

## **Assimilation of Problematic Voices within psychotherapeutic work with people with dementia**

*Richard Cheston\**

### **Abstract**

This paper presents an outline of how the assimilation of problematic voices model (APV) can be used as a framework to understand changes in awareness of people with dementia. APV is a dialogical model of change developed within psychotherapy process research. Within this framework, the concept of dementia can be understood as being psychologically problematic for people affected by the illness in the sense that the existential threat of dementia prevents an easy assimilation into the person's existing self-concept. Successful assimilation is viewed as the result of a process that involves a series of conversations between a dominant voice, typically asserting a continuation of the status quo, and a problematic voice or voices that articulates emotionally difficult material. This process of assimilation is illustrated through accounts given by people with dementia about their illness within psychotherapy groups run by the author. Representing the accounts of people with dementia in this way is important as it enables a fine grained analysis of changes in expressed awareness, including those that occur during psychosocial interventions, such as psychotherapy or counselling.

*Key words:* assimilation, dementia, awareness, psychotherapy, Alzheimer's disease, identity.

Dementia is a progressive illness, that can be treated but not cured, and that leads to the loss of many of those aspects of self that most people see as central to their being. As such, dementia may represent a profound existential threat to psychological equanimity. Thus, it is perhaps not surprising that a 2008 YouGov poll commissioned by Alzheimer's Research UK showed that thirty-one per cent of 2,000 respondents of all ages feared dementia more than any other illness—more than feared cancer (twenty-seven per cent) or death itself (eighteen per cent). However, while there is a general agreement about the importance of psychological as well as

---

\*Correspondence to: Richard Cheston, Professor of Mental Health Research (dementia), University of the West of England, Glenside Campus, Blackberry Hill, Stapleton, Bristol, BS16 1DD, UK. E-mail: richard.cheston@uwe.ac.uk

social and neurological factors (e.g. Clare, 2010), in the development of people with dementia's awareness about their illness, the way in which these factors interact and affect a person's capacity to talk about their problems is not clear.

### **The assimilation of problematic voices model of therapeutic change**

Psychotherapy process research is a form of qualitative analysis that attends to those factors that facilitate (or inhibit) the occurrence of therapeutically significant events within psychotherapy. In particular psychotherapy process research has focussed on identifying when change occurs before moving on to establish what the active ingredients of psychotherapy are (regardless of the therapeutic orientation of the therapist) and on the inter-personal and intra-psychic mechanisms of change.

The assimilation of problematic voices model (APV), is a model of change developed within psychotherapy process research by Bill Stiles and colleagues (e.g., Honos-Webb, Surko, Stiles, & Greenberg, 1999; Osatuke & Stiles, 2006; Stiles, 1999, 2001; Stiles, Honos-Webb, & Lani, 1999; Stiles, Meshot, Anderson, & Sloan, 1992). APV suggests that most experiences in a person's life are unproblematic and can be assimilated routinely into that person's existing understanding of the world. However, some experiences are so traumatic and their implications are so threatening that they resist an easy or early assimilation. Thus Stiles and others have described a wide range of potentially problematic events, from Jon Jones (a young man acknowledging his homosexuality), to Lisa (who had to address her angry resentment at being mistreated by a husband), and Fatima (whose daughter had been killed in the midst of terror and torture by a repressive political power). The assimilation model has also been applied to the analysis of material from people with learning disabilities (Newman & Beail, 2002). For each of these cases, psychotherapy enabled the individual to assimilate the problematic aspects of these experiences into awareness (Stiles, 2001).

As the assimilation model has developed through a fine-grained analysis of many different therapeutic sessions from not only different clients, but also from therapists working within many different therapeutic modalities, so APV can best be understood as a trans-therapeutic approach. As such the assimilation model is best understood as a generic model of the process of change that occurs within therapy, and by extension, within day-to-day life. It is not intended to be understood as a therapeutic model in its own right. In this paper I will outline how APV can be used to describe changes in the way that people with dementia describe their illness.

## The dialogical process of psychotherapy

In trying to understand what it is that changes during therapy, so the most recent versions of the assimilation model have emphasised the self as context-dependent, shifting, and multiple (e.g., Gergen & Kaye, 1992; Hermans & Kempen, 1992; Mair, 1989). Such post modern or social constructionist theories of the self, often describe a “community of voices”: rather than one, ever present self there are a series of “selves” or “voices”. For people who are struggling to make sense of changes in their life, according to the APV model, it is often because there is conflict between the different voices that make up this community. In these circumstances, one voice (referred to in APV as the dominant voice or DV) can be understood as the voice of continuity, or the preservation of the status quo—it is a powerful voice because it is a voice of certainty, of the need to resist change. Often the DV is a voice that has the pretence of being unemotional, of emphasising the importance of control, of logic, and of disallowing the vaguer expression of emotional unease. In contrast the problematic voice (PV) can be thought of as the voice of change. The problematic voice articulates concerns that something, somehow, is wrong and that change is either necessary or unavoidable. The PV 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 PV 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 PV and the DV is central to the therapeutic process, in that it is through this dialogue between the two voices that assimilation (and thus therapeutic change) occurs.

Initial formulations of the assimilation model represented the process of assimilation as progressing through a series of levels, from level zero (“warding off”) to level seven (“mastery”) (see Table 1). At each level, so the relationship between dominant and problematic voices shifts—from the problematic voice being initially warded off, through its gradual emergence as it gains in strength, until the nature of the problem that the individual faces can become clearer. Intrinsic to this process of discursive change are changes in affect: thus affect is relatively low while the material is warded off, and although it may be heightened as problematic voices emerge, the affect is often experienced as being disconnected from the source of the distress (for instance through paranoid accusations of being attacked). However, as the nature of the internal tension becomes clearer, so affect is linked to this, such that the person is able to

talk about what is distressing them more openly. This more direct expression of the problematic voice may be experienced as emotionally painful. However once the nature of the problem has been clarified, then links can be made between this problem and other aspects of the person's life, so that the meaning and significance of the problem becomes clearer, and possible strategies can be tried out. During this latter process of therapy, the conflict between the voices recedes, and ultimately the strategies that have been successfully tried out become an automatic part of that person's life, and the emotional distress associated with the original problem recedes.

## Methodology

In previous work produced as part of the Dementia Voice project (Cheston, 2004; Cheston, Jones, & Gilliard, 2004; Watkins, Cheston,

**Table 1: Assimilation of problematic experiences scale (APES)**

<i>APES level</i>	<i>Content</i>	<i>Affect</i>
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) that 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	Generalisation through habitual use of problem solution in new situations	Neutral (i.e., this is no longer something to get excited about)

Note: Adapted from Newman and Beail (2002).

Jones, & Gilliard, 2006), the APV model has been used to analyse the way in which a person with dementia describes their illness over the course of a ten week therapy group. This paper is a synthesis of this work and also includes additional, unpublished material from these research projects as well as material collected during twenty years of clinical practice leading both group work and individual psychotherapy for people with dementia. All of the participants in these research projects, and most of them within the clinical context had Mini Mental State Examination (MMSE) scores above 18, which would mean that their level of cognitive impairment would be described as mild or moderate. A fuller account of the role of group psychotherapy within dementia care can be found in Cheston (2009).

However, just as APV is not a model of therapy per se, so in this paper I am not trying to describe this therapeutic work in detail. Instead, in describing the process of assimilation as it relates to people with dementia, this paper presents a different way of conceptualising what is often described in the dementia care literature as “awareness” or “insight”. In particular, APV allows us to understand more about what has frequently been described in phenomenological approaches to this issue as a process of oscillating—moving backwards and forwards between defensive, self-protective positions in which dementia is pushed away, and more realistic, but also perhaps more threatening acceptance.

Where extracts are included here, participants from the Dementia Voice project will be referred to as “Mr” or “Mrs”, while those participants in other forms of clinical work will be referred to through a first name. All names and personal details have been altered to preserve anonymity.

Within the APV model, the concept of dementia can be understood as being problematic for group participants in the sense that the profound existential threat that dementia represents for individuals prevents an easy assimilation into existing schema. In this paper, the model outlined by Stiles and his colleagues will be slightly adapted to focus on the psychological tasks that dementia confronts people with. Thus the eight original levels of Stiles, will be grouped in terms of three tasks: helping dementia to emerge as the problem without the person being emotionally overwhelmed; gaining emotional distance and perspective; and trying out problem solutions or partial solutions.

During this paper I will argue that dementia presents a wealth of psychologically threatening challenges that, for many people, act to prevent assimilation into existing self-concepts. However, with support (that occasionally may include psychotherapy or counselling), many people with dementia are able to adjust to their illness and to work through the problematic emotional threats that come with this. (A more complete

description of how the marker-based manual of Honos-Webb and Lani can be adapted for use with people with dementia is available on request from the author.) The emphasis in this paper will be on the early stages of assimilation, as this is most likely to be the position that most people with dementia find themselves in after receiving their diagnosis. However, APV is not a linear model in which people start at level 0 and finish at level 7, and nor is it inevitable that all people will progress through the different levels. Rather APV presents a description of how the assimilation of the problematic aspects of dementia can occur, so that the person's relationship with their illness can be more easily identified.

## **Helping dementia to emerge as the problem without being overwhelmed**

### ***Level zero: warding off***

[Warding off] represents a drastic failure of episodic and semantic memory. Events and facts related to the problematic experiences are not consciously recalled. On the other hand, there may be evidence of implicit memory in the form of symbolised symptoms or actions that can be traced to the problematic experience (sometimes called acting out). Of particular interest is the evident impetus of warded-off problematic experiences—the tendency for problems to influence daily life in the form of symptoms or other manifestations even though they are not in awareness. (Stiles, Honos-Webb, & Lani, 1999, p. 1216)

In order to prevent the person from being emotionally overwhelmed by their experiences, information and knowledge about dementia may be pushed away or warded off. Clients working at this level tend either to ignore their dementia-related symptoms or to attribute them to less threatening causes, such as a physical or sensory disability or just to a process of growing older.

Although the person with dementia may maintain a powerful, outward determination that nothing is wrong, often their avoidance of dementia-related experiences (such as refusing to meet a doctor or nurse from a mental health team) suggests that at some level they know enough to want to not know any more. Thus, when surrounded by reminders of their failings, and by their illness, a person with dementia has (at one level) to know that they do not want to know about this material simply in order to maintain (at another level) their ignorance. The position that is assumed by some people with dementia, therefore, can involve a deliberate, if unconscious, attendance to those aspects of their world that support their existing sense of self, and the simultaneous warding off or psychological pushing away of those aspects of their experiences that cannot be accommodated.

The way in which the person talks about themselves is just one aspect of a much wider social positioning involving avoidance, cover-up, and denial and with powerful emotional responses and changes in inter-personal relationships. One powerful emotion that is associated with this avoidance of dementia is that of shame (Cheston, 2005; Gilbert & Andrews, 1998). Shame is associated with a desire to hide some aspect of self that might be taken to be morally reprehensible. Feelings of shame are, in effect, contagious—those around the person may become complicit in preventing the exposure of these deficits, and thus attempt to avoid triggering the person with dementia into experiencing the distress associated with such exposure. Additionally, the warded off material may well be expressed in other ways, such as the development of paranoid ideation about being under attack or being threatened, or the indirect expression of loss. The affect associated with this pushing away of the threatening and problematic material may include powerful expressions of narcissistic rage in which the fury that exists within the person at the unfairness of dementia is projected out or externalised onto people around the person with dementia. The indirect expression of emotion is often described within psychoanalytic literature as “acting out”.

One way to understand this process in more detail is to look at the relationship that can develop between a person with dementia who is emotionally fragile and who is warding off conscious expression of their dementia and their family carer, who is often a spouse. The person with dementia can only survive if another fills the gap in their world—the cookery, the washing up, and the other elements of a daily life that they now struggle to manage. Yet, no matter how well a person’s life is organised, and no matter how effective that person is at avoiding threats of exposure, a gap inevitably arises between reality as it is, and the non-reality of the DV that the person attempts to articulate. This disparity can amount to a potential narcissistic slight—the awareness for people with a fragile sense of self that their idealised view of themselves has been compromised. As a defence against this sense of being overwhelmed by such a breakdown in their self-concept, the blame for the compromised ideal can be placed outside the person where it can be attacked. The other thus comes to enact a joint role as both care-giver and scapegoat. This is what seems to have happened with James and Muriel (see case study).

### **James and Muriel—warding off and acting out**

James was referred to psychology after he had attended a memory clinic where he had been given a diagnosis of probable Alzheimer’s disease. During the assessment process he had been dismissive and sarcastic, and when offered feedback about the tests results he had contemptuously rejected the diagnosis. When I met James in an out-patient clinic,

he insisted that there was nothing wrong with him, and that the assessment results were an aberration. As he was clear that he saw no need to meet me, our session was brief but in going along with his assertion that a mistake had been made, I suggested that as a compromise I could visit him at home so that I could find out more about his family's concerns for him.

When I visited James at his home, he refused to see me and told me instead to speak with his wife, Muriel, who was the one who had the problem. I asked her what she made of her husband's memory and she told me of his repeated mistakes around, for instance, shopping, paying bills, or driving and how he would angrily blame her whenever things went wrong for him. Although his memory was poor, Muriel felt that in many ways James was behaving in just the same way now as he had always done. While living in Central America, for instance, he had hidden in a cupboard during thunderstorms, but then threatened her and their young family with a loaded revolver. More recently, when he had been frustrated by his dementia he had assaulted her on several occasions, including holding a knife against her throat. Often she had found hand written notes in which James bitterly blamed members of his family for stealing from him and accusing them of plotting to get rid of him. His denial of dementia seemed to be one more way in which he pushed away those parts of his life that he could not tolerate.

I met Muriel regularly to talk about the dilemmas involved in caring for a man who refused to acknowledge that he needed care. Whenever I visited, James would make a joke about whether I had come to take him to the "loony bin" before going on to insist that all he needed was to have a holiday in his childhood home of South Africa. He would then dismiss me and vanish upstairs. My meetings with Muriel eventually stretched over three years until James' death from cancer, and through this time we discussed James' need to live in a bubble. When the bubble was intact, then to the outside world James was outwardly affable and charming. Inside the bubble, James could hold a position of being the same person as he had always understood himself to be—superior in ability and tastes to those around him. But the bubble was fragile and could be easily pierced by reality, and when it did burst, James reacted to even small threats to his self-esteem by blaming and attacking those around him.

During the time that I knew Muriel she managed to find a way within the relationship to hold onto the world as it really was, not as James would have it to be. She started singing in a local choir and worked around James' objections to tidy up the accumulation of twenty years of hoarding newspapers and magazines in their spare room (that he had previously kept locked) so that visitors could stay



overnight and allow her to have a break. In effect, James and Muriel found a manner of living together in which both of them avoided situations in which he would feel undermined or slighted. Thus Muriel took care to avoid confronting James with what he could not do, and he retreated more and more into his dreams of going on safari. With this, and many other steps Muriel found a way to care for James without pricking his narcissistic bubble, and at the same time began to reclaim her life from his domination.

### ***Level one: unwanted voices***

When material related to the person's experience of dementia leaks through their attempts to ward it off and emerges into conscious awareness, then this will be experienced as distressing as it threatens the loss of psychological equilibrium. The assimilation model suggests that there are at least two indications, or markers, of this leakage through of unwanted voices: a fear of losing control; and the externalisation of problems.

*Fear of Loss of Control* Honos-Webb and Stiles (1998) describe how clients may feel that,

he or she should be able to cope with the distressing material without acknowledging its psychological/emotional bases. And may use phrases such as "tough it out" or "soldier on". The emphasis is on controlling or suppressing painful emotional material.

While there is a high level of affect (typically to do with fear and anxiety) around material associated with problematic aspects of dementia, otherwise the person's expression of emotion is generally controlled. However, if the person with dementia is placed in a position of having to confront their problems, then they may be distressed by this potential loss of control over their life. Clients may describe talking or thinking about dementia as being too disruptive or threatening to be tolerated—it is as if being required to think about the changes that have occurred is too frightening to put into words. In this way, when working with people with dementia we need to be especially clear about a number of ethical issues that talking to people about their dementia may provoke.

In order to illustrate some of these dilemmas, I will describe an incident that occurred in the first few minutes of one group within the Dementia Voice project. Mr E attended this, the first session of the group after working extensively with my co-worker in individual therapy. The dilemma presented there had been similar to that described in the case example of Muriel and James presented above—in this instance Mr E's reluctance to think about what had changed, and his immersion in being busy was causing great distress for his wife and threatening her ability to

care for him. Although unlike James, Mr E could openly recognise that he had problems, he was similar in the sense that he clearly experienced these as enormously frightening, and like James he retreated away from them—albeit into his garden rather than into fantasy. While recognising his right not to continue to work on these issues, the dilemma for us as therapists was that without addressing these issues, the likelihood was that his wife might be unable to continue to care for him. Although it was possible to continue individual therapy, Mr E was also offered group therapy in the hope that witnessing others also struggling with these issues might make his own internal conflicts more manageable. In trying to articulate his dilemma about whether or not to be in the group, so Mr E struggled to put the conflict between the DV (not to think) and the PV (awareness of something being wrong) into words:

*Mr E:* I find what we're doing now, it brings all memories to me, so and being around listening to you all, talking. I find I just want to be, . . . I don't think a memory loss and I don't, talking, and being around each other, . . . I'm not being funny about that. I'm trying to make a point that I'd rather be at home doing what I need to do, and want to do . . . And this is why I really don't want to talk about that you know, I mean I'm sure it's being selfish but, it's just the way I feel about it, I don't really want to be here.

*Facilitator:* Sometimes the things you remember that are the most painful, and you do want to forget about it all.

*Mr E:* Yes, that's exactly, yes that's exactly what it is . . . Well I just, don't want to be here. I just want to be. I've got lots of things I'd like to do, and er. Well, I can't think about coming here, it just brings it all back.

As Mr E was clearly expressing that he had withdrawn his consent to be in the group we, as facilitators we suggested to him that it would be all right for him to leave if that was what he would prefer—an offer that he accepted.

*The externalisation of problems.* This marker can be seen when material related to dementia is referred to indirectly (for instance as “the problem” or as “it”) or externalised and identified as a problem belonging only to other people. Elsewhere I have described the way in which material related to dementia that is too threatening to be expressed directly, can be expressed through the use of narrative (Cheston, 1996; Cheston, Jones, & Gilliard, 2004). Such indirect exploration of themes associated with dementia can occur through discourse drawing on the threat of catastrophe, or on the losses associated with a war, theft, or

disability. Thus one man I worked with on an in-patient ward for people with severe levels of dementia clearly found some of the issues that had been raised in a group by a female participant to be very difficult. She had spoken of her anger and upset at being treated by staff as if she did not know what was happening. Later I went to find him, and we spoke generally about life on the ward in a way that he could not do in the group. He told me of how his father used to have a grand-father clock that eventually broke down. The clock could not be repaired and no longer worked—it could not tell the time or strike the hour, but his father had kept it because he loved to look at it. He told me that eventually we all broke down, but that did not mean you were not important.

These narratives often have a structure, for instance first establishing whether a threat exists, then asserting that the threat is real, and finally exploring whether or not the threat can be survived. One function of these stories is to act as a metaphor for the dementia, allowing those emotions associated with dementia (the problematic voice) to be explored in a controlled and focussed way without directly challenging the dominant voice.

### ***Level two: vague awareness—the emergence of talk about dementia-related problems***

In this level, the client manages to acknowledge the existence of problems, even if they are still not reliably able to name their problems as specifically being associated with dementia. Alternatively, where the relevance of dementia is acknowledged, it will be constrained or limited to a few specific problems or otherwise minimised or downplayed.

The affect associated with the assertion of the DV (“there’s nothing wrong”) is often an angry rejection of the problematic aspects of dementia and indeed the hallmark of this level is psychological pain or panic, often expressed in intense, negative emotion. Across these initial stages, the person’s affect changes—whereas in the initial stages, there is a general dampening down of emotional responsiveness, in level two, the person’s affect increases dramatically—the person with dementia, in struggling to integrate the knowledge of their dementia may be intensely upset, distressed, or angry.

The existence of the problematic experience is acknowledged, but as yet this intrusion of dementia is not fully formed or clearly expressed and the person with dementia seems to be caught up in the emotion of the moment. The person with dementia may describe behaviours or episodes from their daily life that are connected to cognitive errors associated with dementia but that are unexpected and that they can not fully explain. The client may describe feelings of sadness, vulnerability,

or distress associated with their experiences of dementia but without being able to step back from them. Indications of this level include expressions of feeling stupid, silly, or hurt, or the person may be angry or irritated about some aspect of dementia. Thus Peter, a participant in a group I ran said:

But it's the quality of the emotions inside me that really, really gets to me. Because I think I've done something terribly wrong. Not wrong, entirely wrong, it's just that it *goes* wrong. I mean today, I didn't have a clue where I was going to go to put my car. I don't think that comes into your mind, and as soon as that started, I just felt ridiculous. I can't describe how really, really stupid I felt.

The person with dementia is in distress, therefore, and this distress seems to come from some internal conflict relating to an aspect of dementia. At times the person, in struggling to integrate the knowledge of their position, may describe feeling overwhelmed and feel that things are getting worse. As one client said in the Dementia Voice project, "I just think that I'm going backwards and not forwards".

### **Identifying dementia as the problem while gaining distance and perspective**

The main issues in the first three levels described above relate to the emergence of dementia as a problem for the individual—they move from warding off the acknowledgement of dementia to a relatively unformed expression of distress and concern. This is a journey that brings with it the risk for the person with dementia of being emotionally overwhelmed by this awareness. In contrast, the next two levels are characterised by an increased ability to talk about dementia and the gradual reduction of emotional distress. This is linked to the person gaining a perspective on their problems so that the intensity of their feelings diminishes and they feel more in control of themselves and their lives.

#### ***Level three: clarifying dementia as the problem***

The naming of dementia as the problem enables the client to talk about the impact that dementia is having on them and to describe how the dementia makes them feel (e.g., being angry, silly, embarrassed, or sad). Within this level, the person is not as caught up in the emotion of the moment as they are in the previous levels. Instead, this level is marked by the emergence of mixed feelings about dementia—the person is able to describe both the sense of something being wrong, *and* also their reaction to this. This stepping back from one's feelings may be indicated by participants using the past tense, and also the way in which a behaviour

(e.g., hiding away, covering up, being silent) is associated with a feeling that the dementia-related experience has caused (e.g., being embarrassed, being scared). Sometimes this takes the form of “yes . . . but . . .” statements in which the person seems curious about their apparently mixed feelings—this use of connectors indicating a number of different ways to approach his dementia is shown by Mr K:

*Mr K:* I tend to forget things that I’ve done the day before. It can be a bit embarrassing. If I’m, if I’m er, I’m reminded I get cross . . . , . . . I suppose I’m feeling a bit silly when I’ve forgotten . . . Well I realise I’m being silly, but even so I get a bit cross at times.

*Facilitator:* Are you cross with yourself or another person?

*Mr K:* I suppose it is against myself and I’m also, initially, I’m cross with the person who reminds me [laughs].

A marker of this level is the way in which the person with dementia is able to articulate both the problematic voice (for instance of fear or distress at something being wrong) and also the dominant voice that there must be a way through. The client often feels stuck between these different ways of approaching their dementia—they may see no way out, and feel unable to act in order to change things. Honos-Webb and Stiles (1998) describe this conflict between the dominant and problematic voices as being the hallmark of this level. As Katie told her therapy group:

I went into the local shop, around the corner from ours and I got to the front of the queue, and they asked me for my money, and I couldn’t find it. I didn’t know what I wanted or where I was so I ran out, and my husband was there. He said “what are you making such a fuss about?”. He always treats me as if I’m a little girl, it’s embarrassing, but he’s right—I need to try harder and to do things, but I’m scared to do them, so I don’t know what to do.

During this level the client is approaching an identification of what it is about dementia that is difficult for them to tolerate. This will vary in that for some people with dementia it is the lack of a cure that makes dementia intolerable, while for others it may be the prospect of deterioration or feeling guilty and embarrassed at the effect of their dementia on their family. In this level, there is a statement of the way in which dementia represents a problem, even if this is being pushed away and talked about indirectly. However, there is no sense at this level of how to find a way through this problem. As Mrs H explained:

*Mrs H:* I'm just going to sit back and let nature take its course, I think, and then if it gets really bad I'll wear a notice but I haven't yet worked out what I'm going to put on that notice [laughs], but it depends on my mood I should think. But no I must admit to keep it as quiet as possible, I push it to the back I must admit, I don't sort of analyse it. I think probably you know, I'm whatever it is, ninety-four or something you know. I just let it go over me, yes really I do. I don't pay too much attention to it at all. My life goes on very much in the same way as it always has been. So whether that means that I'm just unfeeling in all situations, but I don't feel it would, or whether it just means that, I don't know if it's a weak nature, and I can't do anything about this [laughs] but I mean it does bring some peace of mind sometimes.

For some people, the awareness of powerful, but mixed and conflicting feelings about dementia may be expressed as a sense of going mad. Consequently the person may avoid going to places where this feeling would be intensified, or where their dementia would be uncovered. As Donald, a man with significant communication problems told me about his experiences of coming to a therapy groups:

Well to me, I just, it was frightening really, because I just didn't know what was happening and I thought well has something happened which I can't get back? Am I going to sort of have to go in a home and sit down there until I die sort of thing?

A lot of things go through your head and you just have to work it out. When I came to you I mean I could see that there was other people there with exactly the same thing . . . I could feel that by talking to those, they were in virtually the same position as I was. You know I mean they were having trouble and I was having trouble. So I'm not being sort of out-talked all the time by these because I can keep my thing in there and as I've found out now because of you I can now go in and sort of take the realm and talk to them

Well you already know this, but the biggest thing was to me was that I was going to go down and be a loony, and they were all going to go "yer, yer, yer" [gestures with index finger of hand, pointing and rotating it against his head].

#### ***Level four: understanding and gaining perspective***

From the perspective of the assimilation model, the development of insight is not just about recognising that one has dementia, but also involves an articulated understanding of what the problematic aspects of that illness are. This might concern understanding how their response to

dementia is shaped by concerns they have had throughout their life. Thus Mr B told his group:

You see I think the essential difference is that I was brought up as a boy to learn to stand on your own two feet. In the navy the whole basis of the navy training is that every man jack on board should stand up on his own two feet. So fundamentally, you develop this idea that other people are around and are very useful and helpful, particularly if they are doing things that you want them to do. But the idea that you can actually begin to rely on other people to do things that you don't want to, or you can't remember how, or you didn't have any intention to do anyway, is something I've begun to learn in the last four or five years.

The feature that distinguishes this level is that the person with dementia understands how their feelings about dementia relate to their wider life. This continues the process by which the person moves away from being emotionally overwhelmed by the dementia to being able to talk about it. As well as making links with their past, the person may also describe ways in which the feelings that dementia causes (such as embarrassment) can be managed. Alternatively, they may describe how inter-personal relationships are affected—both by their own way of coping with dementia and by the changes in how others relate to them. In contrast to previous levels which are characterised by a sense of being stuck, this begins to give way to some sense that the feelings around the dementia can be managed. As Edith told her group:

I know that my husband finds it hard when I can't remember things, it must be awful for him. So I try not to say anything at those times, or to go to my room when I want to cry. I know that it's silly, to have to cry, but I want to hide it from him, so that he doesn't worry. He's got enough to put up with, and even if it makes me feel a bit more lonely, well I feel that at least I'm doing something for him for a change.

The person's level of affect may be mixed with some unpleasant recognition, but with curiosity and even pleasant surprise as they begin to make sense out of the feelings that the dementia has provoked. Often the process of gaining distance can be augmented through the use of humour or by comparing themselves with others in a worse position. Thus, Mr D described how he used humour as a way of stepping back:

I've taken the view, when I first arrived there, I had very little idea about what was going on. It was probably not until she popped along, we had spoken about various things I became more, what's the word, I was more aware I think. When I first walked in there, but after a very, very

short period of time, we had a good laugh. And it was to me just what I wanted to see and hear . . . I think the difference is being, it's a continuation of Alzheimer's if you like. You could say, you could just say that it makes me feel good, even though I know I've got Alzheimer's, I can still laugh, I don't have to just sit here and go, oh God.

The client is able to acknowledge both the dementia, and their dominant (e.g., fearful, ashamed, or angry) reaction to this, but to distance themselves from this reaction, either by setting out how different situations produce different responses, or by describing ways in which they can switch from one internal state to another. Within a therapy group the person with dementia may be able to describe how being with others who experience the same problems, is different to being at home or with strangers. Thus participants in two different groups both contrasted the openness of the group and their life away from this therapeutic environment:

*Edith:* Knowing that you're all the same [in the support group] so you don't feel too embarrassed. My family and that, they don't know how to handle it. I can't go out on my own, I always have to go out with someone in case I have that feeling [having a panic attack]. I'm scared.

*Doreen:* It's important to be able to come and open my mind. If I was to say these things back where I live, to talk to other people there as I talk here, then I would be embarrassed. I would worry that they would all think that I was doolally.

## **Working through, trying out problem solutions**

### ***Level five: application and working through***

In the higher levels of the assimilation model, the person with dementia is able to find partial solutions to their problem, for instance through making decisions about their life and their care. Often, they are able to talk about having made a change in how they understand their life and their dementia—and how others see them. At the same time, people understand that the problem of dementia has not left them and that indeed, their physical and mental well-being will deteriorate. In week nine of his group, Mr B looked back on the changes that he had made:

*Mrs A:* You have to face it to start with.

*Mr B:* Well I think that's inevitable, we all wouldn't be here if we didn't do that. And so once we've accepted it, you need help from other people, you need help from ourselves, we need help from groups like



this. I find I've got a great deal of moral uplift by coming here. Meeting with you, listening to the way you do it. And I don't see the problem now it frightened me the way, the problem of declining memory, until I came here the way I did before, . . .

*Mrs A:* You didn't accept it then before

*Mr B:* Well I did accept it but it frightened me, because I thought, well I'm going mad, I'm going crazy. What am, what am I going to be like in another five years? But now I realise that everyone here has the problem. So right stage two, so we're all going to get the problem, what do we do about it? You have to develop techniques to help you to remember.

Clients who work at this level are able to integrate the problematic and the dominant voices in order to make tangible progress towards resolving those problems that occur in daily living. This new understanding is used to work on a problem in which the client may describe considering alternatives. Their affect is positive, business like, and optimistic even though these decisions are being taken in the awareness that the larger problem of dementia cannot be avoided. These clients recognise both that this can be only a partial or unsuccessful solution, yet also manage to express hope for the future (Wolverson, Clarke, & Moniz-Cook, 2010). As Brian said in a review of the groups he had attended:

*Brian:* The group has been a helpful place to share information and get tips! It's helped me develop confidence to move forward and keep doing things in spite of my dementia.

### ***Level six: resourcefulness and problem solution***

Clients who talk about themselves at this level describe feeling positive (including a sense of pride or accomplishment) about having changed in their relationship with their dementia. This may include trying out a new strategy, or describing some more subtle change, including a change in how they understand and feel about their illness. This accomplishment and change is important to the client, and their affect reflects this as it tends towards being positive, satisfied, and proud of achievements. As part of this process, the client may reflect on a specific change in which an aspect of their dementia that had previously been problematic has now been integrated. Lishman (2012) gives an example of how Len, after receiving his diagnosis is able to look back at how he had previously coped.

*Len:* I mean I tried to cover up which I suppose is a natural thing to do, 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.

Alternatively, other people may notice how the person has changed, as Mr B from the Dementia Voice project noticed change in one of the other participants:

*Mrs A:* . . . I've met a lot of people who are rather ashamed of not being like everybody else, but I mean none of us are like everybody else—

*Mrs F:* —I was like that . . . I was just saying I didn't want anybody to know anything about it . . . Not going out the front door—being ashamed of the name and . . .

*Mr B:* I think F has changed probably more than anyone else, do you? I think that F has got to grips with the problem very well indeed, you've gone much more extraverted than when you first started. You talk to everyone now, you say what you think.

### **Level seven: mastery**

For Stiles and his colleagues, this level represented the point at which the psychotherapy patient no longer needed to continue to work on a problem—it had ceased to be of concern to them, and its emotional force had been spent. As such, it is a level that does not translate easily into dementia care that, because of the progressive nature and profound emotional threat, might be understood as continuing to represent a threat to well-being. However, although rare, there do seem to be some examples that suggest that the person who is working at this level is able to integrate dementia into the whole of their life. The existence of dementia is acknowledged and recognised but no longer defines them as a person. We might expect that the emotional aspects of that change for themselves and for others are also recognised, and that the person's affect is positive but no longer excitable. At the end of a psychotherapy group, Dave spoke about how he had changed his life after addressing his fears about dementia:

*Dave:* What will be, will be. There's nothing you can do about this except to try and make the most of each day as it comes, and to let your mind go free. I know that what's going to come will be difficult,

but I will accept it at the time. It's still the same old me in here, and once you put your mind to it, life carries on.

## **Discussion**

The capacity of people with dementia to discuss different aspects of their illness including the symptoms of cognitive loss—its cause, care, and prognosis—is one of the most researched areas of dementia research (Clare, 2010). The interaction between cognitive, neurological, and social processes as well as the way in which emotion shapes a person's response makes this a complex area to investigate. Within this context, adopting the assimilation model as a means of positioning dementia as an existentially threatening trauma has a number of important implications for research and clinical practice.

### ***The importance of ambivalence: approaching and avoiding***

Representing the emergence of awareness as the product of a dialogue between dominant and problematic voices reflects a recurring theme in research into awareness: the central nature of ambivalence. Preston, Marshall, and Bucks (2007), for instance, describe the accounts of people they interviewed as including “accepting vs. fighting it” and “avoidance vs. being open”. Elsewhere in the literature there are descriptions of psychological balancing between persevering with a problem and knowing when to “let it go”, and between covering up and being open about difficulties (Clare, 2003; Pearce, Clare, & Pistrang, 2002). Thus Lishman (2012) in a study of eight people before and after receiving a diagnosis of dementia from a memory clinic, shows that their discourse moves forward and backwards during the course of their interviews across three or four of the APV levels. In her study the dialogue between the PV and the DV is played out through approaching and then retreating from awareness. This process of shifting awareness is similar to that described by Pearce, Clare, and Pistrang (2002) who carried out semi-structured interviews with twenty men with Alzheimer's disease and their wives, using interpretative phenomenological analysis. They found that for some couples, the avoidance of talking together appeared to be part of a cyclical process of slowly turning to face the situation, rather than accepting it immediately. Pearce and colleagues suggested that these men managed their sense of self by balancing their wish to maintain a prior sense of self against their need to reappraise and construct a new sense of self:

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. 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, Clare, & Evans, 2004, p. 344)

Adopting the APV model places the duality of people with dementia both knowing and not knowing about their dementia within the context of research into how people generally assimilate problematic and traumatic material. Within this framework the intra-psychic and inter-personal processes involved in mediating awareness amongst people with dementia are similar to those that mediate awareness of any traumatic event.

The nature of ambivalence means that in many cases, people with dementia are not just undecided about whether to engage with their diagnosis, but may be actively avoiding doing so. In these circumstances there is an ethical duty on clinicians not only to respect their choice but also to ensure that we do no harm. In these circumstances we need to recognise that there may be instances when to bring the issue of dementia to the fore is to risk raising an emotionally loaded threat that the individual will not have the resources to address, and that might well cause them great distress. At the same time we must also recognise both that a person's failure to recognise what is happening to them may dramatically compromise their life, and also, that for at least some people, if these ideas are raised in a sympathetic and sensitive way, then they may be able to think about their problems in a more constructive way. As clinicians we must both be sensitive to our clients withdrawing their consent to these discussions about dementia, and also be able to assess the person's capacity to do so. On occasion we will be more effective if we support the people around that person and recognising that it is not always beneficial for a person to assimilate the knowledge of their dementia.

### ***Awareness is both social and personal***

The assimilation model does not view the self as a single, internal entity, rather the self is seen as inherently social with both the PV and the DV representing the internalisation of voices from the social world. More generally in dementia care, there has long been a recognition that insight is connected to the social world—for instance, Kitwood (1997) suggested that levels of insight of residents in a nursing home would be a reliable index for the quality of the care provided within that home. Other representations of self in the dementia care literature also echo this social nature of identity. Sabat (2002), for instance, describes self as containing three related concepts, all of which are enacted in the social world.

Crucial to this representation of self is the idea of positioning—that is to say the way in which within a social interaction, individuals struggle to present a version of themselves that is consistent with their conception of their identity, and react towards the identity that others seem to be constructing for them. In dementia care, often those social identities that are available to people with dementia are defined around the illness, and position people with dementia as incompetent in some way (Sabat & Harré, 1995). As Linda Clare has pointed out:

. . . the expression of awareness may be influenced by a range of psychosocial and socio-environmental factors including expectations, values and social norms, the dynamics of interpersonal relationships and interactions, and the surrounding context, and may be modulated by motivated psychological processes such as avoidance or denial . . . reflecting situational responses or life-long dispositions. (Clare, 2010, p. 21)

It is probably not a coincidence that many of the examples I have given in this paper come from group therapy. Given that many of the elements that make dementia problematic for people are social in nature (for instance, the fear of forgetting someone's name, or of making a mistake and being thought to be stupid), bringing together people with dementia in a group can have powerful therapeutic effects, so long as the problematic nature of the dementia is addressed. At the same time, however, meeting other people who have the same problems as you do, may be precisely the thing that many people are trying to avoid—as was the case with Mr E. Thus both individual as well as group therapy are clearly important.

The capacity of human beings to assimilate problematic experiences depends not only on the social world around them, but also on internal factors of resilience and fragility (Windle, 2011). Psychology is replete with different ways of representing such internal factors. To take one example, terror management theory or TMT (e.g., Solomon, Greenberg, & Pyszczynski, 1991) suggests that the variation between individuals in the way in which they react to reminders of their own death is related to a series of factors including levels of self-esteem, avoidant attachment, and narcissism. Thus high levels of self-esteem seem to act as a buffer against death anxiety, while in turn high levels of self esteem seem to result from an ability to find meaning in the world, and to have a strong sense of one's place within it. From this basis, we can speculate those people with dementia who are able to look more directly at their own illness (that carries with it a prognosis of continued deterioration leading to death) will be those who have a strong and secure sense of their own worth that does not depend on *what they do*, but concerns *who they are*. For these people, the loss of valued social roles and competencies that

are a feature of dementia will be less threatening than for those people whose self-esteem depends crucially on doing and achieving.

Understanding dementia as a potentially problematic experience, enables us to understand that some people with dementia may be able to process and assimilate knowledge of this illness into their existing sense of self, and to arrive at an integrated understanding of themselves from which they can make mature decisions about their world, their dependency, and their future. However, there will be other people, possibly those whose self-esteem is more vulnerable, or people who inhabit more fragile social worlds, for whom this knowledge will resist such assimilation. For this group of people, there are potentially many different aspects of their experiences that may be problematic. In the Dementia Voice project, the problematic aspect of dementia for Mr B seems to have been a fear that his loss of memory meant that he had lost his intelligence; for Mrs H it was the fear of what she would be like just before she died—a fear of becoming useless; while for Donald it was a concern that other people thought he was mad. For many others, like Mr E, their dementia will be too awful to bear to think about.

### ***The interaction between cognitive decline and awareness***

The process by which people come to be able to describe themselves as having a dementia is made complex because of the enormity of the psychological change that is involved. It is further complicated, but for many not made impossible, both by the cognitive impairments that an individual experiences, in particular those difficulties in retaining information in short-term memory and the difficulty in articulating, communicating, and verbalising that frequently are a part of dementia.

Thus, deterioration in cognitive functioning will inevitably alter the person's capacity to assimilate material—partly because cognitive changes mean that it will become harder to articulate and to hold onto the PV. In addition, these cognitive changes may interact with the DV so that the cognitive process of warding off may become strengthened. However, just as it is possible that people with low levels of neurological impairment, but who are personally fragile, like James in the case study presented here, may resist assimilation of their diagnosis, so some more resilient people who have relatively high levels of neurological impairment can, under the right circumstances, describe complex aspects of their life circumstances. Clare (Clare, Rowlands, Bruce, Surr, & Downs, 2008a,b), for instance, has argued that nearly two-thirds of the people that she interviewed were able to demonstrate thoughtful consideration of an aspect of their situation and the implications that this carried, such as being brought to live in a residential home, losing their spouse, or

reflecting on their experience of dying. This capacity for reflection also seems to be true, for at least some people, even where there are more severe levels of neurological impairment. Thus Godwin and Waters (2009) report twelve interviews with patients with advanced dementia living in hospital wards, nursing homes, or a hospice. Despite their advanced dementia, the people in their study appeared to have, and were able to express, views on the end-of-life care. Moreover, there was some evidence to suggest that some of these views may have evolved since the person was diagnosed, leading to a greater acceptance of death.

### ***The inter-dependence of emotional and cognitive processes***

The APV model makes clear that there is not a simple relationship between affect and assimilation: thus it is not the case that as a person with dementia becomes more insightful, then they automatically become more or less depressed. In the earlier levels of assimilation, material that is being warded off may be expressed in a disguised form, for instance through narrative, or enacted through the person's behaviour. The person's affect may, however, be relatively calm and controlled, with expressions of emotional distress apparently unconnected to awareness of their dementia.

Where a person is able to move from warding off knowledge of dementia, through to having unwanted thoughts about this and a vague awareness (APV levels zero to two) so their levels of affect rise. However, as the problem becomes clearer, and as there is a more mature assimilation of the problematic voice, so affect reduces. The person with dementia has managed to work through some of the psychological threats that their illness causes. However, the assimilation model also allows the possibility that over the course of time, as neurological functioning becomes more and more impaired, so the nature of this threat will change—thus presenting fresh challenges to assimilation.

An apparent lack of awareness on the part of a person with dementia about their illness, or their partial and variable expression of insight is not an incidental aspect of clinical work with people with dementia. Rather, the need to help individuals with dementia to develop and to sustain their emotional understanding of their illness has a central role within dementia care. Thus, the frequent focus in dementia care on cognitive rehabilitation needs to be matched with an understanding of the importance of the potential emotional threat of dementia. For instance, techniques of rehabilitation that might be appropriate for people who have processed the emotionally threatening aspects of their dementia, and are able to work at the later stages of assimilation, are unlikely to be effective

for those people struggling to assimilate the problematic nature of their dementia. Alongside recovery we need to recognise the importance of grieving (Sutton-Smith, personal communication).

Dementia represents a profound existential threat—it threatens our sense of who we are, and of how life should be. Neurological changes may compromise our ability to recognise those around us as the people that we have loved and who have shaped our lives. Our ability to use language to express ourselves may be reduced, while our memory for the recent past, and for holding on to a sense of narrative continuity becomes frayed. With decreasing ability comes increasing dependency and, for many, the sense of shame may inhibit their capacity to face what is happening. But as humans, we have a need to make sense of life—and to live our lives within the framework that this meaning creates for us. In Sabat and Harré's phrase, we are semiotic beings (Sabat & Harré, 1994). This meaning making is both social and personal—both involving cognitive resources and emotional challenges. The assimilation model provides one mechanism for understanding this process, and for recognising both the potential for change and the emotional obstacles that may prevent this.

### **Acknowledgements**

I could never have begun this work without the patience and tolerance of those people who have not only attended the groups I have run, but by talking with me about their fears, hopes, and tragedies have allowed me to understand more about dementia. I am grateful for the support I have received from my colleagues who have run the groups with me and to many others (most recently Emma Lishman and Naomi Betts) who have worked with me using the assimilation model. I am also grateful to Jane Gilliard and to Kerry Jones, who were my collaborators on the Dementia Voice project which was funded by a grant from the Mental Health Foundation. Our original analysis of material for this project was supported by funding from the Research Department of Avon and Wiltshire Mental Health trust. Finally, I must acknowledge the encouragement and prompting of Deirdre Sutton-Smith through more than ten years of supervision.

### **References**

- Cheston, R. (1996). Stories and metaphors: talking about the past in a psychotherapy group for people with dementia. *Ageing and Society*, 16(5): 579–602.
- Cheston, R. (2004). Top-dogs and under-dogs: marginalising problematic voices. In: A. Innes, C. Archibald, and C. Murphy (Eds.), *Dementia: An Inclusive Future? Marginalised groups and marginalised areas of dementia research* (pp. 153–168). London: Jessica Kingsley.



- Cheston, R. (2005). Shame and avoidance: issues of remembering and forgetting with people with dementia. *Context: the Magazine for Family Therapy and Systemic Practice*, 77: 19–22.
- Cheston, R. (2009). Group psychotherapy for people with early dementia. In: E. Moniz-Cook & J. Manthorpe (Eds.), *Early Psychosocial Interventions in Dementia: Evidence-based Practice* (pp. 135–145). London: Jessica Kingsley.
- Cheston, R., Jones, K., & Gilliard, J. (2004). “Falling into a hole”: narrative and emotional change in a psychotherapy group for people with dementia. *Dementia: the International Journal of Social Research and Policy*, 3(1): 95–103.
- Clare, L. (2003). Managing threats to self: awareness in early stage Alzheimer’s disease. *Social Science & Medicine*, 57(6): 1017–1029.
- Clare, L. (2010). Awareness in people with severe dementia: review and integration. *Aging and Mental Health*, 14(1): 20–32.
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008a). “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. *Social Science and Medicine*, 66(11): 2366–2377.
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008b). The experience of living with dementia in residential care: an interpretative phenomenological analysis. *The Gerontologist*, 48(6): 711–720.
- Gergen, K., & Kaye, J. (1992). Beyond narrative in the negotiation of therapeutic meaning. In: S. McNamee & K. Gergen (Eds.), *Therapy as Social Construction* (pp. 166–185). London: Sage.
- Gilbert, P., & Andrews, B. (1998). *Shame: Interpersonal Behaviour, Psychopathology and Culture*. Oxford: Oxford University Press.
- Godwin, B., & Waters, H. (2009). “In solitary confinement”: planning end-of-life well-being with people with advanced dementia, their family and professional carers. *Mortality*, 14(3): 265–285.
- Hermans, H., & Kempen, H. (1992). The dialogical self: beyond individualism and rationalism. *American Psychologist*, 47(1): 23–33.
- Honos-Webb, L., & Stiles, W. (1998). Reformulation of assimilation analysis in terms of voices. *Psychotherapy*, 35(1): 23–33.
- Honos-Webb, L., Surko, M., Stiles, W., & Greenberg, L. (1999). Assimilation of voices in psychotherapy: the case of Jan. *Journal of Counselling Psychology*, 46(4): 448–460.
- Kitwood, T. (1997). *Dementia Reconsidered: the Person Comes First*. Buckingham: Open University Press.
- Lishman, E. (2012). *The Paradox of Dementia: Meaning Making Before and After Receiving a Diagnosis of Dementia*. Dissertation for Phd submitted to Exeter University.
- Mair, M. (1989). *Between Psychology and Psychotherapy: a Poetics of Experience*. London: Taylor & Frances/Routledge.
- Newman, D., & Beail, N. (2002). Monitoring change in psychotherapy with people with intellectual disabilities: the application of the Assimilation of Problematic Experiences Scale. *Journal of Applied Research in Intellectual Disabilities*, 15(1): 48–60.

- Osatuke, K., & Stiles, W. (2006). Problematic internal voices in clients with borderline features: an elaboration of the assimilation model. *Journal of Constructivist Psychology, 19*(4): 287–319.
- Pearce, A., Clare, L., & Pistrang, N. (2002). Managing sense of self: coping in the early stages of Alzheimer's disease. *Dementia, 1*(2): 173–192.
- Preston, L., Marshall, A., & Bucks, R. (2007). Investigating the way that older people cope with dementia: a qualitative study. *Aging and Mental Health, 11*(2): 131–143.
- Robinson, L., Clare, L., & Evans, K. (2004). Making sense of dementia and adjusting to loss: psychological reactions to a diagnosis of dementia in couples. *Aging and Mental Health, 9*(4): 337–347.
- Sabat, S. (2002). Epistemological issues in the study of insight in people with Alzheimer's disease. *Dementia: the International Journal of Social Research and Practice, 1*(3): 279–293.
- Sabat, S. R., & Harré, R. (1994). The Alzheimer's disease sufferer as a semiotic subject. *Philosophy, Psychiatry, and Psychology, 1*(3): 145–160.
- Sabat, S. R., & Harré, R. (1995). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society, 12*(4): 443–461.
- Solomon, S., Greenberg, J., & Pyszczynski, T. (1991). A terror management theory of social behaviour: the psychological function of self-esteem and cultural world views. In: M. Zanna (Ed.), *Advances in Experimental Social Psychology, Vol. 24* (pp. 91–155). San Diego, CA: Academic Press.
- Stiles, W. (1999). Signs and voices in psychotherapy. *Psychotherapy Research, 9*(1): 1–21.
- Stiles, W. (2001). Assimilation of problematic experiences. *Psychotherapy, 38*(4): 462–465.
- Stiles, W., Honos-Web, L., & Lani, J. (1999). Some functions of narrative in the assimilation of problematic experiences. *Journal of Clinical Psychology, 55*(10): 1213–1226.
- Stiles, W., Meshot, C., Anderson, T., & Sloan, W. (1992). Assimilation of problematic experiences: the case of John Jones. *Psychotherapy Research, 2*(2): 81–101.
- Watkins, R., Cheston, R., Jones, K., & Gilliard, J. (2006). "Coming out" with Alzheimer's disease: changes in awareness during a psychotherapy group for people with dementia. *Aging and Mental Health, 10*(2): 166–176.
- Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology, 21*(2): 152–169.
- Wolverson (Radbourne), E., Clarke, C., & Moniz-Cook, E. (2010). Remaining hopeful in early stage dementia: a qualitative study. *Aging and Mental Health, 14*(4): 450–460.