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Psychology Specialists  
Working With Older People

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# Psychology Specialists Working With Older People

## AIMS

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

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# Editorial

Arlene Astell

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**W**ELCOME TO THE Annual Conference edition of the *Newsletter*, which this year was held in the historic city of York. I am sure everyone who attended will join with me in thanking the Conference Organising Group for their efforts in making this such an enjoyable and memorable event. The PSIGE Executive I know will be grateful for being spared the traditional embarrassment of attempting country dancing at the Ceilidh by the delightful and atmospheric Spanish-themed conference dinner of tapas followed by a salsa class. For those who couldn't make it this year, I hope the selection of papers from the conference, along with the reports from our bursary recipients, will whet your appetite for coming along to next year's conference in Swansea.

This issue kicks off with Kathryn Quinn's award-winning paper on a project she conducted as part of her DClinPsych on attitudes to mental illness among older people. Kathryn was awarded the PSIGE Research Prize 2008 for this thoughtful and well-argued piece of research, which is a fine example of the high standard of research being conducted by trainees working with older people across the country. I hope that this encourages all current final year trainees and those who have completed their training in the past two years to consider submitting a paper on their thesis to the PSIGE Research competition 2009.

The next paper by Elspeth Stirling is based on her very popular conference session on Positive Psychology of Ageing, for which the room was filled to bursting. I am sure this paper will be of equal interest to everyone who was lucky enough to squeeze in and those of you who couldn't make it. A paper describing work carried out by Maggie Ellis and I with people who have

advanced dementia and can no longer speak follows this. This research, which forms part of Maggie's PhD thesis, was presented for the first time at York and we were delighted with the audience reaction and feedback to the presentation. As with all of the other authors in this edition we would welcome further questions or comments from the PSIGE membership on the research reported here.

The next paper by Nancy Pachana describes her pioneering work to raise awareness and recognition of anxiety among older people. We were very fortunate to have Nancy over from Australia to present her work at the PSIGE conference and I know that some people also had the opportunity to attend workshops she ran prior to conference. The next paper by Lucy Piggitt and colleagues describes a very interesting project taking place in Liverpool examining emotional reactions to stroke among patients and family caregivers. This paper describes the pilot phase of the project, which is an ongoing piece of work. In the next paper Sarah Jeffrey and Steve Davies describe a piece of work carried out to examine the needs of a day hospital population following service restructuring. This will be a familiar scenario and the findings should be of relevance to many of the membership dealing with similar service demands.

Louisa Shirley's paper is based on her workshop describing the development of the Northumberland County Challenging Behaviour Team. This arose directly from the amount of interest shown at the 2007 Annual Conference in the work taking place in the North East of England which is leading the way in developing services to respond to behaviour that services find challenging to deal with. This is followed by another paper from the North East by

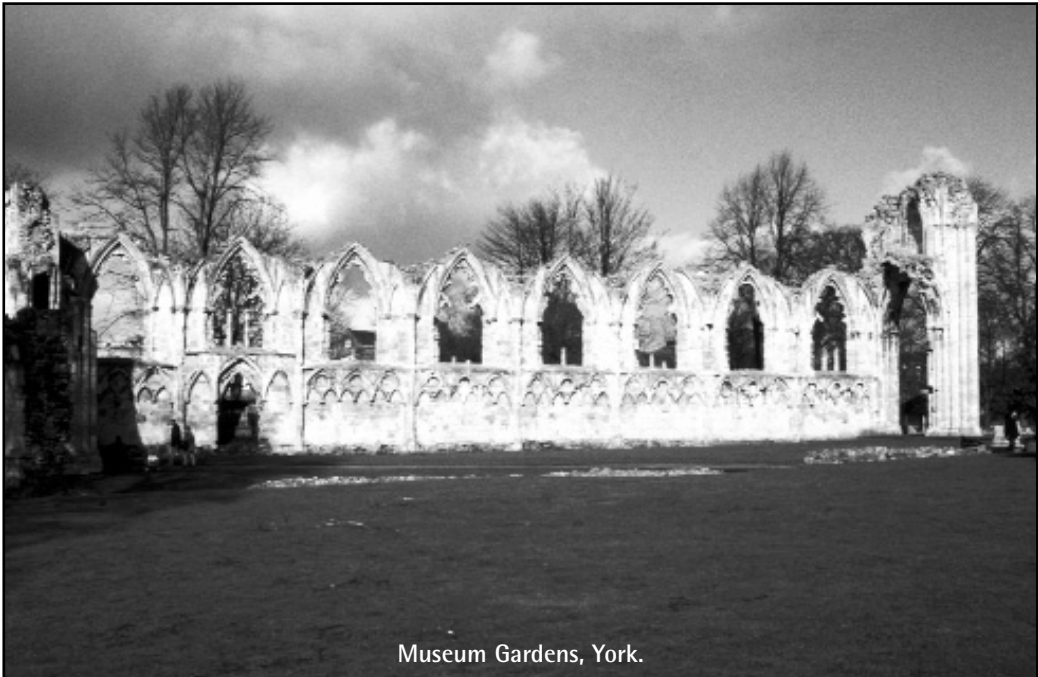
Faye Fraser and Ian James describing further investigation of the use of dolls in nursing homes for people with dementia. This is a topic that arouses strong feelings and debate about which readers are invited to make up their own minds. The final paper of this edition describes work that I have been involved in to develop computer technology for people with dementia. This is a part of an ongoing multidisciplinary collaboration to develop technology for people with dementia that started in 2001. This paper gives a flavour of the two main projects – CIRCA and Living in the Moment – we have carried out so far and our attempts to enable people with dementia to participate as partners in the research.

I hope that this gives you a flavour of the breadth and depth of the work presented at this year's conference. I would like to thank all of the presenters who submitted a paper on their conference presentation to be shared with the wider PSIGE membership. I would also encourage all those presenters who didn't manage to get a version of their talk or poster to me over the summer to please submit it by 15 January for publication in the April issue.

To round off the annual conference edition are a selection of Bursary reports from Trainees and Assistants, many of whom were attending for the first time. I hope to see them and you next year in South Wales.

**Arlene Astell**

*Editor*



Museum Gardens, York.

# Chair's Letter

Sinclair Lough

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**B**Y THE TIME you read this we will be well into Autumn. I hope everyone managed to make the best of a very soggy summer. One of the highlights for me was the annual PSIGE National Conference at York in July. I was only able to attend for one day but feedback I've had from those who attended all of it has been excellent. Thanks very much to those of you from Yorkshire/Humberside for putting together such a fantastic event.

Attending as Chair certainly puts the national conference in a different perspective. One of my duties was to chair the AGM which I actually felt quite nervous about despite decades of experience of giving workshops, etc. I'm still reflecting on what that was about! Perhaps one of the reasons was that I'd asked the Division of Clinical Psychology (DCP) Chair, Jenny Taylor, to attend as the contentious issue of PSIGE's relationship with the DCP and the British Psychological Society was firmly on the agenda. Jenny gave a very spirited argument for us to stay with them. However, the vote from the floor was for the National Committee to option appraise the nature of our relationship and then put these options to a ballot. I've had feedback since then that some people seem to think the vote at the

AGM was an agreement to leave the DCP. Please be reassured (or otherwise) that this was not the case. Discussions at the AGM made it clear that we have to separate our issues with the DCP from our issues with the Society and that is certainly the way we will pursue matters. This will be picked up at our strategy meeting later this month.

The conference dinner and entertainment were great. Those of you take *Clinical Psychology Forum* may have spotted the reference to PSIGE in August's 'Notes from the Chair'. Looks like we take the lead amongst other faculties for 'partying the hardest'. Let's keep up that reputation!

Since the national conference the major activity for me as Chair has been co-ordinating the Society's response to the National Dementia Strategy. That took up a fair chunk of August. Thank you to all who contributed. When the polished article comes back from the Society I'll ask Patrick to place it on the website.

Finally thanks to the North West group for the articles in the last newsletter. Excellent quality delivered in a remarkable time.

**Sinclair**

# Research Prize Winner – Older peoples' attitudes to mental illness

Kathryn M. Quinn

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*Despite the prevalence of mental health problems in later life, older people markedly underutilise mental health services. A greater awareness of factors influencing older peoples' attitudes to mental illness may therefore improve awareness and treatment of mental disorders in this population. This study used a mixed methodology approach to explore and compare older peoples' attitudes to mental illness in a sample of clinical and non-clinical participants. Results indicated that, similar to younger people, older people endorsed a range of positive and negative attitudes to mental illness. However, when attitudes to mental illness were considered within the context of ageing and experience a more complex pattern of results emerged. While negative attitudes to mental illness were associated with negative attitudes to ageing across the entire sample, clinical participants (and those with prior experience of mental illness) reported more positive attitudes to mental illness and more negative attitudes to ageing than non-clinical participants, for whom the reverse was true. Attitudes were also differentially related to health-behaviour outcomes. The results suggest that attitudes to mental illness and ageing may be linked and mediated by personal experience and capacity for psychological self-regulation in the face of age-associated adversity.*

**O**LDER PEOPLE are a growing sector of the population and worldwide demographic projections indicate that this trend is set to continue (Laidlaw & Baikie, 2007). With increasing longevity, the patterns of health and illness have changed, and there has been a shift away from the leading causes of death from acute infectious diseases to chronic illness and multiple co-morbidities. Chronic mental health difficulties, particularly sub-syndromal presentations of depression and anxiety, may be common in older people (Chew-Graham et al., 2004), yet in contrast to high demand for general medical services, older people significantly under-utilise mental health services. This has been attributed to a number of factors including cohort beliefs, the widespread existence of stigmatising attitudes, lack of familiarity with and experience of mental health services, and prevalence of both internal and external ageism (Knight, 1999; Laidlaw et al., 2003; Levy, 2003).

That negative stereotypes exist both in relation to mental illness and to ageing is well documented (e.g. Crisp et al., 2005., Hayward & Bright, 1997; Levy, 2003), yet the nature and pattern of associations between these variables is far from clear. Levy (2003) for example, presented persuasive evidence that negative implicit ageist attitudes and stereotypes operate unconsciously to impact judgements, perceptions, beliefs and attitudes in other domains, and are consolidated over time. Specifically, Levy (2003) put forward a developmental hypothesis positing that as people grow older, ageist stereotypes internalised at a young age gradually become self-stereotypes, thus influencing the older person's perception of other older individuals as well as of themselves.

With respect to empirical research relating to attitudes to mental illness the literature is somewhat mixed. On the one hand, several studies attest to the prevalence of stigmatising and negative attitudes

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\* Dr K. Quinn; Dr L. Murray (Clinical Psychology Department, NHS Fife); Dr K. Laidlaw (Section of Clinical and Health Psychology, School of Health in Social Science, University of Edinburgh).

towards mental illness, particularly mental illness as it occurs in later life (e.g. Crisp et al., 2005; Hayward & Bright, 1997). Such attitudes are reported as apparent in both younger and older adults, although both inter- and intra-cohort attitudinal differences have also been identified (see, for example, Brockington et al., 1993; Scottish Executive, 2004). On the other hand, there is evidence to suggest that attitudes are changing over time. Specifically that they are becoming increasingly positive and exhibit a greater degree of concordance between younger and older adults in this regard than previously thought (e.g. Currin et al., 1998; Segal et al., 2005). Many gaps in the literature are also apparent. For example, little is known about whether attitudes to mental illness, particularly in the oldest-old, are simply a reflection of broader underlying ageist stereotypes. Law (2003), for example, demonstrated that the 'understandability' phenomenon in older people (i.e. the belief that depression is a normal part of ageing; Blanchard, 1992) was reflective of an ageist misconception.

Widespread stigma associated with mental illness is considered to further multiply the difficulties for older people with mental health problems through the effects of double stigmatisation (Sartorius, 2003), or exclusion due to mental illness *and* old age. In a recent survey of 900 older people (The UK Inquiry into Mental Health and Well-Being in Later Life; Mental Health Foundation & Age Concern, 2006), discrimination on the basis of age was perceived as the most common type of prejudice experienced by people aged 55 and over, and considered to exert a negative effect on mental health. The results of national surveys implemented both in the UK and abroad highlight the prevalence of negative attitudes to mental illness in both younger and older people, while educational campaigns have tended to produce only small and short-lived attitudinal changes (Crisp et al., 2005). In this context it is particularly disheartening to note that high profile national campaigns aimed at tackling issues

of stigma and discrimination, such as the 'See Me' campaign ([www.seemescotland.org](http://www.seemescotland.org)) in Scotland (Scottish Executive, 2003–2006), and the Changing Minds educational initiative in England (Royal College of Psychiatrists; Crisp, 1999; James, 1998), have largely failed to address the needs and views of the older population. This situation exists despite evidence highlighting the beneficial effects of knowledge, increased awareness, and personal experience of mental health services on attitudes (Lobban et al., 2003).

Negative attitudes and beliefs may lead to under-reporting and misdiagnosis of problems, increased physical and psychological morbidity with associated increasing health care costs, poor health-related behaviours, and significant reductions in quality of life. To date, however, little empirical evidence exists to either support or refute the presence or effects of such attitudes. Studies of the attitudes and beliefs of older people towards mental health disorders have reported inconsistent results, with differences in part attributable to a broad range of methodologies (i.e. questionnaires, door-to-door interviews, telephone interviews, vignettes, etc.), and to lack of appropriate comparison groups (e.g. Lundervold & Young, 1992). Similarly, a large proportion of studies report the attitudes of healthy individuals, while the opinions of clinical samples have largely been neglected (Brockington et al., 1993). In general, findings suggest that older people, particularly those of a lower educational level and social class, are less favourable towards mental illness and mental health services, while familiarity with and experience of mental health issues leads to more positive attitudes (Hayward & Bright, 1997; Robb et al., 2003).

However, a review of the extant literature provides evidence of a '*positive cohort shift*' in older peoples' attitudes toward mental health services (Currin et al., 1998, p.506). Currin et al. (1998) compared the views of two independent samples of older adults recruited 14 years apart, in 1977 (earlier-born cohort) and 1991 (later-born cohort) and found that the

later-born cohort were less rigid and stereotypical in their thinking about mental illness than the earlier-born cohort. Moreover, attitudes to mental illness appeared bound up with ageist misconceptions such that more individuals from the earlier-born cohort harboured stereotypes of ageing that included beliefs in the symptoms of mental illness as simply part of the ageing process. In contrast, the later-born cohort demonstrated a broader understanding of the range of issues related to mental illness, a greater awareness of services offered by mental health providers, and had used more mental health services in the past (suggesting a positive impact of personal experience). In addition, the later-born cohort were more educated, had higher incomes, better health, and were more likely to be open to treatment and willing to seek help for mental health difficulties. Cohort differences remained after controlling for various demographic factors including age and level of education. Based on these data, Currin et al. (1998) concluded that later-born older cohorts' biases toward mental illness are less negative than those of earlier-born older cohorts', *'a finding with numerous implications for the design and implementation of mental health services for future cohorts of older persons'* (p.506).

Given the complexity of attitudinal research thus far outlined and in concordance with indications in the literature that negative attitudes may contribute a significant barrier to help seeking for mental health problems in later life (e.g. Pepin, 2006; Sarkisian et al., 2003), the current study aimed to explore older peoples' attitudes to mental illness in the context of attitudes to ageing, experience, and health-related outcomes. It was hypothesised that negative attitudes to mental illness would be associated with more fundamental (underlying) negative attitudes to ageing and be mediated by personal experience. In addition, it was considered that negative attitudes to mental illness and to ageing would correlate with less reported engagement in pro-active health-related behaviours and lower subjective well-being.

## Method

The study combined qualitative and quantitative methods. Initially, focus groups were undertaken with a group of clinical and of non-clinical participants with the primary aim of piloting a draft questionnaire, and to provide a descriptive overview of themes describing older peoples' attitudes to mental illness. A cross-sectional independent groups design was then employed to compare attitudes to mental illness in a clinical sample of older people currently in receipt of mental health services (psychological or psychiatric services) to attitudes of a sample of older people from the general (i.e. non-clinical) population.

### *Inclusion and Exclusion criteria*

Participants were recruited to the study according to the following inclusion criteria. For the non-clinical sample, participants had to be age 65 and above, community-dwelling, not currently in receipt of mental health services, and able to provide written informed consent. For the clinical sample, the same criteria applied although participants had to be currently in receipt of mental health services. In both conditions, participants were excluded from the study if they were under 65 years (age 65 was selected as the standard service cut-off criterion for access to older people's mental health services in the locality where the research took place), if there was evidence of organic deterioration or significant cognitive impairment, if the participant was currently in receipt of electroconvulsive therapy, if there were indications of poorly managed severe and enduring mental illness, if there was evidence of suicidality, substance abuse, or previous head injury (all of the latter to be ascertained via clinician judgement for the clinical sample, or group representative judgement for the non-clinical sample).



**Sample**

Clinical participants were recruited with the assistance of clinicians from the Area Clinical Psychology Service and the Area Old Age Psychiatry Service. The non-clinical sample of participants was identified with the assistance of the local branch of Age Concern and of the Elderly Forum, with additional participants identified latterly through another Older People's Forum in a different locality. For both groups, potential participants were approached about the research study and provided with a study invitation pack for self-return. Overall, approximately 709 study invitation packs were distributed and 74 completed questionnaires were returned. The final sample was comprised of 50 females (67.6 per cent) and 24 males (32.4 per cent). The overall mean age of the participants was 77.63 years (SD 8.04), with the non-clinical group slightly older on average than the clinical group (Table 1).

**Ethical approval**

Ethical approval for the study was sought and obtained from the local Research Ethics Committee, and permission was sought and received from the Research and Development department of the primary care division of the Community Health Partnership (CHP) to recruit participants for both the clinical and non-clinical samples.

**Measures**

A questionnaire was constructed for the study. In addition to provision of sociodemographic information, the questionnaire comprised sections on Attitudes to Mental Illness, Attitudes to Ageing, and Health and Well-Being. Each section comprised psychometrically established sub-scales or scales outlined as follows:

Table 1: Demographic data for non-clinical and clinical samples.

	Non-clinical (N=50)	Clinical (N=24)	Statistic* (df)	Sig. (2-tailed)
<b>Demographic:</b>				
Age	79.84 (SD 8.05)	72.59 (SD 5.42)	$t_{(70)}=4.47$	$p<0.001$
<b>Gender</b>				
Male	15	9	$2_{(1)}=0.42$	$p=0.52$
Female	35	15		
<b>Marital Status</b>				
Single/divorced	6	6	$2_{(2)}=3.31$	$p=0.19$
Married/Partnered	19	9		
Widowed	25	7		
<b>Education</b>				
Secondary school	31	15	$2_{(2)}=0.69$	$p=0.71$
Trade certificate	3	1		
College/University	11	3		

\*Some categories collapsed to increase expected cell count.

## 1. Attitudes to Mental Illness

*Items from the National Survey  
(Scottish Executive, 2004)*

Nine items were included (with permission) from the second National Scottish Survey of public attitudes to mental health (entitled 'Well? What do you think?'; Scottish Executive, 2004). The items reflect prevalent themes identified in the literature regarding public perceptions of mental illness. Responses are scored on a Likert scale ranging from 1=strongly agree to 5=strongly disagree, with 6=don't know. At the time of writing no details were available regarding the psychometric properties of the items.

*Barriers to Mental Health Services Scale  
(BMHSS subscales; Pepin, 2006)*

The BMHSS was recently developed by Pepin (2006) to measure barriers to mental health services in younger and older adults. The BMHSS comprises a total of 10 subscales (58 items) representing both internal and external barriers to help-seeking. Data reported by Pepin (2006) regarding internal consistency of the BMHSS indicate sub-scale alphas range from 0.32 to 0.78, with five of the 10 sub-scale alphas scoring over 0.70. Subscales can be considered independently, and those relating to 'Ageism' (six items; range 6 to 30) and 'Stigma' (five items; range 5 to 25) were considered most relevant for inclusion in the current study (Cronbach's alpha 0.63 and 0.73, respectively). Responses are scored on a five-point Likert scale where 1=strongly disagree, and 5=strongly agree. Subscale scores are derived from summing individual item scores. Positively oriented items on both subscales are reverse coded such that higher scores are indicative of more negative attitudes to mental illness.

*Understandability Questionnaire (Law, 2003)*

The Understandability measure comprises three attitudinal statements to depression in later life, designed to reflect the following conceptualisation: 'It is natural to be depressed in late life because there are good reasons for it,

therefore, there is no point in treatment' (Law, 2003, p.36). The statements were generated from the relevant literature and from the results of focus group discussions and clinical experience with older people (see Law, 2003, for further details). Items are rated on a seven-point Likert-type scale ranging from 1=agree strongly to 7=disagree strongly. Items are reverse coded and summated to obtain a total 'understandability' score ranging from 3 to 21, with higher scores indicative of greater belief that depression is a normal consequence of old age.

## 2. Attitudes to Ageing

*Attitudes to Ageing Questionnaire (AAQ)  
(Laidlaw et al., 2007)*

The AAQ (Laidlaw et al., 2007) is a 24-item self-report measure designed to assess attitudes towards ageing and the ageing process. The AAQ comprises three subscales relating to 'psychological growth' (explicitly positive focus; eight items), 'psychosocial loss' (explicitly negative focus; eight items), and 'physical change' (mixed physical functioning focus; eight items), with good psychometric performance indicated through both classical (e.g. exploratory factor analyses) and modern methods (e.g. confirmatory factor analyses; item response theory). Published Cronbach alpha values for each of the subscales range from 0.68 to 0.84, with an overall scale fit of 93.8 per cent for the three-factor model. Recommended scoring of the scale consists of a profile set of three subscale scores. Items relating to each subscale are scored on a five-point Likert scale with variation in response descriptors across items, as follows: items one to seven, 1=strongly disagree to 5=strongly agree; items eight to 24, 1=not at all true to 5=extremely true. Items are summed to provide an overall score for each subscale (range 8 to 40), with a higher score reflecting stronger endorsement of the predominant theme of that particular subscale (e.g. higher score on 'psychological loss'=stronger endorsement of loss-deficit model of ageing).

*The Rame Questionnaire (Parnell et al., 2001)*

The Rame Questionnaire (Parnell et al., 2001) is designed to measure internalised ageism in an older adult population. The measure comprises 23 items relating to fear of the ageing process, deterioration in physical and cognitive ability, illness, inability to learn new tasks, reduction of sexual desire, and beliefs that older people require constant help and contribute little to society. The scale was developed in a sample of 40 older people attending day centres across the UK, and is reported to demonstrate good internal reliability (Cronbach's alpha=0.81). However, to date, the scale has been insufficiently tested to determine broader psychometric properties such as factor structure, or the establishment of normative scores (Law, 2003). The Rame contains eight positively oriented items (e.g. *'I am keeping in touch with today's society'*) and 12 negatively oriented items (e.g. *'My best achievements are in the past'*), in addition to three re-phrased repeat items included to assess respondent understanding (not scored). Items are scored on a four-point Likert scale ranging from 'disagree strongly' to 'agree strongly', and scored either 0 to 3 or 3 to 0, as appropriate, with 3 indicating higher internalised ageism (i.e. positively oriented items are reversed scored). Items are summed to provide a total scale score out of 60.

### **3. Health and Well-being**

*The General Health Questionnaire (GHQ-12; Goldberg, 1992)*

The General Health Questionnaire (GHQ; Goldberg, 1978) is a widely used and validated measure of non-psychotic psychiatric symptoms in the general population. The 12-item version of the General Health Questionnaire (GHQ-12; Goldberg, 1992) was used in the current study as a shortened version of the well-validated full version, the GHQ-60, as it has equally good psychometric properties (i.e. in a series of studies Cronbach's alpha ranged from 0.82 to 0.90; split-half reliability was 0.83, and test-retest reliability was 0.73; sensitivity in detecting

cases of psychiatric disorder reported as 93.5 per cent, with 78.5 per cent specificity; see Johnston et al., 1995, for a brief review). The Likert scoring method of the GHQ-12 was used in the current study since it also reportedly gives a less skewed distribution of scores than the traditional GHQ method (Johnston et al., 1995). Using Likert scoring item responses are assigned scores of 0, 1, 2, or 3, ranging from 'Not at all' to 'Much more than usual', as appropriate. Responses are then summed to provide an overall total score (from 0 to 36) with a higher score indicating poorer psychological health.

*Reported Health Behaviours Checklist (RHBC; Prohaska et al., 1985)*

The RHBC (Prohaska et al., 1985) is a 21-item self-report measure of respondent health-related behaviours. The first 15 items of the scale relate to preventative health actions such as taking vitamins, undertaking regular aerobic exercise, and having regular medical check-ups. A further six cognitive/affective items cover aspects such as avoidance of emotional distress, positive thinking, and acceptance. Items are scored on a five-point Likert scale where response options reflect frequency of performance of each behaviour ranging from 1=never to 5=always. The total score for the scale, and totals for the 'Health Action' (range 15 to 75) and 'Cognitive-Affective' (range 6 to 30) subscales can be calculated (Kincey et al., 2003). High scores indicate high levels of reported positive health behaviours. At the time of writing no published data could be found documenting scale internal consistency.

## **Results**

### *Qualitative data analysis*

Focus group data were analysed using Framework Analysis (Ritchie & Spencer, 1994), a qualitative method originally developed for applied policy research but gaining popularity in health-related research (Lacey & Luff, 2001). Framework Analysis shares many of the common features of content or 'thematic' analysis, and provides a systematic

and visible outline of stages of the analytic process. A primarily inductive approach in which categories and themes are developed directly from the data, this form of analysis also allows for inclusion of *a priori* as well as emergent concepts in coding. The process involves five key stages (Table 2), which can either be undertaken in a linear fashion<sup>1</sup> following data collection, or when data collection and analysis are undertaken concurrently.

Using Framework Analysis, focus group discussions were fully transcribed and identifying information removed. Transcripts were then read and re-read and an initial coding framework developed. The provisional thematic framework was further refined through an iterative process of indexing and charting of data, with continual reference to the original transcripts. Transcripts were indexed using numerical codes (relating to the thematic framework) to identify specific pieces of data (i.e. words or phrases) corre-

sponding to different themes. Where themes were identified which did not accord with the initial classification, new ones were developed.

Thematic charts were created outlining major and constituent themes, and relationships within the data further explored by review of developing themes and direct quotations of relevance to each theme. Data were continually re-assessed and re-coded in this manner until no new themes could be identified. Although group transcripts were analysed separately, results were subsequently integrated to facilitate an overall comparison (Powell & Single, 1996). Data were managed using NVIVO (Version 7; QSR International). A reflexive approach was adopted throughout, acknowledging the centrality of the researcher in the research process, with attempts made to differentiate participant description from researcher interpretation (Willig, 2001).

Table 2: Qualitative analysis outline.

<p><b>Key Stages of Framework Analysis:</b></p> <ul style="list-style-type: none"><li>● <i>Familiarisation</i>: whole or partial transcription and reading of the data.</li><li>● <i>Identifying a thematic framework</i>: development of an initial coding framework both from <i>a priori</i> issues and from emerging issues identified during the familiarisation stage. The thematic framework should be developed and refined during subsequent stages of analysis.</li><li>● <i>Indexing/Coding</i>: the process of applying the thematic framework to the data, using numerical or textual codes to identify specific pieces of data which correspond to differing themes.</li><li>● <i>Charting</i>: creating charts of the data using headings from the thematic framework.</li><li>● <i>Mapping and Interpretation</i>: the search for patterns, associations, concepts, or explanations in the data, aided by visual schematics.</li></ul>
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(Source: Lacey & Luff, 2001, p.9)

<sup>1</sup> In this regard, Framework Analysis differs from a classical Grounded Theory approach in which a key feature is the identification of emergent themes through the simultaneous collection and analysis of data using the constant comparative method.

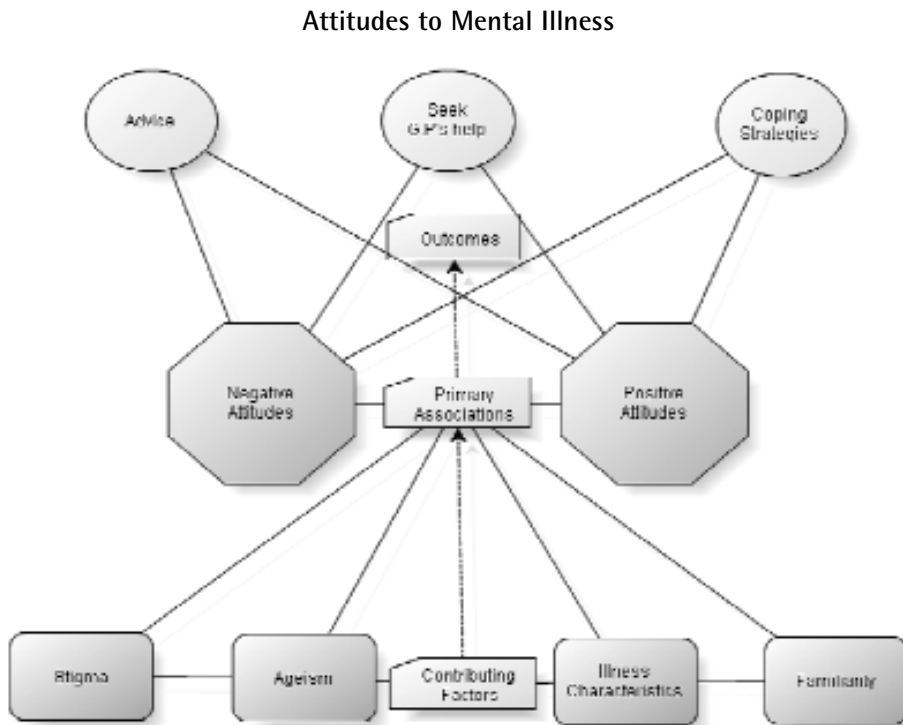
**Results from focus groups**

Results from focus group analyses indicated that participants endorsed a broad range of attitudes to mental illness. Attitudes were more explicitly negative in those with no prior experience of mental health difficulties (i.e. non-clinical participants), and were related to individual fears of becoming mentally ill, of being institutionalised, or of loss of mental faculties, resulting in communicative barriers between people with and without mental health problems. Fears of mental illness appeared to be underpinned by perceived stigma, social rejection (endorsed by clinical participants), and a general lack of public awareness and understanding related to the 'invisibility' of conditions such as depression. In addition, age-related differences were perceived in terms of attributions of mental illness, such that mental illness in later life was perceived as 'understandable' by society, and particularly by health professionals, who were

perceived to hold lower expectations of older peoples' coping resources and potential treatment responsiveness.

Interestingly, positive attitudes were found to co-exist with negative attitudes in participants from both groups. However, further discussion revealed that the positive attitudes of non-clinical participants were permeated by internalised ageism such that the focus of participants' benevolence was directed largely towards younger people with mental health problems, who were deemed more deserving of good mental health. Figure 1 presents a schematic outline of identified themes, and the proposed associations between attitudes and other factors. It is possible to hypothesise that the ways in which individuals encounter and make sense of these factors in light of personal history and experience may in turn impact upon decisions to engage in health-related behaviours and/or specific coping strategies such as denial or acceptance.

Figure 1: Mapping of Themes from Qualitative Analysis.



### Quantitative data analysis

Data were analysed using the Statistical Package for the Social Sciences (SPSS; Version 14). An examination of minimum and maximum values, means and standard deviations was conducted to determine accuracy of data entry. Missing values were assigned a numerical value that identified these data within the data-set. Testing of the respective hypotheses was undertaken using parametric tests given that assumptions of variable measurement, normality of distribution and homogeneity of variance were met. Otherwise non-parametric tests were used.

### Summary of results from quantitative analysis

Results from the comparison of attitudes to mental illness and ageing across study groups indicate that participants endorsed a range of positive and negative views of mental illness. Analysis of Covariance (ANCOVA), with age as the covariate, was used to establish whether responses differed in terms of general attitudes to mental illness (as assessed by responses to the nine items from the National Survey; Scottish Executive, 2004) according to clinical status. Univariate analyses revealed that, after adjusting for the effect of age on outcome, there was no significant effect of clinical status on attitudes to mental illness on eight out of nine attitudinal items (Table 3). A significant inter-group difference was found for item 8 (i.e. *People with mental health problems should have the same rights as anyone else*). An examination of mean scores and standard deviations for non-clinical and clinical samples on this variable indicated that the clinical group expressed more lenient views regarding the rights of individuals with mental health problems than participants in the non-clinical group ( $F_{(1,69)}=4.81, p=0.03$ ).

Interestingly, when attitudes to mental illness were considered within the broader context of ageing and personal experience, a more complex pattern of results emerged. Across the entire sample, as expected, nega-

tive attitudes to ageing were associated with negative attitudes to mental illness. In line with the study hypothesis, significant positive correlations were found between negative attitudes to ageing, particularly attitudes relating to a loss-deficit view of ageing (as measured by higher scores on the composite AAQ scale and on the AAQ Loss sub-scale), and negative attitudes to mental illness, particularly those attitudes reflecting 'understandability' (AAQ Loss: Understandability,  $r=.42, p<0.001$ ), and the perceived stigma of mental illness (AAQ Loss: BMHSS Stigma,  $r=.20, p<0.05$ ).

However, differential effects were found in relation to study groups. Specifically, participants who were, to all intents and purposes, ageing well and who reported less clinical experience (i.e. the non-clinical group), reported more positive attitudes to ageing and more negative attitudes to mental illness. Conversely, participants currently attending services for mental health difficulties, and those with prior experience of mental illness (i.e. the clinical group), reported more positive attitudes to mental illness, and more negative attitudes to ageing (Tables 4a and 4b). These results lend support to the view that attitudes to mental illness and ageing may be linked and mediated in both directions by personal experience.

With regard to the hypothesised relationship between attitudes and health-related behaviours, participants who endorsed more negative attitudes to ageing and expressed attitudes consistent with internalised ageism (i.e. the clinical group), also reported less health-related behaviours ( $F_{(1,72)}=15.56, p<0.001$ ), and lower subjective well-being ( $F_{(1,72)}=17.62, p<0.001$ ). Conversely, participants who endorsed more positive attitudes to ageing (i.e. the non-clinical group) also provided stronger endorsement of healthy behaviours and higher subjective well-being. The largest inter-group difference was observed in relation to the RHBC 'Cognitive Affective' subscale ( $F_{(1,72)}=26.93, p<0.001$ ), indicating that clinical participants reported

**Table 3: Between-group comparison of attitudes to national survey items.**

Survey Item	Group	Mean* (1-5)	Std Dev	95% CI	d.f.	F (Sig.)	Effect Size* & Observed Power
1. If I was suffering from mental health problems I wouldn't want people knowing about it.	Non-clinical (N=50)	2.77	1.15	2.42-3.11	1.69	1.33 (p=0.30)	d=0.31 P=0.21
	Clinical (N=22**)	3.14	1.25	2.61-3.69			
2. The public should be better protected from people with mental health problems.	Non-clinical (N=50)	2.90	1.34	2.53-3.31	1.69	0.34 (p=0.56)	d=0.21 P=0.09
	Clinical (N=22)	3.18	1.33	2.53-3.75			
3. Anyone can suffer from mental health problems.	Non-clinical (N=50)	1.21	0.40	1.04-1.34	1.69	2.58 (p=0.11)	d=0.29 P=0.35
	Clinical (N=22)	1.36	0.73	1.18-1.66			
4. I would find it hard to talk to someone with mental health problems.	Non-clinical (N=50)	3.49	1.17	3.27-3.91	1.69	0.58 (p=0.45)	d=0.49 P=0.12
	Clinical (N=22)	4.06	1.07	3.33-4.33			
5. People are generally caring and sympathetic to people with mental health problems.	Non-clinical (N=50)	2.84	1.18	2.50-3.23	1.69	0.34 (p=0.56)	d=0.09 P=0.09
	Clinical (N=22)	2.73	1.35	2.10-3.23			
6. People with mental health problems are often dangerous.	Non-clinical (N=50)	3.30	1.14	2.98-3.65	1.69	0.82 (p=0.37)	d=0.30 P=0.15
	Clinical (N=22)	3.65	1.16	3.09-4.14			
7. The majority of people with mental health problems recover.	Non-clinical (N=50)	2.81	0.90	2.49-3.07	1.69	0.21 (p=0.65)	d=0.23 P=0.07
	Clinical (N=22)	2.58	1.16	2.20-3.10			
8. People with mental health problems should have the same rights as anyone else.	Non-clinical (N=50)	1.70	0.88	1.48-1.94	1.69	4.81 (p=0.03)	d=0.56 P=0.58
	Clinical (N=22)	1.26	0.43	0.87-1.58			
9. People with mental health problems are largely to blame for their own condition.	Non-clinical (N=50)	4.19	1.22	3.91-4.57	1.69	0.25 (p=0.62)	d=0.28 P=0.08
	Clinical (N=22)	4.51	0.91	3.89-4.91			

\* Mean score after missing values replaced.

+ Calculated according to Cohen's d formula (see Clark-Carter, 2004, p.181).

\*\* Two participants declined to give their age resulting in data for N=22 for analysis of covariance (with age as covariate).

Table 4a: Comparison of attitudes to mental illness in later life according to experience.

Measure/Sub-scale	Group	Mean	Std Dev	d.f.	t* (Sig.)	Mean diff 95% CI	Effect Size* & Observed Power
BMHSS: 'Ageism'	With prior experience (N=33)	12.50	3.27	65	2.55 (p=0.007)	-2.40 (-4.28 to -0.52)	d=0.60 P=0.71
	Without prior experience (N=34)	14.90	4.36				
BMHSS: 'Stigma'	With prior experience (N=33)	9.38	2.58	65	0.89 (p=0.20)	-0.51 (-1.66 to -0.64)	d=0.20 P=0.14
	Without prior experience (N=34)	9.89	2.12				
Understandability	With prior experience (N=33)	8.85	3.95	65	0.40 (p=0.34)	-0.36 (-2.12 to 1.41)	d=0.10 P=0.07
	Without prior experience (N=34)	9.20	3.24				

\* Equal variances assumed (i.e. Levene's test non-significant). Significance is one-tailed.

+ Calculated according to Cohen's d formula (see Clark-Carter, 2004, p.181).

Table 4b: Comparison of attitudes to ageing by clinical status.

Measure/Sub-scale	Group	Mean	Std Dev	95% CI	d.f.	t* (Sig.)	Effect Size* & Observed Power
AAQ: Composite	Non-clinical (N=50)	57.44	10.08	54.58-60.30	1,72	15.67 (p<0.001)	d=0.90 P=0.97
	Clinical (N=24)	67.42	10.30	63.29-71.55			
AAQ: 'Growth'	Non-clinical (N=50)	29.17	3.87	27.95-30.39	1,72	7.49 (p=0.008)	d=-0.65 P=0.77
	Clinical (N=24)	26.22	5.16	24.47-27.99			
AAQ: 'Loss'	Non-clinical (N=50)	17.22	6.20	15.60-18.84	1,72	2.26 (p=0.14)	d=0.37 P=0.38
	Clinical (N=24)	19.37	4.62	17.03-21.70			
AAQ: 'Physical'	Non-clinical (N=50)	26.62	4.19	25.41-27.82	1,72	21.34 (p<0.001)	d=-1.01 P=0.99
	Clinical (N=24)	21.72	4.43	19.98-23.46			
RAME	Non-clinical (N=50)	26.50	7.55	24.61-28.38	1,72	11.28 (p<0.001)	d=0.78 P=0.91
	Clinical (N=24)	32.07	4.31	29.36-34.80			

\* Mean score after missing values replaced. Higher score equates to stronger endorsement of the predominant theme of the sub-scale.

+ Calculated according to Cohen's d formula (see Clark-Carter, 2004, p.181).



engagement in fewer cognitive-emotional regulation strategies than non-clinical participants with implications both for the potential onset and maintenance of mental health difficulties.

Finally, whole sample regression analysis indicated that endorsement of positive attitudes to ageing (as assessed by the AAQ subscales 'Growth' and 'Physical') accounted for over 22 per cent of the variance in health-behaviour outcomes (Table 5).

**Discussion**

This study explored older peoples' attitudes to mental illness in relation to their attitudes to ageing, experience of mental illness, and health-related outcomes. Results from both the qualitative and quantitative analyses indicated that older people in this sample, akin to studies reporting the attitudes of younger people, endorsed a range of positive and negative views of mental illness. However, when attitudes to mental illness were considered in the context of attitudes to ageing a more complex pattern of results emerged.

As expected negative attitudes to mental illness were associated with negative attitudes to ageing across the entire sample. However, differential group effects were also found indicating that clinical participants (and those with prior experience of mental illness) reported more positive attitudes to

mental illness and more negative attitudes to ageing than non-clinical participants, for whom the reverse was true. While this finding may reflect greater familiarity and experience of mental illness and mental health services of clinical participants, it may also reflect greater capacity on the part of non-clinical participants to approach ageing as a time of continual growth and maximisation of function (Depp & Jeste, 2006), a view further supported by the observed association between positive attitudes to ageing and engagement in health-behaviours and higher subjective well-being. Of course, it is also the case that better psychological self-regulation in ageing may be easier to achieve if one has not yet encountered the potential challenges and losses associated with growing older, and may in fact be a protective factor against the onset of depression and other mental health disorders (Ebner et al., 2006). Further, lack of understanding of mental illness in later life and/or lack of experience of accessing and utilising mental health services may go some way to perpetuating an unduly negative view of mental health problems in individuals who are primarily ageing well.

Interpretation of the results is tempered by a number of methodological shortcomings. Overall response rate was low despite attempts to improve sample size, and it was

**Table 5: Regression model summary statistics for RHBC total score as dependent variable.**

Model (N=72)	R Square	Adjusted R Square	Std Error of the Estimate	R Square Change	F Change	Sig.
1 - AAQ 'Growth' AAQ 'Physical'	.22	.20	8.78	.22	9.93	<i>p</i> <0.001

not possible to ascertain reasons for non-participation. It is, therefore, likely that there was a degree of bias or selectivity in the sample of individuals who consented to participate, rather than the study sample being truly representative of the larger population. Due to the method of recruitment, and despite participants from both groups reporting a broad range of health conditions, it is likely that the non-clinical sample (and to some extent, also the clinical sample) comprised relatively high functioning and articulate individuals who were able to reflect upon and discuss their attitudes in relation to mental illness and ageing. In particular, the clinical sample may have been biased towards those who were relatively well engaged with services and were active service users, thus representing a particular subgroup within the broader older adult population with mental health difficulties who place greater importance on seeking health-care.

As the current study was cross-sectional, involving assessment of all variables of interest at the same time point, it was not possible to provide evidence about the causal mechanisms connecting study variables. For example, whether having negative attitudes actually causes older people to seek less health care for mental health difficulties for modifiable conditions remains unclear. The study design also precludes the opportunity to ascertain if between-group attitudinal differences were the result of cohort effects (i.e. the non-clinical group were older on average) or developmental patterns likely to change over time. The relatively small sample size and imbalanced group numbers prevents definitive conclusions being reached in relation to study hypotheses, highlighting the importance of replication of study findings under more statistically rigorous conditions.

Additional, preferably longitudinal, research is required to further explore potential patterns of interaction between study variables. Such work might address, for

example, whether attitudes to ageing are triggered by individual experiences of mental illness, and whether subjective well-being is an outcome and/or a predictor of attitudes. A number of immediate concerns relating to the present findings are also apparent. For older people, these include the potential failure to recognise symptoms of mental illness, and the disinclination to seek help for potentially modifiable and treatable conditions. This lends support to calls for improved and comprehensive screening of older people for mental health difficulties in primary care settings (Sarkisian et al., 2003).

For clinicians, the results highlight the importance of understanding older clients in terms of cohort factors (Seedsman, 2005), and within a broader gerontological context, since such factors have the potential to influence the process and outcome of therapy (for example, by hindering engagement in therapy and lowering expectations of treatment success). Finally, for health policy makers, study findings point to the necessity of improving awareness of and access to mental health services for older people, and of developing and implementing targeted health education interventions which demystify mental illness in later life, address ageist misconceptions, and prioritise the needs of older people in the mental health agenda. The demographic imperatives of ageing societies are such that a qualitative shift in emphasis is now required away from a focus on lengthening life to increasing years of health and well-being.

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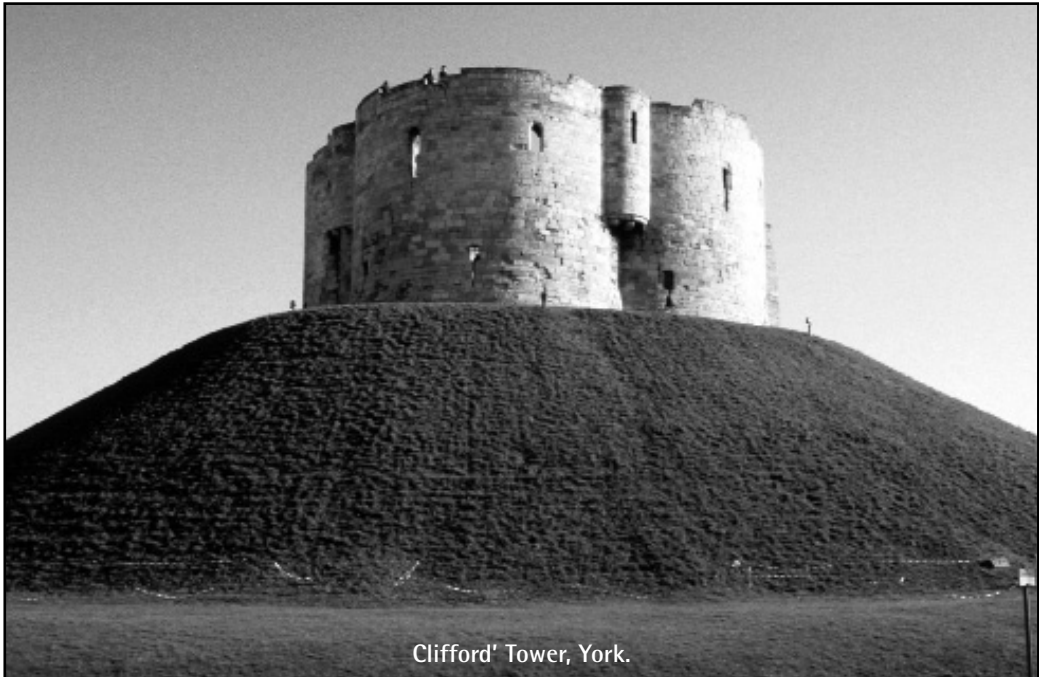
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# Valuing older people: Positive Psychology of later life

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*This paper will briefly define Positive Psychology, examine the ecological context of later life, and identify three core concepts from positive psychology that are particularly pertinent to later life.*

**P**OSITIVE PSYCHOLOGY has been defined as ‘the study and theory of those factors and processes that contribute to positive personal outcomes and development, despite adverse life circumstances’ (Snyder & Lopez, 2005; Seligman, 2005). Positive Psychology addresses *individual attributes* (such as expectancy, resilience, self-efficacy, optimism, creativity, coping, future-mindedness, knowing, wisdom) and *group attributes* (such as pro-social behaviours, responsiveness, responsibility, nurturance, altruism, civility, moderation, tolerance, civic virtues, citizenship) as well as *subjective factors* (such as well-being, life satisfaction, flow, hope, pleasure, happiness).

Bandura (2001) argued that traditional psychological theories grossly over-predict psychopathology, and that there is more to learn from people who do well despite adverse life conditions and experiences (Seligman & Csikszentmihalyi, 2000). Interventions can aim to replicate the circumstances that lead individuals to recover/adapt on their own (Seligman, 1993).

## Why now?

With current ecological imperatives of global sustainability and survival there is an urgent need for human societies to foster pro-social behaviours and attitudes. Individuals in later life commonly encounter adversities and cope naturally with these. Hence the study of later life is an opportunity to ‘fast forward’ our understanding of these highly desirable positive psychological traits and humanitarian competencies. The Positive Psychology

of Ageing is not an optional extra but a key to fostering enduring communities and achieving desirable humanitarian goals – ‘going beyond baseline’ (Keyes, 2003).

## The Anti-Ageing Movement

Despite the unprecedented demographic shift towards a ‘later life society’ (Bond et al., 2007) older people continue to be dealt with in ways that would be deemed unacceptable for other groups. It seems that technology-dependent societies fuelled to pursue the illusions of ‘the perfect individual’ and ‘eternal life’ by sustained denial of death and by defensive concealment of (Sudnow, 1967) and exit-making for, frail older people (Wesley Smith, 2003).

## Three core concepts

### 1. The Effect of Expectancy (the power of beliefs about certain groups in society)

Negative beliefs about later life result in negative images, weak roles, fear, demoralisation, age apartheid and vicious circles of poor psychological well-being. Positive beliefs result in Transcending images, inclusive valued roles, social well being, future-focussed communities and virtuous circles of good psychological well being (Table 1.).

Vicious circles start with *prejudiced beliefs* (commonly, ‘past it’, ‘a burden’), which lead to the individual *acting down* to the belief (e.g. letting go, losing confidence). This in itself leads to *more severe impairment of abilities and relationships* and ultimately to internalised low expectations of self, feeling anxious, alienated, not worthy, and ‘better dead’. The counter is a virtuous circle,

starting with a *positive belief* (e.g. later life seen as an opportunity for coping, developing, nurturing, contributing, regeneration, thriving community), which leads to the individual *acting up* (e.g. participating, contributing, net input to community, showing the way, part of a coherent whole, growing), which in itself leads to enhanced relationships, a sense of self as part of the fabric of the future, and high expectations of self as an agent in social actualization and regeneration.

Despite pervasive negative images such as 1 through 4 (Table 1) not all individuals in later life have long term, pervasive and enduring difficulties with ageing. Adverse events may have an impact but an environment that supports secure and meaningful relationships can strongly positively mediate this. Where individual resilience makes no difference, however, is where certain groups of people are subject to systematic devaluation and exclusion in the wider society. Among older people these groups may include those with dementia whose behaviour presents a challenge to caregivers, those with physical disabilities that impact on communication and behaviour, and those with serious mental health problems with behavioural changes (Wolfensberger, 1998; Kitwood, 1997).

**2. Resilience**

This has been defined as positive development or adaptation in the context of significant adversity (Luthar, Cicchetti & Becker, 2000) and the capacity for successful adaptation, positive functioning, or competence despite risk, chronic stress, or prolonged or severe trauma (Henry, 1999). Resilience fostering conditions in later life are, realistically, hampered by fear and denial about death. Patterns of socially engineered separation are transacted against those who carry these projected fears. The effects on communities are demoralisation, fear of growing old and unstable social structures.

**Resilience accomplishments**

Three conditions have been proposed that need to be accomplished for resilience fostering (Cheston & Bender, 1999; Gilligan, 2000):

1. *A sense of a secure base.* This refers to having the daily, seasonal and yearly routines and rhythms that are typical of the routines and structures in the lives of those people who are not facing adversity; attachment networks with responsive people. Providing continuity of life patterns means challenging the process of ghetto-isation of older frail people. The latter is only a temporary

**Table 1. How beliefs about ageing shape social responses (some examples).**

Belief about ageing	Person seen as	Society's response	Service model
1. Biologically pre-programmed	Close to death	Denial	Separation
2. Disease Decay	Sick Find the cure Wanting to exit	Technology: Euthanasia	Hospital, fund-raising
3. Second childhood	Child again for own safety	Protect/contain pretend living	Caretake, sitting,
4. Broken machine	To be fixed Fix the therapy	Technical: of providers	Therapy, accreditation
5. Ecological, continuity	Keystone part of the environment environment	Take care of each other and the Social inclusion	Community development

- 'solution' and commonly requires serial movements of people.
2. *Self-esteem*. This refers to having supportive social networks, and attachment relationships to reliable and responsive people and success in accomplishing tasks related to one's own interests. Attention to wider life goals, rather than exclusive focus on the disability, commonly brings 'solutions'.
  3. *A sense of agency*. This refers to having internal regulation over one's own life conditions including a sense of control in decisions. A person may be highly dependent on the support of others; however, with the right support they can experience a sense of control and autonomy over their life. Where people, disabled and 'able', share places in their communities there is opportunity for all to maintain agency.
1. Self acceptance vs. regret, shame.
  2. Feeling of personal growth, valued vs. invisible.
  3. Sense of direction, future focus vs. loss of hope.
  4. Feel able to choose, manage and regulate personally suitable contexts vs. loss of autonomy.
  5. Belief in a positive society vs. feeling marginalised.
  6. Seeing a world that is coherent and intelligible vs. alienation.
  7. Feeling of and contributing to community vs. disintegration of self.

### *Resilience interventions*

These would aim to identify protective factors for psychosocial resilience - for example attention to the internal environment and the person (e.g. humour, talents), building on the family and friendships circle (e.g. prosocial competent peers), building within the community (e.g. ties to prosocial organisations that connect people and are socially inclusive) and preventing loss of social roles, reputation and identity.

### *Resilience experiences of relevance to later life*

Everyone at some point in his or her life will experience disability. The question is not how we avoid disability, but rather how well we live with adversity when it is encountered. It is the secondary and tertiary damage that comes with disability that is the hardest to live with. For example, having a poor memory is not in itself incompatible with having a good life – commonly it is the secondary damage, such as experiencing shame, being made to feel invisible, being treated as hopeless, or having autonomy taken away, that diminishes the experience of life as good. It is not often the disability that people report as a 'burden' but the reactions of others to them and their disability. Positive psychology reminds us that the individual may well encounter disability – but *despite* it, or *because* of it, can experience self-acceptance, personal growth, a sense of direction, a sense of regulating one's own personal context, and positive beliefs about society (Keyes, 2003). The following are resilience experiences that may accumulate in later life:

### **3. Self-efficacy**

This has been defined as the individual's beliefs about what he or she is capable of doing, which develop over time and through experience (Bandura, 2001). Psychological experiences that underpin self-efficacy include the sense of being valued, being considered as making a worthwhile contribution by valued others and the capacity to see limitations as opportunities. Finally, happiness is seen as an emergent property and is not tied to any single type of activity.

### *Self-efficacy accomplishments*

Conditions that support and enable person centred assessment and interventions would support self efficacy. For example: information gained from a close respectful continuing relationship with the focus person; together creating a compelling picture of a **desirable** future; identifying available community opportunities and people neces-

sary for this to happen; inviting people to join with the person to make this happen; strengthening personal relationships; helping to expand community opportunities and create new forms of service support.

### ***Self-efficacy experiences***

Research has found high levels of perceived mastery and avowed happiness in 35 per cent of older women (Penninx et al., 1998). Interventions to increase self-efficacy (goal-setting, assignments, awareness of process, agency thoughts) were shown to increase hope and decrease depression in older patients (Klausner et al., 2000). Although pleasant affect was found to decrease in frequency the intensity of positive affect (happiness) did not diminish into later life (Diener et al., 1998).

### ***Self-efficacy interventions***

These would aim to minimise circumstances that exclude, protect, or label a person with 'poor Quality of Life'. They would optimise the opportunities to be (and be seen to be) sharing, responsible and valuing life as it is. In a society whose socioeconomic focus was ecological, later life would be valued as an opportunity for creativity, courage, reflection, citizenship, mastery, optimism, responsibility, trust and other productive psychological traits. Ageing is not a time of inevitable loss of self-efficacy. Environments and communities that can support self-efficacy in later life will themselves be viable environments and strong communities of benefit to members of all ages. Community members in later life contribute perspectives that are of value across the community.

## **Conclusion**

The positive psychology of later life has much in common with Social Role Valorization (SRV; Wolfensberger, 1998). Neither is concerned with putting a gloss on the adversities and life circumstances that occur in later life, or with 'making things cosy in the institution'. On the contrary PP and SRV are reality based, are grounded in the necessities of survival and offer a new paradigm for a new era. In psychological terms, the optimal conditions for individuals in earlier life to learn the competencies and insights to deal successfully with disabilities and adverse life circumstances are provided through the power of modelling – requiring close contacts and sharing places in the community with individuals in later life.

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# A case study of Adaptive Interaction: A new approach to communicating with people with advanced dementia

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**W**E ARE TWO psychologists who work with people who have a diagnosis of dementia, a progressive, deteriorating condition, which typically affects older people and impacts on all aspects of functioning. Between us we have 25 years' of experience working in this field and both have a particular interest in the impact of dementia on communication and the effect this has on relationships between people with dementia and caregivers.

In this chapter we report our first attempt to explore an approach to communication based on Intensive Interaction (II) with an individual in the very advanced stages of dementia. Unlike people with profound learning disabilities or severe autism, for whom II opens up channels of communication for the first time, people with dementia have previously been healthy individuals who communicated through speech. The communication barriers they experience arise from a progressive loss of speech coupled with severe cognitive problems.

In this case study we work with Edie, who is an 81-year-old lady living in a nursing home whose dementia has progressed to the stage where she can no longer speak. We use principles from Intensive Interaction to explore Edie's communication repertoire in an attempt to 'learn her language' now she no longer has speech. We find that Edie retains an urge to communicate with another person and has a range of behaviours that make up her language. We

describe two interactions – one speech-based conversation and the other using the principles of Intensive Interaction – that took place between Edie and one of us (ME) and the outcomes of those interactions.

The findings suggest that an approach to communication based on II has something to offer people with advanced dementia who can no longer speak. However, this population has severe memory problems, which means that no assumptions can be made about building up a repertoire of communication from session to session. Instead, communication partners must approach each interaction with people with advanced dementia as a unique encounter and adapt their behaviour anew each time. We term this approach Adaptive Interaction. In this case study we make no assumptions that Edie will subsequently remember the interaction or the exchange of communication behaviours.

## **Dementia**

Dementia is an illness that involves progressive global decline in all aspects of functioning. Memory is usually affected early in the course of the illness, although all aspects of cognition, including speech, problem solving, perception, decision-making and functional abilities are affected over time (Raia, 1999). The symptoms of dementia impede people's ability to participate in most daily activities, not least of which is communication and participation in social interactions.

The majority of people who develop dementia are over 65 and as the illness develops they experience progressive social isolation (Abad, 2002). This is a result not only of their increasingly impaired communication skills but also arises as a consequence of those around them making fewer attempts to communicate. By the time dementia reaches the later stages, people with a diagnosis may appear to be completely unreachable, which results in those who care for them no longer attempting to engage them in interactions.

### **Communication in advanced dementia**

The communication problems experienced by people with advanced dementia clearly have a huge impact both on them and on those who care for them. For families, communication difficulties put a major strain on maintaining relationships with the person with dementia. Whereas care staff face the challenge of establishing relationships with people whose communication skills are already severely compromised when they first meet. As such, communication and social interactions are extremely difficult and may cease altogether except in pursuance of basic activities of daily living (Bowie & Mountain, 1993). This situation is clearly unsatisfying for both people with dementia and those who care for them.

Improving interpersonal communication in this situation could improve the job satisfaction of care staff and the quality of life of people with dementia (Woods, 1999). The challenge is how to facilitate communication when people with dementia have little or no speech and may only make sounds or repeat isolated words or movements. It is argued, however, that even at this advanced stage people retain many identifiable communication skills (Orange & Purves, 1996) and demonstrate a continued urge to communicate and interact with others (Ellis & Astell; 2004). These retained behaviours could form the basis of an intervention designed specifically for individuals with advanced dementia that has the potential to enhance their lives and the lives of those who care for them.

### **Intensive Interaction**

Intensive Interaction (II) is an approach to interacting with people with severe communication problems that was developed in the 1980's for people with profound learning disabilities. The focus of II is on regular non-verbal and subvocal exchanges with little or no involvement of speech between two people, one of who experiences difficulty communicating with others. The quality of the interaction is all-important in II, and there is no emphasis on task performance or achieving specific outcomes (Nind, 1999). The key to II is that the behaviour of the non-verbal participant is viewed as intentionally communicative.

The basic principles of II reflect the essential communicative processes that occur early in life between caregivers and infants (Nind, 1999). Although the structure and the linguistic contents of these early exchanges are non-verbal, few people would argue that they are without meaning or emotion (Papousek, 1995; cited in Duffy, 1999). Furthermore, Nind (1999) asserted that this similarity in approaches does not mean that people with learning disabilities or, by extension, other severe communication impairments, should be regarded or treated as if they were infants.

II commences with the professional or caregiver becoming familiar with the person they want to communicate with and the types of interactions that this person might engage in. This initial 'connection' is then developed into a set of spontaneous interactive 'games' that are based on the behaviour of the person with communication impairment. For example, a sound or action they make, such as banging on the table, might be reflected back by their partner, either directly or with some variation in the rhythm. The professional or caregiver responds contingently to her partner's behaviours to continuously expand the interactions between them and support their partner to take a more active role in communication.

As II has developed over the years, different aspects of the basic approach have

been emphasised. Hewett (1996) and Nind (1999), for example, both consider the focus of II to be on teaching the 'pre-speech fundamentals' of communication. These fundamentals include turn-taking, shared attention, and eye gaze, which are developed together by the two communication partners (Nind, 1999). In this approach the professional or caregiver is termed the 'teacher' and the communication-impaired partner the 'learner'. The teacher constantly modifies her own interpersonal behaviours such as body language, eye gaze, vocalisations and facial expressions in order to make them as engaging and as meaningful as possible to their communication-impaired partner. It is important for the teacher to be attentive to their partner's behaviour, to create pauses in the interaction and to be open to joining in with rhythms and sounds their partner may make. This may include imitation of certain elements of the communication-impaired partner's behaviour and vocalisations.

In Caldwell's (2005; Caldwell & Horwood, 2007) version of II imitation is the starting point of II: 'a way of capturing attention, a door to enter the inner world of our partners' (2008). Caldwell's approach to II emphasizes exploring the sensory experience of people with profound communication difficulties and attempting to 'learn their language' (Caldwell & Horwood, 2007). One key outcome of this approach is providing a way for people typically regarded as outside the social world to express themselves (*ibid*). This is commonly seen in shifts from solitary self-stimulatory behaviour, such as biting or head banging to engagement in shared activity (Caldwell & Horwood, 2007). By responding in ways that are familiar to the person with severe communication difficulties, *i.e.* initially imitating and then developing them into a shared 'language', it is possible to build and sustain close relationships without speech (Caldwell, 2005).

Studies using II typically employ video-recording to measure developments in communicative responses (*e.g.* Kellett, 2000; 2003; Nind, 1996). For example, Nind

(1996) examined engaged social interaction, smiling, eye contact and looking at the communication partner's face (Nind, 1996). The efficacy of II in increasing the occurrence of such social behaviours in people with severe learning disabilities has been demonstrated in numerous studies (*e.g.* Watson & Fisher, 1997; Stothard, 1998; Samuel & Maggs, 1998). Additionally, several government bodies have noted other benefits of II, including improved quality of life (QCA, 2001a, 2001b; Ofsted, 1997, 2000).

### **Intensive Interaction for advanced dementia**

Such benefits and positive effects on communication are clearly very desirable for people with advanced dementia, who are frequently excluded from the social world. Intensive Interaction appears to have great potential for improving communication between people with advanced dementia and those who care for them. To investigate the usefulness of II for facilitating communication with people with advanced dementia we conducted a single case study. We were guided by principles from both of the variants of II discussed above. Caldwell's (2005, 2007) approach to II with its focus on matched responsiveness and nonverbal behaviour was felt to be best suited to exploiting any retained communication behaviours of people with advanced dementia who no longer have speech. However, Hewett and Nind's (1998) work, which focuses on the pre-speech fundamentals of communication, can be seen as providing a framework for identifying retained communication behaviours. In this case study we attempt to 'learn the language' of a person with advanced dementia and explore the potential for engaging her in meaningful, shared activity.

### **Case study: Edie**

Edie is an 81-year-old lady who has dementia that has reached a very advanced stage. She started to lose speech some years ago but coped initially with everyday tasks such as

shopping by writing a list and giving it to an assistant. Later on in her illness Edie began to engage in less functional activity, such as going out to look for her daughter at her place of work in the middle of the night. She eventually became unable to look after herself at home and was admitted to a local care home. Five years on Edie has no speech at all and is unable to walk. She spends most of the day in bed or in front of the television in the residents' lounge. She receives regular visits from her daughter.

Ethical approval for the study was received from the Multi-Centre Research Ethics Committee designated to consider research proposals covered by Section 51 (3)(f) of the Adults with Incapacity (Scotland) Act 2000. In accordance with this legislation, consent for Edie to participate was sought from her nearest family member, her daughter. The ethical approval included video-recording the interactions with Edie and her daughter also consented to this.

## **Learning Edie's language**

### **Stage 1 – Current communication context**

The first step in learning Edie's language was to explore her current communication context. This involved spending two days in the care home observing the everyday activities and communication that took place. Additional information was collected from the manager of the care home and some of the staff. This highlighted that the team responsible for providing Edie's care found it difficult to communicate with her and engage her in activities of daily living such as eating, bathing and toileting.

Edie's daughter was also interviewed as part of understanding her current communication context. Her daughter identified a number of behaviours that she felt had communicative value for Edie, including a high-pitched sound, sucking and chewing her thumb and laughing.

### **Stage 2 – Baseline interaction**

The next step in learning Edie's language was to collect baseline data on Edie's communi-

cation behaviour. For this we devised a 10-minute session where one of us (ME) went into Edie's room to conduct a spoken conversation consisting of the sort of questions typically asked in day-to-day interactions observed in the care home. These included: 'Did you enjoy your meal?'; 'Did you have a lie in this morning?'; and 'Have you seen the weather outside today?' Each of these closed questions would be followed by a 20-second pause to give Edie the best possible opportunity to respond in some way, for example by nodding or shaking her head.

### **Stage 3 – Intensive Interaction**

Step three of learning Edie's language was to attempt to communicate with her using her own behaviours as the basis of the interaction (Caldwell, 2005, 2007). For this we decided to again allow 10 minutes for the same investigator (ME) to go into Edie's room to conduct a session where she would attend to and imitate Edie's verbal and non-verbal behaviours. For example, if Edie made a vocalisation, ME might attempt to imitate it directly or she might reproduce the rhythm of it in some way, for example by tapping it out on the side of the bed. As such, the investigator would focus on learning Edie's communicative repertoire and reflecting it back to her in a way that was meaningful to Edie.

## **Edie's language**

Based on the evidence gathered from the three stages: (1) Observation and interviews; (2) Baseline interaction; and (3) Intensive Interaction – Edie's communication repertoire was found to encompass eye gaze, sound, movements, facial expressions, and several fundamental elements of communication. These are summarized in Table 1.

We examined the occurrence of these 15 different behaviours across the two one-to-one sessions. The patterns of occurrence of these behaviours were quite different across the two sessions both in the presence and absence of the behaviours and the frequency with which they occurred. To illuminate this

Table 1: Edie's communication behaviours.

Category	Behaviour		
Eyes	Gaze on partner/ partner's eyes	Gaze elsewhere	Eyes closed
Sounds	High-pitched sound	Laughter	Silence
Movements	Sucking and chewing the side of her thumb	Moving her head closer or further away from partner	Moving her head to touch her partner
Facial expressions	Surprise	Smile	Neutral
Fundamental elements	Initiation/introduction of behaviour	Reciprocation of partner's behaviour	Turn-taking

the two sessions are briefly described below, starting with the Baseline Interaction. Time checks are included at points where new behaviours occurred or old behaviours ceased in an attempt to clarify the way each session unfolded. In addition, the patterns of occurrence are displayed for each session (see Figure 1 and Figure 2). For simplicity Figure 1 and Figure 2 are records of whether a behaviour occurred during each minute of the two 10-minute sessions and are neither counts of frequency nor duration.

### Session 1 – Baseline Interaction

When ME entered her room Edie was lying in her bed, which had padded cot-sides. She was lying on her side on two pillows and her eyes were open. When ME asked the first question Edie made a high-pitched sound and stared at her. Edie continued to make the high-pitched sound intermittently whilst looking at ME. Edie's behaviour in response to ME speaking, i.e. making a sound and eye contact, suggested that she wanted to communicate with her.

At 37 seconds into the session Edie became silent and at 39 seconds into the interaction, she closed her eyes. These behaviours could be taken to indicate disengagement by Edie. However, after a few more seconds she opened her eyes and with a surprised expression made the high-pitched sound. ME continued to ask the prepared questions at 20-second intervals. Edie kept

her gaze fixed on ME and at 51 seconds, Edie began chewing her thumb. This activity was one previously identified by Edie's daughter and could serve as a comfort behaviour for Edie (see Coia & Handley, 2008).

At 62 seconds into the 10-minute session Edie closed her eyes and continued to chew her thumb for another five seconds. She then removed her thumb from her mouth and her eyes remained closed for the rest of the session. ME continued to ask the prepared questions allowing time between each for Edie to respond but *she never again opened her eyes, moved or made a sound* during the remainder of the session.

The total interaction lasted for barely one minute of a planned 10-minute session. The exchange revealed that although Edie appeared to respond to speech at the outset of the session (Figure 1), speech alone from her interaction partner failed to maintain her participation. This session confirmed the reports from staff of the difficulties they experienced in communicating with Edie in regard to basic activities of daily living. However, the session also contained a number of behaviours, e.g. high-pitched sound and thumb chewing, that Edie's daughter had suggested have a communicative value. These stood out as exactly the sort of behaviours that are used in II to develop an interaction.

**Figure 1: Presence and absence of Edie's communication behaviours during each minute of the Baseline session.**

Category	Minute	1	2	3	4	5	6	7	8	9
Eyes	Eye contact with partner	■								
	Gaze elsewhere									
	Eyes closed		■	■	■	■	■	■	■	■
Sound	High-pitched sound	■								
	Laughter									
	Silence		■	■	■	■	■	■	■	■
Movements	Chewing thumb	■	■							
	Moving closer/away									
	Touching partner									
Facial expressions	Surprise	■								
	Smile									
	Neutral		■	■	■	■	■	■	■	■
Communication Fundamentals	Initiation	■								
	Reciprocation									
	Turn-taking									

**Session 2 – Intensive Interaction**

At the start of this session Edie was lying in her bed with the padded cot-sides. She was lying on her side on two pillows dozing. ME sat by the side of the bed and stroked Edie's hair whilst softly speaking her name. After 16 seconds Edie opened her eyes and looked directly at ME and made 'her' sound in a high-pitched tone. ME reflected the sound and pitch back to Edie. Edie then repeated the sound and both interaction partners took another two turns each in this manner.

As in the Baseline session, Edie's immediate reaction to ME speaking was to look at her and make the high-pitched sound. In this session, however, rather than continuing to speak, ME adapted her response to match Edie's, which resulted in a brief initial 'dialogue' of several turns each.

At 23 seconds into the interaction, the dialogue changed when Edie put her thumb in her mouth and started sucking and chewing on it, all the time looking into ME's eyes. ME responded by sucking and chewing her thumb. Edie then removed her thumb

from her mouth and made her high-pitched sound. ME responded by taking her thumb from her mouth and repeating the sound made by Edie. Edie then put her thumb back into her mouth, and ME followed suit. In these exchanges Edie took the lead by introducing a new behaviour (thumb-chewing), then reverting to the previous behaviour (high-pitched sound) then returning to thumb chewing, all the time looking intently at ME. ME responded to each of these changes by matching Edie's behaviour.

ME then attempted to change the dialogue by removing her thumb from her mouth and making a sound like Edie's high-pitched one. In response Edie then removed her thumb from her mouth and matched the sound and they then continued to turn-take making this sound for another 20 seconds. This section of dialogue ended when Edie then began sucking her thumb again. In this exchange ME reintroduced one of Edie's behaviours (high-pitched sound) and Edie responded by altering her own behaviour to match ME's.

At 90 seconds into the 10-minute session, ME attempted to change the interaction again by introducing a new element. This was to imitate the rhythm of Edie's thumb chewing through tapping her fingers on the side of the bed. Edie continued to chew her thumb and stared intently at ME. After a few seconds, Edie removed her thumb from her mouth and made her high-pitched sound. ME stopped tapping and repeated the vocal sound and turn-taking resumed using Edie's sound until ME tapped on the bed again. Edie became silent, put her thumb back in her mouth and watched ME's fingers tapping on the bed. She then removed her thumb from her mouth and resumed her high-pitched sound. At 108 seconds, Edie put her thumb in her mouth and immediately removed it when she saw ME do the same. Edie and ME then resumed turn taking with her sound.

In this phase, when ME introduced the new element (rhythmic tapping) there was no discernable change in Edie's behaviour. She continued to chew her thumb while looking intently at ME. However, as ME continue to tap, Edie then stopped chewing and made her high-pitched sound. She did not put her thumb in her mouth again during this session. The turns in this exchange suggest that the introduction of a variation of one her behaviours (thumb-chewing) had less impact for Edie than the matched behaviour. However, she appeared to retain her interest in the interaction as she continued to look at ME and finally reintroduced a previous behaviour (high-pitched sound).

Edie and ME continued the dialogue making the high-pitched sound until 150 seconds into the session, at which point Edie introduced another new behaviour. She lifted her head up from the pillows and moved towards ME's hand, which was resting on the cot-side. Edie rubbed her forehead on ME's hand and ME responded by stroking Edie's hair. ME then attempted to reintroduce one of Edie's previous behaviours, i.e. her thumb-sucking and the rhythm

of it. Again, Edie raised her head, rubbed her forehead against ME's hand and then closed her eyes. ME then made Edie's sound towards her to which she reciprocated followed by a number of turns each. Edie continued to keep her eyes closed for 43 seconds during this part of the interaction.

This phase of the session was notable for Edie introducing touch into the interaction. The dialogue had been proceeding through sound and vision (eye contact) when Edie opened up a third channel of communication, i.e. touch. However, although ME responded by touching Edie's head, she did not match her behaviour, as she had done with Edie's sound.

After the sound turn-taking, Edie then rubbed her head against ME's hand for a third time and ME moved forward and rubbed her own head against Edie's. At this point, Edie opened her eyes and gave a look of surprise followed by the high-pitched sound. The dialogue then took on the form of a spontaneous game of mutual head touching and vocalization. During this phase Edie laughed at several points after she and ME touched heads.

This is perhaps the most exciting part of the interaction as this is when Edie exerted the most control over the situation and was the most animated. Edie was clearly attempting to get closer to ME and to touch her. However, initially ME was focused on maintaining previous elements of the interaction. Once ME recognised Edie's new direction, the interaction took on a new dynamic. From the moment ME touched heads with Edie, communication became much more playful and fun. The two took turns with sounds and touching and both laughed at several points throughout (Figure 2.).

At seven minutes and four seconds into the interaction, Edie fell silent and closed her eyes. She remained like this until the investigator touched her head 46 seconds later, at which point she made her sound and then opened her eyes when ME reciprocated with the sound. The two began turn-taking again using Edie's sound and both laughed



**Figure 2: Presence and absence of Edie's communication behaviours during each minute of the Intensive Interaction Session.**

Category	Minute	1	2	3	4	5	6	7	8	9
Eyes	Eye contact with partner	■	■	■	■	■	■	■	■	■
	Gaze elsewhere	■	■	■	■	■	■	■	■	■
	Eyes closed	■	■	■	■	■	■	■	■	■
Sound	High-pitched sound	■	■	■	■	■	■	■	■	■
	Laughter	■	■	■	■	■	■	■	■	■
	Silence	■	■	■	■	■	■	■	■	■
Movements	Chewing thumb	■	■	■	■	■	■	■	■	■
	Moving closer/away	■	■	■	■	■	■	■	■	■
	Touching partner	■	■	■	■	■	■	■	■	■
Facial expressions	Surprise	■	■	■	■	■	■	■	■	■
	Smile	■	■	■	■	■	■	■	■	■
	Neutral	■	■	■	■	■	■	■	■	■
Communication Fundamentals	Initiation	■	■	■	■	■	■	■	■	■
	Reciprocation	■	■	■	■	■	■	■	■	■
	Turn-taking	■	■	■	■	■	■	■	■	■

several times. At nine minutes and one second, Edie fell silent and then closed her eyes five seconds later. She remained like this for the rest of the session.

This section suggests that perhaps Edie was ready to end the interaction at a point before ME realised. ME attempted to keep the interaction going and Edie reciprocated with enthusiasm for a while but closed her eyes again very soon after. Edie closing her eyes effectively ended the interaction and can be seen as another element of her communication repertoire.

**Discussion**

This case study reports an attempt to ‘learn the language’ of Edie, a lady with advanced dementia, using the principles of Intensive Interaction. This approach revealed that Edie retained a varied set of communication behaviours, including eye gaze, movements and sound, coupled with a desire to interact with other people.

At the start of both sessions Edie made eye contact with the investigator (ME) and a

high-pitched sound. In the Baseline ‘conversation’ session, however, Edie quickly stopped making any sound or eye contact and at 67 seconds into the 10 minutes, effectively disengaged from the interaction. By contrast in the II session, the investigator’s reciprocation of Edie’s initial communication bids, lead to turn-taking and an intricate interaction.

The occurrence of eye contact and the high-pitched sound at the start of both sessions suggests that in both instances Edie wished to communicate with ME. This confirms earlier findings that the urge to communicate is retained even in the advanced stages of dementia (Astell & Ellis, 2006). In addition, when Edie’s daughter viewed the videos she reported that this was also how her mother behaved when she visited.

As well as using sound and eye contact to establish communication, Edie effectively used several different channels of communication during the two interactions with ME. In the baseline session she closed her eyes

and became silent – i.e. she ceased making her two ‘I want to interact’ behaviours – very quickly and withdrew from the interaction. By contrast, in the II session, Edie’s high-pitched sound formed the initial exchange with ME, effectively enabling them to say ‘hello’.

Throughout the rest of the II session, Edie used her eyes and her sound to communicate with ME. ME also used the high-pitched sound both in turn-taking initiated by Edie and to restore their exchange at several points, e.g. when rhythmic tapping did not elicit a response from Edie. In addition to her eyes and sound, Edie introduced movement and touch, which served to change and intensify the interaction. Once ME reciprocated Edie’s touch, the exchange became playful and elicited expression of positive emotion, i.e. laughing.

In addition to new behaviours appearing as the II exchange progressed, it was notable that Edie discontinued chewing her thumb, a behaviour that appeared early in both sessions. Thumb chewing could serve a number of different functions for Edie. Her daughter, for instance, suggested that it is an indicator of boredom. This fits with the notion that such behaviour is a way that people “talk to themselves” which enables them to return to their ‘comfort zones’ (Coia & Handley, 2008). It is possible, that Edie ceased chewing her thumb during the II session because she no longer needed to ‘talk to herself’. However, in the Baseline session Edie closed her eyes and became silent when she stopped chewing her thumb. Together these behaviours signaled disengagement and served to terminate her involvement in the interaction. The idea that Edie’s behaviour has multiple meanings and that behaviour combining occurs suggests that she retains at least some of the basic components of communication and interaction with another person.

We can see other fundamental aspects of communication behaviour such as initiation, turn-taking, using emotional facial expressions (e.g. surprise) and expressing emotion

(e.g. laughter) in Edie’s communication repertoire. This supports previous findings that even in the advanced stages of dementia, people retain the pre-speech fundamentals of communication (Ellis & Astell, 2004; Orange & Purves, 1996). In addition, Edie is able to lead the interaction in several different ways. One is by initiating new behaviours, e.g. thumb sucking, moving towards partner. She is also able to reintroduce old behaviours (thumb-sucking, high-pitched noise) at various points in the interaction. Finally, she is able to end the interaction by closing her eyes and falling silent.

### Caregiver reactions

These findings suggest that Edie not only has a retained communication repertoire but also can engage in social interaction and express herself. This was supported by the reaction of Edie’s daughter on viewing the video recordings of the two sessions. She confirmed that Edie is very responsive to her when she visits and that her interactions with her mother contain similar elements such as moving her face very close to Edie’s. She also reported that holding Edie’s hand, cuddling her and talking to her all resulted in what she interpreted to be a happy and animated response. On watching the video recordings, Edie’s daughter realized that she copied some of her mother’s communicative behaviours when they were interacting without knowing that she was doing it.

Edie’s daughter consented to the care home manager viewing the video recordings. The manager’s reaction was primarily one of surprise and extreme emotion. She commented that she had never seen Edie communicate so readily and with such obvious engagement. These reactions from Edie’s daughter and the care home manager, suggest that using the principles of II to facilitate communication between people with advanced dementia such as Edie and those who care for them would indeed be beneficial. In particular, II has the potential for training and supporting care staff, who may

find it very difficult to know how to respond to people such as Edie who make sounds and repetitive behaviours. It could hopefully give them the confidence to interact with these people who they currently avoid or ignore due to their own discomfort (Kitwood, 1990).

### **Adaptive Interaction**

In order to respond to the communication needs of people with advanced dementia some modification of II is required. Specifically, due to the severe memory problems experienced by people with dementia, II with this population must remain 'in the moment' with no need for any parts of previous interactions to be remembered. Therefore, the communication partner must remain adaptive to the changes in communication by the person with dementia and be willing to start afresh each time. As such, we term this approach Adaptive Interaction.

Adaptive Interaction based on Caldwell's behavioural-matching version of II, appears to have potential as a tool for promoting and supporting communication between people with advanced dementia and those who care for them. This case study uncovered a retained communication repertoire including sounds, movement and eye gaze as well as other basics of communication such as turn taking and facial expressions (Hewett, 1996; Nind, 1996). Excited by these findings, we are currently exploring the

potential of Adaptive Interaction further with five more people with advanced dementia who are no longer able to speak in the hope of going some way towards bringing them back into the social world.

### **Acknowledgements**

We are extremely grateful to Edie and her daughter for participating in this study. We also acknowledge the assistance provided by the manager and staff of the care home where Edie lives. Finally, we are grateful to Phoebe Caldwell for the training and very helpful advice she provided in preparation for carrying out this pilot study. This work was conducted as partial fulfillment of the first author's PhD studies.

Edie recently died very peacefully at the care home she resided in. At her mother's funeral service, Edie's daughter remarked to the minister that although Edie had lost her memory and the ability to speak, dementia could not take away her core humanity. We believe that this chapter illustrates this beautifully and as such dedicate it to Edie's memory and her status as a trailblazer in dementia research.

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# Anxiety in later life and the development of the Geriatric Anxiety Inventory

Nancy A. Pachana

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*Post equitem sedet atra Cura*

At the rider's back sits dark Anxiety. Horace, 65 B.C. – 8 B.C.

**W**HILE DEPRESSION in later life has been a focus of clinical research for a number of years, both clinical and research interest in late-life anxiety has a much briefer history. Over the past decade several articles have been published which focus on both symptoms as well as interventions for late-life anxiety (e.g. Ayers et al., 2007; Wetherell et al., 2001, 2005). This is despite the fact that in a variety of studies, anxiety disorders appear as common if not more common in later life than depressive disorders, particularly among those with co-morbid medical illnesses (c.f. Lenze et al., 2001). Anxiety disorders also account for a large percentage of the burden of mental illness within a population. For example, anxiety disorders account for 24 per cent of the burden of mental disorders in Australia, as compared with schizophrenia, which accounts for five per cent of the burden in that country (Mathers et al., 1999).

Research has shown several factors which increase the risk of developing anxiety disorders over the lifespan, including gender (females have increased risk) and age (which in general decreases risk; Andrews et al., 2001). Despite the fact that the risk of anxiety declines with increasing age (as it does for depression and many other psychiatric disorders, with the notable exception of dementia), the fact remains that anxiety presents in later life in both clinical and neurological samples with some regularity. For example, anxiety is present in 38 per cent of patients with Alzheimer's disease, 56 per cent of patients with early Alzheimer's

disease, and 72 per cent of vascular dementia patients (Qazi et al., 2003; McCurry et al., 2004). Co-morbidity of anxiety and depression in later life is also an issue facing the clinician.

There are a variety of explanations for the apparent decline in anxiety disorders with increasing age, including failure of older adults to disclose symptoms of anxiety, anxiety-related mortality, cohort effects and an interaction between increased age and changing threshold criteria for the diagnosis of anxiety disorders (see Krasucki et al., 1998 for an interesting review of these issues). Palmer and colleagues (1997) have also discussed the difficulties of diagnosing anxiety disorders in older populations.

There are a number of challenges to accurately diagnosing anxiety disorders in later life. These include the fact that ageing brings with it a higher prevalence of certain medical conditions, realistic concerns about physical illnesses, and a higher use of prescription medications. Impaired memory in older cohorts may be interpreted as a sign of anxiety or dementia, with perhaps some tendency to diagnose the latter in primary care settings. Likewise, the symptoms of agitation typical of dementia may be difficult to separate from anxiety in older adults, particularly in residential care facilities.

While interest in screening and assessment of late-life anxiety has increased (Wetherall et al., 2007), until recently choices of assessment tools for anxiety in later life were limited to those that had been initially developed for younger populations. A widely accepted brief instrument to

measure dimensional anxiety in both healthy older adults and those with mental health problems seen in a variety of settings has been lacking. Instruments designed specifically for older adults (e.g. the Geriatric Depression Scale; Yesavage et al., 1983) as well as age-congruent norms for such instruments (Owens et al., 2000) are important. With this in mind, an instrument to measure anxiety symptoms in older populations was developed by Pachana, Byrne and colleagues (Pachana et al., 2007a). This new instrument was created and validated on older populations, and also sought to overcome some limitations of existing instruments. For example, somatic items in some inventories (e.g. Goldberg & Bridges Scale; Goldberg et al., 1988) fail to reflect the somatic nature of some older adults' manifestations of anxiety disorders (Turnbull, 1989). In addition, too great an overlap with somatic symptoms of normal ageing, comorbid medical conditions or medication side effects (e.g. shortness of breath in chronic obstructive pulmonary disorder) was avoided.

The Geriatric Anxiety Inventory (GAI; Pachana et al., 2007a) was patterned after the widely used Geriatric Depression Scale (Yesavage et al., 1983) in terms of ease of use, simplicity of response sets, and brevity. In the first instance symptom severity cut-offs were the target of the research; more finely-detailed scaling of mild to severe anxiety symptoms remain to be developed for this instrument. The GAI is designed to measure severity of anxiety symptoms and is not a diagnostic instrument. This is deliberate on several counts, not the least of which is the variety of anxiety disorders that may present later in life. The initial inventory was piloted for language, etc., on 25 community-dwelling older adults, with wording of questions adjusted accordingly. A panel of experts, including geriatric psychiatrists and psychologists, also examined the draft inventory.

Initially questions were chosen for the GAI based on items derived and modified from previously validated anxiety instruments including the Beck Anxiety Inventory (BAI; Beck et al., 1988) and the State-Trait Anxiety Inventory (Spielberger, 1970). The inventory was validated on a community sample of 452 community-dwelling older adults. Item-total correlations were examined and the inventory reduced to the 20 best-performing items. Reliability and validity of the final 20-item scale were good, with good internal consistency, concurrent validity, and high sensitivity and specificity reported (Pachana et al., 2007a). The inventory was given to an outpatient clinical psychiatry sample, and optimum cut points were determined via receiver operating characteristic analyses (ROC curves) for both general mixed anxious samples as well as GAD specifically (Pachana et al., 2007a) with promising results. The inventory has been used in a number of published and in press studies, including a treatment outcome study with older phobic patients (Andrew & Dulin, 2007; Pachana et al., 2007b).

Future research with the instrument will address its suitability for residential care settings and its utility with neurological samples including Parkinson's patients. The inventory has been translated into 10 languages thus far, including Portuguese, Spanish and Swedish. A version of the instrument for use with patients with more severe dementia, similar to the Cornell Scale for Depression in Dementia, is also in progress.

The inventory is free to use; please contact the author at npachana@psy.uq.edu.au for more information or for copies of articles and the GAI measure itself.

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# Emotional reactions in patients and spousal caregivers following early discharge from hospital after a first stroke: A pilot study

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**I**NFORMAL CAREGIVERS are the unpaid and untrained individuals who provide emotional and practical support to patients on a day-to-day basis. In stroke care, there is already an established literature documenting the vital role that caregivers play in helping patients to realise their potential for recovery. For example, it has been shown that in 'successful' caregiving relationships – where caregivers feel willing and able to provide the support that the patient needs – stroke patients are less likely to develop depression (Norris, Stephens & Kinney, 1990) and are more likely to succeed in their physical rehabilitation (Gillen et al., 1999).

Stroke can affect physical, emotional (mood), and cognitive domains of functioning, often leaving patients with complex patterns of impairment. The current pressure towards early discharge from hospital means that caregivers are confronted with a range of unexpected tasks and emotional challenges with little time to prepare emotionally for the changes in their partner and for their new roles. With an estimated 300,000 people in the UK experiencing moderate to severe physical disability as a result of stroke (National Audit Office, 2005) it is understandable that the stroke caregiving literature has focused on the impact of these physical consequences on caregivers. However, given that prevalence estimates of post-stroke depression range from 20 to 50 per cent (Barker-Collo, 2007) and of stroke-related cognitive impairment from 17 to 38 per cent (Haring, 2002;

Saxena, 2006) research is also needed into how these psychological factors influence caregiver and stroke patient outcomes. The focus of the present small-scale study was on how these factors could affect the emotional reactions of carers to the 'Early Supported Discharge' (ESD) of their relative (Langhorne & Widen-Holmqvist, 2007).

The indications are that ESD is positive for patients: ESD patients show superior physical health at six months post-stroke (Mayo et al., 2000) and improved 'psychological well-being' when compared to patients receiving rehabilitation in hospital (Cunliffe et al., 2004). What is not yet fully understood is the impact of ESD on their caregivers.

There were a number of methodological limitations in the existing literature that we wanted to address in this ongoing study. Firstly, since spousal caregivers make up the majority of stroke caregivers (Hickenbottom et al., 2002) we wanted to confine the study to spousal caregivers and their patients. Secondly, we excluded patients or carers with a formal history of psychiatric or neurological illness. Specifically, we wanted to exclude those with a history of depression, so that where post-stroke emotional disturbance was recorded it was likely to be a direct consequence of stroke/caregiving, rather than the recurrence of a pre-existing illness. Thirdly, we took brief measures of emotionality in caregivers, as it has been shown that individuals scoring highly on this trait react more negatively to caring and are more



prone to develop depression (Hooker et al., 1998). Fourthly, in assessing caregivers, we chose specific 'caregiving scales' rather than non-specific mental health measures. Fifthly, patients underwent a cognitive screen assessing a wide range of cognitive domains. Pre-stroke cognitive level was estimated using information on the education and occupation of patients together with performance on psychometric measures such as the NART (Nelson, 1982) so that we could make valid inferences about the extent to which cognition might have changed post-stroke. All quantitative measures were also supplemented by the collection of qualitative data. The results reported here are from a small number of patients on whom we piloted the measures. Ethical approval was obtained in March, 2007.

## **Method**

**Design:** This exploratory study employed a mixed qualitative and quantitative methodology, observing patient and caregiver outcomes at two time points following stroke.

**Recruitment:** Consecutive first stroke patients and their spousal caregivers were recruited from the stroke unit of a large teaching hospital. All were discharged home within 14 days of their stroke.

**Participants:** This pilot study reports results from the first eight dyads (patient and cohabiting spouse). Of the patients, six were male and two female, with a mean age of 69.75 years. There were two male and six female caregivers, with a mean age of 67.38 years.

**Procedure:** Data collection took place in two phases. At time one (T1: in hospital prior to discharge) the emotional status of patients was assessed using the short-form Geriatric Depression Scale (GDS; Brink & Yesavage, 1982; Yesavage et al., 1983). The cognitive status of patients was assessed using the complete Cambridge Cognitive Examination (CAMCOG; Roth et al., 1988), and this was supplemented by the Immediate Memory (IM) subscale of the Repeatable Battery for

the Assessment of Neuropsychological Status (RBANS; Randolph, 1998). Physical functioning was assessed at the point of discharge using the physician administered Barthel Index (BI; Mahoney & Barthel, 1965; Collin et al., 1988).

At time two (T2: in patients' homes four to six weeks after discharge) the emotional status of patients was again assessed using the GDS. The Mini-Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975) was used as a brief marker of cognitive function, and the National Adult Reading Test (NART; Nelson, 1982) was administered to give an estimate of pre-morbid IQ. Patients also completed the Revised Illness Perceptions Questionnaire (IPQ-R; Moss-Morris et al., 2002) to explore quantitatively their understanding of stroke and its consequences.

Caregivers were also assessed at T2, with mood again being assessed using the GDS. Negative reactions to caregiving were measured by the Caregiving Distress Scale (CDS; Cousins et al., 2002) and positive reactions were measured by the Satisfaction and Mastery subscales of the Caregiver Appraisals Scale (CAS; Lawton et al., 1989). Emotionality in caregivers was measured using the neuroticism subscale of the NEO-Five Factor Inventory (NEO FF-I Costa & McCrae, 1992), the pre-stroke quality of the dyadic relationship between caregiver and patient was estimated by use of the Brief Dyadic Adjustment Scale (DAS; Spanier, 1976; Sharpley & Rogers, 1984), and caregivers also completed the IPQ-R. Qualitative data were also collected from patients and caregivers at this time, exploring feeling about stroke, discharge, and the caregiving experience. Thematic analysis was applied to the qualitative data to establish common and important themes in the lived experience of stroke for patients and caregivers.

## **Results**

All patients displayed only mild physical impairment with BI scores >85, indicating that all were independent in basic Activities

of Daily Living. However, we found that this quantitative measure did not capture all of the physical changes in our sample, with patients reporting that post-stroke fatigue left them restricted in day-to-day activities and limited their lifestyle. Qualitative reports showed that this was extremely frustrating for patients, and caregivers. Carers mentioned taking on responsibilities such as driving or housework that the patient could no longer manage as well as providing extensive emotional support to patients.

At T1 prior to discharge, one patient was found to have mildly depressed mood, whilst at T2 (four to six weeks later) this number had risen to four (see Table 1).

This suggests that some patients were displaying negative emotional reactions to changes in their lives post-stroke. Only one patient was mildly depressed in mood at T1 and T2. Furthermore qualitative data revealed that two patients felt that there had been changes in their temperament, being quicker to anger and having a 'short fuse', two more patients reported that they had become more emotional, displaying emotional responses such as crying 'inappropriately'. This was found distressing by patients and by caregivers, who felt that they were 'on the receiving end' of patients' unpredictable behaviour.

Quantitative assessment of cognitive status at T1 in patients revealed slight problems in a number of areas (see Table 2).

These results may be considered in light of the fact that all estimated pre-morbid IQs fell within the normal range and educational/occupational data did not suggest pre-stroke deficits in any patient.

Scores on the RBANS Immediate Memory scale suggested that three patients had newly acquired memory deficits, with the remaining five patients scoring within the normal range. MMSE scores showed that only two patients scored below the cut-off of 23/24 at time one but by time two all patients fell above the cut-off (see Table 2). The qualitative data showed however that patients and carers were aware of cognitive declines such as the CAMCOG and RBANS scores had indicated. Four dyads, reported memory and attention deficits to be distressing. One patient reported that:

*'... They see you and think "Oh, he's fine" because you can move and you can talk, but the mental side is worse ...'*

In the caregiver interviews, three caregivers had scores on the GDS suggested mildly depressed mood. Scores on the CDS reflected very low levels of distress/burden, whilst scores on the CAS suggested high levels of caregiver satisfaction and mastery.

In contrast to this positive picture, qualitative accounts revealed high levels of anxiety and frustration in caregivers, who were supporting patients as they adjusted to life after stroke. Whilst patients were still able to self-care to a large extent, caregivers

**Table 1: Individual Geriatric Depression Scale (GDS) scores for patients at Time 1 (T1) and Time 2 (T2).**

	P1	P2	P3	P4	P5	P6	P7	P8
T1 GDS (15-Item)	2	3	3	2	2	<b>5</b>	2	1
2 GDS (30-Item)	<b>5</b>	2	3	3	<b>6</b>	<b>8</b>	<b>6</b>	4

Note: Numbers appearing in bold indicate scores above the normal range (with scores of 5 to 8 indicating mildly depressed mood).

Table 2: Patient CAMCOG scores at Time 1(T1) and MMSE scores at T1 and Time 2 (T2).

		P1	P2	P3	P4	P5	P6	P7	P8
CAMCOG Total	(104)	<b>75</b>	82	89	86	90	94	84	83
Orientation	(10)	<b>8</b>	<b>9</b>	10	<b>8</b>	<b>9</b>	10	<b>9</b>	<b>8</b>
Language (Overall)	(30)	25	27	30	26	27	25	25	24
Language Comprehension	(9)	9	<b>8</b>	9	9	9	7	9	<b>7</b>
Language Expression	(21)	16	18	21	17	18	18	16	17
Memory Overall	(27)	<b>18</b>	<b>18</b>	26	21	20	25	<b>19</b>	24
Remote Memory	(6)	5	<b>3</b>	6	<b>3</b>	5	5	4	5
Recent Memory	(4)	4	4	4	4	4	4	4	4
New Learning	(17)	<b>9</b>	<b>11</b>	16	14	<b>11</b>	16	<b>11</b>	15
Attention & Calculation	(9)	6	5	9	8	7	8	9	7
Praxis	(12)	9	11	12	11	9	10	10	8
Abstract Thinking	(8)	<b>2</b>	4	6	4	8	8	6	5
Perception	(8)	7	8	8	8	8	8	<b>6</b>	7
Executive Functioning	(28)	<b>9</b>	<b>13</b>	17	<b>15</b>	21	24	12	<b>15</b>
MMSE T1	(30)	<b>23</b>	26	29	<b>23</b>	24	29	27	27
MMSE T2	(30)	30	25	29	26	28	28	28	24

Note:

Numbers appearing in parenthesis represent maximum attainable scores on each measure.

Numbers appearing in **bold** represent scores below the normal range and indicate problems in this area.

had taken on a great deal more responsibility in their day-to-day lives, for example, they no longer had patient help in tasks like shopping and housework and so sacrificed more of their own free time to these tasks. Where cognitive changes were noted, there was anxiety amongst the caregivers, who felt they had limited understanding of the changes. It was particularly difficult for caregivers where patients lacked insight into their problems. One caregiver reported:

*‘He forgets what he’s doing and wanders away [c]’*

In an attempt to cope, this caregiver engaged in active monitoring, fearing that her husband’s memory problems might lead him to endanger himself or others.

Interestingly, despite the practical and emotional support that they were providing, caregivers did not see themselves as ‘care-giving’ and did not respond to the label. The practical and emotional support they were providing was seen as an extension of an existing role, and caregivers insisted that their spouses did not need ‘care’.

Other themes emerging from the qualitative data were that ESD was seen as positive for both patients and caregivers (‘the sooner the better’), but in most cases dyads were left feeling isolated after discharge. In particular, patients and caregivers felt that they did not have sufficient information about stroke, its causes and consequences, and there were health-related anxieties in both patients and caregivers. Any stroke is a significant life event that is extremely likely to raise anxiety. What is not available to ESD patients however is the ‘comfort’ of having medical staff and hospital facilities around them as a reassurance in the early weeks after stroke.

## Discussion

Despite being discharged from hospital early ( $\leq 14$  days) and having only low levels of physical impairment, there were clear emotional and cognitive disturbances within our sample. This is itself a significant finding and underlines the need for psychological screening in *all* stroke patients regardless of physical status. We found that for both

patients and caregivers, reactions to stroke were defined by these emotional and cognitive consequences of stroke. However, post-stroke fatigue and emotionalism (factors not captured by our quantitative measures) were also important. Whilst our design attempted to address some of the methodological problems of research on the post-stroke experience it is clear that the consequences of stroke are highly complex, and existing models may be too simplistic. Qualitative approaches captured aspects of the post-stroke experience not revealed by the psychometric measures. This may, of course, be due to the choice of measures or to the lack of sensitivity of existing scales.

Both patients and caregivers viewed early discharge from hospital as a positive step, but they reported feeling unsupported and under-informed post-discharge. Clearly, caregivers did feel able to support patients after early discharge, but additional support and information would be helpful in reducing anxiety in the early stages. It was interesting to find that caregivers did not see themselves as filling a new role as 'caregiver' but saw the support that they were providing as an extension of their role as spouse. This may have accounted for some of the discrepancy between our quantitative and qualitative measures of caregiver reaction. It is possible too, that spouses did not see themselves as 'caregivers' because they construed 'caring' to be primarily about providing physical support, rather than emotional support. It is also possible, however, that assuming the

'caregiver role' is something that develops gradually and that assessing dyads so soon after stroke did not give them sufficient time to reflect on new roles. Discharging patients early may also accentuate a belief that any post-stroke changes are temporary, leading caregivers to believe their own role in providing additional support will be transient. Certainly, further research in this area will benefit from assessing stroke caregivers longitudinally to assess any changes in how they view their role.

The early quantitative and qualitative data reported here provides an insight into how even those seemingly little affected physically by stroke are marked psychologically by their experience. Recruitment for this study is ongoing and in time it is hoped that the quantitative data will allow a better understanding of the effect of cognitive and mood variables within the early discharge process besides making a contribution to the wider field of caregiving research.

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# All change: Needs and perceptions of service users involved in an older people's day hospital reconfiguration

Sarah Jeffrey & Steve Davies

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**D**UE TO RAPID service restructuring, the Dormer\* day hospital in Dormerton\* was combined with the Tysoe\* Day Hospital in Tybridge\*, and this amalgamation was relocated to the Tybridge\* Hospital site and staffed by members of the Dormer team. There was speculation that the two day hospital groups differed markedly in terms of their difficulties. This change in needs of the day hospital group was postulated to have serious implications for this team and their practice. A needs assessment was requested to help shape and guide the service to meet the needs of this client group. It was also felt that the transition period represented a valuable and timely opportunity to listen to client views about the day hospital. A focus group was therefore proposed.

## Research aim

The aim of this work was to ascertain the needs of the new day hospital group, both through the perceptions of staff and of clients themselves.

## Needs assessment method

A needs assessment tool, the Health of the Nation Outcome Scale 65+ (HoNOS 65+; Burns et al., 1999) was completed by day hospital staff for each of the clients on their caseload. After excluding those who had not been in attendance for three weeks either through recent referral or staged discharge, 46 clients had these measures completed, of which 12 were male (26 per cent) and 34 were female (74 per cent). The age of clients

ranged from 67 to 96 with a mean age of 79.1 years. Where a Mini-Mental State Examination (MMSE) or Geriatric Depression Scale (GDS) was available in the notes, these were reported.

## Needs assessment results

MMSE scores were available for 31 clients (67.4 per cent of the day hospital population) and ranged from 7 to 30 from a maximum of 30, with an average of 23.0. This data is demonstrated in Tables 1, 2 and 3. Whilst a general cut off score of 24 has been suggested to indicate dementia, supplementary age specific norms have been provided of 28 for those in their 60s and 70s, and 26 for those in their 80s (Bleecker et al., 1988).

Scores on the GDS15 were available for 29 clients (63.0 per cent of the day hospital population) ranging from 0 to 14 with a mean of 6.1. Cut off scores of 5 are considered indicative of significant clinical depression (Agrell & Dehlin, 1989).

HoNOS65+ scores were available for all 46 clients identified. A sum total on the HoNoS65+ was obtained for each individual client in order to assess individual level of need. Totals ranged from 4 to 33, with an average score of 14.6.

The average score per person on the HoNOS65+ was 14.6. This is higher than scores in research by Ashaye et al. (2003) which reported day hospital clients on admission (8.7) and at follow-up or discharge (7.5). These scores are also higher than means reported in another study by

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\*Pseudonyms have been used to protect the anonymity of clients, staff and the service.

Table 1: MMSE scores.

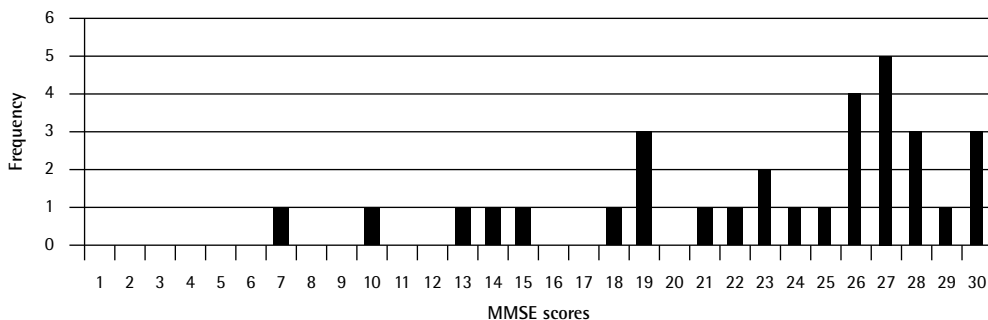


Table 2: Distribution of GDS scores.

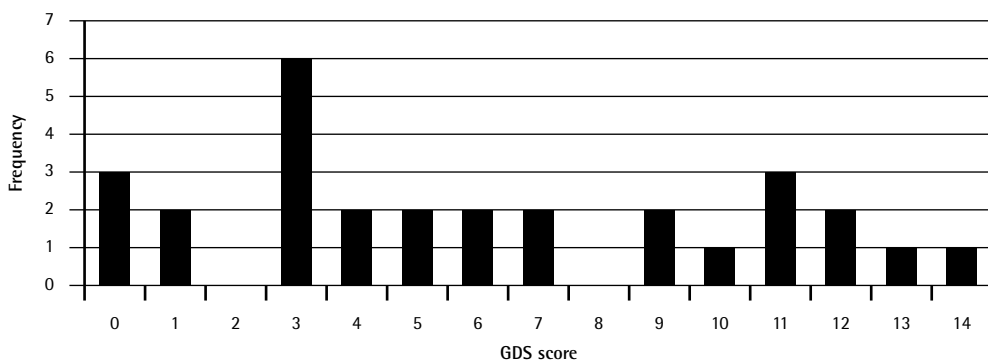
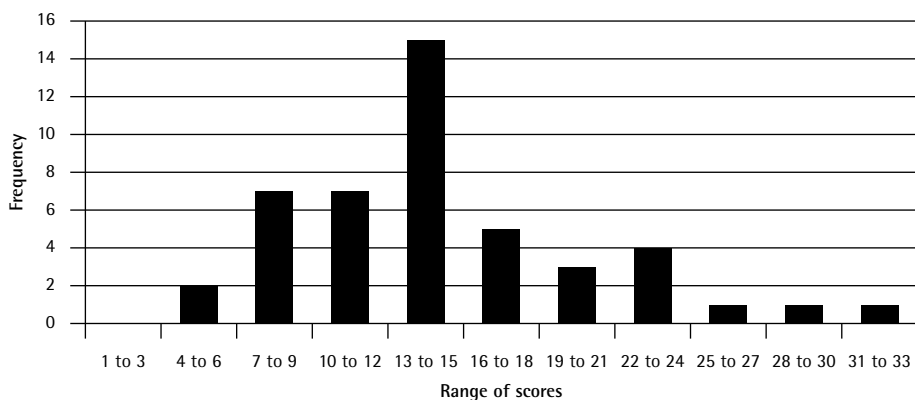


Table 3: Distribution of HoNoS total scores.



Shergill et al. (1999), including day patients (7.1), outpatients (9.2), and even inpatients (12). Our high mean is exceeded only by those in residential care (15.8). Available GDS scores indicate that there are a lot of people who aren't depressed, and may imply that the problems which bring people to the day hospital are varied. MMSE scores indicate a wide range in cognitive function.

### **Focus Groups method**

It was important to additionally consult with clients to discuss what they considered their needs to be and how these needs were being met by the day hospital. A focus group was run with a group of eight 'functional' clients and another with a group of seven 'organic' clients. In line with the principles of person-centred care (Kitwood, 1997), the perspective of clients with dementia was considered important and accessible as research indicates that cognitive impairment does not prevent the expression of a person's views on a variety of topics (Godlove Mozley et al., 1999).

### **Focus Group results**

Overall, the response from clients was that there were high levels of satisfaction. Benefits included being with and getting on with other people, especially those of a similar age, in that it combated the loneliness that the majority of the focus group members felt in the community. The qualities of staff and the variety of activities were highly praised. The respite provided for spouses ('giving my wife a break') and relatives also emerged as an important theme. Whilst discussed positively in terms of giving 'carers' more freedom, related to this was also a sense of feeling a burden to them. One other positive feature about the day hospital was having something to look forward to. Other comments offered in the group included the usefulness of not having to cook, 'feeling different compared to before', and the convenience of attending, including transport arrangements.

The dominant discourse was very positive but when probed for less positive aspects, one minor criticism was that the gender mix was skewed with the attendees being predominantly female, and this was discussed in terms of the potential problems it would generate for the male minority and the influence it had on the types of conversation held in the day hospital. When discussing care plans, care co-ordinators, and what professions they had access to, there was a great deal of confusion with only one or two members in each group having any understanding of what this meant. When probed for negative aspects, the contrast between the old and the current day hospital settings emerged as the strongest theme. The move to a hospital site brought with it a sense of institutionalisation and this had an impact on how they viewed themselves as 'patients', whereas previously they'd felt more like individuals. Other perhaps related issues included the distance Dorner clients had to come and getting used to the new arrangements, especially for Tysoe clients with whom the staff were also unfamiliar. There was a clear sense of loss for both groups.

People felt there were 'not enough conversations about the change'. Difficulties emerged from information, often conflicting, from a variety of sources. They talked about how rumours contributed to it being a confusing time. The lead-up to the move involved people being reviewed and 'turned away'. One group mentioned a meeting that was held a week prior to the move itself, although there was some confusion as to whether clients were invited to go. They understood this ended up as a 'slanging-match'. Most who attended, however, felt that this meeting was useful, but felt an earlier meeting would have cleared up confusion, but others felt their worries would have heightened. Three major themes of these groups were lack of information, consultation and choice, which they recognised was mirrored in the staff.



People talked about how all staff went to great lengths to make the transition as easy as possible. Clients were grateful for this. Tysoe clients talked about the difficulties of having only one member of clerical staff follow them across. They all 'admired the previous workers and the efforts and enthusiasm they put in', encouraging them to 'come here open-minded' and to support one another.

When asked what the most important points that they wanted to be emphasised from these talks, clients mentioned the positives of transport, staff, being treated as an individual, activities, the importance of being listened to and the focus group itself. The more controversial issues of food, convenience of location, facilities, the change from social club to hospital setting and associated 'institutionalisation' were emphasised as important things to feedback. The one message that did come across strongly was that overall people were very satisfied.

### Conclusion

Change is stressful for all concerned, particularly when due to financial imperatives rather than client focus or service-improvement. The first part demonstrates how these clients represent a group of people with a range of needs, in terms of type, number of domains and severity of needs. Although appropriate for a day hospital, their needs are more severe than others reported in the literature. Despite this, the second part demonstrates that they were able to talk openly and insightfully about their experiences at the day hospital currently, but also before and during the changes. Their responses indicate that certain steps could have made this transition easier for all involved. Importantly, they revealed their strengths and resilience in the face of change.

Hopefully this information gathered at this time of transition can be used to inform service reconfigurations in the future, and especially the need for consultation with

those whom it directly impacts, both clients and staff. This was one message that came across clearly about running the focus groups, in that it provided clients an appreciated opportunity to have their voices heard and their opinions valued after an uncertain period when they felt that they had been dictated to and their opinions disregarded. There is considerable evidence in this research of person-centred care being implemented at the front-line level in the form of praise for staff. However, there is a clear need for person-centred principles of care to be reflected in organisational level practice.

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# Developing a new service provision for challenging behaviour in older people's care settings

Louisa J. Shirley

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*At the Nottingham 2007 conference, members of the Newcastle and Northumberland County Challenging Behaviour Services presented a number of papers which described various aspects of the teams' research including a debate around the telling of lies to people with dementia, the impact of care staff's emotional reactions to episodes of challenging behaviour on their care giving behaviour, the use of psychotropic medication in dementia care and an overview of the development of the three challenging behaviour teams using the 'Colombo' approach. There was clear interest from the attendees regarding the process by which the teams were developed. As a result of this interest, a full-day workshop was held at the York 2008 PSIGE conference. This paper is a brief description of the development of the Northumberland County Challenging Behaviour Service. The service uses psychological models and is embedded in an Older People's Psychology Service.*

**I**N THE SPRING OF 2006, patients and staff at St George's Hospital in Northumberland moved to a new specially designed site. It was recognised that this created the opportunity to develop a new culture of care in the Northumberland older people's mental health service. The move consisted of two stages. 'Stage I' was the planning of the physical move between sites, and the redeployment of staff between old and new wards. 'Stage II' was the joint (purchaser-provider) strategic planning and decision-making around the reprovision of some services from hospital wards to community-based initiatives. The old hospital site had two wards with a Continuing Care function. Decreased up-take of continuing care beds, and the recognition that people's needs should be met in community settings, prompted discussions during the redevelopment about redeployment of funds. The two wards previously serving the continuing care function were amalgamated into one and the monies saved from the reduction in the number of beds was used to enhance community provision for the people who would previously have used those beds. That is, those with complex needs and challenging behaviours. The

development of a challenging behaviour service was funded through this bed closure, and was identified as an important element in the success of Stage II.

A number of different models were considered for a community challenging behaviour service. A multi disciplinary steering group consisting of psychiatry, nursing, occupational therapy, psychology and managers of community and in-patient services considered the options. The Newcastle Challenging Behaviour Service had been developed over a number of years and had demonstrated success in avoiding unnecessary moves and hospital admission of people who challenged (James & Stephenson, 2007). This service was embedded in the Psychology service, worked with psychological models, and was led by a Consultant Clinical Psychologist. It was agreed that the Northumberland County Challenging Behaviour Service would follow the same general principles and process of working that the Newcastle team used, with some local differences in service provision to meet the challenges of working across the large rural area covered by the Northumberland part of the Trust.

## **Geography and structures of Older People's Services**

Northumberland County has a population of approximately 54,000 people who could potentially access Older People's Services (Census, 2001). The County has approximately 90 residential and nursing homes. There are six Integrated Community Mental Health Teams corresponding with three rural and three urban localities. In-patient psychiatric provision in Northumberland is, in the main, on one central site. The hospital has two wards for patients whose problems are organic in origin, an assessment ward (24 beds), and a continuing care ward (24 beds). Both of these wards experience high levels of challenging behaviour.

### **The team**

A team was established based on the funds available and the structural and geographical needs of the locality teams. The team consisted of two Challenging Behaviour Clinicians (these roles were taken by nurse specialists), an Assistant Psychologist, and a Principal Psychologist. Clinical supervision and leadership was initially provided by the Consultant Psychologist from Newcastle who was seconded for four sessions a week to work with the NCCBS. Line management for the qualified members of the team was provided by the Head of Older People's Psychology in Northumberland, and the Principal Psychologist managed the work of the Assistant post. More recently, the team leadership and clinical supervision role has become the responsibility of the Principal Psychologist. A Consultant Psychiatrist is available on a regular basis for advice and acts as a liaison between the team and their psychiatry colleagues.

### **Preparing to launch the team**

Between July and November, the team members in post and the lead clinical psychologist began to develop the service. This included identifying and informing stakeholders, developing systems (for referrals, administration, record keeping, and so

on) and appointing the final two members of clinical staff. Between November and January, these systems were piloted by taking a small number of referrals from one locality. A number of stakeholder events were held, including visits to GP practice meetings and meetings with key members of hospital and community staff. Information sheets were sent to all residential and nursing care homes in Northumberland to explain the team's remit, process of working and the referral procedure. The team gained administrative support in November, 2006. The team 'went live' in January, 2007

The NCCBS operational policy was agreed by the steering group and distributed to key stakeholders in March, 2007

## **Model of Service Provision**

### **Core business of team**

The team provides four main functions – client work, training, consultancy, and research.

### **Client work**

The NCCBS takes referrals from multiple agencies through the Community Mental Health Teams from each locality. Each qualified member of the team has capacity to work with up to 12 cases. The Assistant Psychologist holds a case load of up to six clients.

Over a 12 to 14 week period, team members work with care home staff, the residents, and their family and friends to gather information about the person (their life experiences, mental health, physical health, cognitive impairment, environment, communication and so on) and specific information about the difficulties staff are experiencing (through the completion of behaviour charts). On completion of the assessment, the team member runs a number of 'formulation' sessions where they present all the information to groups of care staff in order to provide a context to the person's behaviour. During these sessions, staff and the NCCBS team member begin to

develop new strategies for working with the challenging behaviour. These strategies are written up and form the basis of new care plans. The NCCBS continues to monitor the success of the care plans for up to two months. The NCCBS was commissioned to work with challenging people across all settings (in their own homes, in hospital, in community-based residential/nursing care homes). However, it was agreed that the thrust of the service should initially be working into the private care sector as movement from home into care is often associated with challenging behaviour and many hospital admissions were the result of residential homes being unable to manage someone's challenging behaviour.

### **Teaching and training**

Members of the NCCBS develop and deliver training to a number of different groups. Short training sessions are usually incorporated into the formulation sessions delivered to care staff and are specific to the difficulties presented by the client. The team also contributes to the CPD of clinical psychologists, nurses, social workers and other professionals through workshops and short courses. Members of the team regularly teach clinical psychologists in doctoral training and medics at Teesside and Newcastle Universities.

### **Consultation and supervision**

Team members offer consultation and supervision to CMHT members. Team members are currently attending the six local Community Mental Health Teams' meetings on a regular basis to discuss possible referrals into the team and to feed back on work with clients previously referred by the team. Team members are often asked to provide one-off supervision and consultation with regards to specific cases.

### **Research**

The business of the team is largely the maintenance of clients in community settings through direct (resident) and indirect (staff-

based) work, and through the use of psychosocial interventions. However, there is still little in the way of an evidence base for psychosocial interventions in dementia. The NCCBS aims to contribute to this research base by undertaking practical work-based research.

Current research interests in the team include:

- Care staff's understanding of the impact of pain on challenging behaviour.
- The experience of staff, residents and visiting professionals of working with care home staff from abroad.
- Staff's emotional reactions to challenging behaviour and how it affects their provisions of care.
- Family carers' experience of contributing the work of NCCBS.
- Process factors in delivering effective formulation sessions.

### **Team principles and objectives**

An Operational Policy was developed and agreed in November, 2006. The team used the operational policy as an opportunity to set out the person-centred principles on which its model is based. The service objectives were intended to reflect these principles and to address the practicalities of using this type of model in the environment of care in Northumberland.

### **Service principles**

- All behaviour has meaning and purpose so people's behaviour, even when challenging, can be understood. This understanding often leads the way in identifying unmet needs and in developing care practice.
- People's challenging behaviour is best understood in the context of their current and previous experience, and can be seen as a communication of need.
- People whose behaviour challenges services have the right to receive 'treatment' in their current environment irrespective of whether they have received a diagnosis of dementia.

- People should not be admitted to hospital because of poor care.
- The service supports the use of appropriate medication, but, in line with current guidelines, medication should not be the initial treatment for challenging behaviour.

### **Service objectives**

The objectives of the Northumberland Challenging Behaviour Service have been defined as:

- To promote an holistic, person-centred assessment and formulation framework to NHS, local authority and private providers of older people's care.
- To assist care staff in residential and nursing care homes to understand why a person behaves the way they do when they challenge, and to aid staff to develop their own practice to work more effectively.
- To enhance, rather than supersede current provision by building on the skills and experience already present in locality older people's services.
- To collaborate with Community Teams and other colleagues in identifying and providing the most appropriate service to meet the needs being expressed by a person's challenging behaviour.
- To prevent inappropriate hospital admissions and to maintain people in their current environment wherever possible.
- To continuously monitor team practice.
- To contribute to the current knowledge of psychosocial interventions in the treatment of challenging behaviour through original research and dissemination of research findings.
- To act as a resource for training materials, videos, publications and so on to current services.

### **The process of working**

#### **Referrals**

The integrated Community Mental Health teams in Northumberland operate under a different trust to in-patient services and the NCCB and many of the professionals contributing to multidisciplinary CMHT meetings are employed by different trusts. Services are commissioned and developed through partnership agreements between the trusts. Despite these complexities, the teams have begun to operate a system of Single Point of Access, as advocated by Everybody's Business (2005). In theory, this means that all referrals to members of the wider CMHT are brought to regular team meetings, discussed and allocated by mutual agreement of their needs. While each of the 6 localities manages this process in slightly different ways, the NCCBS has been able to use this system successfully to agree appropriate referrals. Each qualified NCCBS worker liaises with two CMHT's, one urban and one rural. Team members usually attend the CMHT meetings of the localities with which they liaise on a fortnightly basis which provides an opportunity both to discuss cases currently held by the NCCBS and also to input into discussions regarding other cases and potential referrals. This process has been helpful in creating the Referral Criteria outlines in Figure 1. Referrals come to the NCCBS from a variety of sources including psychiatry, GP practices, Physical Disability and Illness (PDI) teams, the Review Team (who provide a long-term monitoring of the placements of people who have been successfully placed by the CMHT and PDI teams), and directly from members of the CMHT's.

#### **Supervision in team**

During the first year of its development, each member of the team received at least one hour's clinical supervision from the seconded Consultant Clinical Psychologist. The Assistant Psychologist and Clinical Psychology trainees on placement with the team were supervised by the Principal

Psychologist. In addition to this, the team met for at least two hours a week for peer supervision during which issues that had arisen with regards the team's development or process would be discussed. This was also the forum in which a number of the formulation sessions underwent a 'practice run'. The Consultant Psychiatrist often joined the team for some of this session which enabled the team members to have ready access to medical input. As the seconded Consultant Psychologist has withdrawn from the team, clinical supervision will become the remit of the Principal Psychologist.

### **Steering group**

The NCCBS has benefited from a steering group of multidisciplinary professionals who have an interest in the service. This group includes general managers of Older People's Services, NCCBS team members, psychiatry, psychology and a Community team leader (who is also a nurse). The group meets on a monthly basis and covers several standing items including the development of the team with a view to working into in-patient settings and into people's own homes. The representation of people from different professions and services allows for a good feedback loop between services and the attendance of the Divisional Manager for Older People's Services in the North ensures links between the purchasers and providers of the service.

### **Audit and evaluation**

The practical demonstration of a challenging behaviour team's success is the number of clients it maintains in their current settings. However, a number of different factors could contribute to the successful maintenance of a placement. The NCCBS uses the Neuropsychiatric Inventory and Care Giver Distress Scale as a pre- and post-intervention measure in an effort to identify the change that has been wrought by the team's intervention. This measure provides a score for the severity and frequency of 12 different challenging behav-

iours, and a score for the distress felt by staff caring for the person presenting the challenge (ref fro NPI-D). The Newcastle Challenging Behaviour Service has demonstrated its success through the use of this measure (ref Amy's paper).

The team keeps other data which has been helpful to feedback to commissioners in the form of an end-of-year report. This information includes records of the length of intervention, the daily activities of the team, and the outcome of the interventions. This data has also been helpful in looking at the profile of the referrals received by the team (for example, which CMHT initiated the referral and who made the original referral to the CMHT)

### **Reflection**

The NCCBS has been well supported by the Trust directorate to which it belongs. Funding issues were considered prior to the team's inception and the budget for the team has remained relatively intact and separate from other caches of money. As a consequence, as key people have left/withdrawn (the Assistant Psychologist and the Consultant Lead Clinician), the proposals made by steering group members regarding the reconfiguration of the team have been acceptable provided they remain within this defined budget. Consequently, the team now runs with two CB clinicians, a newly-created Lead Nurse role with a specific remit to work more closely with the wards, and an enhanced Principal Psychologist role.

Feedback from the CMHT's suggests that, although time intensive, regular attendance at CMHT meetings has increased the credibility of team members and has defined the NCCBS as an accessible service.

The Steering Group has proved invaluable in providing a forum in which ideas and visions can be shared. It provides a space in which to consider some of the systemic problems encountered by the team (how to work best with the wards, how to avoid admissions through closer working with psychiatry colleagues, etc.).

It has been impossible to measure the true impact of the NCCBS on the workload of colleagues, though, anecdotally, colleagues working into care settings have found it beneficial to be able to offer an alternative to antipsychotic medication.

The development of the NCCBS has been systematic and focussed, and has occurred with the support of other services. It is apparent that other organisations around the country are planning to increase their community provision for challenging older people and a number of different models of provision are emerging. We would be happy to share our experiences with other organisations. Further information is available from:

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# Why does doll therapy improve the well-being of some older adults with dementia?

Faye Fraser & Ian James

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**Background:** Several studies have examined the therapeutic use of dolls with people with dementia. These studies have been favourable, although caveats have been noted, resulting in the publication of guidelines. Despite positive findings, an understanding of 'why' the approach is effective for some residents has yet to be established.

**Aims:** The aim is to develop an understanding of why doll therapy improves the well-being of older adults with dementia, in order to direct appropriate, safe, and successful doll usage.

**Method:** Eight participants were interviewed twice using grounded theory qualitative methodology.

**Results:** A diagrammatic representation modelling the impact of the dolls was developed. The content of the model is illustrated via quotes from the participants.

**Conclusion:** The model indicated that the impact of the doll is complex, being influenced by systemic processes between the doll and the resident, as well as the wider networks within the home environment. The central category emerging from this research was that the doll met residents' individual psychological needs.

THE USE OF DOLLS in care settings is not new (Ehrenfeld & Bergman, 1995), but has only recently been studied in a systematic manner (James et al., 2005; Mackenzie et al., 2006a,b; Marsland et al., 2006; Ellingford et al., 2007). Investigations have involved the introduction of dolls and teddy bears into care homes following a standard format (Mackenzie et al., 2006b). Typically, staff are given information and guidelines on their use prior to their introduction (Mackenzie et al., 2007). The findings from these investigations have been favourable for both residents and staff (Mackenzie et al., 2006a,b; James et al., 2006). For example, following the introduction of dolls into two elderly mentally ill homes, the researchers found that 69 per cent of care staff reported improvement in residents' well-being. Specifically, they noted improvements in resident interaction with staff; interaction with other residents; level of activity; happiness/contentment; amenability to care interventions and agitation. As with many interventions, careful planning is needed to address practical aspects and problems that may arise with this approach (i.e. dolls being

mislaid, disputes over ownership, etc.). However, if such aspects are attended to, therapeutic benefits are attainable. The aim of the present study is investigate the reasons why such improvements are obtained in residential care settings.

## Method

### *Participants*

Eight participants from a range of professions and residential care homes were recruited (two psychologists, two qualified nurses, two unqualified care workers, one psychiatrist, one occupational therapist). All either had at least three months' experience of working into a care setting where dolls had been used therapeutically, or had worked with at least two older adults with dementia who had used dolls therapeutically for at least six months.

### *Procedure*

Each participant was interviewed on two occasions. In the initial stages of the first round of interviews, a semi-structured interview schedule was employed. The schedule design was based on core themes emerging

from relevant literature. Examples of 'cue' questions were: In your experience why have dolls been used for people with dementia? Who uses dolls: Are there any reasons why a resident might be more likely to use a doll? Are there any reasons why dolls might be successful for a resident? This approach was selected as it allowed for a central format to be employed during initial interviews. The format was also flexible and open to participants bringing new themes that may not have been anticipated by the researcher. Emerging themes influenced questions in subsequent interviews. Interviews lasted between 45 to 60 minutes. In the second round of interviews, feedback on the emerging model was sought.

Ethical approval was granted by Newcastle, North Tyneside and Northumberland Mental Health NHS Trust Research and Clinical Effectiveness Department.

### Data analysis

In using the method of Grounded Theory, data collection and data analysis occur in an alternating sequence, where analysis begins at the first interview and then feeds back directly into the process of the next interview. Thus it is the analysis that drives the data collection, and is an open and fluid process (Strauss & Corbin, 1998).

Transcripts were scrutinised and 'meaning units' were identified. Meaning units were made up of a statement, a sentence or a paragraph, that described a single phenomenon. These were then labelled according to the main concept being addressed and made up 'sub-categories', e.g. 'mood', 'behaviour' and 'physical health'. As the data collection and analysis continued these sub-categories were then grouped to form higher order categories (Glaser, 1978).

To ensure reliability, a second researcher (another final year trainee clinical psychologist) independently categorised a sample of 51 interview quotations (out of a total of 352 quotations). In this exercise, agreement on the main category was found for 37 quotations (72.5 per cent agreement on main category).

### Results

This section provides a model of the key themes grounded in participants' perspectives and/or further enriched through the integration of established theory base.

In line with Strauss and Corbin's (1990) recommendations, a central category has been highlighted, 'individual needs'. This category represents the main theme of the model (Figure 1), and one that specifically addresses the present research question. The remaining categories and subcategories illustrated in the model will, therefore, not be addressed here, although it is appropriate to stress that they are deemed to play a key role in the overall success of the doll therapy. It is also important to note that for the purpose of this research, the focus is limited to the residential care home setting.

#### *Central category: Individual needs*

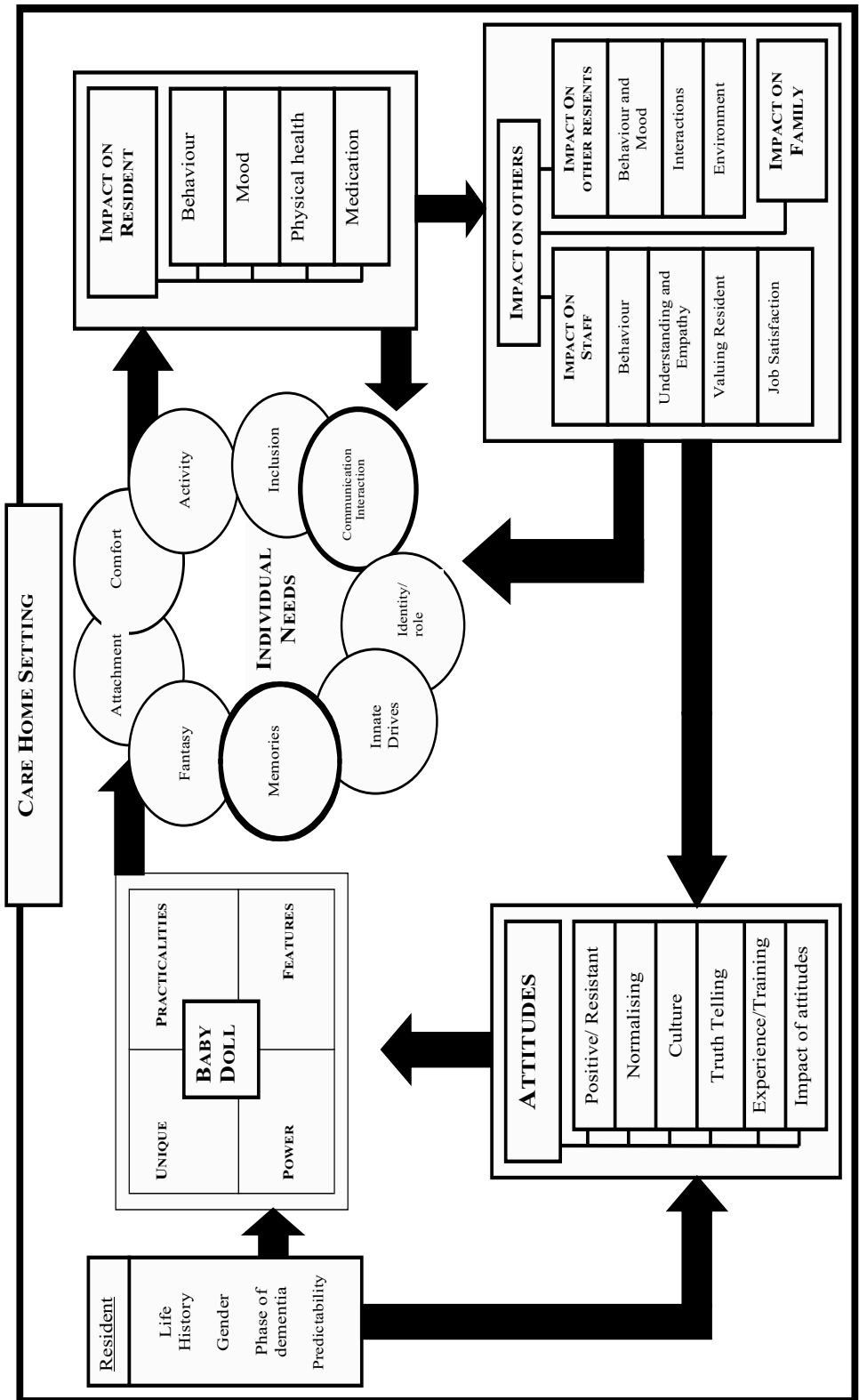
Ultimately, the use of the doll was perceived by participants as meeting residents' individual needs. The cluster of needs uncovered through this research included: attachment, comfort, inclusion, activity and role, communication and interaction, identity, innate drives, and fantasy. Each will be discussed in turn below.

**Attachment:** Participants suggested that when residents move into a care home, they often lose figures and/or objects of meaningful attachment, such as family members, and familiar and sentimental belongings. Participants described behaviours that they believed demonstrated a strong attachment.

*'We've got a few residents where they were attached to just one doll, and they'd recognise it maybe by their clothing... they know which one was theirs.'*  
(Participant 3, Line 40)

*'If a person thinks that doll is their baby and another adult comes to get your child, you're going to go mad. I know I would. I'd have gone really mad, because that's my baby. So again that's got to be quite careful intervention from staff to kind of limit any major kind of problems...'*  
(Participant 5, Line 210)

Figure 1: Model to represent care staff and Health Professional perceptions of doll therapy.



Due to the possibility of negative consequences of attachment behaviour, some participants believed it was important that staff developed creative problem solving strategies to ensure that the residents' health did not suffer as a consequence.

*'We had a lady that was putting the dolls into bed and not actually going into bed herself, because she was putting the dolls in. So we made a little make shift bed for her, for the dolls to go in...'*  
(Participant 2, Line 8)

**Comfort:** Most participants suggested that the doll was offering comfort to the resident through some sort of tactile/sensory stimulation. One participant also felt that the resident received comfort from gaining companionship with a figure which was constant, thus presenting familiarity, reassurance, and overcoming a sense of loneliness.

*'It's about loneliness as well. Even though they've got the doll and the doll doesn't talk back, it's still comforting. They sit nursing it and they're talking, and even though their favourite doll isn't talking back it's still company for them.'*  
(Participant 2, Line 52)

**Activity:** Dolls offer opportunities for simple activity, bringing purpose to residents' day-to-day life, such as care taking activities (nursing, feeding and putting the doll to bed), singing to the doll, and acting out past roles.

*'We've had a lady that never ever used to speak, we put the doll on the chair; we never ever give them directly to any of the residents, she picked it up and she started singing lullabies to the doll.'*  
(Participant 2, Line 19)

Furthermore, due to the progressive cognitive decline experienced in dementia, many participants noted that residents often find it difficult to engage and achieve in many of the activities offered in residential care homes. In contrast the dolls provided a way of gaining a sense of accomplishment.

*'... caring for a child is so very natural, and it's so successful that it gives them that [sense of] '... I've done that okay'... it's not so much memories but the feelings that you've achieved at something and that you feel successful.'*  
(Participant 5, Line 188)

Participants believed that a sense of achievement and enjoyment gained in interaction with the doll could be instrumental in raising a resident's self-esteem.

*'This probably increases self-esteem because if this baby is looking back into your eyes, and they're wrapped up nice and warm in the blanket, and there doing a really good job of looking after it because it's not crying, and its nice and happy, then that is going to give a bit of a boost.'*  
(Participant 6, Line 80)

**Inclusion:** Participant talked about how the doll created opportunities for residents to gain a sense of inclusion. For example, one participant described a situation where a group of residents developed a daily group activity with the dolls.

*'We were finding that between two o'clock and half-past three, this little clique of about four ladies would get hold of their dolls, take them to the dining room where it was lovely and quiet. It was like a mother and toddler group ... they were just sitting talking and doing things with the doll, and bouncing them on their knees.'*  
(Participant 3, Line 243)

**Communication and Interaction:** All participants discussed how the doll has contributed to changes in levels of communication and interaction between the resident and others (staff, other residents, and family members). Some participants felt that as professionals and care staff, we often lack the skills or confidence to communicate effectively with dementia sufferers.

*'I personally don't think that I understand fully how to communicate with cognitively impaired dementia sufferers. We all think that there is*

*nothing behind the façade. Yet our patients sometimes surprise us when completely secret life experiences are revealed, and we are astounded.'*

(Participant 8, Line 43)

Participants suggested that one way in which the dolls allows this barrier to be overcome is by providing a basis for conversation that the resident is able to be involved in, thus providing a common ground between resident and others.

*'So the staff can engage in that conversation, so they don't have to think 'what do I say to someone with dementia', or 'how did I respond to someone who keeps on repeating the same thing'. Once someone has a doll there's a natural cultural conversation going on, so that's the level of engagement.'*

(Participant 4, Line 63)

Participants also described how the doll changed the nature of interactions between resident and staff, from being task orientated to quality care orientated. This point highlights the importance of communication through touch, proximity and eye contact, as opposed to relying on verbal communication with which these residents often struggle.

*'At moment the only sort of touch they'll get between a resident and staff is when someone is being taken to the toilet or being helped to the dinning room. But the fact that people are passing things between each other means you'll get much more contact. You often see staff members going and sitting very close to someone to collect the baby, so that proximity, there's not that distance ... There's better eye contact as well ... I think eye contact is important.'*

(Participant 4, Line 308)

An important point linked to the latter feature emphasised that when considering the success of doll therapy, it is vital to recognise the centrality of the resident-other interactions.

*'I think that another reason why a doll works is that ongoing staff contact and the involvement of the other person and that doll. If you put someone in a room with a doll and they have no social contact and no activity, then the doll wouldn't work, and the person would become depressed.'*

(Participant 6, Line 192)

**Identity/Role:** It was suggested that the dolls cued past memories and the feelings associated with them, providing a sense of continuity with the past. For example, one participant recalled how a resident told her directly that the doll reminded her of being a mother.

*'(resident says) it makes me feel like a mother years ago.'*

(Participant 7, Line 40)

By facilitating the recall of these memories, participants believed that residents were enabled to educate staff and others about their personal history, and their identity, helping the staff to begin to see the person behind the patient.

*'She became a person.'*

(Participant 5, Line 367)

**Innate drives:** Participants described 'instinct-like' behaviours in relation to the dolls. These behaviours were usually discussed in terms of gender differences.

*'For women it might have something to do with the fact that childbearing is really innate. Even if they haven't had a child, this is fulfilling a really strong drive for them.'*

(Participant 6, Line 21)

It was also suggested that as humans, we have an innate wish to engage in social contact.

*'One of the important things about us human beings is the fact that we're very social, and nurturing and holding and physical contact are very important.'*

(Participant 4, Line 120)

**Fantasy:** One participant suggested that the doll may allow a distinct opportunity for resident to engage in fantasy, where they can play out roles, or revert back to earlier times in their lives. She described how each of us in our everyday life may have many opportunities to play out fantasies in our jobs, relationships, and in our own minds. However, residents, especially with dementia have few opportunities to facilitate this process in an adaptive way. The doll may fill this gap.

*'Looking after doll is like playing a game, it requires fantasy.'*  
(Participant 8, Line 138)

**Memories:** It was thought that the dolls played a role in evoking memories. It was suggested that these memories may not necessarily be cognitive in nature, but may also include memories of movements and emotions.

*'... We loose declarative memory, such as thoughts and words, but procedural memory is maintained so what you've got are these very over-learned memories about Kinaesthetic or feelings memories. So the child or the little baby [doll] fits very well into the arm, it feels smooth, and some might be weighted so it does feel in some ways and does connect with previous memories. Whether that's a memory of a child or a childhood memory of having a doll when they were younger, it feels like it's natural, the movements are natural.'*  
(Participant 4, Line 128)

Participants felt that recollection of these memories are beneficial as they may relate to periods of happy times and offer a sense of satisfaction and enjoyment.

*'One lady remembers having a pink doll, or a rag doll. Their Mam's used to crochet things and make dolls for them. They talk about things like that so it shows you their going back and remembering happy times.'*  
(Participant 2, Line 60)

Tapping into past memories of roles was also felt to be beneficial in relieving distress for residents who believe they are at an earlier time in their life.

*'A woman who was very agitated, constantly all day long, she would try to get out of the home, banging on the door, trying to get out of the windows ... She was desperate to get out to go home to look after this child. Once we introduced the dolls, the doll became that child that she wanted to look after, and she very much thought that this was a baby ...'*  
(Participant 1, Line 162).

## Discussion

Figure 1 demonstrates that the impact of the doll is grounded in complex interactions between the resident and the doll, and the resident and the wider systemic processes. To discuss the entire model proposed here would be beyond the scope of this short paper. Instead, the central category of 'individual needs' will be the focus. The individual needs described in this central category appear throughout the literature on dementia care (Kitwood, 1997) and non-pharmacological interventions in dementia. In relation to the present work, the individual needs were attachment, comfort, activity, inclusion, communication/interaction, identity, innate drives, memory and fantasy. Each 'need' will be discussed in terms of the literature.

In relation to attachment (Bowlby, 1979), Kitwood (1997) proposes that there is every reason to suppose that the need for attachment remains when a person has dementia. For many people, the process of dementia is characterised by experiences of loss, separation from attachment figures and feelings of insecurity, each of which closely reflects the central themes of attachment theory (Browne et al., 2005). Furthermore, Miesen (1992) suggests that people with dementia are continually finding themselves in situations that they experience as 'strange', and that this powerfully activates the attachment need. In the current context, it is argued

that the doll acts as an attachment figure (i.e. an object the person owns, identifies with, and feels responsible for).

Similar issues relate to the notion of 'comfort', which carries meanings of tenderness, closeness, security, soothing of sorrow, calming of anxiety, which come from being close to another (Kitwood, 1997). Dolls may be effective here in two ways. Firstly, they can provide direct closeness of contact. For example, many participants described the residents cuddling and kissing the doll throughout the day, and taking them to bed at night. Secondly, the doll promotes interactions from others. Indeed, staff were observed to sit closer to residents and engage in meaningful touch (e.g. dressing or examining the doll together). Hence, the dolls also promote a sense of 'inclusion', whereby the person with dementia appear to feel part of a meaningful social exchange, with the doll being the catalyst of the interaction.

In relation to 'activity', McKee et al. (2005) suggest that those who remain active have better self-images, social interactions, and satisfaction with life (Barrow, 1992). In a review of the literature, Nolan et al. (1995) described the emergence of a depressing picture in which activity within care home environments for elderly patients is extremely limited, with staff-patient interaction being minimal. It is evident from this study that doll therapy is a vehicle for providing meaningful and achievable activities.

Theoretical and research evidence highlights the difficulties often experienced by care staff in trying to achieve a balance between task-focused and psychological care. Rundqvist (1999) suggest that problems in care-giving may be due to poor communication as well as a lack of understanding of patient's wishes and attempts at communication. The data collected through this investigation suggests that one of the main strengths of the doll is that it facilitates this process of communication and interaction. The doll was described as offering a focus of conversation, and a common ground between staff and resident.

Kitwood (1997) suggests that 'identity' is the grounding for person-centred care. This research proposes that the doll promotes the development of identity by evoking past memories of roles, as well as offering the opportunity to act out roles with the doll (e.g. taking a mothering role).

Meaningful activity with the doll is also thought to tap into the issue of fantasy. The roots of occupation and activity are said to lie in infancy (Kitwood, 1997) and may simply consist of play and fantasy (Erikson's, 1977). Thus doll therapy may offer the opportunity to deal with ongoing inner psychological distress in a more adaptive way, and one that is conducive to the care home environment.

### **Clinical implications**

These findings suggest a number of implication for clinical practice. Firstly, the model suggests that providing staff with guidelines on the use of dolls would be beneficial. Such guidelines exist (Mackenzie et al., 2007) informed by the early work undertaken in this project. Secondly, the present findings suggest that the use of the doll should be based on each individual resident's needs, and be guided by the resident. Thirdly, staff and family members should receive training to increase their understanding and awareness of doll use to ensure that guidelines are valued and adhered to. Finally, it is evident that the dolls should be considered as part of a care plan, in conjunction with other interventions.

### **Limitations and future work**

There were a number of limitations in the present study. Firstly, the number of participants interviewed was small. However, no new categories were found during the seventh and eighth interview, suggesting that data saturation was achieved. Secondly, this researcher acknowledges a number of potential biases with respect to the participants. For example, it could be suggested that some of the 'Newcastle' clinicians, having published in the area, were committed to the therapy and may have been overly positive.

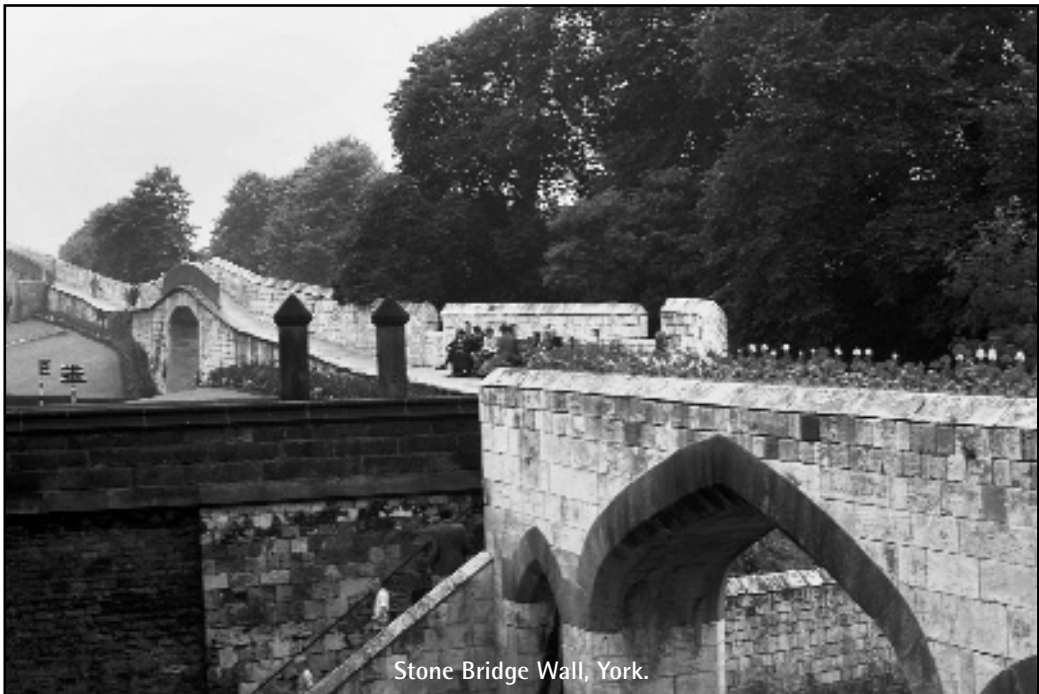
A third issue relates to the question posed in the study – ‘Why does doll therapy improve the well-being of some older adults with dementia?’ The use of the term ‘improve’ may have led to an overly positive data set being generated. Fourthly, this research was carried out with the intention of investigating staff perceptions of doll use within the care home environment. Thus, the findings of this study are limited to this setting.

Knowledge of this area remains in its infancy, suggesting that there is vast scope for future research. Figure 1 shows that many features interact in determining the impact of the approach. Unfortunately, only a few of the aspects could be discussed in this paper, but subsequent papers from this body of data intend to examine other areas of the model of doll usage.

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# Working with people with dementia to develop technology: The CIRCA and Living in the Moment projects

Arlene Astell, Norman Alm, Gary Gowans, Maggie Ellis, Richard Dye, Jim Campbell (deceased) & Phil Vaughan

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*The potential for technology to play a role in the care of people with dementia is increasingly being recognised. This paper describes two projects carried out by a multidisciplinary research team to develop technology to address the psychosocial needs of people with dementia. In the CIRCA project we developed an interactive multimedia computer system usable by people with dementia to support them in shared social activity with caregivers. In the Living in the Moment project we have been working with people with dementia to develop engaging and enjoyable activities for them to carry out independently on the computer.*

## The team

**T**HE TEAM originally formed in Autumn, 2001, and comprised Arlene Astell and Maggie Ellis from the School of Psychology, University of St. Andrews, Norman Alm and Richard Dye from Applied Computing, University of Dundee, and Gary Gowans and Jim Campbell from Graphic Design, Duncan of Jordanstone College of Art and Design. CIRCA was funded for three years by the EPSRC as part of the Extending QUALity Life (EQUAL) research programme. Living in the Moment was also funded by the EPSRC when CIRCA ended and commenced with the same team. Unfortunately Jim died during the first year of LIM and Phil Vaughan who joined us with 10 years' experience in the computer games industry took his place on the team. Alzheimer Scotland and Dundee Social Work department have been our partners in both of these projects.

## CIRCA

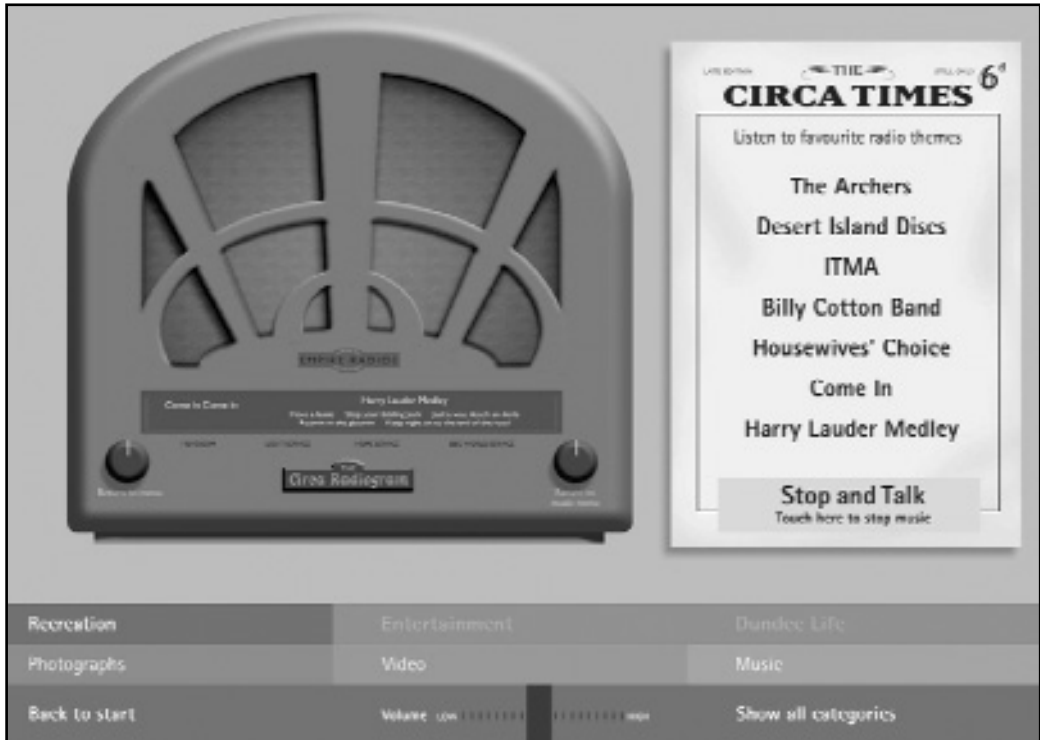
The aim of the Computer Interactive Reminiscence and Communication AID (CIRCA) project was to develop a multimedia computer system to encourage interactions between a person with dementia and a caregiver. CIRCA was developed to take account of and respond to the profiles of spared and impaired cognitive processes of people with

dementia (Astell et al., 2004). Specifically, CIRCA was designed to tackle the working memory problems that are prevalent in dementia and provide a way for people to take advantage of their typically well-preserved long-term memories (Alm et al., 2004).

CIRCA contains a database of video clips, music, songs and photographs, which people with dementia and a caregiver can explore together. Users are offered a choice of three categories (e.g. entertainment, sport and recreation) via a touch screen and select between media (music, photographs, video) within that category (Figure 1). The system takes advantage of hypermedia, which allows users to move between text, sound and graphics at will. There is no 'right place' to be in the system (McKerlie & Preece, 1992), which is ideal for people with working memory problems, as they can enjoy the current stimuli, without having to remember what they were previously talking about.

The CIRCA interface was developed to be as simple as possible whilst appearing attractive and encouraging interaction. To address the problem that people with dementia have coping with multiple sources of information, the interface was designed so that the background and navigation features are in muted colours. In most cases only one

Figure 1: Music selection interface in CIRCA: 'recreation' theme.



item of interest is shown at a time. In this way, even a black-and-white photograph stands out clearly as the point at which the user's attention should be directed (Figure 2). In order to keep the navigation process as simple as possible only three themes are presented at any one time. Each theme is associated with a different colour scheme. When a theme is selected the background colour and colour of all the buttons are changed to reflect the selected theme.

In comparison with traditional reminiscence activities run as one-to-one sessions, CIRCA provides a focus for the person with dementia and caregiver, facilitating a shared activity. The system is a novelty to both parties and they explore it together, neither having any advantage in knowing what will happen. This has the effect of restoring people with dementia to equal partners in the interaction. Indeed, they use the touch screen to make choices and often lead the interaction (Astell, et al., 2007).

In post-session interviews caregivers revealed that they found one-to-one traditional reminiscence sessions a burden and difficult to sustain. They controlled these sessions by asking lots of questions to which the people with dementia passively responded. By contrast people with dementia enjoyed using the CIRCA system and made suggestions as to what else they would like to see in it. Caregivers also enjoyed the CIRCA sessions, particularly the ease with which people with dementia were able to use the system and the reminiscences that were sparked off (Astell, et al., 2007). Caregivers felt that they learnt more about the person with dementia and saw them in a new light. This has obvious potential benefits for the future of their relationships, which should in turn impact on the quality of life of people with dementia.

CIRCA encourages mutual respect between people with dementia and caregivers by facilitating an enjoyable shared

Figure 2: Photograph selection interface in CIRCA: 'Dundee Life' theme.



experience. Both parties interact as equal human beings and the technology provides a way round the working memory difficulties that normally make holding conversations difficult for people with dementia. As such, CIRCA provides people with dementia with an opportunity for success and mastery, which is rare in the dementia care environment (Astell et al., 2007). In addition, CIRCA challenges the often low expectations on the part of caregivers about what people with dementia are capable of.

### Living in the Moment

Living in the Moment emerged from our work developing CIRCA. Specifically we wished to explore the potential of technology to provide satisfying pastimes for people with dementia. Our intention was to develop a system that people with dementia could use on their own, giving them opportunities for autonomy and control.

Computer games encourage mastery and achievement (Gee, 2005) and can provide a 'Flow' experience (Csikszentmihalyi, 1996). This refers to 'immersion in an activity for its own sake with the result that one feels a sense of satisfaction and loses track of time' (Csikszentmihalyi, 1996).

Csikszentmihalyi's (1996) theory of Flow has eight dimensions including: clear goals and immediate feedback; sense of potential control; equilibrium between level of challenge and level of skill; and participation in a self-rewarding experience. 'In order to maintain a person's Flow experience, the activity needs to reach a balance between the challenges of the activity, and the abilities of the participant ... If the challenge is higher than the ability, the activity becomes overwhelming and generates anxiety. If the challenge is lower than the ability, it provokes boredom' (Csikszentmihalyi, 1990). The aim of LIM was to develop

**Figure 3. Virtual botanic garden.**



computer games responsive and appropriate to the needs of people with dementia to enable them to experience flow.

Our initial exploration involved navigating around a 3-D environment. We developed three virtual environments including a botanic garden (Figure 3). Five people with dementia explored the environments on a touch screen (Astell et al., 2006). All participants spontaneously commented about the experience both when using it and afterwards. It was apparent that the botanic garden was the most popular environment. The people with dementia commented on the contents, for example 'lovely garden', 'beautiful flowers', and 'looks like a good pint' (in the pub VR environment). One person went further in relating to the experience with the comment 'I'll sit here (bench in garden) for a while'. Another person commented on the totality of the experience, saying 'the music is in time with it all'

(in the VR botanic garden). A final group of comments reflected the users' reactions to the experience including 'amazing', 'wonderful', 'clever', and 'interesting'.

This initial exploration yielded promising reactions with regard to the engaging properties of the stimuli. People with a diagnosis of dementia were able to imagine themselves in the environments, for example sitting on a bench in the botanic garden or having a pint of beer in the pub environment. Useful comments were also made about the ease with which one could navigate around the environments. These included comments about the size of the arrows and on screen prompts for where to touch. This was important for further developing LIM for people with dementia to use on their own.

We then went on to explore different ways for people to interact with the computer, including video and photograph

Figure 4. Painting a vase.



viewers. However, the bulk of development involved individual games that we took out to a number of our partner day centres for people with dementia to try. One such game is painting a vase (Figure 4), which we piloted as an activity for people to try on their own.

Eighteen people with dementia tried the painting activity, 11 of them in a room by themselves. None of them were computer users and they spent an average of five-and-a-half minutes 'painting' the vase. Each person was interviewed afterwards using a simple questionnaire to establish what they liked and didn't like about the activity and their experience of interacting with the touch screen. This revealed that the majority of people (16/18) enjoyed using the touch screen and found it easy to use. The majority (14/18) enjoyed the painting activity and would like to use it again. Among things people didn't like was 'doing the same thing

all the time' and 'worry about not doing it right'. Among the features they liked was 'pressing buttons and making patterns' and 'you just touch it and the colours come up'.

These findings suggest that people with dementia can adapt very easily to using a touch screen computer designed to be responsive to their needs. Activities based on computer gaming principles can be developed to provide enjoyable and rewarding activities for people with dementia. Activities need to present a level of challenge to keep people with dementia engaged and prevent them from becoming bored. In addition the instructions need to be clear and intuitive to support people to use the system on their own.

### Conclusions

The CIRCA project highlighted the potential for using technology to extend the retained abilities of people with dementia while minimising their impairments. One of

the major benefits of this approach is the positive impact it has on caregivers in challenging their expectations about people with dementia and supporting them to engage in positive social interactions. Living in the Moment has extended our knowledge about how to enable and support people with dementia to use a touch screen computer independently. People with dementia can enjoy immersive and engaging computer games and experience Flow.

People with dementia participated in CIRCA in dyads with a family or professional caregiver. The touch screen system enabled people with dementia to participate in positive interactions as equal partners. In Living in the Moment, people with dementia participated as partners in the research, providing feedback and suggestions on all of the activities at each stage of the project.

### Acknowledgements

The CIRCA project was funded by the EPSRC through the EQUAL (Extending Quality Life) programme through grant number GR/R27020/01 to the first author and Grant number GR/R27020/01 to the third and fifth Authors. Living in the Moment was funded by the EPSRC through grant number GR/T09279/01 to the first author and Grant number GR/T09262/01 to the third and fifth Authors. We are indebted to all of the people with dementia who gave up their time to make this research possible. We also extend our thanks to the family caregivers and staff in our partner organisations that assisted us at all stages of the two projects.

### Correspondence

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# Bursary Reports of the PSIGE Annual Conference 2008

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## **Views from a first-timer**

When I look back at my first experience of a PSIGE conference I realise I arrived with high expectations. I had attended a PSIGE workshop previously and had enjoyed the process of learning formally through the workshop and informally through interesting conversations over lunch and coffee. I was looking forward to the opportunity to hear clinicians speaking about research, practice and organisational issues, and to discuss ideas. Perhaps I had set the bar quite high but I think the conference more than met my expectations.

The programme was packed and my inability to be in two places at the same time presented lots of dilemmas. I moved between glimpses of older Asian women's mental health from the perspective of Community Development Workers, to discussion prompted by a poster about eating disorders in older adults and our tendency to devote relatively little research and discussion time to mental health problems other than anxiety and depression. Within 15 minutes I found myself somewhere else again.

Particularly thought-provoking was a debate introduced by Mike Bird (for the use of a range of psychological models to address the complexity of older adult cases) and Ken Laidlaw (for the use of CBT as the framework for managing complex cases).

Metaphorical pies were thrown and plenty of laughs generated but as a final year trainee I felt that the discussion that followed was very pertinent to my process of considering my own identity as a clinical psychologist and the identity of our profession. Does the simplicity of the CBT model bring clarity in the face of the complexity of older adult cases? What about the role of clinical psychologists as specialists drawing on a range of theoretical models (including but not exclusively CBT) to meet the clients needs? How many techniques and theories from other models can be collected under the CBT umbrella ... and at what point does the umbrella extend so much that it becomes simply a generic clinical psychology umbrella?

By the end of the conference I felt swamped and a bit disorientated by the quantity of information that had come my way in such a short space of time but also felt really glad to have had the opportunity to attend. The experienced opened up new areas of older adult's psychology for me and gave me lots of interesting material to think about in the future.

## **Astri Ablitt**

*Trainee Clinical Psychologist,  
Coventry and Warwickshire Universities  
Doctoral Training Programme.*



### **A highly-praised conference**

This was the first year I have had the opportunity to attend the highly-praised PSIGE conference, and am pleased to say it lived up to my expectations.

Initially, I was immediately struck by the diversity of the workshops and presentations. As a PSIGE conference novice, deciding which workshops and presentations to attend was perhaps the biggest stress of all!

The three-day event began for me with attending Judy Zarit's presentation on *Recognising and treating anxiety disorders in the elderly*. The workshop was well attended and the presentation was both edifying and entertaining throughout. It was particularly interesting to discuss the cultural differences in practice within the UK and America. Judy's anecdotal experience of working in this field demonstrated her vast knowledge and passion for her work. It kicked off the conference to a positive start for me and immediately captured my interest.

The conference continued in this high standard throughout. On reflection, I am impressed by the vast amount of information I received in a short space of time. The pure fact that I was able to listen and partake in discussions around the 'positive psychology of ageing' at the beginning of the day and end the day with thoughts of 'challenging behaviour in dementia' is a credit to the range and calibre of the presentations.

An area of research of personal interest is that of cross cultural research. It was for this reason I felt compelled to attend Ken Laidlaw's presentation on his work around filial piety and attitudes towards ageing. This was a perfect example of the creativity and originality of research that is going on in this field everyday.

The controversial findings of Ian James' presentation around doll therapy in nursing homes, was also compelling and thought provoking. In a society that is rigid around what is socially appropriate and what is deemed as 'person-centred care', a therapy that is quickly judged to be infantile has found such positive results in building relationships between staff and patients, that it raised intriguing questions as to how many other areas could be explored in this manner. It challenged my own thoughts around the therapy and how, on reflection, I too may have pre-judged a pertinent therapy.

Perhaps one of the most personally exciting moments for me was the networking aspect of the conference. As someone who is yet embarking on my career in clinical psychology, it was truly special to meet and hear from names I had added to reference lists, and find them to be humble, hard working individuals with a passion for their work, which was inspiring.

My experience of working with older adults to date has been both varied and exciting, and the PSIGE conference encapsulated that. The conference is an excellent example of the quality of work in this field and is a must for anyone who has the opportunity to attend, whether they are novices or veterans within the field of psychology.

#### **Manreesh Bains**

*Assistant Psychologist,  
Clinical Psychology,  
Northern General Hospital,  
Herries Road,  
Sheffield, S5 7AU.*

### **An excited newcomer**

As a newly-appointed assistant psychologist, with just eight week's experience of working with older adults under my belt, I curiously and excitedly began my PSIGE initiation with the 2008 conference in York. Judith Zarit's workshop, *Quiet desperation: Recognising and treating anxiety disorders in the elderly*, was an excellent introduction to the conference, and gave me ideas for developing my own work with anxious older adults in both individual and group settings. In the afternoon I attended *Developing care pathways for people with depression* led by Don Brechin, Nicky Bradbury and Sarah Dexter-Smith. This was a more interactive workshop; after an initial presentation of the care pathways model, we formed into groups and engaged in a lively discussion of issues that secured in my mind the importance of a separate older adults pathway. This topic became a theme of the conference with the issue of when mental health services require specialist older adult teams or care pathways, and what this might mean for the future of clinical psychology. Overall, the first day had been lively, interesting and engaging and was a taste of what was to come in the following two days.

On day two I made a naïve attempt to flit from room to room in order to get a flavour of the numerous different strands of seminars. I spent as much time looking for the right room, trying to get a easy-exit seat, and watching the clock as I did listening to the wealth of experience on offer. Yet despite this I seemed to come away with so many new opinions, new insights, and a great enthusiasm for my job and future career.

There are numerous things that I will take with me from this experience. I cannot list them all but those that have stuck in my mind include Polly Kaiser's enthusiasm for life story work (something I hope to start with clients on my ward), insights into the developing world of IAPT, the importance of the specialist skills and knowledge of psychologists working with older adults, and that PSIGE conferences are brilliant fun!

### **Helen Crispus Jones**

*Assistant Psychologist,  
Cambridgeshire and Peterborough  
NHS Foundation Trust.*

### **Reflections on presenting a poster**

I am a 'flexible trainee' on the University of Edinburgh/NHS Scotland D.Clin.Psychol. course. This means that I work two-and-a-half days in an older adult department and complete the training placements and teaching in the other half of the week. Training, therefore, takes place over five years and this model of training allows for further development of working in this specialty. Being part of a department for longer than six months, as is typical during training, has allowed me follow up the small-scale research project which I completed a part of my older adults placement, 'Cognitive screening assessments. Is there a training need?' It was this which I chose to present as a poster at the PSIGE conference.

During training we often move onto a new placement shortly after completing our small scale research project and therefore do not have the opportunity to follow through the recommendations made. Being a flexible trainee has given me the chance to implement these, much as a qualified member of the department would. It can be easy to get caught up in clinical work and presenting this research at the PSIGE conference prompted me to follow through the recommendations made.

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Poster presentations are not something we do as part of our training. It has been useful to gain experience of preparing a poster, learning practical things such as how to lay it out and get it printed.

Presenting at the PSIGE conference gave me the opportunity to discuss my research with other psychologists working with older adults. It was great to hear other's ideas and talk about similar work that had taken place in other departments.

It also meant I got one day free at the conference – a big bonus as a trainee!

#### **Anna Everatt**

*Trainee Clinical Psychologist,  
University of Edinburgh.*

### **Divine inspiration**

This year's PSIGE conference was held at the University of York. Navigating the University site from accommodation (merely finding it) to actual conference was much like navigating a David Lynch film. Aesthetic beauty, amazing direction, seeing the same person twice as you discovered you were walking in a circle (again) but ultimately going, nor arriving anywhere ... or did we?

Once the conference was found – well, there the Lynchian themes end.

I thoroughly enjoyed the presentation given by Georgina Beldin and Jan Oyeboode on spirituality, coping and quality of life in old age. Although the facilitators found no direct relationship between religious/spiritual beliefs and quality of life in their sample of people with dementia, it did raise a number of areas for future investigation and a hearty discussion. The suitability of coping measures, can a 'bad' coping style actually be a 'good' coping style? Discussion about the strength of religious/spiritual beliefs ensued and brought up an enriching discussion regarding how, therapeutically, one remains respectful (and effective) in the face of extreme 'distorted' but shared religious beliefs. In a society where religion and spirituality has become something to shy away from, it was refreshing to see how it has been, and may be, incorporated into work with older persons.

The wealth and breath of topics presented on, was almost overwhelming, and it was often difficult to decide which ones to miss and which ones to catch. I never thought I'd attend an academic version of a music festival, but that's what happened!

I think at this stage, in my closing paragraph, I'm supposed to say something about how next year's conference will have to try really hard to better this one/or match it? But I'm an assistant psychologist working in Cardiff, and next year's conference is going to be in Wales. I've already been roped into helping with the entertainment, so I'm (a) a bit scared ... yes, York was that good, and (b) a bit excited! See you next year!

#### **James M. Feeney**

*Assistant Psychologist,  
Cardiff & Vale NHS Trust,  
University Hospital of Wales,  
Heath Park,  
Cardiff, CF14 4XW.*

### Doctoral research poster

York was the second PSIGE conference I have attended. This time I was excited to be presenting a poster of my doctoral research into nurses' experiences of caring for older people with mental health needs in the general hospital. This research had led to questions about staff training and liaison/consultancy roles for clinical psychologists and so it was interesting to hear these issues being discussed in workshops, seminars, and other posters throughout the three days. For example, Dr Sarah Dexter-Smith gave a very helpful account of her experience of implementing formulations within an inpatient setting and Dr Gary Latchford gave his workshop on *Motivational Interviewing* a useful 'twist' by highlighting some handy training tips along the way.

With regards to training staff in dementia care, it was encouraging to learn about recent policies and initiatives that emphasise this need. I was also struck by several ideas that might help staff to interact with and engage older people with dementia. For example, I was fascinated by the computer games for people with dementia (Astell

et al.) and, although these were conceptualised as an activity for people with dementia to do on their own, I think anything that provides the potential for enjoyment is surely a positive addition to dementia care. I felt this was also the case with the (controversial) use of dolls in care homes, as talked about by Ian James. This study highlighted that having a doll seemed to give the older person and their carer a shared focus. For people in the more advanced stages of dementia, it was lovely to watch the positive results captured on video by Ellis and Astell when they adapted the idea of Intensive Interaction from the learning disability field for use with this client group.

In conclusion then, I found the conference very informative and also a lot of fun (especially the salsa!). I hope the ideas that I came across will continue to progress and ultimately provide significant improvements to the care of older people.

### **Samantha Green**

*Trainee Clinical Psychologist,  
Oxford Doctoral Course in Clinical Psychology.*

### **Conference highlights**

I arrived at the 2008 PSIGE conference not knowing quite what to expect being only six weeks into my first assistants post. All my anxieties about being new to the field were quickly laid to rest when I attended Judy Zarit's workshop on recognising anxiety in older adults. Her workshop was accessible and informative. She raised interesting issues about working with older adults that I had not previously considered, such as how someone who has had many years to adapt to their anxiety may present very differently to a younger adult. I gained a great deal from the workshop including increased confidence to go away and set up a relaxation and anxiety management group.

The afternoon was spent in a workshop on care pathways. There was an interesting discussion around what is meant by the term older person and whether there are specialist knowledge and expertise needed for working with older people, and if having separate services in fact discriminate against older adults. This was a continuing theme throughout the conference. The general consensus seemed to be that there were specialist skills and awareness needed when working with older adults but that an arbitrary age of services catering to the over 65s meant that people were not always directed towards the service that was most appropriate for them. There was also significant concern about the inclusiveness of the new IAPT services when it came to older adults.

Other highlights for the conference for me included a lively, and very entertaining, debate between Ken Laidlaw and Mike Bird on CBT and an interesting talk from Aimee Spector on Cognitive Stimulation Therapy.

I came away from the conference feeling very positive about the fact that PSIGE is taking up both an advocacy and campaigning role by challenging the inequalities within the health and social care system which disadvantage older adults and the negative attitudes within society towards older people which create excess disability. So thank you to PSIGE for the bursary and the opportunity to attend the conference, it has definitely made me think positively about working in this area in the future.

#### **Elizabeth Nash**

*Assistant Psychologist,  
Older People's Psychology,  
Cambridgeshire and Peterborough  
Foundation Trust.*

### A positive response

After attending this year's PSIGE conference in York, I considered what I had learnt, and what the experience had meant to me. The concurrent streams, meant there was a diverse range of seminars to attend. However, upon reflection, what I considered to be a prominent theme from the conference was the importance of working not just with the client on an individual basis, but considering the wider system; families, other professionals, services, and carers, all within the context of national policy that shapes how we work with older people.

The first workshop I attended, *Using formulation in inpatient settings*, highlighted the benefits of collaboratively developing formulations within teams in order to develop a shared understanding subsequently leading to more meaningful and individual interventions for our patients. This workshop not only considered the theoretical benefits of formulations in inpatient settings but also provided opportunities to explore best how to set up this process, and tackle barriers to change, through the illustration of services where psychological formulations had been successfully integrated into models of care.

Another important system we work within is the client's family. Steve Zarit's keynote speech provided practical advice, through an engaging and personal account of his experiences of working with family caregivers, reflecting upon the often difficult task of balancing the wants and needs of various family members, the care giver, and, of course, the person who is being cared for through the use of family meetings.

With national policy and the implementation of IAPT influencing the services that will be available to the population, it was helpful to hear in some of the seminars how these ideas have helped to develop and evaluate services but also how healthcare professionals have found these experiences. Of particular interest was the *Developing care pathways for older people with depression* workshop which considered how additional issues related to aging can be incorporated into care pathways, and whether care pathways are best led by service need or clinical need.

Overall, my experience of attending the conference was very positive. It provided the opportunity of three days of learning from the research and experiences of others, but also encouraged me to reflect upon my own work and to consider how I can use some of the ideas discussed at the conference in my own clinical practice.

#### **Katrina Raymond**

, *Trainee Clinical Psychologist,*  
*University of Hull.*

### **A stimulating conference**

I attended the National PSIGE Conference in York this year. I am in my third year of the five-year flexible training programme at the University of Edinburgh, with placements in NHS Fife. The flexible training route is a bit different from the traditional three-year one. It involves the same placements as the traditional training model, along with the equivalent of two years work in one particular specialty – my specialist work component being with the Older People’s Service. By the end of third year flexible trainees are beginning to work at a similar level to newly qualified clinical psychologists entering the older adult profession. One advantage to this model of training is the opportunity to develop skills such as consultancy at this stage. I am beginning to work more autonomously within the Older Adult setting and so found this year’s PSIGE conference particularly timely and helpful.

The main focus of my work component for my final two years of training will involve consultancy in Physical Healthcare settings, such as geriatric continuing care wards. I attended Sarah Dexter-Smith’s workshop on using formulation in in-patient settings. It was refreshing to hear that many of the problems encountered by myself were similar to those discussed in the workshop, and many tips and suggestions were shared, including examples of schematic formulation diagrams which I plan to use with staff groups in Fife.

I also attended a workshop on delirium, which is a condition I previously knew very little about, and have received little teaching on. Again I found the conversations and sharing of experiences within the workshop useful and relevant, and the materials and references provided are an excellent resource that I am confident I will draw on in the coming months.

During the next two days, I attended an interesting mix of talks, both pursuing my existing interests and learning about new things. Highlights for me included a talk on spirituality which has given much food for thought in relation to my thesis proposal, and a series of talks on life story work.

All in all, I found the conference to be a stimulating, educational and thoroughly enjoyable experience – despite arriving home completely exhausted afterwards!

### **Susan Ross**

*Trainee Clinical Psychologist,  
Department of Clinical Psychology,  
Lynebank Hospital,  
Halbeath Road,  
Dunfermline,  
Fife, KY11 4UW.*

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### **A fun-packed few days!**

This year was my first PSIGE conference, so I arrived with a ‘blank slate’, not knowing what to expect. It certainly was an unforgettable experience.

I am reflecting on the experience as I travel back from York on the train and in doing so, I am taking up two seats from the overindulgence on the delicious food that was provided. The organisers most definitely deserve a thank you; the tapas and salsa

themed entertainment was a great way to relax and network. All this has left me happily exhausted. Although I would like to reason that this was all due to the networking and the dancing (which I now realise is not a skill of mine), it is also attributed to the packed and diverse timetable of talks and frantic scribbling of notes, whilst carrying around a heavy bag of handouts and a head full of thoughts, ideas and enthusiasm. The tiredness was certainly worth it!



I enjoyed the fact that the event provided a perfect opportunity to meet with current trainees for peer support. We discussed the distressing experience of applying for a training place and they suggested ways for me to develop both personally and professionally to prepare me for a place on the course; which fuelled my excitement even more! As my current role involves working in a memory clinic alongside being deputy of the journal *Signpost*, I have liaised with many psychologists such as Esme Moniz Cook and Bob Woods. I can now thankfully put faces to names. It's great meeting some eminent professionals who are down to earth and engaging and who all hold a shared passion for the client group

The programme was extremely well organised and particular comprehensive. So much so that I found myself on several occasions stuck in the reception having an internal argument over the pros and cons of which talk to attend and which I had to prioritise. I particularly enjoyed the opening on the 'clinical interventions for family caregivers' by Steve Zarit. Not only did it provide a warm welcome to the event, he also gave a concise way of how to put theory into practice. It was heartening to hear what other services were doing and share ideas which I hope to take away and utilise in my current role within a memory team.

As I have limited knowledge of positive psychology, Elspeth Stirling delivered an excellent foundation to the theory for me; how it can be used to change our thinking and instigated some interesting debates over the wider political and social context of service development. It was emphasised that there needs to be a shift in thinking away from the idea of 'fixing' people in terms of putting a plaster in place and reducing symptoms, to making the ageing process one of a developmental learning cycle. The approach has instilled great hope in me and I look forward to furthering these ideas in my career.

I particularly enjoyed the 'development in practice and research strand', especially the 'adaptive interaction' talk by Arlene Astell and Maggie Ellis. They used some excellent video clips to highlight that imitation and 'learning the language' of the person with dementia can assist us in entering the inner world of the person. They also delivered a talk on the development of computer games for people with dementia. Both talks provided a good overview of the theory and how they could be practically applied to make a difference to the lives of older people with dementia. The ideas fit well with the emerging ideas from positive psychology and acceptance and commitment therapy. Both talks were extremely thought provoking and certainly fulfilled my experiential 'flow'. Hopefully with funding, the research may continue and provide a way of showing that older people with dementia can be happy and content when helped to meet their need to communicate with others. If these ideas can be disseminated across all health professionals, a different culture of care may certainly be on the horizon.

I would like to thank the PSIGE Committee for the bursary which allowed me to have the PSIGE experience. I look forward to helping to organise next year's conference. The plans are certainly underway!

**Tara Seed**

*Assistant Psychologist,  
Cardiff and Vale NHS Trust.*

### **The PSIGE experience**

I was grateful to be granted a PSIGE bursary which allowed me to attend my first PSIGE conference. Day one started with Judy Zarit's workshop on recognising and treating anxiety disorders in the elderly. It was great to hear from a practitioner working in another country (US) to see how clinical work matched up. It was interesting to note the differences such as prescribing abilities and the time period a client may be seen for, but more importantly for me, how similar experiences, including the difficulties, could be. Judy was a very good and entertaining speaker using lots of case examples which as a trainee is invaluable. I came away feeling I had picked up ways to develop my own practice and tips to use with the clients I am currently seeing.

The second workshop I attended focused on developing care pathways for people with depression facilitated by Don Brechin, Nicky Bradbury and Sarah Dexter-Smith. Firstly it highlighted the concerns that psychologists are facing as both the profession and care pathways evolve. It was interesting to hear people try to define what our multi-faceted roles involved and at what points in the pathway they came into play. Secondly it brought home the specific skills required by psychologists working with older adults. Until you are forced to write it all down it can be easy to lose sight of how much specialist knowledge and skills we do utilise. It also made me consider how much specialist knowledge trainees expect their supervisors to have. Finally it made me realise how much work and time was required in developing care pathways. As a trainee I am used to seeing the end products and it can be easy to overlook the complexity of the process. The experience of contributing to even a small part of the development will definitely make me think twice the next time I read such documents.

Over the next two days I was happy to have difficult choices to make about what to attend and took this to be a sign of a good conference. As a trainee without her peers, not knowing most of the other delegates and being at a psychology conference for the first time, the experience could have been very daunting. However, I was struck by how friendly and open people were. It was a great opportunity to mix with people and share ideas and experiences. It felt good to be part of a crowd with the common goal of improving the services offered to older adults.

### **Indhu Sharma**

*Trainee Clinical Psychologist,  
The University of Manchester.*

### **Ghosts, salsa and interesting talks**

I recently attended the PSIGE National Annual conference in York – it was my first ever PSIGE conference but it will not be my last.

The ghost tour which had been arranged for us on the Wednesday was quite an amusing affair (it perhaps wasn't meant to be). The chap running the tour asked us what we did for a living, we also responded (almost in unison) 'Psychologists!' It was at this point I think he realised we were not going to be an easy group to work with!

The entertainment on the other evenings was great too, the BBQ was delicious and the Salsa/Tapas night on the Thursday was really fun – I myself didn't join in with the Salsa owing to my two left feet!

The conference itself was absolutely fantastic; I thoroughly enjoyed every seminar and presentation I went to. I found it really refreshing to see people sharing their knowledge and ideas with each other. There were times when opinions differed but everyone was so respectful of one another and took the time to listen.

Amongst many, I particularly enjoyed the *Life Story Work* seminars by Polly Kaiser and the *Cognitive Stimulation Therapy (CST) for dementia* presentation delivered by Aimee Spector.

I think the conference really brought home to me the fascinating world of working with older adults, the challenges it brings but also the rewards to be gained.

So thank you to everyone, I had a great time and hope to present myself in the future.

#### **Laura Wicks**

*Assistant Psychologist,  
Townsend Hospital,  
St Andrews Healthcare,  
Northampton.*

# North Thames PSIGE

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All (members, non-members, trainees) are welcome to come to the following quarterly meetings held between 3.00 p.m. to 4.30 p.m. usually held within UCL, rooms still to be confirmed.

**Date: 14 October, 2008 – 3.00 p.m.**

**Topic: Older adult sexuality issues.**

**Date: 14 January, 2009 – 3.00 p.m.**

**Location: to be confirmed.**

**Topic: Disclosing the diagnosis of dementia.**

**Date: 23 April, 2009.**

**Location: to be confirmed.**

**Topic: Review of book about CMHTs and people with personality disorders.**

**Date: 10 July 2009.**

**Topic: Cross-cultural cognitive assessment presented by Matthew Jones Chesters.**

For further information, please contact [geraint.price@nhs.net](mailto:geraint.price@nhs.net) or

[Ruth.Lukeman@wlmht.nhs.uk](mailto:Ruth.Lukeman@wlmht.nhs.uk)

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## CORRECTIONS TO ISSUE 104

The following errors appeared in the following article, which we have been asked to point out:

Sarah Race, Young Onset Dementia (pp.63–65).

E-mail address for correspondence about the Young Onset Dementia webpages should be:

Dr Sarah Race: [sarah.race@teew.nhs.uk](mailto:sarah.race@teew.nhs.uk)

Guss, R. et al. should be: Briefing Paper 23. Services for younger people with dementia and the role of Clinical Psychology. Leicester: The British Psychological Society.

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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:  
Mischel, W. (1986). *Introduction to personality*. New York: CBS.
- (2) Journal article:  
Martin, A. & Fedio, P. (1983). Word production and comprehension in Alzheimer's disease: The breakdown of semantic knowledge. *Brain and Language*, 19, 124–141.
- (3) Paper in a book:  
Garrett, M. (1980). Levels of processing in sentence production In B. Butterworth (Ed.), *Language Production (Volume 1) Speech and Talk*. London: Academic Press.

## 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](mailto:aja3@st-and.ac.uk)

When submitting articles please send the following information:

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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](mailto:aja3@st-and.ac.uk)

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