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Journal Item

How to cite:

Clare, Linda; Nelis, Sharon M.; Martyr, Anthony; Whitaker, Christopher J.; Markova, Ivana S.; Roth, Ilona; Woods, Robert T. and Morris, Robin G. (2012). “She might have what I have got”: the potential utility of vignettes as an indirect measure of awareness in early-stage dementia. *Aging & Mental Health*, 16(5) pp. 566–575.

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Version: Accepted Manuscript

Link(s) to article on publisher's website:
<http://dx.doi.org/doi:10.1080/13607863.2011.652594>

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‘She might have what I have got’: the potential utility of vignettes as an indirect measure of awareness in early-stage dementia

Aging & Mental Health

Objectives: In early-stage dementia, awareness at the meta-representational level involving a person’s appraisal of his/her own condition and its implications has usually been assessed by interview, but contextual factors may influence responding. We examined the utility of an indirect, vignette-based method of eliciting awareness.

Method: Three vignettes describing early-stage dementia, established dementia and healthy ageing were used to elicit views of the problem and the kinds of advice that might be helpful for the characters depicted. Responses were obtained from 91 people with early-stage Alzheimer’s, vascular or mixed dementia, 87 carers, and 80 older controls. For the participants with dementia, awareness was assessed in separate in-depth interviews and rated on a 5-point scale for comparison purposes.

Results: Participants with dementia were often able to correctly identify the problems described in the vignettes, although scoring lower than carers or controls. Participants with dementia were also able to offer advice for those depicted, although to a lesser extent than carers or controls. Ability to offer advice was greater where MMSE scores were higher. For participants with dementia, vignette scores were moderately correlated with ratings derived from interviews, and those showing limited or no awareness offered fewer items of advice than those showing some or good awareness. In addition, 29% of participants with dementia spontaneously pointed out similarities between their own condition and that of the person depicted.

Conclusions: The vignette method may be useful where resources preclude the use of in-depth interviews, and may supplement in-depth interviews as part of a multi-dimensional assessment of awareness.

Keywords: Alzheimer's, anosognosia, qualitative, older adults

‘She might have what I have got’: the potential utility of vignettes as an indirect measure of awareness in early-stage dementia

Awareness can be defined as a reasonable or realistic perception or appraisal of a given aspect of one’s situation, functioning or performance, and/or of the resulting implications (Clare, Rowlands, Bruce, Surr, & Downs, 2008). Reductions in awareness may occur early in the course of the main forms of dementia, although degree of awareness appears to vary, with some people showing good awareness and others limited awareness. This has been demonstrated in relation to monitoring of performance on specific tasks, more general evaluations of everyday functioning, and overall response to the condition and its impact (Aalten, van Valen, Clare, Kenny, & Verhey, 2005; DeBettignies, Mahurin, & Pirozzolo, 1990; Derouesne et al., 1999; Verhey, Rozendaal, Ponds, & Jolles, 1993). Awareness can be considered at several levels; the Levels of Awareness Framework (Clare, Marková, Roth, & Morris, 2011) identifies the four levels of sensory registration, performance monitoring, evaluative judgement and meta-representation. Different methods of assessment are applied at each level (Clare, Marková, Verhey & Kenny, 2005), and all have limitations. In this paper we focus on the meta-representational level, and examine appraisals of the condition and its implications and impact. Awareness at this level incorporates knowledge or understanding, the application of this knowledge on a day-to-day basis, and the ability to reflect on the wider consequences and implications and act accordingly (Abreu et al., 2001); consequently, it demands complex reflections on the part of the individual that draw upon diverse aspects of personal knowledge and experience. This is shaped by the individual’s emotions and attitudes, and by cultural perspectives, as well as by the extent to which the individual’s social and interpersonal context supports or hinders the process of reflection (Marková, Clare, Wang, Romero, & Kenny, 2005).

Direct assessment of individuals' awareness about their condition and its implications is usually made on the basis of an interview (Verhey, et al., 1993). However, this approach is not without problems, not least how to interpret the responses given. A limited expression of awareness in this context is sometimes assumed to result from the effects on cognitive function of underlying neuropathology, but a number of authors have pointed out that it may also be affected by the psychological processes involved in dealing with the onset and progression of dementia. These may include, for example, the unconscious or pre-conscious process of denial, or a process of avoidance which is accessible to consciousness, or the minimisation of difficulties ('covering up'), reflecting a conscious recognition of the need to 'save face' by providing what is perceived as a situationally- or socially-acceptable response (Weinstein, Friedland, & Wagner, 1994; Wilson & Dunn, 2004). If the interviewer is also a clinician with responsibility for the person's care, the interviewee may seek to minimise their difficulties for fear of the consequences if the true extent of the impact of the condition were revealed (Clare, 2003). The operation of such motivational factors may affect the extent to which evidence of retained awareness can be elicited through direct inquiry.

A possible means of addressing this difficulty is to employ indirect approaches to eliciting awareness at the level of general understanding of the condition, its implications, and the ways in which it can be managed. One way in which this may be achieved is through the use of vignettes. Vignettes have been employed to elicit participants' reflections about a relevant situation experienced by a fictional character, in order to obtain their views about the nature of the condition evoked by the situation and the ways in which resulting difficulties might be managed. Content-specific vignettes depicting

relevant situations (Veal, 2002) can be useful for exploring sensitive topics which participants may be reluctant to discuss. This approach allows participants to retain some distance from the situations described, and is thought to be experienced as less threatening than direct inquiry (Barter & Renold, 1999; Torres, 2009). The responses that participants give offer an insight into their understanding of the situation and the representations and beliefs that underlie their understanding (Torres, 2009; VonDras, 2009). There is no requirement to relate the information to the self, although self-references may be made spontaneously.

Vignettes have been used to explore understanding of dementia in the general population (Low & Anstey, 2009; Werner, 2006; Werner & Davidson, 2004) and in older people (Von Dras, 2009). This method has also been applied to the assessment of capacity to consent to medical treatment in older patients, including individuals with cognitive impairment (Schmand, Gouwenberg, Smit, & Jonker, 1999; Vellinga, Smit, van Leeuwen, van Tilburg, & Jonker, 2004, 2005). Schmand et al. (1999) concluded that the vignette method is a useful tool in the assessment of capacity in older people with cognitive decline, and is preferable to physician judgement. To the best of our knowledge, however, the vignette method has not hitherto been used as a means of assessing awareness in people with dementia (PwD). Using this method offers the opportunity to establish whether, when considering the situation of others, PwD can identify the kinds of symptoms and difficulties typically associated with dementia and distinguish these from normal aspects of ageing, and whether they can reflect on how such difficulties might be managed. This may provide a useful supplement to the direct interview method as a means of eliciting evidence of awareness.

In the present study, we examined the utility of vignettes as an indirect method of assessing awareness in PwD. First, we sought to establish whether PwD are able to identify and correctly attribute symptoms and behaviours described in the vignettes, and suggest appropriate ways of managing these; responses made by PwD were compared with those made by caregivers and by healthy controls. Second, for the participants with dementia, we compared the results of the indirect assessment using vignettes with a direct assessment of awareness based on detailed interviews with PwD and carers.

Method

Design

This investigation was part of the Memory Impairment and Dementia Awareness Study (MIDAS), a multi-method longitudinal study of awareness in people with early-stage dementia. PwD and their respective carers completed the vignettes and interviews as part of the initial assessment. Two researchers (SN and AM) conducted all assessments. PwD and carers were visited at home, and were each seen separately by one of the researchers. The interviews were conducted first, followed by the vignettes, during the first home visit. Control data were also collected from an opportunistic sample of community dwelling older adults. Ethical approval was granted by the relevant University and NHS Ethics Committees. Informed consent was obtained from all participants.

Participants

Participants in the MIDAS study were recruited from NHS Memory Clinics in North Wales, UK. Inclusion criteria were an ICD-10 (World Health Organisation, 1992) diagnosis of Alzheimer's disease (AD), vascular dementia or mixed Alzheimer's and

vascular dementia, and a score of 18 or above on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). In each case a carer was also recruited. Controls were recruited from the university participant panel and various community sources such as social, church and voluntary groups. MMSE scores were obtained for controls as well as for PwD.

Measures

Vignettes

The content of the vignettes was developed by health professionals with expertise in the assessment and care of older people and PwD. Three vignettes were prepared, which described short scenarios of individuals showing behaviour that implied, or was typical of, established dementia, early-stage dementia and healthy old age (see Appendix 1). The two dementia vignettes did not mention dementia by name, but suggested some problem areas that would be considered indicative of the relevant stage of dementia. One vignette described a difficult situation arising for a healthy older person. Participant understanding of the situations depicted, and the potential solutions available to the people depicted were assessed with the following questions: ‘What might be the problem?’, ‘What advice would you give to [the person described]’, and ‘What advice would you give to the [relative, friend or neighbour, as appropriate] of [the person described]?’ Each vignette was prepared in two versions, with the main character depicted as either male or female. Participants were presented with the version in which the main character was of the opposite gender to their own. This was to provide additional distance and to safeguard against possible distress if they felt the character was too much like themselves or their relatives.

The scoring scheme was developed through independent review of the first 20 sets of responses by members of the research team, who identified response options and a possible scoring system. The research team then met in two calibration sessions to review the vignette responses and decide on rules for rating both problem identification and problem responses. A checklist was developed to enable raters to independently apply codes to the vignettes and to promote inter-rater consensus. After independently rating the 20 sets of responses the raters met to resolve any disagreements such that an adequate level of agreement was established for all items. Refinements were also made to the coding scheme on the basis of these discussions.

Following this development phase, all responses were coded in terms of correct problem identification and the appropriateness of responses to the possible solutions within the scenarios. Problem identification and problem response scores for each vignette ranged from 0-2. For *problem identification* the scoring was as follows: 2 points - precise descriptions suggesting the appropriate diagnostic category or severity relevant to the vignette (e.g. established dementia vignette – Alzheimer’s, dementia, senility; early-stage dementia vignette – early-stage dementia; healthy old age vignette – he’s OK, just needs people calling in; 1 point - general descriptions including alternative possibilities (e.g. established dementia vignette – forgetfulness, stroke; early-stage dementia vignette – physical problem that needs sorting out, depression; healthy old age vignette – no problem); 0 points - no response or inappropriate descriptions (e.g. established dementia vignette – has she not got friends who could help her; early-stage dementia vignette – got lazy; healthy old age vignette – dementia). Total problem identification (VPI) scores across the 3 vignettes range from 0-6. For *problem responses*, ratings were scored on the basis of the type and number of appropriate sets of advice provided for both of the two

main characters within the vignettes using the following scoring system in each case: 2 points - participants provided two or three items of sensible and realistic advice; 1 point - one item of sensible and realistic advice; 0 points - the recommendations made were inappropriate or unclear. Total problem response (VPR) scores for both characters across the 3 vignettes range from 0-12. The VPI and VPR scores were summed to give a total score (VTS, 0-18), with higher scores indicating greater indirect awareness. In addition, a self-reference rating was made when participants spontaneously related something within the vignette to their own experience. Spontaneous self-reference by participants with dementia to the dementia vignettes, whereby they point to similarities between themselves and the character depicted, indicates the ability to make the link between the situation depicted and one's own situation, and may be taken as an indicator of awareness. However, the absence of self-reference does not necessarily indicate the absence of awareness, since self-reference was not formally sought.

Two raters (SN & AM) scored the vignettes, each scoring a randomly allocated proportion with overlap to establish inter-rater reliability. Reliability indices were calculated for problem identification and problem responses separately. Percentage agreement for problem identification for the two raters was 95% (N = 40; 38 agreements, 2 disagreements of 1 point), Cohen's $\kappa = .93$ (Cohen, 1960). The percentage agreement for problem responses was 87.5% (N = 40; 35 agreements, 5 disagreements of 1 point), Cohen's $\kappa = .85$. Further information on the vignettes including coding procedures and instructions is available from the authors.

Interviews

For comparison purposes, awareness in PwD was also assessed directly through detailed interviews conducted separately with the PwD and with the carer. These semi-structured interviews explored the changes associated with the onset and progression of dementia, current functioning, activities of daily living and social interactions, coping, feelings about the situation and its impact, perceptions of the future, and understanding of the disease. PwD and carer interviews were transcribed in full. Ratings of awareness of the condition (interview global ratings; IGR) were made on the basis of the PwD interview supplemented by collateral information from the carer interview. A five-point rating scale was employed: 1 - no evidence of awareness; 2 - limited evidence of awareness; 3 - some evidence of awareness; 4 - moderate evidence of awareness; and 5 - extensive evidence of awareness. Inter-rater reliability indices were calculated for a sample of the ratings and the percentage agreement for the two raters was 88.9% (N=18; 16 agreements, 2 disagreements of 1 point), Cohen's $\kappa = .85$.

Procedure

The vignettes were read aloud by the researcher, and participants were given a written copy of the vignettes to follow. The presentation order of the vignettes was counterbalanced. Respondents were asked to describe how they perceived the situation and difficulties of the person in the scenario and what advice or potential solutions they would propose. The responses to these questions were recorded for all three scenarios. Responses were transcribed verbatim prior to scoring. The semi-structured interviews were conducted on a separate occasion and lasted between 10-60 minutes; a few interviews where the person with dementia showed very little awareness were kept brief, but most interviews allowed for a wide-ranging discussion.

Data analysis

Descriptive content analysis of the problem identification and problem response statements made by PwD was conducted to highlight the most commonly used terms or explanations and suggestions for appropriate responses. To examine whether PwD could correctly recognise and respond to descriptions of dementia within the vignettes, analyses of variance (ANOVA) with post hoc analyses including Bonferroni correction were used to test for significant differences between PwD, carers and controls in VPI, VPR and VTS across the three vignettes. Correlational analysis was employed to examine the relationship between vignette responses, demographic variables and cognitive status. We compared the results of the indirect assessment using vignettes with a direct assessment of awareness based on ratings derived from the interviews by correlating vignette ratings (VPI and VPR) with interview ratings (IGR) and by examining the distribution of VTS scores among participants scoring at each level of IGR. One-way ANOVA with post hoc Games-Howell tests was used to examine differences in VPI, VPR and VTS scores among sub-groups with different IGR scores. Additionally, all instances in which the content of the vignettes was spontaneously related to the participant's own experience were documented, and the extent of self-referencing was examined in sub-groups with different IGR scores.

Results

The participants were 91 PwD, 87 carers, and 80 older controls. Demographic information for all three groups is provided in Table 1. One-way ANOVA indicated significant age differences between the groups ($F_{(2, 255)} = 29.69, p < .001$); there was no

significant age difference between the controls and PwD, but carers were significantly younger than both PwD and controls, which was to be expected as the carer group included both spouses and adult children of the PwD.

((Table 1 near here))

The mean scores for all three groups on problem identification (VPI), problem response (VPR) and total scores (VTS) are presented in Table 2. There were significant differences in VPI ($F_{(2, 255)} = 14.72, p < .001$), with PwD providing fewer appropriate answers than both carers and controls. PwD also provided significantly fewer problem responses than carers or older controls ($F_{(2, 255)} = 16.52, p < .001$). PwD consequently had significantly lower VTS ($F_{(2, 255)} = 24.43, p < .001$).

((Table 2 near here))

Data from the content analysis of the VPI responses is summarised in Table 3. In relation to the two dementia scenarios, although some PwD used terms such as ‘Alzheimer’s’, ‘dementia’ and ‘senile’, in general PwD were much less likely than carers to use these terms, preferring responses relating to memory problems, memory loss or forgetfulness. The majority of PwD did, however, classify the dementia vignettes as reflecting either dementia or memory loss. PwD were also somewhat more likely to offer alternative explanations including old age, physical problems, stroke, isolation, loneliness and depression. Early-stage dementia was sometimes attributed to old age, with PwD no more likely than controls to make this attribution, but this was rarely the case for the established dementia vignette. The majority of PwD, carers and controls correctly

thought that the character described in the healthy ageing vignette did not have a problem. However, PwD and carers were somewhat more likely than controls to perceive a problem in the healthy ageing vignette, suggesting that they may be more sensitised to problems because of their experience.

((Table 3 near here))

Problem responses made by PwD fell into several categories. For the two dementia vignettes, seeking medical help, gaining support from others and implementing strategies for managing memory-related problems and everyday activities were all emphasised. For the established dementia vignette, in addition, the need for care provision was mentioned. For the healthy ageing vignette, responses related to making decisions about care needs and preferences, and gaining support from others. Examples of responses given in each of these categories for each vignette are shown in Table 4.

((Table 4 near here))

There were no significant relationships between age and VPI or VPR for any of the three groups. For PwD, current cognitive function (MMSE) was not related to VPI score, but there was a significant relationship with VPR score ($r_s = .33, p < .001$). MMSE was not related to problem identification or problem responses for the controls (carers did not complete the MMSE).

Vignette scores for the PwD were considered alongside awareness ratings made on the basis of interviews (IGR; $n = 90$). Global awareness ratings were moderately, and

significantly, associated with VPI ($r_s = .22, p < .05$); VPR ($r_s = .32, p < .05$) and VTS ($r_s = .34, p < .001$). These associations remained significant when controlling for MMSE score (VPI $r = .24, p < .05$; VPR $r = .27, p < .05$; VTS $r = .30, p < .05$). Details of the number and percentage scoring at each level on VTS are shown in Table 5 (a).

((Table 5 near here))

Three groups of approximately equal numbers based on IGR score were achieved by combining the ‘no awareness’ (IGR 1) and ‘limited awareness (IGR 2) categories and the ‘moderate awareness’ (IGR 4) and ‘extensive awareness’ (IGR 5) categories. These three sub-groups (‘limited’, ‘some’ and ‘good’ awareness) provided the basis for comparison of vignette scores across the different levels of global awareness shown in the interviews. Mean VPI, VPR and VTS scores for these three groups are summarised in Table 5 (b). There were no significant group differences in VPI ($F_{(2,87)} = 2.12, p > .05$). There were significant differences between sub-groups for VPR ($F_{(2,87)} = 6.37, p = .003$) and VTS ($F_{(2,87)} = 5.61, p = .005$). Post hoc Games-Howell tests indicated that the limited awareness group differed significantly from both other groups for VPR ($p = .005$ for ‘some’ and $p = .01$ for ‘good’) and VTS ($p = .04$ for ‘some’ and $p = .006$ for ‘good’). Thus, those with some or good awareness of their own condition did significantly better in problem responding than those with limited awareness.

We recorded whether PwD spontaneously related some aspect of the vignettes to their own experience. Twenty-one PwD (23%) made self-references in response to one or other vignette and 6 (6%) made a self-reference in response to both dementia vignettes.

For the established dementia vignette, 14% (n = 13) of PwD related the content to their own experience, with reference to their own current functioning:

“[daughter] told me that I got out of bed in my nightie...Sounds like me” (IGR 2)

“Same as me; I’m not quite as bad as that” (IGR 3)

“Memory isn’t it – he has Alzheimer’s. Mine is not that bad yet” (IGR 3)

“Alzheimer’s, I fear that sometimes this is the most difficult story you have told me” (IGR 3)

“Memory loss, isn’t it, worse than me” (IGR 4)

“Sounds like us, that’s me struggling for words, Alzheimer’s. (IGR 5)

For the early-stage dementia vignette, 22% (n = 20) of PwD related the content to their own experience, with comparisons to their own memory functioning:

“I know that problem quite well – memory loss” (IGR 2)

“Memory, difficulty organising things and look after the house. Like me this is, struggle to find words” (IGR 3)

“Sounds like me, the things he’s saying is a lot like I have found” (IGR 4)

“She might have what I have got, she is forgetful” (IGR 4)

“Alzheimer’s disease – that is how I thought at the beginning, I should have gone earlier.” (IGR 5)

Frequency of self-reference to the two dementia vignettes in each sub-group is shown in Table 6. There were no significant correlations between the awareness ratings based on the interviews (IGR) and the number of self-references made by PwD in VPI or VPR responding, suggesting that PwD with lower IGR ratings were just as likely to make self-references as those with higher IGR ratings. ANOVA was used to compare the frequency

of self-references in the three IGR sub-groups. There were no significant differences between the three IGR sub-groups in terms of the total number of self-references made within the vignettes ($F_{(2, 87)} = .29, p > .05$). None of the four participants with an IGR score of 1 (no awareness) related any aspect of the dementia vignettes to themselves or their own situation, but 36% of PwD with limited awareness (IGR 2) gave spontaneous self-references.

((Table 6 near here))

Discussion

This study is the first to compare ratings of awareness derived from an interview-based assessment of awareness with scores elicited through an indirect approach using vignettes. The first question addressed was whether PwD are able to identify and correctly attribute symptoms and behaviours described in the vignettes, and suggest appropriate ways of managing these. The findings demonstrated that PwD were less likely than carers and controls to identify the situation, primarily because they were less likely to use terms such as ‘Alzheimer’s’ or ‘dementia’ and more likely to use general descriptions such as ‘memory loss’ or suggest alternatives such as depression or isolation. This is in line with qualitative studies showing that PwD infrequently use diagnostic labels to describe their condition (Clare, 2003; Clare, Goater, & Woods, 2006), and are more likely to use descriptions such as memory loss or forgetfulness. However, the majority of PwD did identify the dementia vignettes as representing dementia or memory loss, and the healthy ageing vignette as representing normal ageing, demonstrating reasonable understanding of the issues if not the diagnostic categories that are commonly

applied to these. Overall, the findings suggest that most PwD can readily distinguish between normal ageing and dementia, and show some ability to identify signs of dementia in others, although they are likely to talk about this somewhat differently to carers or controls. However, a few PwD gave non-specific or 'don't know' responses. As there was no association between problem identification and MMSE score, this cannot readily be attributed to cognitive impairment, although the MMSE is a relatively crude indicator of cognitive function and a more fine-grained assessment would be more informative. Nevertheless, problem identification might reflect unawareness at the meta-representational level in the sense of either conscious avoidance or unconscious denial (Seiffer, Clare, & Harvey, 2005; Weinstein, et al., 1994).

Although PwD provided somewhat fewer items of advice in the problem response category than carers or controls, they nevertheless did manage to offer suitable suggestions relating to seeking medical help, addressing care needs, gaining support from others and implementing management strategies. In this respect they were able to demonstrate knowledge and understanding of the kinds of approaches that may be helpful for older people with and without dementia. As the problem response score was significantly associated with MMSE score, the more limited extent of advice offered may reflect an effect of cognitive impairment, such that increased impairment makes it harder to reason about the situation and produce a range of responses.

The second question addressed in this study was how the results of an indirect assessment using vignettes compare to those of a direct assessment of awareness based on detailed interviews with PwD and carers. Vignette scores were moderately associated with scores derived from in-depth interviews that reflect awareness at the level of meta-

representation, and this effect remained when controlling for cognitive functioning. A number of studies have demonstrated that different measures of awareness are typically only moderately associated, whether within or between levels of awareness (Howorth & Saper, 2003). Thus, different measurement approaches elicit different aspects of awareness, and it has been noted that the use of multiple measures may be required to provide a comprehensive picture (Clare et al., 2011). Use of vignettes therefore may complement the direct interview method in eliciting awareness at the meta-representational level.

Comparison of vignette scores according to level of awareness based on interview ratings showed that problem identification did not differ but problem response did, with those in the limited or no awareness group being less able to offer advice and suggestions than those classified as having some, moderate or extensive awareness. Again this difference between the problem identification and problem response elements of the vignette suggests that these may represent the operation of different processes and provide different types of information about knowledge and understanding of the condition. Problem response may be more aligned to the expression of explicit awareness and hence this measure would be more informative in this regard. The lack of difference for problem identification suggests different underlying processes, perhaps operating at an implicit level. The pattern of results for problem response indicates that differences arise in particular between the approximately one-third of the sample showing limited or no awareness, and the rest. However, it is striking that 47% of those in the 'limited awareness' group nevertheless scored 9 or above on the VTS. This suggests that the vignette approach may enable some individuals to show more extensive knowledge and understanding than that elicited by a direct interview method.

A number of PwD spontaneously offered self-referential statements in response to the vignettes, likening themselves to the character depicted. The likelihood of making self-referential statements did not differ across the IGR sub-groups, and in fact the greatest number of self-references was made by those who showed limited awareness in interviews, so the vignettes may have particular utility with this group in eliciting acknowledgement of changes or difficulties. Knowledge and understanding of a condition may not always be accompanied by application of this knowledge to the self and to one's own situation (Startup, 1997). However, the current findings show that in some cases this ability is present, and that this can be the case for those with limited awareness according to interview ratings as well as for those with good awareness.

Since the object of awareness, as elicited through the vignette method, is a general understanding of the condition, its effects, its implications, and the practicalities of management, responses made to vignettes can appropriately be compared with a rating of level of awareness made on the basis of a detailed interview. Nevertheless, the two methods are different in that one focuses directly on the individual's own experience and the other takes an indirect approach. There may be differences in the way that knowledge about the self and knowledge about others are represented, with these types of knowledge differentially affected in early-stage dementia. It has been suggested for example that self-knowledge may in some cases not be updated to reflect recent changes (Klein & Gangi, 2010) and therefore judgements about others may be more accurate than judgements about the self. If this is the case, the vignette method could be helpful in identifying the presence of knowledge and understanding about the condition that is not currently being applied to the self, and that could be useful in facilitating and supporting adjustment. However, as the two sets of scores were significantly correlated, the results in

general do not suggest a clear dissociation; rather, the extent of self-reference seen in the 'limited awareness' group suggests that the indirect approach may be especially useful with those who express limited awareness when directly interviewed, enabling them to demonstrate knowledge and understanding that is not otherwise elicited.

To the best of our knowledge, this study has been the first to use vignettes to assess awareness in PwD. The vignettes were developed by a group of experts, and responses suggest that the vignettes did present suitable descriptions of people with established, early-stage or no dementia. However, it is possible that the specificity of the vignettes could be enhanced for future studies, and that the content could be refined. For example, in the vignettes as they stand, the person with early-stage dementia is depicted as worrying about changes in memory while the person with established dementia is depicted as seeming unaware of aspects of functioning, and as this could represent a potential confound in studies of awareness it might be preferable if such references were removed. The decision was taken to score problem identification and problem response separately since it was thought these scores might dissociate to some degree, and this was borne out in practice. Hence, while a total score was calculated, this may be of limited value and it may be advisable to consider problem identification and problem response elements separately. Finally, the self-reference element was particularly informative, and this could be systematised in future by incorporating a final question asking whether the respondent perceives any similarity with the person depicted in the vignette.

Conclusions

This study has shown that vignettes are a useful addition to the range of measures available to elicit awareness at the meta-representational level in early-stage dementia. Asking PwD to suggest what advice might be helpful for those depicted allows PwD to demonstrate their knowledge and understanding of the condition and its implications, even though they may not use recognised diagnostic terms to define it, and this may be especially relevant for those who show limited explicit awareness on direct questioning, while self-referential statements provide some indication of the extent to which this knowledge and understanding can be applied to the self and to one's own situation. The vignette method may be useful where time and resources preclude the use of in-depth interviews with participant and carer as a means of assessing awareness at this level, and may supplement in-depth interviews as part of a multi-dimensional approach to assessment.

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Appendix 1: Vignettes (female character versions)

Vignette 1: established dementia

Mrs. Hughes is a 65-year-old lady who lives alone. Her friend has become concerned about her as she often forgets to do things, such as switching off the oven. She tells the same stories over and over again, without seeming to realise that she has already told her friend. She also tends to miss appointments, for example, at the doctors and hairdressers. Her next door neighbour is also worried as Mrs Hughes knocked on her door late at night saying that she wanted to go to the local shop but couldn't remember the way.

Vignette 2: early-stage dementia

Mrs. Owen is a 72-year-old lady who lives with her husband. Mr. Owen tends to the garden, whilst Mrs. Owen has always taken care of the household chores. However, lately she has been finding it difficult to organise and look after the house. She has also noticed that she sometimes struggles to find her words and doesn't feel able to complete the daily crossword in the newspaper anymore. She is worried that there is a problem with her memory and her husband has suggested that she should go and speak to her GP.

Vignette 3: healthy ageing

Mrs. Roberts is a 90-year-old lady who lives alone. She cooks and cleans for herself and enjoys her hobbies of listening to music, reading, and keeping up with current affairs. Her neighbours often visit for a chat and help with shopping. She speaks to her son on the telephone most days; however, her son is worried about his mother living on her own and would like her to move to a local residential home for older people. Mrs. Roberts has told her son that she is happy at home and doesn't want to move.