

**The development and evaluation of an  
evidence-based psychological therapy  
programme for people with dementia**

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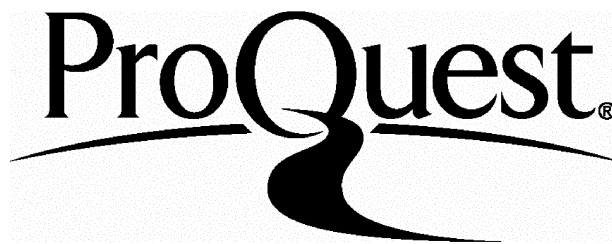
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## **Abstract**

A variety of psychological therapies for dementia have been described over the years. However, research into their effectiveness has been variable, with many studies showing methodological weaknesses. In order to consolidate the existing evidence, systematic reviews on Reality Orientation and Reminiscence Therapy, and a general literature review of the common psychological therapies for dementia were conducted. The results of these were used to design an evidence-based therapy programme for people with dementia, which focused on cognitive stimulation, incorporating elements of reminiscence and multi-sensory stimulation. It was hypothesised that when comparing participants of the programme to no-treatment controls, significant benefits in cognition, behaviour and global functioning would be demonstrated.

Pilot studies in both residential care and day care indicated positive effects of the programme. The pilot studies also resulted in the programme being modified. A multi-centre trial was conducted, involving running the programme in 16 centres and recruiting 142 participants (80 treatment, 62 controls). Groups ran twice weekly for 7 weeks. Assessments were blind, conducted by a separate researcher to the one running the groups. The results showed significant improvements in both measures of cognition and communication for the treatment group compared to the control group. There were also positive trends in depression in favour of the treatment group, but no change in behaviour. A further analysis was conducted excluding the first 3 centres, which had been involved in the programme development and training of the second researcher. Analyses

of the remaining 13 centres found significant improvements in cognition and depression. Males improved significantly more than females in behaviour and communication. Another factor associated with the effectiveness of the programme was the particular centre where the group was located.

This trial has demonstrated that an evidence-based psychological therapy programme can improve cognition, communication and depression in people with dementia, with positive trends in anxiety. The programme should be able to be used by a variety of staff after training in residential or day care settings. Further research could include the evaluation of a staff training package, the possible benefits of a maintenance programme and the potential advantages of combining cognitive stimulation with anti-dementia drugs. Promoting the use of the programme can offer real hope for people with dementia and their carers.

## **Acknowledgements**

I am eternally grateful to my first supervisor, Dr Martin Orrell, for his tireless support, confidence and humour. His enthusiasm and vision turned this project into an exciting challenge. I am greatly appreciative to Professor Bob Woods, my second supervisor, for his wisdom and valuable supervision, and Lindsay Royan and Steve Davies for their clinical supervision and support. I thank Lene Thorgrimsen for her enormous contribution to this project, in running groups and assessments, and for the help of Linda Clare, Nancy Pistrang, Pasco Fearon and Professor Steven Senn.

This research would not have been possible without grants from Barking, Havering and Brentwood NHS trust, and North-Thames NHS executive. Further, I thank Merefields, Goldsmiths, Jewish Care and all the residential homes and day centres in Barking, Havering and Brentwood, Quantum Care (Hertfordshire), Enfield and Camden and Islington who participated. I thank the managers and staff who helped to complete assessments and co-facilitate groups, and all the individuals who partook in this project. Finally, I thank my wonderful family and friends, who have been invaluable in their encouragement and love.

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## **Chapter 1: Introduction**

### **1.0.0. Overview**

*“Work of any kind, even mental work alone, is a means of preventing precocious senility.”* (Lorand, 1913). There has been a longstanding hypothesis that mental activities and stimulation are important in slowing down deterioration in dementia (Cosin et al, 1958). A number of cognition orientated therapies for dementia have been evaluated. Some studies have demonstrated the effectiveness for individuals and groups, for example in improving cognition and mood. However the majority of such trials have had methodological weaknesses, such as being too limited in size to detect clinically important change, and employing unstandardised outcome measures. This is particularly apparent when comparisons to anti-dementia drug trials are made. The latter are generally funded by large pharmaceutical companies, and adhere to licensing requirements including a placebo-controlled, double-blind design and the use of widely accepted cognitive tests. Thus it has been suggested that there is a need for large multi-centre trials on psychological therapies for dementia, in order to show whether or not they might be considered as a “serious competitor” to drugs (Orrell and Woods, 1996).

This chapter presents theories and evidence which suggest that dementia is not simply the consequence of neurological impairment, but that psychosocial factors can play a considerable role in its onset and symptoms. This provides a framework for the subsequent literature review on the psychological therapies, which examines the findings, strengths, weaknesses and criticisms of each. The end of the chapter outlines the plans for this study, which involve the design, implementation and evaluation of an evidence-based therapy programme for people with dementia.

### 1.0.1. Definition of dementia

“Dementia” is an umbrella term, used broadly to describe a number of conditions which are often given separate diagnoses, yet present with similar symptoms. A standard definition was provided by ICD 10 (1992) as: “*A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement....commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.*”

The American Psychiatric Association (DSM IV, 1994) defined dementia as:

- A. The development of multiple *cognitive deficits* manifested by both
  - (1) *memory impairment* (impaired ability to learn new information or to recall previously learned information)
  - (2) one (or more) of the following cognitive disturbances:
    - *aphasia* (language disturbance, i.e. inability to name people or objects)
    - *apraxia* (impaired ability to carry out motor activities despite intact motor function, which may lead to deficits in cooking, dressing or drawing)
    - *agnosia* (failure to recognise or identify objects despite intact sensory function)
    - disturbance in *executive functioning* (planning, organising, sequencing, abstracting)
- B. The deficits in A1 and A2 cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.

- C. The deficits do not occur exclusively during the course of a delirium.
- D. Disturbances are not due to another disorder (e.g. Major Depressive Disorder)
- E. Other symptoms include motor disturbances of gait (leading to falls), disinhibited behaviour, delusions and visual hallucinations.

Some authors have offered more personal depictions of dementia. For example Symonds (1981, p.1709) related it to death, stating that: “ *[Dementia] involves brain cell death; so that if no other illnesses were to supervene it would cause death. It follows that dementia is a form of dying.*” The dementia process may be regarded as a continuum, with stages labelled as mild, moderate and severe (Hughes et al, 1982). The more common dementias (Alzheimer’s and Vascular dementia, see 1.0.3.) typically present in earlier stages with memory impairments, but progress to a stage in which all skills of personality, communication, insight and self-care are lost.

Non-cognitive symptoms of dementia are sometimes described as BPSD (Behavioural and Psychological Symptoms, Devanand and Lawlor, 2000). These include:

- i) Delusions – e.g. that people are stealing things, that their spouse is an impostor, of infidelity (e.g. of a caregiver) or that their place of living is actually not their home. This, for example, may cause attempts to leave residential care.
- ii) Hallucinations (visual or auditory), e.g. of dead relatives or intruders.
- iii) Wandering. Restraint is sometimes used.
- iv) Purposeless activity, e.g. packing and unpacking clothing.
- v) Inappropriate activity, e.g. throwing clothes in the dustbin.
- vi) Physical (e.g. hitting, pushing and biting) and verbal (e.g. screaming and cursing) aggression.

vii) Depression, apathy, anxiety and phobias, e.g. fear of being left alone.

Luxenberg (2000) noted that it might be useful to classify BPSD in a dichotomous manner, with psychological symptoms typically delusions, hallucinations, paranoia, depression, anxiety, reduplications and misidentifications; and behavioural symptoms as aggression, wandering, sleep disturbance, inappropriate eating behaviour and inappropriate sexual behaviour. Folstein and Bylsma (1999) summarised typical mood disorders as slowed thinking, anxiety, tension, apathy, sadness, loss of energy, social withdrawal, somatic complaints, suicidal talk and guilt.

### **1.0.2 A brief conceptual history**

In 1904, the German physician Alois Alzheimer discovered neuritic (or 'senile') plaques in the cerebral cortex of a patient over sixty-five, who had suffered from dementia (Alzheimer, 1904). Three years on, Alzheimer detected senile plaques and neurofibrillary tangles in the brain of a fifty-one year old patient (Alzheimer, 1907). Around this time, it became recognised that the brains of some dementia sufferers showed no degeneration beyond normal expectations at autopsy. Hence this particular type of dementia, involving cerebral atrophy, was named "Alzheimer's", distinctive from dementia as an umbrella term. Alzheimer's work also highlighted a distinction between dementia at the conventional point of old age, and 'presenile dementia' (Perusini, 1909).

Prior to this discovery, the conceptual understanding of dementia was somewhat different. Before 1700, Dementia was accepted as its literal translation from the Latin word *demens*: "Out of one's mind" (Berrios and Porter, 1995). The poet Juvenal, in the 1<sup>st</sup> or 2<sup>nd</sup> Century, is said to have used the term 'dementia' in reference to the mental decrepitude of old age (Weiner, 1991). Willis (1684) described stupidity as a factor of

aging: *“Some at first crafty and ingenious, become by degrees dull, and at length foolish, by the mere declining of age, without any great errors in living”.*

Berrios and Porter (1995) described how dementia was defined in the 1765 French Encyclopaedia (Diderot and d’Alambert, 1765): *“Subjects with Dementia...exhibit foolish behaviour and cannot understand what they are told, cannot remember anything, have no judgement, are sluggish, and retarded....”*. Similarly, the French legal definition at this time was: *“Those in a state of dementia are incapable of informed consent, cannot enter into contracts, sign wills, or be members of a jury.”*

By the nineteenth century, a clear distinction was made between the cognitive impairments of dementia and mental handicap. At this time, dementia referred to deterioration of an individual’s mental functioning and states of cognitive impairment, mostly affecting the elderly and almost always irreversible (Berrios and Porter, 1995). Nonetheless, Alzheimer’s discovery of a neurological basis of dementia may have provided more reason for dementia to be socially accepted as an illness, reducing the scope for labels such as morons, imbeciles, idiots, mongols and cretins (Kitwood 1997b).

### **1.0.3. Types of Dementia**

Different dementias are typically defined by neurological damage and cognitive and behavioural change. Often people are diagnosed as having dementia, the type unclear. However, the models and theories presented in this chapter will show that dementia is not the result of a cause and effect model of organic change, but due to a combination of factors.

*Alzheimer's Disease (AD)* is the most common type of dementia, comprising approximately 40 to 55 per cent of all cases (Arendt and Jones, 1992). It is characterised by gradual onset and continuing cognitive decline, usually starting with memory impairments although sometimes other functions, such as language, show early signs of deterioration. Lowered mood or mild euphoria, hallucinations, delusions and flattened emotional response are frequently found. Diagnosis can only be established with certainty at post mortem, which confirms the clinical diagnosis in about 85 to 90 per cent of cases (Molsa et al, 1984). The brain suffers a general loss of neurons and synaptic connections in certain regions of the cortex (as much as 40% in severe dementia), with raised numbers of neuritic plaques and neurofibrillary tangles being observable on microscopic examination.

*Vascular or Multi-Infarct Dementia* comprises approximately 20-30% of all cases, and consists of a number of small infarctions in the brain, due to a series of tiny strokes. It is characterised by sudden onset and stepwise deterioration, as each vascular episode commonly results in small but sudden deterioration in functioning, and abnormalities in gait. There are other, less frequently found forms of dementia including Lewy Body Dementia, Pick's Disease, Huntington's Chorea, Parkinson's Dementia, Wilson's Disease, Creutzfeld-Jacob disease, HIV or multiple aetiologies.

Earlier distinctions between 'senile' and 'pre-senile' dementia (the cut-off generally being 65 years) have been largely abandoned. Although features of dementia do vary with age, variations generally appear to reflect properties of aging, rather than any fundamental differences in the dementia process (Miller and Morris, 1993). Although a diagnosis of dementia can be made, following criteria such as those set by DSMIV or

ICD10, the actual neurological damage cannot be identified until post mortem. Assessment is therefore complex, and typically involves a thorough investigation into a person's mental and physical state. Cognitive symptoms including memory, orientation and language, are usually tested first, using a variety of standardized assessment measures such as the Rivermead Behavioural Memory Test (Wilson, Cockburn and Baddeley, 1985). Tests are also used to detect perception, planning and organisation, and the ability to perform complex and sequential actions. Non-cognitive symptoms such as apathy, mood disturbance, insight, behaviour and personality changes are frequently assessed by interviewing a carer or next of kin. Chapter 6 describes the scales used in this study in detail.

#### **1.0.4. Normal Aging and the problems of diagnosis**

Aging is a complex process, commonly associated with a number of losses. Even without cognitive impairment, memory loss and other changes associated with dementia, 'normal' old people may experience losses in spouse, friends, occupation, home, health, independence and mobility. Thus depressive symptoms, characteristic of early stages of dementia (apathy, loss of initiative and general decline in performance) frequently occur in normal elderly people. Older people might fear going out and following usual routines, perhaps due to frailty, or the experience of visual or auditory losses that affect their ability to communicate. Butler and Lewis (1977) described how common experiences in old age may cause symptoms similar to dementia: *"The experience of being cut off from normal stimuli...such as in loss of hearing or eyesight, by being marooned, by solitary confinement...may lead to disorganised thinking, depression, panic, delusions and hallucinations."*

Making a diagnosis of dementia is complex, due to the overlap with depression. In the earlier stages, depressive symptoms may result as a person becomes aware of their deficits. In contrast, cognitive deficits are common in depressive illness, due to social withdrawal, loss of interest in environmental cues and subsequent confusion. This sometimes gets described as 'pseudodementia', whereby people initially present complaints of memory loss, but are found on closer evaluation to have no true cognitive deficits (Feinberg and Goodman, 1984). Tariot and Weingartner (1986) hypothesised that depressed patients show more deficits on tasks which require continual attention or effort than on tasks which require automatic processing, due to their deficits being caused by motivational, as opposed to memory problems. Dementia sufferers, however, commonly show deficits on both passive and automatic tasks. The testing situation can result in further complications, as depressed people are prone to anxiety, which may cause them to perform as badly as people with dementia (Raaijmakers and Abbenhuis, 1992). Although the clinical picture of dementia and depression can be similar, implications for treatment and prognosis differ hugely. Dementia may also be confused with amnesia, the main difference being that whereas memory loss is the primary sign of amnesia, symptoms of dementia are far more widespread.

#### **1.0.5. Epidemiology of dementia**

Epidemiological studies show that the prevalence of dementia is directly related to age. The Alzheimer's Disease Society (1998) estimated that AD affects 1 in 1000 aged 40-65, 1 in 200 aged 65-70, 1 in 50 aged 70-80, and 1 in 5 aged over 80. The National Institute of Clinical Excellence (NICE, 2001) estimated that 700,000 people in England and Wales suffer from dementia, of which 400,000 have AD. The life expectancy of those suffering from dementia appears to be increasing with improvements in medication and

services. Ironically, younger sufferers of dementia are more likely to die from it, as older people more frequently die from other causes.

With improvements in health services and overall standards of living, particularly in developed countries, people simply tend to live longer. At the turn of the century, only 25 per cent of the population lived beyond 65 years, yet this was estimated to be over 70 per cent in 1980 (Arendt and Jones, 1992). The World Health Organisation (WHO, 1982) proposed that there will be a continual increase in the numbers of people aged 60 or over worldwide, predicting that by the year 2025, the less developed countries will have an epidemic of dementia comparable to that of Europe in the 1950's. The management of dementia is therefore an ever increasing problem.

#### **1.0.6. Theories of memory in dementia**

Various authors have presented theories hypothesising the way in which memory works, and how aspects of memory interconnect. A distinction is made between 'primary' or 'working' memory, and long term memory processes.

'Primary memory' describes the short-term memory system that temporarily and passively holds information. 'Working memory' describes the system that transforms, manipulates, re-organises and retains information. There are normal, age-related deficits in working memory, which can be demonstrated, for example, in how recall of word lists declines markedly in neuropsychological tests such as the ADAS-Cog (Rosen et al, 1984).

People with dementia tend to be intact on vigilance (being able to detect a stimulus and respond readily). However, there is evidence that they have difficulty shifting attention, both in the visual and auditory domains (Morris, 1999). Further, people with dementia appear to have difficulties sequencing and co-ordinating more than one activity at a time. Baddeley and Hitch's (1974) 'Working Memory Model' (figure 1) is often drawn on when examining the working memory process. In dementia, the main impairment is due to a reduced efficiency of the central executive system, which is used to perform more than one task simultaneously (Baddeley, 1986). Morris and Kopelman (1986) found substantial impairment in task performance in people with dementia when using even simple distracters, such as repeating the word 'the'. Evidence suggests that the articulatory loop system is relatively intact in early AD (Morris, 1984), but that there are impairments in the visuospatial scratchpad. For example, AD patients show impairment on the Corsi Block Span, in which they have to tap out a sequence on an array of nine blocks from memory (Spinnler et al, 1988). As the three systems all rely on each other for effective working memory, these deficits suggest substantial impairments in dementia. Inadequate working of the system results in ineffective encoding of information, with retrieval deficits being an automatic consequence.

Executive impairments have implications for the retrieval of long-term memories, by affecting one's ability to search, link memories with the temporal context and verify the accuracy of memories. Many authors have suggested that long-term memory is composed of a number of separate subsystems (Green, 2000). Primarily, a distinction is made between explicit (declarative) and implicit (non-declarative) memory. 'Implicit memory' refers to an unintentional, unconscious form of memory that does not require recollection of specific episodes. This is relatively unimpaired in dementia. 'Explicit memory'

involves the conscious recollection (recall or recognition) of information from a specific prior episode, and is relatively impaired in dementia.

*Figure 1: The Working Memory Model (Baddeley and Hitch 1974)*

**Articulatory Loop System (ALS)** (Recycles verbal information within immediate memory.)



**Central Executive System (CES)** (Co-ordinates and schedules mental processes.



Composed of a cluster of cognitive processes  
which interact with each other.)

**Visuospatial Scratchpad (VSSP)** (Temporary store of visuospatial material.)

Both episodic and semantic memory are stored within the explicit memory system (Squire and Knowlton, 1995). ‘Episodic memory’ refers to memory for events or personal experiences. It tends to be substantially impaired even at early stages of dementia, for example in recalling events from recent minutes or days, and is an important focus in neuropsychological tests, such as through recall of words or sentences. ‘Semantic memory’ refers to memory about the world, such as facts, rules and concepts including word meanings and abstract concepts. It tends to show impairments slightly later than episodic memory, and some people show no semantic impairments at early

stages of dementia. Difficulties can be shown across a range of tasks, for example in producing a series of words which fit into particular categories such as animals (Morris, 1999). A loss of language content and comprehension reflects deterioration in semantic memory, specifically the meaning of words. This is also reflected in deficits in memory resulting from processing impairments, such as not being able to cluster words into a semantic framework to improve recall, or failing to use semantic cues. To illustrate the latter, using the question “is it a type of bird” would aid recall of the word sparrow for most people, yet does not make a difference in AD (Morris et al, 1999). This suggests a general loss in the meaning of words. Tariot and Weingartner (1986) suggested that impairments in episodic and semantic memory are directly related. Deficits in semantic memory affect performance in episodic memory tasks, because effective encoding of an episode requires access to semantic information.

Autobiographical memory involves remote memories from the past, and consists of both episodic and semantic memory. Normally, people with dementia have strong memories of early years, but difficulty recounting events from recent years. Morris (1994) speculated that this explains why some people start thinking that they are young, as they have no memories to orientate them to present time. Morris attempts to give a neurological explanation, suggesting that as distant memories are recalled numerously, they become ‘overlearned’. Consequently there is a gradual shift of memory traces from primary memory structures, such as the hippocampus, to longterm memory association areas less affected by dementia, and these memories become more resistant to the dementia process. The relative preservation of remote memories explains the popularity of reminiscence as an intervention for dementia (see 1.7.0 onwards).

The implicit memory system involves a variety of information, largely accrued independently of the individual's awareness (Green, 2000), such as perceptual-motor skill learning, classical and operant conditioning, habituation and sensitization, and priming. 'Priming' refers to the increased ability to identify or detect a stimulus as a result of its recent presentation. An example is the stem completion task, in which people are given 3 letter word beginnings (e.g. TAB), and asked to complete them with the first word that comes to mind. People's more frequent completion of words recently presented on a list (e.g. TABLE) than words not presented (e.g. TABLET) indicates the use of implicit memory. Priming does not show significant deficits, as it requires relatively little semantic processing. 'Procedural memory' (memory for skills, such as riding a bike) is also considered implicit and is relatively unimpaired in dementia.

Kopelman (1985) compared the rates of forgetting for AD patients with Korsakoff's patients and healthy controls on tests of both immediate short-term and long-term memory. The latter involved the use of a picture recognition test administered over the course of a week. He found that although AD patients showed severe impairments in short-term memory, their rate of forgetting was similar to normal controls once initial learning had been matched. Kopelman concluded that *"The implication is that the principal problem for all these patients appears to be in acquiring or encoding memories rather than accelerated forgetting."* (Kopelman 1985, p.634).

### **1.1. Rationale for psychological input**

Most psychologists would argue that people with dementia experience disability over and above the disability arising purely from neurological impairment. As stated by Woods (2001, p.7): *"The suggestion is that the person with dementia may well appear more*

*impaired, or to have a more severe level of dementia than is necessitated by the actual neuropathological damage that has been sustained.*” Non-medical explanations of dementia have been offered historically, for example that it is a “defence against the threat of death” (Morgan, 1965). He suggested that the further away an individual’s memories are from the terrifying object of the near future (impending death), the less the memories should be repressed.

In light of this, the author presents an alternative to the purely medical model of dementia, which suggests that deterioration is a direct result of a loss of neuronal circuitry and brain structure. More commonly, it is argued that the presenting dementia is considerably influenced by a diversity of factors such as the environment, social factors and stimulation. The implications are that psychosocial interventions can reduce excess disability and contribute to “rementia”, which Kitwood (1997b) described as the recovery of some of the powers which had been lost, in other words a kind of reversal of the dementia process. The concept of rementia works against the medical model, as if dementia was solely the result of irreversible neurological damage, a significant restoration of cognitive and functional abilities would not be possible.

Evidence for rementia was provided by Sixsmith et al (1993), who studied three ‘homely homes’. These shared a philosophy that emphasised positive care, promoting the well-being, independence and functioning of the residents, and aimed to provide individualised treatment. The authors assessed dependency for all residents monthly over 36 months, finding that a number of people (mostly in one home) who were classified as highly dependent showed behavioural improvements after admission. They argued that this demonstrated how a positive environment and interaction can cause rementia,

although it is difficult to draw conclusions from this study as it is unclear what the factors were leading to significant patterns of change in one home and not the other two.

Similar work was previously conducted by Kihlgren et al (1990), who compared people with dementia in a long-term intervention ward to dementia controls in a normal ward. Staff in the former were given a training program in “Integrity Promoting Care” which is based on presupposing trust, autonomy, initiative and intimacy. Twelve hours of video-recorded interactions during social activities were analysed and interpreted. The treatment participants showed improvements in motor performance and some intellectual functioning, and had lower scores for confusion, anxiety and depression. No changes were observed in controls.

Non-medical models of dementia have been offered by past authors. For example Kitwood (1993) presented a simple equation in an attempt to describe the influences on dementia:

$$\mathbf{D = P + B + H + NI + SP}$$

Where D = Dementia, P = Personality, B = Biography, H = Physical Health, NI = Neurological Impairment and SP = Social Psychology. For example, a person’s personality and life experiences (biography) would shape their reaction to their condition. Their health might interact with neurological impairment, for example through the deleterious effects of some medication. A negative social environment might devalue the person, resulting in greater disability.

Sections 1.1.1 – 1.1.9 discuss factors which might contribute to dementia, drawing on the models and theories generated by past authors and using empirical evidence where possible. These lay the foundations of the author's model of dementia (see 1.2.0.).

### **1.1.1. Neurological factors**

From a medical perspective, AD is typically described as manifested by neurofibrillary plaques, tangles and general neuronal loss. Yet these features are not exclusive to AD, indeed both occur in other conditions such as Down's syndrome and to some extent normal aging. Further, accuracy of diagnosis is problematic, with evidence that 20% or more of cases with the clinical diagnosis of AD are found at autopsy to have other conditions. (McKhann et al, 1984). A lack of correlation between observed neurological change post mortem and symptoms of dementia in the living person was observed as far back as Rothschild in 1937, who found senile lesions in brains of people who showed no clinical change. He suggested that it might be a result of some compensatory mechanism, arguing that the brain might possess similar potentialities as the kidneys, lungs and heart; which can suffer considerable damage yet continue to perform their functions efficiently.

More recently, Kitwood (1997b) drew attention to three fundamental factors. Firstly, some cases of advanced dementia have shown no neurological damage at post-mortem. In contrast, there have been cases of substantial neurological decline with no accompanying dementia symptoms. Secondly, there is a relative lack of correlation between the symptoms of dementia in the living person, and the extent of neurological change at post mortem. Paths of decline amongst people with dementia are often highly disparate. Thirdly, neurological processes proceed very slowly, yet dementia symptoms can appear and proceed much faster, for example following significant life-events such as

hospitalisation. Kitwood thus postulated that decline in dementia is a result of the interrelationship between neurological damage and psychological factors. It should be noted, however, that our understanding of brain processes remains limited. Hence it may be that there are neurological processes occurring in people with dementia beyond the observable plaques and tangles that we are currently unaware of. So for instance Rothschild (1937) would not have known to look for Lewy Bodies in his patients, as Lewy Body dementia was only discovered in the last decade.

More tentative arguments suggest that education might have an effect on both the person's initial brain reserve and their ability to compensate once damage occurs. Katzman (1993) drew attention to a population survey of dementia carried out in Shanghai in 1987 (Yu et al, 1989), which found that the relative risk of developing dementia was approximately twice for those with no education as compared with those with middle and elementary school education. He proposed that secondary school education *"Increases brain reserve by increasing synaptic density in the neocortical association cortex, leading to the delay of symptoms by 4 to 5 years in those with AD, hence halving the prevalence of dementia."* (Katzman, 1993, p.17). Further, he argued that people with high socio-economic status might have greater resistance to dementia, either due to a higher level of neural reserve as a result of premorbid intellect, or due to a tendency to seek more stimulating environments. The latter might help to prevent a decline in cognitive skills. Orrell and Sahakian (1995) suggested two possible links between education and risk of dementia; (i) That education might protect against neurodegeneration, and (ii) That the onset of dementia might be delayed because education had improved neuronal networking so that when neurones died, others could carry out similar functional tasks.

More recently, Gilleard (1997) reviewed a number of international studies of age, education and dementia, concluding that there was a consistent link between educational background and cognitive performance. However, this link was weakened if dementia was diagnosed more broadly using clinical information (including details on the course of the disorder). This latter approach of diagnosis is more common in the UK, where no studies have found a relationship between education and dementia, compared to, say Canada and China. Gilleard proposed that education develops different functional learning systems. Hence rather than just learning to solve everyday problems, formal schooling enables the development of cognitive skills which are less context-based, require abstract thinking, and are more typical of psychometric tests. He asserted that if education did have a substantial influence on dementia, there would have been a consistent drop in developed countries over the last three decades, which has not occurred.

There is also evidence that socio-economic factors such as poor nutrition and health can increase the prevalence of Vascular Dementia (Gorelick et al, 1993). As less educated people are more likely to fall into this bracket, a greater prevalence of Vascular Dementia might affect the overall figures. Lastly, there is an element of bias in psychometric assessments for dementia. For example the MMSE, often used as a screening measure, assumes a level of literacy and numeracy. Hence more intelligent or educated people might not score as having dementia due to the nature of the test, yet less intelligent or educated people might score markedly worse, for example by being unable to read written commands or write a sentence. This was noted by Orrell and Sahakian (1995, p.951): *“The combination of good education and continuing mental activity may mean that people have to undergo more cognitive deterioration before dementia becomes*

*clinically obvious or before their scores in psychological testing are in the range indicating impairment.”*

Further, age and gender might be risk factors associated with neurological change. All epidemiological studies have consistently reported an increased prevalence of dementia with age. For example Jorm et al (1987) found that the prevalence rate doubles every 4.5 years from the age of 60 to 90. Neurological changes associated with AD (senile plaques and neurofibrillary tangles) are often identified in ‘normal’ older people at post mortem, which might, to some extent; account for what authors frequently describe as “age associated cognitive impairment” (e.g. Sherwin, 2000). Amaducci and Lippi (1994) noted that there is a higher incidence of AD in females in almost all age groups in North European and American studies, and also a higher rate of vascular dementia in some of these studies. They pointed out that although some prevalence studies might reflect differential survival rates, differences in incidence are more suggestive of female gender being a risk factor.

These discussions draw attention to two main issues. Firstly, only a partial correlation between neuronal damage and cognitive and behavioural change suggests that other factors might contribute to dementia, as presented in the following sections. Secondly, it is possible that increasing age, gender and minimal education might be risk factors affecting neurological impairment. More specifically, education might improve the person’s ability to adapt to brain damage, either physically (through increased neuronal networking), or mentally (through improved strategies of dealing with new information). However, studies on education and dementia should be evaluated critically, and tests may be biased. These ideas link to theories of ‘Use it or Lose it’, described in 1.1.2.

### 1.1.2. Mental stimulation

The debate in the field of neurobiological research as to whether the brain is more likely to degenerate as a result of over or under-use can be considered historical. Pearl (1924) concluded that *“After roughly age 40 to 45 it appears that a man shortens his life, by definite amounts, in proportion as he performs physically heavy labour.”* This contrasts with the opening statement of Lorand (1913, 1.0.0), that work is a means of preventing *“precocious senility.”* In a more recent review, Swaab (1991) describes how the ‘wear and tear’ argument claims that increased metabolic activity would result in accelerated cellular aging. In contrast, the ‘use it or lose it’ theory states that activation of nerve cells leads to maintenance of neurons during aging and AD, possibly by preferentially stimulating the action of protective mechanisms such as DNA repair.

Swaab made comparisons with the results of several studies on rats, showing increased dendritic branching and cortical thickness following environmental stimulation. He stated that *“The hypothesis that stimulation of activity is necessary to prevent neuronal damage during aging might also explain, at least partly, the fundamental question of why certain neurons degenerate in aging or Alzheimer’s disease while others do not, and why age and Alzheimer pathologies are not manifested to the same degree in different brain structures.”* Swaab (1991, p.321). ‘Use it or lose it’ provides a basis to the argument that mental stimulation in dementia is beneficial, and has been supported empirically by research which demonstrates that engaging in mental activity can improve memory and cognition (Breuil et al, 1994). Research has not confirmed whether stimulation actually creates neuronal change, or whether improvements are more a result of psychological factors. Katzman’s review of research on the effects of education on dementia further supports the ‘use it or lose it’ hypothesis (Katzman, 1993, see 1.1.1.). As dendritic

growth continues in humans well into old age (Buell and Coleman, 1979), there are implications that continued mental activity might delay the onset of dementia.

### 1.1.3. Social Psychology

The manner in which people with dementia are approached, talked to and treated by others has an enormous impact on their self-esteem and well being. Research has shown that shifts, working conditions, social support, staff appraisal and uncooperative or difficult behaviour contribute to stress and burnout in residential and day care staff (Moniz-Cook et al, 2000). This study showed that staff anxiety, supervisor support and the potential for a person-centred, individualised approach to resident care related to staffs' perceived difficulty in managing challenging behaviour. Staff tend to be low-paid, over-worked and receive little supervision or support. Such environmental factors might exacerbate anxiety in staff. Additionally, the opportunity for person-centred, individualised care might be more problematic with low staff-resident ratios and constant time restraints. This raises concern as to how staff might perceive behaviour. Further, Woods (2001, p.12) suggested that challenging behaviour might result from poor communication between people with dementia and their caregivers:

*“Aggression occurs most often during intimate care, when plausibly the person feels most vulnerable and threatened; shouting out may reflect a physical pain that cannot be adequately communicated, or a need for contact for a person who feels abandoned;....wandering may reflect a search for something or someone familiar and safe, in a place that appears strange and frightening.”*

Elderly people are generally viewed as an unattractive group to work with (Woods, 1992), and the low morale of staff can easily reflect onto the patients: *“The staff*

*member's demeanour, tone of voice, facial expression, speed and direction of approach may make the difference between a warm, friendly interaction and an 'aggressive outburst'.*" (Woods, 1992, p.127). Kitwood (1997b) identified seventeen common factors that affect people with dementia and others, particularly by staff in residential care settings (Table 1). He described these negative social aspects as contributing to the "malignant social psychology" of dementia care, drawing connotations with an evil, cancer-like decline. Kitwood suggested that the process of dementia was a "dialectical interplay between neurological impairment and malignant social psychology", stating that: "*A malignant social psychology may actually be damaging to nerve tissue. Dementia may be induced in part, by the stresses of life. Maintaining personhood is both a psychological and a neurological task.*" (Kitwood, 1997b, p.49). However, this suggestion that psychological factors might actually induce neurological change is a source of considerable debate from a pathological viewpoint and is not empirically supported. What appears more likely is that the "malignant social psychology" could exacerbate the damage caused by neurological change or vice-versa.

The strength in Kitwood's work lies in its appeal to people on all levels, from care staff and home carers to academics. However, he acknowledged that much of his evidence (for example on dementia) was anecdotal. Most of his findings were based on outcomes from hours of direct observation, so it might be argued that his ideas are interesting but need to be tested empirically.

*Table 1: Kitwood's 17 factors of a Malignant Social Psychology (Kitwood, 1997b)*

<b>FACTOR</b>	<b>DESCRIPTION</b>
<b>Treachery</b>	Using deception to distract or manipulate a person
<b>Disempowerment</b>	Not allowing a person to use their abilities
<b>Infantalisation</b>	Treating a person like a child
<b>Intimidation</b>	Inducing fear in a person
<b>Labelling</b>	Using a category such as 'dementia' as a basis for interaction
<b>Stigmatisation</b>	Treating the person as a diseased object or outcast
<b>Outpacing</b>	Acting / behaving at a rate too fast for a person to follow or understand
<b>Invalidation</b>	Failing to acknowledge a person's feelings
<b>Banishment</b>	Excluding a person physically or psychologically
<b>Objectification</b>	Treating a person as a 'lump of dead matter'
<b>Ignoring</b>	Acting as if a person is not there
<b>Imposition</b>	Forcing a person to do something
<b>Withholding</b>	Refusing to give attention
<b>Accusation</b>	Blaming a person, perhaps when it is not their fault
<b>Disruption</b>	Disturbing or disrupting them without consideration
<b>Mockery</b>	Making a joke of the person's losses
<b>Disparagement</b>	Telling somebody they are worthless, or damaging their self-esteem

Lastly, some social psychological theorists have discussed our division of “selves”: our “private self”, consisting of personal identity, and our “public self”, presented in episodes of interpersonal interaction with others (Sabat and Harre, 1992). For example, the same person might present as an authoritative professor when with students, an affectionate parent when with their children and a vulnerable patient when at the dentist. Sabat and Harre claimed that ‘selves’ depend for their existence upon co-operation with others in the social context. Thus if the person with dementia attempts to construct a particular self with somebody who does not co-operate in the process, that self will not come into existence. The authors provide an example of someone being introduced as a person who “used to be a lawyer”. This deconstruction, from a successful lawyer into a dependent person with a terminal illness or disease might not only be emotionally damaging for the person with dementia, but redefine the way they see themselves and hence relate to, and are interpreted by others.

#### **1.1.4. Personality**

Authors have described people’s varying coping strategies and adaptive mechanisms, both when being diagnosed and in dealing with dementia. These tend to be indicative of their personality style, life experiences and strategies for coping used throughout life. For example Bahro, Silbber and Sutherland (1995) described the coping mechanisms used in seven people with dementia as denial, externalisation (attributing problems to others), somatization (attributing problems to physical change rather than cognitive loss) and self-blame. Varying coping strategies may be more or less effective for different people in different situations, for example denial could sometimes be adaptive as a protective mechanism.

The Awareness Context (AC) was introduced by Glaser and Strauss (1965) as a way of examining how a person's awareness and understanding of their illness might cause personal trauma and even further symptoms. Regarding dementia, Meisen (1997, p.69) stated that: *"The concept of AC compels us to differentiate very precisely between the real / primary symptoms of the disease (that is, behaviour / cognitive dysfunctioning directly related to brain dysfunctioning), and those reactions caused by the awareness of the symptoms. Without considering AC, all behaviours / symptoms become attributed to brain failure."* This statement might be considered narrow in suggesting that organic change and awareness are the only contributing factors in dementia. One's awareness of their impairments might link to their coping mechanisms and personality. For instance, denial and externalisation might be effective in reducing symptoms due to awareness of dementia, such as depression, apathy, loss of insight and aggression. Clinical observations and research indicate that people's reactions to their illness continue long after their 'illness insight' has disappeared (Meisen, 1993).

Motivation, which might relate to personality and environmental demands, can affect the way in which people with dementia present. Harding and Palfrey (1997), who largely regard dementia as a socially constructed phenomenon, discussed how many people holding down responsible and challenging jobs are unable to accurately recall information such as their car registration plate and roads which they frequently travel on, because they have seen no need to register it in the first place. They suggest that there might be no need for a person living in an institution to know what day or even what year it is, implying that some losses of orientation result from motivational factors.

### 1.1.5. Sensory stimulation

Sensory deficits are typical of old age. Visual impairments frequently prevail, commonly due to eye pathologies such as cataracts and glaucoma. It has been estimated that two thirds of people over sixty-five have some level of hearing loss (Eastwood and Corbin, 1987). For people with dementia, the effect is likely to be exaggerated due to difficulties in attention. An early study by Williams (1956, p.278) suggested that *“It is not so much that [the person with dementia] is unable to receive information through his senses, but that he is unable to select or abstract from all the information, that which is relevant.”*

The first study on results of sensory deprivation in the elderly in 1940s (Cameron, 1941) showed that night-time confusion and wandering in elderly people was due to reduced sensory input, rather than fatigue. Hebb began studying sensory deprivation in 1953 (described in Bower, 1967). He placed experimental subjects (healthy adults) in a soundproof room, blindfolded them and restricted their body movement. Psychological tests were administered before, during and after the isolation period, which lasted from a few hours to some days. Hebb demonstrated that normal individuals placed in these conditions of depravity performed significantly worse than controls, experiencing hallucinations and delusions which continued hours after the conclusion of the experiment. Hallucinations are more likely to occur in environments of partial/diffuse light and noise than in conditions of total darkness and silence.

The sensory deprivation demonstrated here can be likened to the experiences of people with dementia, who usually suffer from impairments in many, if not all their senses. A loss of sensory abilities, combined with an environment lacking in stimuli (i.e. many residential homes) could exacerbate the common symptoms of dementia, such as

confusion. With this in mind, it appears imperative to heighten environmental stimuli as much as possible. Bower (1967, p.1114) stated that: *“An environment stripped of sensory material, which invariably surrounds [institutions], [may well] create a state of cerebral decompensation, attributed to the dementing process, but in part, at least, based on sensory deprivation.”*

Reminiscing Disorientation Theory (RDT; Jones and Burns, 1992) links to research demonstrating the negative effects of a lack of environmental stimulation for people with dementia. RDT states that behaviour is often labelled ‘psychotic’ when people are unable to control shifts between a “state of intense reminiscing” and a “state of being orientated to reality.” For example, people with dementia might call a home carer “mother”, or talk about putting the children to bed, believing that they are in a different time and/or place. Jones and Burns suggest that these ‘misidentifications’ result from extremely impoverished sources of stimulation or information, and a severely damaged information processing system. However, this theory is based on anecdotal evidence, and most of the factors described in sections 1.1.1. – 1.1.9. could contribute to such levels of confusion.

#### **1.1.6. Environment**

Both the physical and social environment have an impact on the person with dementia. The effects of design and architectural features on behaviour and mood have been subject to some debate. Gulak (1991) developed architectural guidelines for psychiatric hospitals, suggesting that beneficial factors include:

- (1) The clear indication of a room’s intended use, for example designing rooms to resemble a living room.
- (2) A variety of spaces to support social interaction, including space for both large

group interaction and more intimate meetings.

- (3) Distinctive colours to enhance activities and space.
- (4) The use of lighting to define space, for example using soft lights to encourage warmth.
- (5) The use of a variety of materials to provide different tactile and visual experiences.

Much attention has been drawn to the social environment and the impact it has on the person with dementia's quality of life. Standardised environment assessment scales have been developed, which draw attention to the factors that might affect well-being. For example the Sheltered Care Environment Scale (SCES), part of the Multiphasic Environmental Assessment procedure (MEAP, Moos and Lemke, 1984) was used by Netten (1991) in a study examining residents' functional abilities. Sub-scales included:

- (i) *Cohesion*: how helpful and supportive staff are to residents and how supportive residents are to each other.
- (ii) *Independence*: how self-sufficient residents are encouraged to be and how much responsibility and self-direction they are encouraged to take.
- (iii) *Self-exploration*: the extent to which residents are encouraged to openly express their feelings and concerns.
- (iv) *Resident Influence*: the extent to which residents can influence the rules and policies of the home, degree to which staff direct them through regulations.

Using the results of the SCES, compiled from forms completed by care staff, Netten classified her sample of 13 homes into three types of regime: positive (opportunities for residents to do or decide things for themselves); mixed (opportunities for freedom and choice in some areas but not in others); and restrictive (narrow and restrictive view of

residents' capabilities, denying opportunities for deciding things for themselves). Additionally, the sample residents were assessed at the beginning and end of a six-month period using cognitive and behavioural measures of the CAPE (Clifton Assessment procedure for the Elderly, Pattie and Gilleard, 1979). She found a significant relationship between regime type and change in level of a) apathy, b) social disturbance and c) orientation over the six months, suggesting that the environment can exert great influence on individual outcomes. However, her sample was not randomised and there were no details of non-survivors.

#### **1.1.7. Physical health**

Physical illness or disabilities may cause dementia-like symptoms, or add further to confusion and deterioration. For example, partial blindness might increase the likelihood of hallucinations, bladder problems could increase constant demands to go to the toilet (which might be interpreted as repetitive shouting), and the side-effects of medication could be deleterious. Poor physical health might make it harder for a person to adapt to the symptoms of dementia. For example, a person finding it difficult to remember appointments who also is immobile might be less motivated to be independent, hence relying on others and deteriorating further.

“Delirium” is defined by reduced clarity of awareness of the environment, and impaired ability to focus, sustain or shift attention; otherwise described as “disturbance of consciousness”. It also involves perceptual disturbances, and cognitive changes such as memory deficits, disorientation and language disturbances. These disturbances develop over a short period of time (usually hours to days) and tends to fluctuate over the course of the day. Commonly, delirium is caused by physical illness such as pneumonia,

infections or reactions to drugs. However, a common cause of delirium is sensory deprivation or sensory overload, due to visual and auditory impairments (Mulligan and Fairweather, 1997).

As described in 1.1.5., sensory impairments are common in old age, and people with dementia have added difficulties in selecting and abstracting incoming information. Additionally, with a monotonous, dulled sensory input / environment, people with dementia are more likely to get delirium, and many people with delirium have an underlying dementia. The psychological consequences of delirium include fluctuating consciousness, agitation and restlessness, problems with concentration and attention and hallucinations, exacerbating the cognitive difficulties of the underlying dementia.

#### **1.1.8. Life events**

Complex and traumatic life events are common in elderly populations. These might include the death of a spouse or friends, loss of independence, loss of health or a change in living environment, such as relocation or modification of an existing environment. People with dementia might find it difficult to cope with such adverse events, due to increased frailty, decreased adaptability and vulnerability to physical and mental ill health. Orrell and Bebbington (1995) suggested that organic impairments often lead to a decreased ability to deal with environmental demands, therefore novel or ambiguous environments increase the level of disorientation. There might be cognitive and emotional elements of change, such as learning the route around a new place or moving away from a lifelong family home.

In a meta-analysis of risk factors in AD, Jorm et al (1991) concluded that case controlled studies showed no evidence that life events were a significant risk factor, although Orrell and Bebbington (1995) argued that the methods were primitive, such as the use of unstandardised measures; and the conclusions unsustainable. They subsequently conducted a controlled study examining the effects of life events in seventy people with dementia before admission to a psychogeriatric unit, compared to fifty dementia controls living in the community and fifty fit elderly people matched for age and gender. This data was used to examine a number of outcomes, reported in different papers. For example, they found that severely threatening life events (such as a diagnosis of cancer) were strongly associated with depressive symptoms, yet events consisting of changes in social environment (such as a move from a house to a flat) were strongly associated with deterioration and admission (Orrell and Bebbington, 1995). Further, they found no link between social environment changes and depressive symptoms, and no link between severe threat events and admission or deterioration. They argued that this demonstrates how changes in the social environment are more important than threat in their capacity to disrupt the functioning of people with dementia. Thus cognitive disruptiveness rather than emotional upset appears to have the greatest impact.

Another study (Orrell and Bebbington, 1998) investigated the relationship between severity of dementia, life events in the preceding six months and hospital admission. They found that life events appeared to increase the relative risk of admission for people with less severe dementia. Similarly, earlier work by Pruchno and Resch (1988) found that people with moderate dementia appeared most adversely affected by relocation, even though it was often to a more suitable or comfortable environment. They suggested that at this stage, adaptive capacity may be reduced yet an awareness of what was happening

maintained. This might be due to a greater awareness of their inability to cope and adapt compared to people at later stages.

Orrell, Butler and Bebbington (2000), conducting a 3-year follow-up on 60 recently admitted people with dementia, found that adverse life events were associated with reduced survival. Fewer survivors had threatening life events in the 3 or 6 months preceding admission than non-survivors, although the differences did not reach significance. It is possible that cognitive deficits occurred before dementia was diagnosed, and that some life events and crises occurred due to early symptoms of the illness. In summary, it appears that life events might play a role in increasing disorientation and depression, causing further deterioration in people with dementia.

#### **1.1.9. Mood**

Woods (2001) asserted that although substantial numbers of people with dementia also have symptoms of depression and / or anxiety, depression co-existing with dementia has received little attention, possibly because of an over-emphasis on distinguishing the two conditions rather than viewing depression as a concomitant of dementia. Eastwood and Reisberg (1996) described the common depressive symptoms in dementia as flattened affect, paucity of speech, slowed gait, generalised psychomotor slowing and poor concentration. Devanand and Lawlor (2000) stated that the reported prevalence of depression in dementia, in cross-sectional studies, ranges from 15% to 50%; though the prevalence of major depression may be lower. Constant losses, such as in memory and ability to perform activities of daily living, are likely to affect mood. This in turn could have negative effects on people's capacity to concentrate and process information.

Orrell and Bebbington (1996) reported that studies estimating the prevalence of anxiety in dementia ranged from 12% to 50%, but found that anxiety was not associated with age, gender, social class or degree of cognitive impairment. People predisposed to higher levels of neuroticism and anxiety might find it harder to deal with the cognitive and behavioural losses in dementia, potentially increasing impairment. This might further exacerbate symptoms. For example a person who experiences anxiety when forgetting the date may avoid trying to remember it in the future, compared to someone less anxious about their memory loss.

#### **1.2.0. The proposed model of dementia**

Dementia is frequently accompanied by neurological change, yet this is by no means a clear picture: the mere existence of people diagnosed with dementia showing little neurological damage at post mortem verifies the complex web of factors contributing to decline. Individual differences may depend on neurological factors (type and severity of dementia, location of brain damage) and psychosocial factors. Having considered the evidence above and alternative non-medical models, the author proposes that dementia is the result of a combination of factors which singularly might or might not have an impact on the individual. Hence an all-encompassing model can be viewed as follows:

$$\mathbf{D = NF + MS + SP + P + SS + E + H + LE + M}$$

Where D = Dementia, NF = Neurological factors (impairment, brain reserve and ability to compensate), MS = Mental Stimulation, SP = Social Psychology, P = Personality, SS = Sensory Stimulation, E = Environment, H = Physical Health, LE = Life Events, M = Mood.

Acceptance of non-medical models of dementia has been the basis of most psychological interventions. Clare and Woods (2001) argued that biopsychosocial models (considering the person's social environment, biology and personal factors) have provided a firm theoretical basis for the application of rehabilitation approaches in dementia. These provide a much broader approach to dementia care. As stated by Sixsmith et al (1993): *“the ‘biomedical’ model is a powerful force that not only shapes the way dementia is defined and conceptualised, but also sets the parameters for the treatment of the condition. If dementia is seen solely as an outcome of an irreversible degeneration of the brain, then care can be nothing more than a matter of ..meeting the basic needs of the patient and making them as comfortable as possible.”*

### **1.2.1. Justification for psychological input**

There is a clear rationale for the use of psychological “therapies”. Although drugs such as Donepezil (Aricept) and Rivastigmine (Exelon), which aim to slow cognitive decline in dementia are now in widespread use, there is an increasing awareness of the potential gains from using stimulation and activity as a means of improving quality of life and reducing the rate of deterioration. This study focuses on treatments based on psychological theory, which generally have cognitive elements in their design and presentation. Consequently, most of the research reviewed in this chapter will have a cognitive outcome measure such as memory or orientation. Other outcomes are also considered, including behaviour and depression.

It might be said that cognitive difficulties (such as disorientation and confusion) come earlier in the course of dementia than behavioural problems (such as wandering and shouting), although this does vary between individuals. Hence by targeting people at

earlier stages of dementia, such as those in day care or recently admitted to residential care, might slow down deterioration and possibly delay the onset of some behavioural symptoms. Additionally, the relationship between cognition and behaviour is tenuous. Hope et al (1999) examined the sequence and pattern of 15 types of behaviour commonly displayed in dementia, by assessing people at four-month intervals. They found no systematic progression from normal to abnormal behaviour, but wide individual variation. Further, they reported that *“the great heterogeneity between cognitive impairment and behavioural changes suggests that the behavioural changes are not solely secondary to cognitive impairment.”* (Hope et al, 1999, p.43) Similarly, Cockburn and Keene (2001) assessed 100 people with dementia yearly until death. Analysing the results of the 48 people with confirmed AD at autopsy, the authors found no systematic relationship between memory deficits and behavioural change. They concluded that behavioural changes in AD are not primarily the result of specific deficiencies in memory or cognition, but instead:

*“They may result from an interaction between the environment and brain degeneration that effects behaviour directly and is not mediated through cognitive impairment, therefore suggesting separate and distinct channels of cognitive and behavioural decline.”* (Cockburn and Keene, 2001, p.214).

Behavioural change might be the result of emotional needs which cannot be expressed cognitively or verbally (Stokes, 1996). For example, rocking behaviour might symbolise a person's need to mother or be mothered. It might be that if people are at a stage in which they are able to express themselves verbally and engage in group work with a cognitive element, behavioural problems might reduce as a result of resolving issues and conflicts. For instance, shouting and aggression might be due to a person feeling ignored

or undervalued. Becoming part of a group in which their opinions and stories are valued might reduce their need to be validated.

There is a wide body of research targeting behavioural problems in dementia. Often, the most effective treatment appears to involve individual training targeting problem behaviour, such as reducing obsessive behaviour (Bird, 2001). Reducing problem behaviour is extremely important for an individual's esteem and quality of life. Behavioural difficulties might create emotional and cognitive problems. However it could be argued that there are potential benefits to anxiety, depression and self-esteem obtained from group programmes involving stimulation and activity, which might be less likely in targeted behavioural training. It might also be that sometimes, targeted behavioural training deals with the symptoms without addressing the route of the problem. The targeting of behaviour is beyond the scope of this thesis, which focuses on group work with dementia typically involving cognitive and/or social engagement (as opposed to behavioural training) and primarily considers cognitive outcomes. Nonetheless, the effects on behaviour will be reviewed and examined where available and possible.

The work of a few leading psychologists in the field has been highly influential in advocating the importance of psychological understanding and input in dementia care. It is important to draw a distinction between the need to find a 'cure' for dementia and the need to improve the treatment and management of dementia. For the latter, the potential input of psychologists is invaluable.

### 1.3. Models of Care

#### 1.3.1. “Personhood” and the “new Culture of Dementia Care” (Kitwood, 1992)

Kitwood drew on the philosopher Buber’s ideas of personhood, along with his own theory of malignant social psychology to develop his own model, a “new culture of dementia care”. It is based on the following underlying principles:

- **The uniqueness of each person.** We each have our own history, personality, likes, dislikes, abilities and beliefs, which combine to make up our identity. If we truly recognise aspects of a person’s individuality, the less important the dementia becomes.
- **Subjectivity.** Each individual has their own way of experiencing things, resulting from lifetime experience. Although nobody can grasp the subjectivity of another, people suffering from dementia are often treated in ways that verge on objectivity. Kitwood attempted to portray the subjective experience of dementia through using written accounts and verbal descriptions of sufferers, and consulting people who had undergone illnesses with dementia-like features (such as meningitis). From these he produced fictional accounts providing great insight into the subjective experience of dementia, depicting the fear, desperation and anxiety in tremendous depth.
- **Relatedness.** Humans have emerged as highly social beings, and being part of small groups constantly reaffirms their existence. The theme of “relatedness” is easily lost in dementia care, and each person’s social being needs to be enhanced, due to the lack of inner stabilisers.

#### 1.3.2. “Integrated Approach” to dementia care (Holden and Woods, 1995)

Holden and Woods (1995) presented an integrated approach to dementia care, which recognises some of the general issues that are relevant to most approaches:

- 1) “ *Attitudes, values and principles underlying the implementation of any approach are of prime importance. Psychological and emotional needs must be addressed as much as the physical needs, which often appear paramount.*” Discussing the importance of individuality, dignity, choice, self-respect and independence; they argued that understanding, empathy and imagination from caregivers is essential.
- 2) Individualisation is essential, as each person is unique. Caregivers should adapt their approach to fit in with the individual’s needs and personality.
- 3) Research has shown that under limited conditions, an ability to learn has been identified. For example, four out of five patients with dementia learned to press a lever to obtain music. (Burgess, Wearden, Cox and Rae, 1992). Such findings discredit arguments that no changes are possible in the cognitive deficits of dementia.
- 4) It is important to target the intervention in a way that is relevant and appropriate for the individual. For instance, a person in a residential home may not want to be constantly reminded of the day of the week, yet learning to find the toilet may be more significant.
- 5) Interventions need to be part of an ongoing programme, and be regularly reviewed and updated. Otherwise, effects are unlikely to be long-lasting.
- 6) The behaviour and attitude of the carers will have a major impact on the quality of life of the person with dementia. The effect of intervention on the caregivers is also of vital importance. This has been shown in various studies, for example Greene et al (1983) found an improvement in carers’ mood whilst their relatives attended Reality Orientation sessions.
- 7) Targets should be individualised and set at a level where changes are likely to occur, so that carers are not disappointed, and patients too pressurised.

- 8) Individual programmes, which draw on extensive assessment of the persons needs and resources, should involve the person and their carer as much as possible.

Drawing on these two models would be a good starting point in the development of therapeutic techniques that aim to improve memory, orientation and general quality of life of people with dementia. They also symbolise the changing attitude of many, in emphasising the feelings and needs of the individual, rather than on mere physical care.

#### **1.4.0. The Development of Psychological Interventions**

An understanding of the importance of mental stimulation for people with impaired senses, or who suffered from reduced sensory input, can be traced back many years. Rosen (1961) discussed how in the second century BC, poets and philosophers who ascribed to the practice of mental hygiene suggested that an active mental life might delay the mental decay of old age. For example Cicero, in 'De Senectute', suggested that old men preserve their intellects if they preserve their interests. The first published controlled study examining therapeutic interventions for people with dementia was that of Cosin et al (1958). The intervention, which included individual craft, domestic and social activities, led to improvements not gained by no-treatment controls. The authors concluded that: *"Deterioration of "communications" through declining mental and physical abilities is not the main source of senile failure, but more basic personality functions described in terms like "drive" or "self-motivation" have become defective."* Hence they recognised the importance of using activities to inspire motivation in under-stimulated elderly people. At the end of the 1950's and early 1960's, the foundations of

some of the more popular psychological interventions; Reality Orientation, Reminiscence Therapy and Validation Therapy, were being laid.

#### **1.5.0. Reality Orientation (RO): Background**

Reality Orientation, or 'RO', is probably the most widely applied and evaluated approach in dementia care, and perhaps the most criticised. Developed in its earliest form in 1958 at the Winter Veterans Administration Hospital in Kansas, USA (Folsom, 1966), its origins lie not in geriatric work, but in an attempt to rehabilitate severely disturbed war veterans. An evaluation of care on this unit showed that physical needs were being met, but that emotional needs of individuals needed constant attention. Nursing assistants took on responsibilities that extended far beyond the daily physical care of their charges, developing occupational and recreational activities. This study appears to be an early demonstration of the importance of therapeutic input in dementia care, introducing the earliest forms of RO in conjunction with a general therapeutic approach.

Taulbee and Folsom (1966) described an RO program which was a modification of earlier work. This consisted of two types of RO; "24 hour RO", where staff attempted to orientate patients to reality at all times and during every activity; and "Classroom RO", which consisted of additional half-hour sessions in which patients were presented with RO material. This included individual calendars, word-letter games and clocks. The "RO board" listed the name of the hospital and its location, the current year, month and day of the week, the name of the next meal, the weather and other details. Participants were taught facts in the classes, such as the date, their name, hometown and former occupation.

Taulbee and Folsom (1966, p.23) describe how each of the four participants improved in turn: *“When they arrived, they were all frightened, unhappy and uncomfortable people, but their look of hopelessness soon changed to hopefulness when we told them their names, where they were, and what date and day of the week it was.”* This highly simplistic quote is likely to provoke both mockery and criticism. The authors make broad assumptions: that any unhappiness can be attributed to memory loss, that by reminding people of simple facts, their unhappiness will diminish and that short-term memory is intact. Although this might appear increasingly unsophisticated as time has passed and the knowledge and understanding of dementia has increased, the authors expressed ideas which were relatively advanced at the time, acknowledging the importance of the people’s feelings and self-esteem: *“The attitude adopted makes the patient feel that he is worth something after all, that he can still accomplish something, that life has not passed him by, and that there are still people in the world who care about him.”* (Taulbee and Folsom, 1966, p.24).

In 1969, a book was published by the American Psychiatric Association on RO as a rehabilitative technique (Stephens, 1969). This coincided with a training programme at Tuscaloosa, where nurses and other staff from all over the USA came to learn the RO approach. These marked the beginning of what many regard as a momentous breakthrough in dementia care, which prior to this had largely been seen as a medical problem with only medical solutions. Folsom claimed that RO was ideally suited to patients with a moderate to severe degree of dementia. More recently, authors (Achterberg, Kok and Salentijn, 1997) have advocated RO for earlier stages of dementia, and alternatives, such as Validation Therapy (see 1.8.0.), as more suited for those at later stages. There were a number of studies conducted on RO in the late 1970’s and 1980’s.

These have included studies on non-dementia populations (Bailey, Brown, Goble and Holden, 1986) and populations of mixed diagnoses (Goldstein et al, 1982). However, most studies have examined dementia populations, and are discussed in the following section. Research has tended to focus on classroom RO, as with 24 hour RO, constant monitoring is necessary to ensure implementation and continuity between staff, hence it is more difficult to evaluate.

### **1.5.1. Reality Orientation: Literature review**

This section will present a narrative review of RO, with criticism of the approach in section 1.5.2. See chapter 2 for a systematic review of the approach or refer to Spector et al (1998a) and Spector et al (2000) for further details of the studies (appendix B). Definitions of experimental designs and features (e.g. RCTs, double-blind, CTs) can be found in appendix D. Initially, the outcomes of RCTs will be discussed.

The first RCT of RO was that of Brook, Degun and Mather (1975). Both treatment and control groups had sessions in an equipped RO room, yet the treatment group were encouraged to use the equipment and their questions answered, and controls received no encouragement, their questions ignored. They found that both groups improved in self-care, orientation and socialisation in the first two of the sixteen weeks, yet after that the control participants deteriorated whilst treatment participants either maintained progress or continued to improve. This showed that active participation from the therapist is necessary to induce change.

Woods (1979) allocated fourteen participants into three groups; RO, "Social Therapy" (non orientation-related group activities, such as dominoes and bingo) and no-treatment

controls. Participants receiving RO improved significantly more than the control and social therapy groups in tests of memory, learning, information and orientation. Staff gave their views anonymously at the end of the experimental period, demonstrating that they were more enthusiastic about Social Therapy than RO. The less favourable staff attitudes in the RO group render the consistently better scores even more remarkable. This study provides evidence that the benefits conferred by RO were more than the non-specific effects of attention. This was also demonstrated by Wallis, Baldwin and Higgenbotham (1983), who blindly assessed participants and randomly allocated them into RO and “diversional occupational therapy” groups (involving group and individual activities which avoided orientation-related conversation). They observed marginal cognitive improvements in both groups, the RO group scoring slightly higher post intervention. The excessively high dropout rate, from 60 to 38 participants over three months, raises some doubt as to the methodological strength of this research.

Hanley, McGuire and Boyd (1981) conducted a larger RCT with fifty-seven participants. They compared RO to a ward orientation training, finding that RO led to significant improvements in verbal orientation, but no change in behaviour. In contrast, significant behavioural change was found following ward orientation training. Ferrario et al (1991) treated thirteen participants with RO (with six no-treatment controls) over 24 weeks. They observed improvements in cognition and reductions in withdrawn behaviour following RO, but no changes between groups in other domains (such as psychomotor performance, depression and irritable behaviour). Gerber et al (1991) studied twenty-four participants in three groups: RO, “Social Interaction” and no treatment control. In addition to usual orientation activities, they gave the RO group simple exercises, self-care and food preparation. The social interaction group participated in recreational

activities such as tea parties, games and listening to music. They found significant improvements in cognitive functioning in both RO and social interaction groups, especially in orientation and language. The control group showed no improvement.

Baines, Saxby and Ehler (1987) used a controlled, cross-over design to compare RO, Reminiscence Therapy (RT) and a no treatment control for fifteen participants. This is the only RCT which has shown significant improvements in behaviour (in addition to cognition) for people receiving RO when compared to controls in the initial four-week study period. Interestingly, it was found that the group receiving RO followed by RT showed improvements in both domains, not matched by the group receiving the two treatments in the reverse order. The results of the life-satisfaction questionnaire showed that some receiving RO reported reductions in life satisfaction, not matched by those receiving RT. The authors suggested that: *“Initially, Reality Orientation had a depressing effect on the mood of the residents because it forced them to face up to the reality of their situation.”* (Baines et al, 1987, p.229). Because there were only five people in each group, we cannot conclude that RO is ‘depressing’. It might be, however, that it could have depressing effects for people not interested in becoming more orientated.

More recently, Breuil et al (1994) conducted a study of “Cognitive Stimulation”. Fifty-six participants were randomly assigned to either a “stimulated” group, involving joining dots, associated words, identifying and classifying objects and other activities similar to RO, or a no treatment control group. The improvement in cognition for the stimulated group was highly significant, with no change for controls. There were no observed changes in verbal fluency, but an increased performance in word list memory following

stimulation. Breuil et al's results are intriguing because participants were given less intervention than in all the other RCTs discussed (hourly sessions, twice a week for five weeks); yet results were the most significant ( $p < 0.01$ ). Additionally the methodology was strong, for example they had a large sample size and assessors were blind to treatment. It may be that the orientation process used here, which slightly differed from that of the other studies (see Table 2) is more advanced theoretically than the concepts of the previous two decades, with an increased knowledge of the memory processes in dementia. This type of RO is more akin to the sophisticated cognitive rehabilitation programmes used in brain injury.

The outcomes of controlled trials have been variable. It has been demonstrated that RO can lead to an increase in effort and ability to concentrate (Coen Mieli et al, 1991); significant positive changes in verbal abilities, but not in other cognitive functions (Zanetti et al, 1995); no significant differences in degree of confusion (Hogstel, 1979); and significant improvements in cognition and behaviour (Reeve and Ivison, 1985). In "A Historical Study of Patient Progress", Letcher, Peterson and Scarbrough (1974) made some interesting observations in terms of degree of change found among participants. They discovered that a small number of men who had been educators showed a substantially higher rate of improvement than men of other occupational backgrounds, and that more highly educated people had a greater tendency to improve. These observations contrast with those of Breuil et al (1994), who found that the lower the educational standard, the higher the gain after stimulation. More research is needed to clarify these opposing viewpoints. Letcher et al also noted a weak tendency for younger men to improve more than the older men. They stated that: *"RO should begin as soon as an individual seems confused, such as immediately after a stroke, surgery, death of a*

*family member....If used as a preventative measure, the individual may be able to make the necessary adjustments to his new situation and avoid long-term hospitalisation.”*  
(Letcher et al, 1974, p.803).

Positive findings have emerged from uncontrolled studies in the field, such as significant improvements in orientation and activities of daily living (Cornbleth and Cornbleth, 1979) and improvements in time and place (but not person) orientation (Gotestam, 1987).

Little research has been conducted on 24-hour RO alone. However, Williams et al (1987) compared ten people receiving 24-hour RO in one ward, described as “modified informal reality orientation”, with ten people receiving no treatment in another. After 12 weeks, they found that the experimental group showed significant improvement in cognitive status and ward orientation, with no change in behavioural measures; whilst the control group declined significantly on behavioural measures. 24-hour RO is difficult to implement, as continuity and commitment between staff is needed; and problematic to evaluate, as without constant monitoring, it is unclear how far the programme has been followed.

### **1.5.2. Reality Orientation: Criticism**

RO has generated considerable criticism over the years. Burton (1982) asserted that some of the research into RO lacks validity; not using techniques, materials and methods sufficiently. He also criticised a lack of generalisation of change to other behavioural domains, with implications that changes were artefactual, not of clinical significance, and had no real impact on patients day-to-day lives. Powell-Proctor and Miller (1982, p.458), in a literature review of RO to that date, concluded that: *“Benefits are small and do not*

*generalise widely and reliably to aspects of behaviour not covered by the RO programme.*" They discussed the implicit assumption of RO; that all mentally infirm elderly people will respond to the same kind of therapeutic approach. The authors argued that the most effective interventions are those that are more closely tailored to the individual. Butler and Lewis (1977) claimed that constant relearning of material can actually contribute to mood and self-esteem problems. It is important to note that only two RCTs had been conducted at this time (Woods, 1979, Hanley et al, 1981), there remained a general lack of substantive and significant findings, and many trials had used poor methodology and non-standardised assessment scales.

Dietch, Hewett and Jones (1989, p.974) argued that *"Nursing staff are cynical about the value of RO... Staff apply the techniques of RO in a rote, uninspired way. The treatment emphasis focuses on the communication of information and instructions rather than on the human, interactional process."* Again, most of these criticisms were written before the stronger trials on RO were conducted, such as Ferrario et al (1991) and Breuil et al (1994).

RO appears to have benefits, as demonstrated in numerous studies, although it is important to acknowledge that it can be applied in a rigid and insensitive way, and therefore be detrimental to its recipients. Folsom's early ideas have perhaps been interpreted by some as a banal 'cure' or 'recipe' for dementia care, by using stringent corrective measures. The two vital elements for its success are that it is applied sensitively, and that it is given to people who *want* to receive it. Many people with dementia are aware of their memory losses, and want to be provided with factual information which may help them to function more independently. Others may have no

interest in orientation information, and find the approach distressing. Woods (1992) argued that virtually any method can be abused and distorted, and that much can be achieved from RO if *“The patient’s individuality as an adult is recognised and respected.”* RO groups appeared to lose some of their popularity in the 1980’s. However, RO boards remain common features in many day centres and residential homes.

#### **1.6.0. Memory-related techniques: Background**

In recent years, whilst appreciating that the underlying concepts of RO are valuable, people have begun to develop new approaches to ‘teaching’ people information, based on a more advanced understanding of the neuropsychology of dementia and the way that the memory works. Although some of these approaches remain at their infancy, have not been subject to quantitative analysis, and the concepts leading to their success are not fully understood, they do offer important insights into the best ways to facilitate learning, using more individualised approaches. Memory impairment is frequently one of the first symptoms of dementia. In the earlier stages, an awareness of impairments, primarily in short-term memory, is a common cause of anxiety and distress. Research has suggested that older people often do not use the most efficient or effective memory skills, such as failing to use semantic cues (see 1.0.6.). Although a common suggestion for dealing with memory loss is the use of RO, the literature suggests that two principle memory-related strategies have been adopted by practitioners; external memory aids, and internal memory strategies.

### 1.6.1. External aids

The use of external aids such as large clocks, calendars and information (RO) boards, containing details such as the date, next meal, menu and daily activities, has become increasingly popular. Such aids tend to reduce the problems and anxiety caused by memory loss rather than actually improve memory, and are common in places which adopt an RO approach. For example Williams et al (1987) described a programme of modified 24 hour RO, for which the environment was manipulated by using signposts, colour coding and information. This resulted in improvements in spatial and verbal orientation. Although Woods (1994) suggested that adapting the environment “*reduces the need to remember*”, environmental changes are clearly more effective with staff collaboration, drawing people’s attention to the signs. Further examples of memory aids include writing notes, using name cards, using photos as prompts for long-term memory, emphasising the use of recognition rather than recall, and using short sentences.

The use of personal memory aids for three individuals was demonstrated by Bourgeois (1990). A list of personal facts which caused memory failures was compiled by the experimenter and the participants’ husbands, including names of people and orientation facts. These were summarised as ten declarative sentences, combined with pictures and inserted into a plastic wallet, or ‘prosthetic memory aid’. The four month experiment began with a baseline period in which the experimenter conversed with the participant using three basic prompts, but without memory aids. This was followed by twice daily treatment sessions with the experimenter, and twice weekly probes with a familiar conversational partner, in which participants were given the wallet and instructed them to use it in conversation. Results showed people making more statements of fact and fewer ambiguous utterances once trained in three topics (‘day’, ‘life’, ‘yourself’), with increases

more than doubling or tripling baseline rates of performance. Most treatment effects were maintained at three and six-week follow-up sessions. Yet there was no evidence of the effectiveness of the wallets outside the experimental situation which is where the real value of the findings would be, casting doubt on the validity of this intervention. It would be interesting to know how important these three individuals regarded their ability to remember and use facts in conversation. Advocates of the Validation approach (see 1.8.0.) would argue that the emotional rather than factual content is of greater significance. Yet as they were described as 'middle-stage AD', it is possible that their ability to converse was still a great concern and frustration for them.

### **1.6.2. Internal strategies**

'Internal' memory training strategies might involve working through the alphabet in order to identify the first letter of a forgotten word, or making a visual association between a name and another object/word. Research has suggested that although useful for normal elderly populations, benefits of memory strategies for people with dementia tend to be small or non-existent, particularly for people at later stages of the illness. Backman (1992) explains how *"The methods used are based on strategies that require a considerable amount of cognitive effort and associative skills that are severely impaired in Alzheimer's."* This might explain the limited number of studies on memory training strategies for dementia populations, compared to the extensive literature for non-dementia populations (Scogin, 1992).

Quayhagen and Quayhagen (1989) assessed the efficacy of a home based cognitive stimulation programme on family dyads. Ten people with dementia were given six hours of treatment per week for eight months by their carer. The programme consisted of

communication skills (conversations involving facts and opinions, memory exercises such as verbal and non-verbal recall and recognition) and problem-solving (planning, conceptualisation and categorisation). They found that the cognitive functioning of the ten treatment patients was maintained over time, whereas it dropped for the six patients in the no-treatment control group. 70% of caregivers reported more effective coping methods and resources for themselves, and enhanced interaction and reduced depression in their relatives. However, caregivers' negative reactions, including feelings of anger and frustration, were also reported.

Similarly, Zarit, Zarit and Reeve (1982) conducted a memory training programme for people with dementia and their carers, yet this trial was randomised, and treatment was in a group format. The authors were able to compare the effectiveness of both internal and external strategies. The didactic training, involving fourteen participants, consisted of teaching people to form mental images of words to remember, and linking pairs of words with mental images. The problem-solving training, involving eleven participants, comprised of forming practical steps to manage day-to-day problems, which included using reminders (notebook and calendars) and reorganisation of household objects. Ten people formed a waiting-list control group. The authors found slight, short-lived improvements in recall in the didactic group compared to the two others, and no differences in recognition. The carers of those in both training groups were more depressed after the sessions, with no change in the control group. The authors suggest that this might be a result of observing their relative in the class, which highlighted the extent of their impairment.

Sandman (1993) trained eleven people with AD, accompanied by their carers to (i) learn

the names and interests of each other, (ii) recall the content of a television programme, (iii) recall details surrounding a significant event of the week and (iv) recall details from film clips. In a four-week programme, the people with dementia showed improvements in all areas, *“with the effortful procedures of rehearsal and engagement of “automatic” processes.”* (Sandman, 1993, p.27). Schreiber et al (1999) trained people to find their way around a virtual apartment, through a ten-session computer-based memory training programme. Sessions, which increased in complexity, involved immediate retention (e.g. “Please search for the couch”) and delayed retention (“Remember the task you have just solved. Please solve this task again”). A control group engaged in social interaction whilst the groups ran. The authors found a significant improvement in immediate recall of meaningful visual information (NAI Picture test, Oswald and Fleischmann, 1982) and a strong trend in retention of topographical information (RMBT, Wilson, Cockburn and Baddeley, 1985). Results suggested that improvements in mnemonic abilities (tasks involving some mental organisation or association to facilitate recall) were domain-specific, but that there was a direct link to real-life settings in that treatment subjects showed an improved retention of topographic material when they had to remember and walk a verbally given route. Although limited by sample size, this study showed the potential of both immediate and delayed retention in people with mild to moderate dementia. It also introduces a new concept of computerised memory training, which might be a more productive method in the future, relying less on staff and carers.

Yesavage (1981, p.77) stipulated that *“results of memory retraining programmes have been mixed, but most promising in the less impaired populations.”* He attempted to correlate improvement following memory retraining with initial scores in mini mental state examination (MMSE, Folstein, Folstein and McHugh, 1975), hypothesising that the

most impaired patients would show the least improvement. He examined 300 people involved in memory retraining courses of two parts; a relaxation/concentration element, and a training element involving mnemonics. Yesavage concluded that i) 'Normal aged' (people who score MMSE >25) perform quite well in memory retraining; ii) 'Mild dementia' (people who score MMSE of 18-24) show *some* improvement, but of minimal practical significance; iii) 'Severe dementia' (people who score less than MMSE 18) appear not to benefit. Nonetheless, although validated and tested for reliability, it is important to recognise the limitations of the MMSE as a brief and crude measure.

### **1.6.3. Spaced-retrieval training**

Spaced-retrieval involves learning and retaining information by recalling it over increasingly long periods of time. When a retrieval is correct, the interval preceding the next recall is increased. When a retrieval is incorrect, the person is asked to repeat the correct response, and the following interval length remains the same until a correct response is made, when it is subsequently lengthened. Camp et al (1993) argued that spaced-retrieval engages our implicit memory, as it seemingly requires little cognitive effort and people may be unaware of being 'taught'. As it appears that implicit memory is relatively intact for dementia sufferers, it might be that this is a superior learning technique to the more traditional memory-training strategies. However, this is mere speculation and the precise mechanisms of spaced retrieval remain unclear.

Camp et al (1996) studied the effects of teaching people with AD to use calendars as external memory aids. Spaced-retrieval was used to teach participants to learn the strategy of i) remembering to use the calendars, ii) complete the two tasks written for each day, and iii) sign his / her name each day. The authors found that participants with

mild to moderate dementia were able to recall the strategy over a one-week period. Translating the learned strategy into action was also successful, with the signed calendar pages averaging 81%, and participants completing 59% of the secondary tasks. People who did not complete the assigned tasks sometimes used the calendars to suit their own needs, for example by writing messages and reminders. Results also indicated that calendars continued to be used well after the conclusion of the study. Participants failed to improve in tests of general memory ability, suggesting that the effects did not extend to other domains. Bird, Alexopoulos and Adamowicz (1995) described how for four out of five people with dementia, individual behaviour modification programmes using spaced retrieval were successful in modifying obsessive demands, inappropriate urinating or intrusive aggressive behaviour.

#### **1.6.4. Errorless Learning**

'Errorless learning' is the reduction or elimination of incorrect responses during learning. It has been successfully applied to people with learning disabilities, but research into its use in dementia is at its infancy. Clare et al (1999) reported how errorless learning was used to teach face-name associations to six people in early stages of dementia. Names are taught through repeated exposure and rehearsal. In order to reduce error, people are encouraged only to respond if they are sure that the answer is correct, otherwise answering "I don't know." Results have been extremely promising although further research is needed, and the precise mechanisms that facilitate change remain unclear. However as errors are minimised, participants have an increased experience of success. The use of errorless learning might be a more effective way of teaching orientation information to groups of people, although at present has only been used as an individualised approach.

### **1.6.5 Question Asking Reading**

'Question Asking Reading' (QAR) is based on Vygotsky's concept of the 'zone of proximal development', implying that an ability which an individual might not demonstrate alone can be demonstrated with support from others. Stevens, King and Camp (1993) gave groups of participants a story, continually asking them questions as they read. This encouraged people to interact more with each other, with a subsequent increase in memory for the content of the stories. The authors then trained staff at two day centres to implement this approach. Within each centre, the QAR approach was compared to a control group, in which reading material was presented in a usual way. Although they demonstrated that QAR again increased verbal interaction between group members, and also that staff with little training could learn to apply this approach, memory for content of the stories was not improved following QAR. This might have been a result of the participants involved in this study, who were more impaired than those used in their previous one.

### **1.6.6. Memory-Related Techniques: Conclusions**

Stevens et al's (1993) findings, although merely tentative, suggest that support from others might create a more relaxed, interactive learning experience, hence facilitate more improvements in memory. Further, Backman (1992) stated that a person needs help both during learning and retrieval to reach optimal potential. This was later demonstrated by Sandman (1993), who found that recall of a television programme improved when people worked with their relatives in creating their own test questions on it, therefore establishing their own retrieval cues at the time of learning.

Woods (1994) provided an approach to the “psychological management in dementia”, suggesting that four principle issues should be addressed when considering memory problems in people with dementia:

- (1) A plan should be developed for each individual, according to his or her abilities and deficits (e.g. a person might have relatively good visual memory but poor verbal memory).
- (2) It is important to build on the person’s strengths, for example by “de-emphasizing memorisation as a goal” (Sandman, 1993). Working on the skills that the person still has, allowing them to feel more positive and in control, will enable more success. For example, spaced-retrieval and errorless learning might draw on implicit memory, which is considered relatively intact in AD (Green, 2000).
- (3) The feelings of caregivers must be acknowledged and considered, for example programmes could be designed in such a way that minimal burden is placed on them.
- (4) We must recognise a person’s non-cognitive aspects. The emotional component of a person’s memories and behaviour may be completely different to the cognitive aspects, and are important to address if a person’s quality of life is to be improved.

### **1.7.0. Reminiscence Therapy: Background**

Butler (1963) found early evidence of the use of reminiscing with older people: “*They live by memory rather than by hope, for what is left to them of life is but little compared to the long past.*” (Aristotle, *Rhetoric*, 367-347 B.C.). This depicts a highly negative perspective of reminiscence, portraying ‘memories’ and ‘hope’ as opposing. Butler suggested that in the early 1960s, this old-fashioned view of older people ‘living in the

past', the content and significance of their reminiscence lost and devalued, continued to be held by many. *"The prevailing tendency is to identify reminiscence in the aged with psychological dysfunction and thus to regard it essentially as a symptom."* (Butler, 1963, p.65). He maintained that Reminiscence was equated with escapism; as a means to helping the person fill the void of his later life. There were also suggestions of it obscuring the older persons' awareness of realities of the present, and encouraging *"preoccupation, musing and aimless wandering of the mind."*

Today, Butler's work is considered highly influential in re-introducing the concept of reminiscence as a positive phenomenon in the early 1960's, contrary to its previously held negative image. He defined Reminiscence Therapy (RT) as: *"Vocal or silent recall of events in a persons life, either alone, or with another person or group of people."* (Butler, 1961). It stems from his early work on "Life Review", which he described as: *"A naturally occurring, universal mental process characterised by the progressive return to consciousness of past experiences and the resurgence of unresolved conflicts."* Butler, 1963, p.66). Butler differentiated between the two by stating that RT tends to occur as short, frequent bursts of recall, whereas life review is a form of structured reminiscence.

The strength of RT largely lies in its maximisation of remote memory functions, the last to deteriorate in dementia. For example, a person may not know what day it is, yet have vivid memories of their fifth birthday. It follows that capitalising on long-term memory could potentially have positive effects on self-esteem, through focusing on what the person can, rather than cannot do. RT became a popular form of therapy used for cognitively intact elderly people in the 60's and 70's, yet the first study of RT with a dementia population was that of Kiernat (1979). He discussed the abundance of losses

(such as spouse, home, occupation, independence) experienced by institutionalised elderly, maintaining that: *“The value of their entire lives may be questioned or minimised [resulting in] a special need to reminisce in order to identify with past accomplishments.”* Following a programme of RT, he concluded that *“Conversation can be stimulated, interest can be sparked and attention span can be increased through the recall and review of past life experiences.”* (Kiernat, 1979, p.310). This was an uncontrolled study using subjective assessment scales, and Kiernat suggested that the scores were not an entirely meaningful measure of performance. However, his research was invaluable, as it introduced the idea of using RT with people with dementia. Prior to this, the common belief was that a higher level of memory and comprehension were needed for it to be effective, hence it had generally been used for the ‘normal’ elderly.

### **1.7.1. Reminiscence Therapy: Literature review**

This section will present a narrative review of RT. See chapter 2 for a systematic review of the approach or refer to Spector et al (1998b) for further details of the studies (appendix B). There appear to be three RCTs examining the use of RT for people with dementia. As discussed earlier (1.5.1), Baines et al (1987) compared RT, RO and a no treatment control. They found cognitive and behavioural improvements in participants who received RT after a programme of RO, but no changes in participants receiving RT with no prior treatment. The authors suggested that the skills learned during the RO sessions may have continued to have a positive effect on their behaviour in the RT period. This could also imply that RT might be more beneficial for more orientated people, although this has not been established. Goldwasser, Auerbach and Harkins (1987) conducted a study with twenty-seven participants, receiving either RT, “Supportive Group Therapy” (which focused on present or future events and problems),

or no treatment. They found that RT led to increased depression, an insignificant positive effect on cognition, and no significant behavioural changes. Orten, Allen and Cook (1989) compared RT with a no-treatment control, rating changes using Likert scales which were developed for the study. The experimental group showed a trend towards higher levels of social behaviour, but the authors attributed differences between groups to the experience of leaders. These results should be interpreted with caution, as the outcome measure had not been subject to evaluation.

Cook (1984) described a pilot study of RT, stating that *"Members appeared more alert. The length of their verbal contributions increased. Humour and laughter were more frequently shared."*(Cook 1984, p.93). McKiernan and Yardley (1990) found that people's levels of engagement increased following RT, concluding that it *"has potential as a meaningful and appropriate stimulating activity."*(McKiernan and Yardley, 1990, p.16). Gibson (1994) presented case studies of five people with dementia, discussing the way in which reminiscence can help carers develop an understanding of a person prior to the illness, and how social events can be used to inspire reminiscence. She said: *"We must be willing to enter another's world and share another's experience. To do this, we seek to join their time-scale rather than demand they join ours."*(Gibson 1993, p.60). McClosky (1990) described a program which combined music with RT, designed specifically for people with dementia. Through songs, which were selected especially for the individual after researching their history, the author focused on recalling a memory and invited people to share reminiscences. She portrayed how relaxed and at peace people appeared whilst listening to the music, and cases in which people actually died during the experience. She ascertained that: *"perhaps something in the music gave them permission to die."*(McClosky 1990, p.64).

Some may argue against the validity of RT, due to the limited empirical evidence (Thornton and Brotchie, 1987). Nonetheless, an alternative perspective is offered by Buchanan and Middleton (1994), who claim that the very variables which confound scientific research may be the richest source of evaluating the qualitative elements of RT. They discussed the use of discourse analysis as a means of examining the effectiveness of RT, pointing out that individual differences are vital in detecting if and how RT works, and for whom. In contrast, individual differences are regarded as confounding variables in controlled trials. Analysing discourse can show how RT is constructed by group leaders and presented to participants. Additionally, Buchanan and Middleton described how discourse analysis illustrates the change in perception of RT over the years. They use a quote which suggests that in the early 1970's, it was regarded by some as only being of value to the old person (*"Although this mechanism may seem rigid and tiresome to other persons..."*, Lewis, 1971). However, by the late 1980's, it was considered of social benefit, as a way of educating younger people, through life experiences: *"Reminiscence preserves and transmits the cultural heritage and acknowledges that those who have lived history are its best teachers"* (Gibson, 1989). Hence the perspective of RT has changed from it being regarded as a burden, to a socially active and valuable process. This change is somewhat representative of the more general change in dementia care, where importance is placed on giving people a role, rather than merely trying to make them feel good.

In summary, there is no empirical evidence of the effectiveness of RT, although qualitative accounts do describe benefits. It has certainly been adopted as a popular and highly regarded technique with the elderly. There is clearly a need for more research in the area although it may be that the outcome measures being used are too crude or

inappropriate to assess change, and that new measures, such as quality of life, should be introduced.

### **1.8.0. Validation Therapy (VT): Background**

Originally named “Fantasy Therapy”, this approach was developed by Feil (1967) whilst working as a group therapist in Cleveland, Ohio, for people with dementia. Through detailed case studies, Feil deduced that these people had become disorientated in their seventies and eighties, and when given RO or similar group therapies, they would withdraw, vegetate and become increasingly hostile when confronted with present reality. (Feil, 1967). Hence she developed a new approach, re-named “Validation Therapy” (VT) in 1978, which follows these principle assumptions:

- a) That all behaviour, no matter how trivial it may appear, has meaning.
- b) If it is not possible for a person to remain present in our reality, we must enter their past reality in order to communicate with them.
- c) People in different stages of dementia should not be mixed.

VT places a strong emphasis on touch, close eye contact, mirroring non-verbal behaviour, and matching rhythms and body movements. Feil (1992) provided an example of how the approach could be used for a lady who is looking for her dead mother. Rather than correcting her response (the RO approach), a VT worker might say “Your mother worked very hard. You love her, don’t you?” Feil would argue that by neither insisting that her mother is dead nor pretending that she is alive, such a response reaches the underlying emotional meaning behind the person’s behaviour, allowing her to share her feelings and subsequently lessening her grief. Feil emphasised the importance of acknowledging the meaning behind body movements when speech is impaired. She

illustrated this by describing a man found hammering an imaginary nail. By acknowledging his feelings of usefulness as a carpenter (his former profession), the behaviour reduced, and the man appeared to feel less agitated and isolated.

### *Stages of dementia*

The Validation approach divides dementia into four stages, adopting specific approaches for each. Feil specified that if a person shows behavioural signs characteristic of two stages, they should be placed in the higher stage until they only show behaviour from the lower stage.

*Stage 1) Malorientation.* The person experiences early signs of confusion, typically exhibiting confabulation and self-defensive behaviour, such as blaming others. Here, the focus of VT is on empathic listening, exploring the content of communication by using non-threatening questions, and using repetition and reminiscence. Although some regard VT and RO as opposing, others advocate their use as “companion approaches”, but this usually only applies to stage 1. Validation therapists would argue that beyond this stage, factual information becomes less meaningful, and emotional content paramount.

*Stage 2) Time confusion.* The person loses awareness of time, and impairments in recent memory increase. VT techniques include close eye contact, touch, empathic conversation and linking non-verbal behaviour to unmet needs (e.g. a person rocking their hand to represent mothering a baby).

*Stage 3) Repetitive motion.* Key characteristics are self-stimulating movements and vocalisations, and increasingly contracted posture. VT workers might mirror these repetitive motions and begin to use sensory stimulation.

*Stage 4) Vegetative stage.* Movements are minimal, and the person sleeps, or appears to

be sleeping for most of the day. Validation workers may intervene using movement or sensory stimulation, through applying perfume, massage, singing, music or touch.

### **1.8.1. Validation Therapy: Literature review**

Administering a programme of VT for research purposes can be problematic, as it is more of an ‘approach’ than a concrete ‘therapy’ like RO which has clear methods. Hence research on VT is scarce, and the literature tends to focus on more general activity programmes, where a *validation approach* is adopted. Nonetheless, there have been two RCTs on VT. Toseland et al (1997) compared VT to ‘social contact’ (e.g. music, art and dance) and a no treatment control group. VT groups involved singing, reminiscing and poetry reading, yet adopting a general Validation approach, as outlined earlier. Groups met four times per week, yet after twelve months of intervention, results still provided little support for the effectiveness of VT. Changes reported by nursing staff included reduced physically and verbally aggressive behaviour in the VT group, a significant increase in depression in the social contact group, and no significant changes in the use of psychotropic medications, physical restraints or nursing time needed following VT. As staffs’ observed changes were not verified by non-participant observers and there was no direct assessment of participants, outcome measures might be considered weak. Peoples’ (1982) compared VT, RO and a no treatment control group in an RCT, finding that VT helped some of those described as stages 2 and 3 get in touch with their own feelings, and increased their self-esteem. She found no significant changes in the RO group, and that more people expressed a desire to continue VT than RO. However, the research was flawed as she mixed people of different stages in the same validation group, hence ignoring one of the fundamental guidelines for VT.

Babins, Dillon and Merovitz (1988), in a controlled trial, found that irritability scores increased in the VT group (whilst decreasing slightly for controls), which the authors attributed to the group's discussion of conflicts and self-expression. They also reported no changes in cognition. Jones (1997) summarised the benefits of VT for dementia found in research, including increased overt contentment, verbal abilities, social interaction, socially appropriate behaviour, awareness of incontinence and requests to be orientated. Benefits to staff and family include increased understanding, patience for repetitious stories and requests, more energy to perform basic care tasks, and more positive attitudes towards the dementia process.

### **1.8.2. Validation Therapy: Criticism**

VT clearly has its weaknesses. Morton and Bleathman (1991) presented detailed case studies of three people receiving VT, finding that interaction increased for two people and decreased for the third. They concluded that "*validation may not be the ideal therapy for everybody.*" (Morton and Bleathman 1991, p.330). Babins et al attempted to justify an increase in irritability following VT as a result of "*discussion of conflicts and self-expression.*" This could potentially be problematic in residential homes if people leave the groups feeling unsettled, only to receive little emotional support from overworked staff. The '4 stages' were developed on clinical observations and case histories, and have not been standardised (Babins, 1988). Jones (1997) described how carers commonly view VT as "*colluding with delusion.*" An example of this is encouraging a person to cradle a doll or an imaginary baby, in order to recreate feelings of motherhood. Additionally, this may be regarded as patronising and infantilizing. Research to date has provided little evidence for the effectiveness of VT for dementia. Positive findings tend to be subjective, or resulting from non-standardised assessment scales. Even with conclusive

evidence, it would be difficult to define which aspects of VT are more beneficial, as programmes tend to be so varied. The instruments used to measure change may be inappropriate, or too crude to pick up the more subjective changes reported by nursing staff, psychologists and others. Nevertheless, Kelly (1995) stated that VT has been found to be labour intensive, expensive and having no significant effect on mental status, morale or social behaviour (Robb, Stegman and Wolanin, 1986); and has no significant effect on functional status or level of depression (Scanland and Emershaw, 1993).

## **1.9. Other therapies**

### **1.9.1. Sensory Stimulation / Snoezelen**

The practice of stimulating the senses of people with dementia can be traced back to the early 1970's, when Loew and Silverstone (1971) used touch, smell and taste as part of their programme of 'intensified stimulation and response facilitation for the senile aged'. Over the past three decades, authors have integrated sensory stimulation into programmes of RO (Baines et al, 1987), RT (Kiernat, 1990), and cognitive stimulation (Koh et al, 1994). Residential homes and day centres frequently own an array of sensory materials, such as a 'smell kit' containing bottles of varying odours, foam balls, and music used specifically for relaxation. Although anecdotally, staff may report that the use of sensory materials helps people to relax, there is little experimental demonstration of such effects.

In the 1970's, the concept of "Snoezelen" for people with dementia was developed from the Dutch words for 'doze' and 'sniff', describing the combination of relaxation and sensory stimulation. Snoezelen stimulates the senses using light, sound effects and a variety of materials for touching, smelling and tasting. In the UK, Snoezelen is primarily

promoted by Rompa International, who provide training and advice on their equipment. This includes rotating mirror balls and spotlights, bubble tubes, vibrating pillows, aromatherapy oils and massage pillows. Snoezelen was developed in response to research which suggested that a lack of stimulation is detrimental to the mental health of normal human beings (Cameron, 1941). Many authors advocate the use of Snoezelen for people in the later stages of dementia. Achterberg, Kok and Salentijn (1997) argued that RO is suitable for people in early stages of dementia. As it progresses and the 'here-and-now' becomes less important, VT is more appropriate as it focuses on emotional content. They added that as dementia reaches a stage in which verbal communication is no longer possible, Snoezelen becomes particularly effective.

Descriptive accounts of Snoezelen have reported various outcomes including a calming effect, a tendency towards contentment, maintenance of functional abilities and reduction in staff burn-out (Achterberg, Kok and Salentijn, 1997). However, there are few experimental trials on the effects of Snoezelen. This might be because it is frequently used with people with more severe dementia, for whom objective assessment measures are difficult to use. For example, they may no longer be able to talk, and only vague measures of change, such as eye blinking, might be appropriate. Further, it is often integrated into other treatments which are themselves evaluated. Spaul, Leach and Frampton (1998) studied the effects of Snoezelen on four people with dementia, finding significant behavioural changes in interaction, interest and active looking, with only the latter being maintained after the sessions. With such a small sample and no control group, they concluded that further investigation is necessary, but point out that for people unable to engage in conversation, Snoezelen may offer a context for shared experience and prosocial behaviours.

More recently, Baker et al (2001) conducted an RCT comparing 'MSS' (multisensory stimulation involving music, special lighting, aromas and tactile objects) to activity groups (avoiding the use of the above) for people with moderate to severe dementia. Both treatments involved eight 30-minute sessions over a 4-week period, and effects were investigated both in a day hospital and home environment. The authors found general improvements, with neither treatment appearing more effective than the other. Both groups showed increased attentiveness to their environment following treatment, the MMS group more so. In the day hospital, the activity group increased in amount and initiation of speech, with the MSS group remaining unchanged, yet the MMS group showed significant improvements in mood and behaviour at home, with the activity group declining.

The principal disadvantage of Snoezelen is its cost. For instance, to create a fully equipped Snoezelen room costs around three thousand pounds (Rompa, 1999), and significantly restricts the use of the room for other clinical purposes.

### **1.9.2. Psychotherapy**

There is little reported research on psychotherapy for people with dementia, perhaps because it is both seldom used and difficult to quantify. The ability to remember new information, to integrate and to internalise, are the foundations of psychotherapy. This raises questions as to whether such processes are possible for people with weak cognitive systems, who may not be able to perform such abstract functions or sustain attention. Hausman (1992) pointed out that Freud did not originally intend psychotherapy for older people, claiming that it was inappropriate as they might not possess the cognitive

resources, psychological sophistication and capacity for introspection necessary for the process. However, she argued that dynamic psychotherapy is possible for people with dementia, as three of its goals can almost always be met, no matter how severe the patient's condition: (1) a relationship in which the patient feels cared about, (2) emotional outlet, and (3) enhancement of self-esteem. Other goals, such as 'minimisation of psychological and behavioural problems', and 'increase in coping skills', depend largely on what stage of dementia the person is at.

Hausman described how easily the patient-therapist relationship can be formed, due to the patient's unmet need for somebody empathic, accepting and trustworthy. She outlined the ways in which the process can be adjusted, including more frequent and shorter sessions to counteract waning attention and phonecalls between sessions to keep up continuity. Further, she defined some of the difficulties encountered with dementia patients, which often deter therapists: *"Resentment over the need to spend many extra hours talking to doctors, nursing-home personnel and adult children, anger when and if the patient doesn't recognise you or know your name."* (Hausman, 1992, p.187)

### **1.9.3. Music Therapy**

Music therapy has been defined as *"The planned use of music to improve the functioning in the environment of individuals or groups of persons who are suffering from intellectual, physical or social disadvantage."* (Bright, 1992, p.163). Activities typically include listening to music, playing simple percussion instruments, singing, and movement or dance. It is important that the person is familiar with the music and that it is suited to their individual taste, in order to experience an emotional reaction towards it. Bright (1988) explained how music can be used to evaluate orientation; songs which

mention colours can be used to see how observant a person is of his surroundings, and songs with numbers in the words can encourage the assessment of arithmetic ability.

Music is commonly integrated into psychological interventions, such as RT (Goldwasser et al, 1987); and VT (Toseland et al, 1997; Bleathman and Morton, 1992). Groene (1993) conducted an RCT which compared 'music attention' to 'reading attention' on wandering. He randomly allocated thirty people with moderate to severe dementia, all exhibiting wandering behaviour, to fifteen weeks of either music or reading sessions, finding that the amount of time subjects remained seated, or near to the session area, was longer for music than for reading sessions. A recent Cochrane review on music therapy for dementia (Koger and Brotons, 2000) did not find sufficient empirical evidence, reporting that most of the studies identified were within-subjects designs with the music therapist as the assessor. However, they concluded that anecdotal and qualitative findings suggest that music may be a useful intervention, with studies showing improvements in social behaviours such as participation in group singing, and a reduction in wandering and restlessness during meals. Additionally, it is cheap and easily accessible.

#### **1.9.4. Drama Therapy**

The effectiveness of drama therapy, which utilises reminiscence, role-play, self-expression and socialisation, has been summarised by Sandel and Johnson (1987) as (i) increasing orientation and activation, (ii) facilitating reminiscence, (iii) increasing self-understanding and acceptance, (iv) developing meaningful personal relationships and (iv) building communal spirit. Highlighting a lack of formal research, Wilkinson et al (1998) conducted a pilot study with two consecutive groups, examining the use of drama and movement therapy in dementia. For the first, the focus was on character work and role-

play, and for the second, which used participants with more severe dementia, the emphasis tended to be non-verbal. Activities included playing with balloons and rolling a ball on a parachute. Results showed no differences for treatment participants at a follow-up assessment, compared to a no-treatment control group, although the authors highlighted methodological weaknesses which might have affected the results. They described qualitative outcomes, including “*rich moments of contact, laughter and friendliness*”, and maintained that further research is needed for the approach to be adequately evaluated.

#### **1.10.0. Summary**

As discussed earlier, psychological theory and research suggests that deterioration in dementia is a result of a combination of psychosocial factors such as poor social psychology and lack of environmental stimulation. There is evidently a place for psychologists in constructing an environment and treatment regime which is optimal in terms of reducing cognitive deterioration, and improving other factors such as depression, behavioural difficulties and overall quality of life in dementia.

The research highlights the strengths and weaknesses of the common psychological therapies for dementia. It is important to be aware that each approach has its limitations, and must be applied sensitively to individuals who are suited to it. Research findings are not necessarily indicative of what happens in practice. For instance, although there is empirical evidence supporting the effectiveness of RO, as an intervention it has received much criticism. From the author’s extensive work in residential homes and day centres around London, there has been no evidence of the use of RO groups. Conversely there is little scientific evidence supporting RT, yet anecdotally it appears to be more positively

regarded and frequently used than RO. Some authors in the past have dismissed RT as an unscientific intervention (Thornton and Brotchie, 1987), whereas others have regarded this lack of evidence as an encouragement towards more work being done (Gibson, 1989).

The literature reviewed varied enormously in methodology and design, for example in the quality of outcome measures. These factors should be considered when evaluating the interpretative value of the results. From RCTs, we can ascertain with some certainty that any benefits gained were a consequence of the intervention in question (Breuil et al, 1994). However, groups in themselves can have therapeutic factors, such as installation of hope and universality (Yalom 1995, see chapter 8). It is important that research delineates the specific effects of the treatment from the non-specific effects of the group whenever possible.

The way in which treatments are presented might have some affect on their outcome. For instance, Buchanan and Middleton (1994) discussed the implications of using the word “therapy” in the context of RT, although their suggestions are relevant to all the treatments discussed. They argued that describing it as a “therapy” suggests that it has certain qualities which exceed those of ordinary activities, and can only be provided by people with expertise. High expectations may create apprehension in staff asked to use it, with fears that they might be unable to bring about expected results. On the other hand, presenting RT as “reminiscence” might lower expectations and attract more people towards it, yet it could then be perceived as a ‘normal activity’ for which no skill is needed and which has no standardised procedures.

### 1.11.0. Rationale for study

In recent years, *evidence-based healthcare* has become an integral part of research and practice. This approach implies that clinical decisions must be based on research that clearly demonstrates the evidence of a treatment's effectiveness, primarily through the use of RCTs. This chapter has examined a number of studies that have shown promising results. But as outlined by Orrell and Woods (1996), psychological therapies have suffered from a wide range of methodological problems:

- i) A lack of clarity about what a 'therapy' actually is.
- ii) The small size of studies (most having fewer than thirty participants) make the identification of clinically significant change difficult.
- iii) Outcome measures are often too brief or inappropriate.
- iv) Little or no follow-up.
- v) Inappropriate control groups which might be subject to different psychosocial influences, such as people from a different home or ward.

Additionally, little research has been published in Britain since the 1980's, with a few more recent trials from France, Canada and Australia. Increasingly, decision-makers and budget holders may refuse to consider using treatments unless they are evidence-based. This potentially is a serious problem in the field of psychological therapies, for which the currently available evidence might be considered too limited. Orrell and Woods (1996) suggested that future studies of psychological therapies need to be improved in a number of ways. For example, treatment should be based on a clear defined theoretical model, to allow for replication, and standardised, sensitive instruments should be used, preferably selected from those used for drug trials. They suggested that researchers should collaborate in large multi-centre trials to allow the pooling of results and much larger

groups, which would enable a proper statistical evaluation of the potential effects. This 'gap' in evidence-based research, and the need for rigorous trials; formed the foundations of this study.

Chapter 2 describes the conducting of two Cochrane systematic reviews, on RO and RT for dementia. Chapter 3 shows how these reviews, together with a systematic process of evaluating the literature, were used to design an evidence-based psychological therapy programme, based on cognitive stimulation. Chapters 4 and 5 describe pilot studies in day care and residential care. Chapters 6 – 8 involve the methods, results and discussion of the full, multi-centre trial.

## **Chapter 2: The Systematic Reviews**

### **2.0.0.            Aim**

- ♦ To conduct two systematic reviews, on Reality Orientation (RO) and Reminiscence Therapy (RT) following the framework of the Cochrane Collaboration.

### **2.1.0.            Background**

Evidence-based healthcare advocates that clinical decisions should be based on research which clearly demonstrates the effectiveness of a treatment, and has become an essential part of modern research and practice. Due to NHS reforms in Britain, an enormous emphasis has been placed on assessing the health needs of communities and monitoring services, so that resources can be appropriately allocated. Increasingly, budget holders and decision makers will only consider using treatments which are evidence-based. This is generally achieved by conducting large-scale, blind, randomised controlled trials (RCTs, see glossary, Appendix D), which are considered the most rigorous and least biased sources of evidence (Bowling, 1997).

Chapter 1 reviewed the literature on the common psychological techniques for dementia, which has included a number of RCTs and controlled trials (CTs, see glossary, Appendix D). However, the trials were generally small-scale, the largest (Breuil et al 1994) having 56 participants. They could also be criticised as lacking the methodological rigour required to be considered evidence-based, such as no randomisation, the use of unstandardised outcome measures, and not blinding raters to treatment. The advantage of systematic reviews is that

they pool data from different RCTs and CTs using the statistical process of meta-analysis, yielding a combined outcome. This effectively enlarges the sample size and can be valuable when examining an intervention for which only small trials have been conducted. In theory, systematic reviews should allow clinical decisions to be based on reliable, up-to-date information on how effective a treatment is.

It was decided to conduct reviews on RO and RT because they appeared to be the most well researched psychological interventions for dementia. The introduction showed that there have been a number of RCTs and CTs on both approaches, yet also a lack of consistency in the results and criticism of each. It was intended that systematic reviews, through the process of meta-analysis, would allow more conclusive evidence of the effectiveness of both treatments, using a larger pool of participants. Reviews of VT (Neal and Briggs, 1998) and memory training techniques (Clare et al, 2000) were already in preparation.

### **2.1.1. The Cochrane Collaboration**

The Cochrane Collaboration is an international organisation which prepares, maintains and disseminates systematic reviews of the evidence of health interventions, based on RCTs. The ultimate goal of the Cochrane Collaboration is to produce high-quality systematic reviews, and where possible meta-analyses, of RCTs in all areas of healthcare across the *entire health-care spectrum*. Collaborative review groups consist of people working together in an area of common interest, under the guidance of an editorial team. Reviews are disseminated via the “Cochrane Database of Systematic Reviews”, an electronic, peer-reviewed publication which is updated quarterly. Authors accept the responsibility of continually

ensuring that the reviews are up-to-date and accurate. There is also the opportunity for readers of the database to comment on reviews, and for reviews to be altered in subsequent editions. The reviews reported here were conducted via the Cochrane Dementia and Cognitive Impairment Group (CDCIG) based in Oxford. The Cochrane process was chosen because it would ensure high quality reviews, and due to its international recognition and use.

## **2.2. Method**

### **2.2.1. Search Strategy**

A systematic search for all the available literature evaluating the effectiveness of Reality Orientation (RO) and Reminiscence Therapy (RT) for dementia was conducted. For the purpose of the reviews, only RCTs and CTs were considered. The remaining literature was put aside to be considered later in the design of the programme. A combination of the terms “Reality Orientation”, “Reminiscence Therapy”, “dementia”, “Alzheimer’s”, “controlled study” and “trial” were used to search Medline Express 1966-1997, PsychLIT Journal Articles 1974-1997, PsychLIT Chapters and Books 1/87-12/97, Embase, the Cochrane Database of Systematic Reviews, OMNI (Organising Medical Networked Information), BIDS (Science Citation Index and Social Science Citation Index), Dissertation Abstracts International 1861-1997, and SIGLE (System for Information on Grey Literature). Internet sites were searched (Healthweb, Medweb, Mental Health Infosource, American Psychiatric Association, Internet Mental Health) and the NHS Confederation. A handsearch of journals including Aging and Mental Health, The Gerontologist (1961-1994), Journals of Gerontology (1960-1978), Current Opinion in Psychiatry (1988-1997), Current Research in

Britain: Social Sciences (1991-1995) and the Reminiscence Database (Bender, 1998) was conducted. Additionally, the Alzheimer's Society library was searched, and letters were published in specialist magazines such as "The Psychologist" (the journal of the British Psychological Society), requesting information on unpublished and ongoing trials. Bibliographies of all relevant articles were scanned, and experts in dementia care were consulted.

### **2.2.2. Inclusion Criteria**

All RCTs examining the effects of RO and RT for dementia were included. For RT, due to a shortage of RCTs, CTs were also considered. Participants were people (mean age >55), diagnosed with dementia (or similar, such as AD, cognitive impairment or organic brain syndrome) according to DSM-IV, ICD-10 or comparable. To meet criteria for inclusion, more than 60% of the participants must have completed the study. Programmes needed to involve at least 10 regular therapy groups for a minimum of 3 weeks. Groups, lasting for at least 30 minutes, contained a minimum of 4 people. RO groups involved (amongst other cognitive activities) the presentation, repetition and use of orientation information (time, place and person-related). RT groups involved reminiscing, usually with the assistance of aids such as photographs, music and items of an historical nature. In order to conduct meta-analysis, trials had to have used an outcome measure in at least one of three domains: cognition, behaviour or global change. From the narrative review in chapter 1, these appeared to be the most frequently investigated factors.

### **2.2.3. Data extraction**

As no trials used measures of global change, data were extracted from psychometric tests measuring changes in cognition and behaviour. It was only possible to use one measure of cognition or behaviour from each trial in the meta-analysis, therefore a selection process was necessary to identify the most appropriate scale in trials which used more than one. Cognitive tests were chosen using the following, in decreasing order of importance: i) standardised cognitive tests, ii) orientation tests, iii) short-term memory tests, iv) information tests, v) any test of cognition using some of ii)-iv). Similarly, behavioural tests were selected using i) standardised behavioural tests, ii) tests of activities of daily living (ADL) / adaptive social behaviour. Discussion between the reviewers were used to resolve any queries. Baseline and follow-up data (means and standard deviations) from each scale were required for meta-analysis. In some cases, these were not provided in the papers, and authors were contacted directly.

Each study was critically evaluated by two reviewers, considering various factors which might affect the methodological quality of the study. Quality was assessed according to the four criteria outlined in the Cochrane Collaboration Handbook (Mulrow & Oxman, 1996); selection bias, performance bias, attrition bias and detection bias. Descriptive details were extracted using a standard data extraction form.

#### **2.2.4. Analyses**

RevMan 3.0 (Update Software, 1996) was used, which involved meta-analyses (called “metaview”). For the RO review, analyses were adjusted to the random effects model, due to the heterogeneity of trials. Because trials used different tests to measure the same outcomes, Standardized Mean Differences (SMDs) were used. These were calculated by dividing the difference between the treatment and control means by the pooled standard deviation within each study, thus enabling them to be compared to the other trials in a standardized way. For the RT review, because only one trial was entered, the Weighted Mean Difference (WMD) was used. This calculated the difference between the treatment and control means, divided by the standard deviation. Further, the fixed effects model was used as the single trial implied no issues of heterogeneity.

### **2.3. RO review**

#### **2.3.1. Selection of trials**

From the information in the title and abstract, 43 publications were identified as possibly relevant following the literature search. A reviewer and co-reviewer independently assessed eligibility. 22 publications were immediately excluded: 4 were not trials, 5 examined non-dementia populations, 4 were case studies, 2 were observational studies and 7 were uncontrolled. The remaining 21 trials were all controlled, but of these 6 were clearly not randomized (subjects were "selected" or "chosen") and 2 looked at 24-hour RO only. 6 trials had no mention of randomisation, and authors were contacted and asked directly. One author responded with details of randomisation (Ferrario et al, 1991). The 7 remaining controlled

trials all included the term(s) "randomized" or "randomly assigned". It was decided that this was acceptable for inclusion into the review. Therefore, 8 RCTs were included.

### **2.3.2. Quality of included studies**

A number of biases affected all the included trials. Details of *selection bias* (bias due to group allocation, ie. no randomisation or poor randomisation concealment), *attrition bias* (bias due to dropouts) and *detection bias* (bias due to assessors' awareness of group allocation) are summarized in table 2. Attrition bias was generally as expected in dementia populations, although over a third dropped out in the study of Wallis et al (1983). For this to be investigated effectively, an 'intention to treat analysis' (see 6.5.1.) would have been required, although none of the trials included such analyses. In half of the trials, assessments were made either by people familiar with group membership, or no details were given; hence introducing detection bias.

*Performance bias*, which refers to bias created by people's expectations of treatment, was difficult to evaluate. With psychological interventions, unlike pharmacological treatments, it is impossible to blind patients and staff totally to treatment. Patients may be aware that they are being treated preferentially, and staff involved may have different expectations of treatment groups. Both these factors could affect patients' performance. Additionally, independent assessors may be given clues about group assignment from patients during the assessments. The extent of patients' awareness of treatment depends greatly on how much information is given to them, and their level of comprehension.

There could also have been contamination (elements of one treatment leaking into another) when groups were not held in a separate room, or when staff accidentally brought ideas from one group to another. The latter effect would be reduced with clear therapeutic protocols, the existence of which was not mentioned in any of the studies; although in a personal correspondence, Woods (1998) reported that one was used. Most authors said that the RO groups were held in separate areas, reducing the chance of contamination (Baines et al, 1987; Ferrario et al, 1991; Hanley et al, 1981; Wallis et al, 1983; and Woods, 1979). It is unclear as to where groups were held in the other studies.

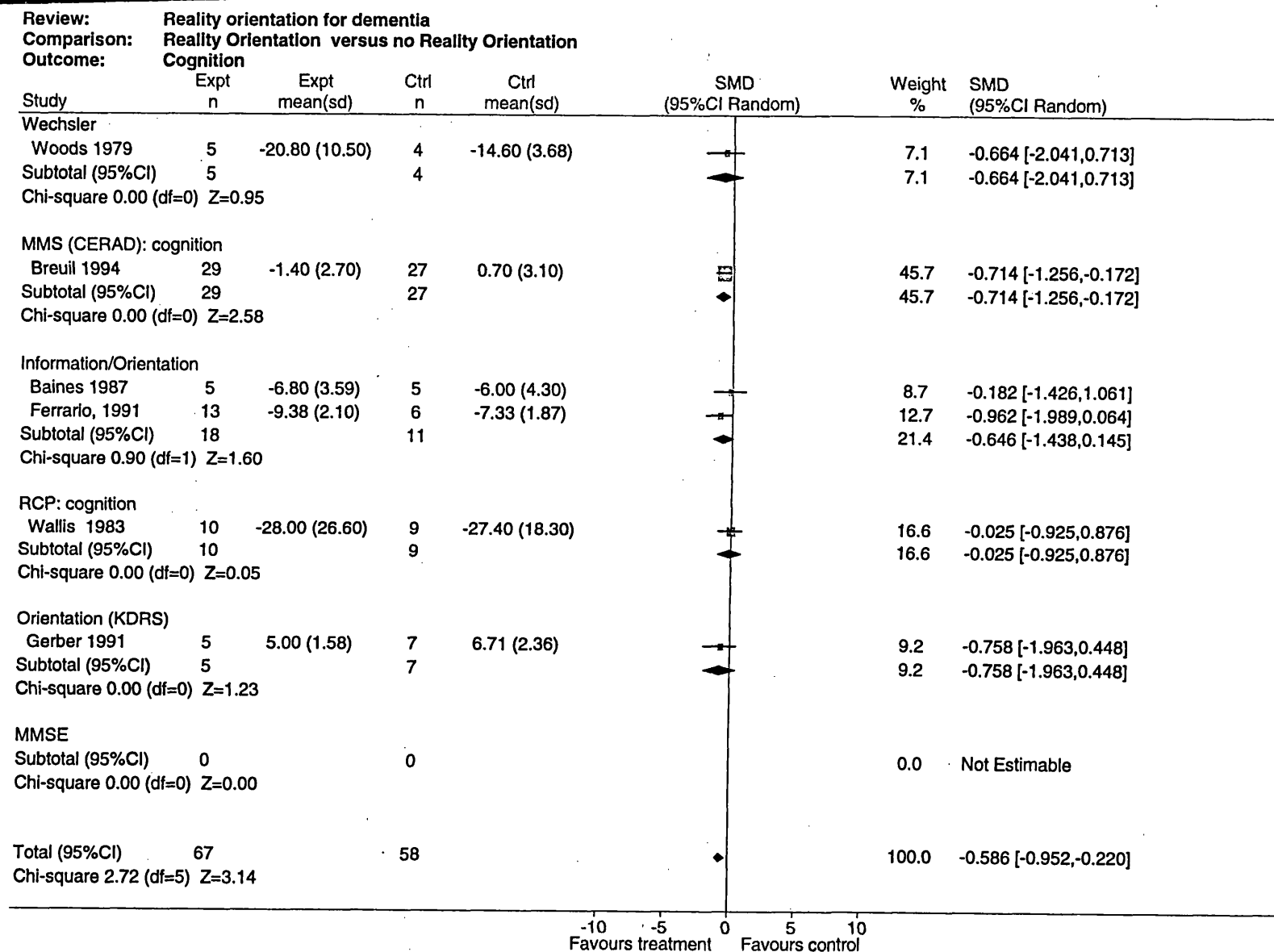
### **2.3.3. Meta-analysis**

Of the 8 studies, only 6 could be entered into Metaview. The others (Baldelli et al, 1993; and Hanley et al, 1981) did not include the statistics needed for the analysis, and authors were contacted with no response. These 6 RCTs yielded a total of 125 subjects (67 treatment subjects, 58 controls). Results for cognition were significant in favour of treatment (see Figure 2). The SMD was -0.59, with a 95% Confidence Interval (CI) of [-0.95, -0.22]. A Cochrane statistical advisor stated that comparing the SMD with a normal distribution indicated that the average score for participants in the treatment group was better than 72% of the control participants' scores. The results were highly influenced by the largest study (Breuil et al, 1994), in which results significantly favoured treatment (SMD= -0.71, 95% CI [-1.26, -0.17]). Although the remaining trials did not individually reach significance, trends were positive and the combined cognitive result significantly favoured RO. All trials contained cognitive measures, with a total of 125 participants.

Only 3 trials used a measure of behaviour. The combined result was again significant in favour of treatment (see Figure 3). The SMD was -0.64, 95% CI [-1.20, -0.08], with a total of 57 participants entered into the analysis (33 experimental, 24 control). Comparing the SMD with a normal distribution indicated that the average score for participants in the treatment groups were better than 74% of the control participants' scores. Trials did not individually reach significance, but the trend favoured RO.

*Table 2: Trials of RO in dementia used in the review*

NAME OF STUDY	AMOUNT OF INTERVENTION	CONTENT OF RO	ALTERNATIVE ACTIVITY	RANDOMIZATION CONCEALMENT	ATTRITION BIAS (DROPOUTS)	DETECTION BIAS
Baines et al (1987)	30 mins 5 times a week 4 weeks	RO board, multisensory stimulation	Reminiscence therapy / no treatment	No details	0/15 dropouts	Assessment by independent psychologist, and staff not involved in therapy
Baldelli et al (1993)	60 mins 3 times a week 3 months	No details	No treatment	No details	0/23 dropouts	No details of assessors.
Breuil et al (1994)	60 mins 2 times a week 5 weeks	Drawing, associated words, object naming / categorising	No treatment	No details	5/61 dropouts (3 experimental, 2 control)	Assessment by psychologist unaware of group membership
Ferrario et al (1991)	60 mins 5 times a week 21 weeks	No details	No treatment	No details	2/21 dropouts (1 in each group, due to illness)	No details of assessors.
Gerber et al (1991)	60 mins 4 times a week 10 weeks	RO board, exercises, food preparation, discussions	Social interaction / no treatment	Random number tables	5/24 dropouts (1 in each of 3 groups died, 2 discharged in RO group)	Assessment by independent person blind to group membership
Hanley et al (1981)	30 mins 4 times a week 12 weeks	RO board, clocks, calendars, maps, posters	No treatment	No details	1/58 dropout (unclear which group)	Ratings for some tests were blind, others were not
Wallis et al (1983)	30 mins 5 times a week 3 months	RO board, general orientation	"Diversional occupational therapy" (group and individual activities)	Drawing from a hat, consecutive allocation	22/60 dropouts. No details of groups (Death (6), illness (8), other (8))	Assessments by senior nurse & OT, blind to group membership
Woods (1979)	30 mins 5 times a week 20 weeks	RO board, orientation discussions / demonstrations	"Social therapy" (various group activities)	Drawing from a hat	4/18 dropouts (1 in each group died, 1 control refused assessment)	Mixture: some assessment blind, some not



**Figure 2: RO Meta-analysis, Cognition.** The length of the lines represents the size of the confidence intervals and the grey boxes, the weight attributed to the trial. Results are significant if they do not cross the centre line. The pooled total lies left to the centre line without touching it, indicating a significant result. MMS = Mini Mental State Examination, CERAD = Consortium to Establish a Registry for Alzheimer's Disease, RCP = Royal College of Physicians, KDRS = Kingston Dementia Rating Scale.

Review: Reality orientation for dementia  
 Comparison: Reality Orientation versus no Reality Orientation  
 Outcome: Behaviour

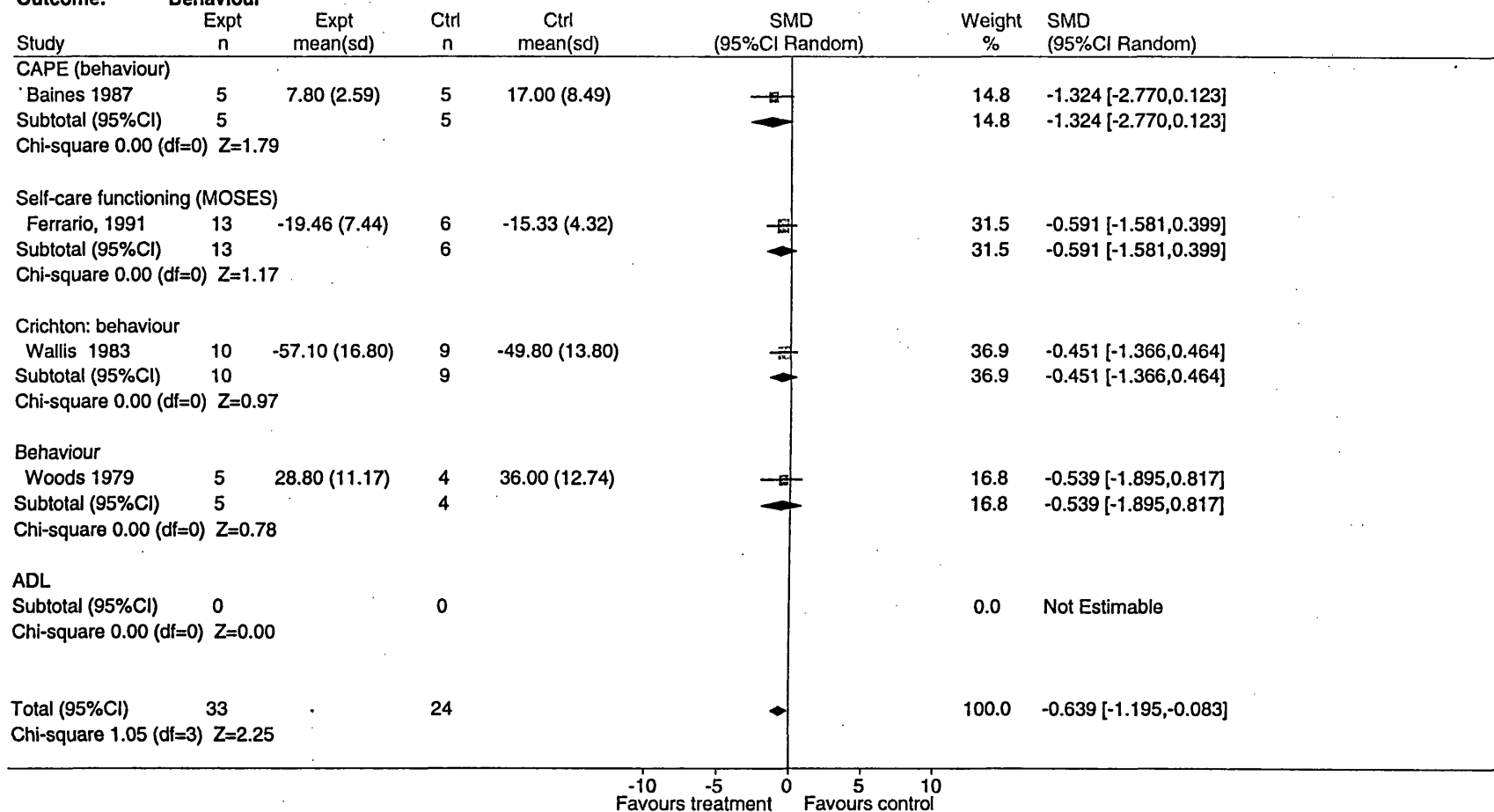


Figure 3: RO Meta-analysis, Behaviour. Unlike the cognition analysis, only 4 trials had behavioural outcome measures. The pooled total lies left to the centre line without touching it, indicating a significant result.

### 2.3.4. Conclusions

Results showed that RO had significant positive effects on both cognition and behaviour for people with dementia. Trials varied greatly in factors such as length of intervention, methodological quality and outcome measures used. There was no observed relationship between the total amount of intervention (in terms of time or length of sessions) and outcome. In fact, the most significant changes resulted from the study with the shortest duration of intervention, 600 minutes in total (Breuil et al, 1997). Additionally, there was variation in the alternative activities offered to control groups, with no treatment in some trials (Baines et al, 1987; Breuil et al, 1994; Ferrario et al, 1991), and an alternative 'social therapy' in others (Gerber et al, 1991; Wallis et al, 1983; and Woods, 1979). The results also showed no relationship between type of control activity and outcome, suggesting that the actual qualities of RO, rather than merely the therapeutic effect of social contact and attention, was effective. The largest study was that of Breuil et al (1994), with a 45.7% weight. It is possible that it slightly differed from the other studies in that its concepts were more theoretically advanced than those of the 1970's (see table 2), and more akin to the sophisticated cognitive rehabilitation programmes used in brain injury.

It is important to look at the advantages and disadvantages of combining the results for meta-analysis. Firstly, the included studies were clearly heterogenous, with variations in the precise intervention used, and the design and conduct of the study. It could be argued that combining such results is not meaningful, and could result in an obscured meta-analysis. Secondly, it has been demonstrated that a reasonable level of bias can be expected in all the

included studies. In treatment trials, this bias usually tends to be in the direction of overestimating the effects of the intervention, and pooling data from different studies adds together these positive biases (Moncrieff, 1998). However, it could also be argued that the studies individually are too small to detect effects that are actually clinically significant, and only combining them achieves the power to detect such effects. Thirdly, one's opinion about whether combining more or less trials is favourable might influence their interpretation of the cognitive and behavioural analyses, which differed in sample size.

A set of criteria for identifying empirically validated treatments was recently developed by the American Psychological Association (Gatz et al, 1998). Rigorous inclusion criteria (including the adherence to standardized treatment manuals) were set for "well established" treatments, and applied to disorders seen in practice. The authors concluded that RO for dementia is "probably efficacious in slowing cognitive decline", lending support to RO as an intervention.

In summary, this review found that classroom RO had benefits for dementia sufferers in both cognitive and behavioural domains, suggesting that RO techniques could be considered as a standard part of dementia care. However, limitations such as heterogeneity and biases should be considered when interpreting the results. It is possible that the benefits of RO may only be short-lived, but a more longterm programme may help sustain improvements. As with all psychological interventions, the success of RO may be dependent on it being used at the appropriate time, by sensitive and experienced practitioners, to receptive patients.

## **2.4. RT review**

### **2.4.1. Selection of trials**

From the information in the title and abstract, 15 publications were identified as possibly relevant following the literature search. 12 were discarded as 2 were not trials, 3 examined non-dementia patients, 1 was a case study, 2 were observational and 4 were controlled trials with neither randomisation nor appropriate outcome measures. This left 3 RCTs. Orten et al (1989) was later excluded due to a lack of clarity in the diagnosis of some subjects, and Goldwasser et al (1987) did not contain statistics needed for entry into metaview. Hence only one trial (Baines et al, 1987) could be entered. This trial was also used in the RO review, as the authors evaluated both RO and RT within the same trial.

### **2.4.2. Quality of included study**

A description of the included study (Baines et al, 1987) can be found in section 2.3.2.

### **2.4.3. Analysis**

As there was only one trial, data could not be combined for meta-analysis. Figures 3 and 4 show the results of the single trial. For the Information/Orientation subscale of the CAPE, WMD = 0.05, 95% CI (-4.37, 4.77). For the behaviour subscale of the CAPE, WMD = -3.3, 95% CI (-14.19, 7.59). Hence both scales showed insignificant results, with a positive trend in behaviour and a negative trend in cognition. No further statements could be generated from these results, as they were too limited.

Figure 4: RT; Cognition. The length of the lines represent the size of the confidence intervals. Crossing the centre line indicates no change in cognition. CAPE = Clifton Assessment Procedure for the Elderly.

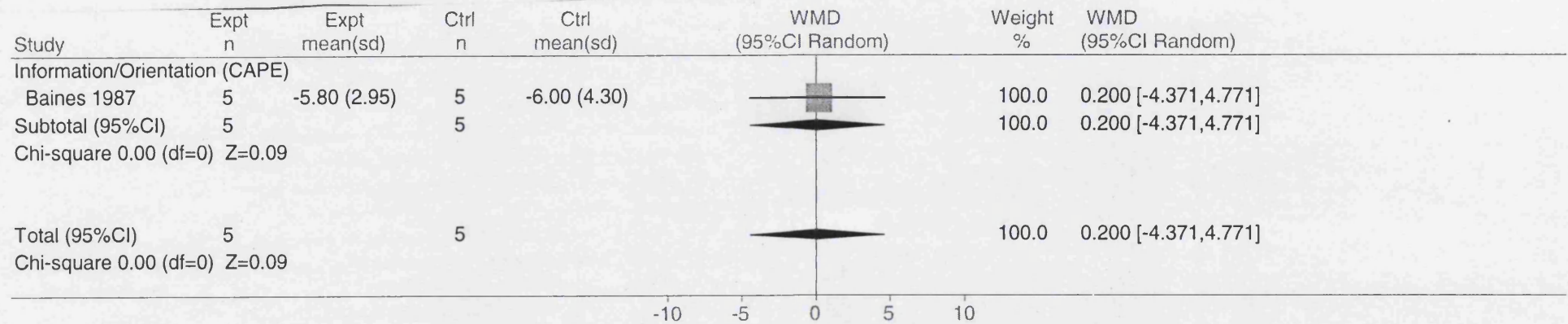
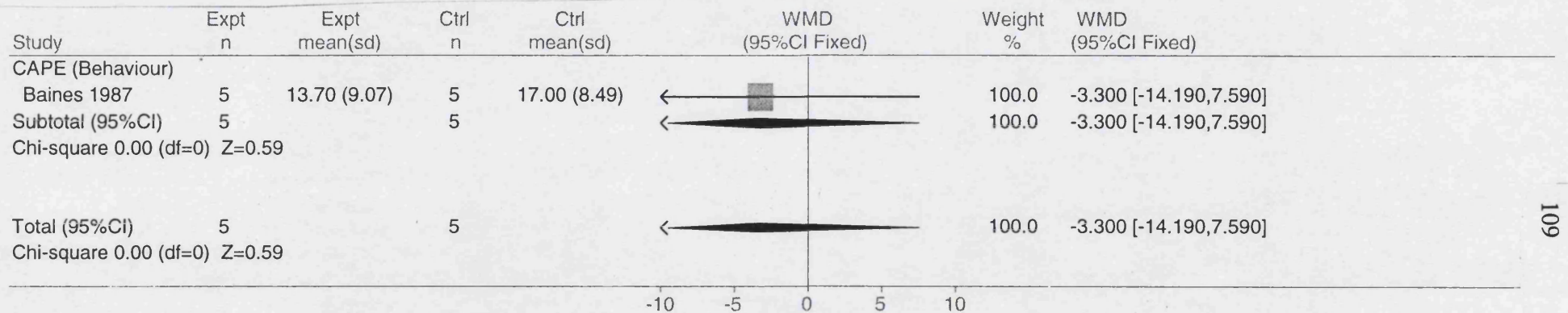


Figure 5: RT; Behaviour. The length of the lines represent the size of the confidence intervals. Crossing the centre line indicates no change in behaviour.



#### 2.4.4. Conclusions

Only one trial (with ten participants) met the inclusion criteria of this review, and results were not statistically significant. The sample size was insufficient to reach any conclusions. It was also limited in that it only examined residents of local authority homes, who may differ from people with dementia living in the community. The two RCTs which were excluded also offered little insight into the effectiveness of RT as a treatment. Goldwasser et al (1987) found a slight but insignificant improvement in cognition in the RT group compared to the two others, no differences at all in behaviour, and a significant increase in depression for the RT group. Orten et al (1989) found that RT participants scored (insignificantly) higher in a “social behaviour scale”, and no correlation between social isolation and ability to participate in RT. Baines found that participants benefited more in both cognition and behaviour from RT following four weeks of RO, than from RT alone, suggesting that RT might be more beneficial for people with a higher level of orientation.

In summary, this review highlights the urgent need for more RCTs and generally more empirical research in the field. This should be interpreted as a positive outcome, indeed Williams (1998) stated that *“If we confine systematic reviews to areas where there are lots of RCTs, then work becomes data-driven rather than question-driven.*

*Finding no RCT’s is extremely important: this is our only chance of influencing funding authorities to conduct the trials that should have been done years ago.”*

Reported benefits of RT are mostly anecdotal, and research evidence is not strong enough to reach any firm conclusions. Research is needed to define when and how it should be used, and how it compares to other psychological therapies used in dementia care, such as RO and VT.

### **2.5.0. General implications for research**

The reviews show that RCTs in psychological therapies are possible and are potentially informative, but that there is a need for trials of better quality and methodology. With psychological interventions, unlike drug trials, double blinding is impossible and contamination between groups more likely. Assessing the success of any psychological therapy can be problematic, with difficulties evaluating the therapeutic alliance between patients and therapists, and the empathy and sensitivity with which the therapy is carried out. These variations might produce variations in results that cannot be easily accounted for. Qualitative studies, such as case studies, may offer further insight into the better features of the therapies, the most effective ways in which they may be applied and the types of people most suited, and can be used in combination with RCTs.

Further research could examine which features of RO and RT have greater or lesser benefits, and in what circumstances. For example, one could examine the effects of treatment on people at different stages of dementia or in different group sizes. Additionally, research could i) compare results in residential homes and day centres; ii) examine other outcomes, such as quality of life; iii) look at more individualised treatment approaches; and iv) include follow-up assessments to examine how sustainable any benefits are. Additionally, it would be interesting to compare 24 hour with classroom RO, and consider how they might compliment each other.

### **2.6.0. General implications for practice**

There was no evidence in the trials included that either RO or RT had any serious side-effects. However, three cases of adverse psychological and emotional effects following RO have been reported (Dietch, Hewett & Jones, 1989) and it is essential that RO is given sensitively to people who freely choose to participate. It may be, for example, that people still residing in the community are more concerned about retaining factual information than those in residential care.

It has been shown that RO participants can actually perform worse at a 10-week follow-up than prior to treatment (Gerber et al, 1991), suggesting that benefits gained from RO may be lost. Conversely, Wallis et al (1983) found that people gained higher scores in both cognitive and behavioural tests one month post-intervention. The review provided no evidence of long-term benefits of RO, and perhaps for RO to have more lasting effects, there should be a detailed schedule of reinforcement and follow-up, with a continuous, ongoing programme. For example, interventions such as RO boards and signs could be used when a person is disorientated and distressed. Perhaps the introduction of a 24 hour RO programme might be a good way to retain what has been learned if the continuation of classroom RO is not practical (Williams et al, 1987).

Similarly, any benefits of RT were lost at a follow-up (Goldwasser et al, 1987; Orten et al 1989), suggesting that it might be more useful if part of a continuous, ongoing program, or more realistically that features of it could be integrated into the daily activity programme.

### **2.7.0. Potential problems**

The RT review was presented at the Age Exchange “European Reminiscence Network Conference” (Vienna, 1998). The speakers discussed the development, implementation and evaluation of reminiscence work with people with dementia and their carers, with a focus on “positive communication”. The systematic review aroused interest, debate and controversy, with two main factors emerging. Firstly, it became apparent that the inconclusiveness of the review could potentially be misinterpreted as a suggestion that RT does not work. This was illustrated by the actions of one person, who was reported to have attempted to stop any reminiscence work in her borough after reading the review. In actual fact, the review stated that there is no empirical research to date that shows benefits of RT, and that only the conducting of well-designed RCTs will provide evidence-based answers. Secondly, discussion focused on the morals and ethics of evaluating RT scientifically. Many carers felt that fitting something so personal and human into the boundaries of scientific analysis could jeopardize all its *real* qualities, such as intimacy, self-esteem and identity. They argued that these subjective emotions could not be measured by scientists in the form of an RCT.

### **2.8.0. General summary and conclusions**

The two Cochrane reviews have been incorporated into the Cochrane database (Spector et al, 1998a,b) and have appeared as peer reviewed journal publications (Spector et al, 2000; Spector et al, 2001). These papers are included in appendix B. The RO review showed both cognitive and behavioural benefits of RO for people with dementia. The RT review was inconclusive, due to a lack of trials. Clearly, the evaluation of psychological interventions in the form of RCTs can be problematic,

and there is much to be learnt from qualitative research such as who might benefit more from treatment, why, and how. Nonetheless, for RO and RT to be scientifically recognised, they need to be evaluated in a quantitative, empirical manner, and can then be considered 'evidence-based.' It is essential that the evidence gap is narrowed and more trials are conducted, as otherwise health and social services may not consider it a priority for funding. The following chapter will discuss how the systematic reviews contributed to the development of the therapeutic programme.

## **Chapter 3: Development of the Therapeutic Programme**

### **3.0.0. Aims**

- To obtain all the available literature on the most prominent psychological interventions for dementia.
- To use a systematic approach to identify the most beneficial elements of each intervention, and to design an evidence-based therapy programme.

### **3.1.0. Search Strategy.**

A comprehensive search was conducted for all the available literature on RO, RT, VT and memory-related techniques. The search procedure was part of the process for and identical to that used in the Cochrane reviews (see 2.2.1.). The terms “Reality Orientation”, “Reminiscence Therapy”, “Validation Therapy”, “Memory Training”, “Cognitive Stimulation”, “Therapy”, “dementia”, “Alzheimer’s” and “trial” were entered into the databases. Searches for unpublished or ongoing research or research written in different languages involved writing letters in special interest magazines, approaching leading specialists, and searching all bibliographies for further references (see chapter 2).

### **3.1.1. Tabulating the results**

Having gathered the literature, each paper was examined in turn. The authors intended to consider which activities and tasks each study used to make up their programme, and to then look at the results of the trial. Hence the methodological design, content of sessions and outcome of each study were tabulated (see table 3). It was intended that by using the

information from these simple tables, a clearer picture could be formed of as to which elements of each type of therapy might have been more or less effective. Studies lacking details of the content of the intervention were omitted from the tables, as they would not be of help in the design of the programme.

### **3.2.0. Designing the programme**

The underlying basis of the programme stemmed from the RO systematic review, which suggested significant benefits in both cognition and behaviour following RO for dementia sufferers. However, the results of the RO review were strongly weighted by the study of Breuil et al (1994), the largest trial with the most significant results. Activities in sessions included connecting dots to form pictures of common objects, drawing common objects from different perspectives, associated words, and naming and categorising objects. The author arranged to meet the neuropsychologist who supervised this trial and observe the ongoing 'cognitive stimulation' groups. The Broca Hospital in Paris had set up a service for people who had recently been diagnosed with dementia at the memory clinic. These people attended twice weekly groups with the aim of maintaining their memory, and allowing them to function in the community for as long as possible.

Table 3: Details of interventions and outcomes within studies. (Interventions incorporated into the programme are highlighted in italics)

AUTHORS, INTERVENTION, QUALITY/DETAILS	DESCRIPTION (TREATMENT GROUP)	OUTCOME FOLLOWING TREATMENT
<i>RO / Randomised Controlled Trials</i>		
Baines et al (1987) 15Ps (RO=5, RT=5, C=5)	RO board, <i>old &amp; current newspapers, personal &amp; local photos, materials to stimulate all senses (eg. Cinnamon, silk, honey).</i>	Sig. Improvement in behaviour. Positive trends in cognition and communication. Positive effects reported by staff.
Breuil et al (1994) Blind RCT, 56 Ps (CS=29, C=27)	Copying pictures, <i>associated words, naming &amp; categorizing objects.</i>	Sig. Improvement in cognition.
Gerber et al (1991) 24Ps (RO=8, SC=8, C=8)	<i>Simple exercises, self-care, food preparation, orientation.</i> Room with RO board, large clock, coloured illustrations.	Sig. Improvement in orientation & language in both RO & social interaction groups.
Goldstein et al (1982) 14Ps (RO=7, C=7)	Reading RO board, <i>naming people</i> , use of RO questionnaire (eg. day, month season, etc.)	Sig. Improvement in orientation. No change in ADL.
Hanley et al (1981) 57 Ps (RO=28, C=29)	RO board, clocks, calendars, <i>maps &amp; posters. Room overlooked garden area to enable discussion.</i>	Sig improvement in verbal orientation in response to basic orientation items. No change in behaviour.
Hogstel (1979) 44Ps (RO=22, C=22)	Introductions, reading RO board, tell time, discuss lunch menu. Patients had large clock & calendar in bedrooms. Additional input from staff outside RO class.	No change in degree of confusion. Observations: RO patients became more co-operative, and began communicating much more with each other.
Voekel (1978) 20 Ps (RO=10, SS=10)	Greeting, touching, RO board, calendars, clocks, antiques. Simple activities, eg. Identifying pictures.	No change in mental status following RO. Sig. Improvement in SS group.
Wallis et al (1983) 38 Ps (RO=18, C=20)	<i>Repetition of orientation information (eg. time, place, weather).</i> Charts, pictures, touching objects & material.	Positive trends in cognition and behaviour.

Table3 (continued): Details of interventions and outcomes within studies

AUTHORS, INTERVENTION, QUALITY/DETAILS	DESCRIPTION (TREATMENT GROUP)	OUTCOME FOLLOWING TREATMENT
Woods (1979) 14Ps (RO=5, ST=5, C=4)	Daily personal diary, <i>group activities (dominoes, spelling, bingo). Naming objects</i> , reading RO board.	Sig. improvement in memory, learning, information & orientation in RO group.
<b>RO: Controlled Trials / Other</b>		
Barnes (1974) ABA, 6 Ps, No statistics	RO board, calendar, <i>maps. Discussed names</i> , lunch menu, etc.	Positive trend in questionnaire which showed learning and behavioural change.
Citrin & Dixon (1977) CT, 25 Ps (RO=12, C=13)	Personal & environmental information presented individually, 24 hr RO.	Sig. Improvement in RO Information sheet. Geriatric Rating Scale was inconclusive.
Coen Mieli et al (1991) CT. No. of Ps & method of allocation unknown.	Space & time orientation, <i>memory prompting, naming objects</i> & body parts, training cognitive, semantic & phonetic abilities.	Positive trend in cognition. Patients became less passive. Increase in effort & ability to concentrate.
Cornbleth & Cornbleth (1979) ABA, 22Ps	RO board, copying, telling time, <i>counting money</i> .	Sig. improvement in orientation and ADL.
Gotestam (1987) ABA, 5Ps	Time Orientation: diary, clock. <i>Person Orientation: name games. Room Orientation: maps</i> and nameplates on walls.	Sig. improvements in time and room orientation, insig. improvement in person orientation.
Greene (1979); RO ABA, 3Ps, No statistics	"Personal Orientation Questionnaire" for each person. ( <i>Time, place, current affairs, family, friends, history</i> )	Improvement in orientation, generalising to other areas of behaviour.
Reeve & Ivison (1985) CT, 20 Ps (RO=10, C=10)	Classroom & 24 hour RO (environmental symbols, signposts, clocks & 2 RO boards)	Sig. improvements in cognition and behaviour.
Zanetti et al (1995) CT, 28 Ps (RO=16, C=12)	Early classes: <i>personal, time &amp; space orientation</i> Later: <i>historical events, famous people, attention, memory &amp; visuospatial exercises</i> .	Sig. improvement in verbal abilities. No changes in other cognitive functions or disability measures. No changes in self-rated depression scores.

Table 3 (continued): Details of interventions and outcomes within studies

AUTHORS, INTERVENTION, QUALITY/DETAILS	DESCRIPTION (TREATMENT GROUP)	OUTCOME FOLLOWING TREATMENT
<i>RT, Memory Techniques, VT</i>		
Baines et al (1987); RT RCT, 15 Ps (RT=5, RO=5, C=5)	<i>Old photos (local scenes, personal), books, magazines, newspapers, domestic articles.</i>	Negative trend in information /orientation after RT. Positive trend in behaviour. Positive staff reports, eg. got to know people better.
Bourgeois (1990); Memory training ABA, 3Ps	Developed prosthetic memory aids: plastic wallets containing information of personal relevance (photos, daily schedule, etc.)	Content & quality of conversation doubled or tripled, using Likert ratings.
Goldwasser et al (1987); RT RCT, 30 Ps (RT=10, SS=10, C=10)	Topics: <i>food, family</i> , personal artefacts, <i>jobs, songs, music</i> , celebrations.	Positive trend in cognition. Increased depression. No change in behaviour.
Kiernat (1990); RT, ABA, 23 Ps	<i>Topics in chronological sequence. Multisensory materials, pictures, recordings, historical items.</i>	Positive qualitative results. E.g. people initially only responded to direct questions from staff, later to questions from other residents without prompts.
Koh et al (1994); CS. CT, quasi randomised, 30 Ps (15=CS, 15=C)	Basic elements of RO, RT and remotivation. <i>Weekly discussion topics</i> e.g. <i>money</i> , hobbies, pets, fruit and festivals. <i>Stimulated all senses.</i>	Sig. Improvements in mental state score.
Orten et al (1989); RT RCT, 56 Ps (RT=28, C=28)	<i>Structured topics, covering life-span.</i> Pictures & memorabilia discouraged.	Insig. improvement in social behaviour. Group differences attributed to experience of leaders.
Quayhagen & Quayhagen (1989); Cognitive stimulation given on one-to-one basis by caregivers. Non-randomised.	Communication exercises: conversation skills, facts, opinion, etc; memory-provoking techniques: verbal & non-verbal; problem-solving exercises: planning / categorization.	Qualitative findings reported by caregivers: improved emotional status of patients, maintenance over time in aspects of cognitive functioning. No improvement in carer well-being.
Toseland et al (1997); VT RCT, single blind, 88 Ps (VT=31, SC=29, C=28)	Four segments. i) Warm greetings, hold hands, sing songs. ii) Focus on topic of interest, reminisce. iii) Activity, eg. poetry. Iv) Refreshments, goodbyes. Used Feil's Validation approach throughout.	Limited support for VT. Staff reported reduced physically & verbally aggressive behaviour (not reported by observers). No change in medication, physical restraint or nursing time needed.

### Glossary (Table 3)

RCT	= Randomised Controlled Trial	SC	= Social Contact group
CT	= Controlled Trial	SS	= Social Support group
ABA	= Repeated measures (ABA) design	ST	= Social Therapy group
C	= Control group	CS	= Cognitive Stimulation
RO	= Reality Orientation group	Sig.	= Significant ( $p < 0.05$ )
RT	= Reminiscence Therapy group	Insig.	= Insignificant
VT	= Validation Therapy group	Ps	= Participants

Sessions began with introductions, orientation-related discussion and short-term memory prompts, such as asking people what they did the previous night or what the news headlines were. This was followed by people completing a practical task individually, which was then completed on the board by the group leader. In a session observed by the author, participants were presented with a list of (Easter) shopping and prices, and were required to calculate the cost of the entire shopping list. The hospital staff found that people attending these groups managed to maintain their functioning and live reasonably independently for longer than expected.

These groups took place in a room which resembled a classroom, with the 'teacher' wearing a white coat. It is important to recognise that these individuals had chosen to accept this regimented approach. Yet running similar groups in residential homes could lead to difficulties, as people are typically institutionalised, are not required to care for themselves, often lack the motivation to take part in activities, and are sometimes unaware of the extent of their cognitive decline. Even in day centres where functioning is typically higher and

people more independent, many individuals might not choose to attend groups with such explicit aims. Because the current programme was intended primarily for residential homes and some day centres, a more indirect way of using similar principles was considered in its design.

RO was the only psychological intervention for dementia that had demonstrated significant benefits following Cochrane review. Therefore, the programme was primarily designed through combining features found in the RCTs of RO that showed promising results. However, most of the trials were conducted in the late 1970's and 1980's, and the content and format might be considered somewhat 'out of date'. Since then, there have been advances in the understanding of strategies which might be used to result in cognitive improvement. This has coincided with criticism of RO, mainly when it may have been applied in a rigid, uncaring and insensitive manner. More modern approaches which stem from the earlier RO work might be described as 'cognitive stimulation' (Quayhagen and Quayhagen, 1989; Breuil et al, 1994). This programme was designed using some of the ideas of the early RO studies, but might be considered more akin to the cognitive stimulation work of the 1990's.

The team designing the programme included two clinical psychologists, Steve Davies and Bob Woods, who had extensive experience in running groups for people with dementia. There has been strong circumstantial and clinical support for the subjective benefits of RT, primarily that people enjoy it, and that it increases interaction and engagement (Woods, 1996; Gibson, 1993). Therefore it was felt that three sessions encouraging long-term

memories would complement the programme, even though the results of the RT review were inconclusive. Although the research on Validation Therapy provided no empirical evidence of its effectiveness, validation as an approach which encourages sensitivity and warmth, through empathic listening, eye contact and validating peoples communication and behaviour; was utilised in the programme whenever possible.

The elements of individual studies which were incorporated into the programme are highlighted in italics in table 3. These were drawn primarily from RCTs with positive results. The initial programme consisted of seventeen, forty-five minute sessions in four phases: 1) The senses, 2) Remembering who you are, 3) Remembering people and objects, 4) Everyday practical issues. Sessions began by welcoming the group, singing the ‘theme song’ and consuming tea and biscuits, before the activity took place. At the end of sessions, the discussion and ideas were summarised, the theme song sung again, and the group said its farewells.

### **3.2.1. The phases**

*Phase 1, The Senses*; incorporated multisensory stimulation (see Baines et al, 1987; Koh et al, 1994; Kiernat, 1990; table 3). Sensory elements were introduced, to be continued in all subsequent sessions (‘theme tune’, scented candle, unusual biscuits, lava lamp). This aimed to create a sense of continuity, and to differentiate the sensory experience of these groups from usual activities. These non-threatening sessions were also an effective way for the leader to identify the abilities of the group.

*Phase 2, Remembering the past;* involved three sessions of structured reminiscence (see Kiernat, 1990; table 3). Sessions had specific themes in chronological sequence: childhood, adolescence/early adulthood, experiences over the years. It was anticipated that this process might play some role in orientating people to the present time.

*Phase 3: People and objects;* involved naming and using objects, associated words (see Breuil et al, 1994; Woods, 1979; table 3).

*Phase 4: Everyday practical issues;* involved using money and place orientation (Koh et al, 1994; table 3). The final session was designed as a summing up and consolidation session, ending with a tea party.

### **3.2.2. Content of Individual sessions**

(1): *Sound.* Sounds were played from a “sound effects” CD, for people to guess (such as animals, weather and traffic). The memories and feelings which the sounds provoked, favourite and worst sounds were discussed. A theme tune was selected, to be played at the beginning and end of subsequent sessions.

(2): *Smell.* A “smell kit” containing reminiscent fragrances (such as germolene and Blackpool Rock), and everyday familiar smells (such as new cut grass and leather) was used. The use of smell and how it relates to other senses was discussed. A scented candle was introduced, to be used in all subsequent sessions.

(3): *Taste.* Distinctive foods (spicy, bitter, sour, sweet, plain, salty) were tasted, and discussion focused on food and taste, how tastes have changed and the social value of food.

(4): *Touch*. Various fabrics (silk, wool, fur, crepe de Chine and satin), objects of differing textures (hairbrush, sand paper, stone), tactile “koosh” balls and coloured “slime” (which can be used to make different shapes) were felt and discussed.

(5): *Sight*. Excerpts from “The Wizard of Oz” and “Casablanca” were shown. A “lava lamp” (to be used in subsequent sessions), and photos of “Old London” were introduced.

(6/7/8): *Personal Profiles (Early Childhood/Adolescence/Experiences during different era’s)*. Information about group members was collected, starting with date of birth and early childhood (session 6), adolescence / early adulthood (session 7), and later life (session 8). Information was written on a flipchart. The session involved time orientation, by referring to what one person might be doing at a point in another’s life, or by referring to historical events of the time.

(9): *People from the past*. “Famous Faces” cards were used, with discussion on why particular faces are more memorable than others, and strategies we might use to help re-learn names.

(10): *Promoting identification of the group*. Large fluorescent name badges were made for the group, with discussion on the meaning of names, dealing with forgetting people’s names and strategies for remembering them.

(11): *Photographs of group members and staff*. A Polaroid camera was used to take photos of the group and staff during the session. Word associations were used to link names to faces.

(12): *Remembering people in the family*. Family photos were gathered together, re-introducing the concept of name associations.

(13): *Faces and Objects*. Objects were introduced alongside faces, by re-using the famous faces cards, and the “Object Recognition Task” from the Visual Object Space Perception Battery (VOSP).

(14): *Familiar Objects*. Using a Reminiscence Kit, containing old-fashioned everyday objects (eg. “Sunlight Soap”, darning mushroom), the group discussed the way that objects have changed.

(15): *Using money*. The group looked at old and new coins, discussing the physical changes of money, and how values and prices have changed. Pictures of modern objects from a catalogue were shown, and the group asked to guess the current price.

(16): *Knowing your way around*. The group was shown a map of the local area, and marked landmarks on it with coloured stickers, such as their homes and places of interest. A plan of the UK was created on a flipchart, by asking people where they were born, have lived, and visited, and marking these places on the plan.

(17): *Consolidation / tea party*. The names of group members and staff were revised, the more successful elements of the programme reiterated, and the group had a tea party.

### **3.2.3. Guiding Principles**

A summary of the principles supporting the programme’s design were developed as five “guiding principles”. Based on an increased understanding of memory processes, the authors’ expertise and some of the principles found in past literature, they were to be attached to the programme and presented with it at centres where it would be run. Essentially, they were principles that were both followed in the design of the programme, and guidelines for group co-ordinators to follow when running groups. It was intended that

these principles might be developed further and made more explicit if a guiding manual was made, as part of a separate, subsequent project. They were:

- (1) Experiential learning, involving the use of all five senses to promote cognitive stimulation and memory processes.
- (2) Focused psychological interventions that address the difficulties of everyday living, such as orientation and using money. The focus should be on activities which might still be of use to people, rather than things of no practical relevance.
- (3) Acknowledging the emotional lives of people with dementia. This is modelled on Kitwood's ideology, emphasising the importance of treating people with dementia as individuals (see chapter 1). Additionally, validating the person's feelings (Feil, 1972) should be done when possible.
- (4) Encouraging implicit learning. Material should be made personally relevant when feasible, making sessions more interesting and aiding memory processes.
- (5) The reciprocal, psychological process (involving cognitive and emotional states) in which people with dementia and those who care for them learn more about each other's capabilities and vulnerabilities. This is based on Kitwood's ideas of collaboration between people with dementia and their carers.

### **3.3.0. Summary**

This chapter has described the development of an evidence-based therapy programme using information extracted through systematic review of the literature. The reviews suggested that cognition-based therapies are the most beneficial. This programme, combining elements of primarily cognition-based interventions used successfully in past research, was designed by a

team of experts in the field. The following chapter will describe the piloting of the programme in a day centre.

#### **3.4.0. Hypotheses of the study**

- 1) Pilot studies in day care and residential care will demonstrate preliminary evidence of the effectiveness of the programme for people with dementia, such as improvements in cognition and behaviour, and show that a multi-centre RCT is feasible.
- 2) In a multi-centre, single-blind, randomised controlled trial, people with dementia in residential and day care who receive the programme will show significant benefits in cognition, behaviour, communication and global functioning when compared to no-treatment controls.

## **Chapter 4: The Pilot Study; Day Care**

### **4.0.0. Hypothesis**

- A pilot study in a day centre for people with dementia will demonstrate preliminary evidence of effectiveness of the programme, such as improvements in cognition and behaviour.

### **4.0.1. Aim**

- To investigate the qualitative and quantitative effects of the programme and the effectiveness of individual sessions, by running a pilot study in a day centre for people with dementia.

### **4.1.0. Recruitment of the centre**

Martin Orrell (MO) approached a day centre in Essex, which had links with the Princess Alexandra Hospital where the team was based. The managers were given the protocol, which explained the aims and objectives of the project, and subsequently agreed to participate. There were twenty-eight attendees in total, approximately ten to twelve attending each day. The centre specialised in dementia care, and most staff had some specialist training. There was a favourable staff-client ratio and a homely atmosphere.

### **4.1.1. Recruitment of participants**

The following inclusion criteria were developed:

- i) Diagnosis of dementia according to DSM IV (American Psychiatric Association, 1994).

ii) Mild to moderate dementia, as indicated by:

- ◆ Mini-Mental State Examination (MMSE, Folstein et al, 1975) score between 10 and 24.
- ◆ Some ability to communicate and understand communication (a score of 1 or 0 in questions 12 and 13 of the CAPE Behaviour Rating Scale, Pattie and Gilleard, 1979).

iii) No serious hearing or visual impairments which might affect people's ability to co-operate in the group.

iv) No serious health problems which may affect people's ability to attend groups.

v) No challenging behaviour which could disrupt group activities (loud or constant talking, wandering about, etc).

vi) Attendance at the centre on Tuesdays and Fridays (the days agreed to run the groups).

These were presented to the staff, who with Aimee Spector (AS) went through the list of attendees one by one, and identified fifteen possibly suitable people to be assessed.

#### **4.1.2. Assessment measures**

A range of instruments were used for participants, staff and the researcher. Fuller details of the scales are provided in the method (6.2.0.).

a) *Mini-Mental State Examination* (MMSE), (Folstein et al, 1975). A brief test of cognitive function, with good reliability and validity. b) *Alzheimer's Disease Assessment Scale - Cognition* (ADAS-Cog), (Rosen et al, 1984). A sensitive test measuring cognitive function, including more items which assess short-term memory. c) *Story Recall Task*, from the AMIPB (Adult Memory and Information Processing Battery, Coughlan & Hollows, 1986). A test in which the participant is read a short, detailed account, and

asked to recall as many details both immediately afterwards and 30 minutes later. d) *Holden Communication Scale* (Holden and Woods, 1995). A staff rated scale that covers the participant's social behaviour and communication. e) *Clinical Dementia Rating* (CDR), (Hughes et al, 1982). Rated by the researcher, this provides a global rating of dementia severity. f) *Cornell Scale for Depression in Dementia* (Alexopoulos et al, 1988). Rated by the researcher, this looks at depression in dementia using information from interviews with carers and participants, and case notes. g) *Rating Anxiety in Dementia* (RAID), (Shankar et al, 1999). Rated by the researcher, this looks at anxiety from interviews with carers and participants, and case notes. h) *Behaviour & Mood Disturbance Scale* (BMD), (Greene et al, 1982). A staff rated scale evaluating changes in the participant's behaviour, function and disturbance in the home setting. i) *Behaviour Rating Scale* (from the Clifton Assessment Procedures for the Elderly (CAPE); Pattie and Gilleard, 1979). A staff rated scale evaluating general behaviour and dependency.

#### **4.1.3. Procedure**

The fifteen people suggested by staff were screened using the MMSE. Twelve fitted the inclusion criteria, and full assessments were conducted in the week prior to treatment. Of the remaining three, one refused assessment, one became excessively agitated and one had severe dementia. Participants were randomly allocated to treatment and control groups, by drawing numbers (corresponding with names) from a sealed container. The control group received usual care whilst the groups ran, which often involved drawing, games, discussion or crafts led by a staff member. Seventeen, 45 minute sessions ran twice weekly in a quiet room, led by the researcher and a member of staff acting as co-facilitator. Follow-up assessments were completed in the week following treatment.

#### 4.2.0. Main results

Of the twelve participants, two dropped out; one in the control group (who left the centre), and one in the treatment group (who refused to participate), leaving five in each. People in the group attended between ten and seventeen sessions (mean = 13.2). Descriptive details of the participants are provided in table 4.

*Table 4: Day care: Descriptive characteristics of participants*

CHARACTERISTICS	TREATMENT	CONTROL	ALL
Total number	5	5	10
Mean age (sd)	84.4 (6.2)	85.6 (3.9)	85.0 (5.8)
Gender ratio (female, male)	3f, 2m	4f, 1m	7f, 3m
Numbers (baseline) at each CDR level* (0.5 / 1 / 2)	(1 / 3 / 1)	(2 / 3 / 0)	(3 / 6 / 1)
Mean baseline MMSE (sd)	13.2 (5.9)	17.2 (4.8)	15.2 (5.5)

\* 0.5 = questionable dementia, 1 = mild dementia, 2 = moderate dementia (see 6.2.0.)

An independent samples t-test was used to calculate between group differences between the two assessment stages (Table 5). The Mann-Whitney U test was used for the CDR as it is an ordinal measure, hence non-parametric analysis was required. The programme was associated with changes in cognition, with a significant improvement in ADAS-Cog in the treatment group, compared to controls. Similarly there was a positive trend in MMSE. Anxiety and depression fell in the treatment group and increased for controls, both scales (RAID and Cornell) showing a significant difference between groups. There were no changes in behaviour (BMD, BRS) for the treatment group, although on both

scales, controls worsened. The severity of dementia (CDR) increased in both groups, yet more so for controls, this difference reaching significance. A notable outcome was that participants' communication, as measured by the Holden Communication Scale, actually improved for controls and declined in the treatment group, this difference reaching significance.

#### **4.2.1. Results – feedback from sessions**

##### *Phase 1: The Senses*

People found the smells difficult to identify, but appeared to find the process of smelling them interesting. Touch appeared to be the strongest sensory ability of the group. The film excerpts and pictures stimulated discussion, and people became quite fixated on the lava lamp. Most of the group had never experienced such acute flavours before the taste session (bitter, sour, spicy), which resulted in some suspicion as to why they were given something 'unpleasant'. Generally, the senses sessions offered a gentle introduction to the programme, allowing the co-ordinators to judge how people responded to it and their potential limitations.

##### *Phase 2: Remembering who you are*

Participants had clear memories of early childhood and were eager to share them with the group, yet some appeared to find questions on adolescence intrusive, and became defensive. For many, adolescence coincided with the war and generated unpleasant memories.

*Table 5: Day Care: Baseline and follow-up data for treatment and control groups, and between groups differences using the independent t-test (and Mann-Whitney for CDR)*

OUTCOME / TEST USED	GROUP	BASELINE: (T1)	FOLLOW-UP: (T2)	MEAN DIF	BETWEEN GROUP DIF
Cognition / MMSE	Treatment	13.2 (5.9)	15.6 (6.7)	+ 2.4	t = 1.64 p=0.07
	Control	17.2 (4.8)	15.6 (6.1)	- 1.6	
Cognition / ADAS-Cog	Treatment	65.4 (12.5)	71.0 (14.1)	+ 5.6	T=2.15 p=0.03*
	Control	72.2 (18.0)	69.4 (15.4)	- 2.8	
Anxiety / RAID	Treatment	24.0 (9.1)	11.8 (8.4)	+ 12.3	T=-2.34 P=0.03*
	Control	8.3 (1.2)	19.3 (9.5)	- 11.0	
Depression / Cornell	Treatment	19.0 (2.9)	10.3 (3.1)	+ 8.8	T= -4.26 P =0.004*
	Control	9.7 (0.6)	16.0 (5.3)	- 6.3	
Communication / Holden	Treatment	10.6 (2.6)	11.8 (3.0)	- 1.2	T= 3.13 P =0.007*
	Control	13.6 (1.1)	10.4 (1.5)	+ 3.2	
Behaviour / BRS	Treatment	15.5 (5.0)	16.0 (4.2)	- 0.5	T=-0.43 P =0.37
	Control	12.5 (10.6)	16.5 (0.7)	- 4.0	
Behaviour / BMD	Treatment	55.5 (12.7)	54.0 (8.2)	+ 1.5	t = -1.47 p = 0.10
	Control	43.5 (18.3)	55.0 (18.6)	- 11.5	
Global / CDR	Treatment	2.0 (0.8)	2.3 (0.5)	-0.3	Z = -1.75 P = 0.04
	Control	1.0 (0.0)	2.5 (0.7)	- 1.5	

\* = significant (p<0.05) using one-tailed significance test

( ) = standard deviations

+ = change in positive direction

- = change in negative direction

### *Phase 3: Remembering people*

People enjoyed discussing the pictures of themselves, the staff, their families and famous people. Attempting to 'teach' each others names through the use of name-badges and rehearsal was perceived as patronising, and created hostility. The group showed little interest in the object recognition task. The reminiscence kit generated discussion.

### *Phase 4: Everyday practical issues*

These were perhaps the most successful. They were conducted in the form of a game, which was non-threatening to individuals, and all were keen to participate.

#### **4.2.2. Qualitative results: Individual cases**

**KS** was extremely hard of hearing, making it difficult for him to become involved in the group. He tended to 'switch off' quite easily, although became animated when talking about his childhood, of which he still had clear memories. He was found playing with a tactile "koosh" ball 30 minutes after the 'touch' session ended, appearing to be rather engrossed. This suggests that it may have had a therapeutic effect for him.

**MV** commented that the session on early childhood "Went so quickly", and on a separate occasion, that "I could play with this [koosh ball] all day." She was expressive and talkative throughout the programme, and was happy to participate. Towards the end of the programme, she sometimes supported **KS** when walking back to the lounge.

**MB** was talkative, yet concerned that the group was run by a psychologist, and feared a connection with the hospital. He worried about being "put away", and despite reassurance felt that he was being assessed. He became defensive in the 'adolescence' session, stating that these were "painful times", and was anxious that sensitive topics

would not come up again. Despite this, he made a substantial contribution to the group, and seemed to enjoy the sessions.

HC was talkative and relaxed throughout. His relationship with MB seemed to develop, as they complimented and supported each other on their stories. He always commented that he had enjoyed himself after the sessions ended.

AZ was at a later stage of dementia than the rest of the group, hence her contributions tended to be more muddled than the others. She was attached to MT, and frequently reluctant to attend when MT refused. However, at times she came out of her shell and participated well.

#### **4.3.0. Discussion**

The programme was generally popular and well tolerated, with a low dropout rate. The benefits in cognition were extremely promising, considering the expected deterioration in people with dementia over a 2-month period. The results indicated that like past research (Breuil et al, 1994; Koh et al, 1994), the groups may have been effective in stimulating cognition and memory. Although the control group scored higher than the treatment group at baseline in MMSE and ADAS-Cog, these differences were not significant. The programme led to significant reductions in depression and anxiety, yet these results should be interpreted cautiously as groups were poorly matched. The treatment group was more anxious and depressed than the control group at baseline, these between-group differences reaching significance (RAID:  $t = 2.89$ ,  $p = 0.03$ ; Cornell:  $t = 5.29$ ,  $p = 0.003$ ). A surprising result was that communication appeared to get significantly worse following treatment, but again there was a significant difference between the two groups at baseline on the Holden ( $t = -2.36$ ,  $p = 0.05$ ). Relationships between participants developed during the course of the programme. Overall, the group appeared to enjoy sharing their

experiences. Although only at pilot level, these quantitative results were extremely positive, but suggested that larger samples were needed for effective evaluation of the programme.

#### **4.3.1. Limitations**

The interpretative value of the results were limited, due to the small sample size. Additionally, groups were not matched at the outset in anxiety, depression and communication. It is unclear why communication appeared to deteriorate, but it might have been the result of a poor sample. The severe deafness of one participant suggested that the inclusion criteria for hearing and vision could have been more stringent, in order to exclude people who are not capable of using the material in the sessions or communicating with other group members. There was the possibility of rater bias as assessments were conducted by the group co-ordinator and staff, both who were aware of group allocation.

Most staff had received specific training in dementia care and they offered a varied daily activity programme. Thus they might have been disappointed by some of the sessions which were similar to their own activities, perhaps expecting something 'new and improved'. On average only ten people attended the centre each day, hence staff felt awkward inviting half of them into another room for the group, essentially splitting them up from their friends and taking them away from whatever activity they might be engaged in. Some staff expressed concern that this might actually affect their relationships with them, especially as some people appeared to feel excluded. This problem indicated that groups might be more successful in a larger centre, where

selecting a few individuals would not make others feel so excluded. If repeated in a smaller centre, the management of group selection would need to be reconsidered.

#### **4.3.2. Modifying the programme**

Following a team review of the programme, the following was decided:

- 1) The sound effects CD could be more effective if alternated with familiar songs, to prevent people from losing concentration.
- 2) Tastes with reminiscent value might be more pleasurable than unusual tastes, which were alien to some of the group and aroused suspicion.
- 3) For the session on familiar objects, modern objects (such as a mobile phone) might make an interesting contrast to the objects in the reminiscence kit.
- 4) The 'everyday practical issues' sessions, which were presented in the form of a game / quiz, were particularly successful, suggesting that presenting other sessions in a more 'game-like' manner could be beneficial.
- 5) In session 7, it was decided to abandon the flip chart and to address the reminiscence sessions in the social context of era's (1940's, 1950's etc.), hence making the discussion more general and allowing participants to only share personal experiences when they felt comfortable. However, the session on eras elicited minimal response, and it was clear that more conversational stimuli such as newspaper cuttings, music and pictures were needed.
- 6) The group responded better when given concrete material to discuss. For instance, response was better towards the smell kit, objects of different textures and the money quiz than to the discussion different era's and strategies for remembering names. All discussion should therefore be accompanied by specific aids or activities. Memory cues for different eras could have included pictures of influential people of the time or

newspaper cuttings, and discussions of names could involve developing a name association quiz.

#### **4.3.3. Changes for the residential pilot**

The “Story Recall” test was too difficult for the participants, as most were unable to respond at all. As people in residential care are likely to be even more confused, it was decided to no longer use this test. Assessments would instead include a test of autobiographical memory, examining the effects of the programme on implicit, as well as explicit memory. Some features of the programme were successful and would be repeated, including the senses, everyday practical issues and famous faces. Discussion on keeping safe and the making of name badges would be excluded from the programme. Sessions on the past would be approached using appropriate aids, and avoiding direct confrontation and questioning. ‘Teaching’ and rehearsal would also be avoided, and where possible, activities would be presented in the form of a game. Discussions would be accompanied with concrete aids, for example sessions on eras with newspaper articles, pictures and/or music. The focus would primarily be on harnessing implicit, rather than explicit memory; thus minimising confrontative memory processing and promoting general memory stimulation.

#### **4.4.0. Summary**

In support of the hypothesis, the programme generated significant effects in cognition. Contrary to the hypothesis, there were no changes in behaviour. There were also significant improvements in anxiety, depression and global functioning in treatment participants compared to controls. However, this was a small pilot study with limitations

including poor matching of groups. Qualitative observation helped to identify some of the programme's strengths and weaknesses, for example it was evident that using concrete material and presenting sessions in a game-like style might be more beneficial. The programme was refined and modified for the residential care pilot, described in chapter 5.

## **Chapter 5: Pilot study; Residential Care**

### **5.0.0. Hypothesis**

- A pilot study in three residential homes will demonstrate further evidence of the effectiveness of the programme, showing that a larger scale RCT is feasible.

### **5.0.1. Aim**

- To pilot the programme in three residential homes, to gather preliminary evidence of its effectiveness, and to determine the feasibility of a larger scale RCT.

### **5.1.0. Selection of homes**

It was arranged to run the programme in the social services residential home attached to the day centre used in the pilot study (home A), which has links with the Princess Alexandra Hospital. It housed around 60 residents. The other residential homes were part of Jewish Care, a large charitable organisation with which AS had links through previous work. The project was presented to a team at their head office. Information was provided about the aims and objectives of the project, the programme, the assessment scales used, the time and commitment required from each centre and the inclusion criteria. When presenting the inclusion criteria, it was emphasised that a minimum of eight people were required for the project to run. The team suggested two homes which they thought might be suitable to participate. Home B, in North London, housed 55 residents, including a specialist dementia unit (from which most were too impaired to enter the study). Home C, also in North London, housed approximately 60 residents. Each home was visited by AS, who discussed the nature

and content of the research with management and staff. This included the outcomes of the pilot study, the content of the programme, the level of involvement required by the home and the potential benefits of the project. All agreed to participate.

### **5.1.1. The revised programme**

Following the day care pilot, during which extensive notes were taken on people's responses to each session, the team met and discussed ways in which the programme could be improved for the residential care pilot study. Unsuccessful elements were omitted, resulting in a cut from seventeen to fifteen sessions. The revised programme was as follows:

#### *Phase 1: The senses*

This phase was cut to four sessions, with smell and taste combined:

- (1) Hearing. This included music from the 1940's in addition to sound effects, providing variation.
- (2) Smell and taste. Taste focused on reminiscent tastes such as old fashioned drinks and sweets. 'Unusual' tastes were omitted, as they had generated hostile reactions from some people.
- (3) Texture / Touch.
- (4) Sight.

#### *Phase 2: Remembering who you are*

This phase remained practically the same, although newspaper cuttings were used as prompts to encourage memories from different eras. In session 5, memory diaries were

introduced, with an aim to develop a personal collection of thoughts and memories to be kept when the programme was completed. These included a covering page, with spaces for personal details such as name, date and place of birth, childhood address, parents', brothers and sisters names. Participants were encouraged to write notes in the diaries, such as their thoughts, feelings or experiences at the end of each session (accompanied by the day's date.)

Group leaders would write on behalf of those unable to. Sessions in Phase 2 were:

(5) Self-summary (Growing up) / Up to 1930's

(6) Middle years / 1940's - 1950's

(7) Recent years

### *Phase 3: Recognising People and Objects*

This phase was cut from six to five sessions. The recognising objects task (which had not proved successful) was abolished, and the three 'objects' sessions were reduced to two more practical sessions. Sessions in phase 3 were:

(8) Recognising famous people from the past

(9) Recognising people in the group and staff members

(10) Recognising people in the family

(11) Familiar and modern objects. The reminiscence kit was contrasted with a demonstration of more modern objects, such as a mobile phone and a 'diskman'

(12) Using familiar objects. The group were to use familiar objects by completing a practical task, such as baking a cake.

*Phase 4: Everyday practical issues*

(13) Identifying and using money

(14) Knowing your way around. The 'keeping safe' element of this session was abolished, as it only appeared to cause distress, and was less applicable for people in residential care.

(15) Summing up and consolidation / tea party

### **5.1.2. Assessment measures**

The story recall test was disregarded as it proved too complex for this client group. The BMD caused confusion with some staff raters due to the wording of the questions in double negatives, and was replaced by the Behavioural Assessment Scale of Late Life (BASOLL, Brooker et al, 1993). This includes six scales, rated by staff: self-care, memory and orientation, challenging behaviour, sensory abilities, mood and mobility; and has demonstrated good reliability and validity. The Autobiographical Memory Interview (AMI) (Kopelman et al, 1989) was also added. The AMI assesses people's ability to recall facts from past life, and recall specific incidents, covering childhood, early adult life and recent events. It has good reliability and internal validity. As the full assessment takes approximately one hour to complete, a shortened version was developed for the project. This included the same sections as the original, but with fewer questions in each, selected by AS and SD. It employed the same scoring system as the original, but had a smaller total.

The revised assessment measures were therefore:

1) Cognition: Mini-Mental State Examination (MMSE)

Alzheimer's Disease Assessment Scale-Cognition (ADAS-Cog).

- 2) Memory: Autobiographical Memory Interview (AMI).
  - 3) Behaviour: Behaviour Rating Scale (BRS)  
Behavioural Assessment of Later Life (BASOLL)
  - 4) Communication: Holden Communication Scale
  - 5) Global factors: Clinical Dementia Rating (CDR)
  - 6) Depression: Cornell Scale for Depression in Dementia
  - 7) Anxiety: Rating Anxiety in Dementia (RAID)
- (See chapter 6 for further details of each scale)

### **5.1.3. Inclusion criteria**

Inclusion criteria remained the same (see 4.1.1.), although exclusion of people with hearing and visual impairments was more stringent due to the difficulties that they were likely to experience in groups, as shown in the day centre. Decisions concerning how likely they were to benefit from and cope with the programme's material were made on an individual basis.

### **5.1.4. Procedure**

The project ran in Home A. Eight people met the inclusion criteria; five were randomly allocated to the treatment group, and three became controls. When complete, the project took place in homes B and C simultaneously. In Home B, seven people met the inclusion criteria, five entered the treatment group, and two became controls. In Home C, eight people met the inclusion criteria, five entered the treatment group, and three became controls.

### 5.2.0. Results

The mean number of sessions attended was 14.6 in home A, 13.3 in home B and 12.25 in home C. There were no dropouts in home A, four in home B: two treatment (illness), two controls (one death, one refusal), and two in home C: one treatment (refusal to attend programme), one control (refusal at follow-up assessment). Hence complete data was obtained from eight people in home A, three in home B, and six in home C. This data was combined, resulting in complete data from 12 treatment and 5 control participants. Descriptive details of participants are provided in table 6. A between group analysis was conducted, using independent t-tests. Results are shown in table 7.

*Table 6: Residential care: Descriptive details of participants*

CHARACTERISTICS	TREATMENT	CONTROL	ALL
Total number	12	5	17
Mean age (sd)	87.1 (5.7)	83.7 (8.1)	85.9 (6.6)
Gender ratio (female, male)	9f, 3m	4f, 1m	13f, 4m
Numbers (baseline) at each CDR level* (0.5 / 1 / 2 / 3)	(1 / 2 / 7 / 2)	(1 / 3 / 1 / 0)	(2 / 5 / 8 / 2)
Mean MMSE 1 (sd),	11.1 (3.6)	13.8 (3.7)	12.2 (4.3)

\*0.5 = questionable dementia, 1 = mild dementia, 2 = moderate dementia, 3 = severe

dementia (see 6.2.0.)

Both groups showed improvements in tests of cognition (MMSE, Adas-Cog), which were marginally greater for the treatment group, although insignificant. Both showed

improvements in levels of anxiety and depression, and a deterioration in communication over the 8 weeks. The behavioural measures showed a decline in both groups, including the 'challenging behaviour' element of the Basoll. Both groups showed improvements in autobiographical memory, treatments more than controls. There was a significant improvement in global dementia score (CDR) over the 8 week period, with the treatment group showing an improvement and the control group, a decline. Controls actually showed marginal improvements in 'memory and orientation', and 'mood' in the Basoll, and the treatment group showed marginal improvements in 'mobility' and 'self-care'. There was a significant improvement in sensory abilities in the treatment group.

### **5.2.1. Qualitative results**

#### *Home A*

The group were talkative and showed interest in all the material and activities. Writing in the memory diaries, such as a fact or opinion which had been discussed in the session, became a focal point. It was also an effective orientation exercise, as date and time would be written. Three people wrote themselves, the others dictated to the group leaders. LS would always ask when the next meeting would be, express enjoyment and offer thanks. She became more confident in groups as the programme developed. IJ suffered from serious health problems which caused great distress, yet once involved in sessions, appeared more content. A friendship developed between IJ and LS, who sat together and shared private jokes. SC rarely spoke unless prompted, was permanently drowsy and often fell asleep. However, in two sessions, she became extremely verbal, humorous and chatty. Staff attributed these variations to the effects of medication.

*Table 7: Residential Care: Baseline and follow-up data for treatment and control groups, and between group differences using the independent t-test (and Mann-Whitney for CDR)*

OUTCOME TEST USED /	GROUP	BASELINE: (T1)	FOLLOW-UP: (T2)	MEAN DIF	BETWEEN GROUP DIF
Cognition MMSE	Treatment	11.1 (3.6)	14.2 (5.2)	+ 3.1	t=0.90 p=0.25
	Control	13.8 (3.7)	15.4 (5.5)	+ 1.6	
Cognition ADAS-Cog	Treatment	64.3 (11.2)	66.3 (12.3)	+ 2.0	t=0.14 p=0.45
	Control	71.0 (11.2)	72.3 (15.3)	+ 1.3	
Long-term memory / AMI	Treatment	12.6 (5.4)	15.9 (7.5)	+3.4	t=0.38 P=0.21
	Control	12.1 (7.2)	13.3 (8.9)	+1.2	
Anxiety / RAID	Treatment	4.9 (4.3)	4.8 (3.5)	+ 0.1	t=0.70 p=0.25
	Control	7.7 (3.8)	6.2 (3.7)	+ 1.5	
Depression Cornell	Treatment	4.5 (3.0)	3.9 (2.4)	+ 0.6	T=-0.23 p=0.41
	Control	5.5 (2.0)	5.3 (3.5)	+ 0.2	
Communication / Holden	Treatment	14.3 (8.3)	14.8 (9.0)	- 0.5	t=-1.06 p=0.15
	Control	11.0 (9.1)	14.8 (8.1)	- 3.8	
Behaviour BRS	Treatment	12.8 (3.9)	14.0 (4.5)	- 1.3	t=1.01 p=0.16
	Control	13.0 (3.0)	12.5 (4.9)	+ 0.5	
Global / CDR	Treatment	2.1 (0.7)	2.0 (0.6)	+ 0.2	z=-2.33 p=0.01*
	Control	0.9 (0.7)	1.4 (0.7)	- 0.5	

\* = significant (p<0.05), 1-tailed significance

( ) = standard deviations

+ = change in positive direction

- = change in negative direction

*Table 7 continued: Baseline and follow-up data for treatment and control groups, and between groups differences using the independent t-test*

OUTCOME TEST USED /	GROUP	BASELINE: (T1)	FOLLOW-UP: (T2)	MEAN DIF	BETWEEN GROUP DIF
Behaviour Basoll (total)	Treatment	23.5 (8.9)	25.5 (14.7)	-2.0	T=0.04 P=0.48
	Control	21.7 (12.4)	23.5 (14.1)	-1.8	
Challenging behaviour Basoll /	Treatment	1.5 (1.3)	2.0 (1.7)	-0.5	t=-0.69 P=0.25
	Control	2.2 (1.5)	3.0 (2.4)	-0.8	
Memory orientation & Basoll /	Treatment	6.2 (3.3)	6.2 (4.3)	0	t=0.63 P=0.27
	Control	7.0 (5.4)	6.3 (6.5)	+0.7	
Mobility Basoll /	Treatment	0.9 (1.0)	0.8 (1.0)	+0.1	t=-1.00 P=0.17
	Control	0.7 (0.5)	0.7 (0.5)	0	
Mood / Basoll	Treatment	1.7 (1.6)	3.9 (5.8)	-2.2	t=1.60 P=0.06
	Control	3.3 (2.3)	3.0 (1.6)	+0.3	
Self-care Basoll /	Treatment	12.8 (5.6)	12.1 (6.8)	+0.7	t=-1.21 P=0.12
	Control	7.2 (6.1)	8.7 (5.6)	-1.5	
Sensory abilities / Basoll	Treatment	1.2 (0.9)	0.5 (0.7)	+0.7	t=-2.08 P=0.03*
	Control	1.3 (1.0)	1.5 (0.8)	-0.2	

\* = significant ( $p < 0.05$ ), 1-tailed significance

( ) = standard deviations

+ = change in positive direction

- = change in negative direction

WJ was warm, friendly and talkative, but sometimes needed to be interrupted to let others speak. She greatly enjoyed contributing to discussion, clearly relishing the opportunity of being listened to, and cried in the final session. AW was the least impaired of the group. The staff co-facilitator recognised dramatic changes in her as she became really expressive and animated in the group setting, compared to her usual, extremely passive state. There were no dropouts. As follows are some quotes written in their memory diaries during the final session:

*“A meeting sadly for the last time, I have enjoyed our getting together.” “I liked it very much and I enjoyed it as well. I think it was very nice of you to give us the time.” “Today has been the last group. We’ve had a lovely time. Looking forward to the next ones”. “I enjoyed the social gathering and being with the other people. God bless them all.”*

### *Home B*

The project began with a co-facilitator who appeared disinterested and restless during sessions. Additionally, the manager arranged sessions when there were concurrent activities, such as the doctors round. These problems were resolved by session five, by moving the groups to quieter days and changing the co-facilitator. The two women in the group, who tended to be more talkative, dropped out in session 5, leaving three men. From this point, the reminiscence elements became problematic, with one man too reluctant, and another too impaired, to reminisce. The group showed no interest in certain elements of the programme (memory diaries, lava lamp, theme tune), which were abandoned. Generally, they were not a talkative group of people, making some of the sessions difficult. However, after an attempt to make the programme more ‘male orientated’, (see 5.3.2.), things started to improve.

JA had a stroke, leaving him physically impaired and with little short-term or long-term memory. Initially he was shy and withdrawn, responding minimally when spoken to, yet after time he began to smile more, show greater confidence, and often volunteer information. In the final session, he said "I hear you are leaving us" at least half an hour after he was told, a positive response considering the weakness of his short-term memory. BL appeared to enjoy the sessions, particularly reminiscing; although he involved himself minimally, was often drowsy and sometimes fell asleep. MD was the least confused group member. Although initially rather sarcastic, in the course of the program it became clear that he actually enjoyed the sessions, increasingly contributing to discussion. In the final session, he said "Why do you have to stop coming? Why are you letting us down?" The group members rarely directed comments to each other, and only really conversed with the group leader.

### *Home C*

Due to factors including the Christmas and New Year period, there were gaps between some sessions which affected the continuity of the programme. The group was dismissive towards the memory diaries, which were subsequently not used. HJ continually showed interest and involvement, being the most talkative participant. She always expressed enthusiasm when asked to come to the groups. Her physical health deteriorated quite rapidly, and in later sessions, she was sometimes sleepy and confused. DA was hindered somewhat by her hearing, and only talked when spoken to. She often complained of physical ailments, yet appeared quite content in the group. She became highly animated in the cookery session.

FG's input was limited to when she was asked direct questions. FC was always reluctant to attend groups, like any activity, due to a general lack of motivation, depression and poor physical health. Yet once in the group, she was quite a conversationalist, and appeared to benefit. No relationships appeared to develop between group members. There was some variation in ability amongst the group, with two people more cognitively able than the others.

### **5.2.2. Overview of sessions**

#### *1 Hearing*

Generally, response to the 'sound effects' CD was minimal. People appeared bored, and even the minority without any hearing loss found it difficult to interpret the sounds. In home C, one person questioned the point of this activity, which created apprehension amongst the others. Home A sang along to the theme tune "Somewhere over the Rainbow" at all times, whereas the other groups showed no interest. Response to the popular songs was mixed. In home C, the session provoked discussion on music, favourite musicians and dancing.

#### *2) Smell / Taste*

The smell kit generated reasonable interest, although few people were able to correctly identify any smells. They also found the concept of certain smells in a bottle (such as cut grass) rather difficult to grasp. More practically, whilst the smells were being passed round, other members of the group became distracted. In home A, the reminiscent tastes (eg. pear drops, ginger beer), were greeted with enthusiasm and discussion. The taste element was less effective in homes B and C, as only kosher food could be used, which was difficult to obtain. In home C, each person was given a different flavoured sweet, and asked to guess

which of five named fruits it was (strawberry, raspberry, cherry, lemon, orange). None were able to guess correctly, showing quite severe impairments in taste.

### 3) *Touch*

Some people appeared to enjoy feeling the different textures, more for sheer tactile stimulation, rather than as a conversation stimulus. The fur, silk, velvet, koosh balls and coloured slime were particularly popular. This task seemed to be more appealing for the women, stimulating discussion about clothes and fashion. The men showed little interest in the materials, suggesting that more male-orientated objects need to be introduced here, such as work-related objects. Touch appeared to be the most preserved sense for the people overall.

### 4) *Sight*

Video clips generated interest in all homes, although it was unclear how well people could actually see the material, and it may have been the combined visual and auditory experience which created the interest. Clips included “The Wizard of Oz” (one of the first colour films), and “Titanic” (which showed historical costumes and illustrated the modern use of special effects). The lava lamp only aroused interest in Home A. It proved to be fairly impractical, as the lights need to be turned off for maximum effect, preventing other activities from occurring concurrently. Pictures of the ‘Jewish East End’ were shown to homes B and C, with positive reactions from those living there. Colourful pictures of places around the world were shown, with little reaction from most people. The majority had some level of visual impairment, and found it difficult to see the details of pictures, especially those that they were not familiar with.

### *5) Self-summary (growing up) / Up to 1930's*

In Home A, people were eager to write in their diaries, to share stories and to listen to others. The other groups showed no interest in the diaries, which were abandoned. The newspaper articles were unsuccessful in homes B and C, as most of the events bore no personal relevance in the people's lives, although in home A, some points stimulated discussion. Home C were keen to discuss their childhood, such as where they lived, what their bedrooms looked like and who they shared with. This activity was particularly difficult in home B, as the group were so reluctant to reminisce.

### *6) Middle years / 1940's - 1950's*

This session was successful in home A, as the focus was on writing in the diaries. For the others, interest in the newspaper articles was minimal, and in home B it was difficult to get the conversation going.

### *7) Recent years*

This session involved a combination of discussing articles from more recent eras (1960's onwards), and bringing in several newspapers and magazines from that particular day, from which selected articles, issues and pictures were discussed. The latter activity generally generated discussion. There was a noticeable improvement in home B, as it was possible to select more appropriate topics for the three men to discuss, such as sports and politics.

### *8) Recognising famous faces*

This task generated a mixed reaction across the groups. For some, it stimulated conversation and thought, yet people tended to find it extremely difficult. This may have been the result of both poor visual ability and memory loss.

### *9) Recognising people in the group and staff*

Homes A and C enjoyed the process of taking the Polaroid photographs, watching them develop and keeping them. In home B, the men were fairly disinterested. The groups showed no interest in learning names, and most appeared to have difficulties distinguishing facial features in the pictures. This task seemed insufficient to fill an entire session.

### *10) Recognising people in the family*

This was successful in homes A and C, where people enjoyed looking at their own and each others' photos. Home B tended to forget who people in the photos were, and showed little interest in each others' families. In all three homes, one person owned no photographs, which excluded them from this activity. Looking at photos did not fill a whole session, and it was difficult to involve the whole group, as only one person could look at each photo at a time.

### *11) Familiar (and modern) objects*

The reminiscence kit encouraged much interest and discussion in homes A and C, with people explaining how and why the objects were used, and giving washing and darning advice. Many of the objects were of more relevance to women, such as cleaning products, hence there was less interest in home B, where people were more interested in a demonstration of a mobile phone ringing, and listening to a CD.

### *12) Using familiar objects*

Homes A and C were given the task of baking a cake. Both groups were completely engrossed in the task, each person making some contribution. All had their own opinions and cooking tips. The quieter members of both groups became animated. In home B, the men were given a shoe to lace and polish, and a lightbulb and plug to fix to a lamp. One man

became absorbed in the shoe lacing and polishing task. The lamp task proved complicated, although the men were keen to guide the group leader, explaining what to do.

### *13) Identifying and Using money*

Overall the money quiz generated discussion, interest and laughter. People seemed to enjoy comparing old and new coins, discussing how much things used to cost, how much they got paid, and so on.

### *14) Knowing your way around*

In homes A and B, a map of the UK was produced, as people were all from different parts of the country. This was a fairly effective task, but generally only one or two people were really able to contribute. A map of London was produced in home C, as all the group had lived there. Again, contribution was primarily from one person. This task proved quite difficult for some people, especially the cognitively impaired.

### *15) Consolidation / tea party*

Elements of the programme which had been successful were reiterated, such as a review of the daily papers in home B. Most participants seemed disappointed that the programme was ending.

## **5.3.0. Discussion**

Quantitative results showed minimal effects. The only significant outcome was in global factors (CDR), with the treatment group showing global improvements and controls, decline. Nonetheless, this second pilot study demonstrated qualitatively that individuals did benefit, and was useful in further demonstrating how effective different elements of the programme were.

### 5.3.1. Limitations

Treatment and control groups were not matched at baseline (controls scoring higher in cognition, communication, anxiety and depression), and ideally would have been more homogenous. This baseline difference was significant in cognition (MMSE:  $t = -2.65$ ,  $p = 0.01$ ), but not in the other variables. There was some detection bias, as staff completing the assessments were aware of group allocation, which may have influenced their expectations. Additionally, the researcher both ran the groups and administered assessment measures. Hence she was not blind to group allocation, and had formed relationships with treatment participants by the second assessment, which could have affected their interactions with her. Ideally, assessments would be conducted by blind raters. There was the possibility of performance bias, in that participants' awareness and expectations of treatment may have affected their attitude and behaviour during assessment.

The 'sensory abilities' section of the Basoll showed a significant change in favour of treatment over the eight weeks. The two questions in this section refer to ability to see and hear, which are extremely unlikely to change to this degree over two months. Although the same member of staff (preferably the key worker) was asked to complete the assessment measures for each individual on both occasions, there were frequently different raters at baseline and follow-up, due to factors including annual leave and sickness. Both might have had alternative perceptions of the person's sensory abilities, yet this shows poor inter-rater reliability. Further, if staff are unaware of patients' ability to see and hear, are they likely to give an accurate assessment of more subjective factors? For example, a staff member with a

good relationship with a participant might view their ability to communicate differently to one with a poor relationship with the same person, hence producing two different outcomes on the Holden communication scale.

There were no dropouts in home A, four in home B and two in home C. Because the number of dropouts were equal in both treatment and control groups, attrition was unlikely to be a result of treatment. As it was a struggle to recruit enough suitable subjects, people were sometimes asked on two or more occasions to be assessed at baseline. This resulted in some ambivalent participants at the outset, hence it was not surprising that some refused second assessment. It should be noted that the project ran during winter in homes B and C, the highest period for mortality, and a flu epidemic in home B caused many to fall sick.

### **5.3.2. General issues**

The introduction of the memory diaries in Home A created a sense of continuity between sessions. Confused participants remembered being part of the group once presented with their own diary, which contained pictures of themselves and things they had written. At the end of the programme, they appeared proud to be able to keep something which they had personally produced. However, this was an individual activity, thus it was essential that it only occupied a small part of the session in order to keep group momentum going. The diaries were less popular in homes B and C, where a minority appeared threatened by the prospect of having to write something, and verbalising this may have instilled fears in the others.

In home B, the group comprised of three men, and highlighted parts of the programme which were less male orientated. For instance, the men showed little interest in the 'touch' session, which primarily focused on feeling different materials, and the creative session, which in other groups had been cookery. Additionally, these men appeared to get restless unless they were actually *doing* something, whereas the women tended to be happy just looking at things and engaging in conversation. Therefore it is important to incorporate activity-based, as well as discussion-based elements into each session, to cater for all needs.

This residential pilot provided more insight into which elements of the programme were or were not effective. It emerged that using an isolated sense might not be as effective as a combined, multi-sensory experience, the latter being more typical of real life. For instance, the smell kit contained smells of things of which in a more natural situation, might be recognised through an alternative sense. To illustrate this, 'the dentist' is a situation which people might identify by certain visual images or sounds, before considering its smell. Therefore, presenting a person with dementia with a bottle containing oil which smells of 'the dentist' is a highly artificial phenomenon. Additionally, asking a person with limited sensory abilities to rely on a single sense might be unreasonable. It was thus decided to introduce combined sensory experiences in the final modifications of the programme. Another factor which emerged was the difficulty encountered when people attempted to remember 'middle years', with a suggestion that focusing reminiscence sessions around 'themes' might be more beneficial.

#### **5.4.0. Summary**

Supporting the hypothesis, this residential care pilot study has further demonstrated potential benefits of the programme, such as positive trends in cognition; suggesting that a larger scale RCT is feasible. The discussion of further reactions towards the programme and its limitations will be used in the process of developing its final modifications. Chapter 6 will describe how the final version of the programme, and its use in the full multi-centre trial.

## **Chapter 6: Methods**

### **6.0. Procedure**

#### **6.0.1. Recruitment of centres**

MO wrote to key people in various health authorities and organisations, asking for support to run the project in residential homes and day centres within their trust. Letters supporting the project were obtained from Brentwood, Havering and Barking, Enfield and Camden and Islington NHS Trusts, and Quantum Care (a voluntary organisation in Hertfordshire). A booklet or list of all the private and local authority residential homes, nursing homes and day centres in each trust was obtained from social services (Quantum Care provided its own list). The contact details and number of residents were provided. All day centres, and residential homes with a minimum of fifteen residents were contacted. A minimum of fifteen was chosen for the following reason. At least eight suitable participants were required to run the project, of which five would be randomised into the treatment group and three into the control group. Five was considered the minimum for a group to run, in light of the high attrition rate in this population and group numbers used in past research. The pilot study had used three large homes, each with at least fifty residents, yet only eight suitable participants were found in two and in the third, only seven. Hence it seemed extremely unlikely that homes with less than fifteen residents would have at least eight who were suitable.

Initial contact was by post. The introductory letter provided a background to the project, what it involved and its main objectives (see Appendix C). It was accompanied by a copy of

the information sheet and consent form, see 6.3.0., and following the BHB phase, a copy of the inclusion criteria (see figure 6). The letter stated:

- i) What was being offered: fourteen varied sessions, full cognitive assessments of the participants and an opportunity for staff to learn about running small groups.
- ii) What was required: a minimum of eight suitable participants, staff completion of assessments scales pre and post intervention and a member of staff to co-facilitate groups.

The letter was followed by a phonecall to the manager approximately five days later. Discussion usually involved the content of the programme, the commitment needed by staff (in terms of assessments and co-facilitating groups) and practical issues (such as an available room and the best days and times for running groups). In the first BHB stage, visits were arranged to discuss the project further. For homes which appeared suitable, full assessments were planned at a time to fit in with a block (see table 8, weeks 2 onwards). A second researcher (LT) was employed at this stage, to enable blind assessment and increase the number of groups running. Assessments were arranged in 6 places over a 3 week period, to be split between AS and LT, the two researchers.

### **6.0.2. Introduction of screening**

Putting a week aside both to select participants and complete full assessments proved unsuccessful. Centres frequently did not have enough suitable participants and there would usually not be enough time to find an alternative centre within that week. In fact, only 16 out of the 37 centres screened (43%) were suitable. It became apparent that determining which

centres were suitable before arranging assessments would enable more effective planning and time-keeping. Subsequently, the week of screening was introduced in the second phase (Quantum Care, Camden and Islington and Enfield). Initial introductions and screening were combined into one meeting.

In the pilot studies and early groups, a brief summary of the inclusion criteria were provided in the initial letter. Staff appeared to find this summary too vague a tool to determine how many suitable participants there were prior to screening. Hence the researchers would often arrive at a centre, only to discover that there were few (if any) suitable participants. It appeared that if the inclusion criteria were presented in a more concrete way prior to visits, time could be saved by avoiding visiting unsuitable centres. Thus the inclusion criteria flow chart (figure 6) was introduced. The introductory letter requested that staff went through figure 6 with their entire list of residents (or attendees at day centres), in order to ascertain an idea of the number of potential participants.

The inclusion criteria were used to determine a list of people to screen, either by staff prior to the visit, or by staff and the researcher on the day of screening. People were screened using the MMSE. During this assessment, (i) – (viii) of the inclusion criteria (see 6.0.3.) were determined. It was always encouraged that a member of staff sat in on the screening, and that cases were discussed individually. Frequently, the types of participants required for the project became clearer to staff once observing screening and discussing individuals with the researcher, enabling them to suggest more appropriate people to be screened.



Table 8: The researchers' typical 12-week working pattern

	WEEK 1	WEEK 2	WEEK 3	WEEK 4	WEEKS 5-9	WEEK 10	WEEK 11	WEEK 12
AS	Screen 6 places ► 3 suitable (X,Y,Z)	Full assessments in X	Run groups in A. Full assessments in Y.	Run groups in A, B. Full assessments in Z.	Run groups in A, B, C.	Follow-up assessments in X. Run groups in B, C.	Follow-up assessments in Y. Run groups in C.	Follow-up assessments in Z. All groups finished.
LT	Screen 6 places ► 3 suitable (A,B,C)	Full assessments in A	Run groups in X. Full assessments in B.	Run groups in X, Y. Full assessments in C.	Run groups in X, Y, Z.	Follow-up assessments in A. Run groups in Y, Z.	Follow-up assessments in B. Run groups in Z.	Follow-up assessments in C. All groups finished.

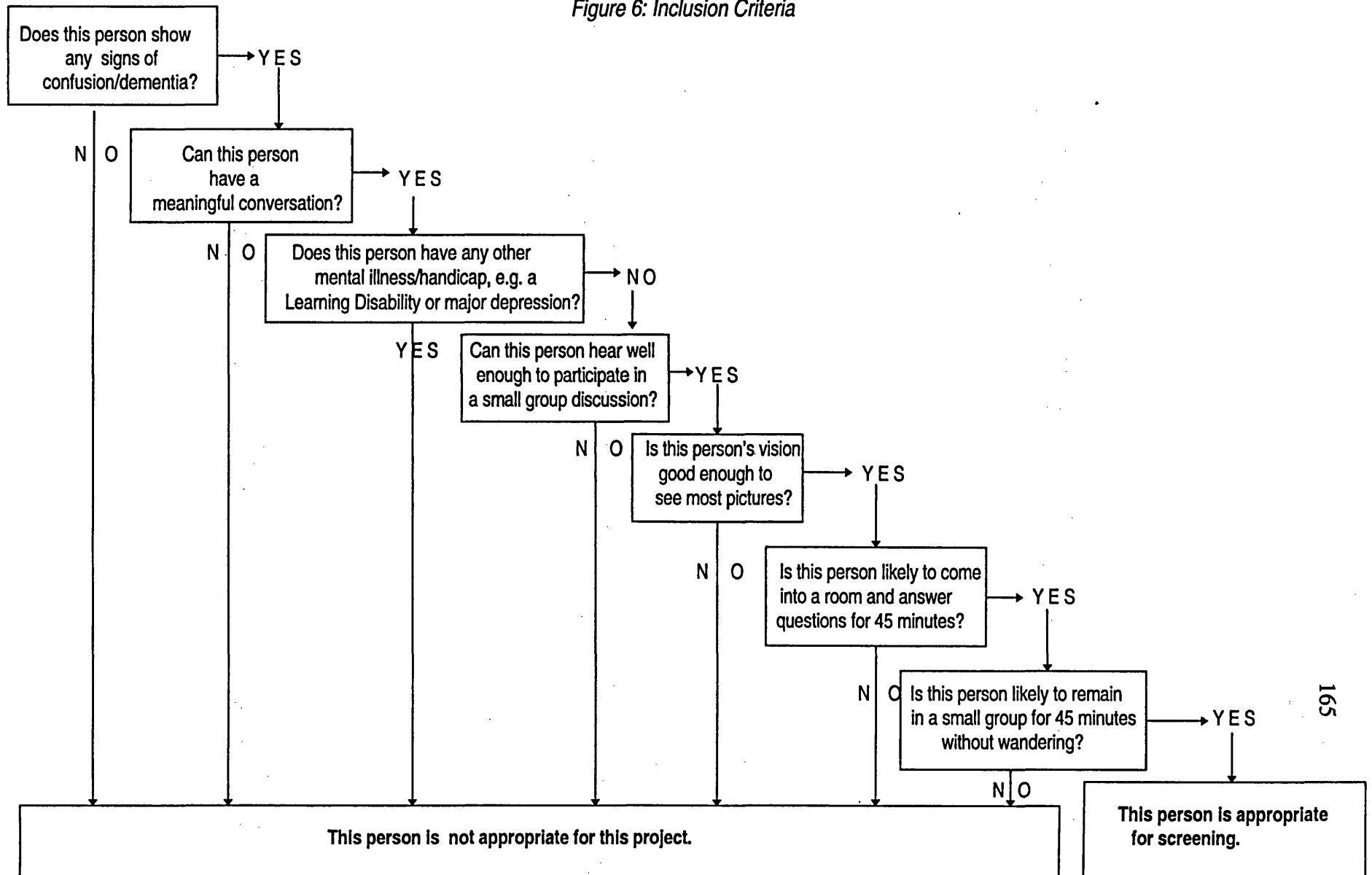
### **6.0.3. Inclusion criteria**

People were considered suitable for full assessment and participation if they:

- i) Met the DSM IV criteria for dementia.
- ii) Scored between 10 and 24 on the MMSE.
- iii) Had some ability to communicate and understand communication (a score of 1 or 0 in questions 12 and 13 of the CAPE Behaviour Rating Scale, Pattie and Gilleard, 1979). This was determined by the researcher during the screening.
- iv) Were able to see and hear well enough to participate in the group and make use of most of the material in the programme, as determined by the researcher.
- v) Did not exhibit persistent behavioural patterns which might deter them from participation, including constant wandering, shouting, or aggression. This was determined by the researcher through observation and discussions with staff.
- vi) Usually agreed to participate in activities, as determined by staff.
- vii) Did not have a diagnosis of a physical illness / disability which could affect their participation (such as a cancer sufferer needing to make regular hospital visits).
- viii) Did not have a diagnosis of a learning disability.

In homes and day centres with at least eight suitable participants, full assessments were administered in the week prior to, and the week following the intervention. The two researchers alternated so that in each centre, either AS or Lene Thorgrimsen (LT) completed both assessments (blind to group allocation) and the other ran the groups.

Figure 6: Inclusion Criteria



#### **6.0.4. Randomisation**

A list of the participants' names was numbered (e.g. 1-8). Counters displaying corresponding numbers were drawn from a sealed container. The first five drawn were allocated to the treatment group and the remainder to controls. Randomisation was blindly conducted by the researcher who had not done the assessments, hence did not know who the individuals were.

#### **6.0.5. Running groups**

The project began in BHB, then moving to Quantum Care, Enfield and finally Camden and Islington. Groups ran in 16 centres. The first 3 centres were considered part of the development and training process. Groups in centres A and B involved testing the modified programme. Additionally, as the research assistant had not yet started, baseline and follow-up assessments were conducted by different people (baseline by AS and follow-up by an OT). Baseline assessments and groups at centre C were conducted jointly by AS and LT (the research assistant), in order for LT to learn how to assess and run the programme. Again, follow-up assessments were conducted by a different person (a psychologist). Although in theory the assessments should be reliable between raters, there is a chance of some variability in the way in which questions are asked and answers interpreted, so ideally the same person should assess at baseline and follow-up.

It was planned that both AS and LT would run groups in three centres at a time, within each region. Table 8 demonstrates a typical working pattern over a 12-week block. With an average of eight participants in each centre, it was aimed to recruit up to 48 people in each

block. An attempt was made for the researchers to run groups in centres of close proximity, minimising time spent travelling between groups.

### **6.2.0. Modifications to the programme**

Modifications were made in group meetings, following discussion on reactions towards the programme (see 5.2.2.); and a finalised version was produced. A summary of the main changes follows:

- 1) A primary focus on RO / cognitive stimulation, with reminiscence and multi-sensory stimulation as tools to aid the cognitive stimulatory process was reiterated.
- 2) Sessions which focused on individual senses were removed. Isolating the senses caused difficulties, as senses were so commonly impaired. So for example, the 'sounds' exercise was altered so that sound effects were now accompanied with pictures, allowing people to rely on two, as opposed to one sense. It was intended that multisensory stimulation would be incorporated more naturally into the programme.
- 3) The memory diary was abolished as it was too individualised an activity, and did not interest everyone. Instead an RO board, which presented both personal and orientation information, was introduced. In session one, people would be asked to suggest a name for the group. The facilitator might also suggest names, and a decision would be made by voting. The board would provide a focus, reminding people of the name and nature of the group, and creating continuity. Figure 7 shows an example of how the board might appear.
- 4) Each session would begin with the same warm-up activity, typically a soft ball game. This was a gentle, non-cognitive exercise, aiming to create continuity and orientation by

beginning all sessions with the same theme. There was the option of introducing a cognitive element where appropriate, such as getting people to say their name or that of the person they were throwing to, or commenting on something else such as their favourite meal or colour when catching the ball.

*Figure 7: RO board*

<p><b>THE SUNSHINE GROUP, AT LINKSVIEW DAY CENTRE</b></p> <p><i>THURSDAY 18<sup>TH</sup> DECEMBER 2000 AT 10.30</i></p> <p><b>ONE WEEK UNTIL CHRISTMAS!!</b></p> <p><b>MEMBERS: MARY</b>  <b>HARRY</b>  <b>DICK</b>  <b>JOAN</b>  <b>BETTY</b></p> <p><b>SESSION 5: CURRENT AFFAIRS</b></p> <p><b>LAST WEEK WE TALKED ABOUT DIFFERENT FOOD</b></p> <p><b>WE WILL MEET AGAIN AT 2.00 TODAY, TO TALK ABOUT PEOPLE FROM THE PAST</b></p>
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- 5) The 'reminiscence phase' was removed, as people found it difficult to distinguish between eras. A session on childhood was maintained, and additionally more general

themes, such as 'food' were introduced to allow people to use reminiscence more naturally but also focus on current day issues.

- 6) The content of sessions was slightly alternated to encourage the use of opinion rather than fact. For example in the faces session, five copies of each picture were produced, and each person was to be given three pictures at a time. Hence the facilitator could ask questions such as "who looks the youngest?", "what do these people have in common?", "who is the most attractive?" Factual information could be introduced as an optional extra.
- 7) A choice of at least one activity was added to each session, enabling the facilitator to adapt the session according to the group's capabilities, interests and gender mix. For example, men sometimes appeared to prefer practical tasks, whereas women often seemed to enjoy discussion.
- 8) Multiple copies of material were produced where possible, e.g. in the current affairs and famous faces sessions; to prevent a loss of concentration from things being passed around.

The following sessions were removed entirely:

- (1) Smell and taste, (2) texture / touch and (3) sight: They proved too difficult for people and created unnatural situations, such as identifying 'the dentist' purely through smell.
- (4) Middle years: People found this period difficult to recollect, often reverting back to childhood.
- (5) Recognising people in the group. Learning peoples' names was too explicit, and people appeared to find it patronising.

(6) Recognising people in the family. It was only possible to obtain family photographs from some people, excluding the others. Additionally, this activity tended to create egocentric, as opposed to group activity.

(7) Familiar and modern objects. People often appeared unaware that the objects in the reminiscence kit were old and no longer used. Hence their reaction to these objects (such as a dolly peg) which they viewed as quite ordinary was, understandably, minimal. It was also hard to engage the group, as when passing things around the others became distracted.

#### **6.1.0. The finalised programme**

Sessions:

1) Physical game(s). Examples:

- Skittles or indoor boules.
- Throwing a soft ball around, and asking people to say things about themselves as they caught the ball; such as their name, where they lived, their former occupation or their favourite food.

This aimed to be a gentle introduction to the programme, helping to familiarise people with each other and the setting. A cognitive element could be introduced, such as getting people to calculate their scores in certain games. People would be asked to give the group a name, and the nature of the programme over the next seven weeks would be explained.

2) Sound. Examples:

- Matching the sounds of different animals and occupations to corresponding pictures.
- Playing of different percussion instruments along to familiar music.

3) Childhood. Examples:

- Individual completion of a copy of the first page of the memory diary (name of mother, father, siblings; schools attended etc).
- Reconstruction of a person's house or bedroom on the board, through discussion.
- Demonstration of childhood toys, such as jacks and hoopla.

4) Food. Examples:

- Use of imitation or real groceries to categorise objects (eg. special occasions, savory, sweet).
- Demonstration of how the above would have been used to make a meal.
- Tasting of food with reminiscent value, eg. cream soda, ginger beer, bread pudding.

5) Current day. Examples:

- Discussion of contemporary issues such as abortion, royalty and adoption, using multiple, laminated copies of interesting articles.
- Use of cue cards to stimulate discussion. Questions include 'who do you most admire?' and 'what is your favourite charity?'

6) Faces / scenes. Examples:

- Use of multiple, laminated pictures of famous people. Individuals are given one or more picture at a time, and asked to comment on factors such as oldest / youngest looking, most attractive, etc.
- Use of a Polaroid camera.

7) Associated words.

- Word completion tasks. E.g. proverbs ('a stitch in time....'), famous couples ('Punch and...').
- Song completion. Present the first few words of a song (e.g. 'We'll meet again...'), and ask the group to sing a few lines.

8) Using objects. Examples:

- Cookery.
- Seasonal collage.

9) Categorizing objects. Examples:

- Playing of a game (e.g. 'Topix'), in which one person picks a card with a letter on it and another picks a category (which can be made up by the facilitator to make the activity more easy.) Examples are countries, mens' names and colours.
- Brainstorming within a category (e.g. 'Christmas things', 'alcoholic drinks'), to be written on the board.

10) Orientation. Examples:

- Construction of a map of England, the local area or the home / day centre on the board, through people's responses to prompts. (e.g. 'where would the post office be?')
- Use of enlarged London tube map or map of England to prompt discussion.

11) Using money. Examples:

- Guessing the price of objects or pictures of objects.
- Matching the price-tag with the object.
- Demonstration of old coins, and discussion of how much people used to get paid, the price of a loaf of bread, etc.

12) Number-related activity. Examples:

- Bingo
- Pelmanism

13) Word-related activity. Examples:

- Large crossword or word-search.
- 'Hangman', which involves guessing the letters to complete a word. Category would be provided, e.g. 'a type of drink.'

14) Quiz / consolidation. Activities:

- Discussion of how the groups went, bringing back material from popular sessions.
- Quiz (with prizes for all) and tea party.

### 6.2.0. Assessment measures

a) *Mini-Mental State Examination* (MMSE), (Folstein et al, 1975). The original version of the MMSE is an 11-item set of simple tasks presented informally to the participant. It involves orientation to time, orientation to place, registration of three words, attention and calculation, recall, language and visual construction. It has a maximum score of 30 points, with 23 normally considered as the border between cognitive impairment (23 or less) and normal performance (24 or more). Reliability and validity are satisfactory. The MMSE is well known worldwide and is frequently used in the evaluation of psychological therapies and drug trials, enabling this study to easily be compared to others.

b) *Alzheimer's Disease Assessment Scale - Cognition* (ADAS-Cog), (Rosen et al, 1984).

This is a more sensitive scale administered to the participant, measuring cognitive function and including more items which assess short-term memory. The ADAS is divided into two parts, a cognitive part (ADAS-Cog) and a non-cognitive part, which may be used separately and has not been included. ADAS-Cog includes word recall and recognition, naming objects, following commands, orientation, praxis, drawing and observations of language ability. Inter-rater reliability, test-retest reliability and validity are high (Rosen et al, 1984). It was chosen because it is frequently used in drug trials as the principal cognitive measure, allowing the effects of the programme to be compared to anti-dementia drugs. The standardised scoring method (used in drug trials) from 0-70, with 70 indicating the most impairment, was used for the main study. However in the

pilot studies, the alternative method (summation of correct responses) was used as a result of earlier advice from a local researcher working in the memory clinic.

c) *Holden Communication Scale* (Holden and Woods, 1995). This is a 12-item scale, completed by staff. It covers a range of social behaviour and communication variables, including conversation, attempts at communication, awareness, pleasure, humour and responsiveness. Staff circle one of 5 responses for each variable (scoring from 0-4), which most adequately describes the person's behaviour in the two weeks prior to assessment. It correlates well with measures of dependency and cognition, and was chosen because it includes variables which might be particularly responsive to change following small-group work.

d) *Clinical Dementia Rating* (CDR), (Hughes et al, 1982). This provides a global rating of dementia severity and is commonly used in clinical settings and treatment trials. Based on the interview with the participant and staff / carer, it assesses dementia in six domains: memory, orientation, judgement & problem solving, communication skills, domestic skills and personal care. It stages dementia in five levels, 0 = no impairment, 0.5 = questionable dementia, 1 = mild dementia, 2 = moderate dementia, 3 = severe dementia. Good reliability and validity have been demonstrated.

e) *Cornell Scale for Depression in Dementia* (Alexopoulos et al, 1988). This rates symptoms and signs of depression in dementia in the week prior to assessment, using information from interviews with staff and participants. It scores symptoms from 0-2,

where 0 = absent, 1 = mild / intermittent and 2 = severe (and a = unable to evaluate.) It includes eighteen items under five broad categories: mood related signs, behavioural disturbance, physical signs, biological functions and ideational disturbance. It was included to assess any improvements in mood related to the intervention. A score of 7 or more suggests clinical depression. Good reliability and validity have been demonstrated.

f) *Rating Anxiety in Dementia* (RAID), (Shankar et al, 1999). This rates symptoms and signs of the participant's anxiety in the two weeks prior to assessment, using interviews with staff and participants. It scores symptoms from 0 to 3, where 0= absent, 1= mild or intermittent, 2 = moderate and 3 = severe (and u = unable to evaluate). There are eighteen questions in four main categories: worry, apprehension and vigilance, motor tension and autonomic hypersensitivity. Additionally, there are two questions on phobias and panic attacks. A total score of eleven and above indicates significant clinical anxiety (Shankar et al, 1999). It has good inter-rater and test-retest reliability, and was included to measure whether the intervention has any effects on anxiety.

g) *Behaviour Rating Scale* (from the Clifton Assessment Procedures for the Elderly (CAPE); Pattie and Gilleard, 1979). The eighteen questions of the CAPE BRS cover general behaviour, personal care and behaviour towards others. Questions include an evaluation of the person's ability to bathe and dress, walk, take care of personal appearance, socialize, keep active, communicate, understand communication, help out in the home / ward, and sleep. Staff or carers are asked to circle one of three given answers,

in response to each question. It has good reliability and validity, and was included to assess the overall level of functional impairment and dependency.

### **6.3.0. Ethics permission**

Ethics approval was obtained from Local Research Ethics Committees (LRECs) in each health trust, and the Multicentre Research Ethics Committee (MREC). Only minor administrative details were required from the LRECs, with no amendments to the project or forms requested. The information sheet (see Appendix C) stated that the project looked at the effects of activity groups for people with memory problems. The term 'dementia' was avoided because many participants had not been formally diagnosed, hence it would have been unethical to present them with this label. The participants were asked to sign the consent form in the presence of a witness (a member of staff), and the researcher was required to sign, confirming that they had explained the nature of the trial to the participant. Some participants in day centres had carers, who were given forms to sign. However, participants were free to make their own choice as to whether or not to join in, and carer participation was an optional extra. If staff felt that a person was unable to understand the nature of the research, they would automatically be excluded. It usually followed that they would be too impaired for the project.

### **6.4.0. Power analysis**

As part of the development of the protocol, power analysis calculations were made. Statistical power is a measure of how likely the study is to produce a statistically significant result for a difference between groups of a given magnitude. It is essential in ensuring that a

study is designed so that it has a good chance of detecting statistical differences, if they exist (Bowling, 1997). A power calculation was performed using the pilot study data on the MMSE as a major cognitive outcome measure. Combining the day-centre and residential care samples, the mean difference in MMSE score at follow-up was 3.1, with a standard deviation of 5.5 for MMSE scores in both treatment and control groups. This gave an estimated effect size of 0.56 ( $3.1 / 5.5$ ). Referring to the appropriate table in *Sample Size Tables for Clinical Studies* (Machin, Campbell, Fayers and Pinol, 1997), with power set at 80%, a 0.05 level of significance and an effect size of 0.55; the sample size needed in both treatment and control conditions was 53. This implied that to achieve an 80% chance of detecting the specified difference of 3.1 points, significant at the 5% level, a total sample size of 106 people would be necessary.

#### **6.5.0. Statistical Analyses**

Assessments were scored and data entered into SPSS (version 10) by one researcher and checked by the other. ANCOVA (analysis of covariance) was used as the method of analysis. It was chosen because it controls for variability in pre-test scores (the 'covariate'). It is a sensitive test which increases the power of an F-test for the main effects or interaction by removing the predictable variance associated with covariates from the error term. This implies that undesirable variance in the dependent variable (e.g. individual differences) are estimated by scores on covariates. By providing adjustments, the relationship between the dependent variable and covariates are removed from the error term.

Statistical advisers were consulted on the methods of multivariate analysis. It was suggested that initially, the main effects alone should be entered into the ANCOVA. Hence if investigating MMSE, the model would include MMSE1, MMSE2, centre and condition. An additional analysis should include the interaction of centre and condition. This is because treatment participants might not be considered to be one large group receiving an identical intervention, but as a set of groups receiving an intervention of which the effects were a result of a) the content of the programme (which was fixed); and b) the group dynamics (which were variable). Hence the random effects model was used, as this model allows centres to be considered a random factor. Analysis was performed for treatment and control participants within each centre, and then combined between centres to get an overall result. An advisor suggested that this should be conducted separately to a main effects only model, as there is no certainty as to how SPSS weights centres (e.g. according to size or equally), reducing the accuracy of the calculations.

Instructions to SPSS, when analysing the MMSE using ANCOVA were as follows:

*Analyse -> general linear model -> univariate*

*Dependent variable:* MMSE 2 (MMSE at follow-up)

*Fixed factor:* Condition (1 = treatment, 2 = control)

*Random factor:* Centre (1-16)

*Covariates:* MMSE 1 (MMSE at baseline)

Age

Gender

Additionally, the *model* option was entered, and *type II error* was highlighted. This considers the effect of the intervention once the covariates and the effect of the centres are taken into account. The main effects of 'condition', 'centre', 'MMSE1', 'age' and 'gender' were highlighted. An interaction between 'centre' and 'condition' was created in the second analysis. Analyses were conducted for i) all 16 centres, and ii) 13 centres, omitting the first three which were considered part of the development and training process.

Before conducting the ANCOVAs, tests of normality were performed on the MMSE, ADAS-Cog, RAID, Cornell, Holden and BRS to determine suitability to parametric analysis. Tests were not required for the CDR as it is an ordinal measure and non-parametric analyses were performed. Using the Kolmogorov-Smirnov test, results were not significant for the ADAS-Cog, Holden and BRS, suggesting a normal distribution. The MMSE showed a significant result ( $p=0.003$ ), yet having viewed the frequency histogram (see Appendix D), a statistical advisor suggested that visually, the spread appeared not to deviate significantly from normality. Further, with such a large sample size it is likely that a deviance from normality would show statistical significance due to a few extreme cases. Yet if visually appearing reasonably normally distributed, it is recommended to use parametric tests, which are robust in dealing with deviations from normality. As stated by Howell (1997), some people argue in favour of using parametric tests in every case, claiming that: "*The assumptions normally cited as being required of parametric tests are overly restrictive in practice, and parametric tests are remarkably unaffected by violations of distribution assumptions.*" (Howell, 1997, p.646)

Because there is no non-parametric equivalent to the ANCOVA, which controls for both the effects of covariates and the random effect of centres, it was advised to use the ANCOVA for all outcome measures. However, as the RAID and Cornell clearly deviated from a normal distribution, both statistically and as represented by histograms; non-parametric tests were used to compare and/or support the results (see 7.1.5.).

### **6.5.1. Intention to treat analysis**

It was important to include people who refused to attend sessions in the analysis, as well as those who took part, because if these people differ in some way, then the implication is that the sample members who agree to participate may not be representative of the target population. Hence an 'intention to treat' analysis was conducted. This involves including all the people who were randomised, whether they took part in the programme (i.e. accepted treatment) or not. In comparison to 'per protocol analysis', which only includes people who accepted treatment, it avoids attrition biases and increases external validity.

### **6.5.2. Qualitative analyses**

The researchers made notes following each session, including comments on individuals and the group as a whole. Staff in each centre, especially those co-facilitating the groups, were encouraged to make comments on any changes they had observed in individuals both inside and outside the group setting, and on group dynamics. A summary of the qualitative observations made by the researcher and staff for each home and day centre can be found in the results.

## **Chapter 7: Results**

### **7.0.0. Response rate**

122 centres were initially contacted by post and follow-up phone-calls. Of these, 85 were excluded, usually due to not being interested (e.g. no response to the letter or phonecalls, stating that they were too busy) or a lack of participants. Nobody expressed disapproval of the project. 37 centres were screened, which involved screening 444 people. Of these centres, 21 had less than 8 suitable participants, hence were excluded. Finally, 16 centres (13 residential homes and 3 day centres) were included in the project. In these 16 centres, 192 people were screened and 50 (26%) were excluded because:

- i) 25 had MMSE <10 and / or severe communication difficulties, as determined by the CAPE-BRS.
- ii) 5 were too hearing-impaired
- iii) 2 were too visually impaired
- iv) 10 did not have dementia
- v) 2 had learning disabilities
- vi) 5 became distressed or aggressive when assessed
- vii) 1 died between screening and full assessment

The above are the primary reasons for exclusion, although some people fell within more than one category. Approximately one person in each centre refused to be screened. Typically, they would say that they were too tired, were feeling unwell or were busy. They would usually be approached a second time.

*Table 9: Centres contacted, excluded, screened and included in the study.*

REGION	CONTACTED	EXCLUDED	SCREENED	INCLUDED
BHB	29 (20 r, 9 d)	17 (6 ne, 10 ni, 1 cd)	12	7 (5 r, 2 d)
Quantum Care	28 (28 r)	18 (1 ne, 16 ni, 1 cd)	10	6 (6 r)
Enfield	34 (29 r, 5 d)	26 (16 ne, 10 ni)	8	2 (1 r, 1 d)
Camden and Islington	31 (17 r, 14 d)	24 (6 ne, 11 ni, 3 cd, 4 nd)	7	1 (1 r)
<i>Total</i>	<i>122(94 r, 28 d)</i>	<i>85 (29 ne, 47 ni, 5 cd, 4 nd)</i>	<i>37</i>	<i>16 (13 r, 3 d)</i>

**Key:**

**BHB** Barking, Havering and Brentwood

**r** residential care

**d** day care

**ne** not enough suitable people, determined by inclusion criteria

**ni** not interested

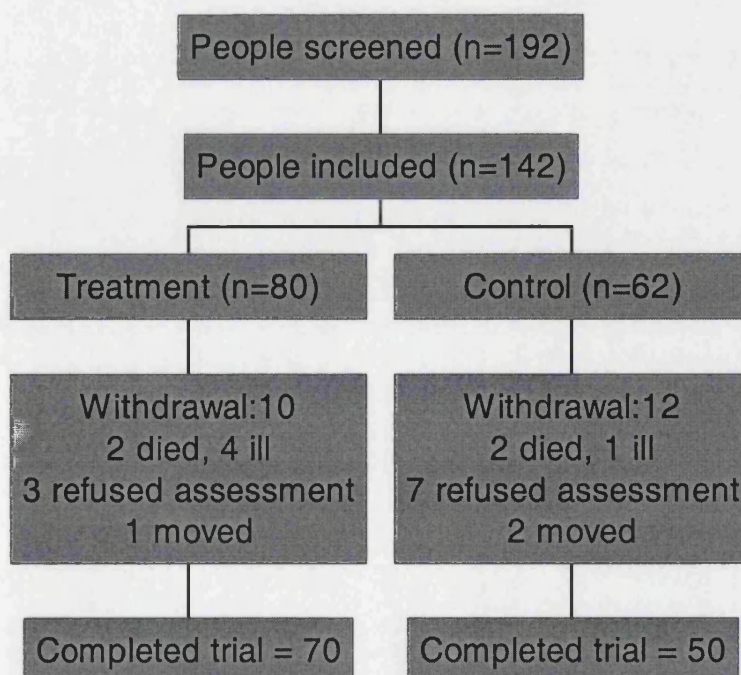
**cd** closing down

**nd** no dementia clients

### 7.0.1. Attrition

There were 80 treatment participants at baseline and 70 at follow-up; 2 died, 4 were ill or hospitalised, 1 moved away and 3 refused second assessment. The latter were 3 people who had refused to come to most sessions. There were 62 control participants at baseline and 50 at follow-up; 2 died, 1 was ill or hospitalised, 2 moved away and 7 refused second assessments. Of the latter, 3 stated that they felt too ill, 3 too tired, and one became aggressive during the re-assessment. See figure 8.

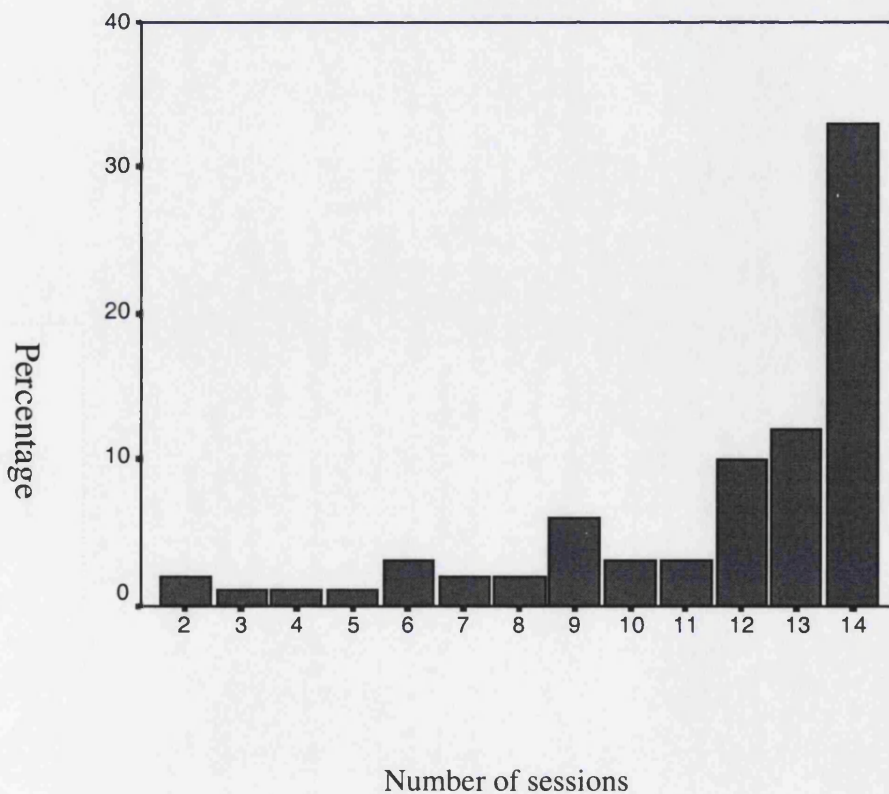
*Figure 8: Reasons for attrition*



### 7.0.2. Attendance

89% of people attended 7 or more sessions. The mean attendance was 11.6 sessions (sd = 3.2) with a minimum of 2 and a maximum of 14 sessions attended. The lowest mean attendance rate within centre was 7 and the highest was 14. Two centres had mean attendance rates of 9 sessions, and the remaining 13 centres had mean attendance rates ranging between 10 and 14 sessions. Overall there were only five people who attended five or less sessions. Of the two people who only attended (the first) two sessions, one died and one was hospitalised. The remaining three attended three, four and five sessions; refusing to participate in any more. Two verbally expressed their dislike for the group. One said that she did not want to come, without providing an explanation.

Figure 9: Graph showing the percentage of participants attending 2-14 sessions



### **7.0.3. Characteristics of participants**

There were 142 participants, 80 treatment and 62 control. Examining the literature, it was decided that five was the minimum number required for a group. Due to difficulties in recruiting more than eight people in each centre, typically five people would be allocated to the treatment group and three became controls. The treatment group was slightly older, had a higher ratio of women and a slightly lower mean baseline MMSE than the control group. Table 8 compares treatment and control participants' characteristics in terms of age, gender, baseline MMSE and baseline CDR, and provides information about the total participant group. The numbers in each CDR level show that there were similar numbers in each group who could be described as having 'mild' and 'moderate' dementia, and 4 people overall with 'questionable dementia'. Separate data is provided for the participants in the 13 centre analysis, i.e. excluding participants in the 1<sup>st</sup> three centres. Using an independent samples t-test, there were no significant differences between treatment and control groups at baseline in age ( $t = 1.33$ ,  $p = 0.19$ ) and baseline MMSE ( $t = -1.01$ ,  $p = 0.31$ ). Using a chi squared test, there were no significant differences between groups in gender (chi squared = 0.56,  $p > 0.1$ ).

### **7.0.4. Characteristics of centres**

The study included 13 residential homes and 3 day centres. 7 centres were in BHB, 6 in Quantum Care, 2 in Enfield and 1 in Camden and Islington. There were a minimum of 8 and a maximum of 11 participants in each centre, with a mean of 8.8.

Table 10: Descriptive characteristics of participants

CHARACTERISTICS	TREATMENT	CONTROL	ALL
Total number	<b>80</b> 65	<b>62</b> 50	<b>142</b> 115
Mean age (sd), [range]	<b>86.5(5.9) [66,101]</b> 86.3(6.2) [66,101]	<b>84.8(7.6) [66,99]</b> 85.1(7.7) [10,22]	<b>85.8(6.7) [66,101]</b> 85.8(6.9) [66,101]
Gender ratio (female, male)	<b>4.7 : 1 (66, 14)</b> 4.4:1 (53, 12)	<b>3.4 : 1 (48, 14)</b> 4:1 (40, 10)	<b>4.1 : 1(114, 28)</b> 4.2:1 (93, 22)
Numbers (baseline) at each CDR level* (0.5 / 1 / 2)	<b>(3 / 37 / 40)</b> (3 / 29 / 33)	<b>( 1 / 30 / 31)</b> (1 / 23 / 26)	<b>(4 / 67 / 71)</b> (4 / 52 / 59)
Mean MMSE 1 (sd), [range]	<b>13.7 (3.8) [7, 22]</b> 13.4 (3.7) [7, 22]	<b>14.3 (3.5) [8, 22]</b> 14.3 (3.6) [10, 22]	<b>13.9 (3.7) [7, 22]</b> 13.8 (3.7) [7, 22]

**Bold print = 16 centres**, Standard print = 13 centres

\* 0.5 = questionable dementia, 1 = mild dementia, 2 = moderate dementia

### 7.1.0. Analyses

The first analysis included all 16 centres. The second analysis of 13 centres excluded the first 3, which differed in quality from the rest in that they involved the final development of the programme and training of the second researcher. Significance levels, set at 5%, are presented from the ANCOVA comparing groups (treatment and control) in all instances. Significant results between other variables (centre and/or gender) are included when they occurred. Results are from the ANCOVA which included main effects only.

This is because when separate analyses were conducted which included an interaction (centre\*condition), significance levels did not change for any outcomes, hence there were no further results to add. The statistical advisor suggested that if an interaction did not change the significance of a main effects only model, it would be preferable to include the latter, which is more precise (see 6.5.0). Paired t-tests were used to examine within-group changes. Mean differences and total change are indicated with '+ve' if the change indicated improvement and '-ve' if it indicated deterioration. The mean differences are calculated as an average of the mean difference column (e.g. MMSE dif = MMSE2 – MMSE1). Occasionally they might appear incorrect, for example for the treatment group, BRS1 = 11.01, BRS2 = 11.18 and BRSdif = -0.31. This discrepancy is because differences were only calculated for cases in which both baseline and follow-up data were available, thus excluding some of the BRS1 data and calculating the mean from a smaller sample. Figures in square brackets [] represent confidence intervals. In all tables, statistically significant differences are marked with an asterisk (\*).

### 7.2.0. Cognition

Two measures of cognition were used, the MMSE and the ADAS-Cog. Table 11 looks at the MMSE for all 16 centres. The mean treatment group score improved significantly ( $p=0.00$ ) between baseline and follow-up (+1.31). The mean control group score fell ( $-0.70$ ), with a positive total change between groups (+2.01) from a maximum total of 30. Using an ANCOVA, there was a significant difference between treatment and control conditions ( $p=0.009$ ), and no significant effects of other factors.

*Table 11: MMSE (baseline, follow-up, differences), ANCOVA for 16 centres*

	MMSE 1	MMSE 2	MMSE DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	13.66 (3.84)  [12.68, 14.43]	14.87 (4.51)  [13.79, 15.95]	+ve 1.31 (3.73)  t = -2.95  p = 0.00*	F = 7.15  P = 0.009*	N / A
Control	14.29 (3.53)  [13.32 , 15.32]	13.62 (4.63)  [12.38, 14.866]	-ve 0.70 (3.70)  t = 1.37  p = 0.18		
Total change = +ve 2.01					

Table 12 looks at the MMSE for the 13 centres. The mean treatment group score improved significantly ( $p=0.000$ ) between baseline and follow-up (+1.67) points. The mean control group score fell (-1.07), which was a significant decline ( $p=0.04$ ). This resulted in a positive change between groups (+2.74), greater than that in the analysis of the 16 centres (+2.01). Using an ANCOVA, there was a significant difference between treatment and control conditions ( $p=0.000$ ), but no significant effects of other factors.

*Table 12: MMSE (baseline, follow-up, differences), ANCOVA for 13 centres*

	MMSE 1	MMSE 2	MMSE DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	13.38 (3.69)	14.95 (4.48)	+ve 1.67 (3.37)  t = -3.73  p = 0.000*	F = 13.30  P =0.000*	N / A
Control	14.28 (3.58)	13.15 (4.35)	-ve 1.07 (3.40)  t = 2.09  p = 0.04*		
Total change = +ve 2.74					

Table 13 looks at the ADAS-Cog for the 16 centres. The mean treatment group score improved significantly ( $p=0.02$ ) between baseline and follow-up (+2.04). The mean control group score fell (-0.82), with a positive total change between groups (+2.86) from a maximum score of 70. Using an ANCOVA, there was a significant difference between treatment and control conditions ( $p=0.000$ ). There was also a significant difference between centres ( $p=0.001$ ), see 7.7.0.

*Table 13: ADAS-Cog (baseline, follow-up, differences), ANCOVA for 16 centres*

	ADAS 1	ADAS 2	ADAS DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	27.89 (7.11)  [26.18, 29.73]	25.91 (8.93)  [23.76, 28.07]	+ve 2.04 (6.95)  t = 2.46  p = 0.02*	F = 8.54  P = 0.000*	F = 2.90  P = 0.001*  (centres)
Control	27.46 (7.70)  [25.64, 29.76]	28.52 (9.30)  [26.02, 31.01]	-ve 0.82 (4.71)  t = -1.25  p = 0.22		
Total change = +ve 2.86					

Table 14 looks at the ADAS-Cog for the 13 centres. The mean treatment group score improved significantly ( $p=0.00$ ) between baseline and follow-up (+3.38). The mean control group score fell (-0.51), with a positive total change between groups (+3.89). This was greater than the mean group difference in the 16 centre analysis (+2.86). Using an ANCOVA, there was a significant difference between treatment and control conditions ( $p=0.000$ ). There was also a significant difference between centres ( $p=0.021$ ), see 7.7.0. This lower variation between centres can be attributed to the removal of the first three centres, two of which showed a decline in ADAS-Cog, in contrast to the improvement in all but one of the other centres.

*Table 14: ADAS-Cog (baseline, follow-up, differences), ANCOVA for 13 centres*

	ADAS 1	ADAS 2	ADAS DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	28.34 (7.34)	24.94 (8.21)	+ve 3.38 (6.02)  t = 4.24  p = 0.00*	F = 14.44  P = 0.000*	F = 2.18  P=0.021  (centre)
Control	27.91 (7.90)	28.88 (9.68)	-ve 0.51 (4.65)  t = -0.72  p = 0.47		
Total change = +ve 3.89					

Hence analyses of 13 and 16 centres in both measures of cognition resulted in similar effects, with slightly stronger significance levels and fewer between group changes for the 13 centres.

### 7.2.1. ADAS-Cog: Sub-scale analysis

Further analysis was performed on the 11 sub-scales of the ADAS-Cog, using data from all 16 centres (see table 15). Non-parametric analysis (Mann Whitney U Test) was used because sub-scales were so small (most scoring from 0-5), and some used ordinal data. The only sub-scale to show significant between group differences was “following commands” ( $p = 0.01$ ).

*Table 15: Sub-scale analysis of the ADAS-Cog using the Mann Whitney U Test*

ADAS-COG SUBSCALE	TREATMENT DIFF	CONTROL DIFF	BETWEEN GROUP DIFF (MANN WHITNEY U TEST)
Word recall	-0.20 (2.45)	+0.15 (1.01)	$Z = -0.51, p = 0.61$
Naming objects & fingers	+0.33 (1.21)	0 (1.05)	$Z = -1.29, p = 0.19$
Following commands	+0.74 (1.26)	+0.13 (1.22)	$Z = -2.51, p = 0.01^*$
Constructional praxis	+0.27 (1.17)	0 (1.24)	$Z = -0.92, p = 0.36$
Ideational praxis	0 (1.63)	0 (1.26)	$Z = -0.89, p = 0.37$
Orientation	+0.34 (1.54)	0 (1.33)	$Z = -1.58, p = 0.11$
Word recognition	+0.23 (2.52)	+0.13 (2.29)	$Z = -0.08, p = 0.94$
Spoken language ability	-0.13 (0.62)	-0.22 (0.64)	$Z = -1.46, p = 0.15$
Comprehension of spoken language	-0.15 (0.80)	0 (0.52)	$Z = -0.39, p = 0.69$
Word-finding difficulty in spontaneous speech	-0.16 (0.70)	-0.31 (0.73)	$Z = -1.25, p = 0.21$
Remembering test instructions	0 (1.55)	-0.31 (1.66)	$Z = -0.81, p = 0.42$

### 7.2.2. ADAS-Cog: Multiple Regression

Multiple regression analysis was performed to examine the best predictors of outcome as measured by total ADAS-Cog change. Gender, age, and baseline scores on depression, anxiety, communication and behaviour were entered as factors, and results are shown in table 16. No factors showed a significant effect, supporting the results of the ANCOVA which showed no effects of age and gender.

*Table 16: Predictors of outcome (ADAS-Cog), using multiple regression*

FACTORS	REGRESSION
Age	Beta coefficient = -0.04, t= -0.54, p = 0.59
Gender	Beta coefficient = -0.02, t= -0.35, p = 0.72
Baseline anxiety (RAID 1)	Beta coefficient = 0.10, t = 1.05, p = 0.30
Baseline depression (Cornell 1)	Beta coefficient = -0.18, t= -1.83, p = 0.07
Baseline communication (Holden 1)	Beta coefficient = -0.04, t = 0.59, p = 0.56
Baseline behaviour (BRS 1)	Beta coefficient = 0.04, t = 0.53, p = 0.60

### 7.3.0. Behaviour

Table 17 looks at behaviour measured by the CAPE-BRS for the 16 centres. The mean score fell in both treatment (-0.31) and control groups (-0.44), resulting in a mean group difference of +0.13 out of a maximum total of 36. Using an ANCOVA, there were no differences between conditions, but significant differences between gender ( $p = 0.002$ ), see table 19; and centre ( $p = 0.003$ ), see 7.7.0.

*Table 17: CAPE-BRS (baseline, follow-up, differences), ANCOVA for 16 centres*

	BRS 1	BRS 2	BRS DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	11.07 (4.44)  [10.22, 12.39]	11.18 (4.75)  88, 12.12]	-ve 0.31 (4.64)  t = 0.55  p = 0.58	F = 0.97  P = 0.33	F = 2.51  P = 0.003*  (centre)
Control	11.49 (4.66)  [10.11, 12.55]	11.95 (5.09)  [10.51, 13.02]	- ve 0.44 (5.58)  t = -0.58  p = 0.57		F = 9.65  P = 0.002*  (gender)
Total change = +0.13					

Table 18 looks at behaviour measured by the CAPE-BRS for the 13 centres. The mean score fell in both treatment (-0.21) and control groups (-0.36). However, this resulted in a positive trend, with a mean group difference of +0.15. Using an ANCOVA, there were no differences between conditions ( $p=0.48$ ), but significant differences between centres ( $p = 0.005$ ), see 7.7.0. and gender ( $p = 0.019$ ), see table 19. Hence in analysing the data from 13 and 16 centres produced extremely similar results in behaviour.

*Table 18: CAPE-BRS (baseline, follow-up, differences), ANCOVA for 13 centres*

	BRS 1	BRS 2	BRS DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTOR
Treatment	11.09 (4.58)	11.41 (4.92)	-ve 0.21 (4.96)  t – 0.31  p = 0.76	F = 0.50  P = 0.482	F = 2.63  P=0.005*  (centre)
Control	11.53 (5.09)	11.89 (5.38)	-ve 0.36 (5.94)  t = -0.40  p = 0.69		F = 5.72  P=0.019*  (gender)
Total change = +ve 0.15					

Both analyses showed a significant difference between genders. Table 19 examines the nature of this difference, by comparing the difference (16 centres) between treatment females and control females with the difference between treatment males and control males. The mean score for females in the treatment group improved (+ 0.56) and controls declined (-0.05), with a positive between group difference of +0.61. However, males declined in both groups, controls (-1.83) more than treatment (-0.92). This resulted in a positive between group difference of +0.91, greater than that of the females. The significant difference in the ANCOVA represents treatment males deteriorating significantly less in relation to control males, compared with the difference between treatment females and control females.

*Table 19: Gender differences on mean BRS score*

<b>GROUP</b>	<b>FEMALE / TREAT</b>	<b>FEMALE / CONTR</b>	<b>FEMALE DIF (TREAT- CONTR)</b>	<b>MALE / TREAT</b>	<b>MALE / CONTR</b>	<b>MALE DIF (TREAT- CONTR)</b>
<b>MEAN BRS SCORE (T2-T1)</b>	<b>+ 0.56</b>	<b>- 0.05</b>	<b>+ 0.61</b>	<b>- 0.92</b>	<b>- 1.83</b>	<b>+ 0.91</b>

**Key:**

T1 = Baseline assessment

T2 = Follow-up assessment

TREAT = Treatment group

CONTR = Control group

#### 7.4.0. Global dementia rating

Due to the ordinal nature of the CDR, the nature of change from baseline to follow-up (deterioration, no change or improvement) was investigated (see table 20). Using chi squared, there were no significant difference between groups. Additionally, more people deteriorated and less improved in treatment, as opposed to control groups.

*Table 20: Cross-tabulation of the CDR scores and chi-squared analysis*

GROUP	DETERIORATION	NO CHANGE	IMPROVEMENT	TOTAL	CHI SQUARED
Treatment	14 (22%)	44 (70%)	5 (8%)	63	Chi square = 2.28 P = 0.13
Control	5 (11%)	32 (71%)	8 (18%)	45	
Total	19 (18%)	76 (70%)	13 (12%)	108	

### 7.5.0. Communication

Table 21 looks at communication, measured by the Holden, for the 16 centres. There was a mean improvement in the treatment group (+0.3) and a significant decline in the control group (-3.15). This resulted in a positive between group difference of +3.45 out of a maximum score of 48. Using an ANCOVA, there was a significant difference between conditions ( $p=0.053$ ), and a significant difference between centre ( $p=0.014$ ), see 7.7.0., and gender ( $p = 0.000$ ), see table 23.

*Table 21: HOLDEN (baseline, follow-up, differences), ANCOVA for 16 centres*

	HOLDEN 1	HOLDEN 2	HOLDEN DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	10.82 (5.52)  [9.18, 11.63]	10.53 (5.64)  [8.99,11.82]	+ve 0.3 (5.76)  t = 0.00  p = 1.00	F = 3.83  P = 0.053*	F = 2.13  P = 0.014*  (centre)
Control	9.98 (5.07)  [8.59, 11.41]	13.08 (6.30)  [11.53, 14.78]	-ve 3.15 (6.46)  t = -3.52  p = 0.00*		F = 13.09  P = 0.000*  (gender)
Total change = +ve 3.45					

Table 22 looks at communication, measured by the Holden, for the 13 centres. There was a mean decline in both the treatment group (-0.59) and control group (-3.74), the latter reaching significance ( $p=0.00$ ). This resulted in a between group difference of +3.15. Using an ANCOVA, there was no significant difference between conditions, but a significant difference between gender ( $p = 0.002$ ), see table 23.

*Table 22: HOLDEN (baseline, follow-up, differences), ANCOVA for 13 centres*

	HOLDEN 1	HOLDEN 2	HOLDEN DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	10.87 (5.02)	11.09 (5.67)	-ve 0.59 (5.72)  t = -0.76  p = 0.45	F = 2.41  P = 0.13	F = 10.79  P = 0.002*  (gender)
Control	9.82 (4.79)	13.70 (6.48)	-ve 3.74 (6.83)  t = -3.55  p = 0.00*		
Total change = + 3. 15					

Both analyses showed a significant difference between genders. Table 23 examines the nature of this difference (16 centres) by comparing the difference between treatment females and control females with the difference between treatment males and control males. The mean score for females in the treatment group improved (+ 0.33) and controls declined (-2.60), with a positive between group difference of +2.93. However, males declined in both groups, controls (-5.00) more than treatment (-1.58). This resulted in a positive between group difference of +3.42, greater than that of the females. The significant difference in the ANCOVA represents treatment males deteriorating significantly less in relation to control males, compared with the difference between treatment females and control females.

*Table 23: Gender differences on mean Holden score*

GROUP	FEMALE / TREAT	FEMALE / CONTR	FEMALE DIF (TREAT- CONTR)	MALE / TREAT	MALE / CONTR	MALE DIF (TREAT- CONTR)
MEAN HOLDEN SCORE (T2-T1)	+ 0.33	- 2.60	+ 2.93	- 1.58	- 5.00	+ 3.42

**Key:**

T1 = Baseline assessment

T2 = Follow-up assessment

TREAT = Treatment group

CONTR = Control group

## 7.6.0. Mood

### 7.6.1. Anxiety

Table 24 looks at anxiety, measured by the RAID, for the 16 centres. There was a mean improvement in the treatment group (+0.10) and a decline in the control group (-0.96), resulting in a between group difference of +1.06 out of a maximum score of 60. Using an ANCOVA, there was no difference between conditions, but a significant difference between centres ( $p=0.000$ ), see 7.7.0.

*Table 24: RAID (baseline, follow-up, differences), ANCOVA for 16 centres*

	RAID 1	RAID 2	RAID DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	7.78 (8.22)  [5.88, 9.54]	7.60 (7.57)  [5.76, 9.45]	+ve 0.10 (9.48)  t = 0.09  p = 0.93	F = 1.62  P = 0.21	F = 4.60  P = 0.000*  (centre)
Control	8.21 (6.61)  [5.97, 10.23]	9.31 (7.97)  [6.91, 11.21]	-ve 0.96 (8.94)  t = -0.76  p = 0.45		
Total change = +ve 1.06					

Table 25 looks at anxiety, measured by the RAID, for the 13 centres. Again there was a mean improvement in the treatment group (+1.51) and a decline in the control group (-1.05), resulting in a between group difference of +2.56 which showed a positive trend. Using an ANCOVA, there was no difference between conditions, but a significant difference between centres ( $p=0.021$ ), see 7.7.0. Hence the 13 centre analysis showed slightly stronger positive trends in anxiety than the 16 centre analysis, with neither reaching significance between conditions in the ANCOVA.

*Table 25: RAID (baseline, follow-up, differences), ANCOVA for 13 centres*

	RAID 1	RAID 2	RAID DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	8.68 (8.71)	7.17 (6.44)	+ve 1.51 (9.61)  t = 1.14  p = 0.26	F = 2.83  P = 0.10	F = 2.23  P = 0.021*  (centre)
Control	8.54 (6.96)	9.32 (8.04)	-ve 1.05 (9.50)  t = -0.71  p = 0.48		
Total change = +ve 2.56					

### 7.6.2. Depression

Table 26 looks at depression, measured by the Cornell, for the 16 centres. There was a mean improvement in the treatment group (+0.30) and a decline in the control group (-0.25), resulting in a between group difference of +0.55 out of a maximum score of 38. Using an ANCOVA, there were no differences between conditions, but a significant difference between centres ( $p=0.001$ ), see 7.7.0.

*Table 26: Cornell (baseline, follow-up, differences), ANCOVA for 16 centres*

	CORNELL 1	CORNELL 2	CORNELL DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	4.59 (4.89)  [3.34, 5.67]	4.21 (4.99)  [2.94, 5.47]	+ve 0.30 (5.46)  t = 0.46  p = 0.65	F = 0.84  P = 0.36	F = 0.36  P = 0.001*  (centre)
Control	5.28 (4.72)  [3.65, 6.37]	5.37 (5.65)  [3.78, 6.74]	-ve 0.25 (7.08)  t = -0.25  p = 0.80		
Total change = +ve 0.55					

Table 27 looks at depression, measured by the Cornell, for the 13 centres. There was a mean improvement in the treatment group (+1.51) and a decline in the control group (-0.55), resulting in a between group difference of +2.06. Using an ANCOVA, there was a significant difference between conditions ( $p=0.051$ ) and a significant difference between centres ( $p=0.010$ ), see 7.7.0.

*Table 27: Cornell (baseline, follow-up, differences), ANCOVA for 13 centres*

	CORNELL 1	CORNELL 2	CORNELL DIF / SIGNIFICANCE	ANCOVA: TREATMENT / CONTROL	ANCOVA: OTHER FACTORS
Treatment	5.39 (5.05)	3.87 (4.30)	+ve 1.51 (4.79)  t = 2.30  p = 0.03	P = 0.051*	P = 0.010*  (centre)
Control	5.52 (5.03)	5.66 (5.99)	-ve 0.55 (7.68)  t = -0.46  p = 0.65		
Total change = +ve 2.06					

### 7.6.3. Non-parametric tests

Additionally, non-parametric tests were performed because the data from the RAID and Cornell were not normally distributed. Two Wilcoxon tests were performed to examine within group differences in the treatment and control groups on both measures. Additionally, these analyses were conducted with data from the 13 centres. Results are presented in table 28, which show no significant differences except for the treatment group (13 centres), which showed a significant improvement in the Cornell. This supports the significant improvement found in the Cornell when performing an ANCOVA using data from the 13 centres.

*Table 28: Wilcoxon tests examining within group changes on the RAID and Cornell*

OUTCOME / GROUP	16 CENTRES	13 CENTRES
RAID / treatment	Z = -0.37, p = 0.36	Z = -0.84, p = 0.2
RAID / control	Z = -0.65, p = 0.26	Z = -0.73, p = 0.43
Cornell / treatment	Z = -0.96, p = 0.17	Z = -2.67, p = 0.04*
Cornell / control	Z = -0.11, p = 0.46	Z = -0.25, p = 0.4

### 7.7.0. Between centre differences

The ANCOVAs showed significant differences between centres in measures of cognition (ADAS-Cog), behaviour, communication, anxiety and depression, demonstrating a variation of extent of change within centres. For all these 5 outcomes, the significance level reduced in the between centres analysis when looking at 13, as opposed to 16 centres. This represents the removal of the 1<sup>st</sup> three centres, which showed atypical results with more variation than the other centres. Table 29 shows the mean difference in ADAS-Cog between treatment and control groups within each centre (mean difference = mean treatment score – mean control score), highlighting the appreciable differences between centres. Positive values indicate improvement, negative indicate decline.

*Table 29: Mean ADAS-Cog difference by centre*

CENTRE	ADAS-COG DIFFERENCE
A	-2.6
B	-2.4
C	+ 0.8
D	+0.6
E	+1.8
F	+8.9
G	+5.0
H	+3.0
I	-0.5
J	+5.0
K	+3.0
L	-1.3
M	+9.5
N	+6.3
O	+6.9
P	+2.4

### 7.8.0. Numbers needed to treat

Livingstone and Katona (2000, p.203) suggested that the “*concept of ‘Numbers Needed to Treat’ (NNT) is useful in rendering RCT data meaningful for clinical decision-making, since it conveys both statistical and clinical information intelligibly*”. NNT calculates the number of people who needed to be treated in a particular intervention in order to achieve one favourable outcome. It is calculated as the reciprocal of the ‘absolute risk reduction’: the difference in the proportion experiencing a specified adverse outcome between the control and treatment groups. Using the formulae and framework provided by Livingstone and Katona, two NNT analyses on the ADAS-Cog were performed in this study:

- i) calculating no deterioration ( $\geq 0$ ) as improvement and any deterioration ( $< 0$ ) as adverse
- ii) calculating  $\geq 4$  as improvement and  $\leq 3$  as adverse.

*Table 30: Numbers needed to treat: ADAS-Cog, no deterioration*

Condition	0+	-ve	Missing	Total
Treatment	53	19	8	80
Control	25	27	10	62

% adverse events in treatment group =  $19/72 = 26\%$  (0.26)

% adverse events in control group =  $27/52 = 52\%$  (0.52)

$NNT = 1 / (0.52 - 0.26) = 1 / 0.26 = 3.85$

Lower confidence interval =  $1/0.5248 = 1.91$

Upper confidence interval =  $1/0.1635 = 6.12$

Rounded to the nearest whole numbers, the above implies that 4 people needed to be treated in order for one to benefit, with a confidence interval of 2 to 6.

*Table 31: Numbers needed to treat: ADAS-Cog, improvement  $\geq 4$*

Condition	4+	3-	Missing	Total
Treatment	32	40	8	80
Control	10	42	10	62

% adverse events in treatment group =  $40/72 = 56\%$  (0.56)

% adverse events in control group =  $42/52 = 81\%$  (0.81)

$NNT = 1 / (0.81 - 0.56) = 1 / 0.25 = 4$

Lower confidence interval =  $1 / 0.3676 = 2.72$

Upper confidence interval =  $1 / 0.1382 = 7.24$

Rounded to the nearest whole numbers, the above implies that 4 people needed to be treated in order for one to benefit, with a confidence interval of 3 to 7.

### 7.9.0. Qualitative data

In order to assess the quality of each centre and how conducive they were to this kind of group work, the researchers wrote brief notes following all sessions. These were summarised for each centre, with points on the a) institution, b) staff / co-facilitator, c) group, and d) participants (see appendix D). Notes and comments focused particularly on:

- The general ethos and environment in the home / day centre.
- Attitudes of and interactions with management and staff.
- Involvement of co-facilitators.
- Group or individual reactions to the activities in the session.
- Group dynamics.
- Development of relationships and changes in behaviour.

Table 32 summarises some of the points and key themes identified from these summaries.

Comments are made on the centre, staff, management, co-facilitator and group.

Individuals are mentioned where relevant, e.g. if they had an impact on the group

dynamics. The 5<sup>th</sup> column ('Quality rating') breaks down the information from table 32

further, by rating managers attitude, atmosphere, co-facilitator's input, group atmosphere

and group participation from 0-2, yielding a total score (maximum = 10). These scores

were agreed on by the two researchers at the conclusion of the trial, on the basis of their

experiences in both assessing and running groups. For a description of the scores, see the

"key" following the table.

Table 32: Qualitative details of centres

CENTRE ID	CENTRE, STAFF, MANAGEMENT	CO-FACILITATOR	GROUP	QUALITY RATING	
A – DC	Friendly & lively. Management supportive & enthusiastic about research.	Co-facilitator saw research as pointless, “already doing the same activities.” Attended 1 <sup>st</sup> 3 sessions, subsequently “too busy”.	Small DC (10-12 people), ongoing activities. Attending group sometimes meant leaving friends. People initially reluctant, more relaxed in later sessions. All talkative and involved. Appeared to enjoy discussing present more than past. 1 person hostile & suspicious, “like being back at school”. 1 person more impaired, supported by group.	Managers attitude	2
				Home atmosphere	2
				Co-facilitator input	0
				Group atmosphere	1
				Group participation	0
				Total	5
B – RC	Positive atmosphere, staff friendly to researchers & each other. Box created by management for notes from groups remained empty.	Co-facilitator’s input inconsistent due to other commitments. Other staff sometimes joined instead. Often knew nothing about project & made little input.	Group lively, bonded well. More interested in concrete tasks (e.g. using objects) than discussion (e.g. current affairs). All contributed fairly evenly. 1 refused to attend after session 4 – appeared to view groups as a test. A new friendship developed between 2 people. 1 person adopted role as ‘entertainer’, often telling stories and jokes.	Managers attitude	2
				Home atmosphere	2
				Co-facilitator input	1
				Group atmosphere	2
				Group participation	1
				Total	8
C – RC	Clear hierarchy and tension between management and staff. Unhelpful with assessments.	Co-facilitator initially enthusiastic, mentioned her ‘CV’. Attended 3 sessions. Passive, directed comments to researchers, not group. Subsequently “too busy”.	Low attendance rate. 1 person refused to attend after 1 <sup>st</sup> session, 1 was often ill, another was depressed and refused about half. Some sessions very good, with 2 people extremely enthusiastic. 1 lady constantly questioned where she was, sometimes causing confusion in the group.	Managers attitude	1
				Home atmosphere	0
				Co-facilitator input	0
				Group atmosphere	1
				Group participation	1
				Total	3
D – RC	Friendly staff & management. Home had a positive feel, people sometimes said that they enjoyed living there.	Person allocated to co-facilitate often unavailable. Usually, another staff member would join, typically friendly & involved.	Group bonded extremely well. Men more talkative. Enjoyed problem-solving sessions (e.g. categorising objects) more than discussion (e.g. current affairs). Staff observed substantial improvements in 1 man’s communication outside group. 1 man became the ‘entertainer’.	Managers attitude	1
				Home atmosphere	2
				Co-facilitator input	1
				Group atmosphere	2
				Group participation	2
				Total	8

Table 32 (continued): Qualitative details of centres

CENTRE ID	CENTRE, STAFF, MANAGEMENT	CO-FACILITATOR	GROUP	QUALITY RATING	
E – DC	Active & involved staff. Unhelpful & disinterested management.	Co-facilitator friendly & involved. Disappointed when groups finished. Occupational Therapist interested & positive.	Group bonded well. Asked when next sessions were, expressed sadness at groups ending. Found it hard to actively engage without a concrete task, e.g. in current affairs session. 1 person claimed that he was a volunteer at DC. Became defensive when his difficulties became apparent.	Managers attitude	0
				Home atmosphere	2
				Co-facilitator input	2
				Group atmosphere	2
				Group participation	2
				Total	8
F – RC	Highly institutionalised.* Serious, unapproachable management & staff. Refused to complete some assessment measures.	Co-facilitator misinformed by management that project was a “training course”. Once explained properly, her negative attitude improved, expectations became more realistic.	Participants de-motivated, reluctant to attend. Appeared indicative of institution & general apathy. Not used to being in a different lounge. Took time to feel comfortable in sessions, usually more lively by the end. Quite impaired as a group, enjoying less cognitive sessions (e.g. physical games). 1 person was socially anxious, had to leave before some sessions ended. Another continually asked where she was. Low attendance rate due to illness and one death.	Managers attitude	0
				Home atmosphere	0
				Co-facilitator input	1
				Group atmosphere	0
				Group participation	0
				Total	1
G – RC	Pleasant atmosphere. Management helpful & friendly, staff positive towards group.	Co-facilitator only available for 2 sessions. Other members of staff assisted. All interested, participated well.	Group bonded well. All at different stages of dementia, yet supported each other with positive feedback. Found discussion & abstract tasks (e.g. categorising objects, word game) more difficult. 1 person blossomed in group, when taken away from wife’s control. Another had poor hearing & communication. Often told long, repetitive stories which distracted people from task at hand.	Managers attitude	2
				Home atmosphere	2
				Co-facilitator input	1
				Group atmosphere	2
				Group participation	2
				Total	9

Table 32 (continued): Qualitative details of centres

CENTRE ID	CENTRE, STAFF, MANAGEMENT	CO-FACILITATOR	GROUP	QUALITY RATING	
H – RC	Institutionalised. Encourage 'learned helplessness'** in residents. Manager extremely helpful. Did most preparation for group himself. Staff generally unhelpful.	Activities co-ordinator given role as co-facilitator. Overtly expressed interest, yet actively manipulated project, perhaps due to perceived threat. Sessions moved to alternative day, run by researcher alone.	Group did not bond well, unwilling & unable to engage. Some sessions quite good. Food perceived as 'boring', using / categorising objects & word games as 'too difficult'. 1 person expressed constant confusion about her living arrangements, annoying others. 1 person adopted the role as 'joker', seemingly as a defence. One had a stroke and had some problems with speech. Others sometimes treated her suspiciously, yet she appeared to enjoy & remember groups.	Managers attitude	2
				Home atmosphere	0
				Co-facilitator input	0
				Group atmosphere	0
				Group participation	2
				Total	4
I – RC	Initial friendly atmosphere, but institutionalisation soon became apparent. Manager's initial enthusiasm waned.	2 co-facilitators. Only attended a few sessions, otherwise too busy.	Group remained fragmented throughout. 2 female members detached themselves from 2 men. Found some activities difficult (quiz, categorising objects, word game), consequently expressing negative views. 2 people left mid-session a couple of times, due to not liking the activities. A woman was defensive, concerned that others would laugh at her (which they didn't).	Managers attitude	1
				Home atmosphere	0
				Co-facilitator input	1
				Group atmosphere	1
				Group participation	1
				Total	4
J – RC	Manager expressed hurry to be involved in project, yet had no time available.	Manager reluctant to allocate time of 1 person to act as co-facilitator. Different staff attended 1 <sup>st</sup> few sessions, researcher ran group alone from session 6 onwards.	Group bonded well, people mutually supportive. Lively, friendly atmosphere; appeared to enjoy content of all sessions. 2 people were particularly lively and jovial in all sessions. 1 person was variable, sometimes talkative & disinhibited, other times unable to engage & seemingly depressed.	Managers attitude	1
				Home atmosphere	1
				Co-facilitator input	0
				Group atmosphere	2
				Group participation	2
				Total	6

Table 32 (continued): Qualitative details of centres

CENTRE ID	CENTRE, STAFF, MANAGEMENT	CO-FACILITATOR	GROUP	QUALITY RATING	
K – RC	Management & staff approached project in a serious, committed way.	Co-facilitator committed to project. Always prepared room & made notes for staff / relatives. Planned to continue group after project.	Lively & engaging group. Good at listening, taking turns to speak. After 1 <sup>st</sup> few sessions, people became relaxed and opinionated. 1 domineering / mildly aggressive person calmed down once comfortable with setting. Relatives observed improvements in confidence & communication of 2 people. A friendship developed.	Managers attitude	2
				Home atmosphere	1
				Co-facilitator input	2
				Group atmosphere	2
				Group participation	2
				Total	9
L – RC	Highly institutionalised. Staff hostile towards research.	Co-facilitator appeared to expect noticeable, dramatic changes. Her obvious disappointment created tension in group.	Weak dynamics. People rarely communicated with each other, reluctant to participate in activities. High refusal rate. Felt uncomfortable coming into another lounge. Only 1 person appeared to enjoy groups.	Managers attitude	1
				Home atmosphere	0
				Co-facilitator input	0
				Group atmosphere	0
				Group participation	0
				Total	1
M – RC	Friendly, positive home. Residents treated respectfully by staff and management.	Activities coordinator was co-facilitator throughout. Enthusiastic, had room and people ready, shared ideas.	Excellent dynamics, enjoyed all sessions. 2 people tended to be the most talkative. Commented on how much they enjoyed "Sunshine Group". 2 quiet people supported and encouraged by more outgoing members.	Managers attitude	2
				Home atmosphere	2
				Co-facilitator input	2
				Group atmosphere	2
				Group participation	2
				Total	10
N – RC	Friendly atmosphere, regular activities. Manager had no involvement with project, passed down to activities coordinators.	2 activities coordinators both interested & friendly. Found it difficult to spare time to co-facilitate group.	Group divided itself into 2 halves. Appeared to dislike each other, yet attracted to group by unusual dynamics. Discussion-orientated sessions more successful, with lively debates. The 1 man was often disinhibited, which appeared to annoy the group.	Managers attitude	1
				Home atmosphere	2
				Co-facilitator input	1
				Group atmosphere	1
				Group participation	2
				Total	7

Table 32 (continued): Qualitative details of centres

CENTRE ID	CENTRE, STAFF, MANAGEMENT	CO-FACILITATOR	GROUP	QUALITY RATING	
O – DC / RC	Manager serious & knowledgeable about research. Positive, friendly staff.	Co-facilitator extremely enthusiastic. Took notes, planned to continue (and start other) groups.	Excellent interaction and participation, interest in all activities. Became friends, showed interest in each others' stories. One person constantly expressed wish to die. Another consoled her, providing her with a role. All very sad at termination of groups.	Managers attitude	2
				Home atmosphere	2
				Co-facilitator input	2
				Group atmosphere	2
				Group participation	1
				Total	9
P – RC	Institutionalised. Management unhelpful, sometimes actively avoidant, e.g. arranged for sessions when group on outing.	Co-facilitator attended 3 sessions, made minimal input. Was otherwise 'unavailable'. Avoided completing assessments.	Excellent communication. People often directed comments more to each other than to facilitator. Sessions often involved jokes and laughter, initiated by 1 lady. All had interesting opinions, appeared to enjoy discussion. 1 softly spoken person talked over in early groups. In later sessions, became more assertive.	Managers attitude	0
				Home atmosphere	0
				Co-facilitator input	0
				Group atmosphere	2
				Group participation	2
				Total	4

**Key**

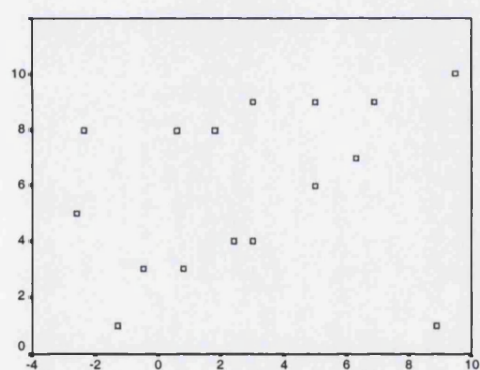
<b>RC:</b>	Residential care		
<b>DC:</b>	Day care		
<b>*Institutionalised:</b>	So used to living in or being part of an institution, that one becomes alike to it or unable to live independently.		
<b>**Learned helplessness:</b>	Developed passivity as a response to institutionalisation, e.g. using a wheelchair when able to walk slowly.		
<b>Manager's attitude:</b>	0 = hostile	1 = average	2 = favourable
<b>Atmosphere:</b>	0 = institutionalised	1 = average	2 = friendly / happy
<b>Input from co-facilitator:</b>	0 = avoidant / no co-facilitator	1 = average	2 = actively involved
<b>Group atmosphere:</b>	0 = poor interaction / dynamics	1 = average	2 = good interaction/dynamics
<b>Mean participation:</b>	0 = > 9 sessions	1 = 9 – 12 sessions	2 = 12 – 14 sessions

### 7.10.0. Further analysis of qualitative ratings

Pearson's correlation was used to investigate the relationship between the total quality rating for each centre (see table 32) and the mean ADAS-Cog change. The correlation coefficient was 0.27, which was insignificant ( $p = 0.32$ ). This is demonstrated visually by a scatter plot (figure 10).

*Figure 10: Scatter plot showing the correlation between mean ADAS-Cog score and quality ratings within centres*

Quality rating



Mean ADAS-Cog score

## **Chapter 8: Discussion**

### **8.0.0 Overview**

The evidence-based therapy programme designed in this study ran in 16 centres over a period of one year, recruiting 142 participants with dementia. An analysis of covariance showed significant improvements in both measures of cognition, depression and communication, a positive trend in anxiety and no change in behaviour or global functioning. There was a significant variation in the extent of change between centres in cognition, behaviour, communication, anxiety and depression. Further, males improved significantly more than females in behaviour and communication.

These findings should make an important contribution to both science and practice. Although there is a body of research on the various psychological interventions for dementia, much of it lacks methodological rigour and might not be considered 'evidence-based'. The available RCTs are reasonably small scale (the largest, Breuil et al (1994) having 56 participants); and could be criticised for weaknesses such as selection and detection biases. The Cochrane Review on RO (Spector et al, 1998a) combined data from the six most rigorous trials to date, yet only yielded a total of 125 subjects. As far as the author is aware, this current study is the only evidence-based trial of such scale examining cognition-focused therapies for dementia.

### **8.0.1. Recruitment of centres**

Due to the scale of the study, a substantial number of centres were required and an even greater number contacted, as only a proportion were actually included. Numerous phonecalls were made, due to difficulties in getting hold of managers and messages not

being passed on. The inclusion criteria chart was successful in eliminating some of the inappropriate centres before screening, and in BHB and Quantum Care over half the centres screened were included. Recruitment proved more difficult in Enfield and Camden and Islington. In Enfield, this was due to the small size of homes, most having less than 30 residents. Centres in Camden and Islington were often unsuitable as they tended to be smaller and have a much higher number of clients with long-term mental health problems (such as schizophrenia), who could not be included.

In two centres, the researcher began full assessments but the project fell through, due to two people in each refusing full assessment post screening. In both, there were no further suitable participants. On three occasions, managers had double-booked or forgotten that screening had been arranged, hence the researcher had to re-schedule. As half a day was put aside for screening, this project illustrates how much time is required when recruiting centres for such a large trial with explicit inclusion criteria.

### **8.0.2. Recruitment of participants**

Initially, inclusion criteria were described in a short paragraph and staff would frequently produce lists of people to screen of which many were unsuitable. The introduction of the inclusion criteria flow-chart (figure 6) helped to clarify the types of people required, and subsequently staff produced more appropriate lists for screening. Nine exceptional cases with an MMSE score of less than 10 were included (7 with MMSE = 9, 1 with MMSE = 8, and 1 with MMSE = 7). They were all discussed in supervision prior to inclusion. These were people who fitted all the other inclusion criteria, including being able to have a meaningful conversation, and who the researcher felt would be capable of completing the ADAS-Cog and understanding the material presented in sessions. Low scores were

commonly due to a combination of factors including mild depression and poor education. In contrast, there were other people who were excluded despite having scored 10 or over, because they had serious communication difficulties.

Full assessment took between 20 minutes and an hour, and people's reactions towards the questions varied. Some appeared uncomfortable and embarrassed, whereas others seemingly enjoyed the one-to-one contact and viewed the questions as an interesting 'quiz'. Often, people would ask to stay and answer more questions once the assessments were completed.

### **8.0.3. Attendance**

All people who were randomised into the group would be invited to every session, regardless of how many they had previously refused. In the development and training stage (centres A-C), there was a level of non-attendance due to people feeling tired or ill. Staff often claimed that these individuals refused to participate in most activities. Hence in the development of the inclusion criteria chart, it was asked "Does this person agree to participate in most activities?" This reduced the number of people who persistently refused sessions due to being generally de-motivated.

Attendance varied between homes. Excluding illness and death, there appeared to be two main influential factors; i) the level of institutionalisation, which sometimes affected peoples' level of motivation; and ii) group dynamics, which influenced how successful the group was. Centre L had the lowest mean attendance rate (7 sessions). It was a particularly institutionalised residential home with few activities occurring, people rarely leaving their lounge and a general air of apathy (see table 32, centre L). Two individuals

attended 4 and 7 sessions respectively, refusing to come to other sessions because they were “not interested”. They appeared resentful when arriving and usually refused to engage, creating apathy amongst the rest of the group. Overall, the dynamics were weak and it appeared that these people simply did not like being in the group setting, and did not want to participate in activities. Centre L was given a quality rating score of 1.

Centre O had the highest attendance rate (14 sessions). This residential home had highly structured days involving regular activities (exercise in the morning and games in the afternoon), hence was similar to many day centres. The group were used to participating in activities, socialising with others and moving between rooms. The participants frequently commented on how much they liked the home and were grateful to be there. This might suggest that the happy and positive environment had a strengthening effect on people’s motivation. The quality rating score here was 9.

#### **8.0.4. Dropouts**

8% of the treatment group and 19% of controls did not complete follow-up assessments. This difference was mainly due to numbers refusing to be assessed; 3 treatment participants (4%) compared to 7 controls (11%). Results showed a significant improvement in communication in the treatment group, which might have affected their willingness to be assessed. Further, because of their participation in the groups, they may have become more accustomed to being taken into different surroundings and being asked questions by an unfamiliar person.

## 8.1. Interpretation of results

### 8.1.1. Main results

#### *Significant improvements in cognition*

The most marked result in the study was the significant improvement in both measures of cognition, supporting the findings of past authors (see table 3). For example, Breuil et al (1994) found significant improvements in the MMSE and Woods et al (1979) found significant improvements in memory, learning and orientation using the Weschler memory scale.

Although most showed positive trends, the only sub-scale in the ADAS-Cog to show significant between group differences was “following commands”, which involves giving the person five commands ranging from one to five steps. It is interesting to note that this task appears similar to ideational praxis, which involves the task of sending an imaginary letter to oneself. There is also an overlap with word recall in that the increasing number of steps involves the use of short-term memory. Hence it might have been that the ideational praxis task was more difficult as it involved more executive functioning (planning, organising and sequencing) than the following commands task. Executive functioning is often impaired in dementia (see 1.0.1.). Additionally, people might have found following commands less overwhelming than the word recall task, with an ostensible focus on *doing* rather than *remembering*. Perhaps the former people felt more capable of. Another explanation is that people became more accustomed to doing what was asked of them following group participation, and that the commands were similar to some of the tasks performed in groups, such as in using objects. In contrast, other tasks were less akin to those done in groups, and relied on other abilities.

For instance, people with apraxia (impaired ability to carry out motor abilities despite intact motor function) would have found copying shapes particularly difficult.

The overall ADAS-Cog change indicated improvement in a number of factors. With the exception of explicit rehearsal in place orientation, which is directly questioned, there is no obvious reason why participation in groups should have had a direct practice effect on any other tasks in the ADAS-Cog, such as word recall and recognition. This suggests that generalised cognitive effects resulted from inclusion in the programme. Regression did not define any factors as predictive of ADAS-Cog score.

#### *No change in behaviour*

Contrary to the hypothesis, there was no change in behaviour. The meta-analysis in the Cochrane review included four studies and showed a significant behavioural difference. However, only one individual study (Baines et al, 1987) found a significant difference in behaviour. Woods (1979) noted that in his trial, several of the areas assessed (such as dressing, feeding and continence) were not in any way connected with the content of treatment, and no specific steps were taken to generalise orientation to behaviour. Later, Woods (1996) pointed out that changes in function and dependence are few in RO trials. He argued that an environment encouraging dependence may counteract any behavioural benefits from group sessions, and that changes in cognition are unlikely to have any impact on areas of functional dependence described in the CAPE-BRS, such as feeding and dressing. The CAPE-BRS may also be insensitive to change.

Zanetti et al (1995) also argued that behavioural outcome measures such as the Activities of Daily Living (ADL, Katz et al, 1970) and the Instrumental Activities of Daily Living

(IADL, Lawton and Brody, 1969) are not sensitive enough to detect the functional impact of cognitive stimulation programmes. They selected 20 activities of daily living (e.g. dressing, cooking and writing), using the time taken to perform each task as the outcome measure. They compared four 'normal' elderly controls to four people with AD, the latter receiving 3 weeks of daily one-hour sessions in which they had to perform these activities. This study found a marked improvement in AD patients in both trained and not trained activities, moving towards performance levels of the 'normal' controls. Although only a pilot, it suggests that direct observational measures may detect changes unrecognised in staff behavioural assessment scales. Similarly, Woods (1979) had earlier commented that the Crichton scale is a relatively crude way of assessing behaviour, and that a finer assessment of behaviour, such as through direct observation, might be a superior indicator of change.

As mentioned in 1.2.1., the relationship between cognitive and behavioural change is unclear (Cockburn and Keane, 2001). Whereas this programme might have accessed cognitive factors, which may be more closely related to anxiety, communication and depression, more direct behavioural training might be required for observable functional change. Finally, an individual's problem behaviour is often perceived differently by different staff, and its impact on them can vary greatly (Moniz-Cook et al, 2000). They found that staff anxiety, supervisor support and the potential for a person-centred, individualised approach to resident care related to staff perceptions of behaviour as challenging. The latter suggests that the more staff are able to relate to the residents as individuals and are able to offer them help and support, the less they perceive difficult behaviour as challenging. They added that knowing more about the person's history and pre-morbid condition can enable a fuller understanding of them.

### *Communication*

There were significant improvements in communication, supporting the findings of Baines et al (1987) who found significant improvements in the Holden. Communication is a factor which is likely to deteriorate for individuals once moving into residential care. For example, chairs are often placed around the walls, making it difficult for people to converse. The small group context was likely to be novel for many of the participants, perhaps re-exercising unused communication skills.

### *Mood*

There were significant improvements in depression and positive trends in anxiety. The feeling of 'connecting' with others in the group might have reduced feelings of isolation, and subsequently depression. Only one RO trial examined depression (Zanetti et al, 1995), finding no changes, and Goldwasser et al (1987) found increased depression following RT. Anxiety, which had not been assessed in previous research, might have reduced with improved orientation or increased exposure to success, enabling people to feel more in control of their world. These results should be interpreted with an element of caution due to the non-parametric nature of the data, although the Wilcoxon tests did support the findings. Further, Howell (1997) argued that many people believe that for most cases, parametric tests are sufficiently robust to deal with data from skewed distributions.

### *Global functioning*

There was no change between groups in the CDR. Approximately 70% in each group showed no difference, yet examining the scale it can be seen that substantial change is

required for an individual's score to move between one grade and another. The CDR was useful as a baseline measure of dementia severity, yet modest change was expected at most. In part, it draws from information provided by staff, therefore might be less indicative of actual performance than the ADAS-Cog and MMSE, which are based on direct patient interview.

### **8.1.2. Differences between centres**

There was a significant variation between centres in measures of behaviour, communication, anxiety and depression. In institutionalised centres where there were poor staff-patient relationships and dependency was encouraged, it might have been that the effects of groups were not strong enough to combat the consistent effects of a negative environment.

The experience of the researcher appeared to influence the success of the group process. Table 29 (chapter 7), which shows the mean ADAS-Cog difference by centre, demonstrates a tendency for the ADAS-Cog difference to be greater in centres used later in the project. (Centres I and L showed a decline. Problems experienced in running groups in these centres are described in table 32). It can be assumed that over time, the researchers developed an increased confidence in running groups and became more experienced in handling difficult situations and tailoring sessions to fit in with individuals needs and capabilities.

Groups including people at different stages of dementia were sometimes difficult to run. People with milder dementia could become irritated by the more severe, and observing their confusion might have been off-putting, hence detrimental to the group process. The

researchers discussed difficult groups in the regular clinical supervision sessions. Pitching the sessions at an appropriate level is clearly important.

### **8.1.3. Age and gender**

Age did not have an impact on any of the outcomes. This suggests that although increasing age is a risk factor in dementia, response to cognitive stimulation does not differ according to age. However, it is important to note that the age range of the population was limited, with most people in their eighties (mean = 85.8 years, standard deviation = 6.7). Hence if age did have an effect, it might not be detected from this sample. There were gender differences in behaviour and communication. In both measures, females in the treatment group slightly improved, female controls slightly declined, and males in both groups declined (controls more than treatment). Because the difference between treatment and control males was greater than that between treatment and control females, males improved significantly more than females. Why control males showed such a marked decline remains unexplained. However, the control male sample only consisted of 14 people, and there were a few extreme cases which might have weighted the mean result. For example, one man deteriorated by 25 points on the Holden and 18 points on the BRS. Changes in medication, physical health or life events might have contributed to such discrepancies.

One might speculate as to why the female treatment group was the only one to show an improvement. Firstly, females might be accustomed to spending more time in group discussion and interaction than men. Additionally, the circumstances and content of past group interaction would have been different, with women spending more time talking with other women in the home, and men with other men in the workplace. The group

ambience might have resembled the former more closely. In groups, people often talked about how certain things made them *feel*, perhaps something that females are more likely to be comfortable with. The group environment might have exercised previously formed communication skills (used infrequently in the residential care setting), bringing about improvements in the Holden Communication Scale. For men, being a minority (there was often one man and four women in the group) could have created discomfort and a reduced ability to communicate. It is interesting to note that only one group was male dominated, consisting of three men and two more passive women. Here, there were dramatic improvements on BRS and Holden for each man, for example one man improved by 15 points on the Holden and by 8 points on the BRS. Hence perhaps the peer support of other men was an important factor. This might reflect a more general issue in residential and day care, where men are usually a minority.

Secondly, it might be that some of the questions in the BRS are more female-orientated. For example, one question asks if the person helps out in the home / ward, and another if they are willing to do things suggested of them. However, it might be that staff more frequently invite women to help with tasks in the home (such as laying the table), a task more traditionally done by women. The Holden and CAPE-BRS show some overlap, for example the BRS contains questions regarding ability to socialise and communicate. This might explain the similar patterns in gender between the two.

#### **8.1.4. Numbers needed to treat (NNT)**

Livingstone and Katona (2000) systematically searched Medline for RCTs on anti-dementia drugs (Tacrine, Rivastigmine and Donepezil), and conducted NNT analyses on

each. Analyses were performed identically in this study, considering two levels of change as improvement, so that a direct comparison could be made (see table 33).

*Table 33: Numbers needed to treat – Comparison to anti-dementia drug trials*

<b>TREATMENT</b>	<b>ANALYSIS (1): NNT [CONF. INTERVAL]</b>	<b>ANALYSIS (2): NNT [CONF. INTERVAL]</b>
<b>This programme</b>	4 [2 – 6]	4 [3 – 7]
<b>Rivastigmine</b> (Corey-Bloom et al, 1998; Rosler et al, 1999)	4 [3 – 6]	13 [7 – 11]
<b>Donepezil</b> (Rogers et al, 1998)	5 [4 – 9]	10 [5 –180]
<b>Tacrine</b> (Knapp et al, 1994)	-	7 [3 – 10]

Analysis (1) = ADAS-Cog, with no deterioration as improvement

Analysis (2) = ADAS-Cog, with increase  $\geq 4$  as improvement

These comparisons show that for small improvements, the programme is as effective as Rivastigmine and more effective than Donepezil with regard to numbers needed to treat. Yet for greater improvements, less people need to be treated with this programme than they do with Rivastigmine, Donepezil or Tacrine in order for one to benefit. These results are particularly powerful because the drug programmes lasted for 24, 26 or 30 weeks, compared to only 7 weeks of cognitive stimulation.

#### **8.1.5. Qualitative results**

Table 32 provides the researchers' qualitative descriptions of each home, with more detailed notes available in appendix D. The total quality ratings were correlated with the

mean cognitive change (figure 10), yet there was no relationship and no patterns emerged. For example in some extremely institutionalised settings, there were great cognitive improvements in groups, perhaps resulting from the stark contrast the programme made to the monotony of people's usual routine. On the other hand, groups in some institutional settings showed little or no change, maybe because any positive effects of twice weekly sessions were counteracted by more influential negative factors such as minimal interaction with staff and other residents, and no other activities or stimulation. However, quality ratings were made loosely by the researchers through subjective opinion, hence were subject to bias. Further, managers attitude and co-facilitator input (which contributed to 40% of the total quality score) were unlikely to have had any direct effect on cognitive change, hence substantially reducing the likelihood of any correlation. It would be interesting to examine further how influential these factors were on the success of the programme, and whether they had an effect on other factors such as communication and depression. An alternative method of qualitative analysis might be beneficial, such as grounded theory. However, it was not feasible within the resources to conduct an in-depth qualitative analysis, nor was it a key component of this study.

### **8.2.0. Comparison with past research**

Referring back to chapter 2, table 2; aspects of this study can be compared to other RCTs on RO. This trial is over double the size of the largest past RO trial (Breuil et al, 1994) which had 56 participants. The duration of intervention (630 minutes in total) was relatively short in comparison: Breuil et al (1994) and Baines et al (1987) both had 600 minutes of intervention in total, and the other trials were substantially longer. For

example, Ferrario et al's (1991) groups totalled 6300 minutes: 60 minutes, 5 times a week for 21 weeks. The short duration of this programme lends further credit to the results. The overall attrition rate of 15% (8% treatment, 19% controls) appeared average; in the other RO trials, attrition ranged from 0% to 37%. As described in chapter 3, the programme employed similar activities and themes as past trials in RO (particularly Breuil et al, 1994), and elements from RT and memory training programmes.

This study supports the results of past studies which have found significant improvements in cognition (Woods 1979, Hanley et al 1981, Ferrario et al 1991, Baldelli et al 1993, Breuil et al 1994), see table 2. Baines et al (1987) found significant improvements in behaviour, which were not found in the present, or any other studies. Apart from Baines et al (1987), who assessed communication, and Zanetti et al (1995) who assessed depression, cognition and behaviour (or ADL) were the primary outcomes assessed. No trials used power calculations to determine their sample size, or an intention to treat analysis. Three trials conducted follow-up assessments, one suggesting that RO participants performed worse at a 10-week follow-up than before (Gerber et al, 1991), and two suggesting that benefits were maintained (Wallis et al, 1983; Baines et al, 1987). Baines et al found that a reasonably high level of functioning can be maintained over a four-week break from groups, and losses in functioning which occur when people are not in groups can be made up once groups restart.

### **8.3.0. Staff / institutional issues**

Activities and stimulation are not adequately recognised by social care authorities, for example inspection regimes have little assessment of psychological care, with more

attention paid to physical factors such as heating and toilets (Department of Health, 2001). This was reflected in the experience of the researchers, who had some difficulty persuading staff that stimulation and activity should play an important role in a person's care. Being used to watching people deteriorate, some staff may have found it hard to believe that improvements could be made. The general ethos suggested that interaction with residents was low on the list of priorities, with endless physical tasks such as washing and toileting always needing attention. In fact, staff having a conversation with a resident might be criticised as being idle, with one person commenting that "there are always beds to be made".

Moniz-Cook et al (2000) suggested that with more information about the residents, such as their life history and pre-morbid personality, staff might find it easier to see them as individuals and adopt a person-centred style to resident care. Interestingly, they found that qualified staff (matrons, officers and nurses) have more difficulty in managing challenging behaviour than the less qualified, such as care assistants. This has practical implications, such as increases in psychotropic medication.

It was challenging to work with staff who had themselves become somewhat institutionalised. This depended greatly on the management style, support, environment and hierarchy between staff at different levels. Some homes had the feeling of a closed system, not used to having outsiders spending reasonable amounts of time there. Because the researchers were offering something new, staff may have feared that the project could expose what they were not doing, or pitfalls in the organisation.

A level of staff input and co-operation was essential for the successful running of the project. For example, staff time was required to create a suitable list of people for screening and to complete assessment measures. The latter was time-consuming, and it was necessary that management made an allowance for this in the week prior to commencing groups. The following problems commonly arose:

- i) Staff assessments were not completed by the agreed date, often delaying the start of groups. Sometimes, it appeared that staff were genuinely too busy, and the manager had not given them extra time to do the work. At other times, it may have been that staff avoided the assessments. The researchers would routinely go through all the forms to ensure that staff understood the questions. Yet they required a reasonable level of literacy and on occasion it might have been that certain wording was difficult for them to comprehend.
- ii) The staff co-facilitator(s) were unavailable, typically stating that they were too busy. It was requested that one staff member acted as co-facilitator, to create consistency and continuity between sessions, to observe changes in group dynamics and to pass on information to other staff for future use. All managers chose one co-facilitator, or two to alternate. However, the nominated co-facilitator(s) only attended the whole programme in five centres, and in seven centres attended three or less sessions.
- iii) Activities co-ordinators (AC) were often allocated as co-facilitator. In four centres, the AC showed active resistance towards the project, for example by arranging other activities that coincided with groups, or making continuous distracting comments during sessions. In some instances they might have felt threatened by the idea of researchers offering a free service, which could

potentially be better than their own. If the project was a success and people attending groups improved, the value of their activity work, which had sometimes been going on for years, could be questioned. Alternatively, they might have felt that they had been doing their job for much longer than the researchers, and knew better. In contrast, some ACs were extremely helpful, viewing the project as an opportunity to enhance their jobs and share their experiences. In one home, the project appeared to provide a focus for the AC, who learnt to type in order to produce a booklet describing the sessions for relatives and staff.

- iv) A random staff member would be asked to join a session minutes before its commencement, knowing nothing about the project and making little, if any contribution. This was often indicative of their perception of their role as task orientated (e.g. to take people in and out of the room and to the toilet), as opposed to person orientated (e.g. to talk to them). In homes where a hierarchy between management, senior staff and care workers was apparent, care staff might have been purposely excluded from the project. It is possible that some staff who were genuinely interested in the project underplayed their enthusiasm, fearing that others would accuse them of using it to 'score points' with the manager.
- v) Staff appeared disappointed with the content of sessions, particularly those in day centres who often ran similar activities themselves. It was necessary here to emphasise the purpose of the project, and that it did not involve advanced equipment or dramatic, life-changing results.
- vi) Staff were misinformed by management about the nature of the project, perhaps in an attempt to motivate them. In one home, the co-facilitator had been told that it was a "training course". Although the nature and purpose of the research was

explained by the researcher, this particular person appeared disappointed, with unfulfilled expectations.

- vii) Staff used the project to complete part of an NVQ. Some people lost interest fairly rapidly, suggesting that perhaps once their involvement had been sufficient to include in their NVQ, they no longer felt the need to participate.

### **8.3.1. Common clinical issues**

- i) Repetitive introduction of difficult issues, such as a wish to die by one resident. This sometimes appeared to distress the group and interrupt the activity at hand. Individual therapy might have been more suitable for those experiencing extreme grief or depression. It was important to acknowledge the feelings of individuals, yet difficult for the nature of the group to focus on personal issues. The situation was sometimes improved for one depressed person by the co-facilitator sitting next to her and providing non-verbal comfort, such as holding her hand and maintaining close eye contact.
- ii) People talking over each other. In some groups it was difficult to get individuals to engage with each other, being more interested in talking to the group leader. Losses in both hearing and social skills might have been influencing factors. Further, shy or softly spoken people were sometimes not heard by other group members.
- iii) People finding the group setting unusual or uncomfortable. Many people of the generation currently in their eighties moved from parental to marital homes and were rarely exposed to living with peers or communal activity. It might have also been that men typically talked to men in the work environment and women talked to women at home, with mixed group activity less common.

- iv) One antagonistic group member. For example, one group had a disinhibited man, and another, an aggressive woman who would occasionally shout at the leaders and other group members. On both occasions, conflict developed in the group. If either had caused serious offence to individuals or had been disruptive to the group process, they may have no longer been invited to sessions. However, in both cases they appeared to fuel debate, perhaps making the groups more stimulating for the individuals.

#### **8.4. Mechanisms of change**

In chapter 1 (1.1.), the author proposed the following model:

$$D = NF + MS + SP + P + SS + E + H + LE + M$$

Where D = Dementia, NF = Neurological factors, MS = Mental Stimulation, SP = Social Psychology, P = Personality, SS = Sensory Stimulation, E = Environment, H = Physical Health, LE = Life Events, M = Mood. Dementia is largely determined by cognitive deficits, and cognition significantly improved in this study. Therefore, it is probable that the intervention had a positive impact on some of the factors in the equation. As follows are some suggestions, based on psychological theory, the author's observations and empirical outcomes from the study; as to some of the possible mechanisms that might have contributed to the observed improvements in this study. It is likely that individual change resulted from a combination of these elements.

##### **8.4.1. Neurological factors and mental stimulation**

Various authors (e.g. Swaab, 1991; Katzman, 1993) have speculated that cognitive stimulation can actually stimulate cell growth, through the creation of neuronal pathways through learning. It is possible that this programme generated such change, contributing to the observed significant improvement in cognition. This makes the assumptions that neural pathways can degenerate through lack of use, and that new pathways can be formed to compensate for damaged or dead pathways. Regarding RO, Stephens (1969) suggested that: *“The process can reawaken unused neural pathways and stimulate the patients to develop new ways of functioning to compensate for organic brain damage that has resulted either from injury or progressive senility, or from deterioration through misuse.”* It has been suggested that more educated people might have a reduced chance of getting dementia (Katzman, 1993), perhaps due to improved neural networking. Through ‘re-education’, the programme might have improved networking in a similar way. Further, it is possible that physiological neuroprotective effects were stimulated, so that when neurones died others could carry out similar functional tasks. Orrell and Woods (1996, p.191) stated that *“neuropathological and neurochemical changes may set upper limits on performance, but psychological approaches could assist the person with dementia in functioning closer to these limits than is often the case.”*

#### **8.4.2. An enriched learning environment**

The enriched learning environment could link in with the “mental stimulation” and “environment” aspects of the dementia equation. In the usual environment, people might sometimes be overwhelmed by information, finding it hard to select or abstract what is relevant. The learning environment during sessions was designed to be optimal for people with dementia. For example, the facilitators emphasised the use of opinion and preserved skills wherever possible. The ‘food’, ‘childhood’ and ‘using objects’ sessions

focused on implicit memory. They allowed people to interact naturally with the objects and build on automatic, well preserved skills, such as in demonstrating how to use the toys and how to combine food to make a meal. The integration of reminiscence throughout the programme, which builds on remote memories, focused on people's strengths and abilities. In usual activities, people might have been more accustomed to feelings of failure, not being able to care for themselves anymore or rely on their memory in order to be independent. The programme therefore might have tapped into similar theoretical concepts of Spaced Retrieval Training and Errorless Learning, in that getting more things correct increases performance due to increased exposure to success, and hence improves self-esteem.

Relative preservation of semantically related material may explain why certain aspects of RO are successful. Miller and Morris (1993, p.115) give the example of tasks involving learning names of people in response to a specific cue (e.g. who is the current prime minister?) as involving strengthening existing semantic associations between the question and the answer. Bridging exercises, such as using standard, personalised warm-up procedures (e.g. singing "You are my sunshine" at the beginning of each "Sunshine Group") might have assisted the learning process through priming.

Encoding could have been more effective during groups than in the usual environment. For example, people might have been disorientated to time because days usually had no meaning, with no enjoyable events differentiating them. Yet learning the days on which groups took place and being presented with orientation information on a board which also contained the names of individuals and the group (e.g. "The Sunshine Group") might have become personally meaningful and have accessed implicit memory. Further,

if people felt less depressed and more able to communicate, they may have selected and abstracted information more effectively. The groups might have encouraged people to engage with their surroundings more, having a direct effect on some of the outcomes. For example, the Holden Communication Scale asks about “interest and response to objects”.

Stimulation and time and place orientation might have improved people’s ability to shift between “states of intense reminiscing” and “states of being orientated to reality” (Reminiscing Disorientation Theory (Jones and Burns, 1992); see 1.1.5.). Further, support from the group and the facilitators was received at the time of learning, which past authors have suggested is helpful in facilitating learning through creating a more relaxed, interactive experience (Backman 1992, Sandman 1993).

#### **8.4.3. Social Psychology**

Earlier, Kitwood’s theory of a “Malignant Social Psychology” was described (see 1.1.3.). It could be argued that groups directly worked against these negative factors (such as disempowerment and infantilisation), instead creating an environment of empathy, support and respect between people with dementia, researchers and staff. In groups, people had the opportunity to offer opinions, share stories, build new relationships and take the time they needed in discussion or activity. Groups involved “Positive Person Work” (PPW, Kitwood, 1997, p.90), which he described as involving factors *including*:

- Recognition: acknowledging the person as an individual. An attempt was made for people to learn each others’ names in the warm-up exercise, and often they would be given nicknames. People were encouraged to share unique stories, for example, in

‘childhood’, people read their personal histories to the group, including family names and where they lived.

- **Negotiation:** consulting people about their preferences. Individuals voted on a group name. Emphasis in all sessions was on opinion, such as in ‘food’ (e.g. “what would you put together to make a meal for two?”) and ‘faces / scenes’ (e.g. “who do you think was the most attractive / oldest?”)
- **Collaboration:** working together. This was exercised throughout the programme, for example in the creation of a map, the making of a cake and in teams for the quiz.
- **Play:** an exercise in spontaneity and self-expression. Sessions were designed to be ‘game-like’, without rigid boundaries so that people could be unconstrained and expressive. The ball throwing warm-up was an opportunity for people to share experiences and stories since previous sessions, or show simple preferences, such as their favourite food or holiday destination.
- **Relaxation.** Participants often described sessions as “relaxing”, particularly after playing percussion instruments in ‘sound’, and making apple crumble in ‘using objects’. More importantly, the aim was that people were able to express and enjoy themselves in a relaxed, non-confrontational environment.

This positive person work links with the Validation approach (Feil, 1972), which was adopted as one of the guiding principles, to be used by the leaders when appropriate (see 3.2.3.). Some participants might have become socially withdrawn because they felt depressed. Anxiety and depression might have suppressed baseline cognitive scores as a result. Validating peoples’ feelings, for example by acknowledging their emotional meaning, might have positively affected people’s self-esteem and reduced anxiety, particularly when people had difficulties expressing themselves verbally. The

researchers attempted to avoid situations where people were confronted with things that they could not do. For example when using the RO board, clues were given, people were given the time they needed, and questions were asked of the group as opposed to individuals. This might have contrasted with everyday interactions, where cues are rarely provided to aid retrieval of information and in which people are often prevented from doing things at their own pace. For instance, people are often rushed at mealtimes in order for staff to clear up quickly. It was highlighted by the researchers that groups should be a place for people to feel comfortable expressing needs and feelings, the importance of which would be recognised.

In sessions, people often discussed their occupations, interests and background, their opinions and preferences valued. This may have positively reinforced their own and others' perceptions of their "public self" (Sabat and Harre, 1992). For example, a person who had previously been a cook took control in the cookery session, reminding herself and others of her social role and increasing her self-esteem.

A behavioural explanation is that through praise and recognition, groups positively reinforced questioning, thinking and interacting with other people, objects and the environment. This might have extended to outside the groups, with people communicating more effectively and responding to the environment and others. Woods (1979, p.506), in describing RO, stated that "*These general effects could also result from practice at and reinforcement of being attentive and concentrating on cognitive tasks as are usually carried out in RO sessions.*" Positive reinforcement works directly against a malignant social psychology, which involves not recognising or reinforcing behaviour.

Yalom (1995) highlighted “ten therapeutic factors” of groups:

1. Installation of hope
2. Universality
3. Imparting information
4. Altruism
5. The corrective recapitulation of the primary family group
6. Development of socialising techniques
7. Imitative behaviour
8. Interpersonal learning
9. Group cohesiveness
10. Catharsis

Some of these factors might have contributed to change in this study. An ‘installation of hope’ might have been achieved by including activities in the programme which people were able to do successfully, highlighting their preserved abilities. In groups, the disconfirmation of people’s feelings of uniqueness might have been a powerful source of relief (‘universality’). For example, jokes regarding memory loss were often made between group members. Further, people’s awareness of their dementia as not being unique may have reduced some symptoms which were exaggerated by the awareness of it, such as depression and apathy (see “Awareness Context”, 1.1.4.). The researchers offering of simple explanations about memory loss in old age (‘imparting information’) sometimes appeared to alleviate stress in individuals. Group members sometimes offered their own interpretations or tips to each other, again reducing anxiety on both sides. Being part of a small group with regular meetings might have induced feelings of belonging (‘group cohesiveness’), in contrast to the feeling of anonymity in residential

care. In many groups, individuals offered support to each other, perhaps giving them a sense of purpose ('altruism'). It could be argued that factors 6-8 are less likely to occur in groups of people with dementia. Short-term memory difficulties would have made it difficult for new insights to be maintained, and to consolidate and use information.

#### **8.4.4. Sensory Stimulation**

The programme incorporated multi-sensory stimulation, such as in the sound effects and food sessions. Sessions frequently involved looking at, listening to and feeling things. An attempt was made to avoid situations where people had to rely on a single sense, which may have been impaired. Baker et al (2001) found improvements in mood and behaviour following multisensory stimulation (see 1.9.1.). They suggested that during sessions, people received more appropriate stimulation than in their everyday environment, which might enable them to become more engaged and focused on the environment around them both inside and outside sessions. Multi-sensory stimulation might make memories more distinctive and easier to recall, improving the learning environment and enabling a focus on what people can, rather than cannot do.

#### **8.4.5. Environment**

The social environment during groups was typically quite different to the usual environment that people were accustomed to. This difference may have been more marked in residential care homes. Groups often had a positive influence on the four sub-scales of the Sheltered Care Environment Scale (see 1.1.6.) They were:

- (i) Cohesion: with staff co-facilitators and residents showing support and interest in each other.

- (ii) Independence: with people encouraged to make decisions and engage in tasks independently.
- (iii) Self-exploration: with opportunities to share stories, feelings, thoughts and opinions.
- (iv) Resident influence: with a choice of activities often presented in sessions, residents allowed to name the group, etc.

Nonetheless, because these factors did not extend outside the group context, they were unlikely to have had an influence on functional ability, as demonstrated in Netten's sample (Netten, 1991). Additionally, the facilitators attempted to make the physical environment as appealing as possible. For example, the group would typically sit around a table or in a small circle with comfortable chairs. The same room would be used throughout the programme for consistency, and often things produced in sessions (such as the map) would be kept in the room and looked at again. This often gave people a sense of achievement and aided memory through continuity.

#### **8.4.6. Global change**

This study showed significant improvements in cognition, depression and communication, suggesting that these factors might be inter-related. For example, a person's cognition might improve as a result of stimulation in the group. This might subsequently make them feel less depressed, and more willing and able to communicate. Alternatively, communication might improve as a result of exposure to the group and more frequent conversing and expressing of opinions. This might reduce depression, enabling the person to take in more from the environment and increasing their alertness, thus improving their cognitive performance. This was summarised by Woods (1992, p.128), who stated that *"If RO produced a general increase in the person's cognitive*

*functioning – in alertness, concentration, new learning ability etc, as well as in verbal orientation – then performance in a number of other areas could be facilitated.”*

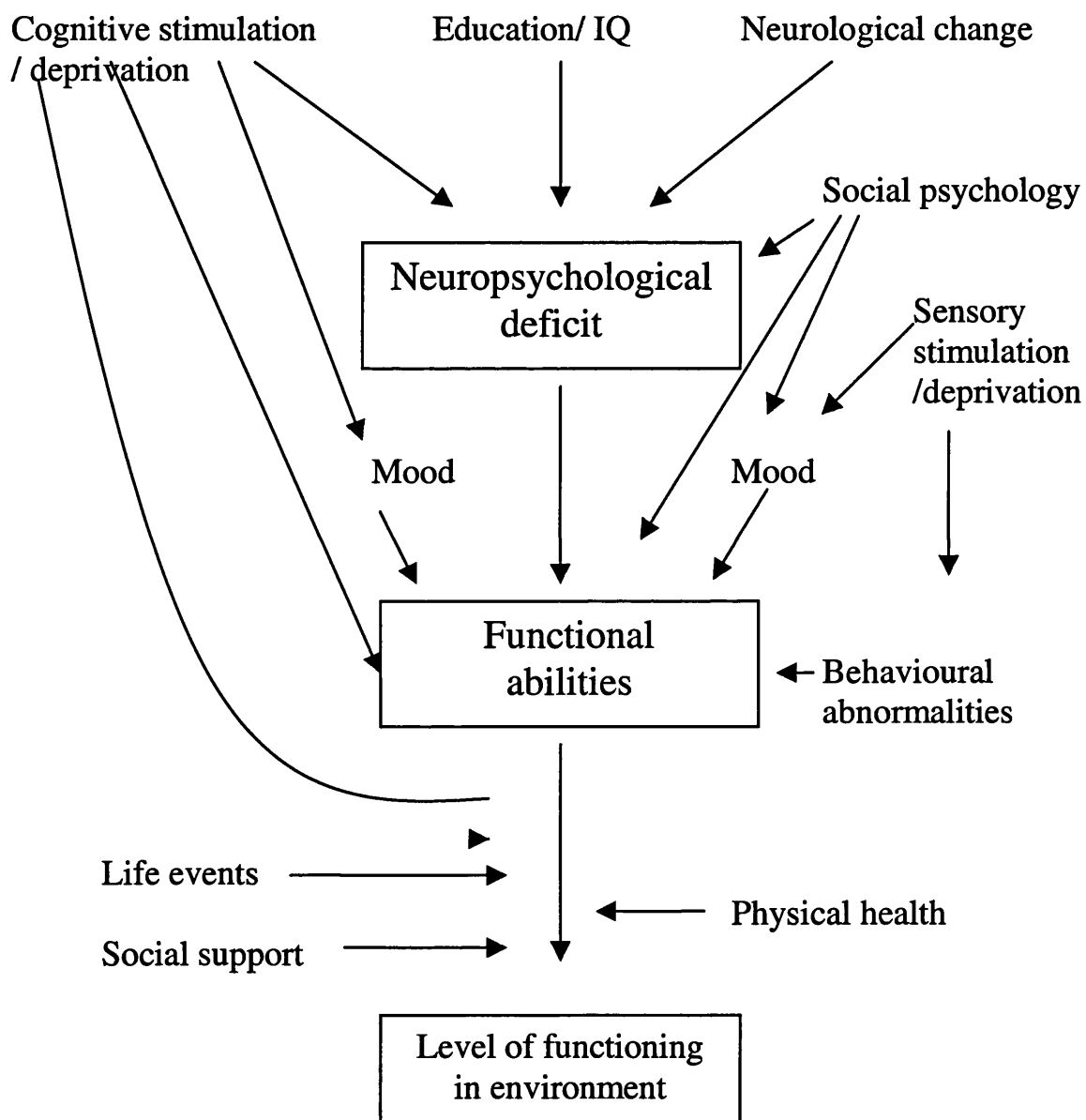
Similarly De Rotrou et al (2000), in a small cognitive stimulation study in follow-up to Breuil et al (1994); stated that cognitive stimulation accesses (i) Cognitive factors (attentional, perceptive, verbal, intellectual); ii) Psychological and social factors (restoration of confidence, motivation, reinforcement of social ties and feelings of belonging to a group). Both appeared to be accessed in this current study.

Although a global connection between cognition and communication, depression and anxiety seems likely, the link with behaviour appears tenuous. Woods (1979, p.506) questioned “*whether it is enough to provide cognitive re-training, or whether training in the actual behaviour of feeding, dressing, toileting or whatever is required.*” (see 1.2.1.).

## **8.5. The revised model**

The significant improvements in cognition, depression and communication following treatment provide further evidence for “*rementia*”, and some of the possible mechanisms of change have been discussed. However, the effects of factors such as physical illness, life events and social support were beyond the scope of this thesis, and may help account for individual differences. Figure 11, a biopsychosocial model indicating the possible role of cognitive stimulation for people with dementia, is an extension of the formula presented in chapter 1. It shows aspects which might contribute to neuropsychological deficits: cognitive stimulation / deprivation, educational and IQ factors, neurological change and social psychology. Further, cognitive stimulation, social psychology, sensory

*Figure 11: Biopsychosocial model to indicate the possible role of cognitive stimulation for people with dementia*



stimulation / deprivation and behavioural abnormalities could all impact on functional abilities. The first three might affect functional abilities via mood. Lastly, significant life events, social support and physical health might have an impact on how people actually function in the environment. This model is based on the observations drawn from the study, and speculation as to how and why change might have occurred. It is by no means exhaustive, the factors discussed might not necessary link in where they are placed and some causative factors might not be covered.

## **8.6. Limitations**

RCTs are considered the most rigorous and “true” of experimental designs (Bowling, 1997). Through random assignment to treatment and control conditions, the risk of extraneous variables confounding the results is minimised. However, as follows are some limitations created by the experimental design in the current study:

### **8.6.1. Methods**

Data from centres A, B and C is likely to have differed in quality from the rest. Baseline assessments were conducted by the first researcher, and follow-ups by an OT in centres A and B, and a trainee psychologist in centre C. The OT had never previously conducted neuropsychological tests and there were some delays in conducting the follow-up assessments. Additionally, the programme described in chapter 5 was employed, and the finalised 14 session programme was only used in centre D onwards. Due to these potential confounders, the first 3 centres were described as the ‘development and training phase’, and separate analyses were carried out excluding them.

Direct patient assessments (MMSE, ADAS-Cog) and the CDR were rated blindly by one researcher. Staff assessments (BRS, Holden, RAID, Cornell) were conducted blindly in some centres, and not in others. Due to staff shortages and problems, managers occasionally asked staff co-facilitating groups to complete assessments. This would result in bias both due to their lack of blinding to group membership, and their increased level of interaction with treatment participants. More frequently, staff assessors were not involved in groups, but could have observed which participants were involved in treatment. It was also difficult to get the same staff raters to complete baseline and follow-up assessments, due to shift work, annual leave etc. Due to differing relations and interactions with residents, their subjective ratings of factors such as anxiety might have varied, causing discrepancies in the results. However, this would have affected treatment and control participants equally.

In examining a breakdown of the results from individual centres, a trend was apparent in that improvements were greater in centres used later than in the earlier ones (e.g. see table 29). This might suggest a practice effect, in that the researchers became more experienced and hence better group facilitators as the project progressed. However, statistical examination of this was avoided, due to methodological complications. Firstly, the centres did not run in a clear succession, for example centres 1-2, 3-7, 8-13 and 14-16 ran at approximately the same time. Additionally, groups in centres 3 onwards were run by either AS or LT, AS who had previously run groups in 6 centres and LT in none. Therefore the experience of the facilitators differed over the course of the project.

Orten, Allen and Cook (1989) attributed the discrepancy in their results from three RT groups to the differential skill of the leaders. By the end of this project, the formerly

inexperienced group leaders had developed through practice and clinical supervision. Inexperienced group leaders were specifically chosen, to demonstrate that skilled clinicians were not needed for successful running of groups. This aim was achieved, as there were improvements in early groups. However, the development of expertise was an inevitable consequence.

Many centres were excluded, due to insufficient numbers. The use of cluster randomisation, involving randomising “clusters” (centres) into treatment and control conditions (as opposed to individuals) might have been useful. For example, it could have allowed centres with 5-7 suitable candidates to be included, and equal numbers of participants placed in treatment and control groups. A disadvantage of cluster randomisation is that large numbers of clusters are needed to ensure statistical power and external validity (Bowling, 1997). More importantly, the significant difference between centres on many factors in this study shows that it would have been difficult to ensure the comparability of clusters.

#### **8.6.2. Recruitment difficulties**

Rigorous inclusion criteria were necessary to ensure that the participants had general similarities and were comparable. They were also designed with the aim of recruiting people who were able to participate and unlikely to drop out. There were two disadvantages to this. Firstly, it meant that it was difficult to recruit sufficient people from each centre who fitted all the criteria, with lots of ‘borderline’ candidates who met some of the requirements. Hence a large number of centres had to be discarded due to insufficient numbers. Nevertheless, many of the excluded homes would still not have

been able to run such groups as part of their routine activities, due to a lack of suitable participants.

Secondly, if the programme were used in a non-research situation, restrictions on who could be included would be fewer in order to allow more people and centres to utilise it. Groups would probably be selected through clinical judgement, considering how people would mix and whether they had similar backgrounds and interests. In some cases, the MMSE might not even be used as a screening device. Hence if the programme were run independently in any residential home or day centre, people with poorer vision or hearing, or with more communication difficulties, might be included to make up numbers. Whether these people would benefit as much, or in the same ways, as those carefully selected for the purposes of the RCT is open to question. If the population used in this study differs to that likely to be used in practice, the external validity of the study is reduced.

Alternatively, the programme could be modified and simplified, and run with a group of more confused people who scored less than 10 on the MMSE. A few people included in the study later appeared substantially more confused than the rest of the group, sometimes irritating others. Yet having all participants at a similar, lower level of functioning, and pitching the activities at their level, could be successful.

### **8.6.3. Varying control conditions**

Differences in control conditions between centres meant that the 'control group' was not homogenous. Some centres were extremely active and control participants were frequently occupied. Others rarely adopted activities and the controls did just literally do

‘nothing.’ In one day centre, only ten to twelve people attended each day. When five people left the room to attend the group, the remaining attendees essentially became a small group who also engaged in an activity run by staff. Thus it could be argued that this centre did not have a ‘no treatment’ control group comparable to that in many of the residential homes. Further, there was a possibility of ‘contamination’ between groups (which is when staff use elements of the treatment with controls), although there was no actual evidence of it. This would have been more likely in centres where activities coordinators acted as staff co-facilitators. However, in most cases staff who co-facilitated did not run any activities outside this project.

#### **8.6.4. Confounding variables**

*“With a large number of uncontrolled, extraneous variables it is impossible to isolate the one variable that is hypothesised as the cause of the other; hence the possibility always exists of alternative explanations.”* (Bowling, 1997, p.193). There was no certainty that the dependent variable was solely affected by the independent, reducing internal validity. Treatment could not be defined merely as participation in the programme, but as participation within the confines of the group. Hence people in groups which bonded well, where people became friends, shared stories and felt comfortable, were involved in a different experience to people in groups involving individuals who did not get on or want to be there. A negative reaction of one person sometimes affected the entire group’s feelings, for example one comment that the ‘using objects’ session was “childish” caused a subsequent loss of interest from the group. Additionally, medication and life events affected people’s response to treatment. To illustrate the latter, one person deteriorated rapidly in the course of the programme, from being reasonably outspoken to saying almost nothing. This behaviour coincided with her sister’s death.

#### **8.6.5. Lack of follow-up**

There is evidence that the programme was beneficial, but it is unclear whether the observed improvements lasted for any period of time, due to a lack of follow-up. The absence of follow-up assessments has been a criticism of authors in the past (Orrell and Woods, 1996), yet was beyond the scope of this thesis.

#### **8.6.6. Performance Bias / The “Hawthorne effect” (Roethlisberger and Dickson, 1939)**

The Hawthorne Effect describes the way in which participants change as a result of being treated differently. For example, their knowledge of the study might influence their behaviour, or they may act differently because someone is taking an interest in them. This effect might have been particularly pronounced in institutionalised residential homes, where people were often not treated as individuals or given much attention beyond physical care. The effects of being invited to something new, being part of a small group, and asked opinions could in itself induce change. In addition, staff might have observed and attended to treatment participants more, due to their own expectations of treatment. As mentioned in Chapter 2, “performance bias” is extremely difficult to control for in studies of this type. Unlike drug trials, in which people are usually unaware of their treatment and a placebo effect is possible, people in this study were aware of their treatment as they were active participants. This renders double-blinding impossible.

It should also be noted that participation for a few individuals might have had a negative effect. For one lady, attending groups appeared to highlight her loss of abilities, making her self-conscious and distressed.

#### **8.6.7. Undetected qualitative changes**

Participation in groups was highly interactive, and there might have been subjective changes which could not be detected through quantitative assessment measures. Although brief notes were made following sessions and summarised as a table, additional qualitative methods of analysis (such as discourse analysis) might have picked up more subjective factors, such as the effects of the group on confidence, interaction, self-esteem and happiness.

#### **8.6.8. No control for non-specific attention**

It could be argued that the results might not be due to ‘cognitive stimulation’ per se, and that increased attention and social interaction could have brought about the changes. In theory, this could have been controlled for by using an active control group which engaged in non-cognitive, social activities whilst the intervention ran. However, it is extremely difficult to define where the boundaries of cognitive stimulation lie, and to ensure that there is no overlap. Further, the scale of this project implied that resources were too limited to cater for a social activity control group. Nonetheless, it has already been demonstrated in past RO trials (e.g. Gerber et al, 1991, Wallis et al, 1983) that RO participants perform better than social controls, suggesting that changes are due to the specific effects of RO rather than the non-specific effects of attention (see Spector et al 1998a, 2000).

#### **8.6.9. Bias in outcome measures**

The results rely solely on quantitative outcome measures that might be subject to bias. For example, the MMSE and ADAS-Cog show bias in terms of education and ethnic

group. A poorly educated person with mild dementia might score similarly to a well educated person with moderate dementia on the MMSE, due to the need for literacy and numeracy to answer some questions (see 1.1.1.). The ADAS-Cog assumes English as a first language. For instance the object recognition, word recognition and word recall tasks were designed using high frequency and low frequency English words. One participant was able to name objects in Hindi but not English. Due to a lack of guidelines, this would have reduced her total score, although it may have been that she was making as many correct responses as another person who had always spoken English as their first language. Additionally, performance on memory tests is influenced by personal factors, such as motivational state and performance anxiety.

#### **8.6.10. Limitations of staff assessment**

Past authors have commented that staffs' perception of positive changes in residents may differ from that of relatives and outside professionals (Robb et al, 1986). For example, staff may primarily perceive improvements in terms of changes in personal care, whereas for professionals, gains in social behaviour and recognition of feelings may appear more important. As many of the outcome measures were completed by staff (Holden, BRS) or using staff comments (RAID, Cornell, CDR), these conflicting viewpoints could potentially confound results.

Staff often commented on individual changes in this study, including people being more talkative, engaging and sociable. However in one instance, staff complained that a lady left sessions "particularly confused, constantly asking where she was, what day it was, etc". Although one might argue that this demonstrated a positive change, such as an interest in the environment and improved communication, staff perceived this behaviour

as negative, further commenting that it might be better if she no longer came to groups. In this extreme case, the staff's clear preference towards passivity may even have been detrimental to the group work being successful.

These factors are an important consideration, as a lack of consistency in and out of the group context might prevent benefits from groups being maintained for any lasting period. It could be distressing for a person who leaves a session feeling talkative and sociable, confronted by staff with no time to interact. Although this was a one-off case, these factors should be considered when planning future groups.

#### **8.7.0. How meaningful is 'gold standard' research in this field?**

This trial, due to its size, design and methodological quality, might be considered to have reached the 'gold standard' of evidence-based research, which is classified as category 1 evidence (RCT, meta-analysis or systematic review). But actually how meaningful is it to conduct high quality RCTs in this domain? One might argue that the study does not demonstrate the process of change, and why some individuals showed dramatic improvements yet others worsened. Further, it does not explain which elements of the programme were more or less effective, and there is little evidence that the particular combination of activities used in the programme was better or worse than any other.

On the other hand, one might argue that unlike with drugs, the precise ingredients do not need to be clear, that mechanisms of change can never be fully understood, and that only suggestions can be made (see 8.5.). Further, qualitative analyses might enrich the findings, yet could never be a substitute. There are numerous qualitative studies in the area which suggest how specific treatments affect individuals, yet they cannot be used to

make broad statements concerning the effectiveness of this treatment. This large sample consisted of people from a number of different centres, hence external validity was high. Outcome measures used had been subjected to reliability and validity checks, and results can be compared specifically to those of other trials looking at different treatments. Hence this psychological treatment now uses common and standardised methodology as per other evidence-based treatments for dementia and is directly comparable to drugs. This evidence-based trial should play an important role by encouraging cognitive stimulation to be considered an important intervention in the well-being of people with dementia.

## **8.8. Future research**

### **8.8.1. Maintenance programme and follow-up**

Follow-up assessments could be conducted every 3 to 6 months for up to one year after completion of the programme, in order to investigate whether any benefits last and if so, for how long. Future research could additionally involve designing a low-key maintenance programme, with the aim of maintaining benefits from the programme. This might be designed as an RCT, using the full assessment measures. This would also allow a more detailed follow-up of a larger sample of people who attended the programme without maintenance, painting a clearer picture of the longevity of benefits.

### **8.8.2. Staff Training**

If the programme is to be further used, staff need to be trained in how to run groups in a systematic yet flexible way. As noted by Baines (1987, p.229): *“Staff who had run the group (and some other staff) were enthusiastic about the effects of the research on the home: they said that they were eager to receive more training of a similar nature.”* This

could be the focus of both future research and practice. Staff training could involve presentations and workshops, the use of videos and a detailed manual. The latter could contain information on selecting people and groups, motivating people, ways of varying the content and level of each session to suit the group's interests and abilities, and tips on dealing with common difficulties, such as domineering group members. It could be beneficial to interview staff who were involved in the trial, and incorporate feedback from them into the design of the manual. A further study could look at the effectiveness of the programme when run by care staff, trained in its use. Qualitative data examining staffs' attitudes towards the training programme could also be useful.

### **8.8.3. Qualitative analyses**

Qualitative analysis might enrich the results and pick up unidentified factors. For example, detailed fieldnotes describing every interaction in each session could be used to develop "grounded theory" (Glaser and Strauss, 1967). This refers to discovering theory from data that have been systematically gathered and analysed. By making frequent comparisons across data, theoretical propositions can be developed and modified so that they fit the data. It could be argued that by using quantitative outcome measures, we are pre-determining the variables that are likely to change (e.g. cognition, anxiety etc). Having no preconceived categories of change might shed light on alternative factors which are likely to occur as a result of the intervention.

### **8.8.4. Quality of Life**

Increasingly, quality of life is being considered a vital outcome to be measured in dementia care research (Brod et al, 1996). An extension to this current project (Thorgrimsen, 2001) is examining the effects of this programme on quality of life using

the QOL-AD (Logston et al, 1999). This involves participants self-rating aspects of their own quality of life (such as physical health and memory) as poor, fair, good or excellent. There is also a separate scale for carers. The results of this trial would be useful in evaluating how the programme affects the way that individuals feel.

#### **8.8.5. Economic analysis**

An economic analysis of the programme is required to perform cost-benefit calculations. In an extension to this project, Client Services Receipt Inventories (CSRI) were completed in conjunction with baseline and follow-up assessments, in order to assess the effect of the programme on the 'cost' of a person. The CSRI estimates the total cost of services used by participants (e.g. hospital services, day services, GP, social workers) and their medication. The outcomes of the analysis would be particularly useful if comparing the treatment to anti-dementia drugs. Further, this data could be used to examine the effects of medication and illness on people participating in the programme, and might help to explain the extreme changes observed in isolated individuals.

#### **8.8.6. Carer stress**

The effects of the programme on family carers could be investigated, as changes in cognition, depression and communication for people with dementia are likely to influence their behaviour and relationships at home. Such analyses may be more useful for day centre attendees living with home carers. Carer assessments, such as the Relatives Stress Scale (RSS, Greene et al, 1982) and the General Health Questionnaire (GHQ, Goldberg 1978) could be used in conjunction with staff and patient ratings, at baseline and follow-up. They would demonstrate how participation in the programme affected aspects for carers, such as health, sleep, confidence and social activities.

### **8.8.7. Comparison to anti-dementia drugs**

The results of this study could be compared to those of trials of the three main anti-dementia drugs, Donepezil (Aricept) and Rivastigmine (Exelon). These trials used the ADAS-Cog as the primary outcome measure. NICE guidelines (2001) looked at the available RCTs and stated that both drugs showed statistically significant improvements in cognition compared with placebo. Average improvements were about 3 points on the ADAS-Cog over a 6 month period. Table 34 compares the ADAS-Cog change of 2.86 in this trial to that of the larger drug trials. All trials ran for much longer (12 to 26 weeks), yet had similar levels of improvement to this treatment, with the exception of an improvement of 3.78 (Corey-Bloom et al, 1998) using a high dose of Rivastigmine. This was 0.92 points better than the current trial, but it involved 26 (as opposed to 7) weeks of treatment and the medication had a large number of potential side effects. Less serious side effects are common in both drugs (see table 34), and more serious side effects have also been reported. Gastrointestinal side effects are the predominant adverse events associated with both drugs. This study could also be compared to Galantamine (Reminyl) and Tetrahydroaminoacridine (Tacrine).

*Table 34: Comparison of the programme to Donepezil and Rivastigmine*

TRIAL	THERAPY	WEEKS	PARTICIP- ANTS (N)	ADAS-COG: MEAN IMPROVEMENT	SIDE EFFECTS
Spector et al, 2001	Cognitive stimulation	7	142	2.86 (p<0.05)	None
Rogers et al, 1998	Donepezil (Aricept)	24	473	2.88 (p<0.001)	Diarrhoea, nausea, vomiting, muscle cramps,
Burns et al, 1999	Donepezil (Aricept)	24	818	2.9 (p<0.001)	fatigue, insomnia twice as common with Donepezil compared to placebo
Corey-Bloom et al, 1998	Rivastigmine (Exelon)	26	699	3.78 (p<0.001)	Diarrhoea, nausea, vomiting, abdominal pain,
Rosler et al, 1999	Rivastigmine	26	725	2.58 (p<0.05)	dizziness, headache, anorexia

It would be interesting to examine the effects of combining anti-dementia drugs with the current programme, which offers advantages not found when taking drugs, such as an increase in social contact and an opportunity to express opinions and ideas. Orrell and Woods (1996, p.191) stated that *“If psychological approaches are conceptualized as encouraging the expression of the full range of abilities and skills available to the person, ultimately pharmacological and psychological approaches will be viewed as complementary.”*

#### **8.8.8. Sub-scale analyses**

Most of the assessment measures used could be broken down further in order to perform sub-scale analyses (see 6.2.0. for details of the sub-scales of each measure). For example, the RAID has eighteen questions in four sub-scales: worry, apprehension and vigilance, motor tension and autonomic hypersensitivity. Examining sub-scales individually might be useful in detecting which factors are more or less sensitive to change.

#### **8.9.0. Implications for practice**

This study has demonstrated that the programme has clear benefits for participants. It was run by researchers, relatively inexperienced in group work for people with dementia at the outset. Hence staff in residential homes and day centres should be able to run the programme independently if provided with clear guidelines and training. The team plan to produce a manual on running the programme, and run staff training workshops (see 8.8.2.). With information on how to produce or buy the equipment, sessions should be fairly self-contained and require little planning. This should allow a ‘mix and match’

approach, where staff with limited time can slot 45-minute sessions into their weekly routine.

This study resulted in change of approximately two points on the MMSE and three points on the ADAS-Cog. Critics might argue that this means little in clinical terms, making no real differences to people's lives. Yet this was a steady cognitive improvement across an extremely large sample. Although it is a blunt tool, two points on the MMSE equates to the average deterioration of over six months for someone with dementia. It might also imply that a person is more orientated or is more able to follow instructions. Additionally, staff-rated significant improvements in other domains (depression and communication) demonstrate that the programme clearly had wider implications.

It could be argued that improvements in self-care, such as finding the toilet and dressing, are what staff, carers and people with dementia themselves would prefer to see. Such changes might do more to increase the person's dignity and self-respect. Yet the inability to perform certain activities of daily living might in some cases be a result of problems in communicating needs, and this programme has demonstrated improvements in communication. Further, a reduction in depression has positive connotations for quality of life, which is increasingly being recognised as an essential consideration in any intervention for dementia (see 8.8.4.).

It might be advantageous to create environmental changes as a supplement to the programme. Hanley et al (1981) compared RO groups to ward orientation training, in which people were taught to locate different areas in the hospital. They concluded that

*“the effectiveness of the ward training analogue of 24 hour RO in improving orientation behaviour is quite dramatic, and overshadows the relatively minor improvements in verbal orientation obtained with class RO”.* (Hanley et al, 1981, p.13). This suggests that more practical, behavioural type interventions might complement RO, in bringing about behavioural, as well as cognitive change. Further changes might involve seating people in small groups, who have similar interests or abilities around coffee tables, as opposed to in long rows of seats or around the walls in large lounges. Staff could use RO boards, and encourage people to refer to them for information. Names and times of groups could feature here. Clear signposting and the effective use of colour and lighting could also have benefits (Gulak, 1991).

Benefits would be maximised if all care staff had some understanding of what the programme involved, why it was used and what its effects were likely to be. It is important for staff to be accommodating and offer some continuity outside sessions. For example, if people leave groups stimulated and with lots of questions, staff should take the time to answer them rather than leave them frustrated.

The study does not determine whether the programme would be as beneficial, or session topics as suitable or appealing to people in different countries or from different cultural groups. Further research would be required to investigate this.

#### **8.10.0. Conclusions**

This study has added insight and empirical evidence to the current knowledge base of psychological therapies for dementia. As in other more recent studies (Breuil et al, 1994), the intervention is described as ‘Cognitive Stimulation’. This is because it slightly

differs to the original, explicit (and sometimes prescriptive) RO work of the 1970's and 1980's. The programme drew on our increased understanding of memory, such as the benefits of harnessing implicit memory. Further, its design considered the effects of a negative social environment (Kitwood, 1992) and sensory deprivation in exacerbating the symptoms of dementia. Learning might have been facilitated through the natural introduction of reminiscence and multi-sensory stimulation, and by making explicit information more personally meaningful. To illustrate the latter, the focus of the RO board was the name of the group and content of sessions, with time and place orientation a secondary objective.

This study has confirmed the results of the Cochrane review (Spector et al, 1998a); that an intervention based on the fundamental principles of RO can significantly improve cognition. It also widens the knowledge base by demonstrating that other factors not previously investigated (communication and depression) can improve significantly, opening the debate as to how these factors might be interrelated. This trial has achieved high standards of methodological quality and significant improvements in cognition, both which compare very favourably with the methods and results found in major anti-dementia drug trials. Biases tended to be a result of the nature of the intervention, rather than of the design per se, such as the inability to blind participants to treatment. Disseminating these findings should be a way of demonstrating that cognitive stimulation can slow down deterioration and improve communication and depression in dementia. Future research needs to identify the most effective ways of teaching care staff to implement this programme, the possible benefits of a maintenance programme and the potential effects of combining cognitive stimulation with drug therapy.

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# Appendix A:

# Assessment Scales

# **MINI MENTAL STATE EXAMINATION (MMSE)**

Patient's Name \_\_\_\_\_ Patient# \_\_\_\_\_

Examiner's Name \_\_\_\_\_ Date: \_\_\_\_\_

Patient  
Score

Maximum  
Score

## **Orientation**

\_\_\_\_\_ 5 What is the (year) (season) (date) (day) (month)?  
\_\_\_\_\_ 5 Where are we (country) (state) (county) (city) (clinic)?

## **Registration**

\_\_\_\_\_ 3 Name three objects, allotting one second to say each one. Then ask the patient to name all three objects after you have said them. Give one point for each answer. Repeat them until he hears all three. Count trials and record number.

APPLE TABLE PENNY

Number of trials \_\_\_\_\_

## **Attention and Calculation**

\_\_\_\_\_ 5 Begin with 100 and count backward by 7 (stop after five answers): 93, 86, 79, 72, 65. Score one point for each correct answer.

## **Recall**

\_\_\_\_\_ 3 Ask the patient to repeat the objects above (See Registration). Give one point for each correct answer.

## **Language**

\_\_\_\_\_ 2 Naming: Show a pencil and a watch and ask the patient to name them.

\_\_\_\_\_ 1 Repetition: Repeat the following: "No ifs, ands, or buts."

\_\_\_\_\_ 3 Three-Stage Command: Follow the three-stage command, "Take a paper in your right hand; fold it in half; and put it on the table."

\_\_\_\_\_ 1 Reading: Read and obey the following. "Close your eyes" (show the patient the item written on reverse side).

\_\_\_\_\_ 1 Writing: Write a sentence (on reverse side).

\_\_\_\_\_ 1 Copying: Copy the design of the intersecting pentagons (on reverse side).

\_\_\_\_\_ 30 Total Score Possible

Adapted from Folstein MF, Folstein S, McHugh PR. "Mini-mental state": a practical method for grading the clinician. *J Psychiatr Res* 12: 129-136

Continued on reverse

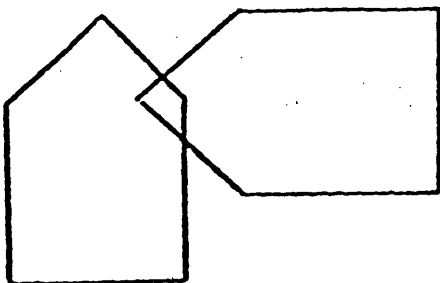
CLOSE YOUR EYES

---

WRITE A SENTENCE

---

COPY DESIGN



# ALZHEIMER'S DISEASE ASSESSMENT SCALE – COGNITION (ADAS-COG)

1. WORD RECALL TASK				WEEK 56		DATE		
						DAY	MO.	YR.
<p>The patient reads 10 high imagery words on cards exposed successively for 2 seconds each. The patient then recalls the words aloud in any order. Three trials of reading and recall are given. Place a check in the box of each word recalled correctly.</p>								
TRIAL 1		TRIAL 2		TRIAL 3				
BLOOD		FIRE		CAMP				
CAMP		TOY		PLANT				
COTTON		BLOOD		OCEAN				
FIRE		STEAM		FIRE				
HALL		COTTON		TOY				
LAD		OCEAN		STEAM				
PLANT		CAMP		BLOOD				
OCEAN		LAD		HALL				
STEAM		PLANT		COTTON				
TOY		HALL		LAD				
TOTAL CORRECT RESPONSES:		TRIAL 1 _____		TRIAL 2 _____		TRIAL 3 _____		
2. NAMING OBJECTS AND FINGERS								
<p>The patient is asked to name 12 randomly presented real objects whose frequency values are high, medium and low. The patient is also asked to name the fingers of his/her dominant hand. Standard clues may be used to assist those patients having difficulty.</p>								
<p>Place a check in the box which corresponds to each object/finger named correctly. If no objects/fingers are named correctly, check "NONE" <input type="checkbox"/>.</p>								
<p><b>OBJECT</b></p> <p><input type="checkbox"/> flower</p> <p><input type="checkbox"/> bed</p> <p><input type="checkbox"/> whistle</p> <p><input type="checkbox"/> pencil</p> <p><input type="checkbox"/> rattle</p> <p><input type="checkbox"/> mask</p> <p><input type="checkbox"/> scissors</p> <p><input type="checkbox"/> comb</p> <p><input type="checkbox"/> wallet</p> <p><input type="checkbox"/> harmonica</p> <p><input type="checkbox"/> stethoscope</p> <p><input type="checkbox"/> funnel</p>			<p><b>STANDARD CLUE</b></p> <p>grows in garden</p> <p>used for sleeping</p> <p>makes sound when blown</p> <p>used for writing</p> <p>a baby's toy</p> <p>hides your face</p> <p>cuts paper</p> <p>used on hair</p> <p>holds your money</p> <p>a musical instrument</p> <p>doctor uses it to listen to your heart</p> <p>used to fill a bottle</p>					
<p><b>FINGER</b></p> <p><input type="checkbox"/> thumb</p> <p><input type="checkbox"/> index (pointer, forefinger)</p> <p><input type="checkbox"/> middle</p> <p><input type="checkbox"/> ring</p> <p><input type="checkbox"/> pinky (little finger)</p>								

3. COMMANDS	WEEK 56	DATE		
		DAY	MO.	YR.

The patient is given 5 commands ranging from 1 to 5 steps. Each of the 5 commands may be repeated only once in its entirety. Each command is scored as a whole, and if the patient fails a single step, the response is considered incorrect. For the 3<sup>rd</sup> and 4<sup>th</sup> commands, line up on the table in front of the patient, a pencil, a watch and a card in that order, from the right to the left of the patient.

Place a check in the box which corresponds to each command performed correctly. If the patient does not perform any of the commands correctly, check "NONE" ☐.



- |  |   |
|--|---|
| <input type="checkbox"/> Make a fist   | <input type="checkbox"/> Put the watch on the other side of the pencil and turn over the card |
| <input type="checkbox"/> Point to the ceiling, then to the floor             | <input type="checkbox"/> Tap each shoulder twice with two fingers keeping your eyes shut      |
| <input type="checkbox"/> Put the pencil on top of the card, then put it back |   |

#### 4. CONSTRUCTIONAL PRAXIS

The patient's ability to copy four geometric forms is assessed. These forms, in order of presentation are:

##### FORM

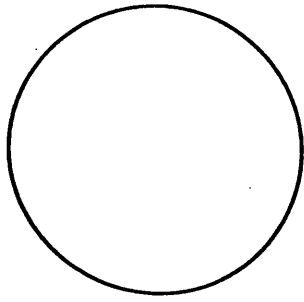
##### SCORING CRITERIA

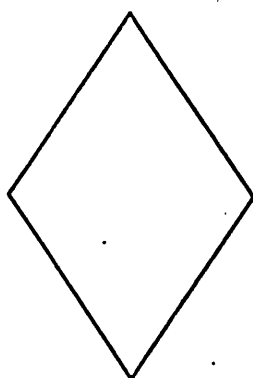
- |                               |   |  |
|-------------------------------|---|--|
| 1. Circle                     |   | A closed curved figure.  |
| 2. Two overlapping rectangles |  | Forms must be four-sided and overlap must be similar to presented form. Changes in size are not scored.                    |
| 3. Rhombus (diamond)          |   | Figure must be four-sided, correctly (obliquely) oriented, and the sides approximately equal length.                       |
| 4. Cube                       |  | The form is three-dimensional, with front face in the correct orientation, internal lines drawn correctly between corners. |

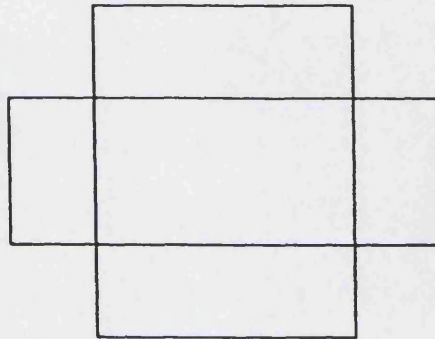
Each form is located in the upper middle of a sheet of white paper. Two attempts are permitted.

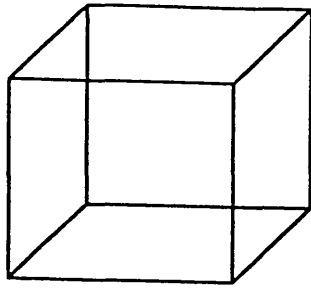
Place a check in the box which corresponds to each figure drawn correctly. If the patient makes an attempt but draws no forms correctly, place a check in the box marked "Some attempted but drew no forms correctly." If the patient scribbles or writes words but draws no forms, place a check in the box which corresponds to this action.

- |   |  |
|---|--|
| <input type="checkbox"/> Circle                     | <input type="checkbox"/> Some attempted but drew no forms correctly    |
| <input type="checkbox"/> Two overlapping rectangles | <input type="checkbox"/> Patient drew no forms; scribbled; wrote words |
| <input type="checkbox"/> Rhombus                    |  |
| <input type="checkbox"/> Cube                       |  |









## 5. IDEATIONAL PRAXIS

WEEK 56

DATE		
DAY	MO.	YR.

The patient is given an 8 1/2" x 11" (A4) sheet of paper and a long envelope. The patient is instructed to pretend to send a letter to himself or herself. If the patient forgets part of the task, or is having difficulty on one or more components, the patient can be reinstructed once for each component. Impairment on this item should reflect dysfunction in executing an overlearned task only and not recall difficulty.

Check each step completed correctly or check "NONE" ☐.

- |   |  |
|---|--|
| <input type="checkbox"/> Fold letter            | <input type="checkbox"/> Address envelope          |
| <input type="checkbox"/> Put letter in envelope | <input type="checkbox"/> Indicate where stamp goes |
| <input type="checkbox"/> Seal envelope          |  |

## 6. ORIENTATION

The components of orientation are full name, date, day of the week, name of the place, month, year, season and time of day.

Check each item answered correctly or check "NONE" ☐.

- |   |   |
|---|---|
| <input type="checkbox"/> What is your <u>surname</u> and your <u>first name</u> ? | <input type="checkbox"/> What <u>month</u> is it?                               |
| <input type="checkbox"/> What <u>date</u> is it today?                            | <input type="checkbox"/> What <u>year</u> is it?                                |
| <input type="checkbox"/> What <u>day of the week</u> is it?                       | <input type="checkbox"/> What <u>season</u> is it?                              |
| <input type="checkbox"/> Tell me the name of the <u>place</u> where we are.       | <input type="checkbox"/> Without looking at your watch, what <u>time</u> is it? |

HLR USE ONLY

## 7. WORD RECOGNITION TASK

WEEK 56

DATE

DAY MO. YR.

The patient reads aloud 12 high imagery words presented in writing successively for 2 seconds each. These words are then randomly mixed with 12 words the patient has not seen. For each of the 24 words presented, the patient must respond by saying "yes" if the word was presented previously and "no" if it was not. If the patient responds appropriately, i.e., "yes" or "no", then recall of the instructions is accurate. If the patient fails to respond, this signifies that the instructions have been forgotten. Then instruction is repeated. Each instance of failure to recall instructions is noted and summed up at the bottom of the page (for item 11).

Larger words are the original words and the patient should answer "yes" or "old"; Smaller words are new words and the patient should answer "no" or "new". Place a check in the box which corresponds to the patient's response for each word presented. The total correct for each trial is equal to the number of check marks in unshaded boxes.

TRIAL 1	YES (OLD)	NO (NEW)	TRIAL 2	YES (OLD)	NO (NEW)
RIVER			BRIDGE		
EVENT			EVENT		
QUEEN			UMBRELLA		
BROTHER			HINT		
THOUGHT			EXCUSE		
LOBSTER			DOVE		
POSITION			LOBSTER		
MISSILE			RING		
CAMP			CRITERION		
DOVE			CAUSE		
FATE			STEAK		
UMBRELLA			CORPORATION		
BELIEF			MISSILE		
GOLF			RIVER		
PERMISSION			PYRAMID		
PROXY			ASPECT		
BUSTER			PENDULUM		
CONCEPT			PROXY		
PIANIST			MOTIVE		
CRITERION			POSITION		
GENDER			BELIEF		
HINT			ELBOW		
BULLET			QUEEN		
INTELLECT			LEGALITY		
TOTAL CORRECT			TOTAL CORRECT		

HOW MANY TIMES WERE INSTRUCTIONS REPEATED? \_\_\_\_\_ (see item 11)

**8. SPOKEN LANGUAGE ABILITY**

WEEK 56

DATE

DAY MO. YR.

Language abilities are evaluated throughout the interview and on specific tests. The following items should be scored based on the patient's abilities with the preceding seven items. This item is a global rating of the quality of speech, i.e., clarity, difficulty in making oneself understood. Quantity and word finding difficulty are not rated on this item.

Place a check in the box which most closely corresponds to the patient's level of impairment in spoken language.

- |  |  |
|--|--|
| <input type="checkbox"/> 0 None: patient speaks clearly and/or is understandable | <input type="checkbox"/> 3 Moderate: patient has difficulty 25–50% of the time                 |
| <input type="checkbox"/> 1 Very mild: one instance of lack of understandability  | <input type="checkbox"/> 4 Moderately severe: patient has difficulty more than 50% of the time |
| <input type="checkbox"/> 2 Mild: Patient has difficulty <25% of the time         | <input type="checkbox"/> 5 Severe: One or two word utterances; fluent, but empty speech; mute  |

**9. COMPREHENSION OF SPOKEN LANGUAGE**

This item evaluates the patient's ability to understand speech. Do not include responses to commands (item 3)

Place a check in the box which most closely corresponds to the patient's level of impairment in comprehension of spoken language.

- |  |   |
|--|---|
| <input type="checkbox"/> 0 Normal: patient understands                           | <input type="checkbox"/> 4 Moderately severe: patient only occasionally responds correctly; i.e., yes–no questions  |
| <input type="checkbox"/> 1 Very mild: One instance of misunderstanding           | <input type="checkbox"/> 5 Severe: patient rarely responds to questions appropriately; not due to poverty of speech |
| <input type="checkbox"/> 2 Mild: 3–5 instances of misunderstanding               |   |
| <input type="checkbox"/> 3 Moderate: requires several repetitions and rephrasing |   |

**10. WORD-FINDING DIFFICULTY IN SPONTANEOUS SPEECH**

Language abilities are evaluated throughout the interview and on specific tests. The patient has difficulty in finding the desired word in spontaneous speech. The problem may be overcome by circumlocution, i.e., giving explanatory phrases or nearly satisfactory synonyms. Do not include finger and object naming in this rating (item 2).

Place a check in the box which corresponds to the patient's level of impairment in word-finding.

- |  |   |
|--|---|
| <input type="checkbox"/> 0 None  | <input type="checkbox"/> 3 Moderate: loss of words without compensation on occasion                             |
| <input type="checkbox"/> 1 Very mild: One or 2 instances, not clinically significant | <input type="checkbox"/> 4 Moderately severe: frequent loss of words without compensation                       |
| <input type="checkbox"/> 2 Mild: noticeable circumlocution or synonym substitution   | <input type="checkbox"/> 5 Severe: nearly total loss of content words; speech sounds empty; 1–2 word utterances |

**11. REMEMBERING TEST INSTRUCTIONS**

(The patient's ability to remember the requirements of the recognition task is evaluated)

**See 7. WORD RECOGNITION TASK**

HOW MANY TIMES WERE INSTRUCTIONS REPEATED?

Place a check in the box which corresponds to the patient's level of impairment with remembering test instructions.

- |  |   |
|--|---|
| <input type="checkbox"/> 0 None                                    | <input type="checkbox"/> 4 Moderately severe: must be reminded 5 or 6 times |
| <input type="checkbox"/> 1 Very mild: for got once                 | <input type="checkbox"/> 5 Severe: must be reminded 7 or more times         |
| <input type="checkbox"/> 2 Mild: must be reminded 2 times          |   |
| <input type="checkbox"/> 3 Moderate: must be reminded 3 or 4 times |   |

# **HOLDEN COMMUNICATION SCALE**

Score:	0	1	2	3	4
<b>Conversation</b>					
1. Response:	Initiates conversation, deeply involved with anyone	Good for those familiar to him/her	Fair response to those close by. No initiation of conversation	Rather confused Poor comprehension	Rarely or never converses
2. Interest in past events:	Long full account of past events	Fairly good description	Short. Description a little confused	Confused or disinterested	No response
3. Pleasure:	Shows real pleasure in situation/achievement	Smiles and shows interest	Variable response, slight smile, vague	Rarely shows even a smile	No response or just weeps
4. Humour:	Creates situation or tells funny story on own initiative	Enjoys comic situations or stories	Needs an explanation and encouragement to respond	Vague smile, simply copies others	No response or negativistic
<b>Awareness and knowledge</b>					
5. Names:	Knows most people's names on ward	Knows a few names	Needs a constant reminder	Knows own name only	Forgotten even own name
6. General orientation:	Knows day, month, weather, time and whereabouts	Can forget one or two items	Usually gets two right but tries	Vague, may guess one	Very confused
7. General knowledge:	Good on current events, generally able	Outstanding events only Fair on general knowledge	No current knowledge Poor general information	Confused about many things Gets anxious and upset	Confused about everything Does not respond
8. Ability to join in Game etc:	Joins in games and activities with ease	Requires careful instructions but joins in	Can only join in simple activities	Becomes anxious and upset	Cannot or will not join in
<b>Communication</b>					
9. Speech:	No known difficulty	Slight hesitation or odd wording	Very few words, mainly automatic phrases	Inappropriate words, odd sounds.	Little or no verbalization
10. Attempts at communication:	Communicates with ease	Tries hard to speak clearly	Tries to draw - gesticulates needs etc.	Nodding Euphoric laughter, weeping, aggressive	No attempt
11. Interest and response to objects:	Responds with interest and comment	Despite difficulties, shows interest	Shows some interest, but rather vague	Weeps, rejects objects, shows aggression	No response No comprehension
12. Success in communication:	Clearly understood	Uses gestures and sounds effectively	Understanding restricted to a few people	Becomes frustrated and angry	Makes no attempt

NAME	DATE	CDR SCALE				CDR =
	CDR 0	CDR 0.5	CDR 1	CDR 2	CDR 3	
<b>MEMORY</b>  306	No memory loss or slight inconsistent forgetfulness	Mild consistent forgetfulness; partial recollection of events;	Moderate memory loss; more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained, new memory rapidly lost	Severe memory loss; only fragments remain	
<b>ORIENTATION</b>	Fully orientated Aware of time, day, month and place	Fully orientated Aware of time, day, month and place	Some difficulty with time, day etc; oriented for familiar places and people, but not those which are unfamiliar	Usually disorientated in time, often for place	Severe disorientation except for own name	
<b>JUDGEMENT PROBLEM SOLVING DECISION MAKING</b>	Solves everyday problems well; judgement good in relation to past performance	Only doubtful impairment in solving problems	Moderate difficulty in handling complex problems	Severely impaired in handling problems	Unable to make judgements or solve problems	
<b>JOB, SHOPPING, HANDLING MONEY, PAYING BILLS</b>	Independent function at usual level in job, shopping business and financial affairs, volunteer and social groups	Only doubtful impairment or mild if any in these activities	Unable to function independently at these activities though may still be engaged in some.	Unable to function independently outside the home		
<b>HOME(COOKING, HOUSEWORK) HOBBIES, INTERESTS</b>	Normal	Only slightly impaired	Mild but definite impairment Difficult chores, and more complicated hobbies abandoned.	Simple chores preserved; very restricted interests.	No significant function in the home	
<b>PERSONAL CARE</b>	Fully capable of self care	Fully capable of self care	Needs occasional prompting	Requires assistance in dressing, washing, keeping of personal effects	Requires much help with personal care; often incontinent.	

#### SCORING

Impairment must be due to cognitive loss. Memory is the primary category in determining the CDR, the others are secondary.

If at least 3 secondary categories are given the same numerical score as memory, then CDR = M

If at least 3 secondary categories are given a greater or lesser score than memory, then CDR = score of majority of secondary categories.

If at least 3 secondary categories are scored on one side of the memory score, and two primary categories on the other, then CDR = M

M

0

JPS

JSHB

HH

CORNELL SCALE FOR DEPRESSION IN DEMENTIA		RATER'S INITIALS	DATE		
			DAY	MO.	YR.
PATIENT STATUS AT TIME OF EVALUATION (Check one) <input type="checkbox"/> 0 INPATIENT <input type="checkbox"/> 1 NURSING HOME RESIDENT <input type="checkbox"/> 2 OUTPATIENT					
SCORING SYSTEM a = UNABLE TO EVALUATE      0 = ABSENT      1 = MILD OR INTERMITTENT      2 = SEVERE					
RATINGS SHOULD BE BASED ON SYMPTOMS AND SIGNS OCCURRING DURING THE WEEK PRIOR TO INTERVIEW. NO SCORE SHOULD BE GIVEN IF SYMPTOMS RESULT FROM PHYSICAL DISABILITY OR ILLNESS.					WRITE SCORE BELOW
A.  MOOD-RELATED SIGNS	1. ANXIETY (Anxious expression, ruminations, worrying)				
	2. SADNESS (Sad expression, sad voice, tearfulness)				
	3. LACK OF REACTIVITY TO PLEASANT EVENTS				
	4. IRRITABILITY (Easily annoyed, short tempered)				
B.  BEHAVIORAL DISTURBANCE	5. AGITATION (Restlessness, handwringing, hairpulling)				
	6. RETARDATION (Slow movements, slow speech, slow reactions)				
	7. MULTIPLE PHYSICAL COMPLAINTS (Score 0 if GI symptoms only)				
	8. LOSS OF INTEREST (Less involved in usual activities) (Score only if change occurred acutely, i.e., in less than 1 month)				
C.  PHYSICAL SIGNS	9. APPETITE LOSS (Eating less than usual)				
	10. WEIGHT LOSS (Score 2 if greater than 5 lb. in 1 month)				
	11. LACK OF ENERGY (Fatigues easily, unable to sustain activities) (Score only if change occurred acutely, i.e., in less than 1 month)				
D.  CYCLIC FUNCTIONS	12. DIURNAL VARIATION OF MOOD (Symptoms worse in the morning)				
	13. DIFFICULTY FALLING ASLEEP (Later than usual for this individual)				
	14. MULTIPLE AWAKENINGS DURING SLEEP				
	15. EARLY MORNING AWAKENING (Earlier than usual for this individual)				
E.  IDEATIONAL DISTURBANCE	16. SUICIDE (Feels life is not worth living, has suicidal wishes, or makes suicide attempt)				
	17. POOR SELF-ESTEEM (Self-blame, self-depreciation, feelings of failure)				
	18. PESSIMISM (Anticipation of the worst)				
	19. MOOD-CONGRUENT DELUSIONS (Delusions of poverty, illness, or loss)				

### RATING ANXIETY IN DEMENTIA- RAID

PATIENTS NAME: \_\_\_\_\_ DOB: \_\_\_\_\_ HOSPITALNO: \_\_\_\_\_

RATER'S NAME: \_\_\_\_\_ OCCUPATION : \_\_\_\_\_ DATE: \_\_\_\_\_

Patients status at the time of evaluation:

1.In patient 2.out patient 3.Day hospital/daycentre patient 4.Other(specify).....

Scoring system:

U.Unable to evaluate 0.Absent 1.Mild or Intermittent 2.Moderate 3.severe

Rating should be based on symptoms and signs occurring during two weeks prior to the interview. No score should be given if symptoms result from physical disability or illness. SCORE

A	WORRY	1.	Worry about physical health.	
		2.	Worry about cognitive performance.(failing memory,getting lostwhen goesout,not able to follow conversation.)	
		3.	Worry over finances ,family problems,physical health of relatives.	
		4.	Worry associated with false belief and /or perception.	
		5.	Worry over trifles.(repeatedly call for attention over trivial matters)	
B	APPREHENSION & VIGILANCE.	6.	Frightened and anxious (keyed up and on the edge)	
		7.	Sensitivity to noise.(exaggerated startle response)	
		8.	Sleep disturbance.(Trouble falling or staying asleep)	
		9.	Irritability (More easily annoyed than usual,short tempered and angry outbursts.)	
C.	MOTORTENSION	10	Trembling	
		11	Motor tension (complain of headache,other bodyaches and pains)	
		12	Restlessness (Fidgeting, could not sit still,pacing, wringing hands, picking at clothes)	
		13	Fatigueability,Tiredness	
D.	AUTONOMIC HYPERSENSITIVITY.	14	Palpitations (complains of heart racing or thumping )	
		15.	Dry mouth. ( not due to medication ) sinking feeling in stomach.	
		16	Shortness of breath (even when not exerting)	
		17	Dizziness or light-headedness (complains as if going to faint )	
		18	Sweating, flushes or chills ,tingling or numbness of fingers and toes.	
E.	PHOBIAS:(Fears which are excessive ,that do not make sense and tend to avoid - like afraid of crowds, going out alone, being in a small room; or being frightened by some kind of animals, heights etc.)			
F.	PANIC ATTACKS:(Feelings of anxiety or dread that are so strong that they simply have to do something to stop them, like immediately leaving the place , phoning the relatives ,going to see a neighbour etc.)			

## CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY (CAPE)

## Behaviour Rating Scale

Name: ..... Date of birth: .....

Current address/placement: .....

Please ring the appropriate number for each item

- |  |   |   |
|--|---|---|
| 1. When bathing or dressing, he/she requires:  | — no assistance   | 0 |
|  | — some assistance   | 1 |
|  | — maximum assistance  | 2 |
| 2. With regard to walking, he/she:   | — shows no signs of weakness  | 0 |
|  | — walks slowly without aid, or uses a stick   | 1 |
|  | — is unable to walk, or if able to walk, needs frame, crutches or someone by his/her side | 2 |
| 3. He/she is incontinent of urine and/or faeces (day or night):  | — never   | 0 |
|  | — sometimes (once or twice per week)  | 1 |
|  | — frequently (3 times per week or more)   | 2 |
| 4. He/she is in bed during the day (bed does not include couch, settee, etc):  | — never   | 0 |
|  | — sometimes   | 1 |
|  | — almost always   | 2 |
| 5. He/she is confused (unable to find way around, loses possessions, etc):   | — almost never confused   | 0 |
|  | — sometimes confused  | 1 |
|  | — almost always confused  | 2 |
| 6. When left to his/her own devices, his/her appearance (clothes and/or hair) is:  | — almost never disorderly   | 0 |
|  | — sometimes disorderly  | 1 |
|  | — almost always disorderly  | 2 |
| 7. If allowed outside, he/she would:   | — never need supervision  | 0 |
|  | — sometimes need supervision  | 1 |
|  | — always need supervision   | 2 |
| 8. He/she helps out in the home/ward:  | — often helps out   | 0 |
|  | — sometimes helps out   | 1 |
|  | — never helps out   | 2 |
| 9. He/she keeps him/herself occupied in a constructive or useful activity (works, reads, plays games, has hobbies, etc): | — almost always occupied  | 0 |
|  | — sometimes occupied  | 1 |
|  | — almost never occupied   | 2 |
| 10. He/she socialises with others:   | — does establish a good relationship with others  | 0 |
|  | — has some difficulty establishing good relationships                                     | 1 |
|  | — has a great deal of difficulty establishing good relationships                          | 2 |
| 11. He/she is willing to do things suggested or asked of him/her:  | — often goes along  | 0 |
|  | — sometimes goes along  | 1 |
|  | — almost never goes along   | 2 |

12. He/she understands what you communicate to him/her (you may use speaking, writing, or gesturing):
- understands almost everything you communicate 0
  - understands some of what you communicate 1
  - understands almost nothing of what you communicate 2
13. He/she communicates in any manner (by speaking, writing or gesturing):
- well enough to make him/herself easily understood at all times 0
  - can be understood sometimes or with some difficulty 1
  - can rarely or never be understood for whatever reason 2
14. He/she is objectionable to others during the day (loud or constant talking, pilfering, soiling furniture, interfering with affairs of others):
- rarely or never 0
  - sometimes 1
  - frequently 2
15. He/she is objectionable to others during the night (loud or constant talking, pilfering, soiling furniture, interfering in affairs of others, wandering about, etc.):
- rarely or never 0
  - sometimes 1
  - frequently 2
16. He/she accuses others of doing him/her bodily harm or stealing his/her personal possessions — if you are sure the accusations are true, rate zero, otherwise rate one or two:
- never 0
  - sometimes 1
  - frequently 2
17. He/she hoards apparently meaningless items (wads of paper, string, scraps of food, etc.):
- never 0
  - sometimes 1
  - frequently 2
18. His/her sleep pattern at night is:
- almost never awake 0
  - sometimes awake 1
  - often awake 2

Eyesight:  
(tick which applies)

- can see (or can see with glasses)
- partially blind
- totally blind

Hearing:  
(tick which applies)

- no hearing difficulties, without hearing aid
- no hearing difficulties, though requires hearing aid
- has hearing difficulties which interfere with communication
- is very deaf

Rated by: ..... Date: .....

Staff/Relative

# Behavioural Assessment Scale of Later Life (BASOLL)

Self-care		Description <i>Does that mean that he/she ...?</i>	Comments & notes
1	Can he/she bathe self?	0 Has a bath without help. 1 Needs prompting to have a bath. 2 Finds bathing distressing. 3 Is unable to bath self.	Note any physical disability which makes bathing difficult.  Note whether person has used bath regularly in the past.
2	Can he/she wash self?	0 Washes self without help. 1 Washes self if prompted. 2 Needs some physical help to wash. 3 Unable to wash self at all.	
3	Can he/she dress self?	0 Dresses unaided. 1 Occasionally misses buttons. 2 Puts things on in wrong order, or misses them out, or puts on more than one of the same item. 3 Unable to dress at all.	
4	Is he/she able to keep self tidy, eg. hair, nails, face?	0 Grooms self without assistance. 1 Grooms self adequately if prompted. 2 Needs some assistance or supervision. 3 Unable to keep self tidy.	
5	Does he/she use the toilet appropriately?	0 Fully continent. 1 Accidents occur at night (or would do if client was not taken to toilet). 2 Does not use toilet appropriately during the day (or would be incontinent if not taken). 3 Doubly incontinent.	<b>CONTINENCE:</b> If not using the toilet appropriately is he/she: (a) Misidentifying other objects as toilet, eg. urinating in the sink? (b) Not being able to reach the toilet quickly enough, eg. urgency incontinence? (c) Not being able to locate the toilet? (d) Unaware of bladder being full? Is the problem faecal incontinence only?
6	Can he/she feed self?	0 Eats with knife and fork (or other appropriate utensils). 1 Eats with spoon. 2 Eats finger food, eg. sandwiches. 3 Appears unable to feed self at all.	
7	How well can he/she understand what you want him/her to do?	0 Understands without any difficulty. 1 Understands simple instructions. 2 Understands simple instructions only if much gesturing (and other non-verbal communication) used. 3 Appears to have no understanding.	Does the person have a hearing impairment?
8	How well can he/she tell you what he/she wants?	0 Uses language normally. 1 Has difficulty finding correct words for things. 2 Can express self using simple words and gestures. 3 Unable to express self through language consistently.	Is speech slurred or impaired?
9	Does he/she have enough concentration to complete simple tasks, eg. laying table?	0 Normal concentration. 1 Needs to be prompted to stay on task. 2 Needs supervision to complete. 3 Unable to concentrate at all.	Does the person get objects muddled up?
10	Can he/she keep self occupied?	0 Most of the time. 1 Has long periods of inactivity (eg. 3 hours or more during the day) on some days. 2 Has long periods of inactivity (eg. 3 hours or more) every day. 3 Unable to occupy self at all.	

Add all the scores in column 2 for items 1–10 to get the **TOTAL SELF-CARE SCORE**. Transfer score to summary sheet.

Memory & orientation		Description <i>Does that mean that he/she ...?</i>	Comments & notes
11	Does he/she relive situations from the past, eg. talking as if mother was still alive?	0 Never. 1 Has in the past. 2 Has in the past week. 3 Daily or has no coherent speech.	Does this happen at particular times of the day?
12	Does he/she keep asking the same questions over and over?	0 Never. 1 Has in the past. 2 Has in the past week. 3 Daily or has no coherent speech.	Does this happen at particular times of the day?
13	Does he/she do the same actions over and over again, eg. folding papers, picking at clothes?	0 Never. 1 Has done in the past 2 Has done in the past week. 3 Does so daily or is completely inactive.	
14	Does he/she lose or misplace things?	0 Very rarely. 1 Has occurred in the past. 2 Has occurred in the past week. 3 Does so daily or is unaware of possessions.	
15	Can he/she hold a conversation that makes sense to others?	0 Almost always. 1 Has been a problem in the past. 2 Can maintain a simple conversation. 3 Conversation is not generally possible.	
16	Does he/she forget what day of the week it is?	0 Rarely occurs. 1 Has occurred in the past. 2 Has occurred in the past week. 3 Appears not to be aware of time.	
17	Does he/she become very restless, eg. pacing around?	0 Never. 1 Has in the past. 2 Has in the past week. 3 Occurs daily.	Does this happen at particular times of the day?
18	Does he/she recognize familiar people, eg. neighbours, grandchildren?	0 Always recognizes. 1 Has <i>not</i> recognized familiar people in the past. 2 Has failed to recognize in the past week. 3 Fails to recognize daily or seems unaware of people's identity.	Does he/she recognize main carer?
19	Does he/she hide things eg. money?	0 Very rarely. 1 Has occurred in the past. 2 Has occurred in the past week. 3 Does so daily or seems unaware of possessions.	

Add all the scores in column 2 for items 11–19 to get the **TOTAL MEMORY & ORIENTATION SCORE**.  
Transfer score to summary sheet.

<b>Challenging behaviours</b>		<b>Description</b> <i>Does that mean that he/she ...?</i>	<b>Comments &amp; notes</b>
<b>20</b>	<b>Does he/she threaten to harm you or other people?</b>	0 Never. 1 Has in the past. 2 Has in the past week. 3 Daily.	Provide full description.
<b>21</b>	<b>Is he/she destructive of materials around him/her, eg. clothes, furniture?</b>	0 Never. 1 Has been in the past. 2 Has been in the past week. 3 Occurs daily.	Provide full description.
<b>22</b>	<b>Does he/she do things that could be disturbing to other people?</b>	0 Never. 1 Has done in the past. 2 Has done in the past week. 3 Occurs daily.	Provide full description, eg: removing clothes in public, losing temper, hitting, spitting, being over-familiar, injuring self, swearing, other.
<b>23</b>	<b>Does he/she do things that could be dangerous to self or others?</b>	0 Never. 1 Has done in the past. 2 Has happened in the past week. 3 Occurs daily.	Provide full description, eg: careless smoking, leaving cooking/kettle unattended, turning gas on without igniting, putting things too close to fire, inflicting self-injury, eg. biting self, leaving front door open, wandering without due regard to safety, other – please state.
<b>24</b>	<b>Does he/she withdraw from social contact?</b>	0 Never. 1 Has in the past. 2 Has in the past week. 3 Whenever possible.	

Add all the scores in column 2 for items 20–24 to get the **TOTAL CHALLENGING BEHAVIOUR SCORE**.  
Transfer score to summary sheet.

Mood	Description <i>Does that mean that he/she ...?</i>	Comments & notes
25 Does he/she wake up at night?	0 Very rarely. 1 Has done in the past. 2 Has done in the past week. 3 Wakes every night.	Bed time ..... Rising time ..... (a) Does he/she seem confused at night? (b) Does he/she have problems getting off to sleep? (c) Does he/she wake up repeatedly through the night?
26 Does he/she complain of feeling depressed?	0 Very rarely. 1 Has in the past. 2 Has in the past week. 3 Daily.	
27 Does he/she express thoughts about suicide, death?	0 Never. 1 Has in the past. 2 Has in the past week. 3 Daily.	
28 Is he/she continually 'going on' about things, eg. his/her bowels, cleanliness, checking safety measures, plugs, locks?	0 Never. 1 Has in the past. 2 Has in the past week. 3 Daily.	
29 Does he/she complain of poor appetite/inability to eat?	0 Never. 1 Has in the past. 2 Has in the past week. 3 Daily.	Does the client say why he/she cannot eat? Does the client appear to have lost weight lately?
30 Does he/she act in a suspicious or secretive manner?	0 Never. 1 Has in the past. 2 Has in the past week. 3 Daily.	Give a full description.
31 Does he/she see or hear things that are not there?	0 Never. 1 Has in the past. 2 Has in the past week. 3 Daily.	Give a full description.
32 Does he/she imagine strange things or have odd thoughts, eg. that he/she has a terminal illness?	0 Never. 1 Has in the past. 2 Has in the past week. 3 Daily.	Give a full description.
33 Does he/she think others are trying to do him/her harm or plotting against him/her?	0 Never. 1 Has in the past. 2 Has in the past week. 3 Daily.	Give a full description.

Add all the scores in column 2 for items 25–33 to get the **TOTAL MOOD SCORE**. Transfer score to summary sheet.

Sensory abilities		Description <i>Does that mean that he/she ...?</i>	Comments & notes		
34	How well can he/she see?	0 Able to see print or fine details. 1 Able to find way round without bumping into things. 2 Perceives light. 3 Totally blind.	Spectacles	YES	NO
			Registered blind	YES	NO
35	How well can he/she hear?	0 No problem. 1 Need to speak very clearly. 2 Need to shout. 3 Deaf.	Hearing aid?	YES	NO

Add the scores in column 2 for items 34 and 35 to get the **TOTAL SENSORY ABILITIES SCORE**.  
Transfer score to summary sheet.

Mobility		Description <i>Does that mean that he/she ...?</i>	Comments & notes		
36	Can he/she walk?	0 Walks unaided. 1 Ambulant with assistance of: stick, frame walker, railing, another person. 2 Sits unsupported in chair or wheelchair but cannot propel self without help. 3 Cannot sit unsupported.	Can he/she get on toilet?	YES	NO
				WITH AID	
			Can he/she rise from chair?	YES	NO
				WITH AID	
			Can he/she transfer from bed to chair?	YES	NO
				WITH AID	

Note the score in column 2 for item 36 to get the **TOTAL MOBILITY SCORE**. Transfer score to summary sheet.

**SUMMARY SHEET**

Behaviour scale	Question numbers	Score	Percentage score	Comments & notes
Self-care	<input type="text"/> 1 to <input type="text"/> 10	<input type="text"/> out of 30	score divided by 30 multiplied by 100 = <input type="text"/>	
Memory & orientation	<input type="text"/> 11 to <input type="text"/> 19	<input type="text"/> out of 27	score divided by 27 multiplied by 100 = <input type="text"/>	
Challenging behaviour	<input type="text"/> 20 to <input type="text"/> 24	<input type="text"/> out of 15	score divided by 15 multiplied by 100 = <input type="text"/>	
Mood	<input type="text"/> 25 to <input type="text"/> 33	<input type="text"/> out of 27	score divided by 27 multiplied by 100 = <input type="text"/>	
Sensory abilities	<input type="text"/> 34 to <input type="text"/> 35	<input type="text"/> out of 6	score divided by 6 multiplied by 100 = <input type="text"/>	
Mobility	<input type="text"/> 36	<input type="text"/> out of 3	score divided by 3 multiplied by 100 = <input type="text"/>	

Which are the priority needs in terms of care planning?

NUMBER	
GROUP	
DATE	

BMD

(Rated with the assistance of the interviewer who presents a card with the rating scale shown)

Please think about how often or how much (...) has done each of the following during the last two weeks, and how stressful it has been if it has occurred.

Rating scale for frequency of negative behaviour:

- 0 = never/not at all
- 1 = rarely /a little
- 2 = sometimes/moderately
- 3 = frequently/quite a lot
- 4 = always/considerably

Rating scale for stressfulness of behaviour:

- 0 = not at all
- 1 = a little
- 2 = moderately
- 3 = quite a lot
- 4 = considerably

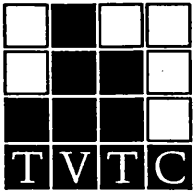
Does he/she:

- 1 - fail to take part in family conversations -----
- how stressful is it ? -----
- 2 - not read newspapers, magazines, etc. -----
- how stressful is it ? -----
- 3- sit around doing nothing -----
- how stressful is it ? -----
- 4 - not show an interest in news about friends and relatives -----
- how stressful is it ? -----
- 5 - not start and maintain a sensible conversation -----
- how stressful is it -----

- |     |   |       |
|-----|---|-------|
| 6-  | not respond sensibly when spoken to ?                 | ----- |
| -   | how stressful is it ?                                 | ----- |
| 7-  | not understand what is said to him or her             | ----- |
| -   | how stressful is it ?                                 | ----- |
| 8-  | not watch or follow television                        | ----- |
| -   | how stressful is it ?                                 | ----- |
| 9-  | not keep him/herself busy doing useful things         | ----- |
| -   | how stressful is it ?                                 | ----- |
| 10- | fails recognise familiar people                       | ----- |
| -   | how stressful is it ?                                 | ----- |
| 11- | get mixed up about where he/she is                    | ----- |
| -   | how stressful is it ?                                 | ----- |
| 12- | get mixed up about the day, year, etc                 | ----- |
| -   | how stressful is it ?                                 | ----- |
| 13- | have to be prevented from wandering outside the house | ----- |
| -   | how stressful is it ?                                 | ----- |
| 14- | hoard useless things                                  | ----- |
| -   | how stressful is it ?                                 | ----- |
| 15- | talk nonsense   | ----- |
| -   | how stressful is it ?                                 | ----- |
| 16- | appear restless and agitated                          | ----- |
| -   | how stressful is it ?                                 | ----- |
| 17- | get lost in the house                                 | ----- |
| -   | how stressful is it ?                                 | ----- |
| 18- | wander outside the house at night                     | ----- |
| -   | how stressful is it ?                                 | ----- |

- 19- endanger him/herself -----
- - how stressful is it ? -----
- 20- pace up and down wringing his/her hands -----
- how stressful is it ? -----
- 21- wander off the subject -----
- how stressful is it ? -----
- 22- talk aloud to him/herself -----
- how stressful is it ? -----
- 23- seem lost in a world of his/her own -----
- how stressful is it ? -----
- 24- have mood changes for no apparent reason -----
- how stressful is it ? -----
- 25- become irritable and easily upset -----
- how stressful is it ? -----
- 26- go on and on about certain things -----
- how stressful is it ? -----
- 27- accuse people of things -----
- how stressful is it ? -----
- 28- become angry and threatening -----
- how stressful is it ? -----
- 29- appear ~~angry~~ and depressed -----
- how stressful is it ? -----
- 30- talk all the time -----
- how stressful is it ? -----

Adapted from Greene J.G et al Age and Ageing (1982) 11.121-12



Thames Valley  
Test Company

# AMI

## The Autobiographical Memory Interview

### Scoring sheet

#### Note

Please follow the instructions provided in the Manual when using this Scoring sheet.

For all autobiographical incidents questions please refer to pages 6 and 7, and Appendix 1 of the Manual for scoring details and examples.

#### Subject's details

---

Name

Age

Date of birth

Date of test

Reason for referral

---

Question

Scoring details

Max  
score

Score

## Section A: Childhood

## Part 1: Period before school

## 1.1 Subject's address before going to school


Correct = 2  
 Street and town only = 1  
 Town or street only = 1/2

2

--

## 1.2 Names of three friends or neighbours from the period before the subject went to school


Each correct = 1  
 Each first name only = 1/2

3

--

Maximum = 5

Total

--

A1 Recall of an incident from the period before the subject went to school  
(Prompts: 'Your first memory?', 'Involving a brother or sister?')


3

--

Question	Scoring details	Max score	Score
<b>Part 2: First school (i.e. 5-11 years)</b>			
2.1 Name of first school	Correct = 1	1	
<input type="text"/>			
2.2 Location of this school	Town or city = 1	1	
<input type="text"/>			
2.3 Subject's age when starting at this school	Correct = 1	1	
<input type="text"/>			
2.4 Subject's address when starting at this school	Correct = 2 Street <i>and</i> town only = 1 Town <i>or</i> street only = 1/2	2	
<input type="text"/>			
<input type="text"/>			
2.5 Names of three teachers or friends from this school (Prompts: 'The headteacher?', 'Your form teacher?', 'A friend?')	Each correct name = 1 Each first name only = 1/2	3	
<input type="text"/>			
<input type="text"/>			
<input type="text"/>			
Maximum = 8		Total	
<hr/>			
A2 Recall of an incident occurring while at primary school (age 5-11 years) (Prompts: 'Involving a teacher?', 'Involving a friend?')		3	
<input type="text"/>			
<input type="text"/>			
<input type="text"/>			
<input type="text"/>			
<input type="text"/>			

**Part 3: Main secondary or high school (i.e. 11-18 years)**

3.1 Name of secondary (or high) school

Correct = 1

1

3.2 Location of this secondary (or high) school

Town or city = 1

1

3.3 Number and level of examinations obtained at secondary school

Correct number and  
level of qualifications = 1  
Level only = 1/2

1

*American users:* Year of graduation or year of leaving high school

Correct year = 1

3.4 Subject's address whilst attending secondary (or high) school

Correct = 2

2

Street and town only = 1  
Town or street only = 1/23.5 Names of three teachers or friends from secondary (or high) school  
(Prompts: 'The headteacher?', 'Your form teacher?', 'A friend?')  
  
Each correct name = 1  
Each first name only = 1/2

3

Maximum = 8

Total

A3 Recall of an incident while at secondary (or high) school (age 11-18 years)  
(Prompts: 'Involving a teacher?', 'Involving a friend?')  
  
  
  

3

**Childhood section summary****Personal semantic****Autobiographical incidents**

Part 1: Period before school

Maximum = 5

Maximum = 3

Part 2: First school

Maximum = 8

Maximum = 3

Part 3: Main secondary (or high) school

Maximum = 8

Maximum = 3

Maximum total = 21

Maximum total = 9

Question

Scoring details

Max  
score

Score

## Section B: Early adult life

## Part 4: Career

## 4.1 Qualification(s) obtained after leaving school


Correct recall of  
qualifications or stating  
'No qualifications' = 1  
'Don't know' or  
inaccurate response = 0

1

--

## 4.2 Either If qualification(s) obtained: name of course and educational institution

Course
Institution

Name of course = 1  
Name of institution = 1

2

--

Or If no qualifications obtained: first job

--

Correct = 1

and name of firm or organisation

--

Correct = 1

## 4.3 Subject's address while obtaining qualification(s) or in first job


Correct = 2  
Street and town only = 1  
Town or street only = 1/2

2

--

4.4 Names of three friends or colleagues from this period  
(Prompts: 'The Principal' or 'The boss?', 'The tutor' or 'Your foreman?',  
'Any class-mates' or 'Any work-mates?')


Each correct name = 1  
Each first name only = 1/2

3

--

Maximum total = 8

Total

--

## A4 Recall of an incident from college or the first job

(Prompts: 'Your first day at work or college?', 'An incident with a friend?')


3

--

Question

Scoring details

Max  
score

Score

**Part 5: Wedding****5.1 Either If married in the late teens, twenties or early thirties:**

date when subject was married

Correct = 1

2

Year only = 1/2

and place where this marriage was held

Town or city = 1

Or If not married in this time period:

name of someone else whose marriage the subject attended

Correct = 1

and place where this marriage was held

Town or city = 1

**5.2 Subject's address before this wedding**  

Correct = 2

2

Street and town only = 1

Town or street only = 1/2

**5.3 Subject's address after this wedding**  

Correct = 2

2

Street and town only = 1

Town or street only = 1/2

**5.4 Name of best-man from this wedding (or any guest)**

Correct name = 1

1

First name only = 1/2

**5.5 Name of bridesmaid from this wedding (or a guest)**

Correct name = 1

1

First name only = 1/2

**5.6 Bride's (or own) maiden name (or a guest)**

Correct name = 1

1

First name only = 1/2

Maximum total = 9

Total

**A5 Recall of an incident from this wedding**

(Prompts: 'An incident involving a guest at the wedding?', 'An incident at the reception?')

3

## Question

## Scoring details

**Part 6: Children and meeting someone new in the subject's twenties**

6.1 Name of subject's first child (or a nephew, niece or child of a close friend)

Correct = 1

1

6.2 Date of birth of this child (or age of a nephew, niece or child of a close friend)

Correct year = 1/2

1/2

6.3 Place of birth of this child

Town or city = 1/2

1/2

6.4 Name of subject's second child  
(or another nephew, niece or child of a close friend)

Correct = 1

1

6.5 Date of birth of this child (or age of a nephew, niece or child of a close friend)

Correct year = 1/2

1/2

6.6 Place of birth of this child

Town or city = 1/2

1/2

Maximum total = 4

Total

A6 Recall of a first encounter with someone while the subject was in his or her twenties  
(Prompts: 'Meeting someone in an interview?', 'Meeting someone on holiday or at work?')
  
  
  
  


3

**Early adult life section summary****Personal semantic****Autobiographical incidents**

Part 4: Career

Maximum = 8

Maximum = 3

Part 5: Wedding

Maximum = 9

Maximum = 3

Part 6: Children and meeting someone new

Maximum = 4

Maximum = 3

Maximum total = 21

Maximum total = 9

Question

Scoring details

Max  
score

Score

## Section C: Recent life

## Part 7: Present hospital or institution

7.1 Name of hospital or place where seen

Correct = 1

1

7.2 Location of this hospital or institution

Town or city = 1

1

7.3 Date of arrival at this hospital or institution

Month or year = 1

1

7.4 Subject's current address

Correct = 2

2

Street and town only = 1

Town or street only = 1/2

7.5 Names of three staff members or fellow patients from this hospital or institution (or three current neighbours or colleagues)

Each correct name = 1

3

Each first name only = 1/2

Maximum total = 8

Total

A7 Recall of an incident which has occurred at this hospital or institution  
(Prompts: 'Involving the other patients?', 'To do with the doctors or nurses?'  
or two other appropriate prompts e.g.: 'Involving the warden?', 'Involving the  
daily care staff?', 'Involving the social worker?', 'Involving the psychologist?')

3

Question

Scoring details

Max  
score

Score

**Part 8: Previous hospital or institution**

- 8.1 Name of previous hospital or institution, or name of last hospital visited  
(which must be from the last 5 years)

Correct = 1

1

- 8.2 Location of this hospital or institution

Town or city = 1

1

- 8.3 Date of arrival (or visit) at this hospital or institution

Month or year = 1

1

- 8.4 Subject's address when attending (or visiting) this hospital or institution


Correct = 2

2

Street and town only = 1

Town or street only = 1/2

- 8.5 Names of three friends, colleagues or acquaintances connected with this  
hospitalisation (or three people who have visited in the last year)


Each correct name = 1

3

Each first name only = 1/2

Maximum total = 8

Total

- A8 Recall of an incident involving a relative or visitor in the last year  
(Prompts: 'A visit by or to a relative?', 'Involving some news about a relative?')


3

**Part 9: Last Christmas or Thanksgiving**

9.1 Place where subject spent last Christmas or Thanksgiving

Correct = 1

1

9.2 Name of a person with whom subject spent last Christmas or Thanksgiving

Correct name = 1

1

First name only = 1/2

Maximum total = 2

Total

**Part 10: Holiday or journey**10.1 Place where subject visited on a holiday or a journey in the last year  
(or holiday or journey within the last 5 years)

Correct = 1

1

10.2 Month (or year) in which this holiday or journey took place

Month or year = 1

1

10.3 Name of a person with whom the subject went on this holiday or journey

Correct name = 1

1

First name only = 1/2

Maximum total = 3

Total

A9 Recall of an incident which took place while on any holiday or journey within the last 5 years  
(Prompts: 'At the place you visited?', 'Involving someone you met?')


3

**Recent life section summary****Personal semantic****Autobiographical incidents**

Part 7: Present hospital or institution

Maximum = 8

Maximum = 3

Part 8: Previous hospital or institution

Maximum = 8

Maximum = 3

Part 9: Last Christmas or Thanksgiving

Maximum = 2

Maximum = 3

Part 10: Holiday or journey

Maximum = 3

Maximum = 3

Maximum total = 21

Maximum total = 9

Total score summary	Personal semantic	Autobiographical incidents
Section A: Childhood	Maximum = 21	Maximum = 9
Section B: Early adult life	Maximum = 21	Maximum = 9
Section C: Recent life	Maximum = 21	Maximum = 9
	Maximum total = 63	Maximum total = 27

Thames Valley Test Company  
 7-9 The Green  
 Flempton  
 Bury St Edmunds  
 Suffolk  
 IP28 6EL  
 England

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 ISBN 0 9514322 5 7

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# AMIPB

## MEMORY

FORM 1

NAME \_\_\_\_\_

DATE \_\_\_\_\_

AGE \_\_\_\_\_ DOB \_\_\_\_\_

REF. NO. \_\_\_\_\_

### LIST LEARNING

	A1	A2	A3	A4	A5	A6	B
Butter	--	--	--	--	--	--	Dance -
Orange	--	--	--	--	--	--	Nail -
Ink	--	--	--	--	--	--	Monkey -
Fire	--	--	--	--	--	--	River -
Shell	--	--	--	--	--	--	Prison -
Salad	--	--	--	--	--	--	Grease -
Kitchen	--	--	--	--	--	--	Friend -
Goat	--	--	--	--	--	--	Clock -
Thunder	--	--	--	--	--	--	Cheese -
Bag	--	--	--	--	--	--	Square -
Temple	--	--	--	--	--	--	Sailor -
Needle	--	--	--	--	--	--	Pencil -
Train	--	--	--	--	--	--	Flower -
Skirt	--	--	--	--	--	--	Knife -
Hedge	--	--	--	--	--	--	Tiger -
SCORE	--	--	--	--	--	--	-

### LIST LEARNING - Form 1

	Score	%ile range
Total A1-A5	_____	_____
A6	_____	_____
B	_____	_____
Intrusions	_____	_____

### DESIGN LEARNING - Form 1

	Score	%ile range
Total A1-A5	_____	_____
A6	_____	_____
B	_____	_____
Intrusions	_____	_____

STORY RECALL - IMMEDIATE

Mrs Angela / Harper / was sitting in her bedroom / mending the curtains / when she heard a noise / coming from the kitchen / . She rushed to investigate / and found a boy / climbing out of the window / with her handbag / . She threw a vase at him / but it missed / and he ran off laughing / . She chased after him / past the shops / and into the park / but he got away / by squeezing through some railings / . On her way back home / Mrs Harper phoned / the police / . She described / the thief as quite tall / and neatly dressed / . He had a scar / on his face / but she could not remember / the colour of his hair / .

\* Score 1 if implied

Score (Max 56) \_\_\_\_\_

STORY RECALL - DELAYED

Mrs Angela / Harper / was sitting in her bedroom / mending the curtains / when she heard a noise / coming from the kitchen / . She rushed to investigate / and found a boy / climbing out of the window / with her handbag / . She threw a vase at him / but it missed / and he ran off laughing / . She chased after him / past the shops / and into the park / but he got away / by squeezing through some railings / . On her way back home / Mrs Harper phoned / the police / . She described / the thief as quite tall / and neatly dressed / . He had a scar / on his face / but she could not remember / the colour of his hair / .

\* Score 1 if implied

Score (Max 56) \_\_\_\_\_

STORY RECALL - Form 1

	Score	%ile range
Immediate (I)	_____	_____
Delayed (D)	_____	_____
Retained % (D/I)	_____	_____

FIGURE RECALL - Form 1

	Score	%	%ile range
Copy(C)	_____ *	(C/80)	_____
Immediate(I)	_____ *	(I/C)	_____
Delayed(D)	_____ *	(D/C)	_____
Retained %		(D/I)	_____

\* Max = 80

# **APPENDIX B:**

# **PUBLICATIONS**

# Reality orientation for dementia

Spector A, Orrell M, Davies S, Woods B

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This review should be cited as: Spector A, Orrell M, Davies S, Woods B. Reality orientation for dementia (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

A substantive amendment to this systematic review was last made on 25 May 2000. Cochrane reviews are regularly checked and updated if necessary.

**Background:** Reality Orientation (RO) was first described as a technique to improve the quality of life of confused elderly people, although its origins lie in an attempt to rehabilitate severely disturbed war veterans, not in geriatric work. It operates through the presentation of orientation information (eg time, place and person-related) which is thought to provide the person with a greater understanding of their surroundings, possibly resulting in an improved sense of control and self-esteem.

There has been criticism of RO in clinical practice, with some fear that it has been applied in a mechanical fashion and has been insensitive to the needs of the individual. There is also a suggestion that constant relearning of material can actually contribute to mood and self-esteem problems.

There is often little consistent application of psychological therapies in dementia services, so a systematic review of the available evidence is important in order to identify the effectiveness of the different therapies. Subsequently, guidelines for their use can be made on a sound evidence base.

**Objectives:** To assess the evidence of effectiveness for the use of Reality Orientation (RO) as a classroom-based therapy on elderly persons with dementia.

**Search strategy:** Computerised databases were searched independently by 2 reviewers entering the terms 'Reality Orientation, dementia, control, trial or study'. Relevant web sites were searched and some hand searching was conducted by the reviewer. Specialists in the field were approached for undocumented material, and all publications found were searched for additional references.

**Selection criteria:** All randomised controlled trials (RCTs), and all controlled trials with some degree of concealment, blinding or control for bias (second order evidence) of Reality Orientation as an intervention for dementia were included. The criteria for inclusion/exclusion involved systematic assessment of the quality of study design and the risk of bias, using a standard data extraction form. A measure of cognitive and/or behavioural change was needed.

**Data collection and analysis:** Data were extracted independently by both reviewers, using a previously tested data extraction form. Authors were contacted for data not provided in the papers. Psychological scales measuring cognitive and behavioural changes were examined.

**Main results:** 6 RCTs were entered in the analysis, with a total of 125 subjects (67 in experimental groups, 58 in control groups). Results were divided into 2 subsections: cognition and behaviour.

Change in cognitive and behavioural outcomes showed a significant effect in

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favour of treatment.

**Reviewers' conclusions:** There is some evidence that RO has benefits on both cognition and behaviour for dementia sufferers. Further research could examine which features of RO are particularly effective. It is unclear how far the benefits of RO extend after the end of treatment, but it appears that a continued programme may be needed to sustain potential benefits.

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## Background

Reality Orientation (RO) was first described by Folsom 1966 as a technique to improve the quality of life of confused elderly people, although its origins lie in an attempt to rehabilitate severely disturbed war veterans, not in geriatric work. It operates through the presentation of orientation information (eg time, place and person-related) which is thought to provide the person with a greater understanding of their surroundings, possibly resulting in an improved sense of control and self-esteem. Prior to this there had been little research on psychological therapies for dementia (Folsom 1966). At the time, RO was regarded by many as a major breakthrough, marking the beginnings of a psychological impact in dementia care, which had previously been seen primarily as a medical problem with medical solutions.

RO can be of a continuous 24 hour type, whereby staff orientate the patients to reality at all times, or of a 'classroom' type, where groups of elderly people meet on a regular basis to engage in orientation-related activities. A prominent focus of classroom RO is often the 'RO board', which typically displays information such as the day, date, weather, name of next meal and location.

There have been a large number of studies on classroom RO since Folsom 1966, many reporting positive findings. For example, Salter 1975 reported improvements in: "Orientation to reality and in motivation toward self care, responsibility and social involvement." Cornbleth, 1979 reported: "...gains in daily functioning and in verbal orientation, suggesting that the residents' increased orientation information became generalized to their everyday behaviour". Controlled studies have shown varied results. Hanley et al 1981, amongst others, found that classroom RO led to some improvement in cognitive function, with no effect on behaviour; whereas Baines 1987 found positive effects on behaviour.

Williams et al 87 assessed 24 hour RO on confused elderly subjects, demonstrating that experimental subjects showed significant improvement in cognitive status and ward orientation, and remained stable on behavioural measures, whereas control subjects deteriorated significantly in behavioural measures; Various studies have looked at classroom and 24 hour RO together, including Citrin 1977, who found significant positive changes in orientation.

There has been criticism of RO in clinical practice, with some fear that it has been applied in a mechanical fashion and has been insensitive to the needs of the individual (Powell-Proctor 1982). Butler & Lewis 1977 said that constant relearning of material can actually contribute to mood and self-esteem problems. RO has lost some of its popularity, but nevertheless some of its principles have been incorporated into standard clinical practice (eg RO boards.) In many settings, it has been overtaken by more popular developments such as Validation therapy (Feil 1971), which focuses on the emotional content of the conversation and behaviour of people with dementia.

There is often little consistent application of psychological interventions in dementia services, so a systematic review of the available evidence is important in order to identify the effectiveness of the different therapies. Subsequently, guidelines for their use can be made on a sound evidence base.

## Objectives

This review examines the evidence of effectiveness of classroom RO on sufferers of dementia. Subjects attended RO classes for a minimum 3-week period. The review considered whether or not classroom RO has any significant effect on cognition and behaviour.

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A secondary objective was to study the nature of the intervention in terms of frequency, mode of application, desirable outcomes and any possible adverse effects it may have.

## **Criteria for considering studies for this review**

### **Types of studies**

All RCTs were included. Any missing data were requested from the authors. One reviewer rejected all non-relevant reports from the search yields and retained any that were of possible relevance for consideration by the second reviewer. These were then selected or rejected from further consideration, independently by both reviewers, on the basis of study methodology and quality criteria designed to assess concealment, blinding and possible bias.

### **Types of participants**

Elderly people (mean age >55) diagnosed with dementia (cognitive impairment, Alzheimer's disease, organic brain syndrome, etc) according to DSM-IV, ICD-10 or comparable. It was necessary that more than 60% of the subjects completed the study.

### **Types of intervention**

Subjects attended regular meetings (at least 10 ) for a minimum period of minimum 3 weeks. These varied from 30-60 minutes, and involved the presentation, repetition and use of orientation information. There were a minimum of 4 subjects in each group.

### **Types of outcome measures**

Outcomes measured were cognition and behaviour. In some cases, trials used more than one scale to measure outcome. For example, Baines used measures of cognition, Information/Orientation and Mental Ability (both from the CAPE); and 2 measures of behaviour, Behaviour (CAPE) and Problem Behaviour (Jeffrey). For the purposes of MetaView, it was only possible to use one scale from each study. Cognitive tests were chosen using the following criteria (in decreasing order of importance):

- 1) Well recognised, published cognitive tests.
- 2) Short-term memory tests.
- 3) Orientation tests.
- 4) Information tests.
- 5) Any test of cognition using some of 2-4.

Behavioural tests were selected using the following criteria:

- 1) Well recognised, published behavioural tests.
- 2) Tests primarily measuring ADL/Behaviour.
- 3) Tests not related to cognition/emotion.

## **Search strategy for identification of studies**

See: Collaborative Review Group search strategy

The reviewers independently carried out the following searches, the results of which will be described in full in the review. The terms 'Reality Orientation, dementia, controlled study and trial' were used to search the following:

1. MEDLINE Express 1966-1997
2. PsycLIT Journal Articles 1974-1997  
PsycLIT Chapters and Books 1/87-12/97
3. EMBASE
4. Cochrane Database of Systematic Reviews
5. OMNI (Organising Medical Networked Information)
6. BIDS (Science Citation Index and Social Science Citation Index)
7. Dissertation Abstracts International: 1861-1997
8. SIGLE

Internet sites

1. Health web, including: Medweb  
Mental Health Info source  
American Psychiatric Association  
Internet Mental Health  
Mental Health Net
2. NHS Confederation

Hand searched:

1. Aging and Mental Health
2. The Gerontologist (1961-1994)
3. Journal of Gerontology (1960-1978)
4. Current Opinion in Psychiatry (1988-1997)
5. Current Research in Britain: Social Sciences(1991-1995)
6. British Psychological Society conference proceedings (Feb and Aug 1997)

Additional sources:

1. The ADS (Alzheimer's Disease Society) library.
2. Letters were published in PSIGE (Psychologists Special Interest Group for the Elderly) and the BPS (British Psychological Society) magazines, requesting information on any controlled trials which may not easily be discovered (eg. unpublished papers.)
3. Personal contact was made with various specialists in the field.

Additionally, the reference lists of all papers were searched for further references, and reviewers searched personal holdings of references to reports and trials. The searches were repeated independently by 2 reviewers, and the results are described fully.

An updated search was conducted by the Cochrane Dementia and Cognitive Impairment Group's (CDCIG) search editor in April 2000. Using the search terms Reality Orientation, Reality therapy, dementia (exploded where possible), dement\*, randomised, double, placebo and control\*, the following were searched:

AMED (Allied and Complementary Medicine Database): 1985-1999 (08); British Nursing Index Sept 1999; RCN Journals Database 1985-1996; Embase: 1989-2000 (02); Medline 1966-2000 (04); Cinahl 1982-2000 (01); PsychLit 1887-2000 (02); SIGLE 1980-1999 (06); and the CDCIG specialised register. Additionally, the Web was searched using Copernic.

## Methods of the review

Two reviewers independently considered the studies selected against explicit criteria for inclusion in the meta analysis.

Selection of trials:

Forty three publications were identified through the literature search. Where possible, abstracts were read before obtaining papers, but in many cases, decisions as to whether to obtain the paper were based on the title. A reviewer and co-reviewer independently assessed eligibility. Twenty two publications were immediately disregarded; 4 were not trials, 5 examined non-dementia populations, 4 were case studies, 2 were observational studies and 7 were uncontrolled. The remaining 21 trials were all controlled. Six had no mention of randomisation, 6 were clearly not randomised (eg subjects were "selected" or "chosen") and 2 looked at 24 hour RO only. For the 6 unclear trials, authors were contacted and asked if subjects had been randomly assigned to groups. One author (Ferrario) wrote back saying that his trial was randomised. The 7 remaining controlled trials all included the term(s) "randomised", "randomly assigned" or similar. It was decided that this was acceptable for inclusion into the review. Therefore, 8 RCTs were included.

Data extraction:

Descriptive characteristics (such as quality of randomisation and blinding) and study results were extracted by 2 independent reviewers using a standard data extraction form.

Disagreements were resolved by discussion. One reviewer is highly experienced in dementia care from both a clinical and academic viewpoint.

Additionally, letters/e-mails were sent to all authors of controlled trials asking for essential information (statistics and/or details of randomisation).

The 2 reviewers independently pooled data across studies, where possible, and analyses of the data was carried out with appropriate statistical models.

## **Description of studies**

The included studies varied in patient characteristics, length of individual RO sessions, number of sessions and duration, activities which defined Reality Orientation, the activity of the control group and outcome measures. These factors will be considered in turn:

### **1) Patient Characteristics:**

Baines 1987: "Moderate-to-severe impairment of cognitive functioning." No details of further illnesses/medication.

Baldelli, 1993: "Alzheimers (SDAT) ". No detail of further illnesses/medication of included subjects, but subjects with "general deterioration" were excluded.

Breuil 1994: "Diagnosis of dementia established by DSM-III." More stringent exclusion criteria (eg. subjects excluded with aphasia, agnosia and personality disorders.) Details of drugs authorized: included anti-depressants, thyroid replacement and sedatives.

Ferrario, 1991: "Institutionalised elderly patients with cognitive disturbances." No subjects were on pharmacological treatment which affected cognitive functions, and none had anemia, severe metabolic and/or cardiorespiratory failure.

Gerber 1991: "Diagnosis according to DSM-III criteria for primary degenerative dementia, nearly all cases associated with Alzheimer's disease." Patients received psychoactive medications as part of their regular treatment.

Hanley 1981: "Mild-grave dementia score on the Koskela test." No details of further illnesses / medication.

Wallis 1983: "Long-stay and demented or withdrawn or both, regardless of the diagnosis." No details of further illnesses / medication.

Woods 1979: "Memory quotient of 70 or less on the Weschler Memory Scale and reported as disorientated." No details of further illnesses/medication.

All subjects were residential patients, apart from in Breuil 1994, whose participants were outpatients.

### **2) Length, number and duration of sessions:**

Baines 1987: 30 minutes, 5 times a week, for 4 weeks.

Baldelli, 1993: 60 minutes, 3 times a week for 3 months.

Breuil 1994: 60 minutes, 2 times a week, for 5 weeks.

Ferrario, 1991: 60 minutes, 5 times a week, for 21 weeks.

Gerber 1991: 60 minutes, 4 times a week, for 10 weeks.

Hanley 1981: 30 minutes, 4 times a week, for 12 weeks.

Wallis 1983: 30 minutes, 5 times a week, for 3 months.

Woods 1979: 30 minutes, 5 times a week, for 20 weeks.

### **3) Activities During Reality Orientation:**

Baines 1987: RO board (day, weather, photographs, newspapers etc), materials to stimulate all five senses.

Baldelli, 1993: No details given.

Breuil 1994: Drawing, associated words, object naming and categorising.

Ferrario, 1991: No details given.

Gerber 1991: RO board, exercises, food preparation, orientation discussions.

Hanley 1981: RO board, clocks, calendars, maps, posters.

Wallis 1983: RO board, repetition of orientation information.

Woods 1979: RO board, orientation discussions, demonstrations.

Note: None of the included trials adopted 24 hour RO in addition to classroom sessions.

#### 4) Control group(s) activities:

Baines 1987: Reminiscence therapy or no treatment.

Baldelli, 1993: No treatment.

Breuil 1994: No treatment ("non-stimulated".)

Ferrario, 1991: No treatment.

Gerber 1991: Social interaction or regular hospital care.

Hanley 1981: No treatment.

Wallis 1983: "Diversional Occupational Therapy": patients given a choice of a variety of group and individual activities. Visual RO material was left on the walls, but orientation was only mentioned if it occurred in normal conversations.

Woods 1979: "Social Therapy": various non RO group activities.

#### 5) Outcome measures:

Cognitive tests were used in all the studies. The cognitive subscale of the Global Dementia Scale (Gerber 1991) had to be obtained directly from the author. Wallis 1983, Ferrario, 1991, Baldelli, 1993, Hanley 1981 and Baines 1987 used behavioural scales.

### Methodological quality

#### 1) Selection Bias: Randomisation Concealment

Only Wallis described the method of randomisation (drawing from a hat and consecutive allocation) in the original paper. Details of randomisation were requested from the authors. Gerber 1991 stated that subjects were assigned randomly by generating 2 random number tables and assigning consecutive men and women to 3 groups according to the table. Woods 1979 said that drawing from a hat was used. Ferrario, 1991, Hanley 1981 and Baldelli, 1993 did not mention randomization in the paper, but in responding to written requests for further information, stated that their trials were randomised (with no detail of the methods used). In view of the lack of information on methods of randomisation, we did not assign a formal quality score to the studies.

#### 2) Performance bias:

With psychological interventions, unlike drug trials, it is impossible to totally blind patients and staff to treatment. Patients will often be aware that they are being treated preferentially, staff involved may have different expectations of treatment groups, and independent assessors may be given clues from patients during the assessments. There may also be 'contamination' between groups, in terms of groups not being held in separate rooms and staff bringing ideas from one group to another. The latter effect would be reduced with clear therapeutic protocols, the existence of which was not mentioned in any of the studies, although in a personal correspondence, Woods 1979 stated that "Checks were made to ensure compliance with the therapeutic protocol".

Most of the studies did not provide ample information to draw conclusions about contamination and blinding. Wallis 1983 and Baines 1987 both stated that the staff were unaware of the allocation of patients to groups, as they were removed from the setting for treatment. There is no evidence of blinding in the other studies. Whether the patients were blind to treatment is a controversial issue, depending on how much information was given to them, and their level of comprehension.

Baines 1987, Ferrario, 1991, Wallis 1983, Woods 1979 and Hanley 1981 said that the RO groups were held in separate areas, reducing the chance of contamination. Information regarding where groups were held was not provided in the other studies.

#### 3) Attrition bias

Baines 1987: 0 dropouts (/15).

Baldelli, 1993 0 dropouts (/23).

Breuil 1994: 5 dropouts (/61). (3 RO, 2 controls). "All those who for any reason did not attend all evaluation and training sessions were eliminated". No further information.

Ferrario, 1991: 2 dropouts (/21). 1 in each group (pneumonia and stroke). This information was provided in a letter received from the author, not in the original paper.

Gerber 1991: 5 dropouts (/24). RO group: 1 died, 2 discharged to nursing homes. Social interaction: 1 died. Control group: 1 died.

Hanley 1981: 1 dropout (/58), due to being transferred.

Wallis 1983: 22 dropouts (/60). Death (6), physical illness (8), refusal (5), could never be found (2) and visitors every day (1). Patients eliminated had less than 20% attendance. No detail of which group they were in.

Woods 1979: 4 dropouts (/18). 1 in each group died, 1 man in control group refused assessment.

#### 4) Detection bias

Baines 1987: Assessments were made by an independent psychologist, and staff who knew the residents well but were not involved with the therapy groups.

Baldelli, 1993: No details given of who assessors were.

Breuil 1994: Neuropsychological tests were administered by a neuropsychology technician who was unaware of group membership.

Ferrario, 1991: No details given of who assessors were.

Gerber 1991: Assessments made by an independent examiner who was blind to group membership.

Hanley 1981: Assessments made by raters who were blind in 1 test, partially blind in 1 test and not blind in another.

Wallis 1983: Assessments made by senior nurse and OTs: none knew which group patients were in.

Woods 1979: Outcomes pooled results from various tests. Crichton rating scale independently conducted by 2 staff members, not participating and unaware of group membership. Cognitive assessment carried out by psychologists (some blind to group membership, others not.) Staff unaware of experimental hypothesis and were given the expectation that both RO and social therapy would be effective.

## Results

Results are presented in 3 separate tables.

Out of the 8 included studies, 6 were entered into MetaView. The other 2 studies did not include published data needed for the analysis; authors were contacted with no response. From these 6 RCTs there was a total of 125 subjects (67 in experimental groups, 58 in control groups). Analyses were adjusted to the random effects model, due to the heterogeneity of trials, and standardised mean differences (SMD), because trials used different tests to measure the same outcomes. Results were presented under 2 headings: cognition and behavior.

The results in the cognition section were significant in favour of treatment. The standardised mean difference (SMD) was -0.586, with a 95% Confidence Interval (CI) (-0.952, -0.220). All studies contained cognitive measures, therefore a total of 125 subjects were included. Results were weighted by Breuil 1994, the largest study. Their results were significant in favour of treatment, with an SMD of -0.714, 95% CI (-1.256, -0.172).

The results of the other 5 studies were insignificant, but for all, the trend was in the direction of favouring treatment (hence a negative value for the SMD). For Woods 1979, the SMD was -0.664, 95% CI (-2.041, 0.713); for Baines 1987 the SMD was -0.812, 95% CI (-1.426, 1.061); for Ferrario, 1991, the SMD was -0.962, 95% CI (-1.989, 0.064); for Gerber 1991 the SMD was -0.758, 95% CI (-1.963, 0.448); and for Wallis 1983 the SMD was -0.025, 95% CI (-0.925, 0.876). Results were pooled for Baines 1987 and Ferrario, 1991 Information/Orientation tests; other authors used different measures of cognition.

The total behavioural result was significant in favour of treatment, with an SMD of -0.659, 95% CI (-1.268, -0.050). Only 3 of the studies used behavioural outcome measures (Baines 1987, Ferrario, 1991 and Wallis 1983), with a total of 48 subjects (28 experimental, 20 control). All 3 had insignificant results, but the trend was in favour of treatment (negative values). Wallis

1983 was weighted at 44.4%; the SMD was -0.451, 95% CI (-1.366, 0.464). Ferrario, 1991 was weighted at 37.9%, SMD -0.591, 95% CI (-1.581, 0.399). Baines 1987 was weighted at 17.7%, SMD -1.324, 95% CI (-2.770, 0.123). The behavioural measures in the 3 studies were all different.

## Summary of analyses

### MetaView: Tables and Figures

## Discussion

Six RCTs with a total of 125 subjects met the inclusion criteria for the MetaView. Results showed that RO had a significant positive effect on cognition and behaviour. Results from cognition were more precise, due to a sample size of 125, compared to 48 for behaviour.

Trials varied greatly in factors such as length of intervention, methodological quality and outcome measures. It is interesting to briefly examine how such non-specific variables may, if at all, affect outcome. When looking at amount of intervention and the cognition analysis, we can see that Ferrario, 1991, who gave subjects significantly more RO than any of the other trials (6300 minutes in total), had the highest SMD (-0.962) in favour of treatment compared to the other trials (although results were not significant). Yet the results do not show a relationship between amount of intervention and cognitive outcome. In fact, Breuil 1994, who only gave subjects 600 minutes of RO in total (the least amount of all 6), had more significant positive results in favour of RO than all the other trials. Similarly, the results did not show a relationship between amount of intervention and behavioural outcome, or a pattern between length of sessions and outcomes.

There was some variation in the alternative activities offered to control groups, for instance Ferrario, 1991, Breuil 1994 and Baines 1987 gave no treatment to control groups, whereas Gerber 1991, Wallis 1983 and Woods 1979 provided control groups with some alternative 'social' therapy. Results showed no relationship between control group activity and outcome, suggesting that the actual qualities of RO, rather than merely the therapeutic effect of social contact and attention, may affect individual outcomes. However, staff may have had greater expectations from the RO group, which may have affected performance.

Results suggest positive effects of RO on both cognition and behaviour, with all studies showing preference to treatment over control. However, it is difficult to deduce which aspects of RO may be beneficial. Trials varied in the length, duration and content of sessions, yet the results do not provide any insight into the ideal amount/quality of input, and so on. Additionally, the entire concept of assessing the success of any psychological therapy can be highly problematic, as it is not possible to account for variables such as the therapeutic alliance between patients and therapists, and the sensitivity with which the therapy is given. It is difficult to assess the more subjective aspects of RO just by reading a written account, yet it may be these very variations which produced variations in results.

### Strength of Evidence

The search for reports was comprehensive. Experts in the field from the UK, USA and Australia were contacted, so it is hoped that few, if any, trials were missed. The quality of the included trials appears adequate. All trials were randomised, with details of randomisation procedures for half of them. The majority of assessors were blind to treatment groups. The observed effects were generally not large, but there was consistency across studies in that trends were in the same direction.

There are no reported side-effects of RO. There were 38 dropouts in the 6 studies with available data. 22 were in Wallis 1983, and no details were provided concerning which groups they were in. Of the remaining 16, there are details of 8 experimental subjects and 6 controls. Of these, it is clear that 3 experimental subjects and 3 controls died; others, for example, went to hospital or were discharged. Hence there is no evidence in this study that RO has a significant effect on death and/or illness.

Gerber 1991 found that RO subjects actually performed worse at a 10-week follow-up than prior to treatment, concluding that benefits gained from RO were lost. Conversely, Wallis 1983

found that subjects gained higher scores in both cognitive and behavioural tests 1 month post-intervention. Hence this study provides no clear evidence of long term benefits of RO.

## **Reviewers' conclusions**

### **Implications for practice**

This review found that classroom RO had clear benefits to dementia sufferers in both cognitive and behavioural domains, suggesting that RO techniques should be considered as part of a more general dementia care programme. There is no evidence here of long term benefits of RO, although Wallis 1983 shows that within the 1st month some skills can be retained. This suggests that for RO to have more lasting effects, there should be a detailed schedule of reinforcement and follow-up, with a continuous, ongoing program, such as using RO boards and signs when a person is disorientated and distressed. Perhaps the introduction of a 24 hour RO programme might be a good way to retain what has been learned if the continuation of classroom RO is not practical.

In summary, there is good evidence for the benefits to RO, but these may only be short-lived and should be incorporated into a more long term programme. The main danger of RO is of it being applied in a mechanical, rigid way (Powell-Proctor 1982).

### **Implications for research**

There is a clear need for more double-blind, RCTs of Reality Orientation, particularly multicentre RCTs. RCTs may be particularly valuable if used in conjunction with more qualitative studies, such as case studies. These may offer a greater insight into the better features of RO, the more successful ways in which it may be applied and the types of people most suited; yet are limited by factors such as lack of controls and subjective assessment. As with all psychological interventions, the success of RO may be dependent on it being used at the appropriate time, by a sensitive and experienced practitioner, to a receptive patient.

What seems necessary is research examining which features of RO have greater or lesser benefits, and in what circumstances, for example looking at different duration and /or severity of dementia or different group sizes. Additionally, there appears to be a need for more research examining:

- i) 24 hour versus classroom RO (and how they may compliment each other).
- ii) Other outcomes, such as quality of life.
- iii) More individualised treatment approaches. What may be needed is more detailed assessments of everyday memory skills and their remediation in individual programmes, rather than the 'mass teaching' of generic orientation skills.
- iv) RO in residential homes versus day centres.

## **GLOSSARY**

**Agnosia:** a condition in which a person is unable to consciously recognise the meaning of objects.

**Aphasia:** a condition involving the partial or complete loss of language ability.

**ADL:** activities of daily living, such as dressing and eating.

**Behavioural:** pertaining to behaviour.

**Blinding:** concealing the assignment of people to experimental and control groups.

**Cognition:** mental behaviours, such as thinking and reasoning.

**Control group:** the group in the research which is not exposed to the intervention.

**Double-blind:** a situation in which neither the person being assessed nor the person doing the assessment is aware of group membership.

**DSM IV:** Diagnostic and Statistical Manual (number IV). The official system for classification of psychological and psychiatric disorders, prepared by the American Psychiatric Association.

**Experimental:** the group in the research which is exposed to the intervention.

**Heterogeneity:** groups, data (etc) which show marked dissimilarity.

**ICD10:** International Classification of Diseases (number 10). A system of classification of diseases developed by the World Health Organisation.

**Meta-analysis:** the statistical process of combining data from different studies.

**Protocol:** the original plan of an experiment.

**Therapeutic alliance:** the relationship developed between patient and therapist during therapy.

**RCT (randomised controlled trial):** trial in which people are randomly allocated to a control group and one or more intervention groups.

## **Acknowledgements**

We would also like to thank the following contributors for their help: Peter Smith, Sue O'Kell, Dr. Mike Bender, Prof Peter Coleman, Lindsay Royan, Claire Morris and Rachelle Doody, Dr. Gary Gerber, David Dickinson, Faith Gibson, Tessa Perrin, Harold Zepelin, Ermano Ferrario, Dr Clarke Harris, and Dr Ronald Toseland.

## **Potential conflict of interest**

None

## **Characteristics of included studies**

Table: Characteristics of included studies

## **Characteristics of excluded studies**

### **Study : Citrin 1977**

No randomisation.

### **Study : Coen-Mieli D 1991**

No evidence of randomisation.

### **Study : Goldstein 1982**

Not all subjects had Dementia.

### **Study : Harris 1976**

No evidence of randomisation.

### **Study : Hogstel 1979**

Subjects may not have dementia.

### **Study : Johnson 1981**

No randomisation.

### **Study : Reeve 1985**

No randomisation.

### **Study : Zanetti 1995**

Non-randomised.

### **Study : Zepelin 1977**

No evidence of randomisation.

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\* indicates the major publication for the study

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### **Coversheet**

#### **Title**

Reality orientation for dementia

#### **Reviewer(s)**

Spector A, Orrell M, Davies S, Woods B

#### **Contribution of Reviewer(s)**

Martin Orrell and first named reviewer (Aimee Spector) extracted data, assessed methodological quality of studies and developed inclusion/exclusion criteria.

Aimee Spector wrote the body of the text, which was edited by Martin Orrell, Steve Davies and Bob Woods.

**Issue protocol first published:** 1998 Issue 2

**Issue review first published:** 1998 Issue 3

**Date of most recent amendment:** 06 September 2000

**Date of most recent substantive amendment:** 25 May 2000

**Most recent changes:** 23rd May 2000

Synopsis and glossary added

**Date new studies sought but none found:** Information not supplied by reviewer

**Date new studies found but not yet included/excluded:** Information not supplied by reviewer

**Date new studies found and included/excluded:** Information not supplied by reviewer

**Date reviewers' conclusions section amended:** Information not supplied by reviewer

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**Extramural sources of support to the review**

- North Thames NHS Executive UK

**Intramural sources of support to the review**

- University College London UK

**Synopsis**

This review examines the effectiveness of classroom Reality Orientation (RO) for people with dementia. RO involves the repetition and use of information related to the present time, place and person; in a regular group setting. RO aims to help people with dementia become more orientated and aware of their surroundings. After searching the literature, six suitable randomised controlled trials looking at RO for dementia were found. Data from these were combined to obtain an overall result using a larger sample size. This result showed that cognition (memory and orientation) and behaviour of people attending RO sessions improved significantly more than those whom had received either no treatment or a social intervention. However, it is not known whether the positive effects of RO continue after the RO programme has finished. It may be worthwhile for it to be part of an ongoing programme. RO requires brief training, and is fairly good in terms of time and resources. It is important that RO is used in a sensitive, personal manner to people who want to be orientated to reality, and not applied in a rigid and insensitive way.

**Keywords**

Aged; Behavior Therapy/methods; Cognition Disorders/therapy;  
Dementia/psychology/\*therapy; Human; Middle Age; \*Orientation; Psychotherapy, Group;

# Reminiscence therapy for dementia

Spector A, Orrell M, Davies S, Woods RT

This review should be cited as: Spector A, Orrell M, Davies S, Woods RT. Reminiscence therapy for dementia (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

A substantive amendment to this systematic review was last made on 25 May 2000. Cochrane reviews are regularly checked and updated if necessary.

**Background:** Reminiscence Therapy (RT) has been defined as vocal or silent recall of events in a person's life, either alone, or with another person or group of people. It typically involves group meetings, at least once a week, in which participants are encouraged to talk about past events, often assisted by aids such as photos, music, objects and videos of the past.

There is, often, little consistent application of psychological therapies in dementia services. A number of these 'therapies' were greeted with enthusiasm by health care practitioners in under stimulating care environments. They were expected to work miracles and their 'failure' to do this has led to their widespread disuse. A systematic review of the available evidence is important in order to identify the effectiveness of the different therapies. Subsequently, guidelines for their use can be made on a sound evidence base.

**Objectives:** RT involves groups of elderly people talking of past events, assisted by aids such as videos, pictures and archives, as a means of communicating and reflecting upon their life experiences. The objective of the review is to assess the effects of RT for dementia.

**Search strategy:** We searched the Cochrane Controlled Trials Register, MEDLINE, PSYCHLIT, EMBASE, OMNI, BIDS, Dissertation Abstracts International, SIGLE and reference lists of relevant articles up to 1998, and we contacted specialists in the field. We also searched relevant Internet sites and we hand searched Aging and Mental Health, the Gerontologist, Journal of Gerontology, Current Opinion in Psychiatry, Current Research in Britain: Social Sciences, British Psychological Society conference proceedings and Reminiscence database.

**Selection criteria:** Randomised controlled trials and quasi-randomised trials of RT for dementia in elderly people.

**Data collection and analysis:** Two reviewers independently extracted data and assessed trial quality.

**Main results:** Two trials are included in the review, but only one trial with 15 participants had extractable data. The results were statistically non-significant for both cognition and behaviour.

**Reviewers' conclusions:** No firm conclusions could be reached regarding the effectiveness of RT for dementia. The review highlighted the urgent need for more systematic research in the area.

## Background

RT stems from Butler 1963's early work on "Life Review". He described this as a naturally

occurring mental process in which past experiences and unresolved conflicts are brought into consciousness. Originally a psychoanalytic concept, RT was used by practitioners as a component of occupational nursing in long-stay institutions for older people. It aims to help elderly people to put their experiences into perspective and prepare for death.

Because remote memory is usually the last to deteriorate, it was intended that reminiscence could be an effective means of communication for memory-impaired people, focusing on an ability which often remains comparatively intact until later in the disease process. Hence, the process of reminiscence was developed as a therapeutic technique, RT, defined by Woods 1992 as "vocal or silent recall of events in a person's life, either alone or with another person or group of people". The work usually involves group meetings, at least once a week, in which participants are encouraged to talk about past events, often assisted by aids such as photographs, music, archive recordings and videos. Ebersole 1978 identified some of the therapeutic factors of RT as cohort identification, socialisation, inter-generational sharing, memory stimulation and self-actualisation.

The early 1970s was a time when health care practitioners were becoming increasingly aware of the potentially invaluable input of psychologists in the field of dementia care, and in the broader field of geriatrics. At this time, the main alternative to RT was Reality Orientation, first described by Folsom 1966 as the presentation and relearning of orientation information, aiming to improve sense of control and self-esteem.

Research has been conducted on the effects of RT with non-dementia populations, but the first study conducted on older people with dementia was by Kiernat 1979. Although this was an uncontrolled study using subjective assessment, Kiernat 1979 concluded that "Conversation can be stimulated, interest can be sparked and attention span can be increased."

Most importantly, he introduced the idea of using RT on people with dementia, whereas previously, many had believed that people must have a certain degree of memory and comprehension to benefit from it. Since 1979, there have been various studies on RT with dementia populations (including Lesser 1981, Cook 1984). However, only three randomised controlled trials appear to have been conducted (Baines 1987, Goldwasser 1987, Orten 1989), and discussed later.

There is often little consistent application of psychological therapies in dementia services. A number of these 'therapies' were greeted with enthusiasm by health care practitioners in understimulating care environments. They were expected to work miracles and their 'failure' to do this has led to their widespread disuse. A systematic review of the available evidence is important in order to identify the effectiveness of the different therapies. Subsequently, guidelines for their use can be made on a sound evidence base.

## **Objectives**

This review considers the effects of RT (RT) on people with dementia. For trial to be included, clients must have attended RT sessions for a minimum 4-week period. The review examines whether or not RT has any significant effect on cognition and behaviour.

## **Criteria for considering studies for this review**

### **Types of studies**

All RCTs which considered RT as an intervention for dementia were included in the review. Because this only resulted in 2 trials, controlled trials with no randomisation were to be considered, but none was found. Both reviewers (AS & MO) independently assessed the retrieved trials and any disagreement on inclusion/exclusion was resolved by discussion.

### **Types of participants**

Older people (mean age >55) diagnosed with dementia, cognitive impairment, Alzheimer's disease, organic brain syndrome, etc, according to DSM-IV, ICD-10 or comparable. Only trials in which more than 60% of the subjects completed the study are included.

### **Types of intervention**

Regular meetings of small groups (of at least 4 people), which involve the process of reminiscing, possibly aided by means such as photographs, music and videos of the past. They are attended for a minimum 4-week period (minimum 8 sessions over a maximum of 12 months).

### **Types of outcome measures**

Outcomes recorded were cognition and behaviour. Baines 1987 used 2 cognitive measures, Information/Orientation and Mental Ability (both from the CAPE (Pattie 1979); and 2 behavioural measures, Behaviour (CAPE) and Problem Behaviour (Jeffery 1981). For statistical analysis in MetaView, it was only possible to use one scale for each measure. The cognitive test was chosen using the following criteria (in decreasing order of importance):

- 1) Well recognised, published cognitive tests.
- 2) Short-term memory tests.
- 3) Orientation tests.
- 4) Information tests.
- 5) Any test of cognition using some of 2-4.

The behavioural test was selected using the following criteria:

- 1) Well recognised, published behavioural tests.
- 2) Tests primarily measuring ADL/Behaviour.
- 3) Tests not related to cognition/emotion.

### **Search strategy for identification of studies**

See: Collaborative Review Group search strategy

The terms 'RT', 'dementia', 'control' and 'trial or study' were used to search the following:

1. MEDLINE Express 1966-1997
2. PsycLIT Journal Articles 1974-1997  
PsycLIT Chapters and Books 1/87-12/97
3. EMBASE
4. Cochrane Database of Systematic Reviews
5. OMNI (Organising Medical Networked Information)
6. BIDS (Science Citation Index and Social Science Citation Index)
7. Dissertation Abstracts International: 1861-1997
8. SIGLE

#### **Internet sites**

1. Healthweb, including: Medweb  
Mental Health Infosource  
American Psychiatric Association  
Internet Mental Health  
Mental Health Net
2. NHS Confederation

#### **Hand searched:**

1. Aging and Mental Health
2. The Gerontologist (1961-1994)
3. Journal of Gerontology (1960-1978)
4. Current Opinion in Psychiatry (1988-1997)
5. Current Research in Britain: Social Sciences (1991-1995)
6. British Psychological Society conference proceedings (Feb and Aug 1997)
7. Reminiscence database (Collated by M.Bender, 1995)

#### **Additional sources:**

1. The ADS (Alzheimer's Disease Society) library
2. Letters were published in PS IGE (Psychologists Special Interest Group for the Elderly) and

the BP (British Psychological Society) magazines, requesting information on any controlled trials which may not easily be discovered (eg. unpublished papers.)

3. Personal contact was made with various specialists in the field.

Additionally, reference lists of all papers were searched for further references, and reviewers searched personal holdings of references to reports and trials. The searches were repeated independently by 2 reviewers.

An updated search was conducted by the Cochrane Dementia and Cognitive Impairment Group's (CDCIG) search editor in April 2000. Using the search terms reminiscence, dementia (exploded where possible), dement\*, alzheimer\*, randomised, double, single and control\*, the following were searched:

Embase: 1980-2000 (02); Medline 1966-2000 (04); Cinahl 1982-2000 (01); PsychLit 1887-2000 (02); SIGLE 1980-1999 (06), OMNI and the CDCIG specialised register.

## Methods of the review

Two reviewers (AS & MO) independently considered the studies selected against explicit criteria for inclusion in the meta analysis.

### SELECTION OF TRIALS

Fifteen publications were identified through the literature searches. Where possible, abstracts were read before obtaining papers, but in many cases, decisions as to whether or not to obtain the paper were based on the title. A reviewer (AS) and co-reviewer (MO) independently assessed eligibility. Twelve papers were discarded as 2 were not trials, 3 examined non-demented patients, 1 was a case study, 2 were observational and 4 were controlled trials with neither randomisation nor appropriate outcome measures. Three RCTs were found. One was then discarded due to lack of clarity in diagnosis, leaving 2 RCTs.

### DATA EXTRACTION

Data were extracted from psychometric tests measuring changes in cognition and behaviour. Descriptive characteristics (such as quality of randomisation and blinding) and study results were extracted by 2 independent reviewers using a standard data extraction form. Disagreements were resolved by discussion. Additionally, letters/e-mails were sent to all authors of controlled trials asking for essential information (statistics and/or details of randomisation).

## Description of studies

Baines 1987 used 15 subjects with 'moderate to severe impairment of cognitive functioning'. No details of further illnesses or medication were given. Subjects were randomly assigned to 3 groups of 5: RT, Reality Orientation (RO) or an untreated control group. For the purpose of this study, only the relationship between RT and no treatment was discussed. Intervention (RT and RO) was for 30 minutes, 5 times a week for 4 weeks. RT sessions were based on the format suggested by Norris, 1986; using a set of audio/slide programmes designed to facilitate reminiscence, old photographs (local scenes and personal), books, magazines, newspapers and domestic articles. Outcomes measured were Information/Orientation (Cognitive) and Behaviour; before and immediately after the 4-week intervention.

Goldwasser 1987 used 30 subjects with a clinical diagnosis of dementia. No details of further illnesses or medication were given. They were randomly assigned to 3 groups of 10: RT, Social support and no treatment. Intervention (RT and social support) was for 30 minutes, twice a week for 5 weeks. Reminiscence topics included food, family, early memories, adjustments, losses, jobs and music. The social support group focused on present and future events and problems. Outcomes measured were cognition, ADL (Activities of daily Living - behaviour) and depression; pre-intervention, 1 week post-intervention and at a 6-week follow-up.

## Methodological quality

### 1) SELECTION BIAS

Baines 1987: Method of randomisation unclear.

Goldwasser 1987: Method of randomisation unclear.

## 2) PERFORMANCE BIAS

With psychological interventions, unlike drug trials, it is impossible to blind patients and staff totally to treatment. Patients will often be aware that they are being treated preferentially, staff involved may have different expectations of treatment groups, and independent assessors may be given clues from patients during the assessments. There may also be contamination between groups, in terms of groups not being held in separate rooms and staff bringing ideas from one group to another. The latter effect would be reduced with clear therapeutic protocols, the existence of which was not mentioned in either of the studies. It was difficult to draw conclusions about contamination and blinding, although the following information was given:

Baines 1987

Staff were unaware of the allocation of patients to groups, as they were removed from the setting for treatment. Contamination: RT group was held in a separate room, but the same staff conducted RO and RT, so they could have discussed the 2 groups, and come up with common solutions which are not within the boundaries of RT. This would be less likely if there was a written treatment protocol, of which there is no evidence.

Goldwasser 1987

No details are given of where groups were held. The same facilitators conducted RT and social support, which may have resulted in some contamination across groups.

## 3) ATTRITION BIAS

Baines 1987

0/15 dropouts

Goldwasser 1987

3/30 dropouts. 1 person in RT group died, therefore 1 person in each of other 2 groups was randomly dropped.

## 4) DETECTION BIAS

Baines 1987

Assessments were made by an independent psychologist, and staff who knew the residents well but were not involved with the therapy groups.

Goldwasser 1987

Assessments were made by a psychology graduate, a registered nurse and a practical nurse, none of whom were aware of the conditions to which subjects were assigned.

## Results

Data could only be extracted from one trial (Baines 1987), as the data needed for MetaView were not available in the Goldwasser 1987 paper, and could not be obtained directly from the author. Results were divided into 2 subsections, cognition and behaviour, both which showed insignificant results.

For the Information/Orientation subscale of the CAPE, the weighted mean difference (WMD) was 0.049, with a 95% confidence interval (-4.371, 4.771).

For the behaviour subscale of the CAPE, the WMD was -3.3, with a 95% confidence interval (-14.190, 7.590). Thus there was a trend in favour of treatment.

## Summary of analyses

MetaView: Tables and Figures

## Discussion

Only 1 RCT, with 10 subjects, met the inclusion criteria of this review and had data that could be analysed. Results were statistically insignificant, although there was a trend towards favouring treatment in the behavioural outcome. It is both problematic to reach any conclusions from this limited data, and difficult to generalise as it only examined residents of local authority

homes, who may differ from people with dementia living in the community. Therefore, other research which could not be included in the analysis, is considered.

It was not possible to obtain adequate data for entry into MetaView from the Goldwasser 1987 study. However, the authors found a slight, but insignificant improvement in cognitive status for the RT group compared to the 2 others, no differences at all in behavioural assessment, and a significant increase in depression for the RT group. The latter measure may have been biased because initial depression scores were higher for this group.

Orten 1989 conducted a study on 56 "moderately confused" nursing home residents. Experimental subjects had weekly, 45 minute RT sessions for 16 weeks. The control group received no treatment. Subjects were assessed on a Social Behaviour Scale developed by the authors. They found that experimental subjects achieved slightly higher (but non-significant) levels on the scale. The authors also found no correlation between social isolation and ability to participate in RT. This study was limited in that the assessment scale used had no external validity or generalisability, and rating was not blind. They discussed the importance of the skill of the therapist. They had divided RT subjects into 3 groups, finding a discrepancy in the results. They partly attributed this to the distinct difference in level of experience of the group leaders, as more experienced leaders achieved slightly more favourable results. They highlighted the importance of systematic training, especially to non-professionals, before RT is given.

There have been various other studies on RT. Kiernat 1979 used subjective, individual ratings on 23 confused nursing home residents after a period of RT, finding that it stimulated conversation and interest, and increased attention. Cook 1984 described a pilot study of RT on 17 confused nursing home residents. She said that it encouraged active and spontaneous participation, promoting socialization and personal contact. "Members appeared more alert. Humour and laughter were more frequently shared." Gibson 1993 conducted 5 individual case studies, describing changes in staff attitude: "Staff became excited, intrigued and fascinated with the person's past."

Therefore, evidence suggests that there may be some beneficial elements to RT, but there is a clear need for more research in the field. The evaluation of any psychological therapy is likely to cause potential difficulties and limitations, with problems accounting for variables such as the therapeutic alliance between patients and therapists, and the sensitivity and skill with which the therapy is given. It is difficult to assess the more subjective aspects of RT just by reading a written account. Additionally, neither the subjects nor the therapist can be entirely prevented from holding preconceived ideas about treatment and placebo effects.

## **Reviewers' conclusions**

### **Implications for practice**

Goldwasser 1987 discussed the short term nature of RT, finding that any benefits immediately after treatment were quickly lost in a 5-week follow-up. This was also found by Orten 1989. This suggests that if RT is to be beneficial, perhaps it should be part of a continuous, ongoing program; or, more realistically, some features of it could become part of daily activities.

Baines 1987 selected participants for the groups on the basis of cognitive status. Ideally, initial assessment should include psychological, as well as cognitive factors.

There may be some benefits to RT, but research evidence is not strong enough to reach any firm conclusions. It is also difficult to deduce when and how it should be used, and how it compares to other psychological therapies that are widely used in dementia care, such as Validation Therapy (Feil 1967) and Reality Orientation (Folsom 1966). Baines found that subjects benefited more, both cognitively and behaviourally, from RT following 4 weeks of Reality Orientation, than from RT alone. This suggests that one may benefit more from RT if more orientated, hence that it may be more beneficial in the earlier stages of dementia.

Finally, there was no mention of any harms of RT in the trials examined. There may be financial implications, but in the absence of evidence this cannot be discussed in this current

review.

In summary, this review is not able to provide sufficient information to reach any conclusions about the implications of RT in clinical practice. Benefits may, for instance, be non-specific, related to the benefits of systematic, structured activity and attention rather than RT itself; and are difficult to assess without clear treatment protocols.

### **Implications for research**

There is a clear need for more randomised controlled trials of RT.

What appears vital is research to examine which features of RT have greater or lesser benefits, and in what circumstances, for example looking at different stages of dementia or different group sizes. Once this has been established, clear therapeutic protocols are needed for the guidance of staff conducting the treatment, and to reduce the chances of contamination.

RCTs may be more valuable if used in conjunction with more qualitative studies, such as case studies. These may offer a greater insight into the more effective features of RT, the more successful ways in which it may be applied, and the types of people most suited; yet are limited by factors such as lack of controls and subjective assessment methods. Ultimately, the success of RT may be dependent on it being used at the appropriate time, by a sensitive and experienced practitioner, with suitable patients.

Finally, research could examine RT as an active dialogue between participants (staff and clients), looking at changes in activity programs and the clinical environment, and RT as part of an ongoing process.

### **GLOSSARY**

**Agnosia:** a condition in which a person is unable to consciously recognise the meaning of objects.

**Aphasia:** a condition involving the partial or complete loss of language ability.

**ADL:** activities of daily living, such as dressing and eating.

**Behavioural:** pertaining to behaviour.

**Blinding:** concealing the assignment of people to experimental and control groups.

**Cognition:** mental behaviours, such as thinking and reasoning.

**Control group:** the group in the research which is not exposed to the intervention.

**Double-blind:** a situation in which neither the person being assessed nor the person doing the assessment is aware of group membership.

**DSM IV:** Diagnostic and Statistical Manual (number IV). The official system for classification of psychological and psychiatric disorders, prepared by the American Psychiatric Association.

**Experimental:** the group in the research which is exposed to the intervention.

**ICD10:** International Classification of Diseases (number 10). A system of classification of diseases developed by the World Health Organisation.

**Meta-analysis:** the statistical process of combining data from different studies.

**Protocol:** the original plan of an experiment.

**Therapeutic alliance:** the relationship developed between patient and therapist during therapy.

**RCT (randomised controlled trial):** trial in which people are randomly allocated to a control group and one or more intervention groups.

### **Acknowledgements**

We would like to thank the following contributors for their help: Peter Smith, Sue O'Kell, Dr. Mike Bender, Prof Peter Coleman, Lindsay Royan, Claire Morris and Rachelle Doody.

## Potential conflict of interest

None

## Characteristics of included studies

Table: Characteristics of included studies

## Characteristics of excluded studies

**Study : Head 1990**

No randomization

**Study : McKiernan 1990**

No randomization.

**Study : Orten 1989**

Population without clear diagnosis of dementia.

## References

### References to studies included in this review

**Baines 1987** *{published data only}*

Baines S, Saxby P, Ehler K. Reality Orientation and Reminiscence Therapy: a controlled cross-over study of Elderly Confused People. *British Journal of Psychology* 1987;151:222-31.

**Goldwasser 1987** *{published data only}*

Goldwasser AN, Auerbach SM, Harkins SW. Cognitive, affective and behavioural effects of Reminiscence Group Therapy on Demented elderly. *Int J Aging and Human Development* 1987;25(3):209-22.

*\* indicates the major publication for the study*

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**Head 1990**

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hutchinson

rattenbury

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1992.

## Coversheet

### Title

Reminiscence therapy for dementia

### Reviewer(s)

Spector A, Orrell M, Davies S, Woods RT

### Contribution of Reviewer(s)

Information not supplied by reviewer

**Issue protocol first published:** 1998 Issue 2

**Issue review first published:** 1998 Issue 3

**Date of most recent amendment:** 06 September 2000

**Date of most recent substantive amendment:** 25 May 2000

**Most recent changes:** Information not supplied by reviewer

**Date new studies sought but none found:** Information not supplied by reviewer

**Date new studies found but not yet included/excluded:** Information not supplied by reviewer

**Date new studies found and included/excluded:** Information not supplied by reviewer

**Date reviewers' conclusions section amended:** Information not supplied by reviewer

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### Extramural sources of support to the review

- North Thames NHS Executive UK

### Intramural sources of support to the review

- University College London UK

## Synopsis

This review examines the effectiveness of Reminiscence Therapy (RT) for people with dementia. RT involves the vocal or silent recall of events in a person's life, either alone, or with another person or group of people. RT groups are often assisted by aids such as videos, pictures and archives, as a means of communicating and reflecting upon life experiences. After searching the literature, only one suitable randomised controlled trial looking at RT for dementia was found. Results were insignificant, due to the lack of evidence, yet other data suggests that RT can be beneficial. Hence the review highlights the urgent need for more quality research in the field, for a conclusive systematic review.

The effectiveness of classroom reality orientation (RO) in dementia was evaluated by conducting a systematic literature review. This yielded 43 studies, of which 6 were randomized controlled trials meeting the inclusion criteria (containing 125 subjects.) Results were subjected to meta-analysis. Effects on cognition and behavior were significant in favor of treatment (cognition standardized mean difference [SMD] = -0.59; 95% confidence interval [CI] -0.95--0.22; behavior SMD = -0.64, 95% CI = -1.20--0.08). The evidence indicates that RO has benefits on both cognition and behavior for dementia sufferers. However, a continued program may be needed to sustain potential benefits. Future research should evaluate RO in well-designed multicenter trials.

**Key Words:** Memory impairment, Alzheimers, Cognition, Behavior, Therapy

## Reality Orientation for Dementia: A Systematic Review of the Evidence of Effectiveness from Randomized Controlled Trials

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Reality orientation (RO) was first described (Taulbee & Folsom, 1966) as a technique to improve the quality of life of confused elderly people, although its origins lie in an attempt to rehabilitate severely disturbed war veterans. RO involves the presentation of orientation and memory information, relating, for example, to time, place, and person. This was thought to provide the person with a greater understanding of his or her surroundings, possibly resulting in an improved sense of control and self-esteem. Before this there had been little research on psychological therapies for dementia (Cosin, Mort, Post, Westropp, & Williams, 1958). The early RO work marked the advent of the use of psychological therapies in the care of dementia, which had previously been seen primarily as a medical problem with medical interventions.

RO can be of a continuous 24-hr type, whereby staff involve the patients in reality-based communication in every contact throughout the day, or "classroom RO," where groups of people meet on a regular basis to engage in orientation-related activities. A prominent focus of classroom RO is often the "RO board," which typically displays information such as the day, date, weather, name of next meal, and other

details (Holden & Woods, 1995). There have been a number of studies on classroom RO since Taulbee and Folsom (1966), many reporting positive findings. For example, improvements were reported in "orientation to reality and in motivation toward selfcare, responsibility and social involvement" (Salter & Salter, 1975, p. 406). Controlled studies have shown varied results. Some authors have found that classroom RO can lead to some improvements in cognitive function, with no effect on behavior (e.g., Hanley, McGuire and Boyd, 1981), whereas others have found positive effects on behavior, with no significant changes in cognition (Baines, Saxby, & Ehlert, 1987). There has been criticism of RO in clinical practice, with concern that it has sometimes been applied in a mechanical fashion and has been insensitive to the needs of the individual (e.g., Powell-Proctor & Miller, 1982). Moreover, it has been argued that constant relearning of material can actually contribute to problems in mood and self-esteem (Butler & Lewis, 1977). In recent years, RO has lost some of its popularity, but nevertheless a number of its principles have been incorporated into everyday clinical practice (e.g., RO boards). In many settings, it has been overtaken by more popular developments such as validation therapy (Feil, 1971), which is not primarily memory oriented. There has also been increasing interest in the use of cognitive rehabilitation for people with dementia (e.g., Quayhagen & Quayhagen, 1989). Thus, a reconsideration of the efficacy of RO is timely.

RO studies have often been small in size and of variable quality, making the effectiveness of RO open to debate, due to the lack of a sound evidence base. There has also been a lack of clear guidance for clinicians and practitioners, and little consistent application of psychological therapies like RO in dementia services. The aim of this study was to conduct a sys-

We would like to thank the following for their help and support: Susan Okell, Dr. Mike Bender, Professor Peter Coleman, Lindsay Royan, Claire Morris, Dr. Rachelle Doody, Dr. Gary Gerber, Faith Gibson, Dr. Tessa Perrin, David Dickinson, Ermini Ferrario, and Peter Smith.

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tematic review of RO trials in dementia. It was carried out under the auspices of the Cochrane Collaboration Cognitive Impairment and Dementia group, based in Oxford, United Kingdom.

## Methods

### Search Method

We conducted a systematic search for randomized controlled trials (RCTs) evaluating the effectiveness of classroom RO with dementia sufferers. A combination of the terms *reality orientation*, *dementia*, *alzheimers*, *controlled study* and *trial* were used to search Medline Express 1966–1997 (1988), PsycLIT (1967) Journal Articles 1974–1997, PsycLIT (1967) Chapters and Books 1/87–12/97, Embase (1980), the Cochrane Database of Systematic Reviews (1998), OMNI (Organising Medical Networked Information), BIDS (Science Citation Index and Social Science Citation Index, 1994), Dissertation Abstracts International: 1861–1997, and SIGLE (System for Information on Grey Literature). We searched internet sites for relevant information: Healthweb, including Medweb (Mental Health Infosource, American Psychiatric Association, Internet Mental Health, Mental Health Net), and the National Health Service Confederation. The following journals were handsearched: *Aging and Mental Health*, *The Gerontologist* (1961–1994), *Journals of Gerontology* (1960–1978), *Current Opinion in Psychiatry* (1988–1997), and *Current Research in Britain, Social Sciences* (1991–1995). In addition, we searched in the Alzheimer's Disease Society library, and letters were published in PSIGE magazine (Psychologists Special Interest Group in the Elderly) and *The Psychologist*, the journal of the British Psychological Society, requesting information on any RCTs which might otherwise be missed, such as unpublished papers. Bibliographies of all relevant articles were scanned, and an optimally sensitive search strategy was additionally performed by a coreviewer. Experts in dementia care were consulted.

### Inclusion Criteria

**Studies.**—All RCTs examining the effect of RO for dementia were initially included. Authors were contacted for missing data, such as details of randomization, means, and standard deviations.

**Participants.**—Participants were elderly people (mean age >55) diagnosed with dementia (cognitive impairment, Alzheimer's disease, organic brain syndrome, etc.) according to the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., American Psychiatric Association, 1994), *International Classification of Mental and Behavioral Disorders* (10; World Health Organization, 1992), or comparable. For inclusion, it was necessary for more than 60% of the participants to have completed the study.

**Interventions.**—Participants attended regular therapy groups (at least 10) for a minimum period of 3 weeks.

These groups from 30–60 min, involving (among other cognitive activities) the presentation, repetition, and use of orientation information (time, place, and person related). There was a minimum of 4 participants in each group.

**Outcome measures.**—Cognitive and/or behavioral outcome measures were necessary for entry into the review.

### Data Extraction

Descriptive characteristics (such as quality of randomization and blinding) and study results were extracted by means of a standard data extraction form. Additionally, letters and E-mails were sent to all authors of controlled trials asking for essential information (statistics and/or details of randomization). Data were extracted from psychometric tests measuring changes in cognition and behavior. Where possible, the data were independently pooled across studies. In some cases, trials used more than one scale to measure similar outcomes (Baines et al., 1987). For the purpose of meta-analysis, it was only possible to use one scale from each study. Cognitive tests were chosen by using the following criteria (in decreasing order of importance): (a) well-recognized published cognitive tests; (b) orientation tests; (c) short-term memory tests; (d) information tests; (e) any test of cognition using some of b–d. Behavioral tests were selected using the following criteria (in decreasing order of importance): (a) well-recognized, published behavioral tests and (b) primarily tests of activities of daily living/adaptive social behavior. Discussion between the two reviewers and the other authors were used to resolve any queries.

### Analyses

RevMan 3.0 (Update Software, 1996) was used. Analyses were adjusted to the random effects model, due to the heterogeneity of trials. Because trials used different tests to measure the same outcomes, standardized mean differences (SMDs) were used. These were calculated by dividing the difference between the treatment and control means by the pooled standard deviation within each study, thus enabling them to be compared with the other trials in a standardized way.

## Results

### Selection of Trials

Forty-three publications were identified through the literature search. A reviewer and coreviewer independently assessed eligibility. Twenty-two publications were immediately excluded: four were not trials, 5 examined nondementia populations, 4 were case studies, 2 were observational studies, and 7 were uncontrolled. The remaining 21 trials were all controlled, but of these 6 were clearly not randomized (e.g., participants were selected or chosen), and 2 looked at 24-hr RO only. This left 13 trials, and of these 6 had no mention of randomization; authors

were contacted and asked if (and how) participants had been randomly assigned to groups. One of these trials was randomized (Ferrario, Cappa, Molaschi, Rocco, & Fabris, 1991). The other 7 controlled trials all included the term(s) *randomized*, *randomly assigned*, or similar. We decided that this was acceptable for inclusion into the review. Therefore, eight RCTs were included in the analysis.

#### Quality of Included Studies

The quality of each study was assessed according to the four criteria outlined in the Cochrane Collaboration Handbook (Mulrow & Oxman, 1996): selection bias, performance bias, attrition bias, and detection bias. Details of randomization concealment (detection bias) can be seen in Table 1. In view of the lack of detailed information on methods of randomization, we did not assign a formal quality score to the studies.

Performance bias was difficult to evaluate. With psychological interventions, unlike drug trials, it is impossible to blind patients and staff totally to treatment. Patients may be aware that they are being treated preferentially, staff involved may have different expectations of treatment groups, and independent assessors may be given clues about group assignment from patients during the assessments. There may also be contamination between groups, in terms of groups not being held in separate rooms and staff bringing ideas from one group to another. The latter effect would be reduced with clear therapeutic protocols, the existence of which was not mentioned in any of the studies; although B. Woods (personal communication, 1998) stated that "checks were made to ensure compliance with the therapeutic protocol." Most of the studies did not provide enough information to draw conclusions about contamination and blinding. The authors of two trials (Baines et al., 1987; Wallis, Baldwin, & Higgenbotham, 1983) both

Table 1. Bias in Reality Orientation (RO) Studies

Name of study	Amount of intervention	Content of RO	Alternative activity	Randomization concealment	Attrition bias (dropouts)	Detection bias
Baines et al. (1987)	30 min 5 times a week 4 weeks	RO board, multisensory stimulation	Reminiscence therapy/no treatment	No details	0/15 dropouts	Assessment by independent psychologist and staff not involved in therapy No details of assessors
Baldelli et al. (1993)	60 min 3 times a week 3 months	No details	No treatment	No details	0/23 dropouts	Assessment by psychologist unaware of group membership No details of assessors
Breuil et al. (1994)	60 min 2 times a week 5 weeks	Drawing, associated words, object naming/categorizing	No treatment	No details	5/61 dropouts (3 experimental, 2 control)	Assessment by psychologist unaware of group membership No details of assessors
Ferrario et al. (1991)	60 min 5 times a week 21 weeks	No details	No treatment	No details	2/21 dropouts (1 in each group, due to illness)	Assessment by independent person blind to group membership Ratings for some tests were blind, others were not
Gerber et al. (1991)	60 min 4 times a week 10 weeks	RO board, exercises, food preparation, discussions	Social interaction/no treatment	Random number tables	5/24 dropouts (1 in each of 3 groups died, 2 discharged in RO group) 1/58 dropout (unclear which group, due to transfer)	Assessments by senior nurse & occupational therapists, unaware of group membership Mixture: some assessments blind, some not
Hanley et al. (1981)	30 min 4 times a week 12 weeks	RO board, clocks, calendars, maps, posters	No treatment	No details	22/60 dropouts. No details of groups (death, 6; illness, 8; other, 8)	Assessments by senior nurse & occupational therapists, unaware of group membership Mixture: some assessments blind, some not
Wallis et al. (1983)	30 min 5 times a week 3 months	RO board, general orientation	"Diversional occupational therapy" (group and individual activities)	Drawing from a hat, consecutive allocation	4/18 dropouts (1 in each group died, 1 control refused assessment)	
Woods (1979)	30 min 5 times a week 20 weeks	RO board, orientation discussions/demonstrations	"Social therapy" (various group activities)	Drawing from a hat		

stated that the staff were unaware of the allocation of patients to groups, as they were removed from the setting for treatment. There was no evidence of blinding in the other studies. How far patients were blind to treatment remains a controversial issue. This would depend on how much information was given to them and their level of comprehension. Most authors said that the RO groups were held in separate areas, reducing the chance of contamination (Baines et al., 1987; Ferrario et al., 1991; Hanley et al., 1981; Wallis et al., 1983; Woods, 1979). The groups may have been held in separate rooms in the other studies, although this information was not provided. The nature of the biases and differences between studies (such as length and content of RO sessions) were considered as variables affecting outcomes and are discussed subsequently.

### Meta-Analysis

Out of the eight studies, only six could be entered into "Metaview" (the Cochrane term for meta-analysis). The other two studies (Baldelli et al., 1993; Hanley et al., 1981) did not include the means and standard deviations on tests before and after the intervention, which were needed for the analysis. The authors were contacted with no response. From these six RCTs there was a total of 125 participants (67 in experimental groups, 58 in control groups).

The overall results in the cognition section were significantly in favor of treatment (Figure 1). The stan-

dardized mean difference was  $-0.59$ , with a 95% confidence interval (CI) of  $-0.95$  to  $-0.22$ . Comparing the standardized mean difference with a normal distribution indicated that the average score for patients in the treatment groups was better than 72% of the control patients' scores. All studies contained cognitive measures, with a total of 125 participants.

The results were highly influenced by the largest study (Breuil et al., 1994). These results (on the Mini Mental State Exam) were significant in favor of treatment (SMD =  $-0.71$ , 95% CI =  $-1.26$  to  $-0.17$ ). For the other studies, statistics were as follows: Using the Weschler Memory Scale, SMD =  $-0.66$ , 95% CI =  $-2.04$  to  $-0.71$  (Woods, 1979); using the Information/Orientation subscale of the Clifton Assessment Procedures for the Elderly (CAPE; Pattie & Gilleard, 1979), SMD =  $-0.81$ , 95% CI =  $-1.43$  to  $-1.06$  (Baines et al., 1987); using the Information/Orientation subscale of the Clifton Assessment Schedule (CAS; Pattie & Gilleard, 1976), SMD =  $-0.96$ , 95% CI =  $-1.99$  to  $-0.06$  (Ferrario et al., 1991); using the Orientation subscale of the Kingston Dementia Rating Scale (KDRS), SMD =  $-0.76$ , 95% CI =  $-1.96$  to  $-0.45$  (Gerber et al., 1991); and using the cognitive subscale of the Royal College of Physicians (RCP; Hodkinson, 1973), SMD =  $-0.03$ , 95% CI =  $-0.93$  to  $-0.88$  (Wallis et al., 1983). These results were not individually significant (confidence intervals overlapping zero); in all, the trend favored treatment (implying a negative value for the SMDs).

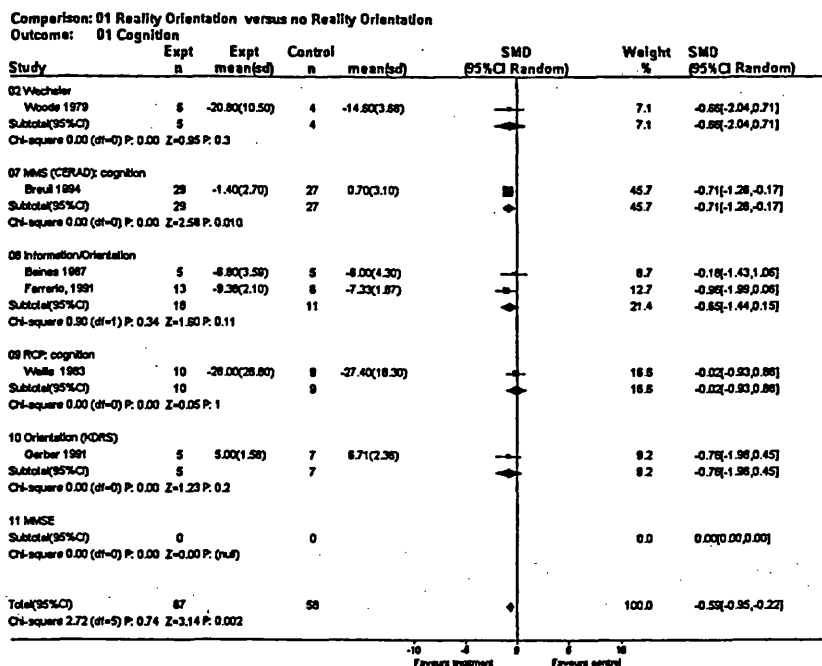


Figure 1: Meta-analysis: Cognitive outcomes. The length of the lines represents the size of the confidence intervals and the gray boxes, the weight attributed to the trial. Results are significant if they do not cross the center line. The pooled total lies left of the center line, without touching it, indicating a significant result. SMD = standardized mean difference, CI = confidence interval, MMS = Mini Mental State Exam, CERAD = Consortium to Establish a Registry for Alzheimer's Disease, RCP = Royal College of Physicians, KDRS = Kingston Dementia Rating Scale.

The total result for behavior was again significantly in favor of treatment (see Figure 2). The SMD was  $-0.64$ , with a 95% CI of  $-1.20$ – $0.08$ , with a total of 57 subjects (33 experimental, 24 control). Comparing the SMD with a normal distribution indicates that the average score for patients in the treatment groups was better than 74% of the control patients' scores. All individual studies had insignificant results, but the trends were again in favor of treatment. Statistics were as follows: using the Crichton, SMD =  $-0.45$ , 95% CI =  $-1.37$ – $0.46$  (Wallis et al., 1983); using the Self-Care Functioning subscale of the MOSES (Helmes, Csapo, & Short, 1987), SMD =  $-0.59$ , 95% CI =  $-1.58$ – $0.40$  (Ferrario et al., 1991); using the Crichton, SMD =  $-0.54$ , 95% CI =  $-1.90$ – $0.82$  (Woods, 1979); and using the Behavioural subscale of the CAPE, SMD =  $-1.32$ , 95% CI =  $-2.77$ – $0.12$  (Baines et al., 1987).

## Discussion

This has been the first systematic review of RO in dementia. Six RCTs with a total of 125 participants met the inclusion criteria for the metanalysis (Spector, Orrell, Davies, & Woods, 1998). Trials varied greatly in factors such as length of intervention, methodological quality, and outcome measures. However, the results showed that RO had significant positive effects on both cognition and behavior. Results for cognition were more precise, due to a sample size of 125, compared with 57 for behavior.

The study (Ferrario et al., 1991) in which participants received much more RO than any of the other trials (105 hr in total) had the highest cognitive SMD ( $-0.96$ ) in favor of treatment; however, our results

did not show a clear relationship between amount of intervention and cognitive outcome. Additionally, the trial (Breuil et al., 1994) in which participants were given the least amount of RO (10 hr) was the only one to yield significant positive findings favoring RO. Many of the smaller RO trials are vulnerable to Type II statistical error due to insufficient numbers. Similarly, the results did not show a relationship between amount of intervention and behavioral outcome, or a pattern between length of sessions and outcomes.

The overall SMD ( $-0.59$ ) was of a similar size to the SMD ( $-0.71$ ) of the Breuil et al. (1994) study, which found a 2.1-point benefit on the Mini Mental State Exam for the stimulated group compared with the control group. Because Mini Mental State Exam scores are thought to decline by on average 4 points per year for dementia, the benefits of RO might equate to a 6-month delay in the usual cognitive deterioration. How far such a delay is of functional benefit to an individual patient would necessarily vary. The orientation process used by Breuil et al.'s (1994) study slightly differed from the other studies (see Table 1), being more advanced theoretically than the 1970s concepts, as much more was known about the neuropsychology of dementia. Their techniques were more akin to the sophisticated cognitive rehabilitation programs used in brain injury.

There was variation in the alternative activities offered to control groups, with some trials giving them no treatment (Baines et al., 1987; Breuil et al., 1994; Ferrario et al., 1991) and others providing control groups with some alternative social therapy (Gerber et al., 1991; Wallis et al., 1983; Woods, 1979). Our results showed no effects of these differences on out-

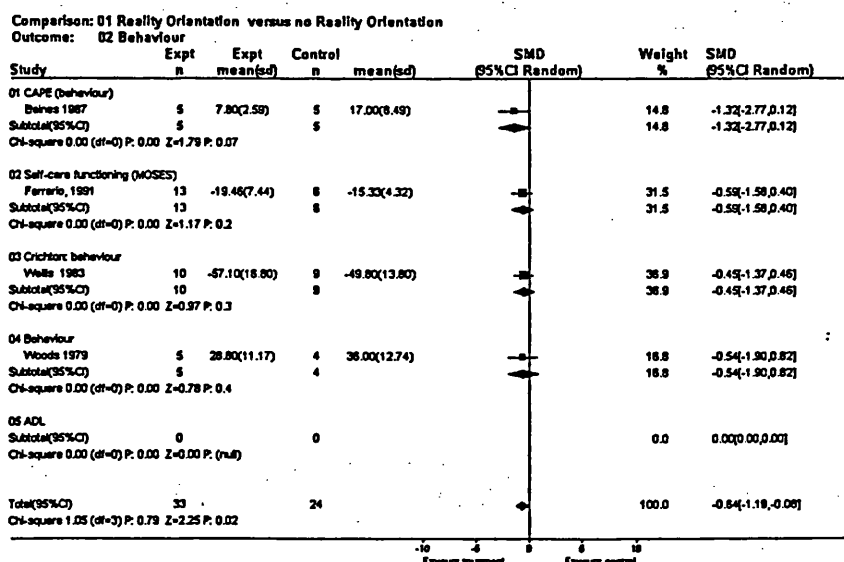


Figure 2: Meta-analysis: Behavioural outcome. Unlike the cognitive analysis, only four trials had behavioral outcome measures, with a total of 57 subjects. The total pooled outcome lies to the left of the center line, without crossing it, indicating a significant result. SMD = standardized mean difference, CI = confidence interval, CAPE = Clifton Assessment Procedures for the Elderly; MOSES = Multidimensional Observation Scale for Elderly Subjects.

come, suggesting that the actual qualities of RO, rather than merely the therapeutic effect of social contact and attention, may affect individual outcomes. However, staff may have had greater expectations from the RO group, which may have affected participants' performance.

There were 38 dropouts in the six studies with available data. In one study (Wallis et al., 1983), there were 22 dropouts, but no details were provided as to which groups they were in. Of the remaining 16, there were details of 8 RO participants and 6 controls. From these, it was clear that 3 experimental participants and 3 controls died; others, for example, went to the hospital or were discharged. Hence, there was no evidence in this study that RO had serious side effects. However, cases of adverse psychological and emotional effects in patients have been reported (Dietch, Hewett, & Jones, 1989). It has even been stated that "challenging their fantasies or attempting to educate and continually re-educate people with dementia is probably of no value" (Reisberg, 1981, p. 149).

There has been some evidence that RO patients actually performed worse at a 10-week follow-up than before treatment (Gerber et al., 1991), suggesting that benefits gained from RO were lost. Conversely, another study found that participants gained higher scores in both cognitive and behavioral tests 1 month postintervention (Wallis et al., 1983). The present analysis has provided no clear evidence of the long-term benefits of RO primarily because of a lack of follow-up data. It has been suggested that for RO to have more lasting effects, there should be a detailed schedule of reinforcement and follow-up, with a continuous, ongoing program. For example, low-key interventions like RO boards and signs could be used when a person is disoriented and distressed. The introduction of a 24-hr RO program might be a good way to retain what has been learned if the continuation of classroom RO is not feasible (Williams, Reeve, Iverson, & Kavanaugh, 1987).

With psychological interventions, unlike drug trials, double blinding is not possible and contamination between groups is more likely. Hence RCTs may be especially valuable if used in conjunction with more qualitative studies, such as case studies, or quasi-experimental studies in which different treatments are carried out in different centers. These may offer a greater insight into the most effective features of RO, the most effective ways in which it may be applied, and the types of people most suited. As with all psychological interventions, the success of RO may be dependent on it being used at the appropriate time, by sensitive and experienced practitioners, to receptive patients.

Future research should investigate the relationship between classroom and 24-hr RO; other outcomes, such as quality of life; more individualized psychological treatment approaches for people with dementia, with more detailed assessments of everyday memory skills and their remediation in individual programs; and how long the benefits of RO remain after treatment and whether continuation therapy is

effective. In summary, this review found that classroom RO had clear benefits to patients with dementia in both cognitive and behavioral domains, suggesting that RO techniques should be considered as an important component of dementia care. The benefits of short-term RO may only be short lived, but a more long-term program may help sustain improvements. This review has shown that RCTs are possible in this field but that there is a need for multicenter trials of better quality and design methodology that include a clear rationale for the interventions used. We have recently been awarded grants to conduct a multicenter trial.

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Received October 1, 1998

Accepted November 30, 1999

Decision Editor: Vernon L. Greene, PhD

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NEUROPSYCHOLOGICAL REHABILITATION, 2001, 11 (3/4), 377-397

## **Can reality orientation be rehabilitated? Development and piloting of an evidence-based programme of cognition-based therapies for people with dementia**

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This study describes the development and implementation of a programme of cognition-based therapies for dementia. The programme was designed by distilling the evidence of the effectiveness of Reality Orientation and related approaches, following a broad-based systematic review. The most beneficial elements identified from previous studies were extracted and incorporated into the programme, using the expertise of specialists in the field. The programme comprised of 15 45-min, twice weekly sessions. It ran in one day centre and three residential homes, involving 27 people with dementia (17 treatment and 10 control subjects). The results of the pilot study showed positive trends in cognition, and trends towards reduced depression and anxiety following treatment. No negative effects were identified. We discuss how the outcomes of the pilot study were used to modify the programme, which now has a stronger cognitive element. This refined programme is currently being tested as part of a large multicentre, randomised controlled trial.

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We would like to thank the National Health Service Executive North Thames for funding this project, as part of their research and development programme on the health of older people. We also thank Harry Cayton, Chief Executive of the Alzheimer's Society, for enabling this project to be carried out in partnership with the Society.

## INTRODUCTION

Reality Orientation (RO) is the archetypal approach to cognitive rehabilitation in dementia (Holden & Woods, 1995). Taulbee and Folsom (1966) described RO as a technique to improve the quality of life of confused elderly people, although its origins lay in an attempt to rehabilitate patients with long-term mental health problems in Veterans' Administration hospitals (Ruskin & Talbott, 1993). RO operated through the presentation and repetition of orientation information, which was thought to provide the person with a greater understanding of their surroundings, possibly resulting in an improved sense of control and self-esteem. RO can be of a continuous 24 hour nature, whereby staff involve the patients in reality throughout the day, or of a "classroom" type, where groups of elderly people meet on a regular basis to engage in orientation-related activities (Brook, Degun, & Mather, 1975). Woods (1979) found that classroom RO led to some improvement in cognitive function, with no effect on behaviour, whereas Baines, Saxby, and Ehlert (1987) found significant positive effects on behaviour, with no significant changes in cognition. A programme of classroom and 24 hour RO together has demonstrated significant positive changes in orientation (Citrin & Dixon, 1977).

RO lost its initial popularity in the 1980s, largely due to criticism of it being applied in a rigid and insensitive manner. More modern strategies which aim to improve cognition in dementia frequently involve memory training and cognitive stimulation programmes. Zarit, Zarit, and Reeve (1982) provided subjects with "didactic training" (forming mental images of words) and "problem solving" (practical steps to manage daily problems, e.g., notebooks and calendars). They reported small and short-lived changes in memory performance, but increased depression in caregivers. The use of external memory aids, such as diaries, calendars, large clocks and clear signposting are becoming increasingly common for people with dementia. More recent research is identifying ways of creating an optimal learning environment. For example, "errorless learning" involves encouraging people, when learning new information, only to respond when they are sure that they are correct; and "spaced-retrieval" involves learning and retaining information by actively recalling information over increasingly long periods of time (Camp, Foss, O'Hanlon, & Stevens, 1996; Clare, Wilson, Breen, & Hodges, 1999).

Other therapies commonly described in dementia care include "Reminiscence Therapy" (RT), which typically involves weekly meetings that promote the discussion of past events, often assisted with aids such as photographs, music, archive recordings, videos and items with an historical connection; and "Validation Therapy" (VT), which aims to validate the feelings of people with dementia by concentrating on the underlying meaning of their behaviour, rather than correcting it.

There has been much interest in the various therapies and approaches to dementia care, yet there is a distinct lack of quality, up-to-date research and information available about how helpful the approaches are. Additionally, many care staff are uncertain about the best approaches to use, and of the scale of their potential impact. With more information on how care staff may positively contribute to dementia care, their level of satisfaction and morale may increase. This paper is in three parts; first, we report the use of a comprehensive analysis of the evidence in the literature to develop a cognition-based therapy programme; second, we report pilot data on the use of the programme in a day centre and three residential homes; finally, we discuss the modification of the programme based on the experience gained from the pilot work.

Our ultimate aim is to develop a group-based programme which staff in residential homes and day centres may learn to use with confidence as a means of enhancing and maintaining group members' level of function. This could form one component of a person's plan of care—we certainly do not envisage such an approach obviating the need for additional individualised interventions aimed at the whole range of the person's needs.

## DESIGNING AN EVIDENCE-BASED PROGRAMME

### Cochrane Reviews

In order to consolidate the existing evidence, the authors (Spector, Orrell, Davies, & Woods, 1998a,b) conducted two Cochrane Systematic Reviews on the effectiveness of RO and RT as psychological interventions for people with dementia, using evidence from randomised controlled trials (RCTs). Combining the results from six RCTs, the RO review showed that people receiving RO improved significantly more than controls in both cognition and behaviour. The RT review was inconclusive, due to only one RCT being included, and highlighted an enormous gap in research. An inconclusive systematic review of Validation Therapy (Neal & Briggs, 1999) is also available, and a review of memory training is planned.

### Systematic literature evaluation

A comprehensive literature search was conducted, which included searching Medline, PsychLIT, Embase, BIDS (Science Citation Index and Social Science Citation Index), OMNI (Organising Medical Networked Information), Dissertation Abstracts International, the Cochrane Database of Systematic Reviews, and SIGLE (System for Information on Grey Literature). Once all the literature on the principal psychological interventions (RO, RT, VT and memory training) was gathered, trials which provided details of the content of the programme and activities used were considered further. The therapeutic content of each study, and subsequent outcomes, were tabulated (see Table 1).

TABLE 1  
Details of studies (interventions incorporated into the programme are in italics)

<i>Authors, intervention, quality/details</i>	<i>Description (treatment group)</i>	<i>Outcome following treatment</i>
Breuil et al. (1994); RO RCT, blind. 56 Ss (CS = 29, C = 27)	<i>Copying pictures, associated words, naming and categorising objects.</i>	Significant improvement in cognition.
Wallis, Baldwin, & Higginbotham (1983); RO RCT, 33 Ss (RO = 18, C = 20)	Repetition of orientation information (e.g., time, place, weather). Charts, pictures, <i>touching objects and material.</i>	No change in cognition. Insignificant positive trend in behaviour.
Gerber et al. (1991); RO RCT, 24 Ss (RO = 8, SC = 8, C = 8)	Simple exercises, self-care, <i>food preparation</i> , orientation room with RO board, large clock, coloured illustrations.	Improved cognition in both RO and social interaction groups, especially in orientation and language (both significant)
Woods (1979); RO RCT, 14 Ss (RO = 5, ST = 5, C = 4)	Daily personal diary, group activities (dominoes, spelling, bingo). <i>Naming objects</i> , reading RO board.	Significant improvement in memory, learning, information and orientation in RO groups.
Hogstel (1979); RO RCT, 44 Ss (RO = 22, C = 22)	Introductions, reading RO board, tell time, discuss lunch menu. Patients had large clock and calendar in bedrooms. Additional input from staff outside RO class.	No significant differences. Observations: RO patients became more co-operative, and began communicating much more with each other.
Baines et al. (1987); RO RCT, 15 Ss (RO = 5, RT = 5, C = 5)	RO board, <i>old and current newspapers, personal and local photos, materials to stimulate all senses (e.g., cinnamon, silk, honey).</i>	Significant improvement in behaviour. No significant change in cognition. Positive effects reported by staff.
Goldstein et al. (1982); RO RCT, 14 Ss (RC = 7, C = 7)	Reading RO board, naming people, use of RO questionnaire (e.g., day, month, season, etc.).	Insignificant improvement in ADL.

<i>Authors, intervention, quality/details</i>	<i>Description (treatment group)</i>	<i>Outcome following treatment</i>
Hanley, McGuire, & Boyd (1981); RO RCT, 57 Ss (RO = 28, C = 29)	RO board, clocks, calendars, <i>maps</i> and posters. Room overlooked garden area to enable discussion.	Significant improvement in verbal orientation, in response to basic orientation items. No changes in behaviour.
Voekel (1978); RO RCT, 20 Ss (RO = 10, RT = 10). No statistics used.	Greeting, touching, RO board, calendars, clocks, antiques. Simple activities, e.g., identifying pictures.	No significant improvement in RO group, significant improvement in RT group.
Coen Mieli et al. (1991); RO CT. No. of Ss and method of allocation unknown.	Space and <i>time orientation</i> , <i>memory prompting</i> , <i>naming objects</i> and body parts, training cognitive, semantic and phonetic abilities.	"Medium" overall improvement. Patients become less passive Increase in effort and ability to concentrate.
Zanetti et al. (1995); RO CT, 28 Ss (RO = 16, C = 12)	Early classes: personal, time and space orientation. Later: <i>historical events</i> , <i>famous people</i> , attention, memory and visuospatial exercises.	Significant improvement in verbal abilities. No changes in other cognitive functions or disability measures. No changes in self-rated depression scores.
Citrin & Dixon (1977); RO CT, 25 Ss (RO = 12, C = 13)	Personal and environmental information presented individually, 24 hr RO.	Significant improvement in RO information sheet. Geriatric Rating Scale was inconclusive.
Reeve & Ivison (1985); RO CT, 20 Ss (RO = 10, C = 10)	Classroom and 24 hour RO (environmental symbols, signposts, clocks and 2 RO boards).	Significant improvements in cognition and behaviour.
Gotestam (1987); RO ABA, 5 Ss	Time Orientation: diary, clock. <i>Person orientation: name games</i> . Room orientation: maps and nameplates on walls.	Significant improvements in time and room orientation, insignificant improvement in person orientation.
Combleth & Cornbleth (1979); RO ABA, 22 Ss	RO board, copying, telling time, <i>counting money</i> .	Significant improvement in orientation and ADL.
Barnes (1974); RO ABA, 6 Ss, No statistics	RO board, calendar, maps. Discussed names, lunch menu, etc.	Insignificant improvement (questionnaire).

TABLE 1 continued

<i>Authors, intervention, quality/details</i>	<i>Description (treatment group)</i>	<i>Outcome following treatment</i>
Greene, Nicol, & Jamieson (1979); RO ABA, 3 Ss, No statistics	"Personal Orientation Questionnaire" for each person. (Time, place, <i>current affairs</i> , family, friends, history.)	Increased orientation, generalising to other areas of behaviour (especially other items of information).
Goldwasser, Averbach, & Harkins (1987), RT RCT, 30 Ss (RT = 10, SS = 10, C = 10)	Topics: food, family personal artefacts, jobs, songs, music, celebrations.	Increased depression. Insignificant improvement in cognition. No significant change in behaviour.
Baines et al. (1987); RT RCT, 15 Ss (RT = 5, RO = 5, C = 5)	<i>Old photos (local scenes, personal)</i> , books, magazines, newspapers, domestic articles.	Insignificant decrease in information/orientation after RT. Insignificant improvement in behaviour. Positive staff reports, e.g., got to know people better.
Orten, Allen, & Cook (1989); RT RCT, 56 Ss (RT = 28, C = 28)	Structured topics, covering life-span. Pictures and memorabilia discouraged.	Insignificant improvement in social behaviour. Group differences attributed to experience of leaders.
Kiernat (1979); RT ABA, 23 Ss	<i>Topics in chronological sequence. Multisensory materials</i> , e.g., popped corn to add sound and smell to circus discussion. <i>Pictures</i> , recordings, historical items.	Positive qualitative results, e.g., initially only responded to direct questions from staff. Later responded to other residents without prompting.
Gibson (1993); RT 5 individual case studies.	<i>Chronological events, family life and work</i> , major life crises, landmarks and transitions, place lived and visited.	"Staff became excited, intrigued and fascinated with the person's past." "Music especially evocative."
Zarit et al. (1982); Cognitive stimulation RCT, 35 Ss (and caretakers) in 3 groups (didactic training, problem solving, control)	Didactic training: Forming mental images of words, linking words with images. Problem-solving: Practical management of daily problems, e.g., notebooks, calendars.	Small and short-lived changes in memory performance. Increased depression in caregivers.

<i>Authors, intervention, quality/details</i>	<i>Description (treatment group)</i>	<i>Outcome following treatment</i>
Koh et al. (1994); "3R Mental Stimulation" CT, Quasi-randomised. 39 Ss (E = 15, C = 15)	Basic elements of RT, RO and remotivation. <i>Weekly discussion topics, e.g., money, hobbies, pets, fruit, and festivals. Stimulated all senses.</i>	Significant improvement in mental state score.
Quayhagen & Quayhagen (1989); Cognitive stimulation given on one-to-one basis by caregivers. Non-randomised.	<i>Communication exercises: Conversation skills, facts, opinion, etc.; memory-provoking techniques: verbal and non-verbal; problem- solving exercises: planning/categorisation.</i>	Qualitative findings reported by caregivers: improved emotional status of patients, maintenance over time in aspects of cognitive functioning. No improvement in carer well-being.
Bourgeois (1990); Memory training ABA, 3 Ss	Developed prosthetic memory aids: plastic wallets containing information of personal relevance (photos, daily schedule, etc.).	Content and quality of conversation doubled or tripled, but highly qualitative with Likert ratings.
Toseland et al. (1997); VT RCT, single blind, 88 Ss (VT = 31, SC = 29, C = 28)	Four segments. (1) Warm greetings, hold hands, sing songs. (2) Focus on topic of interest, reminisce. (3) Activity, e.g., poetry. (4) Refreshments, goodbyes. Used Feil's validation approach throughout.	Limited support for VT. Staff reported reduced physically and verbally aggressive behaviour (not reported by observers). No change in medication, physical restraint, or nursing time needed.
Bleathman & Morton (1992); VT Qualitative accounts, 20 groups	Welcoming, hand-shaking and holding, <i>singing</i> , discussion (on planned theme), closing song, thanking, refreshments. Roles given, e.g., song leader, welcomer, and hostess.	Individual observations, e.g., one person expressed empathic understanding, another expressed the desire to kill herself.

RCT = Randomised Controlled Trial, CT = Controlled Trial, ABA = Repeated measures (ABA) design, Ss = Subjects, RO = Reality Orientation group, RT = Reminiscence Therapy group, VT = Validation Therapy group, SC = Social Contact group, SS = Social Support group, ST = Social Therapy group, CS = Cognitive Stimulation group, Significant =  $p < .05$ , E = Experimental group.

Studies which did not include this information were excluded from these tables, as they provided little insight into which features of each intervention might be more or less beneficial. Studies with positive outcomes were drawn out from the tables, and the contents of the intervention examined. Through this process, potentially beneficial elements of each type of therapy were identified, and were incorporated into the design of the new programme. Priority was given to studies with stronger design methodology, such as RCTs. In Table 1, the studies and elements which contributed to the design of this programme are highlighted in italic type.

The most influential study in the design of this programme was that of Breuil and colleagues (1994). This was a single blind RCT, demonstrating the strongest improvements in cognition and memory of all the trials examined. Additionally, it weighted the results of the Cochrane review, being the largest study. The authors described their technique as "Cognitive Stimulation", although others (Holden & Woods, 1995) have compared it to RO. Subjects attended 10 hourly therapy sessions; activities included connecting dots to form pictures of common objects, drawing common objects from different perspectives, associated words, and naming and categorising objects.

### Design of the package

The five "guiding principles" of the programme, developed from the literature search and the extensive clinical experience of the research team, were as follows:

1. Experiential learning involving the use of all five senses to promote cognitive stimulation and memory processes.
2. Focused psychological interventions which address the difficulties of everyday living.
3. Acknowledgment of the emotional lives and enhancement of the cognitive skills of people with dementia.
4. Implicit learning (familiarity and "intuition"), rather than explicit "teaching". Extensive rehearsal and consolidation of essential information about themselves and their world are thought to be most beneficial.
5. The reciprocal, psychological process (involving cognitive and emotional states) in which people with dementia and those who care for them learn more about each other's capabilities and vulnerabilities.

These principles were observed when designing and running the groups, and draw in part on the understanding of dementia set out by Kitwood (1990). Kitwood offered a deeper insight into dementia care, emphasising the

importance of treating people with dementia as individual adults, with much to contribute when staff are able to recognise their "personhood" (Kitwood, 1997; Woods, 1999). These principles were vital in ensuring that the programme did not repeat the insensitivity and rigidity that became associated with some applications of RO (Dietch, Hewett, & Jones, 1989; Gubrium & Ksander, 1975).

A 15 session programme was designed with four phases; (1) The senses, (2) Remembering the past, (3) People and objects, (4) Everyday practical issues. Sessions were planned to last 45 min, commencing with a 10 min "introductory phase", where the group was to be welcomed, the "theme song" sung, and tea and biscuits consumed. The "intervention phase" was to be of 25 min duration, with sessions ending with a 10 min "consolidation phase", where the discussion and ideas were to be summarised, the theme song sung again, and farewells said.

### Phase 1: The Senses

This phase involving sound, vision, smell/taste, and touch used multisensory stimulation, which has been used successfully in other programmes. Sensory elements were introduced, to be continued in all subsequent sessions ("theme tune", scented candle, unusual biscuits, lava lamp). This aimed to help identify the abilities of the group, create a sense of continuity, and to differentiate the sensory experience of these sessions from usual activities.

### Phase 2: Remembering the past

This phase concerned growing up, work and home, and recent years. The RT review was inconclusive, but there was strong clinical support and evidence from other studies for the benefits of reminiscence; that people enjoy it, and that it increases interaction and engagement (Gibson, 1993; Woods & McKiernan, 1995). Hence these chronological reminiscence sessions were incorporated into the programme.

### Phase 3: People and objects

This phase, recognising people from the past, recognising people in the group and staff members, recognising people in the family, familiar and modern objects, and using familiar objects, was based on Breuil et al.'s (1994) study, which placed great emphasis on the use of common objects, and naming and categorising objects. Naming objects was also used by Woods (1979), as part of an RO programme. Breuil et al.'s use of associated words was incorporated into the sessions on people.

#### Phase 4: Everyday practical issues

This was a general orientation phase, with a session on identifying and using money (also used by Koh et al., 1994), and a session on knowing your way around. The final session was designed as a summing up and consolidation session, ending with a tea party.

### THE PILOT STUDY

#### Method

The programme was piloted in a day centre and three residential homes. The research team had existing clinical links with the day centre and one home, and Jewish Care put forward two of their homes to participate. Ethical approval was obtained through the appropriate NHS research ethics committee.

Inclusion criteria were as follows:

1. Diagnosis of dementia according to DSM IV criteria; the sub-type of dementia was not evaluated, as the programme was designed to be used with the typical residential and day-care population, where reliable information of this type is often not available, and many mixed dementias are found.
2. No severe hearing or visual impairments which might affect the participant's ability to co-operate in a group.
3. Some ability to communicate and understand communication (a score of 1 or 0 in questions 12 and 13 of the CAPE Behaviour Rating Scale; Pattie & Gilleard, 1979).
4. No serious health problems that could affect the ability to attend groups.
5. No challenging behaviour that could disrupt group activities (loud or constant talking, wandering about, etc.).

All participants were assessed in the week prior to the first group session, and the week following the final group session. Staff and carers completed the relevant assessment forms at the same times. Data collected included demographic details and a range of scales for subjects and carers. Thirty five participants completed the first assessment, 12 from the day centre and 23 from the three residential homes. Their mean age was 85.7 years ( $SD = 6.7$ ), ranging from 71 to 95 years. The treatment group comprised six participants from the day centre, and five from each of the three homes. Four of the treatment group and four of the controls were not assessed at follow-up. Reasons for attrition included refusal (3), ill health (4), and the person moving away (1). Thus baseline and follow-up data are available for 10 participants in the control group and 17 in the experimental group. Ten family care givers of people attending the day centre took part, with staff completing the relevant

assessments for the two day-centre attenders without carers and for participants in the residential homes. Participants were randomly allocated to treatment and control groups in each setting, by drawing names from a sealed container. Treatment groups were led by a member of the research team, with a staff member from the home/centre as co-facilitator, in a separate room. Participants in the control groups received usual care during the group sessions.

### Instruments

1. *Mini-Mental State Examination* (MMSE; Folstein, Folstein, & McHugh, 1975): A brief test of cognitive function, with good reliability and validity. It is widely used in the evaluation of psychological therapies, enabling this study to be easily compared to others.
2. *Alzheimer's Disease Assessment Scale—Cognition* (ADAS-Cog; Rosen, Mohs, & Davis, 1984): A more sensitive scale measuring cognitive function, which includes additional items assessing short-term memory. It is frequently used in drug trials as the principal cognitive outcome measure.
3. *Holden Communication Scale* (Holden & Woods, 1995): Completed by staff, this covers the patient's social behaviour and communication, including conversation, awareness, pleasure, humour, and responsiveness.
4. *Clinical Dementia Rating* (CDR; Hughes et al., 1982): Completed by the researcher, this provides a global rating of dementia severity, including memory, orientation, judgement and problem solving, communication skills, domestic skills, and personal care.
5. *Cornell Scale for Depression in Dementia* (Alexopoulos, Abrams, Young, & Shamoian, 1988): This evaluates depression in dementia (mood-related signs, behavioural disturbance, physical signs, biological functions and ideational disturbance) using information from clinician's interviews with carers and patients.
6. *Rating Anxiety in Dementia* (RAID; Shankar, Walker, Frost, & Orrell, 1999): Rates anxiety from interviews with carers and patients. Categories are worry, apprehension and vigilance, motor tension, autonomic hypersensitivity, phobias, and panic attacks. It has good reliability and validity.
7. *Behaviour Rating Scale* (from the Clifton Assessment Procedures for the Elderly, CAPE; Pattie & Gilleard, 1979): Completed by the carer, this evaluates general behaviour, including personal care, behaviour towards others, and level of dependency.
8. *General Health Questionnaire* (GHQ-12; Goldberg, 1978): A standard self-report scale which has been frequently used to measure carer mental health, with demonstrated validity and reliability.
9. *Relative's Stress (RS) Scale*. (Greene, Smith, Gardiner, & Timbury, 1982): This evaluates carer stress arising specifically from care giving.

## Results

An analysis of covariance was used to compare the follow-up score between groups in each test, with baseline score as the covariate (Table 2). The programme was associated with positive trends in cognition, demonstrated by the ADAS-Cog and MMSE. Anxiety (measured by the RAID) and depression (Cornell) both fell in the treatment group and rose for controls, the Cornell reaching significance. Behaviour (BRS) and communication (Holden) declined marginally in both groups. The severity of dementia (CDR) increased for controls, demonstrating an overall decline in this group. Two scales examined the effect of the programme on carers. Care-giving stress (RS) increased slightly in the treatment group and more substantially for controls. There was a significant improvement in carers' general psychological distress in the treatment group (GHQ), with little change for the controls.

## REVIEW AND MODIFICATION OF THE PROGRAMME

### Phase 1: The senses

There were a number of difficulties encountered with this phase. It proved problematic to find particular smells, tastes or visual material which most people could identify and/or relate to. People appeared to enjoy feeling different textures in the tactile session, although the predominantly male group in one of the residential homes did question the "point" of this activity. On the positive side, these sessions generally focused on pleasant sensations, not highlighting people's areas of deficit. They offered a gentle introduction to the programme, allowing the co-ordinators to judge how people responded and their potential limitations. However, it appeared that isolating the senses in this way was highly artificial, as most real-life experiences are multisensory. Asking a person with dementia, for whom sensory abilities are already impaired, to identify something when provided with information from only one sensory modality was evidently unrealistic. Accordingly, the senses phase, as such, was not included in the modified programme, but an attempt was made to introduce multisensory material implicitly throughout the programme.

### Phase 2: Remembering the past

Sessions on childhood stirred clear memories, and were generally successful. As later life was discussed, memories tended to fade and discussion frequently reverted back to childhood. Introducing newspaper articles as prompts for discussion on different eras was unsuccessful. People had little memory for historical information where it held no personal meaning for them. Individuals varied enormously in their reactions to "old" objects from the "reminiscence

TABLE 2  
Means (and standard deviations) for each group at baseline and follow-up, extent of changes on each scale,  
and test of between group difference at follow-up

Variable assessed	Test used	Baseline scores Treatment control	Follow-up scores Treatment control	Change (+: positive direction, -: negative)	Between group differences: Ancova
Cognition	MMSE	11.5 (4.4)	14.6 (5.5)	+3.1	$t = -1.8$
		15.5 (4.4)	15.5 (5.5)	0	$p = .08$
	Adas - Cog	63.5 (11.9)	67.8 (12.6)	+4.3	$t = -0.9$
		71.7 (14.5)	70.7 (14.5)	-1	$p = .4$
Anxiety	RAID	9.7 (10.2)	6.6 (5.7)	+3.1	$t = 1.7$
		8.1 (3.2)	11.3 (8.9)	-3.2	$p = .09$
Depression	Cornell	8.1 (7.1)	5.5 (3.8)	+2.6	$t = 2.6$
		7.3 (2.6)	9.5 (6.7)	-2.2	$p = .02^*$
Communication	Holden	13.2 (7.2)	13.9 (7.7)	-0.7	$t = -0.2$
		12.6 (6.8)	13.1 (6.5)	-0.5	$p = .9$
Behaviour	BRS	13.4 (4.2)	14.5 (4.4)	-1.1	$t = -0.5$
		12.7 (5.1)	13.3 (4.9)	-0.6	$p = .7$
Global	CDR	2.1 (0.7)	1.9 (0.5)	+0.2	$t = 1.3$
		0.9 (0.6)	1.9 (0.7)	-1	$p = .2$
Carer (N = 10)	RS	29.0 (4.6)	30.0 (11.9)	-1	$t = 1.1$
		24.0 (18.8)	33.0 (18.8)	-9	$p = .3$
	GHQ	4.8 (2.8)	1.0 (0.8)	+3.8	$t = 2.8$
		5.7 (3.1)	6.0 (3.6)	-0.3	$p = .04^*$

Treatment group scores are in standard font, control group scores are in italics. \*  $p < .05$

box" with some often reverting back to the "old days", and others more interested in the here and now. Thus, for example, a "dolly peg" may not generate enthusiasm, as people are unlikely to have strong emotional memories of this object; indeed, a person with dementia may not be aware that this is even an unusual or old-fashioned item. On the other hand, showing people a mobile phone and demonstrating the different sounds it makes generated great enthusiasm in the pilot study. It is intended that the new programme provides scope for reminiscence as a natural component of the entire programme, in that all activities may create scope to reminisce; for many, talking about their past was an important way to contribute. A specific session on early memories has been retained.

### Phase 3: People and objects

People enjoyed both taking and discussing pictures of themselves, the staff and their families. The pictures of famous faces were less successful, as people were sometimes only able to recognise very few faces, hence this session has been modified for the new programme. Attempting to "teach" each others' names through the use of name-badges and rehearsal was perceived as patronising, and created hostility, and so will not be retained. The session on using objects, which involved either making an apple crumble or changing a fuse, was an excellent way of enabling a number of people actively to engage in a collective task. Many appeared fascinated when demonstrated the use of various modern objects, such as a mobile phone and personal CD player.

### Phase 4: Everyday practical issues

Guessing the prices of modern objects in the session on using money created laughter and debate. The orientation session involved collectively creating a plan of either the home, day centre or local town. This generated optimal input from all the groups. Constructing these sessions in a game-like way appeared to be enjoyable and non-threatening for the group. Using the day's newspapers, particularly those containing lots of pictures, was extremely evocative. The group responded better when given concrete material to discuss, such as the money quiz and the creation of the map of Britain, and in the modified programme, all discussion is accompanied by specific aids or activities.

### Responding to different levels of ability

Based on the reactions of the four groups, it was clear that provision needed to be made for differing levels of ability. In the modified programme, most sessions are presented at two levels, depending on the ability of the group. Although for most groups, a combination of these two levels should be used,

the more able groups might focus more on level 1 and the less able, on level 2. The modified programme is shown in the Appendix.

## DISCUSSION

This study shows that it is feasible to develop a programme of psychological therapies, based on systematic evaluation of the literature and a careful appraisal of the evidence for effectiveness. The programme was popular and generally well tolerated. Positive trends in cognition, depression and anxiety were demonstrated. There were minimal changes in behaviour and communication. In the limited day-centre sample, relatives' stress increased in the control group, and there was an appreciable improvement in relatives' general psychological distress in the treatment group. If the findings in carers were to be supported by our larger study this would add further value to the programme and be the first replication of Greene, Timbury, Smith, and Gardiner's (1983) report of the impact of RO on relatives' stress in a day-hospital context.

The American Psychiatric Association, in their 1997 Practice Guideline on the treatment and management of dementia, suggest that the small gains associated with cognitive approaches such as RO do not justify the risk of negative effects. On the other hand, Gatz et al. (1998), using American Psychological Association criteria conclude that "reality orientation is probably efficacious in slowing cognitive decline". They point out, as we have acknowledged, that cognitive approaches can be implemented without sufficient sensitivity to the patient, leading to possible frustration and distress in the patient. So far, under the relatively controlled conditions of the pilot study, it appears that our efforts to develop a cognitive programme that is respectful and sensitive have borne fruit, in that participants' affect appeared to improve as well as cognition. Given that RO is the first psychosocial approach to dementia to find support from a Cochrane systematic review, we would argue that the effort to ensure any programme we develop is delivered appropriately is worth while.

## Limitations

Problems in scheduling sessions were encountered in the day centre, as only around 10 clients attended each day, and activities tended to occur at all times. It was sometimes difficult to invite half those attending to the other room, essentially splitting them up from their friends and taking them away from whatever activity they might be engaged in. Additionally, the staff, who had received extensive training in dementia care, appeared slightly disappointed that parts of the programme involved elements found in their daily activities, perhaps expecting something "new and improved". These problems did not occur in the residential homes, as people were typically taken out of a lounge of up to 30 people, other activities seldom occurred, and staff did not have the

unusually large amount of training found in the day centre. The context in which any intervention occurs has a great influence on it (see, for example, Woods, 1994, p. 441).

These early results must be interpreted with some caution. The population was small, and random allocation did not produce samples that were well matched, with the treatment group scoring lower in cognition and higher in anxiety and depression than controls at the outset. Although the analysis of covariance statistically adjusts for differences at baseline, these two slightly different populations could potentially have differed in their reaction to the programme. Additionally, there was the possibility of rater bias, as assessments were conducted by the group coordinator, staff and carers, all aware of group allocation. The treatment group inevitably received more attention than the control group, and an attention-placebo control would provide a stronger test of the specific efficacy of the procedures used. This may be especially the case for the residential homes, where there were relatively few alternate activities. Although numbers are too small for a comparative analysis, the results appeared more positive from the day centre than from the residential homes, despite the evident difference in existing stimulation and activity in the two contexts.

The results included here are presented as preliminary and in need of replication, although we have attempted to use a conservative statistical analysis to reduce the risk of overstating the current findings. We were not able to control for other factors that might have led to between-group differences, e.g., health changes, changes in medication, etc., although we have no reason to suspect that these were more likely in one group than the other.

Given the weight afforded by the Cochrane review to the cognitive stimulation work reported by Breuil et al. (1994) we have made a detailed comparison of our approach with the on-going programme of cognitive stimulation on which their report was based, led by Jocelyne de Rotrou, neuropsychologist at the Hospital Broca in Paris. There, people attend twice weekly sessions which are similar to traditional RO groups, with a large component of each session involving people engaging in a cognitive task, such as calculating the price of a shopping list. The Paris participants and our samples differed in the severity of dementia and their attitude to their cognitive difficulties. In Paris, people who had recently been diagnosed with dementia were attending groups with the aim of improving their cognition and allowing them to function independently. People in long-term residential care may have different attitudes towards their cognition, or indeed be less aware of its failings. For this reason, sessions in our programme are presented in a "game-like" manner, involving teams; so that cognitive stimulation is less overt, and individual failings are not so apparent. Explicit memory, as in learning the names of other people in the group, or seeking recall of specific historical events, led in our programme to participants potentially being exposed to the extent of their difficulty. The primary focus of

the modified programme is on harnessing implicit memory, emphasising active engagement with materials and the plentiful provision of retrieval cues. This minimises conscious memorisation, with the danger of overt failure and promotes general cognitive stimulation and individual well-being.

### Future plans

Using the modified programme, a large multi-centre, randomised controlled trial is now under way. This trial also includes a quality of life measure and an economic evaluation of the programme. The programme now divides sessions into "levels", to cater for groups of different abilities. A detailed manual to accompany the programme is being prepared (available from the authors) which should provide the group leader with both a choice of content for each session, and activities to suit a range of abilities.

This study has described the development, piloting and modification of an evidence-based package of cognitive-based therapies for people with dementia. Benefits in the pilot study include improved cognition, and reduced anxiety and depression following treatment. Perhaps just as important, there were no evident negative effects on the person with dementia or his/her relatives. This paper demonstrates that an evidence-based approach, tempered with the input of experienced clinicians, is feasible, but replication of these preliminary findings with a larger sample size and more rigorous methodology is needed before it can be claimed that they add to the evidence-base for the benefits of cognition-based psychological therapies for people with dementia.

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## APPENDIX 1

### At beginning of each session:

1. Five minute warm-up, such as soft ball game. When throwing the ball, people may either state their own name or (for the more able) the name of the person they are throwing the ball to.
2. Discuss the day, month, year, season, time, name and address of home.
3. Short-term memory prompts, such as asking people what they had for breakfast/lunch, what they thought of yesterday's weather.
4. Discuss something that is currently in the news.

### Sessions

1. Physical game, such as rollaball or indoor boules, which involves teamwork. This should be a relatively relaxed activity for the first session, incorporating movement, touch and score calculations.
2. Sound: Sound effects tapes, which include different categories, such as "indoor sounds" and "outdoor sounds", to be matched with the correct picture. This provides people with both visual and auditory stimulation, making the task easier. Percussion instruments given to each person in the group, to be played with music (such as popular 1940s music).
3. Childhood: Activities include people filling out a sheet asking their name, father's name, mother's name, schools attended, etc.; construction of their childhood bedroom or house on a board; and demonstrating the use of old-fashioned childhood toys.
4. Food: Using miniature grocery replicas which have been priced, give people a budget and a scenario, e.g., dinner for four. Alternatively, categorise these objects, e.g., different mealtimes, special occasions, savoury foods. Additionally, eat food with reminiscent or personal meaning, and brainstorm food categories on the whiteboard.
5. Current affairs: Discuss issues from a selection of the day's national and local newspapers, and picture magazines. Use cue cards to evoke conversation on news, views, attitudes, dreams and aspirations.
6. Faces/scenes: To reduce the attentional problem of only one person being able to look at each picture at a time, multiple sets of the famous faces cards (added to more modern pictures) have been created. Give people four cards. Ask them to identify named person/scene. Ask opinions, e.g., most beautiful, oldest. Attempt to use opinions to generate memories for names.
7. Associated words/discussion: Sentence completion task. Includes amounts (e.g., a cup of . . .), famous couples (e.g., Laurel and . . .), famous places (e.g., Westminster . . .). Use "Golden Expression" cards to stimulate discussion, e.g., "What do you think of medicine today?"
8. Using objects: Creative session, such as cookery. Multiple tasks enable all to participate (e.g., greasing bowl, mixing ingredients, making crumble mixture, peeling and slicing apples).
9. Categorising objects: People think of words beginning with a particular letter (picked from a card) in a particular category (picked from a card). Alternatively, brainstorm categories on board.

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10. Orientation: Construct map of England, local area or home on whiteboard. Fill in the "map" by asking the group to suggest different places or landmarks, such as the post office, and draw them in the appropriate position.
11. Using money: Use laminated cut-outs of common objects from a catalogue, with prices on the back. Tasks could involve guessing the prices, adding prices (how much will the bill be?), or matching the pricetag with the object.
12. Number game: involving the recognition and use of numbers.
13. Word identification game ("Hangman"): involving the recognition and use of letters and words. Draw a number of dashes for each letter of a word, and ask the group to guess the letters. Incorrect letters contribute to the drawing of a "hangman" and losing the game. The group is required to guess the word.
14. Team games: divide the group into two teams, ask them to choose a team name, and play trivia quiz. Give prizes to all the group, and say farewells.

Manuscript received August 2000

Revised manuscript received October 2000

# Developing an evidence based therapy programme

Aimee Spector, Martin Orrell, Stephen Davies and Bob Woods report on the development and initial evaluation of an evidence-based therapeutic programme for people with dementia.



Aimee Spector (above) is a Research Fellow and Dr Martin Orrell a Reader in Psychiatry of the Ageing, in the Dept. of Psychiatry and Behavioural Sciences, University College London; Stephen Davies is Consultant Clinical Psychologist, Services for Older People at Princess Alexandra Hospital, Harlow; Bob Woods is Professor of Clinical Psychology of the Elderly, University of Wales.

The use of various psychological interventions for people with dementia has been discussed since the late 1950s (Cosin *et al* 1958). Reality Orientation (RO), the presentation and repetition of orientation information (time, place and person-related), was developed in its earliest form in 1958 (Folsom 1966); it has since become the most widely evaluated approach and perhaps the most criticised (Powell-Proctor & Miller 1982). Butler (1963) defined Reminiscence Therapy (RT) as "Vocal or silent recall of events in a person's life, either alone, or with another person or group of people." RO and RT have subsequently become common group techniques for dementia, yet practically no UK research on either has been conducted since the mid 1980s.

More recently, other techniques have attracted interest, notably Feil's (1967) validation therapy (Toseland *et al* 1997), memory training strategies (Zarit *et al* 1982), and sensory stimulation (Spaull *et al* 1998). In the past four decades, these various approaches have been applied, evaluated, discussed and criticised. It is unclear how often each is used in practice, although evidence indicates that RO has lost some popularity since the 1980s, and RT is probably the most widely applied approach.

## Randomised controlled trials

The aim of our project was twofold. Firstly, we intended to scrutinise the literature, separating trials of weak design and poor methodological quality from those of scientific rigour and positive outcomes. Subsequently, we would begin the task of filtering out the more successful elements of each intervention. Once identified, our next aim was to design and pilot our own "evidence-based" package of therapies for dementia, hence applying theory into practice. Increasingly, clinicians and decision-makers are looking for evidence-based interventions: interventions for which there is clear evidence of effectiveness from randomised controlled trials (RCTs). By randomly allocating subjects to treatment and control conditions, minimal bias can be expected. This type of design is becoming an integral part of modern research and practice.

We conducted two systematic reviews

(Spector *et al* 1998a,b) examining the evidence from existing research for the effectiveness of RO and RT for dementia. The RO review, combining the results from six RCTs, showed that RO can result in both cognitive and behavioural benefits for dementia sufferers.

The RT review found that only one existing study was sufficiently well designed and conducted to meet the criteria for inclusion. As a result, there was insufficient scientific evidence to reach conclusions about the effectiveness of RT. This highlighted the urgency for further well-designed clinical trials of RT. Despite this, the numerous qualitative and anecdotal, highly positive accounts of RT were acknowledged (Gibson 1993).

A systematic review of the effectiveness of validation therapy (Neal & Briggs 1998) found two RCTs, and so suggested that more randomised controlled trials are needed for the evidence of its effectiveness.

## Extracting effective elements

Having completed a thorough search for the available literature on all the interventions described, we developed a systematic process for identifying and extracting the most effective elements from each intervention, going through each relevant study in turn. These elements were integrated into the development of an "evidence-based" therapy programme for people with dementia.

Other factors which were also considered when designing the programme included discussions with experienced clinicians, salient qualitative research, and the outcomes of the systematic reviews. The resulting programme involved elements of RO, RT, cognitive stimulation and sensory stimulation. The structure of the programme was divided into four phases:

- 1) The senses
- 2) Remembering who you are
- 3) People and objects
- 4) Everyday practical issues.

It was largely based on the approach of Breuil *et al* (1994), who found that a randomised controlled trial of cognitive stimulation led to significant cognitive improvements for people with dementia.

In addition, we developed five "guiding principles", which were observed

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when designing and running the groups. These indicated that the most therapeutic factors were:

- experiential learning involving the use of all five senses to promote cognitive stimulation and memory processes;
- focused psychological interventions which address the difficulties of everyday living;
- acknowledging the emotional lives and enhancing the cognitive skills of people with dementia;
- implicit learning (familiarity and "intuition"), rather than explicit "teaching";
- the reciprocal, psychological process in which people with dementia and those who care for them learn more about each other's capabilities and vulnerabilities.

The initial 17-session programme was conducted twice weekly at a day centre in Essex. Of the 12 participants involved, all diagnosed with dementia, six were randomly allocated to the treatment group (although one dropped out), and six to the "no-treatment" control group (but one left the centre).

### Promising results

Assessments were made before and after the intervention. Results were extremely promising, with significant improvements in cognition, and reductions in depression and anxiety following treatment. There was also an improvement in carers' general health following treatment; and qualitative data noted the development of friendships.

The programme was subsequently modified, and run in three residential homes. The residential results were combined, and there were indications that the treatment group had improved compared to the controls. However, the benefits were less evident than in the day centre group.

Various practical problems were experienced in residential care, including a higher rate of dropout. This may be expected as the population tends to be more frail. The programme was aimed at people with mild to moderate dementia, making recruitment in residential care more difficult, because severity of dementia was greater than in day care. For a proper statistical analysis, a much larger sample size will be needed. We are currently modifying the programme for a multi-centre trial. This will run in a large number of day centres and residential homes over the next two years, particu-



*We aspire to developing a programme that will help to slow cognitive decline, but also be enjoyable and stimulating for people, improving their mood*

larly in the Barking, Havering and Brentwood area.

We were very pleased to see that people enjoyed these groups. This enjoyment was expressed, for example, in the memory diaries written in one of the residential groups over the course of the programme. Comments recorded in the final session included "A meeting sadly for the last time, I have enjoyed our getting together"; "Today has been the last group. We've had a lovely time"; "I enjoyed the social gathering and being with the other people."

We aspire to developing a programme that will help to slow cognitive decline, but also be enjoyable and stimulating for people, improving their mood. Many people with dementia feel isolated because they have difficulty with social interactions.

### Future plans

Much of the research in the past has been poorly defined and also confined to academic literature. This means that often good work has not been translated into practice. If our study shows that the programme has been successful, we intend to disseminate our work by providing training courses for staff working with people with dementia. By following a protocol, which will include clear guidelines for individual differences and choices of activity within each session to suit the particular group, staff will be

shown how to apply this programme in practice. This training programme will also be evaluated to see that it is being done effectively. We hope that this will be a simple and effective way of improving quality of life and dementia care in the future.

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Aimee Spector is currently supported by a Research Fellowship funded by Brentwood, Havering and Barking NHS Trust. This project was funded by a grant from North-Thames NHS Executive.

# Appendix C:

# Letters/Forms

**Information Sheet: Evidence-based psychological therapy programme for people with memory problems**

This project looks at the effects of activity groups for people with memory problems. It takes place in a number of day centres and residential homes in London and the South-East area, hoping to find out which things help older people cope with memory problems. We would like to invite you to participate in our project.

Taking part would involve being interviewed for about 45 minutes, using standard forms. Some people would then be allocated to the groups, which will involve attending two 45-minute sessions per week for 7 weeks. Other people will not be involved in the groups, and will continue with normal activities during these times. Allocation to the groups will be entirely random. The groups will be interesting and varied, involving discussion, games, quizzes, cookery etc. They should be enjoyable and will usually involve people you know. The aim of the groups is to help memory and for us to learn what works best. No medication is involved, therefore it is very unlikely that there will be any side effects. However, very occasionally people may feel slightly frustrated or distressed by some of the activities if they have difficulty with them, and this may last for a few minutes. After 7 weeks, we will talk to you again. Eventually, we hope to train staff working with people with memory problems, so that they can also run groups like these, to help people to have more stimulating and varied lives. By taking part in this important study, you will be helping numerous other people in the future, as we hope that this project will influence health and social services to provide the care, support and stimulation needed by people like yourselves.

Taking part is your choice, and if you do not it will not affect your treatment in any way. You can leave the project at any time, without having to explain why. Information obtained from your interviews is confidential, your name will remain anonymous to all involved, and the outcome of the interviews will not affect you in any way. If you have any concerns or questions about this research, please contact AS or LT (telephone numbers provided).

**Participant Consent Form: Evidence-based psychological therapy programme for people with memory problems**

- (1) I know that the trial is designed to help the care of older people. I am aware that I may withdraw my consent at any stage, without having to explain why, and that any information obtained from me will remain entirely confidential. I know that my participation in/withdrawal from this project will not affect my usual treatment in any way.

I had a written explanation about this research (attached to this form). Any questions have been answered for me by AS or LT.

I agree/do not agree to participate in the project.

Signed: .....  
.....

Date:

- (2) WITNESS (a member of staff from the Centre) to signature of participant, and to the fact that (s)he has read the supporting document and freely given her/his consent.

Signed: .....  
.....

Date:

- (3) I (member of project team) confirm that I have explained to the participant the nature and effects of the trial.

Signed: .....  
.....

Date:

**Letter to residential homes / day centres**

*London, xx.yy.xx*

Dear sir / madm,

Following conversations with Dr X and Dr Y in Camden & Islington Community Health Services NHS Trust, we are now contacting all residential homes and day care facilities for the elderly in Camden and Islington. This is to find out which are interested in participating in a project examining the effects of a group therapy programme on people suffering from early stages of confusion or dementia. This involves running groups and conducting short assessments before and after to see what, if any, effects the groups had on them.

**What we offer:**

- Full individual assessments of cognition and quality of life at the beginning and end of the project.
- 14, 45-minute sessions which involve activities to stimulate cognitive abilities, reminiscence and reality orientation. They are aimed at being interesting and fun, and we have found that people usually enjoy the groups and that they have positive effects on behaviour, mood and cognitive function. Sessions run twice a week for 7 weeks. We bring in all the equipment needed.
- An opportunity for staff to learn more about running groups for people with dementia.

**What we need:**

- A minimum of 8 people with mild dementia who fit our inclusion criteria (see attached sheet).
- A member of staff to run the groups with us. We hope that this might be a training mechanism for staff, and that the activities might be continued after the programme is completed.
- The manager or a senior staff member to complete questionnaires, which examine the person's use of services. This takes approximately 10 minutes per questionnaire, so with 8 people it would take about 1 ½ hours. This needs to be done at the beginning and end of the project, to identify any changes.
- A member of staff to complete questionnaires which examine the person's communication, behaviour, anxiety and depression. Again, these take approximately 10 minutes per questionnaire (approximately 1 ½ hours in total), and need to be done at the beginning and end of the project, to identify any changes. It is essential that we take the staff's perspectives into consideration.

Once we have identified 8 or more suitable people, half will be randomly placed in the group, and the rest will continue with their usual routine. Comparing these two groups helps us to see whether the programme makes a difference. The groups need to be held in a separate, quiet room. We hope with our research to find evidence that running groups with people with dementia is worthwhile and has a positive effect on them and their surroundings. We also aim to develop a practical and simple package, which everyone who wants to run groups with people with dementia can use.

If you are interested in participating in our project, we would be most grateful if you could run through the enclosed flow chart with your list of residents. This should help to identify whether you have enough suitable people to run the project. If you think you have, we will come in for a few hours and do a preliminary assessment, to see whether or not there are enough people. We have also included an information sheet and consent form. Please keep this and we will discuss it further on the phone.

If you are interested in us running a group in your day centre, please do get in contact with us on the above address, or telephone LT.

Thank you very much for your time.

Yours sincerely,

AS, LT

# Appendix D:

Miscellaneous

## **Glossary**

*Randomised Controlled Trial (RCT)*: Involves the random allocation of participants to two or more conditions, including a control group that receives no treatment, an alternative treatment or a placebo. They are considered the most methodologically sound and controlled for bias.

*Controlled trial (CT)*: As above, but without random allocation.

*Double blind*: (a) Assessors are unaware of the treatment given to participants and (b) participants are unaware of the treatment they have received.

*Single-blind*: Either (a) or (b).

### **Maintenance Programme**

- 1) Childhood. Questions from the memory diaries were used as prompts for discussion. (e.g. “describe your childhood bedroom”.) Use of childhood toys and games.
- 2) Current affairs (1). Duplicate copies of discussion-provoking articles from newspapers were used to generate opinion and debate.
- 3) Current affairs (2). As above.
- 4) Using objects (1). This involved making a chocolate cake.
- 5) Number game (bingo).
- 6) Quiz, involving two teams.
- 7) Music session. This involved the playing of musical instruments, singing along to old songs and a ‘song completion game’, where people are given the 1<sup>st</sup> few words of a song and are asked to sing the remainder.
- 8) Physical games, such as hoopla, skittles, boules and football. The group were encouraged to calculate the scores.
- 9) Categorising objects. New ‘odd one out’ sheets were used, in which 4 words were presented on a sheet and the group required to guess the odd one out. The topix game was used again (naming objects beginning with a particular letter in a certain category).
- 10) Using objects (2). The reminiscence kit and modern objects (such as a mobile phone) were looked at and discussed.
- 11) Useful tips. A book called “what our grandmothers knew” was used to generate a discussion of useful tips, e.g. soothing burns, treating milk.
- 12) Golden expressions cards (1). Cards asking discussion-provoking questions were passed around the group. E.g. “what is your favourite charity?” “How are elderly people treated by society?”
- 13) Golden expressions cards (2). As above.
- 14) Opinions on different types of art. Pictures from a calendar were used to ask people’s opinions, e.g. on modern and impressionist art.
- 15) Famous faces (2). Pictures of people from the past were used to make comparisons and to generate discussion.
- 16) Word completion (2), from life expression book. E.g. completion of proverbs and famous couples.

### **Notes from individual centres**

#### **A - DC**

*The institution and staff / co-facilitator:* The manager and one senior staff member were extremely supportive and enthusiastic about introducing research into this day centre. The other senior appeared to view it as pointless, continually stating that they were doing 'exactly the same activities' in normal sessions. There were approximately ten attendees each day, all who had their own seat in the room and had got to know each other. Hence breaking the group up, particularly twice in one day (as was necessary because most people only attended once a week) often caused upset both amongst the group and other attendants. Additionally, the centre had a morning and afternoon activity programme, which meant that the five group members had to leave an alternative session. The group was held in the same room as the day centre, separated by an artificial partition. Hence noise from the centre or people wandering in sometimes caused disruption. Staff tended to be too busy to co-facilitate groups.

*The group:* Early sessions were difficult, as individuals were reluctant to leave activities in the main lounge, and some had friends who were not in the group. One person was particularly hostile, making comments such as "That lady makes me feel like I'm back at school". However, by session five, people appeared more settled and sessions improved. The group were more interested in talking about the present day than the past, especially current affairs. Generally, they were all talkative, appeared to enjoy each others' company, and conversation often diverged to different areas, such as fashion and beauty.

*Individuals:* MB was initially suspicious of the project, continually asking "what the groups were for". This may have been a reaction to her awareness of her recent

memory problems. She appeared more relaxed as the programme went on, and developed a friendship with MT, who seemed to enjoy all the sessions. CK was often reluctant to attend sessions, but once there became actively involved. FP was more impaired and shyer than the rest of the group, yet the support and acceptance she obtained from the others seemed to build her confidence during the programme. MA was a lively and positive group member, who often introduced interesting topics of conversation into the sessions.

## **B - RC**

*The institution and staff / co-facilitator:* Generally, there was a positive atmosphere and staff were friendly to the researchers and each other. The manager and senior staff were interested in the project initially, labelling a box “psychological therapies”, with the intention of it storing notes written by staff during sessions. Unfortunately, staff were not committed to taking notes, and at the end of the programme, the box was empty. The staff member allocated to co-facilitate groups was often expected to guard the office whilst groups ran, making her input inconsistent, as she tended to run in and out of sessions. Other members of staff were sometimes asked to join in, but they often knew nothing about programme and made little input.

*The group:* The group gelled well and sessions were typically lively. As a group, they appeared to be more interested in concrete tasks, rather than more abstract discussion. For example, they found the current affairs session challenging, but appeared completely absorbed in the using objects session. The orientation session was particularly successful because they all came from the same part of East London, and were able to form a comprehensive map of the area. The four group members tended to contribute fairly evenly, with nobody dominating discussion.

*Individuals:* BC was highly anxious and appeared to view the sessions as a test, refusing to come to groups after session 4. Staff remarked on a noticeable change in ES, who became more expressive and confident as the groups progressed. BG was the most animated group member and often took the role as ‘entertainer’; telling stories and jokes. A friendship between BG and AP appeared to develop through the course of the programme, both who seemed to enjoy sessions. MW was a friendly and communicative group member, who always commented on what ‘fun’ she’d had at the end of sessions.

## **C -RC**

*The institution:* During the course of the project, it became increasingly clear that this was a highly institutionalised setting, although initially the atmosphere had felt relaxed.

*The staff/co-facilitator:* There was noticeable tension between what the management wanted (the project), and what the staff felt they had time for. This became increasingly apparent as the management limited its involvement. The initial co-facilitator attended two sessions, in which she looked bored. When talking, she addressed the other group facilitators in a quiet voice, ignoring the needs of the group members. It was apparent that she had volunteered for the project as a way to enhance her CV. In the remaining sessions a string of staff who were disinterested and / or entirely uninformed about the project attended.

*The group:* Some people seemed to enjoy the group, whilst others refused to attend. The average turnout was 2-3, hence some sessions were rather challenging. However, most sessions went well, including sound, early memories, famous faces, associated words, and orientation.

*Individuals:* SR was defensive, and did not want to attend the group. When he did, he was disruptive and somewhat disinhibited. JM attended all sessions when she was well enough, and enjoyed the activities. SL was initially very anxious, constantly wondering where she was. However, within minutes, she began to relax and enjoy the activities, which she was extremely good at. LR did not engage in most group sessions, and refused to attend the last ones. GB had visual difficulties, which prevented him from participating in sessions which focused on visual material. However, he always made an effort to engage himself at some level, and was friendly towards other group members.

#### **D - RC**

*The institution and staff / co-facilitator:* Staff and management were friendly and helpful with the assessments. The home had a positive feel to it, and group members sometimes commented that they enjoyed living there. One person was allocated to co-facilitate, but was often unavailable. Usually, another staff member would join in, and most were friendly and involved.

*The group:* People seemed to get on remarkably well. The three men tended to be more talkative than the women. TS adopted an 'entertaining' role, and the group seemed to enjoy his stories. There was a range in severity of dementia within the group, yet this did not appear to cause problems. The group seemed to enjoy the problem-solving sessions, such as categorising objects, the quiz and the sound effects tapes; more than the discussion-based sessions, such as current affairs.

*Individuals:* BG was a quiet man, who spent most of his time reading and rarely socialised with other residents. Staff were surprised at how much he enjoyed sessions, always asking when the next group was and checking that relatives' visits did not

coincide with groups. As the programme progressed, he became more outgoing and talkative towards other group members. LM was 100 years of age, and often commented that she was “too old for all this”. She was extremely hard of hearing, and frequently did not get involved. It was unclear whether this was due to her deafness or de-motivation. However, she could be quite sarcastic and would often make comments which made the rest of the group laugh. TS was a lively man who always got involved in activities and was friendly to the group. He often told stories which engaged the group, however sometimes he would tell the same long story at least twice in one session, and had to be interrupted by the facilitator. KC was also rather deaf, but tried to get involved in sessions and often expressed interesting views and ideas. HC was more impaired than the rest of the group, and appeared to be rather conscious of this. Staff said that he sometimes expressed anxiety before sessions, but that this was typical of his personality. However, he appeared to enjoy the groups and become more confident as the programme progressed. HC and TS became friends.

## **E - DC**

*The institution:* This was an active and involved day centre.

*The staff/co-facilitator:* The co-facilitator was friendly, interested & involved. She enjoyed the group, and was disappointed when it finished. The OTA responsible for activities was also interested and positive. However, management was particularly unhelpful and disinterested.

*The group:* The group bonded well, and all members seemed to enjoy the sessions. Towards the end of the group they started asking when the next session was, and they expressed sadness when ending the programme. Sound, early memories, food, and associated words sessions went particularly well. Current affairs and sessions

involving discussion and expression of opinions were less successful. Members found it hard to actively engage without a game or a concrete task at hand.

*Individuals:* RF found it hard to engage most of the time, possibly having difficulties with some activities. He occasionally expressed racist views, yet appeared to have problems dealing with the negative reactions of other group members. RW had relatively good insight and enjoyed the group very much. She found most activities within her abilities, and was keen to 'jog her brain'. AM got easily lost in repetitions about his disabilities, but enjoyed the sessions when he was able not to. Due to heavy medication, he found it hard to stay awake some sessions. He went into hospital after session 7, and did not return for the remainder of the programme. MP had more severe dementia than the rest of the group, and her constant repetition appeared to irritate others. However, she enjoyed the group. AK had the perception of being a volunteer at the day centre, and was defensive about being in the group. This was resolved by allowing him this role in the group as well, but he still found some sessions hard when his difficulties became apparent to him.

## **F - RC**

*The institution and staff / co-facilitator:* The home was extremely institutionalised, with serious and unapproachable managers. The co-facilitator had been informed by management that the project was a 'course'; perhaps as a way to entice her into co-running groups. She subsequently felt rather disappointed during earlier sessions, as was evident in her behaviour. However, she informed the researcher of this misunderstanding after session 7. Once the purpose of the project was explained

properly to her, cooperation improved and her expectations appeared to be more realistic.

*The group:* The participants were noticeably more institutionalised than those in other centres, indicative of the home as a whole. Their de-motivation was evident in the reasonable level of persuasion needed for them to attend groups. The refusal rate was quite high, with people arguing that they “couldn’t be bothered.” However, once in the groups they generally appeared to enjoy themselves, hence this was likely to be more representative of the general apathy in the home, rather than feelings towards the group. The people were not used to being in an environment other than their own lounge, which caused some confusion with regards to where they were. As a group, they were reasonably impaired, hence found sessions such as hangman and famous faces difficult. They appeared to enjoy the less cognitive sessions, such as physical games.

*Individuals:* FS experienced panic attacks before coming to a few sessions, and sometimes became socially anxious. However, when she felt more relaxed, her input was extremely positive and she was warm and friendly to other group members. MR was typically anxious at the beginning of sessions, yet always expressed enjoyment and appreciation by the end. FS was the only man in the group, and rarely contributed. The co-facilitator suggested that being with a group of women may have felt somewhat unnatural to him, as his entire working life had solely involved men. RP became ill with heart problems, which meant that she missed quite a few sessions; and often fell asleep in the ones that she attended. MN appeared to enjoy the sessions. One group member died after session four.

## G - RC

*The institution:* Generally, there was a good atmosphere in the home.

*The staff/co-facilitator:* The staff were positive towards the group, and management were helpful and friendly. The co-facilitator was only able to attend two sessions due to shift work, and there were random members of staff present in other sessions. However, they were all interested and nice, and participated well.

*The group:* The group members bonded well, and were keen to engage in activities. Although all at different stages of dementia, they accepted each others' difficulties and gave each other positive feedback. Particularly successful sessions were games, sounds, early memories, food, famous faces, associated words, orientation, and bingo. Current affairs, hangman, categorising objects, money and some discussions were found harder.

*Individuals:* HF was hard to tear away from his wife, but blossomed in the group, away from her control and influence. His visual impairment prevented him from participating in bingo. EF was the least impaired in the group, but had a significant hearing loss which made it difficult for her to engage with others. She was somewhat of a storyteller, which was great where the stories were relevant to the given session. However, they became rather disruptive when being unconnected to the topic, distracting and interrupting others from the task at hand. She frequently expressed her enjoyment of the 'meetings', which reminded her of her active political background. PW had a very limited short-term memory, and would find some activities difficult, such as bingo. She seemed to enjoy the group but would occasionally become restless, saying that she wanted to go home and cook for her husband and children. EL was withdrawn and more confused than the rest of the group. She kept her eyes closed for most sessions, but was not sleeping. She found all activities hard to engage

in, with the exception of associated words and bingo, which she enjoyed. She did not seem to enjoy the group, frequently expressing her inability to 'do anything'.

## **H - RC**

*The institution:* This home was rather institutionalised, with a passive atmosphere. An attitude of learned helplessness was frequently expressed.

*The staff/co-facilitator:* The manager was very helpful, in contrast to his staff. He ended up doing most of the preparations for the group himself, including gathering the group members together. The activities co-ordinator was allocated the role as co-facilitator. Although overtly expressing a great interest in the project, she actively sabotaged the group in a number of ways. It was agreed with the manager that the group be moved to another day when she would not be able to attend.

*The group:* The group did not bond well, and were not willing or able to engage with each other. Towards the end of the programme, another resident asked to join in. Although not having dementia, she was understanding and interested, and helped to improve the group dynamics. Relatively good sessions were famous faces, associated words, sound, bingo and current affairs. Unsuccessful sessions included food, using objects, categorising objects and word games, in which the first was perceived as boring, and the others too difficult.

*Individuals:* MG was detached and reluctant to join in the activities. She seemed anxious about her poor short-term memory, but occasionally smiled and seemed to enjoy herself. AB was the most impaired of the group, but appeared to lack insight into her difficulties, thus always trying hard to participate and seemingly enjoying herself. Her repetitiveness annoyed the other members, and confusion as to her living arrangements puzzled them. She sometimes became restless, wanting to go home to

her family, and worrying about not having her coat or handbag. SM was diabetic but did not adhere to her diet, thus was variable in mood and physical well being. When well, she joined in the activities, and seemed to like doing so, but more frequently she would be unwell, and not able to come to or stay in the group. EJ had suffered a stroke, hence could not use one arm and had some problems with speech. She really enjoyed the group and remembered it from sessions to session, but was sometimes treated suspiciously by others and found some activities difficult. VC had a very impaired short-term memory, and became the joker of the group, using this as her defence. Her behaviour was sometimes quite disinhibited, and she was reluctant to join in any group activity. She did not seem to like the group, and probably would not have kept coming had she been able to remember what the group was. She may also have had difficulties not getting the desired response from the group leader towards her behaviour.

## **I - RC**

*The institution:* On the surface, this home was pleasant, with nice decoration and an initial friendly atmosphere. In reality, it was more institutionalised than it appeared.

*The staff/co-facilitator:* The manager was particularly interested in being part of the project, but her enthusiasm waned through the course of the group. There were two identified co-facilitators, both who attended a few sessions in which they were enthusiastic although somewhat misguided as to the purpose of a group. They were not willing or able to arrange their workload in order to attend the majority of sessions.

*The group:* The group did not bond well, but remained fragmented throughout, with the two female group members detaching themselves from the two men. The group

also found some activities difficult, such as the quiz, categorising objects and word games. When this occurred, they became angry and upset, and expressed negative views about the group.

*Individuals:* MB was the least confused participant, and quite defensive and suspicious about the group and the two men in it. She left the session on a couple of occasions, and would probably not have continued coming if she had remembered what the group was about. DC got anxious, upset and angry about the group activities on several occasions, and left a couple of the sessions halfway through. She was very much influenced by the opinions of MB, who she had been friends with for some time. CP deteriorated physically throughout the course of the group and his medication also changed, thus he found it very hard to remain awake and engage in the activities. GN was a transsexual woman, who the other group members thought was a man, and in the group was referred to as such. She was very defensive about having to do 'womanly' things, and expressed negative views about the group and groups in general. She was also worried about the other group members laughing at her, a fear which was never reinforced. It did not seem like she enjoyed the group, but possibly kept attending it because she enjoyed the attention from the group leader.

## **J - RC**

*The institution:* The home consisted of a number of bungalows, and the atmosphere varied between them. It did not appear particularly institutionalised, but not especially active or individualistic either.

*The staff/co-facilitator:* The manager was very interested in being involved in the project, but had no time to do so. Thus the preparations were delegated to senior members of staff, who due to the authoritarian manner in which this was done, did it

quite reluctantly. The manager was reluctant to allocate the time of one member of staff to act as a co-facilitator. Consequently, a number of different people attended the first few sessions. From session 6 onwards, the researcher ran groups alone.

*The group:* The group bonded well, and the members were mutually supportive. There was a lively and friendly atmosphere, and all sessions generally went well.

*Individuals:* PP had a severely impaired short-term memory, which she made frequent references to. She tried to engage in the activities, and did not seem to get upset when finding them difficult. MD was the liveliest member of the group, and was consistently talkative and keen to participate in activities. TP was extremely variable in mood and confusion. In some sessions she would be talkative, lively, and somewhat disinhibited in her disclosure of personal information, whilst at other times unable to engage and seemingly depressed. She would sometimes go off the toilet, and never return to the group. DW moved after the first six sessions. In these sessions she seemed quite uncomfortable, possibly due to her being relatively young and insightful about her memory difficulties. LR was talkative and happy to engage in the group activities for most of the sessions. In some sessions she would be tearful, expressing a strong sense of loss. She passed away shortly after the end of the group.

## **K - RC**

*The institution and staff / co-facilitator:* The general approach in this home appeared to be extremely positive, with people treated as individuals and their opinions respected. The activities lady co-facilitated all sessions, except when she was on holiday. She was extremely cooperative, with the room prepared and people seated when the researcher arrived. She reminded people that it was the “Sunshine group” in

advance, and made sure that other activities did not coincide with sessions. Other staff who assisted when she was on leave were also very helpful.

*The group:* People got on well and often asked each other questions. Two group members (who were friends) tended to be the most talkative, and the group was quieter if either were not there. Songs including the word 'sunshine', such as 'you are my sunshine', were often sung during sessions, and there was always a happy atmosphere. The group seemed to like the material in most sessions, particularly famous faces and current affairs (in which they were able to express their opinions). Childhood was more sensitive, as AP had been 'found', and often said that she "didn't know who she was", which caused some upset.

*Individuals:* AP was extremely lively, friendly towards other group members; and got the discussion going. As sessions progressed, she increasingly paid compliments to the man in the group (RH), who appeared oblivious to her advances! MF was a quiet lady who had to be asked direct questions in order for her to participate. However, in some sessions she was extremely jovial, and always laughed when the ball was thrown at the beginning of sessions. RH was a softly spoken, quiet man; who seemed to be popular with the group. He impressed the others by answering difficult questions in the associated words and quiz sessions, and was engrossed in the cookery. DG's dementia was more severe than the rest of the group, and she was anxious and nervous. Sometimes, her anxiety prevented her from being able to participate in activities effectively, yet at other times she was calm and often giggly. KT was the least confused member of the group who tended to lose her patience with the others, yet expressed this in a non-offensive manner which made the others laugh. Staff commented that she always looked forward to groups.

## L - RC

*The institution and staff / co-facilitator:* There was an unfriendly atmosphere in this home. The co-facilitator planned to use this project as part of her NVQ. When the group dynamics appeared not to be working, she lost interest in the project, saw it as a failure, and sat in sessions looking bored and annoyed. Her negative attitude might have further contributed to the group's apathy. Additionally, she was critical of the activities themselves, perhaps harboring unrealistic expectations.

*The group:* The dynamics were weak. People in the group rarely communicated with each other, only with the facilitators. The co-facilitator said that they thought groups were "boring", yet it is unclear who had actually said this. Two people refused to come to many sessions, usually saying that they "could not be bothered". It appeared that there was a general environment of under stimulation, resulting in apathy. Only one person was reasonably talkative and appeared to enjoy the sessions. Direct questions often had to be asked to get people to converse. Staff commented that people never left their lounges, hence coming into an unfamiliar room in such an institutionalised setting probably added to their de-motivation. Practical sessions were more successful, particularly cookery and categorising objects, the latter which was described as "enjoyable" and "more educational than the others" by the group.

*Individuals:* AS was very conscious of her disabilities, complaining of headaches and dizziness when she appeared unable to do something. She often refused to come to sessions, perhaps due to a fear of failure or exposure. RL was the most talkative of the group, and attempted to get involved in the given activity. She appeared to enjoy the challenge of the sessions. BT was a quiet man who was seemingly disinterested and inattentive, yet would occasionally make comments which suggested that he had actually been concentrating, contrary to his appearance. GS looked bored in sessions,

and contributed little. She sometimes appeared depressed. DP enjoyed spending time alone in her room, and often refused to come to sessions. Staff later commented that she rarely participated in any activities.

## **M - RC**

*The institution and staff / co-facilitator:* This was an organised home, committed to the project. For example, the co-facilitator always had the room and participants ready in time for the sessions. She took the project seriously, typing out notes at the end of each session which were available for other staff and relatives to read. She intended to start small groups with other residents once this project terminated.

*The group:* This was a lively and engaging group. The dynamics were difficult in earlier sessions, as one group member tended to monopolise sessions and was sometimes rude to the others. However, she developed a friendship with another person and subsequently appeared to be more relaxed and less aggressive in later sessions. As a group, they were good at listening to each other and taking it in turns to speak. The co-facilitator noticed that by session 4, people were appearing more relaxed and 'coming out of their shells'. The group was chatty and opinionated, hence sessions such as current affairs and childhood were particularly successful. They did not appear to enjoy the cookery session, which was unusual.

*Individuals:* JN had recently moved into the home, and was initially shy and reserved. However, her relatives commented that she became more verbal, outgoing and happy once starting the groups. In later sessions, she often told lengthly and detailed stories. Staff feared that PA might create problems in the group, as she tended to be rude and aggressive to staff and residents. She was sometimes domineering and rude in earlier sessions, yet the co-facilitator was surprised at how co-operative she

was, particularly in later sessions once she had become friendly with GP. Perhaps the additional attention she received from being part of a small group improved her confidence. GP always appeared to enjoy sessions. She became made friends with PA, and sometimes answered her back when she was being antagonistic. The co-facilitator attributed this to an increase in confidence. Margaret was fairly reserved, but smiled and laughed a lot and seemed to enjoy groups. MB suffered from a bereavement and was depressed in some sessions; yet in others, she was highly co-operative.

## **N - RC**

*The institution:* The home had a friendly atmosphere, and seemed to value the importance of cognitive stimulation, having regular organised activities.

*The staff/co-facilitator:* The two activities co-ordinators involved in the project were both interested and quite friendly, although seemed to find it difficult to spare the time needed to prepare for the project and co-facilitate the group.

*The Tuesday Group:* The group had interesting dynamics and divided itself into two halves; one rather sexually orientated and the other one quite repulsed by that. This ongoing theme may have attracted people to the group; it seemed that they loved to hate each other. Most sessions went well, particularly the more discussion – orientated ones; with lively debates taking place.

*Individuals:* HBU had a relatively intact short-term memory, and engaged well in the activities, frequently expressing her enjoyment. JE had the most impaired short-term memory among the group members, and would sometimes find it difficult to remain focused on the session topic. She would subsequently become disinhibited and disruptive, talking about something irrelevant and annoying most of the group. HL

was the only man in the group, and quite sexually disinhibited. His mood varied - sometimes he was talkative and engaging and at other times detached. This was further reinforced by his hearing impairment. She seemed to enjoy the group, and joined in the activities with ease. FJ attended most sessions, but was often late, due to difficulties with getting dressed and ready. She would occasionally become restless and irritable, expressing negative views about being in a group.

### **O – RC/DC**

*The institution and staff / co-facilitator:* There was a happy atmosphere in this day centre. It was part of a residential home in which three of the group members lived. The other two lived in the community. One staff member co-facilitated the group in most sessions. She saw the project as an opportunity for her to learn to improve her skills as an activity coordinator. She always prepared the group, commenting on how interesting the sessions were and how much the group enjoyed them. At the end of the programme, she brought a 'thank-you' card for the researcher, which the group signed. Another member of staff co-facilitated two sessions and was also interested and involved. It appeared that the centre viewed the project as a positive learning experience.

*The group:* The group interacted very well. There were only four group members from session 3 onwards. Three of them made similar contributions and enjoyed listening to each other. They did not know each other prior to the project, but by the end had become friends. One person was less involved, and would often interject inappropriately when others were talking, making comments about wanting to die. The facilitators sometimes had to calmly interrupt her so as to keep the groups focussed. GW began to console and support her when she displayed her depression in

later sessions. The group seemed to enjoy all the sessions, and expressed sadness at the end of the programme.

*Individuals:* OB went to hospital after session 2 and attended no more groups. GW was extremely conscious of her dementia. This caused much anxiety, especially in earlier sessions when she often referred to “that illness I have”. However, her reduction in anxiety over the course of the programme was quite dramatic. She became confident and appeared to enjoy helping others, for example by repeating things to people who couldn’t hear as well, and consoling L in her depression. Staff commented that she became more sociable outside the groups, with other people in the day centre. L was rather deaf, which made it difficult for her to participate in group discussion. She also had depressive episodes, which made her quite demotivated. However, she often misheard and misinterpreted things that people had said, which amused the rest of the group. L appeared to enjoy making other people laugh. ET appeared to enjoy the sessions and was challenged by the material, often appearing deep in thought when asked questions. MA made a significant contribution, and often commented on how enjoyable the groups were.

## **P - RC**

*The institution and staff / co-facilitator:* Staff were unhelpful and sometimes actively avoidant towards the project. There appeared to be miscommunication both in terms of what the project was about and when groups were running. When the researcher arrived for the first session, nobody knew anything about the project. Groups were arranged by telephone with the manager, who rarely passed on information to staff; and she arranged sessions for one day on which all the group were on an outing. The

co-facilitator only attended two sessions, in which she remained passive. The remainder of the sessions were run by the researcher alone.

*The group:* People communicated remarkably well, often directing comments to each other more than to the facilitator. One lady was very softly spoken and often got talked over, yet this improved as sessions progressed and she became more assertive. They appeared to enjoy most sessions, but all refused to play bingo!

*Individuals:* VG appeared to enjoy the sessions as a means to share her stories and opinions with others. She injected a lot of fun and laughter into the group. MR was involved in groups, yet on some level appeared not to realise that she was confused. She refused to come to some sessions, and may have thought that she was 'different' to the others. LC and GS were both talkative, and always seemed pleased to be invited to groups. AR was a quiet, softly spoken lady. In earlier sessions, she said very little, but her confidence appeared to develop as the programme progressed. She made an increasing contribution to conversation, and in later sessions frequently made jokes.

Frequency histogram showing the distribution of the MMSE

