



Illness representations in caregivers of people with dementia

Catherine Quinn, Ian Rees Jones & Linda Clare

To cite this article: Catherine Quinn, Ian Rees Jones & Linda Clare (2017) Illness representations in caregivers of people with dementia, *Aging & Mental Health*, 21:5, 553-561, DOI: [10.1080/13607863.2015.1128882](https://doi.org/10.1080/13607863.2015.1128882)

To link to this article: <https://doi.org/10.1080/13607863.2015.1128882>



© 2016 The Author(s). Published by Taylor & Francis.



Published online: 05 Jan 2016.



Submit your article to this journal [↗](#)



Article views: 2266



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 6 View citing articles [↗](#)

Illness representations in caregivers of people with dementia

Catherine Quinn^a, Ian Rees Jones^b and Linda Clare^a

^aDepartment of Psychology, REACH: The Centre for Research in Ageing and Cognitive Health, University of Exeter, Exeter, UK; ^bWISERD – Wales Institute of Social & Economic Research, Data & Methods, Cardiff University, Cardiff, UK

ABSTRACT

Objectives: Illness representations shape responses to illness experienced by the self or by others. The illness representations held by family members of those with long-term conditions such as dementia influence their understanding of what is happening to the person and how they respond and provide support. The aim of this study is to explore components of illness representations (label, cause, control and timeline) in caregivers of people with dementia.

Method: This was an exploratory study; the data reported came from the Memory Impairment and Dementia Awareness Study (MIDAS). Data from semi-structured interviews with 50 caregivers of people with dementia were analysed using content analysis.

Results: The majority of caregivers gave accounts that appeared to endorse a medical/diagnostic label, although many used different terms interchangeably. Caregivers differentiated between direct causes and contributory factors, but the predominant explanation was that dementia had a biological cause. Other perceived causes were hereditary factors, ageing, lifestyle, life events and environmental factors. A limited number of caregivers were able to identify things that people with dementia could do to help manage the condition, while others thought nothing could be done. There were varying views about the efficacy of medication. In terms of timeline, there was considerable uncertainty about how dementia would progress over time.

Conclusion: The extent of uncertainty about the cause, timeline and controllability of dementia indicated that caregivers need information on these areas. Tailored information and support taking account of caregivers' existing representations may be most beneficial.

ARTICLE HISTORY

Received 23 October 2015
Accepted 29 November 2015

KEYWORDS

Alzheimer's disease; adjustment; cause; common sense model; qualitative methodology

Introduction

Family members of people who develop dementia are often the first to pick up on early symptoms or changes, but they may not understand the symptoms they are observing and, even with a diagnosis, experience difficulties in attributing changes to the person's dementia (Chenoweth & Spencer, 1986; Quinn, Clare, Pearce, & van Dijkhuizen, 2008). Studies exploring caregivers' understandings of dementia have found that caregivers may minimise the seriousness of symptoms by attributing them to ageing (Askham, 1995; Gray, Jimenez, Cucciare, Tong, & Gallagher-Thompson, 2009; Morgan & Laing, 1991), to the person never having had a good memory (Quinn et al., 2008) or to life events (Paton, Johnston, Katona, & Livingston, 2004). Caregivers' beliefs about dementia can influence their understanding of the behaviours they are observing. For instance, they may attribute symptoms such as problematic behaviours to the person and not to dementia (Paton et al., 2004). Negative attributions about the person's behaviour, for instance believing the behaviour to be manipulative, have been also linked to caregiver resentment and depression (Martin-Cook, Remakel-Davis, Svetlik, Hynan, & Weiner, 2003). Therefore, caregivers' understanding of dementia can influence how they respond to the person. Thus, it is important to explore the underlying beliefs that influence caregivers' understanding of dementia. There has been relatively little research specifically exploring these 'illness representations'. This study will draw on the illness

representations component of the common sense model (CSM) to explore these beliefs in caregivers of people with dementia.

The CSM describes the processes involved as a person attempts to make sense of symptoms he/she is experiencing. According to the CSM, in order to make sense of symptoms, a person will develop individualised illness representations. It is proposed that these comprise of five components: label, cause, timeline, controllability and consequences (Diefenbach & Leventhal, 1996; Hagger & Orbell, 2003). Since the original development of the CSM, the nature of the five components of illness representations has been elaborated further. For instance, the cure/control dimension may involve two separate areas: beliefs about personal control and beliefs in the efficacy of treatment and appropriateness of recommended advice (Moss-Morris et al., 2002). In the CSM, the components are not held in isolation but as part of a schema, in which they can influence each other. In addition, illness representations are not static and may alter as the person receives new information about the condition.

Research on patients' illness representations provides support for the CSM and has found links between these illness representations and outcomes such as patient well-being (Hagger & Orbell, 2003). In addition, the illness representations that patients hold can have an impact on initial help or support seeking, coping and illness management, such as adherence to treatment programmes or medication

(Hampson, Glasgow, & Toobert, 1990; Heijmans & de Ridder, 1998). There are individual differences in the meaning people assign to symptoms and in their acceptance of a specific disease label. The individual personal context can have an influence on the development of illness representations. For instance, a family history of illness can influence perceptions of vulnerability to illness (Diefenbach & Leventhal, 1996). In addition, social and cultural factors can influence a person's understanding of his/her symptoms, willingness to accept an illness label and help-seeking behaviour (Leventhal et al. 1997). Ageing may also have an influence on whether a symptom is attributed to illness or considered to be a sign of normal ageing (Diefenbach & Leventhal, 1996; Prohaska, Keller, Leventhal, & Leventhal, 1987).

Although patients' illness representations have important implications for their understanding and their coping efforts, it is equally important to consider the influence of the beliefs held by others in the patient's network. The illness representations held by family members can potentially influence their emotional response to the condition and the way in which they respond to the patient (Lobban, Barrowclough, & Jones, 2003; Searle, Norman, Thompson, & Vedhara, 2007; Shiloh, Rashuk-Rosenthal, & Benyamini, 2002). Few studies have specifically explored illness representations in family members of people with dementia. Glidewell, Johnston, and Thomas (2012) reported a single case study which found similarities and differences in the illness representations held by the person with dementia, the caregiver and the general practitioner. Roberts and Connell (2000) reported a quantitative examination of illness representations in first-degree relatives of people with dementia. Although the relatives were generally knowledgeable about dementia, they still held misconceptions and had unrealistic beliefs about the potential for treatment. However, this study did not explore the label or timeline components of illness representations. In addition, questions of controllability focused on future treatment developments and did not explore other forms of controllability, for instance, personal control.

To date, no study has explicitly explored illness representations in informal caregivers of people with dementia. It is important to understand the factors that can influence caregivers' beliefs about dementia, particularly as these beliefs could potentially have an impact on how they respond and provide support to the person. Therefore, the aim of this study is to explore illness representations in caregivers of people with dementia. As there has been considerable research on caregivers' reports of the consequences of caregiving (e.g. Pinquart & Sörensen, 2003, 2004), in this study, we have chosen to focus on four components of illness representations: label, cause, control and timeline. Focusing on these four components provides insight into caregivers' understandings of their relative's condition.

Methods

Design

This was an exploratory study using qualitative methodology. Caregivers were interviewed as part of the Memory Impairment and Dementia Awareness Study (MIDAS). MIDAS was a longitudinal, mixed-methods study on awareness in people with early-stage dementia and involved people with dementia and their informal caregivers (Clare et al., 2012). People with dementia and caregivers were assessed on entry to the study and again

at 12- and 20-month time points, and semi-structured interviews were conducted separately with people with dementia and caregivers on entry to the study and 12 months later. Questions on illness representations were incorporated into the interview protocol at the 12-month follow-up. This paper reports an analysis of pre-existing data from interviews with caregivers that were conducted at this 12-month time point.

Participants

The participants in the present study were the caregivers of people with dementia. In the MIDAS study, people with early-stage dementia were the primary participants and were recruited from Memory Clinics in North Wales, UK. The inclusion criteria for the person included an ICD-10 diagnosis of Alzheimer's disease, vascular dementia or mixed Alzheimer's and vascular dementia (WHO, 1992), a score of 18 or above on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), and availability of a spouse, partner, other family member or friend (termed the 'caregiver') who was willing to contribute (full details of the eligibility criteria can be found in Clare et al., 2012). If the person with dementia was eligible to take part in the study, then his/her caregiver could also take part; there were no specific inclusion or exclusion criteria for the caregivers. Sixty-four caregivers were interviewed at the 12-month follow-up assessments; questions about illness representations were included in the interviews with 50 of these caregivers.

Ethical approval was obtained from the University Research Ethics Committee and the relevant NHS Local Research Ethics Committee. Written informed consent was given by all the study participants. In order to maintain confidentiality, all participants' details were anonymised and pseudonyms were used in the transcripts of the interviews.

Data collection

Caregivers were interviewed by one of the researchers working on the MIDAS study. The majority of the interviews were conducted in the participants' homes, although some took up the option to be interviewed at the University. The interviews lasted from 14 to 46 minutes, with the average length of the interviews being approximately 27 minutes. These interviews were tape-recorded for later transcription. The interviews followed a semi-structured interview schedule; caregivers were asked about any changes in the person with dementia since the researcher last visited, and about the perceived impact of these changes on both the caregiver and person with dementia. Specific topics were then introduced to explore caregivers' illness representations:

- What do you call the condition your relative/friend has and what does this label mean to you?
- What do you think caused or causes this condition?
- What can be done about this condition? Are there any kinds of treatment (e.g. medication) that could help? Are there things that people can do to help themselves?
- How do you think this condition will progress over time? What do you expect to happen?

Care was taken to ensure that the caregivers did not become distressed during the interviews as some of the topics could be considered to be particularly sensitive by the caregivers. There were some interviews which did not cover all the above topics relating to illness representations and this is reflected in the results.

Data analysis

Transcripts of the interviews were analysed in the NVivo software package using content analysis. We choose to employ a directed approach to content analysis (Hsieh & Shannon, 2005) and used the components of illness representations to develop the initial coding. The first stage of the analysis involved the researcher (Author A) coding all instances of illness representations within the transcripts. In order to reduce the risk of individual bias in the coding, nine transcripts (15% of the transcripts) were independently coded by two researchers (Authors A and C). Inter-rater reliability was 79.30% and exceeded the criterion of 70% needed to ensure confidence in the coding process (Miles & Huberman, 1994). All the identified extracts for each component of illness representations were then collated together and further analysis was conducted to create subcategories within each component.

Results

The characteristics of the 50 caregivers are described in Table 1 and the characteristics of the people with dementia are described in Table 2. The majority of the caregivers were female (60%) and were the spouse of the person with dementia (60%). Just over half of the people with dementia were female (55.6%) and their MMSE scores ranged from 8 to 30 (M 22.58). Just over half (54%) of the people with dementia were taking a medication for their dementia, such as Donepezil.

The findings for the four components of illness representations will be presented first. This includes the percentages of participants who endorsed a particular viewpoint; however, it

Table 1. Characteristics of the caregivers.

Variables	<i>N</i> (%)
Gender (female)	30 (60)
Age (<i>M</i> , <i>SD</i>)	66.49 (14.51)
Ethnicity	
White British	48 (96)
White Irish	1 (2)
White Other	1 (2)
Relationship to person with dementia	
Spouse	30 (60)
Partner	1 (2)
Son/daughter	14 (28)
Sibling	2 (4)
Niece/nephew	2 (4)
Friend	1 (2)
Residing with person with dementia (Yes)	35 (64.8)
Length of caregiving in months (<i>M</i> , <i>SD</i>)	46.8 (28.4)
How many hours do they provide help for	
≤ 36 hours per week	23 (46)
>36 hours per week	27 (54)

Table 2. Characteristics of the people with dementia.

Variables	<i>N</i> (%)
Gender (female)	30 (55.6)
Age (<i>M</i> , <i>SD</i>)	78.18 (8.43)
Ethnicity	
White British	53
White Irish	1
Diagnosis	
Alzheimer's disease	32 (64)
Vascular dementia	11 (22)
Mixed dementia	7 (14)
MMSE score (<i>M</i> , <i>SD</i>)	22.58 (4.72)
On dementia medication (Yes)	27 (54)

should be noted that some participants held multiple views. The discussion of the components is followed by a preliminary consideration of possible patterns in the data.

Label

All caregivers were asked about the label they used to describe the person's condition. The majority (66%) of caregivers used a medical/diagnostic label to refer to their relative's condition. Some used specific terms such as Alzheimer's or vascular dementia, whilst others used the more generic term of dementia. Many used these terms interchangeably throughout their interviews, for instance referring to a specific diagnosis such as Alzheimer's and then later referring to dementia. It was evident that some were using the diagnostic term provided to them by the memory clinic, although this could cause confusion particularly if the diagnosis had changed: 'Well, we've had two diagnoses... We've had vascular dementia, and the last diagnosis we had was mild Alzheimer's' (R021).

Some people had diagnoses of mixed dementia and this influenced the term the caregivers used:

I call it vascular dementia. It is actually mixed, the diagnosis is mixed. We say vascular dementia because then it makes people ask you oh, what's that? Is that Alzheimer's? and then I try to explain to people like the difference in the causes of it (R003).

Some caregivers questioned the diagnostic label, particularly as terms could be linked to feelings of stigma. There were negative connotations associated with certain labels; for instance, one caregiver was certain her husband had dementia not Alzheimer's, which was viewed as 'worse'. Uncertainty was also linked to a lack of understanding about the condition; for instance, one caregiver expressed the view that Alzheimer's was something that 'younger people got' whereas dementia was associated with old age.

Only 4% of caregivers used labels that were linked to the symptoms of dementia, referring to the condition as 'memory loss'. Some caregivers (14%) used terms interchangeably in their interview, employing both diagnostic labels and symptom-linked labels such as 'short-term memory loss' or 'forgetfulness'.

There could be differences between the labels the caregivers used to describe the condition and the labels they said they used when talking with the person with dementia. This could be to prevent confusion, as terms like 'memory problems' were a simpler way of explaining the person's problems to them rather than using terms like 'Alzheimer's'. However, it may have also been a way of protecting the person as some were concerned that diagnostic labels would cause distress; terms linked to symptoms were considered to be more acceptable:

She was, when she was put on Aricept she knew she was on it, and the words used were short-term memory loss, the word dementia or Alzheimer's never, ever used in front of her ... because I think it would be far too distressing (R014).

There were caregivers who did not have a label for the person's condition (16%) and did not know what to call it. In terms of the labels used, one caregiver did question the importance placed on labels, suggesting the label used did not matter; what was important was that there was a recognition that something was wrong with the person: 'I've seen people with bad Alzheimer's, uh, though they seem to say it's

not major Alzheimer's... it doesn't matter; you could call it 'beriberi'. He's got something wrong' (R021).

Cause

Cause was discussed in 78% of interviews. The caregivers identified multiple causes of dementia, attributing it to controllable factors such as lifestyle or uncontrollable factors such as ageing or genetic causes. There seemed to be a differentiation between factors that were perceived as direct causes of dementia and factors that were perceived as contributing to dementia.

In 52% of the interviews where cause was discussed, the predominant explanation was that dementia had a biological causation, with caregivers referring to both changes in the brain and vascular problems. These caregivers were able to attribute dementia to something going wrong in the person's brain. Some commented that it was linked to vascular problems such as the blood supply or oxygen not properly getting through to the brain:

The blood supply not getting through and ... sometimes it does and sometimes it doesn't and, you know, that's why some days he's a lot clearer than another day, because there's odd days when he's in a fog, it's as though he's in a total fog, and I only, can only assume that the blood supply's not getting through very well (R010).

They could recall medical explanations, using terminology such as 'strokes' or 'TIAs'. Using a biological explanation, they could make a connection between something happening in the person's brain and a decline in the person's cognitive functions. The caregivers developed their own understanding of what was happening in the person's brain, using their own terminology and metaphors. For instance, one caregiver described the damage to blood vessels in the brain as 'the riverbed silting up'. Caregivers described a 'deterioration' in the person's brain. Simple explanations related dementia to damage to the brain, parts of the brain 'dying' or to the brain 'shrinking'. Others tried to describe more complex changes in the brain, using their knowledge of the condition or terms they had picked up from medical professionals. Dementia could be caused by brain cells 'dying', a chemical imbalance or 'proteins' in the brain. It was clear that these caregivers had some knowledge about what was happening in the brain but, as is to be expected, did not fully understand the processes involved:

I know it's, it's to do with the brain but I don't know what actually what causes it. I mean nobody really has gone into it except it's, just they say it's a chemical imbalance and, and what not but exactly what it does to the brain I don't, I just do not know (R062).

For three caregivers who proposed biological explanations, dementia was seen as a hereditary condition, based on the knowledge that other members of the family had suffered from it. For adult-child caregivers, this knowledge seemed to cause some anxiety as it made them reflect on whether they would also develop dementia. Some used humour to joke about this in the interviews, and others had discussed their concerns with siblings.

In 12% of the interviews where cause was discussed, the caregivers attributed the symptoms of dementia to the ageing process. Dementia was intrinsically linked to ageing as it was seen as a condition that 'a lot of old people get'. It was also perceived as normal for older people to have problems

with their memory and to be forgetful; as one caregiver commented: 'I think it's old age more than anything else, old age' (R090).

Caregivers also identified controllable factors (8% of the interviews where cause was discussed) within the person's lifestyle or environment that could have contributed to developing dementia. Dementia could have resulted from worry or stress impacting on the person's memory. Linked to this were causes connected to past stressful life-events, such as bankruptcy. Two caregivers spoke of a lack of stimulation, which although it may not have directly caused dementia may have contributed to its occurrence: 'She had no stimulus, nothing ... no hobbies, nothing, and I do think it's a contributory factor ... no doubt' (R014).

For all those caregivers who could identify causes of dementia, there were others (28% of interviews where cause was discussed) who simply did not know what the causes were. For some, this was based on a lack of knowledge about dementia, and for others, it seemed to be based on an awareness that we do not really know what causes dementia: 'Well does anybody know [the cause of dementia]? Well I – nobody knows. What's the cause of it? If they knew the cause they would cure it wouldn't they?'(R089).

It should also be noted that a small minority of caregivers could identify more than one possible cause, and were uncertain as to what was actually causing the condition.

Control

Control was discussed in 88% of interviews. From these responses, two main sub-categories emerged, which focused on personal control and control through the use of medications. In the 88% of interviews that discussed control, 56% of caregivers discussed personal control and 62% of caregivers discussed control through medication. It was evident that there was overlap between these two sub-categories; in 30% of cases, participants discussed both personal control and control through use of medication, while 26% discussed only personal control and 32% discussed only medication. The sub-category of personal control encompassed both beliefs on whether the condition could be cured and beliefs about what could be done to manage the condition. In terms of managing the condition, some caregivers (20% of the interviews where personal control was discussed) described ways in which the progression of dementia could be slowed down. It was important to motivate the person to do things and stay occupied. They wanted to try to maintain stimulation by keeping the person active and getting out and about, as it was felt that if the person was left to sit and do nothing, this would accelerate decline. They actively sought guidance from health care professionals on the best way to help the person and thought that there were techniques the person could use to help his/her memory problems:

The people that she speaks to and you know all the little exercises and things, like the little cards with the days and writing things down it's all helped her to, you know, keep some kind of maintenance system going (R065).

In contrast, other caregivers (30% of interviews where personal control was discussed) did not believe that anything could be done to help people with dementia. There was little that could be done to either control the deterioration in dementia or cure it. Some felt the person was too impaired to

be helped now as it was impossible to repair the person's damaged brain. Memories that were lost could not be restored; as one caregiver commented: 'You, you can't put, you can't put back what's been lost can you?' (R086).

Some caregivers thought that people with dementia could not help themselves to get better, either because they were too impaired or because it would involve changing pre-existing habits. For instance, one caregiver recognised that people with dementia could use memory aids to help their memory, but thought they could not help themselves to get better:

I suppose if you could learn to rely on, er, diaries and prompts and lists and things like that, you'd be happier but if you were trying to remember all the time – but as this is a progressive disease, I don't know. I don't know that you could help yourself to get better (R049).

Only one caregiver expressed uncertainty as to whether dementia could be controlled, whilst a small percentage of caregivers (4% of interviews where personal control was discussed) took a more hopeful stance, hoping that research would eventually result in the development of a cure for dementia. As one caregiver commented: 'I'm depressed about the future, but hopeful in the sense that research is now going to find there's a cure for nearly everything now' (R015).

Some caregivers also talked about the role of medication in the control of dementia. Of these, most caregivers (44% of interviews where medication was discussed) believed that medication for memory difficulties could have a positive impact. This belief was based either on something they had heard or on direct experience of observing changes in the person's condition when she/he was taking medication. Beliefs ranged from believing the medication was stabilising the person's condition to perceptions that it was slowing down the deterioration. Others saw improvements in the person:

I think that's helped her a lot from what she was before she had it. I think it's made a big difference and I don't know whether it's maybe that that's keeping her on that even keel, I mean I don't think she's – she's obviously never gonna get better but she's a bit better than she was (R083).

There were other caregivers (18% of interviews where medication was discussed) who were uncertain as to whether the medication was having an impact on the person's memory difficulties and were disappointed that the person had not dramatically improved:

Well, if they're giving her tablets, I can't see that it's doing any good... let's put it that way, you hear of these people that turn round and say, 'Oh, I took so-and-so and so-and-so, and my God, I'm back to normal again now. There's no way that she's anywhere near normal' (R024).

It was difficult to tell whether any observed improvements should be attributed to medication or to other factors. With a fluctuating condition, caregivers were uncertain as to whether the person would have deteriorated more quickly without the medication. They were aware that the effects from the medication were not permanent; some had initially noticed an improvement but now found the person was deteriorating.

Timeline

Timeline was discussed in 70% of interviews; of these, many (18% of interviews that discussed timeline) were uncertain as to how the person's dementia was going to progress over time. Some simply did not know, and others felt it would be

difficult to predict how dementia would progress. People with dementia deteriorate at different rates and it would be difficult for caregivers to compare the decline of the person to others. Although these caregivers said they did not know what would happen in the future, it was clear that, even in this group, there was an understanding that the person would decline. However, they did not know how things would progress and what they should expect in the future; as one caregiver commented: 'I hear that it stabilises and then you just go down again. I don't know. So I don't know' (R019).

It is likely that caregivers were using information obtained from medical professionals or other sources to guide their understanding of the progression of dementia. Some made reference in their interviews to asking for advice from the memory clinic. Some caregivers (10% of interviews where timeline was discussed) understood that the person's condition would not improve; as one caregiver commented: 'I explain it to myself like this is a gradual process. It isn't going to get better' (R082).

Others (8% of interviews where timeline was discussed) were just hoping that the person's condition would remain stable and not get any worse. Some were hopeful that medication or management of health conditions would stabilise the person's dementia, while others were actively avoiding thinking about the future: 'Oh I dread to think about it [the future], I, I just hope that he doesn't really get any worse' (R026). In contrast, other caregivers (34% of interviews where timeline was discussed) had thought about the future and were fully aware that the person would deteriorate, with dementia getting 'worse and worse'. Knowledge of the progressive nature of dementia was linked to feelings of depression and anxiety about the future. These caregivers were aware that the person would get worse but it was not something they were 'looking forward to'. Although they knew it would get worse, some were not sure what this would entail. Others demonstrated more awareness of how the condition would progress over time:

He starts to lose more of his, erm, functioning abilities doesn't he and then, erm, he's going to need more and more help with cooking and cleaning and then he won't be able to stay in the house on his own, so he'll have to move with us or he'll go to an old people's home ... and then ... do ... eventually do they like lose ... all his ... err, the ability to walk and ... go to the toilet and things as well? (R031).

Patterns in the components

As the elements of the illness representations are not held in isolation, but are linked as part of a schema in which they can influence each other, we qualitatively explored whether there were any patterns in the data. As the majority of the caregivers used a diagnostic label, we focused on the other three components. Due to the size of the sample, the findings should be interpreted with caution, but there is preliminary evidence that views on ageing as a causal factor were clustered around feelings that the person would get worse. In addition, views that the cause was due to changes in the brain were clustered around views that the person would get worse and that nothing that could be done to control the condition. Views that the cause was vascular problems were clustered around feelings that the condition could be managed, whilst those who identified the condition as hereditary were hopeful for a cure. Finally, views that the condition would get worse,

as opposed to staying the same, were clustered around feelings that nothing could be done to control the condition.

Discussion

This study has been the first to explore illness representations in a sample of caregivers of people with dementia. Caregivers tended to use diagnostic labels in describing the person's condition, but expressed considerable uncertainty about the cause, timeline and controllability of the condition. The findings also indicate that some of these viewpoints were influenced by information provided by health care professionals. These findings have implications for the provision of support and information for caregivers of people with dementia. They also raise the question of how important it is for caregivers to have 'accurate' illness representations.

The findings indicate that labels could be used interchangeably. Some caregivers fluctuated from referring to diagnostic terms to more symptom-based terms, such as memory problems. In addition, there is evidence that some caregivers were tailoring the terms they used when talking to the person, preferring more acceptable terms such as 'short-term memory loss'. These types of labels may be less stigmatising; research has found that people with dementia assign negative connotations to terms such as 'dementia', preferring to use less technical terms to describe their experiences (Langdon, Eagle, & Warner, 2007). However, by using symptoms as the label, this may lessen the perceived severity of the condition and has the risk of normalising what is happening to the person. It may also make it more difficult for the person with dementia to understand what is happening. The findings raise the question of whether the use of a diagnostic label is important; instead, it may be more important that there is a recognition that there is something wrong and the person is appropriately supported. The term 'dementia' and the medicalisation of what has previously been considered as a natural part of the ageing process has been criticised (e.g. Davis, 2004). Whilst terms like dementia may be valuable for diagnosis and patient management (Kurz & Lautenschlager, 2010), the label used may be less important for people with dementia and their families.

The caregivers in the current study were primarily attributing the cause of dementia to uncontrollable factors. This differs from reports that care partners of people with MCI were more likely to attribute the MCI to controllable factors (Rodakowski, Gentry, Garand, & Lingler, 2014). This may be due to differences in knowledge about the causes of these two different conditions, particularly as MCI is a more recent diagnostic category. For the caregivers in the current study, attributing the condition to uncontrollable sources may have been more helpful to them and the person with dementia. In particular, it may have prevented any blaming of the person with dementia for the condition or its effects. This relates to theories on illness causation (Pill & Scott, 1982). These differentiate between causes which are considered to be external to the person and more internal causes in which the person is considered to be responsible for his/her illness. Thus, if the person's illness is perceived as having external causes, then this relates to feelings that the person should not be blamed for his/her illness as she/he is not responsible for it.

The main cause identified by the caregivers in the current study related to changes within the person's brain, either due to biological processes or due to physiological processes. This

may have been connected with the majority of caregivers using a diagnostic label. Even though it was evident that the caregivers did not understand the underlying mechanisms involved, they had clearly endeavoured to find out information and had tried to understand what underlies the condition. Alternative causes suggested were ageing, lifestyle, environment, life events and hereditary factors. Other studies have reported problems in the brain, genetic factors and ageing as the main causal factors identified by caregivers of people with dementia (Glidewell et al., 2012; Hinton & Levkoff, 1999; Roberts & Connell, 2000). Similarly, people with dementia attribute the cause of their dementia to ageing, life events, life stress, environmental factors and hereditary factors (Clare, Goater, & Woods, 2006; Harman & Clare, 2006; Langdon et al., 2007; Matchwick, Domone, Leroi, & Simpson, 2014). Some caregivers did not know the causes of dementia, or identified multiple possible factors, which may have been due to a lack of knowledge about causal factors (Werner, 2001). Alternatively, Matchwick et al. (2014) suggested that people with dementia had difficulty identifying the cause of their condition because it was perceived as a chronic condition with a slow onset thus making it difficult to link to a specific causal event, and this might also apply to some caregivers. Caregivers in the current study appeared to distinguish between direct and indirect causes, identifying factors that just contributed to dementia. Interestingly, in this study, ageing was not perceived as a main causal factor, which implies that the caregivers were not normalising the difficulties the person was experiencing as reflecting ageing processes in general. This may relate to the sample selected for this study; all participants had attended a memory clinic and had received a diagnosis.

The categories of timeline and control seemed to be interlinked. There was more uncertainty about the timeline of dementia, with many not knowing how it would progress and others hoping the person would remain stable. Similar views have been found in people with dementia, with some reporting that the condition would deteriorate and others feeling it would remain stable (Clare et al., 2006). Lack of awareness about future progression may have simply been due to a lack of knowledge, particularly as caregivers had noted that progression is not uniform. However, it may have also been a form of coping, with caregivers avoiding thinking about the future. Views on progression could be linked to beliefs about the possibilities for controlling dementia. Whilst caregivers were aware that there was no cure, some were hopeful about the development of future treatments. This is a more realistic view than that of the caregivers in the study by Roberts and Connell (2000) who felt treatment developments were very likely to produce a cure within the participants' lifetime. In terms of control, whilst there are no treatments that can halt the progression of the condition, there are techniques that can help people to manage the symptoms (e.g. Clare et al., 2010). This understanding is reflected in the caregivers' responses to questions on control which focused on both personal control and treatment control, supporting research proposing that there are two distinct components of control (Moss-Morris et al., 2002). Some felt that dementia could be managed, whilst others believed nothing could be done. Suggested management techniques included using memory aids, such as diaries, which would help the person to remember. Views on these components of illness representations may have been influenced by cultural representations of dementia,

which tend to be negative (Peel, 2014). In an analysis of media reports on dementia, Peel (2014) identified that the predominant emphasis was on the 'catastrophic' nature of dementia and the 'horror' of the condition. By focusing on this aspect of the condition, there may be less public knowledge of the methods that can help people to manage the condition.

The findings of this study have implications for the disclosure of diagnosis to people with dementia and their caregivers. Health care professionals need to understand that the illness representations that people have can influence their processing of the information provided. It has been suggested that health care professionals can be unaware of people's illness representations as they rarely ask for their ideas during medical consultations (Petrie, Jago, & Devcich, 2007). Many caregivers will have already developed their own representations, and if professionals can elicit these, then they can tailor the information they give accordingly. In addition, health care professionals might also consider the terms they use when providing a diagnosis and the influence of their own illness representations. Caregivers in this study had been in contact with memory clinics and their beliefs were understandably influenced by information that health care professionals had provided. It has been reported that health care professionals do use a variety of terms in discussing the diagnosis, using lay language as well as more clinical terms (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Connell, Boise, Stuckey, Holmes, & Hudson, 2004). This is particularly important as caregivers may have encountered a multitude of health care professionals, each with differing perspectives on the condition. However, just using a diagnostic label does not necessarily facilitate understanding (Peel, 2015) and people may need more information. Whilst it would not be possible for them to tailor the language used in each encounter, they need to be aware of the impact of the terms used on the person.

The findings of this study also have implications for information and support interventions for caregivers. Whilst there have been interventions developed for caregivers that aim to educate them about dementia, the illness representations that the caregiver holds may be a barrier to implementing such interventions. In order to be effective, these interventions need to identify and appropriately address these beliefs, particularly as the findings provide preliminary evidence that different beliefs about causal factors may be linked to different views on control. Illness representations can be targeted in interventions; representational interventions involve understanding the person's pre-existing illness representations and working with the person to deal with these so that new information can be introduced (Donovan & Ward, 2001). However, it may not be important for caregivers to have an accurate understanding of dementia as long as there is a recognition that something is 'wrong'. For instance, in terms of cause, our findings suggest that it is important for caregivers to recognise that dementia has a biological cause, without needing to focus on the specific underlying processes. Inaccurate views of the timeline of the condition or an avoidance of considering the future may be a form of coping that may not need to be challenged unless the caregiver believes the condition will get better. However, it is also important to consider the implications of these views for the person with dementia. In terms of control, caregivers who feel that nothing can be done may dissuade the person from attempting to manage his/her condition. Thus, in terms of interventions for people with

dementia, these findings suggest that it is important to consider both the person's and caregiver's views on the condition. For instance, self-management interventions involve the person taking an active role in managing his/her condition, and people with dementia do use these techniques (Toms, Quinn, Anderson, & Clare, 2015). However, it may be difficult to encourage those who believe that nothing can be done or who normalise symptoms to implement self-management techniques.

Our findings provide insight into the illness representations held by caregivers. The nature of the sample and the method used for collecting data do place some limitations on our findings. As we interviewed the participants, we have to consider whether the context and the nature of the questions asked may have influenced the answers. There has been some debate about 'illness narratives' and whether participants' accounts in interviews are 'authentic' narratives of their personal experience (Atkinson & Silverman, 1997). We used interview data that were collected as part of a wider study exploring awareness in dementia. As this was an analysis of pre-existing data, there was no opportunity to add additional questions to the interview schedule or to explore topics in more detail with individual caregivers. For instance, it would have been interesting to have further exploration of the labels the caregivers used with people with dementia and with others. In addition, as the questions on illness representations were introduced later in the interviews and some caregivers were less willing than others to engage in discussion, the topic of illness representations was not explored with some caregivers. Some of the caregivers found the questions difficult to answer as they covered sensitive topics, such as timeline. The findings from other studies indicate that participants find it helpful to talk through sensitive issues in interviews (e.g. Squire, 1999). Other interview techniques, such as biographical-interpretative methods, have been used to elicit the participants' narratives on sensitive issues (e.g. Hollway & Jefferson, 1997) and could be incorporated into research on this area.

The participants were primarily White British, and cultural factors can have an impact on a person's development of illness representations. There is evidence that ethnicity and cross-cultural differences can influence people's understandings of dementia (e.g. Dilworth-Anderson & Gibson, 2002; Gray et al., 2009; Hinton & Levkoff, 1999). Future research could explore illness representations in a more ethnically diverse group of caregivers and consider cross-cultural differences. Whilst all the people with dementia in the study were recruited from memory clinics and some caregivers could recall the term the doctor used during diagnosis, we have no verification of the actual wording used to convey the diagnosis. Some studies have collected data from the diagnostic meeting (e.g. Aminzadeh et al., 2007; Peel, 2015) and future studies could incorporate this element of data collection.

Illness representation components are not held in isolation but are part of a schema. Whilst we did attempt to look at patterns in the data, this was difficult as the caregivers tended to use the same label and there was less data for the questions on timeline. However, we did identify some tentative patterns that could be explored in further research. This study explored only four components of illness representations and future work should explore the other dimensions of the CSM: consequences and coping. It would also be interesting to explore whether the illness representations caregivers hold influence

their response to the person and their relationship with them. In addition, it would be interesting to explore the concordance of caregivers' illness representations with those of the person with dementia, and the impact of the extent of concordance on the person's well-being. As illness representations are not static, it would also be useful to explore longitudinal changes in illness representations over time.

Conclusion

Caregivers tended to use diagnostic labels in describing the person's condition, though there was more uncertainty about the cause, timeline and controllability of the condition. Health care professionals will benefit from understanding people's conceptualisation of dementia so that they can offer better support. In order to be effective, interventions aimed at helping caregivers need to identify and appropriately address these underlying beliefs. However, it is also important to judge whether the person's representations need to be altered. In addition, the label the caregivers use to describe the condition may be less important as long as there is a general recognition that the person with dementia has a condition that impacts, for instance, on his/her memory. Whilst it may not always be appropriate to alter these beliefs, the findings of this study indicate that caregivers do need further information about the causes of dementia and techniques for its management.

Acknowledgements

We gratefully acknowledge MIDAS researchers Sharon Nelis and Anthony Martyr, MIDAS co-investigators Ivana Markova, Robin Morris, Ilona Roth and Bob Woods, and all the MIDAS participants who contributed to the study.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

The MIDAS study was funded by the Economic and Social Research Council (UK) [RES-062-23-0371]. For information on how to access the MIDAS database please see the website: <http://psychology.exeter.ac.uk/reach/>. Data analysis for the present paper was funded by the NeuroSKILL project, a joint Welsh/Irish partnership, part funded by the European Regional Development Fund through the Ireland Wales Programme 2007–2013. For the preparation of the paper, we gratefully acknowledge the support of the Economic and Social Research Council (UK) and the National Institute for Health Research (UK) through grant ES/L001853/1 'Improving the experience of dementia and enhancing active life: living well with dementia' (Investigators: L. Clare, I.R. Jones, C. Victor, J.V. Hindle, R.W. Jones, M. Knapp, M.D. Kopelman, A. Martyr, R.G. Morris, S.M. Nelis, J.A. Pickett, C. Quinn, J.M. Rusted, N.M. Savitch, and J.M. Thom).

References

Aminzadeh, F., Byszewski, A., Molnar, F.J., & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging & Mental Health, 11*(3), 281–290.

Askham, J. (1995). Making sense of dementia: Carers' perceptions. *Ageing & Society, 15*(1), 103–114. doi:10.1017/S0144686x00002142

Atkinson, P., & Silverman, D. (1997). Kundera's immortality: The interview society and the invention of the self. *Qualitative Inquiry, 3*(3), 304–325.

Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. *The Gerontologist, 26*(3), 267–272. doi:10.1093/geront/26.3.267

Clare, L., Goater, T., & Woods, B. (2006). Illness representations in early-stage dementia: A preliminary investigation. *International Journal of Geriatric Psychiatry, 21*(8), 761–767. doi:10.1002/gps.1558

Clare, L., Linden, D.E., Woods, R.T., Whitaker, R., Evans, S.J., Parkinson, C.H., ... Rugg, M.D. (2010). Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer disease: A single-blind randomized controlled trial of clinical efficacy. *The American Journal of Geriatric Psychiatry, 18*(10), 928–939. doi:10.1097/JGP.0b013e3181d5792a

Clare, L., Nelis, S.M., Martyr, A., Whitaker, C.J., Marková, I.S., Roth, I., ... Morris, R.G. (2012). Longitudinal trajectories of awareness in early-stage dementia. *Alzheimer Disease & Associated Disorders, 26*(2), 140–147. doi:10.1097/WAD.0b013e31822c55c4

Connell, C.M., Boise, L., Stuckey, J.C., Holmes, S.B., & Hudson, M.L. (2004). Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *The Gerontologist, 44*(4), 500–507. doi:10.1093/geront/44.4.500

Davis, D.H. (2004). Dementia: Sociological and philosophical constructions. *Social Science and Medicine, 58*, 369–278. doi:10.1016/S0277-9536(03)00202-8

Diefenbach, M.A., & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress and the Homeless, 5*(1), 11–37. doi:10.1007/BF02090456

Dilworth-Anderson, P., & Gibson, B.E. (2002). The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. *Alzheimer Disease and Associated Disorders, 16*(Suppl. 2), S56–S63. doi:10.1097/00002093-200200002-00005

Donovan, H.S., & Ward, S. (2001). A representational approach to patient education. *Journal of Nursing Scholarship, 33*(3), 211–216. doi:10.1111/j.1547-5069.2001.00211.x

Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*(3), 189–198. doi:10.1016/0022-3956(75)90026-6

Glidewell, L., Johnston, M., & Thomas, R. (2012). Shared understandings of dementia? An application of the common sense self-regulation model to a case study. *Dementia, 11*(2), 217–250. doi:10.1177/1471301211416611

Gray, H.L., Jimenez, D.E., Cucciare, M.A., Tong, H.Q., & Gallagher-Thompson, D. (2009). Ethnic differences in beliefs regarding Alzheimer disease among dementia family caregivers. *The American Journal of Geriatric Psychiatry, 17*(11), 925–933. doi:10.1097/JGP.0b013e3181ad4f3c

Hagger, M.S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health, 18*(2), 141–184. doi:10.1080/088704403100081321

Hampson, S.E., Glasgow, R.E., & Toobert, D.J. (1990). Personal models of diabetes and their relations to self-care activities. *Health Psychology, 9*(5), 632–646. doi:10.1037/0278-6133.9.5.632

Harman, G., & Clare, L. (2006). Illness representations and lived experience in early-stage dementia. *Qualitative Health Research, 16*(4), 484–502. doi:10.1177/1049732306286851

Heijmans, M., & de Ridder, D. (1998). Assessing illness representations of chronic illness: Explorations of their disease-specific nature. *Journal of Behavioral Medicine, 21*(5), 485–503. doi:10.1023/A:1018788427100

Hinton, W.L., & Levkoff, S. (1999). Constructing Alzheimer's: Narratives of lost identities, confusion and loneliness in old age. *Culture, Medicine and Psychiatry, 23*(4), 453–475. doi:10.1023/A:1005516002792

Hollway, W., & Jefferson, T. (1997). Eliciting narrative through the in-depth interview. *Qualitative Inquiry, 3*(1), 53–70.

Hsieh, H.-F., & Shannon, S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277–1288. doi:10.1177/1049732305276687

Kurz, A.F., & Lautenschlager, N.T. (2010). The concept of dementia: Retain, reframe, rename or replace? *International Psychogeriatrics, 22*(1), 37–42. doi:10.1017/S1041610209991013

Langdon, S.A., Eagle, A., & Warner, J. (2007). Making sense of dementia in the social world: A qualitative study. *Social Science and Medicine, 64*(4), 989–1000. doi:10.1016/j.socscimed.2006.10.029

Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M.A., Leventhal, E. A., Patrick-Miller, L., ... Keith, J. (1997). Illness representations: Theoretical foundations. In K.J. Petrie & J.A. Weinman (Eds.), *Perceptions of health and illness: Current research and applications*. London: Harwood Academic.

Lobban, F., Barrowclough, C., & Jones, S. (2003). A review of the role of illness models in severe mental illness. *Clinical Psychology Review, 23*(2), 171–196. doi:10.1016/S0272-7358(02)00230-1

- Martin-Cook, K., Remakel-Davis, B., Svetlik, D., Hynan, L.S., & Weiner, M.F. (2003). Caregiver attribution and resentment in dementia care. *American Journal of Alzheimers Disease and Other Dementias*, 18(6), 366–374.
- Matchwick, C., Domone, R., Leroi, I., & Simpson, J. (2014). Perceptions of cause and control in people with Alzheimer's disease. *The Gerontologist*, 54(2), 268–276. doi:10.1093/geront/gnt014
- Miles, M.B., & Huberman, A.M. (1994). *Qualitative data analysis*. Thousand Oaks, CA: Sage.
- Morgan, D.G., & Laing, G.P. (1991). The diagnosis of Alzheimer's disease: Spouse's perspectives. *Qualitative Health Research*, 1(3), 370–387. doi:10.1177/104973239100100306
- Moss-Morris, R., Weinman, J., Petrie, K.J., Horne, R., Cameron, L.D., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health*, 17(1), 1–16. doi:10.1080/08870440290001494
- Paton, J., Johnston, K., Katona, C., & Livingston, G. (2004). What causes problems in Alzheimer's disease: Attributions by caregivers. A qualitative study. *International Journal of Geriatric Psychiatry*, 19(6), 527–532. doi:10.1002/gps.1118
- Peel, E. (2014). 'The living death of Alzheimer's' versus 'take a walk to keep dementia at bay': Representations of dementia in print media and carer discourse. *Sociology of Health & Illness*, 36(6), 885–901. doi:10.1111/1467-9566.12122
- Peel, E. (2015). Diagnostic communication in the memory clinic: A conversation analytic perspective. *Aging & Mental Health*, 19(12), 1123–1130. doi:10.1080/13607863.2014.1003289
- Petrie, K.J., Jago, L.A., & Devcich, D.A. (2007). The role of illness perceptions in patients with medical conditions. *Current Opinions in Psychiatry*, 20, 163–167.
- Pill, R. & Scott, N.C.H. (1982). Concepts of illness causation and responsibility: Some preliminary data from a sample of working class mothers. *Social Science and Medicine*, 16(1), 43–52. doi:10.1016/0277-9536(82)90422-1
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and non-caregivers in psychological health and physical health: A meta analysis. *Psychology & Aging*, 18(2), 250–267. doi:10.1037/0882-7974.18.2.250
- Pinquart, M., & Sörensen, S. (2004). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: A meta-analytic comparison. *Aging & Mental Health*, 8(5), 438–449. doi:10.1080/13607860410001725036
- Prohaska, T.R., Keller, M.L., Leventhal, E.A., & Leventhal, H. (1987). Impact of symptoms and aging attribution on emotions and coping. *Health Psychology*, 6(6), 495–514. doi:10.1037/0278-6133.6.6.495
- Quinn, C., Clare, L., Pearce, A., & van Dijkhuizen, M. (2008). The experience of providing care in the early stages of dementia: An interpretative phenomenological analysis. *Aging & Mental Health*, 12(6), 769–778. doi:10.1080/13607860802380623
- Roberts, J.S., & Connell, C.M. (2000). Illness representations among first-degree relatives of people with Alzheimer disease. *Alzheimer Disease & Associated Disorders*, 14(3), 129–136.
- Rodakowski, J., Gentry, A., Garand, L., & Lingler, J.H. (2014). Attribution of mild cognitive impairment etiology in patients and their care partners. *International Journal of Geriatric Psychiatry*, 29(5), 464–469. doi:10.1002/gps.4028
- Searle, A., Norman, P., Thompson, R., & Vedhara, K. (2007). Illness representations among patients with type 2 diabetes and their partners: Relationships with self-management behaviors. *Journal of Psychosomatic Research*, 63(2), 175–184. doi:10.1016/j.psychores.2007.02.006
- Shiloh, S., Rashuk-Rosenthal, D., & Benyamini, Y. (2002). Illness causal attributions: An exploratory study of their structure and associations with other illness cognitions and perceptions of control. *Journal of Behavioral Medicine*, 25(4), 373–393. doi:10.1023/A:1015818532390
- Squire, C. (1999). "Neighbors who might become friends": Selves, genres, and citizenship in narratives of HIV. *The Sociological Quarterly*, 40(1), 109–137.
- Toms, G.R., Quinn, C., Anderson, D.E., & Clare, L. (2015). Help yourself: Perspectives on self-management from people with dementia and their caregivers. *Qualitative Health Research*, 25(1), 87–98. doi:10.1177/1049732314549604
- Werner, P. (2001). Correlates of family caregivers' knowledge about Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 16(1), 32–38. doi:10.1002/1099-1166(200101)16:13.0.Co;2-2
- WHO. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: Division of Mental Health, World Health Organisation.