

## Abstract

**Aims and objectives:** The aim of the study was to identify pre-clinical signs of dementia by exploring the experiences of family care-givers and professional care assistants.

**Background:** Dementia results in disability, emotional strain and financial loss for people with dementia, family members and nations. Informal identification of social and behavioural risk signifiers could facilitate timely interventions with potential to delay onset of serious disability.

**Design:** A retrospective qualitative approach using a naturalistic interpretive design was used. Focus groups enabled in-depth understanding of the participants' experiences of life or work with people who subsequently developed dementia.

**Methods:** Purposive sampling was used to recruit family carers and professional carers who had cared for people who later developed dementia. The data from focus groups were fully transcribed, and anonymised; and transcripts analysed by two researchers. These researchers coded and analysed the transcripts independently; subsequently overlapping and similar themes were identified and consensus reached on final themes. A third researcher was invited to review the analysis and ensure trustworthiness of the study findings.

**Results:** Findings revealed that pre-clinical signs of dementia were identifiable in retrospect. Participants' accounts resulted in four themes, 'Lowered Threshold of Frustration' (LTF), 'Insight and Coping Strategies', 'Early signs of poor memory' and 'Alarming Events'.

**Conclusions:** Earlier recognition of pre-clinical signs of dementia would allow affected individuals to follow health promotion advice and plan for the future. Identification of social exclusion prior to diagnosis has implications for anti-stigma campaigns and development of 'dementia-friendly communities'.

**Relevance to clinical practice:** Health care professionals could work with those at risk, facilitating lifestyle changes to postpone symptoms and advance planning for improved autonomy. Pre-dementia should be viewed as a disability for which reasonable adjustments can be made at a community level, to enhance and extend emotional well-being and social inclusion.

**Key words:** Dementia, pre-clinical, risk, health promotion, social inclusion

## INTRODUCTION

Dementia is an umbrella term that refers to a group of conditions in which memory and other functions gradually become impaired due to changes affecting the brain (Jenkins, Ginesi, & Keenan, 2016). Dementia is not caused by old age but is an age-related condition (Prince, 2015). As the global population is ageing, higher numbers are predicted: by 2050, 135 million people may be affected (Robinson, Tang, & Taylor, 2015). Seven percent of people aged over 65 have dementia (Alzheimer's Society, 2014). Dementia results in high levels of disability, emotional strain and financial loss for people with dementia and their family members (Jenkins et al., 2016). In addition, dementia is costly for local and national services. Internationally dementia is estimated to cost \$604 billion per year (Prince, 2015).

While screening for dementia has been discouraged due to the perception that unnecessary anxiety results from 'an outcome that is both uncertain and unalterable' (Harvard Women's Health Watch, 2014), there is an alternative perspective which suggests population-based insights into risk reduction factors could be applied by individuals who have early awareness of risk. For example, by facilitating timely life style changes (Opie, Ralston, & Walker, 2013) and forward planning (Trueland, 2013). If dementia could be delayed by an average of five years, individuals would have a better quality of life for a longer time period (Sabia et al., 2012), the number of people living with the condition would be halved (Prince, Albanese, Guerchet, & Prina, 2014) and £21 billion globally per annum be saved (Alzheimer's Research UK, 2014).

Imaging techniques show Amyloid B deposits in the brains of those who later develop dementia decades before symptoms develop (Masdeu & Pascual, 2016). In this pre-clinical or 'prodromal' period, very early symptoms of dementia are subtle and may be mistaken for normal signs of ageing (Boyd, 2013). However, earlier recognition of the significance of pre-clinical social and behavioural signs would be beneficial. Alternative, informal means of identifying social and behavioural signifiers of risk could enable a window of opportunity for implementation of health promoting and treatment interventions with the potential to delay onset of serious disability.

The aim of this study was to use focus groups to identify pre-clinical signs of dementia. We explored the experiences of family and professional care-givers who had lived and worked with people who later went on to develop the condition.

## **BACKGROUND**

The exact causes of most types of dementia are not completely understood, but it is thought that in the most common form of dementia, Alzheimer's disease, a 'toxic cascade' of damage to brain cells is triggered by genetic, lifestyle and environmental factors (Prince et al., 2014). While types of dementia have specific histopathological findings (plaques, tangles, Lewy bodies), the pathology of dementias is often mixed, so that people with Alzheimer's, Vascular dementia, Lewy Body disease and other types often have overlapping patterns of neuronal atrophy, and as time goes on, similar histories of memory and functional decline (Jenkins et al., 2016). The subtlety of early symptoms of dementia, General Practitioners' ambivalence about early diagnosis, therapeutic nihilism and the stigma still associated with dementia combine to result in late diagnosis, despite evidence of benefit and government guidelines (National Institute for Health and Care Excellence, 2006). Treatments currently licensed for dementia does not 'cure' dementia, but for some people they slow the progress of the condition while improving mood and functioning (Buckley & Salpeter, 2015). Research studies investigating efficacy of new treatments and re-purposed existing medications are ongoing (Jenkins et al., 2016), despite recent setbacks including Pfizer's withdrawal from neuroscience research (De Strooper, 2018).

The sooner treatment is begun, the better the outcome (partly due to a better starting point), so medication should be given much earlier in the disease process to have any real impact (Alzheimer's Association, 2017). Even though identification of a pre-clinical condition may have negative consequences, such as low mood due to anticipated loss of autonomy, social status and aspects of self (Mitchell, McCollum, & Monaghan, 2013), people with dementia prefer an explanation for the difficulties they encounter (van den Dungen et al., 2014). Other benefits of early diagnosis include empowerment of the individual to make choices about the future, follow health promotion advice,

get their affairs in order and be open with family and friends to maximise understanding and support (Mitchell et al., 2013). Implementation of these strategies would result in significant financial savings from delayed admissions to care homes (Banerjee & Wittenberg, 2009). In addition, government plans (in Europe and globally) that emphasise the importance of early diagnosis and initiatives to combat stigma may result in greater social inclusion of people living with dementia, enhancing their ability to 'live well' (Department of Health, 2015; Pot & Petrea, 2013). This is essential because of the potential negative impact of social isolation and exclusion. Kitwood's (1997) work highlights a socially constructed process in which age and frailty combine to attract 'Malignant Social Psychology' or stigmatising interactions that both contribute towards and highlight cognitive impairment. He suggests that this undermines older people, leading to low mood and internalised stigmatisation that combines with societal processes to further marginalise those who may be cognitively impaired. (Beard & Neary, 2013) critique the trend for early diagnosis in the face of limited treatment and support, echoing Kitwood's concerns around medicalisation of ageing and stigmatising diagnoses.

Differentiation between 'normal ageing', depression and 'mild cognitive impairment' can be challenging (Kaschel, Logie, Kazén, & Della Sala, 2009) and there is a risk of both under and over-diagnosis of dementia (Skinner, Scott, & Martin, 2016). However, medical treatment is not the only potential positive outcome of identification of risk, as the long 'prodromal' period allows those potentially at higher risk to adjust their behaviour in order to both reduce risk and postpone cognitive decline (Lafortune et al., 2016).

Strategies to identify biomarkers for dementia already exist but involve intrusive tests, for example of plasma, cerebrospinal fluids or using scans (Positron Emission Tomography or Magnetic Resonance Imaging), and tend to be expensive and not reliably indicative (Ritchie, Flicker, Smailagic, Noel-Storr, & McShane, 2012; Smailagic et al., 2015). 'Everyday life' potential indicators of dementia overlap with those of other conditions including depression, delirium, infection, constipation and diabetes (Jenkins et al., 2016), so prompt assessment of actual symptoms is required to ensure any treatable conditions are identified and appropriately managed. In advance of identifiable and treatable symptoms, small signs may flag up and allow individuals and health professionals to intervene at an earlier stage of 'pre-dementia'.

The 'Everyday life' pre-clinical signs have been identified anecdotally, and have been explored in more depth using a range of quantitative research methodologies. Signs include subjective complaints of memory problems, reduced 'cognitively-complex activities of daily living' (Peres et al., 2011), history of low mood (Stella et al., 2014) and feelings of loneliness (Donovan et al., 2017), all of which are associated with subsequent cognitive decline. Personality changes (Delrieu et al., 2015), perseveration (Stella et al., 2014), intellectual, humour and language changes have also been identified (Benke, 2011; Clark et al., 2016; Lust et al., 2015; Mura et al., 2014). Evidence also highlights physical changes, for example with sleep pattern, gait and appetite (Benke, 2011; Stella et al., 2014; Verghese, Wang, Lipton, & Holtzer, 2013)

Qualitative studies exploring the experiences of people at high risk of developing dementia have not yet been carried out, as this group of people is difficult to identify. Similarly, there are few qualitative studies exploring the experiences of people with mild cognitive impairment, a state argued to be on a continuum between the prodromal pre-dementia stage and diagnosable dementia. Beard and Neary (2013) triangulated qualitative approaches (focus groups and interviews) to explore

the experiences of 18 people diagnosed with MCI, which is associated with higher risk of later dementia. Their respondents recognised they had memory problems, which they generally normalised by ascribing them to the ageing process. These accounts confirmed awareness of the stigma surrounding dementia itself and the authors' analysis highlighted how stigma associated with Alzheimer's type dementia was perceived as similarly damaging for people who are potentially living through very early stages. Beard and Neary (2013) recognise the importance of 'living with dementia' as opposed to accepting an inevitable decline as usually emphasised in biomedical research. While identification of prodromal stages of living with memory problems may attract stigma, this timeframe also offers a window of opportunity for living well and making positive adjustments.

## **METHODS**

### **Study Aim**

It is possible that further prodromal indicators could be identified. Research into the experiences of people in early stages of dementia and others is needed to develop further insights (Alzheimer's Research UK, 2015). This study explored the experiences and perceptions of family and professional carers who have known people who subsequently went on to develop dementia. Thus, the study aimed to explore the views, experiences and perceptions of family care-givers and professional care assistants to identify pre-clinical signs of dementia.

### **Design**

The study was guided by a retrospective qualitative approach, to encourage participants to recall and share experiences of individuals' they care for before they were diagnosed with dementia (Holloway & Galvin, 2016). A focus group study was conducted in the Midlands (West and East), England. Focus group interviews promote active discussions among the participants, and the group interaction aids spontaneous disclosure that allowed the researchers to explore participants' experiences, beliefs and opinions (Then, Rankin, & Ali, 2014). This approach facilitated an in-depth understanding of the participants' experiences of life or work with people who subsequently went on to develop dementia.

### **Group composition**

Family care-givers have a different relationship with the people for whom they were caring as compared to the professional care-givers; therefore, it was assumed they might have different experiences and perceptions. Two separate sets of focus groups were conducted allowing participants to be more comfortable among people with similar circumstances (Jayasekara, 2012), which not only encourages sharing perceptions and experiences but also more interaction.

### **Participants**

Purposive sampling was used to recruit family carers of people with dementia and professional carers who had cared for people who developed dementia. This was to ensure that both groups could recall a time before individuals' dementia became obvious and shared. Information about the study was circulated to a charitable organisation that supports people with dementia and their families, and to a home care agency. Interested carers, who had experience caring for people before

they were diagnosed with Dementia, were invited to attend the focus groups. The carers reflected a diverse society in relation to ethnicity, sexuality, age and gender.

### Data Collection

Focus groups were conducted between March and May 2016. Four focus groups were conducted, in total ten family carers and ten professional carers took part in the study. Focus groups for family carers were conducted at a carers' group in a day hospital and in a library local to the carers' homes. The focus groups for professional care assistants were conducted in a study room at their workplace. A moderator and two observers conducted the focus groups. Each focus group lasted approximately an hour and consisted of open-ended questions, based on a guide (Table 1), to ensure consistent questioning between all four focus groups. Questions were asked in any order, to enhance the flow and respond to the thread of conversation. The interviewer followed the discussions closely, without influencing the discussion, and the observers were silently taking notes. While the semi-structured interview guide was not piloted tested, the questions focused on carers' experiences of the time before the person they care for developed dementia. Additionally, the guide was reviewed by three researchers to ensure the questions would encourage participation among the participants. The focus groups interactions and discussions were audio-recorded, transcribed verbatim and anonymised.

Table 1: Focus group guide informed by literature, experience and personal insights

The central question explored the experiences or behaviour that might be forerunners of dementia which develops many years later.
How long has the person you care for had dementia?
Is there anything in their health history that might have contributed? (prompt: e.g. high BP, diabetes, concussion)
Did you / the person you care for have any concerns about memory? Did you/they worry?
What were the first indications of any problems?
Were there any unusual events that, looking back, might be part of a pattern? (prompt: out of character behaviour, indication of altered judgement, 'funny ways')
Did you notice any physical changes (weight change, speed of walking, eating and drinking habits)
Any changes in attitude or behaviour?
How were you/they feeling before the diagnosis and the years before that?
Is there anything else that you would like to tell us about that might be relevant to understanding peoples' experiences before they develop dementia?

## **Data analysis**

The analysis adopted a naturalistic interpretive design and followed the guidelines proposed in Braun and Clarke's (2006) thematic framework. Thus, the focus groups recording were transcribed verbatim by a team of people who were not part of the study, to ensure the transcription was not influenced by ideas from the research. Next, all the notes and anonymised transcripts were analysed independently by two researchers, with the intention of reducing opportunities for bias. This involved reading the data several times and noting initial ideas, leading to the generation of initial codes using an open coding procedure. This allowed each researcher to derive a thematic map, which was later followed up by several discussions between the two researchers, whereby overlapping and similar themes were identified, and consensus on final themes was achieved. The data analysis was done manually to encourage a deeper understanding of the data. It was agreed that four focus groups (two from each group) were sufficient, as similar points arose from the latter groups and no new information or further themes were forthcoming (Fusch & Ness, 2015).

## **Trustworthiness**

One of the primary concern in a qualitative study design is rigour and trustworthiness of the findings; according to Guba and Lincoln (1994), this can be improved by ensuring dependability, credibility and transferability of the findings. Hence, several measures were incorporated in the analysis to ensure this. A third researcher, who was not part of the study team nor data collection stage was invited to review all the interpretation and derived themes ensuring that final themes were derived from the data and reflected the study aim. In cases of discrepancies, modifications were made through discussion between all three researchers to ensure credibility and understandability, along with corroborating that the themes reflected the study aim. Data was analysed seven months after collection, due to concerns about recall bias and 'churn' in both participant groups respondent validation was not conducted.

## **Ethical Considerations**

Ethical approval was obtained from Birmingham City University Research Ethics Committee. Participants read an information sheet and gave informed consent and confidentiality issues were discussed at the beginning of each focus group. During this project, research materials have included consent forms, interview recordings, interview notes and transcripts of interviews with research participants. This data was anonymised, and then stored only on a secure University Network drive.

The family carers also described their current stressors during the focus groups. They were supported and if necessary signposted to further advice. They also shared ongoing anxieties about the reasons for their relatives' dementia and concerns about the 'starting point'. These issues were not the primary focus of this project but could indicate the need for further research.

## **FINDINGS**

Two focus groups of family carers, with six participants in one and four in the other, then two focus groups with professional carers (five in each group) were conducted. The group dynamics of all groups were positive, with almost all participants contributing. Thematic analysis, using the six stages outlined by Braun and Clarke (2006), resulted in four themes: ' ,Lowered Threshold of

Frustration (LTF) 'Insight and Coping Strategies', 'Early signs of poor memory' and 'Alarming Events'. Family carers were better placed to comment on the timeframe of interest, due to their longstanding, close relationships with the people who went on to develop dementia. Hence, there are more quotes from family carers than from the professional carers.

### **Lowered Threshold of Frustration (LTF)**

This theme arose in all four focus groups. Participants could relate stories in which the people they now care for had become uncharacteristically intolerant, more inclined to show their frustration and less able to manage difficult emotions. Professional carers identified frustration as a common difficulty:

*'Frustrated, more frustrated.'*

*'Yes'*

*'I've noticed more frustration with the gentleman, very frustrated because he was like he didn't... he felt that nobody was understanding him'*

(Professional carers)

Family carers did not specifically use the term 'frustration', but gave examples where this seemed relevant:

*'I think Mum got a bit more bolshie actually... although before that she was not a quiet person, she'd always said what she thought but she did seem to get a bit more outspoken and didn't care who she was saying it to. I think she possibly upset one or two of her friends by being a bit too outspoken'*

(Family carer)

In this second example, the wife was empathetic despite not understanding her husband's response:

*'He swore at me in Iceland (shop) and it wasn't him. And I said, 'Okay, I'll leave the shopping. I'm sorry about it, I'll leave the shopping.' And I took him out... and I thought, 'this isn't him' but when he realised what he'd done, he said 'I'm sorry about that'*

(Family carer)

When looking back to the years prior to the person's diagnosis well before the symptoms became obvious, family carers could recognise times when they had adjusted their own behaviour to try to make life go more smoothly. They did not seem to be aware of this pattern or the reasons for it at the time, but on looking back could identify these adjustments, described by one participant as 'thinking for two'. Professional carers were more able to use their experience to identify and name frustration, then anticipate and manage potential problems. Family carers initially were not aware of the significance of the pattern that was emerging, but noted that other people outside the family had changed in their attitude towards the person, being aware that they needed to keep an eye out for them, but sometimes avoiding them or allowing friendships to wane. In this theme participants spoke not only about people they cared for, but others they knew who they felt may have early signs or who they later knew to have dementia.

*'You just have to be very aware of what you say as well, it's just a continual battle inside you to make sure you say the right words, you say it in the right context, and it can get very, very, stressful'*

(Family carer)

It seems that experiences of being with those who went on to develop dementia were already stressful at times for friends and relatives, perhaps leading to avoidance. The family carers could identify that the social network was shrinking well before the dementia was diagnosed.

*'Basically everyone that she used to know... they used to be round every weekend, it wasn't just us as a family, it would be near enough everyone, so all of a sudden she's got no-one going in, and there's no friends who are able to come across as often .... this is before she even got diagnosed with dementia as well, so it's still kind of the loneliness that gets to you then'*

(Family carer)

These quotes illustrate the dynamics of changing relationships, in which anxieties, communication problems and subtly alienating behaviours combine in a process where family members recognise problems, but are not able to name them. Other people may begin to distance themselves, leaving the person who may be developing dementia and their close family members isolated when they are beginning to need support.

### **Insight and Coping Strategies**

Awareness of poor memory was confirmed by our participants who reported how changes to behaviour emerged due to awareness of memory issues:

*'I think he's going to get, he's got a bit of dementia coming. And he's always wanting to do something, he's always wanting his brain to, 'I want to do something, I need to keep my brain going' ... This is what he's always like, 'I need to keep my brain working'*

(Professional carer)

*'she works at a bank but she's taking redundancy because she won't admit... at the moment she writes everything down'*

(Family carer)

A family carer described how his wife used her insight to respond for the well-being of others:

*'she was a lay reader at church for over 30 years and she would still prepare sermons and deliver them. About four years ago, she decided that she'd done enough and because she was afraid she'd dry up part way through, and she used to take funerals but she was also afraid there that she would dry up partway through you see'*

(Family carer)

Similarly, a carer's husband perhaps began to lack confidence:



*'he used to love going to the meetings at Wolverhampton and he used to make an excuse to say, "oh it's busy going out" or "I don't want to drive the car in the dark" and I never thought about that'*

(Family carer)

These examples show that people with some insight into incipient dementia can make adjustments to their activities, aiming for the best outcomes for themselves and other people. In recognising their own potential memory problems, the people who went on to develop dementia, employed strategies to maintain their mental functioning and adjusted to protect themselves from marginalisation. They could reduce their responsibilities and seemed to be withdrawing from activities that might reveal their difficulties, both to minimise others' inconvenience and to protect their own identity. However, they did not explicitly share concerns about the implications of the deficits, perhaps due to a belief about 'normal ageing', or because the changes were insidious, allowing gradual adjustments, or perhaps due to concerns about potential social exclusion.

### **Early signs of poor memory**

In retrospect, many of the examples and incidents described by the participants were clearly caused by early memory problems. While we asked about pre-dementia changes, it is possible that late diagnosis meant that some of the reported signs actually reflected early, undiagnosed dementia rather than pre-dementia. However, at the time, observers did not 'put two and two together'. Geographical disorientation (getting lost) seemed to be common.

*'he kept getting lost when he was out. And I would say, 'Oh you've been here before' 'Have I? I don't remember this'*

(Family carer)

*'she was driving in her car and driving off the village where we live and she said she had no idea where she was driving to'*

(Family carer)

*'she'd be forgetting things, she'd always forget. "Oh I forgot to do this, I forgot to do that" and we just thought it was old age, it's just the way it is'*

(Family carer)

It is possible that geographical disorientation is more obvious to an observer than other forms of disorientation because of the discrepancy between expectations of confident way-finding and the person's actual behaviour. While memory problems are understood by lay people to be a symptom of dementia, perhaps lay beliefs about forgetfulness and normal ageing are more deeply embedded.

### **Alarming Events**

Later stages of dementia are associated with increased risks due to symptoms such as poor memory, difficulties with reasoning, lack of awareness of dangers and problems with sequencing. Repetitive questioning and absent-mindedness are stereotypically considered by lay people to be caused by

age-related changes or 'senior moments'. However, our participants mentioned examples of difficulties with managing risk and memory related crises well before they realised that the cause might be dementia.

*'I mean there was one incident where mum set fire to the kitchen, which at the time we put down to a one-off, she'd left the chip pan on and she sat down to eat her tea; she was in a little bungalow, and suddenly noticed fire out of the corner of her eye and went in, picked the bowl of water up, threw it at the chip pan and it went ... I mean she looked like she'd been down the mine when I got there. And then proceeds to mop the floor before she pulls the red cord to call the Fire Brigade in case the fireman came and slipped on the floor, and Social Services did come out to her and ask her things and we all sort of put it down to, well, okay it's something anybody can do, but now when you think about it, possibly that could have been part of it. We're never going to know are we?'*

(Family carer)

In this example, the mother's behaviour revealed possible cognitive changes which together may have contributed to this risky situation. She not only forgot the pan, but also forgot how to manage a 'grease fire'. Her judgement (or possibly sequencing ability) was impaired, in that she prioritised responding to the wet floor over extinguishing the fire. The description highlights her considerate nature and it is clear that she could perceive and address risk to other people.

Through their close relationships with people who went on to develop dementia, participants could highlight subtle signs that stood out in the context of the norms of their relationships.

Family member participants' accounts indicated that they learnt to regulate their own behaviour to level out the 'emotional temperature' for their own sakes as well as that of the affected person. At first, they were unaware of their own adjustments and described examples of unconscious adaptation. Later they adapted consciously and occasionally found others had done the same, for example siblings and contemporaries of the affected person dropped hints about the need to 'keep an eye on' them, indicating that the older generation had noticed problems but were perhaps protecting the person's dignity using coded messages and entreaties.

Family member participants described patience and forbearance, but also their own stress. Although at this early stage not 'a carer' their relationships had shifted subtly so that they were alert to anticipate and pre-empt difficulties, leading to inequality in carrying out the emotional work of the relationships. All the participants reported a sense of isolation, which was compounded by the trend for friends (perhaps alienated by the affected person's expression of LTF or perceived rudeness) to keep a distance.

## **DISCUSSION**

Our first theme and indicator of incipient dementia was 'Lowered Threshold of Frustration'. This indication seems to be a response to the difficulties of managing stress when usual coping strategies become less effective. Often broadly described as 'personality changes' (Boyd 2013), more specific difficulties in responding equably to stress showed how our participants' relations and clients were less able to manage frustration many years before diagnosis, possibly due to early dementia-related brain changes.

Extreme responses to difficulties in later dementia have in the past been labelled as 'catastrophic reactions' (Vroomen, Bosmans, van Hout, & de Rooij, 2013) and it is likely that LTF is a less severe form of this problem. Nowadays, these reactions are reframed as distress in the context of disabling environments or relationships (Brooker & Latham, 2015). In the context of pre-dementia LTC, both the disability and disabling context are unseen. This means that it is very difficult for others to explain the person's behaviour and to adjust to it.

Kitwood's (1997) 'malignant social psychology' theory suggests process in which the social value of an individual is diminished and they become progressively more excluded and denigrated when dementia is identified. Our findings indicate that this process begins before diagnosis, perhaps due to current emphasis on the 'medical surveillance' of older people in relation to memory (Beard & Neary, 2013). Donovan et al. (2017) found that people with high amyloid levels reported feelings of loneliness before any clinical signs of dementia became apparent, which appears to confirm this hypothesis. Brannelly (2011) explored the phenomenon of 'social death', suggesting that identification of dementia is associated with a dehumanising dynamic involving distancing and exclusion within family groups with marginalisation and discrimination being the norm in wider society. There is an ethical risk to early identification, as labelling a potentially vulnerable person could further highlight difference and an unwanted identity (Beard & Neary, 2013). The professional carer participants noted a change to the apparent social status of the people with early signs of memory problems. Family members spoke to and about their loved ones in a different way, highlighting difference and implying distance.

However, the conversational tone was different when the difficulties were perceived as isolated crises. Our participants could describe examples which in retrospect seem dementia-related, but at the time were explained as an aberration or sign of eccentricity. Family members described these events with warmth and humour, often emphasising their relative's positive qualities, contrasting with the less inclusive language used to describe behaviour which was more obviously part of a dementia syndrome. As members of a dementia-stigmatising society (Williamson, 2015), it is not surprising that participants had internalised devaluing perceptions of people living with dementia themselves. However, they also expressed anger about others' social neglect of the person who now has dementia and resentment about the low level of support from their wider social networks. 'Courtesy stigma' or stigma by association (Goffman, 1963) may also isolate family members, particularly spouses, of people who go on to develop dementia and the family carers in our study identified their own feelings of loneliness, corresponding to the marginalisation of the person they now look after. The role of carer for a person with dementia is associated with risk of low mood and isolation (Jenkins et al., 2016); it may be that an exclusionary social process is already progressing in parallel for both parties during the prodromal period.

By the time dementia is identified, an individual is already becoming marginalised because their LTF means other people can find them difficult. Anti-stigma campaigns are perhaps therefore too late for many in maintaining social inclusion. In addition, campaigns that promote inclusion depend on knowing who is being targeted, so paradoxically the people who most need inclusion may risk being excluded by default from the campaigns designed to assist them. The person's disability at this stage is invisible, even though it is subtly attracting 'malignant social psychology' (Kitwood, 1997), later to be compounded by more explicit dementia-related stigmatisation (Beard & Neary, 2013).

The professional carers' ability to recognise dementia-related signs pre-diagnosis may result from familiarity with later symptoms enabling recognition of the early counterparts. Late problems include disinhibition, anxiety and need for reassurance, and practical issues such as difficulties with washing and dressing (Jenkins et al., 2016). Beard and Neary (2013) respondents, who had MCI, were keen to define their own problems as different to those of people with dementia itself. Similarly, the professional carers in our study found their clients confided concerns about memory changes to them, sometimes while taking steps aimed at protecting their memory and functioning abilities. Both groups could relate examples when the affected person adjusted their own behaviour to pre-empt problems, indicating insight, with intention to avoid dementia-related difficulties and maintain a positive non-stigmatised identity.

## **RELEVANCE TO CLINICAL PRACTICE**

This was a small study with interesting findings. Further research is needed to establish the extent to which our conclusions can be extrapolated to other contexts. The aim was to explore very early indicators of dementia to reveal a window of opportunity to enable a person identified as at risk to make lifestyle changes to improve their long-term cognitive functioning. In identifying LTF, the associated adjustments made by the person with memory problems themselves and others in their social network, we tentatively highlight opportunities for earlier identification and subsequent health adjustments, while also raising questions about the implications of social exclusion of people who later go on to develop dementia.

### **Identification and health promotion**

'Lowered Threshold of Frustration' could be used as a simple inexpensive means of identifying a person at increased risk of dementia. A simple question such as 'Do you find you become angry or frustrated much more quickly than before?' that identifies reduced tolerance of frustration could be included in routine health checks that include depression identification. This could flag up the possibility of early dementia-related changes and offer the option to explore the risk further and discuss lifestyle changes. Depression is a risk factor for dementia, it can be difficult to differentiate the two (they share some symptoms, e.g. disturbed sleep, apathy, low mood) and it is possible that the two conditions have a shared causal pathway (Prince et al., 2014). Health promotion advice for the two conditions also overlaps, so for example patients could be advised to spend more time walking outside, to connect to their social network more and to get involved in activities that are enjoyable and stimulating. General health advice such as reducing alcohol intake, stopping smoking, eating a healthy diet and exercising more are important (Lafortune et al., 2016).

The purpose of the lifestyle changes is not to prevent dementia, but to postpone it. A pre-dementia support strategy could promote lifestyle changes, include advice and options for building cognitive reserve (eg brain training clubs), and include memory clinic referral and early prescription of Aricept or other anti-dementia medication. Stress and time management strategies could be taught, to reduce stress and the immune system responses that are thought to contribute to inflammatory processes (Ginesi, Jenkins, & Keenan, 2016). Medical practices alerted to potential future dementia-related problems could signpost to local resources, such as the Alzheimer's Society, if required. This strategy changes perception of appropriate dementia responses from medicalisation towards inclusion of a more social model of understanding (Williamson, 2015). This should reduce

therapeutic nihilism, normalise dementia as a disability, empower individuals and harness community engagement.

### **Social Inclusion**

Our findings indicate that social exclusion may begin before a person develops dementia and well before diagnosis. This has implications for anti-stigma campaigns and the developing nature of 'dementia friendly communities', which we suggest should also become 'pre-dementia friendly'

Physical and social environments could be adjusted to become minimally frustrating, so as not to trigger a sign of LTF. In common with other disabilities, those living with them have the right to expect that others will make enabling adjustments (Williamson, 2015). As people in pre-clinical stages of dementia are generally unaware of their specific needs, we should aim to make these dementia-friendly adjustments in all public spaces, in a move of solidarity, but also for the common good.

Dementia-friendly adjustments could include easily navigable towns, easy to read architecture (eg. entrances are clear), brighter lighting, wayfinding aids, clear signposting and use of design to convey purpose (Duffin, 2014). Public-facing employees should be trained in dementia awareness and in warm, clear communication skills (Duffin, 2014). In common with adjustments for other disabilities, these adjustments should be beneficial for all. Technological developments can empower citizens by designing in ease of use and anticipatory responsiveness (Asghar, Cang, & Yu, 2018).

In addition to environmental changes we need to consider how we talk about dementia. Media guidelines on normalising dementia postponement strategies, admitting to concerns about dementia, avoiding stigmatising terms and being dementia inclusive should help to challenge marginalisation (Williamson, 2015). We should promote a message of hope rather than fear while putting measures in place to promote cognitive health for individuals and support social inclusion by facilitating dementia-friendly strategies for communities.

### **STRENGTHS AND LIMITATIONS**

The four themes presented in this study reflect participants' retrospective accounts enabling insight into experiences of people in the prodromal stages of dementia. We recognise that the 'early signs of dementia' theme overlap with known symptomatology, the remaining themes add to knowledge about the experiences and behaviour of people living with early cognitive changes. The strategies adopted in the study design can be considered a strength for ensuring rigour and trustworthiness of qualitative findings.

A potential limitation is our sample was limited to two geographical (East and West Midlands) locations, whereby a broader sample might have added further insights. As we were asking for participants to look back to a time before the person they cared for had dementia (between 5-20 years), it is possible that some of the participants could not recall all the examples. Also, questions may have triggered some of the family carers to confuse the past with current stressors. Hence, precautions were taken when analysing the data to ensure the themes identified explored further pre-clinical signs of dementia. Our findings confirmed awareness of difficulties on the part of people who later developed dementia, so asking recently diagnosed people with early dementia about their perceptions and experiences would add valuable perspectives.

## CONCLUSIONS

Our findings indicate that people in prodromal stages of dementia undergo subtle dementia-related behavioural changes that affect their relationships with other people. This leads to social exclusion, which occurs prior to stigma-related social exclusion associated with more obvious symptoms and actual diagnosis. The social exclusion of people in prodromal stages of dementia has implications for inclusion strategies, which should be based on a social model understanding of dementia. The concept of 'Lowered Threshold of Frustration' is useful, having applicability for identification of future dementia risk and health promotion. The benefits of the window of opportunity for health-promoting behavioural changes that may postpone cognitive impairment should be complemented by initiatives that facilitate societal changes to ensure the social inclusion of people who may be at higher risk of developing dementia.

### Summary Box

'What does this paper contribute to the wider global clinical community?'

- 'Lowered Threshold of Frustration' is a useful concept for raising healthcare professionals' awareness of possible elevated risk of later dementia in their service-users.
- Earlier recognition of identified pre-clinical signs of dementia could allow potentially at-risk individuals to work with healthcare professionals in following health promotion advice and planning for the future.
- Social isolation occurs prior to development of dementia. Social inclusion programmes should respond to the needs of people experiencing pre-clinical signs of dementia through environmental and interpersonal adjustments.

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