AIMS

◆ to promote opportunities for the exchange of knowledge and expertise between members;
◆ to promote a greater appreciation of psychological factors in ageing;
◆ to advise and participate in matters of teaching and training;
◆ to stimulate research and disseminate research findings;
◆ to act in an advisory capacity on issues relating to the well-being and provision for care for older people;
◆ to foster an exchange of information and ideas with other professional and voluntary groups.

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WELCOME TO THE Wessex Edition of the PSIGE newsletter.

First of all, where is Wessex? Does it really exist? Established in the sixth century, the kingdom of Wessex changed shape many times in its 300-year life. The name Wessex is short for West Saxony and at its largest, in King Alfred the Great’s time, this kingdom stretched from Cornwall to Kent. It was King Alfred’s resistance to the Vikings which eventually led to the emergence of the English State. (The statue of King Alfred in Winchester is shown on the front cover.) Since then Wessex has been recreated many times, most famously by Thomas Hardy in the 19th century. Hardy used Wessex as the setting for his poems and novels and a little known fact that you might like to store for future pub quizzes is that he also named his bad-tempered dog Wessex.

Nowadays, Wessex is defined in many different ways – using archaeological or historical sources, where the Wessex dialect was spoken or by Thomas Hardy’s map. Organisations bearing the name Wessex include counties as far ranging as Devon and Oxfordshire.

Wessex PSIGE was originally based on the Wessex NHS region, but with NHS reorganisations, the Wessex region has long since ceased to exist either as an NHS structure or for Clinical Psychology training purposes (there used to be a Wessex training scheme). Despite all the reorganisations, we have stayed together as the original Wessex PSIGE with our boundaries stretching from Swindon, Bath and Dorchester in the West to Portsmouth in the East and from Basingstoke in the North to Southampton and the Isle of Wight in the South. Unfortunately there are parts of this area that do not have an older adult psychology service and according to PSIGE manpower figures, we are well below average for psychologists per older adult population. We have about 16 paid-up PSIGE members and usually an attendance of eight to 10 at our quarterly meetings, which we hold in Salisbury.

We have had some very interesting presentations over the last year, three of which are included as articles in this edition: Liz Young’s presentation on borderline personality disorder in older adults, Laura Preston’s qualitative research into coping in early stage dementia and Paul Whitby’s paper on inpatient care. Most recently, Nicola Ford from East Dorset made us all envious with a description of her involvement in the ‘Distress and Well-being’ project. Developed by an independent charity, Hope and Care, who offer advocacy and support to people over 55, the project enabled Nicola to provide an exceptionally accessible, user-friendly and effective service to older adults with mild to moderate anxiety or depression.

Each year, we combine with the Southampton University Clinical Training Course to put on a workshop. This year Jason Hepple came to provide a workshop entitled ‘CAT and later life’. He gave a very absorbing introduction to CAT drawing on art and philosophy. For our next workshop, we are arranging for Mike Bird to visit us, while over here from Australia. The theme of his workshop will be psychosocial approaches to challenging behaviour.

I hope you enjoy this edition of the PSIGE newsletter. Have fun with the baby competition.

Ann Marshall
Wessex PSIGE convenor.
At the Committee’s strategy meeting last September, two of the objectives we set ourselves for this year focused on reviewing our links within the BPS/DCP and considering how we could engage more effectively with the wider political agenda. Although our quarterly meetings in London start at 11.00 a.m. and finish at 4.00 p.m. we struggle to get through the routine business, leaving little time for creative discussion. However, thanks to financial support from the DCP, we were able to buy in the services of an outside facilitator and 11 of us stayed on for an additional day following our meeting in April specifically to progress these objectives. It proved a very useful time for reflection and generated a number of ideas which we will be progressing over the next few months.

All full members will have received through the post notification of our forthcoming AGM and a nomination form for committee membership. Do please consider standing. As part of the day described above we agreed that, as committee members, we share a passion and commitment to older people and have fun working alongside likeminded people. Being on the committee provides the opportunity for individual learning as well as a chance to influence, create and encourage change. How can you resist?
Personality disorders in older people

Liz Young with Dr Laura Bocci

There has been some discussion recently about the issue of personality disorders (PD) in older people, whether this is an appropriate diagnosis for this age group, and indeed whether either the term or the diagnosis have any value. In this short review article, I want to look in general at these issues, the presentation of these kinds of problems among older people, particularly borderline personality disorder, and to raise for discussion how psychologists might usefully work with these difficulties. How much awareness is there amongst the older adults services of personality disorder, is there an ageism inherent in the lack of diagnosis in older people, and should we even use the term ‘personality disorder’?

Outline of personality disorder
PDs are said to arise where personality traits, the enduring patterns of perceiving and relating to the environment and the self (APA, 1994), are inflexible, maladaptive and cause significant distress or impairment (Himelick & Walsh, 2002). According to traditional clinical opinion, the severity of PD diminishes and disappears by middle or old age, and people with personality disorders cause less trouble for themselves, their families and their doctors as they reach middle and old age. However, there is sparse evidence for this view, and some recent research suggests rather that the changes and losses of old age may exacerbate existing PDs, or produce new difficulties in older age.

Borderline Personality Disorder (BPD) is characterised by patterns of impulsivity, mood, identity and interpersonal instability (Johnson, 1999). In younger adults, it is associated with impulsivity, self-injurious and parasuicidal behaviour, difficulty with emotional regulation and fear of abandonment. It is a disorder that evokes strong counter-transferential reactions in those who work with people experiencing it. There has been little consensus about the disorder in older adults, but those working with older people will be familiar with patients in long-term care environments who seem to both experience and create problems in the setting through being disruptive and demanding, and who find difficulty in adjusting to the routines set (Rosowsky & Gurian, 1992).

Prevalence and diagnosis
Estimates of prevalence of PD in the older adult population vary considerably according to the sample and diagnostic assessments used. A decline in the prevalence rates of PD among psychiatric outpatients (Molinari & Marmion, 1993) and inpatients (Kenan et al., 2000) has been reported whereas others report that personality disorders may continue through the lifespan and worsen with age (Siegel & Small, 1986). The only large-scale epidemiological study of PD reported that cluster B disorders (narcissistic, histrionic and borderline) show as a reverse J-shaped curve (Reich, Nduagube & Yates, 1988), where the core traits decline from mid-adulthood to about age 60 and then seem to increase in a small upturn (Rosowsky & Gurian, 1992). Meta-analysis of research suggests that BPD, in particular, is reported to be present in 1.4 per cent of people over 50 years (Abrams & Horowitz, 1999). The lack of consensus regarding prevalence is partly explained by the lack of consensus on how BPD presents in older adults. It has been suggested that some of the worst cases of BPD (about seven per cent) do not progress into old age due to successful suicide attempts (Howard & Bergman, 1993). However, the majority of younger BPD individuals do grow older, and
research is divided between suggesting that there is a remission or mellowing of symptoms in middle age (Himelick & Walsh, 2002, Kenan et al., 2000) and that symptoms do not remit but change with age (Rosowsky & Gurian, 1991; Zweig & Hillman, 1999).

But clearly, estimates of prevalence depend on diagnosis and the tools used. Existing scales used with the younger population are criticised for lacking reliability, (Clarkin, Speilman & Klausner, 1999), and for being insensitive to the features of BPD presentation in older age (Hill et al., 1998, Rosowsky & Gurian, 1991). In addition, the diagnosis of psychiatric and/or medical illness may overshadow and complicate the diagnosis of PD (Dougherty, 1999). Traditionally, clinicians have been found to diagnose fewer PDs in older adults, perhaps as a result of clinicians’ belief that PDs do not occur in old age, possibly an age-related diagnostic bias (Hillman et al., 1997). So prevalence rates may well be underestimated. In terms of the DSM, a study by Rosowsky and Gurian (1992) found that the only criteria on the DSM III-R that discriminated between older people with and without BPD were interpersonal relations, affect and anger, and insensitive criteria were found to be impulsiveness and identity disturbance. In summary, there appear to be features of ‘borderlineness’ that are constant and remain in older people – difficulty with social life, therapeutic relationships (splitting, etc.), unstable and intense personal relationships, affective instability and control of anger. It would appear that not all the criteria for BPD are appropriate and diagnostic in older people.

It seems that some of the features of BPD seem to persist, whilst others may become less apparent with age: self-mutilation, impulsivity, substance abuse, aspects of identity disturbance and paranoid ideation. (Hill et al., 1998). It may also be that because of psychosocial changes, the older person shows symptoms more congruent with their current context. For example, the impulsivity often shown by younger adults in this context may not be a feature with older people because of increased frailty, lack of access to risky situations, and less tolerance of alcohol or drugs. Instead, older people may show anorexia, polypharmacy, or non-compliance with or sabotage of medical care. The picture of unstable relationships seen in younger people may transmute into an older person being critical or demanding, creating splits among caregivers. Jason Hepple has produced a useful comparison of BPD features at young and older ages (see Table 1).

Discussion
So what then is it that we see in older people in our care? Are we seeing BPD and other PDs? It seems that there are three possible alternatives: firstly, that the disorder is lifelong, and unremitting, and that what is seen in old age is simply what has been there all the time. Secondly, this could be a new-onset disorder in old age. Thirdly, it may be that there is a PD at a younger age, which in midlife has been contained and managed by the structures and resources within marriage, children, work, etc., but which re-emerges in later life as these structures drop away, and other challenges in terms of ill health, disability and loss of independence become prominent. This third possibility has been termed ‘bound’ personality disorder (Rosowsky & Gurian 1991), and presented and modified by Hepple (2004) as follows:

Increased life events + reduced coping abilities = Unmasking of borderline traits

So the loss of partner, friends, job and financial status, social role, independence or cognitive ability, and perhaps reducing coping ability in terms of depression or cognitive impairment, could combine with pre-existing difficulties to produce PD-type symptoms. This last view seems to ring true for many people working in the older adult services. Most will be familiar with patients such as Mrs. D.
Dora D is a 77-year-old lady, a widow living in residential/nursing care. She has one daughter who lives locally, and does her best to visit regularly, despite the demands of family and work life. Another daughter died about ten years ago. Dora has had a somewhat unconventional life. She had a difficult childhood, with unstable parents who were unable to provide firm boundaries or unconditional love, and two marriages, neither of which were very satisfactory, even though each lasted more than 10 years, showing that Dora has had some success in forming and maintaining relationships. In her working life, Dora had a succession of jobs, interspersed with periods of being at home caring for her children. She has also been an amateur artist, and has shown and sold some of her paintings. Dora had a quite severe CVA about two years ago that has left her paralysed on one side, and she reports constant pain and shows signs of depression. In the nursing home, she is at times verbally aggressive to staff and can be physically aggressive too, throwing books and glasses at staff. She makes very frequent demands on staff, ringing the bell every few minutes for very minor needs such as having the TV channel changed. Staff have noticed that her demands increase when she is aware of another patient is in need or very ill. She is unco-operative with physical care, yet demands it at busy times. However, on a good day, she can be pleasant and entertaining, and seems to have a few favourites amongst the staff. But in recent weeks, Dora has also taken to ringing 999 on her mobile phone to summon an ambulance or police, and this has happened several times, day and night. Staff have become angry and hostile to Dora, and now she has been given notice to leave the home, so that her family is having to find other accommodation for her. It should be added that this is the third care home from which Dora has been given notice.

The home has asked for an assessment of Dora’s needs by the local mental health team, ostensibly to see if there is any way of modifying her behaviour to make it possible for her to stay, even though she has already been given notice to leave.

Following assessment, a formulation was arrived at which suggested that Dora was someone with a deep need for security and attention, based on her rather emotionally

Table 1: Comparison of BPD features at young and older ages (from Hepple et al., 2002).

<table>
<thead>
<tr>
<th>DSM IV trait</th>
<th>Differences in older people</th>
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<tr>
<td>Frantic efforts to avoid abandonment</td>
<td>Fear of institutionalisation, over-demanding of caregivers</td>
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<tr>
<td>Unstable relationships</td>
<td>Highly critical and demanding of caregivers (powerful splitting)</td>
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<tr>
<td>Unstable self-image</td>
<td>Lack of ability to engage in age-appropriate life-tasks</td>
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<tr>
<td>Impulsivity</td>
<td>Less recklessness</td>
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<tr>
<td>Self-harming behaviours</td>
<td>Less overt self-harm. More self-neglect, abuse of prescribed medication, somatisation,</td>
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<tr>
<td></td>
<td>food as control</td>
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<tr>
<td>Affective lability</td>
<td>Affective lability</td>
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<tr>
<td>Chronic feelings of emptiness</td>
<td>Hopeless resignation</td>
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<tr>
<td>Intense anger</td>
<td>Passive-aggressive</td>
</tr>
<tr>
<td>Transient paranoid or dissociative</td>
<td>Accusatory, critical</td>
</tr>
<tr>
<td>symptoms</td>
<td>Pseudodementia</td>
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</tbody>
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deprived early life. Following multiple physical, emotional and social losses, she had become angry and resentful, but was unable to express these feelings in an appropriate manner. She could no longer paint and had also, therefore, lost that means of expression, and was left feeling that the only form of expression and means of control over her life was by aggression to those around her. Her need for love seemed like a big hole inside, which could be temporarily filled by attention, but which emptied out quickly when she was alone, hence the repeated attempts to have company.

It was felt that Dora was not accessible or open to individual therapeutic approaches, and that working with the staff group to help them offer firm boundaries and structured care for Dora was the best route. Unfortunately, the home was unwilling or unable to implement any changes, and Dora was moved on. As a suitable home was not available, she was moved into a newly refurbished geriatric hospital ward, where she responded well to a strict timetable and a unified approach by staff. Working with members of the mental health team, staff were able to ensure firm boundaries and to implement an approach to Dora’s care which included some helpful and creative therapies, more social interaction and intellectual stimulation for Dora. To date, she is doing well on this regime.

**Conclusion**

It seems that these kinds of problems are relatively common conditions, although prevalence is hard to establish accurately. So how much awareness of personality disorder is there in the older adult mental health services? Is this something that workers recognise amongst their client group or caseload? Is the term ‘personality disorder’ one that is appropriate, or, being a slightly different disorder than presents in the younger age group, should we find another term to describe that seen in older people? And how should we be working with this type of problem – specialist sub-teams, specialist support for CMHTs and residential care homes? To quote NIMHE, ‘access to good support and supervision is essential, without this staff may experience burnout and exhaustion’. Few would argue that people with personality disorders are some of the hardest and most demanding clients to work with, having the capacity to raise levels of anxiety and negative feelings amongst staff, whether in residential care or in the community. Working successfully with these clients seems to involve the provision of clear boundaries and a unified approach, not an easy thing to provide when care is given by various different staff members. Perhaps there is a need to offer a greater degree of indirect work with homes and wards, working with the staff group to ensure containment and boundaries.

This has been a very speedy look at the whole issue of difficult mental health problems in older people. It would be interesting to hear more discussion of the issues, and to see further research in terms of diagnostic tools specifically for older people.

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References


UNDERSTANDING THE WAY that older people cope with dementia has important implications for the enhancement of psychological well-being and quality of life of this group of people. Research exploring individuals’ perspectives of coping with dementia is still in its very early stages: there are few studies directly investigating this area, in contrast to the relatively large body of research pertaining to the coping of supporters of people with dementia. This may be due to the ethical complexities and personal involvement required on the part of the researcher to engage individuals with dementia in such research (also see Wilkinson 2000). A few of these have explored sense of self, or identity, in relation to coping in people with dementia (Clare, 2002; Pearce, Clare & Pistrang, 2002; Harris & Sterin, 1999). For example, Clare (2002) found that conflict was experienced between wanting to deny/minimise changes (self-protective tendencies, such as ‘holding on’ and compensating) and simultaneously acknowledge, accept and integrate changes with identity (integrative tendencies, such as developing a fighting spirit and coming to terms with difficulties). Similarly, Pearce, Clare and Pistrang (2002) found that sense of self was managed by an ongoing process that combined maintaining an ongoing sense of self and re-appraising/reconstructing a new sense of self.

This article presents findings from a more comprehensive study of experiences of coping with dementia. It was intended to elicit the views of people with mild dementia about the range of ways in which they coped with various difficulties faced, without imposing preconceptions about coping challenges, or the nature of coping. Unlike most previous studies, no explicit focus on identity was intended when conducting interviews, but this spontaneously emerged as a major theme in people’s accounts of coping with dementia.

Method
Participants
Twelve people with mild dementia (MMSE 19–28) were recruited via a Community Mental Health Team for the study. Participants’ ages ranged from 58 to 81 (mean 71.08, SD 7.44) years; five were female and seven male. Eleven participants were taking acetylcholinesterase-inhibiting medication. All participants were of white ethnic origin; 11 were British, and one man was European (but had lived in England for 20 years). All had been told of their diagnosis of dementia, which occurred between two and 20 months prior to participation: nine had been diagnosed with Alzheimer’s disease (AD), three with vascular dementia.

Procedure
Questions for the interview schedule were designed to be open-ended, and no presup-
positions were made as to what constituted coping or managing difficulties. The first two interviews were initially considered as pilots, but later included in the study due to the minimal changes made to the procedure following piloting.

Interviews lasted between 40 minutes and three hours (length was determined by the interviewee), and were tape-recorded. The semi-structured interview prompted a comprehensive exploration of the range of challenges participants faced as a result of dementia (e.g. ‘Has there been anything difficult that you have had to manage/deal with/cope with?’ ‘Could you tell me a bit more about this?’ ‘What separates a good day from a bad day?’), and the ways in which they coped with these (e.g. ‘So how do you think you coped with this?’/’What helped you to manage this?’/’How did you react?’). Towards the end of the interview, participants were invited to consider what advice they would give to someone who had recently been diagnosed with similar difficulties to themselves. The schedule was designed to be flexible, allowing unanticipated topics or themes related to coping to be discussed (see Smith, 2004). Interviewers also drew upon clinical interviewing skills to provide more specific prompts.

Data management and analysis
The tape-recorded interviews were transcribed by the interviewers according to clearly established guidelines (Silverman, 2001). Analysis of interviews was based on the IPA procedure outlined by Smith, Jarman and Osborn (1999), which aims to provide a comprehensive account of shared themes that are representative of the original texts. The analysis process involved describing and interpreting the meaning of all relevant information from each transcript, and grouping these meanings into thematic clusters, through an iterative process of reading and re-reading. Once this had been completed for each transcript, a shared theme analysis was conducted. Similar or related themes were grouped, to produce shared theme clusters. This resulted in hierarchical structure of themes that represented all 12 accounts. The analysis was considered complete when it resulted in a coherent, comprehensive account of coping in dementia, as understood and conveyed by participants, which included interpretations on a number of levels (Smith, 2004). The excerpts contributing to each theme were studied again to devise a full verbatim account of the content of each theme. Where there was diversity within sub-themes, this was described in full. Measures were taken to ensure quality of results (see Elliott, Fischer & Rennie, 1999; and Yardley, 2000).

Validity checks
Discussion between the authors, peer review and consultation with experts in IPA were used extensively throughout the analysis to provide validity checks and ensure the comprehensiveness of interpretations, resulting in minor revisions throughout the process. In particular, these were used to reflect upon and limit the effects of the personal biases of the first author, who carried out the analysis. A formal check of the validity of the analysis and interpretation of participants’ accounts was carried out by the second interviewer (who had not had any input into the analysis process beyond transcription) and a second independent person with knowledge of IPA. All original excerpts contributing to five of the sub-themes (chosen randomly) were closely scrutinised, and the ‘paper trail’ through the stages of analysis followed for verification. No changes were made as a result of this. The resultant analysis was validated as being free of logical contradictions, with a sensible theme structure that had a coherent unity (Smith, 2004).

Results
‘Managing identity in relation to dementia’ was one of three major themes to emerge from the analysis of participants’ accounts. Managing identity was repeatedly referred to as not only a challenge of dementia, but also
a way of managing dementia by protecting the participants’ sense of identity. The sense of identity, or self (‘who I am/me’), was referred to in terms of continuity, integration and perception of self. It had sub-themes of continuity between the past and present self, discontinuity between the past and present self, integration of dementia, lack of integration of dementia, self as able/valued and self as substandard, which are described below.

**Continuity between the Past and Present Self**
Participants referred to an ongoing use of skills, enjoyment in the same activities, and/or continuity of personal characteristics (characterised by, ‘I still’/’I never was’).

‘When I come to write a birthday card for the family, [name of husband] does a lot of the kind of writing. But when it’s for the family I really like to write it. I love choosing cards that I, you know … It’s always been part of my life is choosing the card for the person’ *(participant had previously spoken about difficulty with handwriting)*. (P211, 10–16)

There was evidence of both a natural sense of continuity, and an ongoing effort to maintain a sense of continuity in some areas. Participants spoke of pre-existing skills (e.g. organisation, having a routine) becoming more valuable. Some talked about or demonstrated focusing on characteristics and roles that were unaffected by dementia. Continuity was achieved by both integrating dementia with the self and/or viewing dementia as detached from the self (see ‘Integration of dementia’ and ‘Lack of integration of dementia’).

**Discontinuity between the Past and Present Self**
Interviewees referred to perceiving changes resulting from their experience of dementia as discontinuous with their prior sense of self. This involved acknowledgement of a decrease in valued abilities and characteristics.

‘…but it’s not as good as it should be. It’s not as good as it used to be, therefore, it irritates from that point of view … not quick enough’ *(participant talking about his ability to think logically)*. (P207, 873–878)

However, some participants’ also recognised positive new skills and/or characteristics, developed as a result of their experience with dementia (see ‘Being positive’).

**Integration of dementia**
Some participants demonstrated having integrated experiences of dementia with their pre-existing sense of identity. This was evident from participants relating current difficulties to pre-existing characteristics or perceived areas of weakness; making direct references to dementia being ‘my problem’ or ‘part of me’; and/or acknowledging dementia as one of the different aspects of the self.

‘…and when I go there, I go to be a woman. It’s the women’s group. It’s not like when I go to the memory club to be, um, well to be with other people with Alzheimer’s. Which is good for me as well. I go there as someone who has Alzheimer’s if you, um [pause]. It’s the different bits of me at these places, um [pause]. It’s all me, but I’m being most conscious of the woman bit with the women and the Alzheimer’s bit at the club.’ *(P211, 591–604)*

**Lack of integration of dementia**
Others indicated that they did not relate dementia to their identity. There were descriptions of dementia as a series of highly unfamiliar, and sometimes traumatic, episodes. There was also evidence of denial of having dementia; and of dissociation and/or minimisation of frightening or serious episodes, whilst less serious episodes had been accepted and integrated.

‘But I knew exactly where I was at and it hasn’t happened since … I was petrified … it made me think of how people that really lose their memory,
because that’s just what I call a blip wasn’t it. It must be terrible’ (participant talking about becoming disorientated). (P202, 449–457)

Some participants spoke of difficulties accepting and integrating their own acknowledgement of difficulties.

“Yes, I think I start opening cupboards, and then I stop and think. And I think it’s partly because my, my [pause]. My brain understands the um, oh, [pause]. My brain refuses to accept the idea that my thinking processes have slowed down [pause]. …And it, it’s as if, if I give it a bit more thought I’d get it right the first time, but I don’t like the idea of accepting the fact that my thought process is no longer as efficient as it used to be.’ (P203, 61–69)

Self as able/valued

Many people repeatedly referred to positive aspects of the self through reference to skills, achievements, characteristics and others’ perceptions of them. There were many examples of this directly proceeding talk about ‘inabilities’ or difficulties. One participant explicitly commented on the importance of positive sources of esteem in the context of what she was unable to do.

‘…is another big lift when you think there are so many things that I just can’t do’ (participant referring to newly-acquired skills in alternative therapies). (P211, 157–159)

Participants spoke of positive aspects of both the past and present self. Many asserted identities as ‘helpers’, and were eager to aid others by taking part in the research. A number of participants commented that their abilities were masked by the challenges of dementia. In the following example, the participant described how he was able to answer the question, but could not access the words from his memory long enough to communicate them.

‘It was something [pause]. It was something that you asked me, something you asked me. Instantly the answer is formulated in the brain, and. Before I could even answer, put it into words that you could hear, I then knew I’d lost the first word of what I wanted to say.’ (P201, 44–49)

The only positive sense of self that emerged from the accounts of a few participants took the form of assertions against the negative positioning of others, or the acknowledgement of an absence of negatives.

‘So I haven’t wasted your time, then.’ (P212, 444)

Self as substandard

A majority of participants (half of whom also asserted the self as positive) gave frequent indications of feeling that they were ‘substandard’, or not good enough, in comparison with other people and/or the past self. Participants indicated perceiving themselves as silly, stupid, daft or weak as a result of dementia. There was also evidence of self-criticism and self-blame. Some people spoke of the negative identities ascribed to them as a result of dementia, such as being disabled, a child, stupid, or frightening. There were also indications of participants feeling insane or ‘round the twist’.

‘And she treated me like I was a little girl.’ (P212, 108)

All participants engaged well in the interviews, providing relevant, coherent and detailed accounts related to coping in dementia. However, the risk that some participants took in volunteering to engage in the research was clear in some cases, through anxieties voiced about not being able to articulate sufficiently well, or of contributions not being useful or ‘good enough’. These were balanced by motivations to take part. All participants commented that they had enjoyed and/or benefited from the process of the interview. They particularly commented on having had the opportunity to reflect on experiences and speak openly, and to be useful in contributing to the research. One participant contrasted this to his experiences of dementia, which he perceived as useless and
destructive. There was evidence in at least three interviews of people further developing their understandings and viewpoints as the interview progressed (see Kvale, 1996).

**Discussion**

Unlike previous studies investigating identity in coping with dementia (e.g. Clare, 2002), the larger study from which these results are derived did not specifically aim to investigate sense of identity in relation to coping in dementia. Identity spontaneously emerged from participants’ accounts in relation to coping, highlighting its centrality in relation to the coping processes of people with mild dementia.

Overall, managing identity can be viewed as a something with which people with dementia have to cope. However, accounts of coping suggest that focussing on identity in these ways also provides a means of actively managing dementia. For some people, their lack of integration of the dementia with their identity was a source of difficulty, while for others not integrating it was a means of protecting their prior, more positive sense of self. For yet others integrating the dementia was a way of coping. For some participants, ‘discontinuity between past and present self’ involved the development of new skills and ways of being. This can also be considered as coping, in terms of creating compensatory sources of meaning and positive self-esteem.

It is interesting to note how participants who contributed to ‘self as substandard’ also contributed to ‘self as able/valued’. It is possible that identity management involves actively compensating for or counteracting a negative sense of self resulting from experiences of dementia, by acknowledging more positive aspects of identity. Charmaz (1987) proposed that individuals with chronic illness attempt to salvage a sense of self by maintaining some positive past images in the face of present adverse circumstances, as is evident here. Previous studies have also highlighted the role of both the past and present self in dementia (e.g. Kemp, 2003; Harris & Sterin, 1999).

The results of this study can be linked to those of previous studies on coping with dementia and aspects of the broader literature on coping. For example, sub-themes of continuity and discontinuity relate to Pearce, Clare and Pistrang’s (2001) concepts of maintaining an ongoing sense of self and re-appraising/reconstructing a new sense of self. Themes regarding continuity/discontinuity and the integration of dementia with the self are also supported by Charmaz’s (1987) conceptions of people faced by chronic illness re-evaluating their previous identities. Literature from Leventhal and Nerenz (1980) also offers parallels to integration and lack of integration of dementia with the self, with reference to fusion with or compartmentalisation of chronic illness.

With reference to the literature on coping in later life, findings indicate that managing the self (e.g. Erikson, Erikson & Kivnick, 1986) continue to have relevance to older people when they are faced with dementia.

The present study represents exploratory research, which is intended to provide a basis from which further research can be developed. Further research is needed to validate findings and investigate how well these themes represent coping in people in later stages of dementia, how identity in relation to coping changes over time, and whether the sub-themes can be generalised to people with different demographic characteristics. It would be useful to extend findings by conducting longitudinal case studies (e.g. see Mills, 1997) to explore how identity and coping changes as dementia progresses.

Although further research is required to validate findings, the present study has potential implications when considering the enhancement of psychological well-being and quality of life of individuals. Findings from this study suggest a number of potential psychological interventions for people with dementia. These include cognitive approaches focussing on identity issues, such as helping individuals to integrate dementia
with their sense of identity, reflect on issues of continuity, and promote more positive self-esteem (although there are likely to be individual differences in terms of what is most helpful). It has been confirmed that people with dementia can provide rich accounts of their experiences in engaging in collaborative, reciprocal research. Ethical issues need not pose a barrier to engaging people with dementia in research; furthermore, it could be considered unethical to exclude them. The abilities and strengths of people with dementia have been highlighted, contrary to the assumptions often made about this group of people. It is important that such research is also communicated at a wider, societal level, to help develop more accurate understandings of dementia. Beginning to address these attitudes could make a significant difference as it has been indicated, both here and in previous research, that the attitudes and actions of others in response to dementia have a major impact on self-esteem and well-being (see Kitwood, 1993; McGregor & Bell, 1993).

Acknowledgements
The authors would like to acknowledge the personal contributions that individual participants made to make this research possible. It is hoped that individuals’ expressed desires to be helpful to others in some way, and to create something constructive from their negative and often destructive experiences, are realised.

We would also like to thank Becky Barrett, for her contribution in carrying out and transcribing four of the interviews, and performing the formal validity check on the findings; and Dr Maureen Gupta, for her help recruiting participants.

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THE DIAGNOSIS OF dementia is being made earlier than ever, thus increasing the likelihood that an individual will be diagnosed at a time in their illness when they may be acutely aware of their difficulties. Research suggests that people with dementia tend towards either a ‘self-protective way’ of coping in that they deny or minimise the changes to themselves, or an ‘integrative’ way of coping in that they acknowledge the changes and seek to integrate them into their self-concept (Clare, 2001). Kitwood (1990) has emphasised the importance of the social environment in influencing how well people cope with a dementing illness. This suggests that a safe, empathic environment may encourage people to feel able to talk about and acknowledge their losses (Bender & Cheston, 1997). Such an environment can be provided by a support group. There have been a number of reports in the literature of support groups for people with early dementia (e.g. Haggerty, 1990; Peach & Duff, 1991; Labarge & Trtanj, 1995; Synder et al., 1995; Yale, 1995; Cheston, 2000). In a support group, a mixture of people who possess different ways of coping can help one another to find a balance between denying the illness on the one hand and being overwhelmed by it on the other (Cheston et al., 2003).

However, as people are being diagnosed with dementia at an increasingly early stage, and being maintained at this stage for considerable periods with anti-dementia medications, their need may be for support for a longer period of time than has traditionally been offered in group interventions. A few reported groups have run on a long-term basis (e.g. Haggerty, 1990; Peach & Duff, 1991) but there has been little formal evaluation.

In any support group, factors such as universality (feeling you are not the only one) and being accepted by a group are very therapeutic (Yalom, 1985; Nichols & Jenkinson, 1991) and it has been these factors which have been found to be most beneficial in dementia support groups (Peach & Duff, 1991; Labarge & Trtanj, 1995; Yale 1995; Hawkins & Eagger, 1999; Thrower, 1998; Scarboro, 2000). Clinical experience suggests, however, that in groups lasting only eight weeks, group members may only just begin to get to know each other and thus reach a high level of disclosure as the group is coming to an end. By contrast, in longer-term groups (lasting several months or more) people start to meet socially, outside the group to support one another. This article reports the evaluation of a 24-week support group for people with recently diagnosed dementia.

Method
Participants
Participants were referred to the group by a psychiatrist based in a Memory Clinic which was part of a Community Mental Health Team for Older Adults. They had all been given a diagnosis of dementia and had demonstrated some insight into their memory loss. They were orientated for time and place, could focus on the topic being discussed and, after a full explanation of what the group entailed, gave informed consent to join the group.

The intervention
The group ran weekly for one and a quarter hours, starting with refreshments. The group leaders were a clinical psychologist with more than five years experience of running...
dementia support groups and a community psychiatric nurse who specialised in dementia and had previously run one eight week dementia support group.

At the first session, the aims of the group and group rules such as confidentiality were discussed. The agreed aims were for people to meet others with memory problems and to share ways of coping. The group members were then encouraged to talk about the kind of problems they experienced with their memory and the ways in which their memories still worked well, e.g. for past memories and some skills. Participants were then shown a simplified model of memory and memory processing and strategies based on this model for managing memory difficulties were discussed.

Subsequent sessions focussed on emotional reactions, anxiety management, coping with social situations, the effects of dementia on relationships and maintaining skills and self-esteem. During the early stages of the group, the sessions were structured by the group leaders. Increasingly, however, the sessions became less structured and were dominated by participants raising their own concerns or ideas for discussion. The role of group leaders became more facilitative as a result. One of the group leaders took notes of the main issues discussed at each session and these were typed and given to participants the following week to aid continuity and also so that they could show relatives what they were discussing in the group if they wished. No confidential information was disclosed in these notes.

Evaluation
The group members were assessed at eight weeks from the start of the group and at 20 weeks (four weeks before the end of the group so as to avoid the possible confounding effects of the ending of the group on efficacy measures). Initial administration was carried out by the group leaders. Subsequent assessments and interviews were carried out by an assistant psychologist. The assistant also observed the groups but did not take part in the discussions or act as a group leader.

The outcome of the group was assessed in four ways: interviews with participants and carers; observation of the sessions; rating of the importance of therapeutic factors and mood scales.

1. Structured interviews
Participants and their carers (where available) were interviewed about their evaluation of the group at eight and 20 weeks. The interview included questions about what participants remembered from the group, whether it helped in how they coped and anything they did not like about the group.

2. Observation of the group sessions
An assistant psychologist observed each group noting non-verbal behaviour. The sessions were also audio-recorded. Each session was transcribed and a thematic analysis conducted. For each relevant statement or behaviour, themes and functions of that behaviour were interpreted. Once this was complete for all statements, common or frequent sub-themes were derived. These were then grouped into major themes. The original statements were then re-examined in chronological order, and, within the themes, similarities, differences and trends were extracted.

3. Ratings of therapeutic factors
Yalom (1985) has proposed 11 therapeutic factors to be important features of the success of group psychotherapy. Eight of these were selected by the authors as they were considered to be the most relevant to dementia support groups. These were: Information from group leaders; Being part of a group; Meeting others with similar problems; The opportunity to talk about my feelings; The opportunity to be open about personal matters; Learning ways of coping from other group
members; Having the chance to give support to other group members; and, Getting hope from seeing that other people could cope with their problems. Participants, carers and group leaders/observer were asked to rank these factors in order of helpfulness, with 1 = most helpful and 8 = least helpful. The eight factors were presented on separate strips of card so that they could be sorted into order physically. The median rank was then calculated for each of the three groups of raters.

4. Mood scales
The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) was completed with the participants and the Cornell Scale for Depression (Alexopoulos et al., 1988) and the Rating scale for Anxiety in Dementia (Shankar et al., 1999) were completed with both participants and carers (where available). All measures were administered before the group, after eight and 20 weeks.

Results
Five participants attended Session 1. A further four joined at sessions four, 11, 13 and 18 respectively. Six were men and three women. Six were living with their spouse, one with a daughter and two alone. Participants ranged in age from 58 to 81 (M = 71.7, SD = 6.7). Seven had been diagnosed with Alzheimer’s dementia and two with vascular dementia. Mini-Mental State Examination scores at the time of referral ranged from 22 to 28 (M = 26.0, SD = 1.9). All participants were taking an anti-dementia medication: five were taking Donepezil® and four Galantamine®. Five participants were also taking anti-depressant medication, but had started this at least three months before the start of the group and were on stable doses.

1. Structured interviews
Eight week assessment
Six participants were interviewed at the eight week assessment and four carers (one person lived alone and had no other carer who could comment and one carer did not want to be interviewed).

Three people said that they liked meeting other people with similar problems; one person said ‘It is a nice group, but I don’t know what it is for’ and one said he found the company helpful. One gentleman said he wasn’t sure how much the group applied to him. The participants did not mention any specific coping strategies which they used as a result of attending the group – some were using memory aids but had been using these before the group. However, three people mentioned that the group helped them to worry less or accept the problems more.

When asked about things they did not like, the only comment was from one person who said he had found it difficult to talk in a group initially but this had improved.

All the participants described the atmosphere in the group and the group leaders as ‘nice’, ‘friendly’ or having ‘an ideal approach’.

Of the carers, one reported that her father had become easier to talk to since starting the group ‘more open with the family’ and another daughter said she found the notes useful for prompting discussion with her father. One carer said that her husband ‘has a lovely time and comes home in a good mood’ and described the notes as interesting and well-written. However, the carer of the gentleman who was not sure if the group applied to him, felt that her husband left feeling depressed and said she felt the notes were not sufficiently detailed.

20-week assessment
Eight participants completed the 20-week assessment – three people had joined the group after the eight week assessment and one of the original members had become too ill to continue attending.

As at the eight-week assessment, the most common reason for finding the group helpful was meeting other people with the same problems (four people made explicit
comments about this such as ‘helps me cope by knowing there are others’; ‘I feel I am not alone’). However, compared with the eight week assessment, there were more detailed comments about ways in which the group had helped: ‘It gets you out meeting people, you can talk about problems’; ‘I can get tips and make suggestions, it has helped my general state of mind’. Additionally several people mentioned using memory aids and strategies as a result of the group: ‘I use associations’; ‘tips on learning names’; ‘writing things down’; ‘the group definitely makes you think, practising associations is helpful’; ‘hints to remember names is helpful, now I try and listen and concentrate.’

At the 20-week assessment, the participants were asked for thoughts and reflections on what the group had meant to them: ‘I know help is there if I need it’; ‘the group has helped me to understand what I was going through and what was happening’; ‘it gives me something to look forward to and makes me feel better about myself’; ‘it means a lot, I live alone and look forward to meeting other people, I would be sorry if it stopped’; ‘a place where I can go where people understand my problems’; ‘it is important and semi-comforting to think it is a common problem, if there was no such thing as the group, we would be all be worse off’.

When asked about unhelpful aspects of the group, the main comments were from the youngest and most active members of the group (one was still working) ‘I feel bad for the others in the group and it is frightening to think about losing your ability to judge things’; ‘it’s less interesting if the same questions come up each time’; and ‘I find it interesting to hear what others have to say – some I can relate to and some I can’t – too much time is spent on what group members have done that week, they do not have the full life that I have’. One other person also commented that some people did not talk and contribute enough. Finally, the gentleman who said at the eight week assessment that he felt uncomfortable speaking in a group reported this again at the final assessment.

Comments from carers were very similar to those of the participants: ‘The group makes her feel that she is not alone, she sees other who are worse’; ‘it helps to have someone to check things with’; ‘the group is a good idea’; ‘its very positive’. The two carers of the younger, more active group members reflected their relatives’ concerns: They had attended a carers’ group and found it frightening to hear about people who were worse off and to think about the future. However, a carer of an older group member who had also attended the carers’ group said he would like to know more about the prognosis.

2. Observations of the group sessions

Themes from the transcript

The main themes which emerged in the initial six to eight weeks of the group were: cognitive deterioration, loss of abilities, reactions of others both to the diagnosis and to problems caused by the disease; impact of the illness on family members; protective behaviour of family members; coping by being open with others; medication and causes of dementia.

Changes in themes

When participants discussed changes in themselves in the first seven weeks of the study period, the statements generally regarded negative changes including deterioration of memory, lack of time awareness, difficulty adapting to change, poor motivation and resulting reduction in perceived usefulness and organisation. After Week 7, negative statements about changes were balanced in quantity by positive changes experienced, for example, re-starting activities or maintaining cognitive ability. From the beginning of the group, it was evident that participants felt that remembering other people’s names was an important part of belonging to the group and it was, therefore, decided to incorporate a name learning exercise over the weeks both to assist with this and demonstrate the points made about memory in the early sessions. By
the end of the group, everybody had learnt everybody else’s name and gained a great sense of achievement from this. Statements regarding identity were reasonably uncommon but when they were made, they were generally positive throughout the study period: e.g. a comment in Week 3, ‘I am a strong person and I thought ‘I am not going to let this get to me’

Statements about other people’s reactions were generally more emotionally negative as time progressed. Additionally, after Week 6, statements regarding other people were less likely to be concerned with how the behaviour of others affected the individual, and more likely to reflect on how the behaviour of the individual affected others. For example, in Week 4, one participant said ‘My youngest brother is never ill and is not very tolerant with me’, while in Week 9, another participant commented ‘... being inadequate and being angry with myself that I left it all (for her) to deal with’.

With factual issues (medication, explanations for memory problems, and specifically why these individuals had been affected), two separate changes were observed around Week 15 of the study period. Firstly, questions were less likely to be directed to the staff present and more commonly directed to and answered by the group members themselves. For example, one group member explained in Week 20 ‘You will find the article in that Which magazine, it has got all about (memory problems) and what they can do to help’. A second observation was that, initially, group members discussed the immediate future: e.g. ‘Is this (group) to a view of getting back to normal? (Week 9), but after Week 15, questions and observations were focussed on more distant future and ways to help forthcoming generations, for example by taking part in research.

Statements focussed on worries and anxieties increased in quantity from Week 1 to Week 7, where after they stabilised. Constant themes included worrying about failure, cognitive deterioration, and the impact on the family; in terms of both practical limitations and also causing anxiety to family members.

Conversation regarding loss focussed initially on abilities and roles, e.g. ‘my memory used to be very good – my boss used to rely on me for all his appointments’. After Week 15, statements were more directed towards interpersonal and social losses. For example, ‘We are a big family and they will all talk at the same time, they will all remember but I can’t do that any more’. Other social aspects of loss include losing touch with friends and having difficulty in maintaining conversation.

Throughout the group, the participants made empathic and encouraging comments to one another and emphasised, similarities between themselves and their problems. Statements regarding differences between participants were typically concerned with situational differences as opposed to differences in personality or in problems experienced. Problem-solving and brainstorming solutions among the participants occurred from Week 5 and statements reflecting group cohesion and evaluation, which were universally positive, increased throughout the study period such as ‘it is good that we are all the same’ and ‘I like to know that I am not the only one’.

Finally, statements regarding coping methods changed throughout the study period. In the first 10 weeks, different suggestions were made for methods of coping; including writing things down, using diaries and calendars, distraction, organisation, humour and being open. These suggestions were evaluated both positively and negatively, but negative evaluations reduced after 10 weeks. Coping suggestions also changed from being mainly practical to more concerned with attitude and cognitive methods e.g. comment in Week 17 ‘And so what? You can’t remember somebody’s name ... big deal’

3. Ratings of therapeutic factors

‘Being part of a group’ was rated as the most helpful factor by the group members. ‘Infor-
Information from group leaders and ‘Meeting others with similar problems’ were placed in the three most helpful factors by group members and group leaders. Carers rated ‘Meeting others with similar problems’ and ‘Learning ways of coping from other group members’ jointly as the third most helpful factors (see Table 1 above).

### Table 1: Median rank for each therapeutic factor for each group of raters.

<table>
<thead>
<tr>
<th>Therapeutic factor</th>
<th>Group members</th>
<th>Group leaders/observer</th>
<th>Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being part of a group</td>
<td>1.5</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Information from group leaders</td>
<td>2.5</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Meeting others with similar problems</td>
<td>3</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>The opportunity to talk about my feelings</td>
<td>4</td>
<td>5.5</td>
<td>6</td>
</tr>
<tr>
<td>The opportunity to be open about personal matters</td>
<td>5</td>
<td>7.5</td>
<td>7</td>
</tr>
<tr>
<td>Learning ways of coping from other group members</td>
<td>6</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Having the chance to give support to other group members</td>
<td>7</td>
<td>6.5</td>
<td>6</td>
</tr>
<tr>
<td>Getting hope from seeing that other people could cope with their problems</td>
<td>7</td>
<td>7.5</td>
<td>7</td>
</tr>
</tbody>
</table>

*Note: Median ranks, 1 = most helpful; 8 = least helpful*

### 4. Mood Scales

Because of the numbers of missing variables, inferential statistical analysis was not appropriate. However, an individual differences analysis was conducted using Reliable Change (Jacobson & Truax, 1991) for each of Baseline to Week 8 and Baseline to Week 20 change comparisons using published values of reliability for each measure and the SD from the baseline assessment. Change, up or down, greater than the Reliable Change Criterion for each measure should be regarded as reliable.

### Table 2: Mood data (N=9).

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>Week 8</th>
<th>Week 20</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Anxiety and Depression Scale</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>6.7 (6.7), 0-16¹</td>
<td>5.4 (4.4), 1-13</td>
<td>6.1 (3.6), 0-12²</td>
</tr>
<tr>
<td>Depression</td>
<td>7.3 (2.7), 3-10²</td>
<td>5.8 (3.7), 1-14</td>
<td>5.3 (4.1), 2-13²</td>
</tr>
<tr>
<td>Cornell Scale for Depression</td>
<td>9.0 (1.7), 7-11¹</td>
<td>8.4 (3.9), 2-13</td>
<td>9.3 (4.6), 2-17²</td>
</tr>
<tr>
<td>Rating Anxiety in Dementia (RAID)</td>
<td>10.3 (4.4), 3-15¹</td>
<td>11.1 (5.9), 5-21</td>
<td>11.4 (5.7), 1-18²</td>
</tr>
</tbody>
</table>

*Note: ¹ is N = 6; ² is N = 8; ³ is N = 7.*
Of the seven participants for whom repeated test results were available on at least one of the four measures, significant improvements were shown only on the HADS Depression sub-scale in three different participants at Week 8 for one, and at Week 20 for two others. Reliable decline in mood scores was also found in at least one measure in six of seven participants. It should be noted, however, that for two of six participants showing significant decline in mood at Week 8, mood levels had either returned to baseline or reliably improved by Week 20. Furthermore, there was also a degree of inconsistency between the numbers of participants showing change depending on whether the measure was rated by the participant alone or the carer also contributed to the scores. Only on one participant rated measure was reliable improvement detected.

### Discussion

The main aim of the study was to look at whether people in the early stage of dementia benefited from a long-term support group rather than just an eight-week group. From the participants’ and carers’ evaluations, some benefits were clear from the longer period: the participants were able to describe more ways in which the group helped them to cope, both with memory strategies and in dealing with emotional aspects. The transcript analysis showed that in the group participants became more positive about using strategies for coping, group cohesion increased, they started to help each other to problem-solve, relied less on the group leaders and talked more about their social relationships and their concerns about the effect of their illness on their families. Being part of a group and meeting others with similar problems were seen as important factors by the participants, carers and the group leaders, although information from the group leaders was also seen as very important by the participants and carers.

Although the qualitative evaluation showed that most people found the group beneficial, there were some negative aspects such as anxiety about speaking in a group and concerns about seeing people who were worse off. As far as possible, people were put in the group who were at a very similar stage, although inevitably there were some differences in age and ability. Not all of the more able people saw the latter as a problem. For some, feeling that there were others worse off and that they could help them was reported as a positive.

### Table 3: Number of participants showing reliable change, either better or worse, for each measure at Week 8 and at Week 20 by comparison with Baseline.

<table>
<thead>
<tr>
<th>Measure Change</th>
<th>Reliable Week 8 – Baseline</th>
<th>Week 20 – Baseline</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 7 criterion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant rated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>4.9</td>
<td>0</td>
</tr>
<tr>
<td>Depression</td>
<td>2.4</td>
<td>1</td>
</tr>
<tr>
<td>Participant and carer rated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cornell Scale for Depression</td>
<td>1.9</td>
<td>0</td>
</tr>
<tr>
<td>Rating Anxiety in Dementia (RAID)</td>
<td>4.9</td>
<td>0</td>
</tr>
</tbody>
</table>

*Note: Participants may show change on more than one measure.*
The benefits shown in the interviews and session transcripts were not clearly matched by the mood scores for the whole group. For some individuals there were improvements in mood. Of the seven participants for whom repeated data were available, 43 per cent showed reliable improvements in HADS depression scores either at Week 8 or 20. Even in those individuals who showed decline at Week 8, however, one-third recovered or improved reliably by Week 20. This finding was in the context of increasing physical problems in three participants which appeared to contribute to worsening mood, despite the group. Further more it is difficult to know how accurately the participant’s mood was reflected by the measures as there was generally poor agreement between the measures completed by just the participants and those that also involved the carer.

As the study was an evaluation of clinical practice and not a controlled study, it was not possible to make comparisons with people who did not attend a group or who attended a purely social group. Furthermore, the group was open-ended to avoid anyone having a long wait to join a group (and it is possible that established group members can help new members), but there may have been different results if a closed group had been evaluated.

Acknowledgement
Thanks to Rick Cheston for his help in planning this study.

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References

A long-term support group for people in the early stage of dementia

PSIGE Newsletter, No. 90, July 2005 23


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The Association for Psychoanalytic Psychotherapy in the NHS (APP) and the Tavistock Clinic announce a one-day conference

‘War, Survival and Remembrance: Memories and meaning for older people’

Tuesday 27 September 2005
The Imperial War Museum, Manchester.

The conference programme will also include film presentations being shown as part of the Museum’s own programme of events including Children and War, Why War? and Weapons of War?

For further information contact Annabel Thomas, APP Conference Administrator, PO Box 707, Gerrards Cross, Bucks SL9 0XS.

Tel/Fax: 01494 581539 or e-mail: app@athomas99.freeserve.co.uk.

Or view the APP website: www.app-nhs.org.uk.
The Dementia Voice Group Psychotherapy project

Richard Cheston

The DEMENTIA VOICE GROUP PSYCHOTHERAPY project was an 18-month long project funded by a grant from the Mental Health Foundation and a smaller grant from Avon and Wiltshire Mental Health Partnership. The project itself was a collaboration between myself and Jane Gilliard and Kerry Jones, from Dementia Voice, the South-West Regional Dementia Resource centre.

This project had two elements: first of all the creation of six psychotherapy groups across South-West 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. Each group lasted for 10 weeks, with each session lasting for approximately an hour-and-a-quarter and being facilitated by myself in collaboration with either one or two locally-based co-facilitators.

The design of this study utilised baseline and follow-up measures rather than a separate control group, with data being collected at four time points on participants’ medication use, levels of anxiety using the RAID (Shankar et al., 1999) and levels of depression using the Cornell scale (Alexopoulos et al., 1988). This enabled three separate phases to be established within the project: a baseline period of between five and 10 weeks, an intervention period of 10 sessions during which the groups took place; and a 10-week follow-up period. In addition to measuring affect, levels of cognitive functioning and other demographic information were collected at the start of the baseline period.

Therapeutic content
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 for group participants was to think about was ‘what it’s like when your memory isn’t as good as it used to be.’ The task of the group therapists was to facilitate this process of reflection by interpreting material that was brought to the group in terms of its underlying emotional significance and within the context of the group processes. As such this approach differs markedly from other therapeutic forms of work with people with dementia such as Validation Therapy (e.g. Feil, 1993), Life-review Therapy (e.g. Garland, 1994) or Reminiscence Therapy (e.g. Bender, 1994).

Referral criteria
Referral criteria for the groups were developed from those set out by Yale (1995). They stated that the person had to have a diagnosis of Alzheimer’s disease or another form of dementia; that he or she acknowledged, at least occasionally, both that they had a memory problem and that this was more than just the effects of old age; and that he or she was willing to attend a support group. For the purposes of the research project, an additional criterion was used, that potential participants had to have a MMSE score of at least 18.

Quantitative analysis of data
Fifty-one people in all were referred to the groups, of whom 42 were assessed as meeting the research and clinical criteria for entry into the groups. Of these 42 people, only 19 people completed all three phases of the research project: 10 participants were referred too late to be included in the base-
line interviews; eight people dropped out because of health reasons; two people left the groups because they did not think they would benefit; one person declined to be interviewed for the research project, and as the diagnosis of two others could not be adequately established they were included in the groups but not the research arm of the project.

Participants
Thirty of the 42 participants who attended the groups lived at home with members of their family (mainly their spouse). Ten other participants lived at home on their own, while the remaining two lived in residential accommodation. The average age of participants was 73 (ranging from the youngest participant of 53 to the oldest who was 88).

No statistically significant differences were identified between the 19 participants who completed all three phases of the project and either those 10 participants who were included in the baseline interviews, but who dropped out for one reason or another before the end of the project, or the 10 people who were referred too late for baseline interviews. Cheston, Jones and Gilliard (2003a) have presented a detailed analysis of the data using a series of repeated measures ANOVAs. The main findings of this analysis were:

1. **Depression.** The average level of depression as measured by the Cornell increased during the baseline phase but then fell substantially during the treatment period and remained relatively stable during the follow-up indicating a statistically significant within subjects effect ($p=0.034$).

2. **Anxiety.** For the RAID scores, levels of anxiety fell slightly during the baseline phase and more substantially during the intervention before rising slightly during the follow-up period. As the probability of this change occurring by chance was 0.0500, this change is best described as being of borderline statistical significance.

3. **Possible effects of medication.** Nine of the 19 participants used some form of medication (either anti-depressants, anxiolytics, or cognitive enhancers) at some point during the course of the project. Although the type of medication used did not significantly influence the level of affect, analysis using a repeated measures ANOVA indicated that there was a significant interaction between participants’ use of any form of medication during the group and depression levels as measured by the Cornell. However, a detailed post-hoc analysis suggested that the fall in levels of depression during the intervention occurred independently of the use of any form of medication.

Qualitative analysis: Changes in awareness
Although it is important to establish the impact of the groups on levels of anxiety and depression, as a clinician I have been equally interested in the way in which participants’ changed more generally over the 10 sessions that each group ran for. In particular, some participants seemed to become far more able to talk about themselves as having problems for instance with their memory. In trying to make sense of this growth of awareness we have used the assimilation model of psychotherapeutic change (e.g. Stiles et al., 1992, 1995, 1999; Honos-Webb et al., 1999). According to this model during psychotherapy difficult or problematic experiences or thoughts are first of all pushed away, and are then gradually worked through. As an individual becomes aware of these problematic experiences, so their level of anxiety or distress initially increases but then subsides as the experiences become gradually assimilated into their existing patterns of awareness.

Two case studies have been carried out looking at the process by which this assimilation of the problematic experience of being aware of Alzheimer’s disease took place within different groups. In the first case study (Cheston, Jones & Gilliard, 2004b) we exam-
ined the process by which one group participant, Martin, explored issues of threat and loss through an indirect process involving the use of stories and metaphors. In the second case study (Watkins, Cheston, Jones & Gilliard, 2005) Becky Watkins and I analysed transcripts developed from audiotapes recorded during the 10 sessions over which one of the six groups ran. We focussed on the changes in awareness shown as the group progressed by one group participant, Robert. The analysis of this material involved asking an independent consensus group to rate transcripts and tape recordings of those extracts from the group in which Robert talked about Alzheimer’s disease using the Assimilation of Problematic Experiences Scale or APES.

During the first session Robert defined his problem as a selective loss of short-term memory that did not affect other areas of his life. He referred to other people that he knew at a club that he attended, saying, ‘half of them have got Alzheimer’s or something near.’ This suggested to us that during this session he was in a position of warding off awareness of both his diagnostic status and the implications of this.

The pivotal session for Robert individually seems to have been session four. In this session, a series of participants in the group responded to Robert’s challenge (‘I don’t think that anyone here has Alzheimer’s disease’) by asserting not only that they did have Alzheimer’s disease but also that they felt frightened, guilty or ashamed at the knowledge. We argued that until the fourth session Robert’s inability to confront his feelings of shame and fear prevented him from addressing other emotions, such as anger and loss. The key therapeutic factor, arguably, was that the group managed to convey to Robert that shame and fear were experiences shared by the group as a whole. We argued that until the fourth session Robert’s inability to confront his feelings of shame and fear prevented him from addressing other emotions, such as anger and loss. The key therapeutic factor, arguably, was that the group managed to convey to Robert that shame and fear were experiences shared by the group as a whole. Once the ability of the other group members to articulate their feelings of shame and fear had allowed Robert to confront his own avoidance, so he was able to move through the psychotherapeutic process of assimilation described elsewhere by Stiles and produce more insightful accounts of his position. Thus in the ninth session Robert reflected upon how he had changed over the course of the group:

Robert: … I don’t see the problem now the way, the problem of declining memory, the way I did before…

Janet: You didn’t accept it then before?

Robert: Well I did accept it but it frightened me. But I thought, well, I’m going mad, I’m going crazy. I thought what am I going to be like in another five years?

Summary

This study presented data from nineteen people with dementia who, after a baseline period of six weeks completed a ten-week period of group psychotherapy followed by a further 10-week follow-up period. The results indicated that changes in levels of one outcome measure, the Cornell scale for depression, were statistically significant, with changes in levels of anxiety as measured by the RAID, falling at borderline significance. After an initial increase during the baseline period, the mean scores of the Cornell decreased during the intervention phase with this improvement in average levels of affect being maintained during the follow-up. The change in mean Cornell scores crossed the clinically significant cut-off point level of seven during the intervention phase, indicating that the change was of both clinical as well as statistical significance. Post-hoc analysis suggests that this result was not due to an interaction between the intervention and the effects of medication, and indeed the statistically significant change was present even when those participants who took anti-depressant medication were removed from the analysis.

Finding a statistically significant effect across the three phases does not, in itself, provide evidence that it was the group psychotherapy, rather than for instance some incidental effect of being gathered together, which has produced this change in scores during the intervention period. Clearly there is a need for a great deal of
clinical and research work to be carried out before we can begin to have confidence about group psychotherapy per se lowering levels of depression amongst people with dementia with mild or moderate levels of cognitive impairment. However, to the best of our knowledge, this research is one of the first substantive investigations into the effectiveness of psychotherapeutically based work with people with dementia. More importantly it appears to be amongst the first studies to provide statistical evidence that psychotherapy may be having an impact upon levels of affect.

Psychotherapy and people with dementia
The participants in these groups were not necessarily typical of a wider population of people with dementia: in particular they were people whom all, to a greater or lesser extent, had a capacity and a willingness to talk about themselves and their memory problems. Thus, group psychotherapy is not something that all people with dementia would be able to enter into or to benefit from, just as many people without a cognitive impairment would not wish to be part of such a therapeutic experience.

The groups in this project required that participants have a capacity both to engage with other people and to think about themselves and their difficulties in the context of other people: other people both similar and dissimilar to themselves. The process of meeting others in a similar position brings both hope and threat: hope because to experience others in a similar position is to have a sense of not being on one’s own; threat because to be in a group required participants to remember that they cannot remember, to talk about their difficulties in talking and to face the possible exposure of parts of themselves that they may have chosen to hide. A central task for group facilitators is to manage the tensions within the group as participants deal with these themes of hope and threat. In doing so, the group alternates between approaching and avoiding the nature of their similarity. Thus one concept that we have tried to describe has been that of ‘forgetfulness’ (e.g. Cheston, Jones & Gilliard, 2003b) which involves the way that the experiences of participants concerns not just a failure of short-term memory and other cognitive impairments, but the pain and distress of being forgotten about themselves and, at times a wish to be forgotten about and to forget about oneself.

The capacity of a group to allow participants to explore different, sometimes potentially shameful aspects of them is related to the extent that participants experienced the group as a safe place (Cheston, 2005). While Robert was able to directly challenge the diagnosis of Alzheimer’s disease, other participants in other groups could only find an indirect way of voicing their fears. These groups provided a setting in which people can gain a sense that they have not been forgotten, that they will be remembered, that what has happened has been important. As one group member said: ‘Just because I’ve got a failing memory, doesn’t mean that I’m a failure.’

Acknowledgements
I would like to thank all those people who took part in the groups and the research, their care givers, friends and relatives who supported our work. I would also like to thank Becky Watkins, Jane Gilliard, Kerry Jones, Anna Littlechild, Jane House, Sandy Preen, Kirsty Thorne, Jennifer Peak, Pat Lysaght, Liz Young, Suzanne Davis and Elisabeth Bartlett for all their hard work in facilitating and evaluating the groups. Many other people have contributed to the project, and are due thanks: in particular Deirdre Sutton-Smith for her valuable supervision, Gordon Taylor for his advice on statistics and to Mike Bender, Ann Marshall and Andrea Hirons and the team, behind the scenes, at Dementia Voice for their support.

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References
Inpatient dementia care: A Sisyphean task?

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Sisyphus was condemned by the gods to eternal labour. His task was to roll a boulder to the top of a great mountain. From there it would roll back down and Sisyphus would start to push it up again. The cycle repeated itself endlessly. The gods considered that there was no punishment more dreadful than futile and hopeless labour. Famously Sisyphus was lionised by Camus (1942/2000) as the perfect absurd hero whose merit lay in his constant struggle and effort in the face of certain disappointment.

If he were not a pagan Sisyphus would be a perfect candidate to become the patron saint of all involved in residential care of people with dementia. The condition of Sisyphus and that of many dementia care workers seems similar. Like Sisyphus we are engaged in continuous effort to move something onward and upward. A moment’s inattention or slackening of effort and the whole thing starts to slip backwards. Things return to where they were and we are back at the beginning. Yet, time after time, the best professional carers dust themselves down, spit on their hands and apply themselves again to the task of getting on with it and, once again, trying to make things better.

In this article I shall try to look at some of the reasons why the rock is so heavy and the mountain so steep. Based on this I shall try to give some ideas about what could be done to ease care staff’s Sisyphean labours and make success less elusive.

The problem

That there is a problem with any form of residential care for people with dementia is clear. There is a constant stream of reports, investigations, scandals and convictions concerning poor quality care, neglect and abuse. A recent visit to the Elder Abuse website (www.elderabuse.org.uk) revealed 42 press reports in a single month. Parmelee (2004) in a recent editorial in the Journal of the American Geriatric Society said that ‘as long as there have been nursing homes ... there has been controversy about the quality of care they provide’. In Britain the Commission for Healthcare Improvement (2003) (now the Healthcare Commission), in a report on Rowan Ward in Manchester, stated its concern that the same issues (of neglect and abuse) keep cropping up within the NHS. The matter of poor quality of care seems to be both chronic and, in the long term, intractable (for reviews see Glendinning, 1997; and Wardhaugh & Wilding 1993).
Social psychology
There are three studies from social psychology that I believe can shed a light on the nature of this problem. These are some golden oldies that most psychologists should have at least some passing acquaintance with so I will not dwell too long on descriptions.

Conformity
Asch’s studies demonstrated the propensity of a fair proportion of people to fall in with others in group situations. The classic experiment used the discrimination of a length of a line. Asch (1951) found that by themselves people had no difficulty making the discrimination. However, when put in with a group of people who gave an incorrect reply 75 per cent of the participants gave in to the group pressure and conformed by also giving the incorrect answer. The point is that, in some group circumstances, an individual’s judgements may be sometimes set aside because of pressure from the group.

Obedience
Milgram (1974) demonstrated the ease with which many ordinary people could be persuaded to deliver electric shocks to others. His experimental manipulation was, at most, no more intimidating than having a man in a white coat from a prestigious institution explain the rules of the experiment that the subject thought he or she was participating in and then repeating the mantra ‘the rules require that you continue’ should the subject show any signs of reluctance. The now infamous result was that, against all predictions, up to 65 per cent of subjects went all the way and pressed all of the electric shock buttons up to the one marked XXXXX; this despite the agonised screams and eventual silence of the ‘victim’ (who was, of course, a confederate of Milgram’s). The point from this study is the rather chilling way that many people ignore their conscience and their reason if an authority figure is instructing them to behave in an inhuman manner.

Out-group prejudice
The third study is the classic Stanford Prison Experiment (Haney, Banks & Zimbardo, 1973) in which a group of US students, especially chosen for their stability and ‘normality’ were divided into Guards and Prisoners. Very rapidly large differences began to appear in the behaviour and mental states of the two groups. The projected two-week experiment had to be shut down after six days because of the emergence of sadistic behaviour in the ‘Guards’ group and possible signs of emotional breakdown in the ‘Prisoners’ group. The Evil Situation triumphed over the Good People. The ‘Guards’ began to act sadistically; humiliation, suffering and pain were inflicted on the other participants who had, by random allocation not through any fault of their own, been allotted the inferior role of ‘Prisoner’.

What seems to be happening here is a demonstration that the formation of a group identity, even a spurious one as in the Stanford case, carries with it a tendency to construe out-group members in a negative manner. This is the flip side of humanity’s sociable nature and predisposition to form bonds. In cases where strong emotion is aroused behaviour towards out-group members can be hostile and aggressive (Hewstone, Rubin & Willis, 2002). If one perceives the person before one as less than fully human then there appear to be fewer constraints on one’s conscience. On wards and in nursing homes the danger is clear. The staff may easily become cut off from their patients, despite the close proximity of both groups. An ‘empathy gap’ appears between staff and patients which is really a gulf of understanding. At the worst this may become the first step towards neglect and inhumanity towards the less powerful group. I use the diagram in Figure 1 (overleaf) to illustrate this and most people I have spoke to find it a fair representation of what is going on. The social worlds of the staff and the patients’ are entwined but not actually touching. The two groups of people could be living in different countries because their
group memberships are so different and the way they see the world is so utterly unalike. Taken together I believe these three studies give us a good basis for understanding why good quality of care is so difficult to achieve; why it is that any attempt to achieve good quality of inpatient or residential care for people with dementia feels like pushing a large boulder up a steep slope. The answer lies in the fact that institutional care, particularly long term care, inevitably carries with it risks that the patient or client will come to be viewed as an out-group member. Consequently, the usual moral judgements about the correct way to deal with these people will be interrupted and at times frankly unethical behaviour can be expected. As Zimbardo says, it is not so much a matter of a few bad apples spoiling a barrel more a case of a rotten barrel liable to afflict all the apples. Once such an environment is established the tendency to conformity (Asch) and obedience to authority (Milgram) keep the vicious cycle turning.

**Performance management**

Embedded within any institution are various hierarchies of management that are supposed to be responsible for assuring that the purposes of the institution are achieved. The explicit explanation for how this is achieved goes by the way of various Performance Management routines. I believe that in many cases poor performance management contributes to low standards of care because it fails to get to grips with the negative social pressures implicit in staff groups in residential care.

In terms of producing a quality output the most successful approach to performance management has been based loosely on a behavioural model. Stated briefly, such a model requires that staff at work should have:

- A clear idea of what the task requires;
- A clear idea of what is considered a good enough performance;
- Feedback on success and failure;
- Rewards and sanctions as appropriate.

My experience of inpatient units strongly suggests that many of these features of performance management are commonly missing. Instead, Ward Managers, Matrons, Officers in Charge and above rely on good nature, professionalism, training and exhortation. Sometimes such a strategy works, mostly it is inadequate.

Psychologists should be used to the notion that setting specific goals is a prerequisite to achieving a measurable outcome. If you don’t know where you are going then you are likely to end up somewhere else. But what could a clear idea of the task of...
dementia care be? Too often we appear to rely on Mission Statements or a Philosophy of Care. These are only the first step and by themselves are inadequate. Aims such as ‘We will provide personalised care and assure the maintenance of dignity’ need to be operationalised even if this is done in a clumsy manner. Wardhaugh and Wilding (1993) in their discussion of the ‘Pindown’ regime say ‘An organisation without the direction and framework which clear aims and objectives provide is at risk. Secondary aims take over. Care and rehabilitation are replaced by the goals of order and control.’ (p.18)

Following on from the above, if no clear goals are set then it is difficult to see how anybody could know if they are achieving those goals. The position is doubly difficult when one is dealing with chronic conditions because it is not always clear what is possible with any individual given his or her level of disability and the progression of the disorder.

Only rarely do care staff receive any accurate and detailed feedback on their performance. For example, there is often discussion over the merits of giving reassurance versus the potential of encouraging dependence. Ideas about the different courses of action seem to be based on personal biases and preferences. Staff act but rarely, if ever, seek informational feedback on how their behaviour has affected their patients’ behaviour, mood, quality of life or whatever is being targeted.

On the matter of rewards and sanctions there are several points at which inpatient care management practices are less than optimal. Firstly, it is quite clear that of all the rewards available in the NHS (formal, informal, monetary, social or whatever) few are delivered in response to good patient care. Is it not clear that if you wish to attract kudos and raise your profile and career prospects, no matter what profession you belong to then you had better get out from the clinical work and get involved in research, project planning, management, working parties, training, writing papers, appearing at conferences, making presentations and the like. The biggest payoffs in the health service are gained by almost anything other than direct healthcare. The second point is that, if good care is frequently subjected to an extinction regime then problems with care are often ignored or avoided. Too often one hears of poor practice going tolerated or unchecked because senior staff lack the confidence or skills to deal with things that they well know should not be happening.

The performance management of care staff on wards and in homes is a skilled matter that is frequently left to chance. It involves knowledge about training, motivation, teamwork, goal setting and feedback all of which are suitable topics for psychologists to get involved with (Clements & Zarkowska, 1994).

**So what can be done?**

Each ward or Nursing Home works as a system. It is clear from the arguments I have put forward that if these systems are not deliberately manipulated then it is likely that they will run downhill. Unless very conscious and deliberate efforts are made to direct the system then poor care, neglect and even abuse may well occur.

We need to consider what are the sources of power or influence that can be manipulated in the cause of good care, not simply become pessimistic when facing up realistically to the enormity of the task facing us. In Figure 2 (overleaf) I show that there are two major classes of inputs that can be potentially harnessed beneficially.

**Staff input** refers to the skills, knowledge and attitudes that individual staff bring to the resi-

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1 We can take some comfort from the exceptions to the rules that were found by Asch and Milgram. It is also worth pointing out the complementary field of study to conformity, the study of minority influence and change, e.g. Moscovici (1985).
Residential care situation. So, this covers not only the knowledge of challenging behaviour, the side effects of drugs, food hygiene, reminiscence therapy and how to give a bed bath, but also the attitude with which these skills are put into practice. Usually we consider this to be the Person Centred Care approach but it has gone under various guises over the years. As a nurse put it to me, anybody can give a bed bath but it takes a skilled nurse to give that bed bath in a way that leaves the patient feeling safe, calm, dignified and cared for, as well as clean.

Traditionally responses to the problem of poor quality care have been directed almost entirely at improving the skills and attitudes of direct care staff. Although this seems an obvious solution it has been shown many times to be inadequate (Furnham, 1997; Georgiades & Phillimore, 1975; Woods & Cullen, 1983). We may well rely heavily on the individual skills and commitment of thousands of direct care staff but when the situation goes badly wrong then further, organisational, interventions are required. Good, heroic, individual efforts are necessary for good care, but are rarely sufficient on their own.

Management pressure refers to the influence that the organisational hierarchy brings to bear on the ward or the care home. Too frequently these pressures are financial or bureaucratic or if they do concern quality of care they often concentrate on measurable proxies such as size of bedrooms, number of fire exits or access to telephones. Not to be sneezed at, but again not quite getting to the heart of the problem. Instead of this there could be, cascading down from the highest levels to the ward manager or head of home, demands for a demonstrable high level of quality of care. Furthermore this push for quality should be regarded as primary and non-negotiable. Nearly all other management pressures should be viewed as secondary and allowable only to the extent that they support direct care staff in providing good quality care.
This might beg the question of how one might demonstrate, or measure good quality care. You might like to consider a similar question. How do managers know if they are looking after their budgets competently? The answer would be that they receive regular statements of their various balances, income and expenditure. If things go wrong then their managers and the finance department very quickly tell them about it. This model of corrective feedback might be useful for managers who are interested in the quality of care of the units they are responsible for. Imagine if every manager received monthly, at least, accurate reports on the quality of the care delivered on his or her wards. This could be compared against some agreed benchmark, baseline or target. Every year the manager can demonstrate either an increase in quality of care, a maintenance of high quality care of, if things were not going well, a decline in quality of care. Imagine, also, if running through the organisation there was an ethos of demanding high quality care so fierce that managers had it written into their yearly appraisals. Their salary increases and chances of promotion would depend upon high performance in this area in the same way that they now depend on budgetary discipline. This would go some way to bringing the power of the organisation into play in the cause of high quality care. Performance management in terms of knowing what is going on, rewarding good care, dealing with problems early and supporting staff would become the central part of management’s role.

Some practical ideas
Figure 2 shows that any successful intervention needs to have at least two prongs (there is a third, which is patient or carer feedback and which should also be factored in). Consequently, any intervention will need to address both these areas.

At the organisational level we should be arguing for a persistent focus on quality of care that both demands and supports the very highest levels of care from the organisation’s front line staff. This can be done through clinical governance and audit mechanisms, through supporting voluntary groups, above all through constantly making the argument that what is important is the experience of the older adults under our care.

At the individual staff level we could be breaking down the ‘empathy gap’, building on a shared humanity, involving all staff and improving skills through training.

This may seem a tall order but there is one way that it can be approached. There is a way that is fairly simple, has been around for a few years and is eminently applicable in most clinical situations. People who have worked in Learning Disabilities, people who have done action research or some kinds of qualitative research will be aware of the power of putting oneself in the position of another person. A common example is the nurse or doctor who suddenly finds themself a patient in the health service. ‘I never thought it would be like this’ they say. Usually the experience is described as revelatory and results in some fundamental behaviour change toward their patients when they return to work.

This way of looking at the lived experience of patients is familiar to most people in the Older Adult field as part of the process of dementia care mapping (DCM). Probably the best known and most thoroughly evaluated procedure at present (Brooker et al., 1998) it represents a particular ‘brand’ of non-participant observation the potential of which is enormous if only it were done more. There are other ways of achieving some measure of the quality of care within an institution using different tools (Dean et al., 1993; McFayden, 1984) and no doubt others will be constructed, but the principle remains the same. The observers leaves their roles, and to a degree their relationships, in the ‘staff world’ and spends some time, usually many hours, visiting the ‘patients’ world’. Whilst doing this they observe, take notes and make ratings of what is happening. Their attention is directed exclusively toward the experience of the residents. Their results are then fed back to other team members.
The benefits of this process are huge. From the social psychological point of view there is a direct assault on the in-group out-group empathy gap. From the performance management position: (a) the observers receive direct feedback on the nature of the caring regime to which they belong; and (b) managers receive information of a direct and qualitative nature about the quality of care provided in their wards or homes. This is killing two birds, at least, with a single stone.

These sorts of procedures need to be carried out regularly and continuously. Most of us are aware of the short-term enthusiasm and longer-term cynicism generated by hit-and-run interventions that do not include the ward staff. If there is a long-term commitment then all staff can become involved and not just a few highly trained senior staff or visiting researchers. Also, a picture can be built up over time of the way that quality of care is changing, or not, on that particular unit. Feedback can be given to care staff and to senior managers. Quality of care claims it’s place in the spotlight. Is it too ambitious to imagine a unit where some form of prolonged observation and data gathering goes on say once a fortnight; where all staff from care assistants to consultants are involved, and maybe some voluntary groups or carers too; where the data gathered is used on the ward and by managers to demonstrate good care or to identify problem areas? Ambitious, yes. Impossible, well no more so than pushing a rock up a hill.

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References


In September 2003 we both had the opportunity to take this course at the Institute of Psychiatry, Maudsley Hospital, London, part of King’s College London. We had both felt a desire to increase our knowledge and expertise in Neuropsychology which arose from a shift in referral patterns in our respective Older People’s Mental Health services. The availability of ACHEIs and an enhanced public awareness about dementia had contributed to an increase in the number of people being investigated for memory problems. Often these are younger people referred at an earlier stage in their difficulties. Places were available on the course and we liked the syllabus, so both of us were interviewed and accepted over the phone. Felicity was fully funded and Ros 75 per cent funded (which I think is about being in the right place at the right time and asking for the right thing!). We each enrolled in a slightly different version of the course which ran simultaneously and required attendance at the IOP every Tuesday for an academic year. We had the same lectures and both completed two assessed essays. Felicity undertook the established course and submitted five case reports presenting one to her group. Ros participated in group discussions of prescribed journal articles and passed four gruelling exams taken in September 2004. These were introduced to satisfy the knowledge component of the requirements to become a full practitioner member of the Division of Clinical Neuropsychology.

Travelling to London by train was both a gigantic effort and organisational achievement (organising three school-aged kids and a husband for Ros’s absence from 6.15 a.m. to 7.30 p.m. and extra childcare arrangements for both) and a joy (a seat on the train in peace for one hour). However, both Ros and Felicity had to suss out the subtle platform queuing arrangements and social etiquette of train travel. There was no extra time to see the sights of London except from the train window, when lectures were over we would both dash out to get the first bus and train available. Ros was so tired she virtually fell into bed on Tuesday at 8.30 p.m., children permitting. Felicity abandoned constructive activity and slumped in front of the TV. Family adjustment extended well beyond the Tuesday to encompass long hours of study. Their support was invaluable.

There were many other enjoyable aspects to this course. The peer group were great – 16 like-minded people to discuss and gossip with and of course the intellectual stimulation the course provided and space to think and reflect and make all those vital links. The quality of the teaching was excellent with highly expert clinicians contributing. The course was well organised with the provision of useful handouts. There were undoubtedly some shortcomings, the teaching was largely didactic and the course Ros did had no room for case reports and discussion.

However, despite the exam trauma (Ros means never again) we both reflect on our years experience with a great deal of satisfaction and appreciate what a privilege it was to be able to participate in such a significant course in CPD. Was it really necessary for an OA CP to participate in such an extensive course my colleague asked? Well probably not but there are so few options still for specific Neuropsychology courses for OA specialists that this was to best choice available. We both enjoyed it and benefited from it immensely. We believe that our clinical practice has improved and our increased expertise is recognised within our respective services.

WE BOTH PASSED WITH MERIT!
Reinventing the wheel

I was recently in post on a locum basis in East Sussex (OPMHS) with the remit of developing some written resources for clients and carers coming to the Memory Clinic. The process that followed I feel warrants some reflection on how services use and develop such resources and is the purpose of this brief article.

My brief was to develop something that would support people with the new and often anxiety provoking process of coming to a Memory Clinic and include ways of empowering them on issues such as choices during the assessment process and what they might expect from such a service. A leaflet already existed but was used sporadically and was very medically focused. Further thought on this issue resulted in us deciding to also create something to give to people once a diagnosis was given, with focus on practical advice and psychological processes often present at this difficult time.

With these ideas in mind I set to the task of putting something together. It was at this point that a major issue arose for me which prompted this article. On searching through the Internet and other odd resources scattered around the department I discovered an abundance of really useful information relevant to my project; indeed, many of these resources were written exactly on the topics I was intending. Furthermore most were unfamiliar to the team.

I also contacted several other psychologists working in Older People’s services and found they too were trying to develop resources of a similar nature, each aiming to write something from scratch. One key question that jumped out at me was: ‘Why are we all trying to reinvent the wheel?’

We all know finding time in our day to day working lives if difficult and therefore detailed searches through Internet sites, other existing resources and phoning round departments is unlikely to be a priority or indeed a reality. In view of this I felt that it makes sense to raise awareness of the wealth of information (i.e. leaflets, handouts, booklets, articles) that already exists and that it might be helpful for PSIGE to centrally hold some of these valuable resources, both from national organisations but also from local services, which teams could access and use themselves without having to write something from scratch. It may be that some of the text will need to be amended to fit local services but I’m sure most of the work people have put in is useful to other services and most importantly to clients and carers.

I would encourage clinicians to give some thought to this issue and perhaps contribute any pieces of work they have done to Debby Townson who already holds a list of some leaflets. With the constant time pressures we are under, I’m all for making life easier!!

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Then ...

Pictured on this page are members of Wessex PSIGE when they were babies.

Opposite are pictures of them now.

Have a go at matching them.

First correct entry wins a bottle of wine.
and ... NOW!
PSIGE Committee 2003/2004

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Editors’ Note: Please let us know of any changes or errors.
Notes
Notes
Notes for Contributors

Articles
Contributions in the form of short articles on any aspect of psychological theory or practice with older people are always welcome. As the Newsletter aims to cover a broad cross section of work with older people, we are happy to consider academic, descriptive, discursive, or review articles for publication.
Articles should be submitted three months before publication (January, April, July, October).

Research Updates
The Newsletter is particularly keen to publish contributions concerning ongoing research. These can reflect any stage in the research process, e.g. ideas for discussion or early stage results, which are not ready for formal publication. Try to keep them below 500 words.
The Editorial Board reserves the right to make minor changes to any submissions. Where major editing is necessary, the authors will be informed.
All contributions must be typed. Where possible, please send two hard copies and an electronic version on disk, preferably saved as a Word file. Please submit articles double-spaced in plain text. Full articles should ideally be no more than 3000 words.
Language should be inherently respectful to older people and consistent with the British Psychological Society’s guidelines.

Letters to the Editors
The Editors welcome correspondence which combines brevity with rational argument. Letters may be edited if more than 250 words in length.

All contributions should be sent to:
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