



The
British
Psychological
Society

Psychology Specialists
Working With Older People

PSIGE Newsletter

No. 114 – January 2011

OXFORD REGION EDITION



www.psige.org

ISSN: 1360-3671



www.psigе.org

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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ISSN: 1360-3671

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PSIGE is the Faculty for Old Age Psychology
(British Psychological Society, Division of Clinical Psychology).

Letter from the Editor

Louisa Shirley

MANY THANKS to our Guest Editor, Debbie Sheward, who has facilitated the production of the papers presented here from the Oxford Geographical Group and represented the Group through the writing of the Guest Editorial. As I am continuing to receive good quality submissions from PSIGE members whose work does not reflect the themes we have chosen for this year, the Oxford group have kindly agreed to host some of these papers. Coincidentally, a number of the papers that have been submitted from non-Oxford colleagues have shared foci with the Oxford group's papers and so I have not separated the papers geographically, but rather, tried to group them together in a way that allows the papers to support each other.

We begin the edition considering therapeutic interventions with both dementia sufferers and with their carers. Hartley, Taylor and de Madariaga Lopez detail the benefits of a pilot study for a group of care home residents where psychology was supported by other professionals in initiating a Cognitive Stimulation Therapy (CST) group, and where the impetus was originally (and encouragingly) from the care home's manager. Teh and Crawford go on to reference a theoretical model that might help us to understand and articulate the success of CST and which might be a helpful structure within which to evaluate this further. A further paper by Andargachew presents a summary of the literature and a case study to illustrate Simulated Presence Therapy. In this paper, we learn who might be most suitable for and benefit from this therapeutic approach and Andargachew uses case study material to support her presentation of the research. Appleton describes the 'life' of a support group for people suffering from dementia. I think many

people reading this paper will be touched by the ambience of resilience and the continued richness of experience that the people attending this group were able to access. Appleton also makes mention of the enhancement of social identity through being part of the group, reflecting the suggestion in Yeh and Crawford's paper that groups allow people to express other aspects of themselves; those relating to others (relational) and to group membership (collective). Another paper describing in detail the promotion of personhood in dementia sufferers is by Bruce-Hay, Dodds, Stapleton and Crellin in which three practitioners describe their own experiences of working closely in dementia settings from different theoretical backgrounds, but sharing a sense of joining more closely with the world of their clients.

Roach gives us a helpful overview on the literature supporting psychosocial interventions for dementia sufferers which is followed by a paper outlining a specific intervention for care givers of people with dementia by Stone and Beevers. In this paper, they examine the effects of three pilot study groups aimed at improving the psychological well-being of care givers. The groups were based on a structure that had originally been used to work with carers individually and which has been revised as a group 'product' in order to meet the demand for the service.

A paper which brings the experiences of dementia sufferers and their carers together is a psychodynamic perspective presented here by Terry. This paper is thought provoking and questions the validity of some of the tacit beliefs we may have held about the relationship between carers and those they care for.

Finally, two non-dementia-related papers are presented by Watts and Kemp. Watts gives a good overview of psychological interventions suggested for older people with personality disorder which is followed by Kemp's thorough description of working therapeutically in groups with older people whose presentation (though not initially diagnosis) suggests they have a personality disorder. Both of these papers have additional reading in their references which make strong cases for a more proactive approach in recognising the experiences of people with these specific relational and social problems, and in increasing the access of all practitioners in older people's services to knowledge about how best to work with this group of people.

As always, the quality of the submissions to the *Newsletter* has been high and I am grateful to all the contributors for their timely submissions. I already have a healthy group of papers accumulating for the 'Early Careers' edition due to come out in April. Remember, this edition will feature papers from trainees, assistants, and relatively newly qualified psychologists, and I would be glad to hear from course tutors or employers who would like to make a contribution. I have printed the *Newsletter* rota in this edition for a reminder to those who may have a Geographical edition coming up.

Finally, could I please remind people that, although the format of the *Newsletter* is much less formal than some other publications, we need the references quoted in the text and in the reference section to follow the guidelines in the inside back cover of the *Newsletter*. In terms of groups of authors (et al.), please follow APA guidelines. These are easily accessible through the internet. Thanks.

Best wishes for the New Year.

Louisa

Letter from the Guest Editor

Debbie Sheward

WELCOME to the January 2011 issue of the *Newsletter*. This year brings further challenges for those of us who work in the NHS. Locally in all areas of mental health, whole teams are being re-configured and in some cases combined with other teams; in Berkshire day hospitals providing services to older people will be closing and there is a proposal to have all in-patient provision for Berkshire on one site. No doubt PSIGE members across the UK are encountering similar changes and cuts.

The Oxford PSIGE region includes Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire, and we are fortunate to host the Oxford Clinical Psychology Training Course. We meet six times a year to listen to presentations which stimulate great interest and discussion, to catch up on developments in our services across the region and, importantly, for mutual support. Psychologists working with older people are thinly spread

in our region – perhaps one per locality – so attending PSIGE meetings is all the more helpful. Increasingly, people from non-government organisations concerned with furthering the interests of older people are also attending our meetings. This is an exciting development and we welcome their contributions to discussions and to the work in different localities.

Thank you to members across the region for submitting contributions; these cover a range of topics, and are indicative of the varied and innovative psychological therapies and approaches that are made available to those of all disciplines who work with older people. I hope you find in them something to inspire and encourage you as you face the new year, as I certainly have in previous issues.

Debbie



Letter from the Chair

Don Brechin

IT SEEMS to have been a busy start to the New Year for many of us, and I am afraid that one consequence of this is that I have been slow in getting around to writing my letter for this edition of the *Newsletter*. So, my apologies for the delay in the *Newsletter* coming out to you – it is down to me!

Fortunately, I have a smokescreen behind which I can partially hide – namely the production of an additional (special edition) *Newsletter* on Older People and IAPT. This arrived through the letter box in January and is the first product of our IAPT workstream. I am pleased to say that this workstream proceeds at a rapid pace, bolstered by the government announcement in November that IAPT will be extended to Older People and a number of other groups. At short notice I was invited to attend the New Savoy Partnerships conference in November at which Paul Burstow made the announcement, and I was asked to speak to the conference about the implications of this for older people. I am pleased to say that I had an early draft of the *Newsletter* to hand, so any factual inaccuracies in what I said are largely due to the articles contained within (thank you to all of the contributors). Also, thanks to Polly Kaiser for her hard work in ensuring that PSIGE was included in the press release from the conference.

The national committee has firmed up its plans for taking this work forward in 2011 after Kevin Jarman from the national IAPT Team at the Department of Health joined us at our January meeting. This work will continue to be co-ordinated by Cath Burley, Julia Boot and Louise Bergin, and they will

be working with the DH team over the next few months to scope out how IAPT services will need to be configured to be fit for purpose for older people. We also hope that this work can be used to supporting parallel developments in Scotland and Wales. Overall, this promises to be a very exciting time for us, and is the culmination of many years of hard work by many people across the country.

The dementia workstream is also proving to be productive. Following discussions with the Department of Health, PSIGE is now one of the stakeholders working with the Alzheimer's Society to produce a pathway for the management of behavioural symptoms of dementia. This project involves a number of professional bodies working together to articulate the alternatives to antipsychotic medication so that commissioners and providers are able to meet the government target of reducing prescription of these medicines by two thirds. I attended an initial stakeholder meeting in early February, and I will be working with Liz Baikie and Lyn Sutcliffe on the committee to co-ordinate the PSIGE contribution to this project. Our hope is to work with PSIGE members to summarise the evidence and examples of good practice that we know are out so that these can feature in the pathway. Any contributions gratefully received!

So, a busy start to 2011 and hopefully a productive year ahead.

Best wishes.

Don Brechin

Creative service delivery: A pilot study of a mixed ability Cognitive Stimulation Therapy group in a residential home setting

Emma Hartley, Julia Taylor & Marta de Madariaga Lopez

A pilot project for delivering Cognitive Stimulation Therapy (CST) to a group of residents with varying cognitive, sensory and physical abilities. The group members were selected by the home manager with the aim of offering this intervention to all residents who may benefit from attending the sessions. This method of selection resulted in a large heterogeneous group of older adults requiring a flexible and creative delivery of activities within the framework of the manualised CST programme. Outcomes for the group were positive, indicated by the average increase in Mini Mental State Examination (MMSE) scores of 1.31 points.

A MAJOR PRIORITY of *The National Dementia Strategy, Living Well with Dementia* (Department of Health, 2009), is raising the quality of care for people with dementia and their carers. A subsequent publication from the Department of Health, *Quality Outcomes for People with Dementia*, (Department of Health, 2010) includes, as one of its four main priorities, living well with dementia in care homes. The report notes that often in such settings dependency on care home staff is increasing and many residents of care homes are poorly occupied. The report acknowledges the need for the Department of Health to focus on sustainable outcomes, which will have the greatest impact for those with dementia and their carers at a local level.

NICE guidelines (2006) on care for people with dementia and their families have acknowledged the importance of both the social and medical aspects of the condition. Whilst there have been recent changes to the NICE guidelines which are due for implementation in March 2011, at present, limitations in the eligibility for prescription of dementia medications have resulted in the need for the development of alternative evidence-based treatments for people experiencing dementia.

Even when the new guidelines are implemented in the NHS there will remain those in community settings and care homes with cognitive and memory difficulties that do not meet diagnostic criteria. There will be many with types of dementias and other cognitive impairments that are not treatable with current medications. Even for those patients who have a dementia or cognitive difficulty that may be treated with a medication, this will not resolve the increasing dependency and under-occupation prevalent in some care home settings.

It therefore remains a priority of clinicians delivering services through Older Adults Community Mental Health Teams (OA-CMHT) to continue to deliver psychosocial interventions in a way that is inclusive, cost effective and beneficial to older adults and their carers. The cost effectiveness of Cognitive Stimulation Therapy (CST) was analysed and evidenced by Knapp et al. (2006) suggesting that the benefits of CST can be delivered in an economically worthwhile way. Development and subsequent growth in evidence base of the effectiveness of CST provides the OA-CMHT with a structured, evidence-based intervention that can be delivered in a variety of settings.

In general, cognitive stimulation involves engagement in a range of group activities and discussions aimed at the general enhancement of cognitive and social functioning (Clare & Woods, 2004). CST (Spector et al., 2000; Woods et al., 2005) is a brief treatment originally designed for people with mild to moderate dementia. CST interventions involve 14 sessions of themed activities, which run over a seven-week period. Sessions aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group (Spector et al., 2006).

The potential benefits of general cognitive stimulation for people with more advanced dementia were initially demonstrated through the adaptation of reality orientation (Woods, 2002). The first RCT of CST conducted in 23 centres (residential homes and day centres) showed that CST led to significant benefits in cognitive functioning, as measured by the MMSE and the ADAS-COG (Spector et al., 2003). The authors concluded that for larger improvements in cognition, CST is equally effective as several dementia drugs. Furthermore, CST led to significant improvements in quality of life, as rated by the participants using the QoL-AD. NICE (2006) recommend the use of group Cognitive Stimulation for people with mild to moderate dementia, irrespective of drug treatments received.

Clare and Woods (2001) highlighted the importance of social interaction as an integral part of CST. The authors queried whether the benefits of CST derive mainly, or partly, from the social interaction rather than from the cognition-focused components. Furthermore, they posit that CST may be beneficial because it tackles aspects of under-functioning resulting from social environments that are insufficiently stimulating and rewarding, and not because their content focuses on cognition.

The study

In order to meet the varied needs of the heterogeneous group adaptations were made to the manualised CST protocol (Spector et al., 2006) for the purposes of this pilot group. The session content was approached in a very fluid and flexible way in order to be responsive to the needs of individuals as well as engaging and appropriate for all those of all abilities.

Aims of the group

Service perspective:

- To assess the feasibility of running a CST group in a residential environment with participants of mixed ability levels.
- To assess the impact of CST on cognition and quality of life.
- To encourage the residential home to facilitate the ongoing provision of CST in the home.

In order to achieve the aims stated above the CST group sought to:

- Create an environment where people learn and strengthen their existing resources, to enable them to functioning at their maximum capacity.
- Promote the principles of person-centred care.
- Create consistency and continuity between sessions to minimise confusion and aid retrieval.

Referrals and assessment

Referrals to the group were recommended by the residential home manager with formal referral from the GP. The home manager was not given specific guidelines, he was requested to select group members who had some memory or other cognitive difficulty who may benefit from a programme of activities designed to stimulate cognition. No formal diagnosis of a dementia was required and there were no exclusion criteria. Pre- and Post-group assessment of cognitive and memory function was carried out using the MMSE, and quality of life assessment was carried out using the questionnaire Quality of Life in Alzheimer's disease Questionnaire (QoL-AD; Logsdon et al., 2002).

The group setting

The group took place in a private 19-bed residential home in a quiet, rural location. The home was recently rated 'good' by the quality care commission. Mental health input to the home is provided by the OA-CMHT, which provides services for clients with both 'organic' and 'functional' difficulties.

The group members

Eight residents were referred and assessed. During the first week of the CST programme two further residents, new to the home, were assessed and joined the group. Table 1 provides a summary of demographic information, number of sessions attended and indicates the range of MMSE scores at assessment. Attendance at the group ranged from 6/14 sessions to 14/14 sessions. Reasons for non-attendance included physical illness, trips away from the home by residents, and visits to the home by family and friends of residents. At the beginning of each session, group members were individually invited to join the group and had the option to decline for any reason.

The group facilitators

As the range of cognitive, sensory and physical functioning was diverse the group ran with four facilitators. Two facilitators were from the OA-CMHT. A trainee psychologist was the lead facilitator, with an assistant psychologist providing additional support. The residential home manager and a deputy manager were also engaged as facilitators. There were four aims in engaging residential home staff to co-facilitate the CST group:

Sustainability

Through modelling group facilitation and supporting care home staff to become increasingly involved in running the group, staff to develop skills and creative ideas that would enable them to continue to develop the group once the CST programme was concluded.

Reducing dependency

By demonstrating the abilities of individuals within the group through the activities rather than focussing on disabilities;

Increasing occupation

By learning together which activities were engaging and enjoyable for individuals and the group as a whole, and demonstrating the simplicity and usefulness of a programme of activities that improved the quality of life of the residents;

Fostering relationships

When the idea of this pilot CST group was conceived, one of the primary perceived benefits was to improve the delivery of services into the diverse community settings encountered regularly by the OA-CMHT. This pilot study was designed to incorporate provision for ongoing support and service delivery into the residential home, with the OA-CMHT team supporting and empowering the staff to deliver services to their residents.

Furthermore, there was an improvement in understanding, and the breaking down of barriers between the staff at the home and the residents through inclusive participation

Table 1: Summary of demographic information.

	N	Age		No. of sessions attended		MMSE score at assessment	
		M	SD	M	SD	M	SD
Gender							
M	5	87.8	2.28	11.8	3.35	21.4	6.69
F	5	89.2	6.38	12.6	2.07	16.2	8.70

in many of the activities. By the fourth week of the programme, residential home staff felt skilled and confident and the trainee psychologist was able to facilitate the group as the sole person from the OA-CMHT present at the sessions.

The group programme

Although the approach to this group was responsive to the individuals within the group, the framework of sessions was provided by the CST manual. The sessions ran for seven weeks, twice weekly. The group followed a similar format in every session and was guided by the CST manual (Spector et al., 2006), which is illustrated below:

Activities carried out in every session:

- Welcome to the group and creation/handing out of name labels.
- Singing the opening theme song (*Somewhere Over The Rainbow*).
- Orientation Exercises (Day, Date, Month, Year, Season, Location of home, something going on in the news).
- Ball Game. A soft ball was passed around the group and when the resident caught the ball they answered the questions 'where do you come from?' and 'what is your favourite colour'.
- Themed activity – see Table 2 for a detailed description of each session.
- Closing theme song (*We'll Meet Again*).
- Summary of session and feedback obtained from the group.
- Group was thanked for attending and informed of the topic for the next session.

The group requested that the ball game be played at the beginning of each session, and it was felt this was a good way of asking questions each session to get to know each other better. A summary of the main themed activities is provided in Table 2. Many of these activities are based on the session themes provided in the CST Manual, but simplified to be delivered in an inclusive way to the diverse group of individual members.

Throughout all sessions, extensive use was made of flip charts, on which topics and

questions were written clearly, and verbal responses of group members were recorded. This was to ensure those with hearing difficulties were able to understand the dialogue of other group members and contribute to discussions.

The variations from the manual were adopted as the sessions progressed to ensure all group members felt they were of value to the group as a whole, felt their contributions were valued, felt included, and activities could be engaged in by members of all abilities.

Outcomes

Patient measures

Following the end of the CST group, all participants were reassessed using the MMSE and QoL-AD. A breakdown of the participant's pre and post intervention MMSE and QoL-AD scores are presented in Table 3 below.

Following the intervention the average MMSE score for the group was 20.11 (range 13 to 30). This represents almost a two-point improvement overall. Four participants showed an improvement in MMSE scores, two participants showed deterioration and three participants' scores remained stable. Following the intervention, the average QoL-AD score for the group was 30.1 (range 16 to 49). This represents a 0.4 reduction overall in ratings of quality of life. When comparing pre- and post-intervention scores, five participants showed an improvement in quality of life and five participants demonstrated a deterioration.

Qualitative feedback from participants

Subjective feedback about the group was also sought from each participant. Gaining feedback presented some challenges as it relied upon participants being able to recall attendance and contents of the sessions. Despite this all participants reported that they would be willing to attend a CST group in the future. Participants commented that they enjoyed the group as it was something to do. Playing hangman and singing were deemed

Table 2: Outline of session contents and adaptations made from the manual.

Session Number	Session Theme	Themed Activity
1	Physical Games	Ball Game. A soft ball was passed around the group and when the resident caught the ball they answered the questions 'Where do you come from?' and 'What is your favourite colour?'. Session 1 also included generating a group name, voting for a theme song (different opening and closing songs were requested by the group members).
2	Sounds	A song quiz was devised using popular songs from the 1940s 1950s and 1960s. Due to the sensory difficulties, the quiz questions were answered by the group together and were presented in the format of a 'missing words' game. Clues were provided by playing parts of the song to the group, and by visual picture clues.
3	Childhood	A picture book of old toys and games was created and given to each resident. A discussion of the difference between the types of toys and resources available now compared to when the group members were children was held and each member was encouraged to share a story about their favourite toy or game as a child.
4	Food	Group members looked at and held items from a 1950s kitchen and guessed what they were used for, following which they guessed different food types from the kitchen (pickles, sauces and jams) and what they may accompany. During the activities participants tasted a variety of old fashioned sweets.
5	Current Affairs	A current newspaper article (Appendix 5) was used to prompt a group discussion about how children/ differ/s now to when the participants were younger.
6	Faces	Famous faces cards were passed around the group and each participant was asked to guess the name of the famous person on the card (without looking at the answer on the back!). The participant then shared their famous face card with the rest of the group and a group discussion was held about what was known and felt about that person.
7	Word Association	Group members together answered quiz questions in the format of a missing words game guessing the missing words from well known sayings and phrases.
8	Categorising Objects	For this activity the group divided into two small groups and with the support of a facilitator were asked to generate the name of as many countries, musical instruments and animals as possible. Each team then fed back the total numbers and the winning team for each category received a prize.
9	Number Games	Following the success of the small group exercise in the previous session, the group was divided into two smaller groups and one group played snap using playing cards while the other group played dominos. Each group was supported by a facilitator.
10	Being Creative	The facilitators made the recipe for peppermint creams and each participant was given a portion of the mixture and encouraged to make their own peppermint creams. The group was then able to eat the sweets they made.
11	Word Games	As the main activity the group played Hangman. Initially the facilitators chose the word to guess but as the session progressed the participants made suggestions of words to guess,
12	Orientation	For the main activity, each group member was given a map of the UK and a map of the world and was asked to mark on it where they come from and places they had visited. Following this each participant fed back to the whole group.
13	Money	Participants were given pictures of various items and asked to guess how much they cost at the present time. The current pricing was compared with how much things used to cost. The group engaged in a discussion about the increased cost of things since they were younger.
14	Games	For the final session, participants were given a choice of how they would like to spend the session. The group decided that they would like to play hangman again.

Table 3: MMSE and QoL-AD scores at assessment and reassessment.

Resident	MMSE*		QoL-AD**	
	Pre	Post	Pre	Post
1	5	13	30	33
2	16	16	28	17
3	26	19	32	26
4	12	- ***	37	49
5	21	24	33	30
6	30	30	30	42
7	25	22	31	39
8	25	26	35	27
9	14	17	21	22
10	14	14	28	16
Average score	18.8	20.11	30.5	30.1

* >24 Mild Cognitive Impairment, 18–24 Mild Dementia, 12–17 Moderate Dementia, <12 Severe Dementia.

** Higher scores on the QoL-AD are indicative of better quality of life.

*** Member absent during post intervention sessions.

enjoyable by most group members. The only suggestion for improvement was to include a general knowledge quiz.

Qualitative feedback from facilitators

The facilitators engaged in reflective practice following each session. Overall all facilitators agreed that they felt the group had been a success and the residential home staff were keen to explore how they could continue to facilitate a CST group with the support of the psychology service within the OA-CMHT. It was agreed that following the end of the group the home manager would meet with the clinical psychologist to discuss development of the CST programme within the home. It was also agreed that the clinical psychologist would provide supervision to the staff members facilitating the CST group for one year.

Discussion

The outcome measures indicated CST is a successful and relevant intervention for the participants. The outcomes achieved add to the growing evidence base for the effective-

ness of CST in improving cognition. It is interesting to reflect on the mechanisms for change for this group, as despite improvement in cognition scores, QoL remained the same. It could be hypothesised that because they live in a residential home the participants had little control over changing their social environment, thus QoL scores remained stable.

Although group interventions appear to be a popular choice for the delivery of psychosocial intervention, it should be borne in mind that people with dementia are a heterogeneous group. Evaluation of outcomes at a group level may mask variability and therefore it is also important to consider individual differences in response to treatment. As noted by (Cheston, 1998) when considering the effectiveness of an intervention it is important to attend to both group and individual outcomes, group process and subjective experience as well as overall scores on standardised measures.

When considering effectiveness of the intervention it is also important to consider the progressive nature of dementia and the

impact this has on psychometric data. Due to organisational demands including the time involved in organising the group there was a significant delay between the assessments and the start of the group. Yet despite the time delay and the possible impact of advancing severity of the cognitive decline, significant gains were observed in MMSE scores at re-assessment.

This pilot has demonstrated the feasibility of running a CST group in a residential home with mixed ability participants and has provided the skills and expertise needed to continue to facilitate such a programme of activities in the home by the residential home staff themselves. In follow-up discussions, staff reported feeling positive and enthusiastic about initiating a programme of activities of their own design to continue working with residents in the spirit of the CST format. Furthermore, staff at the home reported feeling comfortable in continuing to work with the OA-CMHT to deliver interventions in the future. They described feeling supported by, and able to use ongoing clinical support and supervision in an advisory and consultative way to enhance and facilitate their own work in the residential home to benefit their residents.

In working together with staff of the residential home in this way, the cost effectiveness of delivering services to patients and carers in line with the recommendations of the National Dementia Strategy by increasing skills and minimising dependency has been maximised. By enabling and empowering carers to deliver and participate in the interventions themselves, this type of team working and expertise sharing is both sustainable and empowering and will have a continuing impact on service delivery at a local level.

In conclusion, it appears that CST can be successfully adapted to be used with participants with varying degree of cognitive difficulties and sensory impairments. In order to investigate the systemic impact of CST interventions, future work could seek to investigate the impact of CST groups on the satisfaction levels of staff working with clients who receive CST.

Acknowledgements

We would like to thank the staff and residents of the residential home for their commitment and dedication in delivering this pilot intervention and giving their permission for publication of this article.

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The dementia patient and other identities: Exploring the role identity theories have in explaining the effects of Cognitive Stimulation Therapy in people with dementia

Ying Teh & Stephanie Crawford

WE HAVE BEEN involved in establishing and co-facilitating a Cognitive Stimulation Therapy (CST) group for people with dementia within an interim care ward in an acute care setting. CST is an evidence-based, psychosocial, group-based treatment for people with dementia (Spector et al., 2003). Participation in CST was found, in a Randomised Controlled Trial, to lead to significant improvements in quality of life and cognition (Spector et al., 2003); however, a theoretical explanation for these impressive results has not been put forward. We believe identity theories may provide a framework for understanding the improvements in quality of life which have been associated with CST. In this article we will briefly explain identity theories before going on to detail how we think they can be applied to dementia and CST. We will provide an example from our CST group to demonstrate how we use identity theories to aid our understanding of CST in clinical practice. Finally, we will conclude by considering the clinical implications of using identity theories within a medical setting.

Brewer and Gardner (1996) propose that there are three forms of 'self': individual, relational and collective. Individual self is defined as the idiosyncratic, unique attributes which separate the self from others. The relational self is the aspects of the 'self' that are defined by interpersonal relationships and the collective self is when one defines

their 'self' in terms of group membership. Contextual and environmental factors determine which form of 'self' predominates at any one time. Shifts in the dominant 'self' can be frequent and fluid; that is they can alter as a result of social interactions and location (for example the dominant self may vary depending on whether you are at work or home). Symptoms of dementia may affect an individual's ability to independently integrate and maintain the different forms of 'self'. People with dementia may also have reduced opportunities to experience different forms of the self. For example, dementia symptoms may over time impair the day-to-day skills of a woman with dementia. As a result, the pre-morbid housekeeper part of her 'individual self' might become diminished and/or lost. Similarly, forgetting past relationship experiences with family and friends may impact on the relational self and withdrawing from social groups (e.g. bingo, bowls) due to dementia symptoms may negatively affect the collective self. We believe that the 'collective self' may be particularly important within a hospital or care home environment and that social identity theory (a theory of the collective self) is a helpful way of understanding its effect on a person with dementia.

Social identity theory relates to an individual categorising him/herself as a member of a particular social group. It is theorised that individuals define their identity through comparing the similarities between them-

selves and their group and contrasting the differences of their group compared to other groups (Tajfel & Turner, 1979).

In hospitals and care homes, there are clear divisions between the collective identities of patient and professional. Previous studies have suggested that health settings encourage individuals to identify with either the role of doctor (this could be substituted with other health professionals) or patient (Watson & Gallois, 2002). This relationship centres on an imbalance in power and for patients is characterised by a loss of control and increased obedience (Contrada & Ashmore, 1999). Acquisition of the 'patient' identity is known to diminish an individual's ability to see themselves in terms of other social identities (Haslam et al., 2009): this may have a highly negative impact on mental health and well-being. We propose that the 'patient' identity is likely to be particularly salient in people with dementia. It seems plausible to suggest that dementia may erode the ability to spontaneously access memories of different forms of identity. As a result, people with dementia may be less able to shift independently between different forms of self, especially when they remain within a static and rigid environmental context, such as a hospital ward or care home. In addition, such a setting is also likely to limit the external opportunities to engage in activities/interactions which trigger different forms of the self.

Within an identity framework, it could be hypothesised that CST groups create an environment which encourages group members to think of themselves and fellow members in terms of their different forms of 'self'. Through doing so, individuals are no longer restricted to only the collective identity of 'patient'. It may be hypothesised that CST's routine rich environment and cued discussions, which centre on personal opinions rather than facts, enable people with dementia to recall memories of their different individual, relational and collective identities. By enhancing positive feelings of well-being associated with these different

identities CST may, in turn, offer protection against the negative patient identity (Haslam et al., 2009; Jetten et al., 2009). This hypothesis fits with our personal experiences of co-facilitating a CST group within an acute setting. We have outlined below an example from one of our CST sessions which we feel demonstrates how CST allows people with dementia a safe space to rediscover significant premorbid identities.

During one CST session a map of Glasgow was introduced and group members were invited to identify the area of Glasgow they were from. Each member answered accordingly, without volunteering any further information. The facilitator disclosed the area of Glasgow she was from and reflected that group members were from different areas across the city. After a moment of consideration, a group member remarked jokingly to the facilitator 'Oooh, that's a posh area, you must have a bit of money', and then went on to remark on the comparatively poorer area she was from. Another member joined in the conversation and commented that since he was from the east end of the city he would have had a similar upbringing to the woman. This conversation continued in a light-hearted and jovial manner as group members explored their differences and similarities based upon the area which they were from. This conversation was free flowing and did not require the facilitator to maintain it as the CST group members spoke with confidence and in detail about their Glaswegian upbringings.

In a social identity framework, this example may highlight a 'shift' in the group members' perceptions of themselves and each other which could be attributed to a change of social identity salience. The dominant group identity shifted from being a 'patient' group to a group of Glaswegians. Within the CST group context the Glaswegian identity was a positive collective identity which each member shared. The group facilitator identifying herself as a fellow Glaswegian as opposed to an NHS professional may

have diminished the patient-professional power imbalance and further enhanced the collective group identity. We would suggest that CST provides a contextual shift which acts as a catalyst, prompting people with dementia to alter the dominant self. Shifting to an alternative dominant self may lead to benefits in quality of life by breaking the passive patient identity which typically predominates throughout the hospital and/or care home day.

In terms of the cognitive improvements CST has been shown to have, we wonder whether experiencing and sharing different forms of the self allows people with dementia to activate parts of their brain and practice language skills which would probably remain unused within the restrictive patient identity. We hope to consider this possibility further in future. In addition, the identity theory considerations outlined in this article have led us to consider the dominant form of 'self' that staff within the acute setting tend to access. We have started to contemplate why NHS staff can have difficulty shifting from their dominant 'professional' self and the impact this professional self may have on people with dementia. We intend to explore these issues in more detail in future, with a further article.

In conclusion, in this piece, we have proposed that identity theories, particularly Social Identity theory, may have a role in explaining the quality of life benefits found in CST studies for people with dementia. Our hypotheses suggest that when working with people with dementia it may be helpful to be mindful of the potential importance of their individual identities and the possible need to actively encourage people with dementia to shift away from the 'patient self' and explore their other identities. We believe that viewing people with dementia as individuals who each have a unique collection of different 'self' identities and actively trying to encourage the activation of these forms of self, is to truly work in a person centred way, with a theoretical understanding of the importance of doing so.

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RIVER THAMES AT GODSTOW



Simulated Presence Therapy: A psychological approach to challenging behaviour in dementia care

Sara Andargachew

This is an overview of a psychological approach to agitation in people with dementia, called Simulated Presence Therapy (SPT). I will begin by reviewing the literature on the topic and will go on to illustrate the technique using a case example. Any potential identifying information about this client has been changed.

The literature

Dementia

THERE ARE approximately 700,000 people living with dementia in the UK. This number, which is predicted to increase to over one million by 2025 (Alzheimer's Society, 2007). The most common cause of dementia is AD (Alzheimer's Society, 2010). Challenging behaviours that commonly present with dementia are agitation, wandering, apathy and disruptive vocal activity (NICE, 2006). The NICE (2006) guidelines for dementia indicate that medication for challenging behaviours should only be considered as a last resort.

Psychological models

There is patchy evidence to support a number of non-pharmacological strategies designed to decrease challenging behaviour for people with dementia. Cochrane reviews, including those on light therapy (Forbes et al., 2004), massage and touch (Viggo Hansen et al., 2006), music therapy (Vink et al., 2003), and validation therapy (Nael & Barton Wright, 2003) highlight inconsistent results and the need for more rigorous research.

Simulated Presence Therapy (SPT)

SPT is a psychological technique that was specifically developed to manage challenging behaviour for people with dementia. The aim of SPT is to replicate a carer's presence in a way that brings comfort to the

client with dementia (Woods & Ashley, 1995). This is achieved by audio-taping someone close to the client, talking about positive experiences and shared memories from the client's life, aimed at evoking positive emotions.

A meta-analysis on the effectiveness of SPT for individuals with dementia (Zetteler, 2008) reviewed seven empirical studies in the area. They found a moderate combined positive effect and concluded that SPT may be an effective intervention for clients with challenging behaviour and dementia. All studies analysed showed a reduction in disruptive behaviour, agitation or distress following SPT. Some research on the topic advocated SPT as a method of improving quality of life (e.g. Cheston et al., 2007), whereas others emphasise its potential to reduce challenging behaviour (e.g. Woods & Ashley, 1995).

Factors affecting SPT outcome

Peak and Cheston (2002) conducted a study into the effectiveness of SPT and concluded that there may be important individual differences in responses to SPT. They found that those clients who were rated as having the most secure attachment history benefited most from SPT. On a related note, it has been observed that higher quality relationships between the client and the person taping themselves are more likely to produce beneficial effects (Werner et al., 2000). Miesen (1993) suggested that the voice of an

adult attachment figure may help to reduce any separation anxiety experienced by the person with dementia.

Bayles et al. (2006) suggested that the most suitable candidates for SPT are those who retain conversational skills but have moderate to severe dementia, meaning they do not remember the content of the audiotape. Werner et al. (2000) also found that those who benefited from SPT tended to be more cognitively impaired and that the extent to which the clients benefited from the tapes increased with an increase in expressions of love on the tape and if the content included past, rather than recent, family events. Garland et al. (2007) asserted that recording events from the person's history taps into their remote memory, which is often a strength of people with dementia.

The literature included variations in the method of administering SPT. One study that revealed SPT as particularly successful (Woods & Ashley, 1995) employed a method of scheduled SPT twice daily at times when challenging behaviours were anticipated. In another study (Miller et al., 2001), staff were asked to implement SPT after an episode of agitation.

Limitations of the evidence for SPT

There is currently no consensus about the mechanisms of change in SPT and more research is required. There is also some evidence that SPT can increase agitation in some cases (e.g. Garland et al., 2007). This highlights the need for close monitoring of clients' responses to SPT. Cheston et al. (2007) found that the effectiveness of SPT seemed to diminish across sessions, possibly due to clients becoming progressively more familiar with the tape. These limitations highlight the importance of a holistic approach. SPT may be one part of meeting a client's bio-psycho-social needs, but other techniques such as completing functional analyses of behaviour, increasing behavioural activation and meaningful social interaction are also important.

Case illustration

Referral information

John, an 85-year-old man, diagnosed with Alzheimer's disease (AD), was referred to psychology for input regarding a reported deterioration in his dementia and challenging behaviour. The referral described increased confusion, agitation and verbal and physical aggression.

Presenting issues

John presented as disorientated at the initial meeting. However, his mood seemed stable and he seemed calm. When I asked him 'How do you find it here?' he described being satisfied, but he also implied that he was somewhere entirely different. He did not seem to remember who I was by the end of the conversation.

Care worker's perspective

The care workers reported that while John was often very pleasant and calm, he became very agitated and unsettled approximately twice weekly. They described him as verbally and physically aggressive during these times. They reported a deterioration in John's cognitive functioning over the last few months. They described him spending much of his time walking around the home looking for and asking after his wife. A staff member (Sue) completed a Quality of Life for AD (QoL-AD; Logsdon et al., 2002) questionnaire and marked five out of 13 areas as 'poor'.

The care workers were able to identify triggers to John's behaviour. They reported that he was particularly unsettled after lunchtime, during personal care and if he was interrupted mid-conversation. They also reported that he would ask to telephone his wife (Norma), forgetting that he had just spoken to her and would become agitated when reminded of this. John also sometimes forgot where his bedroom was.

Norma's perspective

Norma described having a very close relationship with her husband. She became

tearful when describing her sadness at how John had deteriorated. They continued to be very loving and affectionate towards each other and she seemed to be one of few people that John recognised.

Medication

John's low Mini Mental State Examination score meant that he was eligible for an anticholinesterase medication, such as Aricept, used in the treatment of AD. However, John and his wife were not interested in this as John suffered with a medical condition which they felt would be exacerbated by the medication. He was not on any medication for behavioural difficulties.

Formulation

Predisposing factors

John was diagnosed with AD four years ago. He was described as a relatively volatile man, even before his diagnosis. His frustrations with declining cognitive functioning were also likely to be amplified by a high premorbid IQ level. He was also described as a very proud, private and independent man.

Precipitating factors

People around John reported a decline in his cognitive functioning. They reported that he tended to get lost more, was forgetting that his wife had visited/telephoned more and was much more disorientated than previously. A urinary tract infection was ruled out at this stage.

Maintaining factors

The deterioration in John's cognitive functioning was the primary factor contributing to and maintaining his agitation. This fits with literature indicating that increased agitation and confusion are common when people are diagnosed with dementia (NICE, 2006). This decline also meant that he became much more agitated about not seeing his wife, because he would forget he had just seen her. This was causing agitation on a daily basis. It also took staff time to adapt to his new presentation. John did not

take well to the invasion of privacy and dependence that came with enhanced support with personal care from a predominantly female care team.

Protective factors

John's close relationships with Norma and his son were clearly protective. Their relationship was protective for other reasons; he was still able to fulfil his wife's emotional needs and while many of their conversations were nonsensical, the love that they expressed for one another remained as genuine as it always had.

Rationale for intervention

John appeared to be a good candidate for SPT. There was strong evidence to suggest that he was securely attached to his parents and had maintained healthy adult relationships, which Peak and Cheston (2002) suggest maximise the potential benefits of SPT. Werner et al. (2000) observed that the quality of the relationship of the person recording the SPT tape impacted on its success and John's close relationship with his wife fulfilled this criterion. Miesen's (1993) assertion that SPT is likely to reduce separation anxiety was also promising for John, as he seemed to experience this every time Norma left after visits. John's dementia was at a moderate to severe level, meaning that he was likely to forget the contents of the tape, which is an advantage for this approach (Bayles et al., 2006; Werner et al., 2000). He did, however, retain some conversational abilities, another predictor of positive outcomes (Bayles et al., 2006).

SPT intervention

Two sessions were spent with Norma discussing the prospect of SPT. Norma was keen to talk about John and her experience of the dementia. She clearly missed him as he was. While she was slightly apprehensive about how John would receive the tape, she reported enjoying the process and was very creative about how to make it an emotionally positive experience for John. She decided

that it would feel most natural if she recorded her voice as if she was having a telephone conversation with John, a method that was successfully used in a study of SPT (Garland et al., 2007). She created a 15-minute recording about memories they had together of going to concerts, musicians they both loved, family members and events that were positive and significant, all laced with expressions of love and adoration. The most challenging element for Norma was keeping to memories from a long time ago, as suggested by Werner et al. (2000), rather than more recent memories.

The period after meal times was identified as a time that John became particularly agitated, perhaps because Norma's weekly visits were after lunchtime. We therefore decided to implement SPT after lunch. On the first occasion John listened to the tape with me shortly before Norma was due to visit. He seemed delighted that Norma had recorded a message for him and listened intently. Norma joined us immediately after he had listened to the tape, affording us the opportunity to discuss the tape before he forgot about it. He responded extremely well to the recording, remarking that it was 'beautiful' and how lucky he was to have his wife's love. Norma also seemed pleased with his response and proud of her achievement. The conversation quickly moved onto other topics and John had forgotten about the recording when we reintroduced it into the conversation minutes later.

A file including record forms and SPT instructions was given to the care team. I nominated Sue, one of the more enthusiastic and senior care team members, to lead the implementation of SPT, with my weekly input. She seemed keen to take this role. I went through the record sheets and instructions with Sue initially, and we then attended a staff meeting together to pass this onto the team. Three other team members who were enthusiastic about SPT and felt they had a good relationship with John, were identified to be the key SPT implementers.

The plan was to implement SPT twice daily, after lunch and before personal care times (usually evenings). It was also agreed that if John became agitated, SPT could be used as a strategy to help keep him calm once other de-escalation strategies had been used. The idea was to use SPT to lift John's mood, in a largely preventative way.

This was implemented for a month and was usually facilitated once daily. The plan was for care staff to continue implementing this indefinitely and to regularly review SPT with his wife to maintain optimal benefits and reduce the risk of SPT becoming less effective over time, as noted in Cheston et al.'s (2007) study. At the end of my input, a template for reviewing SPT was left with the team, outlining what to look out for and what to do in the event of a setback. John was discharged from psychological services.

Evaluation

John made significant improvements over the course of the intervention. His agitation and behavioural difficulties reduced significantly, his mood and quality of life seemed to improve and his relationship with his wife also seemed to be enhanced. The primary evaluation of John's improvements was the reduction in number of aggressive incidents from twice per week, to only one incident in two months. This change did seem to coincide with the introduction of SPT.

The recording of John's agitation levels before and after SPT suggested it was contributing to his well-being. In the first 23 times he listened to the tape, John's agitation level reduced every time, apart from once. Staff recorded his response to the tape, qualitatively and quantitatively each time. One comment, which was representative of most, read: '(John) listened carefully to the tape, taking it in, very happy at the end, smiling and pleased to hear Norma'. The chart below shows an improvement in John's mood/agitation levels from pre- to post-listening to the tape.

Table 1: Simulated Presence Therapy.

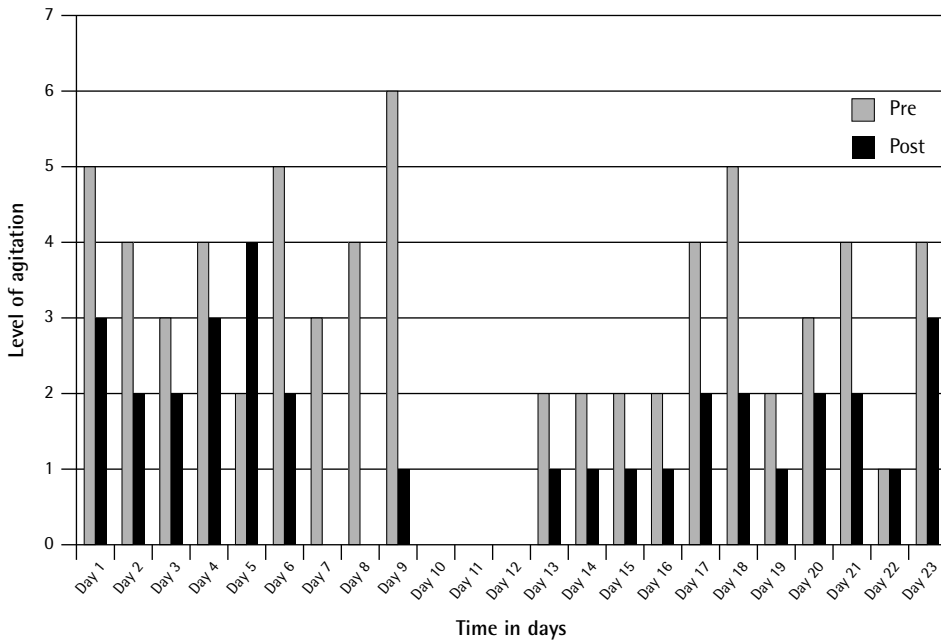


Table 1 shows how John’s agitation rating seemed to decrease each time the tape was played to him, apart from on day five, when his rating went up.

Quality of life

John’s quality of life rating, as measured by the QOL-AD questionnaire, improved from 26/52 to 34/52. Sue rated the quality of his ‘mood’ and ‘life as a whole’ as changing from ‘poor’ to ‘good’ at post-treatment. She rated his marriage as changing from ‘good’ to ‘excellent’ and his ‘physical health’ and ‘self as a whole’ as changing from ‘fair’ to ‘good’. She also felt that his ability to do chores had improved from ‘poor’ to ‘fair’ as he had started shaving and dressing more independently.

John’s perspective

John’s speech seemed to include more positive content as time progressed. During the assessment phase, he often communicated worries or complaints, whereas during the intervention phase, he would be more likely to tell me about more positive thoughts or events. He remained disorientated, but seemed less agitated about this.

Norma’s perspective

Norma reported enjoying visits more. She also started telephoning John more regularly. She said he seemed more engaging and chatty and seemed to be smiling more. Norma’s involvement in SPT allowed her to feel that she was contributing to John’s care, even though she was not able to live with him, which in turn seemed to reduce her feelings of guilt about his move to a care home.

Observations

Staff reported that John seemed more relaxed and that they had not experienced any difficulties with him for a long time. He seemed to be pacing around the care home and asking for his wife less. They also said they felt much less on edge with John, and felt he was less 'irritable'.

Discussion

While the evidence base for SPT is relatively sparse, this intervention has seemed to fit well with the existing literature. In keeping with the meta-analysis (Zetteler, 2008), John did experience a reduction in disruptive behaviour, agitation and distress following each session of SPT. His quality of life also seemed to improve, a goal of SPT that Cheston et al. (2007) advocate. John seemed like a good candidate based upon attachment (Peak & Cheston, 2002), severity of dementia (e.g. Bayles et al., 2006) and the quality of his relationship with Norma (Werner et al., 2000), which may have contributed to the success of SPT. SPT was largely used as a preventative measure, being scheduled in at particular times, following the guidance outlined by Woods and Ashley (1995). However, there were a few occasions where John was given the tape to listen to when he was feeling agitated, and on these occasions, his agitation consistently reduced from 6/10 to 0,1,2/10. This may indicate that Miller et al.'s (2001) approach to SPT at times of crisis is also a viable technique. Also, given the possible side-effects of anti-psychotic medication for challenging behaviour (Douglas et al., 2004; Ayalon et al., 2006) it was particularly encouraging that this non-pharmacological approach significantly reduced John's agitation.

Conclusions

This work gave me a glimpse into the world of someone with dementia and the challenges that they and their carers have to overcome as well as the lack of resources available to educate and support carers of people with dementia. These observations seem in line with the Alzheimer's Society's (2009) request for the Government to triple dementia research funding.

I have also reflected on the potential longevity of this intervention, given the degenerative nature of AD. John may get to the stage where he has forgotten who his wife is, making the SPT intervention obsolete and the more practical techniques, more significant.

Overall, this was a rewarding clinical experience and I felt privileged to have known John and Norma. I found that I was investing a great deal of emotional energy into this work. This may in part be due to the emotional impact of observing the difference between John when he was relaxed and content, compared to his distress when he was wondering where his wife was and becoming agitated as a result. This highlighted his potential to me and I always felt that there would be a way to support John and the system around him to maximise the amount of time he spent feeling content.

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The looking glass selves: A support group for people with dementia

Claire Appleton

In this article I will describe the development of a support group for people in the early stages of dementia which has been running for approximately four years in the Gateshead Area. The group, known as the 'Living with Dementia Group', continues to evolve both in terms of its membership and its core functions.

Impetus for the group

THE National Service Framework for Older People (DOH, 2001) standards two and seven, highlight the need to ensure that older adults, including those with dementia, are treated as individuals, that they receive an appropriate and timely package of care which meets their needs and that their mental health is promoted and supported. The National Institute for Clinical Excellence (NICE, 2006) guidelines for dementia emphasise the need to promote and maintain the independence of people with dementia. More recently the National Dementia Strategy identified the development of peer support and learning networks as one of its 17 objectives (DOH, 2009).

Locally the impetus for this group came largely from the Gateshead branch of the Alzheimer's Society (GAS) who had for several years provided courses for carers of people with dementia (PWD). These groups are usually short term and combine both information and general support. Feedback from one such group suggested that a joint support group should be set up for both people with dementia and their carers. A working group (composed of a combination of voluntary sector and NHS staff) was set up to examine the possibilities for setting up such a group.

In terms of the literature a growing number of accounts discuss several benefits of psycho-educational groups for both clients with dementia and their carers including improvements in the levels of

depression and coping ability (see Mason, Slatter & Sincock, 2006, for a brief review). Both Yale (1995) and Aggarwal et al. (2005) have suggested that meeting with others provides individuals with a sense of hope, can reduce feelings of isolation, facilitates catharsis, altruism and allows for the exchange of coping strategies.

One of our main dilemmas was whether to have a joint group for both carers and individuals with dementia or whether to focus solely on people with dementia (given that there were existing resources for carers). A discussion amongst the facilitators suggested that there might be advantages and disadvantages of including carers which have been touched on in the literature (see Mason, Slatter & Sincock, 2006). The presence of a carer may lend itself to continuity between sessions and for the generalisation of useful aspects of sessions to home life. Possible disadvantages of carers attending include the presence of different agendas, for example, a carer/guest may wish to heighten insight within the context of a particular interpersonal dynamic.

After much discussion it was decided that we would aim to pilot a short-term group solely for PWD. We felt that at a time when many roles have been lost it might be useful to give members the opportunity to meet without carers in order to maintain a sense of autonomy.

The aims of the pilot group were:

- To provide a time limited support, information and activity group (eight sessions on a weekly basis).
- To allow an opportunity for socialisation reducing isolation and the realisation that the PWD is not alone.
- To allow for fears and worries to be shared openly in a supportive environment.
- To provide an opportunity for coping strategies to be exchanged and to facilitate problem solving.
- To encourage members to take an active role in the group and also in their everyday life.

Pre-group questionnaires/ needs assessment

In order to further assess the needs of potential group members we sent a questionnaire to 12 users of a hospital day unit which catered for people with dementia and four individuals with a diagnosis identified by an advocacy worker. They identified several areas of interest which were then included in the eight-week programme.

Screening and selection

Potential participants were identified via the above questionnaires and screening was carried out by three members of the team.

Yale (1995) has identified the importance of screening individuals thoroughly before including them in a support group. During the screening interview the following areas were covered:

- An explanation of the purpose of the group.
- Establishing awareness of diagnosis (this was a complicated procedure which had to be carried out sensitively in order to prevent potentially distressing an individual with little insight into their condition).
- Further information (i.e. was there anything in particular they wanted to know relating to dementia).

- Mood State (as measured by the Hospital and Anxiety and Depression Scale).
- MMSE (in order to assess level of cognitive impairment).

Out of the six people screened initially four were felt to be suitable for inclusion in the group and one person was felt to be unsuitable because of the degree of cognitive impairment she displayed (i.e. she was significantly more cognitively impaired than the others). The other person declined to take part in the group. A further two candidates were identified by the specialist dementia nurse at short notice. Therefore, at the beginning of the group there were six members (five male and one female) all with a diagnosis of dementia of varying types (three were diagnosed with dementia with Lewy Bodies, three with dementia of Alzheimer's type). After the first session one member (the female) dropped out of the group due to ill health so effectively the group was an all male one. All five members had early stage dementia (i.e. a MMSE of 20 or above). Only one member had clinically significant levels of anxiety as identified by the HAD.

The group itself was organised and run by a range of Alzheimer's, NHS and social services staff (including a clinical psychologist, advocacy worker, dementia support officer, psychiatric nurses, dementia specialist nurse and latterly a social worker).

Group content

The structure of each two-hour session was split. The first part of the session involved an outside speaker coming to talk to the group about various topics. After a coffee break there would be an open session where group members had the opportunity to talk informally about any issue. Table 1 briefly summarises the content of the programme.

The life of the group: Overview

The initial pilot group was very well received and the members indicated that they wished it to continue. This initial group has continued to evolve, moving through several phases over the past four years which are

Table 1: Content of the first eight-week course.

Session	Content
1	Setting the scene: The purpose of the group was explained, ground rules covered including confidentiality, a video of a support group for people with dementia to further orientate members to the idea.
2	Psychiatry: A local psychiatrist provided an overview of dementia including different types, biological basis (in non technical terms), the effect of dementia on memory, the course of dementia, current treatments available.
3	Life story work: This session was due originally to be taken by an occupational therapist with a focus on how memory works. Unfortunately due to circumstances the occupational therapist was unable to take part in the group and instead an advocacy worker and group facilitator discussed life story work and the potential benefits of such work.
4	Benefits advice: A benefits advisor from a local voluntary organisation talked about the various benefits that people may be entitled to and the criteria which would have to be met for each benefit. As with all of the other talks written handouts were provide to allow for the consolidation of information and were placed in individual folders which group members could take home and discuss with their carers if they wanted to.
5	Support services available locally: An outline of services available locally including those provided by health, social services and the voluntary sector. Interestingly this session prompted a great deal of discussion around people's hopes and fears regarding the future including the possibility of requiring nursing and residential care. From a psychological point of view it seemed to provide a very useful opportunity to ventilate such feelings of fear in a safe environment which allowed for containment by both the facilitators and other group members. It was felt that the openness with which members talked about their fears suggested that as a group they were becoming more cohesive and supportive towards each other as the group progressed. In the second part of the session an occupational therapist talked briefly about how memory works and various strategies.
6	Health and Well-Being Session: This session focused on general well being with a talk from a nutritionist on the benefits of healthy eating. This session included a tasting session where fresh fruit was provided. In the second eight-week course we included a session on psychological coping strategies, for example, dealing with stress, different perspectives on problems (CBT influenced) and forms of support.
7	Group choice: The group decided to use this session to visit a local museum.
8	Farewell session: Brief recap on areas covered, thanking of participants for their contribution. Ways forward were discussed including the possibility of the group continuing.

summarised in Table 2. Each phase can be thought of as involving various 'tasks' or activity areas.

Various aspects of psychoanalytic thought are useful in considering the various phases that groups go through and the tasks that might be encountered. Attachment theory (Bowlby, 1988) can provide a useful framework with which to consider how a group develops and matures. Initially individuals are required to come together and develop an attachment to the group. During these early stages it was felt appropriate for facilitators to provide more structure in order to provide a safe, holding and containing environment to contain group member's anxieties and fears (Bion, 1961). As the group matures and its identity develops it begins to act as its own container and becomes less dependent on its facilitators. This has been demonstrated on several occasions within our group but perhaps most movingly when one of the member's partners died. The group members were able to provide a containing role and have appeared this member's transition to widowhood. Had this event occurred earlier in the life of the group one can imagine that it would have been the facilitators and not the group members who would have been concerned more about providing this kind of support.

Evaluation and follow-up

The main source of evaluation has been from questionnaires and semi-structured interviews with participants. Feedback from both the first and second groups was very positive, both from group members and their carers.

A simple questionnaire was administered at the end of the first eight-week course. Participants felt that they had gained a greater insight into their dementia and that it had been beneficial to have the group exclusively for people with dementia. Carers comments also reflected the benefits of having a separate group, for example, one carer commented 'I think (group member) benefited as it was nice for him to get out on

his own among a group and be independent. I thought it was also good for him to discuss things with other people'. There was also the suggestion from several carers that attendance at the group had the unexpected benefit of respite for them with comments such as 'I knew he was out and it meant I had the afternoon to myself – but I also knew he was enjoying himself'. Several carers felt that it was important for the group to remain exclusively for people with dementia because it facilitated time apart whilst also promoting a sense of independence for the person with dementia.

With the second group of participants a person out with the group (a clinical psychologist) was asked to evaluate it. We felt that this would facilitate a greater degree of objectivity. A combination of a Likert-style questionnaire and a semi-structured interview were used with both group members and carers in order to obtain their views on the group. As with the first group there was good attendance with no more than one person missing a session. Participants had felt that the group had made them feel more confident, supported and that it had helped them adjust to having dementia. All of the participants said that they would recommend the group to other people. When carers were interviewed they felt that the group had helped their client/family member adjust to having a diagnosis of dementia and that they would also recommend the group to other people. Sixty-six per cent of carers (N=4) also felt that it was appropriate that the individual attended on their own (without the carer). Benefits that the participants and carers believed had achieved via the group pertained to the opportunity to socialise with others and education about dementia. Qualitative interviews suggested that the carers believed the group had been useful in both emotional (confidence and happiness) and behavioural (becoming more active) development of the person with dementia. Benefits to the carer mainly focused around respite.

Table 2: The different phases of the Dementia Support Group.

Phase 1	Phase 2
<p>First eight-week course Main areas of activity, cohering as a group, developing a secure safe place in which participants can share experiences and make decisions. Structure was important in terms of providing containment.</p>	<p>Monthly meetings Participants continue to share experiences and there is more of a trend towards members making decisions in terms of the nature and purpose of the group. Issues of loss are raised as several group members experience physical health difficulties and deterioration in their cognitive ability.</p>
Phase 3	Phase 4
<p>Second eight-week course As above, this time the group has a very different feel; group participants are far more talkative and eager to share their experiences. Friendships are made which are lived outside of the group.</p>	<p>Monthly meetings Participants from the first and second eight-week groups join together to form a larger group. This group coheres fairly quickly. Loss again permeates the group with the death of two of its members and the significant cognitive deterioration of another. In spite of this the group remains a lively and creative force. Participants show increased autonomy in terms of decisions inside and outside of the group and express their appreciation for their peers. Members are involved in several consultation exercises including the National Dementia Strategy. They also share their views on the process of receiving a diagnosis of dementia which helps to shape local clinical procedure in this area (see Buckinghamshire in this edition).</p>

Conclusion

Our experience suggests that there were many benefits in developing a support group for people with dementia.

Benefits to the group members and their carers

Both group members and carers were able to highlight specific benefits from attending the group such as the opportunity to meet others in the same situation, the promotion of independence and autonomy and the opportunity for respite for carers.

Discussions within the group highlighted the difficulties for people with dementia in maintaining or preserving their identity. This is described in detail in a paper by Gillies and Johnston (2004) who conducted interviews with people with dementia and compared the difficulties they experienced vis a vis identity preservation with cancer patients. They refer to Cooley's (1902) concept of 'the looking glass self' to describe how we are a reflection of what others observe in us. 'Thus how we develop self esteem is through a process of reflected appraisal and we can only know our own self, our social identity, through the responses of others' (p.439, 2004). As in Gillies paper we observed how dementia respondents appeared to reclaim their identity through reminiscing about earlier life achievements but that furthermore they appeared to use the group and each other to weigh up their current strengths in the face of constant reminders from others (e.g. family, friends and professionals) of their decline.

Benefits to facilitators/the services

Facilitators felt their understanding of the experience of people with dementia was genuinely deepened. The initial anxiety on the part of the professionals regarding the resilience of group members lessened as we became aware of the general resilience of group members. As such we feel that this experience fundamentally changed our own assumptions of the abilities of people in the early stages of dementia.

Multi-disciplinary working enhanced links between the voluntary and statutory services and we believe led to the more appropriate use of resources (e.g. cross referral).

Importantly the group provided an opportunity for users to actively inform service provision. This began in the initial screening procedure when we became aware that it was not always clear who had been told had a diagnosis of dementia. This led us to think in some detail about this process in terms of the dual processes of informed consent and disclosure of diagnosis. A focus group was held with group members in order to gain their views about the process of obtaining a diagnosis which has been used to inform service provision within the Gateshead area. The results from this study will appear as a paper (Buckingham, Appleton & Collerton, accepted for publication) in the next edition of the *PSIGE Newsletter*. In addition members have been actively involved in consultation regarding the National Dementia Strategy.

Final thoughts

Our experience of setting up a support group for people with dementia has illustrated that they can have a valuable role in helping to preserve the person's sense of identity and lessen their sense of isolation. Furthermore with minimal guidance such groups can help participants deal with the inevitable losses and chronic stress that such a condition can engender. Finally the development of the support group has helped us as professionals think about how we provide services to this group generally and has influenced service provision in related areas.

Acknowledgements

The author would like to thank and acknowledge all members of the living with dementia group and to the core facilitators of the group: Yvonne Curling, Dorothy Lumsden, Julie McAlpine, Annie Osbourne, Joyce Stratford and Carol Wilson.

Grateful acknowledgements also to Stuart Sadler, Clinical Psychologist, who helped evaluate the second living with dementia group and whose questionnaire has been used subsequently.

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A toe in the water: Person-centred counselling approaches to working with people with dementia

Pamela Bruce-Hay, Penny Dodds, Sally Stapleton & Clare Crellin

Written by three different authors from three different professional backgrounds this article shows the varied ways in which the Person Centred Approach to working with people with dementia is being used in Sussex. The authors, Pamela Bruce-Hay, a Person-Centred Counsellor at Salvington Lodge Hospital, Worthing, Penny Dodds, a Nursing Lecturer Practitioner in West Sussex, and Sally Stapleton, a Clinical Psychologist in Worthing and West Sussex travelled along very different paths each developing a distinctive approach to Person-Centred practice. In the article which follows, Penny Dodds introduces Prouty's Pre-Therapy Contact Reflections as the framework from which she teaches day care and ward staff how to make contact and emotional connection with people with dementia. Pamela Bruce-Hay has integrated Prouty, Lipinska and Kitwood into her one-to-one counselling. She shows how she succeeds in helping clients with dementia to establish contact with reality, with themselves, and with another. Sally Stapleton has drawn on her training as a Dementia Care Mapper in developing a person-centred approach to neuropsychological assessment. She is also involved in bringing about an organisational and local 'tide of change' through developing psychological mindedness based on Kitwood's principles. In this article, each of the three authors shares a unique experience of trying to step into the world of the person with dementia that they are working with, an experience that they collectively describe as trying to 'dip our toes in the water'. These are highly personal and person-centred accounts that are nonetheless based on clearly articulated theoretical positions.

A Nursing Lecturer Practitioner's perspective

In my opinion (PD), in order to begin to communicate with people with dementia in a way which is person-centred, we need to offer staff practical strategies. It could be argued that some of the literature on person-centred approaches to dementia care focus on the values, principles and attitudes underpinning interactions, at the expense of practical and tangible ways of putting the principles into action. The Rogerian Humanist principles have been evident in the literature. Kitwood's work is underpinned by the person-centred philosophy (Kitwood, 1997). Likewise, Killick and Allan (2001) give descriptions of listening and responding which clearly show how they engage with the subjective experience of clients.

It is possibly rather confusing that the term 'person-centred' has been adopted in dementia care as a short hand for a wide range of approaches which draw on a variety of different theoretical traditions (see Morton, 1999). However, in the psychotherapeutic sense of the word, person-centredness carries with it a theoretical and historical tradition. Embedded in this are the core components of being empathic, acceptance and genuineness in being with the other. Through this, the worker is able to attend to the subjective experience of the person with dementia; to see, notice and attend to their world. Arguably, this appears easier on paper than in practice. This may be especially the case when the majority of staff who provide the day-to-day care and interactions with people with dementia are those with the

least training, with little support for emotional work. The context and environment of day-to-day care for people with dementia in residential or inpatient settings is far different from a therapy room or environment.

There may be an inherent tension in asking people without a psychological or psychotherapeutic background to adopt a position of being person-centred in their interactions. It may be tempting to hold a nihilistic view that attaining person-centred practice may be unattainable, or that the difficulties in helping staff achieve ways of interacting, which hold within them the principles of person-centredness, are insurmountable.

Dipping my toe in the water

One approach which has been piloted in dementia care within Sussex Partnership NHS Foundation Trust has been the use of Garry Prouty's Pre-Therapy (Prouty, Van Werde & Portner 2002; Dodds 2008a, 2008b). Pre-Therapy stands out as being person-centred in the psychotherapeutic sense whilst at the same time holding the potential to have a very real practical application in the field of dementia care. In order to begin to try and move daily care nearer the waters edge, Garry Prouty's Pre-Therapy may provide a way into begin to change practice.

Pre-Therapy is the theory and practice of making psychological contact with people who cannot express what they are thinking and feeling, due to a disturbance of their emotional or mental health (Prouty et al., 2002). A therapist or worker uses particular techniques, called contact reflections, to facilitate the restoration of emotional contact. Contact reflections are the practical application and what the therapist 'does' in relation to the behaviour of the client.

The foundation of Pre-Therapy is the synthesis of two traditions within psychotherapy. First, the relationship focus of Rogerian person-centred psychotherapy. Second, the 'focusing' of Gendlin's existen-

tial psychotherapy, which emphasises reflecting that which is concrete, as a way to access the client's own experiencing process. Prouty's philosophical position is that humans live and experience their own perception of the world through a concrete, physical and 'embodied' way and that humans live in interactions with others.

Whilst the philosophical and theoretical foundations of Pre-Therapy are complex, the practical application of what the worker does is relatively conceptually simple. The techniques within Pre-Therapy are termed Contact Work. They are used with a person who is deemed to have difficulty in being in contact with themselves, their situation or environment and having difficulty making contact or connection with others. When a worker engages in contact work the worker aims to facilitate a person in having more contact with themselves, their surroundings and with others around them. To establish contact, the worker uses reflections.

Workers use concrete reflections of the person's facial expression, bodily movements, words and their environment or situation. The aim is to use reflections to establish a connection or engagement with the client – this is known as getting contact. Once contact, however minute, is indicated, workers may use reiteration – repeating contact reflections and observations of the person's response to reflections (Saunders, 2007). See Table 1 for examples of contact reflections.

It is through the use of the contact reflections, that the worker aims to facilitate the person to be able to move towards a position of being more expressive, more in touch with their own affect, moods, surroundings and facilitate greater contact or connection with others.

A basic principle of Pre-Therapy is that it ends once contact has been established. In other words, it is the process used to facilitate engagement, and, once this has been established, the worker moves on to using congruent responses.

Table 1: Examples of contact reflections.

Contact reflection	Action of Therapist	Example
Situational Reflections (SR)	The therapist uses the world around the person and makes a reflective statement about the situation. These reflections strengthen the reality contact function.	'John is standing in the corridor.' 'The birds are singing.' 'The chair is here.'
Facial Reflections (FR)	The therapist notices and makes a reflective statement about the client's face. These reflections strengthen the affective contact function.	'Grace's face is sad.' 'Your eyes are closed.'
Bodily Reflections (BR)	The therapist reflects verbally and/or non-verbally the body position, or movement of the client. These reflections strengthen the client's experience of themselves within their body.	'Anna's hand is on her head.' 'Shoulders are hunched.'
Word-for-Word Reflections (WWR)	Words or elements of sentences are offered back as a verbal reflection to the client. These reflections strengthen the communicative contact function.	Client: 'and you and it' Therapist: 'you and it'
Reiterative Reflections (RR)	These reflections rest on the idea of offering a statement that aims to re-contact or strengthen contact. Any contact reflection that has worked is repeated. This may be immediate or longer term where the therapist refers to a previous dialogue.	Client: smiles. Therapist: 'you smile.' (Client: has eye contact with therapist.) Therapist: 'you look at me and smile.'

So, if we are asking staff to dip their toes in the water, to be able to hold a position of being person-centred, attuning to the subjective experience of the other, and having an openness to the experience of another, then it may be that the practical and accessible nature of Prouty's Pre-Therapy contact work is one way to achieve this.

A Person-Centred Counsellor's perspective

The recent publication of *Person-Centred Counselling for People with Dementia: Making Sense of Self* by Danuta Lipinska in 2009 was a ground breaking moment in person-centred counselling and dementia care. For me (PBH) this book sums up the experiences that I have shared with people with dementia in one-to-one sessions since I began using person-centred counselling skills, alongside my work as an activities co-ordinator in an older persons' mental health unit in 2004. I have been working with people with

dementia as a person-centred counsellor within a hospital setting since May 2006. During this time, for one year, I have also provided one-to-one counselling and group sessions with service users of a respite unit and day centre for people with dementia. Further insight into the emotional impact of dementia has come from within my counselling relationships with carers of the above service users. This has provided me with profound learning experiences about how the lives of people with dementia affect those people who closely share their world.

Lipinska (2009) highlights that a common theme of counselling sessions with people with dementia is 'Making Sense of Self':

'In this unique narrative called "living with dementia" the names and places may be missing; the place where you were born, your school or career, the lovers, parents, even children may fade into the unremembered, made inaccessible by

damaged cells resulting in impaired function. And yet, part of the determination to Make Sense of Self finds a voice in the telling of the narrative in verbal and non-verbal ways. The spirit finds a way to make itself known, in accordance with or in spite of neurology, throughout the process of dementia until the very end of the journey and often beyond. (Lipinska, 2009, pp.24–25).

My experiences have mirrored those of Lipinska. In my own work as a person-centred counsellor there have been two overarching influences. The first has been Martin Buber:

‘The purpose of relation is the relation itself – the touching you. For as soon as we touch a you, we are touched by a breath of eternal life.’ (Buber, 1937, pp.112–113)

The second overarching influence has been Professor Tom Kitwood. When I began working with people with dementia I was astounded by the *lack* of relational experiences that people with dementia encounter on a day-to-day basis. I was also shocked to hear some of the views about person-centred counselling with people with dementia. For example, in the course of working with professionals from different care organisations, an individual said to me ‘There’s no point in offering counselling to people with dementia, we all know that their brains are scrambled.’

I was helped to understand these experiences by the work of Kitwood (1997). He described the concept of ‘malignant social psychology’. This helps to explain how the personhood of a person with dementia can be undermined by others. Episodes of malignant social psychology are not carried out by individuals with malicious intent, rather these episodes arise from a culture of care that does not recognise the psychological needs of people with dementia. The ‘old culture’ generally denied the existence of psychological need in people with dementia, or blanked it out with tranquilising medication. It involved only minimal interaction,

and then, mostly around basic care needs. Kitwood’s approach to the ‘new culture of care’ brings into focus the uniqueness of each person, respectful of what they might have accomplished and compassionate to what they have endured. It reinstates emotion as the source of human life, and emphasises the fact that our existence is essentially social. His new culture is committed to engaging with psychological need. It has a highly positive view of interaction, seeing it as the truly healing component of care.

Although Professor Tom Kitwood sadly passed away in 1998, the Bradford Dementia Group have continued to further his ideas for the benefit of people with dementia. I was pleased to see that Professor Tom Kitwood also referenced Martin Buber and, therefore, immediately felt I had a connection with his own writings.

Why offer counselling?

In my one-to-one work with people with dementia, I have learnt that individuals can encounter a number of different negative experiences in response to a diagnosis of dementia. The themes of these experiences are anxiety/fear, frustration/anger and grief/loss/low self-esteem.

In my opinion, people diagnosed with dementia need someone to empathise with their situation, without judgement, whilst offering support to enable them to deal with all the different emotions that they might experience. Each person is an individual in a unique situation and has their own way of responding to the many different problems faced everyday. Person-centred counselling can provide a safe, therapeutic environment for a person with dementia and their family when they might be overwhelmed by these difficult feelings. It can enable the expression, understanding and acceptance of such feelings and can help in coming to terms with them.

I imagine that the lived experience of dementia is like the water in a river that fluctuates constantly, yet retains its basic char-

acter. The river symbolises the true self that remains constant beneath all the outer changes that a person with dementia experiences. We can put one toe in the water and make contact with the ever shifting feelings of someone who is experiencing dementia. I imagine that there are occasions when the feelings and thoughts of someone experiencing dementia resemble a whirlpool, a swirl of disarray, chaos and confusion. How frightening to have to encounter this alone. How much better would this feel if one had someone to swim alongside of you until you reach calmer waters?

Christine Bryden, a lady with dementia who has written about her own experiences, validates these views:

‘In our crisis of identity and our fragmentation, we need you to acknowledge who we are, to listen to our emotion and pain and treat us with dignity, worthy of respect. The fear of future decline is a terrible thing to live with... So I believe it is wrong to deny us help with the whole gamut of emotions we will experience along the journey of their disease.’ (Bryden, 2005, p.131.)

‘Provide specialist counselling for us, as well as support groups if we would like to go to these.’ (Bryden, 2005, p.133).

I was saddened to read that in 2009, only six of the 240 branches of the Alzheimer’s Society offer a professional counselling service (Brown, 2009).

Dipping my toe in the water

‘The counsellor might be one of those persons who may be able to co-navigate the way forward into these uncharted waters; the quest of Making Sense of Self.’ (Lipinska, 2009, p.43)

As a person-centred counsellor working with people with dementia, I draw on techniques from Pre-therapy. For example, I use pre-therapy contact reflections to help clients with dementia establish contact with reality, with themselves and with others.

People with dementia express their experiences with words, movement, body

language, facial expression and situation. This can sometimes appear confused, muddled and even meaningless. However, pre-therapy techniques used within the framework of person-centred counselling can have a place in the ongoing communication that needs to happen if we are to provide a therapeutic environment and enable the person to re-connect with their world and the world around them.

‘When we walk our way and encounter a man who comes towards us, walking his way, we know our way only and not his; for his comes to life for us only in the encounter.’ (Buber, 1937, p.124)

As a person-centred counsellor, working empathically with clients who have either a confirmed diagnosis of dementia or an unconfirmed form of dementia, my concern is always to consider the quality of the relationship between myself and my client. I endeavour to understand, without judgement, their experiential world and their words and behaviour in response to it. I respect the client’s attempt to communicate and make themselves understood and I never underestimate their potential for growth. However, I am aware that as the symptoms of dementia increase, the ability to restore functioning becomes unrealistic and then I see my role as one of ‘being with another’ – an act of palliative care.

A Clinical Psychologist’s perspective

As a clinical psychologist (SS) I draw on a number of psychological models in my work with people with dementia. The most influential of these has been that of person centred dementia care, including the Enriched Model of dementia, originally proposed by the late Professor Tom Kitwood (Kitwood, 1997) and further developed by the Bradford Dementia Group (Brooker & Surr, 2005).

Dipping my toe in the water

In 2004, I completed my training as a Dementia Care Mapper. This has allowed me to develop other ways of trying to step into

the world of the person with dementia that I am working with. In 2005, I completed my advanced DCM training and in the same year, the eighth edition of DCM (DCM-8) was published. I was fortunate in being able to attend the first DCM-8 update training day at the PSIGE conference in 2005.

In DCM-8, the concept of 'personal detractors' (specific examples of malignant social psychology which undermine an individual's psychological needs) is paired with the concept of 'personal enhancers'. A personal enhancer is the name given to specific examples of care practice that support a person's psychological needs. As a clinical psychologist, I could clearly see the origins of these from within psychological therapy. In my experience, the provision of a list of personal detractors, and the alternative personal enhancers, provides the language through which care staff can generate ideas about how to helpfully support a person with dementia. This can apply to team members of any service who work with people with dementia or possible dementia. The concept of personal enhancers from DCM, therefore, gives information about ways that people can support a person rather than just knowing how not to support a person. This gives tangible ways of helping a team to meet a person's needs. When team members are successful, they are more likely to use these strategies again and feel more motivated and confident (e.g. Donnelan et al., 1988).

Neuropsychological assessment:

What's Dementia Care Mapping (DCM) got to do with it?

As part of my clinical psychology role, I provide input across a number of different teams. I draw on the theory of person-centred dementia care and concepts from DCM very frequently in my work with people with dementia within inpatient services or other care settings, as would be expected. However, I equally use concepts from DCM to inform my approach to neuropsychological assessment and feedback sessions.

I have been greatly influenced by Christine Bryden's comments on her experience of the neuropsychological assessment process.

'The psychometric tests were exhausting and I was puzzled as to why some things had seemed so hard and yet others quite easy. I had great difficulty remembering numbers, making pictures into a story, working out what was so special about the arrangements of blocks set out before me, and making my way through a maze. My mind was often blank when trying to recall the various shopping lists and stories.' (Bryden, 2005, p.98)

Objective Two of the National Dementia Strategy highlights the need for 'Good quality early diagnosis and intervention for all' (Department of Health, 2009 p.33). In my opinion, it is possible to offer 'Person-Centred Neuropsychology'. My neuropsychology practice has been hugely influenced by clinical psychologists who have written on the use of pre-diagnostic counselling (e.g. Williams, 2002; Williams, 2005; Clare, 2008). These approaches are underpinned by person-centred skills. Likewise, the presentation of the results of a neuropsychological assessment in the form of a therapeutic letter, is also an approach that is underpinned by a person-centred (in addition to narrative therapy) framework (Thorn, 2005).

I find myself using many different personal enhancers in my work with a person with possible dementia, during all stages of the neuropsychological assessment and feedback process. I am not suggesting for one moment that this involves deviating from the instructions in the neuropsychology test manual. This would not, in my view, be person-centred as it would result in invalidating the results, which is disrespectful to a person with possible dementia. I refer instead to the process of the neuropsychological assessment. The neuropsychological assessment process could be one that is filled with all sorts of personal detractors if the clinical psychologist is not very mindful. The way that I think about malignant social psychology and personal detractors

tions is that they are like walking down a path that is set with traps. They are just there, set, waiting for you to fall right into them. Personally, I find that I often experience that I can get into the trap of 'outpacing' a person (Brooker & Surr, 2005). I find that this sometimes might happen if a person has developed compensatory strategies, to help support their self esteem, in the face of underlying cognitive difficulties. When a person's compensatory strategies are working very effectively I am more likely to fall straight into the trap of 'outpacing' and go at a pace that is far too fast for the person. However, as soon as I notice myself falling into this trap, I can use my DCM skills to notice that this is happening, and then I know how to get out of the trap. My internal 'Dementia Care Mapper' voice switches on and gently advises me to 'go at a relaxed pace'. Christine Bryden offers similar advice:

'It is best to look at us, to make sure there is eye contact and that we are attending from the beginning of what you say. Speak clearly and not too fast. Slow down when you speak, so we can follow you, for we have gaps in reception and understanding – and the faster you talk, the more we will miss.' (Bryden, 2005, p.140)

On becoming a person-centred organisation:

The tide of change

Within the previous volume of the *PSIGE Newsletter*, you will see an article that my colleagues and I have written about our experiences with DCM in Sussex. You will notice that is written by representatives from a number of agencies and including people with dementia. For me, the model of person-centred care has provided a shared language with which to communicate on issues related to dementia care. Pamela, Penny and myself

are all Dementia Care Mappers and have each incorporated this role into our day-to-day work with people with dementia. As a clinical psychologist, I feel that it is part of my role to work within an organisation and help to support the development of psychological approaches and psychological mindedness for the benefit of service users, carers and staff. To continue the theme of water related analogies, I refer back to the writings of Professor Tom Kitwood. This is the first paragraph from his book *Dementia Reconsidered*.

'In the world of nature there are some tides that rise dramatically. The sea is a turmoil of gigantic waves; the cliffs tremble and spray flies into the air. Other tides rise quietly, creeping forward over miles of mud and sand, and causing no obvious disturbance. Although their advance is hardly noticed, they are powerful and persistent nonetheless. It is so too with the tides that change the course of human history.' (Kitwood, 1997, p.1)

This has been my experience of working within organisations that provide services to people with dementia. In many ways, we have come a long way, slowly and surely since Kitwood wrote this in 1997. Who could have imagined that aromatherapy would be suggested as a preferred alternative to medication within a NICE guideline (NICE/SCIE 2006) for working with people with dementia? 2009 has seen the National Dementia Strategy, entitled 'Living well with dementia' which will support a number of organisations in making improvements to services specifically for people with dementia. The title 'Living Well with Dementia' speaks of how perceptions of dementia have gradually advanced up the shoreline. My hope is that in the process of dipping our toes in the water, we will each contribute to the tide of change.

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A critical review of psychosocial interventions for dementia caregivers

Louise Roach

IN THE UK, there are currently approximately 700,000 people living with dementia; however, this is predicted to increase to over one million people by 2025 (Alzheimer's Society, 2007). Two-thirds of people with dementia live in the community; either alone or with family members (Alzheimer's Society, 2008) and family caregivers provide large amounts of care for people with dementia. It has been estimated that by providing informal care, family caregivers save the state approximately £6 billion per year (Alzheimer's Society, 2007). However, providing significant levels of care to family members with dementia is not without its consequences; as well as having social and financial implications for the caregiver, caregivers suffer higher levels of depression and anxiety, greater incidence of physical health problems and a shortened life expectancy (Schulz et al., 2005).

Given the large numbers of dementia caregivers and the significant negative consequences of caregiving, it is not surprising that there has been a substantial quantity of research evaluating psychosocial interventions for dementia caregivers. Although early studies judged interventions to be effective, they relied on measures of participant satisfaction rather than more standard outcome measures, such as emotional distress, burden or subjective well being (Sorensen et al., 2002). Critical reviews of the literature (e.g. Callahan, 1989) led to a resurgence of studies in this area with improved methodology. There is now large body of research literature, with numerous systematic reviews and meta-analyses conducted. Given the large volume of research and the limited scope of this article, the focus will remain on systematic reviews

and meta-analyses published concerning psychosocial interventions for caregivers.

Effectiveness of psychosocial interventions by outcome

Caregiver burden

Caregiver burden is one of the most commonly measured outcomes in intervention studies, usually measured using the Zarit Burden Interview (Zarit & Zarit, 1990), which includes both an objective and subjective measure of burden. At best, reviews have found a small effect size of interventions on burden (Knight et al., 1993; Pinquart & Sorensen, 2006; Sorensen et al., 2002), although others have found no significant effects (Acton & Kang, 2001; Brodaty et al., 2003; Selwood et al., 2007). Cooke and colleagues (2001) noted that only 30 per cent of studies included in their systematic review found a significant effect on caregiver burden, whilst for other studies, this has been as low as eight per cent (Acton & Kang, 2001). Trends have been found for individual interventions to have a larger effect on burden than group interventions (Knight et al., 1993), and for more recent studies to have stronger effects on burden (Pinquart & Sorensen, 2006), therefore, with methodological improvements in future, further meta-analyses may find stronger effects.

Emotional distress

Various outcomes, such as psychological distress, depression, anxiety and other measures of negative affect have been synthesised to form this outcome category. The evidence from systematic reviews and meta-analyses is much more consistent for this outcome; there is strong evidence that psychosocial interventions yield small to

moderate effect sizes for improvement in emotional distress (Brodaty et al., 2003; Cooke et al., 2001; Gallagher-Thompson & Coon, 2007; Knight et al., 1993; Selwood et al., 2007; Sorensen et al., 2002). Knight and colleagues' (1993) results suggest that individual interventions produce larger effects than group interventions, and cognitive behavioural interventions also seem to be particularly effective for reducing emotional distress in dementia caregivers (Gallagher-Thompson & Coon, 2007; Selwood et al., 2007). Small to moderate effect sizes of psychosocial interventions have also been found for subjective well-being amongst caregivers (Pinquart & Sorensen, 2006; Sorensen et al., 2002).

Knowledge and ability

Psychosocial interventions have been shown to have moderate effect sizes for increasing knowledge and abilities of dementia caregivers (Brodaty et al., 2003; Pinquart & Sorensen, 2006; Sorensen et al., 2002), both immediately post-intervention and also at follow-up, on average seven to 11 months post-intervention.

Care receiver symptoms

Studies have produced conflicting results regarding the effectiveness of psychosocial interventions for care receiver symptoms; Brodaty et al. (2003) found a moderate to strong effect size, however, this meta-analysis only included three studies which had used care receiver symptoms as an outcome measure, whereas two later meta-analyses, which included 28 and 33 studies examining care receiver outcomes respectively, both found very small effect sizes (Pinquart & Sorensen, 2006; Sorensen et al., 2002). Studies included in Brodaty et al.'s (2003) meta-analysis focused on care receiver depression as the outcome, as rated by the caregiver, which arguably may be more subjective and more likely to be influenced by a halo effect than the latter two meta-analyses, which included studies using measures of more objective outcomes, such

as cognitive and behavioural problems and functional skills.

Effectiveness of psychosocial interventions by intervention type

Psycho-educational interventions

Psycho-educational interventions are one of the most common intervention types, which may be due to the fact that they are often less resource-intensive than other interventions, such as individual psychotherapy. Selwood et al.'s (2007) systematic review argues that research evidence indicates psycho-education alone has little benefit and is not effective for caregiver burden, depression or distress. However, two larger meta-analyses have found that psycho-educational interventions have small to moderate effect sizes on burden, depression, subjective well-being, knowledge and care receiver symptoms. An interesting distinction has been found, however: information provision alone only has a significant effect on the ability and knowledge of a caregiver; psycho-educational interventions requiring active participation by the caregiver, for example, through role-play, have significant effects on burden, depression, subjective well-being and symptoms of the care receiver, as well as caregiver knowledge (Pinquart & Sorensen, 2006).

Skill building interventions

In a systematic review of the evidence base, Selwood et al. (2007) concluded that there is strong evidence to suggest that both individual and group interventions teaching coping strategies to caregivers are effective interventions for depression, although the evidence for the effects of these interventions on caregiver burden is inconsistent. A systematic review which combined both psychoeducation and skill building into one intervention category found a large effect size for such interventions on emotional distress (Gallagher-Thompson & Coon, 2007). It is interesting to note that although Pinquart and Sorensen (2006) categorised 'active participation' interventions as psychoeducational, this approach may well

be more accurately described as skill building, and the results from their meta-analysis were consistent with the systematic reviews described here; having significant effects on emotional distress and burden.

Psychotherapeutic interventions

The majority of studies of psychotherapy for caregiver distress have evaluated either a behavioural or a cognitive behavioural therapy (CBT) approach. In their systematic review of the effective components of caregiver interventions, Cooke et al., (2001) found that 42 to 54 per cent of interventions containing cognitive components led to improvements in psychological well-being. Selwood et al. (2007) reviewed behavioural therapy interventions, and found that behavioural approaches used in a group format, or individual behavioural interventions lasting less than six sessions were not effective for caregiver depression, burden or distress. However, individual behavioural interventions lasting six or more sessions were very effective for caregiver depression and the effects lasted to follow-up at up to 32 months. Another review has found CBT interventions to have a large effect on caregiver distress (Gallagher-Thompson & Coon, 2007), and a large meta-analysis found CBT to have a small to moderate effect on burden and a moderate to large effect on depression (Pinquart & Sorensen, 2006).

Multicomponent interventions

The evidence regarding the effectiveness of multicomponent interventions is conflicting. Multicomponent interventions have been found to have small effects on burden and depression (Acton & Kang, 2001; Gallagher-Thompson & Coon, 2007), but these findings are based on a very small number of studies. One meta-analysis found moderate to large effects on burden, well-being and knowledge (Sorensen et al., 2002), however, a larger and more recent meta-analysis found no significant effects of multicomponent interventions on most outcomes, other than a moderate effect on institutionalisa-

tion, which was significantly delayed following these interventions. Based on this inconsistent evidence, it is difficult to conclude whether 'more' intervention leads to better outcomes.

Limitations of evidence

Methodologically, studies evaluating psychosocial interventions for caregivers have been improving with time (Pinquart & Sorensen, 2006); however, the quality of studies is often short of current 'gold standards'. Meta-analyses and systematic reviews are dependent upon the quality of the primary studies that they review, and so poor primary studies lead to poor quality reviews.

Primary studies

Basic aspects of good study design are often lacking; for example some studies still contain no control group (e.g. Coen et al., 1999); if there is a control condition, participants are not always randomised to treatment or control groups. Drop-out rates are frequently unreported, and intention to treat analysis is not commonly used. There is often no consideration of whether a study has adequate power to detect significant effects (Pusey & Richards, 2001).

The design of the evaluation often lacks rigour, with a 'scattergun' approach taken to outcome measures, rather than clear thought about the theorised mechanism of change within the intervention, the expected changes and, therefore, the most appropriate outcome measures to use. The choice of outcomes and outcome measures in studies has also been criticised. The Zarit Burden Interview (Zarit & Zarit, 1990) is not thought to be a sensitive measure to change (Knight et al., 1993), and it has been suggested that burden may not be an appropriate outcome to measure (Acton & Kang, 2001) as it is a multidimensional and global concept, which may not change for caregivers as the person with dementia continues to decline and require increasing levels of care. Emotional distress may be a better outcome measure, as despite the inevitable

deterioration in dementia, the caregiver may learn new cognitive and behavioural strategies which reduce emotional distress despite the care recipient's decline and the consequent burden.

Participants in intervention studies are often self-selected, and frequently do not meet criteria for psychiatric 'caseness', which may lead to floor effects within studies, limiting the opportunity to detect significant effects of the intervention (Gallagher-Thompson & Coon, 2007). If it is not practical to limit treatment to caregivers with the poorest mental health, then an initial measure of psychological distress should be used as a covariate in the analysis (Knight et al., 1993).

Finally, the actual intervention procedure is usually poorly described and rarely manualised. This limits analyses of the effectiveness of different types of interventions, as review authors may have to make arbitrary choices as to which category an intervention belongs in. It also limits the ability of other researchers to replicate findings.

Systematic reviews and meta-analyses

Numerous systematic reviews and meta-analyses have been published, helping to synthesise the results of the caregiving literature. There is often disagreement between reviews, however, which may in part reflect the differing inclusion criteria used in these studies. Studies using random assignment to treatment or control conditions found smaller improvements for psychological distress, subjective well-being, ability and care receiver symptoms (Sorensen et al., 2002), therefore, reviews with less stringent inclusion criteria are more likely to report larger effect sizes, which may be spurious.

The majority of reviews have focused on interventions for dementia caregivers; however, some have also included caregivers of people solely with physical health problems (e.g. Gallagher-Thompson & Coon, 2007; Sorensen et al., 2002). This potentially reduces the weight of the review's conclusions, as the caregiving challenges

posed by physical illness and dementia are quite different; for example, caregivers of people with dementia have to cope with cognitive and behavioural problems, as well as the degenerative nature of the illness.

The attempt to evaluate which parts of interventions are most beneficial for caregivers, by breaking interventions into component parts, or grouping them into categories is an excellent research aim, which should be beneficial for clinicians when designing interventions in future. However, although conclusions have been drawn about the components or types of interventions that are most effective, due to the poor description of interventions in primary studies, these conclusions should be considered provisional at this stage, as classifications have sometimes been made somewhat arbitrarily.

Directions for future research

The advances made in caregiving research over the past 30 years is undoubtedly significant, however, many of the methodological recommendations made in Knight et al.'s (1993) article still need to be addressed. Aside from this, future research should move towards establishing when caregiver interventions are most effective, and for whom. People with dementia are cared for not only by their spouses, but also by their adult children. It is likely that the challenges faced by the two groups of caregivers will differ, due to the different type of relationship with the care recipient as well as different responsibilities, such as caring for their own children as well as working. Relatively little is known about which type of caregiver benefits from which type of intervention, although it has been suggested that spouses benefit less from interventions than adult children (Sorensen et al., 2002).

The quality of the relationship between caregiver and care recipient, premorbidly as well as at the current time, may well influence how much a caregiver benefits from an intervention. A premorbidly difficult relationship may lead to greater levels of psycho-

logical distress in the caregiver (Zarit & Edwards, 2008), as well as engendering a sense of hopelessness that nothing can be changed, limiting their ability to put newly learned strategies into practice. Preliminary evidence suggests that attachment styles in caregivers and care recipients are associated with differing levels of psychological distress (Magai & Cohen, 1998; Perren et al., 2007).

Our current understanding of the 'dosage' required for interventions to be effective is also limited; it appears that longer interventions are more effective in reducing levels of depression (Pinquart & Sorensen, 2006), however, future research should aim to establish what the optimum length of intervention is (Knight et al., 1993). Equally, little consideration has been given so far as to whether interventions are more effective at earlier or later stages of the care recipient's dementia (Gallagher-Thompson & Coon, 2007; Sorensen et al., 2002). One might speculate that early intervention may reduce the likelihood of later difficulties; however, it may be that the caregiver has relatively few problems to cope with at this stage and is unable to practise applying new skills or knowledge.

Future research studies may also benefit from looking at economic outcomes such as delayed institutionalisation, as well as reductions in psychological distress. Given the current spending restraint, interventions are more likely to be funded and supported if a sound economic case can be made for their use.

Conclusion

Since the initial evaluations of interventions for caregivers in the 1980s, this area of research has grown considerably. Dementia caregivers show less improvement from interventions than caregivers of people with physical health problems (Sorensen et al., 2002), which has been attributed to the multiple challenges that dementia caregivers face, including physical health, cognitive and behavioural problems, as well as the progressive nature of the disease. Despite

this, psychosocial interventions have been shown to be effective for reducing emotional distress and improving caregiver knowledge and subjective well-being (Gallagher-Thompson & Coon, 2007; Pinquart & Sorensen, 2006; Sorensen et al., 2002). Providing interventions for dementia caregivers is still worthwhile, it simply presents a greater challenge to clinicians and researchers to provide the most effective intervention for this group.

Within the NHS, clinical psychologists can play a key role in improving the evidence base, by evaluating the interventions that they offer and address the research limitations identified above in their studies. The NHS does operate with limited resources however, and so it is difficult to justify the use of interventions with very small effect sizes, or those which are effective for caregivers who do not meet levels of psychiatric 'case-ness'. A more fruitful avenue may be to work in partnership with voluntary agencies, providing supervision and research consultancy to staff providing the intervention. The responsibility lies with clinicians and researchers to improve the quality of the evidence base in order to justify developing new services to support caregivers, and improve the quality of life for both dementia caregivers and people with dementia.

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Meeting the needs of carers: Applying a CBT for Carers package to groups. Does it reduce levels of depression?

Candy Stone & Lisa Beevers

This article describes three pilot CBT for carers groups that have been delivered and led by psychological services in Oxfordshire since 2008. The authors discuss how they have modified an original package designed for individual therapy for group work. The content of sessions is summarised and the outcome of pre- and post-scores of depression and well-being measures are presented and discussed.

USING cognitive behaviour therapy (CBT) to help depressed carers is not a new intervention. Marriott et al. (2000) demonstrated in their randomised controlled trial (RCT) that a CBT for carers intervention can improve levels of depression and distress when compared with carers in two control groups (no interview/no intervention group and interview/no intervention group). Marriott et al.'s intervention package was derived and modified from a cognitive behavioural family intervention developed in the treatment of schizophrenia (Tarrier et al. 1988).

Individual therapy based on Marriott's package has been available in Oxfordshire for some time. It has been delivered by clinicians who have attended a three-day training course based on Marriott's model. Over the past two years, however, an increase in referrals of carers to psychological services has been observed. It is speculated that this is as a consequence of the launch of the National Dementia Strategy (Department of Health, 2009) and a document specifically focussing on the needs of carers (*Carers at the heart of 21st century families and communities*, DOH (2008)).

The term 'carer' for the purpose of this article is defined as any person who 'spends a significant proportion of their life providing unpaid support to family or ... friends' (DOH, 2008) and is a carer of someone with dementia. All participants of

the groups described in this pilot were spouses.

In order to deliver a timely and efficient service to carers of people with dementia, three pilot groups were delivered to depressed carers in north and west Oxfordshire. The groups were facilitated by two clinical psychologists (one for each area) and one other community mental health team (CMHT) member from each team.

The groups

Of the three groups, the first ran from 2008 and the second and third from 2009. Each group consisted of 14 sessions with each session lasting 90 minutes. Groups 1 and 2 ran fortnightly (over one year) and Group 3 ran weekly (over six months). Referrals came from GPs, Memory Clinics and CMHT staff. Carers were referred if they were struggling with their role as a carer, had difficulty coming to terms with the diagnosis given to their relative and had symptoms of depression.

Changes to CBT for Carers package

All facilitators had received training in house in individual CBT for carers. This package was modified for a group format by the authors.

In contrast to Marriott et al.'s original study (2000), carers of people with any type of dementia were included in the groups rather than just carers of people with

Alzheimer's disease. There was also less focus on the lengthy questionnaire used to elicit beliefs about dementia and the role of caring (Knowledge about Dementia Interview, KADI). The group programme involved a broader knowledge and discussion of different types of dementias.

There was also a wider discussion of coping strategies based on the variety of coping styles relevant to group members. Carers had the opportunity to learn from each other and each session was longer than individual sessions to allow time for discussion between members.

The programme

Marriott's model is based upon the stress vulnerability family coping skills model. The programme incorporates a number of components felt to be essential to equip carers to manage their emotions with their caring role. Sessions themes are presented in Table 1 below.

Group outcomes

Outcome measures varied across the three groups as there were questions about which would be most helpful and sensitive to distress and change in this client group. The authors were influenced by the choice of measures used in Marriott's RCT (2000). There were also changes in service requirements for outcome data between 2008 and

2009 with the introduction of the Clinical Outcomes and Routine Evaluation (CORE) (Evans et al., 2002) outcome measure.

Outcomes were measured for all three groups using a range of questionnaires and also a structured interview.

What outcome measures were used?

Table 2 shows what outcome measures were used. Individual feedback interviews took place for 12 individuals by two members of Psychological Services who were not involved in running the groups. They were asked the following questions as part of a structured interview:

1. Did you find the group useful? In what way?
2. Looking at the content of the group, which topics were most helpful and which were least helpful?
3. If you attend other carers groups, in what way this group different, if at all?
4. Did you experience any practical difficulties in attending the CBT for Carers group?
5. Would you change anything about the group?
6. Has attending the group influenced the way you are with the person you care for? If yes, in what way?
7. Is there anything else you would like to add about the group?

Table 1: Themes covered in CBT for Carers group.

What is dementia? Relaxation and how to look after yourself. Sources of support and lifestyle choices. Coping Strategies. Managing difficult behaviours. Thoughts – Feelings – Behaviour links. Thought diaries and thinking errors. Using cognitive behaviour therapy to reduce the stress of caring.

Table 2: Outcome measures used.

Group	Beck Depression Inventory (BDI)	Clinical Outcomes in Routine Evaluation (Core 34)	General Health Questionnaire (GHQ - 28)
1 (N=3)	✓	x	✓
2 (N=3)	x	✓	x
3 (N=7)	x	✓	✓

Were depression levels reduced?

The numbers of participants are too small to undergo sophisticated statistical analysis. Despite this, a reduction in scores was observed for 11 out of the 13 participants. Individual pre- and post-measure scores are presented in Figures 1 to 3 overleaf.

A reduction in scores is also reflected in mean scores of Core -34 and General Health Questionnaire -28. Despite carers reporting clinical symptoms of distress and depression at interview before the groups began, the outcome measures suggest only mild symptomatology on CORE -34 pre-group for Group 2 and moderate levels for Group 3.

Mean scores on GHQ -28 for Groups 1 and 3 are low, falling within the minimal range pre- and post-groups. The GHQ -28 was not administered to Group 2.

Mean CORE -34 scores

Mean CORE -34 scores		
	Before	After
Group 2	14.4	11.3
Group 3	16.04	13.4

General Health Questionnaire outcomes

Mean GHQ -28 scores		
	Before	After
Group 1	12	5.7
Group 3	6.4	6.4

Summary of structured interviews feedback

Of the 13 participants 12 were interviewed. All of the participants reported finding the group useful. Components reported to be most useful included relaxation and how to look after yourself, managing difficult behaviour and coping with caring. A number of participants also mentioned the value of the social support that they gained from being part of a group.

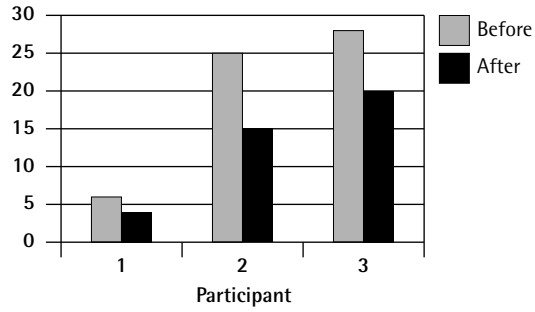
There were no clear themes when asked what was least useful. Some participants did comment however that there was never enough time in their day to do the CBT homework and complete diaries.

When asked if they felt the group had influenced their caring behaviours, participants felt they were more able to stop and think before reacting to stressful situations involving their spouse. They were also more aware of their own emotional reactions, felt they could manage their anger better and generally felt more able to cope with managing difficult behaviours.

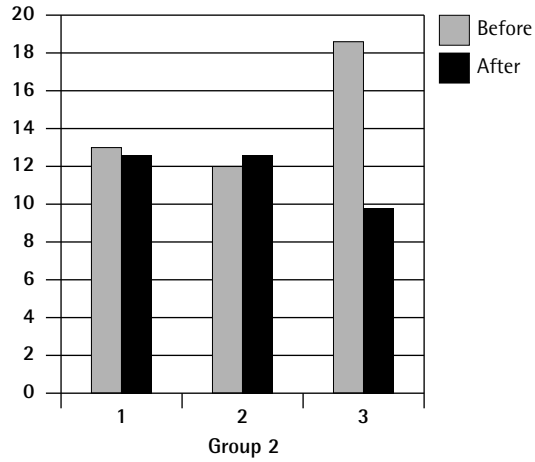
In comparison to more general open carers groups that carers had attended, the following quote summarised the general feeling of all participants:

'It was useful as it was focussed on the problems we face, in the other group (general open carers group) it's easy to talk about the day to day small talk things. As CBT group was more structured ... we could talk about our feelings and vent them. You don't get that in other group which is more practical. Our emotional needs are met in CBT group.'

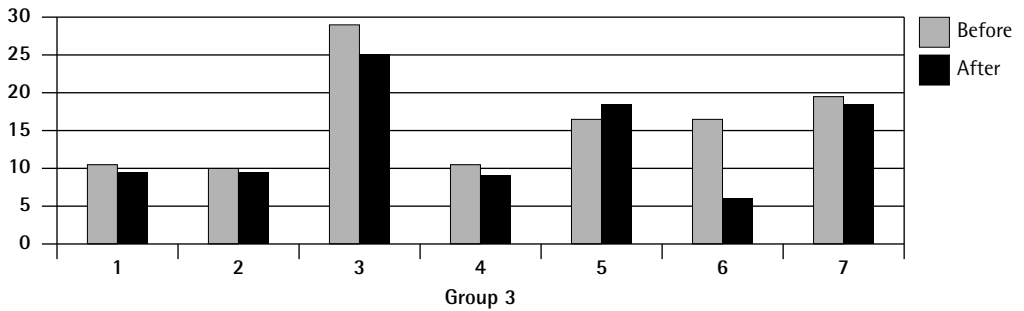
Pre- and Post-Group Beck Depression Inventory Scores for Group 1 (N=3).



Pre- and Post-Group CORE -34 scores for Group 2 (N=3).



Pre- and Post-Group CORE scores for Group 3 (N=7).



Other pertinent comments included:

'We all had a common bond.'

'I realised dementia is permanent and it isn't my fault.'

'The people in the group were willing to listen to and be direct with me which I like.'

'We were asked how we were as carers rather than how my husband with dementia is.'

No specific changes were recommended other than some queries about whether the levels of detail about dementia including pictures of the brain were necessary. Others commented that they would have liked the group to continue meeting or have more sessions.

Summary and conclusions

It is encouraging to see a reduction in scores in all measures used but these changes are small. The pilot's findings are limited by the small numbers in the three groups. This pilot did not employ a control group however in Marriott's original study (2000) depression scores in the no intervention group increased over time. Given that dementia is a progressive condition it could be hypothesised that participants in these pilot studies would have experienced an increase in levels of depression without the group intervention. A randomised controlled trial including groups is needed to support or dismiss this hypothesis.

The overall feedback about the usefulness of the groups is overwhelmingly positive and although there is not recognition from all carers that CBT itself was useful, it is interesting to observe that they report thinking differently and managing difficult behaviours better. The authors propose that this is due to a shift in cognitions about their roles as carers.

On the whole the authors felt that offering this package in a group format offered several benefits over individual work. It allowed carers to consider and learn from the experiences of others in similar positions and as the comments support, it also provides a social element to therapy that individual work can not offer.

Future CBT for carer's group work in Oxfordshire is being planned. No major changes are planned for the package as it exists. However, a broader range of outcome measures will be included. At the present time GAD -7 (Spitzer et al., 2006), PHQ 9 (Kroenke et al., 2001), GHQ -12 (Goldberg, 1978), Core 10 (Evans et al., 2002) and Relative Stress Scale (Ulstein et al., 2007) are being considered as alternatives to those used in this pilot study.

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A psychodynamic perspective on dementia care

Paul Terry

THERE IS an increasing body of literature on dementia from psychodynamically informed clinicians. A recent comprehensive review of the psychoanalytic and neuropsychological literature on the condition includes a discussion of its early, intermediate and advanced stages (Evans, 2008). The 'early stage' of dementia refers to the stage at which sufferers are aware of increasing memory problems, and the 'advanced stage' to when sufferers lose all independent capacities of language and bodily function, and are usually in institutional care. In this article, I will offer a psychodynamic contribution to thinking about the care of those who suffer from dementia, and, in particular, about the impact of dementia on sufferers and carers.

Dementia stirs unconscious fears that can have a profoundly negative effect on the quality of care and add to the distress of sufferers. These fears need to be understood so that carers can be helped to avoid contributing to their clients' disabled states. I shall concentrate on aspects of care with those at the early and advanced stages of dementia. These observations about care are also relevant to the intermediate stage, which I see as a transition between the early and advanced stages.

Fears of dependency and death

Dementia in its advanced stages can reduce its victims to abject dependency and helplessness, stirring in carers their worst fears of growing old. Psychodynamic and psychoanalytic counselling and psychotherapy with older people reveal ubiquitous fears of dependency and death (Terry, 2006). Fears of dependency in later life may be associated with difficulties in dependency relationships

in early life, when external factors, such as a maternal breakdown, or internal factors, such as envy, may interfere with a satisfactory mother-infant relationship. Following such difficulties, the anticipation of becoming dependent again in old age can bring an apprehension that dependency needs will once again not be met. Often these fears are unconscious, and sometimes alluded to in conscious fears of dying over a protracted time, and a dread that there will not be dependable love and care.

The psychoanalyst, Elliot Jaques, has described a typical unconscious experience of death, represented in the dream of one of his patients, in which the patient was lying dead in a coffin, sliced up though connected with a thread of nerve to her brain and so able to experience everything, knowing that she was dead but unable to speak or move (1965). This unconscious death experience is portrayed in actuality by people suffering from severe dementia, who are able to experience pain and distress but no longer able to communicate their experience, and thus reduced to terrifying states of helplessness, dependent on others for their every need. In contrast to dementia, however, in the unconscious experience of death, the self is still present, just as in conscious fantasies about death we imagine ourselves looking on at our funeral. The psychoanalyst, Franco De Masi, has pointed out that what is unimaginable is 'nothingness', i.e. the annihilation of the self (2004). Death is thus a psychological trauma unlike any other trauma, and essentially unthinkable. People suffering from dementia develop amnesia for their loved ones and ultimately for their own identity – an horrific experience of the loss of self that De Masi describes as so traumatic in the

anticipation of death. It is perhaps not so surprising that dementia sufferers are sometimes described as the 'living dead'.

Projective identification and dementia

It is especially important to understand the nature of underlying fears that are stirred by dementia, because if those who care for sufferers are not adequately supported then the carers' undigested fears can worsen the disabling effects of the illness. The process through which carers' unmanaged fears can add to the distress of their clients is termed 'projective identification'. This unconscious defence works by splitting off deep-seated unmanageable feelings, which are then believed to reside in someone else, often someone who has a particular vulnerability to such feelings. The unconscious belief affects our behaviour towards the other, and the unwanted feelings are induced in the other with the result that the other experiences those feelings as his or her own.

The projective process is illustrated in the following observation of people suffering from dementia in the dayroom of a dementia unit. The observation was made by clinical psychology trainee, Michele Cloherty, who as part of her training used to visit a dementia unit once week. Names have been changed to preserve confidentiality.

There are several older people seated in the day room. Apart from the observer no staff are present. One woman says, 'Someone has stolen my tin of biscuits, and we all know who it is!' She stares at one of the other women, who remains silent and seems unresponsive. One of the men, Mr Hart, is wearing a suit and tie. A carer comes in and says, 'Take your coat off Bill, it's too warm in here.' The carer leaves. Mr Hart then looks at a book of crossword puzzles and says nothing. His wife, who is visiting, sits alongside him and says crossly to him: 'Where is the pen? I'm not going to give you another pen if you're going to lose them!' Another woman, Mrs Reed, who seemed to be sleeping, opens her eyes and smiles at the observer saying, 'No more pens.' A different carer comes in and gives Mrs Reed a cup of

tea, telling her not to spill it. Mrs Reed tries to put the cup and saucer on the floor. The carer tells her where to put it. The carer leaves. Mr Hart's wife tells him to drink his tea.

Typically, in my experience, care staff spend minimal time with residents in such settings; a reflection, I believe, of the disturbing worries that are stirred by close contact with dementia sufferers. The exchanges between the carers and clients are infantilising, consisting of instructions as though to a small child. Client stories of theft are also familiar. In the above observation, the themes of the stolen biscuits and the lost pen suggest that these clients may be unconsciously aware at some level of what has been stolen and lost through the incapacitating effects of their dementia, and also through the way their carers effectively rob them of any remaining capacities by treating them as if they have none left. Underlying the carer's infantilisation of the dementia sufferers is a projection of dread of helplessness and dependency, feelings that find ready hooks in people who are afflicted by failing physical and mental capacities.

The observation continued:

Mrs Reed tries to get up out of her chair. The observer feels frightened that she will fall. Mrs Reed flops down in her chair. Later she tries to get up again. She manages to stand up just when a carer comes in and says, 'Sit down Eileen; you'll break your back!' Mrs Reed sits immediately. The observer is shocked. The carer leaves. Mrs Reed tries again. This time the observer feels like urging her on and wants to say, 'Come on, you can do it.' Another carer comes in and says to Mrs Reed, 'Sit down or you'll fall.' Once again Mrs Reed tries. The carer says impatiently, 'Sit down! What's the matter with you!'; and then, looking more closely, as though talking to a naughty child, 'Oh you've gotten yourself wet!' The carer brings a wheelchair and takes Mrs Reed away. (Terry, 2008)

This observation provides a shocking illustration of how someone suffering from dementia and struggling to assert their dignity can be reduced to the status of an

incontinent infant. Consciously, the carers are trying to help the client as best they can, just as most carers want to help their clients. However, following prolonged and unsupported exposure to the trauma and helplessness of caring for those in terrifying states of deterioration, carers may often contribute to the clients' disabled states, and in some cases commit acts of abuse. An added pressure on carers in our current culture of blame is the fear of ordinary accidents and mistakes, and the dread of litigation and punishment that may follow.

Projective identification works both ways, which means that carers can also be on the receiving end of powerful projections of unbearable feelings from their clients. In the illustration above, Mrs Reed may want someone to know and understand her terror of a mind that is falling apart. Carers may, therefore, need to be able to bear not only their own fears of dependency and death, but also those same fears in their clients. This is a tall order, particularly when carers are unsupported and no one is there to help them appreciate that their uncomfortable feelings are natural and understandable. If carers can be provided with support to think about their own feelings, they may come to understand more about the feelings of their clients, particularly those feelings for which the clients no longer have words, but which are induced in the carers in the hope that someone might be able to take in their emotional experience. Clinical psychologist and psychoanalytic psychotherapist Andrew Balfour has written of an experience of being in a group with people suffering from dementia, when he found himself becoming more and more irritated with a woman who kept screaming incomprehensibly at the top of her voice. When he said to her that he felt she was very angry, for a few moments she became lucid and spoke movingly of a relentless frustration (Balfour, 2007). Such understanding may not be able to change disturbing behaviour – Balfour admitted that this woman was soon screaming again. However, having some understanding can

make such behaviour more bearable for carers who are exposed to it for many hours each day.

The value of understanding and support

An understanding of projective identification contributes to various psychoanalytically informed non-verbal therapies which have been successfully developed for people with dementia, including art, music, drama and dance therapy, and which are particularly helpful in the intermediate stage of dementia (Evans & Garner, 2004). Helping carers to understand more about projective identification can also be a means of enabling them to understand and communicate with dementia sufferers, especially those in advanced stages of dementia for whom language is no longer available. Essentially, this means reminding carers of the sensitivity and receptiveness that a parent, especially a mother or primary carer, brings to caring for a baby who has no words. This is not to reduce dementia sufferers to infants, but to recognise that skills and sensitivities in parenting can be usefully drawn upon to help carers make sense of and find meaning in behaviour that otherwise might be dismissed as a meaningless source of irritation or 'attention seeking'. Carers need to be provided with support, time and space to reflect upon the fears and frustrations stirred by their work, so that they can contain such feelings rather than project them and thereby add to their clients' distress and incapacity.

It is also important to bear in mind that, unlike infants, dementia sufferers have long histories. Although dementia erodes and eventually erases the memories of these histories, carers can be important repositories for life stories and individual identities. It is particularly important therefore that carers are encouraged to know the histories of their dementing clients, because this knowledge can increase their sensitivity towards their clients when the clients can no longer explain their feelings and behaviour.

Carers need support to get to know their clients, because such knowledge and intimacy can bring greater anguish as they witness the clients' suffering. Without adequate support, carers may try to protect themselves by remaining detached and ignorant of their clients' former lives. Psychoanalyst Margot Waddell (2000) writes of a woman suffering from dementia, with little capacity left for verbal communication, who became very distressed at the sudden noise of an approaching storm. Her daughter was able to offer much more than the reassurance that it was only a storm because of her knowledge of her mother's history. She recognised and talked about how the noise must have reminded her mother of frightening aspects of her experiences in the Second World War. The mother was very comforted and calmed by her daughter's sensitive response.

If not adequately recognised and supported, the fears that are stirred in the presence of dementia can paralyse the ordinary skills and sensitivities in those caring for sufferers. We are used to responding creatively and playfully to the wordless states of infants, able to share enjoyment in pleasurable contact. However, the same capacities seem to petrify in the face of those who portray our worst fears of dependency and death. Two psychologists, Arlene Astell and Maggie Ellis (2010), have contributed to this field in developing an interactive technique that provides a means of helping carers to engage with those in very advanced stages of dementia, bringing back to life those who seemed lost forever in a deadly withdrawn, inert state. The technique releases and supports the same sensitivities and skills that are available for relating to an infant without words, and can restore a sense of fun and hope to those who are severely disabled by dementia.

Helping to bear what feels unbearable

An understanding of how dementia in its advanced stage can portray the unconscious experience of death, as well as inevitably lead to death, reveals the importance of

mourning. Someone in the early stages of dementia may be helped by being able to begin a process of anticipatory mourning, especially about the end of their life as they have known it. Loved ones may be helped too, if they can mourn the increasing experience of loss of those who are suffering from dementia. These experiences can be hard to face when they mean acknowledging loss that is so devastating and irretrievable. Thus it is not uncommon for family members sometimes to become frustrated and angry about the dementia sufferer's memory lapses and constant repetitions, as though such lapses were deliberate or could be overcome. While frustration is, of course, understandable, anger can be a protection against the painful knowledge that the loved one's forgetting is not deliberate or careless, but a symptom that will only get worse: eventually everything and everyone will be forgotten. I worked with an elderly woman, Julia, who became very irritable with her husband who was developing dementia. She wanted to leave him, and kept insisting that she was fed up with this much older husband. In fact he was only a few years her senior, but he had become a dreadful reminder of the vulnerabilities of being old. This woman became suicidally depressed. Her suicidal state projected her own fears of death into her carers who were worried she would kill herself. Julia's fears of death seemed to be stirred by her husband's worsening dementia, and contributed to her wish to leave him.

Valerie Sinason (1992) has written an eloquent and moving account of psychoanalytic therapy with a man who, because of early onset Alzheimer's disease, had to retire at the early age of 56 from a successful professional life. Sinason pioneered psychoanalytic work with handicapped children and adults, and developed an important understanding of how organic impairment can be exacerbated by emotional factors, contributing to what she describes as a 'secondary handicap'. In her work with this man in the early stages of dementia, Sinason discusses how 'a real organic loss shared a

parallel existence with temporary emotionally caused impairment' (p.97). In particular, when she was able to recognise and interpret this man's anger, he was able to remember words he had forgotten, and sometimes to resume speaking in coherent sentences. Quite soon in this work, Sinason's client spoke of his fears for the future. He asked if life would have any meaning if someone didn't know they were alive. Sinason replied, 'That would indeed be a death, to be stripped of meaning. It would be a death of the mind' (p.102). The client was clearly relieved by her reply.

Sinason's work provides echoes of the frightening impairment suffered by those in the advanced stage of dementia. Sinason's recognition of her client's dread of 'a death of the mind' provides a telling demonstration of how such dread is likely to accompany the news of a dementia diagnosis, and the knowledge that the illness is irreversible. There can be no easy reassurances about such dread. However, Sinason shows that real reassurance comes from being with someone who can bear to recognise and articulate the fear that can arise in the face of dementia, and thus help us to bear what feels unbearable.

Acknowledgments

I would like to express my gratitude to Michele Cloherty for giving me her permission to draw on her observational study of a dementia unit.

This article was first published in the *Healthcare Counselling and Psychotherapy Journal*, Vol. 10, No. 3, a quarterly journal of the British Association for Counselling and Psychotherapy.

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A review of psychological approaches to working with older adults with personality disorders

Louise Watts

DESPITE THE growing interest in personality disorders (PD) and their potential treatability, research relating specifically to older adults with PD is lacking. The appropriateness of diagnostic criteria and assessment tools used to diagnose PD in this age group has been questioned, making research in this area challenging. The current review aims to critically evaluate psychological approaches to working with older adults with PD. A review of the literature revealed just two empirical studies (and one case study) that had been carried out to specifically examine this topic, and had both focused on the use of dialectical behaviour therapy with depressed older adults. The studies are reviewed, followed by a discussion of the relevant literature, existing gaps within research, and recommendations for further research.

Key concepts

The DSM-IV defines PDs as ‘an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual’s culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment’ (American Psychiatric Association, 1994). ‘Normal’ personality is thought to be best conceptualised in terms of dimensions or traits. PDs are described as a set of categorical diagnoses (ICD-10; DSM-IV-TR). The DSM-IV classification system identifies 10 types of PD which can be grouped into three clusters. Cluster A refers to paranoid, schizoid, and schizotypal PD types; Cluster B refers to histrionic, narcissistic, antisocial and borderline PD types; and Cluster C refers to obses-

sive-compulsive, avoidant, and dependent PD types. PD not otherwise specified (PD-NOS) can be utilised when a person meets the general criteria for PD, but not for a specified type (APA, 1994).

There is ongoing debate about the clinical usefulness of the diagnosis of PD, as well as dispute over its categorical conceptualisation, which is said to lead to high levels of co-morbidity, overlapping symptoms, and unreliable diagnoses (Clark, 2007; Jablensky, 2002; Livesley, 2003; Millon, 2002; Tyrer, 2007). The use of a more dimensional approach has been advocated (e.g. Widiger, Simonsen, Sirovatka & Regier, 2006).

Rationale for review

Personality disorders in older adults

PD in the elderly has received very little research attention, despite the potential impact to complicate the course and intervention of other psychological disorders as well as the individual’s quality of life (Abrams et al., 2001). Furthermore, the number of older people in the UK is growing exponentially, and the numbers of older people who require help and support for severe and enduring mental health problems is rising (Morris, 2009). Despite this, older adults with PDs are often excluded from services, or treated by staff who lack skills, training and resources to provide an adequate service. Until recently, people with PD were considered untreatable by many agencies including specialist mental health services. Personality Disorder: No Longer a Diagnosis of Exclusion (Department of Health, 2003a) and the Personality Disorder Capabilities Framework (DoH, 2003b) were developed with the aim of

improving and redesigning services for adults with PD, including training for staff in delivering evidence-based interventions. Unfortunately, consideration of older people is lacking as exemplified in the NICE guidelines for anti-social and borderline PD (NICE, 2008) in which there is no mention of older adults.

Prevalence, assessment and diagnosis of PD in older adults

Studies indicate the overall prevalence of PD to be approximately 20 per cent in people over the age of 50 years (Abrams & Horowitz, 1999), and up to 63 per cent in inpatient populations (Molinari & Marmion, 1995). These figures are comparatively lower than estimates of PD in working age populations (Abrams & Horowitz, 1999). The view that PDs burn out with age (DSM-III-R; APA, 1987) has been moderated to current opinion that some types of PD (often Cluster B) remit with age (DSM-IV; APA, 1994 p.632). This view should however be treated with caution due to the difficulties inherent in the assessment and diagnosis of PD in older adults. For example, Segal, Coolidge and Rosowsky (2006) suggest that current criteria lack face validity for older adults; criteria for avoidant PD includes 'avoids occupational activity' which clearly does not apply to a retiree. Other difficulties include distinguishing between functional impairments caused by personality, rather than physiological or environmental aspects of ageing (Abrams & Bromberg, 2006), difficulties in obtaining information regarding age of onset and accounts of past functioning, a lack of PD assessment tools designed specifically for use with older adults (leaving clinicians relying on clinical orientation and/or counter-transference – Rosowsky & Dougherty, 1998), and the high level of co-morbidity with Axis I disorders such as depression (Morse & Lynch, 2000), and anxiety (Coolidge et al., 2000)

Treatment of older adults with PD

Older adults with PD often present to health services with co-morbid Axis I disorders (or

changes in cognition, or poorly treated medical problems) in the context of a recent stressor and/or dysfunctional interpersonal environment (Zweig, 2008). When co-morbidity exists, treatment efforts tend to be focused on the Axis I disorder, rather than the personality pathology (Abrams & Bromberg, 2006). Studies examining the outcome of psychological interventions have tended to focus on the impact of co-morbid PD on treatment outcome for depression (e.g. Thompson, Gallagher & Czirr, 1988; Gradman, Thompson & Gallagher-Thompson, 1999) rather than evaluating different types of intervention to determine efficacy. The evidence to date suggests that older adults are less responsive to mental health interventions, with personality dysfunction acting as a key factor in remission and relapse (e.g. Thomson, Gallagher & Czirr, 1988). Gaining a better understanding of the most effective ways in which to provide treatment to older adults with PD (with and without comorbid Axis I disorders), is key to providing evidence-based support to this population.

Literature review

Internet search engines and online databases (e.g. Scopus, Science Direct, Google Scholar, Pubmed) were used to search and access the literature. Search terms included personality, personality disorders, older adults, elderly, older people, psychological interventions, and treatment. A manual search of the references of key articles was also carried out to obtain additional relevant literature.

Inclusion criteria for empirical studies in this review were:

1. Studies related to older adults classified as having a PD.
2. Interventions that were based on a psychological model.

The following is a summary and critique of the available research examining the use of psychological interventions for older adults with PD.

Psychological interventions for older adults with PD

From the literature review, it was evident that although various researchers had advocated different psychological interventions for the treatment of PD, very few empirical studies had been carried out to evaluate the effectiveness of these approaches. The work by Lynch and colleagues (e.g. Lynch & Bronner, 2006) sought to address this issue, and to date two empirical studies (and a case study) have been carried out to support the use of Dialectical Behaviour Therapy (DBT) for depressed older adults with PD. A brief overview of DBT will be given, followed by a critique of these studies (see Table 2).

DBT was originally developed as a treatment programme for BPD (Linehan, 1993a,b). It is based on the biosocial theory which proposes that the dysregulation of a person's emotional system results from the combination of a biological predisposition to emotional vulnerability and an invalidating rearing environment. The aim of DBT is to help the client engage in functional and life-enhancing behaviours, even in the presence of intense emotions (Lynch et al., 2006). DBT uses techniques to intervene at the behavioural level (functional analysis) and cognitive level (e.g. skills training), and to provide support (empathy, trauma management). It combines individual with group therapy, the latter of which focuses on distress tolerance, emotional regulation, interpersonal skills, and mindfulness (Lynch & Bronner, 2006).

In the adult population, DBT has received a fair amount of research attention which points to its usefulness in working with personality disordered individuals (e.g. Linehan, 1993a; Linehan et al., 1991). Research examining the efficacy of DBT for older adults is still in its infancy, although this is an area in which interest is growing. Morse and Lynch (2000) believe that DBT may be useful in treating PD in older adults due to its use of multi-modal strategies to target social isolation, interpersonal effectiveness, mindfulness and attentional

control, suicidal behaviour, noncompliance and complicated grief. They suggest that these issues may be salient for older people.

In a preliminary study, Lynch et al., (2003) randomly assigned 34 depressed older adults (60 years and older) to receive 28 weeks of antidepressant medication with clinical management, either alone or plus group DBT skills-training and telephone coaching sessions (MED+DBT). To be eligible, participants had to score >18 on the Hamilton Rating Scale for Depression (HAM-D; Hamilton, 1960), or >19 on the Beck Depression Inventory (BDI; Beck et al., 1961), and to forgo any additional current psychotherapy. Exclusion criteria included diagnosis of bipolar disorder, psychotic symptoms, cognitive impairment, or current ECT. Clinicians who facilitated the DBT group had clinical experience with DBT ranging from six months to five years. The authors chose to use the Personal Style Inventory (PSI; Robins et al., 1994) to examine personality (specifically sociotrophy and autonomy). Results showed that the MED+DBT group led to significant decreases on self-rated depression scores. At six-month follow-up, 71 per cent of the MED+DBT group reached remission, compared to 31 per cent of the medication only group. This difference was significant. Only those in the MED+DBT group showed significant improvements pre to post-intervention on dependency, sociotrophy, and adaptive coping (linked to increased vulnerability to depression). Patients in DBT seemed less concerned about being liked or hurting others feelings, more able to say 'no' to others requests, less apologetic, and felt less responsible for other people's problems. They also showed a non-significant decrease in autonomy indicating movement towards being less self-critical, and greater willingness to accept help from others. The authors suggest that reductions in the severity of these unhelpful personality styles may buffer later encounters with stress, reducing the likelihood of depressive relapse.

Limitations of the study included the small sample size which limited statistical power in demonstrating between group differences (the authors were able to conduct exploratory analysis). There was also a large number of women in the sample, and a lack of description regarding antidepressant medication, and adherence rates. Treatments also differed in the amount of time the patient spent with a clinician, reducing confidence that the differences found were due to the DBT intervention. Furthermore, the DBT programme used differed from Linehan's version (1993a, b), and DBT therapists had not attended standard intensive training. This makes cross study comparisons difficult.

In the second study, Lynch et al. (2007) conducted standard DBT using both individual and group therapy (see Linehan, 1993a, b) with depressed older adults with at least one co-morbid PD. To be eligible, participants had to be 55 years or older, meet criteria for at least one PD, and score >14 on HAM-D (Hamilton, 1960). Exclusion criteria included a diagnosis of bipolar disorder, current psychotic symptoms, ECT treatment, or signs of cognitive impairment. All participants participated in phase one of the study: eight week medication (SSRI) trial. Those who did not respond to phase one (HAM-D score of <10) entered phase two of the study ($N=32$) where participants were randomly allocated to 24 weeks of continued medication management, or medication management plus DBT (MM+DBT). Prior to allocation, the Structured Clinical Interview for DSM-IV (SCID-II; First et al., 1997) and Inventory of Interpersonal Problems – PD (Pilkonis et al., 1996) was administered. The authors found higher rates of remission for the MM+DBT at post-treatment and follow-up, as well as faster rates of remission of depressive symptoms as compared to the medication only condition. At post-treatment and follow-up, the MM+DBT condition also showed lower levels of interpersonal sensitivity and interpersonal aggression.

Limitations of the study included the small sample size in phase two which again limited statistical power in detecting between-group differences. The study also focused on non-responders to medication, which may be a qualitatively different group to a more general sample of older adults with PD. Furthermore, the diagnosis of PD was made on the basis of self-report with no corroborative data sought (Van Aphen et al., 2007). The authors state that the reliability of informant data with this population is questionable due to the interpersonal difficulties that individuals with PD often have. Finally, no participants over the age of 75 years were involved in the study. This limits conclusions that can be drawn about the older adult PD population overall.

Based on their findings, Lynch and colleagues have now adapted the original treatment programme for use with depressed older adults with PD (Lynch et al., 2006, 2007). In the new adapted programme (DBTD+PD), an additional module called 'Radical Openness' is introduced to target cognitive rigidity, a construct thought to commonly occur in older adults with PD that has negative implications for treatment (e.g. Ehrlich & Bauer, 1996; Ogrodniczuk et al., 2003). A greater focus is also placed on the functions of behaviour specifically related to depression, for example, mindfulness aimed at reducing emotional avoidance. One of the key aims of DBTD+PD is to increase emotional experiencing and decrease emotional inhibition which has been linked to poor treatment response (Rosenthal et al., 2005) and suicidal ideation (Lynch et al., 2004).

Cheavens & Lynch (2008) provide a case example of Mrs P, an older adult who responded to an advertisement for treatment of 'emotional and personality problems' (DBTD+PD). She was interviewed using the SCID-II, and HAM-D, and completed several self-report measures. Mrs P met criteria for BPD and experienced significant depressive symptoms. Mrs P completed a full course of individual and

group DBT, alongside antidepressant treatment. Treatment focused on increasing DBT interpersonal effectiveness skills to help Mrs P establish more social support, reducing judgement of herself and others, and increasing value-congruent activities to develop her sense of self. At the end of treatment, Mrs P reported improvement in all areas (although reducing judgemental thinking was most resistant to change). She felt more connected to people, experienced a decrease in loneliness, and became aware of her values for the first time in her life. Post-treatment, her HAM-D scores reduced to a non-significant level of impairment, and she showed reductions in interpersonal aggression and interpersonal sensitivity. Mrs P denied any suicidal ideation up to two months post-treatment. Although this study provides a more in-depth descriptive account of the intervention Mrs P underwent, it lacks the evaluative qualities of an empirical piece of research and cannot be generalised. To further develop this adapted intervention, more rigorously designed research is needed.

Discussion

Given the debate and challenges associated with assessing and diagnosing PD in older adults, it is not surprising that research in this area is under-represented (Cheavens & Lynch, 2008). At present, studies have solely focused on the treatment of depression in older adults with co-morbid PD. PD symptoms have not been a target for intervention in their own right.

Research examining psychological interventions for depressed older adults with PD has so far been limited to DBT. Other psychological approaches have been advocated, but are yet to be empirically studied. Goisman (1999) states that CBT may be the most appropriate treatment for older adults with PD due to its focus on current symptoms, rather than characterological infrastructure (Segal et al., 2006). The cognitive aspect of the therapy may help the client to move away from an egocentric viewpoint,

creating opportunity for an expansion of behavioural options (De Leo et al., 1999). The use of Cognitive Analytical Therapy (CAT) has also been advocated for use with this population. In the adult literature, CAT has been manualised for the treatment of BPD and has been applied and recommended for later life problems of people with narcissistic and borderline PD, and post-traumatic syndromes (Hepple & Sutton, 2004). Hepple (2004) argues that CAT, as well as psychodynamic therapy, should be treatments of choice for this population. The evidence to support this conclusion is however unclear. Other psychological approaches which may be useful in the treatment of PD in older adults include mentalisation-based treatments (Bateman & Fonagy, 1999; 2001; 2004); family therapy and videotherapy (Modekar & Spence, 2008); and therapeutic communities. Psychosocial interventions may also hold some promise for older adults with late-life depression and PD who often find interpersonal relationships challenging (Gum & Cheavens, 2008). Further research is needed to evaluate these approaches for older adults with PD.

At present, DBT seems to be the most promising treatment for older adults with PD (although other psychological interventions have not been systematically evaluated). Adaptations to the original approach are useful in advancing treatment and pursuing increased clinical effectiveness through tailoring interventions to the client group. However, this makes comparative studies more difficult and may increase the likelihood that interventions are adapted in a way that is not evidence-based.

Across the research literature, one of the main limitations of the studies conducted relates to the small samples of participants used (often female and of Caucasian background). Frequently, there is a lack of description regarding treatment and adherence, and there exists huge variation in the number and type of assessment measures used to determine presence of PD, and outcome measures to evaluate effectiveness

of treatment. Further research is needed to address these issues, as well as to systematically evaluate the impact of other psychological approaches in the treatment of older adults with PD. Due to the complex and multi-faceted nature of PD, complex interventions are often called for (Campbell et al., 2000) which may present challenges in conducting comparative reviews, interpreting findings, and understanding mechanisms of change. However, this will be crucial to treatment development and refinement of interventions to maximise efficiency and

effectiveness (Lynch et al., 2006). Further research is also needed to address the needs of older adults in minority groups who may be more difficult to assess and treat due to differing cultural expectations and norms relating to personality and behaviour.

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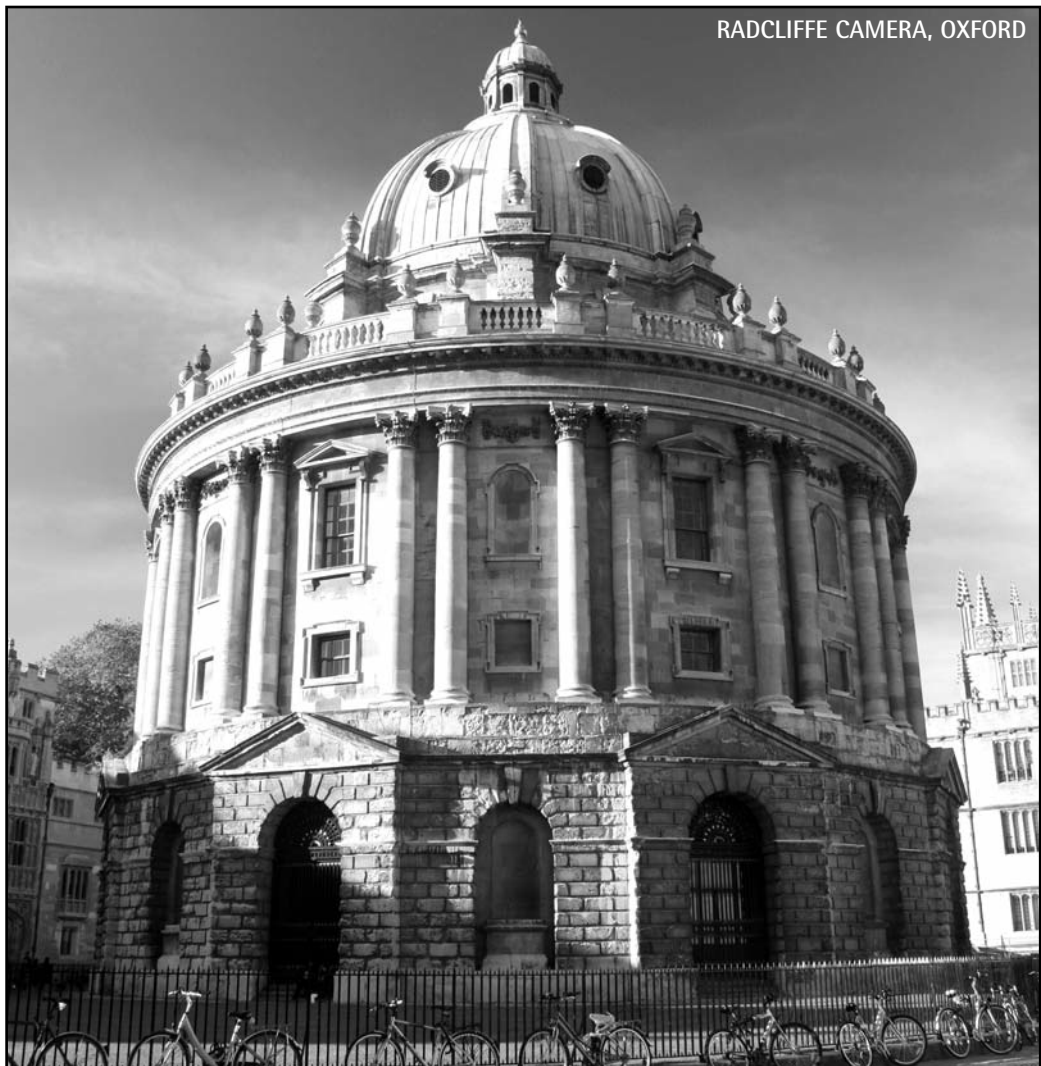
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Personality disorder in later life – a pilot treatment group

Elizabeth Kemp

'Why don't we have the full service – 4.5 days? We have the same difficulties for longer and we have less resources to help us. Why not aim for the sky? Maybe not in my lifetime, but it is needed.'
Group member, 2008.

THIS IS AN ACCOUNT of a collaboration between three Services within Oxfordshire and Buckinghamshire Mental Healthcare Foundation Trust (OBMH). Psychological Services (PS) and Older Adult Community Mental Health Teams (OA CMHTs) have access to a proven treatment model currently applied to a cohort of people under 65 with diagnosed or diagnosable personality disorder (PD) – the Oxfordshire Complex Needs Service (OCNS). In the OA CMHTs there is a shared caseload of clients – over 65 – whose extensive clinical histories include evidence of repeating patterns of interpersonal difficulties and cycles of self-harm/suicidality indicative of their 'complex needs' – stated here as 'probable personality disorder.'

The project was conceived by clinicians in one of the Oxfordshire OA CMHTs in 2004. In conjunction with members of OCNS, it developed into a pilot treatment group for older people with probable personality disorders, which ran between July 2007 and December 2009. The aim was to apply part of the existing OCNS model of treatment to a group of older adult clients, as closely as possible. No additional resources were available, which affected the group itself and all three Services for the duration. Here is a description of the group, some limited clinical outcomes and a selection of observations and reflections on the experience. Wider debate about development of useful services for this group of people is imperative and may include attending to how NHS Service structures and

predominant cultures may be influencing the current situation.

OA service background

Within OBMH, people over 65 with probable personality disorder (usually undiagnosed), access a service from OA CMHTs which takes a primarily maintenance and crisis prevention role. These multidisciplinary teams absorb and contain the distress caused among colleagues in primary health care teams and Social Services support services, in the challenging work with these individuals. Standard psychological and psychosocial treatments may be offered alongside pharmacological interventions, with some temporary positive effect. However, these clients' mental health status rarely changes enduringly, nor does their quality of life in terms of interpersonal relating and independent functioning. Treatment options are soon exhausted. Staff lose confidence in their skills and may develop defensive strategies instead, contributing to potentially counterproductive stasis.

In 2005 an informal, local audit identified four people attending a Day Hospital, who were continuous attenders and high users of wider OA mental health services, their GPs and Social Services. Individual psychiatric notes revealed decades-long histories of mental health difficulties, including unclear applications of standardised diagnosis, many admissions and pharmacological treatments as well as psychological interventions. Similar numbers of such clients were then also identified on the caseloads of the other OA CMHTs.

Another informal audit looked at the profiles of 22 adults of working age (AWA) and 22 OA OBMH inpatients with at least one psychiatric admission in the preceding 12 months. In both groups there was a pattern of regular admissions over preceding years or decades, and a small percentage had a positive diagnosis of personality disorder (AWA 13.6 per cent/OA 9 per cent). Larger numbers in both groups had case histories suggestive of personality disorder (AWA 59 per cent/OA 77 per cent), and the majority of these had positive diagnoses of affective disorders. In the OA group there had been poor response to medication over many years. In every case medication included a benzodiazepine, an atypical antipsychotic and antidepressants.

An increasing body of literature examines the situation of people surviving into the later decades of life while continuing to experience the consequences of the impact of their personality development on life events and relationships. (for example, prevalence and co-morbidity, Coid et al., 2006; Coolidge et al., 2006; and potential changes in presentations of PD as people age Hepple & Sutton, 2004; Segal et al., 2006). There have been attempts to apply established evidence-based treatments to this very particular group of older people. A review of these is printed elsewhere in this publication (Watts, 2011).

Clinical context – OCNS

The Oxfordshire Complex Needs Service (OCNS) offers a four-tier clinical engagement and treatment programme. It employs a community based, Therapeutic Community (TC) model (Pearce & Haigh 2008) and is a fully-resourced and regularly audited service. The ethos is of recovery, underpinned by the premise that PD is treatable, with appropriate psychotherapeutic interventions. This is delivered via a series of therapeutic tasks as each group member moves along their own pathway from engagement, through treatment to reintegration.

The OCNS operates a ‘Hub and Spoke’ tiered model between Oxford and three town bases around the county:

Tier 1: Maximum 12 month attendance – engagement and Options for treatment, in either the ‘Hub’ or a ‘Spoke’.

Tier 2: Twice a week for 18 months – an outpatient Spoke in one of three Oxfordshire market towns.

Tier 3: 4.5 days a week for 18 months – a day programme at the Oxford Hub.

Tier 4: Fortnightly for two hours – gradual disengagement via a Moving On group.

Preliminary outcomes and audit results for one Spoke demonstrated psychological and socio-economic benefits for group attenders (Scott & Attwood, 2009). It was hypothesised that this integrative programme of diagnosis and treatment for 18- to 65-year-olds with diagnosable PD might be able to confer similar benefit in an older population with probable PD.

The over 60s group (‘the group’)

The pilot OA group combined the OCNS Tier 1 and Tier 2 in a single, three-hour, weekly meeting, including assertive engagement, active ongoing assessment, access to a range of therapies and the therapeutic use of group process. It was a slow-open group, with new members joining – and leaving – throughout the two-and-a-half years. The three hours comprised a 75-minute therapy group, which staff group members pre-planned using their collective clinical perspectives, the group experience and weekly joint supervision. This therapy group was sandwiched between shorter Opening and Closing Community meetings, which both had a pre-set agenda. Outside the group members could access a within-group support telephone network, with clear criteria for use. Additional aims were to link family and friends into an existing OCNS support network and for completing group members to access OCNS Tier 4.

A collective profile of group members’ difficulties reflected suicidal behaviour – or threat; self harming; chronic depression

and/or anxiety states; a self perception as affective disordered; abusive or disrupted early attachment relationships with limited life history information; consistently problematic interpersonal relating; lack of insight into their difficulties with associated habitual defensive patterns; significant use of psychotropic medication. Of particular note appeared to be the loss of a sustaining spouse or other family relationships - historic and recent; current acute/chronic stressors of later life and 'role reversal' – for example, becoming a full time carer rather than being the historically cared-for person.

These people are also energetic survivors, assimilating their experience and difficulties via a (to them) coherent-enough set of meanings to enable day-to-day existence. All were tentative about the potential for change after so long.

Assessment and evaluation

The group followed the OCNS assessment and evaluation process making some obvious wording adaptations, for example to reflect activity levels in retirement rather than simply the economic activity of pre-retirement. Tools used were the SCID-II Personality Questionnaire and Structured Clinical Interview for DSM-IV Axis II Personality Disorder (SCID-II) (First et al., 1995); Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM 34) (Barkham et al., 2001); Minimum Data Set (including Standardised Assessment of Personality – Abbreviated Scale (SAPAS) Moran et al., 2003; Social Functioning Questionnaire (Tyrer, 1990); Self Harm Inventory (Sansome et al., 1998); Five-item Mental Health Screening Test (Berwick et al., 1991)).

The measures were used on entry into and at exit from the group.

Interventions and models

The group was facilitated by a multidisciplinary team including a psychiatrist/psychodrama psychotherapist (OCNS); a counselling psychologist (PS) and an occu-

pational therapist (OA CMHT). There was weekly supervision with a group analyst (OCNS).

Therapeutic models

Haigh (1999) describes what distinguishes the therapeutic principles of a Therapeutic Community (TC) from other models of psychotherapy and how they aim to facilitate a corrective secondary emotional development. In this group, developmental group dynamic process included observing and challenging patterns of helpful and unhelpful communication in vivo; building group identity, confidence and ownership and devolving power and responsibility to group members. A coherent responsiveness to individuals' separate needs was founded in the timely use of psychodramatic techniques, which helped to integrate aspects of other therapeutic models for each person. Theoretical models included group dynamic principles and interventions from cognitive behavioural, psychodramatic, systemic, humanistic and creative (exercises using music, drawing, objects) therapies.

Outcomes

Referral and take-up

There were 23 referrals representing all eight Oxfordshire OA CMHT bases. Gender bias towards female referrals was 21/2. Nine women attended the group over the two-and-a-half years, with the largest group cohort being six. Two members had completed the group by December 2009 and the seven others dropped out after different lengths of time.

Compared with the similar initial stage of development of the younger adult service (OCNS), this take up rate of nine out of 23 referrals (39 per cent) represents a good level. Comparison with older people attending anxiety and depression groups within Oxfordshire is favourable. Low referral rates, difficulties with engagement, irregular attendance and longstanding issues over provision of reliable NHS transport are wider OA Service issues also affecting this group.

CMHT contacts

The group replaced all CMHT contact, apart from medication reviews with consultant psychiatrists. Of nine group members, six had significantly reduced contact (94 per cent) with the CMHT during their time in group, compared to in the year prior to their start date. Of the other three, one attended from an inpatient setting as part of discharge planning; another attended straight from another group and the third never detached from the referring CMHT. Three of those who dropped out of treatment, resumed high levels of CMHT input.

Medication usage

All group members were longstanding users of combinations of antidepressant, anxiolytic, benzodiazepine and antipsychotic medications. One person also was prescribed a cholinesterase inhibitor. During their time in the group, most members reduced their reliance on medication significantly. Of the two full attenders, one stopped use altogether. The other had stopped four out of seven medications by December 2009.

Estimated cost saving on medication was £3065 (87 per cent) for four group members. Medication reduction/cessation was not started until well into the group's life as psycho-education around the rationale was needed. Comparison with the previously mentioned OCNS Spoke is favourable, where similar levels of reduction were achieved over the course of treatment (Scott & Attwood 2009).

Psycho-social engagement

Observed and individual subjective reporting of the impact of the group included ability to engage with thoughts and feelings constructively, exposure to depth of emotional experience, participation in group process and treatment including: supporting and challenging each other; recognising strengths and weaknesses, decision-making, increased confidence and proactiveness in the face of ongoing life events. Two group members recorded some

of their experience on video and presented it at a conference.

CORE-OM 34

Two clients were group completers. Of the other seven, only four agreed to complete re-assessment on leaving prematurely. Numbers are so small there can be no significant outcome data. For four *non-completers* there is a small indication of a positive direction of change in three of the four CORE-OM sub-groups: Psychological Symptoms 6 per cent; Functioning 23 per cent; Risk 0 per cent; and Well-Being 2 per cent.

Outcome data for the OCNS Spoke for seven group completers indicate the potential for an OA cohort of a measurable size. Positive change was measured as significant at Psychological Symptoms 48 per cent; Functioning 74 per cent; Risk 96 per cent; and Well-Being 63 per cent (Scott & Attwood, 2009).

Discussion: difference

In this pilot treatment group the intention was to provide OCNS Tier 2/Spoke, incorporating aspects of an OCNS Tier 1/Options Group. Consequently OA group members started the group without the experience and knowledge gained by younger adults who attend OCNS Tier 1 for up to 12 months. Thus the older adults were utterly new to the Therapeutic Community model of working. They joined with minimal appreciation of, or language for, using a personality disorder framework to think about their difficulties. Also they had little understanding of how the use of psychotropic medication might affect their ability to engage with and participate in the group's work.

The ratio between formal diagnosis/no diagnosis is different among younger service users, although the latter do access the OCNS. Most OA group members were assessed as sub-clinical prior to joining. Only one person was assessed to have a positive diagnosis of borderline personality disorder. During the group process diagnosis was revisited and all members met formal diag-

nostic criteria for personality disorder (Clarke & Scott 2006). Clinical issues here include which assessment tools to use and their appropriateness and associated to this, the lack of formal understanding around presentations of personality disorder as people age.

Discussion: uniqueness

This group experience indicates that personality disorder is diagnosable in people over 65 using existing formal tools individually and then via within-group therapeutic re-use (Clarke & Scott, 2006).

Group members needed to learn the TC group culture and much careful time was spent modelling this and developing a working acceptance of it. Also, members were offered psycho-education related to personality disorders and were interested – not fazed – by this alternative explanation of their difficulties.

Two outcomes, which may represent internal shifts from passive reliance on professionals to more personal agency and self-determination, are that group identity and attachment relationships did develop. The structure appeared to provide sufficient containment for this key process to occur. However, a combination of small group size and ambivalent engagement processes probably affected how these more healthy relationships were able to be sustained. Also, significant gains were made in stopping use of psychotropic medications, with positive effects on functioning and ability to start to engage with new change processes. Of note is that when group members dropped out of treatment they sought OA CMHT contact again. The Service response was to resume the accustomed role of maintenance and crisis prevention.

For the clinical team, group analytic supervision was absolutely crucial. The group clinicians' individual responses needed to be acknowledged, understood and utilised via structured, consistent supervisory relationships in combination with ongoing specialist training.

Outside the group itself, OA CMHT consultant psychiatrists were supportive. However, they were not asked to hand over medical responsibility to the group's psychiatrist/staff member. This encouraged breaches in the group's sense of containment and the psychological phenomenon of 'splitting' occurred. The psychologist advised individual colleagues on behavioural management (for example, of inappropriately lengthy telephone calls). Feedback from these colleagues in OA CMHTs, Social Services and inpatient services suggest this succeeded in improving the consistency of response within and between services. It also highlighted between-service cultural differences.

This unique collaboration of three Trust services threw up examples of difference among the predominant cultures, addressed in supervision but otherwise bypassed, due to prioritising the group work in the time available. The fundamental matter is whether older people are offered the same or different services and why.

Future service development

As specialist mental health services for people with personality disorder have developed, a therapeutic chasm is being revealed. Neither those adults now turning 65 years of age and aware of personality disorder, nor the many others over 65 but *unaware* of the role that personality development may be playing in their mental health and interpersonal difficulties, are being effectively engaged by existing mental health services, despite the law and national guidelines on treatments and access (for example, Healthcare Commission, 2009; National Institute for Health and Clinical Excellence, 2009; Equality Act 2010). The debate about how to deliver fair and appropriate mental health services has accompanied this group throughout and continues to stimulate the imagination. Future funders face challenging issues too: evidence-based, positive outcomes may well be evident only after relatively long treatment periods.

There is room for change. Well-evidenced services, taken up by younger people with or without formal PD diagnosis, are now available to draw on, as are the experiences of those who have successfully completed treatment. From the perspective of this small, initial clinical treatment pilot group, there are some important considerations before moving further clinically.

There is a need to examine personal and professional stances and the OA service cultures we work in, as they relate to probable personality disorder in older people. There is literature which addresses this and may help avoid unnecessary repetition (for example, Sampson et al., 2006). An increased awareness of PD and its likely presentations in older adults will need to be formalised in line with current and/or new, age-appropriate diagnostic criteria. A sufficient number of clinicians will require training in appropriate assessment tools to identify PD traits and disorders in the older adult population with confidence.

Within OA Mental Health Services a forum for discussing medication issues, diagnosis, medical responsibility and the parameters of shared care with OA CMHTs would be in the interest of any future group. This would overtly support, rather than inadvertently threaten, the group process.

Inter-agency liaison processes within OA CMHTs and other services may require honing, via stringent care planning, to support consistency during referral, engagement and discharge in the interests of clients' experiences of treatment. Having it on paper is unlikely to suffice. The inclusion of all services' – non-clinical as well as clinical – staff members in training and support for their contact with people with PD is highly recommended.

This is tough yet rewarding work. It may not be for the faint-hearted. It is likely to

require a certain set of personal qualities as much as particular clinical expertise at the outset. A framework of expert supervision and active training is not negotiable. In any event, much preparatory work needs to be done to maximise the potential – and verifiable – success of future clinical interventions.

At present in Oxfordshire and Buckinghamshire we can access tried and tested clinical expertise in personality disorder. Other initiatives exist elsewhere in the UK in different forms. The Therapeutic Community movement is nationwide (www.therapeuticcommunities.org). In OA Services across the UK interest and awareness is growing rapidly. The demographic writing is on the proverbial wall. The under 65s are getting older and older service users may well engage with a renewed curiosity in novel conversations about 'personality disorder' – as alternative conceptualisations of the difficulties they are well aware they have. National guidelines and the law now stipulate that action must follow.

Why not aim for the sky?

Acknowledgements

The nine women who came forward to take up this initiative – trailblazers one and all. Dr Lisle Scott (OCNS) and Sarah Gibson, Occupational Therapist, co-staff group members. Hilary Corcoran, Senior Team Therapist (OCNS), for supervision. Dr Helen Palmer, Clinical Psychologist, for proof reading.

This project simply would not have happened but for the unflinching insistence of Jane Bates (Community Psychiatric Nurse), Dr Lisle Scott and Peter Haworth (OCNS) during the troublesome early stages. The flexibility of service managers, prepared to support this inter-service pilot group for this length of time, is commendable.

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Compiled solely by the author, drawing on various co-developed presentations, reports and articles deriving from the professional and personal experience of the Over 60s group.

Forthcoming Regional Newsletter editions

Region	Date	Submit by
Oxford	January 2011	October 2010
General/themed	April 2011	January 2011
Wessex	July 2011	April 2011
Conference/themed	October 2011	July 2011
Scotland	January 2012	October 2011
General/themed	April 2012	January 2012
Northern	July 2012	April 2012
Conference/themed	October 2012	July 2012
East Anglia	January 2013	October 2012
General/themed	April 2013	January 2013
North West	July 2013	January 2013
Conference/themed	October 2013	July 2013
Yorkshire & Humberside	January 2014	October 2013
General/themed	April 2014	January 2014
Trent	July 2014	April 2014

Each region needs to nominate a Guest Editor to liaise with the Newsletter Editor(s).
Copy needs to be ready for first proofs two months in advance of the publication month.

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Louisa Shirley – *Newsletter Editor*

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Julia Boot – *IAPT Lead*

Becci Dow – *Treasurer and Welsh Representative*

Louise Bergin – *IAPT and Newsletter support*

Recent journal articles by PSIGE members

- Buschenfeld, K, Morris, R, Lockwood, S (2009). The experience of partners of young stroke survivors. *Disability and Rehabilitation*, 31, 1643–1651.
- Gratton, S. & Kneebone, I. (2009). Assessing the psychological needs of patients on a GP managed, step up, step down community hospital ward. *Clinical Psychology Forum*, 199, 33–37.
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If you would like to keep PSIGE members informed about your current publications, please let me have an up-date.

Louisa

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, for example, 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.

When submitting articles please send the following information:

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

Finally, all reports of research should indicate whether or not Ethics Committee approval was awarded, and by which Ethics Committee, or whether the work was carried out as an audit/service evaluation project.

All contributions should be sent to: louisa_shirley@hotmail.com

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