I don't think of it as an illness': illness representations in mild to moderate dementia

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Abstract

The self-regulatory model proposes that illness representations influence adjustment and coping in chronic conditions. Better understanding of the illness representations held by people with dementia could help with targeting information and support so as to optimize adjustment and coping. In this mixed-methods study of illness representations among people with mild to moderate Alzheimer's, vascular or mixed dementia we aimed to clarify the nature of the representations held, to determine whether specific profiles can be identified based on perceptions of the identity and cause of the condition, and to examine associations between these profiles and other participant characteristics. Data were collected in the second wave of the Memory Impairment and Dementia Awareness Study (MIDAS). Sixty-four people with dementia, who had been told their diagnosis at a memory clinic, completed interviews and responded to questionnaires. In each case a carer was also interviewed. Cluster analysis based on responses about identity and cause identified three profiles. 'Illness' cluster participants saw themselves as living with an illness and used diagnostic labels, 'ageing' cluster participants did not use diagnostic labels and viewed their difficulties as related to ageing, and 'no problem' cluster participants considered that they did not have any difficulties. 'Illness' cluster participants had better cognition and better awareness, but lower mood, and perceived more practical consequences, than 'ageing' cluster participants. Holding an 'illness' model may not be advantageous. Rather than encouraging adoption of such a model, it may be preferable to target information and select interventions in line with the person's representation profile.

Key words

Aging

Awareness

Coping behavior

Dementia

Diagnosis

Psychological adjustment

People living with the early stages of dementia respond to the changes they experience in very different ways, with a continuum of response styles ranging from self-adjusting to self-maintaining [1-3]. Better understanding of these differences could make it possible to provide information and support in a way that fits with the individual's personal response style and relational context, and hence maximizes the likely benefits for adjustment and coping. One key element that determines how people respond to, and cope with, chronic conditions is their understanding of the condition, its implications, and what can be done about it. An influential approach to conceptualizing the way in which beliefs about a health condition relate to adjustment and coping is offered by the self-regulatory model (SRM) [4], which has been applied to a wide range of health conditions [5]. Central to this model is the development of illness representations, composed of perceptions of the identity of the condition, its putative cause(s), its likely course or timeline, the possibilities for cure or control, and its practical and emotional consequences [6]. Illness representations are reliably related, across a range of conditions, to well-being and mood [7], physical functioning [8], self-care, help-seeking and treatment adherence [9-10] and social functioning [11]. To optimize the potential for coping effectively, people with different types of illness representation may benefit from different approaches to provision of information, different kinds of communication in consultations, and access to different kinds of support and interventions.

Only a few studies have so far examined illness representations among people with dementia. Our preliminary studies indicated that the SRM provides a useful model for examining the illness representations held by people with early-stage dementia [12-13]. Several recent small-scale qualitative studies further support the relevance of illness representations for coping [14-16]. A key finding is that some people with dementia do not use diagnostic labels to describe their difficulties, and may view the difficulties as a natural part of the ageing process [12].

Perceptions of identity and cause crucially underpin and influence other elements of the illness representation, but in the case of dementia, for many people the representation of difficulties or symptoms may not incorporate a concept of illness at all. This has implications for communication about the diagnosis and the provision of post-diagnostic support. Furthermore, since other family members develop their own beliefs about the condition [17-18] and ways of coping [19-20], similarities and differences in perspective within patient-carer dyads also need to be taken into account [13, 21-22].

This paper presents findings from a study of illness representations among people with early-stage dementia and their family carers. The aim was to clarify the nature and implications of the illness representations held by people with dementia using constructs from the SRM, based on a larger sample than has been studied hitherto. Specific objectives were as follows:

- To determine whether distinct illness representation profiles can be identified based on perceptions of identity and cause.

- To determine how illness representation profiles relate to participant characteristics, cognitive function, awareness, response style, ways of coping, relationship quality and aspects of well-being.

- To examine whether differences in perspective between the person with dementia and the family carer regarding identity and cause are associated with differences in participant characteristics, cognitive function, relationship quality or aspects of well-being.

Materials and Methods

Design

We examined illness representations in a community-dwelling sample of people with mild to moderate Alzheimer's, vascular or mixed dementia participating in the Memory Impairment and Dementia Awareness Study (MIDAS), drawing on data from questionnaires and semi-structured interviews with participants and carers. MIDAS was a longitudinal, mixed-methods study of awareness [23]. People with early-stage dementia were assessed on entry (T1) and again at 12 (T2) and 20 month (T3) time-points. This paper presents data from T2. T1 interviews were also examined where necessary for purposes of clarification. Ethical approval for MIDAS was granted by the relevant University and NHS Ethics Committees.

Participants

MIDAS participants were recruited from Memory Clinics in North Wales, UK. Inclusion criteria were an ICD-10 diagnosis of Alzheimer's disease (AD), vascular dementia or mixed Alzheimer's and vascular dementia [24], a score of 18 or above on the Mini-Mental State Examination (MMSE) [25], ability to communicate verbally in English, and availability of a spouse, partner, other family member or friend who was willing to contribute. Exclusion criteria were concurrent major depression, psychosis or other neurological disorder, and past history of neurological disorder, stroke or brain injury. On entry to the study, participants had been diagnosed between 14 and 72 months previously. According to clinic records, all participants had been told their diagnosis by a member of the clinical team. At T2, 64 people with dementia provided data, and in each case the primary, usually family, carer was also

interviewed. Sample characteristics are summarized in Table 1. On entry to MIDAS, participants had MMSE scores of 18 or above; at T2, scores ranged from 8 to 30, with 56 (88%) having scores of 18 or above.

(((Table 1 near here)))

<u>Measures</u>

People with dementia and carers engaged in semi-structured interviews and completed questionnaires.

In the semi-structured interviews participants with dementia were first asked how they were feeling and whether and how things had changed since T1. They were then asked about their understanding of the condition with regard to the elements of the SRM, including identity, cause, possibilities for control, timeline and the impact and consequences of any difficulties or changes and how they coped with these. Interviews lasted between 6 and 40 minutes. Carers were first asked about how things had been for them and for the participants with dementia since T1, changes they had noticed in the participants, how these affected the participants, and their own reaction to the changes. They were then asked about their understanding of the condition with regard to the elements of the SRM, as above. Interviews lasted between 13 and 46 minutes. All interviews were conducted in a conversational manner. Sensitivity to the preferences and wishes of the participants and carers meant that some interviews did not cover all topic areas. Interviews were audio-recorded for later transcription.

Ratings of the response style of the person with dementia, conceptualized as reflecting awareness at the metacognitive level, made by MIDAS researchers who were not involved in the present analysis, were included. Response style was assessed by means of a global rating applied to the interview transcript, representing an evaluation of response style on a five-point scale from self-adjusting response style (extensive metacognitive awareness) to self-maintaining response style (no evidence of metacognitive awareness) [26].

Quality of life for the person with dementia was assessed with the Quality of Life in Alzheimer's disease (QoL-AD) scale [27]. Mood was assessed with the depression sub-scale of the Hospital Anxiety and Depression Scale (HADS) [28]. Perceived quality of relationship with the carer was assessed with the Positive Affect Index [29]. Memory awareness at the performance monitoring and evaluative judgement level [30] was assessed using the Memory Awareness Rating Scale - Memory Performance Scale (MARS-MPS) [31], as described by [26]; this incorporates administration of the Rivermead Behavioural Memory Test (RBMT) [32]. Awareness of functional ability at the evaluative judgement level was assessed in relation to everyday functioning with the Functional Activities Questionnaire (FAQ) [33], as outlined by [26].

Carers rated the perceived quality of their relationship with the person with dementia on the Positive Affect Index [29].

Data analysis

Interview data from the participants with dementia and carers were subjected to content analysis to identify responses relating to identity and cause. For participants with dementia,

content analysis also covered the other elements of the SRM: control, timeline, emotional and practical consequences, and emotional and practical coping. Inter-rater reliability checks were undertaken for identification of relevant extracts under each component, with 15% of interviews independently coded by two researchers; an acceptable level of 80% reliability was achieved [34-35]. A single researcher coded the remaining interviews. This yielded a listing of all the responses given by each participant in relation to each component of the SRM. The responses under each component were then grouped thematically into content categories providing a characterization of the illness representations elicited.

Cluster analysis based on average between-group linkage using squared Euclidean distance with a specified three-cluster solution elicited clusters derived from a combination of identity and cause. ANOVA and post-hoc Games-Howell tests were used to compare cluster groups with regard to the variables of interest and other elements of the illness representation profile. Responses to each element of the illness representation were categorized and ANOVA was used to compare groups based on these categories with regard to the variables of interest. All analyses were conducted in SPSS v.20.

Findings

Scores on the questionnaire measures and cognitive tests are summarized in Table 2. In describing their experience, 11 participants (17%) said that they did not experience any particular difficulties. Fifty-two participants (81%) mentioned memory difficulties or forgetfulness, and in addition 13 (20%) mentioned doing less or having difficulty with daily activities, 11 (17%) mentioned difficulty with thinking, attention or concentration, and 5 (8%) mentioned difficulty with conversation and word-finding. One participant mentioned only

conversation and word-finding. Twenty (31%) mentioned other significant health problems or physical disabilities, apart from dementia. Of 37 participants asked, 27 (73%) acknowledged that they had attended a memory clinic and spoke about their experiences, while 10 (27%) did not remember or did not acknowledge that they had been to a memory clinic.

(((Table 2 near here)))

Characterizing representations of identity and cause and associations with other factors

All the participants with dementia shared their perceptions of identity. Twenty-four (37.5%) used a diagnostic label such as 'dementia', 'Alzheimer's' or 'vascular dementia', 6 (9%) used a descriptive label such as 'memory loss', 24 (37.5%) had no label for their condition, and 10 (16%) thought there was no condition to label. Label was recoded for analysis into three categories: diagnostic label (n=24); no label or descriptive label (n=30); no problem to label (n=10). Groups based on label type differed significantly in age ($F_{2,61} = 8.16$, p = .001). Post hoc tests indicated that those using diagnostic labels were significantly younger than those using descriptive or no labels (p = .004) and those who perceived no problem (p = .007). Groups based on label also differed in quality of relationship with the carer ($F_{2,60} = 3.66$, p = .032), with those using descriptive or no labels reporting significantly better relationship quality than those who perceived no problem (p = .027). With regard to awareness of memory functioning ($F_{2,61} = 4.69$, p = .009), those perceiving no problem had significantly higher discrepancy scores (indicative of poorer awareness) than those using diagnostic labels (p = .007) or those using descriptive or no labels (p = .037). With regard to awareness of functional ability, those perceiving no problem had significantly higher discrepancy scores (indicative of poorer awareness) than those using diagnostic labels ($F_{2,60} = 4.69$, p = .009).

Carers were much more likely to use a diagnostic label; 52 of the 64 carers (81%) used a diagnostic label, 5 (8%) used a descriptive, symptom-related label and 7 (11%) had no label. Of the 64 participant-carer dyads, participants and carers fell into the same category in 28 cases (44%). In the 36 cases (56%) where members of the dyad used different types of label, the carers all used a diagnostic label while the person with dementia gave a symptom-related label, had no label, or did not perceive any problem requiring a label. Differences in type of label within the dyad were associated with older age in the person with dementia ($F_{1,62} = 11.89$, p = .001) and larger discrepancy scores for evaluative judgements about memory functioning ($F_{1,62} = 5.24$, p = .026) and functional ability ($F_{1,62} = 7.53$, p = .008).

Sixty-one participants with dementia were asked about perceived causes. Thirteen (21%) could not identify any possible causes, 17 (28%) attributed the condition to ageing alone, 21 (35%) gave a biological explanation, 5 (8%) gave a psychosocial or environmental explanation, and 5 (8%) mentioned both biological and psychosocial or environmental factors. In the latter three groups, some participants also mentioned the effects of age; in total 27 participants (44%) mentioned ageing as a cause. Information about perceived cause given by the person with dementia was recoded into three categories for analysis: no cause (n=14); ageing only (n=17); specific causes (n=30). Groups based on cause differed on MMSE score ($F_{2,59} = 6.77$, p = .002), with those giving no cause having significantly lower mean scores than those mentioning specific causes (p = .027).The groups based on cause also differed on awareness of memory functioning at the evaluative judgement level ($F_{2,59} = 3.60$, p = .034), with those mentioning ageing alone having significantly higher discrepancy scores than those mentioning other causes (p = .019).

Carers were also asked about perceived causes; 5 (14%) could not identify any possible causes, 2 (6%) mentioned ageing, 23 (64%) gave a biological explanation, 3 (8%) gave a psychosocial or environmental explanation, and 3 (8%) mentioned both biological and psychosocial or environmental factors.

Profiling illness representations based on identity and cause

For the participants with dementia, cluster analysis was applied combining the two variables of identity (diagnostic label, descriptive/no label, no problem) and cause (none, ageing only, other). A three-cluster solution encompassing 62 participants distinguished those who perceived no problem (n = 10) from the rest; these individuals, labelled the 'no problem' cluster, did not consider that they had any difficulties or symptoms, although they might acknowledge some minor age-related changes. Of the remaining two clusters, one was characterised by use of diagnostic labels and mention of biological or psychosocial/environmental causes, and was labelled the 'illness' cluster (n =29), and the other was characterized by having no or only descriptive labels and mention of only ageing as a cause or no cause, and was labelled the 'ageing' cluster (n = 23).

Mean scores on the questionnaires, awareness measures and cognitive tests for each cluster are shown in Table 2. The 'illness' cluster had better scores for cognition and awareness at the evaluative judgement and performance monitoring levels, but reported higher scores for depression and anxiety and lower scores for quality of life, than the other two groups. The three groups differed significantly on MMSE score ($F_{2,59} = 6.43$, p = .003), depression score ($F_{2,59} = 3.31$, p = .044), memory performance monitoring ($F_{2,59} = 3.55$, p = .035), discrepancy scores for memory functioning ($F_{2,59} = 6.35$, p = .003) and discrepancy scores for awareness

of functional ability ($F_{2,59}$= 3.43, p = .039). Post hoc tests showed that the 'illness' cluster scored better on the MMSE (p = .026), and had higher depression scores (p=.043), than the 'ageing' cluster. The 'illness' cluster also had higher MMSE scores (p = .014), and greater awareness at the evaluative judgement level in relation to memory (p = .003) and functional ability (p = .023), than the 'no problem' cluster. The 'ageing' cluster had higher relationship satisfaction than the 'no problem' cluster (p = .013).

The global interview rating reflecting the continuum of response styles (self-maintaining to self-adjusting) was associated with significant differences in the distribution of response styles across the three clusters (Chi-square df_2 = 36.71, p <.001). As shown in Figure 1, the 'illness' cluster participants were more likely to display a self-adjusting response style and the 'no problem' cluster participants were more likely to display a self-maintaining response style, while the 'ageing' cluster participants tended to fall in the middle of the continuum.

(((Figure 1 near here)))

The clusters differed significantly on dyadic agreement about labels for the condition, with participants in the 'illness' cluster most likely and those in the 'no problem' cluster least likely to use the same label as the carer (Chi-square df_2 = 12.53, p = .002). There were no significant differences between the clusters in relation to gender, education or social class.

Other components of the illness representation

For the participants with dementia, we examined the other components of the illness representation in relation to the emergent clusters based on identity and cause. The findings are summarized in Table 3.

(((Table 3 near here)))

Timeline was examined in relation to both the perceived trajectory over the past year and expectations of the future. Timeline past was recoded for analysis into two categories: got worse (n=26); no change or improved (n= 29). Timeline future was recoded for analysis into two categories: get worse (n=13); stay the same or get better (n=24). There were no significant differences between the groups for timeline past or timeline future on any measure, and nor were there any significant differences between the three clusters in timeline responses.

Control was examined in relation to things that individuals or others could do to help manage the condition. Responses about what individuals or others could do were recoded into two categories for analysis: possibilities for control mentioned (n=24); no possibilities for control mentioned (n=15). These two groups differed significantly on MMSE score ($F_{1,38} = 5.59$, $p = .023$), with those who mentioned possibilities for control scoring higher. There were no significant differences between the three clusters in responses about control. The experience of using dementia medication was also examined. Of 16 participants who correctly indicated that they were taking donepezil or rivastigmine and commented on efficacy, 8 thought the medication was helping a little, 1 thought it was not helping, and 7 did not know.

Emotional consequences included anger, sadness, worry, embarrassment and loss of confidence. Comparing those who did (n = 37) and did not (n = 15) describe emotional consequences, the two groups differed significantly in relationship quality ($F_{1,51}$ = 7.05, p =.011), with those who acknowledged emotional consequences reporting better relationship quality. There were no significant differences between the three clusters with regard to emotional consequences.

Practical consequences included interacting less with others, restrictions in activity, noticing that people treat you differently, doing less, and finding that carers impose restrictions or are critical. Comparing those who did (n = 27) and did not (n = 14) describe practical consequences, the two groups differed significantly on the depression measure ($F_{1,39}$ = 4.78, p = .035) with those who acknowledged practical consequences scoring higher for depression. There were significant differences between the three clusters in reporting of practical consequences (chi-square df $_2$ = 12.27, p = .002). Further comparison of the 'illness' and 'ageing' clusters indicated that the 'illness' cluster participants were significantly more likely than the 'ageing' cluster participants to describe practical consequences of the condition (Fisher's exact test, df $_1$, p= .003).

Characterizing emotional and practical coping

Findings on coping are summarized in Table 4. Use of one or more emotional coping strategies was described by 38 of 42 participants asked (91%). The emotional coping strategies that participants described were grouped into four sub-categories: accepting, warding off, minimizing and fighting. Accepting included taking things as they come, making

the best of things and being positive. Warding off included not thinking or worrying about the situation, and hoping things would improve. Minimizing included regarding difficulties as nothing serious, laughing things off, and acknowledging that others are worse off. Fighting was mentioned by only one participant. Use of at least one practical coping strategy was described by 38 of 45 participants asked (84%). Practical coping strategies were grouped into two sub-categories. General strategies included being open with others, keeping busy, seeking out information and getting practical help. Memory strategies included writing things down or making lists, using a diary or calendar, allowing enough time to retrieve information from memory, and making mental associations. Findings are summarized in Table 4.

(((Table 4 near here)))

There were no significant differences between the clusters in reporting of emotional coping strategies. There were significant differences between the clusters in reporting of practical coping strategies (Chi-square df $_2$ = 17.82, p <.001), but no significant differences when comparing just the 'illness' and 'ageing' clusters, indicating that differences were attributable to lower reporting of practical coping strategies in the 'no problem' cluster.

Discussion

This is among the first studies to apply the SRM in order to develop an understanding of the illness representations held by people with mild to moderate dementia, and is the first to do so using mixed methods in a relatively large and otherwise well-characterized sample. Among this sample of people diagnosed with dementia, all previously informed of the diagnosis, we identified three groups with different illness representation profiles. One group viewed the

condition as an illness, used diagnostic labels and focused on possible causes over and above the link to ageing. These individuals were the most likely to display a self-adjusting response style and were the most accurate in evaluating their own memory performance, but reported more practical consequences and lower mood. A second group viewed the condition as a part of, or caused by, ageing, and were unlikely to use diagnostic labels. These individuals displayed a mixture of response styles from somewhat self-adjusting to somewhat self-maintaining, and were less accurate in evaluating their memory performance. A smaller, third group considered that they did not have a problem beyond dealing with any minor age-related changes. They displayed a self-maintaining response style and would generally be described as showing limited awareness regarding their own performance or functioning. In summary, those whose representations of the condition were more related to viewing it as an illness had better cognition and better awareness at the performance monitoring level, but lower mood, and perceived more practical consequences, than those whose representations were more aligned with viewing the condition as part of the ageing process.

It was possible to elicit participants' views and experiences under each of the components of the illness representation, and this together with the identification of meaningful associations, for example with cognition, mood or response style, supports the utility of the theoretical construct. This is in line with previous findings [12-16]. However, only one of the three resulting profiles, that of the 'illness' group, can strictly be referred to as an 'illness' representation, since those in the 'ageing' group regarded any difficulties as a result of ageing without resorting to using diagnostic categories to explain them, and those in the 'no problem' group did not consider that they had any particular difficulties. A striking feature of these accounts from people experiencing mild to moderate dementia is the extent to which an illness-related perspective is absent. Nearly two-thirds of participants with dementia did not

acknowledge or use a diagnostic label, and nearly half either attributed the condition to ageing or did not identify any cause. As with some other complex conditions, uncertainty is common, and may be important as it allows people to continue to hope [36].

Views about identity and cause were the only elements associated with awareness in terms of accuracy of evaluative judgements about memory and everyday functioning. With regard to the control and consequences aspects of the illness representation and ways of coping, responses from people who viewed the condition as an illness and those who viewed it as a normal part of ageing may have been based on different concepts, but in practice were not markedly different, except that the 'illness' group, being more aware of difficulties, tended to describe more practical consequences. It is to be expected that people may perceive some overlap between the kinds of changes that people may expect to experience with age and the symptoms of early-stage dementia, especially with regard to memory. When discussing control and consequences, and also coping, participants are likely to have focused on these specific changes and their impact, thus limiting the potential for differences in response. When discussing control, more than one in three thought that nothing could be done to help, although contrary to earlier findings [12] this was not associated with higher depression scores.

Despite the widespread view that nothing could be done to help, most participants described some practical coping strategies, often specific to dealing with memory problems. Perhaps most illuminating, however, was the strong emphasis on the use of emotion-focused coping strategies to minimize the emotional impact of changes and symptoms. Emotion-focused coping styles involve creating a perception of the situation that allows it to be experienced as more favorable, or at any rate less unfavorable, and can be contrasted with problem-focused

styles that involve actively confronting the situation and trying to manage it [37]. Only one person spoke, somewhat tentatively, about trying to 'fight' the condition. Participants' preferred stance involved accepting what they saw as inevitable, trying not to think about the condition or let it worry them, and making light of any resulting difficulties. Related to this, with regard to timeline, although expectations of both ageing and dementia might naturally involve some element of decline over time, three-quarters did not explicitly acknowledge that symptoms or difficulties would get worse; this could also be viewed as a form of emotion-focused coping strategy, again pointing to the importance of continuing to hope [36]. While people with dementia are increasingly taking an active role in tackling and managing the effects of the condition, and seeking to inform themselves about how to live with the condition and cope effectively, the nature of the emotion-focused strategies described in this sample suggests that this is far from the norm, and that some of the available small-scale qualitative studies may, through selective recruiting, focus disproportionately on participants who tend to cope by actively seeking information and trying to confront or fight the challenges the condition presents.

Given that many people diagnosed with dementia do not conceptualize the condition in terms of illness or disease, it may be more helpful to think in terms of 'dementia representations' rather than 'illness representations', and to adopt this terminology in future work. Dementia differs in certain crucial ways from many other chronic health conditions. It is clearly closely associated with ageing, it is variously viewed among researchers as a distinct illness or as one end of a continuum of the ageing process [38], and the extent to which individuals are able to show awareness of symptoms and changes associated with dementia varies considerably, whether due to neurological changes, psychological processes or aspects of the social context [26]. Furthermore, in the case of dementia the slow insidious onset of the condition in the

context of age-related change means that it does not necessarily match standard expectations of an illness. Other studies have shown that relatively few individuals with dementia use specific diagnostic labels to describe their condition [1], often focusing instead on the changes they experience, describing features such as memory loss or activity restriction [39]. The current findings support the view that label and cause are key elements in defining the broad dementia representation profile, while control, consequences, timeline and coping (with timeline possibly serving as a sub-element of emotional coping) provide valuable information about adjustment to the challenges of developing and living with dementia.

With regard to dementia representations identified by eliciting views about label and cause, and leaving aside the small proportion of people with dementia who consider that there is nothing wrong, a key question is whether it is advantageous for individuals to hold an 'illness' model rather than an 'ageing' model. There is little in the present findings to suggest that using a diagnostic label and acknowledging specific causal mechanisms is beneficial, or that people who do not make sense of the condition in this way are disadvantaged in any particular respect, or that disagreement between person with dementia and carer as to whether to use a diagnostic label has a significant impact on perceptions of relationship quality. Interventions targeting change in illness representations can play an important role in improving self-management in some chronic conditions [40], but the present findings do not suggest that we should aim to alter representations of dementia to fit an 'illness' model. Rather, it would seem more appropriate to identify the type of dementia representation that a person holds, to target information or advice accordingly, and to hold this in mind when considering what sorts of interventions may be helpful. There is evidence that brief training that enables health professionals to focus on an individual's illness representations can enhance communication within consultations and improve compliance with advice in other chronic conditions [41].

For those with an 'ageing' representation profile, information and advice could be organized around the premise that the ageing process does not affect everyone in the same way and some people develop particular kinds of difficulties in the course of that process. Self-management or support groups that focus on the diagnosis and its implications may be unhelpful for, or seem irrelevant to, those who hold an 'ageing' representation, and may be more usefully targeted specifically at those who hold an 'illness' representation.

With regard to adjustment, whether or not the condition is viewed as an illness, the evident widespread use of emotion-focused coping combined with some application of practical strategies for dealing with the consequences has important implications for the way in which information is given and for the kind of support offered. The use of emotion-focused coping strategies, such as choosing not to think about the situation or telling oneself that things will not get worse, may make daily life more manageable and less uncomfortable. However, it also limits the possibilities for confronting the implications of the situation and planning for the future. Challenging this coping style may risk harmful effects on mood, and needs to be handled very sensitively, although psychotherapeutic group approaches may be beneficial in helping some individuals to move to a greater acknowledgement of their situation [42]. On the other hand, the observation that most people are able to identify practical coping strategies suggests that advice and interventions focused on developing practical ways of managing difficulties, without necessarily emphasizing diagnostic labels or enforcing an 'illness' model, could be helpful to many.

It is often assumed that acceptance of the diagnosis will be beneficial, and indeed this may be an aim of some post-diagnostic groups. For example, one group intervention 'utilized a recovery model of mental health, which emphasizes the importance of helping participants to

find meaning in life, achieving acceptance of their illness and through this to renew hope'
(p.528) [43]. The assimilation process for some individuals may involve an oscillation
between awareness and denial, with some preferring not to explicitly acknowledge their
dementia [44]. Given that mood was better in those who did not show acceptance of a
diagnosis, our results, from a much larger sample, similarly challenge the presumption, often
taken for granted, that acceptance of diagnosis is both desirable and essential to adjustment,
and have important implications for the development of post-diagnostic support for people
with dementia and their carers.

There are some limitations to this study. Participants were recruited from memory clinics,
where they received a diagnosis. All participants had been given the diagnosis in a face-to-
face meeting with a clinician, with a carer present, but we do not know exactly what was
communicated or in what way the information was presented. It is a difficult task to give a
diagnosis of dementia [45] and in some cases communication may have been indirect, with
euphemisms used. If so, this could be expected to have influenced the person's subsequent
understanding of the condition. However, the frequent use of diagnostic labels among the
carers suggests that in general diagnoses had been communicated directly, although carers
may subsequently have chosen not to use a diagnostic label when talking with the person with
dementia. In some cases interviews did not cover all topic areas, and it would have been
preferable to have responses for each element of the model for all participants. However, the
omissions related to burden on participants in the context of the wider MIDAS study, and
hence could not be avoided. Some participants did not consider that they had any difficulties
and as a result of this a few interviews were particularly short. Statistical power for some
analyses may have been limited, meaning that some positive associations may have been
missed. Drawing on the second wave of a longitudinal study meant that whereas all

participants were initially recruited as meeting criteria for early-stage dementia, due to decline in cognitive ability a small number of participants would be more appropriately described as being in the moderate stages at the time of the interview. These participants were retained in the sample as their interview responses were considered valid, but as they formed only a small proportion of the sample caution is needed when drawing any general conclusions about people with moderate dementia. It should also be noted that validity of some measures, such as the HADS, for people with moderate dementia has not been fully established. The development of beliefs about the condition may be influenced by factors that were not explored in this study, such as personal circumstances and social and cultural background [18, 46]. This study yielded no differences relating to gender, education or social class, but further investigation with a larger sample may provide further evidence about the importance of these and other relevant factors.

Conclusions

Illness representations, in this context better termed 'dementia representations', can be elicited from people with mild to moderate dementia in line with the SRM. Three broad profiles can be identified, with individuals either adopting an illness model, viewing any changes as part of the ageing process, or expressing the view that they do not have any difficulties. There seem to be no particular benefits associated with holding an illness model, and therefore attempts to alter a person's dementia representations to fit this model are not indicated, especially given the widespread use of emotion-focused coping. Rather, it may be helpful for information and advice to be targeted in line with the person's dementia representation profile, and for this profile to be taken into account when considering which types of intervention and support may be appropriate.

Acknowledgements

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Table 1. Sample characteristics (n = 64)

	Mean	Range	S.D.
Age	78.41	52 – 92	8.57
Years of education	11.89	8 – 19	2.73
MMSE score	22.83	8 – 30	4.81
Carer age	66.48	34 - 91	14.54
	Frequency (%)		
Gender	34 female (53%) 30 male (47%)		
Social class (based on occupation)	4 professional (6%) 19 managerial and technical (30%) 18 skilled non-manual (28%) 9 skilled manual (14%) 11 partly skilled (17%) 3 unskilled (5%)		
Diagnosis	38 Alzheimer's (59%) 14 vascular dementia (22%) 12 mixed dementia (19%)		
Medication for dementia – donepezil/rivastigmine/galantamine	34 on medication (47%) 30 not on medication (53%)		
Carer gender	42 female (66%) 22 male (34%)		
Carer relationship to participant with dementia	Spouse or partner 37 (58%) Daughter/son 19 (30%) Sibling 2 (3%) Niece/Nephew 3 (4.50%) Friend 3 (4.50%)		

Table 2. Scores on all measures for the whole sample and for the three sub-groups identified by the cluster analysis

	Whole sample n = 64	'Illness' cluster n = 29	'Ageing' cluster n = 23	'No problem' cluster n = 10
Quality of life – QoL-AD	36.53±5.61	35.83±5.88	37.57±4.41	38.20±5.92
Depression – HADS	4.56±3.47	5.52±3.62	3.39±2.57	3.40±3.53
Anxiety – HADS	5.64±3.42	6.28±3.92	4.61±2.79	5.60±2.76
General cognition – MMSE	22.83±4.81	24.90±3.71	21.35±5.33	20.00±4.19
Memory awareness at the performance monitoring level – Memory Performance Ratio*	3.70±3.56	2.55±2.24	5.13±4.79	4.27±2.59
Memory awareness at the evaluative judgement level – Memory Functioning Discrepancy*	.57±.63	.37±.50	.71±.64	1.07±.48
Awareness of functional ability at the evaluative judgement level – Functional Ability Discrepancy*	.78±.71	.63±.75	.88±.53	1.24±.50
Relationship quality – PAI	23.94±3.99	23.75±4.72	25.52±2.41	21.30±3.59
Carer report of relationship quality – PAI	22.81±4.54	22.83±5.14	22.09±3.57	23.40±4.77

Lower ratio and discrepancy scores are taken to indicate greater awareness

Table 3. Illness representation components for the whole sample (n = 64) and the illness (n = 29), ageing (n = 23) and no problem (n = 10) clusters

	N asked		Whole sample N (%)	Illness Cluster N	Ageing Cluster N	No problem Cluster N
Timeline past	60	Got better	3 (5)	3	0	0
		No change	26 (43)	9	8	9
		Got worse	26 (43)	15	10	1
		Don't know	5 (9)	1	4	0
Timeline future	49	Get better	4 (8)	2	2	0
		No change	20 (41)	7	10	3
		Get worse	13 (27)	8	2	3
		Don't know/don't want to think about it	12 (24)	8	2	2
Control	41	Possible	24 (58)	13	10	1
		Not possible	15 (37)	7	4	4
		Don't know	2 (5)	1	1	0
Control – use of medication	44	Taking medication	18 (41)	12	5	1
		Not taking medication	16 (36)	7	6	3
		Don't know	3 (7)	0	3	0
		Inaccurate response	7 (16)*	0	4	3
Consequences - emotional	52	Emotional consequences perceived	37 (71)	22	14	1
		No emotional consequences perceived	15 (29)	5	5	5
Consequences – practical	41	Practical consequences perceived	27 (66)	18	6	1
		No practical consequences perceived	14 (34)	2	9	3
Coping – emotional	42	Emotional coping strategies described	38 (90)	18	13	5
		No emotional coping strategies described	4 (10)	1	1	2
Coping – practical	45	Practical coping strategies described	38 (84)	22	15	1
		No practical strategies described	7 (16)	1	2	4

Includes 5 who thought they were taking medication but were not, and 2 who thought they were not taking medication but were

Table 4. Use of emotional and practical coping strategies for the whole sample (n = 64) and the illness (n = 29), ageing (n = 23) and no problem (n = 10) clusters

	N asked		Whole sample N (%)	Illness Cluster N	Ageing Cluster N	No problem Cluster N
Emotional coping*	42	Accepting	24 (63)	12	9	2
		Warding off	21 (55)	8	8	4
		Minimising	16 (42)	9	4	3
		Fighting	1 (3)	1	0	0
Practical coping*	45	General strategies	22 (58)	14	8	0
		Memory strategies	26 (68)	13	12	1

Participants could report strategies in more than one category for both emotional and practical coping

Figure 1 Response styles in the three illness representation clusters