

**COUPLES' EXPERIENCES OF EARLY-STAGE
DEMENTIA AND OF ATTENDING A MEMORY
REHABILITATION GROUP**

Thesis submitted to the University of Leicester in partial fulfilment
of the Doctorate of Clinical Psychology

Submitted in 2007

By

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STRUCTURE AND WORD COUNT

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SECTION B	Literature Review	(8,000 words)
SECTION C	Research Report	(11,942 words)
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SECTION A
THESIS ABSTRACT

THESIS ABSTRACT

TITLE: Couples' experiences of early-stage dementia and of attending a memory rehabilitation group.

AUTHOR: Emma Jane Dale.

Aims: The thesis had the broad aim of adding to the literature on psychological interventions for people in the early stages of dementia. Specifically, it aimed to explore the lived experience of couples who had attended a memory rehabilitation group.

Literature review: A review of psychological interventions in early-stage dementia raised the following points. Individually tailored cognitive rehabilitation was effective for specific everyday memory problems. Supportive group psychotherapy had the most impact on emotional adjustment and mood. The evidence base for individual psychotherapy was poor. Finally, there were a number of group interventions that provided a mix of psychoeducation and peer support in order to enhance coping, with some also focussing on memory rehabilitation strategies. There was some evidence that such groups could have a protective effect on mood.

Methodology: The research adopted a qualitative approach, using semi-structured interviews to gather the lived experience of four couples who had attended a memory rehabilitation group. The resulting transcripts were analysed using Grounded Theory.

Main findings: The participants outlined how they were coping with early-stage dementia. A key concept was that during their life together the couples had developed a shared memory, which was also affected by the onset of dementia. Thus the changes in the memory of the person with dementia had an emotional and social impact on both the individual and the couple. In response, the couple had the dual task of emotionally adjusting to the changes whilst preserving the shared memory as best they could. The couples were supported in this task by friends, family and services. In particular, the memory rehabilitation group provided the opportunity to develop memory preservation strategies whilst facilitating emotional adjustment, which could explain the protective effect on mood reported in previous studies.

SECTION B
LITERATURE REVIEW

**Psychological interventions in early-stage dementia:
A review of the literature.**

Target journal – British Journal of Clinical Psychology¹.

¹ See Appendix I for 'Notes for Contributors' for the British Journal of Clinical Psychology.

1. ABSTRACT

Purpose: To review the literature on the effectiveness of psychological interventions in early-stage dementia.

Method: A systematic search strategy was used to identify relevant literature. A critical narrative analysis was applied including a methodological critique and a synthesis across studies.

Results: Two main strands of psychological interventions were identified; the neuropsychological and the psychotherapeutic. The neuropsychological literature suggested learning could be enhanced through use of specific cognitive training techniques, in particular spaced retrieval and faded cues, within an errorless learning paradigm. These techniques were most effective as part of an individually tailored cognitive rehabilitation package. Group interventions were less effective cognitively but had a protective effect on mood.

The literature on psychotherapeutic interventions included support groups, group psychotherapy and individual psychotherapy. Support groups were well received by clients, carers and services, with some limited evidence to suggest they had a positive impact on mood. More conclusive evidence was available for supportive group psychotherapy, which had an impact on mood and adjustment. The evidence for individual psychotherapy was sparse and weak.

Conclusion: A range of psychological interventions for early-stage dementia were evaluated. The interventions with the most consistent evidence base were individual cognitive rehabilitation and supportive group psychotherapy. More research is needed, particularly into individual psychotherapy and memory groups.

2. INTRODUCTION

At the present time, there is controversy within the United Kingdom over whether it is cost effective to prescribe cognitive enhancers in the early stages of dementia (NICE, 2006). It, therefore, seems timely to explore the effectiveness of alternative interventions. This review will focus particularly on interventions that address the psychological needs of those with a diagnosis of dementia, an area that had been neglected until relatively recently.

2.1 The shift to early diagnosis

Dementia is currently incurable and studies suggest that with each decline in cognitive ability the cost of caring increases, as does the burden on carers, services and society (Michel *et al.*, 2003). In the 1980s and 1990s, cholinesterase inhibitor medications were introduced. Studies showed they delayed the cognitive decline, as well as the accompanying decline in activities of daily living and global functioning (Giacobini, 2003). This led to an impetus to diagnose dementia in its earlier stages and, to facilitate this, community based “memory clinics” were introduced (Jaldow *et al.*, 2003). As well as providing early diagnosis of dementia, the clinics monitored changes in impairment and provided a participant pool for medication trials.

2.2 Recognising “personhood”

During this same period, the focus of research and clinical practice within psychiatry and clinical psychology was on codifying impairment, allocating people to diagnostic categories and looking into the physical causes. Similarly, caring for people with dementia meant meeting their physical needs, to the neglect of their social and emotional needs (Kitwood, 1993). Kitwood (1993) challenged this depersonalising of people with dementia. He highlighted their need for: emotional containment, validation of their private experiences, social interaction and facilitation to enable them to accomplish acts rather than having them done for them.

2.3 Psychological Interventions for Early-Stage Dementia

Kitwood's challenge also applied to those in the early stages of dementia. Memory problems were being diagnosed and codified earlier, the degree of impairment was being monitored and medication prescribed where appropriate, but the individual, and their family and friends, were often left to cope with the emotional, psychological and social impact on their own.

Psychological interventions have subsequently developed to meet the needs of this client group and it is the aim of the current review to examine the evidence for their effectiveness. Two main strands of intervention have been identified by this review: those that address the psychological and emotional impact, such as individual and group psychotherapy, and those that focus on the neuropsychological aspects, such as cognitive training and cognitive rehabilitation.

3. METHODOLOGY

The review employed a systematic search strategy to identify relevant literature. A critical narrative analysis will be provided, including a critique of methodology and a synthesis across studies.

3.1 Search strategy and search terms

An initial literature search to identify psychological interventions used in the early stages of dementia revealed two main clusters: those employing a psychotherapeutic approach and those employing a neuropsychological approach. Further literature searches were then conducted focussing on these two areas and using key terms identified from the initial search. A summary of the search terms used, the databases searched and the years covered can be found in Table B1. Additional studies were identified through reference lists.

3.2 Inclusion / exclusion criteria

Studies were included if they outlined either a psychotherapeutic or neuropsychological intervention for people in the early stages of dementia, including some formal evaluation of its effectiveness. Studies were included if they made specific reference to some or all of the participants being in the early stages of dementia and/or being categorised as having mild dementia; a Mini Mental State Examination Score (MMSE) of 18 or above. Previous literature reviews in the area were also included.

Studies were excluded if they were exclusively focussed on participants with moderate to severe dementia (e.g. MMSE less than 18) or those with Mild Cognitive Impairment that did not meet formal criteria for dementia. In addition, studies were excluded if they described an intervention but gave no evaluative information.

Table B1: Search terms, databases and years covered

Search terms	Databases	Years
Dementia, Early, Psychol*, Interventions.	Psychinfo Medline	1887 to 31 May 2007 1950 to 31 May 2007
Neuropsycholog*, intervention*, 65+.	Psychinfo	1887 to 31 May 2007
Dementia or Alzheimer's, & Errorless learning, or Spaced retrieval, or Cognitive training, or Cognitive stimulation, or Cognitive rehabilitation.	Psychinfo	1887 to 31 May 2007
Dementia or Alzheimer's, & Psychotherap*.	Psychinfo	1887 to 31 May 2007
<i>Citation Search: Yale, 1995</i>	ISI Web of Science	1995 to 31 May 2007

4. RESULTS

4.1 Overview

In total, forty-one studies were identified that met the review criteria. Table B2 gives a breakdown of studies by intervention type. The intervention with the most published studies was cognitive training. This is based on the principle that regular practice will improve or maintain memory functioning. The intervention with the least amount of supporting evidence was individual psychotherapy, with only one evaluative study published.

Table B2: Summary of Interventions

Neuropsychological Interventions:	No. of studies
Cognitive stimulation	2
Cognitive training	16
Cognitive rehabilitation	5
Literature reviews	4
Sub-total	27

Psychotherapeutic Interventions:	No. of studies
Support groups	7
Group psychotherapy	4
Individual psychotherapy	1
Literature reviews	3
Sub-total	15

Total	41¹
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¹ One of the literature reviews (Scott & Clare, 2003) looked at group interventions in both strands. There were only six literature reviews in total.

Six literature reviews were identified that overlapped with the current review but none had the same scope. In the analysis that follows, these literature reviews will be discussed alongside the relevant individual papers for each intervention as appropriate.

The evidence supporting each of the interventions outlined in Table 2 will be considered in turn, starting with the neuropsychological interventions (Section 4.2) and then the psychotherapeutic interventions (Section 4.3)². The findings across all studies will be summarised (Section 5) before recommendations for future research are made (Section 6) and the clinical implications outlined (Section 7).

4.2 Neuropsychological interventions

There are three main neuropsychological interventions: cognitive stimulation, cognitive training and cognitive rehabilitation. The field can be confusing so the definitions outlined by Clare and Woods (2004) will be adopted in this review, as summarised in table B3.

Table B3: Definitions and Target Groups of Neuropsychological Interventions

Intervention	Definition	Target group
Cognitive stimulation	Non-specific, global stimulation of cognitive functioning.	Moderate to severe dementia.
Cognitive training	Aims to improve specific cognitive functions (e.g. memory, attention, etc.) through regular practice of specific tasks.	Early-stage / mild dementia.
Cognitive rehabilitation	As above but more individualised, personally relevant goals are drawn up to enhance everyday functioning, paying attention to life experience and social context.	Early-stage / mild dementia

² Summary tables of all the studies identified for each intervention can be found in Appendix II.

4.2.1 Cognitive stimulation

One of the first neuropsychological approaches was reality orientation, which involved the presentation of information to reorient people with dementia. It was used within a residential care setting or at a day centre. Moniz-Cook (2006) outlines the development of this approach into the more global Cognitive Stimulation Therapy (CST), pioneered by Spector *et al.* (2001). In their systematic review, Clare and Woods (2004) noted that CST tends to be used for those with more severe dementia within day centres and residential homes.

A more recent study was open to those in the mild stages of the disease (Spector *et al.* 2003). The results of the randomised controlled trial suggested CST could improve cognitive functioning (Spector *et al.* 2003), which could also have an impact on quality of life for both client and carer (Woods *et al.*, 2006). However, although the intervention was open to those with mild dementia, most participants were in the moderate to severe category. Participants were recruited through day centres and residential homes, which could explain this.

To summarise, although cognitive stimulation can, and has been, used with those in the early stages of the disease, more research needs to be done on it's efficacy with this particular client group. There has been more published literature on the use of specific cognitive training techniques.

4.2.2 Cognitive Training

a) Simple repetition with cues.

The most basic cognitive training technique is repetition with cues to aid recall. Graham *et al.* (2001) described the case of a man with semantic dementia who was encouraged to undertake daily rehearsal of lost vocabulary using pictorial and verbal cues. Rote memory of the rehearsed vocabulary improved significantly but the training did not generalise to fluency. Furthermore, the

participant became frustrated and depressed with the need to keep rehearsing the information in order to maintain the benefits.

Similar procedures were adopted by Zanetti *et al.* (2001) to improve procedural memory.

Participants rehearsed activities of daily living for an hour a day, five days a week for three weeks. The total mean time to perform the activities significantly improved for the intervention group and there was a significant difference when compared to controls. However, there was no significant difference in the number of cues needed. The study showed that the participants were able to perform the tasks quicker with practice but were no better at remembering to do them.

b) Spaced retrieval and fading cues

Neuropsychologists have, however, developed more sophisticated techniques. Camp (1989) outlined the potential for memory training using the spaced-retrieval technique with clients with dementia. This involved the repeated presentation of test trials over expanding intervals. Initially, recall immediately followed presentation. Then the recall interval was expanded if recall was successful and reduced if recall was unsuccessful, thus training the individual to remember information over increasingly longer intervals.

A quasi-experimental study by Bird and Kinsella (1996) investigated the effectiveness of spaced retrieval, compared to simple repetition and reminding, for the remembering of an everyday task. They also used a graded sequence of cues that were faded out over successive trials as memory recall improved. Participants with differing degrees of impairment were compared. The results suggested that spaced retrieval with fading cues was better than simple repetition and reminding. It also suggested that the less impaired group performed better but this did not interact with learning method. However, the study only involved two training sessions.

Mounting evidence for the effectiveness of spaced retrieval has since developed. Bourgeois and colleagues (2003) found a significant advantage for spaced retrieval, compared to a cueing hierarchy, in participants with mild to moderate dementia. Hawley and Cherry (2004) provided raw data to suggest that six participants with mild to moderate Alzheimer's Disease could learn new face-name associations using spaced retrieval and that some were able to transfer this to a live person. Similarly, Cherry and Simmons-D'Gerolamo (2005) provided only descriptive statistics to demonstrate an advantage for patients previously trained using the spaced-retrieval technique compared to those new to the technique.

Despite this support for the use of spaced retrieval within the literature, Hochhalter *et al.* (2005) attempted to demonstrate that this was not the only effective rehearsal schedule. In a quasi-experimental design they compared spaced retrieval and expanding rehearsal to three other rehearsal schedules based on retention and number of errors made. There was a significant effect for rehearsal schedule on errors made, with spaced retrieval second from top, but not on retention. They suggested this challenged the alleged supremacy of spaced retrieval techniques but by using errors as a dependent variable they ignored the increasing literature on the importance of errorless learning with this client group.

c) Errorless learning

Winter and Hunkin (1999) introduced the errorless learning paradigm to memory training in early-stage dementia. This involved eliminating or greatly reducing the possibility of the participant making errors during the training process. This was important as participants with cognitive impairments had a tendency to repeat errors. In a single-case study, they demonstrated how the participant was able to relearn old information across four days of training. The results were encouraging but no statistical analysis was performed on the data. Similarly, Abrisqueta-Gomez *et al.* (2004) reported stability or improvement in cognitive functioning for three

participants following an intensive, 2-year errorless learning training programme but did not perform statistical analysis on their data.

Two studies have since confirmed the advantage of errorless learning over errorful learning with participants in the mild to moderate stages of dementia (Haslam *et al.*, 2006; Metzler-Baddeley & Snowden, 2005). Metzler-Baddeley and Snowden (2005) also showed that participants could acquire new information this way but significantly poorer than they could relearn old information. Haslam and colleagues (2006) also showed that errorless learning became more important with increased knowledge specificity.

d) Memory training, social interaction and exercise

The additional benefit that social interaction and exercise might bring to memory training programmes was explored by Arkin (2001). She devised an intensive year long memory training programme that utilised errorless learning and spaced retrieval to enable participants to re-learn biographical information. They were also given language therapy and supported to attend a volunteer work programme once a week. A control group made a memory book and were engaged in unstructured conversation. Both groups exercised twice a week throughout the programme.

The results showed a significant improvement in mood, fitness levels and knowledge of biographical information across both groups, with the only significant difference being increased variability of noun usage for the language group. However, the sample size was small (5 or 6 in each group) and with many different treatment components it is hard to untangle what was working. It seemed that being actively engaged in a treatment programme involving regular social contact had a positive effect on mood and on maintaining biographical information and that regular exercise led to an improvement in fitness levels.

A further update on this programme (Arkin, 2007) supported the original findings and, through comparison with a database of control participants, suggested that the intervention had slowed the cognitive decline of participants involved in the programme for more than a year. This suggests that an intensive programme like this could have an impact on disease progression. Although this is encouraging, it must be reiterated that the intervention sample was still relatively small.

e) Carer as facilitator

All the above programmes were administered by an external facilitator. Quayhagen and Quayhagen (2001) explored the effectiveness of a training programme led by the carer. Participants were randomly allocated to either experimental, control or placebo groups. The experimental group were encouraged to train for an hour a day, five days a week, for 12 weeks, with the main focus on memory but also including problem solving, fluency and communication. The placebo group were encouraged to perform passive activities such as watching TV. The results suggested a significant improvement in immediate memory and verbal fluency for the experimental group compared to controls.

In a second randomised controlled trial reported in the same paper, the training programme was shortened to eight weeks with a mixed focus on memory, problem solving and fluency and communication. The results of this study showed a significant improvement on measures of verbal fluency, as in the original study, and in problem solving. A self-report measure revealed that 71% of carers noticed a major improvement in interactions with their partner. When the results of the two studies were compared there was no significant difference between the two programmes, suggesting the shorter programme was just as effective.

Results of another randomised placebo-controlled study were published in 2001 by Davis and colleagues. They utilised the spaced retrieval technique to enable participants to learn face-name

associations in weekly, hour-long clinic sessions for five weeks. In addition, the participants were engaged in attention stimulating activities for half an hour a day, six days a week, by their carers for the duration of the programme. The placebo group were engaged in unstructured conversation during their weekly clinic visits. The intervention group performed significantly better on the face-name associations and recall of personal information after training than the placebo group but this advantage did not generalise beyond the trained items.

From all three studies outlined above, it seems the involvement of carers in the training programme has been an important step-forward. It also appears that a broader focused but very intensive training programme might lead to some generalisable improvements. Whereas a more focussed, task-specific training programme leads to significant improvement on those tasks but at the expense of more generalisable effects. However, it is not known how long the benefits lasted due to a lack of published follow-up data.

f) Individual vs. group delivery

Although most cognitive training interventions have been delivered on a one-to-one basis, they have been administered in a group format. Koltai *et al.* (2001) reported a randomised controlled trial comparing individual and group memory training to waiting list controls. Their programme involved the use of spaced retrieval, verbal elaboration, repetition, external memory aids and coping strategies.

There was a non-significant trend towards improvement in everyday memory for the treatment group compared to the waiting list, as reported in a self-report scale by participants and carers. There were no significant differences between those who received the intervention individually or in a group. Interestingly, there was a significant effect favouring those with greater insight. This suggested that either those with greater insight reported greater gains in their memory functioning,

or they underestimated their ability pre-intervention and were more realistic post-intervention. Overall, the Koltai study suggested that group interventions could be as effective as individual interventions but the results should be treated with caution as they rely on self-report data.

g) Groups and mood

There may also be additional benefits from the group format. Moore and colleagues (2001) reported the results of a controlled study of a five-week memory training group involving psychoeducation, name-face rehearsal, effortful recall and recall of a recent significant event. The patients and their carers attended the group together and the carers were used as an age-matched control group. The patients showed significant improvements at post intervention on task specific measures, Geriatric Depression Scale and the Kendrick Digit Copy. Carers also reported a significant improvement in their partner's memory functioning via a self-report questionnaire. Not surprisingly there were significant differences between those with the memory problems and their carers on all the memory tasks. The Moore study suggested that groups may have an impact on mood as well as cognition.

A study by Farinamd *et al.* (2006) compared two six-week group interventions; global cognitive stimulation (e.g. recreational activities and group activities) and cognitive specific stimulation (e.g. memory training). The results suggested that both groups showed a similar improvement in daily functioning but the global stimulation programme had more of an effect on reducing behavioural disturbance and care-giver distress at follow-up. This suggests that the group format may have more of an impact than the specific activities involved.

h) Summary

The literature on individual memory training suggested that simple rehearsal and repetition might improve rote memory and performance speed but the need for constant practice could lead to

frustration and depression. More effective results were seen when a specific rehearsal schedule was provided, with spaced retrieval having the most supporting evidence at present. Further benefits were seen when the potential for making errors was greatly reduced or eliminated during training. Involving the carer enabled a more intensive programme to be administered with more potential for generalising out of the training context. Long-term intensive participation in such programmes, particularly if they include a social element, may slow cognitive decline although there is limited evidence for this at present.

It appears that the delivery of memory training in a group format can also be effective, having a potential impact on mood and perception of the patient's memory. Some improvements in task specific measures were also seen, similar to those described in the individual studies. However, there is also evidence to suggest that groups involving recreational activities can be just as effective.

4.2.3 Cognitive rehabilitation

The use of memory training strategies as part of an individually tailored rehabilitation package was pioneered by Clare and colleagues. They used the errorless learning paradigm with a combination of expanding rehearsal (similar to spaced retrieval), mnemonic strategies, and fading cues, depending on the nature of the specific, everyday memory problem chosen.

a) Single case studies

In 2000, they reported the results of multiple single case studies using this approach. Four participants were trained to remember face-name associations or biographical information. Two participants were trained to orient themselves to the date using a calendar. Most showed a significant improvement on task specific measures post intervention and at six month follow-up. One participant had deteriorated significantly at follow up; the couple had stopped using the strategies suggesting the intervention may not have been acceptable to them. The improvements

did not generalise to standardised measures, but this was not the objective of the intervention.

Another single-case study has replicated these findings (Clare *et al.*, 2003)

Bird (2001) reported a single case study where the participant was trained to check a list rather than ask staff where her belongings were. An initial 90-minute training session using spaced retrieval was followed up at 30 minutes, 1 and 4 hours and then staff were encouraged to use a system of fading cues. The number of staff requests eventually reduced to zero. No information on follow up was given so it is not known how long the intervention was successful for.

b) Long-term follow-up

One of the participants from their initial study was followed up over a period of two years by Clare *et al.* (2001). The participant's performance on the task specific measures was maintained for up to a year post intervention but then gradually declined over the second year. However, at two years post intervention his performance was still well above the pre-intervention baseline, despite an overall cognitive decline during this period.

c) Controlled trial

The initial success of the single case studies was followed by a controlled trial of twelve participants (Clare *et al.*, 2002). All were trained in face-name associations using errorless learning, spaced retrieval, mnemonics and fading cues. Training took place across six sessions and the control element was within participants; their performance on trained compared to non-trained items. A significant improvement on trained items was seen at post intervention but not for untrained items and this was maintained up to six months post intervention without further practice; further evidence that this focussed individualised approach can be effective and long lasting.

d) Group format

Cognitive rehabilitation principles have also been utilised in a group format (Cuncliffe *et al.* 2005). This group consisted of seven weekly, ninety-minute sessions focussing on memory problems, current coping strategies, psychoeducation, errorless learning, memory aids and practical applications. It was aimed at those in the early stages of dementia and their live-in carers. The study compared the intervention group to a matched control group at baseline and 3-month follow-up.

Both groups showed deterioration in activities of daily living and memory at 3-month follow-up. For the intervention group, client and carer mood and carer strain remained stable at follow-up, whereas the control group showed significant increases. This suggested that attendance at the group had a protective effect on mood and carer strain, which was in keeping with the findings from cognitive training groups (e.g. Moore *et al.*, 2001). A weakness in the study was the fairly small sample size and the non-randomised allocation to treatment or control due to service constraints.

4.2.4 Literature Reviews

Three reviews have been published. Grandmaison and Simard (2003) reviewed cognitive interventions for enhancing memory functioning in mild to moderate Alzheimer's disease and found 18 studies. They concluded that errorless learning, spaced retrieval and vanishing cues, facilitated by the carer where possible, were the best memory training techniques; findings consistent with the current review.

Scott and Clare (2003) conducted a review of group interventions for people at all stages of dementia. They identified one study suggesting a cognitive stimulation group could have an impact on cognitive functioning and five studies reporting outcomes for memory training groups including

the two studies already discussed in the current review (Koltai *et al.*, 2001; Moore *et al.* 2001)³.

They concluded that positive effects could be achieved through memory training but suggested that individually tailored cognitive rehabilitation packages would be more effective.

Finally, Clare and colleagues conducted a Cochrane Review (2003) into cognitive rehabilitation and cognitive training for dementia, the results of which were published in a peer-reviewed journal (Clare & Woods, 2004). They identified six randomised controlled trials (RCTs) of memory training, of which, four have already been discussed in the current review (Davis *et al.*, 2001; Koltai *et al.*, 2001; Quayhagen & Quayhagen, 2001 (two studies)). Their meta-analysis showed no significant differences compared to controls. No cognitive rehabilitation RCTs were identified but the authors were “cautiously positive” about this approach based on the evidence already discussed in the current review.

4.2.5 Methodological issues

Within the neuropsychological literature, there has been a dependence on single case designs and controlled or quasi-experimental studies with very small sample sizes. Some studies even fail to conduct any basic statistical analyses on their results so the significance or generalisability of their findings could not be ascertained. There have been a handful of randomised controlled trials within the memory training literature but even these are reliant on small sample sizes and do not report any power analyses, so it is not known if the inconsistency in results across studies was due to inadequate power, study design or because the intervention was ineffective. There has been more consistency in design and results within the cognitive rehabilitation literature, partly because the same key researchers have been involved in most of the studies. There have been no studies exploring the experiences of patients and their carers participating in these programmes.

³ Two of the remaining studies focussed exclusively on psychoeducation or problem-solving and the fifth included memory training as part of a much wider therapy programme, which is why they were not included in the present review.

4.2.6 Summary of neuropsychological interventions

Bearing in mind the methodological constraints outlined above, the review of the literature cautiously suggests the following. That learning of both old and new information can be enhanced through the use of cognitive techniques such as spaced retrieval and faded cues, especially within an errorless learning paradigm and as part of an individually tailored programme to address specific, everyday memory problems. Where specific problems are the focus, the results may be longer lasting but less generalisable. Involvement of carers can be useful, as more intensive programmes can be delivered. Also, the opportunity for regular social contact, such as in a group, may have a positive effect on mood for both patient and carer.

4.3 Psychotherapeutic interventions

Within the psychotherapeutic literature, studies evaluating support groups were the most numerous, followed by group psychotherapy. There were hardly any studies exploring the effectiveness of individual psychotherapy.

4.3.1 Support Groups

Support groups work on the principle that meeting and interacting with others in a similar position can be nurturing, healing and empowering (Yale, 1995). Such groups have been set up to support people coping with a range of conditions. Within the field of dementia they were traditionally aimed exclusively at carers, as it was felt that clients lacked the necessary capacity for emotional expression and self reflection (Yale, 1995).

a) Feasibility of client support groups

The development of support groups specifically for people in the early stages of dementia was pioneered by Yale (1995). Yale's groups ran for 8 weekly sessions of 90 minutes duration.

Discussion topics were initially raised by the facilitator but group members became more involved over time. Topics included coping with memory loss and adapting to changes in relationships with others.

Initial evaluation (Yale, 1995) compared the group to treatment as usual at pre, post and two month follow-up. In addition, carers were interviewed, evaluation forms completed and observations and transcripts from each session analysed. The study had only 13 participants and found no statistically significant changes based on outcome measures. Qualitative analysis, however, suggested that participants were able to express their concerns, both in the group and at interview, and clients and carers reported multiple benefits. Overall, the study suggested that such support groups were feasible, wanted and potentially therapeutic.

b) Studies of utility and effectiveness

Time-limited support groups:

In the ten years following Yale's publication, there were anecdotal reports suggesting positive outcomes for similar support groups with people in the early stages of dementia. In their review of group interventions, Scott and Clare (2003) identified three such studies, one of which used formal outcome measures but found no significant changes.

Larger scale service evaluations have been conducted. Two unpublished studies were cited in the NICE Full Guidance (2006). The first (Bird *et al.*, 2004, cited in NICE, 2006) described a 6-8 week programme with 2-hour sessions. Feedback from 84 participants was evaluated and suggested high levels of enjoyment and utility and a decrease in self-rated depression. The second study (Zarit *et al.*, 2004, cited in NICE, 2006) evaluated a 10-week programme for clients and carers and again reported positive ratings on all aspects of the programme.

Short, time-limited support groups were, therefore, perceived very positively by those involved and there was a suggestion that they had an effect on mood. These studies were heavily reliant on self-report measures and there were no comparison groups, so there is little objective evidence of improvement.

Longer-term support groups:

Longer-term groups have also been developed. Marshall *et al.* (2005) evaluated a 24-week support group for those recently diagnosed with dementia. Sessions lasted 75 minutes and focussed on meeting others and sharing ways of coping. Outcomes were reported for 8 participants; most stayed the same or got worse on all measures but two participants showed a reliable improvement in depression ratings. Thematic analysis of session transcripts suggested that more positive changes were experienced after session seven.

An open-ended, user-led support group was reported by Pratt and colleagues (2005). Qualitative feedback suggested that participants found it a useful forum for sharing experiences and mutual support & help, as well as increasing confidence and reducing social isolation.

A survey of 70 people, attending six support groups in the United States, has recently been published (Snyder *et al.*, 2007). Average attendance was just under two years. Again positive feedback was reported on the educational value and social benefits of attendance. Participants also reported feeling better able to accept their diagnosis and cope with their symptoms after participation.

These studies suggest that longer-term support groups were also perceived as useful by those involved, with a suggestion that improvements in mood could occur. Again, there has been little objective evidence of improvement and no comparisons made to a control group. Also it is not

known if there were any additional benefits from longer term attendance compared to the shorter time-limited groups.

d) Process evaluation

Whilst the majority of evaluation studies have looked at feedback and outcomes, some researchers have looked at therapeutic process. Mason *et al.* (2005) evaluated two support groups by videoing and analysing group sessions using Behavioural Interaction Coding (BIC). In addition, interviews with participants were analysed using Interpretative Phenomenological Analysis (IPA).

The BIC analysis suggested that the facilitators tended to ask questions and the participants tended to disclose information. Also, the majority of interactions involved a facilitator and most occurred between a facilitator and an individual participant. This contradicted the usual view that support groups involved participants providing active support to one another. The IPA analysis suggested that participants found it useful although some found the group experience difficult. Despite the results of the BIC, participants felt they were all talking together and the role of the facilitators was to “keep the pot boiling”. They had an emotional memory of being contained, supported and understood within the group, even though their memory to recall the detail was limited and actual frequency of supportive transactions was low.

The findings suggested that the support groups were reliant on the activity of the facilitators; anchoring the group and providing a group memory.

e) Summary

The findings on support groups suggested attendance had been perceived positively by both clients and carers. Such groups relied on strong facilitation by group leaders and a variety of

formats had been tried in terms of duration and whether carers were included. There have been some attempts to evaluate impact of attendance on mood, with some suggestion at improvement in depression, but the results were inconclusive due to small sample sizes and the variety of programmes described and measures used. They were clearly popular programmes for both services and participants but more formal, objective evaluation is required.

4.3.2 Supportive Group Psychotherapy

It is difficult to draw an exact line between support groups and group psychotherapy with this client group. Traditionally, group psychotherapy is led by a qualified therapist adopting a particular therapeutic orientation, such as cognitive-behavioural or psychodynamic psychotherapy, but there have been no published studies formally evaluating such approaches with clients in the early-stages of dementia.

The first kind of group therapy aimed at those in the earlier stages of dementia was Validation Therapy. It was developed by Feil (e.g. 1993) and stressed the importance of acknowledging the feelings that participants reported, even if their statements were not factually correct. Currently, there have been only subjective reports that validation therapy leads to an improvement in functioning for those in the early-stages of dementia (Scott & Clare, 2003).

There is, however, evidence for Supportive Group Psychotherapy from the Dementia Voice group psychotherapy project. The main difference between these groups and the support groups discussed previously was that the facilitators' role was to emphasise the emotional significance of the experiences shared by the group.

a) Outline of the Dementia Voice group psychotherapy project

The project involved setting up and running six 10-week psychotherapy groups of 75 minutes duration, led by two facilitators. The central theme for group discussion was, "what it's like when

your memory isn't as good as it used to be". A qualitative analysis of themes raised in the groups (Cheston *et al.*, 2002) found that forgetfulness was a central theme: not remembering, wanting to forget, being forgotten and wanting to be forgotten.

b) Outcome evaluation

The project has been evaluated through looking at both outcomes and processes. Cheston *et al.* (2003) reported outcomes for 19 participants. Outcome measures were administered at baseline, pre-group, post-group and 10-week follow-up and showed a statistically significant improvement in depression and anxiety. There was however a high drop-out rate (as noted by Scott & Clare, 2003), which suggested the approach may not be palatable to all.

The study had no control group so it cannot be said for certain that the group intervention was responsible for the improvement and not the result of the passage of time or an unknown factor. If the group intervention was responsible it is not known if the therapy itself made the difference or simply being gathered together with others in a similar position. However, Cheston and colleagues have published three qualitative case studies which explore process factors within their groups and address some of these issues.

c) Process evaluation

Metaphorical communication:

In the first study to be published (Cheston, 1996), six group sessions were transcribed and examined to identify narratives that told a coherent story and whose meaning was not obvious at the time. These narratives were then subject to a social constructionist analysis, placing the stories in the context of the group and of living with dementia itself. Through this process it was demonstrated that the talk of people with dementia was not meaningless, even when it involved reminiscence that was not immediately relevant. In particular it emphasised the metaphorical

aspects of talk in describing the experience of dementia; for example, the struggle to maintain a landing strip in the jungle.

Another study (Cheston, 2005) used a similar methodology to show how a participant used story and metaphor to explore issues of threat and loss within the group. Such metaphors relied on interpretation by others and could define and constrain meaning but it made the point that people with dementia were still communicating meaning and not just confused and disorientated. Both these studies suggested that the psychotherapy groups gave the participants the opportunity to explore psychological issues and for their meaning to be shared with others despite the constraints in language and memory.

The assimilation model:

A study by Watkins *et al.* (2006) explicitly tested a possible model for psychotherapeutic change. The assimilation model suggested that the process by which painful or problematic experiences were gradually assimilated into existing schema could be psychologically painful and so these painful experiences could be pushed from conscious awareness and reappear in the form of psychological distress, e.g. anger, depression or panic attacks. It proposed that this process occurred in stages: from being initially unaware, to approaching the material, clarifying the problems, gaining insight and then finally achieving mastery over the painful material. A parallel process of emotional reactions was also proposed; an initial increase in distress followed by a decrease as mastery was achieved, then confidence and positive affect may increase as new solutions were tried.

Testing the assimilation model:

The hypothesised processes were operationalised in the Assimilation of Problematic Experiences Scale (APES). Watkins *et al.* (2006) analysed the transcripts of 10 sessions looking at material

relating to one participant in detail. His problematic experience was defined as “coming to terms with the implications of his diagnosis of Alzheimer’s disease”. Five passages were identified relating to this experience and these were examined and rated using the APES by three clinical psychologists with no prior experience of the project and no knowledge of which session each extract was taken from. In addition, the group facilitators were invited to rate each session using Yalom’s group therapeutic process elements and the participant’s mood was monitored.

In session 1 the participant was rated as being at stage 0; “warding off” the problem, successfully avoiding identifying himself as having Alzheimer’s and showing minimal affect. In session 4 he was still trying to distance himself from the diagnosis but began showing signs of uneasiness at other’s acknowledgement of the disease, this was rated as stage 1 “unwanted thoughts”. Within session 5 he acknowledged Alzheimer’s for the first time, which was rated as stage 2 “vague awareness” but then slipped back into stage 1 immediately afterwards. By session 7 he was rated as being in stage 3 “problem identification” and showing some signs of movement towards stage 4, showing “problem understanding or insight”. His mood ratings showed an increase in depression and anxiety during the group, which fell during the post-group phase. The ratings of Yalom’s therapeutic elements gradually increased across the ten sessions, reaching a peak around sessions 7 and 8.

To summarise, for the chosen participant, attendance at the group involved a process of acknowledging his diagnosis of Alzheimer’s disease but this process was accompanied by an increase in psychological distress. This could be a possible reason why the drop-out rate for the project was high, as some could not tolerate the gradual breaking down of their intra-psycho defences. However, the chosen participant was able to state that he had obtained “a great deal of moral uplift” from attending the group and hearing how others had come to terms with something

he was struggling with and frightened of acknowledging. The authors suggest that, for this particular participant, the 10-week limit to the group may have been too short.

d) Summary

The evidence from the Dementia Voice group psychotherapy project suggested that people in the early stages of dementia could participate in supportive group psychotherapy and that attendance at the group could have a significant impact on mood, lowering levels of depression and anxiety. For some participants, however, attendance at the group led to an initial increase in depression and anxiety as the group encouraged them to face psychologically painful material that they had been avoiding.

The assimilation model of psychotherapeutic change offered a possible explanation for the changes observed although other models have yet to be considered. Whilst this project has added significantly to the research on group psychotherapy, a weakness is that it has not explored the impact of the intervention on carers.

4.3.3 Individual psychotherapy

There has been almost no published evidence for the effectiveness of individual psychotherapeutic approaches. This does not mean, however, that they are not being used. In 1998, a review of psychotherapy for people with dementia (Cheston, 1998) found nine studies describing a range of individual interventions including cognitive-behavioural, psychodynamic, person-centred and eclectic approaches. None of these studies reported any formal evaluation and, since then, only one such study could be identified within the published literature.

The study (Scholey & Woods, 2003) described a pre and post intervention evaluation of eight sessions of cognitive therapy for those in the early stages of dementia experiencing depression.

There was a significant improvement in depression across the group and two of the seven participants showed a significant reliable change in their depression scores. In addition, there were subjective reports of cognitive shifts within the therapy. The study had a small sample size and no control group but is all the published evidence that exists for individual psychotherapy with clients in the early stages of dementia.

Despite the current lack of supporting evidence, individual psychotherapy has been used with this client group and Heason (2005) provides a good overview of the different approaches discussed in the literature. Overall, this has been a neglected area of research, which needs to be addressed by the research community.

4.3.4 Methodological Issues

Within the psychotherapeutic literature, there has been a reliance on self-report measures, rating scales and subjective reports of improvement. This has been particularly apparent in the literature on individual psychotherapy and support groups. More recently, there has been an increasing trend for studies to support outcome based measures with analysis of observations and transcripts of group sessions. This dual emphasis on outcome and process has been used most effectively within the research output of the Dementia Voice group psychotherapy project.

4.3.5 Summary of psychotherapeutic interventions

Psychotherapeutic interventions for people in the early stages of dementia have included support groups, group psychotherapy and individual psychotherapy. A variety of support groups have been reported in the literature but all seem to be perceived as very positive by clients, carers and services. There is some evidence that attendance may lift depression scores but it is currently inconclusive and more formal evaluation is required.

Thanks to the Dementia Voice group psychotherapy project, there is more evidence for the effectiveness of this type of intervention. Attendance has been shown to have a positive effect on client mood and adjustment but this can be a painful process. Finally, the evidence for the effectiveness of individual psychotherapy is extremely weak. One study showed an improvement in depression following cognitive therapy but more research is needed.

5. DISCUSSION

5.1 Summary of findings by interventions

Psychological interventions for individuals in the early stages of dementia were somewhat polarised in nature, focussing on either specific cognitive deficits or on overall well-being. The evidence for neuropsychological interventions suggested that individually tailored programmes focussing on specific, everyday memory problems and using specific cognitive techniques could lead to an improvement in task related performance. This had most impact on the person with dementia and their carer if the skills they learnt were directly relevant to their daily lives. Although most training packages focussed on the individual, the evidence suggested that group training programmes could have a positive effect on client and carer mood.

Within the psychotherapeutic literature, almost all the evaluative studies have been on group approaches. Support groups were perceived positively by clients, carers and services and there was inconclusive evidence that they had an impact on mood. There was more evidence that group psychotherapy had a positive impact on mood and adjustment, although the intense nature of such groups was difficult for some to cope with. It is difficult to tell how different the two approaches actually were in practice and no studies have compared them.

5.2 Group interventions

Group interventions for people in the early stages of dementia were clearly popular and a variety of models have been tried. There was some evidence for a positive impact of group interventions on mood from both the neuropsychological and psychotherapeutic literature. This is particularly interesting as none of the neuropsychological group studies showed significant improvements in or maintenance of participants' cognitive functioning. In fact, one could argue that the impact on mood and carer strain was the main effect and that being in a group with others in a similar situation

was the causative factor. However, as no studies have compared attendance at a memory focussed group to attendance at any other kind of group intervention, such as psychotherapy or a support group, it is not known whether the impact on mood is due to the strategies taught or to more general group therapy processes.

5.3 Individual interventions

Within the neuropsychological literature, the focussed individual interventions were shown to be more effective at addressing specific problems. It could be hypothesised that the same is true with individual psychotherapy, and this is probably what happens in clinical practice. The complete lack of evaluative research in this area, however, means that there is currently no specific evidence base for clinicians to draw on.

6. RECOMMENDATIONS FOR FUTURE RESEARCH

Although the research base for psychological interventions in early-stage dementia is growing, there is considerable potential for further expansion. From the literature, it seems that the development of such interventions has been pioneered by research groups, such as that led by Clare and Cheston. It is the interventions developed by these research groups, cognitive rehabilitation and supportive group psychotherapy, that are the best and most consistently evidenced, but they may not be the only effective interventions. In general, the field needs more of these larger scale research programmes.

The most obvious gap identified by this review is the lack of evaluative studies on individual psychotherapy for people in the early stages of dementia. There is, however, evidence that such interventions are necessary and are being used in clinical practice. The development of an evidence base would not only be a useful resource for clinicians, but also for service managers, so that appropriate resources can be allocated. Without an evidence base, individual psychotherapy will not be recommended in clinical guidance such as that issued by the National Institute of Clinical Excellence, which may impact on future service provision.

The memory training research currently supports the use of spaced retrieval and fading cues within an errorless learning paradigm. Although other rehearsal schedules exist they have not been compared to spaced retrieval within an errorless learning paradigm. There is also mounting evidence in support of these techniques being used within an individual cognitive rehabilitation programme but more studies need to be conducted with larger sample sizes, appropriate control groups and comparisons made between different interventions. The findings also need to be replicated by other researchers.

There have been a number of group interventions developed for this client group and it is difficult to establish the most effective format. There needs to be more objective evaluation of support groups in general, as the current literature relies heavily on self-report data. In particular, research should look at the optimum number of sessions. There is possible overlap between support groups and supportive group psychotherapy and between support groups and memory groups. Some comparative, controlled studies would be helpful to ascertain whether specific content or general group therapy processes are the active elements in such groups, or which combination gives rise to the best interaction.

Therapeutic process research, such as that published by Cheston, could be usefully applied to other interventions, particularly the groups. The experiences of participants taking part in such interventions might also provide useful insights into how the interventions are perceived and what participants have taken from them.

7. CLINICAL IMPLICATIONS

The current evidence suggests that psychological interventions in the early stages of dementia can be effective in improving or maintaining mood, facilitating adjustment and improving performance on everyday memory tasks. It is important to note, however, that some of the interventions used in clinical practice do not yet have an evidence base, such as individual psychotherapy. This is due to lack of research rather than a proven lack of therapeutic benefit. On the basis of the current evidence the following clinical recommendations are made.

Where there are no specific psychological problems, attendance at a memory group or support group may be useful to learn coping strategies and meet others in a similar situation. This may have a protective effect on the psychological health of both client and carer in the future and reduce social isolation. The provision of such groups could be a cost effective way of providing psychological support and reducing isolation in the early stages of dementia.

For those experiencing some adjustment difficulties psychotherapy may be more appropriate. Within the literature there is most evidence for group based interventions, and these may be more cost effective to run, but some will find the approach too painful and may benefit more from individual psychotherapy tailored to their needs. Unfortunately there is virtually no evidence base for the clinician to draw on at present but cognitive therapy has been shown to be of benefit for some people with co-morbid depression (Scholey & Woods, 2003).

Where the patient is experiencing task-specific memory related difficulties, an individually tailored cognitive rehabilitation programme could be useful. This will, however, require careful preparation by the clinician and the support and enthusiasm of both the client and their carer for it to be effective. The best evidence is for training programmes utilising a combination of spaced

retrieval (or expanded rehearsal), fading cues and memory aids, within an errorless learning paradigm.

8. CONCLUSION

This paper has reviewed the literature on psychological interventions for early-stage dementia. Two main strands of intervention have been identified: the neuropsychological and the psychotherapeutic. The best evidenced interventions are individual cognitive rehabilitation training programmes and supportive group psychotherapy. Support groups are also popular and positively received.

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SECTION C
RESEARCH REPORT

**Couples' experiences of early-stage dementia and of attending
a memory rehabilitation group.**

Target journal – British Journal of Clinical Psychology²

² See Appendix I for 'Notes for Contributors' for the British Journal of Clinical Psychology.

1. ABSTRACT

Objectives: To explore the lived experience of people in the early stages of dementia, and their spousal carers, who had attended a memory rehabilitation group.

Design: Qualitative interview based study.

Methods: Four couples (eight participants) were interviewed after attending a seven week memory rehabilitation group. The semi-structured interviews covered their experiences of early-stage dementia and of attending the group intervention. The interviews were transcribed then analysed using Grounded Theory (Charmaz, 2006).

Results: A theory was constructed outlining how the participants were coping with early-stage dementia, both individually and as a couple. A key concept was that the couple had a shared memory, which was also affected by the onset of dementia. The couple 'noticed changes' in the memory of the person with dementia and the emotional and social 'impact of the changes' was felt by both parties. In response, the couple tried to 'emotionally adjust' whilst 'preserving the shared memory' as best they could. In this they were 'being supported' by friends and family, services and the group. As part of this process the couple were engaged in 'monitoring' for further changes and 'comparing' the current situation with that of the past or of other people.

Conclusion: The study outlined how the participants were coping with early-stage dementia and the impact it had on their shared memory. It illustrated how the group intervention supported them with their dual task of adjusting to the changes whilst preserving what they could.

2. INTRODUCTION

For the majority of the twentieth century, dementia research focussed on understanding the neurology and biochemistry of the underlying conditions. The subjective experience of people with dementia was largely ignored, not just in the research literature but also in the social context in which they were cared for.

Over the last two decades, however, a paradigm shift has occurred, emphasising the need to preserve the 'personhood' of the person with dementia (Kitwood, 1993). With this shift there has been increasing interest in the subjective experience of dementia, in order to enrich care practice and develop new therapeutic approaches (Kitwood, 1997).

Advances in medication have led to an emphasis on early diagnosis and intervention (NICE, 2006; National Service Framework for Older People, 2001). A range of psychological interventions for people in early-stage dementia have subsequently developed. This paper will consider the experiences of people who have participated in such an intervention, namely a memory rehabilitation group.

To highlight the need for the present study, an overview of the literature on the subjective experience of dementia and on psychological interventions for early-stage dementia will be given.

2.1 The subjective experience of dementia

2.1.1 Emotional impact

The earliest accounts were in the form of published autobiographies. Kitwood (1997) combined these with careful listening, observation, poetic imagination, role play and consultation in his paper, 'The Experience of Dementia'. He identified three core domains of negative experience; feelings

(e.g. fear, frustration, anxiety and anger), global states (e.g. terror, misery, rage and chaos) and 'burnt out' states (e.g. depression, despair, exhaustion and apathy). An individual could pass through these domains in either direction, highlighting the potential for psychotherapeutic intervention. Kitwood also defined five psychosocial needs – attachment, comfort, identity, occupation and inclusion – which clustered around the central need for love.

Gillies (2000) had to negotiate the ethical dilemma that interviewees were unaware of their diagnosis, as diagnostic disclosure was not routine practice. The interviews, therefore, explored the theme of growing older and memory failing. It is not surprising, then, that the participants normalised their experience in terms of age and used euphemism to describe their difficulties. They also described the humiliating effects of poor memory and how they attempted to cope with their difficulties through practical coping (e.g. memory aids), dependence on carers, avoidance and emotional coping (e.g. accepting).

2.1.2 Coping with early-stage dementia

Subsequent studies looked in more detail at coping styles. Clare (2002) identified a continuum of coping anchored at two poles; self-protective and integrative responding. The self-protective strategies involved the maintenance of a prior or existing sense of self, such as compensating for the difficulties. The integrative responding strategies involved development or adjustment to the self-concept, such as accepting the changes.

The same research team explored possible sex differences. They found that both men and women used the same two coping styles identified by Clare (2002) but with different goals. Men focussed on managing their sense of self (Pearce *et al.*, 2002), whereas women focussed on maintaining their sense of connection to significant others (Dijkhuisen *et al.*, 2006). Research has

not yet considered whether these coping styles apply at higher systemic levels, such as the couple or family.

1.1.3 Social / relational impact

The social impact of the disease was highlighted by Gilmour and Huntington (2005). They identified a tension between independence and the need for support and the re-negotiating of relationships. The dynamics within the spousal relationship were studied by Hellstrom *et al.* (2005). This suggested that one partner may take the lead initially and if this is the person with dementia, control may slowly shift as the disease progresses. It is not surprising that the nature and quality of the relationship prior to the onset of dementia had an impact on how the couple adjusted.

They also looked at how awareness of the disease could be socially co-constructed. Their findings stressed the importance of emotional and relational factors rather than just knowledge. For example, knowledge of the diagnosis may not be shared outside the immediate family for fear of being stigmatised, thus limiting the spread of awareness of the nature of the person's difficulties. Also, awareness may fluctuate over time with one or other party downplaying the impact of the condition to protect them from further emotional pain.

2.2. Psychological interventions for early-stage dementia

The subjective experiences of people with dementia have been shown to be emotionally rich and particularly accessible in the early stages of the disease¹. Increased awareness of natural coping has highlighted a number of avenues for psychological intervention. In fact, the two poles of the natural coping continuum, identified by Clare (2002), mirror the two main strands of psychological interventions in early-stage dementia.

¹ For a more comprehensive overview of the qualitative literature on living with early-stage dementia, the reader is referred to Steeman *et al.* (2006), which integrates 28 studies to tell the story through pre-diagnostic, diagnostic and post-diagnostic phases.

2.2.1 Self-adjusting – psychotherapeutic interventions

A range of individual psychotherapy approaches have been used with this client group (Heason, 2005) but there has been no published research into their effectiveness, apart from a study that suggested cognitive therapy could alleviate depression (Scholey & Woods, 2003). However, there has been more research into group approaches, particularly support groups (e.g. Mason *et al.*, 2005; Yale, 1995) and group psychotherapy (Cheston *et al.* 2003).

To understand the process of therapeutic change occurring during an intervention, it can be helpful to explore the subjective experience of the participants. The Dementia Voice group psychotherapy project has utilised this approach to great effect. They have illustrated how group psychotherapy provided the opportunity for participants to explore psychological issues and for their meaning to be shared with others despite the constraints in language and memory (Cheston, 1996, 2005). A study by Watkins and colleagues (2006) suggested a possible model for psychotherapeutic change – the assimilation model. That is, the group therapy process provided the opportunity for painful or problematic experiences to be gradually assimilated into existing self-schema. This is similar to the self-adjusting coping style identified by Clare (2002).

2.2.2 Self-protective – neuropsychological interventions.

Interventions that introduce practical coping strategies, such as memory aids and other compensatory techniques, could support the person's self-protective drive to maintain their sense of self. Cognitive training and cognitive rehabilitation have been the two key approaches in this area.

Cognitive training programmes used learning techniques, such as spaced retrieval (Camp, 1989) and errorless learning (Winter & Hunkin, 1999), in order to enable the person to learn or re-learn information or cognitive skills. There is some evidence that improvements can be made (e.g. Davis

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The coping continuum mirrors the range of interventions available for those in the early stages of dementia. The experiences of those who have attended psychotherapeutic interventions have proved useful in understanding the process of therapeutic change and support the idea that they facilitate the self-adjusting coping style.

It is hypothesised that neuropsychological interventions facilitate the self-protective coping style but no research on this has been conducted to date. There is also an indication that group memory programmes might be both self-protective and self-adjusting, but again this hypothesis has not yet been tested.

2.4 Aims of research

The aim of the present research was to obtain the perspective of people who have attended a memory rehabilitation group programme. The group is aimed at people in the early stages of dementia and their live-in carer, usually their spouse. The research addressed two main questions:

- What has been the participant's experience of early-stage dementia and how have they coped with this?
- What has been their experience of attending the memory rehabilitation group and what have they taken from it?

In particular, it was expected that the research would explain the observation made in previous research that the group had a protective effect on client and carer mood, adding to the literature on interventions in early stage dementia. The study would also add to the subjective experience literature through giving the perspective of the couple.

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et al., 2001; Quayhagen & Quayhagen, 2001) but there is a debate as to whether these generalise outside of the intervention and how long they last.

Cognitive rehabilitation draws on similar techniques but conducted on an individualised basis as part of a tailored rehabilitation package. There is emerging evidence for its effectiveness (Clare *et al.* 2002; Clare & Woods, 2004).

Cognitive training and rehabilitation programmes have also been delivered in a group context (Cuncliffe *et al.* 2005; Moore *et al.*, 2001), with a suggestion that this may lead to an improvement in mood. The memory rehabilitation group attended by the participants in the present study is of this type.

A number of hypotheses could be made as to why these group interventions had an impact on mood. For example, the group context could also facilitate self-adjustment, which is further enhanced through the attendance of the carer. The intervention would, therefore, combine the two main coping approaches. Exploring the experiences of those who have attended such interventions might help clarify these issues. This perspective is currently missing from the literature.

2.3 Gaps in the literature

The experiential literature has added to our understanding of how individuals cope with the onset of dementia and the impact it has socially and on significant relationships. The analysis has not yet been taken to the next systemic level. For example, it is not known whether the coping continuum outlined by Clare (2002) could also be applied at the level of couple or family. Also, studies typically look at client or carer but rarely both.

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3. METHOD

To meet the research aims, and in keeping with the tradition of lived experience research, a qualitative approach was chosen. Qualitative research in psychology can be conducted within a range of philosophical paradigms (Guba & Lincoln, 1994). Therefore, the theoretical and philosophical orientation of the research will be outlined first, followed by a note on ethical considerations. Further detail on the intervention, participants, data collection and analysis will then be provided.

3.1 Theoretical and philosophical orientation

To enable the reader to judge the extent to which the researcher's background and biases may have influenced the research it is important to be explicit about this (Elliot *et al.*, 1999; Morrow, 2005). The researcher undertook the research as part of her training to become a qualified clinical psychologist and it was conducted within the time-constraints this posed. This was the researcher's first major qualitative research project.

As previously outlined, the researcher was interested in the participants' experiences of living with early-stage dementia and of attending a group intervention. Both the person with dementia and their carers participated actively in the group, so the views of both were important to the study. The carers were seen as participants in their own right, not just there to validate what their partners said, and it was felt that the different perspectives would add richness to the data gathered.

The researcher adopted a critical realist ontological position². In particular, she was aware that the participants' accounts of their experience would be shaped by their individual personality, their cultural background and the context within which their account was given. Also, the researcher's

² For further information on how the researcher's ontological position was arrived at, please see the Critical Appraisal section of this thesis.

training and her cultural background as a White-British, professional female, would affect how she interacted with the participants and interpreted their experience. The aim of the present research, therefore, was not to give an exact picture of the studied world but an interpretative portrayal of it (Charmaz, 2006).

Grounded Theory is an interpretative approach to collecting and analysing qualitative data. It originally emerged from the collaboration between Glazer and Strauss in the 1960s and has since diverged in different theoretical and philosophical directions. The present research followed the approach laid out by Charmaz (2006), which views grounded theory as a set of systematic yet flexible guidelines from which a theory can be constructed to summarise and explain the participant's experiences. The researcher's background may sensitise them to particular themes but the guidelines constantly refer the researcher back to the participant's account, so the emerging theory remains grounded in their experience³. These sensitising themes are seen as a point of departure and should not constrain theory development.

The researcher's point of departure was that the group might help the individual to adjust to changes in their identity and so group therapy processes might be as, or even more, important than the practical strategies they learnt⁴.

3.2 Ethical considerations

3.2.1 Informed consent

Issues of informed consent arise when recruiting participants with cognitive difficulties.

Participants were not recruited unless they had the capacity to give informed consent, as per the

³ In keeping with the grounded theory approach, the researcher reviewed the lived experience literature after analysis of the data from the present study.

⁴ For further information on the theoretical starting point and how the subsequent theory developed, please see Critical Appraisal section of this thesis.

Mental Capacity Act (2005). Written consent was obtained after presentation of verbal and written information about the research, of which the participants retained copies (see Appendix III).

3.2.2 Confidentiality

All information gathered as part of the research was anonymised and pseudonyms were used to protect participants' identities. The information was stored securely and in keeping with both the NHS Trust and University data protection guidelines. Patient confidentiality was maintained throughout.

3.2.3 Participant distress

The potential for participant distress was minimised in the following ways. The researcher liaised with the potential participant's Responsible Medical Officer to ascertain if there were any reasons why participation would not be appropriate. The researcher was supervised by a qualified clinical psychologist with experience of both the client group and the service setting.

3.2.4 Ethical and research governance approval⁵

The study received ethical approval from a NHS Local Research Ethics Committee (LREC) and a University Ethics Committee. The LREC stipulated that both the person with dementia and their carer must agree to participate in the project, in order to preserve patient confidentiality. Research Governance approval was given by both the host and employing NHS Trusts.

3.3. The intervention

The memory rehabilitation group consisted of seven weekly, ninety minute sessions focussing on memory problems, current coping strategies, psychoeducation, errorless learning, memory aids and practical applications. Clients attended the group with their live-in carer, usually their spouse.

⁵ Copies of ethical and research governance approval documents can be found in Appendix IV.

Groups were run three to four times a year, with up to four couples per group, facilitated by a clinical psychologist and another health professional.

3.4 Participants

Potential participants were identified from a list of people who had attended, or were shortly due to attend, the memory rehabilitation group. They were initially approached by the clinical psychologist who ran the group, who was already known to them, after consultation with their Responsible Medical Officer.

The inclusion criteria for the intervention, and hence the research, was as follows. The client had to have a diagnosis of dementia (excluding Lewy-body dementia because of fluctuations in mental state and psychosis), with a Mini-mental state examination score of 18 or higher, and the capacity to give informed consent to participate. The client and carer had to be living together and both had to agree to participate. Participants were excluded if they had a significant, co-morbid diagnosis of a major psychiatric disorder.

Six couples gave consent to be approached by the researcher. On visiting one couple, the researcher felt the person with dementia was not able to give informed consent to participate in the study. A second couple chose not to participate. Four couples were, therefore, recruited into the study; see Table C1 for details of age and diagnosis and Figure C1 for a summary of the researcher's contact with each couple. All participants lived in their own home and were white-European. Clients' occupations were nurse, lecturer, postman and driver. To maintain confidentiality and anonymity the couples will be referred to as Mr and Mrs A, B, C or D, reflecting the order in which they were interviewed.

Table C1: Participants' ages and diagnoses

Participant	Age at interview	Diagnosis
Mr A	82	Mixed (Vascular / Alzheimer's Disease)
Mrs A	-	-
Mr B	84	Alzheimer's Disease
Mrs B	-	-
Mrs C	77	Vascular Dementia
Mr C	-	-
Mr D	80	Alzheimer's Disease
Mrs D	-	-

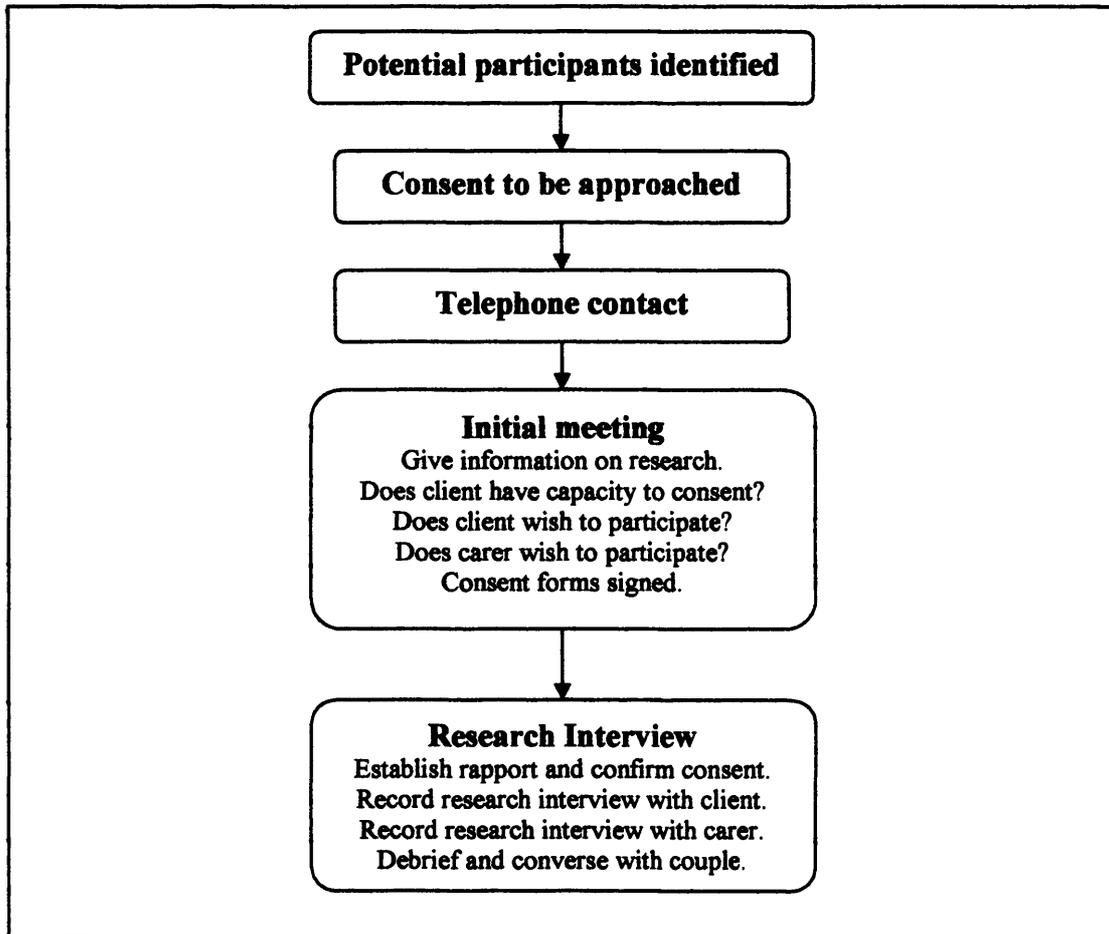


Figure C1: Summary of researcher's contact with participants

3.5 Data collection

In grounded theory, data collection and analysis phases are conducted in parallel and inform each other. The data was gathered through semi-structured interviews; enabling the researcher to have a schedule of topics but remaining open to novel avenues of interest (Smith, 1995). Broad questions were asked initially, becoming more focussed as themes began to emerge from the analysis, with the topic guide being revised after each interview. The initial topic guide covered the following areas⁶:

- How the participant came to be involved in the memory group;
- Their experience of living with a memory problem (or someone with a memory problem);
- Their experience of attending the memory rehabilitation group and what they took from it.

All participants were interviewed after they had completed attendance at the group. Each couple was interviewed separately in their own home. All participants chose to have their partner present during their interview and the researcher respected their wishes. Before recording began, the interviewer established a rapport with the interviewee, explained what the interview would be about and confirmed they still wished to participate. The audio-recorded interviews varied from 20-50 minutes per participant and were transcribed verbatim. After recording the researcher spent time debriefing and conversing with the couple.

3.6 Analysis

3.6.1 Initial coding

Initial coding involved the researcher examining each line of data and writing a brief note at the side which encapsulated what was being said. Following Charmaz's (2006) guidelines, the codes

⁶ The full topic guide and its later revisions can be found in Appendix V.

were kept active and process based.⁷ This enabled the researcher to become immersed in the data and for every word to be given careful consideration.

3.6.2 Memo-writing

The researcher then wrote a memo summarising her thoughts and impressions of what was happening in each interview and identifying particular themes to explore with the next couple to be interviewed. Similar memos were written at all stages of the subsequent analysis. Memo-writing is a key part of grounded theory analysis and not only helps the researcher form their ideas but also makes it easier to show how the analysis developed over time (Charmaz, 2006).

3.6.3 Constant comparative method

The grounded theory principle of constant comparison guided the analytic process. This involved comparing data with data, data with theme, theme with theme, etc., in order to generate successively more abstract concepts and theories. After coding the first four interviews, the codes were copied onto paper and laid out such that codes saying the same or similar things were grouped together and differences were also noted. Visual maps of possible inter-relations were then drawn.

The initial codes were simplified into an inclusive list of focussed codes. For example, where two initial codes were saying similar things, a definitive wording was decided and this became the focussed code. These were then divided into broad groupings. The list of focussed codes was used to line-by-line code subsequent interviews, with the list being revised and refined after each interview.

⁷ For example, 'comparing past to present' rather than 'compared past to present'.

3.6.4 Themes and categories

Over time potential themes were identified. These were placed onto cards and mapped out visually to enable links and differences between themes to become clearer and to identify higher order categories. This formed the basis of a preliminary model, which was used to re-code all eight interviews. Each example of a particular theme was listed in a table. From this it was possible to identify those that were present in all or most of the interviews. Where this was not the case the constant comparative method was again used, going back to the raw data, to refine and collapse themes where appropriate.

3.6.5 Development of a process model

A final list of categories and themes was thus derived. The memos and visual maps drawn at all stages of the analysis were used to arrange the categories and themes into a process model illustrating the links between them.

3.7 Quality Checks⁸

Morrow (2005) identified four criteria for ensuring the quality of qualitative research, irrespective of research paradigm: social validity, subjectivity & reflexivity, adequacy of data and adequacy of interpretation. The social validity of the present research will hopefully be apparent to the reader. The remaining three areas will be considered in turn.

3.7.1 Subjectivity & reflexivity

With regards to subjectivity, the researcher aimed to be explicit about her background and the biases and assumptions she brought to the research. To encourage reflexivity, the researcher kept a research journal for the duration of the project in which she outlined the research process, key decisions and interpretations. In addition, the researcher attended a university based qualitative

⁸ Please see Critical Appraisal section of this thesis for a detailed reflexive account of the research process including methodology, theory development and personal impact.

research support group where key decisions were discussed and challenged and the researcher's coding and model were peer-reviewed.

3.7.2 Adequacy of data

The researcher gathered data from the dual perspective of client and carer in order to give a fuller account of the lived experience. Morrow (2005) noted that number of participants or length of interviews were not useful criteria for judging the adequacy of data gathered. Within grounded theory two criteria are used (Charmaz, 2006); saturation (no new themes emerging) or theoretical sufficiency (sufficient data gathered to produce a rich and informative theory). Whilst it was not possible to achieve saturation within the constraints of this study, the researcher felt the criterion of theoretical sufficiency was met.

3.7.3 Adequacy of interpretation

The researcher had transcript extracts coded by a naïve researcher and explained and justified her analysis within formal research supervision and within the qualitative support group. This helped make the analysis and subsequent model more explicit, coherent and cohesive. To further encourage analytic transparency, the researcher kept an audit trail throughout the analysis, which would enable another researcher to trace the development of the theory, even if they might have taken a different route.

4. RESULTS

4.1 Overview

The interviews provided rich data to explore the experience of living with early-stage dementia. All the couples interviewed had spent most of their adult lives together and had developed a way of relating to each other, a way of coping with significant changes and, in particular, a shared memory of their life together. This shared memory included significant events in their past but also day to day things, such as allocation of household chores. Although only one person had the diagnosis of dementia, both parties felt the impact. The onset of dementia not only threatened the individual's memory and sense of self but also the couple's shared memory and sense of themselves as a couple.

It is worth reiterating that all eight participants chose to have their partner present during their interview. Whilst this may have affected what they felt able to say within the interview, it provided the opportunity to explore the impact on them and how they were coping as a couple.

4.1.1 Categories and themes

Fifteen themes, arranged into six higher order categories, formed the building blocks of the theory (see Table C2). Each theme was present in the majority of interviews (see Appendix VI). The categories and themes will be outlined in full, with supporting quotes, in the coming sections⁹. The overarching theory will first be explained, so that these can be set in context.

4.1.2 Process model

The theoretical links between categories are summarised in Figure C2. The couple noticed changes; the memory of the person with dementia had declined and both they and their partner felt the impact. The emotional impact was a profound sense of loss, accompanied by feelings of

⁹ Further illustrative quotes can be found in Appendix VII.

frustration, anger and anxiety. There was also a social impact, with the person withdrawing from social contact due to anxiety or feeling stigmatised by their problems.

Table C2: Categories and Themes

Category	Theme
Noticing Changes	Remembering & Forgetting
Impact of Changes	Emotional impact
	Social impact
Monitoring & Comparing	Monitoring
	Comparing
Preserving the shared memory	Compensating
	Practising remembering
	Carer becoming memory aid
Emotionally adjusting	Questioning
	Normalising
	Justifying
	Accepting
Being supported	Services
	Family & Friends
	Group

The sense of loss drove the couple to preserve what was left of the shared memory, through compensatory strategies, practising remembering and the carer becoming a memory aid. In tandem, and sometimes in tension, with the need to preserve was the need to emotionally adjust to the changes. This was done initially through questioning, normalising or justifying what was

happening. The person might then reach a point of acceptance. The support they received from family, friends and services, including the group intervention, impacted on and potentially facilitated these coping mechanisms.

Monitoring for further changes and comparing the person with their past self or with others seemed to occur at all stages in this process. This worked alongside and potentially facilitated the other psychological processes, such as grieving and adjustment.

4.2 Noticing Changes – Remembering & Forgetting

Mr D describes the changes he noticed in himself:

“...Basically, I was having problems with memory. Nothing too serious but it was it was annoying. It was irritating...(...)... Where’ve you put that down? G-Going in a room, now I’ve brought it in, no it’s not its in another room where you’ve left it. That sort of... trivial things you might say... but they irritated.”

Mr D (Client) Interview 8: 15-17, 21-24

For the other couples, it was the carer to whom the changes became most apparent:

“Erm, I’d felt for two or three months that (*husband’s*) behaviour wasn’t quite the same as it was. He he always had got a regular routine. Every night, when we went to bed, he would: make sure the shed was locked; alter the calendar ...(...)...; lock the back door. I was getting up in the morning sometimes and finding that these things weren’t being done, or perhaps part of them would be done but not all of them. And I thought, this doesn’t seem right to me.”

Mrs A (Carer) Interview 2: 14-18, 21-25

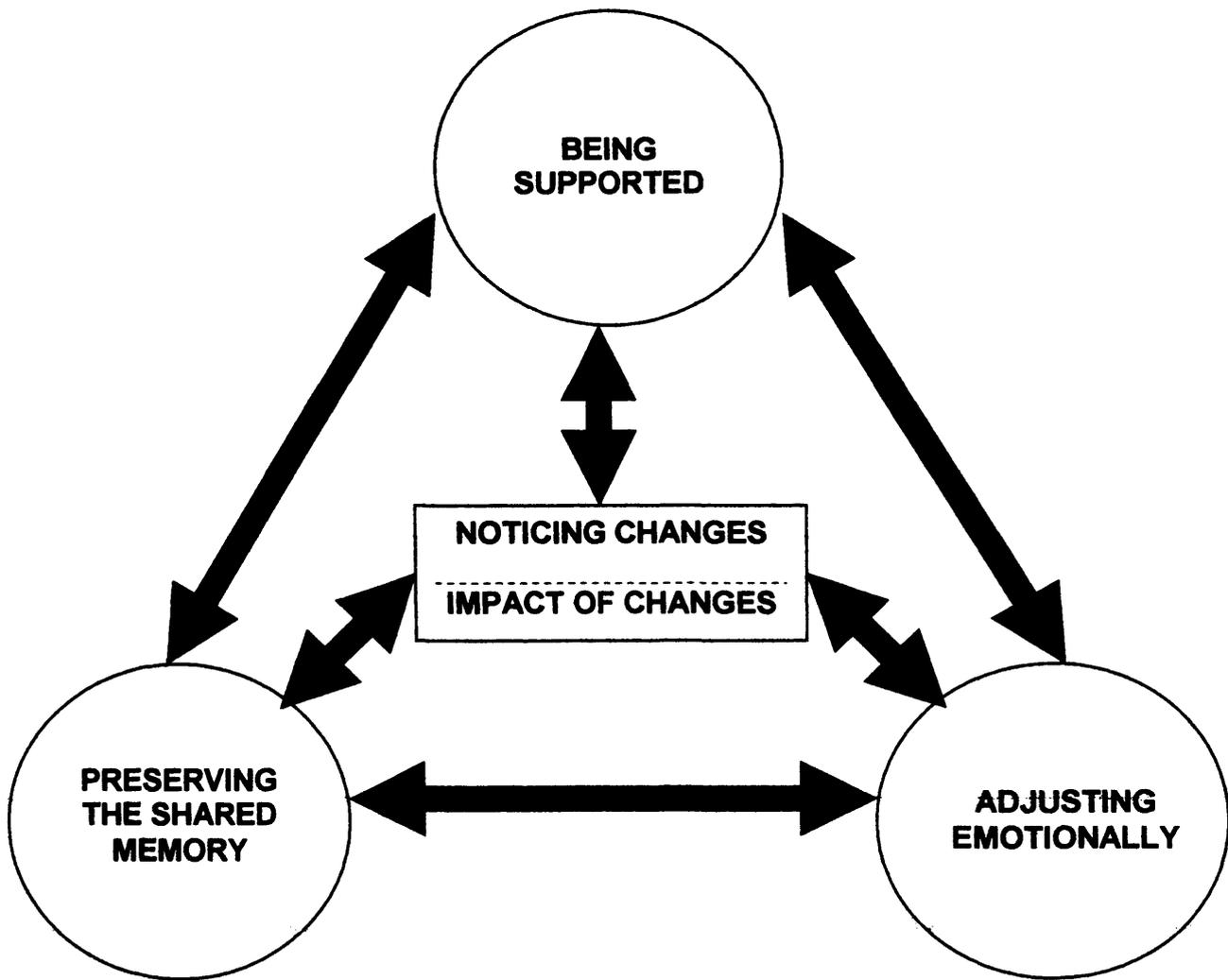


Figure C2: Grounded theory process model

For Mrs A, the changes in the practical, everyday component of their shared memory alerted her to the fact that something was wrong. For Mr C, it was evident in his wife's conversation:

“She was repeating a lot of things. And that's right. And er repeating a lot of things and even (*daughter*) and (*son*) noticed it, and others...”

Mr C (Carer) Interview 6: 30-32

Although the changes may have been obvious to some, the couple may downplay them initially:

“...I just thought, well I expect it's just getting old and you just forget things...(.)... he used to forget a lot of things...ever such a lot of things and...oh and you could tell him something and he'd swear blind you'd never told him. He was convinced you'd never told him.”

Mrs B (Carer) Interview 4: 61-62,125-128

Mrs B went on to describe how this had led to arguments, with her husband adamant that he had not been told and Mrs B keen to prove he had. For all the couples, the changes were difficulties remembering and forgetting things. For Mrs C, there was an ironic twist. She was no longer able to forget traumatic memories from her childhood during the war:

“I'm trying to forget it. If I can help it I don't want to think about it. I can see it in my head now.”

Mrs C (Client) Interview 5: 532-533

This inability to control what you remember and what you forget was also raised by Mr D:

“... when I was a kid at school, six years old, I could tell you the names of the whole
...(laughs)...that sticks. Why? Occasionally it pops in...() I could go to get them screw
them up and put something else in to replace them... but no you can't.”

Mr D (Client) Interview 8: 1060-1063, 1070-1071

So, the growing awareness of these changes had destabilised a system that had developed over decades of marriage. These changes had an impact: emotionally and socially, individually and on the couple.

4.3 Impact of Changes

4.3.1 Emotional impact

a) Loss

The main emotional impact was a profound sense of loss:

“What’s annoyed me is I’m losing all erm I’m losing all the things that I knew in the past...()...it’s a lot of waste...()...I mean they were all at my hands...()...I lose the words. I meant to say something and I can’t can’t find the words. I knew the word...I knew the word I wanted, I’ll say to myself, but now it’s gone. Where’s it gone?...()...I can’t speak by word, in the full point of the thing, as it should be and I’ve known words in the past, and things, all that I’ve learnt and they’ve thrown. They’re gone. They’ve gone. I have to do without them now. I have to show, I mean I could have shown perhaps a little bit of elegance in speaking but not now, not now.”

Mr A (Client) Interview 1: 135-136; 258, 264, 283-286, 510-516

Loss was also a significant issue for Mrs C. Whenever the interviewer asked about her memory problems, she would instead recall her experiences during the war in Germany:

“Well always, I think I blame the invasion of the Russians and the Poles in Germany and that was really very tense and worrying, yeah... (...)... Cause you know we had to leave our area where we lived and now the Poles moved in. We had to... we couldn't get anything for the house which my parents worked for but that's life. That's it ... (...)... Leave and live over in the West yeah. West Germany. It's just one of those things... (...)... We went away with a wagon pulling our belongings behind us; a long queue for miles and miles. Still, it's just one of those things. Well, I was only a child then.”

Mrs C (Client) Interview 5: 23-25, 251-255, 519-520, 524-527

The current loss could have triggered emotional memories of past losses and could be metaphorical communication about her current situation: having to leave familiar territory, a painful and difficult journey with little reward or recompense for losses, a sense of powerlessness and acceptance of fate. Carers also described a sense of loss:

“There are obviously things that I miss. I would like to go out a bit more. I haven't had to stop going out because (*husband*) is all right on his own for a while... (...)... But we used to enjoy holidays but that's something that (*husband*) feels, no he can't do anymore, which is a pity.”

Mrs A (Carer) Interview 2:312-316, 325-327

With loss goes the process of grieving and all the emotions associated with it. Anger, frustration and anxiety were the main emotions expressed within the interviews.

b) Anger / frustration

Not knowing whether your memory will fail at a critical point was annoying:

“Sometimes it’s good. Sometimes it’s there. Sometimes it isn’t... and that is irritating to say the least.”

Mr D (Client) Interview 8: 35-37

This occurred during his interview and his exasperation was evident:

“Yes (*pause*) and basically we...what was the name of the group we'd started? What in fact happened was, we got a group together so now we wan...oh hell...(*exasperated tone of voice*). I can't (*pause*) I haven't got enough of a memory left to tell... (*laughs*)”

Mr D (Client) Interview 8: 977-982

Carer's also got frustrated, as noted by Mrs B:

“You need a lot of patience (*pause*) especially when they do think that they have forgotten, long ago. They'd swear blind that you'd never told them. That can be very, very frustrating...”

Mrs B (Carer) Interview 4: 373-377

c) Anxiety

Another response to public memory failure was anxiety and embarrassment:

“...it's embarrassing to have a situation where if I try to be all right and use the words I want want to use but it fails. Um. If I get nervous. Get nervous. Terribly nervous. Cold and sweaty. That's why I keep away clear from it. “

Mr A (Client) Interview 1: 300-301

The mixture of anxiety and embarrassment led Mr A to withdraw:

“I don’t go about so much no. I go out but I don’t go out so much and I don’t like going with crowds to erm to dinner or something like that or even though that I even though I know them. I don’t like to get into a conversation.”

Mr A (Client) Interview 1: 246-249

Mr D found strangers most difficult to cope with:

“Strangers. You don’t know how to handle them. At one time...you learn how to handle people you don’t know or that you know very little of. You can handle them. You know...you did it automatically but that doesn’t work quite so well... (...)... It...if it’s a...shutdown... complete shutdown...the brain shuts down...you can’t do anything about it...its gone. But otherwise, I don’t know...being overcautious I suppose is probably what’s happening. You’re scared, now hang about, how... what’s gonna happen here?”

Mr D (Client) Interview 8: 1015-1019, 1024-1029

4.3.2 Social impact

It is clear that anxiety had a social and emotional impact. Carers also noted social changes:

“... we don’t really go out anywhere much to socialise with many people...”

Mrs A (Carer) Interview 2: 283-284

The client’s anxiety was one reason for this but there also seemed to be a stigma associated with having memory problems. Mr B described his reaction to not remembering something he thought he should have done:

“Yeah... and you feel really stupid... yeah.”

Mr B (Client) Interview 3: 219

His wife also feared that her husband would be seen as stupid:

“... it's nice to know that these people who do have the short-term memory loss; they're not getting treated as if they're stupid or something because that is awful and there's the proper treatment what people can give them.”

Mrs B (Carer) Interview 4: 604-608

For Mr and Mrs C, it was a fear of being seen as mad (*Interview 6: 1015-1019*). This meant they did not want to tell people but it was difficult to keep it a secret:

“I mean, when people meet (*wife*) they – well we don't meet many people now do we? – but people do know, love, because, they just they just know, sort of thing. You wondered once why (*son*), if (*son*) knew. Well they knew because they they, you kept repeating things. That's part of the thing, isn't it? Repeating things. You can't help it. It can't be helped at all but they know, it's noticed, you see, if you keep repeating the same thing all the time.”

Mr C (Carer) Interview 6: 1087-1097

However, not all the couples felt stigmatised:

“There could be (*a stigma*)... could be...but I suppose it depends at what stage you're at. I personally don't think (*husband*) is at a very advanced stage... (...)...I know it's maybe your own approach to these things as well... yeah... (...)...I suppose if you feel it's a bad situation then you maybe instil this on someone else or something like that.”

Mrs D (Carer) Interview 7: 267-269, 275-276, 280-282

The implication for Mrs D was that perception of stigma was a projection of one's own internal feelings about the situation. To summarise, the impact of the memory problems were both emotional (loss, frustration and anger) and social (anxiety and stigma).

4.4. Preserving the Shared Memory

The fear of further losses drove the couples to preserve individual and shared memories in three main ways: compensating, practising remembering and the carer becoming a memory aid.

4.4.1 Compensating

a) Finding a way round:

In order to keep going, the client had to find ways of working round their difficulties:

“You’ve got to find ways round it. Sometimes sometimes I get it right, sometimes I don’t... (...)...I think this is the way we’re learning to handle things. They’re learning, I’m learning, how to get round it. You’re not going to change it, how do you get round it?”

Mr D (Client) Interview 8: 584-586, 681-685

Mr A described how he managed this within conversations:

“Yeah, sometimes I have to feel my way around using the words I wouldn’t have used, less intellectual words or having having to find something that will carry me through. But it’s a lot of waste.”

Mr A (Client) Interview 1: 255-258

There is a sense of having to muddle through with whatever you can access at the time. The carers also compensated for their partner’s difficulties:

“...if he puts things away in the wrong cupboard I just move them and put them in the right cupboard...”

Mrs D (Carer) Interview 7: 318-319

b) Strategies and memory aids:

The couples used a number of strategies to aid memory:

“Well the calendar – putting things straight down. And when we go er like (*wife*) your bedside table is where you er keep things isn’t it? ...(...)... So do I and I told her about when I go out – keys in pocket, purse there, that there, all those sort of memory things that you know you’ve done it er go off and you’re there.”

Mr C (Carer) Interview 6: 541-543, 547-550

A weekly routine was also felt to be useful:

“...And I think that probably, because we do set things on set days, perhaps (*husband*) finds it easier to remember what day it is, because he will often ask me, “what day is it?”. Er, but I think he’s more inclined to know that, all right it must be Thursday because we’re going to Tesco, or something like that. “

Mrs A (Carer) Interview 2:, 200-207

4.4.2 Practising remembering

Another intuitive response was to practise remembering. This was illustrated by Mrs B’s response to being asked what had most helped her husband:

“And I think the things that (*group facilitator*) did with (*Mr B*) like...erm...making him remember. He'd send him round...this was not in the group, this was at home, and...er...he'd put, take something, put it down on say that table over there, then he'd ask him all kinds of kind of questions for say, half an hour, or chat, just a normal chat and then all of a sudden, out of the blue he'd say "could you get me my..." whatever and (*Mr B*) had got to remember where that had been put ...(...)... Clever, very clever. Very good.”

Mrs B (Carer) Interview 4: 229-239, 243

It sounds like Mrs B was describing an individual memory training session. This made intuitive sense to her. What she was actually describing was her husband's cognitive assessment. Mr D also felt the most helpful thing he had done was practise remembering using a brain training game on a handheld gaming device:

“That's right. That's the idea. Gradually, something that you can't remember, do it again, and again, and again, and gradually it starts to come back, which is exactly what it says it's trying to do. And it works. It takes time, but it works...(...)...It's practice. The idea is you've got to learn... The idea is ... all behind it...you've got to learn to remember, and that sounds daft I know but it works...(...)...the idea is apparently, if you concentrate it will slowly come back.”

Mr D (Client) Interview 6: 121-124, 139-147, 163-165, 194-196

Constant practice and repetition was also the approach adopted by Mrs C's husband and family. This had become so much a part of Mr C's interaction with his wife that he took every opportunity to do this within his interview, drawing his wife in and seeing what she could remember, as this extract illustrates:

“Mr C Can you tell (*interviewer*), if it means anything, where you’ve been in the last few weeks?

Mrs C Here at home.

Mr C No. I mean visits, to where?

Mrs C To the doctor, to the surgery?

Mr C Yeah. Yeah, but anything bigger than that? Well I’m helping now to try and think back. It’s exactly what (*daughter*) tries to do to try and help... Am I doing wrong (*to interviewer*)? Or should I be help...

I No, that’s OK.

Mrs C Anything bigger than here?

Mr C Yes, can you think where you’ve been in the last few weeks and it’s all on the calendar. I’m helping you to say, “Oh of course...”

Mrs C No.

Mr C Because it’s helping you to...

Mrs C Do you think of friends or neighbours or... what do you mean?

I Something to do with your health.

Mr C It's to do with health, oh yeah. It's to do with doctors and health and things.

Mrs C Been to the hospital, yes.

Mr C We get it. That's it."

Mr and Mrs C Interview 6: 862-897

There was a sense of it being a guessing game, which even the interviewer was drawn into. However, there was also a sense of desperation on the part of Mr D, willing his wife to remember their shared past. Throughout the interview he constantly checked to see how much his wife remembered. At one point he stopped mid story to check if his wife remembered the year they got married (*Interview 6: 761-769*). She did and he then continued with the story. One wonders what would happen the day she got this wrong, how devastated he would be that an important aspect of their shared memory had been forgotten.

It is interesting to note that Mrs C was able to say and remember more within her husband's interview than in her own, so this strategy had been successful up to a point. However, Mr D points out what happens when you stop practising:

"...it works. But as I say, it's slipped away a bit now but that's not surprising with me being away for a couple of weeks."

Mr D (Client) Interview 8: 241-243

4.4.3 Carer becoming a memory aid

The third main preservation strategy is where the carer holds more of the shared memory and acts like a human memory aid. The person with the memory problems may be aware of this and appreciate it:

“I do my best and (*husband*) helps me a lot. I ask him, “Do you know where so and so and so and so was.” And he’ll say, “Oh, you put it there”. And I’m very grateful that he is still with me.”

Mrs C (Client) Interview 5: 372-375

It is often easier to ask your partner than to consult a written memory aid:

“... when (*psychologist*) was reiterating about what you do to remember things, the other gentleman, he was a bit of a joker, and he always used to say “oh, ask the wife, ask the wife”. Well, of course, (*laughs*) that’s what (*husband*) does anyway. He’s got his own calendar upstairs but who writes the things on it? Erm, and he will often ask me rather than looking on his calendar.”

Mrs A (Carer) Interview 2: 169-176

Mr A acknowledged this and jokingly referred to his wife as, “the calendar girl” (*Interview 1: 430*).

Recognition of their role as a memory aid meant carers wanted to be present for important appointments, such as the memory group:

“...I didn’t want him going on his own anyway because if he can’t remember something it’s best if you’re there to see what has gone off and what’s going off... (...)... So you know what has been said.”

Mrs B (Carer) Interview 4: 47-50, 56

This also applied to medical appointments:

“You used to go there on your own. But since this business started, when it started, I’ve always gone in with you. Always. Every time. I sit there quietly and they ask you questions and, when it’s needed, then I come in. Like like now, yes.”

Mr C (Carer) Interview 6: 852-855

Trying to remember everything was difficult though:

“...even though you can't accept it all and take it in yourself...erm...you knew what had been said and exactly what the situation was.”

Mrs D (Carer) Interview 7: 175-177

Through all these extracts it is possible to see the efforts the couples were making to preserve memories, individual and shared, using whatever resources they had. However, there was a parallel need to acknowledge that things were different.

4.5. Emotionally adjusting

4.5.1 Questioning

One of the early stages was questioning what had happened and why. Trying to make sense of it all:

“ When you think, I can cook. I can clean and all that...()...I don't understand it, why I should forget other things.”

Mrs C (Client) Interview 6: 978-982

This was further complicated when there were compounding factors:

“But I can’t blame that on one thing and it’s happening because of another...(…)... I don’t know really which is the one. Was it the stroke or was it because I’ve deteriorated?...”

Mr A (Client) Interview 1: 93-94, 98-99

Mr A tended to ultimately blame his stroke for his problems but his wife had a different view:

“I’ve told you how I think about the the stroke. He made such a good recovery afterwards and was back to doing everything as normal, that I don’t think everything can be blamed on the stroke.”

Mrs A (Carer) Interview 2: 410-414

Mr D freely admitted that he had tried to understand what was going on but had come to the following conclusion:

**“That’s the way the world goes; the way the memory plays. What was it...somebody...
(*pause*). I’m trying to describe this... what was it... how it worked and the upshot was,
nobody knows how it works. It’s mysterious, I think, is the only word to describe it.”**

Mr D (Client) Interview 8: 1072-1077

Understanding what and why led to another question:

“I mean er the big question is, can anything be done about it? Is there? I don’t know. Can memory be, can it be er dealt with or...”

Mr C (Carer) Interview 6: 1195-1197

The underlying drive was if it could be understood then something could be done about it. This was probably behind the decision to seek help from the GP.

4.5.2 Normalising

One of the frequent explanations given was that the memory problems were just a normal part of ageing:

“I'm sure that er group that we went to helped no end (*pause*) either that or I'm so used to it now that you don't think anything about it... (...)... I mean as far as I'm concerned he's just normal now. There's none of this forgetting, oh I can't remember you telling me that or what have you and you've got to bear in mind that everybody, when you get to our ages, you do forget things and this is just normal happening and we both do that and I'm sure that everybody else does that's in their 80's... (...)... So I couldn't honestly say there is anything really now that he forgets any more than I do.”

Mrs B (Carer) Interview 4: 90-92, 135-142, 171-180

If it was a normal part of ageing then, as Mrs C says:

“I think it will happen to all every people eventually.”

Mrs C (Client) Interview 5: 175

This belief could have been a comfort and destigmatised the difficulties. Socialising was easier in settings where such problems were common:

“Yes, I mean, if I go over there tonight, we’ll be playing darts, or whatever else is on tonight. It’s just a fun night. But you see, over there, there’s a hell of a lot of other people that have got the same position. In that place... (...)... Well ‘cause you just accept them.”

Mr D (Client) Interview 8: 470-470-474, 478

Normalising what was happening reduced the perceived stigma but made accepting the reality of what was happening more difficult.

4.5.3 Justifying

When something happened which doesn’t fit into the normalised view there was a need to justify it. Mrs B had come to the view that her husband was normal and his memory was no worse than hers. Therefore, when he forgot something she needed to explain this:

“... but the thing is, sometimes it's not that he's forgotten, he's too busy wanting to do something different... (...)... like today it wasn't because he had forgotten, he just didn't want to leave off what he was doing... (...)... Looking for something rather than go and get his tablets. So that isn't called forgetfulness that is "I don't want to do it until I'm ready””

Mrs B (Carer) Interview 4: 115-116, 160-164

The need for justification also came when someone drew attention to the difficulties:

“Mr C ... once again... you can't always remember.

Mrs C I do (*husband*). Daily, I remember. I mean cooking...

Mr C We're trying to help...

Mrs C I can cook anything, you know. All that I've done ten years ago or today. “

Mr and Mrs C Interview 6: 413-421

4.5.4 Accepting

Eventually, along with the questioning, normalising and justifying, came a sense of acceptance.

When asked if his memory problems had an impact on his daily life, Mr B gave the following response:

“(*pause*) Yeah it that but then again...you've got to live with it...()... I mean it's no a..(*pause*) it's a...it's a disadvantage to me but er...I don't...I just get on with the job ... ()...It's not a problem because I can get on with it now.”

Mr B (Client) Interview 3: 61-62, 70-72, 83-84

Mr B had got to the point where he recognised his difficulties but rather than fighting it, as he had done initially, he had accepted it and moved on. This was something Mr C wanted for his wife:

“And the doctor did say, even yesterday, they've all said it, is that you have to face the facts. Er he said you were, er, vascular dementia it's called, and he said others have got it and that's why you get this pressure on your head.”

Mr C (Carer) Interview 6: 992-996

He felt he had already reached this stage himself:

“You accept things and that's it. You do what you can and what you can't, you can't. Not to worry about it. “

Mr C (Carer) Interview 6: 1138-1139

The process of adjustment and the drive to preserve what's left could be in tension but could also come together:

“I think basically what I'm trying to do is to condense what I've still got and to hell with the rest of it. I think that's the attitude....(....)... Use it, develop it , use these things what I've got (*brain training games*) and use your little bit that you can handle and for the rest of it, there's no point worrying about it. If you can't handle it, you can't handle it...(....)... There's nothing to do about it except make the best of it (*pause*). So....”

Mr D (Client) Interview 8: 1043-1045, 1049-1053, 1094-1095

4.6. Being Supported

The couples all had some form of social support, either family, friends or local services, including the memory rehabilitation group.

4.6.1 Family and friends

Having family nearby offered respite from caring:

“...having the support there, I felt confident enough in December to go away. I was only away for, was it 3 nights ... (....)...I'd left everything for (*husband*). I'd prepared meals, and put them in the freezer, that were easy for him to do and (*son and daughter-in-law*) would pop in to make sure everything was okay.”

Mrs A (Carer) Interview 2: 383-385, 388-392

Mr and Mrs B also had close family nearby that offered practical support:

“Oh yes. Yes. They're here all the time. Erm...they did all the decorating of this when they got it...(gives details of all the work they did)... Oh, lots of support, yes. From all of them. We're very, very lucky with our family.”

Mrs B (Carer) Interview 4: 444-446, 479

Contact with friends was also a source of emotional support, although there were problems:

“...But if you’re not doing much, you haven’t got much conversation. So its, that sometimes gets more difficult.”

Mrs A (Carer) Interview 2: 324-325

4.6.2 Services

Initially, contact with services was for diagnosis:

“Because first of all I wanted to take some do something to help her. For starters. And er, where are we, ah we had we went, first of all we went to doc to see my Doctor and he gave her a memory test. That’s how it started really.”

Mr C (Carer) Interview 6: 5-10

The next step was referral to specialist services:

“I was asked to go up to (*CMHT base*)...be interviewed at (*CMHT base*) (*pause*) and it escalated from there...”

Mr B (Client) Interview 3: 6-8

Having to talk to professionals about your partner’s memory problems was a stressful experience for Mr C:

“I was with (*CPN*) quite some time, twenty-twenty-five minutes, half an hour maybe. I answered all the questions. Very nice she was. Just asked me questions. And I thought, “You’ve got to tell the truth.” I mean there is no use pretending and I usually tell the truth

and that's it. Er and er anyway then we went back in the little er waiting room and sat there for a while. My cheeks were all burning.”

Mr C (Carer) Interview 6: 268-276

He later clarified that his cheeks burned when he was stressed. At the CMHT they were identified as possible candidates for the memory rehabilitation group programme:

“... we were asked whether we would like to join this group, which we agreed to...”

Mrs D (Carer) Interview 7: 16-17

4.6.3 Group

At the group, the couples were given the opportunity to learn about ways of managing the memory problems and to meet others in a similar position.

a) Coping strategies:

Mrs B outlined one of the strategies she learnt within the group:

“Erm...I suppose also what (group facilitator) did, like putting words on the board and then saying, why not write it, one way of remembering something, how do you remember things? Write a little note for yourself, things like that. Which, as I said to him, I said I think that's a good idea because I do now and I still do...”

Mrs B (Carer) Interview 4: 210-216

The need for routine and structure was one of the key things that Mrs A took from the group:

“I think possibly, erm, knowing that you’ve got to have a really set routine because that’s easier to remember, if you’re doing things the same way... (...)... we we find that we lead a very structured life”

Mrs A (Carer) Interview 2: 191-193

Whilst some of the couples learnt new strategies, others felt they were doing most of them already:

“But there were things I found handy but, to be honest, a lot of, to be honest, yes, we already do...”

Mr C (Carer) Interview 6: 550-552

Mr D described how he picked up strategies from observing how others coped:

“What you can do is people can... the way you see some people handle things, and think that’s not a bad idea. And your you adopt them... (...)... You say, “Hang about, that’s not a bad idea””.

Mr D (Client) Interview 8: 551-553, 558

b) Facilitating emotional adjustment

Mr B outlined how he found the group helpful:

“Mr B We were shy at first (*pause*) with one another and when we more or less introduced ourselves to one another (*pause*) we seemed to gel...more together...and we talked more... we talked as a group...and we enjoyed talking as a group...and really the time went quick and we enjoyed it... (...)...”

I ... So... erm...looking back over the time you spent in the group, which do you think was the most important bit of it for you?...

Mr B Talking about the problems (*pause*) and (*pause*) you more or less come out...let yourself go...you know...you just talk normally to...and it doesn't bother me at all... (...)...Because we were all in the same boats, so to speak.”

Mr B (Client) Interview 3: 93-98, 134-140, 145-146

In this extract, Mr B describes how spending time with other people with similar difficulties, identifying with them and talking openly about his difficulties had been therapeutic for him.

Observing other people helped Mr C to understand his wife better:

“(Describing a couple in the group) And they were... (*laughs*) she did all the talking he did all the forgetting (*laughs*). But he was a nice chap. He kept talking about dancing. That was his thing. You went it went always back to dancing dancing dancing. Whereas yours (*to wife*) went back to the memories of the war, isn't it?”

Mr C (Carer) Interview 6: 742-747

Although she was disappointed that she had not learned or retained much from the group, Mrs D appreciated the social aspects:

“And this is what we thought in the first instance when we had (*sessions*) one to one. We felt we would be better in a group aspect ...erm...throwing questions from one to the other and seeing how other people were handling the situation... which we were...and we could see some people were worse than others and some people had had this problem longer than others.”

Mrs D (Carer) Interview 7: 111-117

4.7 Monitoring and Comparing

4.7.1 Monitoring

Monitoring took place from the early stages of 'noticing changes' and 'being supported', through to the ongoing process of checking for deterioration. This facilitated 'adjusting emotionally', as change was acknowledged and further change anticipated:

"er, when they gave us the Alzheimer's diagnosis. I thought, well, don't know what to expect here, erm, but it's hard to tell a deterioration, whether that is the condition or part of it is age. But certainly as far as I feel, the progress is slower than I expected."

Mrs A (Carer) Interview 2: 275-280

The client was also monitoring for signs of deterioration, as Mr D states:

"...There's still a wide spread of it there already. It's only the edges that are causing problems..."

Mr D (Client) Interview 8: 1058-1059

Self-monitoring occurred on a day-to-day basis:

"Very often think, "Oh dear me, you've forgotten so and so and so and so." And then it comes back to me."

Mrs C (Client) Interview 5: 290-292

Mr C's constant questioning of his wife's memory was also a form of monitoring. In order to 'preserve the shared memory' he needed to know what she remembered, so he could encourage her to practice or compensate accordingly. Allied to the process of monitoring for changes is that of making comparisons.

4.7.2 Comparing

Comparisons were made between past and present selves and between self (or partner) and others. Mr D compared his past memory abilities with his current situation:

“That was the basic... it was it was against everything I always did. I could always have a pretty good memory but... it’s just... faded out... in sections... (...)... I used to have a good memory. I mean I’m ta..I could recite half an hour lectures and this sort of thing, straight through without the slightest trouble. Now, it’s gone“.

Mr D (Client) Interview 8: 29-31, 61-64

Acknowledging the loss through comparing his past and present selves enabled Mr D to grieve, ‘adjusting emotionally’, and also drove him to ‘preserve the shared memory’ through practice.

Comparing one’s own predicament with that of others could also be helpful:

“I mean when you think of other people...what illness they have...you think to yourself ...what are you whining on? *(pause)* I mean it's no a..*(pause)* it's a...it's a disadvantage to me but er...I don't...I just get on with the job...”

Mr B (Client) Interview 3: 68-70

There seemed to be a general sense that things were not too bad if there was someone worse than you. In response to the statement that his memory was not so good now, Mr D made the following response:

“No, it isn’t. There’s no doubt about that but it’s not working half as bad as some people I could mention *(laughs)*! So, be thankful for small mercies, really.”

Mr D (Client) Interview 8: 81-84

This was a view shared by other interviewees too, although not necessarily quite so explicitly. In fact, the memory group seemed to provide an ideal opportunity for these social comparisons to be made and was one of the ways in which the memory group facilitated emotional adjustment and spurred people into trying new coping strategies.

5. DISCUSSION

5.1 Summary of findings

This study set out to explore the lived experience of couples attending a memory rehabilitation group programme for people in the early stages of dementia and their carers. The participants described the changes they had noticed, the impact it had on them, as individuals and as a couple, and how they were coping. The study introduced the concept of shared memory, something which developed during the couple's life together. When one person's memory became unreliable it also affected the shared memory. To address this, the couples found ways of preserving the shared memory. A parallel coping process was to emotionally adjust to the changes and ultimately to accept them.

It could be argued that either of these coping styles on their own could become problematic. If the couple invested all their energies into preservation, they might eventually burn themselves out, as this will get harder as time goes on. If they just fatalistically accepted what was happening, there was a danger that the person with dementia would underestimate their ability and prematurely withdraw from many of their roles and responsibilities in life. Optimum functioning would be obtained when coping oscillated between phases of adjustment and maintenance. The tendency to monitor how things were and to make comparisons helped with this.

The couples received support from family, friends and services. The couples' experiences of the memory rehabilitation group suggested it supported the preserving

strategies whilst providing the opportunity to meet and interact with others in a similar situation, facilitating emotional adjustment.

5.2 Lived experience literature

Many of the themes in the present study were mirrored in the published lived experience literature. This is particularly interesting considering the researcher did not review this literature until after completion of the analysis, as is recommended in grounded theory studies.

5.2.1 Emotional and social impact

The feelings described by the couples in the present study were similar to the feeling states outlined by Kitwood (1997): fear, frustration, anxiety and anger. The sense of loss and grief has also been noted elsewhere (Derksen *et al.* 2006; Robinson *et al.*, 2005). The social impact of dementia, particularly social embarrassment and stigma, was noted by Gillies (2000) and Hellstrom *et al.* (2005). Changes in social relationships were observed by Gilmour and Huntington (2005) and Derksen *et al.* (2006).

5.2.2 Coping styles

The most striking similarity was with Clare's research into coping styles (2002). The two main coping responses from both studies were almost identical in meaning if not in wording. 'Preserving the shared memory' mapped onto Clare's 'self-protective' style and 'Emotionally adjusting' onto 'integrative responding / adjusting'. The key concept in both studies was the tension between the need to protect or preserve and the need to adjust. The fact that two independent studies have identified

similar processes suggested this could be an important and/or useful way of describing coping in the early stages of dementia.

There was even similarity in how the couples in the two studies did this in practice. The self-protective strategies in Clare's study included compensating through use of memory aids and strategies, trying and relying on partner, which loosely mapped onto the themes of 'compensating', 'practising remembering' and 'partner becoming a memory aid' in the present study.

There was more diversity between the strategies in the adjusting categories but 'accepting' was a theme in both. However, 'normalising' was included in later studies which explored gender differences in coping (Dijkhuisen *et al.*, 2006; Pearce *et al.*, 2002). 'Normalising' and 'accepting' were also themes in Gillies study (2000).

As well as supporting the findings of Clare and colleagues, the present study adds to them. Clare (2002) looked at how the person with dementia coped and so the focus was on preserving or adjusting the self-concept. The present study showed that this also took place at the couple level, preserving or adjusting their sense of who they were as a couple. Likewise, the individual was responding to changes in their memory, whereas the couple were responding to changes in their shared memory.

5.2.3 The dynamics within the relationship

The only other study that has looked qualitatively at the dynamics within couples focussed on awareness (Hellstrom *et al.*, 2005) but also looked at how the couple negotiated a shared view of what was happening. This suggested that one person may

take the lead initially, which may be linked to the pre-morbid dynamics within the relationship. If this person was the client, the study suggested that control would slowly shift towards the carer as the disease progressed.

It would be interesting to see if this also applied to coping style. The present study suggested couples were trying to preserve their sense of who they were as a couple, focussing particularly on the shared memory at this stage. Most relationships involve some form of compromise. If the balance of power shifted towards the carer with time, it would give them the opportunity to reshape the shared memory and the couple's identity as they wished. One might then wonder what impact this would have on the person with dementia.

5.3 Interventions for early-stage dementia

The natural coping styles could be facilitated through intervention. It has already been noted that the two main strands of interventions in early-stage dementia – psychotherapeutic and neuropsychological – map onto the two main coping styles identified -adjusting and preserving / protecting. It is interesting that an intervention adopting a memory rehabilitation approach within a group context facilitated both styles. In fact, the couples in the present study described how they particularly benefited from the group elements of the intervention.

A quantitative, evaluative study into this intervention found that attendance at the memory rehabilitation group had a protective effect on client and carer mood (Cuncliffe *et al*, 2005). The present study suggested this may be because it bolstered the couples' natural coping responses and offered them the opportunity to explore

other ways of coping. As noted above, a balance between preserving and adjusting might lead to maximum functioning and independence for longer.

5.4 Clinical Implications

The current clinical focus within dementia services is person centred care (NICE, 2006). This is an important redressing of the balance following years of ignoring the 'personhood' of the person with dementia (Kitwood, 1993). It might be argued that the concept of shared memory could shift the focus away from the person with dementia again. Seeing the person in isolation, however, is not person-centred care. How they interact with, and are supported by, those around them will have an impact on their mental health and their quality of life. It is important, therefore, to see the person in context.

Shared memory could be important. How the couple manage to maintain their identity as a couple at this stage could have an impact further down the line. It would be interesting to explore how the couples' manage to keep their relationship going, the adjustments they make, as the shared memory slips further away. Having attended a group together and talked to other couples in a similar position might make this easier.

The impetus for the development of memory books, and such like, tends to come once memory has deteriorated to the point where they are needed. The memories fed back to the individual at this stage are what others remembered not what they remembered. The person with dementia's component of the shared memory will have been lost. For both the individual and their partner and family it may be useful to

encourage them, if they can and whilst they still can, to share important personal and family memories. However, this may be difficult depending on how the adjusting / preserving process is going for both the individual and those around them.

The research literature to date, including the present study, suggested that a potential focus for services for people in the early-stages of dementia was to support the natural coping processes. Particularly the need for a balance between adjusting to the changes and preserving what is left, in order to maximise functioning and emotional health. A time-limited group which addresses both of these, such as the memory rehabilitation group, may be a useful first line intervention offered to those in the early stages of dementia and their carer.

A more focussed intervention may be required if the individual's coping is skewed too heavily in either direction. For example, an individualised memory rehabilitation programme may enable an individual to maintain a particular aspect of their memory. Similarly, a psychotherapeutic intervention may facilitate the emotional adjustment process where needed.

5.5 Strengths and limitations of the study

All the participants in the present study were white-European and long-term married. All had support from family & friends. All had adjusted enough to be able to attend all seven sessions of the memory rehabilitation group. All wanted to be present during each other's interviews. As such, it is not known if the issues raised and discussed in this study will be useful outside of this context.

Diversity issues, in particular, have not been addressed and with hindsight it would have been useful to employ more theoretical sampling to interview couples from a wider variety of backgrounds and who had not been together for so long. Unfortunately the time limitations and the available participant pool in the present study made this difficult. However, the similar findings to Clare (2002) suggest the results may be generalised to a degree.

The limitations of the study design also meant that the experiences of those who dropped out or who for whom this type of intervention does not appeal could not be taken into consideration. However, it is not known if they would have agreed to participate in the research even if appropriate ethical provisions had been agreed.

Whilst it is important to note these limitations, and interpret the findings accordingly, this study also has a number of strengths. It is the first study to have explored coping responses within the context of an intervention aimed at those in the early stages of dementia and their carers. The use of grounded theory strategies meant that the experiences of both the person with dementia and their carer could be taken into account. Finally, it has added to a growing literature in this area and has shone a light on how a particular sub-group are coping with the early stages of dementia.

5.6 Quality

The researcher has followed the guidelines for conducting and writing up qualitative research, as outlined by Elliot *et al.* (1999) and Morrow (2005)¹⁰. A

¹⁰ These guidelines have been included in Appendix VIII.

critical appraisal of the research process, including quality issues and the development of the methodology and theory, has also been conducted¹¹.

5.7 Future research

There are a number of possible avenues for future research. Firstly, the current study arose out of an earlier study (Cuncliffe *et al.*, 2005) which provided a quantitative evaluation of the effectiveness of the memory rehabilitation group programme. Taken together, the studies suggested the group had a protective effect on mental health, possibly because it supported both the preserving and adjusting coping responses. A logical next step would be to conduct some process based research, such as recording, transcribing and analysing sessions of the group in order to explore these hypothesised processes in action.

In addition, there has been limited research on how the proposed coping responses develop over time and the optimum balance needed for maximising functioning and maintaining mental health. Based on the research to date, a measure could be developed to ascertain the coping styles employed by a particular couple, which could be used in conjunction with interviews and measures of mental health, within a longitudinal, prospective study.

Another possibility would be to further explore some of the concepts suggested by the current study, such as shared memory. For example, it is not known how the couple maintain a sense of relationship and shared identity as the shared memory slips further away. It would be interesting to interview other couples, including those

¹¹ See critical appraisal section of this thesis.

without dementia, to see if the concept of shared memory actually makes intuitive sense. Also, it would be useful to find out what happens when the shared memory is disrupted for other reasons, such as through separation or divorce.

Finally, studies looking at the lived experience of people from different ethnic, cultural and religious backgrounds are needed, as this will not only ensure the needs of these populations are met but also add richness to the literature, widen its applicability and open up the possibility of their being other ways of coping with early-stage dementia.

6. CONCLUSION

This paper described a qualitative study, using a grounded theory methodology, that explored the experiences of couples living with early-stage dementia and who had attended a memory rehabilitation group. The results were in keeping with similar studies within the lived experience literature, including the emotional and social impact of living with early-stage dementia and coping through employing a mix of strategies to adjust to the changes and preserve what remained.

In addition, the current study has introduced the concept of couples having a shared memory that was also affected by the onset of dementia. As well as the individual employing coping strategies to preserve / adjust their sense of self, the couple are doing this with their shared identity. The current study also suggested that a memory rehabilitation group intervention could facilitate the natural coping process, through facilitating emotional adjustment and outlining strategies to preserve both individual and shared memory.

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SECTION D
CRITICAL APPRAISAL³

³ Written in the first person, in keeping with guidelines on qualitative research.

Conducting clinical research is an important part of the formative process of becoming a Clinical Psychologist. This paper is an opportunity for me to explore my development through the research process and identify learning points for the future. I will begin with clarifying how the research question arose, then outline how the methodology developed to address this, taking into account my epistemological position. Finally, I will describe how my theoretical ideas evolved, quality issues and the personal impact of the research process.

1. Starting point

I attended a research presentation on a memory rehabilitation programme for older people in the early stages of dementia and their carers. The research showed the group had a protective effect on the mental health of both client and carer. The presenting clinician was hoping another research student would take it forward, which I offered to do.

I was interested in the experiences of the couples attending the memory rehabilitation group. Underlying this was a curiosity as to why a group aimed at maintaining memory functioning was having a protective effect on mental health. My field supervisor was particularly interested in identifying the active treatment component and whether the participants viewed their experiences differently before and after the group. We decided to interview both the client and the carer and incorporate some way of looking at process and change.

2. Development of epistemological position

From our initial discussions I was aware of the danger of imposing quantitative research ideals onto a qualitative research design. Neither my field supervisor nor I had conducted qualitative research before but I was aware of the need to be coherent about the epistemological stance of the researcher and the choice of methodology.

2.1 Overview of research paradigms

Guba and Lincoln (1994) outlined four paradigms from which research could be approached. Each paradigm had its own ontology; beliefs on the nature of reality. Positivism is based on the belief that reality is completely apprehendable, whereas post-positivism states that reality exists but could only be imperfectly accessed. The third position is Critical Theory, which states that reality is shaped by social, political, cultural, economic, ethnic and gender values that have crystallised over time but were once fluid. Finally, constructivism argues that our apparent reality is completely constructed and subjective.

At least five epistemological positions, defining the relationship between researcher and researched, can be identified. These were positivism, post-positivism, critical realism, social constructionism and radical constructionism. This could be thought of as a continuum ranging from completely objective (positivism) to completely subjective (radical constructionism).

2.2 Background of the researcher

To enable the reader to identify shifts in my epistemological position over time, I will share some background biographical information. I came into clinical psychology by an unconventional route, as my first degree was in mechanical engineering. Then, my understanding of scientific research was of a quest for knowledge and truth about the world, though I accepted that the current, cutting edge theories were a best fit rather than an absolute truth. Furthermore, over time we would only ever get closer approximations of the truth; a post-positivist position.

On graduating, the reality of working within engineering did not live up to expectation and I developed an interest in clinical psychology. I studied for a Conversion Diploma in Psychology and was initially bemused by the debate on whether psychology was a science. The argument seemed to rest on an overly simplified view of science. This bemusement had mutated into

frustration by the time I was on the Doctorate in Clinical Psychology course and fully encountered the debate on philosophical paradigms.

2.3 Finding my own position

I initially found it hard to place myself into any of the paradigms outlined by Guba and Lincoln (1994). It felt like one had to adopt a relativist position just to enter into a debate on the nature of reality. On reflection I felt my ontological position was now somewhere between post-positivism and critical theory. As I was conducting qualitative research, however, I needed to more clearly define my epistemological position. I did some background reading on philosophy and epistemology and entered into debates with peers and friends on these issues. The Qualitative Research Support Group, run by the course staff, offered the opportunity for clarifying my epistemological position through debate.

Initially, I found it easier to identify those positions that did not fit. I found radical constructionist writings circular and the lack of objectivity irritating. I accepted it might be useful to look at things as though they were completely constructed but not that this was always the case. I also saw that I could not be completely objective, as I accepted that my own background and preconceptions would affect how I interpreted experiential research data. My conclusion, then, was that I was in the middle of the objectivity / subjectivity continuum. My epistemological position was critical realist.

2.4 Further developments

Looking back over the research process I do not think my epistemological position has changed substantially. I found myself naturally interacting with the data during the analytic process. It felt like the participants were making sense of their experiences, sharing them with me in the interview and I was then constructing a theory to explain and summarise what they had said.

I was aware that someone else might construct a different theory with a different focus. When I looked at the lived experience literature after completing my analysis, however, I was struck by the similarity in terms of themes and processes both in their work and mine. This confirmed for me that my research was not completely subjective and although my background and experience had led me to focus on particular aspects, something of the reality of living with early-stage dementia was also present.

3. Developments in methodology

Unlike the consistency of my epistemological position, my methodology has evolved substantially over time.

3.1 Initial research design

It seemed appropriate, from my epistemological position, to think of the memory problems as a phenomenon being experienced and that both participant and researcher were interpreters of this experience. My initial choice of analytical approach was, therefore, Interpretative Phenomenological Analysis (IPA) and there was a precedent for its use with this client group (e.g. Clare, 2002).

It had already been decided that interviews would be the main source of data collection but I still needed a process element. I did not feel there was time for before and after interviews or that there was an appropriate quantitative measure.

Whilst doing some background reading on IPA I discovered a paper by Smith (1999), which used a combination of interviews and repertory grids. The repertory grids were an idiographic method for exploring how the participant perceived their self and their social world and could be repeated at a later date. I felt this could be a useful way of monitoring change over time using

constructs which were important to the participant. A potential drawback was there were no published precedents for repertory grids being used with this client group.

In summary, the initial research design was to construct a repertory grid before attendance at the group, repeat it at the end of the group and follow this with a semi-structured interview, which would be analysed using IPA.

3.2 Switching to grounded theory

Having not conducted qualitative research before, I approached course staff with expertise in this area for feedback on the appropriateness of my design. I was aware of a potential flaw; IPA was designed for use with small, homogenous samples. I was not sure if I could use this methodology and maintain my position that client and carer perspective were equally important. I was advised that either the client or carer view would have to be privileged. If I wanted to keep the different perspectives it would be better to use Grounded Theory.

A difficulty with switching to Grounded Theory was its assumption that the researcher came to the research with little or no background knowledge or assumptions, as it had developed out of a positivist / post-positivist epistemology. I did not feel I could approach the research as a blank screen, completely objective.

I had been advised to look at Charmaz approach. She held that Grounded Theory was a set of neutral strategies and the epistemological stance of the researcher dictated how they were used (Charmaz, 2006). Furthermore, Grounded Theory could be used by researchers from a more subjective epistemological position if the basic assumptions were modified. The researcher's preconceptions and ideas are thus seen as guiding interests and used as 'points of departure'. Also,

the emerging theory should be seen as constructed by the researcher out of, and grounded in, the participants' experiences, rather than being discovered in them.

The overall research design remained the same with the analytic framework changed to Grounded Theory. As it was now possible to look at things from different viewpoints, I decided it would be interesting to add another perspective; the group facilitator would keep a journal for the duration of a group. All the participants would be recruited from this cohort if possible. A cohort was 8 participants (4 couples).

3.3 Ethical considerations

3.3.1 Initial ethical concerns

The main ethical concern was whether the participants would have the capacity to give informed consent. I consulted the Mental Capacity Act (2005) and was reassured that it made explicit reference to the fact that people in the early stages of dementia could still have the capacity to make informed decisions. Also, the decision did not need to be remembered later, as long as they had the capacity to make the decision at the time. The capacity to consent was an inclusion criterion for the group intervention and thus for the research, so I was hoping it would not be an issue.

As client and carer were equal participants in the research, one information sheet and one consent form were produced. I particularly wanted potential participants to be able to make their own decision independent of their partner and this was clearly stated on the information sheet.

The other ethical concerns were those common to all clinical research, that of data protection and participant distress. The data protection guidelines laid out by both the University and the NHS Trust were consulted and followed. Participant distress was to be minimised through consultation

with their responsible clinician prior to being approached and from me receiving clinical supervision from an experienced clinician in the area.

3.3.2 Ethical approval

The Local Research Ethics Committee (LREC) reviewed the research proposal and their main concern was patient confidentiality, which surprised me. They did not want the carer taking part if the client had refused, as it could compromise patient confidentiality. Their recommendation was that both client and carer must participate or neither should participate. In light of this, they wanted separate information sheets and consent forms for client and carer.

Objectively the LREC went well, with only a few minor changes in paperwork required, but it felt like a major blow to my ideal of client and carer as equal participants. I had made significant adjustments to the methodology to accommodate this ideal. I was worried participants would feel obliged to participate because their partner wanted to and that recruitment could be more difficult.

My field supervisor reassured me that recruitment would not be a problem and, on reflection, I could see that once recruited I could still view the couples as equal participants. Looking back, I'm glad this happened as it was the issues that came out of interviewing both client and carer that I found most interesting at analysis.

3.4 Receiving specialist guidance on Grounded Theory

After submission of my proposal to the LREC I was offered specialist supervision in Grounded Theory methodology from a local clinician. This proved to be incredibly helpful but I began to wish I had met with her before submission to ethics. It was my methodology supervisor who first expressed concerns over the amount of data I was trying to collect. I realised that I had been over

ambitious in what I had set out to do but the research had already received ethical and research governance approval in its present form.

My interview schedule had been initially designed for use in an IPA study and had been quite detailed. We were able to streamline it through using general open questions more in keeping with Grounded Theory. Discussion enhanced my understanding of Grounded Theory and we practised coding and identifying themes.

3.5 The impact of the client's cognitive difficulties

3.5.1 Capacity to consent

My concerns were not alleviated by my first contact with a potential participant. The client appeared to have deteriorated since his last assessment at the CMHT and I was concerned about his capacity to consent to participate in the research. I explained the necessary information in simple terms, both verbally and via the written information sheet. He seemed to think I was asking him to sign a contract to run a shop and was reluctant to do so. Either he could not understand what I was asking or he was saying 'no' using metaphorical communication and I did not feel it appropriate to push it any further. The carer wanted to participate but was unable to because of the LREC recommendation.

I was quite despondent, as I had hoped capacity to consent would not be an issue and was also concerned about whether I was expecting too much of participants. The next two couples were, however, happy to participate and there were no issues with capacity to consent from then on. I was also reassured that the interviews would not be a problem, as both these couples seemed quite articulate.

3.5.2 Repertory grids

I was, however, still concerned about the repertory grid methodology. I realised it was effectively a sorting task requiring executive functioning and at least one of the clients would have difficulty with this. I had focussed on how cognitive difficulties might affect capacity to consent but not about ability to complete such a complicated task. I wished I had kept the methodology simpler.

Following discussion with my supervisors and the Qualitative Support Group I decide to drop the repertory grids from the methodology. I decided my main focus was, and should remain, the Grounded Theory analysis of the interview data.

3.6 Introduction of theoretical sampling

The two couples I had recruited were about to attend the memory rehabilitation group. The other two couples in their cohort were not recruited either because they declined to participate or were not suitable. As the interviews were to take place after the group had finished, and given that the interviews were the main focus of the research, I wondered whether it would be interesting to recruit two couples who had already attended the group, relatively recently so that the client remembered attending. It would be useful to see how they felt about it looking back.

I was able to recruit two such couples and so my sample was set. I would interview two couples immediately after attending the group programme and two couples who had attended within the last year.

3.7 Overview of developments in methodology

This was my first major qualitative research project and it has been a steep learning curve. With hindsight, it would have been better to redesign the methodology at the point I shifted from using

IPA to Grounded Theory. As it happened, my methodology evolved as I learnt more about Grounded Theory, received specialist supervision and grew more confident with qualitative research in general.

At the outset I did not realise I was being over ambitious. I was more concerned about setting the net wide enough to catch something interesting. Looking back I wonder if it was difficult for me to trust that interviews alone would be enough to develop a useful theory. As I became more confident in the use of Grounded Theory, I felt more restricted by the additional things I had thrown in and eventually dropped them from the analysis.

Whilst conducting my literature review on interventions for early-stage dementia, I became aware of therapeutic process research (e.g. Cheston, 1996). Whilst this alternative methodology would have addressed the initial research questions through providing a professional view on process, it would also have meant the loss of the subjective experience of the participants.

Although these were important learning points, the research still met my original aim of exploring the participant's experience of early-stage dementia and the group intervention. I will now outline how my theory developed out of these experiences.

4. Theory development

4.1 Point of departure

At the outset we had a number of ideas as to what might be causing the protective effect on mental health. The onset of dementia could be a threat to the client's identity and attendance at the group might help the client to incorporate the diagnosis into their identity. The fact that client and carer are equal participants and no distinction is made in terms of diagnosis might be important. I was curious as to whether group therapy processes or the practical strategies were more important.

I could have specifically addressed each question but might have missed something more important that I had not thought of. Instead, I adopted an explorative approach, in keeping with the use of Grounded Theory, and started with general open-ended questions about the participants' experiences of early-stage dementia and the group intervention.

4.2 Initial impressions following interviews 1-4

I had intended to interview the client and carer separately but both expected to be present for each others interviews. Nothing was explicitly said but this was what naturally happened, as they were interviewed in their own home. After the first interviews I started asking whether the participant wanted to be interviewed on their own but none of them did. In fact, I noticed that often during the client's interview they would look to their partner to clarify facts or for reassurance. I began to wonder if this was one of the ways the couples had learnt to cope with such situations. I could also see the impact the problems might have socially.

After initial coding of the data, I was aware of a sense of stigma associated with having memory problems and a corresponding drive to normalise the condition. There also seemed to be a process of monitoring for change by both client and carer. I introduced some new topics into the interview schedule at this stage: stigma, client / carer relationship and social impact.

4.3 The creative process

4.3.1 Immersion

The first stage in the creative process involved becoming immersed in the data and becoming sensitised to particular themes. This was occasionally accompanied by flashes of inspiration, often late at night when trying to get to sleep.

4.3.2 Flashes of inspiration

The first flash of inspiration was a drawing together of the initial themes into a simple diagram. The key idea was that coping was not an individually focussed, identity driven process, as I had initially hypothesised, but a social and relational process. I had the idea of the couple having a shared memory that had been affected by the onset of dementia. The carer was taking on more responsibility for this shared memory through acting as a memory aid and the process of monitoring was helping to stabilise the system. The stigma and normalisation dynamic occurred at the boundary between the couple and society. I also began to wonder whether the stigma was linked to the client not being able to keep up with their responsibilities in the societal shared memory.

4.3.3 Rumination

I was initially very excited by these ideas but a period of rumination followed. I was aware of the bits that did not fit; a constant nagging feeling that would wake me in the middle of the night. I wondered if I was oversimplifying or off on a theoretical flight of fancy, as Charmaz (2006) warned could happen. I had only just started the constant comparative process, did not have a full list of themes yet and, more importantly, I had not finished data collection. I was engaging in top-down analysis too early. I decided to set aside these ideas for now and re-immersed myself in the data, engaging in the bottom-up process of developing focused codes, recoding interviews, and identifying themes to take forward to the next interview.

4.3.4 An independent view

I took extracts of my transcripts to the Qualitative Support Group and to my methodology supervisor for independent coding. This helped broaden my focus and was a useful way of getting feedback on my ideas. For example, after she had coded an extract from Interview 6, I told my methodology supervisor about the shared memory idea. It intuitively appealed to her and she also wondered whether the carer's need to compensate was a preservation strategy.

4.3.5 Visual mapping

One of the main tools that helped me make sense of all the data was visual mapping. Getting everything into view enabled me to identify similarities, differences and connections. I did this with the initial codes in order to develop a list of focussed codes. Once I had the full list of themes I put together a Venn diagram with my field supervisor. The three circles represented the couple, services and society and helped locate where each theme was operating.

The concept of shared memory was still a central idea and the three circles were renamed 'supporting the shared memory' (services), 'protecting the shared memory' (from society) and 'preserving the shared memory' (the couple). These were the first three supra-ordinate categories and a process model was drawn showing how they interacted with the other categories of 'noticing changes', the 'impact of changes' and the process of 'monitoring and comparing'.

4.4 Being challenged

I took this initial version of my process model to the Qualitative Support Group and attempted to talk them through it. They challenged me on why I had placed so much emphasis on shared rather than individual memory. They wondered whether this was an exaggeration of the normal relationship dynamic or if it gave the more able party the opportunity to reshape the shared memory how they wanted. Finally, the use of 'preserving' and 'protecting' as two separate categories was confusing, as from my explanation they were not easily separable. I found this experience quite challenging and began to doubt my thesis. I decided to go back to my raw data again and re-ground the theory.

4.5 Simplifying and grounding

My model of themes and categories was used to re-code each transcript and supporting extracts for each theme were identified. From this I could see the weaker themes and worked to collapse or

subsume them into stronger themes. This was a systematic, iterative process and it was hard to know when to stop. Eventually I arrived at a point where I had fifteen themes, divided into six categories, all of which were present in the majority of interviews. 'Preserving the shared memory' was still an important category but the other shared memory categories were renamed to be more inclusive. The process of refining and simplifying the model continued as I wrote up the results. Minor changes were made to improve the overall theoretical narrative.

4.6 Reading the literature

On completion of the analysis I read the literature on lived experience in dementia and, as I have said previously, was struck by the similarities to my own model. I debated whether I should change the wording of my categories to match the literature but decided not to. My categories had emerged from my analysis and although there were similarities they were not the same.

4.7 Reflecting on theory development

I found the whole process all consuming and difficult to switch off from at times. The need to become fully immersed in and almost part of my data was necessary to stop me from going off on flights of fancy but I also needed to be able to step outside of it so that the theory could be sufficiently abstract rather than just a description. The views of others helped to ensure my developing theory was coherent, comprehensible and made intuitive sense to someone other than myself.

I feel I was able to use my initial assumptions as points of departure and although there are elements of them in the final theory I do not feel they have overly constrained the theoretical development. In particular, I have moved away from an individualist view towards a social / relational view.

5. Quality

When designing the methodology, I focussed on maintaining quality through triangulation, reflexivity, transparency and coherence (Smith, 2003). In particular, this involved viewing the phenomenon from the dual perspective of client and carer, keeping a research diary, writing theoretical memos, formal research supervision and attending the Qualitative Research Support Group.

During the writing-up phase I found two review articles particularly useful in retrospectively assessing the quality of my research (Elliot *et al.*, 1999; Morrow, 2005). These articles appealed because they provided clear guidelines that could be followed irrespective of philosophical paradigm.¹ Morrow (2005) identified four transcendent criteria, which I used to outline quality issues within the main research report.

I will now expand on this using the more detailed guidelines suggested by Elliot *et al.* (1999). They listed seven criteria. The first was, 'owning one's own perspective'. It has been difficult to be explicit about all the possible biases and assumptions I might have brought to the research because I'm not necessarily conscious of them all. I have at least been clear about my theoretical orientation, background, theoretical points of departure and the context.

The second criterion is, 'situating the sample'. To this end, I have provided basic demographic information for the clients but this was more difficult for the carers as I was reliant on medical records. Unfortunately I did not collect this information at the time of interview, which is a learning point for me.

¹ A summary of both sets of guidelines can be found in Appendix VIII.

Within the research report I have ‘grounded’ the presentation of my analysis in the participants’ words where possible. With regard to ‘credibility checks’, I did not have access to multiple analysts as a research student. Also, I did not feel respondent validation was appropriate given my epistemological position. I have, however, tried to use my research supervisors and the Qualitative Support Group as analytic auditors where possible. I feel this has also helped to make the resulting theory more ‘coherent’.

I believe the research has met the ‘specific task’ of developing understanding of the subjective experience of early-stage dementia and attending a memory rehabilitation group. I acknowledge that more use of theoretical sampling would have been helpful if time and participant pool had allowed. The final criterion is ‘resonance with the reader’, which the reader must judge for themselves.

6. Personal impact

6.1 The research process

One of the most difficult aspects for me was settling on a research topic. It took me over a year to do this for a number of reasons. I was new to the area and did not have many clinical contacts. Entering clinical training opened up a world of possibilities and it was hard to settle on one research topic to the exclusion of others. I also had a couple of false starts where a research idea was taken up by a service and then the process stalled. In the end, however, I was lucky enough to come across a supportive field supervisor researching a topic I was interested in.

The next challenge was developing the methodology, as I have already outlined above. I was new to qualitative research and a bit scared by it initially but the most enjoyable phase was the creative process of theoretical development. Although this was all consuming I feel it played to my analytic strengths and it was a relief when I reached this stage.

I have not been put off from conducting further clinical research but in the future I hope research questions will arise naturally out of the clinical area I am working in. I feel my knowledge and confidence in the use of qualitative methodologies has grown considerably and I now feel competent in using either quantitative or qualitative research methods in the future.

6.2 The Client Group

I was initially nervous about working with clients with dementia. Losing my cognitive abilities is something I fear and I remember getting very distressed by a video charting a man's decline into dementia in the first year of the Doctorate. My older adults' placement had mostly been with stroke patients so I did not have much experience to draw on. My field supervisor had warned me that dementia was a terminal illness and working in the area could raise powerful feelings about our own and other's mortality and vulnerability.

My encounters with the participants, however, alleviated my anxiety about my ability to work with this client group. The couples were open and honest about their situation, very welcoming of me and I could see how they were learning to cope with their situation. It made me realise that a diagnosis of dementia, though devastating, could be survived and that there were things I could do, as a clinical psychologist, to support the adjustment. I was particularly taken with one couple whose good humour challenged by preconception that dementia was, by nature, a depressing condition. My interest in this area has grown and I would now considering work in it upon qualification.

7. Conclusion

The research process has at times been challenging and with the benefit of hindsight there are things I would have done differently, particularly in relation to the methodology. However, I have developed my knowledge and competency in both qualitative research and working with this client group. I particularly enjoyed the process of theory development and hope that my research will add to the literature in the areas of lived experience and interventions for early-stage dementia.

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SECTION E
APPENDICES

APPENDIX I - Notes for Contributors to British Journal of Clinical Psychology

The *British Journal of Clinical Psychology* publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

- Papers reporting original empirical investigations
- Theoretical papers, provided that these are sufficiently related to the empirical data
- Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications
- Brief reports and comments

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Reviewing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship (including personal acknowledgements and institutional affiliations) should be confined to the title page (and the text should be free of such clues as identifiable self-citations, e.g. 'In our earlier work...').

4. Online submission process

1) All manuscripts must be submitted online at <http://bjcp.edmgr.com>.

First-time users: Click the REGISTER button from the menu and enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).

APPENDIX I - Notes for Contributors to British Journal of Clinical Psychology

Registered users: Click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

2) Follow the step-by-step instructions to submit your manuscript.

3) The submission must include the following as separate files:

- Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author - **A title page template is available to download.**
- Abstract
- Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.

4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors - **Editorial Manager - Tutorial for Authors**
Authors can log on at any time to check the status of the manuscript.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions:
British Journal of Clinical Psychology - Structured Abstracts Information
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.

For Guidelines on editorial style, please consult the *APA Publication Manual* published by the American Psychological Association, Washington DC, USA (<http://www.apastyle.org>).

APPENDIX I - Notes for Contributors to British Journal of Clinical Psychology

6. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author and name and address are not included in the word limit.

7. Publication ethics

Code of Conduct - **Code of Conduct, Ethical Principles and Guidelines**
Principles of Publishing - **Principles of Publishing**

8. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

9. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication.

10. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

11. Checklist of requirements

- Abstract (100-250 words)
- Title page (include title, authors' names, affiliations, full contact details)
- Full article text (double-spaced with numbered pages and anonymised)
- References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs
- Tables, figures, captions placed at the end of the article or attached as separate files

APPENDIX II – Summary of studies included in literature review

Table E1: Neuropsychological interventions – cognitive training

Study	Diagnosis	Sample	Intervention	Study Design
Bird & Kinsella, 1996	Alzheimer's & Vascular Demtnia MMSE 7-24	24	Spaced retrieval with fading cues. 2 visits, 3 weeks apart.	Counter-balanced repeated measures. Within p's factor: learning condition Between p's: MMSE
Winter & Hunkin, 1999	Alzheimer's Disease MMSE = 20	1	Errorless learning – relearning old info. 2-trials/day – 4 dys	Single case study
Graham <i>et al.</i> , 2001	Early semantic dementia	1	30 min/day home rehearsal of lost vocabulary combined with pictures and real objects.	Single-case study - 4 wk layered intervention with 6 and 16 wk follow-up (Total 20 wks) - 2 yr follow-up
Zanetti <i>et al.</i> , 2001	Alzheimer's Disease MMSE 15-23	18 (11 intervention - 7 control)	Procedural memory training 1hr/dy, 5 dys/wk, 3 wks Trained in 13 activities of daily living.	Baseline and follow up. Experimental vs. control groups
Arkin, 2001	Early-stage Alzheimer's (MMSE=23, 15-29)	11 (6 intervention - 5 control)	<u>Experimental gp:</u> Errorless learning –spaced retrieval. Biographical info using audiotape (x10 per semester) Language therapy. Volunteer work Student as intervener. <u>Control group:</u> Memory book Unstructured conversation <u>Both:</u> Exercise (2/ wk, 20wks)	Pre and post participation. Outcomes for 1 year (28 weeks) of intervention reported.

APPENDIX II – Summary of studies included in literature review

Study	Diagnosis	Sample	Intervention	Study Design
Quayhagen & Quayhagen, 2001	Early dementia. Alzheimer's DRS >100.	<u>Study 1</u> 56 couples <u>Study 2</u> 30 couples	<u>Study 1:</u> Cognitive stimulation by carer. 1hr/day for 5 days/wk. 7wks on memory 3 wks on problem solving 2 wks on fluency/comm <u>Study 2:</u> As above but only 8 week intervention and focus on all 3 areas every week.	Stratified sample. Randomised to control, placebo or experimental groups. Comparing results of Study 1 with Study 2 using pre and post (3 months) measures. Repeated measures multivariate analysis
Davis <i>et al.</i> , 2001	Alzheimer's MMSE 15-29	37	5 week intervention: - Face-name associations - Spaced Retrieval - Cognitive Stimulation 30 mins/dy, 6 dys/wk 1 hr clinic visit	RCT Intervention vs. placebo ANOVA (2x2)
Koltai, Welsh-Bohmer & Schmechel, 2001	Early stage dementia MMSE 22-26	24	<u>Memory and Coping Group:</u> spaced retrieval, face-name recall strategy, verbal elaboration, concentration/overt repetition, external aids, coping strategies. <u>Individual:</u> 6 x 1 hour sessions	RCT (individual, group, waiting list) Pre / post test design Mann-Whitney U Test

APPENDIX II – Summary of studies included in literature review

Study	Diagnosis	Sample	Intervention	Study Design
Moore <i>et al.</i> , 2001	Alzheimer's Disease	25 patients & their carers	5-week Memory training group for patients & carers - psychoeducation - name-face rehearsal - effortful recall - significant event technique - carer support intervention	Pre and post measures plus 1 month follow-up Care-givers as controls
Bourgeois <i>et al.</i> , 2003	Mild to moderate dementia (MMSE 9-21)	25	Spaced retrieval vs Cueing hierarchy in mastering 25 goals such as using memory aids.	Comparison of techniques. Counterbalanced within and across participants.
Abrisqueta-Gomez <i>et al.</i> , 2004	Early stage Dementia (MMSE 20-26)	3	Individualised cognitive training programme using errorless learning. Twice weekly sessions (1 group, 1 individual) Monthly group meetings for families/carers.	Baseline and after 1 and 2 years intervention
Cherry & Simmons-D'Gerolamo, 2005	Alzheimer's Disease Mild to moderate MMSE 15-22	10 (5 trained, 5 new)	Spaced retrieval - Picking target object from an array of everyday objects. Target object orientation task (TOOT) 9 1hr sessions across 3 weeks.	Exp: 6-11mth follow-up Ctrl: New - Matching by MMSE TOOT – 2 new, 2 old Within participants past vs present Across participants retest vs controls

APPENDIX II – Summary of studies included in literature review

Study	Diagnosis	Sample	Intervention	Study Design
Hochhalter <i>et al.</i> , 2005	Alzheimer's Disease Mild to moderate. (MMSE 6-23)	10 in Ex 1 4 in Exp 2	<u>Experiment 1:</u> Picture/name association for pills using free verbal recall. 4-7 sessions/wk <u>Experiment 2:</u> Connecting dots in pattern.	Within participants Spaced retrieval first then counterbalanced for expanding rehearsal, random rehearsal, uniform massed rehearsal & uniform distributed rehearsal.
Metzler-Baddeley & Snowden, 2005	Alzheimer's Disease Minimal to moderate (MMSE 11-26)	4	Errorless vs. errorful learning. Re-learning vs. novel learning Training in 8 sessions mostly on consecutive days.	Within participants 1 set of new & old info for each of EL & EF. Comparison - baseline & post training.
Haslam <i>et al.</i> , 2006	Dementia	7	Errorless vs. errorful learning Varying levels of knowledge specificity. 2 sessions over 2 weeks	Repeated measures ANOVA
Arkin, 2007	Early-stage probable Alzheimer's Disease	24 clients vs. 245 database controls.	Language enriched programme – 10 week block per semester <u>Cognitive stimulation:</u> 1 session/week Involving 14 tasks to practise attention, explicit memory, judgement and reasoning, planning, problem solving, set-shifting, abstract reasoning and semantic memory. <u>Community Activity:</u> 1 session/week <u>Exercise:</u> 2 sessions/week	Pre and post intervention t-test scores for individuals who had completed 1, 2, 3 and 4 years of the programme. Compared with untreated AD patients tracked through CERAD study using mixed ANOVA

APPENDIX II – Summary of studies included in literature review

Table E2: Neuropsychological interventions – cognitive rehabilitation

Study	Diagnosis	Sample	Intervention	Study Design
Clare <i>et al.</i> 2000	Early stage dementia Alzheimer's (MMSE 21-26)	6	Errorless learning - expanding rehearsal, mnemonics, vanishing cues or forward cueing. Individually tailored. Aimed at specific everyday memory problem.	Multiple single-case experimental design Pre, post & 6 month follow-up. Multiple baseline or ABA designs
Clare <i>et al.</i> 2001	Early stage dementia (Alzheimer's) MMSE 22-26	1	Errorless learning– 11 names of members of his social club Using photographs and during visits to the social club	Single case study Stages: - initial intervention - 9 month follow up - daily practising - 1 st yr weekly tests - real life practice - 2 nd yr monthly tests
Bird, 2001 (same case as Bird 1998)	Early dementia MMSE = 19	1	Spaced retrieval Fading cues 90 min training session then follow up at 30 min, 1 and 4 hrs. Staff then reminded her using faded cues after this.	Single case experimental design

APPENDIX II – Summary of studies included in literature review

Study	Diagnosis	Sample	Intervention	Study Design
Clare <i>et al.</i> , 2002	Early stage dementia (Alzheimer's) MMSE>18	12	Errorless learning – mnemonic, vanishing cues, expanding rehearsal (spaced retrieval) Face-name associations using photographs Baseline = 4 sessions Intervention = 6 sessions Post = 3 sessions Follow up=1,3,6 &12 mnths	Controlled Trial – pre, post & 12 month follow-up Control = recall on untrained items.
Cuncliffe <i>et al.</i> (2005)	Early stage dementia MMSE >= 18	26 intervention 21 Control	Cognitive Rehabilitation Group Weekly for 7 weeks 1 1/2 hour sessions Client & carer attended	Controlled Study (Intervention vs Usual care) Formal evaluation (Baseline and follow up)

APPENDIX II – Summary of studies included in literature review

Table E3: Neuropsychological interventions – literature reviews

Study	Diagnosis	Sample	Intervention	Study Design
Scott & Clare (2003)	All stages of dementia.	1 study 5 studies	<u>Cognitive Stimulation</u> <u>Memory training</u> Including Koltai <i>et al.</i> 2001	Literature review of group based psychological interventions
Grandmaison & Simard, 2003	Mild to moderate Alzheimer's Only	18 studies	Cognitive interventions for enhancing memory function: visual imagery, errorless learning, spaced retrieval, external memory aids, dyadic training	Literature review (to 2001)
Clare <i>et al.</i> , 2003	Early-stage Dementia (Alzheimer's & Vascular)	6 Studies 7 studies	<u>Cognitive training</u> Including Davis, 2001 Koltai 2001 & Quayhagen & Quayhagen <u>Cognitive rehabilitation</u> Including Clare, 1999, 2000, 2001, 2002	Cochrane Systematic Review of Randomized Controlled Trials. Meta analysis for effect sizes Review of single-case and controlled studies
Clare & Woods, 2004	Early-stage Alzheimer's	Literature Review. Same as Cochrane Review above.		

APPENDIX II – Summary of studies included in literature review

Table E4: Psychotherapeutic interventions – support groups

Study	Diagnosis	Sample	Intervention	Study Design
Yale (1995)	Early Stage Dementia MMSE 18 to 24	13	Support Group 8 weekly sessions 1 1/2 hour duration	Pre, post and 2 month follow up Intervention vs. Control Group
Marshall, Bocks & Mander (2005)	Early-stage dementia MMSE 22-29	8	Support Group Weekly 1 1/4 hour sessions	Multi-method evaluation: pre-group and at weeks 8 and 20 of intervention
Mason, Clare & Pistrang (2005)	Early-stage dementia MMSE >=18	11	Support Groups x 2 Weekly 1-hour sessions Open-ended (Mean 9 & 15 wks)	IPA Behavioural Interaction & Coding
Pratt, Clare & Aggarwal, 2005	Early-stage dementia	Not reported	“Talking about memory coffee group” A user-led support group – maintain / support changes to sense of self Open membership	Innovations in practice report
Bird <i>et al.</i> (2004) in NICE Full Guideline (2006)	Early Stage Dementia	84	‘Living with Memory Loss Project’ run by Alzheimer’s Association 6-8 weekly sessions 2-hour duration Clients and carers	Service Evaluation
Zarit <i>et al.</i> (2004) in NICE Full Guideline (2006)	Early Stage Dementia	Not reported	‘Memory Club’ 10 weekly sessions Clients and Carers	Service Evaluation
Snyder, Jenkins & Joosten, 2007	Early-stage Alzheimer’s	70	8 support groups (across USA) Weekly, bimonthly or monthly	Questionnaire based survey - orally administered.

APPENDIX II – Summary of studies included in literature review

Table E5: Psychotherapeutic interventions – supportive psychotherapy groups

Study	Diagnosis	Sample	Intervention	Study Design
Cheston (1996)	Early-stage dementia MMSE \geq 18	2 clients (1M 1F)	Psychotherapy Group Weekly 1 1/4 hour sessions 8-weeks duration	Social constructionist / Narrative Analysis
Cheston, Jones & Gilliard (2003)	Early-stage dementia MMSE \geq 18	19 Clients	Psychotherapy Groups x 6 Weekly 1 1/4 hour sessions 10-weeks duration	Psychotherapy outcome: baseline, pre-group, post-group and follow up.
Cheston, Jones & Gilliard (2004)	Early-stage dementia MMSE \geq 18	1 client (M)	Psychotherapy Group Weekly 1 1/4 hour sessions 10-weeks duration	Case study
Watkins, Cheston, Jones & Gilliard (2006)	Early-stage dementia MMSE \geq 18	1 client (M)	Psychotherapy Group Weekly 1 1/4 hour sessions 10-weeks duration	Case study

Table E6: Psychotherapeutic interventions – individual psychotherapy

Study	Diagnosis	Sample	Intervention	Study Design
Scholey & Woods, 2003	Early stage Dementia & Depression MMSE 20-30	7 patients	8 sessions of Cognitive Therapy	Pre – post study

APPENDIX II – Summary of studies included in literature review

Table E7: Psychotherapeutic interventions – literature reviews

Study	Diagnosis	Sample	Intervention	Study Design
Cheston, 1998	Dementia All stages	19 studies	Group psychotherapy	Narrative literature review
		9 studies	Individual psychotherapy: Eclectic, CBT, psychodynamic & person-centred.	
Scott & Clare (2003)	All stages of dementia part. Mod to severe	4 studies	Validation therapy	Narrative literature review
		1 study	Group psychotherapy	
		1 study	Group CBT	
		3 studies	Support groups	
Heason, 2005	Dementia All stages	Literature review – Narrative overview of approaches.		

APPENDIX III – Information sheets & consent forms

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PARTICIPANT INFORMATION SHEET - CLIENT

PART 1:

Memory Problems and Rehabilitation: The Experience of Older Adults

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Please take time to read the following information carefully and ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

The memory rehabilitation programme for older people and their carers at the (CMHT), is a relatively new service. When we provide new services we need to know whether they are useful or not so that we can make sure that we are giving people good quality care. We are studying the experiences of people who attend the memory rehabilitation programme in order to build a picture of what it is like to live with a memory problem. It is really important for us to hear your perspective, as someone who has a memory problem and has attended the programme, in order to find out what you thought of it and the impact it had on you. One of the researchers is conducting the study as part of her training to become a Clinical Psychologist.

Why have I been invited to participate?

You have been invited to participate because you have a memory problem and are due to attend the memory rehabilitation programme in the coming months. If you agree to take part your carer will also be invited to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide not to take part, or withdraw at any point, it will not affect your current or future care and you will still be able to attend the memory rehabilitation programme. If you decide not to take part your carer will not be invited to take part in your absence and if you withdraw, their data will also be withdrawn.

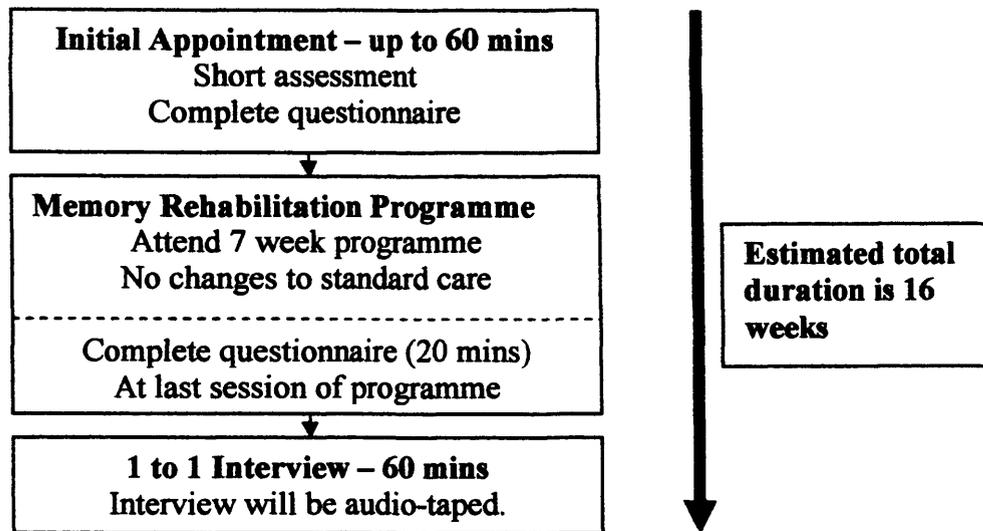
What will be happen to me if I take part?

If you chose to take part in the study you will be given this information sheet to keep and will be asked to sign a consent form. Participation will involve an initial appointment with the researcher, the completion of a questionnaire at the end of the memory rehabilitation programme and a 1 to 1 interview with the researcher to discuss the experience of attending the memory rehabilitation programme.

APPENDIX III – Information sheets & consent forms

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There is the option of breaking down the interview into two parts if you feel it will be too lengthy for you to manage. The flow chart below outlines what will happen when:



What do I have to do?

With the exception of attending the memory rehabilitation programme and meeting with the researcher as outlined above you will not be required to change your normal activities. No medication or physical treatment is involved in the group or as part of the research.

Will I receive out of pocket expenses for taking part in the study?

Travel expenses will be reimbursed, or travel arrangements will be made, for participants wishing to be interviewed at the (*CMHT base*) rather than at home.

What are the possible disadvantages and risks of taking part?

It is possible that individuals may find it uncomfortable to discuss their current problems. Assessment visits will be conducted under the supervision of a qualified Clinical Psychologist and every effort will be taken to ensure that emotional discomfort or distress is minimal.

What are the possible benefits of taking part?

It is hoped that by participating in this research you will help us to build a picture of what it is like to live with a memory problem and to establish what impact attending the memory rehabilitation group can have.

What if something goes wrong?

If you have any complaints regarding your experience of the study then these will be addressed. The details are included in Part 2.

Will my taking part in this study be kept confidential?

Yes, all the information about your participation in this study will be kept confidential. The details are included in Part 2.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

APPENDIX III – Information sheets & consent forms

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PART 2:

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (*Telephone number*). If you remain unhappy you may wish to involve the Patient Advisory Liaison Service (*Telephone number*) or a formal complaint can be addressed to: (*Address and telephone number of NHS Trust complaints department*).

Will my taking part in this study be kept confidential?

Limited information will be gathered from your medical notes at the memory clinic for the purposes of the study and only the researchers will have access to this. Any information that leaves the clinic will have your name and address removed so that you can not be recognised from it. All information will be stored securely and kept strictly confidential. The audiotape of the interview will be transcribed by the researcher and no-one else will get to hear it. Anonymous excerpts from the transcripts may be used to illustrate the results of the study but no individual will be identifiable from this. Your GP will be informed that you are taking part in the study but not of what you share.

What will happen to the results of the research study?

It is planned that the results from this research will be published. It will take approximately 3 years from the start of the study before they are published. If you wish to receive a copy of these results then please ask.

Who is organising and funding the research?

This study is not being funded or organised by any external body.

Who has reviewed the study?

The Local Research Ethics Committee has reviewed and approved this study. A Local Research Ethics Committee (LREC) is a body appointed by the Strategic Health Authority. It consists of a number of members both medical and non-medical who review proposed research within the health district. Their role is to consider the ethical merits of any research, that is to say, a view is taken as to whether the potential advantages of the proposed research, outweigh significant risk to which the participants may be exposed. Research projects are not undertaken unless LREC approval has been gained.

For further information please contact: (*Contact details of researcher*).

APPENDIX III – Information sheets & consent forms

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PARTICIPANT INFORMATION SHEET - CARER

PART 1:

Memory Problems and Rehabilitation: The Experience of Older Adults

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Please take time to read the following information carefully and ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

The memory rehabilitation programme for older people and their carers at the (CMHT), is a relatively new service. When we provide new services we need to know whether they are useful or not so that we can make sure that we are giving people good quality care. We are studying the experiences of people who attend the memory rehabilitation programme in order to build a picture of what it is like to live with a memory problem. As well as hearing from the person with the memory problem themselves, it is really useful for us to hear your perspective, as someone who cares for and lives with someone with a memory problem and who has attended the programme with them. It will help us to know what you thought of the programme and the impact you think it has had on both you and the person you care for. One of the researchers (Emma Dale) is conducting the study as part of her training to become a Clinical Psychologist.

Why have I been invited to participate?

You have been invited to participate because you live with and care for someone with a memory problem who has agreed to take part in the research.

Do I have to take part?

It is up to you to decide whether or not to take part but you can only take part if the person you care for has also agreed to take part. If you decide not to take part, or to withdraw at any time, it will not affect the current or future care of the person you care for and you will still be able to attend the memory rehabilitation programme.

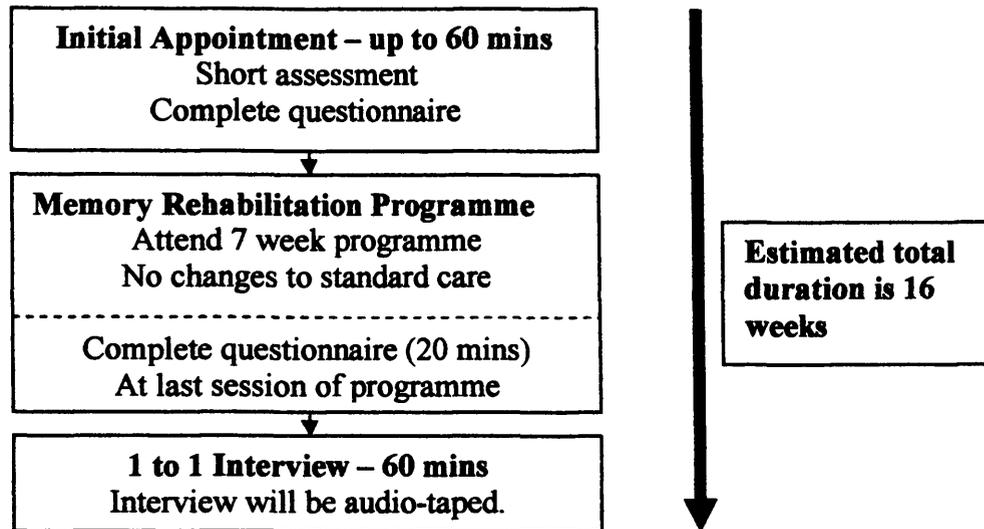
What will be happen to me if I take part?

If you chose to take part in the study you will be given this information sheet to keep and will be asked to sign a consent form. Participation will involve an initial appointment with the researcher, the completion of a questionnaire at the end of the memory rehabilitation programme and a 1 to 1 interview with the researcher to discuss the experience of attending the memory rehabilitation programme.

APPENDIX III – Information sheets & consent forms

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What are the possible benefits of taking part?

It is hoped that by participating in this research you will help us to build a picture of what it is like to live with someone who has a memory problem and to establish what impact attending the memory rehabilitation group together can have.

What if something goes wrong?

If you have any complaints regarding your experience of the study then these will be addressed. The details are included in Part 2.

Will my taking part in this study be kept confidential?

Yes, all the information about your participation in this study will be kept confidential. The details are included in Part 2.

This completes Part 1 of the Information Sheet. If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

APPENDIX III – Information sheets & consent forms

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PART 2:

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions (*Telephone number*). If you remain unhappy you may wish to involve the Patient Advisory Liaison Service (*Telephone number*) or a formal complaint can be addressed to: (*Address and telephone number of NHS Trust complaints department*).

Will my taking part in this study be kept confidential?

All information will be stored securely and kept strictly confidential. Any information that leaves the clinic will have your name and address removed so that you can not be recognised from it. The audiotape of the interview will be transcribed by the researcher and no-one else will get to hear it. Anonymous excerpts from the transcripts may be used to illustrate the results of the study but no individual will be identifiable from this. Your GP will be informed that you are taking part in the study but not of what you share.

What will happen to the results of the research study?

It is planned that the results from this research will be published. It will take approximately 3 years from the start of the study before they are published. If you wish to receive a copy of these results then please ask.

Who is organising and funding the research?

This study is not being funded or organised by any external body.

Who has reviewed the study?

The Local Research Ethics Committee has reviewed and approved this study. A Local Research Ethics Committee (LREC) is a body appointed by the Strategic Health Authority. It consists of a number of members both medical and non-medical who review proposed research within the health district. Their role is to consider the ethical merits of any research, that is to say, a view is taken as to whether the potential advantages of the proposed research, outweigh significant risk to which the participants may be exposed. Research projects are not undertaken unless LREC approval has been gained.

For further information please contact: (*Contact details for researcher*).

APPENDIX III – Information sheets & consent forms

PRINTED ON HEADED PAPER OF HOST TRUST

Study Number:

Patient Identification Number:

CONSENT FORM - CLIENT

Title of Study:

Memory Problems and Rehabilitation: The Experience of Older Adults

Researchers:

Please tick each box:

1. I confirm that I have read and understand the information sheet dated 16.09.06 (version 4) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that if I decide not to take part, to withdraw at any time, without giving any reason, I may do so without my medical care and legal rights being affected.
3. I understand that sections of any of my medical notes may be looked at by the researcher and research team where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
4. I give permission for the interview to be audio-taped and transcribed by the researcher. I understand that all information that could be used to identify me will be removed and that anonymous, verbatim quotes may be used to illustrate the results of the study.
5. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

1 copy for participant; 1 for researcher; 1 to be kept with medical notes

APPENDIX III – Information sheets & consent forms

PRINTED ON HEADED PAPER OF HOST TRUST

Study Number:

Patient Identification Number:

CONSENT FORM - CARER

Title of Study:

Memory Problems and Rehabilitation: The Experience of Older Adults

Researchers:

Please tick each box:

1. I confirm that I have read and understand the information sheet dated 16.09.06 (version 1) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that if I decide not to take part, to withdraw at any time, without giving any reason, I may do so without my medical care and legal rights being affected.
3. I give permission for the interview to be audio-taped and transcribed by the researcher. I understand that all information that could be used to identify me will be removed and that anonymous, verbatim quotes may be used to illustrate the results of the study.
4. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

1 copy for participant; 1 for researcher; 1 to be kept with medical notes

APPENDIX IV – Ethical and research governance approval documents



North Nottinghamshire Local Research Ethics Committee

1 Standard Court
Park Row
Nottingham
NG1 6GN

Telephone: 01159123344
Facsimile: 01159123300

03 November 2006

Ms Emma Dale
Trainee Clinical Psychologist
University of Leicester
Clinical Psychology
104 Regent Road
Leicester, LE1 7LT

Dear Ms Dale,

Full title of study: **Developing a memory problem later in life and attending a memory rehabilitation programme: a qualitative study using grounded theory strategies and repertory grids.**

REC reference number: **06/Q2402/69**

Thank you for your letter of 16 September 2006, responding to the Committee's request for information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		04 August 2006
Investigator CV		01 August 2006
Protocol	4	01 August 2006

Summary/Synopsis	2	03 August 2006
Letter from Sponsor		02 August 2006
Peer Review		22 June 2006
Interview Schedules/Topic Guides	1	30 May 2006
Participant Information Sheet: Client	4	16 September 2006
Participant Information Sheet: Carer	1	16 September 2006
Participant Consent Form: Client	4	16 September 2006
Participant Consent Form: Carer	1	16 September 2006
Response to Request for Further Information		16 September 2006
RMO/GP Letter	3	03 August 2006
Repertory Grid	1	30 May 2006
CV - S Allan		01 August 2006
CV - D Connelly		01 August 2006

Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q2402/69

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Dr David Walsh
Chair

Email: trish.wheat@rushcliffe-pct.nhs.uk

Enclosures: Standard approval conditions

Copy to: Dave Clarke
Leicestershire Partnership NHS Trust

R&D Department for NHS care organisation at lead site - NHCT

E-mail: shirley.mitchell@nottshc.nhs.uk

Research & Development
Duncan Macmillan House
Porchester Road
Mapperley
Nottingham
NG3 6AA

Tel: 0115 969 1300
Fax: 0115 993 4549

Our Ref: AMH/13/11/06

14 November 2006

Ms Emma Dale
Trainee Clinical Psychologist
University of Leicester
Clinical Psychology
104 Regent Road
Leicester
LE1 7LT

Dear Ms Dale

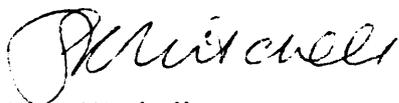
Developing a memory problem later in life and attending a memory rehabilitation programme: a qualitative study using grounded theory strategies and repertory grids

I am writing to confirm that the above study is authorised to take place within our Trust.

This is a very interesting and important field of study. The Trust R&D Department follows up such work to assess its impact and influence on practice and policy. All research registered with the R&D Department is automatically included in the National Research Register (www.update-software.com/national/) and information on all projects is updated quarterly. Therefore, I have enclosed the National Research Register Information Sheet for your completion.

Please note that you cannot commence your research without a Trust honorary contract in place.

Yours sincerely



Shirley Mitchell
Research Governance Lead & Business Manager

Enc

Research & Development Office
Daisy Peake Building
Towers Hospital
Gipsy Lane
Leicester
Tel: 0116-225-3743
Fax: 0116-246-3591
David.Clarke@leicspart.nhs.uk

DC/EJD/69

20 November 2006

Ms Emma Dale
C/o University of Leicester
Clinical Psychology
104 Regent Road
Leicester
LE1 7LT

Dear Emma

Re: Developing a memory problem in later life and attending a memory rehabilitation programme: a qualitative study using grounded theory strategies and repertory grids

I have now received confirmation of a favourable opinion (3rd November 2006) from the North Nottinghamshire Local Research Ethics Committee in respect of the above study.

Under the Research Governance Policy of the Trust, confirmation of appropriate ethical approval is a necessary prerequisite for obtaining Trust Management Approval. I am happy to confirm therefore that Leicestershire Partnership NHS Trust formally approves the study to proceed, subject to the following conditions:

- You abide by the conditions imposed by the REC
- All correspondence with the REC is routed through the Trust Research Office (including the obligatory progress/final report as detailed).
- The agreed protocol is adhered to.
- A summary of any findings is reported to the Trust/Clinical Service/Participants at the conclusion of the study.
- Any changes in the protocol, timescale etc. are notified to the R&D Office
- At the conclusion of the study, a final report form is completed.
- A copy of any subsequent publication is lodged with the Trust.
- That paperwork related to the study may be subject to audit at any time (this requires maintenance of a site file).

This letter also serves as confirmation that as Principal Investigator you are covered by the terms of the Trust's research indemnity for the duration of the project. Please sign and return the attached confirmation sheet without which Trust approval will be rescinded.

With my best wishes on the success of your study.

Regards,



Dr. Dave Clarke
Associate Director (R&D)

Dale, E.J.

From: Colman, Prof A.M. [amc@leicester.ac.uk] **Sent:** Fri 04/05/2007 17:17
To: ejd18@leicester.ac.uk
Cc:
Subject: RE: PC_ethics2006 - Emma Dale
Attachments:

Dear Emma

Your project (Developing a memory problem later in life and attending a memory rehabilitation programme: a qualitative study using grounded theory strategies) has been approved by the Psychology Research Ethics Committee.

This e-mail is the official document of ethical approval and should be printed out and kept for your records or attached to the research report if required - this includes all undergraduate and postgraduate research.

We wish you every success with your study.

Andrew M. Colman
Psychology Research Ethics Committee Chair

-----Original Message-----

From: www-data [mailto:webserver-admin@leicester.ac.uk]
Sent: 04 May 2007 09:21
To: amc@leicester.ac.uk
Subject: PC_ethics2006 - Emma Dale

Proposer: PC_ethics2006 - Emma Dale
email: ejd18@le.ac.uk
status: 3rd Year DCLinPsy
supervisor: Dr Steve Allan
title: Developing a memory problem later in life and attending a memory rehabilitation programme: a qualitative study using grounded theory strategies
date: 04/05/07
preapproval: LMRC
describe:
telvoluntary:
obtainwrittenconsent:
observe:
maywithdraw:
allowomit:
telconfidential:
debrief:

mislead:
distress:
animals:
kids:
sen:
patients:
custody:
criminals:

route:

routeAdesc:

routeBdesc:
RouteBsupp:

APPENDIX V – Interview schedules

Initial interview schedule

Opening question:

1. Can you tell me about how you came to be in the memory group?

Developing the memory problem:

2. When did you first notice the memory problem?

Prompts if needed:

- What was it like?
- What did you think then?
- Who, if anyone, did you talk to about it?
- At what point was the decision made to get it checked out?
- What happened? What happened next?

Living with the memory problem:

3. Tell me what it's like to live with a memory problem (or with someone who has a memory problem).

Prompts if needed:

- How have you learned to handle this?
- What makes for a good day?
- What makes for a bad day?

Impact of the memory problem:

4. What impact do you think the memory problem has had on your life?

Memory rehabilitation group:

5. What has been your experience of attending the memory rehabilitation group?

6. Looking back over your time in the group, what do you think has been most important for you?

7. What have you taken from the group?

Prompts if needed:

- Have you made any changes? If so what?
- Have you tried any of the strategies? How did this go?
- Are you still in contact with anyone from the group?

Ending questions:

8. Is there anything else you think I should know to understand your experience better?

9. Is there anything you would like to ask me?

APPENDIX V – Interview schedules

Interview schedule – First revision

Opening question:

1. Can you tell me about how you came to be in the memory group?

Developing the memory problem:

2. When did you first notice the memory problem?

Prompts if needed:

- What was it like?
- What did you think then?
- Who, if anyone, did you talk to about it?
- At what point was the decision made to get it checked out?
- What happened? What happened next?

Living with the memory problem:

3. Tell me what it's like to live with a memory problem (or with someone who has a memory problem).

Prompts if needed:

- How have you learned to handle this?
- What makes for a good day?
- What makes for a bad day?

Impact of the memory problem:

4. What impact do you think the memory problem has had on your life?

5. What social impact have you noticed?

Prompts if needed:

- When speaking in public or socialising?
- Stigma?

6. What impact has it had on your relationship?

Prompts if needed:

- Attending appointments together?
- Support with memory?

Memory rehabilitation group:

7. What has been your experience of attending the memory rehabilitation group?

8. Looking back over your time in the group, what do you think has been most important?

9. What have you taken from the group?

Prompts if needed:

- Have you made any changes? If so what?
- Have you tried any of the strategies? How did this go?
- Are you still in contact with anyone from the group?

Ending questions:

10. What has it been like to tell me about your memory problems?

11. Is there anything else you think I should know to understand your experience better?

12. Is there anything you would like to ask me?

APPENDIX V – Interview schedules

Interview schedule – second revision

Opening question:

1. Can you tell me how you came to be in the memory group?

Memory group:

2. What has been your experience of attending the memory group?
3. Looking back over your time in the group, what do you think has been most important for you?

Prompts if needed:

- Social aspects
- Particular strategies

Social impact:

4. What was it like meeting other people in a similar position?
5. Other people have said it was really important to them to attend the group with their partner, what do you think about this?

Prompts if needed:

- Helping to remember what happens?
- Socialising as a couple?
- Implementing strategies?

6. What has been the social impact of the memory problems on you as an individual, as a couple, etc.?

Memory problems:

7. Other people have said that they feel quite self-conscious about their memory problems when in social situations, what do you think about this?

Prompts if needed:

- How does it feel talking to me about them?
- Fearing others' perceptions and reactions?
- Feeling there is a stigma attached to dementia or Alzheimer's
- Monitoring own memory? Being monitored?

8. What helps you to cope with your memory problem on a daily basis? OR
9. In what way do you support your partner to manage their memory problems on a daily basis?

Prompts if needed:

- What happens if you notice they forget something?
- Attending appointments together or separately?
- Impact on daily life?
- What is not helpful?

10. What do you feel about the future?
11. Is there anything else you'd like to tell me or to ask me?

APPENDIX VII – Additional illustrative quotes

Within the main body of the research report, quotes were chosen to tell the narrative of the model. Within this appendix, additional quotes will be given to show that the categories and themes apply across the full range of interviews.

1. Noticing Changes: Remembering & Forgetting

The following extract illustrates the changes Mr B noticed in his memory:

I ... what was it that brought you to your GP in the first place? What had you noticed that was different?

Mr B (*Sigh*)....(*Pause*) I don't know what it was actually (*pause*) I know er...I was... er...questioning about short memory loss...

I ... So when did you first notice that?

Mr B (*pause*) Oh...ah...I can't remember (*laughs*)

I Ok... yeah.

Mr B I'd say about 3 year ago?...must be about 3 year ago."

Mr B (Carer) Interview 3: 27-32; 41-48

Similarly, Mrs C describes the changes she noticed in her memory:

I ... can you remember how you came to be in the memory group?

Mrs C Not really no.

I No? Can you remember the kind of problems that you were having? Sort of...

Mrs C Ah, just forgetting things and so, yes. Uh-hmm."

Mrs C (Client) Interview 5: 5-13

Her husband gives a fuller picture of her difficulties, including the difficulty forgetting traumatic memories:

"Yeah er it came up. It came up yesterday it was one of the questions and I said, yes, your memories are, your long memory is pretty good it goes right back. But they are bad memories. It would be nice if you could leave them behind and move on."

Mr C (Carer) Interview 6: 751-755

In the next extract, Mrs D clarifies that it was her husband who first noticed problems in memory:

"It's a long story really. Originally (*husband*) decided he was...that he had problems with his memory..."

Mrs D (Carer) Interview 7: 9-11

APPENDIX VII – Additional illustrative quotes

2. Impact of changes

2.1 Emotional impact: loss

Mr D was not sure if his losses were permanent:

“But, nevertheless, I used to have a good memory. I mean I’m ta..I could recite half an hour lectures and this sort of thing, straight through without the slightest trouble. Now, it’s gone. Or has it?”

Mr D (Client) Interview 8: 61-65

Mr C described how his wife had lost a friend because of how this friend reacted to her memory problems:

“(Repeats name of friend). We went there once, we don’t go there, because you’ve fallen out for some reason. Let’s be honest, that’s the truth of it, isn’t it?...(...)... She got cross ...”

Mr C (Carer) Interview 6: 1041-1043, 1077

2.2 Emotional Impact: Anger and frustration

Mr A expressed his anger about what he has lost:

“What’s annoyed me is I’m losing all erm I’m losing all the things that I knew in the past.”

Mr A (Client) Interview 1: 135

Mr B expressed his anger at the mistreatment of him and his fellow patients when he was admitted to hospital:

“...I lost my temper with that; it was disgusting...*(following an episode of incontinence)*...I lay there and I couldn’t stand it any more and I got up *(pause)* took the sheets of *(pause)* and I didn’t get any sheets until midday *(pause)* they brought sheets, to change them, but they didn’t put them on the bed *(pause)* they didn’t put them on the bed until I got upset again so I just put the clean sheets in myself and lay on the bed until four o’clock in the afternoon.”

Mr B (Client) Interview 3: 334, 368-374

Mr D talks about the changes he has noticed in his frustration levels:

“It’s getting less frustrating. It was very frustrating. It still irritates at times but not to the same extent. “

Mr D (Client) Interview 8: 308-310

The need for patience is emphasised by Mr C:

“I’ve got patience because er *(daughter)* has told me she’s glad I’m patient because it does get a bit er trying sometimes because I’m er trying to keep things going, as well as I can.”

Mr C (Carer) Interview 6: 113-115

Mrs D expressed her frustration that her husband will not let her help him:

“Another thing I find, he can’t take advice. He won’t take advice. And you can’t help him. He won’t be helped. Under any circumstances, you can’t help him, which is difficult.”

Mrs D (Carer) Interview 7: 108-111

APPENDIX VII – Additional illustrative quotes

2.3 Social impact

Mr A outlines how his memory problems have impacted on his social life:

“Yes. Yes it has an impact on my daily life because if I were to get into conversation with people and I find it sometimes I’ve been talking and (*wife*) even (*wife*) has been near me and I’ve blocked it all together because I can’t find... I start something and I can’t carry on with it and I I feel embarrassed. I feel embarrassed about that.”

Mr A (Client) Interview 1: 200-206

For Mr and Mrs D, the changes were that they socialised together less:

“... we don't usually socialise together. We socialise separately more regularly now.”

Mrs D (Carer) Interview 7: 235-236

The fear of being seen as mad was expressed by Mr and Mrs C:

I So, some people don't like using the word dementia, do you...

Mr C I know. Yeah

I What why do you think that might be that people find it hard to...

Mr C Because I think I think they think its all, oh dear, something er going...

Mrs C Going crazy.

Mr C Crazy. Yeah. Mental.”

Mr and Mrs C Interview 6: 1006-1019

Although Mr D was aware that there may be a stigma attached to having memory problems, he had not directly experienced it himself:

“So far I've been lucky, put it this way. I've heard of people say that they've been upset by people coming in and not understanding what they were trying to do. That hasn't hit me yet. I don't want it to either but anyway, there's nothing I can do about it.”

Mr D (Client) Interview 8: 577-581

APPENDIX VII – Additional illustrative quotes

3. Preserving the shared memory

The drive to preserve was explained by Mr D:

“I think I’ve been picked I was picked up in the early stages and this is all helping to slow it down or to, whatever it does. But it works.”

Mr D (Client) Interview 8: 287-289

3.1 Compensating

Using memory aids was the main compensatory strategy. Mrs C described how she used a calendar:

“...very often you put it straight on the calendar so we know I just check, “Oh, I’ve got to go then.”

Mrs C (Client) Interview 5: 142-143

Mr A also used a calendar but sometimes he found it confusing:

“Yes, I look at it to see when appointments are. There’s little else to put down. I don’t go there looking about I’ve done that today or done this today. Trivial things. I mean, triviality gets you down sometimes. You’re putting putting everything down and it’s crowding the calendar up and you can’t read it.”

Mr A (Client) Interview 1: 434-438

In addition to a calendar, Mr D carried a notebook:

“ (*Wife*) gives me a lot of help on that way or I jot things down. I’ve started carrying a little book round ... in my pocket...”

Mr D (Client) Interview 8: 858-859

3.2 Practising remembering

For Mr and Mrs C, practising remembering together was the main way they were trying to preserve memories. They outline how this works:

“Mrs C Very often you say, “Now just think.”

Mr C That’s right. I ask you first. Give you a chance. Like I did before (*mumbles*) =

Mrs C = and I say, “Oh there”, and then it comes. Yeah.”

Mr and Mrs C (Carer and client) Interview 6: 152-157

There were numerous example of this within the interview, some particularly poignant:

“Mr C Yeah. But now do you er agree with what I say (*to wife*). (*Daughter*) often says when we got married... What year did we get married?

APPENDIX VII – Additional illustrative quotes

Mrs C Pardon?

Mr C What year did we get married?

Mrs C (*Gives year*).

Mr C (*Confirms year*) and from then on my little saying has been it's all been onwards and upwards, hasn't it?

Mrs C Yes, definitely."

Mr and Mrs C (Carer and client) Interview 6: 759-772

3.3 Carer becoming a memory aid

Although he had a calendar, Mr D tended to ask his partner rather than look at his calendar. They joke that she is the calendar:

"I've got a calendar now. I've got a calendar upstairs and (*wife*) has a calendar, she's always she has to have a calendar. She's the calendar girl (*laughs*)..."

Mr A (Client) Interview 1: 428-430

Within his interview, Mr A repeatedly looked to his wife for confirmation that what he was saying was accurate, particularly at the beginning before he had built up his confidence. In a different situation she would have probably stepped in to answer the questions:

"I What happened to you for you to get into the memory group?

Mr. A Er, I think it was introduced to me by ... it wasn't was it you (*speaking to his wife*).

Mrs A = Well I'm not supposed to be answering here am I

Mr A = I didn't know anything about it otherwise

I No

Mr A It's vague now about how...

I That's OK. Yeah.

Mr A ... how I got introduced into it.

I Uh huh.

Mr A but er I remember oh I know yes Dr. (*GP*) Dr. (*GP*) pointed it out er to er did he point it out to you or to ... (*speaking to wife*)

I So so one of the doctors pointed it out to you and (*wife*) that it might be something ...

Mr A Yes it originated from Dr. (*GP*)."

Mr A (Client) Interview 1: 8-32

APPENDIX VII – Additional illustrative quotes

A similar thing happened in Mr B's interview but his wife stepped in:

“Mr B I suffer from *(pause)* *(appears to be searching for the right word)*

Mrs B Continence

Mr B Incontinence *(pause)* and I did tell them that, in the hospital.”

Mr and Mrs B (Client and carer) Interview 3: 355-360

Mr D also called on his wife when he could not remember something:

“I So what is it, where do you go across there?”

Mr D *(To wife)* What's the name of it?

Mrs D *(Gives name of social centre)*.

Mr D *(Repeats name)*.”

Mr and Mrs D (Client and carer) Interview 8: 503-519

APPENDIX VII – Additional illustrative quotes

4. Emotionally adjusting

4.1 Questioning

Mrs D observed that her husband's memory appeared to be better when with other people but she could not understand why:

“Mrs D ... he says I confuse him if I speak to him or ask him questions. He says I confuse him...but last week we were away for a week at his sisters and he was perfectly alright. Nobody confused him there when they were talking to him so that's a strange situation.

I Have you got any theories as to why that is?

Mrs D No (*thoughtful tone*)...no...it just gets in my ne... it just...I just gets on his nerves I suppose... I don't know (*laughs*)...”

Mrs D (Carer) Interview 7: 212-225

4.2 Normalising

The interviewees often settled on age as a reason why their memory was failing:

“Yeah. I mean, at 83...you can't grumble can you?”

Mr B (Client) Interview 3: 67

Sometimes the picture was more confusing and age was considered to be only part of the equation:

“...I don't think everything can be blamed on the stroke. It probably has a bearing, and I think age has a little bit of bearing on it and must come into it but I don't know, because until the last few years (*husband*) was always quite an active man but the mobility has stopped him as well, so it it's all these things together.”

Mrs A (Carer) Interview 2: 413-419

One of the underlying fears driving the need to normalise could have been the sense of stigma associated with having memory problems. To counter this, there was a sense that it could happen to anyone:

“Mr C Exactly but no-one's... you see I can't bring words to mind sometimes... don't worry about it. We're not saying ooh, you know, “Why are you like this?” It's one of those things. Could be. Could be anyone.

I Could be me, yes.

Mr C It could. It could be anybody. That loses their... or gets loss of memory.”

Mr C (Carer) Interview 6: 932-940

4.3 Justifying

Mr A was worried that people would not believe that he really had problems:

APPENDIX VII – Additional illustrative quotes

“...But I can’t get people to understand how I feel. The people can’t understand it because they think I’m putting it on or something like that but you wouldn’t put things like that on would you?”

Mr A (Client) Interview 1: 228-236

Mr D believed he could improve his memory through practise but then had to justify why his memory had declined again:

“But as I say, it’s slipped away a bit now but that’s not surprising with me being away for a couple of weeks. “

Mr D (Client) Interview 8: 241-243

4.4 Accepting

The process of moving from a questioning to an accepting stance is outlined by Mrs C, as she described her initial reaction to being in the memory rehabilitation group:

“Mrs C They were, I thought, some were worse than others. So I thought, “what on earth am I doing here?”

I Right. So so what did that feel like?

Mrs C Then I said, “I’ll just make the most of it” and carried on with the conversation and so on. Yes.”

In a similar way, Mrs D described how she now just accepts that was how life was:

“I So there were some people that were worse than other people that were better?

Mrs D Yes...yes...

I So that must have been a bit hard...

Mrs D No, it wasn't hard really. You accept life. It's life isn't it. You accept what's what's going on around you.”

Mrs D (Carer) Interview 7: 125-133

APPENDIX VII – Additional illustrative quotes

5. Being supported

5.1 Family and friends

Maintaining regular contact with family was important for Mrs C:

I So do they do they come to see you often?

Mrs C Well (*son*) is a bit further away but (*daughter*) comes every Tuesday.

I Oh right.

Mrs C Yeah. And she has her dinner here and she works for a (*professional*). So she has a dinner visit at night time and she stays until about nine half-past-nine. Yeah.

I So that's good to see to have some regular contact.

Mrs C Yes. And (*son*) and his wife we go over there and they come over here."

Mrs C (Client) Interview 5: 409-428

It was Mr D's family that gave him the idea of brain training to improve his memory:

I So, whose idea was (*brain training*) then?

Mr D I don't know who...

Mrs D My daughter-in-law...

Mr D =daughter-in-law yes.

I = daughter-in-law.

Mrs D ...it was a Christmas present."

Mr and Mrs D (Client and carer) Interview 8: 181-190

Regular contact with friends was an important life-line for Mrs A:

"...I've still got a group of friends, some of us were at primary school together so you can say how far I'm going back, but we meet once a month and we have lunch...(...)... the purpose of us going is to meet each other and chat, keep up with everybody's news. So, there's that..."

Mrs A(Carer) Interview 2: 316-323

5.2 Services

The process of approaching services and being referred for support was outlined by Mrs A:

"So, I went to Dr (*GP*) and he said, well we need to see (*husband*). He needs to make an appointment to come in and that's when he told us about the (*CMHT*). So he said he would refer us there and that's how we came to be with (*CMHT*)...(...)... So it was probably on the second appointment that they put (*husband*) onto Aricept and we go for usually six monthly

APPENDIX VII – Additional illustrative quotes

appointments to Dr (*psychiatrist A*) clinic. And then we had the, did (*psychologist*) contact us, don't know whether it was by phone or letter or how it was, but anyway... (*psychologist*) was having this memory clinic and it was starting... it was starting at the end of 2004..."

Mrs A (Carer) Interview 2: 25-30, 69,76

5.3 Group – learning about strategies

Within the group, the facilitator offered ideas but also asked the group to share their ideas:

"And like (*husband*) said (*psychologist*) was going into different ways of trying to remember things and erm putting forward ideas and asking us to come up with ideas."

Mrs A (Carer) Interview 2: 102-105

This was also noted by Mrs B:

"And they asked, and like (*group facilitator*) asked you for your comments and things like that. What was asking the ones that was the patient..erm...what their opinions were (*pause*)."

Mrs B (Carer) Interview 4: 294-297

Remembering particularly strategies could be difficult for the client but Mr A still had some memories from the group even after a year:

I Can can what can you remember about going?

Mr A Well just general general things. I can't I can't remember details really.

I Well what what were the general things that you can remember.

Mr A Well, memory. Just losing things and how what to do ... things... things to do to stop... to guard against that sort of thing. Erm. You see I know here what I want to say but I can't find the words.

I It's OK. Take your time.

Mr A It was calendars. That's right. It was on the topic of calendars."

Mr A (Client) Interview 1: 349-363

5.4 Facilitating emotional adjustment

Learning about strategies was only part of what the participants took from the memory rehabilitation group:

"I enjoyed it. I looked on it as a social occasion. Erm, it was nice to go there... coffee and biscuits. Erm, and the other couple were very nice... (...)... I enjoyed it and I was sorry when it came to an end because it was a little outing, a social occasion, apart from learning things."

Mrs A (Carer) Interview 2139-141, 160-162

APPENDIX VII – Additional illustrative quotes

Meeting others in a similar role as yourself was also helpful:

“It was nice. It was nice to meet them, yes. But...er...to chat to them and...er...realise just what you were doing, as the carer, the other people in there were having to do the same kind of things. Yes it was very interesting.”

Mrs B (Carer) Interview 4: 321-325

Meeting others and sharing your past was important for Mrs C:

I Yeah. So what kind of conversations did you have with the others in the group?

Mrs C Oh well, mainly they used to ask me, “Oh, where were you born?” and so on and all that. Then they used to say, “Oh that must have been worse.” Then well like it was bad very bad, yes...

I ... what did you think was most was most useful about going to the group?

Mrs C (*sighs*) Well meeting different people and having conversations and so on...”

Mrs C (Client) Interview 5: 245-251, 299-303

Mr D summed up the importance of the group:

“...Now I think this is the secret; you are not on your own. And that’s one thing that I... has hit hard. You’re not on your own, there’s two other people there (*in the group*), there are people there and outside there must be an awful lot of other people the same.”

Mr D (Client) Interview 8: 269-273

APPENDIX VII – Additional illustrative quotes

6. Monitoring and comparing

6.1 Monitoring

Monitoring took many forms. Monitoring one's own progress:

“It gradually improved but it's not given me back anything that I've lost.

Mr A (Client) Interview 1: 185

Being formally monitored by a professional:

“Well...I was given test, you know,...used tests...and we carried on from there...
... Yeah...and my memory...you know..and..er..I think I got good marks in the end...because
I kept getting better each time we went there...Oh I think I would remember..I did boob
once.”

Mr B (Client) Interview 3: 12-13, 188-191

Monitoring partner for signs of improvement:

“Mrs B But he's nowhere near as bad as he used to be.

I Right

Mrs B No, nowhere near as bad.

I So it feels like things have got a bit better?

Mrs B Oh they've got a lot better (*pause*).”

Mrs B (Carer) Interview 4: 79-87

Monitoring partner for signs of deterioration:

“Mr C ... Oh well you must oh well that have you forgotten then?

Mrs C Hmmm?

Mr C Have you forgotten that?

Mrs C Forgotten, no.

Mr C I mean th-that's the truth...(....)

Mrs C Yeah. Can't remember that.”

Mr and Mrs C (Carer and client) Interview 6: 197-105, 211

Monitoring for signs of disease progression:

“I suppose it depends at what stage you're at I personally don't think (*husband*) is at a very
advanced stage.”

Mrs D (Carer) Interview 7: 267-269

APPENDIX VII – Additional illustrative quotes

6.2 Comparing

Alongside monitoring was the process of comparing oneself with how one used to be. On being given positive feedback within the interview, Mr A replied:

“Well I don’t know. It’s only because I’m bringing the way I’ve I used to be and trying to bring it to the front.”

Mr A (Client) Interview 1: 226-227

Carers also compared their partner’s to how they used to be:

“...But he was going about and happy to do things. Whereas not so much now”

Mrs A (Carer) Interview 2: 264-265

They also compared themselves to how they used to be:

“...at one time, when I was younger, I would go straight out shopping and that was it but now I write a list because I know for sure I'll come out of the...with something short if I don't.”

Mrs B (Carer) Interview 4: 216-219

Comparing the person with the memory problem to others in a similar position took place, particularly in the memory group:

I What was it like meeting other people who were having problems with their memory in the group?

Mrs C They were, I thought, some were worse than others...(...)... they were mainly elderly as well.

I ...So you were thinking their memory problems were a bit worse than yours?

Mrs C I think so, yes.”

Mrs C (Client) Interview 5: 199-202, 212, 218-220

In fact everyone seemed to think others were worse than themselves:

“... we could see some people were worse than others and some people had had this problem longer than others.

Mrs D (Carer) Interview 7: 115-117

Some conditions were seen to be worse than others as well:

“And er er my sister (*name*) she had er she had (*whispers*) Alzheimer’s, which is worse than that, isn’t it. She died of that some years ago. Yeah.”

Mr C (Carer) Interview 6: 1022-1025

APPENDIX VIII – Guidelines for conducting and writing-up qualitative research

The following two sets of guidelines (Elliot *et al.* 1999; Morrow, 2005) were used to guide the conducting and writing-up of this research thesis.

Evolving guidelines for publication of qualitative research - Elliot, Fisher & Rennie, 1999

Elliot *et al.* (1999) listed seven publishability criteria that applied to qualitative and quantitative research and seven that applied particularly to qualitative research. These are summarised below.

A Publishability guidelines shared by both qualitative and quantitative approaches

1. Explicit scientific context and purpose
2. Appropriate methods
3. Respect for participants
4. Specification of methods
5. Appropriate discussion
6. Clarity of presentation
7. Contribution to knowledge

B Publishability guidelines especially pertinent to qualitative research

1. Owing one's own perspective

- specify theoretical orientation
- specify personal anticipations
- disclosure of pertinent values and assumptions

2. Situating the sample

- describe the research participants and their life circumstances

3. Grounding in examples

- provide illustrative examples of data

4. Providing credibility checks

- respondent validation
- multiple analysts or additional analytic auditor
- comparing two or more varied qualitative perspectives
- triangulation with external factors or quantitative data

5. Coherence

- understanding fits together to form a narrative or framework or underlying structure for the phenomenon or domain

6. Accomplishing general vs. specific research tasks

- General – needs to be based on an appropriate range of instances
- Specific – studied and described systematically enough to provide the reader with a basis for attaining that understanding.

7. Resonating with readers

- does it make intuitive sense and fit with the readers own experience.

APPENDIX VIII – Guidelines for conducting and writing-up qualitative research

Recommendations for Conducting and Writing Qualitative Research – Morrow, 2005

Morrow's recommendations are summarised below.

Introduction

Similar to those for a quantitative study but in addition need to:

- distinguish between theory base for topic and for methodology;
- build case for a qualitative investigation;
- provide research questions rather than hypotheses, e.g. how do people understand, construct, manage and interpret their worlds.

Method

Needs to include the following sub-sections (in any order):

- Philosophical assumptions or paradigms underpinning the research;
- Research design (e.g. grounded theory, phenomenology, etc.);
- 'Researcher-as-instrument' statements, i.e. reflexive statements on experience, training, approach to subjectivity, how managed subjectivity (e.g. research journal, etc.);
- Participants including demographics, recruitment, sampling, etc;
- Sources of data, e.g. interviewing philosophy, interview schedule and procedure;
- Data analysis – including analytic steps, data management, immersion, memo-writing, how to avoid over-simplification, role of peer researchers, etc.;
- Address trustworthiness and rigour.

Results

- Should contain only the products of analysis, discussion should be separate.
- Rigorous analysis, involving interplay between data gathering, analysis and interpretation, will aid writing up the results.
- Balance between commentary and supporting evidence.
- Strive for 'thick descriptions'.
- Strive for complexity, beyond listing of themes and categories.

Discussion

- Should resemble that of quantitative study.
- Critique study compared to standards for qualitative research not quantitative.
- Suggestions for future research should include both qualitative and quantitative studies.