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ORIGINAL ARTICLE

'Coming out' with Alzheimer's disease: Changes in awareness during a psychotherapy group for people with dementia

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Abstract

This paper forms part of the second phase of a project looking at those changes that occurred for participants during a series of time-limited psychotherapy groups for people with dementia. Using the Assimilation of Problematic Experiences Scale (APES), the accounts of one participant (Robert) are analyzed across the course of the group. Robert moves from a position in which he wards off awareness that he has dementia of the Alzheimer's type, to being able to joke about having brain changes that are symptomatic of the illness. This change in his discourse about Alzheimer's disease was accompanied by an increase in Robert's levels of affect. However, reflecting on the changes that had occurred for him, Robert commented that before he came to the group he had been frightened, thinking that 'I'm going crazy . . . what am I going to be like in another five years?'. For Robert, coming to the group had meant that this fear had been replaced by the knowledge that he was not alone. In the light of the move towards early diagnosis, the importance of this model of change in awareness as a means of increasing understanding of the process of emotional development is discussed.

> '. . . but I think that a lot of people who I have met who have come out about Alzheimer's were quite shocked because I said that. It did help, it may not have helped others, but I suppose that it helps overcome a feeling of being different.'
>
> Janet, session six.

Introduction

In the UK, two significant service developments have contributed to the development of psychotherapy and psycho-educational groups for people with dementia. First of all the relatively recent decision by central government to provide funds for the National Health Service to prescribe anti-cholinesterase inhibitors has led both to diagnoses being made at an earlier point in the course of the illness, and to these diagnoses being more reliably communicated to patients and their carers. Once the diagnosis has been communicated, then there is clearly a need for services to help the individual to make sense of what, for many, is traumatic news. Indeed, it can be argued that there is a need for counselling or psychotherapy before the assessment process is begun.

Secondly, the growth of person-centred approaches to dementia care has emphasized the importance of attending to the emotional needs of people with dementia (Kitwood, 1997). Thus research now suggests that the psychosocial factors influencing awareness and insight in dementia are complex phenomena varying between each individual, independent of the impact of any neurological change (Pratt & Wilkinson, 2003).

Psychotherapy, change and awareness

A wide range of individual psychotherapeutic work with people with dementia has been described including psychodynamic (e.g., Sinason, 1992), cognitive-behavioural (e.g., Teri & Gallagher-Thompson, 1991) and humanistic (e.g., Stokes & Goudie, 1990). However, probably the single most common means of using psychotherapy as a way of intervening with people with dementia has been through group work (e.g., Yale, 1995). The review by Cheston (1998), for instance, identified over twice as many reports of groups compared to work with individuals. However, the clinical growth of psychotherapeutic and counselling work with people with dementia has not yet been matched by an equivalent growth in research.

Psychotherapy process research

The purpose of psychotherapy is to enable change to occur. Thus the evaluation of psychotherapy

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Table I. Assimilation of Problematic Experiences Scale (APES).

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).
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)

From Newman and Beail (2002), adapted from Barkham, Stiles, Hardy and Field (1996).

involves gathering evidence of such change. Such evidence may lie in the relief of symptoms or alterations in the patterns of relationships, speech and language and can be gathered through quantitative or qualitative means.

In contrast to psychotherapy outcome research, which is almost exclusively based around large scale, quantitative methodological designs, process research involves qualitative methods of analysis examining those changes in an individual's awareness of their problems that occur during psychotherapy (e.g., Elliot, 1983; Greenburg, 1999; Safran et al., 1988). One such method is assimilation analysis, which has sought to define a systematic sequence of changes in the representation of a problematic experience during therapy (Stiles et al., 1992). This model draws on theories of development by Piaget (1972) and Rogers (1961). It can also be viewed in terms of a trans-theoretical model of change (e.g., Prochaska & DiClemente, 1984).

The central concern in the assimilation model of psychotherapeutic change is the process by which painful or problematic experiences are gradually assimilated into existing schema. During the developmental process involved in ordinary learning, experiences are assimilated into existing beliefs or schemas, which in turn are altered to accommodate existing material. Problematic experiences are those which, were they to be assimilated in this way, would be psychologically painful. Instead these experiences are pushed out of conscious awareness, although knowledge of their presence may leak back in the form of symptoms of psychological distress, for example, outbursts of anger, panic attacks or depression.

The assimilation model proposes that the process by which problematic experiences are assimilated in successful psychotherapy involves clients moving through a series of stages or levels, as the painful material is approached, the nature of the problem clarified, insight gained and then mastery over the material achieved. As the problematic material is gradually assimilated into existing schema, so the client experiences a parallel sequence of emotional reactions. A client might move from being oblivious or feeling only vaguely disturbed, to experiencing the content first as painful and then as problematic but less distressing. The assimilation of the problematic material is thus accompanied initially by rises in levels of affect which then decrease, once insight and mastery have been achieved. In the later stages of this process, as the problem is understood and new solutions are tried out, so confidence grows and the client may gain some satisfaction or positive affect from the new way of living (Newman & Beail, 2002).

The assimilation model provides a way of understanding how clients within psychotherapy move from being unaware of the problematic material, through a process of exploration and problem identification, to eventual understanding and insight that permits a wider problem solving approach and final mastery of the problematic experience. This movement through a series of stages is operationalized through the Assimilation of Problematic Experiences Scale (or APES) shown in Table I.

Research using assimilation analysis has focused on client, therapist and observer-defined insight events to trace these stages of assimilation (Stiles et al., 1992; 1995; 1999; Honos-Webb et al., 1999). The model has also been applied to changes in awareness that occur during psychotherapy for individuals with intellectual disabilities (Newman & Beail, 2002). In each case different therapeutic approaches have moved the person along the scale of assimilation without necessarily reaching stage seven. Thus one hypothesis is that the process of change may be dependent on a multiplicity of individual factors. This highlights an important benefit of the assimilation model: it is sensitive to change based on the individual's needs rather than the nature of the intervention or therapist. It is, therefore, potentially applicable in a variety of settings.

Methods

The Dementia Voice group psychotherapy project

This project had two elements: first of all the creation of six psychotherapy groups across Southern England for people who had been diagnosed as having Alzheimer's disease or another form of dementia; and secondly the independent evaluation of these groups. All of the participants had an MMSE score of at least 18, with the highest score being 28. Each group lasted for 10 weeks, with each session lasting for approximately an hour and being facilitated by the second author in collaboration with either one or two co-facilitators who varied from group to group.

Therapeutic content

The central therapeutic issue that participants were asked to discuss was 'what it's like when your memory isn't as good as it used to be'. Participants were encouraged to share their experiences with each other and to discuss the emotional impact of these experiences on them. The role of the facilitators was to reflect upon the emotional significance of these experiences within the context of the group. As such this approach differs markedly from other therapeutic forms of work with people with dementia such as Validation Therapy (Feil, 1990, 1992, 1993), Life-review Therapy (e.g., Garland, 1994), Reminiscence Therapy (e.g., Bender, 1994) and Reality Orientation (e.g., Holden & Woods, 1988). The groups in this project focussed upon the experiences of participants in the here-and-now, and upon the impact of these experiences upon relationships, including those formed within the matrix of the group. The task of the group therapist was to facilitate this process of reflection by interpreting material that was brought to the group in terms of its underlying emotional significance. While each of the six groups was inevitably unique, nevertheless a number of consistent themes emerged as participants talked over the emotional and social tensions caused by their memory loss. A central focus in these groups was that of 'forgetfulness' (Cheston et al., 2002):

- Forgetting—unsurprisingly, groups spent significant time in remembering the experience of not remembering. For one woman the experience of losing her way in a conversation was like falling down a hole, while others likened it to being run over, or dodging cars on a motorway.
- Wanting to forget—for one man the most pressing challenge was not what you forgot, but what you remembered and wanted to forget. As Jenny, a participant in the group that we will describe in this paper put it 'I'm quite happy in a situation unless I choose to sort of sit there and think. And it's when I think about that [her future] that the curtain comes down'.
- Being forgotten about—group participants often described their hurt when they were forgotten about by relatives or by a system which could be experienced as rarely seeming to take the trouble to tell them what was happening.
- Wanting to be forgotten about—for some participants, there was a strong sense of being a burden to their partners, or their children. Instead of being able to support and care for each other, now they were the objects of care themselves. In these circumstance participants described how attempting to slip into the background so that they would not be a burden was one of the few remaining ways available to them of reciprocating the care that they received.

Measures of affect

As part of the project, the third author independently collected data relating to the emotional functioning of participants at five separate time points (Cheston et al., 2003). This independent evaluation included the Cornell scale for depression (Alexopoulous et al., 1988) and the rating scale for anxiety in dementia or RAID (Shankar et al., 1999).

- The Cornell scale (Alexopoulus et al., 1988) is a well-established interview-based measure that assesses the level of depression of people with dementia. Although not originally intended as a diagnostic instrument, a cut-off score of seven or above is commonly taken as indicating a clinical level of depression. Composite ratings on the Cornell scale were based on information gained from interviews with both participants and their main caregivers, usually their husband or wife. Where possible other caregivers were also interviewed, including health care staff and other family members involved in that person's care.
- The RAID (Shankar et al., 1999) is an interview-based measure designed specifically for people with dementia. Like the Cornell, the RAID was designed for the purposes of research rather than as a diagnostic measure, although the authors suggest that a cut-off point of 11 or above should be taken as indicative of a significant level of anxiety. Ratings were again based on interviews with the participants and their main caregivers.

Analysis of the data for depression and anxiety levels for the 19 participants who completed all three phases of the project, using a repeated measure ANOVA provided significant evidence for a treatment effect for Cornell depression scores which was maintained at follow-up. Analysis also revealed a similar non-significant trend towards a reduction in anxiety as measured by the RAID (Cheston et al., 2003).

Intra-session ratings

In order to record levels of therapeutic engagement achieved with the group as a whole during each session, both the facilitators completed a brief questionnaire at the end of each session. This questionnaire was devised as part of the research programme, and involved rating group processes in terms of the ten therapeutic elements identified by Yalom (1970). Sessions were rated on a seven-point scale from counter therapeutic (0) to strongly present (6).

Analysis of the data

Audio-tapes and data collected from 10 sessions of one of the groups in the project were used for this analysis. The analysis presented here draws on methodology outlined by Stiles and his colleagues (e.g., Stiles et al., 1992, 1994, 1995, 1999, Stiles, 2000, 2001; and Newman & Beail, 2002).

Phase A: Identifying themes and mapping interactions

Two researchers carried out the initial analysis: the second author, a clinical psychologist who had facilitated the groups and an assistant psychologist who had not previously participated in any part of the project. The method of analysis developed by Stiles and his colleagues for material from individual psychotherapy was adapted to accommodate the nature of group work so that interactions between individuals could be mapped and group processes recorded (Knodel, 1993). This involved working from the initial transcripts and tapes, so that each session was reviewed and re-reviewed until individual and group themes were identified. Written summaries were then made of the content of the group discussions, and the interactions between participants and facilitators. Changes in group-themes across the sessions were then mapped in relation to group processes.

Phase B: Defining the problematic experience

The aim of this element of the research project was to investigate the way in which participants within the group assimilated knowledge of having dementia of the Alzheimer's type. We decided therefore to analyze material relating to a single participant who before the group began did not acknowledge having a diagnosis of Alzheimer's disease. The participant that we chose to examine was Robert who attended all but one of the 10 sessions.

Robert was a 76-year-old retired solicitor who lived with his wife. He had received a diagnosis of dementia of the Alzheimer's type six months prior to the first session and although he talked about his frustrations at his inability to remember, he did not recognize in pre-therapy sessions that his memory problems were caused by an illness. At the time of the groups he was not being prescribed any form of medication. Robert was selected because of all the group participants he seemed to find it hardest at the beginning of the group to acknowledge that he had been diagnosed as having dementia, and there was therefore the greatest possibility of looking at the emergence of awareness across the course of the group.

The summaries and transcripts for each session were reviewed, highlighting Robert's descriptions of himself, his memory and, where relevant, his diagnosis. Five extracts were identified in which Robert referred both to a memory problem and to Alzheimer's disease. A number of common elements to these extracts were identified that related to difficulties that Robert had in accepting the diagnosis of Alzheimer's disease. From this the following statement of the problematic experience was formulated: 'Robert coming to terms with the implications of his diagnosis of Alzheimer's disease'. This problem statement could be broken down into the following components:

- That his poor short-term memory and other cognitive problems were caused by Alzheimer's disease.
- This is different to normal ageing and involves a general deterioration in his cognitive functioning that is more than just a reduction in his short-term memory.
- That this is a progressive illness involving a continual decline in his abilities.

Phase C: Rating the level of assimilation

The five passages that related to the problematic experience came from sessions one, four, five (two extracts), and seven. Each of these extracts was presented on audiotape and with detailed transcripts to a consensus group of three clinical psychologists (one qualified and two trainees) none of whom had previously been involved in any aspect of the research. A detailed explanation of the assimilation model and about APES was provided using the Manual for Rating Assimilation in Psychotherapy (Honos-Webb, Surko, & Stiles, 1998). Training was given in using this method through a series of guided examples of ratings of therapy sessions. Finally the five extracts (each of which lasted for between one and four minutes) were presented in a random order. The consensus group was not told at what point in the therapeutic process the extracts had occurred, but they were given information as to the immediate clinical context around the extract. Each of the three researchers were first asked to separately rate each extract following the guidance set out in the manual, which encourages the use of intermediate ratings to one decimal place (e.g., 0.9, 1.7, 3.2). When all the extracts had been presented and separately rated by the research group, the consensus group was then asked to listen to the extracts again and to discuss their ratings with each other so that they could reach a consensus rating for each extract.

Results

Group participants

Of the 10 participants in the group, seven were men and three were women. One participant (John) left during the first session, while another participant (Don) left after seven sessions as he had an operation on his leg. Although some participants missed occasional sessions for various reasons, the other eight members of the group continued to attend until the end of the 10 sessions. Participants were aged between 59 and 81 with an average age of 69 years. All were living at home and, apart from two participants who had supportive relatives living nearby, participants lived with their spouse. Eight of the original participants had received a diagnosis of Alzheimer's disease whilst the remaining two had a diagnosis of another form of dementia.

The sessions

The first session began with a simple round of introductions, followed by the facilitators reminding participants about the purpose of the group. Robert defined his difficulty as a selective problem of short-term memory loss, that did not affect other areas of living, but was confined to a poor memory for finding his car, meeting people and so on.

> [1] Robert: I wonder if I could just ask you to give a view of this, I find that my short-term memory is very selective, in the sense that . . . I have all my papers properly filed, very methodical in that sense. Yet yesterday, I went [to town] and my wife was going one way and I was going another way and we arranged to meet, and I couldn't remember where I'd put the car and I couldn't remember where I was going to meet my wife, now that's absolutely typical of my short-term memory problem. For no reason whatsoever, something that is fairly trivial or very important just vanishes completely.

After a brief interruption, Robert then went on to make the first reference in the group to Alzheimer's disease.

> [2] Janet: What about people's names?
> Robert: Generally I'm very good at it . . . err . . . I belong to PROBUS [PROBUS clubs are charitable organizations run largely by retired businessmen] . . . well there are two PROBUS clubs . . . and they are very good because everyone is in the same age bracket and half of them have got Alzheimer's or something near so we've all worked out ways of reminding each other in the conversation. You don't just stand up and say something; you lead into it so other people know what they are doing.

Although Robert introduced the phrase 'Alzheimer's or something near' he distanced himself from the illness by using the phrase 'half of them'. Later on in the session he talked about finding strategies in the group to cope with his short-term memory loss, and to 'stimulate other parts of the brain to find passages through' to 'get a better memory system'. This extract was rated as 0.1 ('warded off') because although Robert talked about having a memory problem and did not resist attempts to introduce it into the conversation, he positioned Alzheimer's disease as something that affected other people and not him. Similarly by searching for a solution, it appeared that he was actively avoiding a wider discussion of his condition.

Session four

Robert attended the second session but not the third. There was then a break for Christmas, so that when Robert attended the fourth session, it had been four weeks since his previous meeting. During the session Dennis voiced his frustrations about having to give up driving because of his Alzheimer's disease. Janet joined in, talking about people's fear and shame of Alzheimer's. She asserted that 'it's up to us as members of the Alzheimer's Society to have as much publicity as we can, and that will bring out a lot of people who are ashamed of it'. Shortly after this Robert questioned whether people needed to talk in terms of having Alzheimer's disease if they had not received a formal diagnosis: '. . . you keep saying you have Alzheimer's, has that been formally diagnosed, because it's not the same thing as memory loss, you know?'. As Dennis and Janet continued to talk about having Alzheimer's disease, so Robert interrupted again,

> [3] Robert: Now there's a premise here that I just don't agree with. The way you're talking, you sound as though you've accepted the fact that you've got Alzheimer's. Now I don't think anyone in this room has got Alzheimer's.

In response to this, four other members of the group who had previously been relatively quiet all acknowledged both that they too had been diagnosed as having Alzheimer's disease, and that they found this diagnosis unsettling and disturbing in some way.

> [4] Facilitator: [Julie] just said that she feels that she definitely has Alzheimer's.
> Julie: I didn't answer because I was ashamed really.
> [5] Facilitator: Robert said that he wondered if anyone in this group had Alzheimer's disease, and Julie said that she does and that she has been told by her doctor.
> Janet: Well I've always come out with it, my family accept it . . .
> [6] Facilitator: Chris, you said earlier that you wouldn't tell other people.
> Chris: Yes I think shameful is perhaps the wrong word, it's just that I wouldn't want to publicise it.
> Walter: it's unfortunate that you've got it.
> [7] Janet: . . . .because I wondered whether you were hesitant about it coming out, because people wouldn't treat you as they had before they knew.
> Chris: That's a possibility I think, yes.

This discussion culminated in Judith describing her fears for the future:

> [8] Judith: I just wonder where it's all going to end, that's my fear . . .
> Janet: When it's going to end?
> Judith: Where it's going to end, where am I going to end up, just before the end, you know.
> Janet: oh, I see you mean, I talk about death.
> Judith: Yeah.
> Janet: To my family and I think the only thing that I'm frightened of is the unknown and that is death to me.
> Judith: And after that? Oh, no I'm worried about what comes just before [laughs] it could be years before, couldn't it?
> Janet: It could be tomorrow.
> Robert: Is it the dying that?
> Judith: I don't feel that at all, no, because we all go through that, no I'm not frightened about that, no. It's not really my religion to say it at all, but I don't know if there's anything else and I'm not going to worry about that right now, you know.
> Facilitator: So what is frightening, when you say about the future?
> Judith: Being, being useless, you know.
> Janet: Yes.
> Judith: Not having all my faculties, I dread that, I dread that, its as if I'm going to come to it one morning, perhaps, you know and think 'oh my godfathers, what's left?', I really worry about that . . . . so I'm quite happy in a situation unless I chose to sort of sit there and think. And it's when I think about that, that the curtain comes down.

Within this session Robert actively avoided any awareness that his memory problems could be attributed to Alzheimer's disease, by twice saying to the group 'I don't think anybody here has got Alzheimer's disease' and asking whether others in the group had actually been diagnosed by a doctor. Consequently, this extract was rated by the consensus group as 0.3 ('warded off'). After this exchange, Robert's affect altered and there seemed to be signs of his being uneasy and apprehensive at other group members' acknowledgement that they had Alzheimer's disease. Later, in part of the session that was not rated by the consensus group Robert stated 'I am very disturbed by this', suggesting that these voices within the group had troubled him, which is consistent with stage one of APES ('unwanted thoughts').

Session five

Robert represented the dominant voice in this session. At the start of the session he produced a written statement that he then read out loud to the group. Robert's affect was heightened from previous sessions, and for the first time in the group, Robert referred to himself as having Alzheimer's disease.

> [9] Robert: What I'm trying to say is that whatever problem a person has we all work the same way, we analyze that problem and we decide the relationship that it has with other events. And when we sum up all of those pieces together we come to a conclusion about what's the right way to go. Now that's the way that we solve problems. But to do that we very often have to rely on our experience. And our experience is either in deep memory or it's in short-term memory. Now the problem with Alzheimer's as it affects me is that I have no problems with retrieving the information in the long-term . . . but, I think I've said this before, it's quite common for me to park a car in the car park and then I can't remember where I've put the car . . . and that's short-term memory.

The consensus group rated this extract as 2.0 ('vague awareness') as although Robert referred to himself as having Alzheimer's disease, he did not develop this statement. There was no direct acknowledgement of this problem as either something more general than short-term memory loss, or as a progressive illness that differed from normal ageing. Shortly after this extract, Robert defined his problems further:

> [10] Robert: All I'm trying to say is that there's no relationship, and I believe that in these meetings we've had a certain suggestion, perhaps subtle suggestion, has been implied that if the intelligence goes down, the short-term memory goes down and if the short-term memory goes down, the intelligence goes down . . . even the most intelligent set of people, who can still do a crossword puzzle etc., can still have Alzheimer's. It's got nothing to do with intelligence, its short-term memory only. . . . .I've found, that once I've made my mind up about that I don't get depressed by it.

Robert's affect during this extract became increasingly angry, and he spoke about being frustrated. In part the anger seemed to be directed against other members of the group whom he stated had associated Alzheimer's disease with a loss of intelligence, in part with the group facilitators whom he said should have helped the group to find ways around his problems of short-term memory loss. This second extract from the session was rated as being 1.6 ('unwanted thoughts')—a stage that is characterized both by a significant rise in affect and by a fear of losing control.

Session seven

Robert opened the session, asking permission to tell everyone some news:

> [11] Robert: Can I tell you something that's happened to me in this last week. I've had a CT scan, which was quite an interesting thing in itself, but I got the results back yesterday and it said that my brain had shrunk very, very slightly in the cavity, which is fairly symptomatic of the onset of Alzheimer's. So I asked, 'well if it's the onset, what happens when you're there' [group laughs], and he said 'very little more'. I mean if you got to the point where you couldn't remember anything at all then the brain wouldn't have got any smaller but it's this shrinkage which brings about this symptom of short-term memory loss, which is quite intriguing. So I'm not particularly bothered by it, but it was interesting to go through it.

Shortly after this, there is another exchange:

> [12] Facilitator: I was just thinking, Robert, you said very calmly that you had the scan and they told you your brain had shrunk.
> Robert: It's still twice as big as everyone else's [group laughs] so it's quite alright. I was quite surprised about that I didn't realise that the brain was an organ that could actually shrink. I don't think any other bones can shrink, but I don't think any other main part of the body can shrink.
> Judith: I think they do [laughs].

The affect within the group is light-hearted, as Dennis remarks 'I mean look at us, we're all sitting here laughing, and we're all quite happy one way or the other, and yes we all have got Alzheimer's and no it's not all that bad'. By contrast to the antagonism of session five, Robert praised other members of the group, including Julie, whom he believed had 'got to grips with the problem more than anyone else'. At the same time there is a slightly manic element to Robert's response as if he still found it hard to take the impact of the diagnosis seriously. It was this rather jocular affect and Robert's statements that 'I'm not particularly bothered by it' (extract 11) which influenced the consensus group to rate the extract as 3.9 ('problem clarification') rather than as the following stage of 'problem understanding or insight'.

Intra-session ratings

As we have described above, at the end of every session the facilitators used a rating scale based on Yalom's 10 therapeutic elements to rate the group. For the purposes of this analysis, the three most relevant therapeutic elements were 'acceptance', 'self-disclosure' and 'self-understanding'. As can be seen from Figure 1 in general terms there was a gradual increase in these levels across the 10 sessions, with the final two sessions showing slight decreases. The only two sessions in which these elements were all scored as being at the maximum level of six, were during sessions seven and eight.

Levels of anxiety and depression

Robert was referred to the group too late to be included in the baseline measure taken prior to the group starting. Consequently data was collected with Robert at four time points only: at the beginning of the group, after seven weeks, at the end of the group and after a 10 week follow-up period. While mean levels of both anxiety and depression for participants as a whole fell during the intervention compared to baseline and follow-up periods, as Figure 2 shows Robert's levels of depression and anxiety rose during the group, falling back somewhat during the post-group phase.

Discussion

Summary of results

During these sessions, Robert moved from a position of warding off awareness of both his diagnostic status and the implications of this (session one), through to a position in which he was able to acknowledge that he had Alzheimer's disease and that as a consequence his condition would worsen as his brain would continue to shrink (session seven). The

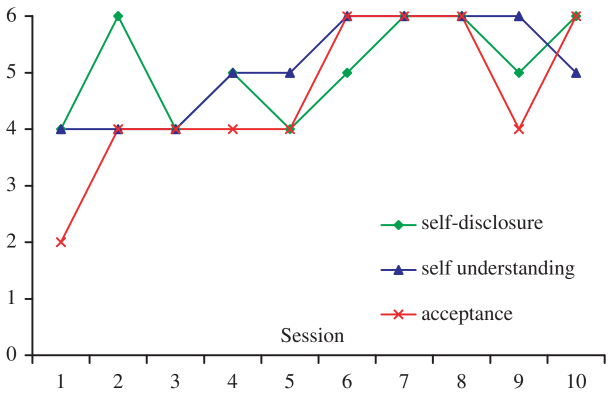

Figure 1. Ratings of therapeutic elements within sessions.

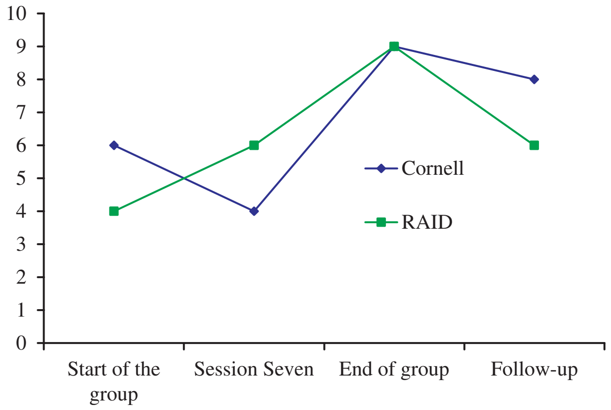

Figure 2. Robert's levels of depression and anxiety during group and follow-up stages.

change in Robert's discourse between the fourth and seventh session is consistent with the high ratings made at the time by the group facilitators of the therapeutic factors operating within the group as a whole. The analysis of group processes suggests that as the sessions progressed, so the majority of group members were able to talk more openly about the meaning and implications of having dementia for them.

An important clinical concern, however, is that the independent measures of mood that were taken at week seven and at the end of the group showed a deterioration in Robert's level of affect. Thus compared to his levels of anxiety at the start of the group, Robert's scores were higher both at week seven and at the end of the group, while his levels of depression fell at week seven compared to the start of the group, only to rise again at the end of the group. Levels of both anxiety and depression fell at the 10-week follow-up once the group had ended.

One interpretation of these changes is that for Robert the experience of becoming more able to articulate an awareness of those problematic aspects of dementia was emotionally distressing. To this extent this growth in awareness may be represented as a harmful process in that it may remove important intra-psychic defences that prevent an individual from being overwhelmed by despair at their prognosis.

Insight, awareness and the assimilation of problematic experiences

Within the disease model of dementia, people with dementia tend to be viewed as either having or not having insight into their condition. As such insight is often represented as a fixed entity, an all-or-nothing state that is similar to the neurological syndrome of agnosognosia. In this paper we have advanced a different perspective, in which, in the case of Robert, coming to terms with the implications of his diagnosis of Alzheimer's disease was seen to be a problematic experience.

Post-modern theories of the self describe a 'community of voices': rather than one ever-present self there are a series of 'selves' context-dependent, shifting and multiple (Hermans & Kempen, 1992). Within the trans-theoretical framework of the APES model, problematic experiences can be understood as developing because a dominant or 'top-dog' voice actively and successfully opposes the integration of an under-dog voice into the community of voices—instead the problematic voice is pushed away. The process of assimilation can be understood as an emerging dialogue between the problematic voice and the community of voices, so that the problematic voice is first approached, then allowed to be relevant, and finally accepted into the community of voices (Honos-Webb & Stiles, 1998).

As such the process within these group sessions in which Robert gradually began to articulate an awareness of his diagnosis and its implications is fundamentally different to the notion of insight as it is often construed within a disease perspective: while insight tends to be seen as a fixed and permanent entity, the emergence of awareness is a gradual process; whereas insight is construed as personal and neurological, the development of awareness is reliant on a secure and supportive psychosocial context; and while the possession of insight is an all-or-nothing state, the development of awareness is hesitant and variable.

Assimilation and socialisation

The problematic experience for Robert was defined in terms of three statements relating to Robert's memory problem, its relationship with normal ageing and the progressive nature of this difficulty. While these problem statements may be superficially unremarkable, they are in fact worthy of closer examination, as each is potentially disputable. Not only is the diagnosis of Alzheimer's disease probable rather than definitive, but also the overlap between normal ageing and dementia is becoming much more apparent as large community samples are followed to post-mortem (Cheston & Bender, 1999). Moreover the rate of decline is known to be highly variable and related to many factors in addition to the neurological process of Alzheimer's disease. Thus it could be contended that what is being rated here is Robert's socialization into the medicalized world of Alzheimer's disease, as his attributions and perceptions of his condition approach more closely those persuaded by the medical model.

However, the argument that has been advanced here has not been that Robert started from a position of denying that Alzheimer's disease did not exist. Robert was clear in sessions one and four that Alzheimer's disease existed but that it could not be taken as applying to him. The development of this position within subsequent sessions did not represent the internalization of a disease model, but rather a negotiation around its relevance. Thus in session five Robert's account involves a debate around the issue of whether to have a poor memory is also to lack intelligence.

At no stage during any of the sessions did anyone in the group suggest to Robert that he was suffering from Alzheimer's disease. Similarly, to the best of the facilitators' knowledge, Robert had been given the results of his CT scan several months before the group began, and not just before week seven, as he had claimed in that session. Robert's awareness that he had been diagnosed as having Alzheimer's disease and that this is a general and progressive condition seems to come from within Robert himself—as if he has begun to listen to a voice that otherwise he had suppressed.

In order to support this argument that the development of awareness for Robert was more than the internalization of a disease model of dementia we will now turn to a final extract taken from week nine of the group. The analysis that we have presented here was limited to statements that Robert made in which he referred to both memory problems and to Alzheimer's disease. Therefore this extract was not given to the consensus-rating group. The final three sessions of the group centred on issues relating to the ending of the group, and in the ninth session Robert reflected upon how he had changed over the course of the group:

> [13] Janet: you have to face it to start with.
> Robert: Well I think that's inevitable, we 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 yourselves, and we need help from groups like this. I find I've, I've got a great deal of moral uplift by coming here. Meeting you, listening to the way you do it. And I don't see the problem now, it frightened me, the problem of declining memory, until I came here, and now I'm not frightened.
> Janet: You didn't accept it then before?
> Robert: Well I did accept it but it frightened me. Because I thought, well, I'm going mad, I'm going crazy. What am I going to be like in another five years? But now I realize that everybody is getting this problem.

Within psychotherapy process research, comments by patients that they are afraid of losing their mind are seen as markers of the early stages of assimilation, in which the problematic material surfaces in the form of unwanted thoughts. Robert's comments in session nine that at the start of the group he had thought that he was going mad or crazy suggest that the group had helped him to engage with feelings and beliefs that he had previously struggled to avoid. The growth of awareness of alternative voices that Robert's discourse suggests is not one in which a benign state of unawareness is supplanted by an affect laden state of emergent awareness, but rather a process in which the problematic voice becomes gradually more apparent. The warding off or suppression of this problematic voice is only achieved at the intra-psychic cost that Robert describes in extract 13 ('Well I did accept it but it frightened me. Because I thought, well, I'm going mad, I'm going crazy. What am I going to be like in another five years?').

The increase in levels of anxiety and depression across the course of the group shown by Robert is consistent with the APES model in which levels of affect rise until insight is established. It may be that for group participants such as Robert, who in the middle and latter stages of the group have begun to address painful and problematic issues such as their diagnosis, the 10-week limit to the group is too short. Had the group been able to continue, then possibly Robert would have been able to continue this process of integration, and, according to the assimilation model, at this point we would have expected his levels of affect to have declined. Although Robert continued to be supported through individual work by one of the facilitators after the end of the group, the ending of the group after 10 weeks may have been more emotionally painful for him than for other group members because it left too many feelings unresolved.

Extending the assimilation model

At present we have relatively little information as to the way in which people with dementia experience or understand their illness. We have even less evidence relating to the way in which people change over the course of their illness, or adjust to specific events, such as gaining a diagnosis, using day hospital care and so forth. Amongst the few models of this process of change that have emerged are those of Keady and Nolan (1994, 1995) who suggest a gradual process in which a person with dementia moves from slipping and suspecting that something is wrong, and then covering this up towards an end stage of disorganization, decline and death. Similarly Cohen, Kennedy and Eisdorfer (1984) also describe people with dementia as moving through an eight-stage process involving first denial, then a variety of emotional responses such as anger, guilt and sadness, towards a gradual separation from the self.

However, while such models are useful both in suggesting that change is possible, and in describing how people cope with the direct and indirect effects of their illness, they do not necessarily allow us to identify either blockages in this process, or ways in which others may facilitate such changes. The APES model, by contrast, describes a model of emotional processing based on a wide body of established psychotherapeutic practice. Although in this paper we have used the model to understand the development of awareness about the diagnosis of Alzheimer's disease, there are many other circumstances where it may inform clinical work. For people with dementia examples of problematic material may include bereavement, the acceptance of appropriate help and physical illnesses. Moreover individuals at different stages in the APES process may benefit from different forms of intervention: for instance where individuals have developed an understanding of their memory difficulties, it may be desirable to help them to develop a sense of control over their situation, perhaps through the creation of a living will. By contrast, at earlier stages in the process of assimilation, the APES model suggests that more exploratory processes to help to work through the person's emotional dilemmas may be more productive.

Conclusion

The research that has presented here has focussed largely on describing those changes that took place for one individual during the course of a 10-week psychotherapy group. As such this analysis is complementary to the data reported elsewhere (Cheston et al., 2003), which showed significant decreases in mean levels of depression and anxiety across 19 participants in group psychotherapy. This paper also supports Tom Kitwood's proposition that levels of awareness for people with Alzheimer's disease are dependent on the psychosocial context in which the individual is located (e.g., Kitwood, 1997). In Kitwood's terms within a benevolent social psychology, individuals with dementia may be able to approach their diagnosis, allow it to be relevant to them, and to accept it as part of them. Within cultures of care in which there is a malevolent social psychology no such change may be possible. Moreover, in the face of being positioned as incompetent, so individuals may angrily assert their competence and consequently be labelled as 'lacking in insight', 'in denial' or 'uncooperative'.

Robert could only change, we would argue, because he heard others speak the voices that he found difficulty in hearing. Yet the opportunity for people with Alzheimer's disease to talk about their memory difficulties, and to hear others talk about their experiences tend to be limited. In part this is because Alzheimer's disease and the other dementias are uniquely challenging. Part of this challenge for those of us who work with people with dementia is to address our own mortality, our own fears about ageing—to hear our own voices about what lies ahead. Unless these personal challenges are acknowledged, then it may be difficult to hear the voices of those we work with.

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