2013). The main barriers to the use of home adaptation here were: a lack of knowledge about home adaptation, attempts to maintain familiarity at home and perceived lack of credibility of sources of advice.

Supporting previous qualitative research by Steeman et al (2006), the participants described their frustration at their reduced competence to complete previously straightforward tasks around the home and feel a corresponding loss of control and dependency on their loved ones. Home adaptation research has provided evidence that the loss of independence and control can be mitigated by modifying the environment, indeed it has been shown that making home adaptations before they are specifically required can delay admission to long term care and prevent hospital admissions (Eriksen, Greenhalgh-Stanley, & Engelhardt, 2015).

Although participants here found maintaining a familiar environment was key in agreement with Damme & Ray-Degges, (2016); Marquardt et al., (2011), their experiences show that Persons with dementia are constantly adapting to change at home due to the progressive nature of dementia, changing technology and environments. Persons with dementia were able to adapt to new environments and equipment if given enough time to do so. Consequently it can be hypothesised that adopting change at the right time could be the most significant factor when considering adapting the home. This indicates that individuals may benefit from targeted, individualised home adaptation advice nearer diagnosis. This would mean home adaptation concepts could be considered when people make other routine alterations to their home and whilst they maintain the ability to adapt to the changes.

The desire to maintain what is familiar is also a way of preserving normality and maintaining identity for Persons with dementia (von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012). This may explain the participants using of phrases such as 'have to' or 'need to' in the response to questions about feelings towards equipment. Participants largely voiced positive feelings towards home adaptations which is in contrast to the findings from previous research studies (Damme & Ray-Degges, 2016; Kruse et al., 2010; Marquardt et al., 2011). The main reason given in the previous studies for declining equipment or adaptations was that the changes were not needed (Kruse et al., 2010; Marquardt et al., 2011). Terms used here such as 'need to' imply that whilst seen as helpful, equipment will be considered only if they are unable to cope without it, a point which is unseen and in the future. Further investigation is needed to ascertain how making modifications to the home nearer to diagnosis impact on the personhood and feelings of normality for the people who live there and whether making earlier adaptation can influence the independence and lived experiences for Persons with dementia and their carers in the long term.

This leads to a further explanation as to why home adaptation has not been considered by the participants here, which is the propensity not to think about the future. Proactively making changes to the home requires coming to terms with their future needs, and therefore has not been discovered as a way of meeting their current needs. The majority of the current participants were in the mild to moderate levels of dementia which means they may still be coming to terms with the dementia diagnosis and therefore are not yet be ready to recognise and utilise the help and information that is available as posited by Boots et al (2015). What remains unclear is whether improved information regarding how the home environment can enhance independence could bring it into the repository of knowledge that Persons with dementia and their carers use to cope with the present.

There is potential for much dementia care information to be received passively if it is not provided at a time where the information responds to an individual need. In this way individuals might not be able to utilise it effectively (Boots et al., 2015). The only participant who had heard of home adaptation in dementia may not have been able to recall the details

of the advice, as she had received the information passively from a support group speaker. This supports evidence which suggests that information should be personalised (Harland & Bath, 2008; Johnson & Case, Donald, 2012; Washington, Meadows, Elliott, & Koopman, 2011) which indicates that responses to information are affected by the context and prior experiences of the individual

The findings presented here shows that it is the lack of knowledge of how the physical environment can specifically support Persons with dementia that represents the most significant barrier to making home adaptations. This demonstrates that home adaptation advice offered by the currently available sources is not being effectively received by Persons with dementia and their carers. Additionally, a lack of perceived credibility may account for why individuals do not use dementia advice (Sweet, Perrier, Podzyhun, & Latimer-Cheung, 2013). This causes a breakdown in the information pathway between home adaptation advice being made available and its translation into modifications in the homes of Persons with dementia.

In order to be able to actively seek information there needs to be either an understanding that there is information available on a subject, or the topic needs to be appropriately and clearly signposted from a main hub of information. For example in the present study, none of the participants had looked for home adaptation information because they did not recognise that it was something that could have an effect on cognitive or behavioural symptoms.

In agreement with previous research, the adaptations which were most likely to be used were those to address physical limitations rather than those shown to improve cognitive or behavioural symptoms (Damme & Ray-Degges, 2016; Gabriel et al., 2015; Marquardt et al., 2011). For example, lighting was changed to prevent mechanical falls rather than increased to improve sleep and behaviour patterns (Torrington & Tregenza, 2007).

Interestingly, information seeking behaviour studies have concluded that carers of Persons with dementia request information regarding the management of behavioural symptoms rather than mobility problems (Koenig, Steiner, & Pierce, 2011). Hence there appears to be a disparity between the desire to learn ways of managing behavioural problems and the use of home adaptation, which has been shown to reduce some behavioural symptoms in dementia. Alternatively this could indicate that dementia support workers for these participants are not offering information regarding how home adaptation can affect dementia symptoms. This may be due to the large amount of information required to present in relatively small time periods or that there is a lack of awareness regarding home adaptation within dementia support workers.

Any home adaptations that were used by participants were self-derived, therefore it is possible that adaptations for physical impairments are more logical to adopt without prior knowledge and consequently are a more easily determined solution. It is also conceivable that adaptations that address common physical problems present less stigma than those which aid cognitive impairments, therefore these are more readily accepted (Brodaty et al., 2005).

### **Limitations to the present study**

Whilst stringent efforts were made to remove bias and inconsistency from the research methodology it must be acknowledged that there were certain limitations. Including Persons

with dementia in the participant dyads meant that only those with mild to moderate symptoms could be recruited. As dementia is progressive in nature it is likely that strategies such as home adaptation may become more prevalent during more advanced stages of the disease.

Due to time and budget constraints, sampling was limited to people from the West Midlands region (United Kingdom) and whilst participants resided in several different NHS trust localities, it is unlikely that their healthcare experiences can be generalised to the wider population.

Participant dyads were given the option to be interviewed together or separately, and all chose to be interviewed together. This may have led to participants withholding experiences or views that the other participant may find distressing and therefore not providing a comprehensive review of their personal experiences.

## **Conclusions**

The presented experiences of participants living with dementia identify that people are making small changes to their living space following diagnosis, predominantly to address physical limitations. The adaptations utilised by participants were largely self-derived and not influenced by home adaptation advice or literature. Where difficulties exist that could be mitigated through the use of home adaptation, individuals do not consider them as a possibility due to a lack of awareness or through a desire to maintain the status quo within the home.

Barriers to home adaptation exist due to a breakdown in the pathway between evidence produced by research, advice dissemination by charities and health care groups, and then being transformed into physical changes in the home. The reported experiences indicate that this breakdown may be part of a more substantial problem: a lack of appropriate, individualised and credible information and support available to Persons with dementia and their carers following a diagnosis of dementia.

Evidence shows that home adaptation can assist in keeping Persons with dementia living at home for longer, and lessen the burden felt by their carers. However there is a need to explore how home adaptation can be better promoted to make it more easily accessible and readily utilised by this population. Furthermore, are there ways to introduce home adaptations to address behavioural and cognitive symptoms which can make them more useable to Persons with dementia and their carers.

## **Ethical Approval**

The study was approved by the UK NHS NRES Committee, Yorkshire & The Humber - Leeds West. Number 15/YH/0352.

## **Declaration of Conflicting Interests**

None declared

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## Appendix 1

*Table 2 Housing details per interview*

Interview	Housing type	Occupancy length	Location
1	Semi detached	24 years	City, Suburban
2	Detached House	32 years	Village, Semi-rural
3	Detached House	28 years	Village, Rural
4	Detached House	36 years	Village, Cul de sac
5	Terraced House	17 months	City, Urban
6	Detached House	44 years	Town, Semi-rural
7	Detached House	36 years	Town, Suburban
8	Terraced House	18 years	City, Urban
9	Bungalow	2 years	Village, Rural
10	Flat	3 years	Town, Suburban