Beliefs About Dementia: Development and Validation of the Representations and Adjustment to Dementia Index (RADIX)

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Objectives: *The Self-Regulation Model (SRM) identifies that the beliefs people hold about an illness can influence their responses to that illness. Although there are generic measures of illness representations, there is a need for a brief tailored measure to use with people with dementia. The aim of this study was to develop and validate a brief measure called the Representations and Adjustment to Dementia Index (RADIX). The RADIX contains questions on the SRM elements: Identity, Cause, Timeline, Control, and Consequences.* **Methods:** *The RADIX validation was conducted with a sample of 385 community-dwelling people with mild to moderate dementia who were taking part in the IDEAL cohort study. Test–retest reliability was conducted over a 4-week period with a separate sample of 20 people with dementia.* **Results:** *The validation process resulted in a reduction in the number of items in the Timeline, Control, and Consequences items. The resulting RADIX demonstrated good acceptability, internal reliability, and test–retest reliability. All the RADIX items had low missing data, indicating good acceptability. The factor analysis confirmed that the Consequences items formed two subscales (practical and emotional consequences) that had Cronbach's α of 8 and 0.91 respectively. Test–retest reliability indicated that the Identity, Timeline, and Control items had moderate reliability and the practical and emotional consequences scales had good reliability.* **Conclusions:** *The RADIX demonstrates acceptable psychometric properties, proves to be a useful measure for exploring people's beliefs about dementia, and could aid the provision of tailored information and support to people with dementia.* (Am J Geriatr Psychiatry 2018; 26:680–689)

Key Words: Alzheimer, illness representations, illness perception, questionnaire, reliability, validity

Highlights

- We developed and validated a measure exploring the beliefs held by people with dementia about their condition, the Representations and Adjustment to Dementia Index (RADIX).
- The RADIX demonstrated acceptable psychometric properties, with good acceptability, internal reliability, and test-retest reliability.

- People with dementia were more likely to use a descriptive term relating to dementia symptoms to describe their condition.
- People with dementia were uncertain about the causes of their condition, and either attributed difficulties to aging or changes in the brain, or were unclear about the cause.
- The RADIX could aid healthcare professionals to provide more personalized information and support for people with dementia.

The beliefs people hold about an illness can impact on their emotional reactions to that illness, their behavior, and their coping responses. These beliefs also shape the manner in which people attempt to make sense of their symptoms. The processes by which this occurs have been described in the Self-Regulation Model (SRM). A key concept of the SRM is that a person creates mental representations of their illness, referred to as illness representations (IRs). These have five components: the Identity the person assigns the illness, and the subsequent beliefs about Cause, Timeline, Cure/Control, and Consequences.[1,2] Support for the SRM has come from research linking IRs and outcomes such as help-seeking, coping, illness management, and well-being.[2–4] Typically, IRs have been measured using generic IR questionnaires that have been used in a variety of medical conditions.[5–7]

The SRM could offer a useful model for examining people's beliefs about dementia and the impact of these on subsequent adjustment. The SRM has been applied to explore beliefs about dementia in carers[8,9] and the general public.[10,11] Only a few studies, however, have explored the beliefs held by people with dementia.[12,13] Although there are existing questionnaires to measure IRs,[5–7] these would not be appropriate for use with people with dementia, particularly as there can be challenges to exploring people's beliefs about dementia. Dementia is very different from other previously studied conditions. It is not a clearly defined disease but an umbrella term for the end pathway of a number of conditions. It is also an age-related condition, and beliefs about aging may include expectations of cognitive and functional decline, which could obviate an understanding of changes in terms of "illness" or "disease". People with dementia vary in awareness of their condition or the resulting symptoms,[14,15] due either to cognitive changes or to psychological processes whereby information about the diagnosis, the condition, or its impact is minimized, warded off, or avoided.[16] The person's understanding of the condition may also be influenced by the views of professionals or carers.[9,17,18] Thus, people with dementia will have varied understandings of their condition and some will have no awareness of any difficulties or changes. Consequently, rather than thinking in terms of IRs it may be more appropriate to focus on "dementia representations" (DRs).[13]

Qualitative studies have provided insights into the DRs held by people with dementia. They show that people with dementia are more likely to use descriptive terms such as "memory loss" to refer to their condition than diagnostic terms such as "Alzheimer disease".[12,13] People with dementia may attribute the cause of their condition to one of a diverse range of factors and may identify multiple consequences of having the condition.[8,12,13,19,20] In terms of timeline and control, whereas some acknowledge that they have a deteriorating condition, others believe their condition will remain stable.[12,13,19,20]

Although qualitative studies provide valuable insights, the nature of data collection means it can be challenging to use this approach with large samples. In addition, the quantity and quality of information elicited about IRs using this approach can be variable.[7] Furthermore, quantitative approaches are needed to explore how DRs are linked to well-being and other outcomes. Nevertheless, only one study has applied quantitative methods to examine DRs in people with dementia. This was achieved by quantifying responses obtained in qualitative interviews and associating the resulting data with responses on measures. Those people with dementia who used a diagnostic label for their condition and reported more practical consequences had higher levels of depressive symptoms. These results provide preliminary evidence that DRs are associated with well-being.

To fully explore the impact of DRs held by people with dementia requires a more standardized quantitative data collection approach, yet, for the reasons just outlined, existing measures of IRs are not suitable for

exploring DRs. In particular, people with dementia can lack awareness of difficulties or changes, and a measure of DRs would need to identity those who lack this awareness. Otherwise it would not be clear if the person was responding to the questions in relation to their dementia or in relation to other difficulties or perceptions of the aging process. The available evidence suggests that to fully explore DRs in people with dementia it is necessary to develop a new tailored measure. This would build on research in the mental health field that has led to the development and use of specific IR measures.[21,22] In this study we aimed to develop and validate a brief new DR measure, the Representations and Adjustment to Dementia Index (RADIX).

METHODS

Stage 1: Development of the RADIX

Item Content

To develop the RADIX item content we examined the categories from our qualitative analysis of DRs in people with dementia.[13] Sixty-four people with mild to moderate dementia were interviewed about their understanding of the condition, exploring each of the five SRM elements. Interview transcripts were subject to content analysis[23] to identify categories relevant to the SRM. These were used to generate a pool of items for the RADIX, using the participants' own words where possible to develop the question wording.

Structure of the RADIX

To develop the RADIX structure we examined existing IRs measures,[5–7] including those tailored to specific conditions.[21,24] Given the cognitive challenges faced by people with dementia, we wanted to develop a brief and accessible measure.

The next stage involved considering several dementia-specific issues in developing the RADIX. A small proportion of people with dementia do not think that they have an illness or any difficulties.[14,15] For example, in one study, when asked about their condition, 10% of people with dementia reported that they had "no problem" and were not experiencing any difficulties or changes.[13] Therefore, DR questions would not be appropriate for these individuals. Accordingly,

initial screening questions were developed to identify such individuals and ensure that they would not be administered the rest of the questionnaire.

Additionally, whereas IRs measures typically explore illness "identity" through the number of symptoms endorsed, in dementia it is more appropriate to explore the terms the person uses to describe the condition.[13] This also allows for the wording of subsequent questions to be tailored accordingly; for example, if the person uses the term "memory problems", the interviewer can adopt this term when asking about cause and so on. Lastly, building on our qualitative work,[9,13] we added a question to determine whether, irrespective of the term used to indicate identity, the person was aware of a specific diagnosis given by a health professional.

Item Format

The final structure of the RADIX includes a screening checklist, followed by questions covering the five SRM categories: Identity, Cause, Timeline, Control, and Consequences.

Section 1: Screening Checklist

The screening checklist contained nine questions requiring a yes/no answer concerning changes the participant might be experiencing; for example, "Have you, a family member, or doctor noticed that you have been having difficulty with concentration?" If the participant responded "yes" to one or more items then section 2 of the RADIX was administered.

Section 2: RADIX

The Identity and Cause questions were open-ended, to tap into the perspective of the person with dementia. If the person was unable to generate a cause, however, then they could choose from a list of possible causes, developed from the categories from our qualitative analysis.[13] For the Timeline items, we were mindful of question sensitivity and the potential for impaired prospection.[25] Thus, we developed different wordings for these questions to identify the best approach. The Timeline and Control questions were rated on a 4-point Likert scale. Questions on Consequences were designed to explore both practical and

emotional consequences, again rated on a 4-point Likert scale. Following the scoring system for existing IR measures, we planned to generate a mean score for both practical and emotional consequences.

Piloting of the RADIX

We sought expert opinion from researchers in the dementia field on the initial questionnaire, which informed a reduction in the number of items. Feedback was also provided by the IDEAL study engagement group (the ALWAYs group), which consists of people with dementia and informal carers.[26] The group provided suggestions to improve the wording of the RADIX instructions and make these more accessible.

The preliminary version of the RADIX was piloted with five people with dementia to check content validity by exploring question comprehensibility and acceptability. The piloting indicated that participants were able to respond to all the questions, but indicated that we needed to consider what to do if participants could not generate an "identity" for their condition. It was decided that in this case the person administering the RADIX could use the term "your condition" or "your difficulties" in subsequent questions. We selected these terms as they were consistent with terms already used in the RADIX. The screening checklist refers to "difficulties" and the Identity question gives the researcher the option of using the terms "difficulties" or "condition".

Stage 2: Validation of the RADIX

Participants

Details of the participants are provided in Table 1.

Participants for the study were the first 385 people with mild to moderate dementia (Mini-Mental State Examination sore, mean: 23.03, SD: 3.73) in the IDEAL cohort[26] at Time 1 who were administered the full questionnaire. This number is greater than the minimum size of 300 suggested for factor analysis where there are low communalities and a small number of loadings.[27]

We recruited an additional sample to assess the test–retest reliability of the RADIX. Participants with mild to moderate dementia were identified from Join Dementia Research, which is a United Kingdom–based online service that enables volunteers with dementia

TABLE 1. Characteristics of the Study Participants with Dementia

Characteristics	N
Validation study (N = 385)	
Sex: Female, N (%)	165 (42.9)
Age in years, mean (SD)	76.25 (8.16)
Ethnicity[a]: White British (%)	370 (96.1)
Other (%)	10 (2.63)
Diagnosis: Alzheimer disease	235 (61)
Mixed dementia	72 (18.7)
Vascular dementia	38 (9.9)
Frontotemporal dementia	9 (2.3)
Parkinson disease dementia	10 (2.6)
Lewy body dementia	10 (2.6)
Unspecified dementia	9 (2.3)
Other dementia	2 (0.5)
Length of time since diagnosis in years, mean (SD)	1.4 (SD 1.4)
Test–retest study (N = 20)	
Sex: Female, N (%)	9 (45)
Age in years, mean (SD)	70.11 (9.96)
Ethnicity: White British (%)	20 (100)
Diagnosis: Alzheimer disease	10 (50)
Mixed dementia	7 (35)
Vascular dementia	3 (15)
Length of time since diagnosis in years, mean (SD)	3.1 (SD 1.67)

[a]Missing data for 5 participants.

to register their interest in taking part in research. The sample size was determined based on similar studies exploring test–retest reliability.[22]

Analysis

As the RADIX contains several subscales covering different DR components (which use different measurement techniques), these have been validated separately. The RADIX validation involved several stages; data analysis was an iterative process whereby analyses were re-run each time an item was removed (Table 2 has details of the removed items). All statistical analyses were conducted using SPSS version 23 (IBM, Armonk, NY).

Validation of the Screening Checklist

Similar to the validation of the identity subscale in the Revised Illness Perception Questionnaire,[6] to explore the acceptability of these items we investigated the frequency checklist items were endorsed by participants. We explored the internal reliability of the scale using the Cronbach α coefficient and the item-total correlations (an acceptable level is ≥0.025, per Lamping

TABLE 2.   RADIX Item Reduction Process

Item Dropped	Rationale
Control: There are medications available to help control my [identity label]	11.5% missing data
Control: Nothing I do will affect my [identity]	8.5% missing data, poor test–retest reliability
Consequences: My [identity label] does not have much effect on my life	Did not associate with other items in the expected direction
Consequences: Despite my [identity label] I feel I am the same person as I used to be	Low communality with other items in factor analysis
Consequences: My [identity label] does not cause any difficulties for family/friends	Low communality with other items in factor analysis

et al.[28]). To examine the effectiveness of the screening in excluding participants who considered that they were not experiencing any difficulties, we examined the Identity data to check whether any participants reported at this stage that they did not have a problem or any difficulties. In the analysis of responses on Identity in Clare et al.,[13] 10% of participants reported that they had "no problem".

Validation of Identity and Cause Sections

Responses to the open-ended questions on Identity and Cause were analyzed using directed content analysis.[23] The data were coded by one person and checked by two other people, and any coding disagreements were discussed in order to reach consensus. We explored the acceptability by examining the amount of missing data; an acceptable level is less than 5%.[28] The second part of the Cause subscale, in which the person has the option to select from a list provided, was validated by examining whether the categories mapped onto the findings from analysis of the first part of the Cause question.

Validation of Timeline Section

We initially developed three items reflecting different possible Timeline outcomes, each rated on a 4-point Likert scale, to identify the best approach in asking about this element. As we noted that participants could be inconsistent in responses to items, we decided to modify the questions by converting them into a single Timeline question with categorical response options (get better, stay the same as it is now, get worse, unsure). We recoded participants' responses to map them onto these new options. For example, those who agreed their condition would "get better" and

disagreed it would "get worse" or "stay the same" were coded as "get better". Discordant responses, for example, agreeing their condition would both "get better" and "stay the same" were coded as "unsure". We explored the acceptability of these new categories by examining whether the amount of missing data was above the acceptable level of less than 5%.[28]

Validation of Control and Consequences Sections

The Consequences items were designed to explore both practical and emotional consequences. To test the construct validity of the Consequences items we utilized exploratory factor analysis using principal components analysis (PCA). Sampling adequacy was assessed using the Kaiser-Meyer-Oblin test and Bartlett's test of sphericity. The results of the Kaiser-Meyer-Oblin (0.851) and the Bartlett test ($\chi^2 = 833.95$, $p \leq 0.001$, $df = 36$) indicated that PCA was appropriate. The PCA was run with both Varimax (orthogonal) and Oblim (oblique) rotation.[27] The findings indicated that the factors were not strongly related, and thus a Varimax rotation was selected. After running the analysis, retaining only factors with an eigenvalue greater than 1, the number of factors retained was guided by the results of the scree test[29] and parallel analysis.[30] Items were examined for low correlations (communality), low factor loadings (≤ 0.32) and high cross-loadings.[27] Internal reliability was examined using the Cronbach's α coefficient (an acceptable level was >0.70) and item-total correlations (an acceptable level was ≥ 0.25).[28]

To examine the acceptability of the Control and Consequences items, we first explored the completeness of the data and the frequency of endorsement of categories (an acceptable level is <80%[28]), which included checking for floor/ceiling effects (an acceptable level

is <80%[28]). Missing data were also examined, with an acceptable level taken to be less than 5%.[28]

Test–Retest Reliability of RADIX Items

The RADIX was completed by 20 participants on two separate occasions, 4 weeks apart. This timeframe was chosen as it had been previously used in examining the test–retest reliability for the Illness Perception Questionnaire.[7] To assess the reliability of Identity, Cause, Timeline, and Control we used the Kappa statistic.[31] We used intra-class correlations, with the threshold for summary scores set at greater than or equal to 0.70,[32] for the Consequences subscales.

RESULTS

Screening Checklist

The analysis of the screening checklist is presented in Table 3. The percentage of participants positively endorsing the items ranged from 33.2% to 83.9%, indicating that all items were relevant. Missing data for all were was within an acceptable range. The checklist had good internal reliability, with item-total correlations less than 0.025. In terms of the effectiveness of the checklist in screening out those who did not acknowledge any difficulties, only six participants (1.6%) who were administered the RADIX referred to having "no problem" in their Identity data. This implies the checklist worked reasonably well in screening out people who believe they had no problem or thought they were not experiencing any difficulties.

TABLE 4. Categories of Responses to Questions on Identity, Diagnosis, and Cause

Categories	N (%)	Test–retest reliability
Identity		0.636, p = 0.002[a]
Descriptive term describing specific symptoms	210 (56.9)	
Diagnostic term	73 (19.8)	
Don't know	33 (8.9)	
Descriptive term describing emotional response	22 (6)	
Aging	14 (3.7)	
Descriptive term describing other changes	8 (2.2)	
No problem	6 (1.6)	
Unclassifiable	3 (0.8)	
Diagnosis		1.00, p < 0.001[a]
Diagnostic term	191 (87.2)	
Descriptive term describing specific symptoms	12 (5.5)	
Don't know	12 (5.5)	
Unclassifiable	4 (1.8)	
Cause:		0.488, p < 0.001[a]
Don't know	98 (25.7)	
Ageing	98 (25.7)	
Changes in the brain	77 (20.2)	
Lifestyle/life events	51 (13.4)	
Hereditary	31 (8.1)	
Illness or disease or physical problem	21 (5.5)	
Unclassifiable	5 (1.3)	

Notes: Unclassifiable refers to responses that did not fit under one of the identified categories and for which a suitable category could not be identified.
[a] Assessed using Cohen's kappa statistic

Identity and Cause

Table 4 presents the analysis of the Identity and Cause questions. A total of 369 (95.8%) participants responded to the Identity question ("What do you call

TABLE 3. Acceptability of Screening Checklist and Test–Retest Reliability

Item	Participants Responded Yes N (%)	Missing Data N (%)	Test–Retest Reliability
Different to how you used to be	323 (83.9)	5 (1.3)	
Being forgetful	316 (82.1)	3 (0.8)	
Difficulty with remembering	280 (72.7.8)	3 (0.8)	
Difficulty with concentration	221 (57.4)	3 (0.8)	
Difficulty with thinking	195 (50.6)	3 (0.8)	
Difficulty with ability to say what you want to say	162 (42.1)	6 (1.6)	
Difficulty planning ahead	133 (34.5)	7 (1.8)	
Difficulty making decisions	128 (33.2)	8 (2.1)	
Difficulty with ability to manage day-to-day activities	115 (29.9)	4 (1)	
Overall scale			0.86, p < 0.001[a]

[a] Assessed using intraclass correlation coefficients.

these [difficulties or condition] that you have?") indicating good acceptability. Over half (56.9%) of the participants used a descriptive term relating to specific symptoms of dementia (e.g., memory difficulties). In relation to the Identity question on diagnosis ("Are you aware of a specific diagnosis? What does the doctor call it?"), 219 participants were aware of their diagnosis; of these, the majority (87.2%) used a diagnostic term.

A total of 381 (99%) responded to the question on the Cause of their condition. The most commonly reported causes were: don't know (25.7%), aging (25.7%), and changes in the brain (20.2%). The categories identified in the analysis of the open-ended question in the first part of the question mapped onto the categories in the fixed response questions, suggesting that these are appropriate categories. We did make one amendment to one of the categories; we expanded the illness category to include more physical causes (e.g., hearing loss).

Timeline, Control, Practical and Emotional Consequences

The findings of the PCA for the Consequences items indicated two components with eigenvalues greater than 1, which was supported by the examination of the shape of the scree plot[29] and findings from a parallel analysis.[30] The resulting structure, presented in Table 5, indicates the presence of two factors—practical consequences and emotional consequences—that explained 55.83% of the variance. All factor loadings were greater than 0.5, which is above the cutoff of 0.32.[27] Both

subscales had good internal reliability; for the practical consequences subscale the item-total correlations were greater than 0.25 and for the emotional consequence subscale the item-total correlations were greater than 0.25.

Table 6 reports the percentage of missing data. The percentage of missing data in the Timeline item was low and in the Control item it was above the acceptable threshold (<5%[28]) but still relatively low. Missing data in practical and emotional consequences items were low. Examination of the score distributions of the individual items indicated that there was no evidence of floor/ceiling effects or high (<80%) endorsement of categories.

Test–Retest Reliability of RADIX Items

The screening checklist had good test–retest reliability. Identity, Timeline, and Control had moderate test–retest reliability, and Diagnosis had strong test–retest reliability. The practical consequences and emotional consequences subscales had good test–retest reliability.

DISCUSSION

The aim of the study was to develop and validate a brief new measure (the RADIX) that would be the first designed specifically to measure DRs in people with dementia. We have demonstrated that the RADIX has good psychometric properties. The screening checklist worked reasonably well, with only six participants

TABLE 5. Factor Structure of the Consequences Subscales

Item	Component 1: Practical Consequences	Component 2: Emotional Consequences
As a result of my [identity label] I get annoyed or frustrated with myself		**0.786**
I feel low or upset when I think about my [identity label]		**0.756**
As a result of my [identity label] I get very angry about what is happening to me		**0.753**
I find myself worrying about my [identity label]		**0.631**
As a result of my [identity label] I feel I have lost my confidence in myself	0.457	**0.552**
As a result of my [identity label] I do not go out as much as I used to	**0.782**	
As a result of my [identity label] I cannot do some of the things I used to do	**0.760**	
As a result of my [identity label] people treat me differently	**0.712**	
As a result of my [identity label] I feel I have lost control over my life	**0.566**	0.379
Total eigenvalue	1.35	3.68
% of variance	14.99	40.84

Notes: To aid readability, loadings below 0.3 are not shown. The wording of RADIX items is personalized so that the interviewer would replace [identity label] with the term the person used to describe their condition or difficulties (e.g., "memory problems" or "Alzheimer's").

TABLE 6. Acceptability of RADIX Items and Test–Retest Reliability

Question	Missing Data N (%)	Test–Retest Reliability
Timeline		
My [identity label] will: get better, stay the same, get worse, unsure	12 (2.1)	0.671, p < 0.001[a]
Control		
There is a lot which I can do to control my [identity label]	34 (8.8)	0.560, p = 0.012 [a]
Practical consequences		0.8 , p = 0.001[b]
As a result of my [identity label] people treat me differently	16 (4)	
As a result of my [identity label] I do not go out as much as I used to	12 (3.1)	
As a result of my [identity label] I cannot do some of the things I used to do	18 (4.7)	
As a result of my [identity label] I feel I have lost control over my life	20 (5.2)	
Emotional consequences		0.91 , p < 0.001 [b]
As a result of my [identity label] I get annoyed or frustrated with myself	11 (2.9)	
As a result of my [identity label] I get very angry about what is happening to me	8 (2.1)	
I feel low or upset when I think about my [identity label]	11 (2.9)	
As a result of my [identity label] I feel I have lost confidence in myself	15 (3.9)	
I find myself worrying about my label	16 (4.2)	

[a]Assessed using Cohen's kappa statistic.
[b]Assessed using intraclass correlation coefficients.

included in the study who felt they did not have any problem. All RADIX items had good acceptability with low levels of missing data. The Control item had higher missing data but, because of the sensitive nature of this question, this is to be expected. Items had good test–retest reliability, although responses to Identity and Cause were less reliable. Studies exploring IRs in other conditions indicate that they tend to remain fairly stable,[33,34] though the SRM does acknowledge that IRs are not static.[2] The RADIX is unlike other measures of IRs, however, in that Identity is measured by the term the person uses rather than the endorsement of symptoms. In addition, the cause of dementia is less clear than in other health conditions. Given that this is the first study to assess DRs on two occasions, albeit a short time apart, further work is needed to explore whether there are longitudinal changes in DRs.

Participants preferred to use descriptive rather than diagnostic terms to refer to their condition; this is consistent with findings showing that people with dementia prefer to use less technical terms to describe their experiences.[13,35] Interestingly, only 56.9% of participants were aware of their specific medical diagnosis and a considerable proportion of the participants were unclear about the cause (25.7%), or attributed changes to aging (25.7%). These findings imply that people with dementia might benefit from information and support to help them better understand their condition. Incorporating the RADIX into pre- and post-diagnostic meetings could enable those healthcare professionals involved in diagnosis,

including old age psychiatrists, to better understand the person's beliefs. This would make it easier to tailor how they talk with the person about the condition and its effects and to identify how best to offer support. DRs may also have an impact on engagement with treatment or medication adherence, and hence understanding these beliefs may support effective treatment and management.

Knowledge of a person's DRs would be beneficial for the appropriate targeting of interventions or psychological therapies, particularly those with an educational element, as a person's beliefs about their condition could act as a barrier to their taking on board new information. The study findings imply that people with dementia would benefit from interventions helping them to better understand their condition. Indeed, interventions have been developed that incorporate the SRM—for instance, a self-management group intervention for people with dementia.[36,37] When developing interventions for people with dementia, it is also important to take into account the influence of caregivers' beliefs. Caregivers develop their own beliefs about dementia[9] and these can differ from those held by the person with dementia.[13] Thus, it may be more appropriate to develop dyadic interventions that address both sets of beliefs. Rather than attempting to change beliefs, it would be more appropriate to identity the person's beliefs and target the type of intervention appropriately.[13] As the SRM proposes that IRs will influence the person's coping responses, such interventions would need to explore the interaction

between beliefs and coping. Addressing beliefs would help to promote effective coping, enabling people with dementia to develop personal coping strategies in response to their diagnosis.[13,16]

In line with measures of IRs,[5–7] the subscales of the RADIX can be used to provide a profile of participants' beliefs. For instance, a participant may use a diagnostic term to describe their condition but attribute the cause to aging and believe their condition will get better. Unlike traditional measures of IRs, we are not proposing that these items are used to assess the accuracy of the person's beliefs, but rather that the RADIX should be used to provide an insight into the person's understanding of their condition. Future studies could explore how these beliefs relate to the person's well-being and other outcomes (e.g., Helder et al.[38]).

The findings of this study indicate that the RADIX is a useful tool for exploring DRs. The nature of the sample does place some limitations on our findings. The sample size for the test–retest reliability evaluation was small. The length of time since diagnosis varied in our participants, and beliefs may change over time. Beliefs may also be influenced by information provided during diagnostic meetings; whereas we have information on the diagnosis, we have no information on how the diagnosis was conveyed. Diagnoses may be explained using a combination of lay language and clinical terms.[19] Further work should explore differences in DRs by characteristics of participants. Expectations of aging could influence beliefs and it is possible that there could be age-related differences in DR, with older participants potentially more likely to attribute changes to aging. Our participants had mild to moderate dementia and it would be interesting to explore the DRs held by people with more severe dementia. The participants in this study were primarily of white British heritage; exploring DRs in a more ethnically diverse sample could illustrate the influence of cultural factors on beliefs about dementia.[39] The RADIX is a self-report measure and there has been debate on the reliability of subjective ratings made by people with dementia, but research on quality of life in dementia has found that even people with severe dementia can reliably self-report their quality of life.[40] Although there can be concerns around subjective ratings because of individuals' awareness of difficulties,[37] the screening checklist was developed to screen out those who did not identify any difficulties or changes.

In conclusion, the RADIX is the first tool specifically designed to explore DRs in people with dementia. The RADIX provides an insight into the DRs of people who have been diagnosed with and are living with dementia. Developing a better understanding of DRs will help healthcare professionals to understand how these beliefs may influence well-being and coping, enabling them to provide more tailored support for people with dementia and identify appropriate intervention options. The RADIX could also be used to explore how DRs can influence a person's responsiveness to an intervention.

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