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What is This?

The paradox of dementia: Changes in assimilation after receiving a diagnosis of dementia

Emma Lishman
College of Life and Environmental Sciences, Exeter University, UK

Richard Cheston
Mental Health Sciences Group, Department of Health and Social Sciences, University of the West of England, UK

Janet Smithson
College of Life and Environmental Sciences, Exeter University, UK.

Abstract

This qualitative study used semi-structured interviews to explore how six people talked about their difficulties before and after a dementia diagnosis. Participants' accounts of their memory problems were analysed in terms of the verbal Markers of Assimilation of Problematic Voices Scale. This analysis indicated that after diagnosis some participants were able to integrate aspects of their illness that had previously been too painful, and which had been warded off. The process by which individuals were able to integrate a dementia diagnosis into their sense of self-involved stepping in and out of awareness, with both acceptance and denial featuring in their accounts as they approached and then retreated from addressing the diagnosis. In contrast, other participants resisted moving towards explicitly acknowledging their dementia but were instead able to express concerns about what this movement would entail, for instance voicing their fears that it would mean that they had surrendered. Social support seems to have been crucial in enabling participants to sustain a positive sense of self in the face of this adjustment.

Corresponding author:
Emma Lishman, College of Life and Environmental Sciences, Exeter University, UK.
Email: emmalishman@hotmail.co.uk

Introduction

In recent years, a series of studies have explored the awareness of people living with dementia about many different aspects of their illness (Cheston, 2005; Clare, 2002, 2003; Clare, Roth, & Pratt, 2005; Clare et al., 2012; Macquarrie, 2005; Sabat, 2002a, 2002b, 2006; Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook, 2006). These have shown that awareness is often variable, functional and social. Moreover, rather than being static and unchanging, people living with dementia move through oscillating levels of avoiding, exploration and understanding (Robinson, Derksen, Scheltens, & Moniz-Cook, 2005). Within the research literature, this movement between differing levels of awareness has been associated with coping styles (Clare et al., 2005), self-identity (Sabat, 2002a) and environments and interactions (Langdon, Eagle, & Warner, 2007). Emerging from these accounts is consensus that when provided with supportive environments at least some people affected by dementia are able to make sense of their illness and to face the psychological implications of this.

However, whilst there is general agreement that awareness is the product of psychosocial processes interacting with cognitive impairments, the ways in which the different background factors interact and the effect they have on a person's capacity to talk about the diagnosis is not clear. One difficulty in carrying out research exploring how people experience and manage the process of receiving a dementia diagnosis is the need to accommodate both the way in which people talk about their difficulties, and the emotion accompanying this talk. An account of how people adjust to dementia that fails to incorporate their emotional response risks being incomplete.

The assimilation of problematic voices

To address the need for a methodological tool that incorporates both an analysis of both what people say, and the emotional load behind this, we have adapted a method of analysis used within psychotherapy process research. The Assimilation Model of psychotherapeutic change (Honos-Webb & Stiles, 1998; Honos-Webb, Surko, Stiles, & Greenberg, 1998; Stiles, 1999, 2001; Stiles et al., 1999; Stiles, Osatuke, Glick, & Mackay, 2002) is a transtheoretical model of the process of change involved in psychotherapy. The Assimilation Model is not a description of how to do therapy, but rather a way of formulating the nature of change that can occur in any form of therapy, or indeed, in everyday life. It has been used extensively to understand how during psychotherapy the meaning and experiences of events change. This involves clients with mental health concerns such as post-traumatic stress (Varvin & Stiles, 1999) and the process of acknowledging loss associated with a learning disability (Newman & Beail, 2002). It has also been applied to psychological intervention with people with dementia (Cheston, Jones, & Gilliard, 2004; Watkins, Cheston, Jones, & Gillard, 2006). A key feature of this model is that in assessing the extent to which an experience has been assimilated into that person's self, it is vitally important to take into account both what is said and the affective tone or context. A summary of the model and its levels are illustrated in Figure 1.

Dementia and the assimilation model

The Assimilation Model suggests that most experiences in a person's life are unproblematic and can be assimilated relatively routinely into that person's existing understanding of the
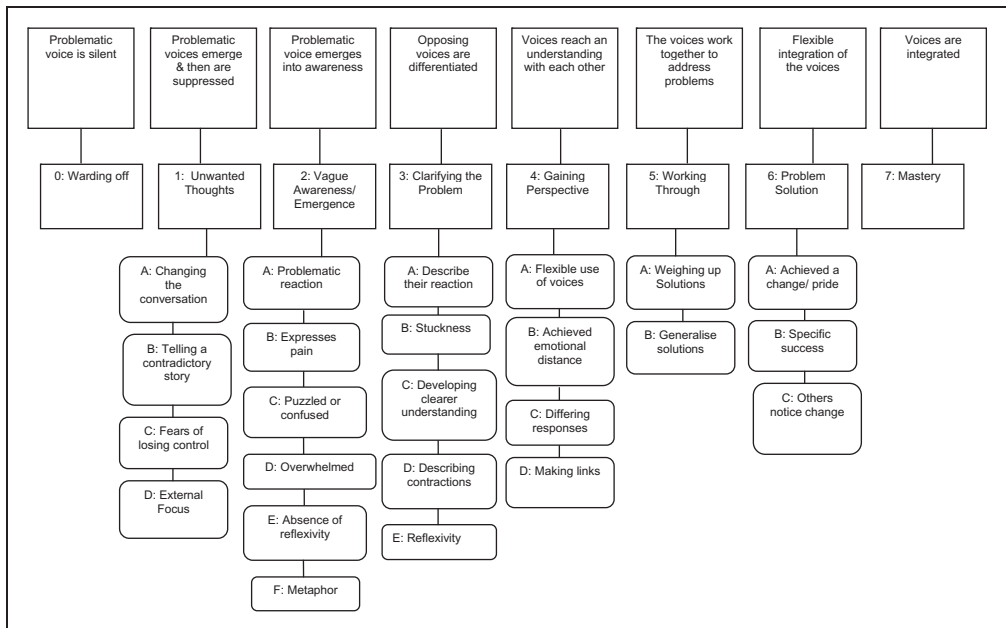
Figure 1. The Assimilation of Problematic Experiences Scale (Based on Honos-Webb et al., 1998)

world. However, some experiences (including, arguably, a diagnosis of dementia) are so traumatic and their implications are so threatening that they can resist an easy or early assimilation into the self (Cheston et al., 2004). In effect being diagnosed with dementia involves a dilemma: either the person faces likelihood of physical and mental deterioration, or they retreat away from the diagnosis into denial. Moreover, dementia often undermines the person's coping resources through its effects on cognition and behaviour, as well as on personal, social and occupational functioning (Kitwood, 1997).

In many ways a dementia diagnosis can be construed in terms of the assimilation of a problematic experience. That is to say, a diagnosis is likely to represent such a powerful threat to the person's psychological equilibrium that it would not be easily assimilated into the self. In the terms of the assimilation model where elements of the threat have not been assimilated, they may remain dissociated and may instead be expressed indirectly. For instance, the person with dementia may express their fears about dementia through stories about a tidal wave (Cheston et al., 2004) or being lost when flying over a jungle (Cheston, 1996) or they may look for long-dead parents, or try to go home (Missen, 1993). In this way whilst direct confrontation with dementia is "warded off", nevertheless some parts of this experience can be experienced, and processed.

"Being in two minds" about dementia: The importance of ambivalence

The assimilation model emphasises the importance of representing the self not as a single, unified entity but instead as context-dependent, shifting and multiple selves. This is consistent with post modern or social constructionist theories of the self which describe a

"*community of voices*" (Gergen & Kaye, 1992; Hermans & Kempen, 1992; Mair, 1989). Thus, the assimilation model suggests that when a person's experiences are highly traumatic or otherwise represent a threat to that person's identity, then conflict can arise between the different voices that make up this community. In these circumstances, one voice (referred to as the Dominant Voice) can be understood as the voice of continuity, or the preservation of the status quo. Often the Dominant Voice is initially experienced as a powerful voice because it is a voice of certainty, of the need to resist the threat of change. In this regard the Dominant Voice is a voice which has the pretence of being unemotional, of emphasising the importance of control and of logic and of disallowing the vaguer expression of emotional unease.

In contrast the Problematic Voice can be thought of as the voice of change. The Problematic Voice articulates a concern that something, somehow is wrong, and that change is either necessary or unavoidable. The Problematic Voice is often the voice of uncertainty and of emotional hesitancy; perhaps it may be the voice of fear pointing towards a threat. At other times, the Problematic Voice can be the voice of sadness and loss that someone or something is missing and needs to be grieved for. The Dominant and Problematic voices that form the community of selves are essentially dialogical, in the sense that "*voices within the self relate to each other through dialogue*" (Honos-Webb & Stiles, 1998, p. 23). This conversation between the Problematic and Dominant Voice is central to the therapeutic process, in that it is through this dialogue between the two voices that assimilation (and thus change) occurs.

During successful assimilation, people come to experience their problems differently through this dialogue between the voices. During this process a problematic voice that is initially warded off or pushed away gradually finds expression and gains in strength until it challenges the dominant community. Therapeutic change is viewed as mutual accommodation; the Problematic Voice and the Dominant Voices change as they develop a shared understanding, so that a new, integrated, voice emerges. The formally non-dominant, Problematic Voice joins the community of voices and, becomes an accepted aspect of one's experience (Honos-Webb & Stiles, 1998; Stiles, 2001). Typically, in therapy this conversation between the Problematic and the Dominant Voice becomes apparent in the client approaching and then retreating from the difficult material, a process that has been described in psychotherapy with people living with dementia (Betts & Cheston, 2012). Similarly qualitative research into awareness amongst people affected by dementia frequently describes an oscillating process featuring both denial and acknowledgement, or in the terms of the Assimilation model alternating between the Problematic and the Dominant Voice. For instance, in a study of couples' shared constructions of, and responses to, the diagnosis of dementia, Robinson, Clare, & Evans (2005) described how:

> "*The thematic analysis describes couples' attempts to make sense of what was happening to the person with dementia and how this process had been influenced by their experiences of receiving a diagnosis of dementia. Their accounts suggested a cyclical process of denial, minimisation and gradual realisation as couples gradually began to accept the changes in the person with dementia were likely to be permanent, linked to an oscillating process of acknowledging what had been lost, as well as carrying on as a couple by focusing on what remained for each person and the couple.*" (Robinson et al., 2005, p, 344)

A description of assimilative change has evolved across a series of case studies (Field, Barkham, Sapiro, Stiles, 1994; Honos-Webb et al., 1998, 1999; Knobloch, Endres, Stiles, &

Silberschatz, 2001; Stiles et al., 2002, 2004) and is summarised in the Assimilation of Problematic Experiences Scale (APES) (Figures 1 and Table 1). The scale has eight incremental levels through which problematic voices progress. These eights levels are referred to as; warded off; unwanted thoughts; vague awareness/acceptance; problem statement/clarification; understanding/insight; working through; problem solution; and mastery. The emotional quality of the different levels is central to this model of change. As the Problematic Voice is gradually assimilated, so the person experiences a parallel sequence of emotional reactions, from being oblivious, to experiencing the content as painful, then as problematic but less distressing (Cheston et al., 2004). In later levels, as the voice is accepted, solutions are tried out, confidence grows and satisfaction is gained. The initial formulations of the Assimilation model in terms of experiences has been adapted in order to aid identification of these different levels by representing them in terms of different voices and by specifying specific speech markers (Honos-Webb et al., 1998; Honos-Webb, Surko, Stiles, & Greenberg, 1999). These markers are indicative of the form of dialogue that occurs at the different levels between the Dominant and the Problematic Voice. Table 1 illustrates how each level of assimilation is associated with a series of speech markers.

The Markers of Assimilation of Problematic Voices Scale (MAPVS) is primarily a research tool, but can also be used to help to formulate clinical problems, and as such has

Table 1. Assimilation of Problematic Experiences Scale

APES level	Content	Affect
0. Warded off	Un-informed, unaware avoidance	Minimal affect, reflecting successful avoidance
1. Unwanted thoughts	Emergence of thoughts associated with discomfort	Unfocused strong emotions (e.g. anxiety, fear, sadness), which are more salient than the content
2. Vague awareness	Problematic experience is acknowledged and uncomfortable associated thoughts are described.	Affect focused on acute psychological pain or panic
3. Problem statement or clarification	Clear problem statement	Negative but manageable affect
4. Understanding/insight	Problem is formulated within a schema including clear connective links	Curiosity of affect, with mixed pleasant and unpleasant recognitions
5. Application/working through	Working on current problem with reference to specific problem-solving efforts	Business-like positive/negative affect linked to outcomes
6. Problem solution	Success with a specific problem	Positive satisfaction linked to accomplishments
7. Mastery	Generalization through habitual use of problem solution in new situations	Neutral (i.e. this is no longer something to get excited about)

Adapted from Newman and Beail (2002).

high clinical relevance (Stiles, 2001; Wilson, 2011). When being used in this way the therapist identifies each problematic experience and assesses the degree to which the problem has been assimilated by the client. They use this as the starting point to help the client move to the next level of assimilation and to measure the level of change during the therapeutic process (Stiles, 2001). MAPVS is unobtrusive in that it allows progress to be monitored as part of the therapeutic dialogue and as such does not intrude into the therapeutic relationships as some other clinical measurements do (Wilson, 2011). The assimilation model thus attempts to bring together process and outcomes in psychotherapy and recognises the dynamic nature of change as involving both cognition and affect (Varvin & Stiles, 1999).

Aims

This study explores whether MAPVS can be used to further the understanding of how people talk about their diagnosis and the symptoms associated with this. The specific aims were as follows:

(1) To use MAPVS to analyse the transcripts of interviews with people before and after an assessment at a memory clinic.
(2) To explore whether markers associated with the Problematic and Dominant voices can be identified and tracked in the transcripts.
(3) To explore whether there are changes in levels of assimilation before and after a participant receives a diagnosis, and thus whether there are changes in the relationships between the Problematic and Dominant Voices.

Method

Participants were recruited from an NHS memory service in the South-West of England. All participants were patients undergoing a dementia assessment which consisted of two elements: an initial assessment, followed often several months later by a second appointment at which the patient would be given a diagnosis and a care plan would be agreed with the service. Data were collected through semi-structured interviews, which were held at two time points; shortly after participants' initial appointment at the clinic and six weeks after their diagnostic appointment. NHS ethics and research governance approval were obtained for the study.[1] The same semi-structured interview schedule was used for both interviews to ensure consistency in how the discussion about the person's memory and diagnosis were approached. Participants' experiences of the following topics were included in the semi-structured interview; their daily life (what they do and enjoy doing), their relationships (family, friends and social situations), their sense of self and their main roles, the assessment process, the impact of their difficulties and changes they had noticed. In order to avoid prompting participants, the interviewer did not herself use the terms "*Alzheimer's disease*" or "*dementia*" unless it had already been mentioned by participants. However, if by the latter stages of the interview, participants had not used one of these terms, then the researcher introduced the phrase indirectly, for instance by commenting "*I know that some older people worry that their memory problem might be caused by dementia – is that something you have thought about*?" Interviews were recorded and transcribed verbatim.

Analysis

To enhance the reliability of the MAPVS, the original coding frame of Honos-Webb et al. (1998) was adapted by the authors using material that had been generated in the Dementia Voice study (Watkins et al., 2006). This adaptation maintained both the structure of the markers' scale, and used the same descriptions of each marker as Honos-Webb had used, but illustrated these by reference to material that was dementia specific.[2] These data were prepared according to the criteria and guidelines from the Stiles' group which have been published in several studies (Honos-Webb & Stiles, 1998; Honos-Webb et al., 1999; Knobloch, Endres, Stiles, & Silberschatz, 2001). This procedure consists of five steps.

(1) **Familiarisation and indexing** requires intensive exposure to the transcripts, making systematic notes to locate passages concerning topics of interest.
(2) **Identifying and choosing themes** involves identifying themes for further detailed analysis. In this context, a "theme" related to the over-arching subject of cognitive loss, changes in roles, relationships and affect.
(3) **Extracting passages** entails extracting passages that include potential markers. Markers are identifiable events that recur throughout the transcripts that indicate important phenomena. Passages relating to the themes being analysed were collated.
(4) **Rating passages** involves rating passages that had been extracted using the manual for rating assimilation (Honos-Webb et al., 1998), which includes guidelines for rating passages, a description of the markers and a guide to prioritising markers.
(5) **Analysis of markers** began by establishing whether the use of the markers-based system of rating assimilation was internally valid. Thus, the level of agreement between researchers across each interview set was calculated. Subsequent analyses involved looking at the overall and individual levels of assimilation and whether there had been a change between the first and second interviews. Assimilation ratings were completed independently by the researchers.

Inter-rater reliability

From the initial six transcribed interviews from the pre-diagnostic phase, 120 extracts were identified and coded. Coding was completed independently by the authors, who also rated their confidence in each rating, and specified which parts of the extract they had based their rating on. In order to increase the reliability of analysis, all extracts where either one of the two raters had estimated their confidence level as being low (i.e. two or below on a five-point scale), were excluded from the analysis. In addition, when the content of the extracts was ambiguous (i.e. the two raters identified different parts of the extract to rate), then detailed discussion took place about which part of extracts constituted a marker and which of the extracts could or could not be coded using the "decision guide" (adapted from the APES scales Honos-Webb et al., 1998). The original ratings were then discarded, and the extract was reanalysed. This resulted in 97 of the original 120 extracts being rated of which 93 were coded in agreement. The four extracts where there was disagreement have been excluded from the analysis.

From the six second interviews (after diagnosis) 124 extracts were identified and again rated independently by the authors. Following the process described earlier 110 extracts remained all of which were coded in agreement.

Results

Ten participants (7 men and 3 women) were interviewed before they had received a diagnosis. All participants defined themselves as white British. Only 6 of these 10 original participants could be interviewed for a second time following their diagnosis, as two declined and delays in the other two participants receiving a diagnostic appointment meant that they couldn't therefore be interviewed within the time frame of this research. In examining the transcripts of the two people who declined to be interviewed following their diagnosis, it appears likely that each of these participants were struggling to assimilate the problematic material related to their diagnosis. This is important, as it shows how emotionally painful the process is, and may suggest that the people whom we were able to interview for a second time may have been more able to assimilate the diagnosis than those who declined our invitation for a second interview. The details of participants and their diagnoses are provided in Table 2.

Overall levels of assimilation

The overall levels of assimilation for the pre-diagnostic interviews is illustrated in Figure 2 and for post-diagnostic interview in Figure 3. During the first interviews (pre diagnosis) participants' levels of assimilation ranged from level 0 (warding off) to level 4 (understanding and gaining perspective), with most extracts (44%) being coded at level 3 (clarifying the problem). During the second interviews (post diagnosis), there were no markers of level 0, whilst at the same time the upper range of levels was wider and included for the first time markers from levels 5 and 6 (working through and problem

Table 2. Details of participants

Participant	Gender	Person present at the interview	Date of first interview	Date of second interview	Diagnosis
Henry	Male	Partner	16 Sept 2011	16 Jan 2012	Alzheimer's
Geoffrey	Male	Wife	6 July 2011	1 Sept 2011	Dementia
Jim	Male	Wife	8 Aug 2011	17 Sept 2012	Dementia
Jill	Female	Husband	26 Aug 2011	16 Jan 2012	Alzheimer's
Doris	Female	Husband	6 Sept 2011	11 Jan 2012	MIC
Len	Male	Wife	7 Sept 2011	17 Feb 2012	Alzheimer's
Fergus	Male	Wife	5 Aug 2011	n/a	Dementia
Adam	Male	Wife	15 Sept 2011	n/a	MIC
Mike	Male	n/a	7 July 2011	n/a	Unknown
Maggie	Female	n/a	7 July 2011	n/a	Dementia

solution). While, again, the most frequent markers occurred at level 3 (40%), a third of extracts were coded above level 3.

Cheston (2013) argues that the eight levels of markers of assimilation can be divided into three stages: emergence (levels 0 to 2); problem clarification (level 3); and working through (levels 4 to 7). Analysing the data using a 3×2 chi-squared test to compare the proportion of markers in each of these three stages before and after participants received a diagnosis of dementia indicated that there was a highly significant level of difference between the markers ($X = 9.82$, df $= 2$, $P = 0.007$).

During both interviews the most common level of assimilation is level 3 (clarifying the problem). At this level, people can name their problem and describe how it makes them feel without being caught up in the emotion of the moment. In other words, both the Problematic and the Dominant Voices are articulated and the person may talk about feeling stuck between these different ways of approaching dementia. Given the timings of the interviews, it is perhaps not surprising that "problem clarification" is the most common level. Participants were at a stage in which they are directly faced with establishing the meaning of their problems, by the very process of assessment and diagnosis. Importantly, however, the finding that participants were engaged in "clarifying the problem" during the
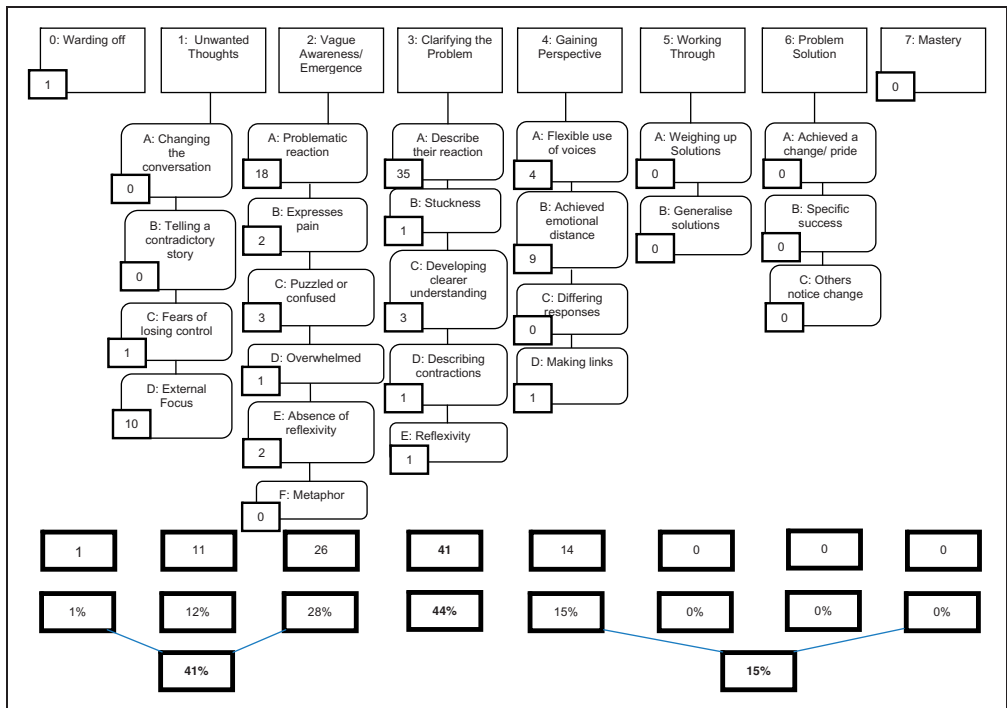

Figure 2. The assimilation of problematic experiences framework and the number of items coded at each level from the six initial interviews (before diagnosis)
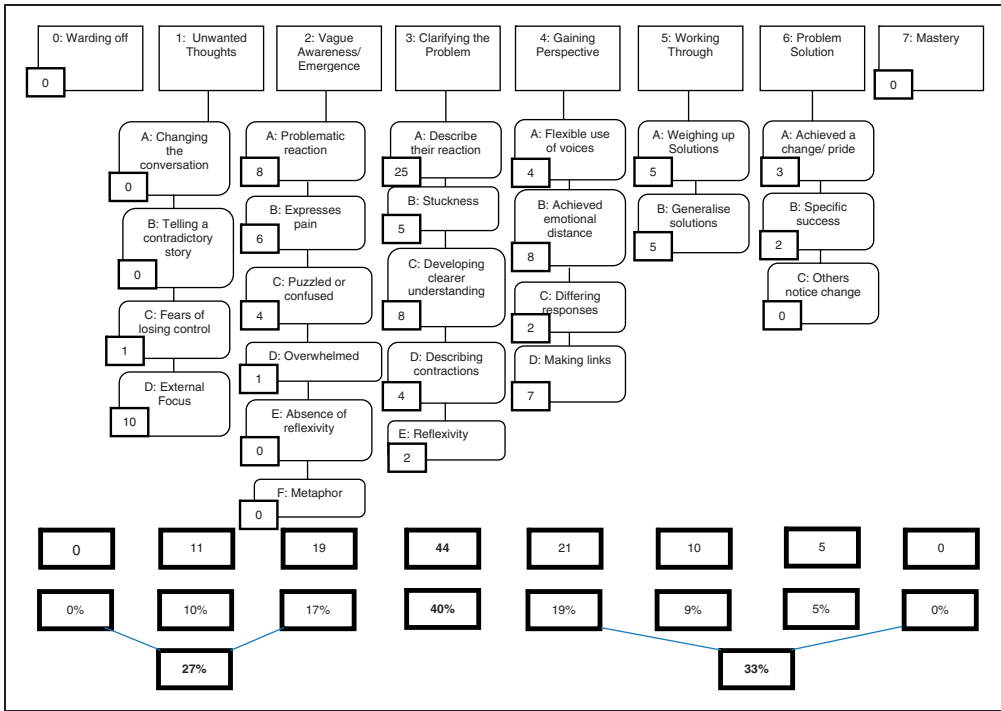
Figure 3. The assimilation of problematic experiences framework and the number of items coded at each level from the six second interviews (following diagnosis)

assessment process is important, as it adds weight to the sense of people with dementia as semiotic beings, trying to establish for themselves the meaning of their cognitive problems including their diagnosis and prognosis, whilst maintain an emotional equilibrium.

Case studies

Although this analysis indicated that there was both a broader range of markers across the group after receiving a diagnosis, and that there was a higher proportion of markers at levels 4 and above, the grouping together of participants' responses risks other important issues, including the changing relationships between the Problematic voice and Dominant Voice, being overlooked. Therefore, a more detailed case by case qualitative analysis aimed at exploring the process of assimilation for individuals across the two interviews was carried out. This analysis is structured on a participant by participant basis so that it can stay closely connected to their experiences and present a clearer picture of individual changes. Graphs have been provided to show a visual illustration of assimilation as interviews progress. The level of assimilation is indicted in brackets following the quotation. Names have been changed and other identifying information has been removed to protect participants' identities.
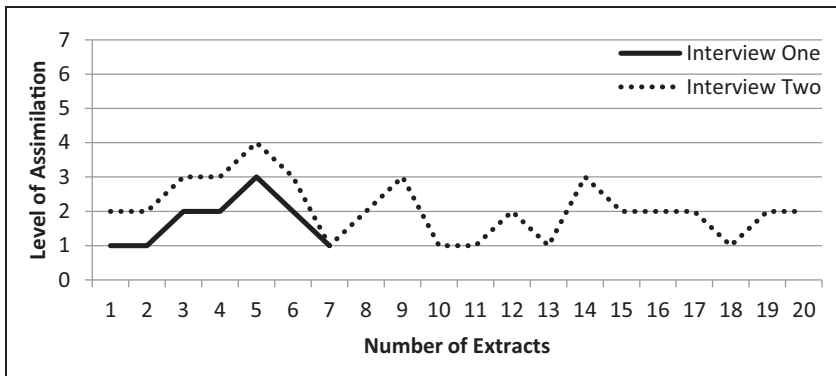
Figure 4. A graph showing the number of extracts drawn from Henry's interviews and the level at which they were coded

Henry

Figure 4 illustrates the number of extracts drawn from Henry's interviews and the level at which they were coded:

First interview: During the first interview, relatively little of Henry's account related to his memory, resulting in fewer extracts for coding. His reluctance to talk about his difficulties is consistent with someone attempting to ward off knowledge of a problematic experience. Even when the Problematic Voice is articulated, the Dominant Voice still remains strong. Thus, Henry counterbalances an enquiry about his memory by stating *"I' not worried, I can always use a diary"* (level 1). Similarly, Henry distracts the conversation from challenging topics by changing the subject (a marker of level 1). Although at times he expresses frustration, but the association between this and Henry's difficulties is not explicit.

> *"I wasn't very happy about it I have to say ... I mean we've got to go next week, for a brain scan [ ] but I'm not very happy about it to be quite honest"* (level 2).

The focus of Henry's attention is external to the self, problems are located "out there" rather than in his subjective experience. He maintains this external focus by telling stories about the problematic voice *"fear of deterioration"* but not explicitly relating these to himself.

Second interview: During the initial part of the second interview, this pattern of "warding off" knowledge about his dementia set during the first interview is maintained. Henry's responses indicate the dominant community's resistance to the Problematic Voice; part of him wants to know about his diagnosis, yet another part does not. When asked if he knows what is causing his problems, Henry replies, "*No, not at all, nobody has said a word [ ]. It hasn't bothered me an awful lot*" (level 1). However his partner suggests that he has chosen to "forget or ignore" his Alzheimer's diagnosis and he replies,

> *"I think you've got to have a positive attitude in life and if you are told you have got this and that you automatically, I think, mentally decide, I haven't, but I agree that my memory is not what it used to be"* (level 2).

In replying to his partner, Henry says "*you have got this or that*", thus avoiding direct expression of the Problematic Voice (and the associated distress) involved in using the name "dementia". By emphasising positive attitude, and the associated "*you automatically, I think, mentally decide you haven't*" he is articulating the characteristics of a Dominant Voice.

Although more forthcoming in the second interview, his main focus stems from his distress at the loss of his driver's licence. Painful affect is evident, as he becomes caught up in the moment of the emotion, the hallmark of level 2 markers.

> "*It worries me when you get a lot of these medical people, oh you shouldn't be doing this, and should you be driving now, those sort of questions that you don't really want to know about [ ]. I mean I have never thought that I shouldn't be driving, and quite frankly I don't want to stop*" (level 2).

Henry feels disempowered by the professionals' recommendations, he wants to deny what is happening, but they do not allow it. In addition to the loss of his licence its removal is damaging to his sense of self, as a person capable of making autonomous decisions.

At times the problematic voice is expressed more clearly in the second interview, with the contrasting voices reaching a partial understanding with each other, "*I don't want to admit that my memory is becoming a little bit difficult [ ] it's not easy to accept*" (level 4). This is very different to his comments in interview one he is stepping away from the "*you automatically, I think, mentally decide, I haven't*" and indicating that this was a defence against the Problematic Voice which is "*not easy to accept*". However, after this the Dominant Voice re-asserts and dismisses material relevant to the Problematic Voice:

> "*If you start worrying yourself too much, I can't do this and I can't do that it affects your whole attitude to life and I don't want to do that [ ]. I have got to an age now where other people are saying, you can't go there, and you can't do this, well that's absolute nonsense*" (level 1).

Henry's interviews demonstrate a complex ambivalence of awareness in which his capacity to discuss his illness varies over the course of the interview as he approaches and retreats from acknowledging his problems, at times he is even able to step back and acknowledge that acceptance of the illness is not easy. A recurring metaphor throughout Henry's account is his representation of the unresolved dialogue between the Problematic and Dominant Voices in terms of a conflict between opposing armies. Thus on three occasions Henry uses the term "waving the white flag" as a way of explaining to denote his determination not to give into the un-named enemy.

> "*Well I think, you have got to have a positive attitude, in life, if you don't you just wave the white flag and you pack it all in, and I don't want that, no*".
> "*. . .mentally you don't want to accept that, and I think that's a good thing, because once you start waving the white flag, you pack up and I don't want that*"
> "*. . .I mean once you have reached the age of 80 its ever so easy to wave the white flag and say oh I can't do this I can't do that but, you have got to have a positive attitude, which I think I have got*".
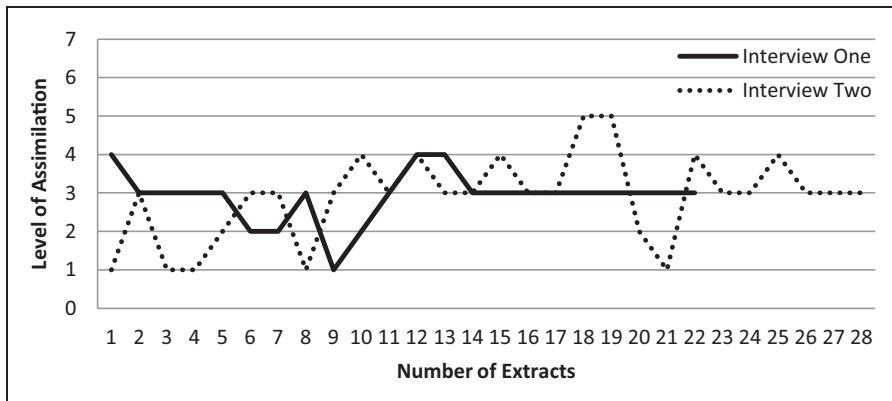
Figure 5. A graph showing the number of extracts drawn from Jill's interviews and the level at which they were coded

Jill

Figure 5 illustrates the number of extracts drawn from Jill's interviews and the level at which they were coded:

First interview: Jill's account of her memory problems was typically rated at level 3 (problem clarification) during the initial interview. Although there were occasions when she indicates her performance "*is not of concern*" to her (level 1), for the most part she was also able to articulate a Problematic Voice which in this context took the form of frustration at something being wrong:

> "*Simple things like when I'm talking to somebody, I forget something silly, that I should have known, it's embarrassing. I used to go out with the ladies from work [] I didn't say nothing, but then I had to say something, I said, well my memory, they said it's alright, don't worry*" (level 3).

Within her account, Jill stresses that it was important for her to have the acceptance of others. Not only is she adjusting to her difficulties, but she is also grappling with how she will be judged by others:

> "*When I'm talking to somebody now with my memory I get halfway through and think, oh what was I going to say? And that's embarrassing. I've done that a few times, but if they're quite happy, good people I talk to them, tell them what's wrong. I've got to otherwise they think I'm barmy you know*" (level 4).

Second interview: At the beginning of the second interview, Jill's husband reports that she has been diagnosed with Alzheimer's. Jill's dialogue then oscillates between "warding off" the Problematic Voice, by saying that she has not had any problems to her acknowledging and articulating the Problematic Voice (in the form of material related to her diagnosis)

> "*I've told most of our family, as long as they accept it, I don't mind now, I've got used to that word you know, as long as it doesn't get any worse that's what I worry about, you can't tell if it gets worse or not, they don't know what causes it really do they?*" (level 3).

Although the modal number of markers that Jill is rated as using in both interviews is Level 3 (problem clarification), Jill advances and retreats from this position, with a range of markers indicating both that the opposing voices can be differentiated and also that the emotional difficulty has not been fully resolved. However, during the second interview Jill is rated as using higher levels of assimilation more often, with an indication that the conflicting voices may yet be assimilated into a more coherent version of her relationship with dementia. In this process Jill's capacity to assimilate the Problematic Voice is vitally interconnected with her social world and in particular she talks about the importance of having the acceptance of others, in assisting her to cope with her diagnosis.

Jim

Figure 6 illustrates the number of extracts drawn from Jim's interviews and the level at which they were coded:

First interview: The relationship between Problematic and Dominant Voices in Jim's initial interview is erratic and changeable. At times his account indicates that the Dominant Voice is negotiating with the Problematic Voice, and yet at other times this Problematic Voice is unarticulated and suppressed. For example, when Jim cannot recall his children's names, he acknowledges "*this is his problem*" but then quickly moves away from the discussion avoiding the discomfort this causes.

As Jim talks about his difficulties, so the Problematic Voice is expressed. However, when asked, about the possible causes of his problems he replies, "*I don't concentrate, I don't always listen properly. I think those are the main reasons why in my particular case, my memory is letting me down*" (level 1). He again pushes away the Problematic Voice, maintaining a powerful determination that nothing is wrong.

Second interview: During his second interview, this oscillating process continues. However in contrast to the initial interview, the Problematic Voice is never completely suppressed. Throughout the interview Jim has difficulties with word finding. Sometimes he is clearly troubled by this, *"what's the word? Oh,'s' oh 's' oh, this is terrible, oh I have let myself down.*
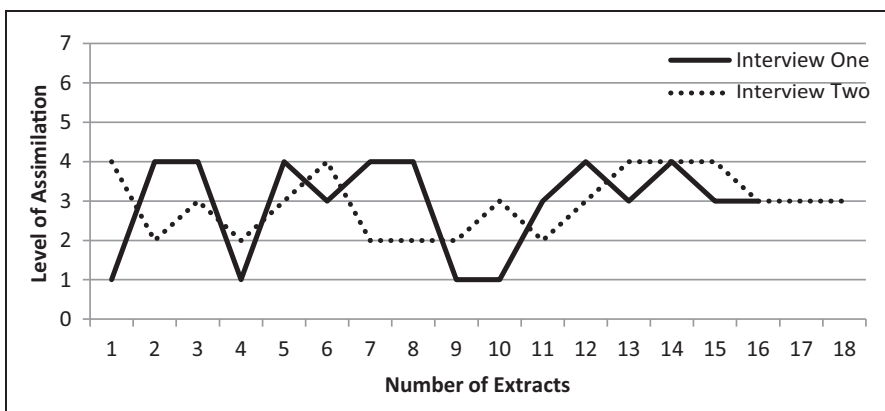

Figure 6. A graph showing the number of extracts drawn from Jim's interviews and the level at which they were coded

Oh I wish I had never started this'' (level 2). However at other times he is able to talk about this difficulty, without becoming irritated or overwhelmed by it.

Throughout both interviews an ebbing and flowing pattern is observed. That is, the Dominant Voice moves between tolerating and accepting the Problematic Voice and then rejecting it. At times, Jim articulates his problems *"I used to be quite hot on memory, it suddenly seems ever since [ ] we retired, that's gradually grown on me that my memory isn't what it was"* (level 4). At other times he appears unconcerned "*it's not something I've worried about"* (level 1). There is ambivalence between persevering with his problem and pushing it away, illustrating that for Jim, awareness is a complex and dynamic process.

Doris

Figure 7 illustrates number of extracts drawn from Doris's interviews and the level at which they were coded:

First interview: Doris's initial interview is characterised by a gradual increase in the levels of assimilation that she expresses. At the beginning of the interview, the Problematic Voice emerges, but is not clearly formulated and she describes her difficulties as "*mixing things up*" (level 1). Doris tells stories that point to the Problematic Voice but these are not clearly described. Thus although she talks about her history of Transient Ischaemic Attacks, the association between these and her current problems is not explicit. During the interview however, the dialogue changes and the Problematic Voice is expressed more clearly.

> *"We're meeting for a meal and I thought I'd drop the bombshell then, I don't want to do it, I don't know how they're going to react [ ]. I've warned them, I've told them that I'm going for a head scan [ ] they know something's happening, cos I thought well it's no good to sort of say, I don't know myself what's going to happen"* (level 4).

Both voices are present, but a conflict between the two can still be heard.
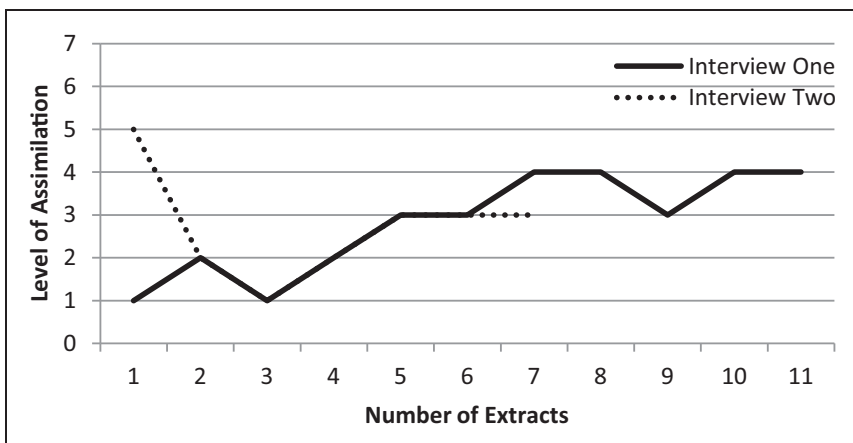

Figure 7. A graph showing the number of extracts drawn from Doris's interviews and the level at which they were coded

Second interview: During the second interview, the Problematic Voice emerges into sustained awareness. Doris is able to describe both the sense of something being wrong, but also other aspects of herself. She is engaged in noticing how she is reacting to the Problematic Voice, and this takes the form of "yes... but..." statements, which is a characteristic marker of level three:

> *"The memory clinic order the scan and the doctor has said that it was, you know it wasn't bad not to worry about but that apparently there is blood vessel damage in the front, which is the memory part which is down to the strokes"* (level 3).

Geoffrey

Figure 8 illustrates the number of extracts drawn from Geoffrey's interviews and the level at which they were coded:

First interview: Geoffrey was the youngest of the participants, and the only one who was aged under 60. During the initial interview the Problematic Voice is emerging into awareness, as he is struggling to integrate the problematic material, resulting in the highly charged negative emotions that are characteristic markers of level two assimilation:

> *"That's quite upsetting when you're trying to think of something and it's not there anymore [ ]. I mean, I used to have quite a sharp brain, things that I do at work now, I've got to really think about, where the icons [ ] for the, software that I use, which is disturbing, I mean I'm not that old really"* (level 2).

Towards the end of the interview, this painful affect associated with loss of abilities reduces in intensity. Although Geoffrey continues to express conflicting feelings, in contrast to previous material there is emotional distance. Within the language of the Assimilation Model, he shifts from talking "**out** of the" dominant voice to being able to
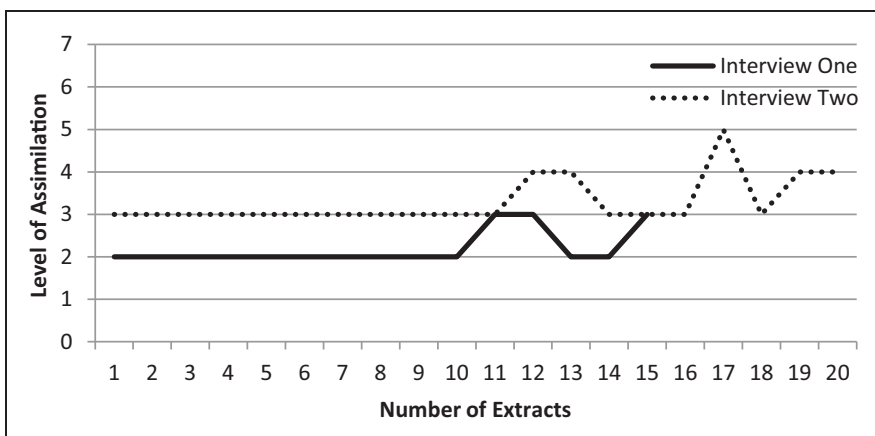

Figure 8. A graph showing the number of extracts drawn from Geoffrey's interviews and the level at which they were coded

talk ''**abou**t the'' dominant voice. Thus Geoffrey describes how withdrawing protects him from the shame of struggling to find words:

''Cos you can't think of the words what have you to say, maybe if you're chatting to somebody it takes you that much longer to have a conversation because you can't think of the words to say so you withdraw'' (level 3).

Second interview: During Geoffrey's second interview, the dialogue again remains stable, although at a slightly higher level, with the opposing voices being more clearly differentiated (level 3).

I have to think about where the icons were on the desktop, for a particular function of a program and I thought that was unusual because normally that would just be second nature (level 3).

In contrast to the initial interview, his narrative is calmer. Both voices can be heard and have equal weighting. As the interview progresses, the voices begin to reach an understanding with one another and Geoffrey describes ways of managing his problems, ''*I've told them my memory isn't as good as it was and I do have problems recalling things so they'll have to make allowances for it, they were quite understanding*'' (level 4).

Len

Figure 9 illustrates the number of extracts drawn from Len's interviews and the level at which they were coded:

First interview: For most of the first interview, Len's affect is negative but manageable, a marker of level 3. The voices are differentiated and both articulated:

''I belong to an organisation [ ]. I used to organise their dinner and dances, but I've resigned from that position because I found that, like memory loss, I'm not like, well everybody will tell you I was very finicky, everything had to be right, a hundred percent, but with this going on, I said, I've got to stand down and somebody else must take over so, I quietly dropped out of that one'' (level 3).
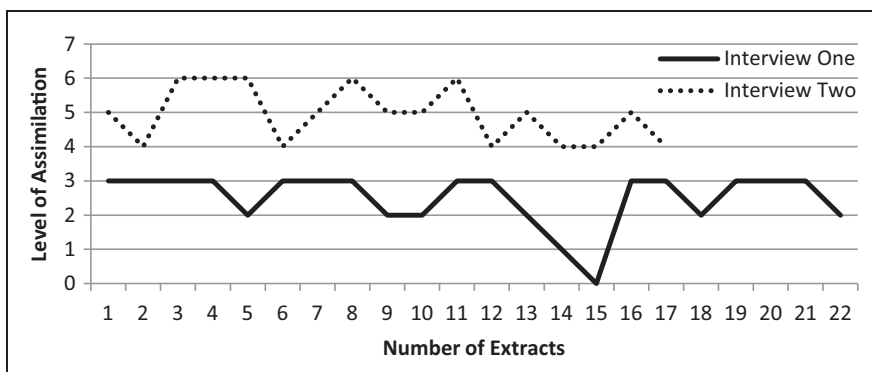

Figure 9. A graph showing the number of extracts drawn from Len's interviews and the level at which they were coded

Len's account expresses doubt and uncertainty about giving up roles that belong to his former self, and he describes how he has responded to change by "*quietly dropping out*". There are times in which the Problematic Voice loses strength and is suppressed, for example when asked about the cause of his difficulties, Len responds to this by warding off the material: "*I haven't given that a thought to be honest with you but I just put it down to just getting old*" (level 0).

Second interview: A considerable shift is apparent in Len's second interview where talks about having made changes in how he understands his life and his dementia and has found partial solutions to his problems (a marker of level 5).

> "*Whereas before I always took the lead in things (wife) has almost taken over that role now and for the first time in our married life I'm doing what I'm told, no, but seriously she's been my right arm, as I say the rules have changed, I'm not as dominant [ ] and I'm just grateful that she was here to help me out*" (level 5).

Len has tried out new strategies and describes changes in him that result from accepting and integrating the problematic voice. There is an acceptance of increasing dependency and an appreciation of the support he has received.

> "*I mean I tried to cover up [ ] yeah, you try to cover up and swear blind that you haven't been told, you know, what you have been told and eventually you accept the reality that you're not right and I think that took a long time for me to recognise it, but I'm glad that it happened, you know I'm glad that it was brought to people's attention*" (level 6).

Len's dialogue indicates not only a changed understanding of his difficulties, but also that he is able to reflect back on his previous position as one in which he was not able to integrate or accept the Problematic Voice.

> "*I think that if people know, they understand, but if you hide it as I did, first going, they get frustrated with you, so if I was advising someone, if they found themselves in the situation I found myself in, I think you've got to be open with people and they may understand instead of thinking oh that silly old fool is losing his marbles*" (level 5).

Discussion

In using the Assimilation Model as a framework for conceptualising how people manage a diagnosis of dementia, this study represents awareness as the product of dialogue between Dominant and Problematic Voices. Initially, aspects of the person's experiences of dementia tended to be pushed away, thus maintaining some emotional equilibrium. Although all of the participants struggled at first with the emotional impact of the dementia diagnosis, the nature of this impact and of the emotional reaction to it differed from participant to participant. Henry's repeated assertions that he won't "*wave the white flag*" are associated with an apparent determination not to name the enemy that threatens to overwhelm him. For Jill, her main concerns were around the risk of embarrassment, while for Jim it was a fear of letting himself down.

Nevertheless, all of the participants indicated some movement between the two interviews, and this was reflected in the significant difference between the markers for the group as a whole. Thus, the higher levels of assimilation that tended to be found during the second

interview indicated that the problematic voice had gained more expression as participants began to assimilate the diagnosis.

Although each account was unique, there were also some common processes of assimilation. In particular, two interlinking processes were found the following:

(1) The centrality of ambivalence: oscillating in and out of awareness
(2) The importance of acceptance and support

The centrality of ambivalence

Participants' dialogues fluctuated through the levels. For Jim, Henry, Len and Jill these fluctuations took notable shifts through the levels with them making gains and then retreating to earlier levels. For Geoffrey and Doris, whose accounts were more consistent, nevertheless they too occasionally fell back on using speech markers that indicated they were warding off the diagnosis. This approaching and retreating from awareness, illustrates the paradox of acceptance and denial which has been observed in other studies. Thus, Macquarrie (2005) found that participants simultaneously both acknowledged and resisted aspects of their disease to maintain agency in the face of cognitive losses. Similarly, Pearce, Clare, and Pistrang (2002) found that denial appeared to be part of a cyclical process of slowly turning to face the situation, rather than accepting it immediately.

Just as for the child exploring a new world who needs to be able to retreat into a safe base, so people with dementia, in seeking to make sense out of the strange situation of dementia, may need to retreat back into a position where they push away or into the back of their minds thoughts of their dementia. In this sense markers of, ''warding off'' or ''unwanted thoughts'' equate to the ''safe base'' of not knowing about their dementia to which participants can retreat as a way of reducing the emotional load. Thus, ambivalence (wanting to know, not wanting to know) regulates the pain and stress of facing the diagnosis with the need for safety and security. This association between dementia and attachment theory is not new. For instance, Missen (1993) claimed that Alzheimer's disease can be considered a ''strange situation'', in which ever increasing experiences insecurity leads to the activation of attachment behaviours.

Rather than finding a direct relationship between impairment and awareness, this study supports the work of Clare (Clare, 2002, 2003, 2010; Clare et al., 2005, 2012), who argues for a more sophisticated understanding. Thus awareness is not simply a cognitive or neurological phenomenon but is also a process of emotional regulation. It is not static or distinct, rather people approach and retreat from awareness, enabling them to gradually face their difficulties. It is this capturing of the emotional experience that makes the assimilation model so helpful. The assimilation model incorporates both the emotional and discursive aspects of expressions of awareness, and yet also, through the medium of Problematic and Dominant Voices, places this dialogue within a social frame. If a person affected by dementia inhabits a social world in which the emphasis is exclusively on carrying on, and where there is little opportunity for reflection, then the Dominant Voice is unlikely to be challenged and the Problematic Voice that articulates that something is wrong, is unlikely to be heard. If, on the other hand, the person lives in a world of where painful emotions can be expressed in safety, then the dialogue between Problematic and Dominant Voice that is necessary for

emotional change is far more likely to occur. A coherent study of awareness, then, needs to incorporate both the profoundly emotional experience of people facing this diagnosis, and the importance of the social milieu.

Understanding awareness as fluctuating and adaptive has important implications. Firstly, if awareness is not fixed or distinct then the use of short interviews, questionnaires, or comparing a person's understanding (for instance of the extent of their memory problems) with some external record for measuring awareness is inevitably misleading (Cheston, 2013). In this study, when participants were initially asked about the cause of their problems they all minimised the severity of their difficulties, for instance by associating them with old age or laziness. If taken at face value these responses could indicate the absence of awareness. Yet all of these participants later went on to indicate a greater level of assimilation. Rather than lack of awareness being symptomatic of the neurological impairments of dementia, these ebbing and flowing patterns of understanding suggest the role of personal and social factors.

The role and importance of acceptance and support

Research exploring dementia's impact on selfhood concludes that the self cannot be seen in isolation. Rather the self is inherently social, dependant on feedback from others and on co-operation between selves. This becomes difficult for people with dementia who are often perceived as confused or burdensome (Sabat, 2002a, 2002b; MacRae, 2010). This study supports these findings. All participants talked about withdrawing to protect themselves from shaming judgments. As found in Langdon, Eagle, and Warner (2007), participants were sensitive to others' responses and these impacted on their attempts to preserve a positive sense of self. Jill and Len particularly described how their families' acceptance was instrumental in their willingness to "face up to" their difficulties, which is consistent with Pratt and Wilkinson's (2003) claims that supportive social contexts permit individuals to approach the diagnosis. Moreover, it is also likely that people who have a strong sense of worth which is not dependent on what they do, but concerns who they are, are likely to do better (Cheston, 2013). This can be seen in Len's interview as he accepts that he can no longer do his old activities, but realises the importance, pleasure and value in being a husband, father and grandfather.

Moreover, the process of "adjusting" to dementia is tied up in social interaction. Where social interactions emphasise aspects of the dementia which participants experience as being problematic (for instance interactions which relate to social embarrassment, emphasise the loss of status or increased levels of dependency) then people living with dementia may be more likely to retreat away from this knowledge. Given that people may vary both in their emotional resilience and in their sensitivity to different aspects of dementia, then we would expect to find substantial variation in the ability of people living with dementia to articulate their concerns about the illness. Accepting and valuing environments are likely to ease the process of assimilation.

Conclusion

In exploring whether the MAPVS can be used to further the understanding of how people experience and manage the process of receiving dementia diagnosis, this study builds on the research evidence suggesting that at least some people are able face the possible deterioration

and begin to "come to terms" with the diagnosis. In addition, the findings begin to illuminate what makes this adjustment possible. Although each participant approached their illness in a unique way some common aspects of coping were observed. All participants ventured in and out of awareness, gradually and partially adjusting to their diagnosis, rather than facing it head on. Social support and acceptance were crucial in enabling participants to sustain a positive sense of self in the face of this adjustment. Moreover, as participants began to assimilate the Problematic Voice, so there was a reduction in negative affect and they were more able to identity different perspectives to their problems.

Within the UK, there has been an increasing emphasis on achieving an early diagnosis for people affected by dementia. One justification for this is that it provides an opportunity for people to adapt more quickly to the diagnosis. Thus Ruth Sutherland, Acting Chief Executive of the Alzheimer's Society suggested in 2010:

> *"An early diagnosis is hugely important as it enables people with dementia to understand their condition, access treatments that could help relieve their symptoms and gives them time to plan for the future. Support following the diagnosis is also vital if people with dementia and their carers are to have the best quality of life possible."* (Sutherland, 2010).

Yet, as this study and others have suggested, for many people an early diagnosis on its own will not be enough to bring about the changes in understanding and planning that are hoped for. In order to support the process of adjustment to a diagnosis, it is important to provide people affected by dementia with a range of opportunities not just to meet others in a similar position, but also to talk about their diagnosis in a supportive and safe environment. Without this social support, it will become harder for many people to face the psychological impact inherent within a diagnosis of dementia without risking being emotionally overwhelmed.

Notes

1. NHS Ethics Committee: South West REC 4 Reference number 11/H0120/9, Avon and Wiltshire Research and Development Consortium Approval Obtained.
2. This adapted version of the markers scale and any other relevant material is available on request from the authors.

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Emma Lishman is a clinical psychologist working in the NHS. She works in a health psychology service and in a renal psychology department. This paper comes from her doctoral research, which she completed at the University of Exeter. She has an interest in supporting people to manage and adjust to living with chronic health conditions.

Richard Cheston worked in the NHS as a consultant clinical psychologist for over 20 years, before taking up a chair in dementia research at UWE in 2012. He has a particular research and clinical focus on supporting people affected by dementia to adjust to the illness.

Janet Smithson is a qualitative social psychology researcher. Her main research interests include gender and discourse, work-life practices and policies, life course transitions, qualitative methodologies, internet-mediated discourse and communication. She is currently researching alternative dispute resolution after separation or divorce. Recent research interests include a study of online support sites for young people who self harm, a study of online professional-service user interaction, and on older people's user of the internet for well-being.