Cognitive rehabilitation in dementia

Thesis submitted for the degree of
Doctorate in Clinical Psychology
University of Leicester

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BA (Hons), PhD

June 2005
Acknowledgements

Thanks to:

My field supervisor, David Connelly, for his commitment and enthusiasm for the intervention and evaluation. His support, advice and positive attitude throughout the project has been greatly valued.

My academic supervisor, Noelle Robertson, for her support, advice and guidance. Her responsiveness and attention to detail have been greatly appreciated.

The NHS Trust and Clinical Psychology Department for their support for the study.

Academic staff of the University of Leicester and fellow trainees for their informal help and support. Particular thanks to John Maltby for his invaluable statistical advice.

The participants of the study who never failed to impress me with their kindness and altruism. They were a great source of knowledge and inspiration.

The staff at the memory clinics for their helpfulness, interest and accommodation. Particular thanks to the Consultants, Walter Bouman and Jonathan Waite, for enabling access to participants and to Mel Grange (CPN) for her unswerving cooperation and support in recruiting the control group.

Lastly I would like to thank my partner and friends for their support, encouragement and understanding through the last three years.
Word Count

Abstract 300
Section 1: Literature Review 6005
Section 2: Research Report 8694
Section 3: Critical Appraisal 2764

Total: Excluding references and appendices 17763
Including references and appendices 25253

Target journal:
British Journal of Clinical Psychology

Thesis structure:

The literature review, research report and critical appraisal sections are largely self-contained in accordance with regulations. See Appendix 1 for a summary of the thesis structure guidelines.
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ABSTRACT

Cognitive rehabilitation in dementia

A.L. Cunliffe

Literature review

Dementia can be extremely disruptive and debilitating to everyday life leading to psychological distress. Cognitive rehabilitation is a relatively new intervention in dementia that could potentially alleviate this.

The aim of the review was to critically evaluate cognitive rehabilitation in dementia. The review revealed a scarcity of research in this area with a number of methodologically limited studies. Despite their limitations the evidence for this intervention was encouraging. Further research employing more robust study designs needs to be conducted focusing on the functional, psychological and social impact of cognitive rehabilitation.

Research report

To evaluate the effectiveness of a memory group providing cognitive rehabilitation a two group controlled design was used. Two matched memory clinics supplied the sample. Outcomes were activities of daily living (ADL), mood and carer strain. Memory deficit was also measured. Data was gathered at baseline and three months through a home visit by a researcher independent of the intervention.

26 intervention and 21 control participants were recruited. No statistically significant differences were found between groups at baseline. At three months deterioration in memory and ADL was observed in both groups. This was statistically significant for ADL. In the intervention group mood in participants and carers and carer strain remained stable with no statistically significant differences. In the control group statistically significant increases in participant depression, carer anxiety and depression and carer strain were observed. Effect sizes indicated a medium effect.

The memory group did not have a positive effect on ADL but appeared to stabilise mood and carer strain. A possible protective effect of the group against psychological distress is a hypothesis that requires further investigation.

Critical appraisal

Reflections on research process including the development of the intervention, the development of the evaluation and conducting the project are discussed.
SECTION 1

LITERATURE REVIEW

Cognitive rehabilitation in dementia
ABSTRACT

Background

Approximately 600,000 people in the UK currently have dementia. This is predicted to rise to 1.2 million over the next 50 years. Dementia presents a significant social and economic burden on individuals, their families, carers and statutory agencies. It can be extremely disruptive and debilitating to everyday life leading to psychological distress in individuals and carers. Cognitive rehabilitation is a relatively new intervention in dementia that could potentially alleviate some of these problems.

Aims

To critically examine the evidence base for cognitive rehabilitation in dementia specifically focusing on spaced retrieval, errorless learning and memory aids with the hope that clinical practice may be better informed and clinically useful research stimulated.

Method

A literature search of English language journals using the Cochrane Library, Psychinfo, Psycrawler, Medline, Embase and Cinahl databases.

Findings

There is a poverty of research in this area with many studies having significant methodological limitations (e.g. small sample sizes, no control group, limited measurement of outcomes and no long term follow-up). Despite this the techniques reviewed appear to show promise in terms of aiding cognitive processes. Relatively little research has comprehensively examined the functional, psychological and social impact of these interventions.

Conclusions

Research and practice in this area is in its infancy and further research is required. In addition to cognitive outcomes, the psychological and functional impact of these interventions needs to be explored using more robust study designs.
1 Aims

The aim of this review is to critically examine the evidence base for cognitive rehabilitation in dementia. This is a relatively new clinical area in dementia and research is in its infancy. By providing a review of this area it is hoped that clinical practice may be better informed and clinically useful research stimulated.

A literature search of English language journals was conducted using the Cochrane Library, Psychinfo, Psycrawler, Medline, Embase and Cinahl databases from 1960 to 2005. The search terms included were: Dementia, rehabilitation, cognitive rehabilitation, errorless learning, spaced retrieval, memory aids, older people, elderly, Alzheimer's, memory, ageing and aging. Additional references were sought out from published reviews of related areas and citations in articles emerging from the computerised search. Articles discussing the nature and prevalence of dementia are also included where they are relevant to the discussion. The search was limited to strategies or techniques which targeted memory problems and did not include psychosocial interventions in dementia (for example adjustment groups). Spaced retrieval, errorless learning and memory aids are focused on as some of the most commonly used cognitive rehabilitation interventions reported in the literature.

The introduction to this review provides an overview of dementia in terms of prevalence, type and psycho-social impact (focusing on acquired, irreversible, progressive forms of dementia rather than transitory ones). Current interventions are then discussed and the need for rehabilitation considered. The evidence for the effectiveness of selected rehabilitation techniques and strategies is then examined. This is followed by a discussion of the implications of the evidence and suggestions for future research.
2 Introduction

2.1 Prevalence of dementia

Dementia is considered to be a set of signs and symptoms of intellectual and/or social deterioration that is greater than would be expected as part of "normal" ageing (Stokes & Holden, 1990). Extensive organic impairment of the intellect, memory and personality is observed. It is acquired, irreversible and progressive (Stokes & Holden, 1990). The prevalence of dementia is reported to increase with age (Medical Research Council, 1998). Approximately 600,000 people in the UK currently have dementia (Department of Health, 2001). The percentage of people with dementia over the age of 65 is 5%, in people over the age of 80 the prevalence increases to 20% (Department of Health, 2001). There are also approximately 17,000 people under the age of 65 with dementia in the UK (Department of Health, 2001). With estimated numbers of people with dementia predicted to rise to 1.2 million over the next 50 years (Department of Health, 2001), dementia presents a significant social and economic burden on individuals, their families, carers and statutory agencies (Royal College of Psychiatrists and The Royal College of Physicians, 1998).

2.2 Types of dementia

The two most common types of dementia are Alzheimer's disease (AD) and vascular dementia. Alzheimer's disease makes up approximately 60% of all cases (Department of Health, 2001). The onset of AD can occur as early as 40-50 years old. In the early stages subtle impairment of memory, language and higher mental abilities such as judgement and abstract thinking occurs. Over several years a gradual
deterioration in intellect and personality is observed and the person becomes increasingly dependent on others.

Vascular dementia is the result of a series of strokes (infarcts) and/or insufficient blood flow to the brain (Department of Health, 2001). It accounts for up to 20% of cases of dementia in the UK. Generally it is observed in people in their 70s and 80s, although it can occur as early as the mid 40s (Stokes & Holden, 1990).

Other dementias include Dementia with Lewy bodies, frontotemporal dementia and semantic dementia. Detailed descriptions of all of these dementias can be found in Appendix 1.

Dementia can be extremely disruptive and debilitating to everyday life. The following section examines the impact of dementia on individuals, carers and society in general.

2.3 The impact of dementia

*Impact on the individual*

Dementia has a substantial impact on the individual. It creates disability and dependency on others. The ability to perform activities of daily living (ADL) is affected by deficits in memory function (Josephsson et al., 1993; Moore, Sandman, McGrady, & Kesslak, 2001), as are conversational and social skills (Moore et al., 2001). The psychological and social impact of this for people with dementia can be considerable. It can change relationships with others (Cheston & Bender, 1999), for example, families often change their normal patterns of interaction once a diagnosis of dementia is confirmed (Quayhagen & Quayhagen, 1989). It can also change roles in their relationships and in society generally. As people become more dependent
they may require institutional care, potentially leading to many losses such as home, role, social networks and independence. Dependency on institutional care can also lead a person to be subject to "malignant social psychology" (Kitwood, 1997) which can include people being disempowered, infantilized and intimidated (Cheston & Bender, 1999).

The psychological impact on a person with dementia can be significant and is influenced by the functional and social consequences discussed above and by the knowledge (in the early stages) that they have a progressively deteriorating, terminal illness. Depression is the most commonly reported affective response (Cheston & Bender, 1999). Prevalence rates vary depending on the criteria used. A review of non-cognitive features of dementia estimates the rate of depressive syndromes as ranging from 12 to 24% (Allen & Burns, 1995). Social withdrawal (Cheston & Bender, 1999; Clare, Woods, Moniz-Cook, & Spector, 2003; Moore et al., 2001), frustration (Moore et al., 2001), reduced self-confidence (Clare, Woods, Moniz-Cook, & Spector, 2003) and anxiety (Bird, 2000; Clare, Woods, Moniz-Cook, & Spector, 2003) are also common. Affective responses to dementia can cause excess cognitive and functional disability (Bird, 2000).

Along with the social and psychological consequences of dementia, people may deteriorate physically as the disease progresses. Therefore the impact of dementia on the sufferer is potentially devastating on a number of levels.

Impact on carers

The impact of dementia can be as detrimental for carers. They can become more socially isolated (Brodaty & Gresham, 1989). Relationships with others can be affected, particularly if they are caring for a spouse with dementia (Quayhagen &
Quayhagen, 1989) as the dynamic of the relationship and levels of affection and intimacy can change. The increase in dependency that is involved in dementia, even in the early stages, can have an impact on carer well being (Quayhagen & Quayhagen, 1989). Carers have to cope with specific manifestations of the condition such as behavioural disturbances (e.g. aggression) and repetitive questioning. Coping with these problems is often in the context of a carer’s own physical health problems and increased frailty. Immune functioning can often be compromised through stress, with adverse affects to health (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991).

Carers of people with dementia can become demoralised (Brodaty & Gresham, 1989), depressed/psychologically distressed (Brodaty & Gresham, 1989; Moffat, 1989; Quayhagen & Quayhagen, 1989), have poorer health (Moffat, 1989) and lower life satisfaction (Quayhagen & Quayhagen, 1989; Ready, Ott, & Grace, 2004). There are also financial implications of caring for someone with dementia (Moore et al., 2001). Carers may have to give up work or reduce their hours if they are of working age. If the person with dementia is of working age when they are diagnosed there may also be a loss of household income. Carers and their families may have to pay for community or institutional care: a substantial financial burden, particularly on a limited income such as a pension.

Impact on society

In 1993 the direct cost to the NHS in England of caring for people with Alzheimer’s disease was estimated to be over £1 billion (Department of Health, 2001). Taking into account the cost of statutory agencies and the costs of informal caring, the total cost of caring for people with dementia has been estimated to be around £6 billion (Department of Health, 2001). With the estimated numbers of
people with dementia predicted to rise to 1.2 million over the next 50 years (Department of Health, 2001), dementia presents a significant social and economic burden on statutory agencies and society in general (Davis, Massman, & Doody, 2001; Royal College of Psychiatrists and The Royal College of Physicians, 1998).

2.4 Current interventions and the need for cognitive rehabilitation

Given the impact that dementia has on the individual, those that care for them and society, it is important that health and social services do all that they can in order to reduce this impact. Traditionally care in dementia has been palliative. More recently pharmacological interventions have meant that more proactive treatment has been available in certain dementias (AD), although this is not restorative. Given that dementia has social and psychological consequences as well as biological, needs at these levels should also be considered (Clare, Wilson, Carter, & Hodges, 2003). Services that can provide rehabilitation to ameliorate affective responses for both patients and carers and reduce the impact of the memory problems in terms of everyday functioning would be a useful addition to current service provision (Clare, Woods, Moniz-Cook, Orrell, & Spector, 2003).

Rehabilitation and the improvement of mental health services for older people are on the agenda of the National Service Framework for Older People (Department of Health, 2001). The National Institute for Clinical Excellence is currently developing guidelines for the management of dementia that includes “treatments aimed at improving cognitive (memory) impairment and the behavioural and psychological symptoms of dementia” (National Institute of Clinical Excellence, 2003, 2004). These guidelines should be completed by October 2006. So along with an identified
clinical need, there is also a political imperative to improve services for people with
dementia, which includes providing rehabilitation.

Rehabilitation in dementia is a relatively new concept. Cognitive rehabilitation is
an approach to helping people with cognitive impairments and their carers build
coping strategies to manage their condition (Clare, Woods, Moniz-Cook, & Spector,
2003). The approach has been developed mainly through work in brain injury and
learning research (Camp et al., 1993; Clare et al., 2000) but is increasingly being used
in dementia (Clare, Woods, Moniz-Cook, & Spector, 2003).

The processes involved in cognitive rehabilitation have been developed largely
from experimental studies. Early research was pessimistic about the ability to help
people with dementia cope with their memory problems. A reduction of memory
plasticity led researchers to argue that attempts to aid encoding or retrieval fail
because of physiological limitations that cannot be compensated for, and that all
efforts to enhance encoding may be unsuccessful (Dick, Kean, & Sands, 1989;
Martin, Brouwers, Cox, & Fedio, 1985). In normal ageing episodic memory can be
improved using techniques that involve imagery, organisation and mnemonics
(Yesavage, 1985). In people with dementia there appear to be few gains made from
the use of these techniques since they require substantial cognitive effort and
associative skills; functions that are impaired in dementia (Bächman, 1992; Bird,
2001; Ford, 1996).

A number of studies have challenged the prevailing idea that efforts to enhance
encoding and retrieval in dementia are fruitless. They have demonstrated that with a
substantial amount of cognitive support at both the encoding and retrieval stages those
experiencing dementia can exhibit improvements in episodic memory compared to
their baseline (Bächman, 1992, 1996; Bird, 2001). Restoration of memory is
unrealistic given the nature of the disorder. However it appears possible to achieve a limited retraining of skills and to maximise the use of remaining skills in people with dementia (Jorm, 1994). A number of studies have evaluated rehabilitative techniques that adopt this approach. However few studies have translated this information into meaningful interventions for those with dementia (Clare et al., 2000; Farina et al., 2002).

A recent Cochrane review of cognitive rehabilitation and cognitive training in dementia concluded that there was no evidence for the effectiveness of cognitive training and insufficient evidence to evaluate individualised cognitive rehabilitation (Clare, Woods, Moniz-Cook, Orrell et al., 2003). However the review was restricted to six studies due to the lack of randomised-controlled trials in this area. Results were unable to be pooled because of the heterogeneity of study designs and outcomes. This perhaps reflects problems in the remit of the review which included a broad range of memory interventions (for example, computerised training, spaced retrieval, cognitive stimulation, problem solving) making comparisons across studies and therefore conclusions about the usefulness of techniques difficult.

This review will concentrate on the evidence relating to specific cognitive rehabilitation techniques in an attempt to provide more clinically useful information: Spaced retrieval, errorless learning and memory aids are some of the more commonly used cognitive rehabilitation interventions described in the literature and will be the focus of this review. Evidence will be considered from a broader variety of study designs. While it is recognised that there are methodological limitations to studies that are not randomised-controlled trials, the poverty of research in this area necessitates a more expansive remit.
In dementia, problems with memory tend to be experienced in terms of declarative (or explicit) memory, with the most pronounced deficit in the early stages being in episodic knowledge. This is likely to reflect a failure to learn rather than faster forgetting or impaired retrieval (Greene, Baddeley, & Hodges, 1996). However given appropriate conditions, support and sufficient time, people with dementia still have the ability to learn and retain some information and skills (Clare, Woods, Moniz-Cook, Orrell et al., 2003). Techniques that have drawn on implicit memory have tended to show greater success (Camp et al., 1993) because they draw on automatic processes that require minimal cognitive effort (Ford, 1996). The following will examine evidence for the effectiveness of spaced retrieval, errorless learning and memory aids in dementia.

(For a more detailed discussion of memory and definitions of memory concepts see Appendix 3).

3.1 Spaced retrieval

Spaced retrieval (or expanded rehearsal) involves recalling information at increasingly longer time intervals, correcting errors through a facilitator and shortening the gap when errors are made until the correct response is achieved. It is a memory strategy that has been found to improve learning (Camp, 1989). The technique was originally developed in an educational setting and requires the person to actively remember material. This has been found to be more effective than simple repetition (Bird, 2001). A number of studies have described and evaluated spaced retrieval:
Moffat (1989) used spaced retrieval to improve naming ability in a client with AD who could retain the name of an object for no more than a few minutes. With spaced retrieval the client showed rapid improvement in naming ability which generalised to items that had not been taught (measured by testing naming ability using pictures). However the study is methodologically problematic because it is difficult to generalise from a single case design and no follow-up was reported. It is therefore not known whether the improvement was sustained or for how long.

Arkin's (2001) study using spaced retrieval reported improved recall of biographical information in 11 people with mild to moderate stage AD. Participants were exposed to an interactive tape-recorded exercise containing information about themselves which provided information to be learnt, prompted retrieval and provided the correct response. This was conducted 20 times over the course of a year. The training sessions were conducted by 22 students who attended six seminars on AD and issues relating to older people before they provided the intervention. A number of other interventions were used including physical exercise, language therapy and voluntary work. It was unclear whether the control group received any intervention such as a placebo or whether they received usual care and if so what this comprised. They found that the intervention group had better Mini Mental State Examination scores (Folstein, Folstein, & McHugh, 1975) than the control group and did better on the project-specific biographical memory test. On neuropsychological subtests of the WMS-R (Wechsler, 1987) and the WAIS-R (Wechsler, 1981) and on tests of verbal fluency and language the two groups performed the same. Therefore although the study was able to show that memory for learned information (i.e. the biographical information) improved with the intervention, this did not generalise to other areas. The reason why there were differences seen between MMSE scores may have been
because a number of items in this measure ask for biographical information, the information that had been learnt over the course of training.

Methodologically there are a number of problems with this study. Firstly, the sample size is small so the study may not have had enough power to show other benefits of the intervention (the authors do not provide information about power calculations or sample size estimates). The control group was only made up of four people, again a very small number. The groups were not randomly allocated, therefore there may have been bias between the two groups. The groups had originally been randomly allocated, however they had found a bias of higher "mental status" in one of the groups and therefore re-allocated people non-randomly. The technique used, while apparently successful (although this could have been a false positive because of the lack of random allocation) was one using fixed intervals for retrieval rather than a gradual lengthening of the space between provision of information and retrieval. It is not clear why the researchers chose this method over the other more commonly used techniques. While there were attempts to standardise the training process by using tape recorded material and by giving the students some teaching, no information is provided on the possible variability 22 different trainers might have introduced into the intervention in terms of presentation of material, levels of motivation, knowledge of the area and individual differences in terms of the ability to build rapport and engage clients in the process. Finally, there was no follow-up after the post treatment measures were done, so the longer term outcomes for the interventions used in this study are unknown.

Davis et al. (2001) facilitated the recall of personal information in people with AD using spaced retrieval. The study sampled 37 people and their carers and randomly allocated them to receive either the intervention (spaced retrieval to recall 7 personal
items of information during clinic visits and cognitive stimulation at home) or a placebo (clinic visits consisting of unstructured conversation and attention stimulating exercises at home). After five weeks the groups crossed over so that the placebo group received the intervention. Following the intervention participants' ability to recall personal information and face-name associations improved. As with the previous study the gains failed to generalise to overall psychometric improvement (various neuropsychological tests and the Geriatric Depression Scale) or improvement in carer-rated quality of life. However the researchers' expectations to restore impaired cognitive function may have been unrealistic - it would have been surprising to have observed a positive change in neuropsychological profile in dementia even after an intervention (Jorm, 1994). What the study showed was a difference between the intervention and placebo groups with regard to performance on the task specific outcomes (the recall of personal information) which indicates that some benefits of learning specific material through spaced retrieval was observed, even though this did not generalise to other areas.

Spaced retrieval has also been found to be beneficial for face-name associations (Camp & McKitrick, 1992; Clare et al., 2000), object location associations (Camp & McKitrick, 1992) and prospective memory of future actions (McKitrick, Camp, & Black, 1992). Camp and McKitrick (1992) found that face-name and object location associations could be retained five times longer following spaced retrieval training. Some researchers have found that employment of the spaced retrieval procedure has resulted in an increase in information retention from seconds to weeks, particularly if carers are involved in maintaining gains (Ford, 1996). While these studies have examined the ability of spaced retrieval to achieve improvements in learning and retention, few have examined the psychological and functional impact this might have
on dementia; these are important factors to consider if the technique is to be used in clinical practice.

Abrisqueta-Gomez et al. (2004) attempted to address the lack of information about functional impact by looking at ADL as well as cognition. Three participants all with AD and on anti-dementia medication were recruited. The researchers employed spaced retrieval techniques along with reality orientation and reminiscence and followed up at 12 and 24 months using a battery of neuropsychological tests, the RBMT [memory deficit] (Wilson, Cockburn, & Baddeley, 1991), the BADLS [ADL function] (Bucks, Ashworth, Wilcock, & Siegfried, 1996) and the RMBP [behavioural problems] (Teri et al., 1992). Disappointingly, the affective impact of the intervention was not examined. Promising results were found in the first year of follow-up with delayed cognitive and functional decline. The stability in cognitive and functional status was not sustained in the second year of follow-up. While this study provided useful information about long term outcomes for these techniques, it is hard to generalise from the results as it only involved three participants and had no comparison group. Means and standard deviations were reported, but no statistical analysis was indicated in the paper, perhaps due to the small sample size.

3.2 Errorless learning

Errorless learning was developed in the field of brain injury and was first used to aid people with learning disabilities (Jones & Eayrs, 1992; Llorente & Gaffan, 1989). It is a method that aims to eliminate or reduce the number of incorrect responses during training and, in doing so, facilitates memory performance (Clare et al., 2000). The technique reduces the complexity of the process of learning and remembering by not allowing people to make mistakes. This means that through the help of a
facilitator, people using the technique do not have to devote cognitive resources to correcting themselves, forgetting the incorrect information and replacing it with the correct information. Participants are also offered the opportunity to experience success at each stage of the learning process, which may be particularly important for people with dementia as their self-esteem can become fragile through repeated failures (Clare et al., 2000). Few studies have examined the use of errorless learning in dementia. Those that have examined it have found some promising results. However, again, studies are limited methodologically by small sample sizes and poor generalisability:

Clare et al. (2000) used errorless learning in a number of single case studies. Six of a potential 16 participants consented to the research. The learning targets were to learn the names of participants within a group that they attended (two participants), the names of famous people (one participant), personal information (one participant) and the use of a memory aid (two participants). An ABA single case design methodology was used and the results were combined for analysis. At the end of treatment and at six month follow-up, five of the six participants showed no significant changes in their neuropsychological profile and the sixth participant’s profile had declined. Significant improvements were found on their specific learning targets following training and carers reported lower memory problem ratings, although this was not statistically significant. In one participant, maintenance of these gains was observed up to two years later, although this was not statistically significant (Clare, Wilson, Carter, Hodges, & Adams, 2001). Self reported depression measured by the Hospital Anxiety and Depression Scale (Snaith & Zigmond, 1994) showed a statistically significant increase. The authors advance the explanation that the intervention increased awareness of memory difficulties, although acknowledged that
this hypothesis needed further investigation. While such benefits of errorless learning for memory look promising (with the cautionary note about the possible psychological impact on participants) it is difficult to generalise from such a small study that was, in effect, six single case studies with varying interventions. The generalisability of the sample is also questionable as it represented only 38% of the potential population available.

More recently errorless learning has been used in a neuro-rehabilitation programme with five mildly impaired participants with Alzheimer’s disease who were taking anti-dementia medication (Ávila, Carvalho, & Seral, 2004). The programme consisted of memory training and ADL training (specifically: telephone use, giving and receiving messages, diary use and taking steps to prepare a sandwich). Significant improvement was observed in functioning using a locally developed outcome measure that related specifically to the ADL skills being trained. Modest improvement in some of the cognitive tests was also noted, although this was not found to be statistically significant. While this study demonstrated that errorless learning can be applied effectively to facilitate the learning and retention of specific ADL skills, it did not demonstrate generalisation to other activities as this was not measured. Again, a small sample size makes it difficult to generalise the findings to the wider population, and in the absence of a comparison group other factors such as the effects of medication on outcome could not be controlled for.

3.3 Memory aids

External memory aids such as diaries, calendars, sign posts, concrete reminders, memory wallets and memory places have been found to improve orientation, memory for personal facts, and memory for appointments and conversation (Bächtman, 1992).
By providing an external method of storage, memory aids allow a high level of retrieval support and place low demands on cognitive operations (Bachman, 1992). Bourgeois (1990) used memory wallets to improve conversational deficits in people with AD. Three participants used memory wallets with pictured and written stimuli to prompt factual statements. Topics included information about their family, the structure of their day and biographical information. Participants were trained by their spouses to utilise them using reinforcement techniques. Participants were observed to make more statements of fact and fewer ambiguous, unintelligible, perseverative or error-laden statements following the intervention. There was also generalisation from wallet statements to other statements. Gains were maintained at three and six week follow-up. Bourgeois built on these findings in a second study examining the effectiveness of the intervention where the intensity of training was reduced from daily training sessions to the use of verbal instructions to use the wallets during conversations (but no training). The effects of the intervention on the production of ambiguous and non-productive statements during conversations were examined (Bourgeois, 1992). Nine people with AD participated in the study. All participants learned to use their wallets to improve their conversations by making more accurate statements; this occurred even in the condition where carer training was not provided (three participants). Impressively, long term maintenance was demonstrated in three participants 30 months after the intervention. The combined results of both studies indicate that the use of memory wallets is efficacious and can be achieved with little systematic training. This has implications for clinical practice. The intervention would require less intensive involvement from clinicians than some of the other approaches to cognitive rehabilitation and may therefore make it a more cost effective option. However, although the results of these studies are promising (Ford, 1996),
more research with larger numbers of participants and a control group would be needed to firmly establish the effectiveness of this intervention.

A similar technique has been reported in the field of brain injury where a memory book was used with a 19 year old with memory deficits following a severe head injury (Sohlberg & Mateer, 1989). The notebook contained sections on orientation, daily agenda, a calendar in which to schedule appointments and important dates, reminders of things to do, environmental information, a feelings log and a names section for recording names and identifying information of new people. The techniques teaching the participant to use the memory book differed to those used in dementia, as the difficulties in learning new information had a different aetiology. Techniques such as rote learning were used successfully. People with dementia have problems with this technique, particularly in AD where there is usually early hippocampus damage affecting the ability to learn new material. Therefore it is unlikely that this study could be successfully replicated in dementia. However, what the study indicates is that success can be attained using this form of memory aid. Provided methods of learning to use the aid are adapted to suit people with dementia, as with the prior studies on memory wallets, this form of memory aid holds much promise and requires further research.

Other external aids to memory that have been used include “memory places”, where the frequency of losing things around the home can be reduced by teaching people with dementia to use one place to store all of their commonly used possessions and to learn to look for them in that place. Moffat (1984) taught a man with pre-senile dementia to use a large brightly coloured bag in which to keep his personal things such as his pipe. Following observations of the usual places where he left the bag a flow chart was constructed of the most likely places to look for the bag when it
could not be found. The chart was placed in the kitchen and contained a card to take with him when searching a room to remind him of why he had gone in there. If the search was unsuccessful he returned to the kitchen, replaced the card and went to the next location on the flow chart. The result was a reduction in repeated questioning, noted by the family, and a consequent reduction in the strain that this was causing (although this was based on anecdotal rather than empirical evidence). Therefore while this information should be treated with caution because it has not been empirically tested, the report illustrates how learning techniques combined with memory aids can be practically applied to improve everyday problems experienced in dementia.

4 Discussion

To summarise, there has been debate in the literature over whether memory problems can be ameliorated in dementia. Early work suggested that the ability to learn new information was unlikely given the physiological limitations imposed by the pathology, and indicated by research attempting to enhance encoding. More recently greater optimism has been shared as researchers have found that new learning in people with dementia is possible provided that a substantial amount of cognitive support is provided at both encoding and retrieval stages of the memory process. This has led to the investigation of various learning techniques designed to maximise learning and retrieval in people with dementia; including spaced retrieval and errorless learning. On a practical level memory aids have been developed to compensate for memory problems. Some success has been demonstrated using these learning techniques and aids to memory indicating that they may hold promise for
memory rehabilitation in dementia. However sample sizes have been small and often single cases. Few studies have used control groups and those that have used them rarely employ random allocation to reduce sampling bias. Many studies have failed to follow-up participants so there is a lack of information available regarding the sustainability of results; of the studies that have used follow-up few have examined long term outcomes. In a number of studies interpretation of outcomes has been in terms of an expectation of improved neuropsychological function. However this is an unrealistic expectation given the degenerative nature of the disease. At best what might be expected is a deceleration of the process, and what might be hoped for are the social and psychological benefits of maintaining function, improving feelings of self-efficacy and reducing carer strain. Few studies have examined the potential functional and psychological impact of memory rehabilitation on dementia sufferers and their carers. Given the impact of dementia in this area, this is a huge omission in current research.

This literature review has identified a clear need for further research on cognitive rehabilitation, particularly its clinical application. Rehabilitation treatment programmes need to be developed to apply beneficial findings from experimental literature in a meaningful and practically useful way. Much of the research has focused on memory interventions for people with Alzheimer’s disease; little has been done to look at the benefits of cognitive rehabilitation for people with other forms of dementia and this imbalance need to be redressed. Cognitive rehabilitation in dementia is a relatively new phenomenon and services to provide it have only begun to be developed. Little is known about the best way to develop these services and provide the interventions. There is, therefore, a substantial gap to be filled in terms of
developing and evaluating cognitive rehabilitation interventions in dementia for use in clinical settings.

The literature indicates that interventions would need to focus on implicit learning and external methods of storage to gain the best possible outcomes. Interventions would also need to involve carers for the most effective and long lasting outcomes (De Vreese, Neri, Fioravanti, Belloi, & Zanetti, 2001; Ford, 1996). Little is known about the effectiveness of providing cognitive rehabilitation interventions in groups, however it could be hypothesized that delivery of the intervention in a group might have psychological benefits in terms of support and reducing stigma (Scarboro, 2000; Scott, Clare, Charlesworth, & Luckie, 2002).

Methodologically, research evaluating cognitive rehabilitation interventions needs to be controlled and of adequate sample size to detect statistically significant benefits. Ideally randomised-controlled trial designs should be used (Clare, Woods, Moniz-Cook, Orrell et al., 2003). Long term follow-up would also be valuable to gain an idea of whether there are any lasting benefits to the interventions. Researchers need to frame their outcomes in the context of progressive decline in cognitive function. Using memory deficit as an outcome per se may be unhelpful. It might be more helpful to compare groups in terms of relative decline and in the context of levels of functioning. Research also needs to examine the psychological impact of the intervention on the individual and their carer and the impact on practical and social functioning. Memory rehabilitation research to date has often overlooked these factors therefore it is important that they are included in future research (De Vreese et al., 2001).
5 Summary

Dementia is a progressively degenerative condition which affects memory, behaviour and social functioning. The impact of dementia on the individual, their carer and society as a whole in terms of its psychological, social, physical and financial effects can be devastating. With the number of people with dementia set to rise considerably in the next 50 years it is important that health and social services address the impact of dementia and provide rehabilitation as well as pharmacological and palliative care. A number of techniques have been developed in the experimental literature with some success. These have been applied as interventions for people with dementia and have shown much promise. However studies applying these techniques have been few and a number of them are methodologically problematic. There has also been relatively little research that has comprehensively included outcomes in terms of functional abilities, social functioning, mood and carer strain. Therefore there is a great need for future research in this field to inform and enhance clinical practice.
REFERENCES


London: Department of Health.


*Disability and Rehabilitation, 16*, 98 - 109.


*Psychosomatic Medicine, 53*, 345 - 362.


SECTION 2

RESEARCH REPORT (Option A)

Does a cognitive rehabilitation programme for older people with a diagnosis of a dementia lead to a reduction in the impact of their memory problems?
ABSTRACT

Objectives
To evaluate the effectiveness of a memory group providing cognitive rehabilitation for dementia.

Design
A two group experimental design compared participants who had received the intervention with a control group.

Methods
Individuals were sampled from two matched memory clinics. One provided the memory group, the other usual care. Outcomes measured were activities of daily living [ADL] (Bristol Activities of Daily Living Scale), mood (Hospital Anxiety and Depression Scale) and carer strain (Carer Strain Index). These were measured at baseline and three months. Memory deficit was measured at baseline (Rivermead Behavioural Memory Test and Mini Mental State Examination) and three months (Rivermead Behavioural Memory Test) for descriptive and contextual purposes.

Baseline and follow-up measures were collected through home visits by a researcher independent from the intervention.

Results
Forty-seven participants consented (26 intervention; 21 control). No statistically significant differences were found between groups at baseline. At three months deterioration in memory and ADL was observed in both groups. This was statistically significant for ADL. In the intervention group mood in participants and carers and carer strain remained stable with no statistically significant differences. In the control group statistically significant increases in participant depression, carer anxiety and depression and carer strain were observed. Effect sizes indicated a medium effect.

Conclusions
While the memory group did not have a positive effect on ADL it appeared to stabilise mood and carer strain. It is possible that providing cognitive rehabilitation in a group has protective effects against psychological distress. This hypothesis requires further investigation.
1 INTRODUCTION

Dementia is a progressively degenerative condition which affects memory, behaviour and social functioning (Green, 2000). The impact of dementia on the individual, their carer and society as a whole in terms of its psychological, social, physical and financial effects can be devastating. With the number of people with dementia set to rise to 1.2 million in the next 50 years (Department of Health, 2001) it is important that health and social services address the impact of dementia and provide rehabilitation as well as pharmacological and palliative care. Cognitive rehabilitation is one approach that attempts to do this. In the context of progressive dementia it aims to enhance the quality of an individual's life rather than aspire to restore pre-morbid levels of cognitive functioning (Ford, 1996).

Rehabilitation and the improvement of mental health services for older people are within the agenda of the National Service Framework for Older People (Department of Health, 2001). The National Institute for Clinical Excellence is currently working on guidelines for the management of dementia that includes in its remit: "treatment aimed at improving cognitive (memory) impairment and the behavioural and psychological symptoms of dementia" (National Institute of Clinical Excellence, 2003, 2004). The work on these guidelines began in March 2003 and is due to be completed by October 2006. Therefore, along with an identified clinical need there is also a political imperative to improve services for people with dementia which includes providing rehabilitation.

People with dementia are rarely totally amnesic and many strategies have explored the use of compensatory mechanisms that exploit existing cognitive systems or modify the individual's environment (Moore, Sandman, McGrady, & Kesslak,
A number of studies have explored the use of specific learning strategies such as errorless learning (Clare et al., 2000; Clare, Wilson, Carter, & Hodges, 2003; Ávila, Carvalho, & Seral, 2004). Some have demonstrated long-term benefits even in the face of disease progression (Clare, Wilson, Carter, Hodges, & Adams, 2001). A number of investigators have explored the use of external memory aids and strategies, which have been found to be beneficial (Moniz-Cook, Agar, Gibson, Win, & Wang, 1998; Scarboro, 2000; Scott, Clare, Charlesworth, & Luckie, 2002). The majority of interventions in this area have targeted individuals. However, some investigators have explored the use of group formats and shown positive benefits both from the content of the group and the experience of meeting others with similar difficulties (Scarboro, 2000; Scott et al., 2002).

The literature indicates that cognitive rehabilitation in dementia is possible and that providing cognitive rehabilitation could potentially improve current service provision for people with dementia. The most helpful cognitive rehabilitation techniques are reported to be implicit learning and external memory aids and it is suggested that there may be benefits to providing cognitive rehabilitation in a group. However, there has been little investigation of the application of these techniques in clinical practice. Studies that have been done have had small sample sizes (often single case designs) and many have lacked control groups and generalisability (Bourgeois, 1990, 1992; Clare et al., 2001; Clare, Wilson, Carter, Roth, & Hodges, 2002). At this time few studies have explicitly linked the use of learning strategies to help individuals consistently use memory aids and even fewer have done this within a group format. There has also been relatively little research in this area that has comprehensively included functional and psycho-social analysis (De Vreese et al., 2001) and examined long term outcomes.
This study proposes to use evidence-based interventions that are structured in a way that aims to maximise compliance by involving carers and uses learning techniques to facilitate the use of external aids more effectively. It is hoped that the inclusion of other people with dementia and their carers will lead to additional benefits from the group experience. Teaching carers and people with dementia learning strategies may also provide a flexible tool for future problem solving. It is anticipated that the group format may facilitate some adjustment and decrease feelings of isolation.

The proposed treatment programme is relatively novel and the evidence base for the clinical application of these rehabilitation strategies in dementia is small. Therefore it is important that its effectiveness is established through an evaluation of the treatment programme and that the evaluation addresses some of the methodological shortcomings of previous studies.

1.1 Research aims

The aims of the investigation are to evaluate the effectiveness of a cognitive rehabilitation programme by comparing people who participate in the programme with a control group using the following outcomes:

- Impact on function:
  - Activities of daily living

- Impact on mood and carer strain:
  - Self-reported anxiety and depression
  - Self reported levels of strain
1.2 Hypotheses

It is hypothesised that, if successful, the cognitive rehabilitation programme will:

- Reduce levels of deterioration in activities of daily living skills
- Improve mood in participants and carers
- Reduce carer strain
2 METHOD

2.1 Rationale

Quantitative methods were chosen for the design of this study in order to answer questions regarding the effectiveness of the memory rehabilitation group. Particular strengths of quantitative research is its ability to establish causal relationships, particularly with experimental designs, enabling the ability to eliminate alternative explanations of a causal relationship (Bryman, 1988). The use of control groups allows researchers to make strong claims about the internal validity of their findings since they can manipulate aspects of participants’ environments to produce different conditions in which outcomes can be compared. Therefore to establish any benefits or hazards attributed to the memory rehabilitation group a controlled experimental design was chosen as a particularly robust design.

The aim of the study was to examine the functional and psychological impact of a memory rehabilitation group on participants, and their carers, in order to establish its effectiveness. Outcomes used were:

- Levels of functioning measured by activities of daily living (carer report)
- Mood (participant and carer self report)
- Carer wellbeing (carer self report)
2.2 Design

A two group design (treatment group and control group) was chosen as the most appropriate method for comparing the intervention with usual practice (Klaber-Moffett, 1991). Although desirable, randomised groups were not possible since the service providing memory rehabilitation was reluctant to withhold treatment from potential recipients for ethical reasons. Therefore two memory clinics were used to access participants; one clinic ran a memory rehabilitation group and the other clinic did not run such a group and was used to recruit control participants. The two clinics were selected because of their match in terms of patient demographics and other services provided to attendees of each clinic.

Follow-up was carried out at three and twelve months. This thesis will be presenting the outcomes up to three months.

A summary of the design of the study can be found in Figure 2.1.
Figure 2.1 Design of the study

Patients from memory clinics identified by clinic staff

\[\downarrow\]

Inclusion/Exclusion criteria applied by researcher

<table>
<thead>
<tr>
<th>Eligible for the study</th>
<th>Not eligible for study</th>
</tr>
</thead>
</table>

\[\downarrow\]

Consent sought

<table>
<thead>
<tr>
<th>Consent given</th>
<th>Consent not given</th>
</tr>
</thead>
</table>

\[\downarrow\]

Baseline information collected

\[\downarrow\]

Intervention group (Memory clinic 1)

\[\downarrow\]

Received intervention

\[\downarrow\]

Outcome data collected 3 months from date baseline data collected

\[\downarrow\]

Control group (Memory clinic 2)

\[\downarrow\]

Received usual care
2.3 Participants

2.3.1 Sample size

Sample size was estimated using the best information available at the time, which was limited due the poverty of research in this area. As the proposed treatment programme was relatively novel, and thus the relevant evidence base for the clinical application of rehabilitation strategies in dementia was limited, the Rivermead Behavioural Memory Test [RBMT] (Wilson, Cockburn, & Baddeley, 1991) was used as the basis of a power calculation - one of the more commonly used measures in studies that have been done in this area. To achieve the difference in RBMT scores observed in other studies of rehabilitation in dementia care (Moniz-Cook et al., 1998) a sample size of 32 in each group was calculated at the 0.05 significance level and with 80% power.

2.3.2 Inclusion criteria

- Diagnosis of Alzheimer’s disease or vascular dementia (see Appendix 4)
- Mini Mental State Examination score (MMSE) equal to or greater than 18 (Folstein, Folstein, & McHugh, 1975)
- Living with carer
- Understanding of English with no receptive dysphasia
- No diagnosis of a major psychiatric disorder (assessed by Responsible Medical Officer)
- Available to attend the seven week programme (intervention group only)
2.4 Data Collection

2.4.1 Ethical considerations

Ethical approval was sought and granted from the local Ethical Committee (see Appendix 5). The purpose and nature of the study was explained to all patients and carers by the researcher. They were reassured that their medical care would not be affected if they did not wish to take part in the study and once involved in the study, they could withdraw at any time. Patients were also reassured that all information would be treated as confidential and stored securely. This was reiterated on the information sheet with which they were issued. Verbal consent was requested and, if given, participants were asked to read and sign a consent form agreeing to take part in the study.

All information was coded with a participant number to ensure confidentiality and locked in a filing cabinet. When information was transposed to computer records, only the coded numbers were used.

Given that participants had mild memory impairment efforts were made to ensure that consent was reaffirmed at each stage of follow-up and during each follow-up session. Only if participants continued to understand the purpose of the study, displayed the capacity to do so and continued to consent was the follow-up process undertaken and completed.

2.4.2 Considerations in the choice of measures

Standardisation, objectivity, validity and reliability were taken into account when considering the choice of outcome measures and the broader study. A more detailed discussion of these issues is available in Appendix 6. Measures were chosen for their
validity, reliability and prior use with the population under study. Standardised measures were adopted for their established procedures to ensure consistency, and for greater communicability of results. The practicality of measures was also a consideration: The outcome measures needed to be fairly quick and simple to use with an elderly and potentially frail client group. Measures that were too long or complicated were felt to be too taxing and time consuming for participants to complete. It was also important that the measures elicited sufficient information to enable worthwhile outcome data to be produced. The instruments used could therefore not be over simplified or too brief without compromising the quality of the information. There was thus a fine balance to be struck in choosing instruments that were neither too burdensome for participants, nor too brief as to be of little use as an instrument of data collection.

2.4.3 Outcomes and measures used

The following provides details of the outcomes chosen for the study, the instruments adopted to measure them together with a rationale:

*Functional activity*

Dementia has a substantial impact on an individual by creating disability and dependency on others. Level of functional activity was therefore considered to be an important measure of the success of an intervention providing memory rehabilitation.

Activities of daily living (ADL) are referred to as the basic physical functions that underlie normal living, such as walking, dressing, going to the toilet, feeding oneself and continence (personal ADL). ADL is widely considered to be a useful construct to measure functional activity by those in the field of rehabilitation (Wade, 1993).
Functional activity is not just about personal ADL, reduced functioning can affect wider aspects of daily life and cause dependency in them. Communication, social interaction, the ability to carry out domestic activities and participate in leisure activities can also be affected (Wade, 1993). These wider aspects of functioning are commonly referred to as "instrumental" or "extended" ADL. Due to the far reaching effects memory problems can have on people’s lives it was important to find a measure that included extended as well as personal ADL in evaluating the memory rehabilitation group.

Functional activity was measured by the Bristol Activities of Daily Living Scale [BADLS] (Bucks, Ashworth, Wilcock, & Siegfried, 1996). It measures personal and extended ADL. Unlike many generic ADL measures, it is designed specifically for people with dementia. The scale has face, construct and concurrent validity and has good test-retest reliability (Bucks et al., 1996). It is sensitive to change over time (Byrne, Wilson, Bucks, Hughes, & Wilcock, 2000). Carers have reported it to be easy to use and it is relatively short (Bucks et al., 1996). The scale has 20 items each rated on a four-point Likert scale (0-3) with a fifth “not applicable” option (scoring 0). Scores range from 0 (indicating no impairment) to 60 (indicating maximum impairment).

Mood

The psychological impact of dementia can be considerable and is influenced by the functional and social consequences of the condition and by the knowledge (in the early stages) that one’s cognitive function is deteriorating (Cheston & Bender, 1999). Mood was thus considered a key measure of the success or failure of a memory rehabilitation intervention. It was important to establish whether the memory group
caused psychological distress to either clients or carers, or whether there were any psychological benefits accrued from the intervention.

Participant and carer mood was measured using the Hospital Anxiety and Depression Scale [HADS] (Zigmond & Snaith, 1983) which screens for symptoms of anxiety and depression. It has the advantage of measuring both anxiety and depression in a single scale and is relatively short and easy to use. The scale also attempts to overcome bias caused by somatic complaints which can feature in many other inventories (Wade, 1993). This is important in an elderly client group where there can be concurrent physical health problems. A comprehensive review of studies of the scale indicates that it has reliability and construct, criterion and content validity (Bjelland, Dahl, Tangen Haug, & Neckelmann, 2002). Its validity for use with older populations has been established (Flint & Rifat, 1996, 2002).

The scale has 14 items, 7 relating to depression and 7 relating to anxiety. Each item is rated on a four-point Likert scale (0-3) with five items reverse scored. Anxiety and depression are scored separately. Scores range from 0 to 21 with higher scores indicating greater distress. Scores are categorised from normal (0-7), mild (8-10), moderate (11-14) to severe (15-21) distress.

Carer well-being

The impact of dementia can have as many adverse consequences for carers as their social and intimate relationships change. The increased dependency and behavioural disturbances that can accompany dementias can place a significant strain on the caring role and potentiate psychological distress. It was considered important, to examine what impact, if any, the memory rehabilitation intervention had on carer strain.
Carer strain was measured using the Carer Strain Index [CSI] (Robinson, 1983). It was chosen as a short, reliable and valid measure of carer distress (Cronbach’s Alpha of 0.86) (Robinson, 1983; Wade, 1993). Many of the items relate directly to the experience of carers of people with dementia, such as, disturbed sleep, emotional adjustments, upsetting behaviour and upsetting personality changes. The index has 13 items where carers simply tick “yes” or “no” to each item. Scores range from 0 to 13, 13 indicating the maximum level of strain.

Memory deficit

Memory deficit was not considered an outcome of the study because the group aspired to enhance individuals’ quality of life rather than restore pre-morbid levels of cognitive functioning (which would be an unrealistic aim in a progressive organic condition such as dementia). However it was measured to provide a descriptive context to the results. The Rivermead Behavioural Memory Test was chosen as a standardised, valid and reliable measure (Wilson, Cockburn, Baddeley, & Hiorns, 1991) with established utility and norms with people under and over the age of 70 (Cockburn & Smith, 1989). It has also been used in other studies in this area (Moniz-Cook et al., 1998) allowing greater comparability of results across studies.

For copies of the outcome measures used (with the exception of the RBMT which can be accessed via the above reference) see Appendix 7.

2.4.4 Method of data collection

Data was collected from face-to-face interviews with participants in their homes. Postal questionnaire was considered as a potentially useful method of data collection.
with the advantage of being largely free from observer bias (Gladman, 1991). However it was considered impractical because it would have relied heavily on untrained carers to help in the completion of the questionnaires, potentially introducing bias in reporting and incorrectly completed questionnaires. It was also decided against in order to avoid low response rates and partially completed forms, leading to missing data and reduced statistical power. There would neither have been time within the constraints of a doctoral project or resources available to maximise response rates effectively. Postal follow-up would also have reduced control over the timing of the completion of questionnaires, producing more variability in the timing of follow up. Finally, in order to monitor memory deficit over the course of the study, the administering of the RBMT required a trained researcher to complete the assessment with participants. Considering all of these factors face-to-face follow-up was decided to be the most suitable method of data collection, using a researcher who was independent of the intervention to reduce the potential for introducing bias into the study.

2.5 Procedure

2.5.1 Recruitment

*Intervention group*

Participants for the intervention group were referred to the researcher conducting the group by staff working at Memory Clinic 1. If they fulfilled the criteria for the study they were contacted and informed about the study and the nature of the intervention, and asked if they would like to participate. Once verbal consent was
given arrangements were made to visit the participant at their home where the study rationale and parameters were re-iterated and supplemented by written information. If volunteers still wished to participate, written consent was sought. Once written consent was obtained, baseline data was collected.

Control group

Participants for the control group were identified by staff at Memory Clinic 2 as fulfilling the criteria for the study. Once identified, staff at the clinic asked potential participants for their permission to be approached by the researcher after their clinic appointment. If they agreed the researcher approached them and explained the study, provided written information about the study and requested their verbal consent. If they consented, arrangements were made to visit them at home where the study was explained to them again and written consent requested. This enabled volunteers to consider whether they wanted to participate rather than making an immediate and potentially pressurised decision at the clinic. Once participants and carers had provided written consent baseline data was collected.

2.5.2 Intervention

The intervention comprised a seven week programme with 1½ hours cognitive rehabilitation delivered on a weekly basis. It was delivered in a group format that also involved carers. The group was facilitated by a clinical psychologist and a trainee clinical psychologist. Other health professionals from the clinical team were also involved in facilitating the groups at times when a trainee clinical psychologist was unavailable for the seven week programme. The programme included thinking about memory problems and current coping strategies, education about memory, learning
about and practically applying errorless learning techniques and learning about and practically applying memory aids. The aim was to combine errorless learning strategies to facilitate the use of memory aids by the end of the programme. An outline of the programme can be found in Appendix 8.

2.5.3 Data collection

Baseline data collection

Baseline data was collected to provide descriptive information about the sample and to provide information from which to compare the two groups to establish whether they had been well matched. It also provided baseline information from which to compare the three month outcomes. The data collected included:

- Demographic information
- Diagnosis and anti-dementia medication (drug type, dose, date commenced)
- Two measures of memory deficit: RBMT and the MMSE (assessed by researcher)
- BADLS (completed by carer)
- Participant and carer HADS (self completed)
- CSI (self completed)

Follow-up data collection

At three months subsequent to baseline data collection, both intervention and control participants were followed up by a home visit where the RBMT, BADLS, HADS and CSI were repeated as before. Visits were done by the independent researcher.
2.6 Pilot Study

A pilot study was conducted to test out the format of the intervention and to make any necessary modifications; to assess the practicalities of data collection; and to assess the suitability of the methods and measures.

The pilot study consisted of the running of one intervention group and following up its participants up to three months and the recruitment and follow-up of two control participants. As a result of the pilot study the intervention was changed in the following ways:

- Educational aspects were simplified and divided into sections with breaks in between.
- The teaching of errorless learning and spaced retrieval was reduced to errorless learning alone as learning more than one technique was found to be too much and too confusing.
- Participant-carer practice within sessions in addition to facilitators modelling techniques was found to be of more benefit than modelling alone and the programme was changed to accommodate this.
- More time was given to the introduction and consideration of ways to use memory aids.
- The practical application of the learning technique with the memory aids was integrated into sessions more than it had been.

The recruitment procedure for the control group was also modified. Originally staff at the clinic were requested to ask potential participants if they would be willing to be approached by the researcher by telephone. This proved to be problematic as
staff appeared to be inconsistent in their approach. There were also practical problems in accessing information required to approach people once they had agreed. The process was therefore altered to enable the researcher to be more involved in the initial phase of recruitment. She attended the clinic each month on the day that the memory clinic was held and was available to explain the study, gain provisional consent and make arrangements for visits at this time.
3 RESULTS

3.1 Participants

A total of 88 people were sampled over the course of one year. Forty-seven consented to the study, 26 people formed the intervention group and 21 the control group. Twelve participants or their carers did not consent to the study. Twenty-nine potential participants were excluded because they failed to meet the inclusion criteria. See Appendix 9 for reasons for exclusion and non-consent.

More people in the control sample (26) were excluded from the study due to the sampling procedure. The intervention group relied on referrals to the group by members of the multi-disciplinary team at the clinic where the intervention was available. The team were familiar with the inclusion criteria and thus tended to refer appropriately. Recruitment to the control group was slower, relying on staff at the clinic to keep the study prominent in their consciousness on busy clinic days. In order to improve the recruitment rate and maximise the potential control sample every patient that attended this memory clinic was considered as a potential candidate for the study and the inclusion/exclusion criteria was applied to them. This led to higher numbers of exclusions in the control group as many clinic attendees were inappropriate for the study.
Figure 3.1 Recruitment and follow up

- Sample population: Memory clinic one, 110 attendees per year
  - 33 referred to study
    - 7 did not enter study
      - 3 excluded
      - 4 did not give consent
  - Intervention: 26 entered intervention group
    - Intervention follow-up: 25 followed up, 1 dropped out

- Sample population: Memory clinic two, 55 attendees per year
  - 55 sampled for study
    - 34 did not enter study
      - 26 excluded
      - 8 did not give consent
  - Control: 21 entered control group
    - Control follow-up: 20 followed up, 1 dropped out
3.1.1 Demographics

Table 3.1 illustrates the characteristics of the sample at baseline. The average age of the sample was 75 years old with men making up almost two thirds of the overall sample (62%). The entire sample was white/European and reflects the demographics of patients attending both clinics. The entire sample was married or co-habiting which is an artefact of the exclusion criteria.

Table 3.1 Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intervention</th>
<th>Control</th>
<th>Both groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (S.D)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years</td>
<td>77 (5.2)</td>
<td>73 (5.9)</td>
<td>75 (5.8)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>17 (65.4%)</td>
<td>12 (57.1%)</td>
<td>29 (61.7%)</td>
</tr>
<tr>
<td>Female</td>
<td>9 (34.6%)</td>
<td>9 (42.9%)</td>
<td>18 (38.3%)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White/European</td>
<td>26 (100%)</td>
<td>21 (100%)</td>
<td>47 (100%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>25 (96.2%)</td>
<td>19 (90.5%)</td>
<td>44 (93.6%)</td>
</tr>
<tr>
<td>Co-habiting</td>
<td>1 (3.9%)</td>
<td>2 (9.5%)</td>
<td>3 (6.4%)</td>
</tr>
<tr>
<td>Work status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>26 (100%)</td>
<td>21 (100%)</td>
<td>47 (100%)</td>
</tr>
</tbody>
</table>

Socio-economic status

Socio-economic status was established based on occupation prior to retirement. The occupations of both participant and spouse/partner were recorded and the higher of the two (indicative of the standard of living within the household) was used. Classification was done using the Office of Population, Census and Survey guidelines for social class based on occupation (Office of Population Censuses and Surveys, 1990).
Table 3.2 Socio-economic status

<table>
<thead>
<tr>
<th>Code</th>
<th>Classification</th>
<th>Intervention</th>
<th>Control</th>
<th>Both groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Professional</td>
<td>4 (15.4%)</td>
<td>0</td>
<td>4 (8.5%)</td>
</tr>
<tr>
<td>II</td>
<td>Managerial and technical</td>
<td>8 (30.8%)</td>
<td>9 (42.9%)</td>
<td>17 (36.2%)</td>
</tr>
<tr>
<td>III NM</td>
<td>Skilled non-manual</td>
<td>8 (30.8%)</td>
<td>5 (23.8%)</td>
<td>13 (27.7%)</td>
</tr>
<tr>
<td>III M</td>
<td>Skilled manual</td>
<td>3 (11.5%)</td>
<td>3 (14.3%)</td>
<td>6 (12.8%)</td>
</tr>
<tr>
<td>IV</td>
<td>Partly skilled</td>
<td>2 (7.7%)</td>
<td>4 (19.1%)</td>
<td>6 (12.8%)</td>
</tr>
<tr>
<td>V</td>
<td>Unskilled</td>
<td>1 (3.8%)</td>
<td>0</td>
<td>1 (2.1%)</td>
</tr>
</tbody>
</table>

The socio-economic distribution indicates that the sample is likely to be largely of middle-class status. This reflects the two geographical areas from which the sample was taken.

3.1.2 Diagnosis

The majority of participants had a diagnosis of Alzheimer’s disease. This is unsurprising given that it is the commonest form of dementia and a large majority of memory clinic patients attend the clinics for anti-dementia medication, which is specifically used in Alzheimer’s disease.

Table 3.3 Diagnosis

<table>
<thead>
<tr>
<th>Type of dementia</th>
<th>Intervention</th>
<th>Control</th>
<th>Both groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s</td>
<td>24 (92.3%)</td>
<td>20 (95.2%)</td>
<td>44 (93.6%)</td>
</tr>
<tr>
<td>Vascular</td>
<td>1 (3.8%)</td>
<td>0</td>
<td>1 (2.1%)</td>
</tr>
<tr>
<td>Mixed Alzheimer’s and vascular</td>
<td>1 (3.8%)</td>
<td>1 (4.8%)</td>
<td>2 (4.3%)</td>
</tr>
</tbody>
</table>
3.1.3 Medication

The majority (81%) of the sample were on anti-dementia medication. Only one of the control group was not on medication. The majority of participants were taking Donepezil (40%). Average doses of medication were similar in each group (between 11 and 12 m.g. per day) although the control group had, on average, been taking their medication for a longer period of time (median of 89 weeks for the control group, as opposed to 66 weeks for the intervention group). This was not a statistically significant difference (Mann Whitney $U = 0.285$, $p = 0.775$).

**Table 3.4 Anti dementia medication**

<table>
<thead>
<tr>
<th>Type of medication</th>
<th>Intervention</th>
<th>Control</th>
<th>Both groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donepezil</td>
<td>13 (50%)</td>
<td>6 (28.6%)</td>
<td>19 (40.4%)</td>
</tr>
<tr>
<td>Rivastigmine</td>
<td>1 (3.8%)</td>
<td>9 (42.9%)</td>
<td>10 (21.3%)</td>
</tr>
<tr>
<td>Galantamine</td>
<td>4 (15.4%)</td>
<td>5 (23.8%)</td>
<td>9 (19.1%)</td>
</tr>
<tr>
<td>No medication</td>
<td>8 (30.8%)</td>
<td>1 (4.8%)</td>
<td>9 (19.1%)</td>
</tr>
</tbody>
</table>

**Table 3.5 Average dose of medication per day**

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
<th>Both groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean dose</td>
<td>12 m.g.</td>
<td>11 m.g.</td>
<td>11 m.g.</td>
</tr>
<tr>
<td>(S.D)</td>
<td>(4.85)</td>
<td>(6.19)</td>
<td>(5.91)</td>
</tr>
<tr>
<td>Range</td>
<td>9-24 m.g.</td>
<td>3-24 m.g.</td>
<td>3-24 m.g.</td>
</tr>
</tbody>
</table>

**Table 3.6 Number of weeks since commencement of medication**

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
<th>Both groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median no. weeks</td>
<td>66</td>
<td>89</td>
<td>69</td>
</tr>
<tr>
<td>Interquartile range</td>
<td>19-121</td>
<td>54-143</td>
<td>33-134</td>
</tr>
</tbody>
</table>
3.2 Analysis

Once data had been collected it was transposed onto a computer database. Data were analysed using the SPSS 12.0 Statistical Package for the Social Sciences. The data was checked and cleaned. There was no missing data within the outcome measures because of the follow-up procedures used. Following inspection of the distributions of the data using box and whisker plots one outlier was identified. A decision was taken to remove this outlier from the analysis because it may have had a disproportionate impact on the statistical tests (Clark-Carter, 1997).

Prior to the analysis the data was examined to establish the appropriate application of statistical tests. Parametric tests are considered to be more powerful and therefore a first choice if the criteria for their application are fulfilled: variance of scores around the mean should be homogenous and scores should display a normal distribution (Clark-Carter, 1997). Visual inspection of data distributions, comparison of the mean and trimmed mean and the Kolmogorov-Smirnov test all indicated that many of the outcome measures at baseline and follow-up were skewed. It may have been possible to transform the data to provide a more normal distribution. However given that the sample was also relatively small and was of a clinical population it was decided that non-parametric statistics were the most appropriate tests to use as they are less sensitive to the impact of small sample sizes and unusual distributions commonly seen in clinical populations.

In keeping with convention within psychological research statistical significance was tested at the 5% level (Clark-Carter, 1997). The groups were compared on baseline measures of memory, ADL, mood and carer strain using the Mann Whitney U test to establish their match. Once equality in baseline characteristics was
established a within subjects repeated measures comparison was then made: baseline scores were compared with three months outcomes within each group using the Wilcoxon Signed Ranks test. The rationale for this was that if there was a difference in outcomes from baseline to three months in one group but not the other then a treatment effect could be concluded. For descriptive purposes memory deficit over time was also examined and reported.

3.3 Baseline measures

Comparison of group scores at baseline can be found in Table 3.7. The Mann-Whitney U test comparing scores between groups indicated no statistically significant differences in memory, ADL, mood or carer strain. It could therefore be assumed that the groups were not significantly different for the purposes of future comparison.

The MMSE and RBMT scores indicated that participants had mild memory difficulties at baseline. This degree of memory deficit was comparative to other studies of cognitive rehabilitation in the field (Clare, Woods, Moniz-Cook, Orrell, & Spector, 2003).
Table 3.7 Baseline comparison of groups

<table>
<thead>
<tr>
<th>Scale</th>
<th>Intervention</th>
<th>Control</th>
<th>Mann-Whitney $U$ value</th>
<th>Statistical Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MMSE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>23.2 (3.51)</td>
<td>21.9 (3.57)</td>
<td>-1.194</td>
<td>0.233</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>23 (21-27)</td>
<td>22 (19-25)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>RBMT Profile score</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>6.2 (5.12)</td>
<td>4.1 (3.92)</td>
<td>-1.393</td>
<td>0.163</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>5 (2-10)</td>
<td>3 (0-6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>RBMT Screening score</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>1.8 (2.05)</td>
<td>1.4 (1.75)</td>
<td>-0.357</td>
<td>0.721</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>1 (0-3)</td>
<td>1 (0-2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>BADLS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>9.5 (7.90)</td>
<td>14.4 (9.08)</td>
<td>-1.727</td>
<td>0.084</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>9 (3-15)</td>
<td>12.5 (8-20)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HADS patient anxiety</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>5.8 (3.68)</td>
<td>7.5 (3.83)</td>
<td>-1.479</td>
<td>0.139</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>5 (3-10)</td>
<td>7.5 (6-10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HADS patient depression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>4.9 (3.13)</td>
<td>3.7 (2.49)</td>
<td>-1.350</td>
<td>0.177</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>4 (2-7)</td>
<td>3 (1-6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HADS carer anxiety</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>8.0 (3.39)</td>
<td>6.7 (3.76)</td>
<td>-1.095</td>
<td>0.273</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>7 (6-10)</td>
<td>7 (4-9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HADS carer depression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>5.5 (4.02)</td>
<td>4.3 (2.94)</td>
<td>-0.919</td>
<td>0.358</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>5 (2-9)</td>
<td>4 (2-7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CSI</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>3.7 (2.29)</td>
<td>4.0 (2.54)</td>
<td>-0.381</td>
<td>0.703</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>4 (2-5)</td>
<td>4 (2-5)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Three of the RBMT measures were not completed at baseline. This reflected some participants’ anxiety about doing the measure. In these cases a clinical decision was taken to remove the measure from data collection to avoid distress to the participant.
3.4  Outcomes at three months

3.4.1  Study progress

Of the 26 intervention participants recruited, all received the intervention. Two participants dropped out of the study at three months, one from the intervention group and one from the control group. The reasons for withdrawal were personal problems and terminal illness. All of the remaining 45 participants were followed up.

Missing data

At three months, five RBMT measures were not completed. Three of these data points were absent because they were not completed at baseline. In addition one participant’s health had deteriorated significantly compromising their ability to complete the RBMT. One further participant declined to complete the test but was happy to complete the other measures. The rest of the outcome measures were completed by all participants. Any missing or ambiguous responses were checked for and clarified during the follow-up visit. As the missing data was the memory measure and therefore descriptive data as opposed to outcome data this was not considered to be problematic to the analysis.

3.4.2  Outcomes

The measures at three months for memory, ADL, mood and carer strain were compared with baseline scores in each group using the Wilcoxon signed rank test. The mean, median, $Z$ scores and their statistical significance with effect size can be found in table 3.8 for the intervention group and table 3.9 for the control group.
The results indicated deterioration in memory (not statistically significant) and ADL (statistically significant) across both groups. In the intervention group levels of anxiety and depression in both participants and carers remained relatively stable with no statistically significant differences. In the control group there was a statistically significant increase in participant depression and carer anxiety and depression. Carer strain was also indicated to statistically significantly increase in the control group between baseline and follow up whereas in the intervention group it remained stable.

The effect sizes of the changes in anxiety, depression and carer strain seen in the control group ranged from 0.52 to 0.62 indicating a medium effect (Clark-Carter, 1997). There was also a medium effect observed in ADL in both groups with effect sizes of 0.53 (intervention group) and 0.64 (control group).
Table 3.8 Intervention group scores at baseline and three months

<table>
<thead>
<tr>
<th>Scale</th>
<th>Intervention at baseline</th>
<th>Intervention at 3 months</th>
<th>Wilcoxon Z score</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>RBMT Profile score</td>
<td>Mean (S.D)</td>
<td>6.2 (5.12)</td>
<td>5.4 (6.10)</td>
<td>-1.858</td>
</tr>
<tr>
<td></td>
<td>Median (IQR)</td>
<td>5 (2-10)</td>
<td>3 (0-12)</td>
<td></td>
</tr>
<tr>
<td>RBMT Screening score</td>
<td>Mean (S.D)</td>
<td>1.8 (2.05)</td>
<td>1.9 (2.62)</td>
<td>-0.232</td>
</tr>
<tr>
<td></td>
<td>Median (IQR)</td>
<td>1 (0-3)</td>
<td>0 (0-4)</td>
<td></td>
</tr>
<tr>
<td>BADLS</td>
<td>Mean (S.D)</td>
<td>9.5 (7.90)</td>
<td>11.8 (7.49)</td>
<td>-2.535</td>
</tr>
<tr>
<td></td>
<td>Median (IQR)</td>
<td>9 (3-15)</td>
<td>10 (4-19)</td>
<td></td>
</tr>
<tr>
<td>HADS patient anxiety</td>
<td>Mean (S.D)</td>
<td>5.8 (3.68)</td>
<td>5.8 (3.94)</td>
<td>-0.088</td>
</tr>
<tr>
<td></td>
<td>Median (IQR)</td>
<td>5 (3-10)</td>
<td>6 (3-9)</td>
<td></td>
</tr>
<tr>
<td>HADS patient depression</td>
<td>Mean (S.D)</td>
<td>4.9 (3.13)</td>
<td>4.4 (2.24)</td>
<td>-0.874</td>
</tr>
<tr>
<td></td>
<td>Median (IQR)</td>
<td>4 (2-7)</td>
<td>4 (2-6)</td>
<td></td>
</tr>
<tr>
<td>HADS carer anxiety</td>
<td>Mean (S.D)</td>
<td>8.0 (3.39)</td>
<td>7.5 (3.43)</td>
<td>-0.928</td>
</tr>
<tr>
<td></td>
<td>Median (IQR)</td>
<td>7 (6-10)</td>
<td>7 (3-10)</td>
<td></td>
</tr>
<tr>
<td>HADS carer depression</td>
<td>Mean (S.D)</td>
<td>5.5 (4.02)</td>
<td>5.7 (3.61)</td>
<td>-0.738</td>
</tr>
<tr>
<td></td>
<td>Median (IQR)</td>
<td>5 (2-9)</td>
<td>6 (3-8)</td>
<td></td>
</tr>
<tr>
<td>CSI</td>
<td>Mean (S.D)</td>
<td>3.7 (2.29)</td>
<td>3.7 (2.87)</td>
<td>-0.432</td>
</tr>
<tr>
<td></td>
<td>Median (IQR)</td>
<td>4 (2-5)</td>
<td>4 (1-7)</td>
<td></td>
</tr>
</tbody>
</table>

* indicates statistically significant at the 5% level of significance

ES = effect size
Table 3.9 Control group scores at baseline and three months

<table>
<thead>
<tr>
<th>Scale</th>
<th>Control at baseline</th>
<th>Control at 3 months</th>
<th>Wilcoxon Z score</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RBMT Profile score</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>4.1 (3.92)</td>
<td>3.6 (3.58)</td>
<td>-1.162</td>
<td>0.245 (ES 0.32)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>3 (0-6)</td>
<td>3 (1-5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>RBMT Screening score</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>1.4 (1.75)</td>
<td>1.3 (1.44)</td>
<td>-0.741</td>
<td>0.458 (ES 0.23)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>1 (0-2)</td>
<td>1 (0-2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>BADLS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>14.4 (9.08)</td>
<td>16.5 (10.96)</td>
<td>-2.644</td>
<td>0.008 * (ES 0.64)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>12.5 (8-20)</td>
<td>12 (9-24)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HADS patient anxiety</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>7.5 (3.83)</td>
<td>7.4 (3.72)</td>
<td>-0.717</td>
<td>0.473 (ES 0.21)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>7.5 (6-10)</td>
<td>7 (5-10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HADS patient depression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>3.7 (2.49)</td>
<td>5.6 (2.99)</td>
<td>-2.244</td>
<td>0.025 * (ES 0.52)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>3 (1-6)</td>
<td>5 (3-8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>HADS carer anxiety</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>6.7 (3.76)</td>
<td>8.1 (4.28)</td>
<td>-2.503</td>
<td>0.012 * (ES 0.61)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>7 (4-9)</td>
<td>8 (4-11)</td>
<td></td>
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<tr>
<td><strong>HADS carer depression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>4.3 (2.94)</td>
<td>5.8 (3.41)</td>
<td>-2.413</td>
<td>0.016 * (ES 0.62)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>4 (2-7)</td>
<td>5 (3-8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CSI</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (S.D)</td>
<td>4.0 (2.54)</td>
<td>4.9 (2.38)</td>
<td>-2.029</td>
<td>0.042 * (ES 0.54)</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>4 (2-5)</td>
<td>4 (4-6)</td>
<td></td>
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</tr>
</tbody>
</table>

* indicates statistically significant at the 5% level of significance

ES = effect size
Distribution of scores

Figure 3.2 shows box and whisker plots of the distribution of scores for each measure at three months, comparing the intervention and control groups. The length of the box represents the interquartile range, containing 50% of cases. The line across the inside of the box represents the median value and the whiskers protruding from the box indicate the range of the scores. Higher scores on the BADLS indicate greater impairment. Higher scores on the HADS and CSI indicate greater levels of distress. Although the analysis revealed significant deterioration in ADL in both groups, the distribution of scores indicated by the box plots show a higher proportion of scores in the upper range in the control group compared to the intervention. This is also appears to be the pattern for the CSI and HADS scores with comparatively more scores falling above the median score in the control group. The distributions therefore indicate an overall trend towards greater deterioration in the control group, although this was not statistically significant for ADL or participant anxiety.

The following section will discuss the implications of these results.
Figure 3.2 Boxplots of three month outcomes

BADLS

CSI

Patient HADS Anxiety

Patient HADS Depression

Carer HADS Anxiety

Carer HADS Depression
4 DISCUSSION

4.1 Summary of results

The aim of the study was to examine the functional and psychological impact a memory rehabilitation group had on participants and their carers in order to establish effectiveness. The outcomes used to evaluate effectiveness were ADL, levels of anxiety and depression and carer strain. Memory deficit was also measured to provide a descriptive context for the results. Outcomes were compared using a two group controlled design. It was hypothesised that, if successful, the cognitive rehabilitation programme would:

- Reduce levels of deterioration in ADL
- Improve mood in participants and carers
- Reduce carer strain

Analysis of baseline measures indicated that the intervention and control group were matched in terms of memory deficit, mood and carer strain, with no statistically significant differences between groups. At three months both groups had deteriorated in memory (non-statistically significant) and ADL (statistically significant). Levels of anxiety and depression in participants and carers of the intervention group remained relatively stable with no statistically significant differences between baseline and three month scores. In the control group a statistically significant increase in participant depression and carer anxiety and depression from baseline to three months was observed. There was also a statistically significant increase in carer strain in the control group from baseline to follow up. In the intervention group no differences in
carer strain were observed. Calculations of effect sizes revealed a medium effect across these outcomes.

4.2 Discussion of results

The promising results of errorless learning in the literature yielded by studies such as Clare et al. (2000) and Ávila et al (2004) were not replicated in this study. As had been expected, memory deteriorated from baseline to follow-up whereas in the Clare study improvement was noted on specific learning tasks and in the Ávila study non-significant improvement was noted in some cognitive tests. It was hypothesised that, as had been seen in the Ávila study, ADL functioning might improve or remain stable, however this also deteriorated. This might be explained by differences in measurement. The Ávila study trained participants to do specific ADL tasks and then measured performance of these tasks as an outcome. No global measures were used to assess whether the training generalised to other aspects of ADL. Bourgeois (1990, 1992) and Moffat’s (1984) studies of memory aids also showed improvement in specific tasks, however, as with the Clare et al. (2000) and Ávila et al. (2004) studies, improvement was measured specifically relating to the task, with no global assessment. This study focused only on a global measure of ADL and showed deterioration over time in both groups. What the study failed to do was to assess whether more task specific learning was being achieved, therefore it is unknown whether the deterioration in ADL was a failure of the intervention specifically or whether the intervention succeeded on a micro level (as with the task specific studies) but failed to generalise. What the study showed was that more general ADL skills appeared to be unaffected by cognitive rehabilitation. It may be that specific training
is needed on each ADL task where improvement is desired in order for cognitive rehabilitation to have an impact on ADL. This fits with some of the more recent literature which discusses the importance of individually tailored interventions (Clare et al., 2003).

However if the lack improvement or stability in ADL was due to the ineffectiveness of the intervention rather that a failure in measurement then possible explanations may be found in the theoretical literature. For example, Camp proposes that the strategies that are likely to have more success in people with dementia are those that require less cognitive effort and rely more heavily on implicit memory (Camp et al., 1993). Internal strategies tend to place more demands on the cognitive system than external ones. Explicit memory tends to be more impaired in people with dementia than implicit memory. It is possible that current cognitive rehabilitation techniques such as spaced retrieval and errorless learning rely too heavily on internal storage and explicit learning strategies and alternative strategies that rely on external storage and implicit learning, such as memory aids combined with conditioning or habituation would be more suitable. However this theory is not substantiated by current research in the field and needs further exploration.

The hypotheses that the intervention would improve mood and reduce carer strain were also unsubstantiated. However differences between the groups in participant depression and carer anxiety, depression and strain indicate that the intervention may have some protective effects against psychological distress. Evidence from the control group indicates that in normal circumstances psychological distress significantly increases alongside deterioration in memory and ADL. In the intervention group levels of psychological distress remained relatively stable despite deterioration in memory and ADL. This differs from the outcomes of other studies
(although the available evidence is scant). For example, Clare et al. (2000) found a statistically significant increase in participant anxiety and depression following their intervention and Davis, Massman and Doody (2001) found no difference in levels of depression between their treatment and control groups. Both of these interventions were delivered individually whereas the current intervention was delivered in a group format. Anecdotal reports from participants and carers about the positive experience of the group were common (see the Critical Appraisal for details). It could be hypothesised that the group experience may have promoted the psychological stability observed, and may parallel reported benefits of groups for people with dementia through their provision of support and reduction of stigma (Scarboro, 2000; Scott et al., 2002).

Delivering cognitive rehabilitation in a group format may have psychological benefits but it reduces the ability to tailor interventions specifically to participants’ needs. While every effort was made to do this during the group intervention, it remains a different experience to one-to-one sessions. This may also be a reason why there failed to be an impact on ADL, however it is difficult to assess without having measured task specific outcomes.

Clare and colleagues describe a relationship between awareness of memory problems and learning performance in dementia, with cognitive rehabilitation outcomes being better for those with greater awareness (Clare, Wilson, Carter, Roth, & Hodges, 2004). They also report a relationship between awareness of memory problems and carer depression, with carer depression being worse when participants are less aware. It is possible that one of the psychological benefits of the group intervention in this study was an impact on participants’ awareness of their memory problems which may have contributed to the psychological stability that was
observed. However this may only account for some of the psychological processes were manifest in the group intervention and further exploration of these processes is required.

Demographically, almost two thirds of the sample were men with dementia/female carer pairs. This may reflect the proportion of male/female carers reported in the literature, with husbands making up approximately one third of spouse carers (Chang & White-Means, 1991; Stone, Cafferata, & Sangl, 1987). The proportion of men to women in the sample differs to that found in the general population above working age where women make up approximately two thirds of the population. Women in the UK commonly live longer with more than half of women over the age of 75 living alone (Office of National Statistics, 2001). Of men aged 74-85 only 26% live alone, rising to 37% over the age of 85 (Office of National Statistics, 2001). This study required participants to be co-habiting and excluded those who lived alone. Therefore the higher proportion of men to women in the study compared to what might be expected in this age group may be explained by the exclusion criteria imposed by the study.

4.3 Limitations of the study

A number of compromises in the study design led to methodological limitations. The control groups were not randomly allocated. Efforts were made to match the groups and subsequent analysis revealed no significant differences between the two groups; however it may be possible that bias was introduced into the study through non-randomisation.
Bias may also have been introduced by using a researcher not masked to treatment allocation to conduct the follow-ups. This was a methodological compromise for practical reasons since there was a lack of personnel available to do the follow-ups. While every effort was made to remain objective and independent of the intervention, the possibility of bias cannot be discounted. However, even with masking, participants often disclose or give clues to their status therefore this would not have been a completely fail safe option had it been possible.

The slightly different sampling methods at each clinic were methodologically unsatisfactory but were necessary in order for the study to function practically and to maximise recruitment. Again this is another possible route for bias to have been introduced into the study.

The study did not achieve the intended sample size therefore it could be argued that it was underpowered. However the medium effect sizes observed in statistically significant outcomes indicate that the reduced sample size may not have elicited type II errors. The implications of a medium effect size is open to debate and depends largely on how much the reader considers these outcomes to be important (Clark-Carter, 1997). However as the review of the literature has indicated, dementia is a distressing and debilitating condition for individuals and carers therefore anything that can be done to alleviate this should be given further consideration, even if the size of the effect is relatively modest.

Another consideration was the study's inability to partial out the interaction effects of medication. Most of the sample was taking anti-dementia medication therefore any potential differences in outcome due to medication effects could not be analysed. As both groups were on medication this was not problematic to the interpretation of the results. Had there not been a control group interpretation may
have been more complicated as it would have been unclear as to whether the findings were due to the intervention or the medication.

The sample was limited, comprising mainly of white/European middle-class individuals. This reflects the demographics of the areas in which sampling occurred. The findings should therefore be interpreted in this cultural context. The impact of the intervention on more ethnically and culturally diverse populations is unknown.

4.4 Implications

4.4.1 Clinical implications

The study has indicated that there may be some protective effects of the cognitive rehabilitation intervention in terms of psychological distress and carer strain. It is unclear which aspects of the intervention were particularly efficacious, but anecdotal feedback from participants and researcher's observations suggest that it may relate to the group experience and processes of adjustment. Further research would need to be done to explore these hypotheses.

If these hypotheses were supported, this would present a challenge to clinical practice as the literature suggests that application of the learning techniques and memory aids themselves may be more successful in improving ADL when tailored to individuals in one-to-one sessions. Again this is a hypothesis that needs further exploration. Currently studies have either trained participants on task specific ADL and measured this but not provided global measures, or as with this study, task specific measures have been overlooked and global measures have been the focus of the research. It is possible that these techniques are only useful in improving ADL when provided by intensive one-to-one sessions.
If both hypotheses are valid then clinical interventions would need to be designed in a way that individualises interventions and provides intensive training but also utilises the group experience with all of the supportive aspects that it may afford.

4.4.2 Future research

It is clear that further research is required. The group process needs to be examined to establish what aspects of the intervention seem to be protective of psychological distress. It is likely that this question would be best answered using qualitative methodology as it is more suited to exploratory work that looks at systemic processes and personal perspectives that are not easily measured or quantified (Bryman, 1988).

It would also be useful to explore whether the intervention as it is provided in this study is successful in improving task specific ADL by measuring success in the ADL tasks that are focused on in sessions. This would help to establish whether the study failed to measure the utility of the intervention in terms of ADL or whether the intervention simply failed in this area. If a study using task specific measures indicated success, and global measures of ADL indicated no effect, then further research would be needed into the most effective way of providing cognitive rehabilitation and whether it is possible to provide it in a way that enables generalisation to other aspects of ADL. A measure of awareness of memory problems might also be usefully included to build upon the findings of the Clare et al. (2004) study and to assess the impact that the group intervention has on awareness, examining which coping styles elicit positive outcomes.

The evidence of these three potential studies could then be combined to develop an intervention. Ideally this would then need to be evaluated through a randomised-
controlled trial of adequate sample size. Depending on the results of the trial, there would then be a strong case for developing cognitive rehabilitation interventions in clinical practice and be far more information available on the most effective ways to do this.

Future research might also benefit from including rates of institutionalisation as an outcome measure along with measures relating to the cost effectiveness of interventions. A possible modification to the design of the current study could be to include a support group that mirrored the intervention in all aspects apart from the provision of cognitive rehabilitation. This could form a control group in an attempt to separate the utility of the supportive elements of the intervention from the cognitive rehabilitation techniques. This form of study would also need to include a control group who received no intervention to allow useful comparisons to be made across the groups. However given the difficulty in recruiting large enough sample sizes in this field of research, such an ambitious study might not be possible.

Lastly, there is a need for research into learning techniques that utilise implicit memory in dementia as it is less impaired in the early stages making the potential for successful learning more conceivable. The development and testing of cognitive rehabilitation techniques that combine external methods of storage such as memory aids with implicit memory may be a useful way forward in the field of research into cognitive rehabilitation in dementia and if found to have utility, may enhance clinical practice.
REFERENCES


Byrne, L. M. T., Wilson, P. M. A., Bucks, R. S., Hughes, A. O., & Wilcock, G. K. (2000). The sensitivity to change over time of the Bristol Activities of Daily


Available:


SECTION 3

CRITICAL APPRAISAL
1 Origins

The study arose from proposals to develop a memory rehabilitation group while I was on placement as a Trainee Clinical Psychologist. Research into the literature revealed that cognitive rehabilitation might enhance current service provision so plans began to devise a group. As the intervention was relatively novel, particularly in a group setting, there was enthusiasm for an evaluation. It was important to find out whether the intervention had utility for local use and to contribute to this under-researched area.

2 Development of the intervention

As this was a new area and very few studies had reported group interventions in cognitive rehabilitation there was no previously evaluated model of treatment structure and process to follow in order to develop the intervention. As much information as possible was drawn from the literature to devise it, however many decisions about approach, style, pacing and content were based on clinical judgement (which it could be argued is very subjective) and information and feedback from the pilot study. Errorless learning and a number of memory aids were determined as the focus of the group. Education about how memory works was also included. Appendix 8 gives an outline of the programme.

People with early stage dementia can often feel intimidated by group situations because they have lost confidence in their social skills. Therefore, as facilitators, my clinical supervisor and I were keen to set a positive tone to the group and make sure that all members felt included and were treated with respect. The group was run with
a person-centred philosophy to avoid potential “malignant social psychology” (Kitwood, 1997). One of the ways in which this was done was by engaging with participants using over-learned and stereotypical social conventions that people with dementia could easily recognise. For example, introductions included formally shaking people’s hands and waiting to be invited to use people’s first names before using them. Participant and carer were not differentiated in the group, conveying the message that each group member had equal value irrespective of their difficulties.

The aim of this person-centred approach was to preserve participants’ dignity, social competence and psychological well-being (Kitwood, 1997); convey respect; and preserve current psychological coping mechanisms (Clare, Wilson, Carter, Roth, & Hodges, 2004). Throughout the programme the emphasis was on making the most of remaining resources and encouraging people to pay more attention to their successes.

Diagnosis was not referred to in the group. Facilitators avoided discussions of diagnosis in an attempt to reduce potential labelling and stigma and to move away from diseased focused thinking. Again this was consonant with the person-centred philosophy. It was felt that it was unnecessary to focus on the cause of the problem since the group aimed to address the consequences of the problem. The group was deliberately called a memory group as opposed to dementia group for these reasons.

Apart from learning about memory and memory techniques and aids, anecdotally there appeared to be other potential benefits derived from the group. Group participants reported an increase in confidence in the person with dementia and greater understanding in carers. Both participants and carers reported the benefits of meeting others experiencing similar difficulties. Many participants were reported to have said that they did not want the group to end. Facilitators’ observations were often of changes in participants and carers over the course of the programme in terms
of their attitudes towards dementia and their levels of acceptance of the condition. It may be that one of the functions of the group was to offer an environment where some adjustment to this difficult and debilitating condition could take place. This may help to explain the apparently protective effect of the intervention seen in the study in terms of psychological distress and carer strain. However it is recognised that these observations are anecdotal and further study is required to examine the process of the group and explore which particular components of it might be useful and why.

3 Development of the evaluation

The evaluation was designed at the same time as the intervention. This had the advantage of enabling integration of the research into the running of the groups from the start. I was keen to examine psychological and functional outcomes as there was a lack of this information in the literature and I thought that they would be important measures of effectiveness of this kind of intervention. There was some debate over whether to include a memory measure because the aim of the intervention was not explicitly to prevent deterioration in memory as this would have been an unrealistic aim. While the measurement of memory involved much more time and effort in data collection it was decided that it should be included to provide important contextual and descriptive information. The literature was searched for appropriate measures. It took much searching to find an appropriate measure of ADL as many of the more commonly used measures were not designed for use in dementia. The Nottingham Extended ADL scale (Lincoln & Gladman, 1992) was considered because of its use with older populations; however it became clear on examining the content that it was
unsuitable because of its focus on physical disability, rather than disabilities that related to cognitive as well as physical impairment.

The timing of follow-up was also debated and three months was felt to be sufficient time for any potential "honeymoon" effects of the intervention to have dissipated. It was also thought that long-term outcomes should be examined. Twelve months was settled upon as an appropriate time point (although the data was not included within the scope of this doctoral project). As has been discussed in the methods section, postal follow-up was considered as an option but rejected because it was impractical within the constraints of doctoral training and because the quantity and quality of data may have been reduced. The various debates and decisions that had to be made highlighted for me how intricately considered research projects have to be and that it is not always an exact science. It also made me appreciate that sometimes, an ideal has to be compromised in order to make a project practical.

A research proposal was prepared, peer reviewed and ethical approval sought and granted following some requested changes to the patient information sheets. This was a new and useful experience. My prior experience in research had been on studies that had already been granted ethical approval, although I had experience of writing grant applications which I found helped with developing the proposal. In the region where this study was conducted applicants are given the option to attend the ethics committee meeting where their proposal is being discussed. Whilst nerve-racking, I found my attendance at this meeting very helpful to the application process as the ethics committee were able to get clarification on things that they were unsure of and I was able to be given clarification on things that they wanted to be changed and why. This experienced has encouraged me to attend ethics committee meetings for future research proposals, where possible.
4 Conducting the research

4.1 Organisation and competing demands

A number of reflections emerge from conducting the research. I knew from conducting previous research the importance of organisation. I created a database at the clinical base from where the study was conducted. This contained participants’ details and calculated the timings of follow-ups so that I could check the dates of when I would need to arrange visits. However I had not appreciated how difficult it would be to run the project within the competing demands of clinical training. My previous experience of research was in a research team where I co-ordinated the project, recruited participants and managed research assistants during data collection. As the sole focus of my job was the research project it was relatively easy to make it run smoothly and feel that it was under control. My experience of this project was somewhat different. I did not always feel that it was running smoothly. I think that this was in part because I had to rely on others to keep me informed and provide me with data, which could be inconsistent at times (often due to the competing demands of their jobs).

It was also hard to stay on top of the project due to my remoteness to the clinical base from where the study was run. I was on placement in a different county in each subsequent placement from when the project began in my first year of training. I also live in a different county to where the project was based. Therefore, while telephone calls, email and regular meetings were useful in the running of the project, it was not the same as being on site and where much more immersion in the project would have been possible.
Along with this, the demands of clinical training also prevented me from being able to fully absorb myself in the project and feel totally in control of it. During the course of this study I was juggling a service evaluation, a small scale research project and three case studies. These had to be fitted into my weekly study day along with the three month follow-ups and latterly the twelve month follow-ups. In addition to academic work, placements demanded much mental and emotional energy and thus depleted resources. So for many reasons I felt like I was not able to be as fully immersed in the study as I would have liked to be and consequently felt less in control.

This experience has taught me the difference between conducting research in a clinical setting and conducting research in a research-dedicated university department. Conducting research as part of a clinical job seems to be much harder because less time can be devoted to it. In order to do further research post qualification I think that it will be important to develop a research team within the clinical department in which I work. Research grants could be applied for to finance research assistants to conduct projects so that the limited time that I will have available could go into supervising the projects. Utilising trainees who are keen to develop doctoral projects might also help to move research forward.

With these reflections in mind, I have also realised how much is still possible even with such difficulties to contend with and feel pleased that I have been able to achieve the project within these constraints.

4.2 Recruitment

Recruitment caused the most concern within the project. While most people that were approached were happy to participate, the numbers of suitable candidates were
fewer than expected, particularly in the control group. This led to a more systematic approach to recruitment at the control clinic, reviewing all patients coming to the clinic for their suitability for the study. I felt that this needed to be done to satisfy myself that all had been done to maximise recruitment in the control group. It was unfortunate for the study that this revealed a shortfall in potential candidates. More research into the potential numbers at this clinic using the study criteria as opposed to the number of clinic attendees generally would have been useful in the planning stage so that this problem could have been anticipated and other options explored.

From these difficulties in recruitment I have learnt the importance of thoroughly examining the feasibility of sampling from particular clinical populations during the planning stage of studies. I have also learnt much about the frustrations that can emerge from doing research where there is high personal investment but limited time.

4.3 Participant contact

The experience of recruiting and following-up participants was very rewarding. People gave up their time, underwent a memory test that effectively highlighted their difficulties and filled out questionnaires that asked quite personal and searching questions. While I tried to make the experience as pleasant and comfortable as possible, I was always struck by the altruism of participants and carers in volunteering for a potentially uncomfortable assessment. Many seemed to appreciate the time and respect they received from me and would comment that they looked forward to my next visit. The use of my clinical skills in terms of building rapport and being sensitive to participants’ self esteem during the follow-up process I believe were very important, particularly in administering the RBMT. For me, this was the essence of making sure that this study was conducted ethically and why on occasions I took the
decision to omit using the RBMT with individuals as the clinical indications were that it would cause distress.

Participants and carers who received the intervention discussed it in very favourable terms. While in an attempt to remain objective and independent I did not encourage discussion of the intervention, the information was often volunteered. Some group participants had kept in contact with each other after the sessions had finished and regularly met with each other. Many discussed appreciating meeting others in similar situations and described feeling less emotionally isolated. Adjustment, normalisation and greater understanding appeared to be common themes. The utility of the learning technique and the memory aids were discussed less, although I was often shown memory boards and calendars to show that they were being used. These discussions, while anecdotal and unsubstantiated, have led to the consideration of further research to examine what elements of the process and experience of the memory group are important. This would help to refine the intervention, which could then be re-tested.

As this anecdote illustrates, it was impossible to be unaware of which treatment group participants were in. Even when participants and carers did not discuss the clinics or the memory groups, it was easy to guess which group they were in by where they lived. Therefore when visiting them at home I was aware that they were either a control or intervention participant. I did my best to remain objective as I knew how important it is for this kind of research to be bias-free. However it is possible that this was a source of bias in the study. The study would have needed to have employed another researcher that could have been masked to treatment allocation to have avoided this problem. This was not an option in this study and was a frustrating compromise that had to be made for practical reasons.
5 General reflections

The experience of developing the intervention and designing and conducting the research project has made me more appreciative of the practical difficulties in putting ideal research methodology into practice. A number of pragmatic compromises had to be made in the design and conduct of this study which weakened it methodologically. In my literature review it was easy to be critical of the shortcomings of other studies. However I think that I now have greater awareness of how difficult these kinds of evaluations are and how difficult it is to produce a study that does not contain methodological imperfections.

Writing up the study using a newly introduced thesis structure was challenging. Producing three self-contained pieces of work with relatively constrained word limits compared to the old style thesis had the advantages of forcing a tighter structure and encouraged more concise language. It also had the advantage of making the preparation of the material for publication a simpler process. However the new style had the disadvantages of necessitating repetition of material and perhaps flowed less well as complete document than the original style of thesis might have done.

6 Summary

Reflecting on the study, I have learnt a number of things:

- That it is not always possible to use previous evidence to develop projects and though not ideal, sometimes subjective decisions based on clinical judgement has to be relied upon.
• About the intricacies of decision making and the practical compromises that sometimes have to be made in order for a study to be functional, even if this weakens the methodological design.

• The usefulness of attending ethical committee meetings in smoothing the application process.

• The difficulties involved in conducting a research project with:
  - Competing demands on time and energy
  - Remoteness to the research base
  - Reliance on others with little power to influence them

• The difficulties in achieving an adequate sample size in this clinical population and the need to assess this thoroughly in the planning stage.

• The frustrations of doing research where there is high personal investment but limited time.

• The rewards of contact with this clinical population and gratitude for their altruism.

• The importance of utilising clinical skills and sensitivity when conducting research with this clinical group.
REFERENCES


APPENDIX 1

Thesis structure guidelines
Description of Guidelines for preparation of the research thesis

Overview

The thesis is required to contain original work. It will involve an investigation with human participants, which is of clinical relevance. The findings should contribute to the knowledge base of clinical psychology and there should be evidence that independent critical power has been exercised. Work should be of a quality suitable for submission to publication in peer-reviewed journals.

The thesis will comprise 4 sections:

Section A – a self-contained review of literature, which adheres to the requirements of a specified peer-reviewed psychology journal, included in the Science or Social Science Citation Index. The word count for such reviews for the journal chosen must fall within a minimum of 5,000 and a maximum of 8,000 words. Suitable target journals might include the British Journal of Clinical Psychology, the Journal of Consulting and Clinical Psychology or the Journal of Health Psychology.

Section B – A self-contained research report, which can be presented in one of two ways:

i. In the general style of the British Journal of Clinical Psychology but with allowance for full reporting of the work completed, together with a detailed presentation of results and full and critical discussion (a minimum of 8,000 words, a maximum of 12,000 words, excluding references)

ii. A shorter report, which complies with guidelines for a specified journal (minimum 5,000 words, maximum 8,000 words, excluding references unless specified by the journal as including references). The journal selected should be peer-reviewed and included in the listings for the Science or Social Science Citation Index.

Section C – Critical appraisal of the research process founded on the keeping of a research diary. If Option ii. has been chosen this section of the thesis should comprise a detailed critique of research methodology with careful specification of the research limitations. This should be written in conjunction with discussion of future research strands and opportunities (minimum 2,000 words, maximum 5,000 words).

Section D – Appendices. These must include letters of approval from the relevant Ethics Committees, copies of any measurements utilised, together with guidelines for submission to journals identified by the literature review and the main research report (where Option ii. has been chosen). Additionally, where Option ii. has been chosen appendices should include detailed descriptive data and any information about hypotheses tested or analyses completed which have not been presented in the paper format. In all cases of qualitative theses clear evidence trails should be included.

continued/.....
APPENDIX 2

Descriptions of dementias

1.1 (a) Alzheimer’s disease (AD)

Alzheimer’s disease is the most common form of dementia, making up approximately 60% of all cases (Department of Health, 2001). The onset of AD can occur as early as 40-50 years old. In the early stages subtle impairment of memory, language and higher mental abilities such as judgement and abstract thinking occurs. Over several years a gradual deterioration in intellect and personality is observed and the person becomes increasingly dependent on others.

Apart from age, risk factors for developing AD include head injury, Down’s syndrome and a family history of AD (although the risk decreases as age of onset increases).

Stokes & Holden (1990) identify three stages in AD type dementia:

**Minimal-mild dementia**

The first stage of AD is characterised by short-term memory loss, with difficulty recalling recent events and misplacing or being unable to find objects. People become disorientated in time and there is poor recall of names of familiar people or places. People in this stage are easily fatigued and find concentrating more difficult. People find abstract thinking more difficult and they may become less flexible in their daily routines. Often reported are emotional changes such as anxiety and irritability.
**Mild-moderate dementia**

The second stage of AD is characterised by deteriorating memory, an increasingly poor attention span and a decline in general intellectual performance. Sufferers may get lost in unfamiliar places, may dwell on the past, make speech errors and have word-finding difficulty. Judgement and the capacity for abstract thought show significant impairment. As the person becomes more confused their behaviour may be experienced as more disruptive such as wandering, aggression and unreasonable demands. Skills learned last tend to be lost first, such as those relating to social independence and occupation. Emotionally a flattening of mood and indifference to family and new or general events is observed.

**Moderate-severe dementia**

This stage begins at the point where remaining skills and abilities would no longer sustain the person’s survival if they were to be left alone. Difficulties in performing basic activities of daily living occur, including self-care. Behaviour appears to lack purpose. Intellectual capacity shows further deterioration and memory deteriorates to the extent of the loss of personal history. As this stage progresses people become unable to recognise themselves or close relatives, and insight disappears. People also deteriorate physically and eventually progress to an almost vegetative state.

Although AD is a state of deterioration, some functions and abilities in individuals may be preserved until (surprisingly) late in the process. The type and duration of preserved abilities depends on the personal characteristics and history of the person with dementia, as well as the influence of the carers and the care environment (Stokes & Holden, 1990).
1.2 (a) **Vascular dementia**

Vascular dementia is the result of a series of strokes (infarcts) and/or insufficient blood flow to the brain (Department of Health, 2001). It accounts for up to 20% of cases of dementia in the UK. Generally it is observed in people in their 70s and 80s, although it can occur as early as the mid 40s (Stokes & Holden, 1990). The small strokes experienced vary in frequency, intensity and location between individuals. They can cause episodes of confusion and loss of cognitive function evidenced, for example, by slurred speech. Physical disability is not severe, contrasting with a serious stroke, and afterwards there is commonly some limited clinical improvement until the next episode (Stokes & Holden, 1990). Deterioration tends to be “stepped” following a succession of infarcts. Many people with vascular dementia tend to die before they reach an advanced dementia, often from a major stroke (Stokes & Holden, 1990).

Clinical presentation tends to be more varied than in AD and depends on the parts of the brain affected. The onset is abrupt as opposed to gradual, focal neurological signs (e.g. aphasias, apraxias and agnosias) and symptoms (e.g. hemiplegia) can be present, night-time confusion and depression are more common and people can become easily emotionally aroused. In contrast to AD, the person’s personality tends to be relatively preserved (Green, 2000).

Risk factors for vascular dementia include a history of cardiovascular problems such as hypertension, strokes and arteriosclerosis. It is possible for AD and vascular dementia to co-exist.
1.3 (a) Dementia with Lewy bodies (DLB)

Dementia with Lewy bodies is found in up to 15% of people with dementia (Department of Health, 2001). It is characterised by symptoms similar to Parkinson’s disease, hallucinations and a tendency to fall. Early stages show deficits in attention, executive function and visuospatial abilities (Green, 2000). Memory impairment may not be significant in the early stages, but occurs with progression. The dementia is characterised by fluctuations in cognition, attention and alertness. Extrapyramidal motor features similar to Parkinson’s disease (rigidity, bradykinesia, hypophonia, masked facies and impaired gait) are also associated with this form of dementia (Green, 2000). Progression of this form of dementia tends to be rapid, with the person becoming severely demented and Parkinsonian within 1–5 years (Green, 2000).

Unique features of DLB include the difficulty to remain alert during the day with episodes of brief unresponsiveness and inattentiveness. Visual hallucinations of people or animals are common, recurrent and detailed. While often having insight that these perceptions are unreal, the person does not tend to find them frightening, although they may find them disturbing (Green, 2000).

1.4 (a) Frontotemporal dementia (FTD)

Frontotemporal dementia is characterised by insidious and progressive behavioural changes in personality and mood (Green, 2000). This usually begins between the ages of 45 and 65 and is estimated to occur in 10–20% of dementia cases. Between 40 and 60% of people with FTD have a familial history of it. Average duration of the dementia is eight years. Changes to personality may include being overactive, disinhibited, impulsive, apathetic, or exhibiting repetitive/stereotypical behaviour. Mood disorders can include depression, emotional lability, manic
behaviour and irritability. People may also show signs of hypersexuality, hyperorality and compulsive attention to detail (Green, 2000). Awareness of changes may be limited and judgement compromised (Green, 2000).

1.5 (a) **Semantic dementia**

Semantic dementia is rare. It is characterised by speech deficits, with content being empty and conveying little information. People with semantic dementia often use vague or idiosyncratic terms. People have severe deficits in comprehending single words or in naming objects and describing their use. Behavioural changes may also be observed, such as reduced concern about others, reduced interests, neglect of routine activities and sometimes a preoccupation with financial affairs (Green, 2000).

**REFERENCES**


London: Department of Health.


APPENDIX 3

Memory theories and concepts

2.1 (a) Theories of memory

In the early 1960s research and theories of memory advanced and new psychological models of memory emerged that were informed by information processing theory (Van der Linden & Van der Kaa, 1989). They looked at the structure of mnemonic systems and the memory strategies that people use. Atkinson and Shiffrin (1968) developed a theoretical model where memory was made up of several storage units:

- Pre-categorical (iconic and echoic memory) which briefly stores sensory information
- Short term memory which is transitional storage with a rapid decline in trace strength, limited capacity, not organised and uses speech coding.
- Long term memory which is permanent storage with a high level of organisation and semantic coding.

However the credibility of the distinction between short term and long term memory was undermined by several studies (Van der Linden & Van der Kaa, 1989). There was much debate over the basic characteristics of the two systems, such as their storage capacities and the length of time information could be stored by each (Van der Linden & Van der Kaa, 1989).
As a result of these problems researchers looked for alternative theories to explain how memory works. The concept of “working memory” was developed by Baddeley and Hitch (1974). This is where a central processor (the central executive) coordinates two “slave” systems: a phonological short term store and a visual short term store (“visual sketch pad”). The central executive oversees the coordination of mental activities and the deployment of limited capacity attentional processing resources to mental activities involved in:

- Rehearsal
- Manipulation
- Organisation of information in short term storage
- Retrieval of information in long term storage

(Green, 2000)

Along with theories of memory systems, theories were developed that classified different forms of information that is stored by those systems. Tulving (1972) developed the idea of episodic and semantic memories. Episodic memory specialises in encoding, storing and retrieving personally experienced events and episodes (encoding is the processing of information in a form that identifies higher-level characteristics of that information and associates it with information already stored in memory to facilitate recall). Such experiences occur at a particular time or place, for example remembering the details of a news story heard on the television the day before or remembering the location of where a wallet is left. Semantic memory specialises in encoding, storing and retrieving general knowledge. They are general concepts developed through experience, the source of which can no longer be
identified, such as the knowledge of word meanings, grammar and abstract concepts. These classifications are separate to the memory systems that deal with the acquisition and use of skills and procedures (procedural memory) (Van der Linden & Van der Kaa, 1989). There is ongoing debate over whether episodic and semantic memory are two distinct functional systems (Van der Linden & Van der Kaa, 1989).

An alternative conceptualisation of memory divides it into declarative (or explicit) memory and non-declarative (or implicit) memory (Green, 2000). Declarative memory includes knowledge based on conscious experience and learning. Semantic and episodic knowledge are stored in this system. Non-declarative memory includes a variety of information which is accrued largely independently of an individual's awareness (Green, 2000). Non-declarative memory includes the learning of perceptual motor skills, classical conditioning and memory priming (Green, 2000). Green (2000) has developed a useful diagram which illustrates this conceptualisation:
2.2 (a) Problems with memory

In order to understand what is going wrong when people experience problems with their memory the nature of recall needs to be understood. Green (2000) describes three stages in remembering new information:

1) *Initial acquisition* – where information is attended, perceived and encoded in the memory system.

2) *Storage in long term memory* – information that is initially acquired is stored here. A vast amount of information is stored, however this is not consciously perceived most of the time. It has the potential to be accessed and enter into awareness as remembered information (like storing information in a filing cabinet).

3) *Retrieval* – this is consciously remembered information and can either be purposefully or automatically remembered. Automatic retrieval can happen when it is cued by current information that is being processed or encoded.

In dementia problems with memory tend to be experienced in terms of declarative (or explicit) memory, with the most pronounced deficit in the early stages being in episodic knowledge. This is likely to reflect a failure to learn rather than faster forgetting or impaired retrieval (Greene, Baddeley, & Hodges, 1996).

In Alzheimer’s disease difficulties are characterised by dysfunction in recent memory i.e. remembering new information. People with Alzheimer’s disease are impaired in the initial acquisition stage and in the storage stage of remembering new information. Remote memory, particularly in the early phase of the disease is relatively preserved (Green, 2000).
In vascular dementia multiple cognitive deficits are present, including memory impairment. Immediate and delayed memory is often less impaired than in Alzheimer’s disease. On tests of delayed memory people with vascular dementia tend to perform better on tests of recognition compared to recall, while people with Alzheimer’s often show impairment in both. People with vascular dementia tend to be more impaired on tests of frontal lobe function, such as those involving planning, sequencing or verbal fluency and may represent problems related to working memory and the central executive system (Green, 2000).

In dementia with Lewy bodies in the early stages deficits tend to be seen in attention, executive function and visuospatial abilities. As discussed above, memory impairment tends not to be prominent in the early stages but is likely to occur as the disease progresses (Green, 2000).

Therefore while the nature and onset of memory difficulties varies depending on the type of dementia people have, memory problems are common to all of the most prevalent dementias experienced by the population.

REFERENCES


APPENDIX 4

ICD-10 diagnostic criteria for dementia

(From Cooper, 1994)

General criteria for dementia

G1 There is evidence of each of the following:

1) A decline in memory, which is most evident in the learning of new information although in more severe cases the recall of previously learned information may also be affected. The impairment applies to both verbal and non-verbal material. The decline should be objectively verified by obtaining a reliable history from an informant, supplemented, if possible, by neuropsychological tests or quantified cognitive assessments. The severity of the decline, with mild impairment as the threshold for diagnosis, should be assessed as follows:

Mild. The degree of memory loss is sufficient to interfere with everyday activities, though not so severe as to be incompatible with independent living. The main function affected is the learning of new material. For example, the individual has difficulty registering, storing and recalling elements involved in daily living, such as where belongings have been put, social arrangements, or information recently imparted by family members.

Moderate. The degree of memory loss represents a serious handicap to independent living. Only highly learned or very familiar material is retained. New information is retained only occasionally and very briefly. Individuals are
unable to recall basic information about their own local geography, what they have recently been doing, or the names of familiar people.

**Severe.** The degree of memory loss is characterised by the complete inability to retain new information. Only fragments of previously learned information remain. The individual fails to recognise even close relatives.

2) A decline in other cognitive abilities characterised by deterioration in judgement and thinking, such as planning and organising, and in the general processing of information. Evidence for this should ideally be obtained from an informant and supplemented, if possible, by neuropsychological tests or quantified objective assessments. Deterioration from previously higher level of performance should be established. The severity of decline, with mild impairment as the threshold for diagnosis should be as follows:

**Mild.** The decline in cognitive abilities causes impaired performance in daily living, but not to a degree that makes the individual dependents on others.

Complicated daily tasks or recreational activities cannot be undertaken.

**Moderate.** The decline in cognitive abilities makes the individual unable to function without the assistance of another in daily living, including shopping and handling money. Within the home, only simple chores can be performed. Activities are increasingly restricted and poorly sustained.

**Severe.** The decline is characterised by an absence, or virtual absence, of intelligible ideation.

The overall severity of the dementia is best expressed as the level of decline in memory or other cognitive abilities, whichever is the more severe (e.g. mild
decline in memory and moderate decline in cognitive abilities indicate a dementia of moderate severity).

G2  Awareness of the environment (i.e. absence of clouding of consciousness) is preserved during a period of time sufficiently long to allow the unequivocal demonstration of the symptoms in criterion G1. When there are superimposed episodes of delirium, the diagnosis of dementia should be deferred.

G3  There is a decline in emotional control or motivation, or a change in social behaviour manifest as at least one of the following:

1) emotional lability
2) irritability
3) apathy
4) coarsening of social behaviour

G4  For a confident clinical diagnosis, the symptoms in criterion G1 should have been present for at least 6 months; if the period since the manifest onset is shorter, the diagnosis should only be tentative.

Dementia in Alzheimer’s disease

Alzheimer’s disease is a primary degenerative cerebral disease of unknown aetiology with characteristic neuropathological and neurochemical features. The disorder is usually insidious in onset and develops slowly but steadily over a period of several years.
A) The general criteria for dementia (G1 – G4) must be met.

B) There is no evidence from the history, physical examination or special investigations for any other possible cause of dementia (e.g. cerebrovascular disease, HIV disease, Parkinson’s disease, Huntington’s disease, normal pressure hydrocephalus), a systemic disorder (e.g. hypothyroidism, vitamin B₁₂ or folic acid deficiency, hypercalcaemia), or alcohol or drug abuse.

The diagnosis is confirmed by post-mortem evidence of neurofibrillary tangles and neuritic plaques in excess of those found in normal ageing of the brain.

The following features support the diagnosis, but are not necessary elements: involvement of cortical functions as evidenced by aphasia, agnosias, apraxia; decrease of motivation and drive, leading to apathy and lack of spontaneity; irritability and disinhibition of social behaviour; evidence from special investigations that there is cerebral atrophy, particularly if this can be shown to be increasing over time. In severe cases there may be Parkinson-like extrapyramidal changes, logoclonia, and epileptic fits.

Vascular dementia

Vascular dementia is the result of infarction of the brain due to vascular disease, including hypertensive cerebrovascular disease. The infarcts are usually very small but cumulative in their effect. Onset is usually in later life.

A) The general criteria for dementia (G1 – G4) must be met.
B) Deficits in higher cognitive function are unevenly distributed, with some functions affected and others relatively spared. Thus memory may be quite markedly affected while thinking, reasoning and information processing may show only mild decline.

C) There is clinical evidence of focal brain damage, manifest as at least one of the following:
   1) unilateral spastic weakness of the limbs
   2) unilaterally increased tendon reflexes
   3) an extended plantar response
   4) pseudobulbar palsy

D) There is evidence from the history, examination or tests, of significant cerebrovascular disease, which may reasonably be judged to be aetiologically related to the dementia (e.g. a history of stroke; evidence of cerebral infarction).

REFERENCES

APPENDIX 5

Copy of ethical approval
ORIENTATION OF PAGE IS AS PER THE ORIGINAL IN THE BOOK.
**Local Research Ethics Committee**

**LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION**

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

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<tr>
<td>Full title of study:</td>
<td>Does a memory rehabilitation programme for older people and their carers lead to a reduction in the impact of their memory problem?</td>
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This study was given a favourable ethical opinion by Local Research Ethics Committee on 17 February 2004. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.
<table>
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<th>Principal Investigator</th>
<th>Post</th>
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<th>Site assessor</th>
<th>Date of favourable opinion for this site</th>
<th>Notes (1)</th>
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<td>Clinical Psychologist</td>
<td>NHS Trust</td>
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<td>Local Research Ethics Committee</td>
<td>24 February 2004</td>
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Approved by the Chair on behalf of the REC:

............................................................. (Signature of Chair/Administrator*)

("delete as applicable)

............................................................. (Name)

(1) The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.
Considerations in the choice of instruments to measure outcomes

4.1 (a) Standardisation

Standardisation of outcome measures is important for several reasons. Firstly, consistency is important in order for a study to have meaningful results. Using standardised measures with precisely defined and comprehensive instructions reduces ambiguity (Gladman, 1991) and improves consistency, as do clearly defined administration procedures that are strictly adhered to. Secondly, using standardised measures that are familiar in the field means that results can be communicated more easily and can be compared with other studies. This is particularly beneficial for subsequent meta-analysis and systematic reviews. Lastly, there is little to be gained from creating a new measure if there is an existing one that is suited to the requirements of the study and there is also evidence to suggest that unstandardised, locally created measures can lead to bias (Marshall et al., 2000). The use of established, standardised measures, therefore, saves time and resources and reduces the risk of introducing bias into a study.

4.2 (a) Objectivity

One of the important underpinnings of quantitative research, and experimental design in particular, is that research is value free. This not only makes the research more likely to be replicable, but means it is viewed as more trustworthy. It is therefore important to make data collection as free from bias as possible.
There are a number of ways bias can be introduced into a study. It can be through a lack of consistent practices in trial administration or data collection. The standardisation of data collection procedures, as discussed above, reduces the risk of this if these procedures are strictly adhered to. Bias can also be introduced through sampling procedures. Random allocation reduces the risk of this (Klaber-Moffett, 1991). If random allocation is not possible then it is important that efforts are made to ensure that groups are matched as much as possible. Bias can occur through the researcher’s involvement in data collection (Gladman, 1991; Klaber-Moffett, 1991; Sackett, 1979). This is known as observer bias and can manifest in a number of ways. One way it can occur is if the researcher knows and is influenced by the outcome of the randomisation procedure. The masking (concealment of allocation) of researchers or assessors involved in data collection reduces the possibility of this form of bias, although it is not always easy to remain masked when interacting with participants during data collection (Gladman, 1991; Siemonsma & Walker, 1997). Another form of observer bias is possible when interacting with participants, this time emerging from participants rather than the researcher. People’s need to be viewed in a positive light is well documented in the literature on impression management and social desirability (Fiske & Taylor, 1991). The presence of a researcher in data collection may therefore introduce bias in this way.

Obtaining information by postal questionnaire reduces the possibility of observer bias (Gladman, 1991); however this method also has problems. Postal data collection introduces problems with response rate and incomplete data. Response rates to postal questionnaires can be low. Apart from reducing the power of a study to detect differences, low response rates can introduce bias if responders differ from non-
responders (Foster, 1998). There are also limitations to the use of this methodology in groups where cognitive function is impaired (Parker et al., 2001).

4.3 (a) Validity

Validity refers to the issue of whether a measure really does reflect the concept to which it is supposed to be referring. There are three main types of validity:

*Construct validity*

Construct validity refers to the extent of concurrence between the results obtained from the measure and the predicted results from the underlying theoretical construct. No correlation between the two would indicate a lack of construct validity.

*Criterion validity*

Criterion validity refers to the testing of the measure against some outside criteria such as another tried and tested measure of accepted validity, expert opinion or its predictive ability. Criterion validity refers to the extent to which the measure agrees with such outside criteria.

*Content validity*

This refers to the individual items within the measure and whether they cover all areas of the construct under examination.

Validity encompasses many different ideas and is not an absolute property of any measure, but a relative one. A measure can be valid for one purpose, but invalid for
another. It is therefore important to ask whether a measure will achieve its intended purpose taking into account what is to be measured and why (Wade & de Jong, 2000).

4.4 (a) Reliability

Reliability refers to the consistency of a measure, the extent to which it repeatedly elicits the same results. For example, a thermometer that gave a different reading each time it was put in water that was at boiling point would be considered a fairly useless piece of equipment because it was unreliable. An instrument can be tested for reliability in a number of ways: It can be over time when nothing is expected to have changed (test-retest reliability); with different assessors administering the test to the same person (inter-rater reliability); or with the same assessor administering the measure on different occasions (intra-rater reliability).

REFERENCES


APPENDIX 7

Outcome measures
“MINI-MENTAL STATE”

Patient ........................................
Examiner ......................................
Date ...........................................

Maximum Score
Score

ORIENTATION

5 ( ) What is the (year) (season) (date) (day) (month)?

5 ( ) Where are we: (country) (county) (town) (hospital) (ward)?

REGISTRATION

3 ( ) Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he learns all 3. Count trials and record.

Trials =

ATTENTION AND CALCULATION

5 ( ) Serial 7s. 1 point for each correct. Stop after 5 answers. Alternatively spell “world” backwards.

RECALL

3 ( ) Ask for the 3 objects repeated above. Give 1 point for each correct.

LANGUAGE AND COPYING

9 ( ) Name a pencil, and watch (2 points)

( ) Repeat the following “No ifs, ands or buts.” (1 point)

( ) Follow a 3-stage command:

“Pick up a paper with your right hand, fold it in half, and put it on the floor” (3 points)

( ) Read and obey the following: CLOSE YOUR EYES (1 point)

( ) Write a sentence (1 point)

( ) Copy design (1 point)

(maximum 30) __________ Total score

ASSESS level of consciousness along a continuum

Alert Drowsy Stupor Coma
CLOSE YOUR EYES

DRAW A CLOCK FACE
BRISTOL ACTIVITIES OF DAILY LIVING SCALE

This questionnaire is designed to reveal the everyday ability of people who have memory difficulties of one form or another.

For each activity (No.s 1-20), statements a–e refer to a different level of ability. Thinking of the last 2 weeks, tick the box that represents your relative’s / friend’s ability.

Only 1 box should be ticked for each activity.
(If in doubt about which box to tick, choose the level of ability which represents the average performance over the last 2 weeks)

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<tr>
<td>1) FOOD</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>a. Selects and prepares food as required</td>
<td>[ ]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Able to prepare food if ingredients set out</td>
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<td>[ ]</td>
<td></td>
<td></td>
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<tr>
<td>c. Can prepare food if prompted step by step</td>
<td></td>
<td>[ ]</td>
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<tr>
<td>d. Unable to prepare food even with prompting and supervision</td>
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<tr>
<td>e. Not applicable</td>
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| 2) EATING |   |   |   |   |   |
| a. Eats appropriately using correct cutlery | [ ] |   |   |   |   |
| b. Eats appropriately if food made manageable and/or uses spoon |   | [ ] |   |   |   |
| c. Uses fingers to eat food |   | [ ] |   |   |   |
| d. Needs to be fed |   |   | [ ] |   |   |
| e. Not applicable |   | [ ] |   | [ ] |   |

| 3) DRINK |   |   |   |   |   |
| a. Selects and prepares drinks as required | [ ] |   |   |   |   |
| b. Can prepare drinks if ingredients left available |   | [ ] |   |   |   |
| c. Can prepare drinks if prompted step by step |   | [ ] |   |   |   |
| d. Unable to make a drink even with prompting and supervision |   |   | [ ] |   |   |
| e. Not applicable |   | [ ] |   | [ ] |   |

| 4) DRINKING |   |   |   |   |   |
| a. Drinks appropriately | [ ] |   |   |   |   |
| b. Drinks appropriately with aids, beaker/straw etc. |   |   | [ ] |   |   |
| c. Does not drink appropriately even with aids but attempts to |   |   |   | [ ] |   |
| d. Has to have drinks administered (fed) |   |   |   | [ ] |   |
| e. Not applicable |   |   |   | [ ] |   |

| 5) DRESSING |   |   |   |   |   |
| a. Selects appropriate clothing and dresses self | [ ] |   |   |   |   |
| b. Puts clothes on in wrong order and/or back to front and/or dirty clothing |   |   | [ ] |   |   |
| c. Unable to dress self but moves limbs to assist |   |   |   | [ ] |   |
| d. Unable to assist and requires total dressing |   |   |   | [ ] |   |
| e. Not applicable |   |   |   | [ ] |   |

| 6) HYGIENE |   |   |   |   |   |
| a. Washes regularly and independently | [ ] |   |   |   |   |
| b. Can wash self if given soap, flannel, towel etc. |   |   | [ ] |   |   |
| c. Can wash self if prompted and supervised |   |   | [ ] |   |   |
| d. Unable to wash self and needs full assistance |   |   |   | [ ] |   |
| e. Not applicable |   |   |   | [ ] |   |

Please turn over
7) **TEETH**
   a. Cleans own teeth/dentures regularly and independently
   b. Cleans teeth/dentures if given appropriate items
   c. Requires some assistance, toothpaste on brush, brush to mouth etc.
   d. Full assistance given
   e. Not applicable

8) **BATH/SHOWER**
   a. Bathes/showers regularly and independently
   b. Needs bath to be drawn/shower turned on but washes independently
   c. Needs supervision and prompting to wash
   d. Totally dependent, needs full assistance
   e. Not applicable

9) **TOILET/COMMODE**
   a. Uses toilet appropriately when required
   b. Needs to be taken to the toilet and given assistance
   c. Incontinent of urine or faeces
   d. Incontinent of urine and faeces
   e. Not applicable

10) **TRANSFERS**
    a. Can get in/out of chair unaided
    b. Can get into a chair but needs help to get out
    c. Need help getting in and out of a chair
    d. Totally dependent on being put into and lifted from a chair
    e. Not applicable

11) **MOBILITY**
    a. Walks independently
    b. Walks with assistance, i.e. furniture, arm for support
    c. Uses aids to mobilize, i.e. frame, sticks etc.
    d. Unable to walk
    e. Not applicable

12) **ORIENTATION – TIME**
    a. Fully oriented to time/day/date etc.
    b. Unaware of time/day etc. but seems unconcerned
    c. Repeatedly asks the time/day/date
    d. Mixes up night and day
    e. Not applicable

13) **ORIENTATION – SPACE**
    a. Fully oriented to surroundings
    b. Orientated to familiar surroundings only
    c. Gets lost in home, needs reminding where bathroom is etc.
    d. Does not recognise home as own and attempts to leave
    e. Not applicable

Please turn over
14) COMMUNICATION
a. Able to hold appropriate conversation
b. Shows understanding and attempts to respond verbally with gestures
c. Can make self understood but difficulty understanding others
d. Does not respond or communicate with others
e. Not applicable

15) TELEPHONE
a. Uses telephone appropriately, including obtaining correct number
b. Uses telephone if number given verbally/visually or predialled
c. Answers telephone but does not make any calls
d. Unable/unwilling to use telephone at all
e. Not applicable

16) HOUSEWORK/GARDENING
a. Able to do housework/gardening to previous standard
b. Able to do housework/gardening but not to previous standard
c. Limited participation even with a lot of supervision
d. Unwilling/unable to participate in previous activities
e. Not applicable

17) SHOPPING
a. Shops to previous standard
b. Only able to shop for 1 or 2 items with or without a list
c. Unable to shop alone, but participates when accompanied
d. Unable to participate in shopping even when accompanied
e. Not applicable

18) FINANCES
a. Responsible for own finances at previous level
b. Unable to write cheque but can sign name and recognises money values
c. Can sign name but unable to recognise money values
d. Unable to sign name or recognise money values
e. Not applicable

19) GAMES/HOBBIES
a. Participates in pastimes/activities to previous standard
b. Participates but needs instruction/supervision
c. Reluctant to join in, very slow, needs coaxing
d. No longer able or willing to join in
e. Not applicable

20) TRANSPORT
a. Able to drive, cycle or use public transport independently
b. Unable to drive but uses public transport or bike etc.
c. Unable to use public transport alone
d. Unable/unwilling to use transport even when accompanied
e. Not applicable

Thank you for taking the time to complete this questionnaire

(Source: Bucks et al 1996)
Hospital Anxiety and Depression Scale (HADS)

Name: ___________________________ Date: ___________________________

Clinicians are aware that emotions play an important part in most illnesses. If your
clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each
item below and underline the reply which comes closest to how you have been feeling
in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don’t take too long over your replies, your immediate reaction to each item will
probably be more accurate than a long, thought-out response.

<table>
<thead>
<tr>
<th>Item</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel tense or 'wound up'</td>
<td></td>
</tr>
<tr>
<td>Most of the time</td>
<td>3</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>2</td>
</tr>
<tr>
<td>From time to time, occasionally</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
<tr>
<td>I still enjoy the things I used to enjoy</td>
<td></td>
</tr>
<tr>
<td>Definitely as much</td>
<td>3</td>
</tr>
<tr>
<td>Not quite so much</td>
<td>2</td>
</tr>
<tr>
<td>Only a little</td>
<td>1</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>0</td>
</tr>
<tr>
<td>I get a sort of frightened feeling as if something awful is about to happen</td>
<td></td>
</tr>
<tr>
<td>Very definitely and quite badly</td>
<td>3</td>
</tr>
<tr>
<td>Yes, but not too badly</td>
<td>2</td>
</tr>
<tr>
<td>A little, but it doesn’t worry me</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
<tr>
<td>I can laugh and see the funny side of things</td>
<td></td>
</tr>
<tr>
<td>As much as I always could</td>
<td>3</td>
</tr>
<tr>
<td>Not quite so much</td>
<td>2</td>
</tr>
<tr>
<td>Definitely not so much now</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
<tr>
<td>Worrying thoughts go through my mind</td>
<td></td>
</tr>
<tr>
<td>A great deal of the time</td>
<td>3</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>2</td>
</tr>
<tr>
<td>Not too often</td>
<td>1</td>
</tr>
<tr>
<td>Very little</td>
<td>0</td>
</tr>
<tr>
<td>I feel cheerful</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>3</td>
</tr>
<tr>
<td>Not often</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>1</td>
</tr>
<tr>
<td>Most of the time</td>
<td>0</td>
</tr>
<tr>
<td>I can sit at ease and feel relaxed</td>
<td></td>
</tr>
<tr>
<td>Definitely</td>
<td>3</td>
</tr>
<tr>
<td>Usually</td>
<td>2</td>
</tr>
<tr>
<td>Not often</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel as if I am slowed down</td>
<td></td>
</tr>
<tr>
<td>Nearly all the time</td>
<td>3</td>
</tr>
<tr>
<td>Very often</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
<tr>
<td>I get a sort of frightened feeling like 'butterflies' in the stomach</td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
<tr>
<td>Occassionally</td>
<td>1</td>
</tr>
<tr>
<td>Quite often</td>
<td>2</td>
</tr>
<tr>
<td>Very often</td>
<td>3</td>
</tr>
<tr>
<td>I have lost interest in my appearance</td>
<td></td>
</tr>
<tr>
<td>Definitely</td>
<td>3</td>
</tr>
<tr>
<td>I don’t take as much care as I should</td>
<td>2</td>
</tr>
<tr>
<td>I may not take quite as much care</td>
<td>1</td>
</tr>
<tr>
<td>I take just as much care as ever</td>
<td>0</td>
</tr>
<tr>
<td>I feel restless as if I have to be on the move</td>
<td></td>
</tr>
<tr>
<td>Very much indeed</td>
<td>3</td>
</tr>
<tr>
<td>Quite a lot</td>
<td>2</td>
</tr>
<tr>
<td>Not very much</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
<tr>
<td>I look forward with enjoyment to things</td>
<td></td>
</tr>
<tr>
<td>As much as I ever did</td>
<td>3</td>
</tr>
<tr>
<td>Rather less than I used to</td>
<td>2</td>
</tr>
<tr>
<td>Definitely less than I used to</td>
<td>1</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>0</td>
</tr>
<tr>
<td>I get sudden feelings of panic</td>
<td></td>
</tr>
<tr>
<td>Very often indeed</td>
<td>3</td>
</tr>
<tr>
<td>Quite often</td>
<td>2</td>
</tr>
<tr>
<td>Not very often</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>0</td>
</tr>
<tr>
<td>I can enjoy a good book or radio or television programme</td>
<td></td>
</tr>
<tr>
<td>Often</td>
<td>3</td>
</tr>
<tr>
<td>Sometimes</td>
<td>2</td>
</tr>
<tr>
<td>Not often</td>
<td>1</td>
</tr>
<tr>
<td>Very seldom</td>
<td>0</td>
</tr>
</tbody>
</table>

Now check that you have answered all the questions

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This edition first published in 1994 by nferNelson Publishing Company Ltd,
414 Chiswick High Road, London W4 5TF
nferNelson is a division of Granada Learning Limited, part of Granada plc
Printed in Great Britain 2/9.02
CARER STRAIN INDEX

Please read this list of things that other people have found difficult in helping out while caring for someone at home. Would you tell me if any of these apply to you by ticking either “yes” or “no” for each of the following statements?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep is disturbed (e.g. because ................ is in and out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>of bed or wanders around at night)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is inconvenient (e.g. because helping takes so much time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>or it is a long drive over to help)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is a physical strain (e.g. because of lifting in and out of</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a chair, effort or concentration is required)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is confining (e.g. helping restricts free time or cannot go</td>
<td></td>
<td></td>
</tr>
<tr>
<td>visiting)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been family adjustments (e.g. because helping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>has disrupted routine; there has been no privacy)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been changes in personal plan (e.g. had to turn</td>
<td></td>
<td></td>
</tr>
<tr>
<td>down a job; could not go on vacation)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been other demands on my time (e.g. from other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>family members)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been emotional adjustments (e.g. because of severe</td>
<td></td>
<td></td>
</tr>
<tr>
<td>arguments)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some behaviour is upsetting (e.g. because of incontinence or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>because ................ has trouble remembering things</td>
<td></td>
<td></td>
</tr>
<tr>
<td>or accuses people of taking things)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is upsetting to find ............... Has changed so much</td>
<td></td>
<td></td>
</tr>
<tr>
<td>from his/her former self (e.g. he/she is a different person</td>
<td></td>
<td></td>
</tr>
<tr>
<td>than he/she used to be)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been work adjustments (e.g. because of having</td>
<td></td>
<td></td>
</tr>
<tr>
<td>to take time off)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is a financial strain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling completely overwhelmed (e.g. because of worry about</td>
<td></td>
<td></td>
</tr>
<tr>
<td>.................. or concerns about how you will manage)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Source: Robinson 1983)
APPENDIX 8

Memory group programme

Session 1

Orientation to group work and programme

- Introductions, group purpose, outline of programme, group rules
- Brainstorm - Impact of memory problems (I) on both client and carer.
  Break
- Brainstorm - Impact of memory problems (II) current strategies.
- Questions/trouble shooting

*Homework:* Memory symptoms diary

Session 2

Models of memory

- Review of previous week
- Models of memory I: The structure of memory
  Break
- Models of memory II: Explicit versus implicit memory
- Group questions regarding models and individual problems

*Homework:* Memory symptoms diary
Session 3

Learning techniques: Errorless learning

- Review of previous week
- Errorless learning teaching
  
  Break
- Individual exercises
- Small group planning homework
- Questions/trouble shooting

*Homework*: Practise errorless learning using personally relevant tasks

Session 4

Memory aids: Notice boards and calendars

- Review of previous week/homework
- Notice boards and calendars teaching
  
  Break
- Small group planning homework (using errorless learning to form new routine)
- Questions/trouble shooting

*Homework*: Choose a frequently asked question. Write information answering that question on the notice board. Use errorless learning to prompt use of notice board to answer question.
Session 5

**Memory aids: Diaries and memory wallets**

- Review of previous week/homework
- Diaries and memory wallets teaching (including example wallet)
- Break
- Small group planning homework
- Questions/trouble shooting

*Homework:* Write daily routine in diary/memory wallet at the beginning of each day. Use notice board to prompt filling in diary/wallet. Prompt use of diary/wallet for information that is needed/answers to questions.

Session 6

**Memory aids: Feedback and fine-tuning**

- Review of previous week/homework
- Small group review of difficulties
- Break
- Creating/reviewing memory wallet design
- Questions/trouble shooting

*Homework*
Session 7

Review: Feedback and fine-tuning

- Review of previous week/homework
- Review of previous topics

Break

- Review of any remaining difficulties/questions
- Group close/follow up plans

Each session was supported by written material. Participants were given a folder in which to keep the notes from each session and their homework diaries.
APPENDIX 9

Reasons for exclusions and non-consent

### Reasons for non-consent

<table>
<thead>
<tr>
<th>Reason given</th>
<th>Intervention group</th>
<th>Control group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient did not want to take part in the study/group</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Carer felt it would be “too much to cope with” / “got enough to do already” / did not want to take part in group</td>
<td>2</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>4</strong></td>
<td><strong>8</strong></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>

### Reasons for exclusion from the study

<table>
<thead>
<tr>
<th>Reason excluded</th>
<th>Intervention group</th>
<th>Control group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>MMSE &lt;18</td>
<td>2</td>
<td>12</td>
<td>14</td>
</tr>
<tr>
<td>No diagnosis of dementia</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Major psychiatric disorder</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>No carer / living alone / living in a nursing home</td>
<td>0</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>3</strong></td>
<td><strong>26</strong></td>
<td><strong>29</strong></td>
</tr>
</tbody>
</table>