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 Editor
Arlene Astell

WELCOME to this issue of the Newsletter, which contains a lively mix of articles from up and down the UK and across the range of experience, from newcomers to the field of working with older adults to some old hands. I am constantly delighted at the steady stream of submissions that appear in my inbox and hope that you will find the contributions in this edition both enjoyable and thought-provoking but also that you will be inspired to submit something for a future issue.

We kick off with two articles on bereavement. First is Susanne Iqbal and David Gracey’s review of the impact of bereavement on cognitive function in older adults. Susanne and David provide a systematic examination of the available literature that I am sure many readers will find useful in their day-to-day work. This is followed by a short contribution from Stéphane Duckett proposing an ecological framework for understanding bereavement. This paper was prompted by an article last year on the impact on older men of the death of their wives (issue 103, 11–22).

Whilst death may have lost some of its taboo status, Laura Meader’s article addresses an issue that many still find difficult to talk about – the sexual needs of older adults living in residential care. This sensitive and thoughtful piece, based on her experiences working as an Assistant Psychologist in an In-Reach team, will, I’m sure be welcomed, by many readers.

A timely but possibly controversial article from Paul Green follows this, raising issues about diagnosis of early or young onset dementia. Paul is a Liaison Nurse and writes from his experience in a memory clinic service, which does not include Clinical Psychology as part of the core team. Paul also raises the issue of provision of psychosocial interventions for clients attending such services and who should deliver them. I am sure many readers will have views on the issues raised in this piece and I would welcome any brief letters for consideration for publication in the next edition of the Newsletter.

A second article on dementia follows from the perspective of another two Assistant Psychologists. Christine Slaughter and Melanie Steeden share their experiences of working in a Home Treatment service for people with dementia. Following this we change direction with Syd Hiskey’s piece on interventions for reactivated PTSD in older adults. Syd shares some interesting insights and advice gained from clinical experience that should chime with many readers.

The next two articles are broadly concerned with stroke. Sophie Dewar and colleagues describe their experiences evaluating an informal support group in stroke rehabilitation. Further experiences are shared in Rachel Attfield and David Wallace’s article on staff training in the jigsaw approach to psychosocial care for people who have survived stroke. The information about barriers to implementation will ring bells with anyone who has carried out staff training and wondered why it never gets into practice.

Ann Davis and colleagues’ article presents some positive insights into care giving drawn from Parkinson’s disease. Finally, the positive theme continues with the paper by Mike Lowis and colleagues looking at optimal ageing. So from death to living as well as possible, that completes the selection for this issue. Enjoy and I look forward to receiving many more insightful, engaging, amusing and uplifting articles over the coming year.

Arlene J. Astell
HOPEFULLY by the time that you read this it will be Spring. It’s been a cold and snowy Winter, which is unusual for this part of the country. The highlight of the Winter for PSIGE was the launch of the National Dementia Strategy on 2 February. This happened to very neatly coincide with a National Committee meeting on the third. As you can imagine it somewhat dominated our discussion, but it gave us a chance to compose a press release for the British Psychological Society.

‘The key problem with the new strategy is that is fails to bite the bullet and recognise that major service redesign is required. It advocates setting up new memory services in addition to all the existing services. This will simply add to the confusion as to who looks after whom. Our group believes that to improve care, all the existing services should be amalgamated into a single memory service that caters for people from the diagnosis of dementia to their death.’

Other problems with dementia care the psychologists fear the new strategy may not tackle include:

- The stigma that still accompanies a diagnosis of dementia.
- A lack of access to therapy services – older people’s mental health teams often have fewer therapists than teams that work with younger clients.
- An over-reliance on memory clinics – innovative services that address people’s changing needs as dementia progresses are important.
- A lack of research – particularly research into psychosocial interventions rather than medical solutions.

Unfortunately the launch of the strategy coincided with a week of adverse weather and after the day of the launch it got lost in the snow reports!

I will keep you informed of other developments in my next letter.

Sinclair Lough
PSIGE Chair.
Bereavement and cognitive function in late-life: A review
Susanne Iqbal & David Gracey

A critical review was carried out to investigate the impact of bereavement on cognitive functioning in older adults. Drawing on electronic databases, reference lists, and relevant journals, articles published between 1974 and January 2008 which reported on bereavement and cognitive functioning in older adults were identified. Five studies (two longitudinal and three cross-sectional studies) fulfilled the inclusion criteria. Although valid conclusions could not be drawn due to the small sample size and other methodological limitations (e.g. differences in cohorts, ages, measures, study design), the current review tentatively revealed that bereavement (and possibly complicated grief) may have a negative impact on cognitive functioning in older adults, to which men seemed particularly vulnerable. High stress levels may also be associated with cognitive decline, although it is still unknown whether these effects are reversible or not. Implications for clinical practice and research are discussed.

Late life and bereavement

The average lifespan is now longer than ever before and the number of older adults is increasing rapidly. Older adults are normally defined as 65 years and older but have been further categorised as young-old (65–75 years), old-old (75–85 years), and oldest-old (85 years plus; Laidlaw et al., 2003). However, older adults are the least homogeneous of all age groups (Futterman et al., 1995) and a better understanding of ageing may be achieved by adopting a developmental perspective which considers coping, resistance to disease, adaptation, disablement, emotional and cognitive functioning (Laidlaw et al., 2003).

Bereavement is defined as the objective situation of having lost a significant other (parents, partners, siblings, friends; Stroebe et al., 2001). Older adults experience the greatest number of bereavements (Hansson & Stroebe, 2007) including loss of a spouse, which is considered one of the most stressful life events (Fitzpatrick, 1998). Grief reactions and grieving, i.e. the process of coping with bereavement (Hansson & Stroebe, 2007), can persist over a long time.

Grief is primarily an emotional reaction to the loss of a loved one. It has many diverse socio-behavioural, physical, psychological and cognitive manifestations (Hansson & Stroebe, 2007). Distinctions have been made between ‘normal’ and ‘complicated’ grief (CG; Prigerson & Jacobs, 2001). In ‘normal’ grief an individual may experience acute suffering but does not experience this as unbearable (Hansson & Stroebe, 2007). In CG an individual experiences symptoms of separation distress (yearning, searching and pre-occupation with the loss) and traumatic distress (disbelief, emotional detachment, bitterness: Prigerson et al., 1999). These symptoms cause significant impairment in functioning for at least two months. Whilst symptoms of depression frequently overlap with grief reactions, a recent review concluded that CG is distinct from both depression and post-traumatic stress disorder (Lichtenthal, Gruess & Prigerson, 2004).

Cognitive functioning

It has been suggested that bereavement may have an impact on cognitive functioning. However, when studying cognitive functioning in older adults, two intellectual abilities need to be considered: ‘crystallised’ and ‘fluid’ intelligence (Horn & Cattell, 1967). Crystallised intelligence represents (acquired) memories and learning (verbal ability and knowledge; Baltes, 1993, 1997) and is measured by most of the verbal subtests of the Wechsler Adult Intelligence
Scale-III (WAIS-III; Wechsler, 1997). Fluid intelligence connotes spatial orientation and basic processing of information (Baltes, 1993, 1997) and is measured by most of the performance subtests of the WAIS-III. Whilst crystallised intelligence increases from childhood throughout adult life and remains relatively stable into the mid-70s, fluid intelligence begins to gradually decline when people get into their 50s (Singer et al., 2003).

Cognitive impairment

It is important to detect cognitive impairment in older adults, which may occur in five per cent of people over 65 (Whalley & Mowat, 2007). However, whilst cognitive functioning may decline as people age, there are major individual differences in rate and onset of decline (Baltes & Baltes, 1990). Whereas a decline in memory functioning is observable in some older adults, others maintain a high level of functioning until a very advanced age (Schaie, 1994). Better memory functioning has been associated with a higher level of education and good physical health (Perlmutter & Nyquist, 1990).

Cognitive decline has been seen as the defining feature of dementia (McKeith & Cummings, 2005). Detection of mild cognitive impairment (MCI; abnormal cognitive functioning not severe enough to meet criteria for dementia) is a key clinical issue because it is associated with accelerated cognitive deterioration and possible conversion to dementia (Steffens & Potter, 2007). The rate of MCI conversion to Alzheimer’s disease is an estimated 10 to 25 per cent per year compared to one to two per cent in healthy controls (Petersen et al., 2001).

Rationale for review

The accumulation of losses and grief experiences can have complex affective and cognitive consequences (Hansson & Stroebe, 2007). Studies on bereavement consistently show that losing a spouse is related to a decline in physical health (Parkes, 1996) and depression (Bennett, 1998; Kraaij, Arensman & Spinhoven, 2001). Cognitive impairment is common in geriatric depression (King & Caine, 1996; McBride & Abeles, 2000), and depressed older adults with co-morbid cognitive impairment may have adverse cognitive outcomes, resulting for example, in hippocampal atrophy (Steffens & Potter, 2007). Furthermore, the cognitive neuroscience of depression highlights a crucial relationship between mood and structural changes in the ageing brain (e.g. shrinkage of the hippocampus).

Until recently, the question of whether grief is associated with cognitive impairment received little attention (Ward, Mathias & Hitchings, 2007). There is some evidence, however, that loss of a spouse is related to some decline in cognitive functioning (e.g. Aartsen, 2003; Grimby, 1993; Sands, 1981–1982) and this would have implications for clinical practice. Whilst it has been recognised that it is important not to misdiagnose depressed older adults as having incipient dementia (e.g. Palsson et al., 2000), the same may apply for those who are grieving following a bereavement. Therefore, it is important to know if bereavement impacts on cognitive functioning. The purpose of this critical review was to summarise and critically evaluate the literature from 1974 to January 2008 to examine what impact bereavement has on cognitive functioning in older adults.

Methodology

Search strategy

A computerised search was conducted using PsychInfo, Medline, ScienceDirect, EBM Reviews, Google Scholar, and the Alzheimer’s Society’s website. The search was restricted to the period between 1974 (when the first study was reported) and January 2008. Furthermore, the PSIGE Newsletter, and reference lists of all identified articles were manually searched. Boolean searching was applied using the following terms: late/r life, stressful life events, bereaved, bereavement, traumatic/complicated/pathological/abnormal grief, grieving, mourning, widow(er)/s/widowed, cognitive functioning/performance/impairment, intellectual functioning,
memory performance, older adults/people, elderly. Leading researchers were contacted to identify possible articles in press. The above search strategy identified 10 articles.

**Inclusion/Exclusion criteria**

Studies reporting on bereavement and cognitive functioning in older adults (≥65 years) were included in this review if they were published in a peer-reviewed journal in English. Of the 10 articles identified, five were excluded: Amster and Krauss (1974) included subjects who had suffered a stroke; Sands and Parker (1978) and Sands (1981–1982) used tests on older adult populations for which no normative data existed; Gribbin et al.’s (1980) participants were aged 40 to 88; Grimby’s (1993) study was a sub-study of the longitudinal multidisciplinary Intervention study of Elderly in Goteborg (IVEG) (Eriksson, Mellstrom & Svanborg, 1987). Her data were included in Grimby and Berg (1995). Whilst an attempt was made to include only studies which reported on age groups ≥65 years, due to the limited literature and paucity of high quality studies, Aartsen et al.’s (2005) and Rosnick et al.’s (2007) studies were included although their participants were 60+. It was considered acceptable to include these two because reliance on chronological age is not that helpful in older adults (Laidlaw et al., 2003). Furthermore, norms exist for several neuropsychological tests (Taylor, 1991), which group 60- to 69-year-olds together. Thus, in total only five studies were included in this review.

**Review of studies**

The present paper reviewed what impact bereavement has on cognitive functioning in older adults. The five included studies were grouped according to study design (longitudinal or cross-sectional). Individual studies were summarised and critiqued separately, from the earliest to the latest, because they used different populations and measures. A general critique and discussion is provided at the end, followed by implications for clinical practice and research.

**Longitudinal studies**

Grimby and Berg (1995) recruited 520 Swedish urban citizens, aged 70 to 76 years, from the IVEG. They assessed the relationship between most stressful life events (health- and death related events, children’s divorce, change of dwelling) and cognitive functioning. Cognitive functioning was measured at 70 and 76 years. A stressful life event interview was conducted at age 76. Life events were recorded in pre-coded categories used in research on life stresses in old age (Mensh, 1983). Tests measured life events, general health, memory functioning, verbal and spatial abilities and perceptual speed. Block design, paired-associate learning, verbal meaning test and memory tests were used.

Descriptive statistics were used for only 275 (129 men and 146 women) of the sample as 245 participants had either died or were too ill to participate. Group and age effects were compared with Pitman’s permutation test. A decline in cognitive functioning was reported for the entire sample, irrespective of stressful life events. Bereaved subjects (eight men and 15 women) showed a significantly (p<.05) larger deterioration in spatial ability. Gender comparisons revealed that bereaved men showed a significantly larger decline in verbal meaning, spatial ability, and digit span backward tests. The authors concluded that the bereavement situation might affect cognitive abilities, with men appearing particularly vulnerable.

Strengths of the Grimby and Berg (1995) study include the longitudinal design and recruitment of a relatively large sample. However, whilst longitudinal studies are advantageous because conclusions can be drawn about causal relationships between variables, the high attrition rate (N=245) threatens the reliability and validity of this study. Attrition is usually greater among the oldest respondents (Hansson & Stroebe, 2007). Conclusions drawn from those who remained in the study (probably the healthiest and most adaptive) are not generalis-
able. Further limitations include the failure to record the magnitude and exact date of events prior to the study. Cognitive functioning tends to be influenced by the magnitude of stressful events (Fitzpatrick, 1998) and ‘peaks’ in grieving exist at different durations of bereavement (Hansson & Stroebe, 2007). No psychometric properties were reported for the measures, although the authors stated that the cognitive tests had been validated and applied to older adults for several decades in Sweden.

Aartsen et al. (2005) recruited 1144 (474 women and 690 men) married, Dutch participants, aged 60 to 85 years, from the Longitudinal Ageing Study Amsterdam (LASA) (Deeg, Knipscheer & Van Tilburg, 1993) in 1992. They were followed up in 1995 and 1998. During this period, 135 females and 69 males (N=204) lost their spouse. Their memory functioning, physical and mental health were all compared with those of non-bereaved (N=929) individuals. Memory functioning was assessed with the 15 Words Test (Saan & Deelman, 1986), derived from the Rey Auditory Verbal Learning Test (RAVLT; Rey 1964). Physical health was measured with functional ability and number of diseases and mental health with the Dutch version of the Centre for Epidemiologic Studies Depression Scale (Radloff, 1977).

Linear regression analysis examined whether rate of memory changes over six years differed between the groups. Cross-domain latent-change models (Willett & Sayer, 1994) estimated and evaluated the extent to which memory changes were related to changes in other domains (physical and mental health), unrelated to widowhood. The results showed that widow(er)s showed greater memory decline over the six-year period, but differences were only statistically significant for men. Memory decline was unrelated to changes in depressive symptoms and physical health. The authors concluded that loss of a spouse was related to greater memory decline, which was independent of depressive symptomatology.

This study has several strengths. By using cross-domain latent-change models, the influence of measurement error and non-linearity of change in memory performance is considered (memory performance is often non-linear due to a learning effect). This procedure increased the reliability of the results. Replacing missing values by estimated values, based on all other study variables, compensates for the weakness of longitudinal studies (i.e. drop out of most vulnerable subjects as discussed above). Physical health, which can affect cognitive functioning, was assessed. Limitations of the study include the reporting of confusing sample sizes (474 women and 690 men, 135/69 bereaved) in the abstract, 1144/219 bereaved in the text). The authors used depression scores as an indirect measure of grief. However, as stated above, grief is a multifaceted concept and depression may be distinct from grief (Prigerson & Jacobs, 2001). Additionally, no distinction was made between a sudden and an anticipated death, even though their impact can differ. Finally, there are age effects on performance of the Rey Auditory-Verbal Learning Test (RAVLT; Spreen & Strauss, 1998). Since this sample included ≥60 year olds, age bias was introduced, limiting the generalisability of the findings.

Cross-sectional studies

Xavier et al. (2002) recruited 77 rural Brazilians, aged between 80- to 95-years-old, who were randomly chosen from the County Hall register. The older adults who met criteria for dementia or delirium (Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV); American Psychiatric Association 1994) were excluded. Thus, 66 (42 women and 24 men) older adults participated. Bereaved (N=21) and non-bereaved (N=45) individuals were compared. A structured interview was used to assess grief and anxiety and depression were identified by the Brazilian validated version of the Structured Clinical Interview for DSM-IV (First et al., 1998) and the Geriatric Depression Scale (Sheik & Yesavage, 1986). Activities of daily living (Katz et al., 1970) and illness (The
Cumulative Illness Rating Scale; Linn, Linn & Gurel, 1968) were also assessed. Neuropsychological tests included: Memory Complaint Questionnaire (Crook, Feher & Larrabee, 1992), Short-care Questionnaire (Tobiansky et al., 1995), Free and Cued Selective Reminding Test (Petersen et al., 1992), Word-List Test (WL; Morris et al., 1984), digit span from the Wechsler Intelligence Scale (WAIS; Wechsler, 1993), Verbal Fluency Test (Butters et al., 1987), Visual Reproduction Test of Figures (Wechsler Memory Scale; Wechsler, 1945), Clinical Dementia Rating (Hughes et al., 1982) and the Mini-Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975). Ageing-associated cognitive decline was calculated according to Levy (1994).

Student’s t-test was used to compare the performance of the bereaved and non-bereaved group on depression, formal education level, activities of daily life, general health, and cognitive evaluations. Differences (psychiatric diagnoses, gender distribution) were assessed by chi-square test. The presence of grief was unrelated to anxiety or depression but was associated with mild cognitive impairment (MMSE, verbal memory tests, $p=.000$, and digit span, $p=.018$). The authors concluded that grief may influence cognitive functioning although it could be the case that individuals with MCI experience strong grief reactions after loss.

Strengths of this study include the use of a comprehensive battery of tests with good psychometric properties. However, no objective grief measure was used. The grief questionnaire assessed the psychological response to the loss of a close relative/friend. Grief was assumed to be present if participants described themselves to be emotionally affected by the loss, and a caretaker reported observable changes in the participant’s behaviour and emotions since the loss. The authors did not provide information about the amount of time since the loss occurred. Therefore, the nature and extent of the grief reaction could not be determined. Also groups were not matched on pre-morbid intellectual ability. Differences in cognitive performance could be due to pre-existing intellectual differences rather than grief. The mean MMSE score was only 19.5 for the bereaved group, which the authors attributed to the low educational level (mean=2.6 years). The generalisability of the results to older people in Western countries is questionable because older adults tend to have more than 2.6 years of education in Western countries (Ward, Mathias & Hitchings, 2007), is questionable.

Ward, Mathias and Hitchings (2007) recruited 50 urban community-dwelling South Australians, aged 65 to 80 years. The bereaved ($N=25$) were members of a grief support group. Non-bereaved ($N=25$) were recruited from senior groups and participant referrals. People with a history of head injury, neurodegenerative disease, psychiatric disorder, or severe illness were excluded. Both samples were matched for age, gender, education, pre-morbid intellectual functioning, and general cognitive ability. They were compared on tests designed to measure verbal fluency, attention, memory, and visuospatial ability. The authors used the Inventory of Complicated Grief (Prigerson et al., 1995), Depression Anxiety Stress Scales (Lovibond & Lovibond, 1995), Multi-Dimensional Support Scale (Winefield, Winefield & Tiggemann, 1992), Wechsler Test of Adult Reading (Wechsler, 2001), MMSE, RAVLT, Benton Visual Retention Test (BVRT; Sivan, 1992), Test of Everyday Attention (Robertson et al., 1994), Trail Making Tests (TMT; Reitan & Wolfson, 1985), RCFT, Controlled Oral Word Association Test (COWA; Spreen & Strauss, 1998) and Symbol Digit.

Student’s $t$-test was used to compare the two groups on the above measures and Cohen’s $d$ was used to calculate effect sizes. Group comparisons were analysed using multivariate analysis of variance and cognitive tests were analysed using hierarchical multiple regression. Pearson’s $r$ correlation coefficients were calculated to examine the relationship between cognitive scores of the bereaved group and various variables. Explanatory
analyses examined the effects of CG.

The two groups were well matched on all variables (e.g. age, gender, education, cognitive ability). The bereaved group was more depressed, anxious and stressed ($p<.01$) and performed worse on cognitive tests measuring verbal fluency, attention, and information-processing (medium to large effect sizes). These differences disappeared when statistically controlled. Only the attentional switching task was not correlated with mood. Of the bereaved group 28 per cent met criteria for CG. They were significantly younger, experienced more stress, and performed significantly worse on the BVRT. The authors concluded that grief associated with death of a spouse had limited association with cognition.

Strengths of the Ward et al. (2007) study include assessment of premorbid intellectual functioning; well matched samples; use of measures with good psychometric properties; and multivariate analysis which increases confidence that differences were not due to Type 1 Error. Limitations include a relatively small sample size and the bereaved group being recruited from a grief support group, which limits the generalisability of the findings. Since most participants were six to 18 months after loss, the more acute effects of bereavement could not be measured. Also a marked decline in performance after age 70 on the BVRT has been reported (Spreeen & Strauss, 1998). Additionally, the physical health of participants was not assessed, which could also have affected cognitive performance.

Rosnick et al. (2007) recruited 466 Americans, aged 60 to 84 years, from the Charlotte County Healthy Ageing study. Analyses were only conducted on 428 participants (216 women and 212 men). The relationship between negative life events (death of parent/spouse/sibling/good friend, someone committing suicide, illness/injury, financial difficulties) and cognitive performance was examined. Tests were used to measure episodic memory, psychomotor speed, attention, negative life events, and neuroticism. Tests included the modified Hopkins Learning Test (Benedict et al., 1998), TMT, Stroop Test (Stroop, 1935), Louisville Older Persons Event Schedule (LOPES; Murrell & Norris, 1984), and the NEO Five Factor Inventory (Costa & McCrae, 1989).

Correlation analyses examined the bivariate associations among demographic characteristics, the aggregate frequency and severity of life event measures, and cognitive performance. Hierarchical multiple regression analysis controlled for possible covariates (personality and demographic) and cognitive variables. Correlation analysis was carried out for individual negative life events. No significant relationship was found between the frequency and severity of individual negative life events and cognitive performance, after controlling for background characteristics. Only multiple negative events and effect ratings were associated with all three cognitive domains under investigation. Correlation analysis only revealed a statistically significant effect between the occurrence of the death of a sibling and episodic memory functioning. The authors concluded that individual negative life events could have an effect on cognitive functioning.

Strengths include the use of multiple cognitive measures and LOPES, which was designed for older adults. Limitations include the presence of confounders in the form of four negative life events participants reported over the previous year, most of which were not bereavement related. The effect of these on each other is unknown. Self-reports of negative life events may be subject to recall bias. Since LOPES only uses a yes/no format, the frequency of negative life events was not assessed. One death might have a different impact than multiple deaths. It was not assessed whether the events were chronic or acute episodes. Participants were ≥60 years old, which introduced an age bias. Whilst 466 participants completed the study, only 428 cases were analysed. No explanation was provided. As in the previous two studies, the cross-sectional design does not permit examination of cause-effect relationships.
Summary findings
All five studies reported some association between bereavement and deterioration or decline in cognitive performance. One study (Grimby & Berg, 1995) found larger deterioration in spatial abilities in the older adult bereaved group, with men’s general cognitive abilities being affected more than women’s. Another study (Ward et al., 2007) found that apparent cognitive decline disappeared when mood was statistically controlled, with the exception of attentional switching. However, those meeting criteria for CG performed worse on memory tests. They were younger and experienced more stress. One further study (Xavier et al., 2002) found grief to be associated with general cognitive impairment. In total, four studies (Aartsen et al., 2005; Rosnick et al., 2007; Ward, Mathias & Hitchings, 2007; Xavier et al., 2002) reported either worse performance on memory tests or greater memory decline in the bereaved group, independent of depressive symptoms (Aartsen et al., 2005; Xavier et al., 2002) and physical health (Aartsen et al., 2005).

General critique and discussion
Whilst this review indicates that bereavement might have a negative impact on cognitive functioning in older adults because the performance of the bereaved was worse or showed a greater cognitive decline, these findings must be regarded with great caution due to methodological limitations. The majority of studies used a cross-sectional design, which does not permit examination of cause-effect relationships. Furthermore, the number of included studies was relatively small and the studies were, strictly speaking, not directly comparable due to considerable differences (e.g. cohorts, age, measures, study design, inclusion of other stressful events) and have various methodological weaknesses as aforementioned. Moreover, the discrepancy between crystal and fluid abilities increases with age (whilst crystallised abilities remain relatively stable until the mid-70s, fluid abilities begin to gradually decline in one’s 50s, (Singer et al., 2003). So if the same tests are used at a later age, the ratio between tests measuring crystal and fluid intelligence must be adjusted. Failure to take this into account decreases the validity of findings. Since ages varied from 60 to 95, one must be cautious when drawing conclusions about the impact of bereavement on cognitive functioning on oldest-old versus old-old, young-old, and younger adults. When conclusions are based on simple comparisons of various cognitive functions across very old and much younger bereaved people, their validity is questionable (Hansson & Stroebe, 2007). In the absence of more robust studies, the following findings are nevertheless noteworthy.

Some association between bereavement and worse cognitive performance or decline was found in all studies. Four studies reported greater memory decline (Aartsen et al., 2005; Rosnick et al., 2007; Ward, Mathias & Hitchings, 2007; Xavier et al., 2002). An age effect was found in one study (Ward, Mathias & Hitchings, 2007). The CG young-old performed worse on memory tasks than old-old. This is in line with Rosnick, Small and Burton (2006), who also found that the young-old bereaved performed worse than old-old individuals on a memory task (delayed naming recall). Considering that this group experienced more stress, it is possible that they might be suppressing unwanted thoughts about the loss of their spouse, which utilises important attention resources during cognitive tasks (Rosnick et al., 2006).

Interestingly, the present findings also indicate that both the loss of a sibling (Rosnick et al., 2007) and friend (Xavier et al., 2002) may impact negatively on memory functioning. This supports the view that friends and family members may be as crucial as a spouse because they provide important social support for older adults (Williams et al., 2007). Moreover, memory decline was observed more often in bereaved men compared to bereaved women in one study (Grimby & Berg, 1995). Rosnick et al. (2006) also found that bereaved men performed worse on a memory test. This is consistent
with previous research suggesting that being male may be a risk factor for complications during bereavement (Stroebe et al., 2001).

Two studies (Ward et al., 2007; Xavier et al., 2002) found the presence of grief or CG to be associated with worse performance on memory tests. Ward et al. (2007) CG subgroup also experienced more stress. Whilst this review cannot establish why CG affected memory functioning, the stress hypothesis could explain how CG could impact on memory (Aartsen et al., 2005). Stress related hypercortisolemia may result in hippocampal atrophy, leading to cognitive impairment (Steffens & Potter, 2007). The hippocampus is vital for learning and memory, and the consolidation of short-term into long-term memory (Sapolsky, 2000). Hence, memory functioning may be affected negatively by the consequences of CG – i.e. through stress. Some researchers (e.g. Hogan, Worden & Schmidt, 2003, 2004) claim that CG is not a separate clinical entity and not dissimilar to depression. The observed memory decline could be the result of depression rather than grief. Depression, which is common following bereavement (Gallagher-Thompson et al., 1993), has been related to lower levels of memory functioning (McBride & Abeless, 2000). However, Ward, Mathias and Hitchings (2007) statistically controlled for depression and found CG had an independent effect on memory decline.

None of the studies differentiated between an anticipated or sudden death. If a significant other suffered for several months and the death was imminent, the bereaved may have had high levels of cortisol for a long time (Aartsen et al., 2005). In Aartsen et al.’s (2005) study, participants presented with depressive symptomatology at the beginning of the study, and their cognitive functioning could have declined prior to losing their spouse. Depression may exacerbate cognitive impairment by depleting cognitive reserves, thus, lowering the threshold for clinical manifestations of cognitive impairment (Steffens & Potter, 2007). Hence, it is impossible to know whether decline in cognitive functioning is due to the loss or due to changes in, for example, mental health, which are affected by bereavement.

The same holds true for physical health effects. Only Aartsen et al. (2005) statistically controlled for physical health and not all studies (e.g. Rosnick et al., 2007; Ward et al., 2007) included health examinations or reported if their participants were taking medication. Medical factors (e.g. sleep apnoea, hypothyroidism) and medications (e.g. steroids, beta blockers) can impair cognitive performance (Steffens & Potter, 2007). Thus, physical health problems or medication could have affected the cognitive functioning of the participants.

Finally, with the exception of Ward et al., (2007), none of the studies assessed the time since the bereavement. Whilst there are significant individual differences in the way people cope with bereavement, most people experience pain and distress. However, little is known about the relationship between emotions and memory. Until recently, neuroscience has concentrated on the cognitive aspects of brain functioning, disregarding emotions. Emotions may play diverse roles in cognitive functioning (Damasio, 2006) and grief seems to be mediated through a complex network involving various cognitive functions, autonomic regulation, and modulation or co-ordination of these functions (Gundel et al., 2003). Different pathways might be activated at different times in the grieving process. Whilst assessment immediately or shortly after the bereavement might indicate some changes in cognitive function, it must be borne in mind that the majority of bereaved individuals reach some level of acceptance within six months (Ray & Prigerson, 2006). So in the absence of CG, this decline could be transient and perhaps reversible. This could explain why Ward et al. (2006) only found a limited association between bereavement and cognitive decline six to 18 months after the loss. In an ongoing longitudinal study, Ward found a steeper change in memory functioning in more recently bereaved individuals (Ward, personal communication, October, 2007).
Clinical implications
The review tentatively indicates that bereavement may have an impact on cognitive functioning in older adults. Therefore, clinicians should address the grief process itself. In particular, assessment and treatment of complex grief (CG) seems vital. The findings showed that the presence of CG may be associated with memory decline. So it might be important for clinical psychologists to detect and treat cognitive impairment in older adults who might be suffering from CG (see Shear et al., 2005). These individuals may have higher stress levels and relaxation training could be used to reduce these. Both attention and memory training could help increase memory functioning. Problem-solving strategies could be beneficial for those preoccupied with the loss (perseverative thinking).

Older men may be more vulnerable to decline after bereavement. Given that the presence of cognitive impairment can adversely influence the person’s response to treatment (Steffens & Potter, 2007), a more active monitoring might be required for those bereaved older adults. However, cognitive impairment shortly after the bereavement could be transient and not necessarily progress to dementia. However, if bereavement is not recognised as a possible cause of morbidity, the chances of misdiagnosis and inappropriate treatment are high (Ward et al., 2007).

Research implications
High quality prospective, longitudinal studies are needed to examine the possible impact of bereavement on cognitive functioning in older adults, taking into account normal ageing processes. The results of this review tentatively indicate that being male and of younger age (youngest-old) may be a risk factor for cognitive decline following bereavement. Further research needs to address this gender and age difference. However, researchers need to be more mindful of the ageing process and should avoid grouping the youngest-old and oldest-old together as their cognitive functioning will invariably differ due to the normal ageing process. Moreover, there is some evidence that high stress levels may affect cognitive functioning. Hence, the physiological markers of stress and how they may affect cognitive performance in bereaved older adults need to be studied. Finally, the possibility that cognitive decline after bereavement could be transient, followed by adaptation and return to previous level of cognitive functioning, requires further investigation.

Conclusions
Whilst this review cannot demonstrate a causal relationship between bereavement and cognitive functioning, and the results must be viewed with caution due to methodological limitations, some interesting findings emerged. Bereavement (and possibly CG) may have a negative impact on cognitive functioning in older adults. Men seem particularly vulnerable. Possibly, high stress levels may be associated with cognitive decline, although it is still unknown whether these effects are reversible or not. For clinical psychologists to better understand and treat possible consequences of bereavement in older adults, the inter-relationship between gender, age, physical and mental functioning, the role of emotions and their short- and long-term impact on cognitive functioning needs to be researched in prospective, longitudinal studies, using valid tests and norms.

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Conceptualizing bereavement: An ecological reply to Wendon-Blixrud

Stéphane Duckett

I here offer in a complimentary reply to Wendon-Blixrud’s excellent paper (PSIGE Newsletter, 103, 11–18), presenting another interpretative explanation of the experience of bereavement which attempts to explain why on a subjective basis we find the loss of another so wrenching.

FOR G.H. MEAD (1934) our Selves are comprised of a subjectively experienced ‘I’ and an objective ‘Me’, that is how I think of myself. This Self resides in an ecological context, which Bronfenbrenner (1979) tells us is layered from micro-systemically (immediate day-to-day relationships) to macro-systemically (wider culture). Within this model there is a reflection of the ecological context we inhabit at any one time within ourselves (an object representation). We effectively have an idea (or ideas) of our place in relation to others.

Our ‘me’, that is how we think of ourselves, emerges from that object representation of our ecology. However, this is complicated by the fact that first, ecologies change over time and secondly that not everything the environment tells us about ourselves becomes absorbed into our definition of self. What governs this process is our attributional judgment (see Kelly’s attributional model drawn from J.S. Mill’s principle of covariation within his personal construct theory). If, on a particular day a colleague responds to me with anger that may mean one thing. However, if many colleagues respond with anger over several days and in several settings I may draw a very different conclusion.

What this effectively means is that our object representation is made up of a patchwork quilt of part and whole ecologies. This allows us to respond to new situations as we draw from past ecologies to make sense of new environments. This is what Mead meant when he spoke of ‘interactionism’, that is the interplay between self and society. This, incidentally, addresses the problem of agency, which bedevils certain expressions of social constructionism.

Alfred had been caring for his invalided wife for many years. He had always appeared vigorous indeed had on occasion alarmed social services in continually declining any help with respect to his wife’s care. Within six months of his wife’s death Alfred developed Chronic Obstructive Pulmonary Disease (COPD). Panic attacks in the early morning hours lead to his repeated hospitalization. Alfred’s definition of Self came from being a carer in which his social reflection was one of admiration from the professionals involved with him and his wife and his family alike. Without this his life lost meaning. He felt invalidated and his health as a consequence deteriorated.

Within this model of Self, bereavement is the subjective awareness of a discrepancy between the absence of a micro-systemic relationship through your ‘I’ and a ‘me’ that is still partially defined through an object representation that no longer has an outward reality. Occasionally as with Alfred during the early morning hours between being half awake and half asleep, he can still feel the weight of his wife’s body next to him in bed and for a brief deluded moment his subjective experience and his objective sense of self are reunited, however the pain emerges as his mind comes into full consciousness and the rift between his internal and external ecologies reasserts itself.

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It is for this reason that our culture has created ghosts and other beliefs in the after-life because they can in part provide us with an often-fleeting sense of resolution or solace.

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Identifying and addressing the sexual needs of older people in residential care

Laura Meader (née Mulcock)

This article explores the literature on sexual need in older people and looks at barriers preventing expression of these needs in the residential care setting. Barriers include staff attitudes, residents’ physical health, and the environment. I include clinical examples to illustrate this, and discuss approaches to supporting care home staff in addressing this often difficult issue.

WHEN RESEARCHING the area of older people’s sexuality, I was surprised at the extent and variety of work published on the topic. It is a subject that attracts wide attention: as I write this, a Swedish study on the sexual activity of older people (Beckman et al., 2008) was featured in today’s BBC news report (‘More over 70s’). My interest in this topic was ignited during my current role. For over a year I have worked in a multidisciplinary In-Reach Team which supports staff working in care homes for older people, on mental health-related and behavioural issues concerning their residents. Approximately 15 per cent of our team’s referrals include a sexual element, from disinhibited sexual behaviour to staff concerns about an emerging sexual relationship between two residents. My experiences of working with staff around these matters have been rich and varied, and I was interested to see whether these experiences were reflected in the literature.

Quantifying and qualifying the need

Sex is considered a basic human need, integral to mental well-being and quality of life throughout adulthood (McAuliffe, Bauer, & Nay, 2007). The importance of addressing the sexual needs of older people is frequently remarked upon (Chandler et al., 2004; Laumann et al., 2006; Parker, 2006). The predominant theme to emerge in the literature is that sexual desire and sexual behaviour continue well into old age. Studies of particular note include the large, albeit somewhat dated, cross-cultural investigation of Winn and Newton (1982). Whilst this study does not include specific information about the participants’ living environments, it is a large-scale investigation of anthropologists’ field reports of sexual activity in older people across 106 non-Westernised cultures. In some cultures sexual activity waned with age, but the researchers cited many examples of sexual vitality in men and women up to a very advanced age. Cultural variation was noted in regard to gender differences in sexual behaviour. In certain societies in South Africa, Peru, and Brazil, women remained interested in sex to a greater age than men. Past child-bearing age these women became more sexually assertive, seeking sexual contact with much younger men. The reverse, where sexual potency was high in older males who had young girls as sexual partners, was reported to occur in Oceanic societies such as on the islands of French Polynesia.

More recently, Ginsberg, Pomerantz, and Kramer-Feely, (2005) looked at the sexual behaviours and preferences of a Western sample of lower-income older people, most of whom were single, practised a Western religion, and lived alone. The majority of the participants reported embracing and kissing regularly, and a significant number stated they wished to engage in more of this type of activity. With regard to behaviours such as masturbation and intercourse, most participants did not engage nor wish to engage in this type of activity.

The newsworthy study of Beckman et al. (2008), one of the most comprehensive and
rigorous studies to date, investigated the sexual behaviours and attitudes of four cohorts of 70-year-olds from a range of living situations in Sweden. With over 1500 participants, the study compared two samples of 70-year-olds in 1971 and 1976 with two samples who were 70 in 1992 and 2000 respectively. Comparing the 2000 cohort with the 1971 cohort, the authors found higher sexual satisfaction in the 2000 cohort and fewer sexual dysfunctions. In addition, the later cohorts were significantly more likely to rate sexuality as an important factor in their life, and this was reflected in these groups being reportedly more sexually active than the earlier cohorts. The authors propose an explanation for their findings based on better socioeconomic status and physical health of the later cohorts, as well as public attitudes, sex education, and the ‘sexual revolution’ of the 1950s and the 1960s.

The diverse findings of the above studies provide evidence for some people’s continued sexual interest into old age, while highlighting the importance of cohort effects as well as cultural, societal, and potentially religious factors in accounting for some variation in preferences. But how accurate can we assume these accounts to be? A self-selection bias is likely in any study of this nature, and this is difficult to avoid since some people will likely refuse to answer sensitive questions. The applicability of previous findings to a British population is dubious, and there is a paucity of data on the sexual activities of older people in care. Nevertheless it is important to bear in mind that many of our clients, including those in care homes, will be sexually active and this may play a significant role in their well-being.

**Barriers to the expression of sexual need in residential care**

Assuming, based on available evidence, that there is a need for sexual activity for many people in later life, what are the barriers to older people expressing these needs? Two recent studies considered the importance of health professionals’ attitudes in approaching clients’ sexuality (Parker, 2006; McAuliffe et al., 2007). McAuliffe et al. (2007) proposed a number of principles of good practice, including that clients should be given the opportunity to express their sexuality where possible. Parker’s (2006) discursive article focused on aspects specific to 24-hour care settings. She noted physical illness, lack of partner, staff attitudes, and lack of privacy in the care environment as predominant factors impacting upon clients’ sexual expression.

In working with the In-Reach Team, barriers to residents’ expressions of sexuality have become evident. In line with the above literature, in my experience potential barriers fall into one or more of three categories: physical and biological factors relating to old age, aspects of the care home environment, and the attitudes and assumptions of significant people in one’s life. These will be addressed in turn.

**Physical and biological challenges**

The natural physical decline that occurs with age brings with it the increased likelihood of acute and chronic health problems, to the detriment of sexual function. In addition to physical morbidity, common mental health problems – particularly depression and anxiety – are associated with sexual dysfunction among older people (Dunn, Croft, & Hackett, 1999). These issues may present a particular challenge for men due to the societal expectation that to be masculine is to be a competent sexual performer (Bignell, 1993).

Fortunately, many of the health problems of old age can be compensated for. This is explored eloquently in Brecher’s (1984) Consumers Union report ‘Love, Sex and Ageing’, which takes the form of a book documenting vivid reports from older people about their attitudes and behaviours relating to sexuality, and includes examples of couples adapting their sexual practices to accommodate a variety of physical health problems.
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For couples, declining health may result in widowhood for the surviving partner. This presents an obvious and significant barrier to sexual needs being met; Ginsberg et al. (2005) found the absence of a partner to be the prevailing reason for lack of sexual activity among the older people they interviewed. Moreover, the majority of participants without a partner expressed a desire for continued sexual contact with another person. Gott and Hinchcliff (2003), however, found the opposite response: single or widowed older people rated sex as significantly less important than did those with a current partner, suggesting something of an acceptance of the barriers to sexual fulfilment, or perhaps a continued sense of loyalty to their deceased partner.

Declining health is not exclusive to care home residents, and this issue does not feature often in the In-Reach Team’s referrals. With regard to single and widowed older people, moving into residential care can offer opportunities for new romantic attachments. There is a dearth of research quantifying this, but some of the barriers to such relationships are discussed below.

Environmental aspects of the communal care setting

Lack of privacy can be a significant barrier to older people’s sexual needs being met. This is particularly the case in residential care where, typically, residents’ potential sexual needs are not considered in planning the care home environment (Parker, 2006). Drawing from my experiences of working in care homes as a care assistant and my work with the In-Reach Team with a broader range of homes, even where residents have their own bedrooms it is rare for these to be lockable from the inside: residents must compromise their right for privacy for their own and others’ safety. There are further compromises to residents’ privacy: staff may enter bedrooms without warning, for example, during night-time checks, and since there is a high likelihood of residents living among people with dementia (Alzheimer’s Society, 2007), disorientation can lead to people entering other residents’ bedrooms inadvertently.

In exploring the environmental design of care homes for older people, McAuliffe et al. (2007) proposed that staff can help ensure residents’ privacy by offering double-bedded rooms and providing ‘do not disturb’ signs. While not being able to offer double rooms, the majority of care staff we have worked with value residents’ privacy. During a training session on sexuality, one staff member described a recurring situation of a male resident who displayed disinhibited behaviour as a result of neurological damage. On frequent occasions, this gentleman was found masturbating to pornographic material with the door open. The staff team described the respectful and protective approach used in closing the gentleman’s bedroom door and explaining to him their reasons for doing so. In this way, the staff was encouraging the resident’s privacy whilst acting to avoid potentially offending other residents or visitors who might walk by.

Attitudes and assumptions

Despite the lack of research concerning the sexual behaviours of older people living in residential care, there is a body of literature on attitudes of older people and care staff on later life sexuality. The attitudes of health professionals and carers towards the sexuality of older people they care for in turn affect the attitudes of the older people themselves (Bouman, Arcelus & Benbow, 2006). Health professionals and care home staff are a heterogeneous group, and the diversity of attitudes towards older people’s sexual interest reflects this (Bouman et al., 2006). My experiences in working with groups of staff mirror these reports: I have encountered comments similar to those found in Bouman et al.’s 2006 literature review, from ‘it’s disgusting and wrong’, to a member of staff saying in a bemused tone, ‘I didn’t think they still ‘did it’ at that age.’ This staff member added that she was pleased that the
couple to whom she was referring had a sexual relationship, as she could see the benefits on mood for both parties. Despite some variation in viewpoints, on the whole the available literature suggests that attitudes towards older people’s sexuality are positive (Story, 1989; Bouman et al., 2006) and my experiences are in alignment with this.

The importance of cultural and historical context in interpreting data on older people’s sexual lives was illustrated earlier, and attitudes play a significant role here. The cohort effect found in Beckman et al.’s (2008) study with regard to differences in sexual behaviours may be explained partly by the prevailing attitudes in society of the period in which these older people grew up and their attitudes were formed. The experiences of a cohort who in their Victorian childhood heard little discussion of sexual matters (Brecher, 1984) could determine their attitudes in adult life and be passed on through the generations (Gibson, 1992). With sexuality rarely discussed, this would suggest a low level of knowledge of sexual issues, which in itself could impact upon people’s attitudes. In a critical literature review exploring this knowledge-attitude link, Hillman and Stricker (1994) found that sex education improved attitudes and increased sexual activity among older people. Beckman et al. (2008) also highlighted the importance of education in improving attitudes towards older people’s sexuality. These researchers considered that greater open-mindedness in 21st century Western society could account for the increased sexual activity of their later cohorts, such that people were more willing to report their sexual behaviours than those in the 1971/1976 age groups.

Increased coverage of older people’s sexuality in the modern media provides evidence for improved attitudes, yet this is somewhat marred by the glaring omission of sexual health issues in Government white papers such as the 2001 National Service Framework for Older People (Bouman et al., 2006).

Addressing the need: the In-Reach approach

Despite the potential embarrassment of discussing the sexual needs of residents under their care, we have found many care home staff to be interested in this topic and unabashed in their discussions. Our training sessions on ‘Sexuality and the Older Person’ often spark heated debate among staff groups on the best approach to take, and most sessions are not without some light-hearted laughter.

The central ethos of our team’s approach, in keeping with the theme of this article, is about recognising sexuality as a need to be met: if this need is not met, it can manifest in socially unacceptable behaviours. Our approach, as espoused by McAuliffe et al. (2007), is person-centred and considers contextual factors where available, such as premorbid aspects of the individual’s sexual preferences, level and type of cognitive and/or neurological impairment, and likely capacity to consent to a sexual relationship. Often, residents’ families have provided staff with useful information such as explaining that their mother had a history of promiscuity and tended to be assertive in attracting men.

Earlier in this article, an approach to managing a resident’s sexual disinhibition was illustrated. Romantic attachments between residents can also pose difficulties for staff. The main issues we have encountered here relate to families finding the match undesirable, or where one member of the partnership has a dementia and questionable capacity to consent to such a relationship. In the former situation and where both parties are consenting, we have supported staff in prioritising the residents’ interests and tactfully explaining this to relatives. If a resident’s capacity to consent to a sexual relationship is questioned, or where abuse is suspected, we advise staff to contact the local Safeguarding Adults team for further assessment and legal advice.
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The In-Reach Team has received occasional referrals relating to male residents without partners asking staff to arrange for prostitutes to visit. In our experience, this scenario has divided staff adhering to a moralistic and restrictive view as opposed to liberal-minded staff who state that they would happily enlist such an outlet for these gentlemen’s sexual need if it were legal. Our approach here is to support staff in finding alternative means for expressing the sexual need, such as ensuring privacy or allowing access to pornography, if appropriate.

Conclusion
Experiences of sexuality and sexual desire are not exclusive to the young. For many older people, the desire for continued sexual contact remains. In the residential care setting, older people face barriers to expressing their sexual needs that go beyond those resulting from physical decline or the loss of a partner. Training and consulting with staff working in care homes can be an effective way of overcoming these barriers. My experience of working in the In-Reach Team has shown me that care staff can be encouraged to accept their residents as potential sexual beings, and in turn can be supported in ensuring that their residents’ sexual needs are met.

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Reviewing diagnostic procedures in a Younger People with Dementia Team

Paul Green

The South West Yorkshire Mental Health NHS Trust’s Younger People with Dementia Team provides specialist support to clients of the Memory Monitoring Service who are under the age of 65. This paper describes the rationale for a new diagnostic pathway (Figure 1) which was developed following the discovery that two of these clients had been inaccurately diagnosed with dementia. The factors which can lead to misdiagnosis, especially in younger adults, are explored and a case study is included to illustrate how this issue was resolved for one particular client. Practitioners need to consider the possibility that cognitive impairment may arise from psychopathology, trauma or depression and a multidisciplinary approach to the issue of diagnosis is required if such difficulties are to be correctly identified. A robust protocol for thorough assessment and effective collaboration between the disciplines of psychiatry, neurology, neuropsychology and nursing is, therefore, essential.

MISDIAGNOSIS of dementia has been identified as a problem for a number of years. For example, a case note audit by Ryan (1994) of 146 patients admitted to Lothian hospitals with a diagnosis of dementia identified a 16 per cent error rate (23 cases). Acute confusional states and depression were the most common causes of diagnostic uncertainty followed by cerebrovascular accidents and psychosis. Similarly, Ferran et al. (1996) examined the first 200 cases referred to a specialist multidisciplinary early onset dementia service based in Liverpool and found that, even after a comprehensive initial assessment, 21.5 per cent had an unknown diagnosis and 10 per cent 'unspecified dementia'. A year later eight per cent of clients could not be diagnosed with a specific type of dementia and one person’s diagnosis was still unknown.

Recent development of memory clinics and greater availability of MRI scans and neuropsychological assessments have enabled clinicians to achieve greater diagnostic accuracy but the potential for errors to occur remains. Amano (2005) cited the case of a 56-year-old man who experienced depressive symptoms and cognitive impairment. His MRI scan showed parietal lobe atrophy consistent with early Alzheimer’s disease and he was prescribed Donepezil following antidepressant therapy but showed no improvement. When his mood lifted, however, his short-term recall gradually improved, decreased volition disappeared and it became apparent that he had been suffering from a depressive pseudo-dementia.

The interpretation of clinical data can sometimes be problematic. Bakchine and Blanchard (2005) pointed out that there is no ‘gold standard’ for the diagnosis of vascular dementia and that it is difficult to rely on the results of MRI scans in the absence of any consensus about which type of lesions are most significant. Moreover, many people with cerebrovascular disease are cognitively impaired but do not have dementia. Hertschel et al. (2005) identified six cases of clients whose initial diagnosis of vascular dementia was found to be inaccurate and their study showed that neuropsychological tests had greater sensitivity and specificity for the exclusion of non-dementia cases than MRI scans.

It is often the presence of other conditions, however, which misleads clinicians into suspecting that a person is suffering from dementia. Depression, for example, can
impact cognitive function, with Maynard (2003) estimating that up to 32 per cent of those referred to memory services for assessment are depressed. Allers et al. (1992) pointed out that clients with PTSD arising from a history of sexual abuse may also present with cognitive impairment and that this possibility needs to be considered during assessment. For example, Hepple (2004) described 10 case histories of people who presented with a syndrome of dependence and behavioural problems similar to those found in some people with dementia but whose cognitive performance remained stable over many years. The results of clinical investigations did not suggest the presence of neurodegeneration but those affected tended to have a past history of mental health problems arising from maladaptive personality traits. These clients were suffering from conversion pseudodementia, ‘a severe regression in the face of overwhelming anxiety and cumulative losses in individuals with borderline, narcissistic and dissociative personality traits stemming from earlier abuse, trauma, abandonment or emotional repression’ (Hepple, 2004, p.966).

Comparisons have also been drawn between dementia symptoms and those found in people with late onset schizophrenia (Zakzaris et al., 2005). Delusional thinking and hallucinations, which are characteristic of schizophrenia, may also be reported in some people with dementia. There are also some similarities between the changes that occur in Alzheimer’s disease in communication and social behaviour and some of the negative symptoms of psychosis such as apathy, poverty of speech and impaired social/emotional skills. Clients suffering from schizophrenia may also manifest impaired learning and poor organisational strategies, similar to that experienced by people with dementia.

The phenomenon of mild cognitive impairment or MCI can also be difficult to differentiate from dementia and may result from stable causes such as post-traumatic encephalopathy or be reversible if due to depression, medication or substance misuse (Morris & Cummings, 2005). Knopman et al. (2003) pointed out that some individuals who complain of memory loss have issues which drive their fears such as a family history of dementia, depression, psychosocial stressors or medical illness. Others have long-standing cognitive deficiencies which do not predict future deterioration. MCI is thus a heterogeneous category and not always a transitional stage to dementia since it covers a range of pathological disorders. The clinical subtypes identified by Petersen (2004) allows differentiation to be made through neuropsychological testing but it is important to remember that there is considerable overlap between MCI and depression as both conditions contain cognitive and affective symptoms (Diercx et al., 2007).

In the face of such complexity, clinicians need to be able to draw upon a range of skills and knowledge if their clients’ problems are to be correctly identified and appropriate interventions employed. However, there is concern that effective collaboration between the various disciplines involved in the diagnostic process does not always take place. A survey of UK practice in the diagnosis and management of younger people with dementia (Cordery et al., 2002) revealed that some patients were managed by consultant neurologists who did not liaise with colleagues in psychiatry and vice versa. Since these professionals tend to assess and manage patients with dementia in different ways, e.g. psychiatrists attend more to symptoms of depression whereas neurologists request more comprehensive investigations, those using their services may be under investigated if managed solely by a psychiatrist and inadequately followed up if managed only by a neurologist. The authors of this survey concluded that ‘the assessment and management of patients with young onset dementia in the UK would be exemplary if the skills of both neurologists and old age psychiatrists were employed in the care of each patient’ (Cordery et al., 2002, p.127). Waldemar et al. (2007) echoed this with
their assertion that a multi-agency, multi-disciplinary approach including neurologists, psychiatrists, psychologists and geriatricians is needed for the development and leadership of teams involved in diagnosing dementia.

Wolfs et al. (2006) argued that a multi-disciplinary approach to diagnosing dementia provides ‘added value’ in allowing better differentiation between subtypes of dementia disorders and detection of co-morbid conditions such as depression because it prevents diagnoses from being biased by the medical speciality of the lead clinician. It should also allow the results of different investigations to be correctly interpreted as part of an holistic assessment rather than being considered in isolation. In 26 per cent of the cases examined by Hertschel et al. (2005) bringing together neuropsychological tests and MRI scans altered the initial diagnosis and increased the size of the ‘no dementia’ group by five per cent.

Collaborative approaches to diagnosis are not new, however, as Ferran et al. (1996) demonstrated in their description of a procedure in which a multidisciplinary team meeting was held at the end of each clinic day to discuss the diagnosis, prognosis and management of each patient who had been seen. A provisional diagnosis would then be issued and reviewed after one-year follow up. The increased number of cases being dealt with in memory clinics might preclude such frequent meetings today but the principle of clinicians from different disciplines meeting together to discuss complex cases and arrive at a shared diagnosis is a sound one. The following case study illustrates how such an approach might have prevented one misdiagnosis which was then corrected after a multidisciplinary review. The accompanying diagram (Figure 1) outlines the new diagnostic pathway developed as part of the review process.

**Case Study**

‘Tom’ is 56-years-old and lives with the youngest of his four children, having recently separated from his wife. He was formerly employed as a mechanical engineer and was involved in design and business development projects before being made redundant 10 years ago. He then did some consultancy work and was a job coach for adults with learning disabilities but is currently receiving incapacity benefits. Tom first experienced mental health problems when he was studying for his finals and had a panic attack followed by a period of depression from which he recovered once he had completed his course and obtained a job. During the next 10 years he married and three of his children were born. He remained in good health and his career developed successfully until he began to experience what were thought at the time to be epileptic seizures, occurring mainly at night. Tom was prescribed large doses of Epilim and Lamotrigine but with little apparent effect and in 1993 he began a process of reducing these medications without medical supervision, a decision which concerned members of his family. He obtained a second opinion from a consultant neurologist who suggested that OCD traits rather than epilepsy might account for his difficulties. He suffered a heart attack in 1998 which followed his redundancy the previous year and was only able to obtain further employment for a brief period following his recovery.

From this point onwards Tom became increasingly focused on a regime of reducing his medication very gradually and began to develop his own explanations for the health problems he had experienced, attributing them to trauma suffered in his mother’s womb. A detailed diary enabled him to chart a range of physical, emotional and psychological effects he perceived as arising from each small reduction in his medication. He also came to believe that the medical profession had done him serious harm and probably caused his heart attack by prescribing
Figure 1: Referral to the Younger People with Dementia Team.

- Assessment by Liaison Nurse – Home Visit.
- Liaison nurse request medical notes, take to Consultant Psychiatrist to request CT/MRI scan.
- Scan.
- - Memory Clinic appointment with Consultant Psychiatrist and Liaison Nurse.
- - Identify need for neurology and/or psychological assessment.
- - Letter of referral to neurology and/or psychology.
- Neurology and/or psychology assessment.
- Feedback results to Consultant Psychiatrist by letter.
- - Memory Clinic appointment with Consultant Psychiatrist.
- - Diagnosis.
- - Future follow-up.
medications which he did not need. These perceptions caused difficulties in his relationship with his wife, especially since he came to view her as overly controlling with an ‘autistic’ personality. Tom came into contact with mental health services as a result of periods of elevated mood when he would express ideas his family regarded as bizarre, i.e. that he was involved in ‘pioneering research’ which would ‘transform neuropsychiatry’. He complained of increased forgetfulness so his psychiatrist arranged an MRI scan which showed ‘mild cerebral atrophy in the parietal lobes and a small chronic left cerebellar infarct.’ This was interpreted as being suggestive of vascular dementia and Tom was referred to the memory service for assessment.

An initial assessment was conducted by a liaison nurse from the Younger People with Dementia Team who noted that Tom’s MMSE score was 29/30 but he complained of difficulties with short-term recall, concentration, motivation and the prioritising, planning and sequencing of tasks. The then consultant in old age psychiatry issued a diagnosis of vascular dementia on the basis of this assessment, the MRI scan and the opinion of the adult psychiatrist. Over the next 18 months Tom became increasingly alienated from his family as personality changes noted by his wife and children became more pronounced. These included being far more talkative and outspoken, increased absorption in his idiosyncratic ideas about the explanation for his difficulties and an obsessive focus on bodily sensations and his ‘experiments’ in reducing his anticonvulsant medication. Tom also said that he did not have either dementia or epilepsy and that the explanation for the apparent changes in his character was that he was now able to discover his true self as he was not ‘repressed’ by medication.

Staff changes and team reorganisation resulted in Tom coming under the care of a different consultant and the appointment of the author as his liaison nurse which allowed a review of his needs to take place. He was continuing to experience frequent ‘seizures’ but there was no further deterioration apparent in his cognitive functioning. His psychiatrist expressed doubts about the original diagnosis and it was agreed that clarification was needed to determine whether Tom was suffering from a deteriorating neurodegenerative condition. The results of a repeat MRI scan confirmed the earlier findings but also showed that there had been no progression in these mild cerebral changes. A full neuropsychological assessment indicated an unusual deficit pattern with high performance on IQ tests but some difficulties apparent with digit span, some memory tasks and word fluency. A discussion between the consultant psychiatrist and the neuropsychologist led to the conclusion that Tom had some cerebrovascular damage which was not progressive and this partly explained his mild cognitive impairment and personality changes which were also influenced by his other mental health difficulties. These findings were reviewed by Tom’s neurologist who also examined him in clinic. He concluded that Tom did not have either dementia or epilepsy and noted that his doses of anticonvulsant medication (5mg Lamotrigine and 50mg Epilim once daily) were at a ‘homeopathic’ level so further withdrawal from them should not cause any difficulties. The ‘seizures’ he experienced were, therefore, manifestations of his psychological difficulties.

A review of the literature on non-epileptic seizures helped to shed further light on Tom’s difficulties. Preuter et al. (2002) found a higher incidence of somatisation, phobic anxiety, interpersonal sensitivity and depression among subjects with pseudoseizures compared to those with epilepsy. Szaflarski et al. (2003) examined HRQOL scores for clients in both these groups and noted that pseudoseizures were correlated with high rates of anxiety, bewilderment, confusion, reduced energy and self-reports of cognitive inefficiency. Findings such as these have led to the conclusion that episodes of altered motor activity, sensation and perception
which can be mistaken for epileptic seizures have a psychological or emotional origin and may respond to CBT (Russell, 2006). The author has been trained in psychosocial interventions so Tom was engaged in a discussion about using collaborative, person-based CBT sessions as a means of resolving his problems and he readily agreed. These are ongoing at the time of writing but some progress has been made. A timeline was used to correlate Tom’s pseudoseizures with other events and experiences which established that they were associated with periods of stress, anxiety and increased involvement in either work related activities or his ‘experiments’ with medication. Guided discovery has enabled him to realise that the loss of his career left him in need of a sense of purpose and he is beginning to question whether he has become too focused on reducing his anticonvulsants as a way of fulfilling this need.

Tom has been referred to a vocational training and rehabilitation service and an art project for people with mental health problems. It is hoped that these activities will provide him with a programme of meaningful activity, raise his self-esteem and reduce his dependence on negative coping strategies. He acknowledges having an ‘obsessive personality’ but has always viewed this as a positive attribute, enabling him to pay attention to detail and achieve his goals. Tom is now being encouraged to explore this perception in the context of his pseudoseizures and to consider what role his beliefs and expectations about side effects from his medication have played in producing these effects. Interventions of this kind illustrate the importance of being able to provide effective therapeutic support to younger people with cognitive impairment which may arise from a complex set of needs. The existence of a specialist team including a practitioner trained in psychosocial interventions allowed this to happen in Tom’s case but many memory services, with their emphasis on monitoring adherence to anticholinesterase inhibitors, may lack the skills and resources to do so.

Conclusion
The case study used here shows how easy it is for a misdiagnosis to occur when selective attention is paid to particular items of clinical data such as scan results or complaints of memory loss which are then interpreted in isolation from their broader context. The clarification achieved with the addition of neuropsychological and neurological assessments and a multidisciplinary discussion about how all the findings should be interpreted demonstrates that this was an avoidable error. Moreover, if such a broad range of information from different sources is required to arrive at an accurate diagnosis, then the notion that this should be a shared, collaborative process rather than the responsibility of a single, lead clinician makes perfect sense. The development of the protocol outlined in Figure 1 is thus the product of conclusions drawn from practical experience as well as the research evidence outlined elsewhere in this paper.

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References


New Kids on the Block: Finding our place (the role of the Assistant Psychologists within the East Kent Dementia Home Treatment Services)

Christine Slaughter & Melanie Steeden

We have both been working within our respective Home Treatment Services as assistant psychologists for over a year now and would like to share our experiences of both the service and our roles within it. We hope that after reading this article other mental health professionals will want to take up the challenge to work in such a diverse and exciting multi-disciplinary team that provides a much needed service to those with a dementia.

The NHS is 60-years-old this year and it has come a long way. With new developments and changing models of care it is now possible and advantageous to care for more people in their own homes and in the community rather than in acute mental health inpatients beds. This is one of several aims held by the recently-formed Home Treatment Service in East Kent. There are currently three teams located in East Kent, which are based in Canterbury, Thanet and Dover/Deal, covering a population of approximately 81,000 over the age of 65 years. It is estimated that in 2005 there were 131,400 people over the age of 65 years in the whole of East Kent. This article will be based on our experiences of working in the Dover/Deal and Thanet Home Treatment Services.

What is different about our Home Treatment Service?
The Home Treatment Service differs from those services which have gone before it. There have been a number of Intermediate Care Services which were set up to target older adults who were ‘at risk’ of being chronically ill or dependent on resources (Godfrey et al., 2005). These services were targeted to help people regain or maintain function and promote community-based living. Although the Intermediate Care model is similar, the Home Treatment Service has been commissioned to work with people with dementia and those who care for them, as can be seen in Table 1, overleaf.

As with Intermediate Care Services, the Home Treatment Service aims to reduce hospital admissions (to acute mental health inpatient beds) and minimise the risk of premature or avoidable dependence on long-term care. However, if after assessment the team feels an admission is necessary then it will work with the individual and those involved to facilitate a smooth and as stress free admission as possible. In order to achieve this a great deal of work is focussed on the facilitation of complex transitions and improving the quality of life for our clients, as outlined in the National Service Framework for Older People (2001). The service also falls in line with recommendation 10 of the consultation on the National Dementia Strategy (2008), which recommends that intermediate care should be made accessible to people with dementia in order for their needs to be met.

In addition all three Home Treatment Services work with the same principle of person centred care, as outlined in NICE guidelines for Dementia (2006); National...
### Table 1: An outline of the Home Treatment Service.

<table>
<thead>
<tr>
<th>The Home Treatment Service</th>
<th>What the Home Treatment Service is not</th>
</tr>
</thead>
<tbody>
<tr>
<td>- We work with individuals who have a diagnosis/probable diagnosis of dementia (without any age barriers).</td>
<td>- It is not a crisis service.</td>
</tr>
<tr>
<td>- We provide an alternative to acute mental health beds.</td>
<td>- Not rapid response.</td>
</tr>
<tr>
<td>- We help facilitate timely discharge from acute mental health inpatient beds.</td>
<td>- It does not provide bed management.</td>
</tr>
<tr>
<td>- We work with complex needs.</td>
<td>- We do not work with people who are not experiencing a dementia.</td>
</tr>
<tr>
<td>- Provide a quick but planned response to referrals.</td>
<td>- We do not undertake the CPA care-co-ordination role.</td>
</tr>
<tr>
<td>- Provide a time limited approach of up to 12 weeks (flexible dependent on needs of individual).</td>
<td>- We do not provide a 24-hour service.</td>
</tr>
<tr>
<td>- We work with individuals who require multi-disciplinary input.</td>
<td>- We do not provide a service at weekends.</td>
</tr>
<tr>
<td>- We work closely with those involved in the individual's care, i.e. professionals, relatives and carers.</td>
<td>- Each profession does not have their own case-load.</td>
</tr>
<tr>
<td>- We use a person-centred approach as described by Brooker (2006) and Morton (2002). The individual is kept informed and at the centre of their care at all stages of our involvement, whenever possible.</td>
<td></td>
</tr>
<tr>
<td>- Our service is Monday to Friday 0830 hours to 1700 hours.</td>
<td></td>
</tr>
<tr>
<td>- We work with individuals in various settings including wards, their own homes and residential care homes.</td>
<td></td>
</tr>
<tr>
<td>- We have a single point of access for referrals via the community mental health team for older people.</td>
<td></td>
</tr>
<tr>
<td>- The teams employ positive risk taking which looks at imaginative ways of finding an acceptable balance between hazards and safety for the individual (Titterton, 2004), in addition to risk management and advocacy.</td>
<td></td>
</tr>
<tr>
<td>- We manage internal and external processes/systems.</td>
<td></td>
</tr>
<tr>
<td>- The team has a shared case load.</td>
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</tbody>
</table>
Service Framework for Older People (2001), and more recently in the consultation on the National Dementia Strategy (2008). From our experience it seems that the Home Treatment Service owes much of its success to this person centred and focused approach as well as its multi-disciplinary way of working.

**It’s all in the mix**
The Home Treatment Services are tertiary services sitting within Community Mental Health Teams for older people (CMHTOP). The service relies on teamwork; therefore, there is a mix of professionals working in each team comprising of occupational therapists, community psychiatric nurses/mental health nurses, support workers, a senior practitioner and assistant psychologists; with psychological input from the local clinical psychologist one day per week. Initially when the services were set up they would have liked to have included qualified clinical psychologists rather than assistant psychologists, however the necessary funding was not available. Although employing assistants rather than qualified psychologists was a compromise, it was agreed that psychological services would still provide considerable input to the service in terms of management, training and developing the teams’ overall ways of working.

**Assessment**
The assessment tool used throughout the services is the Camberwell Assessment of Need for the Elderly (CANE; Orrell & Hancock, 2004) which identifies clients’ met and unmet needs. The CANE assessment helps to facilitate discussion and identifies differing professional opinions on possible ways of meeting the clients’ unmet needs. This assessment process then leads to the development of an intervention plan, which is updated on a weekly basis as the clients’ needs change. At the end of the Home Treatment Service intervention it is anticipated that other services or professionals will be in place to offer a continuation of interventions and care, to ensure a seamless transition of care for both clients and carers.

**The role of Assistant Psychologists within the Home Treatment Service**
Given that the Home Treatment Service has recently completed its first year, we felt that it would be helpful for us to reflect together as assistant psychologists on what have been the challenges and rewards of working within the service.

**Split post**
We are both employed as assistant psychologists within Home Treatment Services on a part-time basis, 0.8 Home Treatment and 0.2 Memory Service work, which involves working within our local CMHTOP’s to support the development of Memory Clinics, neuropsychological testing and Memory Support Groups. Having a split post has created variety and enriched our work experience. As we are responsible for setting our own boundaries between the two posts we have been able to use our time efficiently, being flexible in allocating appropriate time to both roles. Whilst this has been an advantage for us, we recognise that it has at times proved challenging and confusing for those around us.

**Not a traditional role**
As assistant psychologists in newly-developed Home Treatment Services, we feel that our role in this service is not that of a traditional assistant psychologist. From our understanding a more traditional assistant role involves a close working relationship with a qualified clinical psychologist who allocates and plans psychological work for the assistant to undertake. This traditional assistant psychologist role is outlined in *Guidelines for the Employment of Assistant Psychologists* produced by the British Psychological Society in 2007.

In both our teams we are the only psychological practitioner employed to work clinically within the service, with team supervision coming from a clinical psycho-
logist. Our clinical work is allocated through our multi-disciplinary team meetings and not through a clinical psychologist, and it is generally our responsibility to acknowledge what we are competent to do and where we have limitations and need to seek support or decline a request. Therefore, we feel that generally we work in a more autonomous way than a traditional assistant, which we have found has both benefits and challenges.

As the service is now just over a year old, it is still continuing to evolve and find its place within the community services. At the same time the different professionals within the service have needed to find their place within the team, balancing their role as a specific professional from a specific discipline but also as a generic mental health team worker. The three local Home Treatment Services have received a great deal of generic training together, which has enabled us to work as a team, building on our joint training.

**Role diversity**

There is also a specific element to each professional’s role and for us as assistant psychologists we have found it difficult to clarify and explain this role. Our work has been varied and diverse, and has included creating administration systems for the team, conducting relevant audit work, doing clinical work with clients, and bringing a reflective element to the service. Already we have felt that our role has evolved and expect that this will continue as the teams continue to develop and expand. As new staff are recruited, we may find our role more centred on disseminating information regarding best practice, providing reflective input and conducting audit work. In addition, it is likely that our roles will alter as the pressures on the teams change, as the gaps in service provisions change and as new targets are set for the service.

**Tensions and challenges**

At times we have felt expected to perform as qualified clinical psychologists, possibly because we are the only psychological practitioner working clinically within our services. Although we both had considerable experience before coming into these roles, we both recognise our limitations and need for further training before we are able to work to the standard of a qualified clinical psychologist.

Within the service our level of banding in Agenda for Change (DOH, 2004) has caused some confusion and misunderstanding. Both of us are employed as Band 5 higher level assistant psychologists due to our level of experience (both of us having at least two years relevant work experience) and additional qualifications (one of us having a Masters degree in Analysis and Intervention in Learning Disabilities, and the other having a postgraduate certificate in Primary Care Mental Health). However, within the hierarchy/professional development of psychologists we are still unqualified and require doctorate training to register as qualified professionals. In the current Home Treatment Services and Community Mental Health Teams, Band 5 typically represents the first level of a newly-qualified professional such as a nurse or occupational therapist. Therefore, our colleagues who are also at Band 5 in these professions have tended to look to us as equal members of the team, expecting us to work as such. This has consequently led to some debate around what is appropriate for us to do in our roles.

There seem to be some assumptions held by our colleagues about what we can and cannot do in our roles, with colleagues viewing us as in a ‘qualified’ banding they see us as able to take responsibility for clients. This has led us to raise several questions with ourselves and other people supporting us about our roles. We recognise that in some areas we have higher level skills than many of our colleagues as we have received degree-level and higher degree-level education. However, we do not hold a mental health qualification or a professional registration within an organisation, and to be employed we need to be supervised by a
qualified clinical psychologist. Supervision has, therefore, proved to be valuable in allowing us to reflect on these issues and how we can respond to colleagues who may be expecting more from us than we can provide. For us both, it is also important to remember that we do bring many skills to the role, and it is important for these not to be underestimated even if we do not hold a professional qualification or registration.

Given our level of academic qualification, and our level of experience, we feel well positioned to write accurate, sensitive notes and reports, and will readily seek advice when we are unsure. Currently we are expected to do what we feel competent to do and to seek help and advice from our colleagues when appropriate. To this extent we are lucky as we have so many colleagues around us who are willing to support us when we ask for help and clarification, although we wonder to what extent some of them remain confused by our role and boundaries and the ongoing debate. The clinical psychologists who provide our supervision have been central in supporting us and providing support to our teams as a whole. Within our Home Treatment Services and wider Community Mental Health Teams there are opportunities for us to try to educate colleagues about our role. There is a need for honest, open working, particularly within our Home Treatment Service as we express what we feel confident and competent to do, and where we do not feel capable and seeking appropriate supported learning opportunities. This feels appropriate to the role – a developmental role in the psychology discipline, as recommended by the British Psychological Society (2007).

The future role of psychology within HTS
As we have felt that sometimes we work as qualified psychologists and at other times as unqualified psychologists, we have reflected on our role within our services in accordance with New Ways of Working for Applied Psychologists (BPS, 2007). It seems likely that our current roles would fit well with the proposed new role of psychology associates which have been outlined by Taylor and Lavender (2007). Such a role would highlight the level of experience and training required for the post, and would provide further relevant training to a master’s degree level. It has been proposed that although new psychology associates would be in a non-chartered role it is suggested that there would be the need for some level of professional registration. Although the details of the proposed new roles in psychology are still to be finalised, from the information available to date, we both believe that a psychology associate would be appropriately placed to work within the Home Treatment Service.

We are unsure what the future will be for psychology within the Home Treatment Service – will new psychology associate roles be the most appropriate, or will newly qualified clinical psychologists be recruited? Given the complexity of the work referred to Home Treatment Service it is possible that there is the potential for several psychological practitioners to be incorporated into the teams, with a role for assistant psychologists, psychology associates, and newly-qualified clinical psychologists. There is certainly a need for considerable ongoing psychological input to the Home Treatment Service, and the inclusion of psychology at different levels would be valuable in this team.

Although we find our roles challenging and there are ongoing uncertainties and difficulties arising from working in an assistant position in a non-traditional assistant post, we both find our work very stimulating and feel that there remains a position within the Home Treatment Service for psychological practitioners of different levels, including us!

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New Kids on the Block: Finding our place

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Psychological treatments for reactivated post-traumatic distress among older adults

Syd Hiskey

This paper highlights existing literature on psychological treatments for post-traumatic stress disorder (PTSD) reactivated in later life. Unfortunately, empirical research to guide choice of therapy is sparse and mostly lacks supporting data. Those treating this particular presentation are, therefore, left to apply national clinical guidelines, developed for working age adults, while remaining aware of some of the psychological issues unique to the elderly.

While our understanding of post-traumatic stress disorder (PTSD) continues to develop (Joseph, Williams, & Yule, 1997; Yule, 1999), research efforts focus primarily upon adult and child populations (Cook, 2001). As such, there is a relative dearth of work into the experience of posttraumatic distress among older adults (Busuttil, 2004). This is regrettable as the longitudinal signature of the disorder remains uncertain and the literature is peppered with case reports of sufferers who have long periods, up to and including several decades, without distress only to experience a recurrence or reactivation of PTSD symptoms in late life (Hilton, 1997; Orner & de Loos, 1998).

According to the few large-scale studies that exist prevalence rates of such late onset or reactivated PTSD1 among the elderly vary quite markedly (Engdahl et al., 1998; Op den Velde et al., 1993) and so the true extent of the problem remains unknown. Kaiman (2003) however simply claims that the exacerbation of PTSD symptoms among elderly veterans is ‘common’. Moreover, it has been argued that exposure to trauma and its psychological effects remain ‘hidden variables’ in the lives of many older adults (Nichols & Czirr, 1986), which increases the risk that the current impact of distant events may be overlooked in a clinical context. Research highlighting this facet of the disorder may, therefore, be particularly important.

However, empirical studies into the phenomenon are rare (Hiskey et al., 2008) and only a handful consider treatments for the reactivated form of the disorder. In this article I highlight some of this work, which may inform clinical decision-making. To begin with we will briefly review national treatment advice regarding PTSD in adults before moving on to explore some of the specific work that considers reactivated PTSD in older adulthood.

PTSD treatment: General

Current guidelines for the management of PTSD in adults from the National Institute for Clinical Excellence (NICE: March, 2005) state that those with PTSD should be offered either trauma-focused cognitive behavioural therapy or eye movement desensitisation and reprocessing (EMDR) therapy. Drug treatments are not recommended as a first-line treatment in preference to trauma-focused psychological therapy or eye movement desensitisation and reprocessing (EMDR) therapy. Drug treatments are not recommended as a first-line treatment in preference to trauma-focused psychological therapy and should only be considered for those who prefer not to engage in a psychological approach. Of interest, the guidelines state that therapy

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1 For our purposes, and following Solomon et al.’s (1987) notation, the term reactivated PTSD will be used to encompass the notion of both recurrent and delayed-onset PTSD in older adults. It can be argued that the term delayed-onset refers to post-traumatic symptoms that first appeared after a period marked by an absence of trauma response, while the terms reactivated or recurrent PTSD refer to symptoms reappearing following a period of significant amelioration. I note, however, that these terms are often not differentiated within the older adult literature and are, mostly, used interchangeably.
should be offered to those with PTSD regardless of how long it has been since their traumatic event. However, specific mention of issues pertaining to either older adults or reactivated trauma in later life do not feature.

PTSD treatment: Older adults

Specific trauma therapy for older people occasionally features in the PTSD literature. For example, Hyer and Sohnle (2001) described an integrated psychological treatment model that seeks to: stabilise symptoms, build relationships, educate and normalise, work on avoidance symptoms, build on positive memories (that can generalise to current life situations) and decondition trauma memory. They argued that treatment must fuse issues specific to later life (e.g. elder wisdom, life review) with those most relevant to therapy in general (e.g. goals, the therapeutic relationship). Others advocate a broad biopsychosocial approach when working with this group which can feature psychoeducation for both sufferer and family, medication based approaches for re-experiencing, insomnia and hyperarousal type symptoms and psychotherapy for managing avoidance phenomena (Bonwick & Morris, 1996; see also Schreuder, 1997).

Maercker (2002) advocated a structured life-review technique for older adults involving discussion and evaluation of each life-stage and encouraging reminiscence on both positive and negative events. Positive coping experiences are reinforced and three case studies cited where this approach has proved effective. The method clearly draws upon developmental thinking that trauma can be best be resolved in the context of a life lived (see also McInnis-Dittrich, 1996). Likewise, Davies (1997a) citing Robbins’ (1997) four-stage model of treatment for war veterans (featuring disclosure of events, identification of dysfunctional emotions and cognitive content, behavioural change strategies, and termination) as being interwoven with developmental thinking that allows difficulties to be considered from a longitudinal viewpoint with an explicit focus on integration of distant trauma material.

Robbins (1997) argued that disclosure is central when working with remote trauma. He cited the successful application of his treatment approach with 10 older World War II veterans, whilst noting that an additional client dropped out of therapy, as they could not face treatment. All those that remained in therapy are reported to have experienced a considerable reduction in symptoms, most notably intrusions (although measured outcomes were not provided).

Russo, Hersen and Van Hasselt (2001) illustrated a case of successful behavioural treatment using imaginal exposure for reactivated PTSD with therapeutic gains maintained over the following 16 months. Davies (1997b) agreed that behavioural elements of treatment, such as exposure, as well as time for reflection on the meaning of these experiences can aid healing. Non-verbal interventions such as art-based therapies are thought useful when clients are unable to verbalise traumata (Schreuder, 1997). In addition, clinical experience has shown that counselling can be appropriate for older people with dementia who re-experience traumatic material from their past (Davies, 1999).


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1 Solomon et al.’s (1987) work with working-age Israeli veterans with recurrent combat-related PTSD led them to propose two categories of reactivated trauma response. The first, uncomplicated reactivation is characterised by an initial period of distress followed by good interim functioning until further exposure to an event closely resembling the original stressor reactivates symptoms once more. The second, heightened vulnerability can be thought of as when sufferers experience residual distress and are susceptible to reactivation upon exposure to stimuli indirectly reminiscent of the original event. Unfortunately, there does not appear to have been any further work into Solomon et al.’s scheme of reactivation types, for combat-related or any other form of PTSD, and so it is difficult to comment upon the validity of these categories with elderly sufferers.
matching. He suggested that uncomplicated reactivation is dominated by positive symptoms (e.g. intense affective states, intrusive thoughts, psychic numbing) and argued that what he terms ‘a psychoeducational approach’, featuring elements of cognitive restructuring, mobilisation of family resources and exposure based treatments, may be appropriate. In contrast, complicated reactivation is thought characterised by a misalignment between the sufferer and their social surroundings, resulting in social withdrawal and identity disturbance (a disorder of the self) requiring a psychodynamic treatment with an emphasis on process above content to facilitate self-reconstruction.

However, while Hiley-Young’s (1992) notion of client-treatment matching is to be commended, the approach he outlined seems to involve a considerable blurring of treatment boundaries as the psychodynamic therapy he recommends shares some notable features (e.g. cognitive restructuring and positive meaning of events, information giving about stress syndromes, examination of how the victim could behave differently should a similar event occur) with his psychoeducational method. The reader is, therefore, left uncertain as to the active ingredients of either treatment, although it is clear that Hiley-Young favours a personality-based approach in cases of complicated reactivation. As this way of targeting therapy is novel and attempts to draw upon the theoretical literature on reactivated trauma literature in such a direct way it will be interesting to see if data beyond the two case studies presented will be provided to explore this position in greater detail.

In relation to group treatments, Kaiman (2003) described ongoing interactive group psychotherapy with World War II veterans suffering delayed onset or exacerbated PTSD and alluded to improvements in participants’ physical health, enjoyment of life and ability to discuss traumatic experiences with family members (although no formal assessment of these changes is detailed). Similarly, Bonwick (1998) reported encouraging early results in a series of 16-week group treatment programmes with veterans, despite limited improvements in core PTSD symptomatology (although once again data are absent).

In addition, Lipton and Schaffer (1986) ran a group therapy programme for veterans and ex-POWs with delayed PTSD and simply reported that the programme produced ‘excellent’ results. An important goal of the programme was to help members learn to spend less time in their past, which was achieved by discussion of recurring wartime memories with peers who could then offer solutions. The authors argued that the relief of long-held guilt afforded a reduction in symptoms, although I note that antidepressant medication was also widely used which potentially confounds this claim. Lipton and Schaffer (1986) found that most individuals reported feeling better within the second or third group meeting but, as with the above group studies, did not provide data to substantiate their claims regarding the efficacy of the treatment. Although testimonial comments from group attendees commend the benefits of the programme, the absence of formal measurement of symptom changes as a result of participation renders such work most difficult to assess.

Interestingly, the positive benefits of the sense of camaraderie that can be engendered among groups of older veterans has been commented upon (Bonwick & Morris, 1996) as a potentially beneficial feature of group work, although I am unaware of any empirical research that has considered this facet of social support in particular detail. Davies (1997b), however, warned of the advantages and disadvantages of social support in war trauma treatments, as some may feel vulnerable and find their experiences attract censure rather than support from peers. As such, some clients may find a supportive environment rather than a supportive group experience of greater benefit.
Summary
Clearly a range of therapeutic approaches, at both individual and group level, may be applicable for reactivated PTSD among older adults. Unfortunately, the lack of empirical research, limited number of participants featured and almost complete absence of systematic attempts to demonstrate treatment effects leaves the clinician with little to guide their choice of intervention. Substantial treatment models (e.g. Hyer & Sohnle, 2001) by highly experienced workers do exist but rigorous work to substantiate the efficacy of these paradigms has yet to follow.

My own sense is that, for now, we should draw heavily upon national guidelines developed for younger adults while also integrating developmental features unique to later life (e.g. life-review). In this way we acknowledge the substantial evidence base surrounding adult PTSD yet remain mindful of the adaptations this particular client group may require.

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How do you evaluate an informal support group? A pilot example from stroke rehabilitation

Sophie J. Dewar, Jana Jenkins & Ian I. Kneebone

In order to justify the use of limited resources there is an increasing demand to evaluate the effectiveness of interventions within the health service. Despite this, the literature indicates that designing and implementing effective evaluations is difficult and often poorly done. Further, clinicians’ negative perceptions of research may discourage evaluation, resulting in practice that is primarily based on clinical intuition. The current article describes the rationale behind the development of a pilot evaluation strategy for an informal inpatient and carer stroke support group. It is concluded that appropriate evaluation should be determined by the purpose and nature of the intervention under examination as well as the persons involved. Furthermore, it is suggested that valuable feedback regarding clinical practice need not involve time-consuming and complex evaluation.

Background
Why evaluate?

There is a growing demand reflected in both national and local health service policies to evaluate the effectiveness of services (Hall, 2004). More specifically, there is an increasing emphasis placed on demonstrating the success of an intervention or programme by way of positive evaluation. Evaluations are necessary to justify the use of limited time and facilities and as such, much of the recent drive for service evaluation has been financially and pragmatically motivated. Furthermore, evaluation provides a basis to develop recommendations for service improvement (Hall, 2004) and should also be of demonstrable benefit to service users.

Evaluation in clinical practice

Barker, Pistrang and Elliot (2002) describe different types of practitioners in terms of their orientation and use of research methods in clinical practice. These types range along a continuum from clinical scientists, who produce high quality randomised controlled trials (RCTs), to intuitive practitioners, who base their practice on subjective clinical experience and narrative case studies. According to this classification, service evaluation sits in the middle of the continuum under the local clinical scientist model (originally proposed by Trierwieler & Stricker, 1998). Local clinical scientists integrate research methods into their clinical work applying both qualitative and quantitative methods as well as critical thinking skills to evaluate and improve services.

There are several reasons why service evaluation should be differentiated from the research conducted at the level of the clinical scientist model. For instance, as evaluation is inevitably undertaken within the service delivery setting there may be ethical implications of including ‘non-treatment’ control groups as required in some RCTs. Further, the purpose of service evaluation is not to add to an existing knowledge-base or to test theories but to aid in service-level decision-making, frequently as part of a service’s clinical governance objectives (Barker et al., 2002). Such service-level evaluation often takes the form of clinical audit, in which current performance is measured against explicit criteria taken to represent ‘best practice’ standards (National Institute for Clinical Excellence, 2002). However, with newly-developed or informal interventions, such standards may not yet exist, nor would they always be possible to define. In such cases, evaluation can be used simply to
ensure that clinical practice is worthwhile, i.e. to demonstrate to a team or individual clinician that there is benefit derived from an intervention.

**Problems with evaluation in practice**

Despite a general consensus of need as well as institutional demands to evaluate, difficulties are also reported in the literature about how to conduct service evaluation: ‘The issue is not whether to evaluate, but how to’ (Barker et al., 2002, p.203). There is no ‘gold standard’ for developing and implementing evaluation within a clinical service setting. Rather, research indicates that ‘effectiveness’ is an indefinable standard. Furthermore, the achievement of a proficient measurement technique is complicated by substantial differences across studies in what is being evaluated (Hall, 2004). For instance, a recent systematic appraisal of newly-developed interventions in stroke care led to concerns about their efficacy as few had been adequately evaluated (Redfern, McKevitt & Wolfe, 2006).

In addition to difficulties in knowing how to evaluate, clinicians’ negative perceptions of evaluation and research can also impede the process. For example, evaluation is often perceived as requiring high-level skills in research methods in which clinicians typically lack confidence (Barker et al., 2002). Further, as much research is regarded to be both time-consuming and irrelevant to clinical practice it is often given a lower priority than clinical caseloads (Shapiro, 2002).

**Current study**

Below is described the process of developing a pilot evaluation of an informal stroke support group for inpatient stroke survivors and carers. Previous pilot work ruled out the need to demonstrate the feasibility of the group (Hull, Hartigan & Kneebone, 2007). The aim of the evaluation was not to demonstrate that ‘usual care’ is inadequate, rather the focus was placed on piloting an evaluation methodology and to demonstrate a perceived benefit of the support group for the attendees. As such, the following example is aimed at the level of the local clinical scientist and aims to inform about the process of practical evaluation. It does not attempt to argue that the chosen evaluation method is without fault, rather the selection process is elucidated via exploration of the advantages and disadvantages of different methodologies. The chosen evaluation in the current example is simple, yet provides useful data, demonstrating that evaluation need not be time consuming and complex in order to provide valuable feedback on clinical services. As such, the discussion proposes that clinicians can evaluate their interventions meaningfully without the need for complex methodologies.

**Case example**

**Location:** A 10-bedded inpatient stroke rehabilitation ward.

**Background:** It was felt that the introduction of single rooms made informal social contact between patients difficult. A stroke support group (Hull et al., 2007) was, therefore, developed in consideration of the documented benefits of social support in neurological rehabilitation (e.g. Callaghan & Morrissey, 1993).

**Aims:** To develop a weekly social activity for inpatients and their carers in order to enhance social networks, help improve behavioural activation, and to give a break from therapy; a ‘time-out’ from focussing on stroke.

**The Group:** Typical of inpatient stroke populations, those stroke survivors involved in the group had a range of significant physical, cognitive and communication disabilities. Participants were, however, required to be medically stable. Following consultation in an initial meeting with survivors and their carers that considered what they would like to get from a weekly group, invitations to attend an informal, activity-based, ‘afternoon tea’ group were made on a weekly basis. Activities included playing bingo and board games, making Christmas cards and doing puzzles.
Facilitators: A Trainee Clinical Psychologist and an Assistant Clinical Psychologist.

Some difficulties with evaluating the current group
Deciding what to evaluate for an informal support group is difficult given the lack of specific therapeutic focus such as anxiety, depression or stroke-related measures with which to compare. Given this, it was decided to ground the evaluation in the aims of the group, i.e. whether the group enhanced behavioural activation, developed social networks, and provided a ‘time-out’ from demanding rehabilitation activities.

Deciding who should conduct an evaluation can be a complex issue. There is a current focus on ‘service user involvement’ (Department of Health, 2006; National Health Service, 2006; Church, 2008). Indeed, it has been considered that the interests of service users should be primary to any evaluation based in a clinical setting (Barker et al., 2002). However, evaluation solely from the perspective of those who use the service does not provide a complete assessment (Ong, 1993). Pluralistic research stresses the need to take into account various viewpoints, e.g. patients, carers, health care professionals, etc. (Hart & Anthrop, 1999). For this reason it was decided that incorporating multiple perspectives, would allow for a more thorough evaluation of the current group.

Different methods of evaluation considered
Below we discuss the advantages and disadvantages of several methodologies as they apply to our evaluation. We then outline why the final methodology was determined.

● Standardised assessments
Dawson and Heyman (1997) note there is a ‘political pressure’ to rely on quantitative evaluation. Indeed, the literature on stroke support groups contains many examples whereby efficacy is determined following the analysis of pre-group versus post-group scores on standardised assessments using quantitative statistics (e.g. Clark, Rubenach & Windsor 2003; Askim et al., 2004; Smith Forster & Young, 2004). However, by focusing on quantitative outcome measures, evaluations may fail to address how it feels to experience services. An outcome analysis, for instance, might reveal a significant decrease in depression following a group session, despite an individual feeling distressed during the process. Whilst the quantitative statistics generated in this case may indicate a successful evaluation with regards to a reduction in depression scores, they may omit other significant information. Additionally, many support groups are run in an inpatient setting during which time the attendees will be undergoing routine rehabilitation. This makes it impossible to isolate any statistical differences to a result of the group without introducing a control, ‘non-attendance’ or ‘usual care’ group who are prevented from attending, which as noted above, has ethical implications.

Mixed methodologies provide a way of addressing both the process and the outcome of an evaluation, and in many cases may be an excellent choice to provide a thorough evaluation. However, aside from the increase in time and resources required there remains a difficulty in employing quantitative measures to the current informal group. It was not expected that attendance at the group would lead to significant improvements in psychological dimensions such as depression or anxiety that could be measured on standardised assessment instruments. It was, therefore, considered that undertaking such assessments would not have been appropriate. Further, formal assessment at the outset of the group might have discouraged people from attending.

● Interviews
One of the most common qualitative evaluation methods is participant interview. The content of interviews can be transcribed and subjected to various qualitative analyses determined by the topics covered, resources
available and personal preference of the researcher (Tere, 2006). Interviews have been used to a lesser extent than quantitative methods to evaluate stroke support groups although examples can be found (e.g. Pierce et al., 2004). The advantage of interviews is that they include an evaluation of process rather than purely focussing on outcomes. However, interviewing is a time-consuming process.

Time is precious to both staff and interviewees and given the informal nature of the current group it was felt that even unstructured interviews would be seen as a burden by the attendees. Additionally, interviews can introduce a ‘desirability bias’ in responses, with interviewees being reluctant to contribute criticisms (Barker et al., 2002). This, combined with the fact that the evaluation had to be conducted by the group leaders, was considered to be a potential disadvantage given the reserved nature of the attendees in the current group.

- **Systematic observation**

  In systematic observation a recording instrument (often a coding schedule) is developed in order to structure observations and remove observer bias (Mastrofski et al., 1998). Observed behaviours are coded and later analysed. Assuming that the construction is valid, coding schedules can provide an effective method of recording observations.

  No current literature was found in which systematic observation had been used to evaluate a stroke support group. This is not to say it would not be a valid means of evaluation; but there are some drawbacks. Firstly, this method requires somebody to focus solely on observing and completing coding sheets. Given that a support group is likely to work best with two facilitators (National Stroke Association, 1997), systematic observation would require an additional member of staff. Secondly, the presence of someone noting behaviours may create an unnatural environment, particularly in a small group setting. This in turn may lead to affected behaviour or a ‘reactivity problem’ (Barker et al., 2002) that prevents reliable evaluation. Such transparent observation was not considered to be appropriate to the current situation given the group aims, i.e. aiming to create a comfortable environment and facilitate conversation.

- **Questionnaires**

  Questionnaires have been a popular method of evaluating stroke support groups (e.g. Fell & Sams, 2004; Bennet, Barston & Smith, 2007) and provide a simple way of recording opinions in minimal time. The provision of open or closed questions can guide the type and quantity of data obtained, and a variety of response options, e.g. tick boxes, Likert scales, and text boxes can be employed to influence the relative simplicity of completion. Further, questionnaires allow for anonymity of responses, overcoming a desirability bias. Unfortunately, written evaluations may limit the input from those with literacy or mobility difficulties, i.e. in a stroke setting, due to the mobility and/or cognitive difficulties typically seen in neurological rehabilitation.

**Choice of evaluation**

It was decided that due to the informal nature of the current group and the reserved temperament of attendees, qualitative evaluation would be more appropriate than quantitative assessment of outcomes. In order to provide a thorough evaluation, it was determined that both facilitator and attendee perspectives should be incorporated into the evaluation. This allowed for possible discrepancies between facilitator and attendee evaluations, which could highlight ‘hidden’ problems (see Hart, 2001 cited in Hall, 2004), potentially in this instance, issues such as satisfaction with the level of control given to participants, for example.

**Attendee evaluation**

Brief questionnaires were felt to be the most appropriate means of obtaining attendees’ opinions, despite the potential difficulties discussed above. It was thought that the opportunity for anonymity was beneficial in
obtaining honest perceptions from a reserved group (see Figure 1). Further, it was possible to complete questionnaires within the timeframe of the group, minimising the input required from attendees. Both open and closed questions were used and the wording was considered easy to understand. For attendees with mobility or visual difficulties (N=2), it was necessary for a facilitator or family member to help complete the questionnaire. Whilst this necessarily broke anonymity, it was done both in private and with sensitivity. Published evaluations using surveys differ in terms of when questionnaires are completed (e.g. see Fell & Sams, 2004, versus Bennet et al., 2007). In order to minimise the amount of ‘work’ required by attendees, as well as to maintain an informal atmosphere, the current attendees were asked to complete just one written evaluation at the end of all six sessions. However, attendees were asked informally whether or not they had enjoyed themselves at the end of each individual session and their responses were recorded by the facilitators.

Facilitator evaluation
The facilitators completed a self-designed evaluation form immediately after each session (see Figure 2). This recorded observations regarding communication (verbal and non-verbal), a reflection of how the facilitators felt the session went and any lessons learned. Additionally, a detailed weekly report of the session (procedure, materials required, etc.) was written to facilitate the running of future groups. Attendance sheets were also completed weekly to assess the retention of group members.

The Evaluation
Attendee evaluation
The comments given by attendees were positive, e.g. ‘… the whole thing was enjoyable.’ All of the stroke survivors and their carers reported that they enjoyed the group and felt they had benefited from it. Perceived benefits included having an activity to do: ‘[it was] stimulating.’ When asked to rate ‘enjoyment’ of each session on a Likert-type scale, total scores were high and all respondents indicated that they would like to participate in future groups. These findings suggest that the group gave the participants the time and opportunity to engage in activities that may enhance pleasure and mastery thereby impacting upon mood (Lewinsohn, 1974).

Although designed to be a break from therapy, several attendees commented that they felt they had benefited therapeutically: ‘Help you using your brain and hands.’ One respondent noted that ‘[It was] useful to meet and chat with other patients’ indicating that the group was also successful in helping to develop social networks. Five respondents (71 per cent) indicated that they had made friends through the group. Notably one respondent who indicated he had not, only attended one session.

Further support for the success of the group can be seen in the minimal number of suggested improvements: ‘I can’t think of anything that would improve it …’ However, one attendee stated that he would have liked more assistance getting to and from the group.

Facilitator evaluation
Overall both facilitators were pleased with the group and it was felt that the group achieved its aims. Attendees were usually observed to be alert, contented, and interacted well with each other. Feedback (spontaneous and prompted) was positive for all sessions.

It was noted that the group members were reserved, however, the facilitators took the role of ‘leaders’ to help initiate discussion. It was felt that a larger group might have helped to overcome reluctance to communicate but little could be done about the size of the group, as it was dependent on the current inpatient population. Attendance was consistent and the group comprised the same core members despite a ‘drop-in’ format. Despite their reserved nature, it appeared that the attendees wanted to come back.
GROUP EVALUATION QUESTIONNAIRE

1. Overall, have you enjoyed the group?
   Yes ☐ No ☐

2. Do you feel you have benefitted in any way from attending the group?
   Yes ☐ No ☐
   *If yes, please briefly mention how.*

3. Please rate on the scale how much you enjoyed each of the sessions:
   - **Session 1: Word Searches & Crosswords**
     - Very Much ☐ Quite A Bit ☐ Undecided ☐ Not Really ☐ Not At All ☐
   - **Session 2: Bingo**
     - Very Much ☐ Quite A Bit ☐ Undecided ☐ Not Really ☐ Not At All ☐
   - **Session 3: Making Christmas Cards**
     - Very Much ☐ Quite A Bit ☐ Undecided ☐ Not Really ☐ Not At All ☐
   - **Session 4: Playing Cards & Dominos**
     - Very Much ☐ Quite A Bit ☐ Undecided ☐ Not Really ☐ Not At All ☐
   - **Session 5: Watching a Christmas Video**
     - Very Much ☐ Quite A Bit ☐ Undecided ☐ Not Really ☐ Not At All ☐
   - **Session 6: Playing Cards & Puzzles**
     - Very Much ☐ Quite A Bit ☐ Undecided ☐ Not Really ☐ Not At All ☐

4. Would you want to participate in future groups?
   Yes ☐ No ☐

5. Did you feel comfortable during the group sessions?
   Yes ☐ No ☐

6. Do you feel you made friends on the ward by attending the group?
   Yes ☐ No ☐

7. We would be grateful if you could tell us what you feel could be improved if the group were to run again.

8. Were there other activities that you would have liked to do in the group?
   Yes ☐ No ☐
   *If yes, please briefly mention.*

9. Any other comments?
   ...........................................................................................................................................................................................
Figure 2: Template of the facilitator evaluation, completed weekly after each session.

<table>
<thead>
<tr>
<th>SESSION EVALUATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity:</td>
</tr>
<tr>
<td>Facilitators' Opinion of Session: Did you feel the group went well: Yes □ No □</td>
</tr>
<tr>
<td>FEEDBACK FROM ATTENDEES</td>
</tr>
<tr>
<td>1. Spontaneous feedback.</td>
</tr>
<tr>
<td>2. Feedback when asked about the group.</td>
</tr>
<tr>
<td>OBSERVATIONS</td>
</tr>
<tr>
<td>3. Communication</td>
</tr>
<tr>
<td>- Did attendees have conversations with each other/the group facilitators?</td>
</tr>
<tr>
<td>□ Yes, with both.</td>
</tr>
<tr>
<td>□ Yes, with facilitators only.</td>
</tr>
<tr>
<td>□ Yes, with other attendees only.</td>
</tr>
<tr>
<td>Other observations, e.g. barriers to communication, non-verbal communication.</td>
</tr>
<tr>
<td>4. Topics discussed.</td>
</tr>
<tr>
<td>- Did topics discussed cover their stroke specifically? Yes □ No □</td>
</tr>
<tr>
<td>- The Activity</td>
</tr>
<tr>
<td>- The Future</td>
</tr>
<tr>
<td>- The Past</td>
</tr>
<tr>
<td>- Their Worries</td>
</tr>
<tr>
<td>- Other Feelings</td>
</tr>
<tr>
<td>- Their Goals</td>
</tr>
<tr>
<td>- Their Therapy</td>
</tr>
<tr>
<td>- Their Memory</td>
</tr>
<tr>
<td>- Their Speech</td>
</tr>
<tr>
<td>- The Hospital Environment</td>
</tr>
<tr>
<td>- Family</td>
</tr>
<tr>
<td>- Their Hobbies/Interests</td>
</tr>
<tr>
<td>- Going Home</td>
</tr>
<tr>
<td>- Being in Hospital</td>
</tr>
<tr>
<td>- The Staff</td>
</tr>
<tr>
<td>- Other.</td>
</tr>
<tr>
<td>5. Emotions</td>
</tr>
<tr>
<td>- How did the attendees appear (e.g. laughing, smiling, tearful, quiet, sad, etc.)?</td>
</tr>
<tr>
<td>- During the group and when taken back to their room.</td>
</tr>
<tr>
<td>6. Other</td>
</tr>
<tr>
<td>Any other observations made regarding the attendees, the group, interaction, engagements, etc.</td>
</tr>
</tbody>
</table>
Attendees chose the activities ensuring they were enjoyable and they gave a natural starting point to conversation, which was beneficial in helping to develop social networks. Topics of discussion focused around the activity, hobbies, physiotherapy and discharge. The attendees’ stroke or stroke-related topics were never discussed specifically. This was taken to indicate that the attendees enjoyed this group as a time-out from focusing on their stroke.

**Recommendations:**
Develop a rolling programme: Given the positive evaluation, it is proposed that protected time be established after the conclusion of the current group as ‘drop-in’ time for informal activities.

The current positive evaluation is also being used as support for a funding request for the employment of a permanent Assistant Psychology post with responsibility for the stroke rehabilitation ward.

**Conclusions**
There are a number of techniques to choose from when selecting an appropriate method of evaluation, including both quantitative and qualitative methods. As discussed there are advantages and disadvantages associated with each methodology. There is, therefore, no single appropriate method of evaluation for all interventions. The choice of evaluation needs to be logically determined by the purpose and nature of the intervention, the persons involved, the purpose of the evaluation, and the resources available. As Barker et al. (2002) note: ‘evaluation should be as systematic an endeavour as one can manage within practical and organisational constraints’ (p.200). Whilst the current example provided valuable data on which to evaluate the group and develop recommendations, it should be noted that it was a pilot and changes in the methodology may be employed should it be re-run. The authors aim to demonstrate the process rather than advocate a particular strategy.

To determine an appropriate method, the purpose of the evaluation needs to be clearly stated (e.g. to demonstrate a perceived benefit for the attendees), as do the unique aspects of the intervention that are being evaluated (e.g. what are the particular aims?). Reflection, collaboration and collecting data from a variety of sources can help to reduce subjectivity, and provide a comprehensive assessment. Further, an awareness of different viewpoints is important in order to develop a complete evaluation. The techniques chosen for the current case example, whilst logically selected, demonstrate that evaluations need not be time-consuming or complex in order to be suitable and able to provide valuable feedback to support clinical practice.

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How do you evaluate an informal support group?

References


Training about incorporating psycho-social issues into routine care following a stroke – developing a six-piece-jigsaw: What do staff think and is it being used?

Rachel Attfield & David Wallace

The ‘Six-Piece-Jigsaw’ is a clinical tool designed to help staff think about the holistic presentation of clients. Here, we present an evaluation of how the six-piece jigsaw was received by 10 members of staff working in hospital with people who had survived a stroke. This project was conducted as part of the first author’s clinical psychology doctorate. Participants were interviewed about their perception of the training introducing the six-piece-jigsaw. Using thematic analysis, three superordinate themes that emerged were:

- Elements of the training found to be useful (for the service, team, patient and participant);
- Barriers to implementing the six-piece-jigsaw;
- Ideas for the future.

The medical notes of 17 patients of the staff participants were also referred to and used to find any objective evidence of use of the six-piece-jigsaw. Whilst participants considered psycho-social issues to be important for over half of the patients whose medical notes were scanned, these were not documented in all cases. Implications for clinical practice are discussed.

Introduction

The Six-Piece-Jigsaw

The six-piece-jigsaw is a clinical tool designed to support staff when thinking about several aspects of a client’s presentation focusing upon their thoughts, lifestyle, physical sensations, mood, behaviour and immediate surroundings. Each of these elements of a client’s presentation represents a section of the jigsaw. These pieces of the jigsaw then join together to provide a holistic view of the individual; it is a strongly visual tool. For further detail about developing the jigsaw, see Wallace and White (2006) and Carek and Wallace (2006).

The six-piece-jigsaw is collaborative: staff and clients discuss it together. The aim is to promote the adoption of a bio-psycho-social approach (Carek & Wallace, 2006). It was designed to be a tool for understanding the client and also, within the hospital setting, to be a way of widening thought about goal-plans (and client collaboration when setting them). It is not an alternative to psychological input.

In the current study the six-piece-jigsaw was introduced to staff in a two-part training programme. The first training segment was a traditional group workshop lasting approximately two hours. The second component was a 90-minute individual or small group session with the trainer held some months later. During this session, participants brought a completed case-study for discussion (i.e. they considered the six-piece-jigsaw in relation to one particular person).

Parallel to the development of the six-piece-jigsaw there was a focus upon establishing goal planning across the wider hospital trust. This took the form of discussion about how to make goal planning relevant to patient’s needs (Wallace & White, 2006). It was thought that the six-piece-jigsaw was one way of increasing patient-centred goal plans by incorporating the individual’s concerns. The six-piece-jigsaw was initially used on stroke units (the focus of its use in this article), although it is now being used in a variety of settings.
Training about incorporating psycho-social issues into routine care following a stroke

The need to address psycho-social issues in people surviving stroke

Stroke is a major cause of disability in the UK (Kneebone & Dunmore, 2000). Rehabilitation is the main treatment following a stroke and the specific impact of psycho-social factors has been widely discussed. For example, Gainotti (1993) emphasised the complexity of interactions between neurological, psychological and social factors following any form of brain injury. He suggested that not addressing all these aspects in rehabilitation would result in sub-optimum results. Such thinking is reflected in guidelines regarding stroke and rehabilitation. For example, better outcomes are associated with (amongst other things) an assessment of the patient, including their social situation and surrounding environment, prior to hospital discharge (National Service Framework for Older People, standard 5, stroke 2001). It is recommended that survivors of stroke be given the opportunity to talk about the impact that a stroke has had upon them and that issues relating to a patient’s psycho-social situation be reviewed on a regular basis (National Clinical Guidelines for Stroke, 2nd ed., Royal College of Physicians, 2004). Also, working around goals made in collaboration with the patient is thought to decrease anxiety and distress (McGrath & Adams, 1999). A patient’s active involvement in rehabilitation is thought to correlate with subsequent positive physical and psychological adaptation (Rees, Wilcox & Cuddihy, 2002).

In addition to the importance of psycho-social factors being recognised in guidelines, some psychological theories stress the role of idiosyncratic perceptions when considering someone’s view of their health. These will not be discussed in detail here but one such model is the Common Sense Model of Illness Representations (Leventhal, Meyer & Nerenz, 1980). The importance of an individual’s perception of their situation has received more than theoretical support and has been directly researched in relation to stroke. For example, it was found that a patient’s beliefs about stroke (specifically, their perceived control over recovery, the level of fear they had about a subsequent stroke, the changes they perceived in themselves as a result of stroke and any shame associated with these changes) significantly correlated with their level of distress (Townend et al., 2004).

To summarise, the importance of acknowledging psycho-social issues and patients’ views during stroke rehabilitation has been recognised at both theoretical and practical levels.

The importance of evaluating training

Whether or not training delivery has actually affected practice is rarely investigated and when it has been investigated, it has been shown to be notoriously difficult to measure (Mazmanian & Mazmanian, 1999). Some researchers observe that it can be difficult to ensure participants act upon training they have received (e.g. Kirk, 1996). Therefore, those delivering training need to be both skilled as trainers and as agents of change (be it change to attitude, knowledge or practice).

Various explanations have been proposed for whether training is implemented or not. However, the importance of cognitive dissonance or discrepancy analysis is consistently reported within the literature. This refers to a gap between what is perceived to be and what is aspired to be (Festinger, 1957). Fox and Milner (1999) explained the importance of discrepancy analysis by relating it to motivation levels. They argued that motivation to learn is the same as motivation to engage in any activity: there must be a drive to satisfy a perceived need. It is thought that the gap between the perceived state of an individual and the state s/he aspires to be in creates an internal sense of disequilibrium, which the individual is motivated to reduce (Knox, 1990). A linear relationship between perceived need and motivation is hypothesised (Fox & Milner; 1999). However, if this perceived need is too great, it could result in high levels of anxiety and subsequently, aversion.
At the other end of the spectrum, very small, perceived needs are likely to lead to modest anxiety levels and, therefore, minimal motivation. Either extreme will result in poor translation of training into practice.

The aims of this evaluation were:

- To explore staff satisfaction with the training.
- To investigate whether the principles of the six-piece-jigsaw were being incorporated into the goal-plans of individual patients.

**Method**

**Ethical approval**

Airedale Research Ethics Committee gave ethical approval for this study on 1 February, 2006.

**Design**

This study was predominantly qualitative. Interviews were used which had both semi-structured and structured components. The first, and main, part of the interview was semi-structured and aimed to gain an account of the experience of training. This was achieved through open questions used alongside a series of prompts. The second, structured, component aimed to discover if participants had been applying the concepts from training to their clinical practice and was investigated by participants bringing five sets of case notes (of patients admitted within the last two weeks), from which the researcher randomly selected two. These case notes were then considered and reference made to any relevant documentation in them.

**Participants**

All members of staff from the acute stroke unit and the stroke rehabilitation wards who had completed both the training workshop and the individual case study were approached for this piece of research. Ten members of staff (two ward sisters, two senior nurses, two health care assistants, one physiotherapist, one speech and language therapist, one senior occupational therapist and one therapy co-ordinator) agreed to participate and were interviewed individually for 45 to 60 minutes.

**Analysis**

Interviews were tape-recorded and anonymised transcripts were then made which were analysed using thematic analysis (Braun & Clark 2006). Two transcripts were analysed by a second rater to enhance the ‘trustworthiness’ of the data.

**Results**

Figure 1 shows a skeleton of the overall superordinate themes identified by the thematic analysis. These are broken down in more detail in Table 1, where the frequencies of responses are also given. Three superordinate themes emerged: aspects of the jigsaw approach respondents valued; barriers to implementation; and suggestions for the future.
Figure 1: Skeleton of overall results.

- Possible future directions.
- 1. What participants thought about the jigsaw model.
- 2. Is the jigsaw model being incorporated into goal plans?
- Barriers to implementation.
- Negatives.
- Aspects that were valued.
  - For the team.
  - For the service.
  - For the participant.
  - For the patient.
- Longer term aspects.
- About the training.
### Table 1: Results – Themes, examples (and frequencies).

<table>
<thead>
<tr>
<th>For the service</th>
<th>For the participant</th>
<th>For the patient</th>
<th>For the team</th>
<th>Barriers to Implementation</th>
<th>Negatives</th>
<th>Possible future directions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased talk of goal planning (2)</td>
<td>Takes an MDT approach (4)</td>
<td>Reinforces knowledge (7)</td>
<td>Gives them an opportunity to talk (2)</td>
<td>Would be beneficial for other team members (4)</td>
<td>Time (7)</td>
<td>Case study is daunting (1)</td>
</tr>
<tr>
<td>Implications for discharge (1)</td>
<td>Includes the case study (3)</td>
<td>Thought provoking (4)</td>
<td>Involves the patient (1)</td>
<td>Role recognition (1)</td>
<td>Clash with dominant medical model (5)</td>
<td>Narrow examples in training (1)</td>
</tr>
<tr>
<td>Effective use of time (1)</td>
<td>Well delivered (2)</td>
<td>Provides a useful structure (3)</td>
<td></td>
<td>Alternative view to medical model (1)</td>
<td>Acute setting makes it hard to use (3)</td>
<td>Jigsaw is constraining (1)</td>
</tr>
<tr>
<td>Could impact referrals to psychology (1)</td>
<td></td>
<td></td>
<td></td>
<td>Don't need to be qualified to use it (1)</td>
<td>Nobody takes individual responsibility (2)</td>
<td>Refresher course (2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lack of confidence (3)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Individual interest lacking (1)</td>
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</tr>
</tbody>
</table>

**Aspects that were valued**

- About the training
- Longer term aspects
- Reinforces knowledge
- Takes an MDT approach
- Includes the case study
- Well delivered
- Provides a useful structure
- Thought provoking

**Barriers to Implementation**

- Time
- Clash with dominant medical model
- Acute setting makes it hard to use
- Nobody takes individual responsibility
- Lack of confidence
- Individual interest lacking

**Negatives**

- Case study is daunting
- Narrow examples in training

**Possible future directions**

- Individuals to become accountable
- Goal planning around psychological issues
- Refresher course
Aspects valued
When thinking about the aspects that were valued, it can be seen that the most commonly cited benefit for the individual participant was that the training reinforced existing knowledge (an example of this can be seen in Text Box 1). Four participants discussed how the training was valuable when thinking about the team as a whole (e.g. for some, whilst the training reinforced their own knowledge, they felt it would be beneficial for other team members). Participants’ seeing a benefit for others is a potentially important theme. Therefore, an extract from one participant who elaborated on this in more detail can be found in Text Box 2.

Text Box 1: Training is reinforcing.
‘I wasn’t sat there thinking ‘oh, this is all new’ or anything. It’s very much how I’ve been trained anyway I think. I’ve spoken to other people and it’s come across as a big change for them, but for me there weren’t any great shocks.’

Text Box 2: Value for others.
‘I’ve been chatting to nurses and the way nurses and therapists look at goals is very different. We [therapists] are very person-centred and I won’t say that they are not because that would be wrong, but they may do have that medical focus. I mean, there may be goals such as continence that we do need to address, but is that a goal or an objective then if the patient wasn’t involved in setting it? […] What I would hope is that it [training] might make healthcare assistants think a bit more. But the danger is that they go to the training and then seem to slip back into doing things how they’ve always done it. I know there are reasons for that […]. But, it would be great if they [health care assistants] could pick up these ideas ‘cause they are the ones who spend most time with patients.’

Is the Six-Piece-Jigsaw being used?
Given that the six-piece-jigsaw appeared to be valued, its use will now be considered before proceeding to discuss the remaining superordinate themes. To answer the question of whether the jigsaw was being used, the case notes participants brought with them were examined in addition to qualitative comments. Seventeen sets of case notes were analysed rather than the 20 expected (due to two participants being unable to bring enough case notes).

Whilst it was initially planned to look at patient goal-plans this was not possible as they were not available in any of the notes selected (something which was being addressed by the hospital). However, useful information could still be extracted from the case-notes. Of the nine patients for whom it was thought by participants that psycho-social and/or social factors contributed to their presentation, three had this documented in some form. One patient had a completed jigsaw in their file. Whilst objective evidence for having considered psycho-social impact was not always available, participants did discuss this in some detail and often spoke about the issues that would be recorded in the six-piece-jigsaw.

Barriers to implementation and negative aspects
Given that the training appeared to be valued yet the case notes suggested the six-piece-jigsaw was not being regularly used, it seemed important to progress to thinking about the barriers to implementation and to identify any negative aspects of the training. Quite a wide range of barriers to implementation were proposed, but when looking at the frequency of responses, time constraints were discussed more often than any other. Lack of time, the setting and a clash between the philosophy of the training and the medical model approach were the most frequently cited barriers to implementation. These could all be seen as relating more to the wider service than to factors in the control of any individual or the team as a
whole. Barriers at the team and individual level were discussed (i.e. individual interests and levels of confidence), but less frequently than those of the service. Whilst few themes seemed to suggest negative aspects of the training per se, these should still be considered as some could be easily addressed (e.g. narrow case examples within the workshop).

**Future directions**

Several participants progressed to discuss what they felt would be useful in the future. For example, a couple of participants felt that if individuals became responsible for the six-piece-jigsaw, it would be used more regularly. Some felt that drop-in sessions or refresher courses could also help staff maintain confidence in using the tool.

**Discussion**

Clearly this study has many limitations (including how participants may have felt it difficult to criticise the training as the researcher was linked to the psychology department) and is small scale. Also, a biased sample of those who were most interested in this area could have been created by only approaching staff that had completed the (optional) training session and the (optional) case study. It would be interesting to interview those who had attended the workshop but not completed the case study to identify further barriers, or negatives experienced, earlier in the process. In spite of these limitations, discussion of the data gathered is nevertheless useful.

When examining the results as a whole, it can be seen that despite positive aspects of training emerging from the data, the concepts from the training and from the six-piece-jigsaw were not commonly being recorded as having been used in case notes. Given the relatively small size of the stroke unit, it is unlikely that the picture would be much different if more case notes had been gathered or more members of staff interviewed. This finding could be explained in several ways. It is possible that the positive aspects of training were over-reported or the barriers to implementation were too great to overcome. Relating to this observation is the phenomenon illustrated in Text Box 2: the majority of participants felt that the training reinforced existing knowledge rather than provided a new approach but benefits for team members other than the self could be seen, specifically for health care assistants. Whilst only two health care assistants were in the sample interviewed, their comments complicate this issue further: they did not report the benefits of the training to the same extent as some other participants.

Whilst one obviously cannot generalise from such a small sample, some tentative links between the existing literature and the sample of participants interviewed could be made at this point. According to discrepancy analysis, learners must see how training can address a gap that exists in their current practice in order to be motivated to implement change. Some of the staff viewed the training as reinforcement of their current practice, therefore removing some of the motivation to change. Some of these staff were at a senior level; therefore, it is possible, but not certain, that their perception of them already working in this way was accurate. Regardless of the accuracy of their assessment, this line of speculation leads to the suggestion that it may be possible to modify the training slightly in order to highlight the relevance of the training to staff that are familiar with these concepts. This coheres with one of the recommendations given by some participants: that an individual should become accountable for ensuring that jigsaws are completed. One could speculate that if the training gave some of the staff more experienced in approaches similar to the six-piece-jigsaw a supervisory role for other less experienced staff members, this could serve to motivate, encourage ownership at ward level and also provide a source of support for those who were unsure of what to do with information from the jigsaw once collected (an identified barrier to implementation).
When thinking about why the training appeared to be valued yet was not used frequently, one also needs to consider that the information gathered from case notes could reflect a change in practice since the training began. Whilst there were only 3/17 sets of case notes in which psycho-social issues were referenced, this could still reflect an increase in documenting such issues because no baseline audit prior to training delivery was established. Also, of the patients for whom psycho-social issues were reported as being important, participants said they had discussed these concerns with colleagues. Whilst this relies upon self-report, participants were able to discuss such issues with the researcher, suggesting an awareness of them. Again, there is a possibility that this could reflect a change since the training began.

The goals of the training were multifaceted: promoting an awareness of the importance of psycho-social issues, providing a tool with which they could be discussed with the patient and influencing person-centred goal planning. Whilst the first goal may have been met, the latter two require more consideration within the service.

**Conclusions**

The comments from participants in this piece of research suggest that value was given to the training session and to the six-piece-jigsaw. The training served as a reminder for most, was thought-provoking for some and its delivery within a multi-disciplinary format was appreciated, as was the individual case study. Actual use of the six-piece-jigsaw in its absolute form was relatively low (although participants were able to spontaneously discuss psycho-social issues relating to individual patients in detail). Several barriers to implementing concepts from training were highlighted by participants the most frequently cited one being a lack of time in which to complete the tool. Participants made suggestions about what they would ideally like in the future to enable them to apply the jigsaw model and some of these have since been acted upon. There might also be benefit in allocating a supervisory role to some members of staff who felt comfortable with the approach taken by the six-piece-jigsaw.

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Positive reactions to caring in Parkinson’s disease caregivers

Ann Davies, Anna Elderton, Liliana Loftus, Edward Thornton & Christopher Turnbull

There have been extensive reports on the burden, strain and depression experienced by caregivers (CGs) looking after patients with chronic neurological conditions. However, positive or rewarding functions of caring have been more neglected. For example, of 22 studies on caring in Parkinson’s Disease (PD) reviewed by Elderton (2008) only one focused on ‘positive reactions’ to providing care, noting the importance to CGs of finding meaning in the CG task (Konstam et al., 2003).

Furthermore, little is known about how ‘positive reactions’ are structured and whether they relate to CG personality, the quality of the (patient-CG) dyadic relationship and/or the severity and type of the illness. Yet there are compelling reasons for studying factors which might maintain psychological health and well-being in CG’s (Cousins et al., 2007). Principal amongst these is the possibility of avoiding institutionalisation of the patient should the caring relationship break down. Knowing which aspects of caring are viewed positively by CGs might also allow us to support them in a more appropriate and timely way.

From our literature review of CGs looking after patients across a range of illnesses, it was apparent that most studies focus on the negative. In general, benefits of caring are mentioned only if there are specific probes for them, but Hodgson et al. (2004) found that eight out of their 10 PD patient-carer dyads, when asked, reported a positive impact of caregiving on their relationship, especially in affirming the sense of commitment of each to the other. Other studies have mentioned the benefits of a gradual ‘making sense’ of the caring situation, (Tarlow et al., 2004; Pakenham et al., 2007).

In one of our previous studies (Davies et al., 1999), 56 PD CGs were asked: ‘Can you tell me if there are things which you enjoy or find satisfying in your role as carer to _____.’ Seventy-eight per cent reported at least one satisfaction (mean=1.7). Five main sources of satisfaction were mentioned: ‘Satisfaction from accomplishing a duty’ (30 responses); ‘Acting out of love’ (25); ‘Enjoying the company of the relative’ (12); ‘Preventing institutionalisation’ (6) and ‘Learning new skills’ (2). Examples were:

CG 162: ‘It’s not what I would have chosen at all, but yes, I do enjoy his company and being with him more.’

CG 112: ‘I always wanted to be a nurse, and especially since I learned to do the syringe driver and inject T., I have felt like I have become one.’

These radically different responses suggest that individual CGs may derive quite idiosyncratic benefits from caring. For instance, Tarlow et al. (2004) mentioned ‘self-affirmation’ and ‘positive outlook’ as important aspects of caring.

In view of the paucity of information about individual differences in how PD carers react positively, the present study aimed firstly, to examine the relationship between positive responses to caring and a number of key variables: CG personality, coping style and perceived quality of the dyadic relationship. Secondly, we wanted to examine the effect of these variables on carers’ general positive affect (assumed not to be specific to caring but possibly affected by it).

The study received ethical approval in 2007.
Method
A cross-sectional correlational design was used. Seventy-five care-giving spousal partners and patients with a diagnosis of idiopathic PD were referred to the study by their consultants through specialist movement-disorder clinics. Both patients and CGs were over the age of 60, were able to communicate with researchers verbally and in writing and to give informed consent to participation. Patients were not acutely ill and did not suffer from any major illness other than PD at the time of recruitment. Two CGs withdrew consent after their spouse had been assessed. Thus, 73 CGs (18 male, 55 female); of mean age 73.8 years (SD 5.6, range 60 to 85 years) took part. The mean length of the spousal relationship was 47.7 years (SD 11.1, range 2 to 63 years). The 75 PD (male, 56; female 19) patients were of mean age 74.9 years (SD 5.4, range 60 to 88 years). The mean duration of PD was 5.8 years (SD 4.4, range 1 to 25 years). In terms of severity, the Hoehn and Yahr (1967) staging was Stage I (unilateral disease only) 7; II (bilateral but no impairment of balance) 35; III (bilateral with early signs of postural instability) 17: IV (severe disease requiring considerable assistance) 18. There were no stage V patients in the sample.

Patients and CGs were visited at home on two occasions. The first focused on the patient, the second on the CG. Tarlow et al.’s (2004) Positive Aspect of Caring scale (PAC) was administered to CGs. This has nine items: ‘Providing care for my husband/wife has made me feel … useful, needed, appreciated, important, strong, confident, able to appreciate life more, able to develop positive attitudes, able to develop a strong relationship with my spouse.’ Each response was given on a five-point Likert scale (‘disagree a lot’ – ‘agree a lot’). A parallel version was adapted for care-recipients. ‘Receiving care from my husband/wife has made me feel …’ In this sample each version had good internal consistency (α=.87; .90 for CGs and patients respectively). CG positive affect (PA) was assessed by the 10-item positive affect subscale of the PANAS (Watson et al., 1988) (α=.85 in this sample). CGs also completed the 28-item Brief COPE (Carver, 1997) from which subscales of problem-emotion- and dysfunctional-coping styles can be derived (α=. 85, .72 and .60 respectively). CG personality was assessed using the N scale of the short NEO (Costa & McCrae, 1992). The seven-item Dyadic Adjustment Scale (Hunsley et al., 2001) was used to measure CG perception of quality of the dyadic relationship (α=.79 in this sample).

Results
Hooker et al. (1998) suggest that personality of the CG is an important variable in PD CG research. Our previous studies have supported this view especially where CG mental health outcomes are concerned. We were, therefore, ready to control for differences in CG neuroticism (NEO N) in the sample before reaching conclusions about the influence of third variables (such as disease severity) on CG outcomes. However, CG N did not correlate significantly with the specific positive aspects of caring (PAC) measure r=.18 (p>.05). The non specific PA measure did correlate with CG N (r=−.28 (p<.05). The strategy of analysis in examining correlates of PAC was, therefore, to use bi-variate correlations for this variable but partial correlations (controlling for CG N) for PA.

Carers’ positive reactions to caring were significantly related to emotion-focused coping (r=.33 p<.01, mean=22.9, SD=6.2); their number of coping strategies (r=.26 p<.05, mean=4.7, SD=2.6). and the extent to which the patient reported positive aspects of receiving care (r=.38, p<.001, mean=23.2, SD=8.2). CGs’ positive responses to caring were not significantly related to their relative’s severity of PD, MMSE score, or neuroticism nor to the quality of the dyadic relationship or to CG problem-focused or dysfunctional coping style.

When we consider the correlates of general positive affect as measured by the positive subscale of the PANAS (that is, not
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specifically related to caring) the picture is different. The following partial correlations reached significance: CG age (r = −0.33, p < 0.01, older CGs expressed less positive affect); CG problem-focused coping (r = 0.35, p < 0.01); number of coping strategies used by the CG (r = 0.22, p < 0.05); CG rating of quality of present dyadic relationship (r = 0.26, p < 0.05). Surprisingly, the two measures of positivity in carers (PAC and PA) did not correlate significantly.

Discussion
This study indicates that carers of individuals with PD find some aspects of their lives to be positive. It is probable that some of these relate specifically to the CG role and others are non-specific. The fact that CGs report positive affect indicates that whatever the strains of caring, these do not eradicate positive emotion from the CGs’ life. It was notable that the correlates of PAC (a caring-specific measure) differed from those of ‘positive affect’: a measure not specific to caring. It was interesting too, that PAC was not related to illness variables nor to CG or P NEO-N, so Hooker’s (1998) conclusion that CG N must always be considered, may have to be modified.

Most studies of caring point to the benefits of problem-focused coping styles. For instance, Folkman (1997) reported that problem-focused coping contributes to positive affect in the CGs of AIDS patients. This was also found in our PD CG sample. However, the finding that problem-focused coping was not related to the caring-specific PAC measure was unexpected. Emotion-focused coping has sometimes been viewed as conducive to poor mental health outcomes (e.g. Knight et al., 2000) yet here was related to a CGs feeling ‘good’ about the caring task. In the Brief COPE, ‘emotion-focused coping’ covers a number of individual coping strategies including acceptance, positive-re-framing, humour, religion, and seeking emotional support. ‘Acceptance’ was the strategy most used by our PD CGs (90.7 per cent) followed by ‘positive re-framing’ (54.7 per cent).

However, it may be, as Skinner et al. (2003) suggest, that attempts to categorise individual coping strategies into coping styles is no longer fruitful and a finer-grain analysis of coping is necessary.

The prevalence of ‘acceptance strategies’ in those reporting positive reactions to caring suggests that Acceptance and Commitment Therapy (ACT) might be a helpful intervention for PD CG’s. ACT is a third-generation cognitive approach fostering acceptance of unwanted thoughts and feelings and discouragement of avoidance of negative physical sensations, feelings and thoughts, (Hoffman et al., 2008).

Although PAC was not related to how the CG saw the quality of the dyadic relationship, in general, caring for a patient who had positive reactions to receiving care did predict PAC. Furthermore, seeing oneself as a ‘caregiver’ seemed to help. This may be related to seeking ‘meaning’ in the CG role as discussed by Pakenham (2007).

Perhaps it is not surprising that measures anchored in the caring context are more positively correlated than those which span domains (our distinction between measures ‘specific to caring’ as opposed to ‘non-specific’ measures). Our contention is that in studying caring, the CG specific measures are likely to have more explanatory power than non-specific mental health or relationship measures. Certainly, PAC was in no way the ‘mirror-image’ of negative affect or depression but seemed to reveal more about self-esteem gained through adopting the carer role with all that entailed. One can conclude that positive responses to caring are multi-dimensional, and that in future research a study of the structure of these responses is called for.

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Factors associated with optimal ageing: A review of some original research

Michael J. Lowis, Anthony C. Edwards & Mary Burton

AN ONGOING research programme at the University of Northampton (TUON) has already made a number of contributions to the literature on factors associated with optimal ageing. The research team comprises both psychologists and occupational therapists, which has proved to be a productive collaboration. The term ‘optimal ageing’ was favoured by Aldwin and Gilmer (2004), and refers to maintaining a positive outlook and a meaningful level of life satisfaction throughout the lifespan. We preferred this to the term ‘successful ageing’, which can make growing older sound too competitive and with the negative implication that anyone with health deficits has somehow failed the ascribed task of ageing (Strawbridge, Wallhagen & Cohen, 2002).

We consider the TUON studies to be not only worthwhile, but essential in view of the rapid increase in the number of people over retirement age and the associated rise in life expectancy in developed countries (see for example current figures and future projections, UK Office for National Statistics (ONS; 2007, drawing on mid-2006 estimates). In order to enjoy the benefits of longevity, however, people need to be able to cope with the mental and physical changes that most experience with age, and which are often negatively referred to as ‘decline’. It is hoped that the findings from the TUON programme will offer a more positive approach, through enhancing the understanding of how people can effectively cope with life during their senescence.

Review the studies

The first research study was an investigation by Brown and Lowis (2003) into the postulated ninth stage of Erikson’s (1963) Theory of Psychosocial Development. This utilised the measure developed by Lowis and Raubenheimer (1997) to assess resolution of Erikson’s eighth stage (ego-integrity versus despair), along with an original scale to measure gero-transcendence. This latter variable was added as an additional developmental stage by Joan Erikson, in an extended version of the earlier work of her husband Erik (Erikson, 1998). Joan Erikson noted that extreme old age (i.e. 80s and 90s) brought with it new demands and re-evaluations. Drawing on the work of Tornstam (1989), she described attributes of what successful achievement of gero-transcendence entails, including re-emergence of basic trust despite bodily decline, and a looking forward from a materialistic and rational view of life to a more cosmic and transcendent one. Brown and Lowis found empirical support for the hypothesis that, whereas ego integrity will tend to remain static from around retirement age onwards, gero-transcendence will significantly increase ($r=0.30$, $p=0.01$, $N=70$). The clear implication for optimal ageing is the potential for intervention to help individuals attain gero-transcendence and thus life satisfaction in extreme old age, where this has not occurred spontaneously.

In a later study, Lowis et al. (2005) explored the role of religion in mediating a potentially traumatic event, namely the transition from independent domicile to residential care. Fifty men and women (age range 74 to 94, mean 85 years) who had moved into care homes during the previous 12 months, were guided through a battery of
self-report questionnaires. This included measures for life satisfaction (the Life Satisfaction in the Elderly Scale, LSES, Salamon & Conte, 1984), spirituality (the INSPIRIT scale, Kass, Friedman, Lesserman, Zuttermeister & Benson, 1991), a more secular Faith in Nature and Humanity (Elkins et al., 1988), the use of religion as a coping measure, plus organised and non-organised religious practices (all from Mindel & Vaughan, 1978; Krause, 1998). The resulting computed correlations were subjected to a path analysis procedure, which involves stepwise multi-regression. This technique computes which variable(s) most strongly predict(s) the scores on the criterion variable – in this case the LSES measure. The procedure is then repeated with the predictor variable(s) now being designated the criterion (the original criterion variable is removed from the equation), and likewise repeated again until all the significant variables have been accounted for. The final presentation provides an indication of the chain of influences on the criterion variable.

It was found that the only factor to predict significantly the scores on the life satisfaction measure was Faith in Nature and Humanity. Although the use of religion as a coping aid, and spirituality respectively predicted the Nature/humanity scores, there were no significant correlations involving either organised or non-organised religious activities. See Figure 1 for a pictorial representation of this. These findings were largely unanticipated and, taken at face value, fail to support previous research, for example, by Kass et al. (1991) who found a positive relationship between core spiritual experiences and both life satisfaction and a reduction of medical symptoms, and Koenig (2001, 2002) who reported that nearly 90 per cent of medical in-patients older than 60 years used religion to help them cope. Koenig stated that the reason why such beliefs provide this ‘control’ is that religious people believe that God is capable of intervening and that, by praying to Him, they are taking action to improve their condition. The apparently contradictory findings between the present and previous research will be discussed later in this report.

Investigations have also been carried out at TUON on productive and leisure pursuits, pre-retirement occupation, and living arrangements of older adults, to assess the relationship between these and self-rated health. Lee (2000) had found from his large, longitudinal study that both self-assessed global health and external health assessments act as significant but independent predictors of functioning and mortality. To date, three cohorts of male and female participants aged 60-plus and community domiciled, totalling some 230 individuals, have been subjected to structured and semi-structured interviews. Drawing on the data compiled from these by Ball et al. (2007) and Knight et al. (2007), Lowis, Knight and Ball (under review) conducted a quantitative analysis to explore the relationships between the variables assessed. The findings revealed a significant negative correlation between self-rated health and age ($r=0.224$, $p=0.001$), a higher mean health rating for those who lived in houses (i.e. with upper floors) compared with bungalow dwellers [mean bungalow=2.58, mean house=2.17, on a scale of 1=excellent to 4=poor; $t=2.89(207)$, $p=0.004$], and a positive correlation between current self-rated health and approximate seniority of pre-retirement occupation as per the UK Standard Occupational Classification ($r=0.028$, $p=0.002$). See Figure 2 for an illustration of the latter.

It is perhaps not unexpected that health ratings will show a decline with age, although the way one rates one’s health (as compared with an objective medical assessment) is likely to be influenced by one’s attitude toward life and comparisons with other people (Ware, Kasinski & Dewey, 2000). Likewise, the finding of lower health ratings with bungalow dwellers is also intuitively reasonable, and is in keeping with the notion of housing being a major aspect of the environment that affects physical, mental,
Factors associated with optimal ageing and social well-being (Wilcock, 2006). The precise explanation remains to be explored through further research, but it is possible that people will tend to reside in single story accommodation if they have mobility impairment and are unable to cope with stairs. The link between current health and the approximate seniority of pre-retirement occupation was unanticipated but, on reflection, is not counter-intuitive in view of the likelihood that those with the most senior occupations will tend to have the knowledge, the motivation and the finances to care for their health. Wilcock (2006) posited a close relationship between (current) occupation and health, such that when work is perceived as stressful, boring or meaningless, the chance of illness is increased. Could this effect be carried forward to the retirement years? Clearly this finding merits further investigation.

A new study was designed at TUON to seek support for some of the earlier findings, with this time the survey being carried out on retired people who were still living independently (Lowis, Edwards & Burton, in press). A total of 72 women and 61 men, aged 60 to 93 years (mean 72.2 years) completed a battery of self-report questionnaires. The criterion variable this time was the CASP-19 well-being scale for older people (Hyde et al., 2003), and the other measures included a locus of control subscale taken from Recker and Peacock’s (1981) Life Attitude Profile, along with the

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**Figure 1: Path diagram illustrating the inter-relationships between the criterion of life satisfaction and other variables.**

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Life satisfaction
Faith in nature and humanity
Use of religion as a coping strategy
Spirituality Gender
Non-organisational religiosity
Organisational religiosity
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same measures of Coping Religion, Nature and Humanity, and spirituality as were used in the Lowis et al. (2005) study. In addition there were a number of biographical questions that included pre-retirement occupation, nature of current domicile, and a self-rating of average health this time on an expanded scale of 1 (poor) to 10 (excellent).

As before, the scores were subjected to path analysis through stepwise multi-regression. The outcome on this occasion showed that two variables predicted the scores on the criterion (the well-being measure): self-rated (good) health, and (internal) locus of control. At the second iteration, again it was two variables that predicted the locus of control scores: high scores on the Nature/humanity scale, and low scores on the Coping Religion scale. Interestingly, there were no predictors for self-rated health, thus indicating that this is a stand-alone co-predictor of well-being. Taking one step further back, scores on the spirituality scale predicted the outcomes for both Nature/humanity and Coping religion. This is illustrated in Figure 3 (overleaf).

Other significant outcomes of this study were a higher health rating for those who live in houses than in bungalows, and a positive correlation between health and pre-retirement occupation, both confirming the findings obtained by Lowis et al. (under review).

Several conclusions may be drawn from this latest study. It is no doubt unsurprising to find that good self-rated health is a key predictor of satisfaction and well-being in later life, but this might not necessarily so much reflect the outcome of a formal medical examination as a positive attitude toward the physical changes that occur with age. Bath (2003) had noted that there was evidence from many previous studies that good self-rated health is associated with reduced morbidity in the elderly. The fact that we also obtained a positive and significant correlation between self-rated health and (internal) locus of control (the other main predictor of well-being), suggests that those people who take personal responsibility for their lives also regard themselves as relatively healthy. These findings would
Factors associated with optimal ageing support the conclusion of Windsor et al. (2007) that a sense of personal control may be associated with increased longevity and successful ageing.

As with the Lowis et al. (2005) study with care home residents, no direct link was found between spirituality or religiosity and the criterion of coping/well-being, which fails to support previous research, for example, by Kass et al. (1991) and Koenig (2001, 2002). It appeared rather that a more secular faith in the goodness of nature and humanity was a stronger predictor of optimal ageing, although this in turn could have been mediated by religious factors further back in the chain of influences. A finding that superficially seems incongruous is the negative correlation between the use of Coping Religion and (internal) Locus of Control. However, optional comments made on the questionnaire suggest that those participants who are strongly religious may regard their destiny as being in God’s hands rather than their own. They will, therefore, tend to score high on the Coping Religion measure but low on internality of Locus of Control. Another possible explanation for the lack of direct correlations between the religious variables and the criterion is that the evidence points to religious coping mechanisms being most applicable to those who are more severely ill (e.g. McFadden, 2005). Both the 2005 cohort and the latest participants were in relatively robust health, and probably there was a tendency for only those who already had strong religious convictions to make significant use of their faith as a life coping aid.

Conclusions and implications
The research studies so far completed at TUON have identified a number of variables that are significantly associated with optimal ageing, as variously assessed by measures of life satisfaction, well-being, coping, or self-rated health. It is important for older adults to feel that they retain a high degree of control over their lives, even though this may be tempered by practical constraints such as restricted mobility or inadequate finances. Whilst this level of control will be more readily achievable for those who remain independently domiciled, it will be much more problematic for many who are in residential

Figure 3: Path diagram illustrating the inter-relationships between the criterion of life coping and other variables.

![Path diagram](image-url)

Life coping

Locus of control  Health

Faith in Nature and humanity  Coping religion

Spirituality
care. This is no doubt a significant reason why moving into care homes has been described as the ‘choice of last resort’ (McAuley & Blieszner, 1985, in Bee, 1998, p.495), despite such a move alleviating the stress of loneliness and the burden of maintaining one’s own home and security (see Brown & Lowis, 2003). Sensitive care home management can do much to allow their residents to retain at least a degree of independence, for example, through the provisions of options for daily activities, menu, and self-care.

 Whereas good self-rated health may be strongly influenced by attitude of mind: the contrast between a ‘cup half full’ and a ‘cup half empty’ approach to life, medical facilities for older people need to be exemplary both in the diagnosis and treatment of ailments as they arise, and the availability of advice on such healthy options as diet and exercise. Un-addressed concerns on health matters should not be an issue in the twenty-first century, where appropriate re-assurances can do much to alleviate worries that can inhibit optimal ageing.

 The direct influence of religion and spirituality on life satisfaction and well-being was not well supported in the studies reported here, but they remain potential mediatory factors for many who are still relatively healthy and independent, and are likely to achieve a more direct significance for those who are unwell and dependent. There is a need for those who work with older adults to be sympathetic to their client’s religious needs, in order to understand the potential of religion as a coping aid, and to provide opportunities for religious activities and counselling as required. It is pertinent that Shulmansy (2002) reported that previous surveys had found that the numbers of patients who felt that physicians should ask them about their spiritual needs ranged from 41 per cent to 94 per cent, and that this included up to 45 per cent who considered themselves to be non-religious.

 The research programme at TUON continues, and the next study is likely to be a probe into the intriguing finding of a direct link between seniority of pre-retirement occupation and the self-rated health of retirees. As correlational data only imply collateral relationships, not causal ones (although multiple regression can give a hint of the causal pathway), it would be useful to determine the nature of negative influences, for example stress, of the less senior occupations, what personal factors are involved, and why such adverse effects persist into retirement when the burden of work is no longer present. Once a likely causal route is revealed, the potential for intervention in the workplace becomes a possibility.

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References


Exciting Developments in Stroke Services, Kent
We are writing to share our positive experiences of service developments in relation to the implementation of the National Stroke Strategy. Through a combination of dialogue with commissioners and use of the British Psychological Society Briefing Paper Psychological Services for Stroke Survivors and their Families, we are benefiting from significant additional investment in our service to provide psychological assessments and interventions across the stroke care pathway. If recruitment is successful we expect to appoint six Clinical Psychologists, a Counsellor and a Psychology Assistant. We would encourage those of you who may have struggled over the years to develop psychological services for stroke survivors, but given up, to revisit this with the relevant commissioners. As based on our experience, there seems to be a renewed commitment to improving the psychological care of the stroke survivor and their families, a commitment which may not come round again. If you would like to find out more about our service take a look at our website www.headforkent.co.uk or telephone 01622 885923.

The Tavistock and Portman NHS Foundation Trust

Psychodynamic Approaches to Old Age (Ref. D2)
This well-established multidisciplinary course is the first of its kind in the country. It offers an innovative linkage of work-based practice, psychodynamic thinking, observational skills and research in old age settings.

The course aims to strengthen participants in their core roles and enhance the quality of clinical, supervisory and organisational work.

Suitable for professionals working with patients, staff and managers in NHS and Social Care Services and the Voluntary Sector, including nurse practitioners, care home managers, old age psychiatrists, clinical psychologists, social workers, occupational therapists, staff of nursing and residential homes, GPs, counsellors and psychotherapists.

Comments from past students
“This has been the most positive and helpful educational experience that I have had to date, the result largely of the depth of discussion in the group and the skilled facilitation of the tutors.”

The Trust is exploring the possibility of this course gaining academic accreditation in the future.

For further information please contact
Directorate of Education and Training, The Tavistock and Portman NHS Foundation Trust,
Tel: 020 8938 2355, Email: olcadmin@tavi-port.org, Website: www.tavi-port.org/training
Tuesday 19\textsuperscript{th} May 2009
Reading University

Evidence-Based Psychological Treatment for Older People

Update on Research and Treatment

Evidence-based psychological therapies exist for older people with mental health problems. These are constantly evolving.

This Conference aims to:-

- Provide a state-of-the-art update on the range and efficacy of psychological therapies for older people with mental health problems, particularly depression
- Describe innovative, empirically supported interventions for distressed family care-givers
- Examine how Government programmes and policy will shape the availability of psychological therapies for older people

*The conference is designed for mental health professionals working with older people in the public, private and voluntary sectors, together with service users and caregivers with a particular interest in the topic.*

For more information contact cwl@reading.ac.uk or call 0118 378 6668
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Notes for Contributors

The PSIGE Newsletter welcomes the following submissions for publication: articles, research updates, Letters to the Editor, book reviews. These can be on any aspect of psychological theory or practice with older people.

Articles
Articles form the bulk of contents submitted to the Newsletter. 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. These can cover empirical investigations, pilot studies, descriptions of service developments, audits and evaluations.

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).

Articles of any length up to a maximum of 3000 words will be considered. Experimental reports should follow convention in terms of subheadings and sections: Abstract, Introduction, Method, Results, Discussion, References.

References should follow conventional format as in journals such as Psychological Review:
(1) Book reference:

(2) Journal article:

(3) Paper in a book:

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 these submissions below 500 words.

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.

Book reviews
Submissions up to 250 words reviewing a text of relevance and interest to the PSIGE membership will be considered. These submissions must include full details of the book (including publisher).

The Editorial Board reserves the right to make minor changes to any submissions. Where major editing is necessary, the authors will be informed.

Images
The Newsletter is published in black-and-white. It is not advisable to send complicated, colour diagrams. If you are unsure, try printing the image or photograph out on a mono laser printer to check for clarity.

Please send original image files (.tif, .jpg, .eps or the like), not simply a Word document with the pictures imported into it, as these do not print properly.

Submission Procedure
All submissions must be written in language that is inherently respectful to older people and consistent with the British Psychological Society’s guidelines.

All contributions must be word processed. Formatting should be consistent with the British Psychological Society’s guidelines.

Please submit articles as a Word file via e-mail to the Editor, Dr Arlene J. Astell: aja3@st-and.ac.uk

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, all reports of research should 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.

All contributions should be sent to: aja3@st-and.ac.uk
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