A Dementia Voice Project

Group Psychotherapy for people with dementia

Jones K
Cheston R
Gilliard J

Group Psychotherapy for people with dementia

Development, Facilitation and Evaluation of Psychotherapeutic Support Groups

A Dementia Voice Project funded by the Mental Health Foundation

Jones K
Cheston R
Gilliard J

2002

CONTENTS

Executive Summary 7

1 Introduction 11

2 Psychotherapy and People with Dementia 12

2.1 Emotional States 12

2.2 Coping Mechanisms 13

2.3 Psychotherapeutic Intervention 13

2.4 Group Work 14

2.5 Previous Evaluation of Group Work 14

3. The Dementia Voice Project 17

4. Overview 18

4.1 Phase I 18

4.2 Phase II 18

4.3 Facilitators 19

4.4 Demographic Characteristics 20

4.5 Outcomes 22

5. Methodology 23

5.1 Selection Criteria 23

5.2 Data Collection 24

6. Evaluation 25

6.1 Measure of Cognitive Functioning 25

6.2 Outcome Measures 26

6.3 Entry to and Exit from the Groups 27

7. Results 28

7.1 Changes in Group Scores 28

7.2 Coping Style 31

7.3 Impact of Medication on Anxiety and Depression 31

7.4 Reliable Changes in Individual Scores 21

7.5 Further Analysis 33

8. Therapeutic Group Work 34
8.1 Therapeutic Style 34
8.2 Content of the Groups 34
8.3 Issues within the Group 35
8.4 Emotional Change 39
8.5 The Challenge of Trying to Retain Control 41

9. Discussion 45

Tables

Table 1 Participating Facilitators 19
Table 2 Evaluation Phases 24
Table 3 Cornell and RAID Scores by Participants Completing all Five Phases 28
Table 4 Reliable Clinical Change by Cornell and RAID 32

Figures

Figure 1 Mean Average by Participants 20
Figure 2 Participants by Social Class Type 21
Figure 3 Participants Household Type 21
Figure 4 Severity of Cognitive Impairment by Participants 26
Figure 5 Depression (Cornell) Scores for Participants Completing All Five Phases of Research (n=19) and Participants completing Three Phases of Research (n=18) 29
Figure 6 Anxiety (RAID) Scores for Participants Completing All Five Phases of Research and Participants Completing Three Phases (N=8) 30

I want to go back

What am I doing here?

Aren't I going home?

I want go back

I 'll be all right,

I can look after myself

They keep telling me I have to stay here

I have a life you know,

A home to run, a family to see too,

Surely someone knows who I am even if you don't

Anon 2001.

Acknowledgements

The project team would like to thank all those people who participated in the groups and the research, their caregivers, friends, relatives and volunteers who supported our work. We would also like to thank Jane House and Sandy Preen, Kirsty Thorne and Jennifer Peak, Anna Littlechild, Pat Lysaght and Liz Young, Elisabeth Bartlett, and Suzanne Davis for all their hard work in facilitating the groups.

Many others contributed to the project during its eighteen month journey, these include Deidre Sutton – Smith, Mike Bender, Ann Marshall and Andrea Hirons, and the team, behind the scenes at Dementia Voice.

We would also like to thank Barney Kingsland, and Mr and Mrs Jones, for their support.

Executive Summary

‘”Am I the only one with this?’’

“I used to think like that a lot, now I meet the others in the group, I see them, I hear them, and I know I’m not the only one.’’

[Sal, age 72, Group B]

These words were spoken by one of the participants of a project to establish a series of time limited psychotherapeutic support groups for people in the early stages of dementia. They were spoken as they reflected upon the relief they felt about being able to open up and move forward in a group where they felt supported by and listened to.

Establishing support groups for people who have been diagnosed with dementia enables them to meet with others in similar circumstances. A group can be a place where members open up, share their experiences, and learn coping strategies from one another. Furthermore, a group can be somewhere, which permits the person with dementia to let go and to begin to learn to adjust and participate in the grieving process.

The Mental Health Foundation has funded this eighteen-month project. It forms part of a trend toward providing therapeutic support to people who have been diagnosed with dementia. Six groups have been developed, facilitated and evaluated across southern England. Each group lasted for ten weeks, and were facilitated by two to three facilitators. Five groups contained between six to eight people, with the remaining group comprising ten members.

To examine the effectiveness of the groups, both quantitative and qualitative information have been gathered across four different sampling points. Measures of anxiety, depression and coping style were taken independently of the clinical work, at the base line, at the start of the group, in the seventh week of the group, and ten weeks after the group had ended.

Objectives

The objectives of the project have been divided into two parts. The first is concerned with the clinical aims

Clinical aims

- *To enable people with dementia to express feelings of loss*
- *Support people with dementia in addressing grief and other emotional reactions to the process of having dementia*
- *Encourage the sharing of experiences with other people with dementia*
- *Develop coping strategies*

Evaluation

The second is concerned with the evaluation

- *Measure the levels of anxiety and depression experienced by members of the group*

- *Evaluate the coping skills used by people with dementia*

- *Evaluate the process of emotional adjustment and change by drawing on techniques from psychotherapy process research*

- *Evaluate the benefits of psychotherapeutic groups for people with dementia by comparing the changes that occur whilst they wait to join the group, whilst they are in the group, and after the group has ended.*

Outcomes

Of the fifty-one people who were referred, nine were either not suitable for group work, or did not want to attend the groups. Alternative forms of care were discussed with the person and their carer. Forty-two people (17 women and 25 men) agreed to take part in the groups. Five were part of the groups but not the research. Twenty-nine participants were referred sufficiently in advance to be interviewed at the baseline, with a further eight people joining the research in the second stage, at the start of the groups. Nineteen participants completed all stages of the research project, from baseline to follow-up. Analysis of these results indicates a significant fall in mean levels of anxiety and depression over the four stages. For the 8 participants who joined at the start of the groups (second stage) there was evidence of a significant fall in levels of anxiety and depression. In addition, significantly more members revealed evidence of reliable clinical change in levels of depression during the intervention phases of the project, compared to either the baseline or follow-up stages.

1. Introduction

People in the early stages of dementia rarely have the opportunity to discuss their feelings with others with similar experiences (Constant – Astrom, 1997). In part this may be due to a long standing bias against offering psychotherapy and counselling to older people in general (Whitsed – Lipinska, 1998). In addition, over the last twenty years, service provision has tended to focus primarily upon the needs of the carer. However as person - centred forms of care have become established, so reports of the use of counselling with people with dementia have increased in frequency.

Thus the last five years have seen a range of different attempts to provide emotional support for people in the early stages of dementia, often by drawing on techniques from psychotherapy and counselling (Greene et al, 1993; Cheston, 1998). One of the most common means of providing support has been through groups (Yale, 1991; Eagger and Hawkins, 1999). While there has been increasing interest in providing emotional support to people with dementia, there have been very few studies, which have explored the effectiveness of group work. In part this may be explained by the fact that undertaking such a study is fraught with methodological difficulties. Nevertheless, people with dementia are seeking assessment and diagnosis at earlier stages than in previous years. (Eagger and Hawkins, 1999). This is partly because of the introduction of new medication designed to enhance levels of cognitive functioning.

This in turn has led to the need to provide support to enable people to grieve for their losses and to begin the process of learning to adjust to the changes that can come with living with dementia. This project is part of an ongoing trend within social and clinical work to provide a voice to the person with dementia.

2. Psychotherapy and People with Dementia

Psychotherapeutic work with people with dementia has developed rapidly in the last ten years. The work of many including Kitwood (1990) Killick (2000), and Cheston (1998) has contributed to its evolution. However, there still remains, a chasm in the field of dementia care (Yale, 1998). People with dementia are still frequently denied the opportunity to express their feelings and to make sense of their emotions in a safe environment. Consequently it can be difficult for people with dementia to develop coping strategies to address some of the immense changes that being diagnosed with dementia entails.

Part of this stems from the belief that people have nothing to gain from psychotherapy in any of its many forms. Often families' support this view by trying to protect relative's diagnosed with dementia from the most painful emotional issues (Miller, 1989).

2.1 Emotional States

When a person suspects or is informed they have dementia they are likely to experience a range of emotions. Their emotional response has been defined as belonging to four ' discrete states: anxiety; depression; grief and despair or terror. (Bender and Cheston 1997)

Depression and anxiety have been widely documented, particularly, depression being cited as a risk factor (Reding et al, 1985). Anxiety is frequently reported as an affective response to dementia. Solomon and Szwarbo (1992) report that while 49 out of 86 people with dementia were described as having non – specific anxiety, others participants of the study were cited as having more specific fears and panic attacks.

Grief and terror while overlapping with depression and anxiety can be viewed as states in which the individual person living with dementia feels a loss of the sense of self due to their changed status (Miesen, 1992).
In addition, a sense of emptiness and loneliness can pervade particularly when people feel unsupported. Take for instance, the numerous tests a person with dementia undertakes, the many faces they meet, and of the services they are processed through. At the crucial end stage, rarely is a person offered any form of support particularly in the form of counselling, as one might expect in other services such as sexual health or oncology (Jones, et al, 2002) While it is not in the project's remit to consider an in – depth evaluation of issues of diagnosis, it does serve to impact upon the way a person is able to adjust emotionally to the process of dementia**.**

2.2 Coping Mechanisms.

People with dementia have to cope with many issues including threat in its various forms. By threat we mean the threat of progressive neurological deterioration, of change in how people react to them, and of change in how they see themselves in terms of loss of identity. Coping with these threats takes the form of a subtle and often changing process. (Keady and Nolan, 1995)

2.3 Psychotherapeutic Intervention.

There have been a variety of different therapeutic interventions, which have successfully been used for people with dementia. Validation Therapy (Feil, 1992); and Resolution therapy (Stokes and Goodie, 1990) when practised sensitively, and empathically can provide the means to enable a person to make sense of what is happening to them.

2.4 Group Work

Enabling a sense of identity. The telling of stories within a group context for example in reminiscence therapy may enable the person with dementia to relate stories from their past, particularly within a group, and provide them with an identity other than the one which views them only as a person with dementia. (Buchanan and Middleton, 1994).

Emotional processing. Within a group, a person can feel they are being listened to, and feel that their experience is important. This can help to create a sense of being valued as someone distinct from someone who has dementia. Cheston (1998) describes the process further with “the need to listen – to bear witness.” By the process of listening in psychotherapeutic work with the person with dementia, several benefits can begin to emerge.

Not only can we help people with dementia to feel valued, and therefore assist them in tolerating loss in the process of painful change, but also encourage them to find their own way of coping. Through this stage, an understanding of the world can be created to accommodate the changes they experience.

2.5 Previous Evaluation of Group Work

In the last five years, there have been a range of different attempts to provide a safe environment in which people can talk in groups about the issues surrounding dementia such as diagnosis, relationships, changing status, and loss (Eagger and Hawkins; 1999, and Yale 1998). However, there has been little attempt to evaluate systematically either the effectiveness of such support or the means by which emotional change and adjustment occurs.

This is due to a number of factors. Firstly, interest by clinicians in providing psychotherapeutic support to people with dementia, is fairly recent. Secondly, individual clinicians providing such support, often do so alone, and with constraints due to time.

There are also issues surrounding the sensitivity of measures for people in dementia. Nevertheless some small-scale studies have attempted to measure effective outcomes of therapeutic group intervention with people with dementia. In 1994 Yale (1998) assigned 15 patients to either an experimental or control group. The experimental group consisted of the usual level of care. The groups met for 1.5 hours each week, for eight weeks. While Yale was unable to report any significant statistical differences between the two groups, members became more cohesive, more relaxed and self disclosing.

Neal and Briggs (2000) considered validation therapy, and identified only two out of three studies from which data could be obtained. However, even validation therapy, the most influential form of work, had a poor level of evidence to suggest effectiveness. Other small-scale studies (LaBarge and Tranji, 1995; David 1991; Snyder et al, 1995) emphasise the benefits of providing a safe environment in which participants are able to talk about their world and to discuss the way in which they have coped with the changes that have taken place in their lives.

Reports of other group work include Eagger and Hawkins (1999) who attempted to provide emotional support to people with dementia. Though anecdotal in nature they report on the benefits of group work in terms of *curative factors.*

- *Interpersonal learning*
- *Altruism*
- *Cohesiveness*
- *Socialisation*
- *Imparting information to other members*
- *Installation of hope*

Despite the adoption of a new culture of a person centred approach to dementia care, the traditional medical model still dominates methods of care. Given the dearth of research in psychotherapeutic work with people with dementia, it becomes difficult to make a case for a therapeutic approach in any care setting, particularly when services are frequently under resourced. However, evidence base is beginning to emerge for this form of work, and this project plays an important part in developing such evidence-based work.

3. The Dementia Voice Project

Previous evaluations of groups have been anecdotal in nature, and where attempts have been made to assess the effectiveness of psychotherapeutic intervention it has not been possible to indicate any statistical significance. This project aims to apply both statistical and clinical significance in its findings. The data gathered will also, in time enable us to further develop and define a model that accounts for the process of emotional change in the person with dementia.

We are also interested to learn through information about life history and socio economic back ground, case studies, video and audio tapes from groups and interviews from people with dementia, about some of the coping mechanisms adopted through emotional adjustment and change.

4. Overview

4.1 Phase I

Initial phases of the project involved establishing links with a range of personnel and services from the field of dementia care. This was a continual process, with interest expressed as a result of dissemination at voluntary, social and health network meetings, and national conferences.
Contact was made with those who expressed interest and enthusiasm for the project, and by approaching community mental health team's, (CMHT's), memory clinics, social services sector and voluntary groups in the south of England.

4.2 Phase II

The second phase to fieldwork, involved many consultations with senior managers, and interested service personnel and agencies in the health and social care sector. Approval was obtained from two local research ethic committees, to proceed with the study. It proved relatively hard to identify potential group members. In part this may be due to the fact that mental health services are unused to thinking about providing a new service, and that the expectations of the service may in fact be too high.

While many participants resided in urban areas, other members of the same group came from rural areas. This meant that further negotiation and alteration to individual care plans took place to enable people to attend, and access other activities while they were based at the group site. A large travel radius meant that facilitators, and in some cases volunteers, were involved in transporting the individuals to the group themselves.

Occasionally this system proved challenging. It was not unusual for facilitators to arrive at participant's homes, to discover they were unavailable. We had tried several ways to overcome any difficulties in transportation prior to group meetings including communicating and telephone calls if participants permitted it. It was accepted that these situations were an inevitable part of the project.

4.3 Facilitators

With fieldwork sites defined, all co facilitators (see table one) who work with people with dementia attended a two-day workshop developed by the project team entitled, ***"Introduction to counselling with people with dementia''***. The project's clinical psychologist, who has extensive experience of providing emotional support to people with dementia, facilitated each group, working with either one or two co-facilitators. The groups were formed in this way to enable a consistent therapeutic approach.

Table One. Participating Facilitators

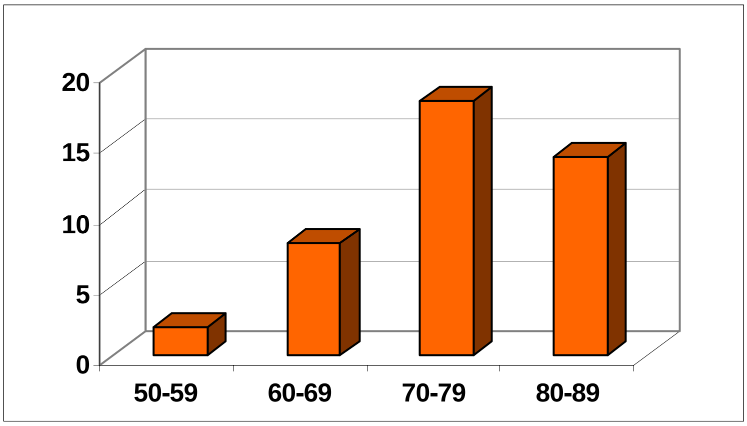
AGENCIES	PARTICIPATING FACILITATORS
NHS	**1 NURSE** **3 CLINICAL PSYCHOLOGISTS** **1 ASSISTANT PSYCHOLOGIST**
VOLUNTARY SECTOR	**1 THERAPIST**
SOCIAL SERVICES	**1 DAY CARE MANAGER** **1 PROJECT WORKER**

4.4 Demographic Characteristics

Individuals came from various regions in the south – west, and resided in both urban towns and cities, and rural farming communities, and villages. Of the 42 participants, 25 were females, and 17 percent males.

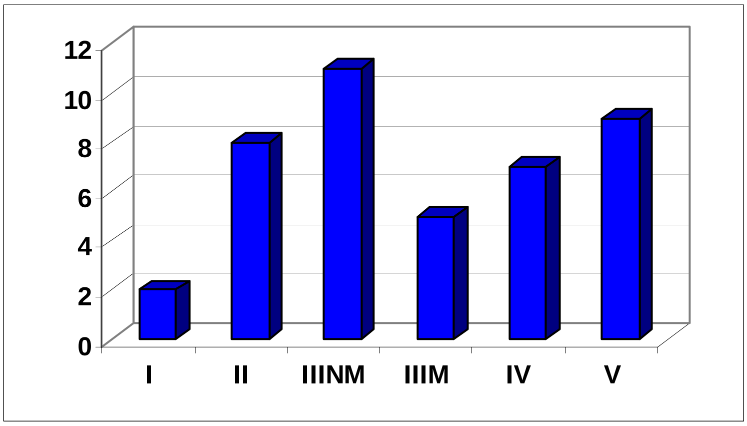
All participants have attained a secondary level of education, with a small number achieving a tertiary level of education. Initially we had defined the selection criteria for participants as that being confined to people aged 65 years and above. However, it was felt that there were individuals who were aged below 65 who could benefit from group work.

Figure One. Mean Average Age by Participants



The average age of participants was 73 years, with the youngest aged 53 years, and the eldest aged 85 years.

Figure Two. Participant's by Social Class Type



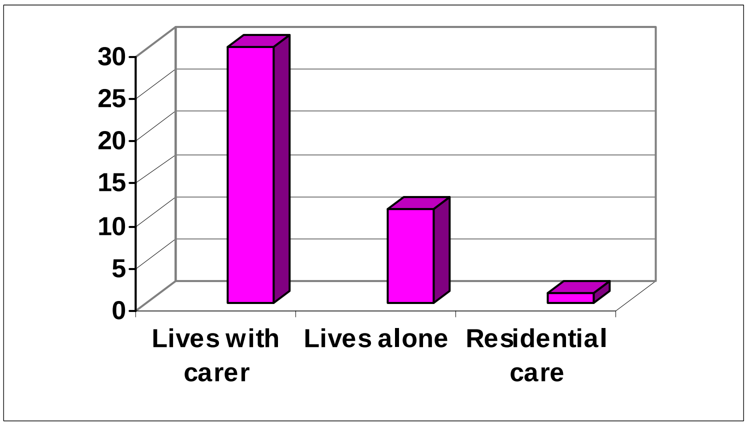
Participants occupy a variety of social class types, defined according to their previous occupations.[1] Of forty-two participants, 11 have been employed as sales people, while 9 have been defined as homemakers.

All homemakers were women participants. Other participants (n=10) occupied social class I and II as professionals in the medical, banking, and musical fields.

Level of Support

All participants resided in their own home, with some level of support.

Figure Three. Participant's Household Type



---

1. Occupational classification is based on the Office for National Statistics definitions. ONS (1999)

Figure 3, shows that out of forty-two participants; thirty resided with members of their family. Primarily, husbands and wives acted as the main carer. In some instances, participants resided with their sons or daughters, while one participant was in receipt of residential care. Of the members who lived alone (n = 11) all received significant support from family, friends, and home care services. Participants, who resided alone, were either widowed or divorced.

4.5 Outcomes

The main outcome of the project so far has been very encouraging, participants with their integrity and courage have benefited in a variety of ways, and so too have carers.

Some facilitators with their enthusiasm have continued beyond the research to provide therapeutic support to people with dementia, thereby providing a valuable support system to the communities they serve.

5. Methodology

In psychotherapy, any methodological approach has its strengths and weaknesses. As yet there exists no ‘ gold standard’ in psychotherapy research. While we are aware of the widely held belief in randomised control trails as being the only means by which to calculate validity in clinical research, they too have limitations. Our methodological approach was defined according to the clinical elements of the research where we are concerned with the qualitative evaluation of providing emotional support, and the quantitative research question: whether or not the groups are able to reduce anxiety and depression during the base – line and follow- up phases.

5.1 Selection Criteria

Participants were recruited from six groups, each containing between six to eight members, from various regions in the south – west. Members were recruited if they met the following selection criteria:-

- Diagnosis of Alzheimer’s or other dementia
- Informed of diagnosis
- Acknowledge memory loss
- Willing to attend group
- No recent psychiatric history
- MMSE score 18 and above

It was also felt that the participant had to have reasonably intact communication skills.

5.2 Data Collection

Quantitative and qualitative data was collected from participants and their carers through assessments and semi – structured interviews, carried out in participants homes over five different sampling points. Participants and carers have been interviewed independently from the clinical work.

Table Two. Evaluation Phases

WEEKS	TIME STAGES
1	T1 BASELINE
2	
3	
4	
5	
6	
7	
8	
9	
10	T2 INTERVENTION GROUP BEGINS
11	
12	
13	
14	
15	
16	
17	
18	
19	
20	T3 GROUP ENDS
21	
22	
23	
24	
25	
26	
27	
28	
29	
30	T4 FOLLOW- UP

Participants were assessed initially, (T1), ten weeks later when the group began (T2), at the end of the group (T3), and ten weeks after the group had ended, (T4). Informed consent as described was obtained at T1.

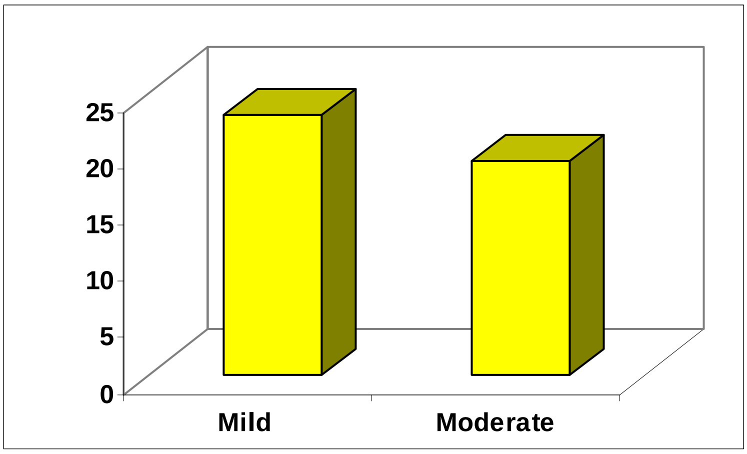
6. EVALUATION

6.1 Measure of Cognitive Functioning (First interview only)

- **The Mini Mental State Examination (MMSE)** (Folstein et al, 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. Participants could achieve a score between zero and thirty, although scores taken below twenty-four are generally taken to indicate a significant impairment in cognitive functioning.

- **The Clinical Dementia Rating Scale or CDR** (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.

Figure Four. Severity of Cognitive Impairment by Participants



Twenty-three participants had a mild level of cognitive functioning impairment, and 19 had moderate levels as measured by the CDR. (Hughes et al, 1982)

6.2 Outcome Measures (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 intended as a diagnostic instrument, nevertheless a cut-off score of 7 is indicative of a clinical level of depression.

- **The RAID** (Shankar et al, 1999) is an interview based measure designed specifically for the purposes of research rather than as a diagnostic measure, although the author suggests that a cut-off point of 11 can be taken as indicative of a significant level of anxiety.

- **Coping Strategy Questionnaire (CSQ)** Although a wide range of coping scales have been developed for use in various settings, as yet none have been validated for use with people with dementia. Consequently, this study developed the Coping Strategy Questionnaire (the CSQ), which was adapted from the IMMEL, a checklist of coping skills designed for use with people with dementia (Keady and Nolan, 1995). The CSQ consisted of six items: -
- **“I laugh about my memory problems”**
- **“ I use lists to help me remember”**
- **“ I think my memory problems are a normal part of growing older”**
- **“ I talk about my memory problem with someone I trust”**
- **“ I get angry about my memory problems”**
- **“ I bottle up my feelings”**

During the research interview carers and group participants were originally asked to rate the participants’ use of six different coping styles on a three point scale of 1 (“ never use”), 2 (“ occasionally use”), and 3 (“ often use”).

6.3 Entry to and Exit from Groups.

Fifty-one people were initially referred, Nine of which did not want to participate. Out of a total of forty-two participants who had attended at least one group session, three participants did not return, as they felt it was inappropriate for them. A further ten participants left due to health problems. Two participants took part in the group but not the research. From the remaining participants, twenty-seven completed the group and follow-up stages. Of these, nineteen had entered at the T1 stage, and eight at the T2 stage.

Using an independent samples t-test, comparisons between those individuals who dropped out of the research compared to those who remained to complete the groups in terms of age, MMSE scores and CORNELL and RAID scores taken at T2 were not significant.

7. RESULTS

7.1 Changes in Group Scores.

Data was analysed using as one-way repeated measures ANOVA to compare scores with the RAID and the CORNELL at four stages (two pre –intervention) [T1 - T2] and two (post-intervention) [T3 – T4]. The mean and standard deviations for these are presented in Table Three for all participants who completed all phases of the project [n=19] and those who entered at the intervention phase [n= 8].

Table Three. Cornell and RAID Scores by Participants Completing All Four phases (n = 19) and Those Completing Three Phases.[2]

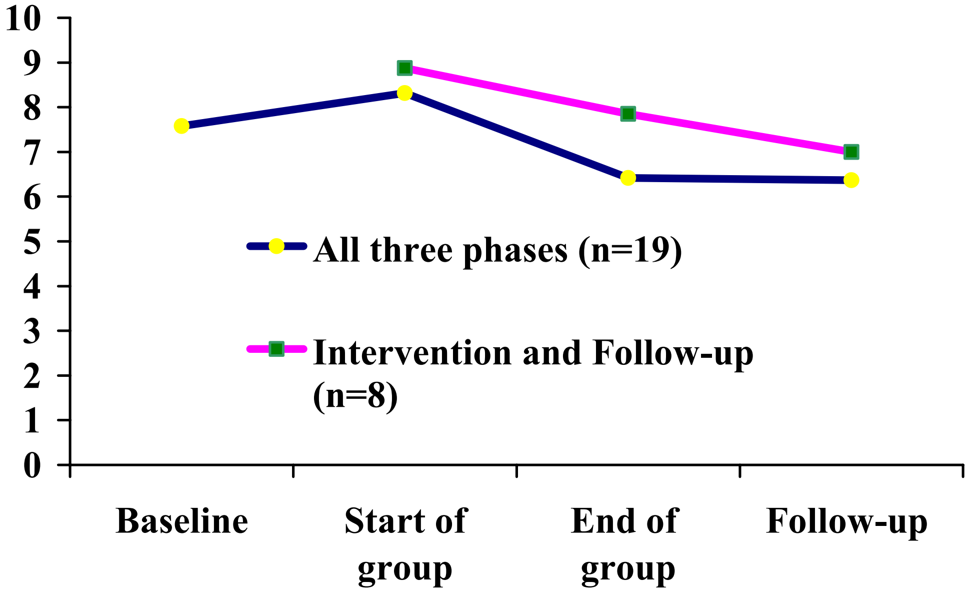
	Entry point	Baseline (T1)	Pre-group (T2)	Post-group (T3)	Follow-up (T4)
Cornell	**Baseline**	**7.58 (2.19)**[2]	**8.32 (3.11)**	**6.42 (2.04)**	**6.37 (3.09)**
	Beginning of Intervention		**8.88 (3.72)**	**7.88 (2.03)**	**7.00 (2.39)**
RAID	**Baseline**	**7.32 (4.34)**	**6.71 (3.20)**	**5.37 (2.50)**	**5.53 (2.63)**
	Beginning of Intervention		**9.75 (4.23)**	**7.88 (3.48)**	**5.13 (3.23)**

---

2. Standard deviation figures are in brackets

1.Depression. As can be seen from Figure Five, the average level of depression for the nineteen participants who completed all three phases of the research increased during the baseline phase but then fell substantially during the treatment period and remained relatively stable during the follow-up. [3] For those eight participants who joined the project at the start of the groups, there was a consistent, significant fall for the eight during both baseline and follow-up periods. [4]

Figure Five. Depression (Cornell) Scores for Participants Who Completed All Phases of Research (n=19) With Participants Completing Three Phases of Research (n= 8)

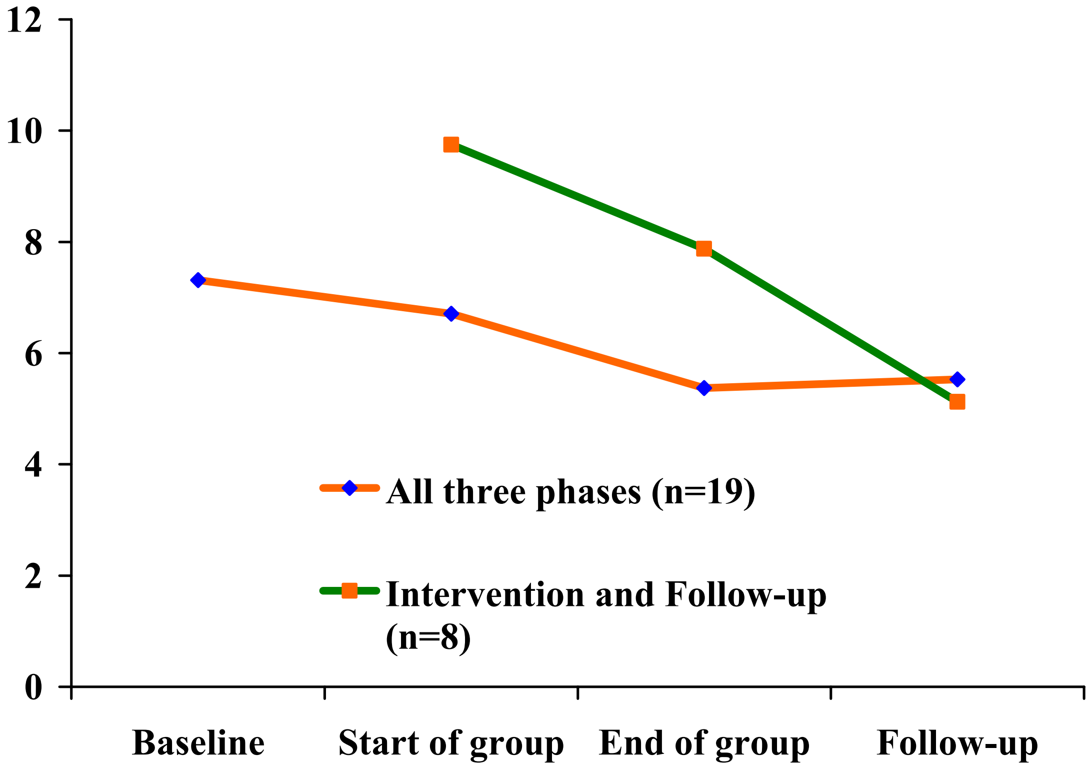


---

[3] 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)*. [4] For the eight participants: *(df=2; p=.478; partial eta=.100)*

2. Anxiety. Where all three phases of the project were completed, levels of anxiety fell slightly during the baseline phase and more substantially during the intervention before rising slightly during the follow-up period. The mean scores for the late entry group showed consistent falls across both the intervention and the follow-up period.

Figure Six. Anxiety (RAID) Scores of Participants who Completed All Phases, and Participants Completing Three Phases (n= 8).



Analysing the data using univariate statistics showed that there was a significant within subjects effect for the RAID scores of all participants. [5]

Effect sizes for both the RAID and the Cornell scores are either close to or above .14, which is generally taken as indicating, that the intervention has had a strong effect.

5. Participants who completed three phases of the project *(df = 3; p = .050; partial eta = .133)* and for those who completed only two phases *(df = 2; p =.010; partial eta = .479)*

7.2 Coping Style

The nineteen participants to complete all phases used a variety of coping strategies, with the most commonly cited being: ***" Believing that my memory problems are a normal part of getting older''*** and ***"Talking to someone who I trust about my memory problems'', and " I use lists to help me remember".*** The latter coping strategy was the only significant interaction between changes in mood and coping style was found.

7.3 Impact of Medication on Levels of Anxiety and Depression

A post-hoc analysis using the three individual medications (anxiolytics, anti-depressants, and cognitive enhancers) provided no evidence of medication influencing levels of decreasing levels of depression throughout the project.

7.4 Reliable Changes in Individual Scores

Analysing data for the group as a whole can provide an important indicator of the effect of the intervention. However, this can be misleading, as it is unable to inform about the clinical impact of the therapeutic intervention on individuals. Therefore data was analysed in terms of the measure of reliable clinical change put forward by Jacobson and Traux (1991), to enable discussion of the clinical impact of this work. All nineteen participants who had completed all research stages were categorised as having: "improved", "unchanged" or "deteriorated" [6]

---

[6] Please Jacobson and Truax (1991)

Table Four. Reliable Clinical Change by Cornell and RAID Scores for Participants Completing All Phases [n=19] [7]

	Deteriorated	**No change**	**Improved**	**Pearson χ**	**Significance levels**
CORNELL					
Baseline	**3**	**15**	**1**	**18.05**	**.000**
Intervention	**2**	**5**	**12**	**8.316**	**.016**
Follow-up	**7**	**6**	**6**	**.25**	**.949**
RAID					
Baseline	**2**	**10**	**7**	**5.16**	**.076**
Intervention	**3**	**6**	**10**	**3.89**	**.143**
Follow-up	**5**	**10**	**4**	**3.26**	**.196**

As observed by table four, for the Cornell scores there was a significant overall change in the proportion of the three reliable change categories across the three phases of the group. Further analysis showed a significantly disproportionate number of participants during the baseline period showed no change in their level of depression. During the intervention significantly higher numbers of participants improved than showed no change or deteriorated. By contrast, the proportions of group participants in each of the three categories over the final, follow-up period were roughly equal. Although similar, the reliable clinical change scores for the RAID were statistically non-significant.

7. Analysed using 3x3 contingency table and chi squared procedure

In addition to those participants who completed all three phases of the project, eight participants who entered the project at T2 completed the intervention and follow-up phases. Although the numbers involved prohibit a meaningful statistical analysis, it is suggested that the group therapy intervention has a positive effect on the emotional level of participants, which is sustained at follow-up.

7.5 Further Analysis

A further development of the project will enable us to observe in detail the way in which group member's talk about their experiences, and explore the extent to which the groups facilitate a process of emotional adjustment. Recently, funding, (£5k) has been obtained to hire an assistant psychologist to explore this work further. With the use of the video, and audio recordings of two groups, and facilitator notes, the assistant psychologist will be drawing on techniques from psychotherapy process research, such as the Assimilation of Problematic Events Scale or Apes (Stiles et al, 1990).

8.Therapeutic Group work

8.1 Therapeutic Style

Reflective listening. The central counselling technique adopted by the facilitators within the group was Resolution Therapy, a form of therapeutic intervention specifically developed for work with people with dementia. (Stokes and Goudie, 1990) Based on humanistic ideas of counselling, Resolution Therapy is a means by which the often hidden emotional message underlying the actions and language used by people with dementia are sensitively reflected back to them. This is can be an effective way of helping people with dementia to make sense of what has been happening to them, and of providing them with emotional support.

Group processes. The lead facilitator for all the groups received regular supervision from a group analyst, in order to gain a greater appreciation of the dynamics of groups, and inter – personal relationships. This provided an insight into functioning of the groups.

8.2 Content of the Groups

The initial sessions were generally structured, with facilitators taking a directive stance. The first session tended to include goal setting, and an educational component. As the groups progressed, discussions were increasingly led by participants, and onto issues that dealt with difficult and distressing emotions.

A central role for facilitators was to help participants to reflect upon the problems they experience in their day-to-day lives and the emotions that these create for them. Although efforts were made to apply a consistent approach across the six groups, each of the groups varied slightly in their format, reflecting the diversity of professional skills that facilitators used in the groups. Additional forms of work carried out in the group included:

- ***Information – giving about practical issues***
- ***Raising issues around memory loss***
- ***Relaxation techniques***
- ***Developing practical coping strategies***

8.3 Issues Within the Group

Within many group sessions the sharing of experiences led to disclosure of their fears and concerns for the future. For participants of one group in particular, a disclosure of fears, led to a deepening of rapport and therapeutic movement within the group. A central and recurring element to the groups, then, concerned what it was like to have been diagnosed with dementia, what it is like to live with dementia in the present, and participants awareness of the future.

Forgetfulness. The core themes of forgetfulness constitute a core variable in thinking about how people experience dementia. The task of facilitators is often to remember the forgetfulness. The theme of ‘’ forgetfulness’’ is much more than having a poor memory for names and faces, for the very words with which to describe and to articulate feelings. It is about more than losing a pair of glasses, of not being to able to remember the day, or how to solve problems.

It is also about how people cope with the emotional consequences of experiencing memory loss for the desire to forget, to be forgotten, for the sense of being forgotten about. For Rose (aged 72 years) it means being forgotten about as someone who has dementia. “ ***I feel like I have a placard around my neck saying Alzheimer’s, as people treat you so differently once they know you have it.’’*** There will also always be concern for the future. ***“ I always worry what will happen next, and at what stage, will I have to be in a home’’*** (Florrie, aged 80 years).

The pain of forgetfulness. There is often much anger and sadness about being reminded of how things have changed. It is about losing your driving license, taking the decision not to drive, or of having the decision made on your behalf, as the car sits in the drive, and the keys remain on the table in the hallway. For those living alone, it meant trying to work harder to remember where the house keys were placed, to avoid knocking on the neighbour’s door for the spare key. Henry shared his feelings surrounding this situation: ***“ I feel such a fool when I can’t find the keys, and I’ve then got to go begging the neighbour for them, and admit I can’t remember where I left mine.’’***

The pain of being forgotten about. People can feel forgotten about in several ways. They can feel excluded on a factual level when they are excluded from receiving important information such as the result of a scan. There is also exclusion on an emotional level, when the person feels that they are no longer seen as someone who has feelings, who experiences emotion. This occurs within systems, and within relationships.

For Jack (aged 66 years), the diagnostic process was a painful experience, which he believed was handled insensitively: ***“I felt terrible, I was talked***

about as though I were no longer there” On hearing the diagnosis, May (aged 79) reflected, “ ***I felt as though I had just been trodden on, as thought I would no longer be a person’’*** Others such as Beth when asked to share their experience of living with dementia, reflected sadly on the way they are now perceived by their friends

Being forgotten about can evoke a variety of emotional reactions. For some there is sadness and despair as people reflect upon the lack of value that the world now places upon them. For others there was a great deal of indignation, and that the world should be made to listen, or as one lady out it**:** “ ***we must come out of the closet with Alzheimer’s’’***. A number of people spoke about how they would disclose to others that they had Alzheimer’s disease, so that others could understand them better:
“These feelings need to come out, people need to talk about these things, we need to put it out there’’.

For many people, being assertive was difficult. More often there was a sense of sadness at what had changed compounded by a wish to forget about themselves and to be forgotten about by others. In part this came from a sense of embarrassment and shame that many felt about them, and a dread of making mistakes in public. There were also participants who wanted to be forgotten about so that they would be less of a burden, or a nuisance: ***“I’m worried about the indignity of it all, and the embarrassment it would mean for all my family’’.***

For many people with dementia, there can be a need to acknowledge the sense of being forgotten about. Often there is anger and sadness about being forgotten about – how people forget that individuals with dementia have feelings too, and how the service thinks it is best not to tell you the result of your test. It is also about how lonely it can be in a crowd by the very fact that people act as though you are not there. As the project facilitator's experience of running groups for people with dementia on an in – patient ward suggests, people worry not only about forgetfulness, but about being forgotten about, on the ward itself. When the group were able to talk about the complexity of some of these issues then people felt safe to explore them.

The wish is often to forget. Not thinking about what is happening seems to be a way of coping for some participants of the groups:- " ***I know I have Alzheimer's, but I try not to think about it, at times I may not even want to acknowledge that I have it ''***. (Sophie aged 75 years). What is pushed away is the sense of anger and injustice, the vulnerability, the absence of safety, the risk of thinking about the future.

Feeling safe to share the pain. While many group members were keen to share their experiences at the outset, there were several members who initially were reluctant to join the group, including Violet. Sharing her discomfort, Violet talked of what it would mean to open up and experience intense emotions by " ***analysing the Alzheimer's to death!***''
For Violet, it meant experiencing fear, distress and sadness. This Violet did, and as she continued to do so, other members, began to share their experiences with her.

After several sessions Violet began to feel less isolated, " ***I now meet others with Alzheimer's, I see them, and I hear them, and I know I am***

not the only one.’’ Violet continued to feel supported, and obtained some sense of self-identity. Violet was also someone who like others in the group, were trying to make sense of what was happening to them. As the groups progressed, Violet spoke with pride and satisfaction as she shared her observations of the changes the group had made in their development: ***“the group has really moved on, there is more serious thought now, a different aspect, which is a natural progress.’’*** If people within the group are helped to think through the tensions between remembering the forgetfulness and forgetting about it, then they can be helped to make emotional change.

8.4 Emotional Change

Peter

Since being diagnosed with Alzheimer’s, Peter has lost his job, his company car, and his driving license. Peter clearly felt these losses deeply. For Peter, they represented a loss of sense of self as the breadwinner within the family, the person the family looked up to and respected, of the friend who would always drive you to the match on Saturday, and of the neighbour who carried out chores when they were unwell. The loss of the driving license has proven to be the most painful, distressing and problematic experience he has endured since diagnosis. His grieving often took the form of tearful anger.

i) Loss

For Peter being prevented from driving was a continual emotional wound. He often talked about his experiences, of how being unable to drive had led to a lack of choice, of when and where to go out, as he felt dependent upon others to drive him to the shops in town, or to visit friends.

Frustrated and saddened by the gradual loss of independence, he talked about trying to cope with his loss by saying goodbye to the car, by taking it for one last drive in the countryside, tearing up the driving license.

ii) A problem shared

Peter shared his distress and anger with the group, which helped to create a sense of shared injustice. During the early sessions, many group members, including Peter talked about their memory difficulty, as the result of external, temporary forces, which they hoped, would be resolved in due course. Being prevented from driving, for some, was a temporary disruption to their lives, and one, which they hoped, would be resolved in due course. As the group continued to meet, so the sense that it was a safe place to talk developed, people felt more able to talk about their problems and to acknowledge their fears, anger, distress and sadness. For some participants including Peter, the anger and distress that framed their discussion in earlier sessions gave way to sadness. Hope of the license being given back gave way to an acceptance that this is how things had to be.

iii) Acceptance

During the final sessions Peter was able to say that while he was saddened at the loss of his license, he felt he had worked through a great deal of his anger, and was beginning to find other ways to remain independent. He informed the group at later sessions that he was ready to sell his car. Peter reflected on the impact the group had had upon him,

“ I can really see that it helps to talk about stuff in that group.’’

Group members often shared their observations about the group, and how having formed some sense of group identity, they had developed an informal support system, by which members could be assured, that they were safe, and cared about by other members.

8.5 The Challenge of Trying to Retain Control

All participants faced challenges in their daily lives. These ranged from practical challenges such as being unable to remember a son's telephone number. There was a sense of having to own up that they were no longer able to remember, or of being found out and seen as no longer able to carry out specific tasks. Being found out for many meant that they would now be treated differently. This meant for a few participants, that they were infantilised and no longer trusted with specific tasks. For others, it meant always being reminded, as Simon (aged 56 years) reflected, " ***Now I am always being told what to do, it winds me right up''***

Stan

Some participants, who resided with their carers, were determined to prove that they could still carry out specific tasks. In the case of running an errand to the supermarket, Stan described his strategy, ***" I go to the local supermarket for my wife, and I know I will forget what it is I went in there for. So I walk around the shop looking at the shelves, until I am reminded what it is I went in there for. I can then go back to the wife and show her I can still do it''.*** For now, Stan continues to prove he can carry out the tasks, he feels he always took for granted.

Life for many of the participants has been about adjusting to situations in which they no longer find themselves in control. No longer able to complete tasks they were once able to, participants describe how they experience a whole range of emotions including embarrassment, shame and anger. Control for many participants is about having choice, and it is about exercising that choice.

For others such as Sylvie (aged 76), the night times are a solace. It is a time when he is able to obtain relief from living daily with dementia: ***" I can't wait for the night, I can go to sleep, I can forget about the dementia for a while''*** Jill (aged 64 years) often looks back on her life, and successful career, and describes how she reflects sadly on her present situation: ***" I've pushed a lot of boats out in my time it is upsetting to think that I'm never going to achieve anything again''*** When asked about their thoughts of the future, Cyril (aged 84 years) shrugged: ***"no point worrying about it there is nothing I can do about it anyway''.***

While all participants face challenges in their daily lives, individually they have developed defence mechanisms to help them to cope with the pain and frustration of living with dementia. For others like Henry (aged 77) life at times is, " ***a series of farcical situations in which there is a conflict of interests between emotions and logic''***. But it is also about trying to hold onto some sense of normality, of trying to retain previous ways of doing things, of being. At times the only way to do this, is to go about one's business, as best as one can, while at the same time blocking out any awareness that things aren't going to get any better.

Coping for the participants also means believing:

- **To live day by day. To live in the here – and – now and never to think about tomorrow until it**
- ***To live in the there – and – then, to carry on with life as if it were a mere repetition of yesterday.***
- ***To just get on with it and not to think about it***
- ***To treat dementia as if it were a battle in which the goal is: " never to give up to always keep fighting on''. (Cyril, aged 89 years).***
- ***To say that if only I could do this or that, have this or that medicine, it'll be alright***
- ***To say that if only I could do this or that, have this or that medicine, it'll be alright***
- ***To say that if only it takes my memory and leaves my intellect I'll*** **be OK**

Life for many of the participants has been a myriad of painful experiences since diagnosis. For some the best way to cope has been to escape and forget about being a person with dementia. There is sadness as people reflect on how they feel they are perceived by others in society, and treated with little respect.

For many members, there has been a strong sense of getting on with things, if only to avoid thinking too much about living with memory loss. Others have used humour to secure momentary release from their fears and a feeling of sadness. Forgetfulness then can be a benign necessity. However, if psychotherapy is, to some extent, the process of thinking about what is happening, then we have to help people remember. This act will only be useful for some people in some situations and under some conditions.

For all the group members the way in which they talk about themselves, their lives and their problems has changed. The existence of emotional support in their lives has prompted this change. This not only has implications about the way we care for people with dementia, but also how people with dementia can make use of emotionally supportive services.

9. Discussion

Traditional views as to the benefits of psychotherapy with people with dementia have changed over the last five years with positive reports of interventions in peer reviews, and many practioners in the field of dementia care striving towards person centred approaches.

The work of many including Feil (1992) and Stokes and Goudie (1990) Kitwood (1997), has contributed to the evolvement of person centred care. However, there is no room for complacency. Previous evaluation of group work have been anecdotal in nature, and where attempts have been made to formally assess the effectiveness of psychotherapeutic intervention they have been unable to indicate any statistical significance. Indeed, Neal and Briggs (2000) identified three studies in which data could reveal no statistical significance for intervention.

Outcomes

This project is therefore one of the first to apply a structured investigation into the effectiveness of group psychotherapeutic intervention for people with dementia. Utilising a series of methodological controls for variable indicators, the outcomes indicate positive results. An intervention of ten weeks, although brief, can yield statistically significant results, with a reduction in anxiety and an overall trend towards decreasing levels of depression. Depression and anxiety scores did not show a return to pre – intervention levels. In addition, other positive outcomes gained as part of the group, continued, and in several cases the gains were increased.

Many participants continue to receive emotional support, while some facilitators have continued to establish support groups for people with dementia, and provide a valuable service to the communities they serve. For many of the participants, being able to share their experiences has helped to create a sense of common identity.

However, in the wider community, the situation is often such that a significant proportion of people with dementia have needs, which are unmet. With an ever-increasing population, particularly in terms of people with dementia, it would be unwise to ignore such needs for much longer. It is vitally important that people are enabled the opportunity to be part of a supportive group, and to feel less isolated, and frightened. With the use of empathic listening skills, people with dementia can begin to feel that they are being heard, and that their life has a meaning too..

In listening to the experiences of people with dementia, this project has aimed not only to provide a voice to the person, in order to better appreciate the emotional processes involved in adjustment and change, but also to provide insight as to the value of psychotherapeutic group work in the provision of emotional support to people with dementia.

References

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

Buchanan, K. and Middleton, D (1994) Reminiscence reviewed: a disclosure analytic perspective. In J. Bornat (Ed). *Reminiscence reviewed: perspectives, evaluation, achievements.* Buckingham: Open University Press

Bender, M., and Cheston, R (1997) Psychotherapeutic work with people with dementia: A review of the literature. *British Journal of Medical Psychology*. **71,** 211 – 231.

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

Contant Astrom, B. (1997) Psychological intervention with the elderly. *Psiquitria – Biologica*. **5**, 352 – 357.

David, P. (1991) Effectiveness of group work with the cognitively impaired older adult. *The American Journal of Alzheimer Care and Related Disorders and Researc*h. July – August, 10 – 16.

Eagger, S. and Hawkins, D. (1999) Group therapy; sharing the pain of diagnosis. *Journal of dementia care*, **7**, 12 – 14.

Feil, N. (1992) Validation therapy. In G. Jones and B. Miesen (Eds). Care giving in dementia. London: Routledge.

Folstein, M.F., Folstein, S.E. and Mc Hugh, R.P. (1975) Mini-mental state. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, **12** (3) 189 – 198.

Greene, J.A., Ingram, T.A., and Johnson, W. (1993) Group psychotherapy for patients with dementia. ***Southern Medical Journal***, **86,** 1033 – 1035.

Hughes, C.P., Berg, L., Danziger, W.L., Cohen, L.A., Martin, R.L. (1982) A new clinical scale for the rating of dementia. *British Journal of Psychiatry,* **140,** 565 – 570.

Jones, K., Cheston, R, and Gilliard, J. (2002) Psychotherapeutic Support Groups for People with Dementia. In B. Miesen and G. Jones (Eds.) *Care Giving in Dementia, Vol 4.* (in review)

Jacobson, N and Truax, P. (1991) Clinnical Significance: a statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology,* **59**, 12 – 19.

Keady, J. and Nolan, M. (1995) IMMEL 1: assessing coping responses in the early stages of dementia. *British Journal of Nursing*, **4,** 129 – 144.

Killick, J.(2000) *You are words*. Dementia poems. London: Hawker Publications.

Kitwood, T. (1997) *Dementia reconsidered: the person comes first*. Buckingham: Open University Press.

Kitwood, T. (1990) Psychotherapy and dementia. *Newsletter of the psychotherapy section of the British Psychological Society,* **8**, 40 – 56.

La Barge, E., Tranji, F. (1995) A support group for people in the early stages of dementia of the Alzheimer type. *Journal of Applied Gerontology,* **14**, 289 – 301.

Miesen, B. (1992) Attachment theory and dementia. In G. Jones and B. Miesen (Eds), *Care –giving in dementia*. London: Routledge.

Miller, A.D. (1989) Opportunities for psychotherapy in the management of dementia. *Journal of Geriatric Psychiatry and Neurology*, **2** , 11 – 17.

Neal, M. and Briggs, M. (2000) *Validation therapy for dementia*. Cochrane database systematic review, 2, CD 001394.

Office for National Statistics (1999) Population Projections. *Population Trends*. **98**, 56 – 57. London: ONS

Reding, M. M., Haycox, J., and Blass, J. (1985) Depression in patients referred to a dementia clinic. *Archives of Neurology,* **42**, 894 – 896.

Shankar, K.K., Walker, M., Frost, D., and Worrell, M.W. (1999) The Development of valid and reliable scale for rating anxiety in dementia (RAID) *Ageing and Mental Health.* **3;** 39 – 49

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

Solomon, K., and Swarzbo, P. (1992) Psychotherapy for patients with dementia. In J.E. Morley., R.M. Coe, R. Strong, and G.T. Grossberg (Eds). *Memory Function and Ageing – Related Disorders. New York: Springer publishing.*

Snyder, L., Quayhagen, M., Sheperd, M, and Bower, S. (1995) Supportive seminar groups: an intervention for early stage dementia patients. *Gerontologist,* **35,** 691 - 695.

Stiles, W., Elliot, R., Llewellyn, S., Firth-Cozens, J., Margison, F., Shapiro, D, and Hardy, G. (1990) Assimilation of Problematic Experiences. *Journal of Clinical Psychology,* **55**, 1213 – 1226.

Whitsed – Lipinska, D. (1998) Counselling services for people with dementia. *Journal of Dementia Care,* **6,** 10 – 11.

Yalom, I.M. (1985) *The Theory and practice of group psychotherapy.* (third edition). New York: Basic books.

Yale, R. (1991) *A guide to facilitating support groups for newly diagnosed Alzheimer's patients*. California: The Alzheimer's Association.

Yale, R. (1998) *Developing Support Groups for Individuals with early stage Alzheimer’s disease; planning, implementation and evaluation.* Baltimore: Health professional press.