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Psychology Specialists Working With Older People

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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Letter from the Chair

Steve Boddington

WELCOME TO THE SPRING edition of the *PSIGE Newsletter*. I would like to remind you that now is the time to book your place at the National Conference in Nottingham on 4–6 July. Lynn Sutcliffe and the conference organising team have been doing a fantastic job in putting together what looks like a fascinating programme (check out the website for more information – www.psig.org/). The overall cost of attendance has been kept down, which is good news for those of us working in the cash-strapped NHS! Please note that there is an exceptional (one-off) bursary fund to help subsidise qualified PSIGE members who have lost their usual training budgets this year. This bursary will stand alongside the usual fund that targets assistants and trainees. It is anticipated that there will be considerable interest in the bursaries, and the scrutiny committee will do their best to allocate the funds in a fair and equitable manner.

Congratulations to Susan Pooley who was selected to win the first PSIGE Research Prize for her thesis work on ‘Maintaining affectional bonds: The significance and meaning of companion animals for pet owners living in homes for older people’. Susan has been asked to present her work at the Nottingham Conference this summer. The panel have also given a special commendation to Paul Wendon for his research on conjugal bereavement in older men, and to Lucy Birch for her research on autobiographical memory in depression.

Steve Boddington
PSIGE Chair.

Letter from the Editor

CLEARLY, 2007 IS A BUMPER YEAR for the PSIGE membership as this edition follows hot on the heels of the Special Issue on driving with dementia and I have it on good authority that the July issue, which is being produced by the Essex and Herts Geographical Group is shaping up brilliantly too.

Submissions continue to come in for the *Newsletter*, which is wonderful. However, for the incoming Editor, whoever they may be(!), may I put in a special plea? When submitting articles could you please make sure you send the following information with the manuscript:

Full name;

Affiliation (title, place of work);

Contact details (should you be willing to be contacted by the membership);

Acknowledgements (as appropriate).

Finally, if you are reporting research, please would you indicate whether or not Ethics Committee approval was awarded, and by which Ethics Committee, or whether the work was carried out as an audit/service evaluation project.

Many thanks, and keep writing.

Romola Bucks

Editor, PSIGE Newsletter.



I am angry with Primo Levi

Stéphane Duckett

Although we may think of suicide as an intensely private act, its consequences are often anything but, and nowhere is this more true than for public figures. I reflect on the impact that Primo Levi's death has had for some of my holocaust surviving clients.

PRIMO LEVI is unfortunately not known to many for his philosophical writings, but rather for the traumatic events of his life; his survival from a concentration camp and later life suicide. Why his suicide shocked many was the fact that here was a well-reasoned and intellectually sober thinker who appeared to have in his post-camp survival, defied his tormentors only to complete their work by taking his own life all those years later. Of course, as I have argued before (Duckett, 2006) drawing a line directly from the past to the present is misleading but that fact almost seems irrelevant to the general public who saw this man as a beacon of death defying reasoned life.

Levi's suicide has become romanticised and somehow is viewed as a noble action. His prominence has given permission to other survivors to take their own lives; much in the same way that the suicide of a family member can somehow make suicide an acceptable action amongst the surviving family. Perhaps in the mind of some it is even stronger in Levi's case, in that it is almost to say, in the distorted and destructive reasoning of his romanticised death, that unless you take your life the experience of the camp was not genuine for you since clearly the pain was not great enough. I found it quite shocking to hear from some of my clients who had survived the camps that there is something of a 'pecking order' amongst survivors; depending on which camp you went to and whether you went to a camp at all or were 'merely' a refugee, whether you lost all or any family members, and the ultimate sanction whether your experience was factual at all. It somehow reminds me of the truly

shocking description that Viktor Frankl gives of the continuous struggle for survival, which took place within the camps.

And, of course, here we come to the rub of it, that Frankl himself spoke of – the guilt of survival or, as Frankel put it, *'there is always a lingering question for a survivor of what they did to survive'*. When this arose once in a group that I was running, one survivor replied angrily that survivors' guilt is a cliché. The fact is, however, that the experience could and did differ enormously from individual to individual despite the common threads. Of course, the issue of what somebody did or did not do in some larger sense from an outsider's point of view, appears meaningless in that nobody but nobody would be in a position to pass judgement on a survivor unless you were able to speak from the survivor's point of view. Actions committed within pathological environments do not define the individual, except within that environment and that is what allows us to speak of soldiers as soldiers and not murderers in times of war unless their targets are an unarmed populace. Context appears to be everything and nowhere is this more true than with respect to suicide.

Durkheim noted that in creating categories of suicide, some will take their lives to affirm their membership of a select group (altruism) and others will do so as a product of *anomie*; that is the social isolation. Perhaps this is where Levi's suicide has crossed the mark. It allows elderly and isolated survivors to recast their death as an affirmation rendering their action noble and not the act of anomie, that it in fact is. It politely accommodates our sensibilities and relieves us of

our culpability in an ageist world where age alone renders you superfluous. The irony of course is that at no other time has the experience of this generation been more relevant than now in helping us guide our way through these very difficult times.

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Adapting CBT using a compassionate mind approach with older people who experience dementia and depression

Paul Green

IT IS POSSIBLE to adapt cognitive behavioural therapy (CBT) in various ways to meet the needs of older adults who are depressed, particularly if due regard is paid to the client's pre-morbid functional belief system and the cohort beliefs common to particular age groups (James *et al.*, 1999; Laidlaw *et al.*, 2004). The therapeutic pessimism which has often inhibited older people's access to psychological treatments (Hepple, 2004) is unwarranted as there is considerable evidence to suggest that they respond positively when offered a clear and structured approach to resolving their difficulties (Doubleday *et al.*, 2002), and this is equally true of clients with dementia. Charlesworth and Reichelt (2004) suggest that using shorter, more frequent and highly structured sessions, which may be taped for review, can make therapy more accessible for those with cognitive impairment, 40 to 50 per cent of whom experience depressive symptoms, with 17 per cent meeting the criteria for major depression (Lavretsky, 2003).

Since completing a secondment at the Clinical Psychology Department, Dewsbury & District Hospital, to develop intermediate skills in CBT, I have been learning how to adapt these to meet the needs of the older adults who attend the Priestley Day Unit where I am employed as a staff nurse. As part of this process, I conducted a literature review (Green, 2006). The following case study illustrates how using a simple diagrammatic formulation, and providing the client with a summary of what has been discussed, can help someone experiencing depression following a diagnosis of dementia explore his difficulties.

Case study

Roger (not the client's real name) is an 81-year-old retired plumber who has a diagnosis of Alzheimer's disease. His wife reported that he had been very low in mood over recent months and reluctant to go out or engage in any meaningful activity. Upon exploration of these issues he described feeling that he had lost his role in life due to no longer being able to drive or perform previously valued activities without assistance, such as gardening and decorating. Roger also acknowledged that he sometimes stopped doing things because he worried about his memory lapses being noticed by others. When asked to give a specific example of this the following formulation was arrived at.

Spoke to a friend at the Conservative club and forgot his name.

↓

Thinks: 'He'll think I'm a real idiot.'

↓

Feels embarrassed about his memory problems.

↓

Stays at home.

↓

Feels fed up and 'a waste of space'.

Solutions

- I would be sympathetic towards another person with memory problems.
- True friends will understand my memory problems and respect me for trying to lead a normal life.
- I participate in a reminiscence group at the day unit and have recalled my

childhood, working life, holidays and hobbies. This encourages other group members to remember their own lives and they value my contribution.

- Continuing to go to the Conservative Club, doing gardening with my wife and keeping active will help me to think more positively about myself and feel better.

The use of linear chains comprising an event, the client's appraisal of it and his emotional and behavioural responses allows complex experiences to be encapsulated more succinctly than the five-item generic model. It is easy for people who experience cognitive impairment to follow and provides a shorthand summary of problems for future reference. This particular example also highlights how the experience of memory problems can trigger feelings of shame and embarrassment which result in a desire to prevent deficits from becoming apparent to others, leading to abandonment of activities and avoidance of others. Cognitions such as 'I am no good', 'I am a failure' and 'I am useless' are common, and the client also believes that these thoughts will be shared by others. Consequently, the urge to hide, avoid exposure and run away predominates (Higginson, 2006). The following diagram outlines how a compassionate mind approach, adapted by Gwyn Higginson from the work of Gilbert (2005), can inform therapy when supporting individuals facing these difficulties.

Compassionate mind approach.



Help others to feel safe, not seek safety through avoidance.



Identify 'inner bully'. What is it saying to the person? Explore impact of memory loss, triggers, thoughts and images.



Encourage empathy for own distress.



Explore memory assets, strengths, hobbies, skills. Identify positive image to help soothe inner bully.

This approach was used to encourage Roger to challenge his negative perception of himself and make use of his abilities. Time was spent visiting him at home and accompanying him on walks in his local area, visits to shops and a café. He was surprised to discover that he did not get lost, could handle money and purchase items without becoming confused and could enjoy pleasant conversations with friends and acquaintances. The benefits of doing this became apparent when, during one such outing, he found himself unable to remember the name of a fellow member of his club whom he happened to meet in a café. Roger explained that he had memory difficulties due to Alzheimer's disease, asked the man his name and continued to hold a conversation with him, but he did not experience any negative thoughts or feelings either at the time or following the encounter.

During one therapy session Roger was asked to imagine how he saw himself when he thought about not being able to do things. He responded by imagining that he was gardening and being unable to perform this task properly. When asked how he would feel towards someone else in that situation he said that he would "feel sorry for him and want to help him". Roger was then encouraged to be as compassionate towards himself as he would be towards another person, to imagine putting an arm around that image of himself struggling to do the gardening and accept comfort and support. He found this soothing and was then asked to identify a more positive image of himself.

Roger had spent 22 years in the Royal Navy and was very proud of this so he imagined himself wearing the medals he had been awarded. The following week he brought these medals with him to the day unit and showed them to other clients and staff.

Roger was subsequently able to identify a number of memory assets such as his wide general knowledge, ability to contribute to group activities, social skills and his recollection.

tions of all the places he had visited. He began to speak more openly about both his difficulties and his remaining abilities, remarking that his good physical health made him feel fortunate for a man of his age.

The Gentlemen's Club

A compassionate mind philosophy is also a useful framework to use when facilitating support groups for people with memory problems. The Gentlemen's Club is an open, informal group for men with memory problems who attend Priestley Day Unit and spend an hour at a café in the hospital grounds on Wednesday mornings discussing their thoughts and feelings. It started with three members but two others have now joined. Over the past eight weeks of its existence several themes have emerged.

Acceptance of losses

The loss of valued skills such as driving, managing finances and decorating is an important issue for all members. Expressing feelings of sadness and worthlessness about these things prompted them to share memories of using valued skills in the past. One recalled driving buses on Sundays for £1 when he worked as a mechanic at a bus depot. Being able to enjoy such memories has led to expressions of 'letting go' and phrases such as 'You can still do a lot' and 'Well, at least we're all here talking.' These reflect a process in which group members see that they are valued by each other and are able to value themselves more.

Acceptance of help

One member said his initial resentment at 'the wife doing everything' had led to rows between them until he realised that 'She's just trying to help and I'd do the same for her.' Discussing this theme enabled others to see family members as intending to be kind and caring rather than domineering, but it was important for each of them not to let people 'take over'. It was suggested that trying to negotiate boundaries with others was more constructive than feeling threat-

ened and then becoming hostile, that it was 'okay' to be cared for by others since 'Some people don't have anyone.'

Take it easy

'You've just got to take it easy' was a remark made a number of times by one group member when the issue of anger was discussed. All agreed that frustration due to forgetting things was a common problem and practical solutions such as notes, lists and the use of calendars were discussed. However, talking to others who were having the same struggles helped individuals to feel better about learning to adjust their expectations of themselves, especially when told 'You're doing fine, don't give yourself a hard time over it.'

We're normal

There was some discussion about different types of dementia, as one member of the group has vascular dementia and the others have been given a diagnosis of Alzheimer's disease. The differences were explained but all felt that their difficulties were primarily due to old age. As one group member put it; 'You don't feel so bad when you see it's just normal' and would point to himself and say 'I'm normal' when this was discussed. This should not be seen as denial or lack of insight but as a means of normalising dementia and enabling group members to make sense of what was happening to them.

Conclusion

The compassionate mind philosophy provides an excellent framework within which therapeutic interventions can be adapted to meet the needs of individuals who experience shame and self attacking as a result of cognitive impairment. It enables practitioners to help clients experience empathy for their own distress and challenge the negative thoughts which prevent them from continuing to fulfil their potential as human beings. When therapies are customised to meet the needs of individual clients, however, the issue of how to evaluate them in a meaningful way

needs to be considered. This has been a largely anecdotal account, drawing on my own and others' experiences, but if good practice is to be established in using such loosely adapted forms of CBT then research will be needed which combines the richness of qualitative accounts with the necessary methodological rigour.

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Person-centred care: The Holy Grail or a muddled and misguided goal

Ian A. James

MANY THERAPISTS SEE person-centred care (PCC) as a clinical aspiration to which to strive. They believe that were person-centred approaches used more widely by services, organisations and in care homes, older people would receive 'quality' care. Indeed, the concept has now become synonymous with good practice and is a goal outlined in the NICE Guidelines for Older People (2006) and the National Service Framework for Older People (Standard 2):

Person-centred care: The aim of this standard is to ensure that older people are treated as individuals and that they receive appropriate and timely packages of care which meet their needs as individuals, regardless of health and social services boundaries.

(NSF Older People, 2001)

Over the last 10 years, the notion of PCC has become central to non-pharmacological treatment strategies. Rarely can one attend a workshop on psychological approaches for people with dementia, without one of the speakers referring to the concept in positive terms. Why has it become so important? This article will explore some of the reasons why it has achieved this status, and then examines some of the problems associated with the concept.

Putting the person before the disorder: One of the reasons behind its popularity is that it marks a change in focus from a medical to a psychological philosophy. In particular, this humanistic perspective can be contrasted with pharmacological approaches. In the case of challenging behaviour, there is a marked contrast between the two treatment philosophies. For example, unlike PCC, medical treatments do not seek to explore or

understand the causes behind problematic feelings or behaviours, rather they principally use powerful tranquillisers or sedatives to try to alleviate the problems.

Good face-validity: A second reason for PCC's popularity is its face-validity. Indeed, it seems logical when dealing with complex problems that one obtains a lot of information about both the nature of the client's difficulties and his/her experiences, including a comprehensive description of the person's background and history.

Endorsements: A further reason for many therapists supporting the use of PCC is that important people in the field have advocated its use (Kitwood, 1997; Stokes, 2002). Stokes (2002, p.61) defines his person-centred concept of care as follows:

Accepting a person is unique (e.g. having a life history, fears, joys and habits).

Acknowledging a person with whom we share much in common.

Recognising the subjective experience of dementia – a world of not knowing.

Despite endorsements from acknowledged experts, when one examines the concept in more detail, major problems start to emerge (Nolan *et al.*, 2004).

Lack of clarity: The first difficulty, and perhaps the most concerning, is the lack of clarity regarding the nature of the term (McCormack, 2004). One of the obvious consequences of this lack of clarity is that all sorts of disparate, and perhaps dubious, practices become 'badged' as PCC. For example, I recall receiving a referral from a care-home concerning a man described as an aggressive thief (i.e. stealing food from

staff and fellow residents). An initial investigation revealed that this life-long vegetarian had recently shown an interest in eating meat. The manager of the home, with the agreement of the man's family, had instructed the staff not to give him meat. This was under the person-centred pretext of preserving the man's dignity. Things came to a head when he started taking food from other people's plates. Following further consultation with the man's family, it had been decided to give him his meal in his room. However, this resourceful chap then started to take food out of the staff fridge in the kitchen. As illustrated in this scenario, the lack of clarity means that actions verging on mistreatment may be justified under the term PCC.

Lack of an evidence-base: A further concern about the use of PCC is the lack of an evidence-base supporting its use. Indeed, in many of the recent reviews of non-pharmacological treatments for people with dementia (Verkaik *et al.*, 2006), one will not find reference to PCC as an approach. To be fair, there are a few controlled studies that have employed person-centred strategies to good effect (e.g. Fossey *et al.*, 2006). However, due to the lack of precision regarding the term, and its generic nature, researchers have treated it as a philosophy rather than a specific form of therapy. This clearly leaves PCC in a difficult position in relation to establishing itself within the scientific community and with our medical colleagues. This is particularly important in relation to the latter group, as they can quite justifiably say 'Neuroleptics might have their problems, but where is the evidence-base for your person-centred work?'

Furthermore, our adherence to this mercurial concept may be making us lazy practitioners. Indeed, the concept may be serving as our 'emperor without clothes' (i.e. holding PCC principles may be an excuse for us not holding an extensive knowledge of the evidence underpinning our clinical practice). For example, consider the

following Small Scale Research Project undertaken in the North of England (Wormsley, 2006). The project involved asking a group of 14 PSIGE members to provide the evidence-base supporting an intervention strategy they had designed to treat a challenging behaviour scenario. An analysis of the interventions demonstrated that over 90 per cent of the strategies contained elements of PCC. Yet, only three psychologists could provide specific studies supporting the use of the treatments they had suggested. Of those who could not provide details, the names of eminent workers in the field were suggested instead (Tom Kitwood, Graham Stokes, Mike Bender). Furthermore, less than 25 per cent of the 14 participants were able correctly, 'off the top-of-their heads', to give details of any empirical studies (authors, description of design and outcome) they could show to a colleague in support of psychosocial interventions for people with dementia.

A further concern about the concept of PCC relates to the fact that some of its proponents can become too fixated on the past. Before discussing the issue further, it is relevant to state that I agree that it is important to undertake life-stories, examine previous coping strategies, and to see the person's current situation in relation to their past. However, I think it is crucial to highlight the danger of continually looking back when one is attempting to meet a person's current needs. Being so retrospective sometimes blinkers us to the notion that people with dementia continue to develop and change during their illness. They will develop new tastes (e.g. interest in music), revise previous life preferences (vegetarians choosing to eat meat), develop new hobbies, etc. I think that we need to be open to the possibilities of people changing and developing, and thus we should see dementia as a further 'developmental life-stage' in the person's growth as an individual.

I also have worries about how useful biographical data can be. For example, a number of care-homes in my locality attest to using PCC due to the fact that the staff

compile life-story books for every resident; for them this is good practice. However, I am currently in discussion with the managers of the homes, suggesting it is only good practice once one starts doing something with the histories; the biographies have not yet informed care-practices.

Our expectations of staff: Notwithstanding the difficulties outlined above, there is a further set of problems associated with getting staff to adopt PCC practices (Woods, 1999). In order to understand this aspect better, first let us examine the staff's perspective, and in particular the care-workers' situation.

'Until we have an understanding and hear accounts of what it is like to be a care assistant – the difficulties, frustrations, the motivations and satisfactions – it is going to be difficult to find psychosocial interventions that they will happily use.'

(Jaques & Innes, 1998)

In truth, it is the care-workers who are with the clients and residents 24 hours a day, who need to be delivering the PCC. Thus, it is this group of people whom we expect to change from their rather task-focussed working strategies (Sixsmith *et al.*, 1993), to more personalised, empathic ways of working. Such a change is fraught with problems for a number of reasons. To illustrate the reasons, I will refer to my experiences of organising services into the local care-homes in the north-east of England

The first problem is the motivation and ability of care-workers to adopt new ways of working. One of the major issues in this respect is the composition of this group of staff: frequently they are poorly educated, poorly trained and poorly paid. There is a lack of a career structure within the homes, leading to the existence of an unstable, transient workforce. A further problem stems from poor leadership, both at the managerial and organisational levels. This is partly due to the fact that the homes are required to make a profit, and thus there is often a 'What do we need to do to get by?' attitude from management. In recent years, this has led to

a large number of foreign workers, with poor English, entering the homes as both qualified and unqualified members of staff. This has created many communication difficulties for residents, families and staff.

The present article reflects a growing trend in the literature calling into question whether PCC is either achievable or appropriate (Packer, 2000; McCormack, 2004; Nolan *et al.*, 2004). Nolan is particularly critical about PCC's focus at the level of the 'individual', at the expense of the systemic and interpersonal domains. In their well argued paper, the authors advocate an alternative framework called the relationship-centred (RC) approach (Mulrooney, 1997). This approach promotes well-being by encouraging greater interdependence between residents and staff, and increased levels of staff respect and caregiver investment.

An alternative: While the latter approach has many positive aspects, it (like PCC) places a large number of demands on staff, requiring them to invest cognitively and emotionally. Owing to the lack of respect and training we invest in staff, it is questionable whether such an approach is tenable. It has been my experience that many of the features outlined above militate against the likelihood of getting staff to adopt humanistic care practices, even with training. This is because PCC, and RC, requires engagement, planning, problem-solving, and effort, all of which I think are often too demanding for carers who are neither valued nor supported sufficiently. Therefore, it is my opinion that, at this time, we should not be training care workers to become person-centred practitioners in the hope that they will suddenly adopt empathic and caring principles. Rather we should be legislating for the use of specific 'positive' ways of working with people with dementia, and thus leave the element of choice out of the matter. I have termed this approach the 'Fast food' scenario. Here, I am highlighting the fact that workers in fast food outlets are 'drilled'

in good customer care practices to respond to all customers in a friendly and courteous manner. They may not really be bothered whether I have a nice day, yet the fact it is said to me as I leave always makes me feel a little better.

In Newcastle we are taking the above views forward with the Commission for Social Care Inspection (CSCI), and asking them to endorse training aimed at improving communication strategies, along the line of customer care practices. This work is in its infancy, but we feel that it is a useful way to approach the difficult issue of how to communicate with people with dementia, in a way that leaves the person with dementia feeling positive about his/her social exchanges.

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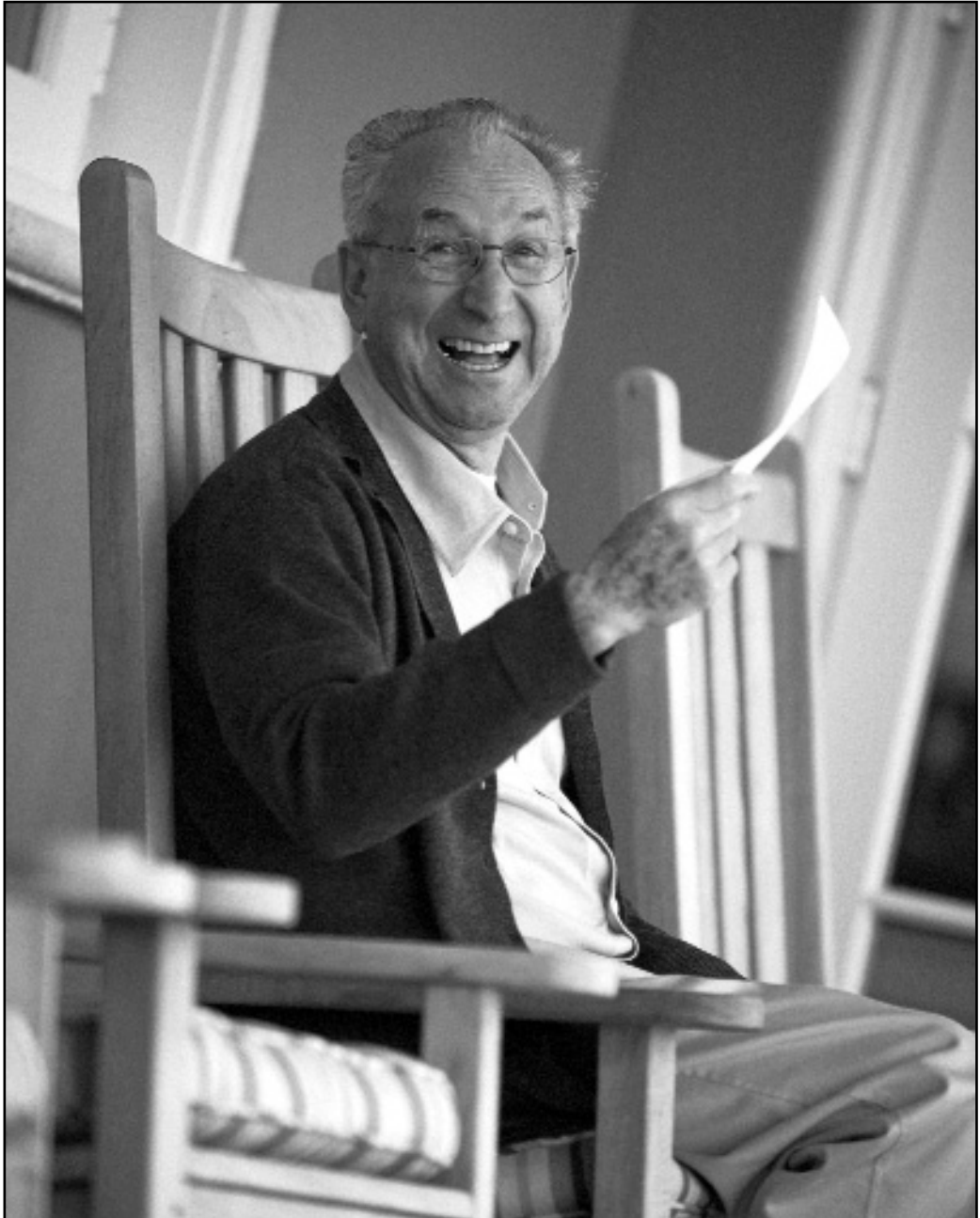
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Post-traumatic stress symptomatology following stroke

Maire Sharkey

This study investigates the prevalence and types of post-traumatic stress symptomatology in a sample of stroke survivors following their first stroke. The results reveal that the stroke was not distressing for most of the sample, and it is possible that some natural recovery may have taken place since stroke onset. However, a small proportion of the 34 stroke patients experienced post-traumatic stress symptomatology following their stroke.

THE DSM-IV (APA, 1994) defines Post-Traumatic Stress Disorder (PTSD) as occurring when a person experiences an extreme stressor that threatens life or physical integrity along with the development of three groups of symptoms – re-experiencing the event, avoiding reminders, and arousal on exposure to the event or reminders of it. Stroke can be viewed as such a sudden life-threatening event.

Despite a great deal of research on depression and quality of life after stroke (e.g. Whyte & Mulsant, 2002), there has been little attention given to PTSD as a possible consequence of stroke.

Case studies have described delayed onset PTSD in post stroke veterans where previous coping strategies had become ineffective (Cassidy & Lyons, 1992) or implicated a thalamic cortical disconnection (Duggal, 2002). By using self-report measures and a structured interview, Sembi *et al.* (1998) found a prevalence of 9.8 per cent in a sample of 61 patients after first-ever stroke. The researchers did not describe the range of time since stroke onset. There was a weak correlation between intrusive thoughts and severity of post stroke disability. The PTSD group reported significantly higher premorbid scores for neuroticism and more post-stroke problems (anxiety, depression, somatic complaints, insomnia, and social dysfunction).

Eccles *et al.* (1999) studied intrusive thoughts and emotionalism within one month of hospital admission. They compared a sample of patients with emotion-

alism and those without by using a relatively weak between-group design. Intrusive thoughts and avoidance were significantly higher for the emotionalism group but emotionalism was not thought to be a direct manifestation of PTSD. Sampson *et al.* (2003) compared hospitalised stroke patients with those admitted with other physical problems such as falls, amputation, and infections. A prevalence of 5.6 per cent experienced PTSD following stroke was reported in a sample of 54 and no significant differences on the severity of mood was found between the groups. The severity of the condition did not appear to predict the occurrence of PTSD like symptoms.

Bruggimann *et al.* (2006) reported that 31 per cent of a sample of 49, suffered significant symptoms one year after a non-severe stroke as measured by The Impact of Events Scale. Symptoms were more frequent in those with more negative appraisals of their stroke experience. Intrusions were more likely following basal ganglia strokes, which may implicate frontosubcortical pathways. PTSD symptoms appeared independent of neurological impairment, amnesia, long-term memory impairment, psychosomatic preoccupation, and physical pain during hospitalisation.

Despite utilising various measurement methods, the research suggests that PTSD may occur following stroke. This paper describes a study investigating the prevalence and types of post-traumatic stress symptomatology in a sample of stroke survivors following their first stroke. It was anticipated

that stroke survivors who reported post-traumatic stress symptoms would also report poorer quality of life.

Methods

Following ethics committee approval, 34 stroke patients agreed to participate from two North Yorkshire NHS trusts of which 14 were female and 20 were male. The mean age was 73.4 years ($SD = 10.7$) and the mean time since stroke onset was 62 weeks ($SD = 26.3$). The average length of hospital stay was five weeks ($SD = 5.5$) and five participants were still receiving rehabilitation treatment. Those who suffered severe communication and cognitive impairments were excluded from the study.

A multi-modal assessment of PTSD was conducted using a structured interview (Clinicians Administered PTSD Scale (CAPS); Blake *et al.*, 1992) and two self-report measures – Penn Inventory of PTSD (Hammaberg, 1992) and the Impact of Events Scale (IES; Horowitz *et al.*, 1979). An independent rater screened 10 per cent of the audio taped interviews and good inter-rater reliability was achieved ($\kappa = .85$). Co-morbidity was assessed with the Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1994). The Stroke – Specific Quality of Life Scale (SS-QoL), a self-report measure was used to assess stroke specific health – related quality of life (William *et al.*, 1999a; Williams *et al.*, 1999b). A cross-sectional design was used with correlational analysis and Independent Samples T-Tests. Given the small sample reporting PTSD, analysis concentrated upon using continuous rather than categorical measurements of PTSD.

Results

One individual achieved a diagnosis of PTSD and scored above cut-off points on PTSD measures. Three individuals indicated sub-threshold PTSD using guidelines derived from Blanchard *et al.* (1995). Table 1 (overleaf) presents the frequency of the three main symptoms groups as rated by the CAPS.

A total of seven reported re-experiencing symptoms. Three to six months marked the onset of symptoms for six of this group. The symptom profile indicated more avoidance and numbing symptoms. Most of this group (13) described symptoms three months from the onset of the stroke. Exactly half the total sample reported hyperarousal symptoms and 12 indicated that symptoms were present by six months post-stroke.

Older age was correlated with lower Penn scores ($r = -.56$, $p = .01$). Fear of another stroke was significantly associated with the Penn ($r = .34$, $p = .05$) and feeling horrified immediately after the time of the stroke was significantly associated to the IES ($r = .38$, $p = .03$). Four participants reported receiving treatment for mood disorders prior to their stroke and their Penn scores were higher compared to those who did not report problems ($t = 2.35$, $p = .03$). This trend may indicate that a pre-trauma history of psychopathology may predispose people to higher rates of PTSD symptoms. More frequent PTSD symptoms on the Penn ($r = -.43$, $p = .01$) and IES ($r = -.35$, $p = .04$) was significantly related to poorer quality of life (SS-QoL). Two participants scored above the clinical cut off for anxiety and two scored above the cut-off for depression. Higher depression scores were significantly related to lower quality of life ($r = -.59$, $p < .01$).

Discussion

Most of this sample seemed to have coped relatively well and it is possible that some natural recovery may have taken place since stroke onset. A small but clinically significant proportion experienced post-traumatic stress symptomatology following first stroke. There are a number of methodological limitations with this study such as sample size, selection bias, and design, thus the results cannot be easily generalised. However, there are a number of implications for practice. As not everyone exposed to a trauma will develop PTSD, we are left with some questions. What is the symptom profile and what are the factors that may predict symp-

Table 1: Frequency of three main symptoms groups.

PTSD Symptoms	N
Re-experiencing symptoms	7
Intrusive recollections of the stroke	3
Psychological distress at exposure to cues	7
Physiological reactivity	1
Avoidance and numbing symptoms	21
Avoidance of thoughts, feelings or conversations	5
Avoidance of activities places or people	2
Inability to recall important aspects of trauma	12
Diminished interest or participation in activities	7
Detachment or estrangement	3
Restricted range of affect	4
Sense of foreshortened future	10
Hyperarousal symptoms	17
Difficulty falling or staying asleep	7
Irritability	7
Difficulty concentrating	12
Hypervigilance	1
Exaggerated startle response	1

tomatology following stroke? Future longitudinal research is required that also includes stroke survivors with communication and cognitive impairments.

Assessment and management protocols for PTSD are lacking for stroke survivors but early screening and monitoring of mood will lead to better identification.

Developing PTSD measures that are standardised with people following neurological impairments will help this process. However, PTSD and stroke have several symptoms in common as well as overlapping with other mood disorders. Therefore, it is necessary to consider the relevant contribution of the neuropsychological consequences, coping styles, idiosyncratic appraisals of the stroke and its impact on PTSD symptoms. This highlights the importance of individualised psychological formulations in developing an understanding of the psychological distress experienced by stroke survivors.

The recognition of PTSD symptoms as occurring following stroke can enable stroke services to target appropriate support and

interventions to assist adjustment and rehabilitation. The efficacy and timing of psychotherapeutic strategies used in the treatment of PTSD remains unproven with stroke survivors. There is limited evidence of the effectiveness of post-stroke psychological interventions (Kneebone & Dunmore, 2000) with other mood disorders. However, case studies such as Lincoln *et al.* (1997) have reported improvements for some depressed stroke patients using CBT. A role for Clinical Psychology would focus on facilitating training on the emotional needs of stroke survivors to patients, relatives, staff, and other agencies.

My clinical experience has demonstrated that providing timely information to stroke survivors and relatives around their emotional experience helps to reduce the negative appraisal of their symptoms. Most participants described experiencing their symptoms by three to six months post-stroke, which usually coincides with the withdrawal of health care services. PTSD symptoms, similar to depression are associated with

poorer quality of life. It is possible that the behavioural manifestation of poor physical health is a reminder of the traumatic aspects of the stroke, thereby eliciting PTSD symptoms. Tedstone and Tarrier (2003) argue that the presence of PTSD symptoms can lead to adverse health effects such as increased morbidity, mortality, and non-compliance. The Royal College of Physicians' (2006) national audit of stroke services stated that 'psychology remains a virtually extinct species'. Despite the cost implications and the current economic

climate within the NHS, we need to continue the struggle for longer-term service provision to enhance the well-being of stroke survivors and carers.

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Weight change and in-patients with dementia: A preliminary study

El-Awad Hamid, Richard Cheston & Rebecca Watkins

Objectives: *The aims of this study were to identify those nursing, psychiatric and psychosocial aspects of care which predicted changes in BMI and body weight amongst people with dementia in the first six and 12 weeks after admission to hospital.*

Participants: *33 patients with moderate or severe levels of cognitive impairment who were admitted to three NHS assessment wards for people with dementia in the South-West of England were recruited. Twenty-one patients were re-assessed after six weeks, with measures repeated again 12 weeks after admission with 15 patients.*

Findings: *A forward stepwise regression model indicated that weight change between admission and six weeks was predicted by the use of anti-psychotic medication, while weight change at 12 weeks was predicted by factors which impeded the patients' capacity to eat (including physical illness). Increases in BMI were related to higher levels of ill-being.*

Conclusions: *The care of people with dementia on in-patient wards should be concerned to identify both those physical and psychological or psychiatric factors which act to prevent individuals from eating, and to develop effective means of intervening with those patients who are at risk of weight loss.*

Keywords: dementia; weight loss; obesity; ill-being.

THERE IS A STRONG AND CONSISTENT relationship between weight loss and hospitalisation amongst older people. For instance, in a systematic review of randomised controlled trials of oral protein and energy supplementation, Milne, Potter and Avenall (2002), noted that 55 per cent of elderly patients were undernourished on admission to hospitals and that increased length of stay was associated with further weight loss.

Weight loss amongst older people is also associated with dementia (Wolf-Klein & Silverstone, 1994). For instance, Cronin-Stubbs *et al.* (1997) found that people with dementia of the Alzheimer's type (DAT) were more likely to lose weight than controls, even control subjects with coronary heart disease and cancer. Amongst older people with dementia, weight loss tends to be associated with a deteriorating clinical picture, including a shorter life span, and is often viewed as an inevitable consequence of the neurological changes associated with dementia. Unsurprisingly, then, weight loss

amongst people with dementia also seems to be more common when people have been hospitalised. Thus Burns, Marsh and Bender (1989) found a relationship between decreased BMI and length of stay in hospital, while White *et al.* (1996) found that functional status and severity of dementia correlated with weight change. In the latter report, results from a six-year longitudinal study showed that compared to a control group, weight gain and weight loss of five per cent or more was more common in DAT patients. The degree of weight loss predicted mortality, while weight gain was protective (White, Piper & Schmader, 1998).

However, there does not seem to be an inevitable relationship between these factors. Thus Wang *et al.* (1997) compared two groups of institutionalised patients, with and without dementia, and controlled for levels of independence. They found no clear association between dementia and weight loss even when participants experienced feeding problems.

Yet, the association between dementia, weight loss, hospitalisation and mortality suggests that this is an important area for clinicians to be concerned about. In particular the shift in dementia care that has occurred over the last 10 years or so in the UK, towards an increased awareness of person-centred care (e.g. Kitwood, 1997), suggests the need to establish whether psychosocial aspects of care, in addition to neurological and other factors are implicated in patterns of weight change. The aims of this study were to look at the nursing, psychiatric and psychosocial aspects of care which predict changes in BMI and body weight amongst people with dementia in the first six and 12 weeks after admission to hospital.

Methodology.

Design: The design of this study involved a repeated measures opportunity sample with participants being recruited over a four month period from three NHS assessment wards for people with dementia in the south-west of England. Data relating to a variety of psychosocial, nursing and medical factors was collected in the first week after admission, and then at six and 12 weeks after admission.

Subjects: 41 participants were admitted to the three wards during the course of the study. Patients were excluded from the study if: consent could not be established (three patients); or if they suffered from a physical disability which prevented measurements from being taken (five). In all 33 patients were assessed in the first week after admission. Six weeks after admission, 10 patients had been discharged while a further two patients unfortunately dying, and, therefore, data was collected from only 21 patients. At 12 weeks a further six patients had been discharged, with all 15 patients who remained being included in the study.

Background information was collected from the patients’ notes concerning: their diagnosis; medication; mobility levels; and level of cognitive functioning using the Mini-Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975). In addition data were collected during the study on:

Height and weight. Patient’s heights were recorded on admission. This allowed the patients’ Body Mass Index (BMI) to be calculated (Centre for Disease Control website, 2005). Participants were always weighed using the same machine. Scales in each of the three facilities were calibrated at each time of use against a portable, electronic set of scales.

Table 1: Demographic details of patients.

Measure	Admission (N = 33)	Six weeks after admission (N = 21)	Twelve weeks after admission (N = 15)
Gender	17 F, 16 M	14 F, 7 M	9 F, 6 M
Mean age	79.12 (SD = 8.23)	80.79 (SD = 8.59)	81.73 (SD = 8.64)
Mean MMSE on admission	15.71 (SD = 6.05) (N = 27)	15.85 (SD = 5.41)	17.25 (SD = 4.881)
Diagnosis	DAT – 18 Vascular: 9 Other: 6	DAT: 12 Vascular: 6 Other: 3	DAT: 7 Vascular: 5 Other: 3
Mobility	75.8% mobile	75% mobile	66.7% mobile
Weight	63.41kg (SD = 13.44)	62.01kg (SD = 11.13)	62.14kg (SD = 11.54)

Well-being and ill-being. Using the Bradford Dementia Group (1997) profile of well-being and ill-being, nursing staff were asked to rate patients according to 15 indicators of well-being and 13 signs of ill-being.

Affect. Levels of depression were measured using the Cornell Scale for Depression in Dementia (Alexopoulos *et al.*, 1988), a well-established interview based measure which is designed for assessing the level of depression of people with dementia. Levels of anxiety were measured at each time point using the Rating Anxiety in Dementia or RAID (Shankar *et al.*, 1999), an interview-based measure again designed specifically for people with dementia.

Behaviour. Nursing staff were asked to assess the patient's physical health and behavioural factors that might impede his or her ability to eat, in terms of being at a low, medium or high level. Factors which could affect a patients' capacity to eat included disability, illness or psychiatric functioning.

Findings

Data were analysed using S-plus Version 2000 for Windows. In order to determine the factors that may help to predict weight change, we created a response variable equal to the change in weight for each patient. Fitting a forward stepwise linear regression

model, the only variable that was found to be significant in predicting weight change at six weeks was the use of atypical anti-psychotic medication in the two weeks before admission ($df = 1$; $R = .569$; $p = .021$). The estimated intercept for this model was not significantly different from zero, and the estimated weight after six weeks for patients taking atypical anti-psychotics at admission compared to those who did not was 3.4kg. At 12 weeks, weight change was predicted by the patients' physical health and other behavioural factors that impeded his or her ability to eat ($df = 1$; $R = .959$; $p = .041$).

It was not possible to calculate BMI for 2 of the 21 in-patients at the six week stage and for 3 of the 15 patients at the 12 week stage. In the case of the 12 week follow-up this reduction in numbers precluded a meaningful statistical analysis. Change in BMI in the first six weeks after admission was best predicted by levels of ill-being on admission ($df = 1$; $R = .641$; $p = .034$) with overweight patients (those with a BMI of above 25) having higher levels of ill-being.

Discussion

This research has been a preliminary attempt to identify those nursing, psychiatric and psychosocial factors that may predict weight change amongst patients on three in-patients wards for people with dementia. Yet is important to note that the results obtained in this preliminary study may be

Table 2: Weight change of in-patients with dementia.

	Six weeks after admission (N = 21)	Twelve weeks after admission (N = 15)
>5% decrease in body weight	4	5
No change	13	6
>5% increase in body weight	4	4

Table 3: relationship between ill-being and healthiness of patients' weights six weeks after admission.

	Six weeks after admission (N = 19)	Mean levels of ill-being
Underweight (BMI less than 18.5)	2	6.00
Within healthy range	10	7.80
Overweight or obese (BMI above 25)	4	4

unreliable due both to the relatively small number of patients included in the study and the number of covariates that we examined. While the models that we produced provide a good fit to the data that we had here, the models are relatively sensitive to outlying values and thus may be of limited use in estimating weight or BMI changes in other settings.

Nevertheless, despite this caution, this is clearly an important area for clinicians not least because of the association between weight loss and higher rates of mortality. The average weight of the 15 patients for whom data were available across the 12 weeks of this study declined from 63.4kg on admission to 62.1kg after 12 weeks. The strongest predictive factor for weight loss at 12 weeks, concerned the presence of physical health and behavioural factors that impeded a person's ability to eat. Those 10 patients in a good state of health with no physical or psychological difficulties that might impede their eating lost an average of 1.03kg. However, those five patients who were either physically unwell, for instance suffering from unstable diabetes or a chest infection, or who consistently declined the chance to eat, lost over twice as much weight (an average of 2.18kg).

Yet, the results also indicate that there seems to be a complex interaction between

psychosocial, nursing and other factors and weight change. For instance, not all patients lost weight – and in many ways, this population is characterised by changes in weight maintenance and stability, rather than by a simple weight loss. Thus almost as many patients at 12 weeks had gained more than five per cent in body weight as had lost the equivalent proportion of body weight. This increase in body weight can partially be explained by medication use and in particular by the use of atypical anti-psychotics. This is consistent with known side-effects of these drug treatments which have shown they can cause moderate weight gain in older people. Moreover, those seven participants who at 12 weeks could be defined as either overweight or obese, had higher average level of ill-being than those patients who were either underweight or within a normal range. It may be that those patients who showed more overt signs of ill-being may be more likely to turn towards food as a source of comfort or were more likely to receive psychotropic medication.

Patient care, therefore, on these in-patient wards should look to identify both those physical and psychological or psychiatric factors which act to prevent individuals from eating, and also higher levels of ill-being. For both groups it is important to prioritise appropriate interventions.

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Tribal stigma

Stéphane Duckett

I here apply Irvin Goffman's model for stigma to the population we serve to see how that might inform my intervention. It raises some potentially uncomfortable questions as to whether we, as psychologists, may on occasion be complicit with an ageist world.

IN A RECENT RADIO INTERVIEW, Harry Cayton, National Director for Patients (BBC News, 3 October, 2006) argued that phrases such as 'frequent flyers' for patients who make regular trips to hospital, 'bed blockers' or 'DNAs' (patients who don't turn up) are demeaning.

Frequent flyers implies that somehow these people want regular trips to hospital, that they are collecting points and that they enjoy the health and life-threatening roundabout of continual admissions, treatment and discharge.

What Mr Cayton is highlighting here is how the use of language from professionals contributes towards stigmatising all patient groups but in particular older patients.

Goffman (1976) defines stigma as any overtly identifying aspects of an individual's presentation that categorises that individual as somehow separate from the general 'norm'. Goffman specifically speaks of three categories of *stigma*. The first are what he calls the 'abominations of the body' or 'physical deformities', the second are 'blemishes of individual character', i.e. 'domineering, unnatural passions, treacherousness, or dishonesty' – qualities that would be inferred from having a conviction for a violent crime, addiction or mental disorder and, lastly, 'tribal stigma', that is the characteristics which identify you as forming part of a particular group such as based on race, religion or as Cayton notes, age.

By definition of course we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination through which we effectively, if often unthinkingly, reduce his life chances.

We construct a stigma theory and ideology to explain his inferiority and account for the danger he represents ... We use specific stigma terms such as 'cripple', 'bastard', 'moron' in our daily intercourse as a source of metaphor and imagery typically without giving thought to the original meaning.'

(Goffman, 1976, p.15)

Goffman goes on to differentiate between what he terms 'virtual' and 'actual' social identity. Virtual refers to what we as onlookers or 'the other' understand of a given individual prior to contact as opposed to what may be the case. I remember once attending a case conference in which a group of professionals attempted to brow-beat a client into accepting residential placement. The client in question had full capacity to make that decision for herself and she responded very much in kind that is assertively. In this instance her virtual social identity, that of being frail and disenfranchised, did not accord with her actual social identity, which was as an accomplished retired academic who knew her mind. However, very clearly this is not always the case and more often than not our elderly clients may indeed find themselves intimidated into taking decisions that they may not necessarily want since:

The stigmatised are tactfully expected to be gentlemanly and not to press their luck; they should not test the limits of the acceptance shown them, nor make it the basis for still further demands.'

(Ibid, p.141)

Goffman talks about the stigmatised subject attempting to 'manage the information', surrounding their stigma in a way of

reducing the tension that emerges from the discrepancy between virtual and actual social identity. For instance an elderly subject may attempt to wear clothes that are more likely associated with a younger person. They may wear make-up or alter their appearance in various ways so as to attempt to 'pass'. The other method of information management that Goffman refers to is 'covering'.

Whereas 'passing' refers to actually altering one's appearance so as to deceive the onlooker, 'covering' refers to an attempt to minimise the presence of stigmata.

It means that the unfairness and pain of having to carry a stigma will never be presented to [normals]; it means that normals will not have to admit to themselves how limited their tactfulness and tolerance is; and it means that normals can remain relatively uncontaminated by intimate contacts with the stigmatised, relatively unthreatened in their identify beliefs.'

(Ibid, p.148)

This is illustrated by a client whom I recently saw; an elderly man who was again quite frail in presentation coming to me and requesting help with managing his communications with professionals, specifically on the phone. He now finds that it takes him a bit more time to generate a sentence. When he knows that he is not responding quickly enough, for instance in a telephone conversation with a public utility representative or the bank, his interlocutor will attempt to fill the apparent void in the conversation by either trying to anticipate his response or simply bringing the conversation to an abrupt end. My initial response to the client's request was to provide him with some pat phrases to allow him to take better control of the situation. For instance, when he knows that he has a difficult conversation to write down the points that he feels he needs to make in bullet points ahead of time so that he is reading from a text in front of him at the phone. Or, if caught unexpectedly, with a simple automatic phrase such as 'let me think about that and I'll call you back'.

However, there is a larger question here that Goffman highlights. Part of my client's anxiety around his delayed communication results from his feeling 'stupid' or that he is going to be dismissed as 'an old fool'. When he becomes more anxious this actually exacerbates his performance. In a sense my providing him with recommendations to 'cover' his stigma, which in this instance is a quavering voice and slowed speech production in fact aids and abets an ageist world which is failing to accommodate my client's needs. The issue here, therefore, is two-fold. In the first instance it has to do with the lack of accommodation mentioned by the professionals providing a service for my client and in the second instance has to do with the extent to which my client identifies with the values expressed by adults, that is if you have the stigma of a quavering and slowed voice you are 'old, foolish and 'stupid'.

'The in-group [stigmatised] and the out-group [normals] then, both present an ego identity for the stigmatised individual, the first largely in political phrasings, the second in psychiatric ones. The individual is told that if he adopts the right line ..., he will have come to terms with himself and be a whole man; he will be an adult with dignity and self-respect.

And in truth he will have accepted a self for himself; but this self is, as it necessarily must be, a resident alien, a voice of the group that speaks for and through him'.

(Ibid, p.149)

Goffman notes how much more difficult stigma are for individuals who have developed the stigma in question later in life when they have had time prior to their actually falling into the stigmatised category to form 'normal views' around what constitutes the stigmatised group such as, in this instance, older people. He/she has therefore internalised the views of an ageist world and seen them as justified such that he/she attempts to cover the evidence of his/her age. Our role as psychologists in this instance becomes more difficult in that we can become tacitly complicit to the intolerance of a wider society.

Is the problem here first and foremost a psychological problem or rather is this not a social problem with psychological consequences? Maybe David Smaill (1993) had it right when he writes *'In order to develop a view of emotional distress which is both helpful and true, one has, I believe, to turn prevalent understandings inside out. Instead of looking inward to detect and eradicate within ourselves the products of 'psychopathology', we need to direct our gaze out into the world to identify the sources of our pain and unhappiness. Instead of burdening ourselves with, in one form or another, the responsibility for 'symptoms' of 'illness', 'neurotic fears', 'unconscious complexes', 'faulty cognitions' and other failures of development and understanding, we would do better to clarify what is wrong with a social world which gives rise to such forms of suffering.'*

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Do older adults with early memory loss wish to be told if subsequently diagnosed with Alzheimer's disease?

Paul Elson

THERE HAS BEEN CONSIDERABLE debate in recent years concerning whether or not patients deemed to be suffering from Alzheimer's disease should be told their diagnosis. A number of studies has shown that physicians are, in fact, reluctant to tell patients their diagnosis and that many such patients are, therefore, not informed (e.g. Rice & Warner, 1994; Vassilas & Donaldson, 1998).

Researchers have adopted various approaches to tackling this question. For example, some studies have sought the views of relatives caring for a person with Alzheimer's disease. These have typically produced mixed findings, with some indicating that the majority of carers are opposed to the idea of disclosing the diagnosis to their relative, while others suggest a more favourable attitude (e.g. Barnes, 1997; Maguire *et al.*, 1996). In contrast, studies that have sought the views of older adult peer groups indicate that many would not want to be told of a hypothetical diagnosis of Alzheimer's disease should they later develop it (Erde *et al.*, 1988; Holroyd *et al.*, 1996).

It is only recently that studies have begun to address the perspective of the patient. Marzanski (2000), for example, found that 21 of the 30 patients whom he interviewed would like to have known what was wrong with them or wished to obtain more information if they already knew. Ten of these patients specified that they would like to know their diagnosis. Similarly, Pratt and Wilkinson (2001) interviewed 24 people, the majority of whom knew their diagnosis, and reported that participants identified a number of opportunities gained from

learning their diagnosis and comparatively few limitations. All of those who knew their diagnosis agreed that patients should be informed of their diagnosis.

There do not yet appear to be any published studies that have specifically sought the views of older adults presenting with memory difficulties regarding their desire subsequently to be informed of a possible diagnosis of Alzheimer's disease. The present study has, therefore, been designed to address this.

Method

Participants were recruited from two NHS Trusts within South Wales and comprised a consecutive sample of patients aged 65 and over referred for investigation of memory complaints. Prior to more formal assessment, they were interviewed concerning their memory difficulties. They were specifically asked whether or not they were suffering any memory problems and, if so, what they considered to be the possible cause and whether they would wish to be informed of the cause if a memory problem were identified. A brief discussion then took place concerning the causes of memory problems in older people, and Alzheimer's disease was mentioned as one of the most common. It was emphasised that this is a progressive disease for which there is presently no cure. Patients were then asked whether or not they would wish to be informed if they were subsequently to be diagnosed with Alzheimer's disease and what were the reasons behind their choice.

Results

A total of 95 patients were referred for investigation of their memory complaints. Of these, 59 denied suffering any difficulties, leaving 36 (38 per cent) patients who were then interviewed (22 women, 14 men). The mean age of participants was 75.9 years ($SD = 5.8$). Twenty-nine patients were later clinically diagnosed with dementia, three with mild cognitive impairment and four were discovered to be cognitively intact and, therefore, non-dementing.

Two-thirds of patients interviewed were uncertain of the cause of their memory problems. However, the remaining patients attributed their memory problems to a variety of causes, the most common being those related to physical health (e.g. stroke; nutritional deficiency), mental health (e.g. stress; depression) and 'old age'.

The majority of patients (31, 86 per cent) stated that they would like to be informed of the underlying cause of their memory problems in a general sense, while slightly fewer (25, 69 per cent) wished to be told if specifically diagnosed with Alzheimer's disease. Participants shared a variety of reasons underlying their decision to be or not to be informed of a diagnosis of Alzheimer's disease. Among those who wished to be told their diagnosis, the most common reason related to the desire to develop advance plans, a wish to be kept well-informed, the facilitation of psychological adjustment and the consideration of treatment. In contrast, the most common reason cited by those people who did not want to be told their diagnosis is that it would cause anxiety or distress.

Discussion

A number of findings emerged from the present study. First, it is clear that many patients were presenting to services without having formulated a clear understanding of the underlying cause of their memory difficulties. It is, therefore, important that any subsequent conversation that the physician may have with the patient concerning the

issue of Alzheimer's disease as a possible cause of memory difficulties, and certainly any intention to disclose the diagnosis, must be conducted with the utmost sensitivity.

Another finding to emerge from the study is that the majority of patients wished to be informed of the overall underlying cause of their memory problems although slightly fewer wished to be told if specifically diagnosed with Alzheimer's disease. This could suggest that some patients only wish to know the cause if it is more benign and the comments made by these people seemed to support this. Nevertheless, the majority of patients did express a desire to know their diagnosis, and therefore the current tendency of practitioners frequently to disclose the diagnosis to carers but not to patients can no longer be justified. However, it is important to recognise that a significant minority of patients did not want to be told of a possible subsequent diagnosis of Alzheimer's disease. This highlights the need to consider each case individually and not routinely to disclose a diagnosis of Alzheimer's disease to patients deemed to be suffering from this disorder.

The present study represents a first step towards ascertaining the preferences of patients presenting with memory complaints subsequently to be informed of their diagnosis and also illustrates the value of discussing these issues with patients prior to conducting investigations. The study also demonstrates that a significant proportion of patients (in this study, nearly 4-in-10) are willing and capable, both cognitively and emotionally, of engaging in discussion around what is a highly sensitive and emotive issue. Further research is now needed to build on these findings.

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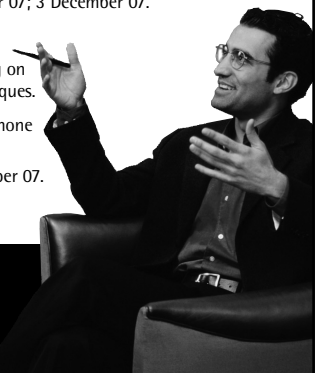
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What are the stressors of carers for older people with dementia: A literature review

Jonathan Hutchins

IN THE UK, THERE IS A GROWING awareness that the population is ageing, with an estimated over 50 per cent of the population being 60+ in the next 10 years. This has been highlighted, on the political stage, by the recent pensions crisis.

With more people ageing there will, inevitably, be the need for more relatives to become carers of older adults due to shortage in services. Indeed, the only option may become private nursing homes for individuals who require additional help or have full time care needs. Furthermore, relatives needing to become carers puts additional strain on their employment responsibilities. Starrels, Ingersoll-Dayton, Dowler and Neal (1997) carried out a study on 1585 employees in America who were caring for an elderly relative whilst working. They identified cognitive and behavioural problems as the strongest predictors for stress in adult caregivers. This has direct effects in terms of the emotional, physical and financial strain that resulted as well as indirect effects on their personal and working lives. This led in some cases to increased staff absenteeism, reduction in work hours, and caregiver refusing promotion. Therefore, the increase in people entering the caring role has implications for the economy and employers, as well as for the carers themselves.

In conjunction with these changes, recent media campaigns have highlighted that older people are more vulnerable to abuse. Indeed, around 1-in-5 older people are abused by people in a caring position. Therefore, one area that is key is carers' needs, and how stressful they may find the situations they are in caring for a relative and how these stressors can be supported from a service point of view.

As part of the NHS services provided by an older people community mental health team, there is a need for psychological support to be offered to carers of clients who have dementia. This is because of the inevitable impact this may have in terms of the client being admitted onto an in patient ward – should care at home break down. The importance of psychological approaches has only increased with the withdrawal of pharmacological treatments that may slow the dementia process, due to a proposed lack of cost effectiveness in the NHS.

It is important to consider what are the primary stressors for carers according to the current research. Starrels *et al.* (1997) highlighted that emotional or cognitive behavioural difficulties in the older person appeared to be more associated with increased levels of emotional, physical and financial stress. A further study that examines if clinical diagnosis and disability are predictors of stress in carers was carried out by Cullen, Grayson and Jorm (1997). Cullen *et al.* (1997) focused on including detailed clinical measures of the severity of cognitive impairment in the older person in 90 older people living in the Australian community with a carer. They also examined the level of disability in the older person by asking their carers information on the older person's behaviour and personality, as well as reporting on their own well-being. They found that the carers' rating of disability in the older person, and of disturbed behaviour, were the strongest predictors for carer well being, in comparison to the relationship between the carer and older person, or the sociodemographic characteristics of the older person or carer. In addition, the further social and work implications are also

stressful (Starrels *et al.*, 1997) to adult caregivers, which can result in feelings of emotional and physical exhaustion.

A study that examined the carer role and their relationship to the older person more closely was carried out by Lyonette and Yardley (2003). These authors examined the influence of work related, carer related and personal factors on carer outcomes in 204 female carers who were working. The authors created two specific measures relating to the personal factors of caring. They examined the external pressures of caring such as guilt, the older person's expectations of care, and perceived disapproval of others. They also examined both intrinsic and extrinsic motivations for caring, as well as the relationship the caregiver had with the recipient in terms of respect, admiration of the older person, or if there was a struggle for power, and if the older person was resistant to caring efforts. The authors highlight several key areas that may make caring more stressful for the caregiver. For example, the carer living with the care recipient, and having a closer relationship with the care recipient were associated with increased carer stress. The authors found that greater extrinsic motivations to care and poorer quality of the relationship with the older person were the most significant predictors of carer stress. The perception of carers towards external pressures, such as feelings of guilt, duty, responsibility, etc., was in turn associated with increased levels of carer stress. Carers who had more intrinsic motivations towards care, such as having admiration for the older person and a better quality relationship with the older person were likely to experience lower levels of stress.

Braekhus, Oksengard, Engedal and Laake (1998) conducted an in-depth study with dementia patients and their carers, which examined social and depressive stress suffered by 92 spouses of patients with mild dementia who attended a memory clinic. The results showed that 25 per cent of spouses highlighted always or often having problems with the following: being

depressed by the situation; having difficulties in getting away on holiday; social life being affected; household routines being upset; and, sleep being interrupted. They also found that social stress was significant and was associated with the patient's level of activities in daily living. Furthermore, they found that carer depressive stress was associated with low mood and behaviour in the client, and that low levels of social support related strongly to depressive complaints in the carer.

Both of these studies highlight the complexity of the carer – client relationship, and how depression in the client can increase carer stress (Braekhus *et al.*, 1998). In addition, disability in the client strongly affects carer well being (Cullen *et al.*, 1997). Beyond the client-carer dyad, the carer's cognitive appraisal of the older person's disability, and the reduction of social roles for the carer in work and personal life (Starrels *et al.*, 1997) were also strong predictors of carer stress. What has not been addressed, to my knowledge, is any additional contribution of cultural factors.

Nonetheless, this research may give services insights as to how to help improve carers' coping.

One such study sought to prevent carer stress and to identify service needs (Nankervis, Schofield, Herrman & Bloch, 1997). The authors sought to identify unmet needs in families of clients, and included 67 carers. Most participants were married, middle aged women looking after parents or husbands of whom half were aged 80+. The authors found unmet needs in most of the families visited, and that service barriers often prevented some needs being met. The authors highlighted carer stress and burden as key unmet needs and recommended more counselling and service supports being available.

Another study, examining the carer-client reciprocal relationship from a service perspective, was carried out by Hoskins, Coleman and McNeely (2005). This was an uncontrolled evaluation of the effectiveness of interventions offered by a community

mental health team (CMHT) to carers of clients with dementia over a two-year time period. The authors used the Carer Strain Index to compare scores of carer stress from initial assessment, to three- and six-month follow up. After initial assessment, the team offered a range of interventions to carers including, providing care workers, providing specialist workers in order to improve memory functioning for clients in their own homes, offering respite care, a carers group and the input of the multidisciplinary team. The authors particularly emphasised the carers group, which provided psycho education, peer support, and goal orientated solutions. Furthermore having strong lines of communication between the team and the carer were also important factors providing practical support quickly. The results showed the interventions the CMHT offered were effective at reducing carer stress from 9.23 in the initial assessment to 6.63 after three months of interventions to 4.12 after six months of intervention. The authors advocate regular use of the Carer Strain Index by CMHTs in order to see if carer needs are being met.

An important consideration for a service is to consider the current services that are available and if they are effective in reducing carer stress. One type of service that is on offer is a day centre that offers treatment, assessment and respite care for older people with dementia and mental health problems. A study carried out in Ireland by Fell, Kenny and MacLachan (2001) examined the benefits to carers of 40 older people. They asked carers to complete measures of carer burden, psychological distress, perceived social support and coping styles. They found that older people's attendance to a day centre did not alleviate carer burden or distress. Furthermore, carer burden and support satisfaction were independently related to psychological distress, whereas coping styles and the number of social supports were not related to carer burden. This research indicates that satisfaction with social support is important.

Another study examining the effectiveness of particular coping methods was carried out in the UK by Graham, Ballard and Sham (1997). They wanted to see if there was an association between 109 carers' knowledge of dementia and levels of physical and psychological distress, and whether knowledge would affect a carers' cognitive appraisal of the situation. The authors found that more knowledgeable carers experienced lower levels of depression but higher rates of anxiety, and that high levels of knowledge did not affect physical health. Furthermore, carers were more likely to have reduced expectations of the older person, and would make positive comparisons with other people as well as feeling more competent and confident as care givers.

These two research studies examine particular interventions that services have offered in terms of increasing carer knowledge of dementia and offering day care services to older people, which may as a result reduce carer burden. The offering of a day service appears to be ineffective in reducing carer stress (Fell *et al.*, 2001) and increasing carer knowledge may reduce depression in carers but potentially increase anxiety (Graham *et al.*, 1997). However, one consistent theme appears to be the importance of cognitive appraisal of the carer's situation to how much stress they experience.

Most research has used quantitative methods, with questionnaires and rating scales examining specific aspects of the carers' experience, stress levels and coping mechanisms. However, it may be possible that a qualitative approach based on open ended questions about carers' current experiences might reveal different results.

One such study looking at spouse carers of people with Alzheimer's disease was carried out by Murray, Schneider, Banerjee and Mann (1999). They interviewed 20 carers from over 14 different countries in the European Union using a semi-structured interview. The most common difficulties expressed were a loss of companionship through diminished quality of communica-

tion, loss of reciprocity as carers experience their partners' growing dependency on them, and deterioration in their partners' social behaviour. Satisfaction from carers came from continued reciprocity, mutual affection, companionship, feeling job satisfaction and the fulfilment of a sense of duty. The authors argue that the responses given from carers from 14 countries express a commonality of experience in the role of caring. Consistent with Lyonette and Yardley (2003), a better quality relationship with the older person was linked to reduced carer stress.

In summary, a number of important stressors have been highlighted by this research, including depressive symptoms in clients (Braekhus *et al.*, 1998), the behaviours of the older person and perceived disability in the older person from the carer (Cullen *et al.*, 1997; Starrels *et al.*, 1997). These stressors can result in reduction of social and work roles in the caregiver, and exhaustion both emotionally and physically (Starrels *et al.*, 1997). In terms of mediators for these stressors, cognitive appraisal has been highlighted as an important area (Cullen *et al.*, 1997) as well as increased psycho-social support and counselling for carers (Lyonette & Yardley, 2003; Nankervis *et al.*, 1997; Hoskins *et al.*, 2005). The mediator stress and coping model (Taylor, 1998) may be a helpful theoretical framework to consider researching or intervening in these areas. Clearly, more research is needed. This could combine quantitative and qualitative approaches, sampling carer stress and psychological distress, and assessing the effectiveness of different psychological interventions.

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PSIGE Research Prize, 2007

THE PSIGE NATIONAL COMMITTEE is delighted to announce the winner of the PSIGE Research Prize, 2007.

Trainees who completed a research thesis relevant to the needs of older people and who graduated between 2004 and 2006 were invited to submit a 3000 word paper. The prize is registration at the PSIGE Conference in Nottingham, 4–6 July, 2007, and an invitation to present the winning research at the conference (bursary value £500). The winning paper will also appear in the Conference issue of the *PSIGE Newsletter* (October, 2007).

We received some excellent submissions so that it was with difficulty that we selected a winner. Please join us in congratulating Dr Susan Pooley. Susan graduated from Salomon's Course in 2006 where she conducted her research under the supervision of Dr Sue Holttum, Dr Paul Camic and Dr June McNicholas. Her research title was: 'Maintaining affectional bonds: The significance and meaning of companion animals for pet owners living in homes for older people'.

In addition, the committee would like to commend Lucy Birch and Paul Wendon for their papers. Lucy's work has been accepted for publication in the *British Journal of Clinical Psychology*, and Paul Wendon's article will also appear in a forthcoming issue of the *PSIGE Newsletter*.

News of Members

Geographical Group web pages on psige.org

Yorkshire and Humberside have led the way with taking ownership of their web page on the PSIGE website. This has been spearheaded and co-ordinated by Clare Hilton. The National Committee applauds Clare and her colleagues for their hard work. We could encourage other Geographical Groups to follow this great example by increasing their input to the website, perhaps beginning with their own web pages. This can be done in liaison with Patrick McGuinness, Tel. 020 8663 8124 (direct) or 020 8663 8137 (admin) or at patrick.mcguinness@slam.nhs.uk.

Updates for Members

What older people want from community health and social care services – research paper

Age Concern (National Council on Ageing, supported by the Department of Health) commissioned Age Concern Research Services to carry out a series of focus groups with older people, and older carers in order to identify what older people want from social care and health services. A White paper describing the results of this process, *What older people want from community health and social care services*, issued 30 January, 2006, can be downloaded from <http://www.ace.org.uk/AgeConcern/Documents/community-health-paper0106.pdf>.

Book Reviews

Spiritual Growth and Care in the Fourth Age of Life

Elizabeth MacKinlay

Jessica Kingsley Publishers. 2006.

272 pages. Paperback. £17.99. ISBN: 978-1-84310-231-1



In her latest book, MacKinlay covers:

- 'Latest research' on the study of 'ageing, spirituality and religion';
- A summary of the research that forms the basis of this book;
- A spiritual assessment tool developed by the author via her studies;
- 'Spiritual tasks of ageing' including 'the search for ultimate meaning' and responding to life's meaning;
- 'Spiritual reminiscence' including suggested topics for six weekly group sessions;
- 'Mental health and dementia';
- 'Worship and use of ritual';
- 'Vulnerability and transcendence';
- 'Relationship and intimacy needs';
- 'Grief, death, dying and spirituality';
- 'Main ethical issues of later life';
- MacKinlay's 'model of spiritual growth and care in the fourth age of life'.

Every chapter has an introduction, conclusion and summary, sometimes complemented by a list of further readings. It has really touched me at times, e.g. when talking about existential or spiritual pain, or when exploring Tornstam's 'gerotranscendence' (1999/2000) as 'a move to a more reflective life' (p.161).

It is a book that may take the psychologist

by surprise, e.g. when MacKinlay includes psychological activities such as 'listening to a patient' or 'facilitating reminiscence' in her list of spiritual behaviours and actions. When reading on, however, the overlap between the psychological and spiritual functions becomes apparent. In addition her, at times, ethnocentric wording, both in the text and in her assessment tool, make it uncomfortable to read.

It is a good book for nurses and ministers; which comes as no surprise given that the author is a nurse and Anglican priest herself. Patients and carers may benefit from it. For psychologists, it may serve as a starting point for further reading or research, or both. Taking her message, that there are spiritual tasks in ageing, to heart will be helpful to psychologists.

Dr D.D.S. Fabry

Doctorate in Clinical Psychology,

Newcastle University.

Depression in Later Life

Jill Manthorpe & Steve Illiffe

Jessica Kingsley Publishers. 2005.

160 pages. Paperback. £13.95. ISBN: 978-1-84310-234-2

Depression in Later Life summarises a range of key issues in relation to this problem specifically as it may affect older people. As such, it differentiates a range of different presentations of depression, such as major, minor, dysthymia, etc., and their defining features, using older adult case scenarios and recommended action plans. The focus of this book is on medical treatment options as opposed to more therapeutic interventions. There are clearly presented chapters that explain the differences between depression and dementia as well as the overlap with anxiety and/or psychosis. The issues of suicide and

self-harm are discussed and the importance of a careful risk assessment stressed. The wider social and familial contexts of depression are included in chapters regarding the importance of carer support and health promotion/prevention. This book provides a clear, readable overview to this area and as such could be recommended as an introductory text for practitioners or as a resource for carers and sufferers.

Angela Kent

Derbyshire.

Obsessive-Compulsive Disorder

J.S. Abramowitz

Hogrefe & Huber. 2006.

104 pages. Paperback. £16.45. ISBN: 978-0-88937-316-7

The book is written to aid mental health professionals when working with individuals with OCD. It describes the conceptualisation, assessment and treatment approaches for OCD from a cognitive behavioural perspective, this being the empirically supported approach.

In terms of content, this book begins with definitions of OCD and describes diagnostic procedures, reviewing the diagnostic tools available and providing details of how to access them. It presents a brief but clear overview of a number of theoretical models used to understand OCD, with the main focus on CBT. The final chapters on assessment, formulation and intervention cover practical considerations for working with people with OCD, for example what should be included in the assessment, how to present the formulation and rationale for a CBT approach to OCD, treatment plans, and intervention techniques. A useful addition to

the book is an appendix consisting of tools and resources that can be reproduced for client work.

The book is clearly written, concise and easily accessible. The use of vignettes and 'clinical pearls' help to illustrate and bring to life the use of practical techniques in clinical work. Sections are well sign posted and easy to find, with markers at the side of the text to help direct to the relevant section. The main strength of the book is the combination of the cognitive-behavioural theoretical understanding of OCD with an emphasis on practical considerations and techniques for the application of this model. It is a really useful and accessible practical resource for both clinicians and trainees working with individuals with OCD.

Katherine MacKinnon

*Trainee Clinical Psychologist,
University of Southampton.*

The Psychology of Ageing (4th edition)

Ian Stuart-Hamilton (Ed.)

Jessica Kingsley. 2006.

352 pages. Paperback. £19.99. ISBN: 978-1-84310-426-1

As promised, this book provided a 'judicious range of references suitable to readers from different backgrounds', making it widely accessible as an introduction to gerontology. The depth and breadth of this book was quite astounding; it is difficult to think of a perspective of gerontology which has not been covered. Moreover, by means of good humour and an easy style, the author has skilfully ensured that this extensive volume of research is an easy and pleasurable read.

As a teacher of psychology, I was impressed by the clear, straightforward way the text was written, making clever and effective use of analogy throughout to easily explain some of the more difficult concepts of gerontology and indeed, Psychology in general. Such clarity makes the book under-

standable and a valuable resource to both those with no familiarity with gerontology as well as those with a more extensive knowledge of the subject. I am sure that I will be quoting text from Prof. Stuart-Hamilton's book to my students in future psychology classes.

The extensive range of research captured and used throughout the book led to a thought-provoking conclusion, which visibly demonstrated the author's passion for the subject and left me hungry for further reading.

Sarah Large

Teacher of Psychology,

St. Augustine's College, Trowbridge.



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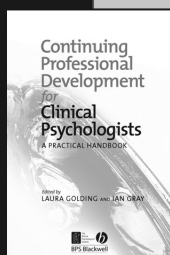
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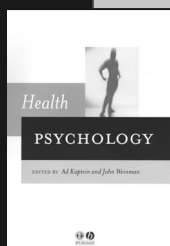
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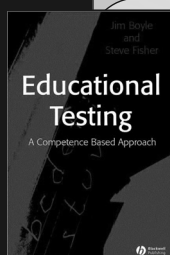


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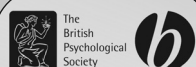
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9.30am Registration
10.00am Welcome and Introduction
4.45pm Close

The National Collaborating Centre for Mental Health and The Royal College of Psychiatrists' Education and Training Centre presents:

THE NICE CLINICAL GUIDELINE ON BIPOLAR DISORDER CONFERENCE

The guideline was developed by the National Collaborating Centre for Mental Health (NCCMH) for NICE and was launched in July 2006. The conference will present the key findings of the guideline with an emphasis on the practicalities of implementation in primary care, secondary care and CAMHS. The programme includes speakers from a variety of fields, including service users who have been involved in the development of the guideline.

Who should attend: Psychiatrists, psychologists, nurses, primary and secondary care professionals.

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Conference Programme:

9.30am Registration and Coffee

10.00am **Welcome and Introduction**
Chair: Mr Paul Farmer, Chief Executive, Mind

10.10am **Current Priorities in Mental Health**
Dr Hugh Griffiths, Deputy National Clinical Director for Mental Health

10.45am **Service Issues and the Challenges of the Guideline: A Professional Perspective**
Mr Stephen Pilling, Facilitator of Bipolar Guideline Development Group (GDG), Joint Director NCCMH and Consultant Clinical Psychologist, Camden and Islington Mental Health and Social Care Trust

11.10am **A Service User's Perspective on the Guideline Development and its Implications**
Mr Robert Westhead, Service User Representative, GDG and Project Manager, Shift Programme, National Institute of Mental Health (NIMHE) and Care Services Improvement Partnership (CSIP)

11.30am Morning Refreshments


National Institute for
Health and Clinical Excellence



12.00pm Workshops

A. Psychological Treatments, Psychosocial Treatments and Lifestyle Advice for Bipolar Disorder

Professor Dominic Lam, Professor of Clinical Psychology, University of Hull

B. Medical and Pharmacological Treatments of Bipolar Disorder

Dr Peter Haddad, GDG member and Consultant in Community Psychiatry, Bolton, Salford and Trafford Mental Health NHS Trust

C. Specialist Services Provision for Bipolar

Professor Richard Morris, GDG member and Professor of Psychiatry and Community Mental Health, University of Nottingham and Queen's Medical Centre, Nottingham University Hospitals NHS Trust

1.00pm Lunch

2.00pm Workshops

D. The Diagnosis and Treatment of Young People and Children with Bipolar Disorder

Dr Tamsin Black, Consultant Clinical Psychologist, The Coburn Adolescent Service, East London and the City Mental Health NHS Trust

E. Early Intervention Services

Dr Clare Lamb, GDG member and Consultant Child & Adolescent Psychiatrist, North Wales Adolescent Service, Conwy & Denbighshire NHS Trust

F. Implications for Primary Care Services

Speaker to be Confirmed

3.00pm Afternoon Refreshments

3.30pm Panel Session

Chair: Mr Paul Farmer and Mr Stephen Pilling
Panel: Workshop Speakers

4.30pm Key Research Questions

Professor Nicol Ferrier, Chair of the GDG, Professor of Psychiatry and Head of Neurology, Neurobiology and Psychiatry, University of Newcastle upon Tyne

4.45pm Close of Conference

For more information and enquiries please contact our Programme Administrator on 020 7977 6652/57 or visit www.rcpsych.ac.uk





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The NICE Clinical Guideline
on Bipolar Disorder Conference**

Wednesday 6 June 2007

Please indicate which workshop sessions you would like to attend:

12.00 - 13.00: A B C
14.00 - 15.00: D E F

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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 (i.e. October for the January issue, January for the April issue, April for the July issue, and July for the October issue).

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.

Submission Procedure

Please submit articles as a Word file via e-mail to romola.bucks@soton.ac.uk. Language should be inherently respectful to older people and consistent with the British Psychological Society's guidelines. Formatting should be consistent with BPS guidelines.

When submitting articles please send the following information:

- Full name
- Affiliation (title, place of work)
- Contact details (should you be willing to be contacted by the membership)
- Acknowledgements (as appropriate).

Finally, if you are reporting research, please indicate whether or not Ethics Committee approval was awarded, and by which Ethics Committee, or whether the work was carried out as an audit/service evaluation project.

Letters to the Editor

The Editor welcomes correspondence which combines brevity with rational argument. Letters may be edited if more than 250 words in length.

All contributions should be sent to: romola.bucks@soton.ac.uk

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