

‘I don’t do like I used to do’: A grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care[☆]

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Abstract

While awareness among people with mild to moderate dementia residing in the community has been extensively studied, little evidence has been presented regarding the extent to which people with moderate to severe dementia living in residential care show awareness of their own situation and functioning. The present study aimed to explore how differing degrees of awareness are manifested in the conversations and interactions of people with dementia living in residential care settings, and to identify theoretical and practical implications. Transcripts of 304 conversations with 80 individuals with dementia living in residential care homes in England and Wales were analysed using a grounded theory approach. All 80 participants demonstrated a degree of retained awareness, and there was considerable evidence of retained awareness throughout the conversations, expressed in relation to the three domains of self, relationship, and the environmental context. Two-thirds of participants also demonstrated at least one instance of unawareness, although demonstrations of retained awareness outweighed indications of unawareness. Unawareness was evident in relation to appraisal of functioning and the meaning ascribed to the situation. A grounded theory model of awareness in people with moderate to severe dementia who still communicate verbally proposes that demonstration of awareness involves a set of analytic and behavioural processes, a scope or timescale, and a focus. Awareness is demonstrated in relation to a given focus and scope through the involvement of cognitive processes of varying degrees of complexity, ranging from registering through appraising and interpreting to reflection. Unawareness may be demonstrated in relation to some elements of process, focus or scope, while other aspects remain unaffected. Understanding more about the capacity for retained awareness and the specific ways in which awareness can be compromised may assist care staff in responding effectively to residents’ needs.

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Introduction

The capacity to show awareness can be defined as the ability to make an accurate appraisal or response in a given domain. For the concept of awareness to be meaningful, it is necessary to specify what it is that the person is aware of. This has been called the ‘object’ of awareness (Marková, Clare, Wang, Romero, & Kenny, 2005). Possible objects of awareness include internal states, external stimuli, symptoms, or changes in functioning. Awareness may be expressed at various levels, from basic perceptual and sensory awareness through to sophisticated self-awareness (Stuss, Picton, & Alexander, 2001). Difficulties arising at each of these levels have been described in people with a range of neurological disorders, including dementia.

Individual variability in aspects of awareness and in relation to a number of different objects has been documented in people with mild to moderate dementia, with studies focusing mainly on identification of deficits in awareness. Neuropsychological models have attempted to account for this variability in terms of changes in cognitive functioning (Morris & Hannesdottir, 2004) while others have pointed to the role of psychological factors (Seiffer, Clare, & Harvey, 2005; Weinstein, Friedland, & Wagner, 1994). Recent reviews have drawn these perspectives together in a biopsychosocial framework, acknowledging the possible influence of contextual factors on the expression of awareness (Clare, 2004a).

Limited attention has been given to awareness and subjective experience in people with dementia living in residential care, who are likely to have moderate to severe levels of impairment. It has been suggested that awareness lessens as scores on cognitive tests decline (Verhey, Rozendaal, Ponds, & Jolles, 1993), with the implication that at a certain stage of cognitive decline awareness is lost. However, correlational studies suggest that the relationship between level of cognitive decline and degree of unawareness is not straightforward (Aalten, van Valen, Clare, Kenny, & Verhey, 2005; Clare, 2004b). Therefore, some awareness might be retained even in the presence of severe cognitive impairment. Consistent with this, recent studies have incorporated the perspective of the person with moderate to severe dementia (Cohen-Mansfield, Golander, & Arnheim, 2000; Cohen-Mansfield, Parpura-Gill, & Golander, 2006; Surr, 2005; Train, Nurock, Kitchen, Manela, & Livingston, 2005), demonstrated the capacity for preserved self-knowledge and self-recognition (Bologna & Camp, 1997; Klein, Cosmides, & Costabile, 2003), highlighted the relevance of episodes of lucidity (Normann, Asplund, & Norberg, 1998; Normann, Norberg,

& Asplund, 2002), and suggested that indicators of awareness may be revealed in conversations and semi-structured interviews (Mayhew, Acton, Yauk, & Hopkins, 2001; Tappen, Williams, Fishman, & Touhy, 1999).

Assumptions of unawareness in severe dementia are also challenged by comparison with evidence drawn from observation of people recovering from severe traumatic brain injury. While demonstrable awareness is absent in coma and vegetative states, people in minimally conscious states show subtle but definite behavioural indications of awareness (Laureys, Owen, & Schiff, 2004). Again this suggests we should expect people with severe dementia to show awareness, at least at the sensory and perceptual level. Consistent with this, preserved reactions to sensory stimuli have been demonstrated in people with very severe dementia (Norberg, Melin, & Asplund, 2003).

There is reason to believe, therefore, that aspects of awareness may be retained in moderate to severe dementia, but little firm evidence has been presented to clarify the extent to which this is the case. Improved understanding in this area could help in enhancing quality of care provision. In order to develop a clearer picture, the present study sought to adopt a methodologically rigorous approach with a large sample of participants who were still able to communicate verbally. We defined awareness as *an accurate appraisal of a given aspect of one’s situation, functioning, or performance, or of the resulting implications*. Appraisals were accepted as accurate if they matched other observable or verifiable criteria, or appeared consistent with, reasonable in, or appropriate to the context in which they were made. The study aimed to explore how differing degrees of awareness are manifested in the conversations and interactions of people with dementia living in residential care settings, and to identify theoretical and practical implications.

Methods

The study utilised an existing data set collected between 1999 and 2001 as part of a study of well-being in people with dementia living in residential care (Bruce, Surr, & Tibbs, 2002). A favourable ethical opinion for the present analysis was granted by the University Research Ethics Committee.

Participants

The participants were 81 people with dementia, 69 women (85%) and 12 men, living in 10 residential care homes in England and Wales, all of whom had

some speech and agreed to audio-recording of conversations. All were white European, most with a Christian background. The majority had left school at a young age. Of the women, many had been housewives, while others had been employed as shop and office workers, receptionists, waitresses, seamstresses, care workers, nurses or teachers. Some had been missionaries or nuns. The male participants included shop-keepers and other small business owners, engineers, teachers, doctors and skilled manual workers.

Each participant lived in one of 10 residential care homes: these included 3 care homes specialising in the care of people with dementia (45 participants), 4 care homes for older people with designated sections devoted to the care of people with dementia (21 participants), and 3 homes catering for a mixed resident group (15 participants). Participants' ages ranged from 59 to 96 years (mean 83.64, s.d. 8.2). Scores on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) on entry to the study ranged from 0 to 20 out of a maximum of 30 (mean 9.76, s.d. 6.66; see Fig. 1). Over half the sample scored 11 or less, and the modal score was 0.

Conversations

The researchers engaged participants in unstructured conversations. This approach was chosen to provide the residents with the maximum possible opportunity to convey their own thoughts and feelings. The number of conversations recorded with each participant ranged from 1 to 8 (Table 1), yielding a total of 307 transcripts. One participant with three transcripts was excluded because we could not distinguish any intelligible words in the participant's communication. The final data set, therefore, consisted of 304

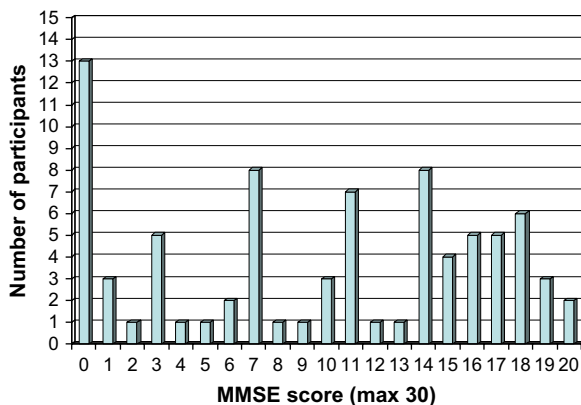


Fig. 1. Distribution of MMSE scores in the participant group.

Table 1
Number of conversations recorded for each participant

Number of conversations	Participants with this number of conversations	Number of transcripts represented
1	15	15
2	13	26
3	16	48
4	8	32
5	8	40
6	6	36
7	10	70
8	5	40
Total	81	307

conversations with 80 participants. Field notes made by the researchers and contextual information derived from records kept by the residential homes were also available for consultation where the researchers needed clarification of events mentioned in the transcripts.

Data analysis

We explored awareness within a grounded theory approach (Charmaz, 2006; Strauss & Corbin, 1997), using QSR NVivo computer-assisted qualitative data analysis software. Initially, through data-driven open and focused coding, categories reflecting manifestations of awareness or unawareness were identified and relations between categories were explored using the constant comparative method in order to explore how awareness was, or was not, expressed in the conversations. In this phase, we also explored the processes evident in the interactions between participant and researcher, which provided the context within which awareness could be expressed. A detailed examination of relevant theoretical constructs, as outlined in recent comprehensive reviews (Clare, 2004a, 2004b; Clare, Marková, Verhey, & Kenny, 2005; Marková et al., 2005), provided the basis for operationalising key elements of awareness identified in theoretical models (Table 2), and a further theory-driven coding phase identified the extent to which these elements were reflected in the data. The results from the complementary data-driven and theory-driven phases were then compared and integrated. This led to the development of a preliminary grounded theory of awareness in people with moderate to severe dementia living in residential care homes.

Credibility and trustworthiness

We attempted to maximise the validity of our account (Elliott, Fischer, & Rennie, 1999; Yardley,

Table 2
Theoretically derived categories examined in the data

Indicators of awareness or unawareness
Responding to external or internal stimuli
Giving accurate descriptions regarding self or environment
Making accurate judgements about own functioning
Engaging in targeted self-presentation
Taking the perspective of others
Engaging in meta-cognitive reflection
Using psychological coping strategies
Contextual factors
Distal contextual factors
Proximal contextual factors

2000) in four main ways. First, we attempted to address our own perspectives and expectations. In particular, we were conscious of our expectation that we would find evidence of retained awareness, and therefore paid careful attention to ensuring that instances of unawareness were not overlooked. Second, 15% of the transcripts were independently analysed by two members of the research team; this represented the proportion of the transcripts that could feasibly be analysed independently by two researchers during the study period. Any differences in coding were then discussed by at least two research team members, and where necessary clarification was sought by consulting the field notes or original interviewer, in order to reach agreement on the most appropriate classification. Third, to assess the face validity of the findings, focus groups were held for care workers in residential homes, family carers of people with dementia, and professionals in dementia care, and individual discussions were held with people who have early stage dementia, in order to explore whether the findings fitted with the experience and observations of those involved. Fourth, in presenting the findings we have used illustrative extracts throughout to show that the analysis is fully grounded in participants' accounts. The names of the participants and of the homes they resided in, which are given following each extract, are pseudonyms.

Results

All 80 participants demonstrated a degree of retained awareness, and both data-driven and theory-driven analyses provided considerable evidence of retained awareness throughout the conversations (Table 3). Demonstrations of retained awareness outweighed indications of unawareness. However, at least one instance of limited awareness was recorded for 52 participants in the theory-driven analysis, and for 50 of these unawareness was recorded in the data-driven analysis

Table 3
Prevalence of awareness and unawareness

	Data-driven analysis	Theory-driven analysis
Awareness	Total instances 16,788	Total instances 8323
	No of participants 80	No of participants 80
Lack of awareness	Total instances 402	Total instances 342
	No of participants 50	No of participants 52

as well (Table 3). Thus all participants demonstrated instances of awareness, and approximately two-thirds also showed at least one indication of unawareness.

The grounded theory analysis identified three overarching categories of process, focus and scope of awareness, and provided support for the relevance of contextual influences. Drawing together the categories of focus, process and scope, and taking into account the relevance of context, we present a preliminary model of a grounded theory of awareness in people with moderate to severe dementia who still communicate verbally (Fig. 2). The demonstration of awareness involves a set of analytic and behavioural processes, a scope, and a specific focus. The focus of awareness could relate to self, relationships with others, or the surrounding environment. Awareness itself is then demonstrated in relation to a given focus through the involvement of cognitive processes of varying degrees of complexity, and accompanied in some cases by behavioural responses. The scope of awareness relates to its expression with regard to differing timescales. Within this model, some elements of process, focus and scope may be affected such that the person appears to be unaware within those domains, while still demonstrating awareness with regard to other aspects. The model acknowledges the influence of a number of contextual factors on the expression of awareness, and we will discuss these before reviewing each of the three overarching categories in turn.

Context

Contextual influences were derived from both the wider and the immediate context. The wider context included the family, the experience of receiving services and care, and the environment of the home. References to the family usually related to practical aspects of the decision to move into residential care and the role of family members, especially daughters, in this:

I got to the ... time .. when I couldn't do me cooking, and I burnt saucepans and I don't know what. So me daughter came up here, and she went

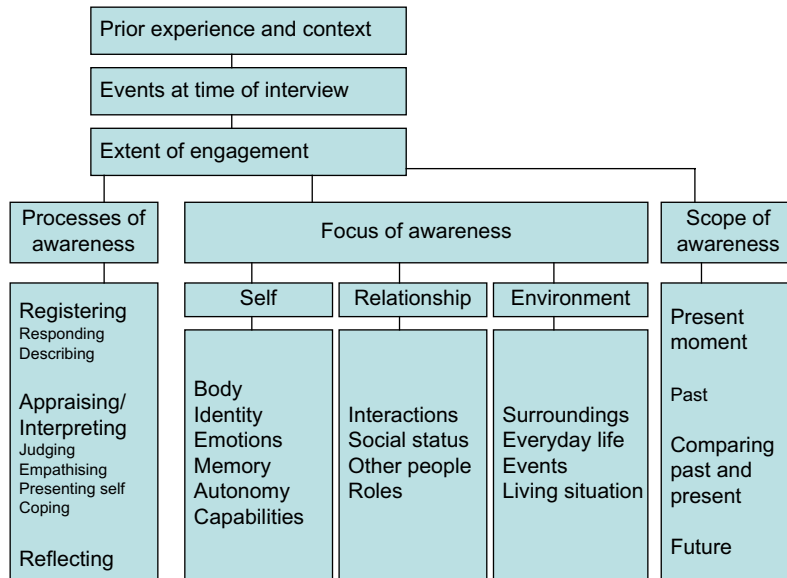


Fig. 2. Towards a grounded theory of awareness in people with moderate to severe dementia living in residential care.

to the one on — Lane, sorting ‘em out, which was the best, you know... and then she had, she brought me up here to see what I thought about it, you know. So .. that’s why I’m here. (Ethel Williams, Barleyfields)

Families could thus support an awareness of the need for care. However, there were no references to discussion with family members about the nature or meaning of ageing, memory loss or dementia, or indeed the proximity of death. Although some residents remained in close contact with family members, there was a sense of being detached from the family:

I feel I’m not attached to my family. (Alice Baker, Eastbridge)

References to experiences of receiving services and care usually involved factual comments, for example, about help provided by particular people:

They’re very kind and she’ll come and if I haven’t drawn the curtains, ‘Leave that, don’t you dare touch them, I’ll do them’. They, they’re carers, they’re very good. So she pulls the curtains for me, ‘cause lifting my arm up, she says ‘Don’t you stretch that arm’. So I can’t fault none of them. (Phyllis Dransfield, Eastbridge)

Carers could, therefore, support the expression of awareness at this practical level. However, while

some participants commented on kindness of staff members or mentioned that they felt well looked after, and some attended religious services provided within the homes, none of the descriptions of the environment suggested the provision of an awareness context in which matters of deep meaning could be discussed. There was often a sense that relationships remained limited:

I’ve no-one here at all. Living with other people doesn’t make you feel less lonely, it makes you feel more lonely... if they’re not people who belong to you. (Sister Janet, Gateholme)

Awareness, or unawareness, was expressed in the immediate context of conversational interactions with a researcher. Events at the time of the conversation, such as experiences of receiving personal care from staff, could impact on what was expressed during the conversation and on the participant’s willingness to engage. This participant had experienced a difficult interaction with staff relating to personal care just before meeting the interviewer, and after expressing her anger to the interviewer decided not to engage:

It’s when you do do do thin’ things which are... opposite to what you intended to do, that makes me opposite me madly... I know just what you can do, but you don’t worry, do you, you don’t do it... You just want to lie to show to m’.... (Helen Sloane, Dykelands)

The interviewers initiated the conversations, but residents retained control of the decision about whether to engage, and whether to continue talking. Residents might be distracted by events or individuals in the surrounding environment, by discomfort arising from internal bodily states, or by their own state of mind. Residents could also show avoidance in response to the interviewer and the direction the conversation was taking, perhaps where the topic became too difficult or potentially upsetting, touched too closely on their limitations, or simply became uninteresting. In these circumstances, residents might react by changing the subject, asking the interviewer a question, starting to sing or hum, or in the most extreme cases leaving the conversation altogether, demonstrating their ability to use a range of coping strategies:

I don't know that I can tell you anything else, love. So... and where do you say you live? (Ethel Williams, Barleyfields)

The interviewers attempted to encourage engagement by providing support, which could include explanations and reassurance, and by responding to residents' expressed needs:

I: What's making you cry?

R: What's making me drum? The lack of life...

I: What would you like to do?

R: I'd be longing to walking out there now with a... home in my hand.

I: We can go for a walk if you want. Would you like to go for a walk?

R: Why not indeed. (Helen Sloane, Dykelands)

Where interviewer and participant processes combined to produce a strong rapport, this facilitated continued engagement and encouraged the expression of awareness.

Focus

The focus of awareness essentially reflects the contents of awareness, and refers to the areas with regard to which awareness was expressed or instances of unawareness were observed. Participants expressed awareness in relation to the three broad domains of self, relationship, and the environmental context.

Awareness of self was shown in relation to body, mind, emotions, and actions. Awareness of physical

self was evident through discussion of bodily sensations, degree of mobility, appearance, age effects and health status:

But the pain now and again, the arm swells here and the fingers kill, but otherwise I'm alright. (Phyllis Dransfield, Eastbridge)

Awareness of their own identity, in terms of what kind of person they were, was evident in descriptions of characteristics and attributes such as religious faith, as well as in autobiographical accounts:

Basically I'm a happy person, get worried and a bit uptight sometimes, but on the whole I enjoy life... (Penelope Seaton, Dykelands)

Awareness of memory problems was demonstrated in various ways. Participants showed awareness that they encountered memory problems in the course of conversation, that they were likely to have difficulties in certain situations because of their memory problems, and that they would forget things:

My memory's gone. (Cameron Charlton, Gateholme)

Some offered explanations for this, saying, for example, that the brain was not working, and some described strategies they used to help themselves remember:

I'm trying to think... oh golly, I shall have to look at er the paper on the board before I could say. (Eileen Moorhead, Alderwood)

There was an awareness of having limited capabilities and of the impact of this:

I used to be er... a bloke that knew different things and all that, you know... I've lost it... Really lost it... And, er, I don't do like I used to do. (Bill Nichols, Hawkshill)

Participants expressed awareness of their current state of mind and their emotions, identifying in particular feelings of sadness, fear, loneliness and boredom:

At the moment I'm... I feel really down. And it's not laziness, is it. (Rose Rhule, Hawkshill)

They also expressed an awareness of their increased dependence on others, their lack of agency and autonomy, and their lack of a sense of purpose or role in life:

I say, 'Well, that's what we've come here for...' We don't like to think of it that way, do we... we haven't come to die, we've just come, we've got

to that stage, haven't we... And we need more help, we can't help ourselves so much. (Nettie Davidson, Alderwood)

Instances of unawareness in this domain involved participants not acknowledging memory problems, limited capabilities, or the need for care. Some participants who had entered residential care because they had been unable to continue living independently nevertheless felt they had no need to be there:

I mean, this is quite pleasant here, but I've had enough of it. I don't think I need in any way to stay... I don't know whether I could get back there [a former job]... probably I could get back if I've been working there once before, they'd say 'Yes, come'. (Jill Brennan, Foxleas)

Awareness of being in relationship with others was evident in a number of ways. There was awareness of participating in a conversation, and of the purpose of the conversation, and a clear understanding of the social etiquette that such a situation demanded:

It's nice though, have a little chat like this.... And same as you, you know nothing about me and I know nothing about you, but you can talk about something and I tell you... (Ida Hancock, Dykelands)

There was an awareness of other residents in the home, shown in comments on their behaviour, health and well-being:

And then Lorna there... oh dear me. Oh no. And then the lady with the white hair, she's very retarded... I mean, you can barely hold a conversation with her. (Penelope Seaton, Dykelands)

Participants spoke of how they perceived their own and others' status and standing within the residential setting:

You see, everybody isn't here permanently. Now me and Jim are, we're permanent. And there's one or two more that are permanent, that never go anywhere. They live here and that's it. And them are the people we've got to think about. (Mabel Sutton, Barleyfields)

Participants were aware of the role they currently held as well as past roles they had taken, and of roles taken by others in the home and within their families:

I like helping other people, which I've done quite a lot of. I mean, I'm not boasting about it but I

have helped a lot people who really needed help, you know... (Mona Brighthouse, Foxleas)

There was an awareness that residents, staff, visitors and professionals held different roles:

Er, it is a very good place to be at the assistants, the nurses and er I don't know what capacity the young man... I think he must be... I don't know whether he's the owner or a manager so I can't say much about that, but he's very... and he's really bothered with me, because I've had a bad week and er... (Ethel Williams, Barleyfields)

Participants perceived the interviewer as someone in a distinct role, with particular knowledge, and the ability in some circumstances to help. An awareness of the feelings and needs of others, including the interviewer, was evident, as well as awareness of the treatment received from others:

She helped me a lot when I first came. She was such a help to me. (Albert Jamison, Alderwood)

In relation to awareness of relationship, some participants seemed unaware of their family context or of losses through bereavement, and there could be confusion about the roles taken by different people in the home, including the interviewer. In this extract, the resident seemed to be interacting with the interviewer as if she were another resident requiring assistance:

Have you just been to the toilet? [Interviewer: I have] Do you want me to take you? [Interviewer: No, thanks, I've just been.] And you've got your [false] teeth going? When did you get them? (Jean Reef, Corbydale)

Awareness of the environment encompassed surroundings, routines, and events. The physical environment and the surroundings in the home were frequently discussed:

I had a couch an' I give it to the battered wives. It was under there, but er it got that way that I couldn't, there was no room to move. 'Cause me son, they bought the carpet and ev' the curtains and everything to match. Yes, so it's me own room... me own pictures and me own plants. (Phyllis Dransfield, Eastbridge)

Participants were aware of conditions outside the home, commenting, for example, on the weather:

But it's wet really, out there, you know, now... (Esme Bowen, Barleyfields)

There was an awareness of the routine in the home, of events and activities within the home, and of visitors coming into the home:

They, they're students, they always come ...to take prayers on a Saturday... They .. they enjoy coming. (Nettie Davidson, Alderwood)

Participants were aware that they were living not in their own homes but in a residential care setting, and of the lack of alternative options:

Someone picked me up and suggested I come here and have a look at it, and if I liked it, stop here. I come and had a look at it and I thought it seemed a useful place ... I wouldn't say it was as good as home...you haven't got that same feeling or love or anything is ... a at a place like this. You're just ... one of a number, group, who are pretty well in a similar position ... but you er do your best... (Charles Amber, Dykelands)

In relation to their environment, some participants lacked awareness of recent events, and seemed unaware of living in the home and the reason for being there. Some indicated they were not staying at the home:

I'm going back home... I'm not staying by any means. (Nora Brown, Dykelands)

Others constructed various explanations about where they were and why:

I can't do as I like here at all... I came in to help and ... couldn't get out. I've had to sleep in a bed. (Sid Walton, Jackdaws)

Processes

The process category reflects the mental processes by which awareness is developed or compromised. The expression of awareness through a range of cognitive processes was evident at different levels of complexity, ranging from registering information about the surroundings to thoughtful reflection on the situation.

The ability to register information was demonstrated through responses and descriptions. Participants responded to both internal bodily states and external stimuli:

Oh, no windows open at all, have they, this morning, they haven't....Mind you, it's a very wet morning... and the trees there are all swaying aren't they.... (Esme Bowen, Barleyfields)

There were many examples of participants giving accurate descriptions of themselves and their environment:

When you get older you... well, I do, when I get old I get daft, I can't remember names (laughs) But er... yes, it's er... and then they told me if I wanted to stay here, I suppose everybody has to do it, er they've to bring their own bedroom suite. Well, my son-in-law brought one of mine last week, so I've... I suppose I'm here now. Because they've done all the... n..negotiating. I erm, I haven't had anything to do with it. They've asked me questions and, you know, so... (Ethel Williams, Barleyfields)

The ability to appraise and interpret was demonstrated through making judgements, empathising, engaging in self-presentation, and applying coping strategies. Participants often made accurate judgements about their own functioning:

...now, I mustn't wait too long or I might miss what I'm thinking. (Una Malton, Eastbridge)

Some were readily able to empathise and take the perspective of others:

Well, I'm not a moaning type, so it's not too bad when anybody comes to see you (laughs). I always think about people who moan and groan and when the people come to see them, you know, it's very disheartening for them, isn't it. They think "Oh dear me, I'm not going there any more" (Molly Sharp, Eastbridge)

Participants showed self-awareness through presenting themselves in particular ways to the researcher, for example, emphasising past experiences or family contexts to demonstrate their status as a person:

There's a bit of Irish in me, you see...That keeps you going. My mother's people were Irish, she was... and I always think "Oh, I must have got it from them". You know. You just haven't got to let things get on top of you. I mean, why let them get on top of you and make you miserable for the rest of your life, the rest of your life's not worth living then, is it? (Molly Sharp, Eastbridge)

Participants appeared to use coping strategies that suggested a degree of awareness; for example, awareness of making a mistake could trigger attempts to cover up:

Well, perhaps er... things have gone wrong, but I'm not gonna let on... They think, they think

everything's OK, but it isn't, I've made a right mess of it... [Interviewer: And so sometimes you cover up when you make a mess?] Yes, I'm not honest enough, when I know I'm wrong. (Alice Baker, Eastbridge)

There were instances of thoughtful reflection on one's own capabilities, functioning and situation:

I feel as though there's nothing the matter with me, and I'm here under false pretences. But, er, every now and again I have common sense comes and ...I've been examined three times and they've all come to the same conclusion, so they must be right, maybe, I must be wrong, I must have... Well, they... they didn't tell me what it was, it was something that... it's common among people of my age, that's all I know, I don't know what the name of it is or... how it operates, but they, they just give me a ti' a ticket for some medicine, I have, I have that, and er they've sent me to this... I don't know what you call them, you know, where it's hospital but it isn't hospital... (Charles Amber, Dykelands)

Lack of awareness was sometimes evident in the ability to give an accurate description, the ability to make an accurate judgement, and the ability to consider and interact with others. Participants sometimes provided inaccurate descriptions of their living situation:

I'm here, my daughter's gone to get me some things I need. It's, er...this is her house. (Isabel Mortlake, Alderwood)

Some made inaccurate judgements about their own functioning and capabilities:

I'm going to get, well, I sold the other [car], I shouldn't, don't think I should have done, but I did, so I'm going to buy another one. (Una Malton, Eastbridge)

Sometimes participants had difficulty taking the perspective of others:

I shall, I shall get shot if I don't, if I let them know what I've been doing... not getting on my way. I should be getting on with my work, with my work... I'd better go and wash up. (Maggie Smithson, Dykelands)

Scope

The scope category related to the time periods with regard to which awareness was demonstrated.

Awareness was expressed in relation to the immediate moment within the conversation as well as more widely. Taking the example of awareness of memory functioning, reference to memory included comments on memory difficulties as they arose in the conversations as well as general reference to not knowing or remembering, and some participants also demonstrated the ability to anticipate that difficulties might arise in particular situations. Participants often commented in the course of a conversation on difficulties they were experiencing at that moment, such as being unable to find the right word, or on aspects of their performance. They showed awareness that they were likely to have difficulties in certain situations because of their memory problems, and that they would forget things:

I think part of the time I did... and you know, my mind doesn't remember it all, but, but other times we had erm... can't say the word I want now. (Jill Brennan, Foxleas)

Participants expressed awareness of their own location in time and of the passage of time:

I can always tell what time of the year it is by the tr' trees. Losing their leaves and they...and budding and ... they look very sorry for themselves at present, don't they. Some leaves'll be popping up. (Mona Brighthouse, Foxleas)

Some realised that it was difficult for them to make accurate judgements about the passing of time:

I've lost count of time. (Jill Brennan, Foxleas)

Awareness was expressed in relation to both past and present, and to changes over time. Participants made comparisons between past and present experience or functioning:

Don't do anything now... I used to do a lot of walking at one time, but... I've just... nothing's right now... I'm not a bit like I used to be... not a bit like I was... when I first came here. (Nettie Davidson, Alderwood)

A few conversations revealed awareness of the future, and of the likely proximity of death:

You wonder what it's [dying is] going to entail ... I can't say I'm frightened, but I wonder sometimes...(Angela Barraclough, Alderwood)

With regard to scope, awareness was most likely to be compromised in relation to location in time, with

some participants confusing past and present experience:

And of course I don't know at the moment whether both my parents are living... I would think if anything disastrous had happened I would have been told, but... whether they're here or not I don't know. Mystery. (Jill Brennan, Foxleas)

Several participants, while being aware they were living away from their parents, felt that they should be at home with them:

I know I miss home... I miss me dad and I miss me mum... she comes and sees me when she can, but...(Charles Amber, Dykelands)

Others felt that, in line with their previous roles in life, they should be at home looking after their families:

I should have been at home, getting all the dinners ready, and putting 'em out for them for when they stepped in. And here I've been all day. (Elizabeth Pickles, Dykelands)

Discussion

As far as we can ascertain, this is the first study to undertake a detailed exploration of awareness among a large sample of people with dementia living in residential care. The findings provide strong evidence that considerable capacity for awareness is retained. We have developed a framework for a grounded theory of awareness in this group, taking into account the nature of the social interactions within which expressions of awareness were elicited and the contextual factors that may influence whether and how participants express awareness.

Our analyses provided extensive evidence of retained awareness as well as an indication of areas in which awareness could sometimes be compromised. The indicators on which the theory-driven analysis was based focused primarily on the cognitive processes involved in awareness. This analysis demonstrated that theoretical concepts previously applied to the study of awareness in early stage dementia (Clare, 2004a) are also relevant to people with moderate and severe dementia. The data-driven analysis facilitated a much broader view, permitting more extensive identification of instances of retained awareness. The identification of the focus category supports the importance of relational models of awareness that specify the indication of an 'object' of awareness (Marková & Berrios,

2001), since it subsumes a number of possible objects, such as mobility, word-finding, mood, daily routine, and so on, in regard to which awareness could be assessed. Identification of the targeted time period or scope as a key element reflects an aspect of awareness that has rarely been considered in existing neuropsychological models of awareness, although a distinction has been proposed between 'on-line', 'emergent' and 'anticipatory' awareness of specific impairments (Crosson et al., 1989; Toglia & Kirk, 2000). Our model extends previous theoretical models of awareness in dementia, in that it incorporates not only the cognitive processes involved in demonstrating awareness but also the *focus* and *scope* of awareness, and identifies areas where awareness could be compromised in regard to process, focus or scope, as well as placing these aspects in the wider context, in line with the biopsychosocial framework (Clare, 2004a).

While the findings provide strong evidence for retained awareness in all participants, there were also examples of unawareness in some participants, albeit fewer in number. Where unawareness was evident, this related primarily either to an inaccurate appraisal of some aspect of one's own functioning or situation, or to a difficulty in making sense of the current situation, which could be accompanied by confusion between past and present. From a cognitive perspective, the extent to which the 'personal database' of self-related knowledge is updated has been proposed as a central component in the accurate appraisal of current functioning (Morris & Hannesdottir, 2004). Difficulties with this process, particularly in the context of limited environmental feedback, could explain manifestations of unawareness in this area. It is less clear whether this could account fully for other aspects of unawareness, for example, unawareness of losses through bereavement, the belief that parents were still alive, or inaccurate attributions about the nature and purpose of the residential home. These could perhaps be interpreted as reflecting a tendency to hold on to a past self and identity (Sabat, 2001), or to experience continuing bonds following bereavement (Shuchter & Zisook, 1993), in the context of cognitive impairments, and may demonstrate how the self-maintaining coping stance (Clare, 2003) develops as dementia progresses.

The concept of the 'awareness context' (Glaser & Strauss, 1965) serves as a reminder that the expression of awareness will be influenced by the extent to which the setting is facilitative. This could be relevant at various levels. Residential care settings may provide relatively limited opportunities to test one's skills and obtain feedback, so that residents are more likely to

draw on past experiences when making appraisals, resulting in inaccurate judgements. With regard to the meanings participants ascribe to their situation, it was noteworthy that although a great deal of fear was expressed, few referred to the future and hardly any mentioned death. Some residents had religious beliefs and participated in religious services within the care homes, which may have provided a forum for considering issues of deeper meaning, but there was no indication that these issues were touched on in contact with family members or care staff. It is possible that a more open awareness context might help to mitigate residents' fears and anxieties.

Our findings provide a preliminary framework for better understanding the extent and expression of awareness among this group. We have acknowledged possible influences resulting from the researchers' prior expectations, interaction with the data and resulting interpretations, and a number of steps were taken to maximise the credibility and trustworthiness of the findings (Elliott et al., 1999; Yardley, 2000). The nature of our sample and our data set does, however, place some limitations on our findings. We only had access to what participants said; it would be valuable to observe in addition what participants do, for example, how they cope with difficulties, as this would provide another dimension to the model of awareness. Furthermore, all our participants were able to communicate verbally. Theoretical models suggest that a degree of retained awareness should be seen even in people who no longer communicate verbally (Laureys et al., 2004; Stuss et al., 2001), but this could not be addressed in the present study. With regard to methodology, this was a somewhat unusual application of grounded theory in that the data were already collected before the analysis began. Thus, data collection was not adapted to take account of emerging information and categories. However, the participants' accounts were in any case elicited in unstructured conversations, as this was considered likely to provide the best opportunity for participants to share their thoughts and feelings, and the sample size was sufficiently large to permit extensive use of the constant comparative method to identify robust categories. The study has demonstrated the feasibility of engaging residents in conversation and eliciting data that illuminates important aspects of their experience, and future studies could perhaps build on this by attempting to use a more structured approach in interviewing. This would also make it possible to explore individual trajectories of, and variability in, awareness over time, and how these relate to extrinsic factors.

Within these constraints, however, our data set provided a wealth of information relating to awareness. This has important practical applications. Our findings suggest that people with moderate to severe dementia are often aware to a considerable degree, perhaps more than is assumed by those most closely involved in providing care. All participants showed some awareness, while some also showed unawareness in certain specific areas. Where residents talk in ways that suggest an unrealistic appraisal of their situation or a confusion between past and present, there is a risk that they will be regarded as unaware in a more general sense, negating the aspects of retained awareness that are also evident. Understanding more about the capacity for retained awareness may help staff to listen and communicate effectively and may encourage them to give credibility to residents' genuine concerns. At the same time, understanding more about the specific ways in which awareness can be compromised may assist staff in distinguishing situations where a resident is unable to be aware, and in responding appropriately so as to provide support and minimise distress.

In summary, our findings add to the theoretical understanding of awareness and unawareness in people with moderate to severe dementia living in residential care. They suggest the participants can be viewed as agents trying to make sense of their situation and maintain a continuous self-narrative in the context of cognitive impairment and a possibly limited awareness context. They also provide a practical demonstration of extensive retained awareness, contributing to the case for devoting resources to the provision of high-quality, person-centred care.

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