Group Psychotherapy and People with Dementia[a]

Dr Richard Cheston[b], Consultant Clinical Psychologist, Avon and Wiltshire Mental Health Care NHS Trust/Honorary Research Fellow, Bath University

Kerry Jones, Research Officer, Dementia Voice,

Professor Jane Gilliard, Director, Dementia Voice/University of the West of England

Mental health foundation/results paper8

04 February 2003

6,500 words

Key words: Alzheimer's disease; dementia; groups; psychotherapy; counselling; depression

Aging and Mental Health, 7 (6), 452-461.

---

[a] This research on which this paper is based was supported by a grant from the Mental Health Foundation

[b] Address for correspondence: Charter House, Seymour Road, Trowbridge, Wiltshire, BA14 8LS, Richard.Cheston@awp.nhs.uk. Fax: 01225-774861

GROUP PSYCHOTHERAPY AND PEOPLE WITH DEMENTIA

ABSTRACT

Although psychotherapy and counselling approaches are being used increasingly with people with dementia, there has been little structured research into the effectiveness of such work. This research reports findings from the evaluation of six, ten week long psychotherapy groups for people with dementia in the south of England. Measures of depression and anxiety were taken independently of the clinical work at four time points: six weeks before the group began, at the start of the group, at the end of the group and at follow-up after a gap of ten-weeks. Forty-two participants entered the project at different points, of whom nineteen completed the baseline, intervention and follow-up phases of the project. Analysis of the data for depression and anxiety levels using a repeated measures ANOVA provided significant evidence for a treatment effect for Cornell depression scores which was maintained at follow-up and a similar non-significant trend towards a reduction in anxiety as measured by the RAID. Although not all people with dementia would be suitable for group psychotherapy, nevertheless this research provides some of the first statistically significant evidence that group psychotherapy may have a role to play in reducing levels of depression of people with mild and moderate levels of dementia.

BACKGROUND

One of the most important developments in person-centred dementia care over the last decade has been the growing awareness of the significance of the perspectives of people with dementia (Woods, 2001). This shift in attention has focussed awareness on the many profound changes and losses that people with dementia experience. One example of this is the assessment process leading up to and immediately following a diagnosis of Alzheimer's disease or a related dementia which is often carried out at a memory clinic. Research suggests that not only is the process of attending a memory clinic often a frightening one for the person being assessed (Keady and Bender, 1998), but that most consultant psychiatrists were reluctant to tell the person with dementia their diagnosis (Rice and Warner, 1994) and that consequently only a minority of people with dementia are formally told of their diagnosis. Indeed even within professional carers, opinion is divided as to what people with dementia should be told, or indeed whether they should be told of their diagnosis at all (Gilliard and Gwilliam, 1996).

In an effort to provide people with dementia with the time and space to make sense of the changes in their lives, there has been a steady increase in the use of psychotherapy and counselling with people with dementia. A wide range of individual psychotherapeutic work with people with dementia has been described including psychodynamic (e.g. Sinason, 1992), cognitive-behavioural (e.g. Teri and Gallacher-Thomson, 1991) and humanistic approaches (e.g. Goudie and Stokes, 1989; Stokes and Goudie, 1990). However, probably the single most common means of using psychotherapy as a way of intervening with people with dementia has been through group work. The review by Cheston (1998a), for instance, identified over twice as many reports of groups compared to work with individuals. This included both directive groups in which the emphasis was on teaching people with dementia about their illness and on encouraging them to use a variety of strategies in order to facilitate adjustment to their impairments (e.g. Thrower, 1998;

Haggerty, 1990; and McAfee et al 1989) and exploratory groups which emphasise helping people to share their feelings about their experiences, especially those of loss with others (e.g. Hawkins and Eagger, 1999; Peach and Duff, 1991; Yale, 1991, 1995).

However, while the clinical development of psychotherapy groups with people with dementia has been relatively rapid, there has, as yet been little systematic evaluation of this work. Moreover, many of those studies that have been published suffer from a variety of methodological problems including a lack of participants, poorly validated outcome measures and the absence of either a control group or a non-intervention phase (Cheston 1998a). For instance, while Validation Therapy (Feil, 1990, 92, 93) is probably the most common form of psychotherapeutic intervention, the systematic and detailed review of the literature carried out by Neal and Briggs (2000) was only able to identify three studies, and could only obtain the data from two of these. They concluded that *"the analysis of data failed to reveal statistically significant results although there were trends towards favouring Validation Therapy for some outcomes".*

METHODOLOGY

The Dementia Voice Group Psychotherapy project. This project had two elements: first of all the creation of six psychotherapy groups across Southern England for people who had been diagnosed as having Alzheimer's disease or another form of dementia; and secondly the independent evaluation of these groups. Each group lasted for ten weeks, with each session lasting for approximately an hour and a quarter and being facilitated by the first author in collaboration with either one or two locally based co-facilitators. Five of the six groups consisted of between six and eight people with the sixth group having ten participants.

Research design. Psychotherapy outcome research presents a series of methodological challenges which no single research design can completely eliminate. By far the most common methodological design is the pretest-posttest control group design in which participants are randomly allocated to either an intervention group or to a control group . However, the use of this methodology as a way of evaluating the impact of psychotherapy has been criticised (e.g. Stiles et al, 1995). There are particular problems when using control groups to evaluate the effectiveness of group psychotherapy. For example, unlike a medical intervention it may be impossible to identify a suitable placebo, in that the act of bringing people together on the basis of a shared diagnosis can be construed as a therapeutic intervention in itself, even where no formal therapeutic work subsequently occurs. This is likely to be particularly problematic where the focus of the therapeutic work concerns shared experiences, as is the case in this research. Moreover, as little reliable work has so far been carried out to identify whether therapy with people with dementia has any impact at all, it is arguably premature to take on the ethical and methodological complexities of a randomised control trial, without first establishing that psychotherapy has an impact using less exacting methodologies.

The design of this study therefore utilised baseline and follow-up measures rather than an entirely separate control group. Data on participants' medication use and levels of anxiety and depression was collected by the second author, acting independently of the clinical process at four time points. This enabled three separate phases to be established within the project: a baseline period of between five and ten weeks, an intervention period of ten sessions during which the groups took place; and a ten week follow-up period. In addition levels of cognitive functioning and other demographic information was collected at the start of the baseline period. Although the design did not involve a randomly allocated control group, a comparison of data between the intervention and the baseline and follow-up phases enabled meaningful conclusions to be reached about the significance of those changes that occurred during the baseline period.

Venues. Four of the six groups were run in community venues with a fifth group being established in a day centre run by a voluntary care group. The sixth group met in a room adjacent to an NHS ward.

Group facilitators. Each group was lead by the first author (who had lead similar groups over the last eight years) working with either one or two co-facilitators. All of the co-facilitators were experienced clinicians based in the locality in which the group was run: one co-facilitator had previous experience of running a support group for people with dementia while another had trained as a family therapist; four were Clinical Psychologists or Psychology Assistants, two were Psychiatric Nurses, while the remaining facilitator was an experienced care worker. Those co-facilitators who had not previously run a group with the first author attended a two day training course carried out by the first two authors.

Therapeutic content. The therapeutic issue that participants were asked to discuss was "*what it's like when your memory isn't as good as it used to be*". Participants were encouraged to share their experiences with each other and to discuss the emotional impact of these experiences on them. The role of the facilitators was to reflect upon the emotional significance of these experiences within the context of the group. As such this approach differs markedly from other therapeutic forms of work with people with dementia such as Validation Therapy, life review (e.g. Garland, xxxx) and Reality Orientation (e.g. Woods, xxxx). Validation therapy, for instance, is based around the idea that as confusion in older people represents a retreat into the past occasioned by unresolved issues and losses, the focus of the therapeutic work is to validate this inward journey in an effort to help the person to resolve those previously repressed memories.

By contrast the groups in this project focussed upon the experiences of participants in the here-and-now, and upon the impact of these experiences upon relationships, including those formed within the matrix of the group. The task of the group therapist was to facilitate this process of reflection by interpreting material that was brought to the group in terms of their underlying emotional significance. A central focus in these groups was that of *"forgetfulness*". This concept has been described in detail elsewhere (e.g. Cheston, Jones and Gilliard, 2002) and involves the way that the experiences of participants concerns not just a failure of short-term memory and other cognitive impairments, but the pain and distress of being forgotten about themselves and, at times a wish to be forgotten about and to forget about oneself. Further details of this form of group psychotherapy can be found elsewhere (e.g. Cheston and Jones, 2000; Cheston, 1998b).

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

Referrals. Referrals of potential participants came from a range of sources including GPs, Community Mental Health Teams (CMHTs), social services, memory clinics and Voluntary groups. It was made clear to all potential referrers that participants would be expected to have received a diagnosis of Dementia of the Alzheimer's type or a similar form of dementia. Where a referral did not originate from a memory clinic or CMHT, the referrer was contacted to confirm that the participant had received a diagnosis of dementia (preferably using DSM IV). In two cases this diagnosis had not occurred, and although both of these participants were subsequently involved in the groups, both were excluded from the data analysis.

Data collection. After being accepted into a group, participants were visited by the second author who asked for their consent to join the research programme. It was stressed that the evaluation both occurred separately from the groups and that non-participation in the evaluation would not affect the ability of participants to attend the groups. The research design called for participants and their care-givers to be interviewed for the first time between five and ten weeks before the group started. In the event, because many referrals were made at a late stage, the median length of time between the baseline interviews and the start of the groups was six weeks. Pre-group interviews took place in the week immediately before the groups began, with the post-intervention interviews occurring in the week immediately after the end of the group. Participants and their carers were interviewed for a final time after a follow-up period of ten weeks.

A. Measures of cognitive functioning (First interview only).

- **The Mini-Mental State Examination** or MMSE (Folstein, Folstein and McHugh, 1975) is a well established screening tool used in both clinical and research settings to give a global assessment of a person's level of cognitive functioning. Participant could achieve a score between zero and thirty, although scores below twenty-four are generally taken to indicate a significant impairment in cognitive functioning.

- **The Clinical Dementia Rating Scale** or CDRS (Hughes et al, 1982) is a global rating device for Dementia of the Alzheimer's type and other related conditions. Participants were rated from 0 ("*no impairment"*) to 3 ("*severe impairment*") on six areas of functioning.

B. Measures of affect (all interviews).

- **The Cornell scale** (Alexopoulus et al, 1988) is a well-established interview based measure which is designed for assessing the level of depression of people with dementia. Although not originally intended as a diagnostic instrument, nevertheless a cut-off score of 7 or above is commonly taken as indicating a clinical level of depression (e.g. Harwood et al, 2000; Vida et al, 1994). Composite ratings on the

Cornell scale were based on information gained from interviews with both participants and their main care-givers, usually their husband or wife. Where possible other care-givers, including health care staff and other family members involved in that person's care were also interviewed.

- **The RAID** (Shankar et al, 1999) is an interview based measure designed specifically for people with dementia. Like the Cornell, the RAID was designed for the purposes of research rather than as a diagnostic measure, although the authors suggest that a cut-off point of 11 or above should be taken as indicative of a significant level of anxiety. Ratings were again based on interviews with the participants and their main care-givers. It is important to note that both the Cornell and the RAID were developed for use primarily with people with moderate and severe forms of dementia, and based on the ratings of nursing staff rather than relatives.

- **Hospital Anxiety and Depression scale** (Zigmond and Snaith, 1983). There is some evidence that people with mild or moderate cognitive impairment can report their mood accurately (Gottlieb, Gur and Gur, 1988; Feher, Larrabee and Thomas, 1992) using self-report measures. However discordance has been found between patient, caregiver and clinician reports of the patient's mood, usually due to patients with dementia who have a general tendency to denial, also denying their low mood (MacKenzie, Robiner and Knopman, 1989; Teri and Wagner 1991; Feher et al, 1992). The Hospital Anxiety and Depression Scale is a self-report measure which has been used with people with the early stages of dementia (e.g. Wands et al, 1990; Barton et al, 2001; Marshall, 2001) although it has not been tested for reliability and validity with this population. The HADS comprises separate sub-scales for anxiety and for depression, with a score of 7 or more on either sub-test indicating a clinically significant level of affect.

ANALYSIS OF DATA.

Table One summarises the pathway by which individuals entered into and left the project and the clinical groups. Fifty-one people in all were referred to the groups, of whom forty-two were assessed as meeting the research and clinical criteria for entry into the groups. Of these 42 people, one person declined to be interviewed for the research project, and the diagnosis of two others could not be adequately established.

Participants. All but two of the 42 participants who attended the groups had been married at some point during their lives, with thirty participants still living at home with members of their family (mainly their spouse). Ten other participants lived at home on their own, while the remaining two lived in residential accommodation. The average age of participants was 73 (ranging from the youngest participant of 53 to the oldest who was 88). Seven participants had been educated at tertiary level, with fourteen others having received further education of some form (generally a professional qualification). The remaining twenty-one participants had left school after receiving secondary education. Group participants were evenly spread between social classes.

Late referrals. Eight group participants were referred to the group too late to be interviewed at the baseline stage and have consequently been excluded from the main part of the analysis (although data was collected from these individuals and their carers at the pre-group stage for comparison purposes). A further two participants were referred too late for even these pre-group assessments to be carried out and were therefore not interviewed at all, but still attended the groups. While there was a tendency for those eight people who were referred late to the groups to have a more severe level of cognitive impairment (as measured by the CDR and the MMSE) and to be more anxious (as measured by the RAID) no significant differences between the two groups were found.

INSERT TABLE ONE ABOUT HERE

Attrition. As Table One shows, ten group participants left the research before all three phases of the project could be completed. One man died, while another seven participants developed physical illnesses that forced them either to leave the group that they had been attending, or meant that they could not be interviewed in the evaluation. Statistical comparisons were made between the 19 participants who completed all three phases of the project and those 10 participants who were included in the baseline interviews, but who dropped out before the end of the project using either parametric (independent samples t-test) or non-parametric (chi-squared) tests. These comparisons included both socio-economic information (living at home with carer, length of time spent in education, social class and age), levels of cognitive impairment (CDR, MMSE scores) and affective levels (scores on Cornell, RAID and HADS). No statistically significant differences were identified. Demographic and cognitive information about group and research participants is summarised in Table Two.

INSERT TABLE TWO ABOUT HERE

In total, 19 people participated in the clinical groups and were also part of all three phases of the research project.

Correlation between outcome measures. As Table Three indicates there was a significant correlation between scores on the Cornell, RAID and the HAD-anx. The HAD-dep scores correlated significantly with scores on the HAD-anx (pearson correlation = .238, n = 76, $\underline{p}$ = .039), but not the Cornell (pearson correlation = .214, n = 76, $\underline{p}$ = .063). The finding of a strong correlation between the RAID and the Cornell is not, perhaps, surprising given that roughly a third of the test items on each scale are shared. However, the fact that the Cornell correlates more strongly with the HAD-anx scale than the HAD-dep scale is surprising and may suggest the need for caution when interpreting the results of the HAD-dep scale.

INSERT TABLE THREE ABOUT HERE

Differences across time for outcome measures. The mean and standard deviations for the HADS-depression, HADS-anxiety, the RAID and the Cornell from the nineteen participants who completed all three phases of the research project is presented in Table Four. This data was analysed using a series of repeated measures ANOVAs.

TABLE FOUR ABOUT HERE

Depression. As can be seen from Figure One, the average level of depression as measured by the Cornell increased during the baseline phase but then fell substantially during the treatment period and remained relatively stable during the follow-up. As the assumption of sphericity, was not violated, the data was analysed using a univariate analysis and showed that there was a significant within subjects effect *(df = 3; p =.034; partial eta = .147).* For the HADS-dep, scores rise from baseline to start of intervention, are relatively unchanged across the course of the group and drop slightly during follow-up but remain at a higher level than during the first, baseline interview. This is a non-significant change *(df = 3; p = .241; partial eta = .074).*

INSERT FIGURES ONE AND TWO ABOUT HERE.

Anxiety. For the RAID scores, levels of anxiety fell slightly during the baseline phase and more substantially during the intervention before rising slightly during the follow-up period (see Figure Two). However, this change was non-significant *(df = 3; p = .050; partial eta = .133).* For the HADS-anx there was a substantial initial rise in levels of anxiety between the baseline interview and the start of the group which is reversed slightly during the intervention phase. Scores continue to fall, during the follow-up phase but remain higher during both the intervention and the follow-up phases than at baseline. This is a non-significant change *(df = 3; p = .071; partial eta = .121)*

Possible effects of medication. Nine of the nineteen participants used some form of medication (either anti-depressants, anxiolytics, or cognitive enhancers) at some point during the course of the project. Although the type of medication used did not significantly influence the level of affect, analysis using a repeated measures ANOVA indicated that there was a significant interaction between participants' use of any form of medication during the group and depression levels as measured by the Cornell (see Figure Three).

INSERT FIGURE THREE ABOUT HERE

A two sided Dunnett's post hoc test suggested that there were two significant differences between participants: at the start of the baseline phase between those participants who did not use medication at all, and those who used medication continually throughout the study (p = *.013*); and at the end of the follow-up phase between those who used medication throughout the study, and those who started using medication during the study (p = *.040*)). This post-hoc analysis, therefore, does not support the possibility that falls in the levels of participant's depression as measured by the Cornell occurred as a result of participants taking or starting to take medication during the course of the treatment period. However, it is possible that the relative stability of levels of depression during the follow-up period may have been partly the result of two of the 19 participants beginning to use anti-depressant medication during this period. In order to further investigate this point, the six participants who used anti-depressant medication at some point during the study were removed from the analysis, and scores from the remaining 13 participants analysed once again using a repeated measures ANOVA. The statistically significant effect for the Cornell not only remained, but was strengthened *(df = 3; p = .029; partial eta = .219)* suggesting that the fall in levels of depression during the intervention as measured by the Cornell occurred independently of the use of any form of medication.

DISCUSSION.

This study presents data from nineteen people with dementia who, after a baseline period of six weeks completed a ten week period of group psychotherapy followed by a further ten week follow-up period. The results indicate that changes in levels of one outcome measure, the Cornell scale for depression, are statistically significant, with a strong trend (p=.0500) towards levels of anxiety as measured by the RAID, falling significantly. After an initial increase during the baseline period, the mean scores of the Cornell decrease during the intervention phase with this improvement in average levels of affect being maintained during the follow-up. The change in mean Cornell scores crosses the clinically significant cut-off point level of 7 during the intervention phase. Post-hoc analysis suggests that this result is not due to an interaction between the intervention and the effects of medication, and indeed the statistically significant change is present even when those participants who took anti-depressant medication are removed from the analysis.

For the RAID the initial fall during the baseline phase accelerates during the intervention, with a slight return to pre-intervention levels during the follow-up phase. There is also a similar, non-significant trend towards HADS-anx showing a material decrease (p=.071), although here the level of anxiety increases substantially before the group begins and even at follow-up has not yet returned to pre-baseline levels.

Validity and reliability of outcome measures. Neither the HAD-dep or the HAD-anx results support the changes that were apparent in the Cornell and RAID scores. However, the reliability of the HADS results may be open to question as the scale was not designed for use either with older people or with people with dementia and has not been validated for use with this population. In this study the HADS-dep results in particular need to be interpreted with some caution, as they did not correlate significantly with the Cornell, which was designed specifically for use with people with dementia.

However, even with the Cornell and the RAID, there is a need to be cautious when interpreting these results. While both the Cornell and the RAID were designed to be used with people with moderate and severe forms of dementia, the composite ratings were intended to be based around interviews with nursing and other care staff. In this study the primary informant in these ratings were relatives, who are likely to have considerably less experience in assessing the symptoms of either depression or anxiety than are formal care staff. Moreover, some research indicates that people with dementia may hide their low mood from relatives (MacKenzie, Rohier and Knapman, 1989).

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

Psychotherapy and people with dementia. The participants in these groups were not necessarily typical of a wider population of people with dementia: in particular they were people who all, to a greater or lesser extent, had a capacity and a willingness to talk about themselves and their memory problems. For some participants, this proved to be too much. One woman, who had been unable to attend the first two sessions of a group withdrew after attending the third and fourth session, while a male participant attended only half of the first session of a group, leaving because he felt that it was not the right environment for him. The overall drop-out rate of two people from six groups is roughly comparable with that from groups aimed at people with other forms of mental health problems. Eight other participants were unable to complete the project for other reasons: one man died while seven other participants became unwell. Although there were no statistically significant differences in terms of mood levels, age, gender or cognitive functioning between those who dropped out and those who continued, the pre-group anxiety levels of the former tended to be higher.

Similarly, the majority of participants in this research still had relatively intact verbal and cognitive skills. All had an MMSE score of 18 or above, while roughly two-thirds were rated as having a “mild” level of cognitive impairment. Thus although some group participants undoubtedly had substantial problems in articulating their needs, this work arguably tells us relatively little about work with people with a lower level of cognitive and verbal fluency.

Group psychotherapy, then, is not something that all people with dementia would be able to enter into or to benefit from, just as many people without a cognitive impairment would not wish to be part of such an experience. The groups in this project required a capacity both to engage with other people and to think about one’s memory problems. It may well be that the trend towards a higher level of anxiety amongst those participants who, for one reason or another, dropped out of the project reflected the fact that for some people with dementia, this is too threatening a task to bear.

Future research. Although a strong argument can be made that the ideal way to understand more about the impact of any form of psychotherapy with any patient population is through the use of randomised control trials, a powerful case can be made that such quantitative, large scale work needs to be complemented by smaller, more detailed investigations into the process of psychotherapeutic change. For instance, qualitative research on the accounts for his memory loss provided by one participant in this project (Watkins et al, 2003) suggest that although this man’s scores on the Cornell and RAID increased during the intervention, nevertheless there was considerable evidence of therapeutic change. Thus at the start of the group he had denied having Alzheimer’s disease, but by the end of the group had been able to use this term to describe himself and to joke about how his scan results had shown that his brain had shrunk. The most likely explanation for the rise in levels of measured affect across the course of the group was that at the start of the group he had suppressed reports of distress. Indeed at the end of the group he reflected on how, when he had first begun to attend he had felt that he was "*going crazy*" but that he couldn't tell anyone

Listening to the changing voices of people with dementia. Listening to the voice of people with dementia inevitably involves listening to the pain, anger and distress that many people with dementia experience. By meeting other people who are experiencing similar problems, so a person with dementia can begin to feel less isolated and less frightened. Rather than push away their problems, so in talking about such emotionally charged experiences, they can begin to process these experiences, and to make sense out of what is happening. The voices of people with dementia can change, but only so long as they are listened to.

The final words in this paper need to go to Violet, who was initially very reluctant to come to the group because she was afraid that she would find it upsetting. We think she spoke for many when she said:

> "*I now meet others, I see them, and I hear them, and I know I am not the only one".*

Acknowledgements

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

References

Alexopoulos G, Abrams R, Young R, and Shamoian C (1988) Cornell scale for depression in dementia, *Biological Psychiatry*, 23, 271-284.

Barton, J, Piney C, Berg M and Parker C (2001) Coping with forgetfulness group, *Newsletter of the Psychologists' Special Interest Group in the Elderly*, 77, 19-25

Cheston R (1998a) Psychotherapy and dementia: a review of the literature. *British Journal of Medical Psychology,* 71, 211-231

Cheston, R. (1998b) Psychotherapeutic work with dementia sufferers, *Social Work Practice,* 12 (2), 199-207.

Cheston R, Jones K and Gilliard J (2002) Remembering and Forgetting: Group work with People with Dementia, in Trevor Adams and Jill Manthorpe (eds) *Dementia Care,* Edward Arnold: London.

Cheston R and Jones K (2000) A place to work it all out together, *Journal of Dementia Care*, **6** (8), 22-24.

Feher, E. Larrabee, G. and Crook, T. (1992) 'Factors attenuating the validity of the Geriatric Depression Scale in a dementia population', *Journal of the American Geriatrics Society* 40: 906 - 909.

Feil, N. (1990) *Validation: The Feil method*. Edward Feil Productions: Cleveland.

Feil. N, (1992) Validation Therapy. *Geriatric Nursing*, May/ June, 129 – 133.

Feil, N. (1993) *The Validation Breakthrough: Simple Techniques for Communicating with Alzheimer's - Type Dementia*. Health Promotions Inc: Baltimore.

Folstein MF, Folstein SE and McHugh PR (1975) “Mini-Mental State”: a practical way for grading the cognitive state of patients for the clinician, *Journal of Psychiatric Residents*, 12, 189-198.

Garland

Gilliard J and Gwilliam C (1996) Sharing the diagnosis: a survey of memory clinics, their policies on informing people with dementia and their families, and the support they offer. *International Journal of Geriatric Psychiatry,* 11, 1001-1003.

Gottlieb, G, Gur, RE and Gur, RC (1988) Reliability of psychiatric scales in patients with dementia of the Alzheimer type *American Journal of Psychiatry,* 145, **7,** 857 - 860.

Goudie, F. and Stokes, G. (1989) Dealing with Confusion. *Nursing Times* 20 September. p 38.

Haggerty, AD (1990) Psychotherapy for patients with Alzheimer’s disease *Advances* **7** (1), 55-60.

Harwood DG, Barker WW, Ownby RL, Bravo M, Aguero H, Duara R, (2000). Depressive symptoms in Alzheimer's disease. An examination among community-dwelling Cuban American patients. *American Journal of Geriatric Psychiatry*, **8** (1), 84-91.

Hawkins D and Eagger S (1999) Group therapy: sharing the pain of the diagnosis, *Journal of Dementia Care*, **6** (5), 12-14

Hughes, CP, Berg, L, Danziger, WL, Cohen, LA, Martin, RL (1982). A new clinical scale for the rating of dementia. *British Journal of Psychiatry,* 140, 565 – 570.

Keady J and Bender M (1998). Changing faces: the purpose and practice of assessing older adults with cognitive impairment, *Health Care in Later Life*, **3** (2), 129-144.

Marshall A (2001) *Coping in early dementia: the findings of a new type of support group,* unpublished Phd thesis, University of Surrey.

Mackenzie, T, Robiner, W, and Knopman, D (1989). Differences between patient and family assessments of depression in Alzheimer's disease, *American Journal of Psychiatry* 146, **9,** 1174 - 1178.

McAfee M, Ruhl P, Bell P and Martichuski D (1989) Including persons with early stage Alzheimer's disease in support groups and strategy planning, *The American Journal of Alzheimer's Disease and Related Disorders and Research*, Nov/Dec 18-22.

Neal, M and Briggs M (2000) *Validation Therapy for dementia,* Cochrane Database Systematic review, 2, CD001394.

Peach E and Duff G (1991) Mutual support groups: a response to the early and often forgotten stage of dementia, *Practice*, **6**, 147-157

Rice K and Warner N (1994) "Breaking the bad news": what do psychiatrists tell patients with dementia about their illness? *International Journal of Geriatric Psychiatry,* 9, 467-471.

Shankar, K.K. Walker, M. Frost, D. and Orrell, M.W. (1999) The Development of a Valid and Reliable Scale for Rating Anxiety in Dementia (RAID) *Aging and Mental Health*. 3; 1; 39 – 49

Sinason, V. (1992) *Mental Handicap and the Human Condition,* London: Free Association.

Stiles, W, Shapiro, D, Harper, H and Morrison, L (1995) Therapist Contributions to Psychotherapeutic Assimilation: An Alternative to the Drug Metaphor. *British Journal of Medical Psychology*, **68**, 1-13.

Stokes G and Goudie F (1990), Counselling confused elderly people, In G Stokes and F Goudie (eds) *Working with Dementia*, Bicester, Oxon: Winslow.

Teri L and Gallacher-Thomson D (1991) Cognitive-behavioural interventions for treatment of depression in Alzheimer's patients, *Gerontologist*, **31**, 413-416.

Teri, L. and Wagner, A. (1991) Assessment of depression in patients with Alzheimer's disease: concordance among informants, *Psychology and Ageing* 6, 2: 280 - 285.

Thrower C (1998) Support and a crucial sense of belonging, *Journal of Dementia Care*, 6 (3), 18-20

Vida S, Des Rosiers P, Carrier L, Gauthier S. (1994) Depression in Alzheimer's disease: receiver operating characteristic analysis of the Cornell Scale for Depression in Dementia and the Hamilton Depression Scale, *Journal of Geriatric Psychiatry and Neurology,* **7** (3),159-62

Wands, K., Merskey., H. Haschinski., V. Fisman., M. Fox., H. and Boniferro, M. (1990) A questionnaire investigation of anxiety and depression in early dementia, *Journal of the American Geriatrics Society,* 38: 535 – 538

Watkins R, Cheston R, Jones K and Gilliard J (2003). "Coming out" with Alzheimer's disease: changes in awareness during a psychotherapy group for people with dementia, *Aging and Mental Health,* in review.

Woods

Woods, R. (2001) Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects *Aging and Mental Health,* 5 (Supplement 1), S7-S16.

Yale R (1991) *A Guide to facilitating Support Groups for newly Diagnosed Alzheimer's Patients,* Greater San Fransisco Bay Area: the Alzheimer's Association.

Yale R (1995), *Developing Support Groups for Individuals with early stage Alzheimer's Disease: Planning, Implementation and Evaluation*. Baltimore: Health Professions Press

Zigmond, A. and Snaith R. (1983) The hospital anxiety and depression scale, *Acta Psychiatrica Scandanavia,* 67: 361 - 370.

Figure One: depression (Cornell and HADS-dep) scores of participants who completed all three phases of the research (n=19)

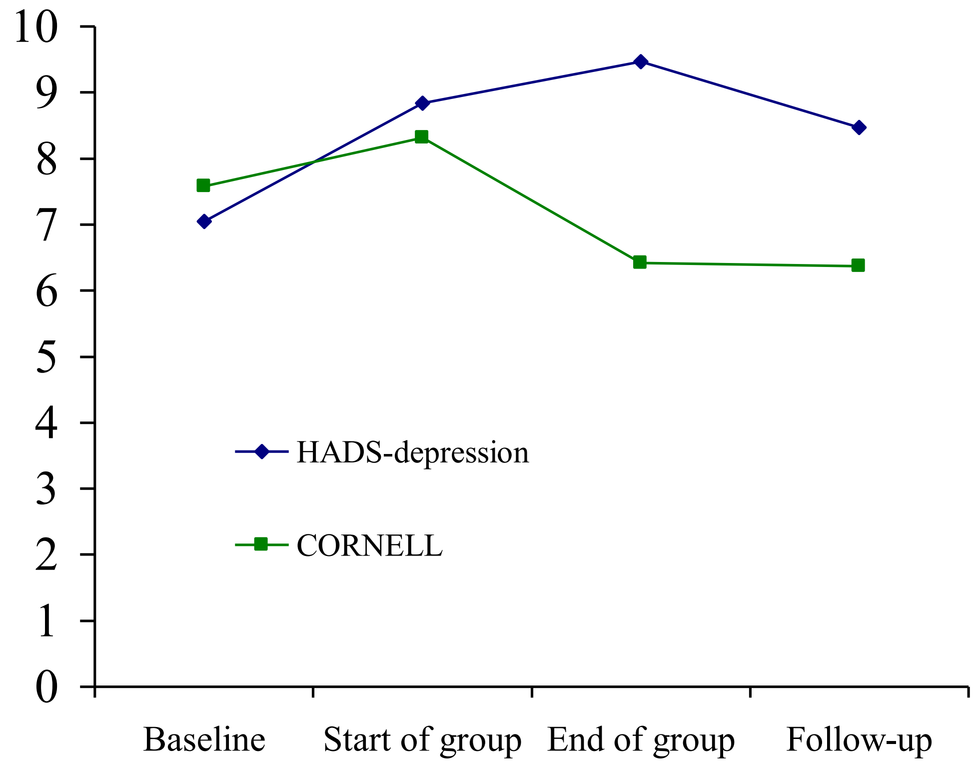

Figure Two: anxiety (RAID and HADS-anx) scores of participants who completed all three phases of research (n=19)

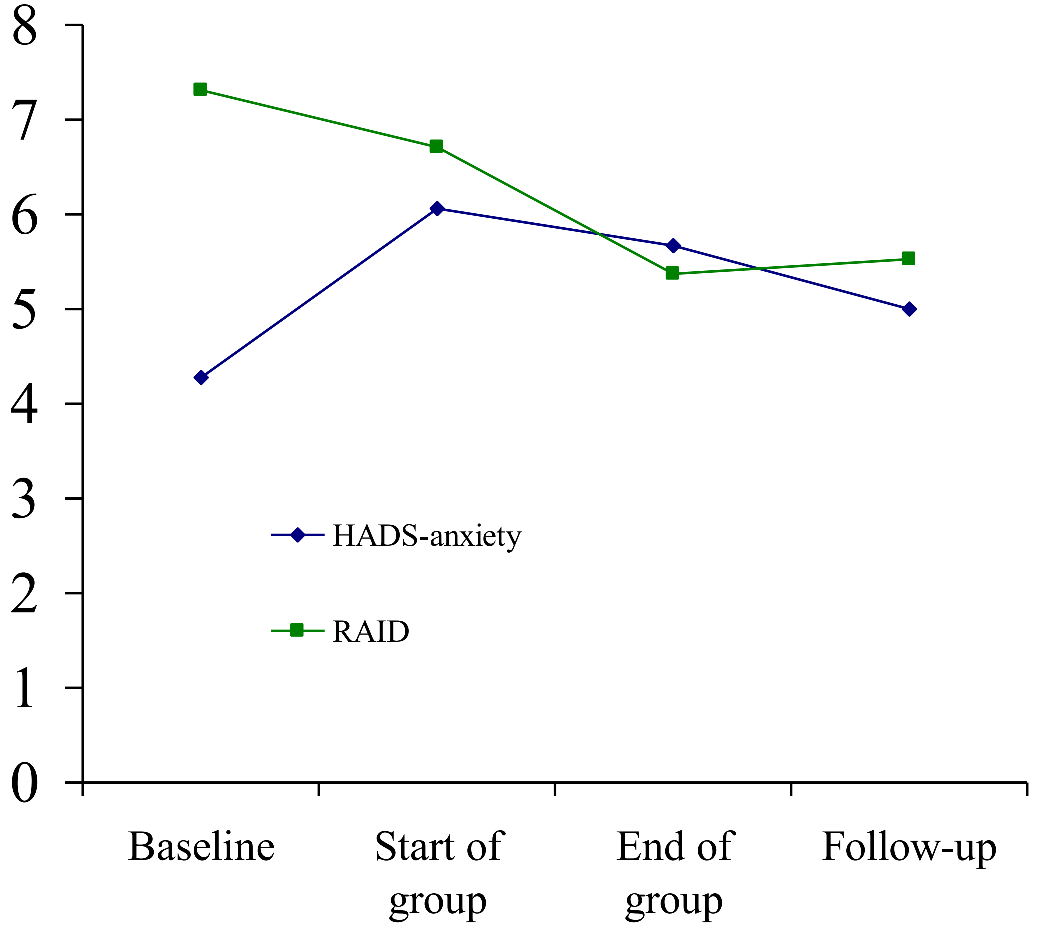

Figure Three: interaction between levels of depression (Cornell scores) and medication use during all three phases of the study.

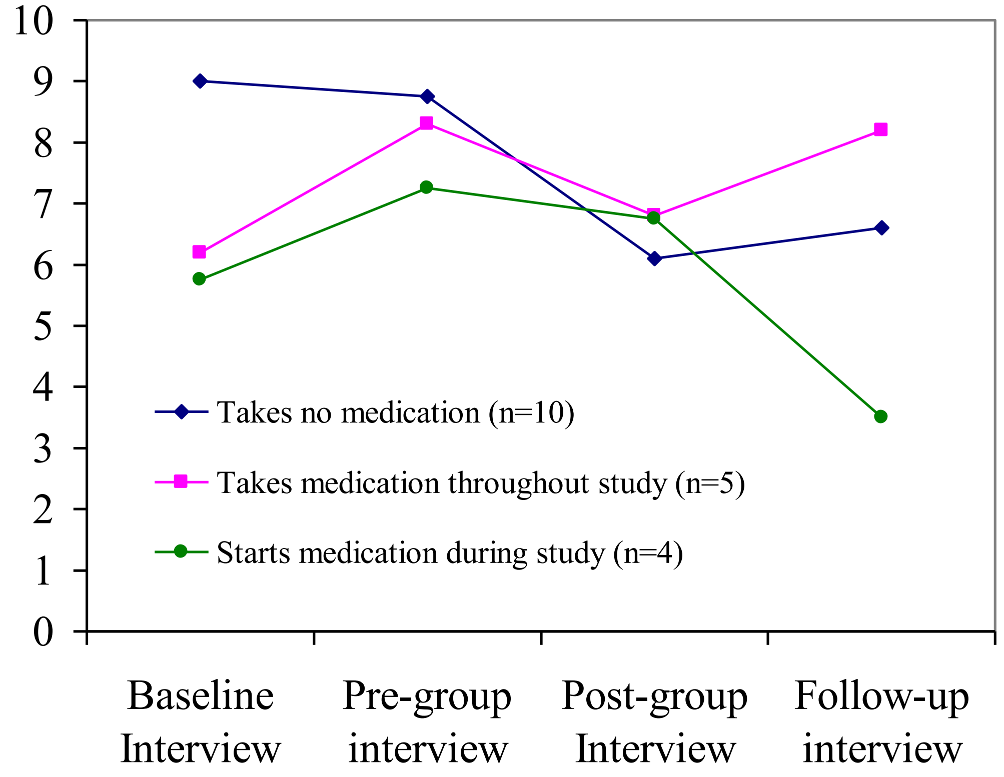

Table one: Group and research participants

Total Number of referrals to groups	**51**
People not suitable for groups or unwilling to attend	9
Total number of group participants	**42**
Group participants with unclear diagnosis	2
Group participants who do not wish to take part in research	1
Participants referred too late for baseline interviews	8
Participants referred too late for pre-group interviews	2
Participants assessed as suitable for groups and participating in baseline interview	**29**
Participants who were unable to complete all three phases because of illness or death	8
Participants who left the group because they did not wish to continue	2
Participants who complete all three stages of research programme	**19**

Table Two: details of participants

	Mean age	Gender		Mean MMSE	CDR		Mean Cornell scores at pre-group interview	Mean RAID scores at pre-group interview	Social class	
		Male	Female		Mild	Moderate			Middle/ upper class	Working class[a]
Completed all three phases of project (n=19)	71.89	13	6	23.21	13	6	8.32 (3.11)	6.71 (3.20)	15	4
Left after baseline interview (n=2)	76.5	0	2	20.50	0	2	-	-	2	0
Left after pre-group interview (n=6)	72.8	4	2	20.60	2	4	9.67	11.9	3	2
Left after end-group interview (n=2)	78.5	1	1	26.50	2	0	9	5	1	1
Late referrals (n=8)	74.7	5	3	22.25	3	5	9.10 (3.25)	8.6 (2.80)	4	4

---

[a] Working class defined as including people whose paid employment was in skilled manual, part-skilled manual and non skilled labour

Table Three: correlations between outcome measures (n=76).

	CORNELL	HAD – depression	RAID
Cornell			
HAD – depression	.214 p=.063,		
RAID	.549, p≤.000	-.063, p=.591	
HAD – anxiety	.238, p=.039	.252, p=.029	.318, p=.005

Table Four: depression and anxiety scores for those who completed all phases of the group (n = 19)

	Baseline interview	**Pre-group interview**	**Post-group interview**	**Follow-up interview**
Cornell	7.58 (2.19)[a]	8.32 (3.11)	6.42 (2.04)	6.37 (3.09)
HADS (depression)	7.11 (3.49)	8.89 (2.96)	8.95 (4.02)	7.95 (4.22)
RAID	7.32 (4.34)	6.71 (3.20)	5.37 (2.50)	5.53 (2.63)
HADS (anxiety)	4.58 (2.48)	6.26 (2.98)	5.79 (2.95)	5.05 (2.46)

---

[a] Standard deviation figures are in brackets