UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

School of Health Professions and Rehabilitation Sciences

The use of multi-sensory stimulation to improve functional performance in older people with dementia: A randomised single blind trial.

by

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Thesis submitted for the degree of Doctor of Philosophy

May 2007

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

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Dementia affects over 750,000 people in the UK (Alzheimer's Society, 2003). Clinicians and managers report dissatisfaction with current healthcare options available for people with dementia (Stubbings & Sharp, 1999). Multisensory Environments (MSEs) utilising advanced stimulating equipment targeting the senses, have been successfully used with individuals with dementia, with learning disabilities and in palliative care (Baker et al, 1997). Despite this, no controlled studies have been conducted to explore the efficacy of this intervention on functional performance. This study explores to what extent, if any, MSEs influence function, mood and behaviour of people with moderate / severe dementia compared with a control activity (gardening). In addition, sensory needs are identified using the Adult Sensory Profile (ASP) to explore whether sensory preferences are associated with changes in performance. Thirty participants were selected from people with moderate / severe dementia and randomly allocated to one of two groups (MSE or control). Following baseline assessment, each participant attended their allocated intervention 3 times a week for 4 weeks. Assessments were carried out before and after each session using the Assessment of Motor and Process Skills (function) and the Neurobehavioural Rating Scale (mood and behaviour). Results revealed significant main effects of the MSE in both function and in mood and behaviour. Sessional analysis revealed significant improvement in motor performance for the MSE group. Overall, both MSE and the control activity were found to improve function, mood and behaviour on a session by session basis. Participants who attended the MSE group and improved significantly in function fell within the low registration quadrant of the ASP. This suggests that MSEs are more suitable for those who require increased sensory stimulation. This study supports the use of sensory activity for people with moderate / severe dementia and recommends the use of the ASP to plan and facilitate activity.

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AUTHOR'S DECLARATION

I, Lesley Collier declare that the thesis entitled

The use of multi-sensory stimulation to improve functional performance in older people with dementia: A randomised single blind trial

And the work presented in it is my own. I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University;
- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has always been clearly stated;
- Where I have consulted the published work of others, this is always clearly attributed;
- Where I have quoted work from others, the source is always given. With the exception of such quotes, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- None of this work has been published before submission.

Signed…………………………………………………………………………………………..

Date…………………………………………..

ACKNOWLEDGEMENTS

I would like to thank all those who have supported me during this time, without whom this study would not have been possible. In particular, I would like to thank:

- The participants and their families, for their willingness to take part and advice in the pilot phase of the study;
- The staff who facilitated the activities alongside busy work routines, but also other members of staff who made me feel welcome in their places of work;
- The Boscombe Alzheimer's Society carers group for their invaluable guidance and support in the development of this study, in particular Rose their chairwoman;
- Dr Romola Bucks, Professor Kathryn McPherson and Dr Caroline Ellis-Hill for their time, support and enthusiasm throughout the four years;
- The Department of Health Research Capacity Development Nursing and Allied Health Professions Award Scheme for selecting me for one of their Research Development Studentship Awards which funded this study;
- Rompa, UK for providing the multi-sensory equipment which was used in locations without multi-sensory environments;
- Bernadette Waters for allowing me time and space to complete the final write up of the thesis;
- My friends at the School of Health Professions and Rehabilitation Sciences who kept me going through the difficult bits and had faith in me;

And of course

Thomas, William and Richard who cheered me on, fed me chocolate, read bits and commented, dragged me away from the computer at the end of the day, gave me lots of love and encouragement, and kept my feet on the ground so I could still be mum and wife.

LIST OF ABBREVIATIONS

AD	Alzheimer's disease
ADL	Activities of Daily Living
AMPS	Assessment of Motor and Process Skills
ASP	Adult Sensory Profile
BADL	Basic Activities of Daily Living
BADLS	Bristol Activities of Daily Living Scale
BIDS	Bath Information and Data Services
BMDS	Behavioural and Mood Disturbance Scale
BPSD	Behavioural and Psychological Symptoms in Dementia
BPRS	Brief Psychiatric Rating Scale
CAPE	Clifton Assessment Procedures for the Elderly
CDR	Clinical Dementia Rating
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COT	College of Occupational Therapists
DAD	Disability Assessment for Dementia
DAFS	Direct Assessment of Functional Status
DLB	Dementia with Lewy Bodies
EMBASE	Excerpta Medica database
FLD	Frontal Lobe Dementia
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disabilities and Health
ITT	Intention to Treat
MSE	Multi-Sensory Environment
MMSE	Mini-Mental State Examination
NICE	National Institute of Health Clinical Excellence
NOSGAR	Nurses Observational Scale for Geriatric patients
NRS	Neurobehavioural Rating Scale
NSF	National Services Framework
OT	Occupational Therapist
PAL	Pool Activity Levels
PLST	Progressively Lowered Stress Threshold
RO	Reality Orientation
RT	Reminiscence Therapy
SI	Sensory Integration
SIGN	Scottish Intercollegiate Guidelines Network
SMMSE	Standardised Mini-Mental State Examination

VaD	Vascular Dementia
VT	Validation Therapy
WHO	World Health Organisation

Chapter 1 Introduction

There is growing consensus that activities and occupations for people with moderate to severe dementia are either not available or fail to match their abilities and skill levels (Kovach, 2000; Richards & Beck, 2004; Voelkl, Ellis, & Walker, 2003). As a treatment strategy, multi-sensory environments have been available for people with dementia for the last 20 years and may offer an activity which can be matched to participant skill level. However, the value of this intervention for people with moderate to severe dementia has yet to be established (Savage, 1996b) and research into its efficacy is limited. This introductory chapter describes the problem of activity engagement in dementia and the context from which the research idea evolved. The importance of the research for clinical practice will be presented and an overview of the thesis given.

1.1   The challenge of facilitating activity in dementia

Alzheimer's disease, vascular dementia and dementia of other aetiology according to DSM-1V (American Psychiatric Association, 2000) criteria and ICD-10 (World Health Organisation, 2003) affects six percent of the European population over age 75 (Hofman, Rocca, & Brayne, 1991; Jorm, Korten, & Henderson, 1987). These progressive disorders present with discrete deficits in cognition, mood, behaviour, and functional ability leading to difficulty with participation in activity (Barberger-Gateau, Rainville, Letenneur, & Dartigues, 2000; Roman, 2002; World Health Organisation, 1997). Although many non-pharmacological interventions are available to try and manage some of the problems presented by dementia, for example, Reminiscence Therapy and Reality Orientation, clinicians and healthcare managers report difficulties in their facilitation (Stubbings & Sharp, 1999). This failure to provide suitable activity may lead to many patients enduring 'twelve hour periods of chair sitting punctuated by corridor pacing and food or toilet experiences' (Perrin, 1997. p.69). Conceivably, these interventions fail due to the effort required by the facilitator to enagage the person with dementia in a suitable activity (Pulsford, 1997f). Despite the inherent difficulties highlighted, this thesis is based on the assumption that facilitating activity is still a worthwhile endeavour.

1.2   A possible solution

The National Framework for Older People (Department of Health, 2001) has a 10 year programme to improve services for older people. This programme takes a positive view of old age, encouraging the development and evaluation of innovative practice. One intervention which can be considered innovative is the use of multi-sensory environments (MSE). MSEs contain a variety of equipment to

stimulate the senses (sight, sound, touch, taste and smell). Using this equipment, MSEs can offer an activity based intervention which is argued to address imbalances in sensoristasis and levels of sensory stimulation by pacing sensory stimulating activity with sensory calming activity. This may assist people with dementia and their carers in coping with confusion and behaviour changes which are consequences of progressive, debilitating illness (Cohen-Mansfield, 2001; Finnema, Droes, Ribbe, & Van Tilburg, 2000; Kovach, 2000).

1.3   Context from which the research question was developed

I was first introduced to multi-sensory environments 10 years ago whilst working as an occupational therapist. The client group I worked with included older people with severe dementia who were resident on a continuing care ward. These people presented with severe agitation and challenging behaviours such as wandering, aggression, shouting and screaming. It seemed that many of the behaviours exhibited were exacerbated by the noisy, over stimulating environment in which the individuals lived. I was curious to see if these behaviours could be modified if the level of environmental stimulation was reduced, and presented in a sequential manner. The use of a multi-sensory environment appeared to be one way of achieving a more controlled sensory load, as the sensory equipment might be sufficiently intense to focus attention without interruption from competing stimuli. In order to test this out, a psychologist and I took one of the patients to a small, multi-sensory room located in a centre for children with learning disabilities. Although the room was covered in soft foam, which made it difficult for the patient to move around, he spent time exploring the equipment and appeared to be listening to the music. On return to the hospital, nursing staff commented on his calm and happy demeanour, and willingness to take part in other activities that were presented to him that day. These positive responses led me to investigate further the use of multi-sensory environments with other people on the continuing care ward. As a result of further positive reactions from other patients, a multi-sensory environment was installed on the continuing care ward.

Since the MSE was installed I have been involved in two studies exploring the use of these environments with older people with dementia (Moffat, Barker, Pinkney, Garside, & Freeman, 1993; Pinkney, 1997). These are described in Chapter 3 alongside subsequent studies (Baker et al., 2001; Burns, Cox, & Plant, 2000; Staal, Pinkney, & Roane, 2003) which have also reported some positive effects on mood and behaviour. However, caution regarding the reliability of the outcome measures used in these trials is needed. Nevertheless, these studies suggest MSEs have the potential to influence mood and behaviour, and, to date, no published, systematic research has investigated how MSEs impact on the functional performance of people with dementia.

1.4   Background and rationale for the study

Multi-sensory environments (MSE) utilise advanced sensory stimulating equipment that targets the five senses of sight, hearing, touch, taste and smell. Visual (sight) stimulation is achieved using a solar projector that casts themed images, for example, an underwater scene with fish; coloured optic fibres and a bubble tube. Auditory (sound) stimulation is achieved by playing music or environmental themes such as bird song. Tactile (touch) stimulation is accomplished using optic fibres to stroke and plait, and textured fabrics. Gustatory (taste) stimulation is achieved by offering small amounts of citrus fruits, sherbert and textured foods such as popcorn, jelly and so forth. Olfactory (smell) stimulation is achieved by using aromatherapy scents and smell pots (small pots containing everyday aromatic items such as cloves or peppermint).

Multi-sensory environments (MSE) have demonstrated some success in the management of behavioural problems in people with dementia and severe learning disabilities, and pain management in palliative care (Baker, Dowling, Wareing, Dawson, & Assey, 1997; Schofield, 1996). Despite these reports, many of these studies are anecdotal and there is little conclusive evidence to suggest benefits can be transferred across client groups (Hutchinson & Hagger, 1991; Thompson & Martin, 1994). Also, little is actually known about how or why they work. As a result, healthcare managers can be reluctant to commit finances to an intervention with a limited research base which is expensive to install.

Despite these limitations studies exploring the emotion-oriented aspects of MSEs suggest that participants find them enjoyable and are able to make independent choices about which piece of equipment they wish to use (Cohen-Mansfield, 2001; Finnema, Droes, Ribbe, & Van Tilburg, 2000). Also, staff feel that these improvements directly impact on the quality of their relationship with the participant (Hope, 2004). Research with older people with severe dementia has built on these findings, as this population is known to find conventional activities difficult to access. After spending time in a MSE, people with dementia are reported to show positive changes in mood and behaviour, and also an increase in attention to their surroundings (Baker et al., 2001g; Moffat et al., 1993). MSEs are also reported to influence the interpersonal interactions and levels of engagement amongst this group (Baker et al., 2001; Spaull, Leach, & Frampton, 1998). As well as reports of positive responses from patients and carers, staff have made reference to the positive effect being in a MSE has on their own perception of stress. Although these studies suggest that MSEs have the potential to influence a person's attention to activity, the environment around them and care givers' perception of stress, they do not suggest how or why this influence occurs.

One theory that may explain these responses is that of sensoristasis (Kovach, 2000). Sensoristasis is the balance between the demand of environmental stimulation and a person's ability to process this stimulation. Studies by Dunn (2001), Ayres (1979) and Ross and Burdick (1981) also suggest that modulating sensory input may influence functional performance in activities of daily living

(ADL). As MSEs have the potential to provide sensory cues it seems likely that this intervention may lead to improvements in functional performance. However, a clear relationship between sensory input and improved functional performance has not yet been established. Moreover, it is also recognised that the mood and behaviour of the person with dementia may influence this performance, so these variables need to be considered when investigating the outcome of MSEs.

1.5   Importance of incorporating activity into clinical practice

People with dementia, at some point in the disease, may develop psychological and behavioural disturbances such as agitation and wandering. This impacts on their ability to maintain functional skills such as self-care (Burns, Byrne, Ballard, & Holmes, 2002). In practice, medication such as neuroleptics and other sedatives are often used to control these disturbances. Although medication offers short term effects it frequently causes side effects such as drowsiness, which compounds the problem of reduced independence. Given these risks, good clinical practice should first exclude the possibility that psychological or behavioural disturbances have a physical cause (e.g. infection or pain) then try non-pharmacological approaches such as multisensory therapies, before considering medication (Douglas, James, & Ballard, 2004). The use of medication is further complicated by the ongoing debate within the National Institute of Health and Clinical Excellence regarding the efficacy of certain medications such as Donepezil, Rivastigmine and Memantine (NICE, 2006).

Activity may offer an alternative way of managing psychological and behavioural disturbances. As in the medication option, activity must be tailored to meet individual needs (Moniz-Cook & Bird, 2003). This approach fits well with the World Health Organisation International Classification of Functioning, Disability and Health (ICF:World Health Organisation, 1997) a framework to describe and measure health and disability. The ICF shifts the focus of service delivery from disability to how people live with health conditions and how these disabilities can be improved by attending to individual needs to achieve a productive, fulfilling life (ability). The College of Occupational Therapists includes the ICF classification within its guidelines 'Occupational therapy defined as a complex intervention' (College of Occupational Therapists, 2003) and has called upon NICE to adopt the ICF classifications in order to redirect the focus of healthcare to activity and participation in clinical practice (College of Occupational Therapists, 2002). Although the number of non-pharmacological therapies and activities for people with moderate to severe dementia is increasing (Douglas et al., 2004), there is need for guidance for those in clinical practice, regarding the most suitable activity to match specific, individual needs. Further discussion of activities available for people with moderate to severe dementia is provided in Chapter 3.

1.6   Lay out of the thesis

The thesis is divided into 9 chapters.

Chapter 1, this chapter introduces the problem and the rationale for the study.

Chapters 2, 3 and 4 offer a critical review of current and seminal literature which is of direct relevance to the study. Chapter 2 presents the distribution of dementia and the common cognitive problems experienced by people with dementia that impact on their ability to participate in activity. Chapter 3 explores the activities that are currently offered, with reference to their limitations given the specific problems presented by people with moderate to severe dementia. Chapter 4 discusses the impact of activity in dementia and presents the multi-sensory environment as a suitable activity which addresses many of the challenges of engaging people with moderate to severe dementia. This leads to the research questions and hypotheses.

Chapter 5 presents the methodology. This includes justification and description of the design used, ethical issues that were addressed, the sampling process, process of data collection and initial data analysis plans.

Chapter 6 presents the assessment tools used with justification for their selection. Primary and secondary assessment tools are explored in-depth with attention to validity and reliability. Reasons for selection are briefly considered.

Chapter 7 presents the pilot study, reporting the outcome and amendments that were incorporated into the main study as a result.

Chapter 8 presents the results. These are presented for each research question, with details of analysis used.

Chapter 9 considers the results in light of other relevant literature. Themes and emerging theoretical perspectives are explored in relation to clinical practice. Strengths and weaknesses of the study are considered alongside implications for clinical practice. Finally, a section on personal reflection has been included, identifying the challenges and successes of the study with consideration of what might have been done differently if the study were to be repeated.

Chapter 2: The challenge of facilitating activity in moderate to severe dementia

2.1   Introduction

Chapter 2 explores the distribution of dementia and the common cognitive problems that dementia brings, with commentary on how those cognitive problems affect engagement in activities. Given that the ability to participate in activity becomes more impaired as dementia progresses, the specific problems experienced in moderate to severe dementia will be explored in relation to their impact on activity and functional performance.

2.2   Prevalence and presentation of Alzheimer's disease and other dementias

Dementia is a syndrome characterised by progressive deficit in cognitive functions which interferes with social and occupational activities (American Psychiatric Association, 2000). Estimates suggest that the number of people with dementia, worldwide, is 15 to 18 million, and it is predicted that by 2025 34 million people will be affected (Alzheimer's society, 2003; Bates, Boote, & Beverley, 2004). Dementia currently affects over 750,000 people in the UK. Of that group, over 18,000 are under the age of 65 years (Alzheimer's Society, 2003).

Prevalence increases with age. However, the percentages differ somewhat according to the diagnostic criteria used (see Table 1), the two most common being the Diagnostic and Statistical Manual of Mental Disorders - Revised (DSM-1V-R: American Psychiatric Association, 2000) and the International Classification of Diseases (ICD - 10: World Health Organisation, 2003). Despite the slight differences in percentages it is clear that, of those classified with dementia, higher numbers have a moderate and severe presentation than those with a mild presentation.

Table 1: Prevalence rates of dementia according to DSM-1V-R and ICD-10

Age	Prevalence					
	DSM-1V-R			ICD -10		
	% with a classification of dementia	Moderate	Severe	% with a classification of dementia	Moderate	Severe
75+	17.4	5.1	4.9	12.4	5.1	4.9
85+	34.8	11.4	9.8	25.7	11.4	9.8

Riedel-Heller, Busse, Aurich, Matschinger, & Angermeyer (2001)

Given only mild dementias are considered treatable with cognitive enhancing medications (Overshott & Burns, 2005) this leaves a large group of people for whom palliative treatments such as sedatives and neuroleptics are the only option. Of this large group the two most common forms of dementia are Alzheimer's disease (AD) and vascular dementia (VaD). Other types include dementia with Lewy bodies (DLB) and frontal lobe dementia (FLD). These will be considered briefly.

2.2.1 Alzheimer's disease

This form of dementia was first described by Alzheimer (1907), and is the most common form of dementia in the Western world (Europe and Northern America), with an estimated prevalence rate of 4% in the population aged 65 – 70 years (Wellin, Svardsudd, Wilhelmsen, Larsson, & Tibblin, 1987). Alzheimer's disease (AD) usually presents with insidious onset accompanied by memory problems, in particular, anterograde episodic memory impairment (difficulty recalling events in the past). Other problems, in the later stages of the disease, include language disturbance (dysphasia; expressive and then receptive), reduced motor skills (dyspraxia) and difficulty in recognising everyday objects (agnosia) (Graham, Emery, & Hodges, 2004). As the disease progresses apathy, agitation, irritability and, occasionally, disinhibition are also common (Del Ser, Hachinski, Merskey, & Munoz, 2005).

2.2.2 Vascular dementia

Whilst memory decline is the cardinal feature of AD, vascular dementia (VaD) can present with primary decline in other cognitive domains (Roman, 2002). VaD is a collective name for a series of dementias associated with deficiencies in circulation of blood in the brain, which lead to brain damage. It is the second most common cause, occurring in 15-30% of people with dementia

(American Psychiatric Association, 2000). A further 20% have VaD in combination with AD (American Psychiatric Association, 2000).

The clinical presentation of VaD varies greatly depending on the location of cerebral damage (Desmond, 2004). Features may include stepwise decline followed by periods of stability (but not in sub-cortical vascular dementia where a more gradual decline is seen); mildly affected memory, which is in contrast to the early and severe memory deficit seen in AD; early and severe executive dysfunction such as disorganised thought, difficulties in problem solving and planning, with particular deficits in verbal fluency and attention; and disorders of gait (Desmond, 2004; Moroney, Bagiella, & Desmond, 1997). People with VaD often also show distinct features such as greater depression and functional impairment compared with patients with AD, at a given level of dysfunction (Groves, Brandt, & Steinberg, 2000).

2.2.3   Dementia with Lewy Bodies

Dementia with Lewy bodies (DLB) affects approximately 100,000 people in the UK (McKeith, O'Brien, & Ballard, 1999) accounting for between 10 to 20 % of people with a diagnosis of dementia (Ballard et al., 2001; Singh, 2005). In 1995, a consortium established consensus criteria for the clinical and pathological diagnosis of DLB (McKeith, Galasko, Kosaka, & Perry, 1996). The core features include fluctuating cognitive impairment with pronounced variation in attention and alertness, visuospatial dysfunction, complex, recurrent visual hallucinations and mild extra-pyramidal features (Boeve, 2005; McKeith et al., 1999). These motor features most typically develop within 12 months of the cognitive impairment. This is in contrast to Parkinson's dementia where the motor symptoms develop prior to the cognitive impairment which more commonly occurs more than 12 months after the first motor signs (Wilcock, 2003). Supportive features of DLB include falls and transient loss of consciousness, neuroleptic sensitivity and systematised delusions (McKeith et al., 1996). DLB has a similar rate of decline to AD and VaD (Ballard et al., 2001) and the clinical signs in the later stages of the disease are also similar (Ince, Perry, & Morris, 1998).

2.2.4   Frontal lobe dementia

Frontal lobe dementia (FLD) is a less common form of dementia with a slow, insidious onset (Gislason, Sjogren, Larsson, & Skoog, 2003). It occurs most frequently between the ages of 40 and 60 years (Passant, Rosen, Gustafson, & Englund, 2005), and affects approximately 18% of people with a diagnosis of dementia over 65 years of age (Gislason et al., 2003).

The concept of FLD was first proposed by the Lund-Manchester Group (1994) following increased reports of atypical dementia and Pick's disease (Amano & Iseki, 1999). Although the onset of FLD

is not dissimilar to AD with dysphasia (difficulty with verbal expression), agnosia (inability to recognise people and objects) and dyspraxia (difficulty with motor function), the core features of FLD are distinct and include disinhibition and personality change, loss of insight, apathy, hyperorality (placing food and non-food objects into the mouth), dietary changes, as well as disorganisation. Less common, language function may also deteriorate with less and less language being used, to the point that in the later stages of the disease the patient is almost mute. These behavioural-personality features relate to the focal lesions in the frontal and temporal lobes (Uchihara, Ikeda, & Tsuchiya, 2003).

In contrast to other dementias, people with FLD have relatively preserved memory and visual spatial skills. They are also more likely to present with psychiatric features such as depression and anxiety in the early stages of the disease, although these may also vary depending on the brain regions affected (Mendez et al., 2005). For example, patients with FLD predominantly affecting the temporal lobes may present with emotional and personality changes such as frivolous behaviour. In contrast, patients with FLD predominantly affecting the frontal lobes may present with apathy and dysexecutive personality changes (Mendez et al., 2005).

2.2.5   Summary

In summary, the clinical diagnosis of dementia encompasses a range of clinical and pathological symptoms. These symptoms, which are influenced by the site of lesions and / or clinical pathology, lead to diagnoses such as AD or VaD. Another system of categorisation used is that of disease severity.

2.3   Severity of dementia and the 'final common pathway'

People with a diagnosis of dementia are frequently described as having mild, moderate or severe dementia depending on the number of clinical manifestations exhibited, the degree of restriction of activity and the consequential reduction in participation (International Classification of Function, Disability and Health, ICF) (World Health Organisation, 2002). In the early stages of these different disease classifications, signs and symptoms are specific and management strategies are tailored to address these specific problems. However, as these diseases progress the diagnosis becomes less relevant as people at the severe end of the spectrum present with very similar patterns of symptoms. Given that there are currently few, if any pharmacological options available for the treatment of severe dementia, coupled with the difficulty of differential diagnosis at this late stage,

treatment strategies tend to focus on the management of behavioural problems. In late dementia, there is greater consistency across the diagnoses in the types of behavioural problems which arise.

Despite the different clinical forms of dementia all result from a progressive, neurodegenerative pathology leading to cognitive and behavioural decline (Lockhart & Lestage, 2003). In the later stages of the disease, the presentation of these features may become indistinguishable amongst the different diagnostic groups. This has been coined the 'final common pathway' (Carlson, Fleming, Smith, & Evans, 1995; Lockhart et al., 2003). This may be defined as a presentation of comparable signs and symptoms that are evident in all forms of dementia. Indeed, Schäufele et al. (2002), Ballard et al. (2001) and Agüero-Torres et al. (1998) describe the similar presentation of AD and VaD in the later stages of the disease. Particular common features include cognitive deficits (attention, executive functioning, language and memory), functional difficulties (in activities of daily living), psychomotor impairment (dyspraxia and poor co-ordination), behavioural difficulties (aggression, agitation, and wandering) and psychiatric disturbance (depression and anxiety) (Schaufele, Bickel, & Weyerer, 2002; Wellin et al., 1987). The problems caused by these features will be explored further with reference to how they present challenges for the provision of and engagement in activity.

2.3.1   Cognitive disorders

2.3.1.1 Attention deficits

Attention refers to a number of cognitive abilities including maintaining an alert state and orienting to sensory stimuli in order to engage in everyday tasks (Fernandez-Duque & Black, 2006). Particular attention deficits seen in moderate and severe dementia include poor selective attention, the inability to shift attention, poor sustained attention, and difficulty dividing attention (Perry & Hodges, 1999). Selective attention is the ability to focus on a single stimulus whilst ignoring competing or distracting stimuli, whilst attentional shift is the ability to move attention from one stimulus to the next (Posner & Petersen, 1990). This may be due to the loss of inhibition by the individual of conflicting and competing stimuli in the immediate environment (Perry et al., 1999; Raizada & Grossberg, 2001). Sustained attention and vigilance is the ability to focus attention over a period of time (Parasuraman & Haxby, 1993). Arousal is particularly relevant in vigilance as the individual needs to be sufficiently alert in order to engage with the task. Finally, divided attention is the sharing of attention between two or more relevant stimuli (Perry et al., 1999). A breakdown in divided attention can lead to a decrease in accuracy in task performance.

In moderate to severe dementia particular problems in trying to engage people in activity include maintaining attention during everyday tasks whilst at the same time ignoring external stimuli (Wilkins, Shallice, & McCarthy, 1987). Attention becomes dependent on the degree of engagement required for each activity and the competition from environmental stimuli. As many activities are

offered within main living areas, there is often considerable interference from irrelevant stimuli. Indeed, Nygård, in a series of studies aggregating findings (Nygard & Ohman, 2001; Nygard & Starkhammer, 2003) identified that people with dementia sought support for activity in which they were engaged from their environment. For example, if the environment was noisy people needed to use more strategies to attend to the activity. This increased demand was more likely to lead to an increase in the length of time taken to complete the task and, possibly, activity breakdown.

The complexity of the task also has an impact on sustained and divided attention. Activities that are complex, involving several stages and requiring multiple skills, are more likely to fail for people with moderate to severe dementia. For example, individuals experience a disproportionate slowing of walking speed whilst simultaneously carrying out a fluency test (Camicioli, Howieson, Lehman, & Kaye, 1997). If the activity is too complex arousal can decline rapidly over time leading to distractibility (Perry et al., 1999). If the activity requires divided attention there may be a catastrophic rate of decline in task accuracy often leading to higher levels of performance error (Baddeley, Baddeley, Bucks, & Wilcock, 2001; Baddeley, Bressi, Della Sala, Logie, & Spinnler, 1991). These problems can be cyclical in nature with inattention due to distraction leading to a breakdown in sustained attention, further contributing to the problem of engaging attention in activity (Cole & Tak, 2006; Craik, Morris, Morris, & Loewen, 1990; Morris, 1994).

2.3.1.2 Executive function

Executive function controls higher order cognitive capabilities such as problem solving, self monitoring, sequencing and awareness (Lezak, 1983) and overlaps with the functions described in attention. Indeed, many tests of executive function also test attention. This is because attention determines which external information is processed before problem solving skills can be utilised. Disorders in executive functioning are seen in severe dementia, often regardless of the diagnosis. They generally occur after the initial amnesic phase and grow worse as the disease progresses. Stuss and Benson (1986) have suggested that executive functioning can be divided into two facilities. The first involves sequencing of behaviours, whilst the second is concerned with drive and motivation.

Whilst many over learnt and automatic behaviours are retained into the later stages of dementia, executive functions are required in order to complete the activity. Examples of executive function deficits are particularly evident in instrumental activities of daily living that involve manipulation of information. For example, following a recipe or finding your way to the shops requires using new information which may need to be modified as the activity progresses, as well as holding in working memory the task instructions, what has been completed and what is left to be done (Levine, Lee, & Fisher, 1993). If the activity requires complex manipulation of information, these resources are exceeded and the activity fails. This is a common problem for people with severe dementia who are often presented with activity that is too complex, in that there is a requirement for them to be able

to plan and sequence their behaviour in order successfully to complete the task (Baum & Edwards, 2003).

2.3.1.3 Language deficits: Expressive and receptive dysphasia

In severe dementia, expressive language impairment is particularly prevalent, being found in 93% of those at the severe end of the spectrum (Kirshner & Bakar, 1995; Schaufele et al., 2002). Problems with language expression include severe loss of fluency, perseveration and non-verbal utterances, for example, muttering and groaning. These problems differ from those experienced by people with global aphasia due to focal lesions, as people with severe dementia are unable to palliate their difficulties using non-verbal communication (Boller, Verny, Hugonot-Diener, & Saxton, 2002). As the disease progresses so language deteriorates with the person making an increasing number of semantic and syntactic errors (Hier, Hagenlocker, & Shindler, 1985).

Another problem area at the severe end of the dementia spectrum is that of receptive dysphasia (difficulty in understanding what has been said) due to the progression of the disease into the parietal lobes, and problems with phonology (loss of accent and intonation). Activities which require verbal communication skills may be compromised for people with moderate to severe dementia, due to their problems with verbal expression and comprehension (Murdoch, Chenery, Wilks, & Boyle, 1987). Activities such as Reminiscence Therapy and Validation Therapy all require a relatively high degree of verbal fluency for the person to participate. Thus, activities which do not rely on verbal communication may be more successful for people with moderate to severe dementia.

2.3.1.4 Memory.

The term memory includes registration, retention and retrieval of information through a series of complex inter-connecting systems (Milner, Squire, & Kandel, 1998). Failure in one area has consequences for the functioning of another (Squire et al., 1990). Memory dysfunction is a critical feature in all forms of dementia and has a direct impact on the individual's ability to participate in every day activity (Cooke, Fisher, Mayberry, & Oakley, 2000; Doble, Fisk, MacPherson, Fisher, & Rockwood, 1997). Memory systems can be divided into implicit and explicit memory (Figure 1) which encompasses both short and long term memory.

Implicit memory encompasses information that is gained independently of the individual's awareness. Examples of activities learnt using implicit memory include walking, dressing or gradually acquired habits and routines (procedural memory). Skills needed to participate in these activities are gained through sensory motor interaction acquired during normal development, classical and operant conditioning as well as habits and routines (Clark, Manns, & Squire, 2002). As this skill acquisition is achieved over time, this memory system could be considered to be part of long term memory.

Figure 1: Memory systems

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                         ┌─────────────────┐
                         │     Memory      │
                         └────────┬────────┘
                  ┌───────────────┴──────────────────────┐
                  ▼                                       ▼
         ┌─────────────────┐                     ┌─────────────────┐
         │ Explicit memory │                     │ Implicit memory │
         └────────┬────────┘                     └────────┬────────┘
          ┌───────┴────────┐                              │
          ▼                ▼                              ▼
  ┌─────────────┐  ┌─────────────────┐          ┌──────────────────┐
  │ Long term   │  │ Short term /    │          │ Habits,          │
  │ memory      │  │ working memory  │          │ sensation and    │
  └──────┬──────┘  └────────┬────────┘          │ skills           │
     ┌───┴────┐         ┌───┴────┐              │ Procedural       │
     ▼        ▼         ▼        ▼              │ memory           │
┌─────────┐┌─────────┐┌───────┐┌─────────┐     └──────────────────┘
│Episodic ││Semantic ││Visual ││Auditory │
│knowledge││knowledge││sketch ││loop     │
│         ││         ││pad    ││         │
└─────────┘└─────────┘└───────┘└─────────┘
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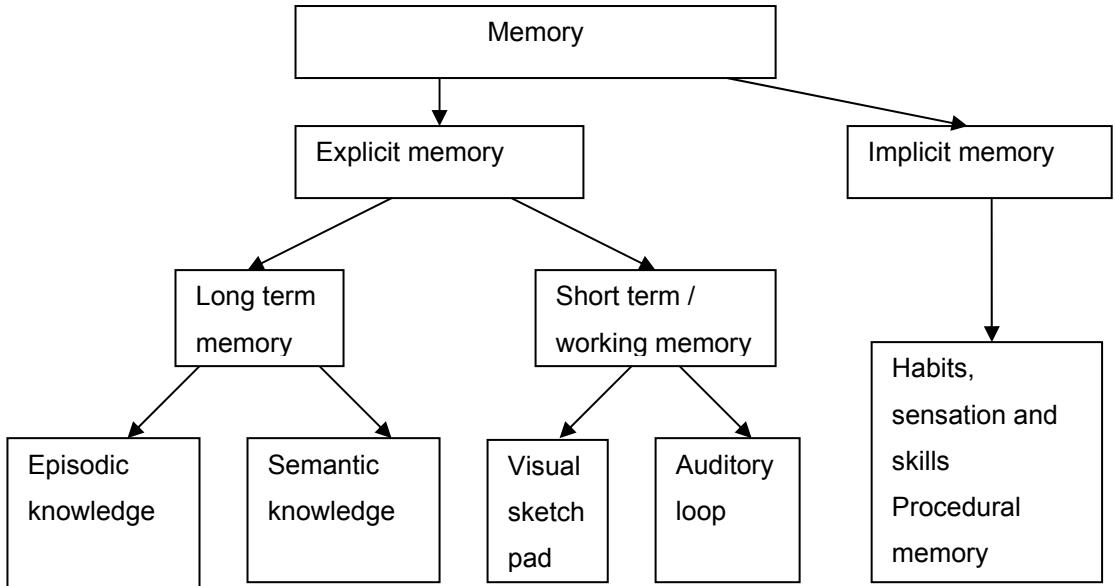
Adapted from Squire (1992)

Explicit memory includes both short term and long term memory. Short term memory utilises a central executive system which co-ordinates and manages information processing and immediate storage (Craik, Morris, Morris, & Loewen, 1990; Morris, 1994). The two main storage systems are visual and verbal. In the visual system, the visual sketch pad processes visual input such as the written word. In the verbal system, the auditory loop system processes verbal input such as the spoken word (Morris, 1994). Long term memory includes both episodic and semantic memory (visual and verbal). Episodic knowledge includes memory for details of past events such as last Christmas and personal experiences. Semantic knowledge includes understanding of language and facts gained through learning and experience, such as, being able to speak another language (Bayles, 2001).

All memory, to some extent, is affected in severe dementia. For example, in Alzheimer's disease the medial temporal lobes and forebrain structures are affected, resulting in impairment of explicit learning and discrete elements of implicit learning such as performance of conceptual tasks (Reber, Martinez, & Weintraub, 2003). Similarly, in vascular dementia, both episodic and semantic memory impairment (explicit learning) are features in the later stages of the disease (Graham et al., 2004). These memory impairments have a direct impact on participation in activity. For example, impairment in short term and long term memory coupled with language comprehension difficulties

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makes the understanding of instructions problematic for the person with dementia. Therefore, activities requiring retention of new information such as Reality Orientation often fail. In early dementia, individuals have difficulty remembering the recent past. As the dementia progresses, they begin to have difficulty remembering the more distant past as well (Boller et al., 2002). This decline leads to difficulty in recalling personal experiences and autobiographical events making activities such as Reminiscence Therapy an unsuitable intervention for people with severe dementia. In contrast, procedural memory may be relatively well preserved so activities that include repetitive, well learnt movements, such as dancing or catching a ball, may be more successful.

2.3.1.5 Dyspraxia

Dyspraxia is thought to affect approximately 40% of people with a diagnosis of severe dementia, and is considered to be one of the main factors leading to falls (O'Keeffe et al., 1996). Although it is a well recognised feature (Cott, Dawson, Sidani, & Wells, 2002) little research has been undertaken to explore its impact on activity for people with severe dementia. Studies with people who have cerebrovascular accidents (strokes) have described two types of dyspraxia which are also evident in dementia (Chainay & Humphreys, 2003; Fitzgerald, McKelvey, & Szeligo, 2002; Zadikoff & Lang, 2005). Ideational dyspraxia is a disorder of the conceptual system which contains knowledge of actions and functional performance. Ideomotor dyspraxia is a disorder in the generation and control of specific movement. Both these forms of dyspraxia make functional performance and activity difficult for people with severe dementia as they may start an activity and then not know how to progress. Alternatively, they may find it difficult to initiate movement to start the activity. Many social activities rely heavily on movement, such as baking or gardening, therefore, people with moderate to severe dementia may find it more challenging independently to complete such activities.

2.3.2   Behavioural and Psychological signs in dementia (BPSD)

Behavioural and psychological features include agitation, anxiety, pacing, depression and aggression. Epidemiological studies confirm there is a strong association between severe dementia and behavioural symptoms (Boller et al., 2002; O'Connor, Pollitt, & Roth, 1990; O'Connor, Aenchbacher, & Dishman, 1993).

2.3.2.1 Agitation and anxiety

Agitation is often seen as a behavioural sign of anxiety and, therefore these two features will be discussed together.

Agitation has been reported in 48 to 75% of people with severe dementia (Merriam, Aronson, Gaston, Wey, & Katz, 1988; Reisberg, Sclan, Franssen, Klugger, & Ferris, 1994). This variation in figures represents the difficulty clinicians have in defining what is meant by agitation (Boller et al., 2002). Key features include inappropriate motor or vocal activity that is not explained by need, such as excessive checking and fiddling (Haupt, Kurz, & Janner, 2000; Hope, Keene, Gedling, Fairburn, & Jacoby, 1998). This can impede the progress of activity in terms of attention to the details and task completion. Because agitation is thought to indicate distress, potential antecedents of behaviour should be addressed (Boller et al., 2002).

A diagnosis of anxiety is equally problematic and is often related to episodes of depression. Teri et al. (1999) report co-morbid anxiety and depression in 54% of cases of people with severe dementia. Anxiety on its own has a higher reported frequency in severe dementia of 70% (Eastwood, 1994). Particular features include frequent requests for attention and general restlessness. The cause of anxiety in severe dementia is difficult to identify due to the severe cognitive impairments presented (Wilkinson et al., 2003) and difficulties in communication. Anxiety impacts on a person's ability to participate in activity due to restless movement and poor attention. Activities which involve sequential events, such as preparing a meal, may serve to exacerbate the problem rather than reduce the level of anxiety (Perrin, 1997). Likewise, Kitwood (Kitwood, 1993; 1997) suggested that anxiety may relate to not having a role or clear idea of one's life purpose. Therefore removing activities that are part of a personal routine may enhance the presenting level of anxiety rather than reduce it.

2.3.2.2 Pacing

Pacing has been reported in 23 to 40% of people with severe dementia (Boller et al., 2002). This behaviour manifests itself as determined walking within a restrictive area often in a state of anxiety or deep thought. As a behavioural problem, pacing is difficult to interpret with conflicting explanations for its cause. Logsdon, Teri & McCurry et al. (1998) claim that pacing and wandering are attempts by the patient to get to a location, possibly home, but due to their severe cognitive impairment this goal is often forgotten. In contrast, Woods (2001) suggests that wandering may reflect the search for someone or something, or be indicative of the search for somewhere safe in a bewildering environment. Wandering may also be perceived as a sign of boredom exacerbated by problems with communication (Carlson et al., 1995). Attention to timing, location of activity and awareness of normal habits and routines may help minimise problems of wandering. For example, a man who used to be a farmer may be restless first thing in the morning as this would have been a time to milk the cows. An early morning walk may achieve that sense of purpose and more accurately reflect his normal work routine.

2.3.2.3 Depression.

Depression is a common feature in dementia (Woods, 2001) with a prevalence rate of 17 to 35% amongst those with severe dementia (Hargrave, Geck, Reed, & Mungas, 2000; Lazarus, Newton, Cohler, Lesser, & Schweon, 1987). The clinical features include tearfulness, low mood, memory loss and apathy, resulting in reduction in activity. Due to the overlap of cognitive features such as memory loss, seen in both depression and dementia, a diagnosis of depression in severe dementia is problematic (Visser, Verhey, Ponds, Kester, & Jolles, 2000). As people age, their sense of well-being becomes more complex due to functional and social losses. This may affect mood leading to depression (Netz, Wu, Becker, & Tenenbaum, 2005; Ruuskanen & Ruoppila, 1995), however, it is unclear whether it is the lack of activity that causes depression or depression that leads to a lack of activity. For people with moderate to severe dementia who have memory loss, low mood and apathy, current activities may appear too complex and challenging for them. Activities such as Reality Orientation and Reminiscence Therapy may be unsuitable due the complex nature of the activity format, specifically, length of the activity and the social discourse required. Motivation is required to engage these activities which are often hugely challenging. Therefore activities that focus on areas that are relatively preserved may be more successful for those with poor motivation.

2.3.2.4 Aggression

Aggression is estimated to occur in 30 to 55% of people with severe dementia (Eastwood, 1994; Patel & Hope, 1993). In particular, Keen, Hope & Fairburn et al. (1999) found that physical aggression in severe dementia was related to loss of self-care, perhaps as a result of the person feeling vulnerable and threatened (Woods, 2001). This problem is undoubtedly exacerbated by impaired verbal skills leading to difficulty in communicating (Keene et al., 1999) which may also contribute to the feelings of vulnerability for the person with dementia. Behavioural problems such as aggressive outbursts can impact on staff and carers when trying to facilitate activities of daily living. These are often cited as reasons for staff burnout and stress (MacPherson, Eastley, Richards, & Mian, 1994)

2.3.3   Movement disorders

Motor co-ordination deteriorates rapidly with 66% of people with severe dementia exhibiting signs (Schaufele et al., 2002). These co-ordination problems include dyspraxia[1], an impairment in the production of skilled movement, and neurological pathology such as extraparymidal signs and myoclonic jerks.

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[1] Dyspraxia may be described as both cognitve and movement impairment. For this thesis the description of dyspraxia has been included under cognitive impairment.

2.3.3.1 Poor co-ordination

Poor co-ordination can also be caused by extrapyramidal signs such as shuffling gait and tremor. Boller et al. (2002) identified these signs in 50% of people with a diagnosis of severe dementia. These were often accompanied by primitive reflexes (Schaufele et al., 2002). Although these two studies support the notion of extra pyramidal signs being a prominent feature of severe dementia they fail to mention whether the signs could be due to an over-use of neuroleptics. Poor co-ordination has a direct effect on the quality of functional performance (Fisher, 2003), therefore activities requiring fine motor skills and precision, such as domestic tasks or some craft activities, may result in safety issues or difficulty in completing the activity for people with moderate to severe dementia.

2.3.3.2 Myoclonic jerks

Another well documented feature of severe dementia is myoclonic jerks (Chui, Teng, Henderson, & Moy, 1985; Franssen, Kluger, Torossian, & Reisberg, 1993). Myoclonic jerks are sudden, involuntary jerking of a muscle or group of muscles. This is sometimes in response to an external event such as the person trying to move, although, there is evidence of myoclonus at rest in severe dementia (Caviness & Brown, 2004). The likelihood of myoclonus increases in the moderate to severe stages of the disease (Caviness, 2003; Caviness et al., 2004). Myoclonus is particularly common (up to 50%) in Alzheimer's disease (Caviness, 2003) but is evident in most types of dementia in the later stages of the disease (with the exception of Vascular dementia), and is associated with other movement disorders such as ataxia (Caviness et al., 2004). This presentation may lead to difficulty in co-ordinating movement necessary for activities of daily living and increase the risk of falls.

2.3.4   Summary

In summary, these features lead to excess disability and hinder participation in activity (Carlson et al., 1995; Zaudig, 2000). This may lead to significant functional challenges, for example loss of self-care skills, marked loss of autonomy and loss of purposeful activity (Baum et al., 2003; Boller et al., 2002). In particular, problems with attention make it difficult for the person to filter out competing stimuli in order to engage in activity. This is compounded by the increasing demand on cognitive reserves which mean strategies that worked before the disease are harder to utilise. Examples of these strategies include choosing a quiet environment in which to undertake complex activity, or choosing activities that are of sufficient challenge to maintain interest but not so difficult that interest wanes. With activity that is too complex, attention and arousal decrease which in turn leads to a decline in task accuracy. The outcome can be agitation and frustration. Loss of fluency has an impact on communication both in a social context and in giving and receiving instructions. These problems, in turn, are hampered by poor short term memory, in particular, difficulty in retaining

instructions. Long term personal and knowledge memory is relatively more preserved but in severe dementia memory recall can be hindered by some of the other difficulties mentioned, such as communication. Failure in participation can lead to regular activity being withdrawn, which in turn may amplify many of the problems mentioned above.

These challenges are seen in all forms of dementia and, despite developments in pharmacological management, little improvement is seen in cognitive and behavioural disorders (Gori, Pientini, & Vespa, 2001; Turner, 2005). Paradoxically, many of the side effects of medication include cognitive and behavioural signs. Activity is considered positively to influence some of these cognitive and behavioural disorders; however, facilitation of activity for those with moderate to severe dementia is variable and few activities have been specifically identified as suitable for people in the later stages of the disease (Farina et al., 2006; Karp et al., 2006). Therefore, Chapter 3 will discuss the evidence for the effectiveness and suitability of the activities currently available to persons with moderate to severe dementia.

Chapter 3 Provision of interventions for people with severe dementia

3.1 Search strategy and literature selection

A literature search was conducted using CINAHL, EMBASE, Psych Lit, BIDS, IBSS Data-base, Medline, and the trials register of the Cochrane Library, and OT Direct research resources. A preliminary search was conducted between the years 1990 – 2005. Once key articles had been identified, a further, extended search was conducted where search results were limited, using hand searches. Contact was also made with international researchers in the field of activity for older people with dementia (Dr Jason Staal, Beth Israel Medical Centre, New York; Dr Roger Baker, Kings Park Community Hospital, Bournemouth; Dr Jenny Chung, Hong Kong Polytechnic University, Hong Kong) to discuss current literature in the field of MSE and the proposed theoretical framework of this study.

Key words used in the literature search included: multi-sensory stimulation; Snoezelen; functional assessment; dementia; functional performance; activities / engagement; Reality orientation; Reminiscence and Reminiscence therapy; recreational therapy; gardening; horticultural therapy and horticulture. Further searches were carried out from the literature identified by reviewing reference lists and conducting an author search.

Assessment of identified, randomised controlled trials was conducted using criteria proposed by Jadad et al. (1996) to assist in examining the rigour of the study and the validity of the stated outcomes.

Other literature was assessed using a framework for ranking evidence evaluating healthcare interventions (Evans, 2003). This hierarchical framework allows systematic evaluation of health related interventions across a range of methodologies. Literature gathered was used to set the scene, explore the problems presented by people with moderate to severe dementia and identify provision of activity for this client group. The next section describes the client group for whom this study was designed.

Despite the lack of empirical evidence supporting a mode of action for activities used for people with dementia, there is evidence that activity is of benefit and that it has the potential to improve mood, behaviour, cognition, motor performance and quality of life. This evidence will be presented along with a proposed theory base to underpin suitable activity. Multi-sensory environments will then be considered as a suitable activity to address some of the issues identified. This, in turn, will lead to the research questions and the methods chapter.

3.2   Activities used in dementia

With the increasing trend to conceptualise dementia from a more psychological perspective, more therapeutic options for care have become available (Bond & Corner, 2001) and psychological therapies have been recommended as a first line treatment for people with dementia (Howard, Ballard, O'Brien, & Burns, 2001). Although there has been a lack of direction, service providers have recognised the need to be more inclusive of different models of disease management, in order to provide a more holistic approach to care. Hughes et al. (2004) also acknowledged that there are an increasing number of treatments available. The more common interventions used specifically with people with moderate to severe dementia are Reality Orientation, Validation Therapy and Reminiscence Therapy. More non-specific activities include activity groups, music groups, cookery groups, art groups and so forth. These latter groups focus more on the social components of the activity with sub-goals being to increase concentration, mood, and participation. The suitability of Reality Orientation, Validation Therapy, and Reminiscence Therapy for people with moderate to severe dementia will now be considered in more detail.

3.2.1   Reminiscence Therapy

Reminiscence Therapy (RT) stems from Butler's early work on 'Life Review' (Butler, 1963). It aims to reflect on past experiences and unresolved conflicts. As long term memory is more likely to be intact in dementia (Cohen & Taylor, 1998; Spector, Orrell, Davis, & Woods, 2003a), RT was believed to be a more appropriate intervention. The activity can be used with a group of individuals, or on a one to one basis. Participants are encouraged to talk about past events and experiences. These memories are often facilitated with pictures, audio and video clips and memorabilia. Coleman (1974) described three types of reminiscence: simple reminiscence consisting of automatic recollection of past events; informative reminiscence which involves sharing memories with others; and life review which is more analytical and reflective.

Reminiscence therapy is seen as a dynamic process of adjustment with key outcomes being: well-being; improved mood, communication and interaction; and improved cognition, particularly autobiographical memory (Bluck & Levine, 1998; Woods, Spector, Jones, Orrell, & Davies, 2005). The process of reminiscence is thought to provide memory stimulation and develop self actualisation by promoting a sense of integrity and adjustment (Bluck et al., 1998; Ebersole, 1978). Reminiscence Therapy also incorporates social interaction and a development of self, however, given the haphazard way RT sessions are run it is doubtful this is achieved (Bluck et al., 1998). Reminiscence therapy and life review are more commonly associated with people with dementia and have grounding in Erikson's theory of psychosocial development (1959). The RT session should provide the opportunity for each individual to explore past experiences and evaluate and

resolve conflict, thereby improving their sense of well-being. However, reflecting on past personal experiences can raise a mixture of responses from pleasure to sadness leading to a conflict of 'integrity versus despair' (Erikson, 1959). How this is managed depends on the skill of the group leader. Also, it is unclear whether staff running RT sessions have the skills to reflect so as to help participants integrate their past experiences, which are critical components in the resolution of 'integrity versus despair' (Kasl-Godley & Gatz, 2000). Clinical experience would suggest that due to the limited experience of most people charged with carrying out these sessions, RT more often remains a social opportunity to discuss briefly major social events such as royal weddings. Ideally activity should reflect a sound theoretical base from which the reasons for taking part are clear. This builds on our understanding of the psychological impact of dementia and ways to manage it, and includes strategies that directly address problems caused by the disease process. This should be supported by empirical evidence for the intervention when used for people with dementia (Kasl-Godley et al., 2000).

A systematic review of studies exploring the efficacy of RT has revealed limited results (Spector et al., 2003a). Goldwasser, Auerbach & Harkins (1987), Orten, Allen, and Cook (1989) and Lai (2004a) report no significant improvement in social behaviour and interaction. However, (Thorgrimsen, Schweitzer, & Orrell, 2002) reported improved behavioural functioning. Significant improvement in cognition was only reported in two trials (Lai, Chi, & Kayser-Jones, 2004; Morgan, 2000). These mixed responses are compounded by methodological weaknesses in each of the studies related to small sample sizes and problems with assessment rigour. Finally, there is a suggestion that RT is only beneficial for people with severe dementia when used in association with other interventions such as Reality Orientation or Validation Therapy; however, there is no description of how this association achieves a positive outcome (Baines, Saxby, & Ehlert, 1987). (Moulin et al., 2002) also observed that the autobiographical memory of people with moderate to severe dementia was not always retained; therefore RT may not be that suitable for some people in the later stages of the disease, especially in Alzheimer's disease where communication may also be limited (Boller et al., 2002). However, RT has been found to improve psychosocial well-being when used within a life-story approach (Lai, Chi, & Kayser-Jones, 2004). Whilst simple and informative reminiscence may be possible for those with severe dementia, life review may be more difficult to achieve due to deficits in autobiographical and episodic memory, and impairments in concentration and language.

Thus, the evidence base for the efficacy of RT is limited (Spector et al., 2003a) with most evidence coming from descriptive and observational studies (Head, Portnoy, & Woods, 1990; McKiernan & Yardley, 1990). Furthermore, RT appears to be inadequate in its ability to map onto problems presented in moderate to severe dementia.

3.2.2   Reality Orientation

Reality Orientation (RO) is one of the most widely used interventions for people with dementia. The concept was first described by Folsom (1966) as an attempt to improve the quality of life for people with dementia by orientating them in time, place and person. Folsom believed this would improve self-esteem and give the individual a greater understanding of their environment. In its early days, it was more commonly used to orient disturbed war veterans rather than being used within hospitals (Folsom, 1966), and latterly with older patients with long-standing mental health problems (Folsom, 1968). Today, RO can be used in a classroom format, where a group of people take part in a range of orientation activities; or a 24 hour format whereby people are oriented to reality at all times. Reality orientation has subsequently become an intervention that requires high input from staff maintaining RO boards and constant correction for the person with dementia (Woods, 2002). It is now enjoying a revival; with research from Europe supporting its use in cognitive stimulation (Breuil, Rotrou, & Forette, 1994; Zanetti, Oriani, & Geroldi, 2002).

Despite RO's longevity there is little evidence to support a sound theoretical base. According to RO philosophy, the confusion experienced by people with dementia is caused by a lack of social reinforcers and environmental cues. By improving orientation, confusion is thought to be reduced and normal behaviour can be resumed (Williams, Reeve, Ivison, & Kavanagh, 1987). There is also no recognition of how RO should be adapted given the different severity levels of dementia. Although Woods (1992) does offer the suggestion that staff should be sensitive to their own body language if working with those at a more severe stage of the disease whose verbal communication is more limited.

There have been a large number of studies exploring the efficacy of RO in dementia (Spector, Orrell, Davis, & Woods, 2000) which suggest positive effects on both cognition and behaviour in terms of re-orientation and improved self care. However, there is debate whether this intervention is ethical given the level of distress it may cause, particularly to those people with moderate to severe dementia who are unable to retain orientation information. For example, it may be inappropriate constantly to remind a person that they are living in a care home, when they have a strong desire to go home (Dietch, Hewett, & Jones, 1989; Powell-Proctor, 1982). Butler (1977) also highlighted this problem, believing the constant re-learning of material contributed to mood and self-esteem problems. More importantly, a systematic review of randomised controlled trials exploring the efficacy of this intervention for people with severe dementia did not show a relationship between the amount of time spent in RO and behavioural outcome (Spector et al., 2000). Indeed, one study (Gerber et al., 1991) actually reported a decline in performance at 10 week follow up as measured by the Kingston Dementia Rating Scale (Pelletier, Hopkins, & Hamilton, 1991) compared to the intervention period.

Reality orientation is considered to assist with orientation and maintenance of reality. However, there is debate as to the efficacy of this approach and concern as to whether this approach is too confrontational for people with more severe dementia (James, Douglas, & Ballard, 2004). Of six randomised controlled trials included in the Cochrane database of systematic reviews (Spector et al., 2000) results indicated a positive effect on mood and behaviour. However, cognition did not significantly improve (Baines et al., 1987; Ferrario, Cappa, Molaschi, Rocco, & Fabris, 1991; Gerber et al., 1991; Wallis, Baldwin, & Higginbotham, 1983; Woods, 1979).

Additional problems seen in moderate to severe dementia include limited semantic and short-term memory (Boller et al., 2002). The person would be unable to retain information given in the RO session for a sufficient length of time that would be of any use. Also the RO session offers little opportunity for engagement due to the high cognitive demands of the activity coupled with the low skill level of the individual (Csikszentmihalyi & LeFevre, 1989). This may explain the behavioural problems reported in Gerber's studies of Reality Orientation with people with moderate to severe dementia (Gerber et al., 1991).

3.2.3   Validation Therapy

Validation Therapy (VT) was developed by Feil between 1980 and 1993, as a way of communicating with a person with dementia by empathizing with feelings and hidden meanings behind confused speech (Feil, 1982). It is considered to be suitable for those with advanced dementia, where other methods such as RT and RO are not appropriate. Validation Therapy involves a group of people meeting on a regular basis to discuss and share experiences of certain events (for example, weddings, Christmas or the arrival of grandchildren), whilst focusing on the feelings and emotions these events provoke. During this meeting the group leader facilitates communication using reminiscence, eye contact, rephrasing muddled speech and observing and reacting to emotions.

Validation Therapy draws heavily on humanistic theory, particularly the work of Rogers (1951), and is based on the acceptance of reality, the personal truth of another's experience and the concept of self. As the dementia progresses the individual's ability to maintain a sense of self is compromised and the person relies more heavily on others to sustain this sense of self, through relationships formed and social interaction (Karon & Widner, 1995; Kasl-Godley et al., 2000). Validation therapy would appear to go some way to address this balance, but it is unclear whether Feil's original concept of VT was actually based on these assumptions. Feil (1993) suggested that some of the features of dementia, such as repetition and retreating into the past, were strategies to avoid stress, boredom and loneliness. Despite these claims VT was not developed from a theoretical model and has attracted considerable criticism (Peoples, 1982; Robb, Stegman, & Wolanin, 1986; Toseland et al., 1997), particularly in relation to Feil's claims.

There are a limited number of randomised controlled trials exploring the efficacy of VT in terms of improving cognition and behaviour. However, none reveals conclusive findings (Peoples, 1982; Robb et al., 1986; Toseland et al., 1997). A review of these studies found no statistical difference between the experimental and control groups using outcome measures on behaviour, cognition or activities of daily living (Neal & Briggs, 2003) It is also clear from a meta analysis of the data that there are substantial methodological weaknesses in the study designs such as lack of clarity in the inclusion criteria and limited description of the intervention criteria (Neal et al., 2003).

Two observational studies (Babins, 1998; Bleathman & Morton, 1996) have suggested there are positive effects of using VT; in particular, an increase in the number of interactions amongst group and staff members. Particular concerns highlighted by these studies include apprehensions that staff perceive Validation Therapy as being personally and emotionally demanding, due to the matching of emotion to create trust in relationships, which in turn may influence staff's ability to adhere to the intervention protocols.

The majority of evidence regarding the efficacy of VT remains anecdotal with insufficient evidence from randomised controlled trials to allow any conclusions to be drawn (Kinnealey, Oliver, & Wilbarger, 1995; Neal et al., 2003). It is also unclear how VT may address the behavioural and cognitive features identified in moderate to severe dementia. However, arguably, this is possibly one of the better interventions for people with moderate to severe dementia as emotional processing is relatively preserved compared to general cognitive ability (Bucks & Radford, 2004; Magai, Cohen, Gomberg, Malatesta, & Culver, 1996). Therefore, by focussing on the emotional interaction with the person with dementia (a key feature of VT) the shift of emphasis moves towards their remaining abilities rather than disabilities.

3.2.4   Social activity

Social activity is often overlooked in the hospital environment, with the focus being on routine activities such as self-care, eating and sleeping (Herzog, Rodgers, & Woodward, 1982). Social activity is naturally diverse and all the studies mentioned below cite different examples. This makes it difficult to identify the most suitable activity for therapeutic purposes. Examples of social activities most commonly seen in hospital and care home environments include quizzes, bingo, skittles, gardening, baking and sing-a-longs. Whilst these activities often have a variable structure they generally involve a gathering of people taking part in an activity in order to socialise, share knowledge and, hopefully, have fun. Gardening, in particular, is one social activity that is sometimes used as part of occupational therapy for people with dementia (Chaplin, 2003; Heath, 2004). For people who report an interest in gardening the activity offers some physical activity, problem solving, memory (particularly procedural memory) and sensory awareness. The activity could also be considered to be multi-sensory.

As social engagement constitutes a wide range of activities no one theory base exists to explain possible outcomes. However, the engagement hypothesis (Arbuckle, Maag, Pushkar, & Chaikelson, 1998) and the 'disuse' hypothesis (Salthouse, 1991) offer two frameworks. The engagement hypothesis suggests that intellectual stimulation during adulthood might preserve capabilities in later life. The process of mental stimulation is thought to reduce confusion by activating neural pathways and re-using patterns of behaviour diminished through disuse (Kasl-Godley et al., 2000). The 'disuse' hypothesis offers an extension of this idea with the 'use it or lose it' adage. The 'disuse' hypothesis suggests an atrophy of cognitive abilities if activity patterns are not maintained.

A systematic review of several longitudinal studies show that cognitive ability is strongly related to social activity and may offer some defence against dementia (Fratiglioni, Paillard-Borg, & Winblad, 2004). Also, Bygren, Konlaan & Johansson (2005) and Glass, de Leon & Berkman (1999) both report longer survival times for those who participate in social activities such as attending cultural events and sharing interests with others. However, the causal association of these relationships is unclear, but it does seem likely that social activity may yield a positive response from the person with dementia when the activity is tailored to meet individual preferences. Other explanations include the likelihood of premorbid social activity influencing the person's desire to continue with familiar habits and routines or, reluctance to take part due to low mood and depression leading to low levels of participation in social activity. Whilst matching familiar habits and routines to individuals is preferable, people with moderate to severe dementia are often unable to participate in an activity to completion. Therefore, social activities are often considered too complex for the person to participate in, and poor attention may lead to the person leaving before the activity has been completed.

3.2.5   Summary

In summary, all the interventions mentioned above reveal persistent problems in terms of their suitability as an activity for people with moderate to severe dementia. Paradoxically, these activities may fail because they require capabilities and effortful strategies that the person with dementia has lost. For example, Reality Orientation, Reminiscence Therapy, Validation Therapy and social activity all require, to some degree, memory, reasoning and basic social skills. Therefore, those with severe dementia would gain limited benefit from any of these activities due to the damage they have experienced and to the higher order cognitive and social skills required (Chung, 2004; Gori et al., 2001; Josephsson & Backman, 1993). Therefore, in selecting suitable activity the key problems would seem to be:

- The lack of substantive evidence that any of these interventions are of benefit for people with moderate to severe dementia or poor evidence with methodological errors;

- A lack of a sound theory base underpinning these interventions (we are unclear what these activities are supposed to achieve for people with moderate to severe dementia);
- A mismatch between the activity and the abilities of people with moderate to severe dementia (skill level required versus skill ability);
- The use of activities more suitable for those with milder forms of dementia and their use also with those with moderate to severe dementia.

Additional problems are also evident which hinder the facilitation of suitable activity. These include a lack of understanding of what it is about the activity that creates engagement for people with moderate to severe dementia and problems with offering these activities due to changes in service delivery. Engagement may be improved if the activity matches personal ability, uses preserved skills, and is supported by staff and environmental cues (Josephsson et al., 1993). Kielhofner (1985) also suggested there is a need to address concomitant factors such as motivation, habits and routines. These additional problems will be explored in more depth.

3.3   Additional barriers to therapeutic activity

Engaging people with moderate to severe dementia in activity is challenging. These challenges include offering an activity that is suitably complex, within a time frame that will hold the person's attention, by a member of staff or carer who has the skills to facilitate when necessary. Additional barriers also include service provision issues which fluctuate with each changing political environment.

3.3.1   Activity engagement in people with moderate to severe dementia: activity versus occupation

Approaches such as Reality Orientation, Reminiscence Therapy and Validation Therapy often fail because little attention is paid to the process of engagement in activity. In particular, cognitive decline, physical frailty and loss of personal identity can make it difficult to identify occupation and activity that is perceived as worthwhile and relevant by the person with dementia as well as by the therapist. This may result in the loss of any attempt to engage people in occupation as those with severe dementia are seen as unable or unlikely to benefit (Chung, 2004; Mozley, 2001). This is possibly due to a mismatch in perception of ability compared with the actual ability of the person with dementia.

There is also confusion between what is seen as activity versus occupation. Occupation is described as:

'everything people do to occupy themselves including self-care, leisure and productivity' (Canadian Association of Occupational Therapists, 2002 p.34).

This definition includes activities of daily living, such as washing and eating, as well as tasks that create a sense of purpose. Whereas occupation is perceived as a primary source of meaning and purpose it may be wrong to assume all occupation provides meaningful activity to all people (Hammell, 2004). People derive meaning from what they do through their own personal framework and culturally shared beliefs of what is meaningful (Jonsson, Borell, & Sadlo, 2000). What is meaningful to one person may not be the same for another. Indeed, from the perspective of people with severe dementia the three categories of self care, leisure and productivity may be perceived as meaningless as they are no longer able to recall their own belief of what is meaningful. Consequently, the focus turns to what they cannot do (disability) rather than what they can do (ability). Many of the activities that are available for people with severe dementia include elements that focus on *disability* rather than on *ability*; for example, Reality Orientation focuses on memory recall, a major feature of severe dementia being memory loss. If the activity offered can only focus on disability we deny the individual the right to partake in activity that provides pleasure and enjoyment. Gilliard (1995) sums this up by reflecting that staff may see people with dementia in terms of their disease rather than in terms of what they are able to do.

However, the notion of providing suitable activity is problematic, given people with severe dementia are reliant on others to support them in taking part. Often activities of daily living are taken over by carers and relatives in an attempt to 'get the job done' rather than allowing the individual the time and the opportunity to do it themselves. However, doing part of the activity may be as important as doing the whole if it meets the individual's skill level and offers meaning. Activities should be considered, not only for their outcome but also for their potential to meet that intrinsic need (Law et al., 1996).

Pulsford (1997) identifies two barriers to successful activity. They are, firstly, the problem of staff offering activity that is too challenging for the person with severe dementia due to a lack of understanding of how to select suitable activity and, secondly, a lack of support within service provision causing staff to focus on routine tasks rather than activity. The consequences of these barriers are negative behaviours, such as hostility and disinterest (Chung, 2004; Kolanowski, Litaker, & Buettner, 2005). These barriers lead staff to withdraw from facilitating activity.

3.3.2   Staffing and service provision issues

Pulsford (1997) recognises that staff find engaging people with dementia in activity challenging, often preferring mundane tasks such as 'tidying the laundry cupboard' (p.707). Pulsford (1997) also notes that staff are reluctant to maintain activity seeing it as 'low priority' (p.705) or 'impossible' (p.707) if long term gains are not achieved. Pulsford therefore argues that the most successful activities, in terms of staff and individual participation, focus on quality of life and sharing of the experience. This enhances morale in staff and the individual, and allows activity to be adapted to meet the individual's needs.

The National Service Framework for Older People (NSF) (Department of Health, 2001) includes a recommendation to change staff attitudes and foster a more positive approach to older people. The framework sets out a 10 year plan to improve services for older people which includes person centred care and improved standards of service provision. Person centred care is identified by the Department of Health as a particular concern as it is felt that current service provision is limited (Baldwin, 2003; Netz et al., 2005). However, the plan is itself limited in that it gives no suggestions for how service provision may be improved. The Care Management Approach for Older People with Serious Mental Health Problems (Department of Health, 2002) also endeavours to address the challenges presented by people with severe dementia. It, too, offers limited guidance, with the main emphasis being on assessment rather than on intervention. Whilst improved assessment is the cornerstone to improved management, the lack of clear direction in management is problematic and consequently day to day management is left to staff who may still perceive activity to be supplementary to general care. For example, Challis et al. (2002) found that departments providing specialist dementia services offer more assessment for people with severe dementia than treatment. This is possibly due to the lack of rigorous research underpinning any of the interventions and the lack of training offered to staff into the mechanics of running an activity (Altus, Engelman, & Mathews, 2002; Hope & Waterman, 2004; Spector et al., 2003b).

3.3.3   Summary

Given the lack of direction from these reports, service providers are left to deal with the challenges presented by people with severe dementia as they see fit. Consequently, services are variable with little known about models of care (Department of Health, 2000; Reilly, Challis, Burns, & Hughes, 2003). Despite these problems there is a strong body of knowledge supporting the use of activity for people with dementia. This includes the effect of activity on cognition, behaviour, physical ability, and well-being. These features will be explored in more depth in Chapter 4.

Chapter 4 Impact of activity and occupation in moderate to severe dementia

This chapter presents a review of the benefits of engaging in activity for people with moderate to severe dementia and explores the theories which might support the use of multi-sensory activity. Finally, research exploring the efficacy of MSEs as an activity for people with cognitive decline will be presented, leading to the research questions and methodological design.

4.1   The benefits in engaging in activity for people with dementia

Although there continues to be a lack of guidance on activity intervention, research has shown that occupational activity for older people with dementia can maintain psychological and physical health (Baum et al., 2003; Chung, 2004; Fabrigoule, 2002). This outcome is evident despite the progressive nature of the dementia disease process. Reduction in activity and increased levels of dependency are apparent in care centres where there is little or no commitment to activity (Gori et al., 2001). This dependency is also perpetuated by carers both within the hospital environment and at home, who see removing activities as a solution for time consuming one to one supervision. This disruption in activity is reflected in the person's behaviour. Wandering and searching may reflect boredom, whilst aggression and agitation may indicate frustration at not being able to take part in activity (Csikszentmihalyi, 1988; Gori et al., 2001; Sharp, Barnes, & McNaughton, 1987). These ideas support the need for activity both to maintain function and cognition, and to moderate mood and behaviour.

Baum (1995) examined the role of occupation in maximising functional performance and reducing disturbed behaviours. Thirty four married women and 38 married men with mild to moderate Alzheimer's disease, living in the community, were randomly selected from the Washington University Alzheimer's Disease Research Centre data-base. Baseline disease severity was measured with the Clinical Dementia Rating (CDR) (Hughes, Berg, Danziger, Coben, & Martin, 1982b). Data were also collected on the Kitchen Task Assessment (Baum & Edwards, 1993) and the Short Portable Mental Status Questionnaire (Pfeiffer, 1975). Carers filled in the Memory Problems Behavioural Checklist (Zarit, Reever, & Bach-Peterson, 1980), completed the Zarit Burden Interview (Zarit, Todd, & Zarit, 1986) and the Activity Card Sort (Baum et al., 1993) reporting on the activities of their spouse. Results revealed a decrease in executive skills significantly associated with the person giving up more occupational activity, and an increase in the amount of help needed to perform basic self-care. In addition, a decrease in activity was directly related to an increase in disturbed behaviour, which itself correlated with increased stress in carers.

These results suggest that activity may be an intervening variable between cognitive functioning and disturbed behaviour.

Further studies have explored the relationship between activity and the development of a diagnosable dementia (Fabrigoule et al., 1995; Scarmeas, Levy, Tang, Manly, & Stern, 2001; Wilson et al., 2002). Scarmeas et al. (2001) were particularly interested in exploring whether participation in activity reduced the risk of Alzheimer's disease. In their study, 1772 participants with no diagnosis of dementia aged 65 years or older were recruited. They were assessed at baseline for participation in leisure activity. The group were followed longitudinally for a period of up to 7 years (*M* 2.9). Levels of participation in leisure activity and incidence of dementia were recorded. After adjustment for age, ethnic group, education and occupation, the results indicated that the risk of dementia was reduced in participants who engaged in high levels of leisure activity. These results provide support for Fabrigoule's study (1995) and are corroborated by Wilson et al. (2002) who also found that engaging in higher levels of cognitively stimulating activities was associated with reduced risk of Alzheimer's disease. The authors argue that the conclusions could also be relevant to other dementias. However, the selection of activities recorded in all three studies was limited, focussing on common activities such as viewing television, listening to the radio, reading, playing games, crafts and visiting museums. Other studies have remarked upon the variety of activities that may decrease the likelihood of dementia, such as physical exercise (Laurin, Verreault, Lindsay, MacPherson, & Rockwood, 2001) and social networking (Wang, Karp, Winblad, & Fratiglioni, 2002).

It is also unclear from these studies which causal factors within the activity influence cognitive functioning. A possible explanation for this association could be the individual's premorbid lifestyle which may have included regular participation in activity. Regular activity may be an indicator of a good physical and mental health status whereas a reduction in activity may be determined by prodromal cognitive symptoms which are a feature of early dementia (Fratiglioni et al., 2004). Furthermore, these studies consider activity levels in people prior to a diagnosis of dementia rather than focussing on the impact of activity during the disease. Consequentl*y,* the basis for the association between activity, dementia and the rate of cognitive decline remains to be established.

4.1.1 The role of activity and occupation in cognitive decline

Gori et al. (2001) endeavoured to explore the association between cognitive decline and activity in dementia. This longitudinal study took a group of 14 people with moderate to severe dementia and randomly allocated them either to an experimental or control group. Over a period of two years the experimental group attended a range of activities that were programmed to occur three times a week. Participants were assessed on the Modified Activity Scale (Feil, 1982) and the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1986). Significant differences were found between

the two groups (p = .006), with the experimental group showing increased arousal, participation and interest. Also, it was noted that although the experimental group's Mini Mental State Examination score (MMSE) (Folstein, Folstein, & McHugh, 1975) from baseline to final activity session dropped 1.6 points per year the level of dependency in these participants remained unaltered.

Whilst this study shows a positive relationship between activity and level of cognitive function there are methodological weaknesses. The Modified Activity Scale and Cohen-Mansfield Agitation Inventory do not directly assess cognitive function although, clearly, elements of cognition are reflected in the components of the assessment. The MMSE, although a commonly used assessment, is purported to record levels of cognitive functioning but has received criticism regarding specificity, reliability and sensitivity (Bowie, Branton, & Holmes, 1999; Jones et al., 2002; Molloy, Alemayehu, & Roberts, 1991; Schulzer, Calne, Snow, & Mak, 1993). Also, the study used a small number of participants which reduces the generalisability of the study.

Kolanowski, Litaker & Buettner (2005) also evaluated the effect of recreational activities using a Need-Driven Dementia-Compromised Behaviour Model (NDB), (Algase et al., 1996). The model asserts that behavioural responses are the result of an unmet need; therefore the activities selected for this trial were adjusted to accommodate skill level and areas of interest of the individual. The results from this cross over experimental design revealed a greater level of participation (both mental and physical) and interest when activities were positively matched with skill level and personal interest.

Whilst cognitive status and physical function explain a significant amount of variance in engagement for people with moderate to severe dementia, there is also an acknowledgement that activity contributes to survival and improvement of mood state (Mozley, 2001). In particular, some studies report secondary goals such as maintaining a level of independence, a sense of well-being, and enhancement of quality of life (Netz et al., 2005; Pulsford, 1997; Voelkl et al., 2003). These will be discussed further.

4.1.2   Impact of activity on well-being

As mentioned above, it is well recognised that the need to participate in activity is essential for health and well-being (Borell, Gustavsson, Sandman, & Kielhofner, 1994; Law et al., 1996; Warr, Butcher, & Robertson, 2004; Wilcox, 1993). Research using RO, VT, RT and social activity all suggest that benefits, in terms of well-being, may be achieved by taking part in these interventions (Carstensen, 1971; Harlow & Cantor, 1996; Kasl-Godley et al., 2000; Lai, Chi, & Kayser-Jones, 2004d; Warr et al., 2004).

Recent studies suggest that people with dementia in residential care spend very little time in structured activity and report low levels of well-being (Norbergh, Asplund, Rassmussen, Nordahl, & Sandman, 2001; Warr et al., 2004). In addition to having a detrimental effect on well-being, remaining unable to participate in activity can also contribute to a loss of self esteem and a loss of a sense of belonging (Chung, 2004; Perrin, 1997). Chung (2004) investigated the types of activities people with dementia participated in and their associated states of well-being. Forty three nursing home residents with dementia were observed at 5 minute intervals over a 10 day period in their daily activities by an occupational therapist. Dementia Care Mapping (Kitwood & Bredin, 1992) was used to report the activities undertaken and the states of well-being experienced. Results revealed that people with severe dementia engaged in significantly more passive activities and their well-being was also observed to be significantly worse than those with mild and moderate dementia. Therefore, a sense of well-being may be associated with positive and enjoyable engagement in activity. This study supported the findings of Norbergh et al. (2001) and Wells, Dawson, Sidani et al. (2000). Norbergh, Asplund & Rassmussen et al. (2001) also reported that well-being in people with severe dementia was compromised by communication problems

Although a significant association is evident, the direction of the effect remains unclear. Activity possibly influences well-being through successful achievement, behavioural expression and other associated outcomes such as social interaction. Alternatively, a sense of well-being may influence willingness to participate in activity. These features were explored by Warr et al. (2004) in a study of well-being, activity frequency and activity type. The results indicated that the range of activities and frequency of participation reduces as we age. Activities such as social interaction, church and charity support were particularly associated with well-being. This study recruited well older people and, conceivably, the activities included may no longer be achievable for people with dementia. However, elements such as social interaction and spiritualism could be included into activity programmes in a modified form, in order to address the preferences of older people. Conversely, well-being may influence activity. Warr et al. (2004) concluded that individuals with a positive sense of well-being may show higher levels of activity, although this may be influenced by other variables, such as being an extrovert (Lucus & Fujita, 2000), or even marital status (Barberger-Gateau, Fabrigoule, Helmer, Rouch, & Dartigues, 1999).

Identifying suitable activity for people with dementia appears to be guided by the assumption that an increase in activity is positively correlated with an increased sense of well-being. However, much debate remains regarding the most suitable type of activities to use for people with moderate to severe dementia, the difficulty in assessing well-being amongst this client group and the anatomical impact of taking part in activity. Given that people with moderate to severe dementia may not be able to participate in hobbies enjoyed in the past, it may be the components of that activity that need to be presented. For example, a woman who enjoyed baking may experience pleasure being able to knead dough and being able to taste the finished product, despite not being able to complete the activity as a whole. Identifying these components may be critical in

constructing an activity that is suitable and desirable for the individual. This form of activity may also provide a level of stimulation which increases arousal and attention due to the simplicity of the task, which in turn may impact on ability to participate. The theory bases underpinning level of stimulation needed to facilitate participation in activity for people with moderate to severe dementia will be explored later in this chapter. Prior to this, consideration will be given to the sensory impairments older people may have which influence their ability to process sensory information, the impact of these sensory changes on activity, and the subsequent potential of sensory stimulation for neurogenesis.

4.1.3   Sensory changes and sensory deprivation, and their impact on activity

Sensory deprivation is a phenomenon where stimulation to an individual's senses is greatly reduced. Common characteristics of sensory deprivation include disorientation, irritability, confusion, lethargy and hallucinatory phenomena (Zubek, 1969). These are features that are also common in dementia. Therefore, by addressing these features of sensory deprivation with sensory stimulation it may be possible to reduce some of the characteristics of dementia. Sensory deprivation can be exacerbated by admission to residential accommodation or hospital (Voelkl et al., 2003) and drugs such as neuroleptics, with their associated side effects such as sedation, only further reduce opportunities for sensory stimulation (Burns et al., 2002).

This is supported by empirical evidence that older people with dementia are at increased risk of sensory deprivation due to sensory changes, deterioration of cognitive skills (loss of social skills and executive functioning) and environmental restrictions such as residential care or living alone (Bower, 1967; MacDonald, 2002; Norberg, Melin, & Asplund, 1986). Sensory changes can be experienced through sensory alterations associated with ageing: specifically visual changes, hearing loss and loss of taste and smell (Appollonio, Carabellese, Frattola, & Trabucchi, 1996; Zegeer, 1986). For example, Weale (1963) estimates that the eye of a 60 year old person receives only a third of light through the pupil compared to that of a 20 year old person. Consequently a stronger light stimulus is needed to achieve the same effect. As vision, hearing, taste and smell are critical for social interaction as well as learning and orientation to the environment, a loss of these senses may lead to dependency, reduced quality of life, and isolation (Valentijn et al., 2005; Zegeer, 1986). Stronger stimuli, greater contrast between stimuli, and allowing time to process the stimuli (as sensory processing takes longer in the older person) can offset the effect of sensory changes (Laurienti, Burdette, Maljian, & Wallace, 2005). This may maximise the person's remaining sensory abilities (Heyn, 2003). However, given variation in stimulus intensity and age related decline it is difficult to know what constitutes stimulus effectiveness. Very few studies have explored the relationship between sensory processing and selection of appropriate stimulation or even which senses are the most appropriate to stimulate (Corso, 1971; Keller, Morton, Thomas, & Potter, 1999; Laurienti et al., 2005). Brown and Dunn (2001) go some way to identifying the

preferred mode of stimulation, but even their method of assessment is open to interpretation. This assessment will be discussed later in this chapter.

As well as considering the need for sensory stimulation, consideration needs also to be given on the complexity of the stimulation (uni-sensory stimulation versus multi-sensory stimulation). Research suggests that multi-sensory stimulation is preferable to uni-sensory stimulation (Hairston, Laurienti, Mishra, Burdette, & Wallace, 2003), although the number of stimuli needed to achieve a suitable multi-sensory experience is unclear. Laurienti et al. (2005) suggest that this is dependent on the level of deterioration of sensory processing in older people, but increased numbers of sensory modalities are more beneficial when the sensory signal is ambiguous. Whilst Laurienti's study used well older people, this finding would also appear to be relevant to older people with dementia, where the majority of stimulation may be perceived to be ambiguous due to limited cognitive ability. Therefore, assessment of preferred sensory modality and activity characteristics would appear to be paramount in selecting the most appropriate level of sensory stimulation within an activity. By getting the level and intensity of stimulation right there may be a potential to influence neural reorganisation (neurogenesis).

4.1.4   Neurogenesis in the ageing brain and its impact on activity

In addition to positive effects of engaging in activity on cognition and behaviour, evidence from neurogenesis studies show that activity also has a positive effect on the development of the brain. Neurogenesis is the proliferation, survival, migration and differentiation of neural cells (Lomassese et al., 2000). Early studies (Bennett, Rosenzweig, & Diamond, 1969; Hebb, 1949; Turner & Greenough, 1985) identified that sensory enrichment has an effect on neural development as demonstrated by increased brain weight, cortical thickness and increased synaptogenesis (creation of new synapses). Later studies have revealed how both young and old brains have a remarkable capacity to be shaped by environmental input (Bavelier & Neville, 2002; Kobayashi, Ohashi, & Ando, 2002). Evidence also exists to support the theory that behavioural and environmental factors can influence neurogenesis (Kempermann, Gast, & Gage, 2002; Rochefort, Gheusi, Vincent, & Lledo, 2002). Indeed, the rate of neural proliferation appears to be highly sensitive to environmental factors and social interaction (Sandeman & Sandeman, 2000). This has implications for people with dementia, as activity and, importantly, an enriched environment may have an effect on the progression of the disease process.

In the adult, neurogenesis has been identified in two key areas of the brain; the olfactory bulb and its associated areas, and the dentate gyrus of the hippocampus. The dentate gyrus (part of the hippocampus, a temporal lobe structure) is known to have a pivotal role in higher cortical functions such as memory and learning. This theory is underpinned by many animal studies which highlight the benefit of physical exercise, social interaction and environmental enrichment on the neural

plasticity and brain weight of rats (Coq & Xerri, 2001; Rochefort et al., 2002; Sandeman et al., 2000). Rats that were exposed to environmental enrichment showed an increase in brain weight. Moreover, those reared in complex environments, during ageing, performed better on learning and memory tasks (Coq et al., 2001). Experiments with mice also revealed an improvement in short-term memory amongst those exposed to enriched environments. It is thought that this adaptation allows the animal to adapt to their changing environment (Lomassese et al., 2000; Rochefort et al., 2002). These findings have also been replicated in studies with crayfish and crickets, where enrichment with sensory stimuli (visual, olfactory, auditory and tactile) increased the production of neural growth and triggered motor activity and exploration (Lomassese et al., 2000).

One of the challenges in stimulating neurogenic effects in the ageing brain might be related to the difficulties of somatic stimulation, where ageing impairs sensory functions such as tactile sensitivity, sensory motor co-ordination, locomotion and exploratory activities (Coq et al., 2001). Decreased sensory function and stress are two features that are common in dementia and severe stress is also known to decrease adult hippocampal neurogenesis (Kempermann et al., 2002). This reduction of neurogenic regulation has been linked to hippocampal pathology, including Alzheimer's disease (Kempermann et al., 2002). This diminished regulation may help explain aspects of cognitive decline seen in dementia (Kempermann et al., 2002; McKhann, 2002). As studies indicate neurogenesis occurs in the hippocampal dentate gyrus throughout life, with low baseline levels only evident in later life, it seems appropriate that activity and environmental enrichment should be maintained in old age (Kobayashi et al., 2002). Indeed, Kempermann (2002) noted that continued exposure to a challenging, stimulating environment has the potential to invoke a large upregulation of neural plasticity, regardless of age, and even after environmental stimulation is discontinued the presence of neurogenesis can still be detected, suggesting that regular stimulation has a carry over effect. Arendt (2001) also reported that behavioural experience not only organises sensory cortical representation but also the rate of neurogenesis in the hippocampus, suggesting regular stimulation may enhance neurogenesis. It also appears the novelty of sensory stimuli rather than continual enriched stimuli affects adult hippocampal neurogenesis. (Lomassese et al., 2000). This is evident in environments where the television is left constantly switched on and no one watches it, in comparison to an unexpected visitor who draws attention. Although our understanding of neurogenesis in humans is limited, these animal studies support the notion that regular activity and a stimulating environment have beneficial effects on cognitive functioning, and, despite the ageing process the hippocampus maintains the potential for neurogenesis. It would also appear that the novelty of stimuli is important in leading to a change in neural structure (Lomassese et al., 2000; Lu & Zhao, 2005); therefore activity should be adaptable in order to maintain interest through novelty and variety of stimuli offered.

4.1.5   Summary

In summary, three key areas support the use of activity with older people with dementia. Firstly, activity has the potential positively to influence cognition and physical health. Evidence also supports the counter argument that poor cognition also leads to reductions in activity. Secondly, reductions in activity lead to a reduced sense of wellbeing, quality of life and functional ability. However, these reductions are reversible given the facilitation of suitable activity. Thirdly, animal studies support the idea that activity increases proliferation of brain cells that are important for memory and learning. Without this level of stimulation sensory deprivation may occur, leading to deterioration of cognitive skills. Therefore, sensory deprivation may be an important determinant of activity. Taken together this evidence suggests that engaging in activity that is highly stimulating, novel and of suitable complexity is likely to benefit people with moderate to severe dementia. Activity for people with moderate to severe dementia is clearly important, however, the key issues revolve around the selection of suitable activity that matches the specific needs of this group. Underpinning this are several theory bases, not normally applied in dementia, which may assist in the facilitation of activity. These will be considered as a justification for a suitable activity alongside a summary of the desirable features of activity for people with dementia.

4.2   Key theories supporting activity for people with moderate to severe dementia

The key theories influencing the selection of activity can be roughly divided into those relating to the individual and those relating to the environment in which the activity takes place. In order to explore these theories in context consideration must be given to what constitutes a successful activity.

4.2.1   Requirements for successful activity

Jones (1996) and Hellen (1998) identified what they considered to be essential requirements for successful activity. They suggest that activity should be: 1. simple – short tasks presented one step at a time with a limited chance for failure; 2. repetitive – being routine and familiar; 3. multi-sensory – including stimulation of sight, sound, touch, taste, smell and movement; 4. safe – with little element of risk; 5. adaptable – spontaneous versus planned and group work versus one to one depending on individual need; and 6. respectful – offering compatibility with age using remaining abilities and skills, incorporating old interests. Although these principles offer a framework in which activity may be designed the outcome is still dependent on individual characteristics. These will be explored in further depth.

4.2.2 The influence of individual characteristics on participation in activity: The Model of Sensory Processing

The problem of sensory deprivation may be exacerbated by the older person failing to process sensory information, due to cerebral atrophy (Bower, 1967). Dunn's Sensory Processing Model originally developed with children (Dunn, 2001) has been expanded to include adults (Brown & Dunn, 2002), and explains behavioural responses to sensation. The model suggests that people fall within one of four sensory quadrants: low registration, sensory seeking, sensory sensitivity, and sensory avoidance. The sensory quadrant in which an individual falls determines the types of responding strategies they may exhibit (Figure 3).

Figure 3: Dunn's Model of Sensory Processing

Threshold / Reactivity	Responding Strategies	
	Passive – behaves passively	**Active** – works against the threshold to control the sensory input
High threshold with low reactivity– needs a lot of stimulus to reach the threshold (tendency to be unresponsive or needs more intense sensory stimuli)	**Low registration quadrant** Does not notice sensory events in everyday life or is slow to respond 'I don't smell things that other people smell' 'I don't get jokes very quickly'	**Sensory seeking quadrant** Looks for sensory experiences in everyday life 'I like spicy food' 'I enjoy having my hair cut'
Low threshold with high reactivity – does not need much stimulus to reach the threshold (tendency to be overly responsive or annoyed with sensory stimuli)	**Sensory sensitivity quadrant** Readily notices sensory stimuli and may be uncomfortable or distracted by them 'I don't like heights' 'I don't like messy rooms'	**Sensory avoiding quadrant** Deliberately acts to reduce or prevent exposure to sensory stimuli 'I only eat familiar food' 'I always wear gloves during messy activities'

Brown & Dunn (2002)

Thresholds indicate how much stimulation is needed before the person responds. The responding strategies reflect an active response, whereby an effort is made to seek out or avoid stimuli; or a

passive response, whereby little or no effort is made to respond to stimuli. People with a high threshold and passive responding strategies fall within the low registration quadrant. They do not notice sensory events in daily life that others notice readily, for example, having dirty hands. Individuals with high thresholds and active responding strategies fall within the sensory seeking quadrant. They enjoy sensory experiences and will actively seek them out. Examples include people who like fairground rides. Those with low thresholds and passive responding strategies fall within the sensory sensitivity quadrant. They notice sensory events more readily than others and are easily distracted; for example, they notice changes in temperature or changes in a familiar environment. Those with low thresholds and active responding strategies fall within the sensory avoidance quadrant. They find ways to avoid sensory input during the day. Examples include leaving a noisy environment or creating rituals, as in those with autistic spectrum disorder (Brown, Dunn, Tollefson, Cromwell, & Filion, 2001).

This model may explain the responses of people with dementia to sensory stimuli. For example, someone constantly playing with a petticoat may be demonstrating the behaviours of a sensory seeker. Those who dislike being touched may be demonstrating the behaviours of a sensory avoider. Although the model describes four distinct quadrants it is possible for individuals to fall across quadrants. For example, a person may display elements of sensory sensitivity and sensory avoidance by readily noticing things they dislike and actively avoiding them. The model offers little explanation of how a person straddling two or more quadrants may be engaged in activity, but may help to explain why some activities fail to engage the person.

However, the Model of Sensory Processing does account for the nervous system's threshold for acting and the person's propensity for responding to those thresholds (Dunn & Westman, 1997). The model suggests that our personal neurological threshold (the point at which we respond or react) causes us to respond in a certain way (behaviour). Dunn suggests that our thresholds are on a continuum and have the potential to fluctuate in different circumstances. However, there is still debate over whether our neurological threshold is a trait or a state characteristic that can fluctuate in different conditions (Pohl, Dunn, & Brown, 2003).

Given that Dunn suggests we all respond differently to sensory stimuli then activity should arguably be tailored to meet individual needs. These needs may also change with age. Indeed, Pohl et al.'s (2003) study explored whether there are age related differences in sensory processing using Dunn's Adult Sensory Profile (Brown et al., 2002). The Adult Sensory Profile is a questionnaire based assessment developed from the Model of Sensory Processing. The profile uses responses to everyday sensory experiences to identify sensory preferences (Brown et al., 2002). The results reveal there are significant differences in the way older adults (65 years +) and young to middle-aged adults (19 – 64 years) notice sensory stimuli. In particular, older adults notice and seek out fewer stimuli than those less than 65 years of age. This behaviour is possibly exacerbated in dementia, as the person with dementia has to allocate more attentional resources to perceive and

interpret sensory information (Baddeley et al., 2001; Perry et al., 1999; Valentijn et al., 2005). This behaviour is also likely to exacerbate the risk of sensory deprivation as there may be fewer resources left for other cognitively demanding tasks. This study illustrates the need to enhance the sensory component of activity, in order to assist with the perception and interpretation of sensory information.

That individuals have different sensory needs may contribute to understanding why many people with dementia fail to participate successfully in activity. Unlike 'well' older people, they may be unable to modify their interaction with the activity in order to adjust the level of stimulation. Thus, an understanding of which sensory quadrant an individual falls within may assist with the selection of appropriately stimulating activity. For example, a person who is a sensory seeker may require activity that provides more intense stimulation, such as getting their hands into clay. In contrast, a sensory avoider may find some activity uncomfortable if the sensory demands are too great such as being part of a large group. Sensory processing is also reliant on the individual being able to integrate the sensory information. Ayres's theory of sensory integration embraces many of the premises of sensory process and, despite being based on work with children with developmental delay, may also go some way to explain why people with moderate to severe dementia have problems with processing the sensory components of activity.

4.2.3   The influence of individual characteristics on participation in activity: Sensory Integration Theory

Ayres developed Sensory Integration Theory to explain the relationship between sensory processing and behavioural responses when they cannot be attributed to neurological damage alone. Ayres (1979) reflects that the ability to cope with the environment diminishes in the absence of an adequate level of stimulus. Once in a state of deprivation, the person's environmental coping process becomes dysfunctional and responses to sensory input become maladaptive. Sensory integration (SI) theory was developed to explain the relationship between behaviour and neural functioning. Ayres defined the sensory integrative process as 'the ability to organise sensory information for use' (Ayres, 1972, P.1) and expanded it by saying 'the brain must select, enhance, inhibit, compare and associate the sensory information in a flexible, constant changing pattern…the brain must integrate it.' (p.11). SI theory suggests that opportunities for engagement in sensorimotor activities rich in tactile, vestibular, and proprioceptive sensations will facilitate sensory integration (Schaaf & Miller, 2005). This approach must accompany the 'just right challenge'. This challenge is to provide an activity that is achievable, age appropriate and goal directed. Active engagement in the challenge will ensure abilities are practiced, rehearsed and retained. King (1983) utilised these principles for people with schizophrenia to address performance deficits in cognition, communication, affect, praxis and activity level. She found an improvement in praxis as well as communication, which led her to conclude that gross motor activities such as those used in

SI go some way to improve 'psychiatric status' (King, 1983). However, King did acknowledge that these improvements were not sustained and research in this area lacked methodological rigour. Using SI principles in this way with adults rather than children led to an alternative approach to address the maladaptive responses of older people with dementia (Ross & Burdick, 1981).

An evaluation of the SI approach was carried out by (Corcoran & Barrett, 1987) among older people with dementia in residential care. Eleven participants with severe dementia were randomly allocated either to a biomechanical intervention or an intervention programme based on the principles of SI. Both groups participated in these activities twice a week for 16 weeks. The Comprehensive Occupational Therapy Evaluation (COTE; Brayman, Kirby, Misenheimer, & Short, 1976) was used to rate behaviour and functional outcome. Results revealed substantial clinical improvement in the experimental group in terms of automatic postural correction, increased attention (M = 2 minutes to M = 40 minutes), significant improvement in communication and significant improvement in task performance scores. Although this small scale study supports the use of SI with older people with dementia, it is limited by its small sample size. Subsequent studies in this area are also limited with the majority of the work in this area concentrating on children with developmental delay (Roley, Clark, Bissell, & Brayman, 2003; Schaaf et al., 2005; Smith, Press, Koenig, & Kinnealey, 2005).

Although individual characteristics are paramount in selecting appropriate activity, performance components of activity must be considered as well. The Model of Sensory Integration highlights the relationship between matching individual ability, task complexity and environmental demands. Dunn (2001), Ayres (1979) and Corcoran (1987) all emphasise the relationship between the person's ability to process and integrate sensory information and the impact of the environment on this process. So often attention is paid to the activity but not to the environment in which it takes place. This environmental influence will be explored through the model of sensoristasis and environmental domicility.

4.2.4   The environmental influence on activity: Sensoristasis

The environmental demands on people with severe dementia have been explored using the Progressively Lowered Stress Threshold (PLST) model (Hall & Buckwalter, 1987) and Lawton's Ecological model (Lawton & Nahemow, 1973). These models suggest that if environmental press (sensory demand) exceeds the individual's ability to process sensory information then function and behaviour will be negatively affected (Kovach, 2000). They propose a delicate balance between the environment and the individual. However, the models offer no explanation of how this balance may be achieved. Kovach (2000) expanded the PLST model to explore balance and named this 'sensoristasis'. Kovach suggests that optimal functional performance will occur if there is a balance

of sensory calming and sensory stimulating activities. An imbalance in sensoristasis may lead to functional and behavioural problems (Figure 4).

Figure 4: Model of imbalances in sensoristasis as applied to people with dementia

| Antecedents | → | Sensoristasis imbalance | → | Cortical sequelae | → | Behavioural sequelae |

Neuro-physiological / psychological decline

Environmental factors

Human intervention

High Stimulus Imbalance → Stress threshold exceeded

Low-stimulus Imbalance → Sensory deprivation

Intrapsychic discomfort

Agitation

Decline in activities of daily living

Decline in social functioning

Model adapted from Kovach (2000).

Tenets of the model include:

People with severe dementia experience imbalance of sensoristasis, caused by neurophysiological or environmental factors such as a noisy living area or busy shop;

Too much high-stimulus activity (noisy environment) can result in one's stress threshold being exceeded. This will occur at a lower stress threshold if the activity is unpleasant or the person is required to process too much sensory information at a pace that is too rapid for them. An example may be where a person is encouraged to attend a large party with unfamiliar people;

Too low a level of stimulus can create a state of sensory deprivation. A common example of induced deprivation is where a carer or healthcare professional does so much for the person that their level of activity is substantially decreased;

States of exceeded stress threshold or sensory deprivation can lead to intrapsychic discomfort (agitated behaviour, decline in ADL and social skills);

By pacing activities to provide a balance between sensory calming and sensory stimulating activity sensoristasis may be achieved.

Kovach applied this model to people with severe dementia and found that, as the dementia progressed, people needed longer periods of sensory calming activities between sensory stimulating activities in order to maximise periods of engagement in activity (Kovach & Meyer Arnold, 1997). She also found that stimulating multiple senses (sight, sound, touch taste, smell) was associated with longer periods of engagement in activity for people with late-stage dementia (Kovach & Magliocco, 1998). This supports the notion that multi-sensory activity may be more engaging for people with moderate to severe dementia than uni-sensory activity.

Voelkl (1990) used the tenents of Lawton's Ecological Model to conduct focus groups with nursing staff, in order to identify environmental barriers to engagement in activity. This model describes the balance between environmental and social demands (Lawton, 1986). The results highlighted the problems of attending to different environmental needs due to the physical environment, but also management of staff attitudes of how time should be spent. More specifically, staff felt that their time was taken up in nursing duties rather than facilitating activity and residents had low expectation of activity taking place. Many activities offered to people with dementia fail to address environmental demand, being conducted in noisy environments often with limited numbers of staff. Consequently, although the activity may be of a suitable level, the person may fail to engage in the activity due to competing demands from the environment.

The balance between environmental demands and activity was also explored by Csikszentmilhalyi in his work on Flow.

4.2.5   Activity characteristics: Flow

Csikszentmilhalyi's work (1975) provides an interesting focus on activity and well-being. In particular, he describes the need for balance between the challenge of the activity and the skills of the individual needed in order to attain engagement or 'Flow' (Figure 5)

Figure 5: The Flow channel
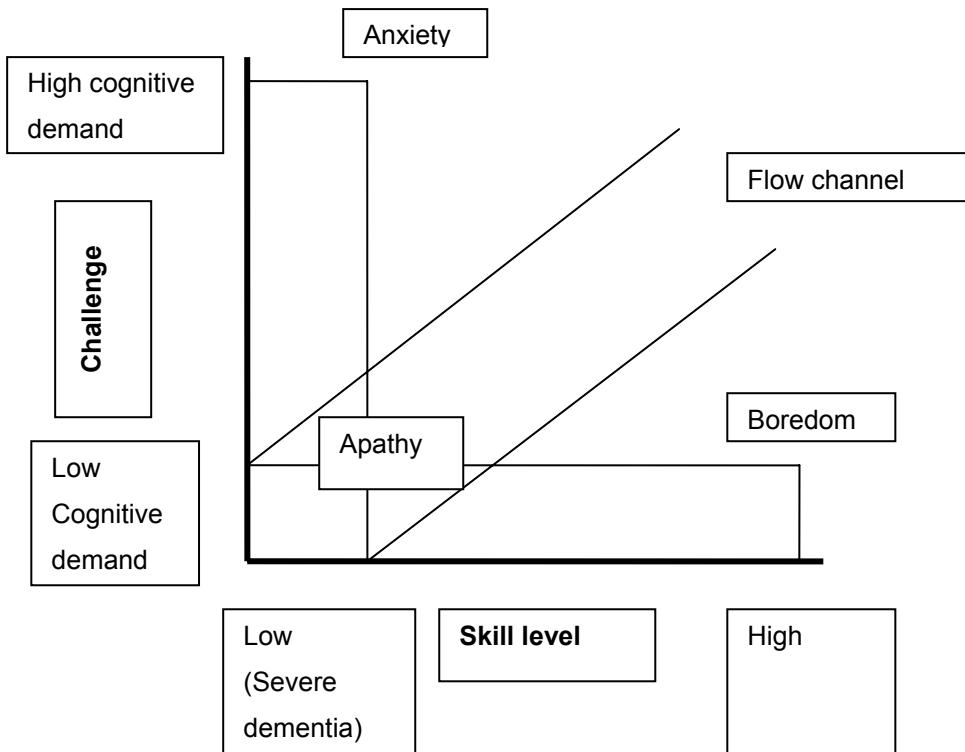
Model adapted from Csikszentmihalyi (1975)

Flow is described as the sense of total involvement in activity driven by self-directed goals (Csikszentmihalyi, 1975). This diagram of the Flow channel illustrates the proposed relationship between the skills of the individual and the challenge offered by the activity (Csikszentmihalyi, 1975). The experience of the activity is perceived to be most positive (Flow) when the individual believes that the activity or environment contains sufficient opportunities (challenges) which are matched to their personal ability (skill level). If the balance is right a sense of well-being can be achieved (Csikszentmihalyi et al., 1989). Many of the activities offered to people with dementia would appear not to address the issues of skill level and challenge which may be an explanation for some of the apathetic or agitated behaviours demonstrated by some people with dementia. These behaviours suggest lack of engagement or loss of a state of Flow.

The concept of Flow has been explored with well adults (Allison & Duncan, 1988; Jacobs, 1994). All these studies report that participants felt at their best when Flow conditions were present (suitable challenges and in control). Participants described Flow experiences as including such moods as 'being happy', 'involved', 'positive' and 'productive' (Jacobs, 1994). Although no such studies have been carried out for people with dementia, the principles of Flow have the potential to

be achieved if the environment and activity are well matched. There appears to be no reason why, by finding activities that are intrinsically motivating, a sense of flow should not be achieved by a person with dementia. This improved engagement could, in turn, promote a sense of well-being (Emerson, 1998).

4.2.6   Summary

In summary, these theories offer a framework from which a suitable activity can be selected and initiated. They all suggest that activity should include an appropriate level of stimulation that challenges the individual to reach their maximum potential (sensory stimulation versus sensory deprivation). The activity should be designed to address individual sensory needs, such as offering a stronger stimulus if initial attempts are unnoticed (sensory processing), and be offered alongside familiar activities and routines (sensory integration). The activity should occur on a regular basis and offer a 'just right challenge' as the person with dementia will find it easier to cope with the demands of the environment if adequate stimulation is provided (sensory integration). The levels or intensity of the activity may need to be adjusted depending on individual needs. Sensoristasis and Flow both explore the relationship between individual competency and environmental demand. If there is an imbalance between the level of environmental stimulation and the person's ability to process that information activity will fail. Finally, if the complexity of the activity, individual needs, and environmental demands are matched, engagement may be achieved.

The principles summarised above also fit with Jones' (1996) and Hellen's (1998) essential requirements for successful activity. However, such provision requires trained staff and a clear directive within service provision. One such activity that may be sufficiently flexible to meet the needs of people with moderate to severe dementia is the multi-sensory environment. This activity will be explored for its potential to fit within the theories described and critically evaluated as an activity for people with moderate to severe dementia.

4.3   Use of Multi-Sensory Environments: a suitable activity for older people with dementia?

The multi-sensory environment (MSE) is a collection of equipment which provides gentle stimulation of all the senses (sight, sound, touch, taste, smell and movement) (see Picture 1). The concept originated in Holland in the early 1980s (Hulsegge & Verheul, 1987) and was used extensively as a leisure activity for adults with learning disabilities. Its potential with other patient groups soon became evident and MSEs are now used in paediatrics, pain management, anxiety

management, acquired head injuries and dementia care (Moffat et al., 1993). MSE can also be accessed by the general public in health clubs and spas.

Picture 1: Example of a multi-sensory environment
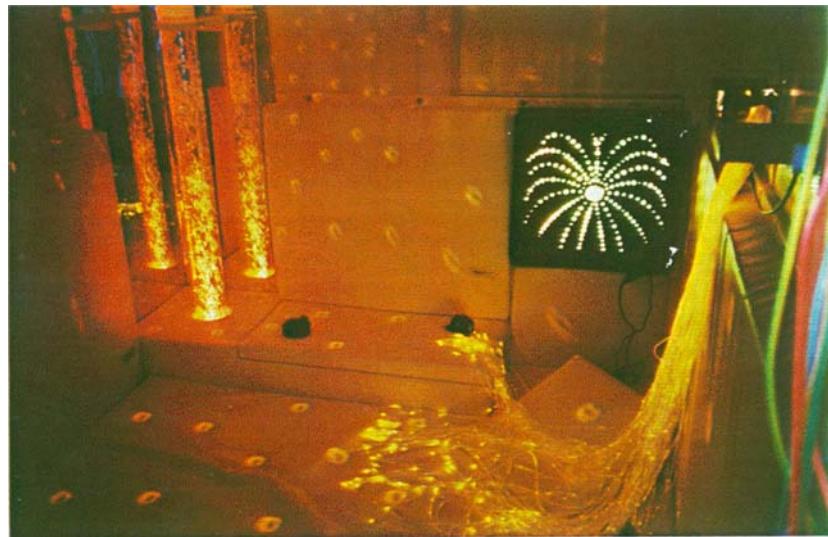
Reproduced with permission from Rompa

MSEs are based on the concept of a 'sensory cafeteria', the opportunity to make sensory choice (Bower, 1967; Cleland & Clark, 1966; Gover & Mesibov, 1978). Research was initially resisted by the designers of multi-sensory environments as they felt formal evaluation would distract from the opportunity for fun and social engagement. They believed multi-sensory environments should offer a leisure activity, free from regulation and prescriptive routines, rather than a therapy aimed at dealing with a problem (Hulsegge et al., 1987). Consequently, initial work focussed entirely on the aesthetic qualities of the environment and case reports of users' enjoyment (Hagger & Hutchinson, 1991; Hulsegge et al., 1987; Hutchinson et al., 1991). Following its development in the UK with people with learning disabilities, further studies explored the potential of MSEs in influencing mood and behaviour. An overview of these studies by Lancioni et al. (2002) reported positive, within-session effects, with two studies reporting longer term effects (Houghton et al., 1998; Withers & Ensum, 1995). However, much of the research with this client group lacks methodological rigour. All the studies have small sample sizes and are, essentially, descriptive, reporting events rather than attempting to measure their efficacy.

Research with older people with dementia has attempted to be more explicit about measuring change as a result of using MSEs. However, robust research exploring the efficacy of MSE with older people with dementia has been limited (Morrissey & Biela, 1997; Savage, 1996). Those

studies that have been undertaken focussed mainly on the influence of MSEs on mood and behaviour (Baker et al., 2003; Baker et al., 2001; Kragt, Holtkamp, van Dongen, van Rossum, & Salentijn, 1997; Moffat et al., 1993; Pinkney, 1997; Spaull et al., 1998). Whilst the outcomes have been positive, small sample sizes and assessment tools with limited sensitivity have made it difficult for clinicians to accept these results with conviction.

A Cochrane review of MSEs or Snoezelen[™ 2] for people with dementia was carried out in 2002 (Chung, Lai, Chung, & French, 2002) and updated two years later (Chung, 2004). This review revealed that only two randomised controlled trials have been conducted using MSE with older people with dementia. Although pooled results suggest the results were not statistically significant, there was a positive trend. These two trials will be considered in more depth.

Kragt et al. (1997) recruited 17 people with dementia, aged 65 or older, who were resident in a nursing home. No baseline measure of dementia was given, but the study reported that the participants were in the advanced stages of dementia. Participants were allocated at random either to Snoezelen[™] (MSE) or a control group. Participants in the MSE group attended the intervention on three consecutive days, at different times, with different facilitators. Each session followed an individualised MSE plan for between 30 minutes and one hour. The control group spent 30 minutes in the living room with other residents, receiving normal care and attention. The Behavioural Observation Scale for Intramural Psychogeriatrics (GIP) (Verstraten & van Eekelen, 1988) was used as an outcome measure. This measured behavioural problems presented by the participants during each of the groups. The results revealed significantly fewer apathetic, restless or repetitive behaviours and fewer disturbances post MSE session. Despite positive results there were methodological weaknesses. Only participants who were known to respond positively to MSEs in the past were recruited to the study. Additionally, assessors were not blind to the treatment group allocation, therefore may have been biased toward the intervention.

Baker et al. (2001) recruited 50 participants, aged 60 years or older who attended day hospitals. All were classified as being in the moderate to advanced stages of dementia on the MMSE (Folstein et al., 1975). Participants were randomly allocated either to the MSE intervention group or a control group. The participants attended eight, 30 minute sessions, twice a week over a four week period. Both experimental and control groups followed a similar format although the control group received a one-to-one activity programme direct from facilitators. Outcomes were mood and behaviour (Behaviour and Mood Disturbance Scale – part of the Clifton Assessment Procedures for the Eldery. CAPE) (Pattie & Gilleard, 1979), the Behaviour Rating Scale and Cognitive Assessment (also from CAPE), within and post session effects (Baker & Dowling, 1995; Baker & Hall, 1988), and general behaviour and maintenance of affect (Baker et al., 1988; Baker et al., 2001). No significant intervention group differences were found. However, various methodological

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[2] Trade name for multi-sensory equipment supplied by Rompa,UK

weaknesses may have influenced the results. The assessments were carried out by different members of staff and carers, consequently variations in interpretations were possible. Also, only two of the assessments (CAPE and REHAB) were standardised. The INTERACT is a non-standardised tool and has an item by item analysis which could lead to an increase in the risk of a false–positive result (type 1 error). When the results of the two studies were entered for meta-analysis and adjusted to a random effects model, the pooled results were not significant (Chung et al., 2002).

These two studies, although inconclusive in their findings, offer some guidance for exploring the positive effects seen elsewhere in MSEs (Baker et al., 1997; Hope, 1998; Long & Haig, 1992; Pinkney, 1997; Spaull et al., 1998). In particular, there is a need to identify outcome measures that are sufficiently sensitive to pick up changes in people with severe dementia. It is also evident that, although mood and behaviour appear to be influenced by MSEs, the mode of the intervention that results in this outcome is unclear. The strength of the MSEs appears to be in the flexibility of their use to adapt to individual need. This may be by providing an enriched multi-sensory experience or through discrete stimulation, possibly using one or two pieces of equipment. In many respects the MSE could be seen to be failure free. It does not place heavy cognitive demands on the individual and can be flexible in the length of time taken in the environment to match individual attention spans (SI and Flow). The level of stimulation can be adapted to give low level stimulation for those with a low stimulus threshold, or high level stimulation for those with high level stimulus threshold (Sensoristasis and Sensory Processing). The range of equipment is suitable for those with physical disabilities and can be adapted to be taken to the individual if mobility is a problem. Essentially MSEs fit the principles of good activity mentioned in the last section including offering an intensity that can be adjusted, the 'just right challenge' and can be offered alongside familiar activities and routines. MSEs also fit well with the principles summarised by Jones (1996) and Hellen (1998) in that the activity can be divided into small steps, it has the potential to be multi-sensory and may be adapted to incorporate personal interests.

In conclusion, these studies reveal that MSEs may offer a role in managing some of the cognitive, behavioural and psychological problems identified in people with severe dementia (Baker et al., 2001; Kragt, Holtkamp, van Dongen, van Rossum, & Salentijn, 1997; van Weert, van Dulmen, Spreeuwenberg, Ribbe, & Bensing, 2005). There is a reduction in agitated behaviour and in wandering and there is an increase in attention (Baker et al., 2001; van Weert, van Dulmen, Spreeuwenberg, Ribbe, & Bensing, 2005). All these features are pre-requisites for activity, and alongside the flexibility of this intervention, may make MSEs a suitable activity for people with moderate to severe dementia.

4.4   Summary

The needs of people with severe dementia provide a continual challenge for healthcare professionals, both in having sufficient time to facilitate activity and in finding an activity that is of suitable complexity and of interest (Challis et al., 2002). Research suggests that activity and occupation are essential in maintaining functional ability as well as addressing quality of life issues (Baum, 1995). Psychosocial approaches such as Reality Orientation, Reminiscence Therapy and Validation Therapy address some of these problems, but fail to meet the more specific needs of people with severe dementia, such as providing the flexibility needed (environmental demand) or the right level of engagement (Lawton, 1986) or addressing the distinct behavioural and psychological symptoms of dementia (Ballard, O'Brien, Reichelt, & Perry, 2002). MSE, by contrast may offer an intervention that can deal with some of these difficulties by addressing environmental needs (sensory processing), offering a high level of flexibility in meeting the occupational demands of the individual (appropriate level of challenge to achieve engagement) (Baker et al., 2001; Dunn, 2001; Kragt, Holtkamp, van Dongen, van Rossum, & Salentijn, 1997), and by addressing behavioural and psychological symptoms (Baker et al., 2001).

As the literature confirms that engagement and environmental demand are associated with successful activity, this study will investigate whether MSEs have a positive effect on discrete elements of functional performance, such as sequencing and accommodation, using the Assessment of Motor and Process Skills (Fisher, 2003). This assessment tool offers a high level of sensitivity, inter-rater and intra-rater reliability (see Chapter 5), whilst offering assessment activities that are achievable by people with moderate to severe dementia. In turn, the effects on mood and behaviour will be explored as these have been linked with functional performance (De Lepeliere et al., 2004). Participant sensory profiles will be considered to explore if there is a link between an identified sensory profile and success in the MSE. Alongside this assessment, intervention sessions will be tailored to address each individual participant's needs, to ensure activity characteristics and environmental demands are addressed. As this is a longitudinal study, predictions will be able to be made about the effect of MSEs on sensory and motor processing compared with a control group (gardening activity).

The next chapter specifies the specific hypotheses to be tested; gaps in knowledge highlighted above are addressed by attempting to answer the following questions:
1. To what extent, if any, do MSEs influence functional performance?
2. To what extent, if any, does the control activity (gardening) influence functional performance?
3. In what way are mood and behaviour affected by MSE compared with the control activity (gardening)?
4. To what extent is the sensory profile of the individual associated with the response to the MSE compared to the control activity (gardening)?

Chapter 5: Methodology

Research on complex interventions with older people with dementia brings challenges in methodological design that are not always evident with other clinical groups (Cohen-Mansfield, 2003). This chapter will present the details of the methodological procedure used, alongside challenges encountered and strategies used to manage them.

5.1   Aim, research questions and hypothesis

Overall aim

To investigate the impact of multi-sensory environments (MSEs) on the functional performance of older people with moderate to severe dementia.

Research questions

1. To what extent, if any, do MSEs influence functional performance?

2. To what extent, if any, does the control activity (gardening) influence functional performance?

3. In what way are mood and behaviour affected by MSEs compared with the control activity (gardening)?

4. To what extent is the sensory profile of the individual associated with the response to the MSE compared to the control activity (gardening)?

Hypotheses.

The primary hypothesis and related null hypothesis to be tested are that:

H_1 There will be a significant difference in ratings of functional performance in people with dementia following participation in the MSE compared to the control activity (gardening).

H_0 There will be no significant difference between ratings of functional performance in people with dementia following participation in either the MSE or the control activity (gardening).

Secondary hypotheses are:

H_1 There will be a significant difference between ratings of mood and behaviour in people with dementia following participation in either the MSE or the control activity (gardening).

H_0 There will be no significant difference between ratings of mood and behaviour in people with dementia following participation in either the MSE or the control activity (gardening).

H_1 There is an association between the sensory profile of the individual and their response to the MSE compared to the control activity (gardening).

H_0 There is no association between the sensory profile of the individual and their response to the MSE compared to the control activity (gardening).

5.2   Research Design

5.2.1   Randomised Control Trial

A randomised, single blind, repeated measures design was used to explore the research questions. Randomised controlled trials are considered to provide the best evidence on the effectiveness of treatments and healthcare interventions (Kirkwood & Sterne, 2003). A randomised controlled trial (RCT) was chosen for this study as the primary goal was to evaluate and compare the efficacy of two interventions (MSE and control intervention). This design offers a means of controlling selection bias, resulting in the two participant groups being as similar as possible at the outset. Despite being recognised as the 'gold standard' for research (Sackett & Hoey, 2000) this method is still open to bias with opportunities for participants and researchers to influence the results. The pilot study was designed to identify challenges to the methodology presented by working with participants who have severe dementia, and to determine those areas where bias and confounding variables are more likely. Challenges identified were then addressed in the design of the main study. Following a discussion of the measures used in Chapter 6, Chapter 7 reports the results of the pilot study, challenges identified and the changes made to the method. Given the challenges of conducting research with vulnerable groups such as people with dementia, the research design was constructed using guidelines from the Medical Research Council: Framework for Trials of Complex Interventions (Medical Research Council Health Services and Public Health Research Board, 2000) (Figure 6).

Figure 6: Framework for trials of complex interventions

Theory	Modelling	Exploratory Trial	Definitive RCT	Long term implementation
Investigation of relevant theory to drive hypothesis	Identify the components of the intervention and underlying mechanisms by which outcome is influenced	Derive a feasible protocol for comparing the intervention with appropriate alternative	Compare a fully defined intervention with an alternative using a protocol that is defensible, reproducible, appropriately powered and adequately controlled	Determine whether others can reliably replicate intervention and results in uncontrolled settings over the long term
Preclinical	Phase 1	Phase II	Phase III	Phase IV

Continuum of increasing evidence

Medical Research Council Health Services and Public Health Research Board (2000)

Operationalisation of this approach in relation to this study is represented in Figure 7.

A period of gathering evidence of assessments used in clinical practice and discussions with other interested groups (such as Alzheimer's Society members and staff groups) regarding the use of MSEs was undertaken. A pilot study was then conducted to evaluate the suitability of measures selected, to identify any methodological challenges (pre-clinical and Phase I & II) and to inform appropriate sample size calculation. In response to the results from the pilot study, the main trial was constructed and implemented (Phase lll). Participants for Phase lll were selected from Nursing Homes and Hospitals within a Strategic Health Authority in the south of England. Those participants who fulfilled the entry criteria were then allocated either to the intervention activity (MSE) or the control activity (gardening) using stratified randomisation (see section 4.2.2). Following a baseline assessment period, participants attended their allocated activity for up to 12 sessions. Measures were completed pre and post activity. Further follow up measures were carried out one month after completion of the intervention period.

Other research designs were considered during the early conceptual stages of this study and are discussed in Chapter 9.

Figure 7: Outline of study based on framework for trials of complex interventions
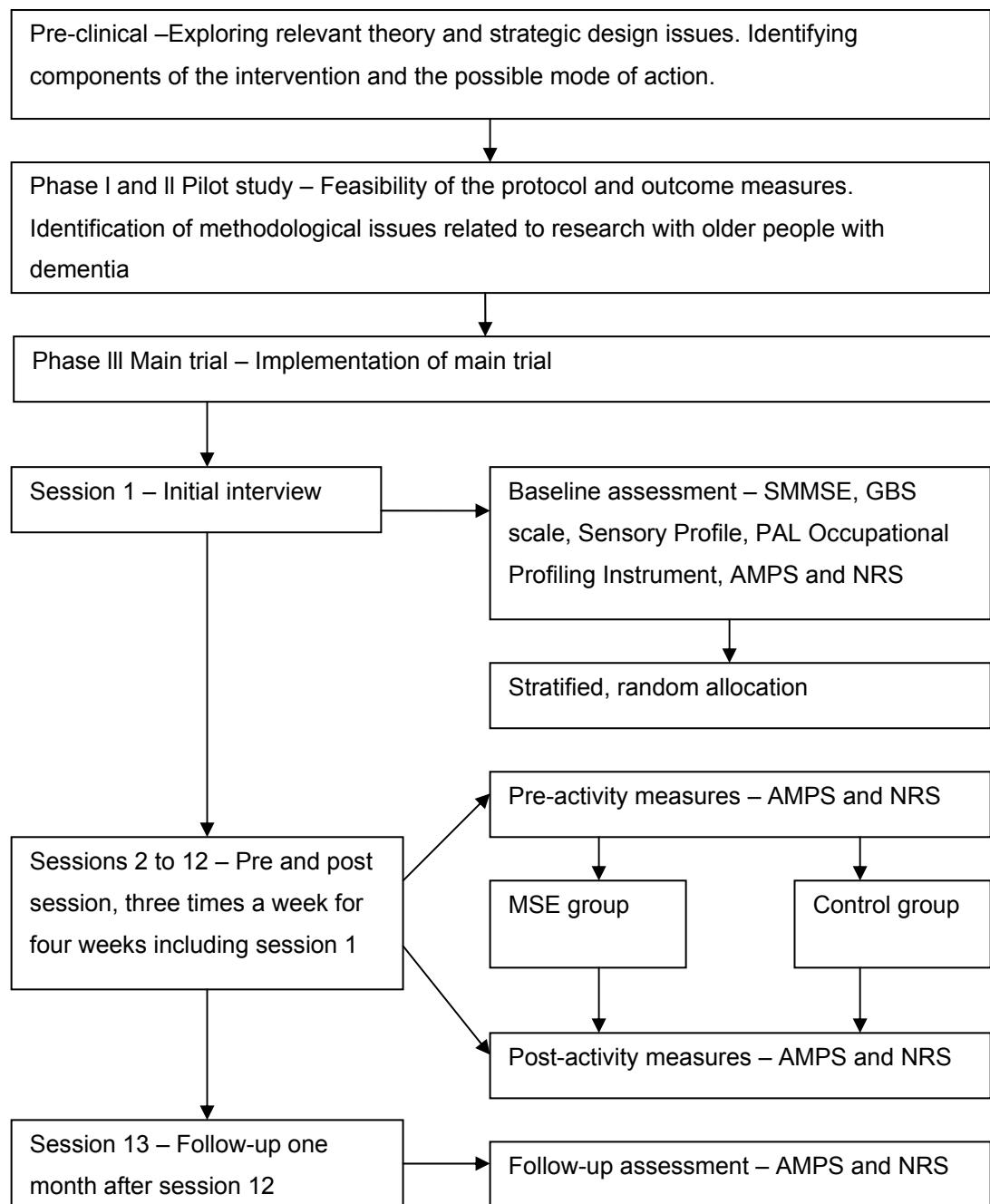
Note. SMMSE – Standardised Mini Mental-State Examination (Molloy et al., 1991); GBS scale (Brane, Gottfries, & Winblad, 2002); Sensory Profile (Brown et al., 2002); PAL instrument for occupational profiling (Pool, 2002); AMPS – Assessment of Motor and Process Skills (Fisher, 2003); NRS – Neurobehavioural Rating Scale (Sultzer, Levin, Mahler, High, & Cummings, 1992).

The primary outcome measure for this study was the Assessment of Motor and Process Skills (AMPS) (Fisher, 2003). This is an assessment of functional performance which is validated with older people with dementia and is a robust and sensitive tool (Park, Fisher, & Velozo, 1993). The secondary outcome measure was the Neurobehavioural Rating Scale (Sultzer et al., 1992). This observational assessment reports levels of mood and behavioural disturbance. It is also validated for use with older people with dementia. More details of the primary and secondary outcome measures and supplementary measures used will be given further on in this chapter and in Chapter 6.

5.2.2   Randomisation

Stratified randomisation was used with this study (Altman, 1999), in order equally to distribute potential confounding variables. These included place of residence at the time of the study (nursing home or hospital), and gender. It was important to ensure the two groups had similar male to female ratios and to replicate gender ratios normally seen in this population group. As the proposed sample size was small (50 participants) only these two strata were used to produce a block randomisation scheme. Full randomisation was not considered suitable for this trial due to the relatively small sample size proposed and the ongoing nature of recruitment of participants across the various hospital locations. Further details of the exact mechanisms used to allocate participants to each group are described later in this chapter.

5.3   Procedure

5.3.1   Ethical considerations

A Local Research Ethics Committee was approached for approval prior to the commencement of the study. Given the relative severity of cognitive impairment in the participants, particular emphasis was given to informing them about the study in a way they could understand, and ensuring consent was obtained (Molinari, McCullough, Coverdale, & Workman, 2006). Cohen-Mansfield (2003) suggests that consent rates and participation can be increased amongst people with dementia by enhancing communication between staff and participants, and by using multiple 'communication channels' (verbal and non-verbal communication). Where-ever possible, explanation and photographs were given to participants to inform them about the interventions in which they might be taking part (see Appendix 1). In addition, where the participant was unable to give consent (due to their inability to understand or retain information regarding the nature of the study or their involvement) written assent was sought from the primary carer. Although initial consent was acquired at the start of the study, verbal agreement to continue was also sought at the

start of each session. Participants were told that they were free to withdraw at any point. In order to ensure their right to refuse was honoured, careful attention was paid to their non-verbal communication. If they appeared distressed or attempted to leave the intervention, they were assisted to do so. Key nurses or therapists were used as facilitators for the interventions as it was felt they would be more sensitive to subtle non-verbal communication from the participants.

5.3.2   Involvement of stakeholders

The National Frame Work for Older People (Department of Health, 2001) stresses the importance of stakeholder involvement in the care of older people. In designing this study, regular meetings were held with stakeholder groups including the Alzheimer's Society; local carer support groups; and healthcare professionals (Doctors, Nurses, Community Psychiatric Nurses, Occupational Therapists and Social Workers) working with older people with dementia. Particular concerns raised by these groups included:

Gaining co-operation from people with severe dementia – prior to the study commencing, time was taken to train key nurse and therapists in managing co-operation without coercion. It was agreed amongst the team that two strategies would be used and if these failed it would be accepted that the participant was refusing consent to take part in that session. These two strategies were
1. Asking the participant to come and look at the room before requesting participation; and,
2. Bringing part of the activity to the participant to show them what they will be doing before requesting participation. The key nurse or therapist maintained a diary for each participant to record their activity and any refusal to take part.

The use of interventions which required intensive staff involvement – staff were concerned that they may struggle to maintain regular input throughout the study period. In discussion with staff, timings for the interventions were arranged to co-ordinate with the ward / day hospital routine. The best time was generally found to be mid-morning. An occupational therapy student was also employed to assist with the interventions.

The use of assessment tools which were perceived as relevant and user friendly for the participants - Most of the tools selected relied on assessor observation, therefore, the participant was not asked to do anything unfamiliar. For example, the Standardised Mini-Mental State Examination (SMMSE; Molloy & Standish, 1997), one of the measures of cognition, was administered as part of a conversation to make the participant feel more at ease. The Assessment of Motor and Process Skills (AMPS; Fisher, 2003), the primary outcome measure, allowed for the use of activities that were relevant for mid-morning, such as: pouring a drink; folding laundry; and, polishing shoes. The remaining assessments relied on information from the key nurse or therapist, carer or relative.

Dissemination of results – a question asked was how could staff learn from this study? It was agreed that the researcher would return, on completion of the study, to present the findings. This would also include advice for clinical practice, as appropriate.

What would happen at the end of the study – would the interventions stop? As most of the centres selected for the study had MSEs, the interventions could be continued. Staff were keen that the routine of the interventions should be maintained on completion of the study.

5.3.3 Sample size and justification

Power is defined as the probability that a statistical test of significance will correctly reject the null hypothesis (Moher, Dulberg, & Wells, 1994). Sample size was calculated using data collected from the primary outcome tool (AMPS) from the pilot study and earlier AMPS studies with older people with and without dementia (Nygard, Bernspang, Fisher, & Winblad, 1993; Oakley & Sunderland, 1997; Park et al., 1993). Prior to the commencement of this trial, no study had used the AMPS to investigate outcomes in MSEs, although data were available from studies using AMPS with older people (see Table 2). Power to detect an effect was set at 80%, which is the level most commonly used in health orientated, randomised control trials, and sufficiently high in a study where risk is small (Moher et al., 1994). The level of .05 was set as the probability of an observed result happening by chance (Type 1 error). It has been suggested that a clinically significant change in AMPS score (that is also statistically significant) requires a difference of 0.5 logits (Fisher, 2003) between the pre and post session assessment. This proposition was based on the analysis of functional performance of 50,571 participants in the AMPS database (Fisher, 2003). This value was used as the change or delta in all sample size calculations.

Sample size was calculated using two sources of evidence. Firstly, as the study was to be powered to find an effect in either the MSE intervention or in the control group, the baseline mean (*M*) and standard deviation (*SD*) from all pilot participants were used to calculate a sample size sufficient to detect a 0.5 change using the Power and Sample Size Programme (Version 2.1.31; Dupont, 1990). As the AMPS has two scores (Motor and Process scores) sample size was calculated separately for each, giving 18 and 24 participants per group for Motor and Process respectively, meaning a total *n* of either 36 or 48 (Table 2). Secondly, given the small number of participants in the pilot study, the predicted sample sizes were compared with calculations from other studies using the AMPS assessment (Table 2; Doble, Fisk, Lewis, & Rockwood, 1999; Doble et al., 1997; Nygard et al., 1993).

Table 2: Predicted sample size from the pilot data compared with other studies

Study	Participants in study (*n*)	Baseline *M*(*SD*)	Predicted sample size per group
Pilot			
MSE and control combined			
Motor	6	0.88 (0.71)	18
Process		0.13 (0.84)	24
Other intervention studies			
(Doble et al., 1999) Study of test-retest reliability of AMPS with older people, without dementia.			
Motor	55	1.7 (0.9)	27
Process		1.0 (0.7)	17
(Nygard et al., 1993) Assessment of ADL in people with mild dementia in clinic versus home.			
Motor	19	2.39 (1.10)	40
Process		0.60 (.63)	14
(Doble et al., 1997) Assessment of ADL in people with and without dementia (group with dementia used for this calculation)			
Motor	20	1.94 (0.60)	13
Process		0.02 (0.59)	13

Note. alpha = .05; Delta = difference of 0.5 logits; Power = 0.80 for all cells analysed. All data reported to two decimal places except where only one decimal place was provided.

Two of the studies included for a comparison of sample size (Doble et al., 1999; Nygard et al., 1993) used participants who were functioning at a higher cognitive level than the participants proposed for this study. As these participants were not representative of those proposed for this study, these figures were rejected. The Doble et al. (1997) data suggested that relatively small samples of 13 per group might be sufficient to find an effect. Data from the pilot, albeit on a smaller sample, suggested as many as 24 participants might be required per group. On reflection, as process scores were less likely to improve given the deteriorating cognitive abilities of participants

(Desmond, 2004; Graham et al., 2004), motor scores were considered to be the most appropriate measure on which to base the calculation of sample size.

As a result, the sample sizes calculated from the pilot data and from studies with similar participants, using motor scores, suggested a conservative sample size of 25 participants per group (total n = 50). This number of participants was also thought to be appropriate, given the time limits imposed by the PhD study, the number of hospital and nursing home sites equipped with MSE facilities, therapists available to facilitate the intervention activities and possible attrition rates.

5.3.4. Recruitment

5.3.4.1 Recruitment of data collection sites

Potential recruitment locations were identified from organisations known to have multi-sensory environments, clinical settings known from previous clinical experience and suggestions from clinical colleagues. Of an initial list of nine locations, five could not be used due to problems with staffing and involvement with other studies; however, the remaining four were willing to participate. These four included one nursing home, one continuing care centre and two hospitals for people with dementia. Initial contact was made through the Head Occupational Therapist or Nurse Manager at each location. One location declined to take part due to short staffing and organisational changes. Of the remaining three, further meetings were arranged to discuss demands of the study, staffing issues and time constraints. Staff training took place at mutually suitable times and honorary contracts, parking permits and police checks were organised for the researcher.

Once data collection commenced it became clear from the non-completion rates for some of the participants that further locations would be needed in order to meet the sample size required. A further two locations were identified and approached (a hospital for people with dementia and social services continuing care) and one centre agreed to take part in the study. Approval from regional Ethics Committees and contractual arrangements for this location were arranged. Whilst inclusion of this extra centre subsequent to the initial proposal assisted in identifying additional participants, it contributed to the problems of maintaining standardisation and reliability of the facilitation styles adopted by the nurse or therapists running the activities. The more centres recruited to the study; the more chance that standardisation of the data collection procedure may be compromised. Staff training and use of activity profiles endeavoured to address some of these issues.

5.3.4.2 Staff Training

In order to maintain parity of activity facilitation amongst staff, across clinical locations, a series of training events was carried out. The manager of each location identified key staff to take part in the study, and a time was arranged to carry out interactive workshops (see Appendix 2). The aim of the workshops was to familiarise staff with equipment to be used in the MSEs, the format to be followed using PAL guidelines, training using the PAL guidelines and facilitating activity, contingency plans in case of critical incidents (such as the participant wishing to leave the MSE) and methods of recording critical incidents. The workshop also included an introduction to the study with details of the normal procedure for data collecting, how to maintain blindness and the ongoing process of consent. An example of the programme is included in Appendix 2. Staff were encouraged to interact with equipment and experiment with different effects. Time was also spent allowing staff to voice any thoughts about the study, identify problems of maintaining consistency of staffing input and continuing activity input after the study had finished. A follow up session was arranged after the initial workshop to arrange starting times that would fit in with the participant's normal routine.

5.3.4.3 Selection and exclusion criteria
Inclusion

Participants were selected from older people with a clinical diagnosis of moderate to severe dementia who were resident on continuing care wards or in nursing homes within an area of the south of England as identified above. Centres selected for the study had a MSE and committed sufficient resources for the duration of the study to allow one to one activity, free from distraction and disturbance. The Standardised Mini-Mental State Examination (SMMSE; Molloy et al., 1991) was used as a measure of overall dementia severity. Individuals scoring between 0 and 17 were suitable for inclusion into the study. This cut off point was chosen to represent people with moderate to severe dementia (Folstein et al., 1975; Josephsson et al., 1993).

Exclusion

Participants were excluded if they had a severe physical disability restricting movement, an uncorrected hearing impairment, or were registered blind. Whilst MSEs has been used successfully with these populations (Hagger et al., 1991), the variability and heterogeneity would be problematic for determining definitive results for this study.

5.2.4.4 Recruitment of participants

Following discussion with the clinical team about inclusion / exclusion criteria, staff were asked to identify potential participants. Clinical staff identified potential participants from people admitted to the ward or nursing home, regardless of when admitted, based on admission assessment, including the SMMSE, and past history. Those identified were then approached by their key nurse

or therapist for a short discussion about the study. Each discussion was tailored to the different comprehension abilities of each individual. If the discussion indicated some interest on the part of the participant, the meeting was followed up with a letter from the host institution (i.e. the clinical service) introducing the researcher, the study, and inviting the potential participant to take part (see Appendix 3). A copy of this letter was also forwarded to the primary care giver. Written consent was sought from the participant (see Appendix 4). Where this was not possible, written assent was sought from the primary care giver (see Appendix 5). After one week, the participant and their primary care giver were contacted to enquire whether they wished to take part. A 'meet and greet' session was organised at each host institution for potential participants and their carers and family members to ask questions about the study, the activities within each treatment group and, to meet the researcher. These sessions were repeated throughout the recruitment phase as potential participants were identified. Once written consent or assent was obtained, three copies were filed (a copy in the participant's medical notes, one in the participant's research file and a copy to the participant or main care giver).

5.3.5   Blindness

A researcher may be biased during pre / post session assessment if aware of which intervention has been used. A single blind design was used in the study as the participants were clearly aware of which activity they were attending (MSE or control activity). Safeguards were put in place to keep the assessor blind to the allocation. However, a record was also kept of any suspicions the researcher had regarding group allocation. The record of suspicions was compared with the actual allocation arrangements on completion of the study, and is discussed under the heading of the reliability of maintaining blindness and structured observation in the Discussion Chapter 9.

Following recruitment, each participant was given a code in order to maintain anonymity, and screened by their key nurse or therapist for relevant strata in order equally to distribute variables. Randomisation was carried out by the Head Occupational Therapist at one of the hospital locations. She managed the allocation of participants to each activity from each stratum. The two strata employed were location of data collection (Nursing Home, Hospital) and gender. As data collection from all locations continued over 18 months, distribution of gender was arranged as each new location commenced the study. Where gender was considered, proportionate sampling was used to reflect the proportion of males to females in continuing care wards and nursing homes. Details of the activity allocation were given to the key nurse / therapist in a sealed envelop. This ensured that, as far as possible, the researcher and any relatives remained blind to the allocation.

Measures pre and post session were carried out in an office at a distance from the activity room/s. This ensured the researcher made every effort to remain unaware of which activity each participant was attending. Primary carers and relatives were asked not to visit during the intervention delivery

period in order to reduce the chance that they might witness the intervention. This was to reduce the chance that they might divulge the activity allocation to the researcher. Participants were not reminded of the blinding procedure by the therapist as it was felt that this may prompt them to talk about the intervention they had attended with the assessor. Instead it was hoped that, given the level of dementia, the participant would fail to remember once they reached the assessor's office. If a participant divulged their activity allocation this was recorded.

5.3.6   Assessments

Assessments tools were selected for their psychometric properties and relevance to people with moderate to severe dementia. A description of the assessments selected and rationale for their use in comparison with other assessments can be found in Chapter 6.

5.3.6.1 Method of data collection

The researcher carried out all data collection in order to ensure the assessment was blind. The researcher was trained to administer the AMPS assessment tool. This training included rater reliability checks, severity rating and test interpretation (AMPS training courses; Harrison Associates). Assessments were carried out at four points for each participant; baseline, pre and post session, and at one month follow up.

5.3.6.2 Assessments

The following baseline assessments were conducted to describe the characteristics of the participants and to provide relevant information regarding the construction of the MSE activity and the control activity sessions: Standardised Mini-Mental State Examination (SMMSE; Molloy et al., 1991) GBS Scale (GBS; Brane et al., 2002), to identify degree of physical inactivity, intellectual impairment, emotional capacity and mental symptoms; the Adult Sensory Profile (ASP; Brown et al., 2002), to identify to which sensory preference a person is oriented; the
Pool Activity Level Instrument for Occupational Profiling (PAL; Pool, 2002), to identify activity profiles for each individual during the MSE or the control group; the Assessment of Motor and Process Skills (AMPS; Fisher, 2003), to establish a baseline level of motor and process skill within functional performance; and the Neurobehavioural Rating Scale (NRS; Sultzer et al., 1992), to establish a baseline level of mood and behaviour problems.

The AMPS and the NRS were used pre and post session over the 12 sessions, in order to monitor changes in functional performance, mood and behaviour (dependent variables). Likewise, they were used at one month follow-up to establish whether any changes in mood, behaviour or functional performance had been sustained.

5.3.7   Intervention activities

Both interventions were facilitated by the key nurse or therapist following a period of training. The training involved the key nurse or therapist learning to run the intervention in a systematic manner. Guidelines for the facilitation of each of the intervention activities are included in Appendix 6. The programme for each session involved an introduction from the key nurse or therapist, ensuring that the participant was willing to take part in the intervention activity. Details were also given to the participant regarding location and approximate length of time of the activity. If a participant showed initial reluctance, the key nurse or therapist left the client for five minutes before repeating the invitation and showing the participant a piece of equipment. If the participant still refused to take part this was considered as non-consent for that session and was recorded as a non-attendance by the researcher.

Participants who agreed were taken to the researcher for pre-session assessment. On completion of the assessment the participant was collected by the key nurse or therapist and taken to the intervention activity (MSE or control). On arrival they were given several minutes to settle before the activity started. Specific details regarding the facilitation method were determined by the PAL assessment. On completion of the activity, the participant was given several minutes to prepare to leave the room. They were then taken by the key nurse or therapist to the researcher for post session assessment. The researcher returned and settled the participant in the location they were in prior to the activity room. Any relevant information regarding their general well-being was reported to the member of staff in charge.

Information and training were also provided to the key nurse or therapist on ensuring voluntary consent was maintained through-out the twelve sessions. Strategies for maintaining the blind status of the study, such as encouraging the participant not to divulge which group they attended to the researcher immediately prior to assessment were also employed.

5.3.7.1 The multi-sensory environment

This activity was run in a quiet area, quiet room or purpose built MSE in the hospital or nursing home. Each participant was shown each piece of equipment in the room based on their results from the PAL assessment and the Adult Sensory Profile (Table 3: Multi-sensory equipment). Pieces of equipment used numbered from one to three. The main overhead lights were switched on so all equipment available for selection was clearly visible. Participants were allowed to choose equipment based on their identified sensory preference, although advice from the key nurse or therapist was available if no equipment was selected. For example, a participant with a visual profile could select from equipment such as the optic fibres or bubble tube. Once a selection had been made by the participant, all extraneous equipment was removed from view. Each session was conducted according to protocols identified by the PAL Instrument for Occupational Profiling

(Pool, 2002) (see Appendix 6). This ensured the application of the interventions was standardised between participants. These protocols describe the length of time recommended to run the session, presentation of the equipment and the format of the session given the participant's level of functioning. An example of the protocol for a participant operating at a reflex level is included below (see 6.2.4 for a description of the reflex level). Remaining protocols are included in Appendix 6.

Protocol for participants in the MSE operating at the Reflex activity level.

Activity objectives
To arouse conscious awareness of self and the immediate environment.

Position of equipment.
Make available to the participant equipment that stimulates all the senses. Directly stimulate the area of the body to be targeted i.e. touching the palm of the hand / arms / feet, shining visual stimuli into the line of vision, placing aromas directly under the nose for olfactory stimulation. Ensure all the senses are stimulated equally. Look for signs that the participant is aware of the equipment such as eye / head / hand movement, verbal responses, moving parts of their body.

Verbal directions
Help the participant to settle and explore equipment. Guide all movements and reinforce with simple, one word directions. Ensure the participant is settled with each piece of equipment before exploring its sensory components. Maintain eye contact and reinforce the activity with appropriate body language and gestures.

Communication and activity characteristics
Bring the participant into the room and settle them in a comfortable chair. If they are in a wheelchair transfer them to an easy chair. Start with main room lights on and slowly dim the lights. The session may last for up to 10 minutes but end the session if the participant is no longer able to concentrate on the task or if they fall asleep (this approach is designed to stimulate rather than relax).

Break each activity down into one step at a time and limit the stimuli to one piece of equipment operating at any one time. Repeat the activity for as long as the participant is able to tolerate it. The activity is in direct response to the level of stimulation needed to arouse.

Guide the participant to explore and handle the equipment. Do not enforce any instructions on how to use or handle the equipment unless the participant is placing himself or herself in danger. Ensure that the participant is able to access the sensory qualities of each piece of equipment, and use body language and tone of voice to enhance the level of stimulation.

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Ending the session

Slowly brighten the room and allow the participant to become accustomed to the everyday environment. Adapt tone of voice and body language to the new environment.

Materials

Each multi-sensory environment had the following equipment (see Table 3). An example of the environment is given in picture 2.

Picture 2: Example of a green multi-sensory environment.

Reproduced with permission from Rompa

Table 3: Multi-sensory environment equipment

Sensory modality	Equipment available
Visual equipment (sight)	Optic fibre sprays, Projector and effect wheels, Mirror ball and spot light, Bubble tube, Bubble machine
Auditory equipment (sound)	Wind chimes, Music CDs (new age, classical, easy listening, meditation), Animal and nature sound CDs (waterfall, bird song, sea shore), White sounds from the equipment, Coloured rain sticks, small percussion instruments.
Tactile equipment (touch / pressure / vibration)	Vibrating cushions / tubes and mattress, Textured cushions, Multi-coloured rain stick, Textured objects.
Olfactory equipment (smell)	Smell pots, Aroma diffuser.
Movement equipment (proprioception / vestibular stimulation)	Rocking chair, equipment will be positioned to encourage reaching.

5.3.7.2 The control activity (gardening)

As previous research has indicated that activity has a positive effect on people with dementia (Dowd & Davidhizar, 2003; Josephsson et al., 1993; Pulsford, 1997), the primary research questions were designed to investigate what were the special qualities of MSEs that might give a positive outcome. Conceivably, it is the unstructured sensory stimulation. Therefore a control activity was selected that had similar sensory qualities as the MSE but a more subtle mode of sensory stimulation and a more structured format. Gardening was chosen as a control for these reasons.

This activity was run in a quiet room away from other people. The participant was asked about the type of gardening activity they would like to do. For those who were unable to make a choice, carers and relatives were consulted. This request was presented as a general request about favourite activities during the initial contact with carers and relatives in order to maintain blindness. The session was facilitated by the nurse or therapist according to protocols identified by the PAL

Instrument for Occupational Profiling (Pool, 2002) (see Appendix 6). An example of the protocol for a participant operating at a sensory level is included below (see 6.2.4 for a description of the sensory level).

Protocol for participants in the control activity (gardening) operating at the Sensory activity level

Activity objectives

To enable the participant to experience the effect of the activity on the senses – sample activity: planting a bulb.

Position of the equipment

Make available equipment that has been identified by the participant. Make sure they are aware of the equipment and materials by guiding the participant's hands, for example, identify the flower pot, compost and bulbs. Look for signs that the participant is aware of the equipment such as eye / head / hand movement, verbal responses, moving parts of their body.

Verbal directions

Help the participant to settle and explore equipment. Break down the activity into one step at a time, for example, waiting until the person has filled the flower pot with compost before giving the next instruction to select a bulb. Maintain eye contact and reinforce the activity with appropriate body language and gestures.

Communication and activity characteristics

Bring the participant into the room and settle them in a comfortable chair. If they are in a wheelchair, transfer them to an easy chair. Repeat elements of the activity if they are enjoyed by the participant; for example, plant more than one bulb. The session may last for up to 15 minutes but end the session if the participant is no longer able to concentrate on the task.

Guide the participant to explore and handle the equipment and materials by limited spoken directions to explanations of movements required to carry out the task.

Ending the session

Pack the equipment and materials away and inform the participant that the activity is over. Reflect on the sensory qualities of the activity i.e. the compost was cold wasn't it?

Materials

Each gardening activity had a number of resources available which had the potential to offer multi-sensory stimulation (Table 4: Gardening equipment).

Table 4: Gardening equipment

Sensory modality	Equipment available
Visual equipment (sight)	Brightly coloured pictures of plants, flowers.
Auditory equipment (sound)	Nurse / therapist talking during the activity, digging and planting sounds, watering plants.
Tactile equipment (touch / pressure / vibration)	Touch and texture of different leaves, feel of compost.
Olfactory equipment (smell)	Smell of flowers, compost.
Movement equipment (proprioception / vestibular stimulation)	Equipment will be positioned to encourage reaching.

5.3.7.3 Comparison of activities

Although both activities had the potential for multi-sensory stimulation there were some distinct similarities and differences between the two groups which need to be considered when interpreting the results (see Tables 5 & 6: Similarities and differences between activities).

Table 5: Similarities between activities

One to one facilitation. - Facilitation of activity by key nurse or therapist	
Length of sessions -	Between 10 - 30 minutes. Activity is ended once the key nurse or therapist notices that the participant has stopped attending.
Frequency of sessions (number). - Three times a week for four weeks (12).	
Location of the room -	Both can be located in a quiet room or area
Intellectual demands on the participant. - Gardening – no intellectual demands if just playing with compost. MSE – participant may just wish to handle the optic fibres.	

Table 6: Differences between activities

Gardening	Multi-sensory environments
Multi-sensory experience.	
Activity has multi-sensory components but each sensory area is not presented to the participant in isolation.	Equipment presented sequentially to stimulate all the senses.
Nature of the stimulus.	
Patterned, sequential stimulus. The nature of the gardening activity is that it has structure. The activity has a goal which may range from planting a bulb to pruning a plant.	Unpatterned stimulus, non-sequential. Choice of stimulus is determined by the participant and may be presented in a random sequence. Goal is covert to the participant.
Familiarity.	
A possible familiar environment / activity (given previous experience). As gardening encompasses a large range of activities it may be possible to find an activity that is familiar and achievable.	Unfamiliar environment / activity. Participants may be reluctant to take part in an unfamiliar activity.
Direction	
Normally structured and directed by key nurse / therapist or participant, however, if the participant is an experienced gardener they may be able to take part without too much guidance.	Non-directive but facilitated by key nurse / therapist in response to the participant.
Intellectual demands on the participant.	
Intellectual demands on the participants. There is a process to follow in order to achieve the goal.	No intellectual demands on the participants. Interacting with the equipment requires very little higher cognitive skill.

5.4   Planned Analysis

5.4.1   Intention to treat analysis

All data were analysed according to intention to treat (ITT).This means participants who commenced treatment and control groups were analysed as part of that group regardless of whether all 12 sessions were completed. Primary analysis used ITT as it avoided bias associated with loss of participants due to lack of co-operation, non adherence, or illness and death. This more accurately reflects what might be observed in clinical practice with patients, particularly those who are frail, being prescribed certain treatment activities but not completing the course of treatment (Hollis & Campbell, 1999).

Although ITT is a more accurate reflection of what may be observed in the clinical setting, the results from ITT can be different from the treatment effect observed for those who complete the full intervention. Therefore, both ITT analysis and completion to session 12 analysis were planned. In order to assess the extent to which ITT led to an underestimation of the efficacy of the intervention, this study reports the number of participants' recruited and violations of the protocol.

5.4.2   Planned statistical analysis

The data were analysed under the four main aims. Initial descriptive analysis describes the groups. Further inferential analysis (parametric or non-parametric where appropriate) was used to explore the data in terms of the success of the MSE in influencing function, mood and behaviour compared with the control activity.

5.4.2.1 Descriptive analysis

Primary analysis of kurtosis and skewness was used to explore whether the data were normally distributed. Skewed data were transformed (log 10 for positive skew, anti-log square root for negative skew). Tests of normality were undertaken using normality plots and the Shapiro-Wilk statistic (a more conservative statistic for smaller sample sizes) (Altman, 1999).

Details of the participant's gender, age and diagnosis were presented alongside the results of the descriptive variables (PAL, Sensory Profile, INTERACT and MMSE). The baseline scores of the dependent variables (AMPS, NRS and Carer Burden) were presented for each of the groups.

Primary analysis compared the descriptive variables (age, gender, sensory profile) and baseline variables (SMMSE & GBS) using χ^2 or, where cells had an expected count of less than 5, Fishers Exact statistic. Baseline dependent variables (AMPS & NRS) were explored using Student's

independent *t* tests or where distributions deviate from the normal, the Mann Whitney *U* statistic. Equal variances may be assumed unless otherwise stated. All data are reported to two or three decimal places. Assuming the data were normally distributed and assumptions were met the following analyses were planned.

5.4.2.2 Research question 1 and 2

To what extent, if any, do MSEs influence functional performance compared with the control activity (gardening)?

To what extent, if any, does the control activity (gardening) influence functional performance?

Baseline to last treatment session / variable end of treatment analysis.

The number of participants who improved from baseline to last treatment session on the AMPS assessment was explored. Differences greater than or equal to 0.5 in the AMPS scores represent a statistically significant change (Fisher, 2003). Analysis of the dependent variables from baseline to last treatment session was conducted using a two way analysis of variance (ANOVA), of time (baseline / last treatment session) by group (MSE / control) for each of the motor and process scores. Analysis of the dependent variables from baseline to session 12 was conducted using a two way analysis of variance (ANOVA), of time (baseline / session 12) by group (MSE / control) for each of the motor and process scores.

If sphericity[3] was violated, as indicated by a significant Mauchly statistic, the more conservative Greenhouse-Geisser statistic was reported.

Adjustments for multiple testing using a Bonferroni correction are also reported where a number of tests are performed.

Sessional analysis.

Sessional analysis was carried out as the effect of the intervention (MSE or control) may be shortlived (van Weert et al., 2004). In order to explore individual differences pre and post session, delta scores were calculated by subtracting each individual's post session AMPS scores from their pre session score for each of the 12 sessions. Positive values indicate improvement and negative values decline. These scores were presented on a line graph.

In order to explore the number of sessions for which an improvement was made, delta scores greater than or equal to 0.5 (representing statistically significant improvement) in motor then in process scores was calculated. A similar analysis was conducted for delta scores greater than or equal to 0.3, which represents clinically significant improvement (Fisher, 2003). Student's

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[3] Sphericity refers to the equality of variance of the differences between each treatment group, and as such, can be likened to the assumption of homogeneity of variance in between group analysis. If sphericity has been violated the Greenhouse-Geisser statistic is used to produce a more conservative estimate which goes someway to correct the deviation (Cohen-Mansfield, 2001).

independent *t*-test was used to check whether the distribution of improvers (using statistical and clinical cut offs of 0.5 and 0.3 logits respectively) and non improvers was the same for both groups. This analysis explores the frequency of a successful outcome and should provide meaningful information for therapists wishing to use these interventions.

5.4.2.3 Research question 3
In what way are mood and behaviour affected by MSEs compared with the control activity group?

Baseline to last treatment session analysis / variable end of treatment analysis.
The number of participants who improved from baseline to last treatment session on the NRS assessment was explored. Analysis of the dependent variables (neurobehavioral scores) was conducted using a two way ANOVA, of time (baseline / last treatment session) by group (MSE / control) for NRS scores. Analysis of the dependent variables from baseline to session 12 was conducted using a two way ANOVA, of time (baseline / session 12) by group (MSE / control). Adjustments for multiple testing using a Bonferroni Correction are also reported where a number of tests are performed.

Sessional analysis.
In order to explore individual differences pre and post session, delta scores were calculated by subtracting each individual's post session NRS scores from their pre session NRS scores over the 12 sessions. Differences were compared using Students independent *t*-tests. A decline in scores indicates an improvement in mood and behaviour. A positive score indicates a decline. Differences greater than or equal to 1.3 in the NRS scores have been shown to represent clinically significant change (McCauley et al., 2001). Percentage of sessions for which an improvement of greater than or equal to 1.3 was also calculated.

5.4.2.4 Research question 4
To what extent is the sensory profile of the individual associated with response to treatment?

A cross tabulation table and χ^2 statistic was used to explore the relationship between participants' sensory profile and their baseline assessment scores. This table shows the number of participants who improved ≥ 0.5 (AMPS score) for each sensory profile. An example is shown below.

	Sensory quadrants			
	Low registration	Sensation seeking	Sensory sensitivity	Sensation avoiding
MSE activity				
Control activity				

This process was repeated using NRS scores greater than or equal to 1.3.

5.5 Summary

This chapter has described the methodology used in designing this study, with details of the method employed to recruit participants with moderate to severe dementia. Details of how the sample size was calculated and how sufficient participants were to be recruited were discussed, with details of contingency plans to reduce attrition rates. Brief details were given of the assessment tools to be used and a comprehensive description of how the activities were to be facilitated. Details were also given of how staff were trained to facilitate the activities in a standardised manner. Details of the proposed analysis of the data were given under each of the research questions. Any alternative or subsequent analysis will be described in the Results Chapter. The pilot study followed the method described in this chapter, to test the feasibility of carrying out this study with people with moderate to severe dementia. Before reporting the results of the pilot study, the next chapter considers the selection of assessment tools and outcome measures in more detail.

Chapter 6 Assessment of function, mood and behaviour in dementia: Measures used in the study

This study was designed to compare the efficacy of two multi-sensory interventions. There was a need to select assessments to describe the population group and to assess the outcome of the interventions.

Assessments were identified from a literature search using Medline, CINAHL, EMBASE, BIDS, IBSS Data-base, and OT Direct. A hand search was also conducted using literature identified in the literature review. Healthcare personnel were also approached to identify assessments that were being used in the clinical environment. The Research Department at the School of Health Professions and Rehabilitation Sciences, University of Southampton and members of the Specialist Section, Occupational Therapy for Older People, at the College of Occupational Therapists were approached to identify assessments commonly used in health research with older people. From this search a selection of assessments was considered.

6.1   Assessment parameters

The assessments identified were considered using the following parameters. For independent variables the following criteria were considered: psychometric properties [4] including face validity, acceptability of the test to the person with dementia and the clinician; content reliability and concurrent validity and ability to discriminate between individuals; ease of administration, including being of a suitable length to suit the reduced attention span of a person with dementia, clear instructions to ensure each assessment is performed in the same manner; designed for people with dementia or used in dementia, and clear indication of whom should complete the assessment.

For dependent variables the parameters were extended to include sensitivity to change in performance. Given that many previous studies exploring the effect of MSE have been criticised for the validity of assessment tools used (Baker et al., 1997; Kragt, Holtkamp, van Dongen, van Rossum, & Salentijn, 1997; Moffat et al., 1993), only those measures that were rigorous on at least four parameters were considered below.

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[4] Psychometric data are reported wherever possible from published material or following contact with authors and publishers.

6.2   Assessment of independent variables

The descriptive variables were the assessments of cognition (Standardised Mini-Mental State Examination; Molloy et al., 1991), global functioning; (GBS; Brane et al., 2002), sensory processing (Adult Sensory Profile; Brown et al., 2002), level of occupational performance (PAL; Pool, 2002). These assessments were carried out at baseline.

6.2.1   Standardised Mini-Mental State Examination

Purpose

The Standardised Mini-Mental State Examination (SMMSE) is a screening tool for cognitive impairment in older people with dementia. The SMMSE is an adapted form of the Mini-Mental State Examination (MMSE; (Folstein et al., 1975). The original MMSE, although widely used as a screening test in research (Molloy et al., 1997; Pearson, Esiri, Hiorns, Wilcock, & Powell, 1985) lacks clear instructions for administration and scoring. This is evident in the 'attention' question where the participant is asked to spell 'WORLD' backwards. The scoring for this question relates to the number of letters in the correct order. The highest possible score is five. As there are 119 possible misspellings of 'WORLD' spelled backwards, inconsistencies in scoring for anything other than correct are likely (Schulzer et al., 1993). Other problems include the lack of a time limit for each question and the variability of conduct across examiners, which leads to variability in the time allowed for a response to each question (Molloy et al., 1997). The SMMSE addresses these weaknesses by standardising administration instructions and scoring.

Administration and Scoring

The SMMSE is an eleven question measure that tests orientation, registration, attention, calculation, recall and language. The maximum score is 30. The standardised format includes setting up, administration and scoring. During setting up the examiner ensures the person has appropriate sensory aids (spectacles and hearing aid) and all props are available. The person is asked if they wish to participate, and informed of the purpose of the test. Each question may be asked up to three times if the person does not seem to understand or has not attempted to answer. During administration the assessor progresses through the questions using verbatim instructions and allowing exact periods of time for the response. Explicit details are given of what constitutes a correct answer.

The SMMSE takes approximately 10 minutes to complete. Results are presented in the same categories as the original MMSE. Scores between 0 – 7 indicate severe cognitive impairment, 8 – 14 indicate moderate cognitive impairment, and 15 – 27 indicate mild cognitive impairment.

Psychometric properties

Test-retest and inter-rater reliabilities are good (.92 and .90 respectively) (Molloy, Alemayehu, & Roberts, 1991). Face, content and concurrent validity are not reported in the literature relating to the SMMSE, however, there appears to be a degree of face and content validity by the nature of the questions. For example, the question 'what year is it?' is clearly a question relating to memory and orientation.

Design and suitability for people with dementia

The SMMSE is a development of the MMSE, a cognitive mental status examination. The MMSE was designed for patients with dementia syndromes, affective disorder with cognitive impairment, mania and Schizophrenia (Folstein et al., 1975).

Conclusion

The SMMSE was selected for this study to act as a screening instrument for dementia severity. The standardised format ensures the assessment is performed in the same manner with all participants and its popularity in the MMSE format in clinical practice makes it a readily acceptable tool for clinicians. Other measures considered were the Mini-Mental State Examination (Folstein et al., 1975), the Blessed Dementia Scale (Blessed, Tomlinson, & Roth, 1968) and the Clifton Assessment Procedures for the Elderly (Pattie et al., 1979). Table 7 describes these measures and identifies the rationale for use of the SMMSE (Table 7).

Table 7: Comparison of published measures for the assessments of cognition in older people

	MMSE	Blessed Dementia Scale	CAPE
Cognition	✔	✔	✔
Other areas **(eg. Behaviour & mood)**	Behaviour	Functional impairment	Psychomotor performance. Is divided into the Cognitive Assessment Scale (CAS) and the Behaviour Rating Scale (BRS)
Main indicators	Dementia, affective disorder with cognitive impairment, mania and Schizophrenia.	People with dementia.	Older people
Time to administer	10 minutes	30 minutes	15 – 25 minutes
Raters	Rating by trained interviewer.	Rated by observer.	Trained interviewer
Scoring	Total possible score 30	Score between 0 (fully preserved capacity) and 28+ (extreme incapacity).	12 item test. Scores ≤ 7 on the information / orientation sub-test indicates cognitive impairment
Test retest reliability	Test retest .98 (Pearsons Correlation Coefficient)	Test retest .98 (Pearsons Correlation Coefficient)	X

Note.   MMSE **-** Mini-mental state examination (Folstein et al., 1975); Blessed Dementia Scale (Blessed et al., 1968); CAPE - Clifton Assessment Procedures for the Elderly (Pattie et al., 1979). ✔ Confirms inclusion of this area in the test   X Data unavailable

	MMSE	Blessed Dementia Scale	CAPE
Inter-rater reliability	Inter-rater reliability .83	Inter-rater reliability .98	Inter-rater reliability 0.8
Concurrent validity	Correlation .78	Correlation with neuropathological changes 0.77	Distinguishes between functional and organic disorders. 92% accuracy in terms of case note diagnosis
Construct validity	X	Construct .90	X
Face validity	X	X	X
Reason for rejection	Scoring and administration anomalies, lack of standardisation, which made this measure insufficiently robust for this study.	Overlaps with other assessments used in the study. Functional questions too complex for people with severe dementia. Additionally, this assessment has low inter-rater reliability (Cole, 1990).	Overlaps with other assessments. Too many domains covered.

6.2.2 GBS scale

Purpose

The GBS scale (Gottfries-Bråne-Steen) (Brane et al., 2002) evaluates a more global functioning of people with dementia. Unlike the SMMSE which reports level of cognitive functioning, the GBS presents a profile of the person with dementia in terms of intellectual, emotional and behavioural responses, and physical ability. This assessment tool was selected in order to illustrate the dementia profile of each of the participants. The GBS scale has been used in other clinical trials to assess global functioning (Augustinsson et al., 1997; Ohkura et al., 1995; Ragneskog, Eriksson, Karlsson, & Gottfries, 1996). The GBS is a profiling assessment and as such the subsections can be considered in isolation as well as part of a composite score.

Administration and scoring

The GBS is a semi-structured, quantitative rating scale which is divided into four subsections measuring, intellectual and emotional responses, activities of daily living and behavioural / psychological features. The scale is completed after a short interview with the person with dementia, their relative, carer, key nurse or therapist.

Each item is scored on a seven point Likert scale, 0 representing no impairment and 6 representing maximum impairment. Anchor points are given for each of the seven severity rating points. Scores between 0 – 1 are considered normal, 1 – 2 mildly impaired, 3 – 4 moderately impaired, 5 – 6 severely impaired. Results for each subsection (intellectual / emotional / ADL / behavioural and psychological) are recorded on a graph giving a clear overview of the person's dementia profile.

Psychometric properties

The inter-rater reliability of the GBS is very good, with correlations between .87 and .93 recorded for healthcare professionals (Brane & Karlsson, 1999). The concurrent validity of the GBS has been tested with the MMSE. The correlation coefficient figures for each of the subsections of the GBS, in comparison with the MMSE, range between .54 and .81. The lower score (.54) reflects the ADL components of the GBS subset which are not represented in the MMSE.

Design and suitability for people with dementia

This assessment was specifically designed for use with people with dementia. The questions are focused on the emotional, intellectual and behavioural responses of people with dementia.

Conclusion

A number of features of GBS make this a suitable descriptive tool for this study. The tool has an easy scoring sheet, giving both a numerical score and a graph to illustrate the profile of the person. The GBS scores are recorded under the sub-sections of emotional responses, intellectual responses, behavioural responses and performance in ADL. This allows the profiles of each individual to be described in depth. Other measures considered were the NIMH Dementia mood

assessment scale (Sunderland et al., 1988) and MOUSEPAD (Allen, Gordon, Hope, & Burns, 1996) Table 8 describes these measures and clarifies the rationale for use of the GBS (Table 8).

Table 8: Comparison of published measures for the assessments of global functioning in older people

	NIMH	MOUSEPAD
Global functioning	✔	✔
Other areas included	Focus on mood and functional capabilities	X
Main indicators	People with mild to moderate dementia.	People with dementia.
Time to administer	20 – 30 minutes	15 – 30 minutes
Raters	Interview by trained raters	Rated by experienced clinicians & interviews with carers.
Scoring	24 item scale. Score relates to mood & dementia severity. Scores between 0 & 6, 6 being more dependent.	59 item instrument with a rating score of 0 (absent) through to 3 (severe).
Test retest reliability	X	Test-retest .43 - .93
Inter-rater reliability	Inter-rater reliability .69 - .74	Inter-rater reliability .43 - .67
Concurrent validity	X	Concurrent .43 - .93
Construct validity	Construct validity .49 - .71	X
Face validity	X	Face validity .43 - .67
Reason for rejection	Not validated with those with moderate to severe dementia.	Does not include a cognitive component. Insufficient. Assessment is too long.

Note. NIMH Dementia mood assessment scale (Sunderland et al., 1988); MOUSEPAD (Allen et al., 1996). ✔ Confirms inclusion of this area in the test X Data unavailable

6.2.3   The Adult Sensory Profile

Purpose

The Adult Sensory Profile is an evaluation of behavioural responses to everyday sensory experiences. It is designed as a trait measure of sensory processing, capturing the more stable and enduring sensory processing preferences of an individual. In identifying these preferences an increased awareness of why people engage in particular behaviours may emerge (Brown et al., 2002). This can help with intervention planning and adaptation of the sensory environment to suit the individual. The Adult Sensory Profile was selected for this study in order to identify sensory processing behaviours and explore whether people who fall within identified sensory quadrants respond better to the multisensory environment.

The Sensory Profile has been used extensively with children. It has also been adapted for use with adults (Brown et al., 2001; Kohlmeyer, 1998). The profile has been used in clinical research exploring response of adults and children to sensory stimuli (Pohl et al., 2003). The Adult Sensory Profile is based on the model of sensory processing model (Dunn, 2001). The model is explored in more depth in Chapter 4.5.2.

Administration and scoring.

The Adult Sensory Profile is a 60 item questionnaire measure which covers the areas of taste / smell processing, movement processing, visual processing, touch processing, activity level and auditory processing. The questions relate to four sensory quadrants, as identified in the model of sensory processing (low registration / sensation seeking / sensory sensitivity / sensation avoiding). The questionnaire may be completed by the person or relatives, carers, therapists or nurses. The person indicates the strength of their response to each of the 60 questions using a likert scale. For example: *'I hum, whistle, sing or make other noises'*. The response may be from 1 = almost never to 5 = almost always. The final scores are calculated by filling in a summary chart (Table 9). A hypothetic score is illustrated in red.

Table 9: Example of an adult sensory profile summary chart

Quadrant	Raw score	-- Much less than most people	- Less than most people	= Similar to most people	+ More than most people	++ Much more than most people
Low registration	**45** / 75	15 - 19	20 – 26	27 – 40	**41 – 51**	52 - 75
Sensation seeking	**66** / 75	15 – 28	29 – 39	40 – 52	53 – 63	**64 - 75**
Sensory sensitivity	**17** / 75	**15 – 18**	19 – 25	26 – 41	42 – 48	49 - 75
Sensation avoiding	**27** / 75	15 – 18	19 – 25	**26 – 42**	43 – 49	50 - 75

Note. The raw scores in red indicate the results of a hypothetical respondent. The area in which this hypothetical respondent falls is highlighted in blue bold.

This summary chart records the scores under each of the sensory quadrants from which a comparison can be made against a normative group. For example, the summary chart above allows the hypothetical respondent's results to be compared against adults aged 65 years and older. The scores can then be plotted on a visual representation of the quadrant profile. The quadrant profile gives a visual interpretation of high frequency response patterns at the perimeter of each quadrant and low frequency response patterns towards the centre of each quadrant. Figure 8 shows an example of the quadrant profile with the scores of a hypothetical participant plotted.

Figure 8: Example of a sensory profile quadrant

Low registration	Sensation seeking
++	++
+	+
=	=
–	–
– –	– –
– –	– –
–	–
=	=
+	+
++	++
Sensory sensitivity	Sensation avoiding
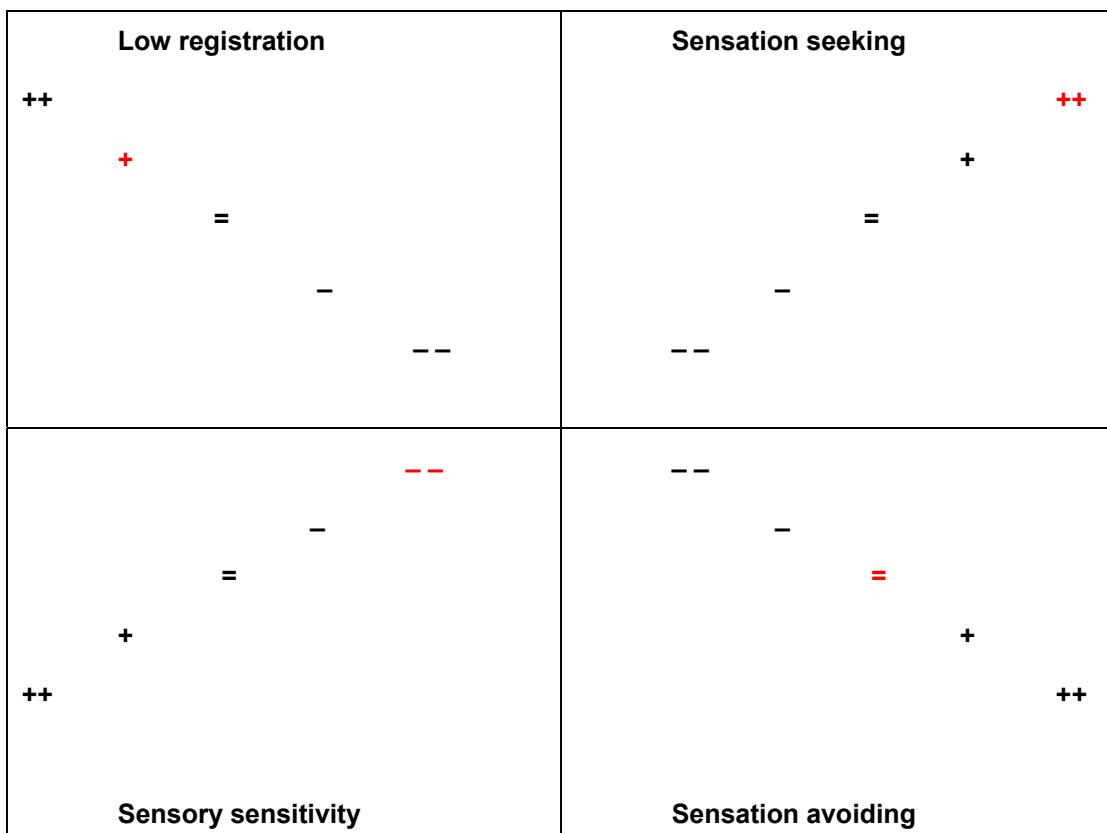
Note. The following symbols are used to represent the classifications on the quadrant profile:

_ _ Much less than most people; **_** Less than most people; **=** Similar to most people; **+** More than most people; **++** Much more than most people; The values in red are those of a hypothetical participant who is more sensory sensitive than most people, but displays sensory seeking and low registration behaviours.

The definitions, as described by Brown et al. (2002), of the classification system on the quadrant profile are as follows:

- Much less than most people = less than 2% of the study population

- Less than most people = between 2% and below 16% of the study population

- Similar to most people = between 16% and 84% of the study population

- More than most people = between greater than 84% and 98% of the study population

- Much more than most people = greater than 98% of the study population

This classification is for comparison with individuals 65 years and older (Brown et al., 2002).

Psychometric properties

The Adult Sensory Profile has good test-retest reliability with coefficient alpha values of .75 for low registration, .75 for sensation seeking, .73 for sensory sensitivity, and .78 for sensation avoiding (Brown et al., 2002). Face validity was determined by eight expert judges from the University of Kansas Medical Centre. They were asked to categorise items according to the intended quadrant. Item acceptability was initially set at 75% (Brown et al., 2001); however, subsequent evaluation has revealed a higher degree of agreement exceeding the previous set criteria (Brown et al., 2002). Item reliability scores suggest sensory sensitivity, low registration and sensation seeking are internally consistent, with alpha scores of .78, .77 and .78 respectively; with more modest internal consistency for sensation seeking, .60 (Brown et al., 2001).

Design and suitability for people with dementia

This assessment has been designed for use with people 65 years and over, with or without illness and / or disability (Brown et al., 2001).

Conclusion

A number of key features of the Adult Sensory Profile were identified which made the Adult Sensory Profile suitable for this study: The Adult Sensory Profile is unobtrusive and easy to administer; It clearly links sensory processing with everyday experiences and It has been used extensively in clinical research (Brown et al., 2001; Dunn, 2001; Dunn et al., 1997; Kinnealey et al., 1995).

As no other assessment exists that assesses sensory profiles no comparison has been made (Brown et al., 2001).

6.2.4   The Pool Activity Level (PAL) Instrument for Occupational Profiling

Purpose

The Pool Activity Level Instrument for Occupational Profiling (PAL) (Pool, 2002) was originally published as part of the Good Practice Guide series from the Bradford Dementia Group. This series was intended as a practical resource for carers of people with dementia. The PAL was designed to give advice on how to engage people with dementia in meaningful activities (Pool, 2002). The PAL was chosen for this study to assist with developing an activity profile of each participant. By using the results from the PAL each participant would be facilitated in the session in a standardised manner by their key nurse or therapist. This was to ensure each participant would receive the appropriate level of support given their occupational profile.

The PAL consists of a life history profile, a checklist describing the way an individual engages in occupations, and an individual action plan that includes directions for facilitating engagement of the person in activities of daily living.

The PAL draws on the model of a person-centred approach and the cognitive disability model. The model of a person centred approach to dementia was proposed by Kitwood (1993). The model suggests that the presentation of dementia is a complex interaction between the person's personality, biography, health, neurological impairment and social psychology. This combination of factors recognises the uniqueness of the person rather than their impairment. The cognitive disability model (Allen, 1985) uses descriptions of how an individual attends to the environment and uses sensory cues and objects. These descriptions are organised into four levels and represent a person's ability to function.

Administration and scoring

The checklist is completed by relevant carers or family members following a period of observation. Once completed, the scores are organised into four activity levels:

- Planned – person can work towards completing a task but may not be able to solve problems that arise during the process.

- Exploratory – person can carry out familiar tasks but is more concerned with the effect of doing the activity rather than the consequences. They may not have the end result in mind.

- Sensory – Person may not have thoughts or ideas about carrying out the activity, they are more concerned with the sensation and their response to the sensation.

- Reflex – person may not be aware of the surrounding environment or even their own body. Movement is a reflex response to stimuli.

The activity level with the highest score represents the current level of functioning. Activity profiles for the MSE and the control activity are available. These profiles cover all four activity levels (see Appendix 6: Activity level profiles)

Psychometric properties

The PAL is currently being validated by the author and the results from this study being undertaken will contribute to this validation process.

Design and suitability for people with dementia

The PAL was exclusively designed for people with dementia.

Conclusion

A number of key features of the PAL were identified which made the PAL the most suitable tool for this study: The PAL is easy to administer as the questions reflect everyday activities; The activity profiles are easy to follow and give clear guidelines to how to facilitate the activity; The PAL is used extensively in the clinical services included in this study and, therefore, has high face validity. No other assessment explicitly identifies levels of occupational performance with guidelines for facilitating activity.

6.3 The assessment of dependent variables

The dependent variables in this study were the level of functional performance and neurobehavioural disturbance, and were measured pre and post activity and at follow-up. Assessments measuring these variables should have good face, construct and concurrent validity and good inter-rater and test testest reliability. Essentially they should also demonstrate sensitivity to change (Bucks et al., 2002). Unfortunately few have demonstrated sufficient validity for this study. The Assessment of Motor and Process Skills (AMPS) was selected as the primary outcome measure for this study.

6.3.1 The primary outcome measure: The Assessment of Motor and Process Skills

Purpose.

The Assessment of Motor and Process Skills (AMPS) is an observational assessment of activity in the World Health Organisation ICIDH-2 system (WHO; World Health Organisation, 1997). The assessment evaluates a person's ability to complete basic activities of daily living (BADL) and instrumental activities of daily living (IADL) independently. These activities are assessed by observing motor and process skills. AMPS simultaneously measures 16 motor and 20 process skills by evaluating the performance of the person as they carry out familiar BADL or IADL tasks (Table 10). Motor skills are the observable movements required to carry out the activity. These include postural, mobility, co-ordination, strength and energy components of the activity related to moving the body or objects in space. Process skills are the observable actions of how the person organises and adapts their performance in order to complete the task. Process skills encompass many of the components of cognition include attention, ideational, organisational and adaptive elements of functional performance which reflect the person's ability to organise and adapt the activity (Robinson & Lumb, 1997).

Table 10: Individual Motor and Process Skills assessed as part of AMPS

Motor skills		Process skills	
Stabilises	Flows	Pace	Searches / Locates
Terminates	Moves	Attends	Gathers
Aligns	Transports	Chooses	Organises
Positions	Lifts	Uses	Restores
Walks	Calibrates	Handles	Navigates
Reaches	Grips	Heeds	Notice / Responds
Bends	Endures	Inquires	Accommodates
Co-ordinates	Pace	Initiates	Adjusts
Manipulates		Continues	Benefits
		Sequences	

Note. AMPS - Assessment of Motor and Process Skills

There are 56 activities of daily living available in the AMPS assessment, ranging from personal care to domestic and home maintenance tasks. These are designed with cultural variations of the same task; for example, eating with chop sticks or eating with a knife and fork. There are also a range of activities that are undertaken by both males and females. The AMPS assessment is unique in that it measures the universal taxonomies that make up BADL and IADL task performance, as well as the outcome of the task (Park et al., 1993).

Administration and scoring

An initial interview allows the participant to select an activity with which they are familiar and which they are willing to perform. Due to the level of dementia of some of the participants in this study, this activity choice was supported by relatives and carers. Prior to the start of the activity the participant is orientated to the task environment and the nature of the task. During the task the participant is observed and rated on a 4 point ordinal scale ranging from competent to deficit on the 16 motor and 20 process skills;

> 4 = Competent performance that supports the action progression and yields good outcome;
>
> 3 = Questionable performance that places the action progression at risk and yields uncertain outcomes;

2 = Ineffective performance that disrupts or interferes with the action progression and
     yields undesirable outcomes;

1 = Markedly deficient performance that impedes the action progression and yields
     unacceptable outcomes.

Raw scores are entered into AMPS software along with coding of rater severity and activity chosen. The software uses Rasch analysis to convert ordinal data into interval scores, taking into account skill item difficulty, task challenge, rater severity and ability of the participant (Fisher, 1994). A graphic report is generated from which the ability measure of the individual is displayed on a continuum of motor and process scores (Figure 9). The higher the score the participant achieves, the higher their ability.

Figure 9: Example of a graphic report generated by the AMPS software

ASSESSMENT OF MOTOR AND PROCESS SKILLS (AMPS)
GRAPHIC REPORT

Client: Mrs. J R
Occupational therapist: Lesley J. Collier

	DATE	MOTOR	PROCESS
Evaluation 1	17/03/2005	0.46	-0.35
Evaluation 2	16/04/2005	0.96	0.57

The numbers on the ADL motor and ADL process scales are units of ADL ability (logits). The results are reported as ADL motor and ADL process measures plotted in relation to the AMPS scale cutoffs. Measures below the cutoffs indicate that there was diminished quality or effectiveness of performance of instrumental and/or personal activities of daily living (ADL). See the AMPS Narrative Report for further information regarding the interpretation of a single AMPS evaluation.

Reproduced within AMPS copyright. Fisher (2003)

Scores are recorded as logits. Improvements of at least 0.5 logits between test one and test two on either the motor or process scale indicates a significant clinical and statistical change. Improvement of 0.3 – 0.4 logits may not be statistically significant but may still have clinical meaning (Fisher, 2003).

Of participants scoring below 1 logit on the process ability scale, 93% will require assistance to live in the community. Of those scoring below 2 logits on the motor ability scale, 16% would be able to live independently in the community despite their physical disability (Fisher, 2003). Logit scores

also have implications for remedial or rehabilitation approaches. As these are not relevant to the study they will not be discussed. For more information see Fisher (2003).

Psychometric properties

Many faceted Rasch analysis (Linacre, 1993) is used to convert the ordinal data into interval level ability measures. These are adjusted to take into account the challenge of the activity and the severity of the rater. These calibrations and measures are expressed in equal interval units of measurement based on the logarithm of the odds (logits) of obtaining a given skill item score when a person is observed performing a given task by a given assessor. To date the AMPS has been used with over 12,000 people from USA, Scandinavia, UK, Australia and New Zealand (Fisher, 2003).

AMPS has demonstrated high inter-rater reliability (95%) amongst trained and calibrated raters (Bernspang, 1999; Fisher, 1994). Raters are trained on a five day course which includes administration procedures, observation and score interpretation. On completion of the course the rater submits twenty completed assessments scored on video case examples to the AMPS organisation. From these assessments a severity rating is given to the rater. The database from which rater severity is calculated includes 46,886 participants.

Studies have revealed that the AMPS process skill scale correlates well (r =.46 to .79) with the Mini-Mental State Examination (Folstein et al., 1975), suggesting that the process aspect of the measure incorporates cognitive skills as featured in the MMSE (Doble, Fisher, Fisk, & MacPherson, 1992; Doble et al., 1997; Robinson & Fisher, 1996).

Design and suitability for people with dementia

Although AMPS was not exclusively designed for people with dementia it has been used successfully as an outcome measure in drug trials with older people with dementia (Oakley et al., 1997). The authors selected AMPS because of its sensitivity to detect change despite the severity of the dementia disease process. Also, due to the variety and complexity of tasks available for assessment, floor and ceiling effects should not be a problem if a suitable challenge is offered (Fisher, 1994). This makes it a suitable measure for a group of people for whom changes in performance may be small.

Conclusion

Three key features were identified which make the AMPS the most suitable measure of function for this study. Firstly, the psychometric properties are well established making this a robust tool to use as a primary outcome measure. Also, the AMPS equal-interval units of measurement can be submitted to additional mathematical calculation making it amenable to test –retest.
Secondly, the global description of ability within the AMPS identifies units (motor and process skills) that impede BADL and IADL performance. These units of occupational performance offer

insight into why someone may have difficulty in performing a task. By being able to identify discrete elements of change in motor and process skills the AMPS will be sensitive enough to pick up any change in functional performance.

Thirdly, AMPS has reduced gender and cultural bias due to the range of activities offered (Duran & Fisher, 1996).

During the initial stages of this study, other functional assessments were investigated. Amongst those considered were the Nurses' Observation Scale for Geriatric Patients (NOSGER; Spiegel et al., 1991), Disabilty Assessment for Dementia (DAD: Gelinas, Gauthier, McIntyre, & Gauthier, 1999), Direct Assessment of Functional Status (Loewenstein et al., 1989), Bristol Activities of daily living (Bucks, Ashworth, Wilcock, & Siegfried, 1996) and Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969). Table 11 presents a summary of those measures including a critique to justify the choice of the AMPS (Table 11).

Table 11: Comparison of published measures for the assessments of functional performance in older people

	NOSGER	BADLS	DAD	DAFS	IADL Scale
BADL / IADL	✔	✔	✔	✔	IADL only
Other areas included	Mood, social behaviour, memory and disturbed behaviour.	No	No	Time orientation and communication	No
Main indicators	Older people with dementia	Older people with dementia living the community	People with Alzheimer's disease living in the community	Cognitive impairment in community residents	Older people
Time to administer	20 – 30 minutes	Approx 15 minutes	20 minutes	30 – 35 minutes over a 12 hour observation period	5 minutes
Raters	Trained interviewer, nurses and care-givers	Self-completion by caregivers of people with dementia	Proxy-respondent assessment.	Trained interviewer	Trained interviewer

Note. BADL – Basic Activities of Daily Living; IADL – Instrumental Activities of Daily Living; NOSGER **-** Nurses' Observation Scale for Geriatric Patients (Spiegel et al., 1991); BADLS - Bristol Activities of Daily Living Scale (Bucks et al., 1996); DAD - Disability Assessment for Dementia (Gelinas et al., 1999); DAFS - Direct Assessment of Functional Status (Loewenstein et al., 1989); IADL Scale - Instrumental Activities of Daily Living Scale (Lawton et al., 1969). ✔ Confirms inclusion of this area in the test   **X** Data unavailable

	NOSGER	BADLS	DAD	DAFS	IADL Scale
Scoring	30 items of behaviour each rated on a 5-point scale	Severity judgements range from independent 0 – no help required to dependence 3 – unable even with supervision.	40 items in 10 areas covering initiation, planned organisation and performance	40 items: 17 related to self-care and 23 to instrumental activities of daily living. Maximum score 93	14 items: 6 BADL, 8 IADL. Maximum score 14
Sensitivity to change	1 point change < 1 = improvement, > 1 = decline	Sensitivity to change = ≤-4 improvement, ≥2 decline, difference	X	Strong correlation with Blessed Dementia Scale sensitivity to change scale	Arbitrary 1 or 2 points suggested as small change
Test retest reliability	Test-retest – .84 to .92	Test-retest - 0.95	Test-retest - .96	Test-retest - .96	
Inter-rater reliability	Inter-rater reliability - .68 to .89	Not recorded as an absolute assessment	Inter-rater reliability - .95	Inter-rater reliability - .95	Inter-rater reliability - .87 to .91
Concurrent validity	Correlations with external criteria .75 - .87	Distinguishes through sensitivity to change	Using panel of healthcare professionals and carers	Scores from people with dementia lower than group from normal population	X

	NOSGER	BADLS	DAD	DAFS	IADL Scale
Construct validity	Significant differences between the 6 NOSGER dimensions ($p < .001$)	4 components with eigenvalues of >1 which explain 65% variance	Construct validity determined in cross-sectional study	Correlation with Blessed Dementia Scale	X
Face validity	Acceptable to nurses and other care givers	Rated as appropriate by carers	High face validity .80	High face validity - .96	Questions directly related to ADL activity
Reason for rejection	Mood and behaviour components overlap other assessments used in the study	Participants not all community based. Assessment to be completed by researcher. Not sensitive enough to pick up the small degrees of change anticipated in this study	Good for describing functional characteristics of the population but, as yet, has no data to support sensitivity to change	Assessment made over 12 hour period. This is too long assessment period for this study	Primarily community based. Outcome is scored on amount of assistance to complete task rather than ability to complete the task.

6.3.2   The Neurobehavioural Rating Scale

Purpose

The Neurobehavioural Rating Scale (NRS) is a multidimensional observational assessment originally designed for use with people with closed head injury to assess mood and behaviour. Levin (1987) and colleagues utilised the Brief Psychiatric Rating Scale (BPRS; Overall & Gorham, 1962) to design an assessment that examined neurobehavioural disturbance. BPRS includes emotional withdrawal, conceptual disorganisation and motor retardation. In developing the NRS Levin et al. (1987) expanded this to include attention, memory deficit, insight and disinhibition. This assessment tool was further validated for use with older people with dementia by Sultzer et al. (Sultzer et al., 1992). Subsequent studies have used this assessment with older people with dementia (Kastango et al., 2002; Mathias, 2003; Sultzer et al., 2003).

During assessment, observations are made regarding levels of anxiety, fatigability, expression, communication and disturbance of mood. Factor analysis of the NRS identified six major components (Sultzer et al., 1992). These factors included:

- Cognition / insight – disorientation, comprehension, poor planning, conceptual disorganisation, inaccurate insight, memory deficit, inattention.

- Agitation / disinhibition - suspiciousness, hostility, disinhibition, agitation, fatigability, inattention, decreased motivation, excitement, tension.

- Behavioural retardation - emotional withdrawal, blunted affect, motor retardation, excitement.

- Anxiety / depression – depressed mood, anxiety, guilt feelings, tension, somatic concern.

- Verbal output disturbance – expressive deficit, articulation defect.

- Psychosis – unusual thought content, hallucinations, suspiciousness, somatic concern.

Administration and scoring

Item rating is based on symptoms observed by the interviewer. The observations are graded using a seven point Likert scale ranging from not present to extremely severe. Results are presented as a single composite score of neurobehavioural disturbance or as individual factor scores. Total Neurobehavioural Rating scores were initially used in the study, although analysis of the factor based scores were also subsequently used.

Psychometric properties

The NRS has a very good inter-rater reliability, r = .93 p = .001 (Sultzer, Berisford, & Gunay, 1995). Cognitive / insight factor scores correlate inversely with MMSE scores, r = -.95, p < .001; (Sultzer et al., 1992). The reliability of the NRS in dementia was found to be similar to that observed in people

with head injuries (Chui et al., 1985; Levin, High, & Goethe, 1987; Sultzer et al., 1995). Sensitivity to change was calculated using mean differences of NRS total scores between 3 and 6 month. A significant change was calculated to be 1.3 (McCauley et al., 2001).

Design and suitability for people with dementia

The NRS assesses a broad range of cognitive, psychiatric and behavioural disturbances and is appropriate for use with people at all stages of dementia (Sultzer et al., 1992). The NRS was originally designed for use with people with head injuries and later validated with people with dementia. The use of this measurement with older people with dementia is supported by strong correlation with other scales that measure similar disturbances (Corrigan, Dickerson, & Fisher, 1990; Levin et al., 1987; Sultzer et al., 1992).

Conclusion

A number of key features of the NRS were identified which made it the most suitable measure of mood and behaviour for this study. NRS has been used with people with different types of dementia, including Alzheimer's disease and Vascular dementia. Given the broad spectrum of behavioural problems seen in different forms of dementia, NRS factor scores can be considered independently from the total score. Also, NRS is rater observed; this is important in this study as many of the participants are likely to have severe dementia which may make communication difficult.

A number of assessments of mood and behavioural disturbance were considered including measures cited in previous research of MSEs for older people with dementia. However, many of these scales, although used with people with dementia, contain items that appear to assess cognitive decline rather than changes in behaviour and mood (Sclan et al., 1996); for example, the Brief Psychiatric Rating Scale (BPRS; Overall et al., 1962), Hamilton Depression Scale (Hamilton, 1960) and NIMH Dementia Mood Assessment Scale (Sunderland et al., 1988). Therefore the two measures described below were selected due to their use in previous MSE studies, the BEHAVE-AD; (BEHAVE-AD; Reisberg et al., 1987) and behavioural disturbance measure, (Greene, Smith, Gardiner, & Timbury, 1982) (Table 12). A third measure, the Clinical Dementia Rating (CDR;Hughes, Berg, Danziger, Coben, & Martin, 1982), was also considered due to it being recognised as one of the gold standards in clinical practice of global rating of dementia (Burns et al., 2002). However, as CRD is primarily a descriptor of dementia rather than a measure of mood and behaviour it was rejected. Table 12 describes these measures and clarifies the rationale for use of the NRS.

Table 12: Comparison of published measures for the assessments of neurobehavioural disturbance in older people

	BEHAVE-AD	BMDS
Behavioural and mood disturbance	Both	Both
Other areas included	No	No
Main indicators	People with Alzheimer's disease with behavioural disturbance.	People with dementia living in the community.
Time to administer	20 minutes	15 – 20 minutes
Raters	Administered by clinician	Assessment by clinician
Scoring	Twenty-five item assessment. Scores for each item range from 0 to 3. Higher scores indicate increased behavioural severity.	Thirty-three items assessed on 3 sub-scales: active/withdrawn, active/disturbed, mood disturbance. Items rated on a 0 – 4 severity scale.
Sensitivity to change	Intraclass correlation coefficient used to determine clinical significance. Greater than five points suggests a change between Global Deterioration Scale severity level 7 and 6 (Reisberg et al., 1988)	Used as an absolute measure
Test retest reliability	Test retest = .96	Test-retest - .84
Inter-rater reliability	Inter-rater reliability - ranging from .61 to 1.00	Used as an absolute measure – not recorded

Note. BEHAVE-AD (Reisberg et al., 1987); BMDS - Behavioural & Mood Disturbance Scale (Greene et al., 1982). ✔ Confirms inclusion of this area in the test **X** Data unavailable

	BEHAVE-AD	BMDS
Concurrent validity	Comparison with GDS suggests significant group differences	Interpretation of factor loadings suggest thee main areas of mood and behavioural disturbance
Construct validity	Inter-rater agreement between BEHAVE-AD categories suggest construct validity	Construct validity - p = < .005
Face validity	All items reflect behaviours that are likely to be disturbing to caregivers	All items reflect behaviours that are likely to be disturbing to caregivers
Reason for rejection	Validated with people with Alzheimer's disease only. Too long to complete for people with severe dementia. Floor effect noted for participant who are described as having severe dementia.	Community based participants only. Fails to separate mood and behavioural components. No evidence of sensitivity to change.

6.4   Summary

Whilst many assessment tools are available for assessment of people with dementia, the selection made for this study focussed firstly on psychometric properties and then acceptability to the participant and clinicians involved in the study. Evaluation of the available assessments revealed strengths and limitations, however, the assessments chosen were well matched to the needs of the study, the timing available for assessment and were acceptable to the participants.

The assessments chosen to describe the dependent variables of dementia severity, mood and behavioural features, sensory preferences and activity profiles were the Standardised Mini-mental State Examination (SMMSE; Molloy et al., 1991), the GBS scale (Gottfries, Brane, Gullberg, & Steen, 1982), the Adult Sensory Profile (ASP; Brown et al., 2002) and the Pal Instrument for Occupational Profiling Tool (PAL; Pool, 2002). Assessments chosen to measure the independent variables of functional performance and mood and behaviour were the Assessment of Motor and Process Skills (AMPS; Fisher, 2003) and the Neurobehavioural Rating Scale (NRS; Sultzer et al., 1992).

Chapter 7 Pilot work

7.1   The Aims

A pilot study was undertaken in order to achieve the following aims:
1. To explore the suitability of the assessment tools.
2. To identify any methodological challenges that were not anticipated in the initial research design.
3. To allow therapy staff time to practice following the research protocol.
4. To identify how long each contact with the participant would take.
5. To check the power calculations in order to determine sample size.

7.2   Research design

A single blind randomised control trial design was used to enable testing of the procedures intended in the full trial comparing the effects of the multi-sensory environment activity with a control activity.

7.2.1   Participant recruitment

Ethics committee approval for this pilot phase was sought at the same time as the main study. The pilot phase took place at a hospital for older people with dementia in Southampton. Two Occupational Therapists working in the hospital identified 11 possible candidates. Three of the original 11 did not meet the inclusion criteria, due to the severity of their dementia. The remaining eight were randomly assigned either to the control activity (gardening) or the MSE activity. An independent occupational therapist placed their names in envelopes, to ensure anonymity, then equally distributed the envelopes to each group. Of the eight participants who started the pilot phase, two were discharged to nursing homes outside of the region soon after starting the study (Figure 10).

Figure 10: CONSORT diagram reporting progress of participants through the pilot study

```
                    ┌─────────────────────────────┐
                    │  Eligible patients N = 8      │
                    │  Randomized = 8               │
                    └─────────────────────────────┘
                                   │
                    ┌──────────────┴──────────────┐
                    │                              │
      ┌──────────────────────────┐   ┌──────────────────────────┐
      │  Multi-sensory stimulation│   │  Control activity         │
      │  n = 4                    │   │  n = 4                    │
      └──────────────────────────┘   └──────────────────────────┘
                    │                              │
      ┌──────────────────────────┐   ┌──────────────────────────┐
      │  Completed trial n = 3    │   │  Completed trial n = 3    │
      │  Discharged before        │   │  Discharged before        │
      │  completion = 1           │   │  completion =1            │
      │                           │   │                           │
      └──────────────────────────┘   └──────────────────────────┘
                    │                              │
      ┌──────────────────────────┐   ┌──────────────────────────┐
      │  Included in analysis n = 3│   │  Included in analysis n = 3│
      └──────────────────────────┘   └──────────────────────────┘
```

.
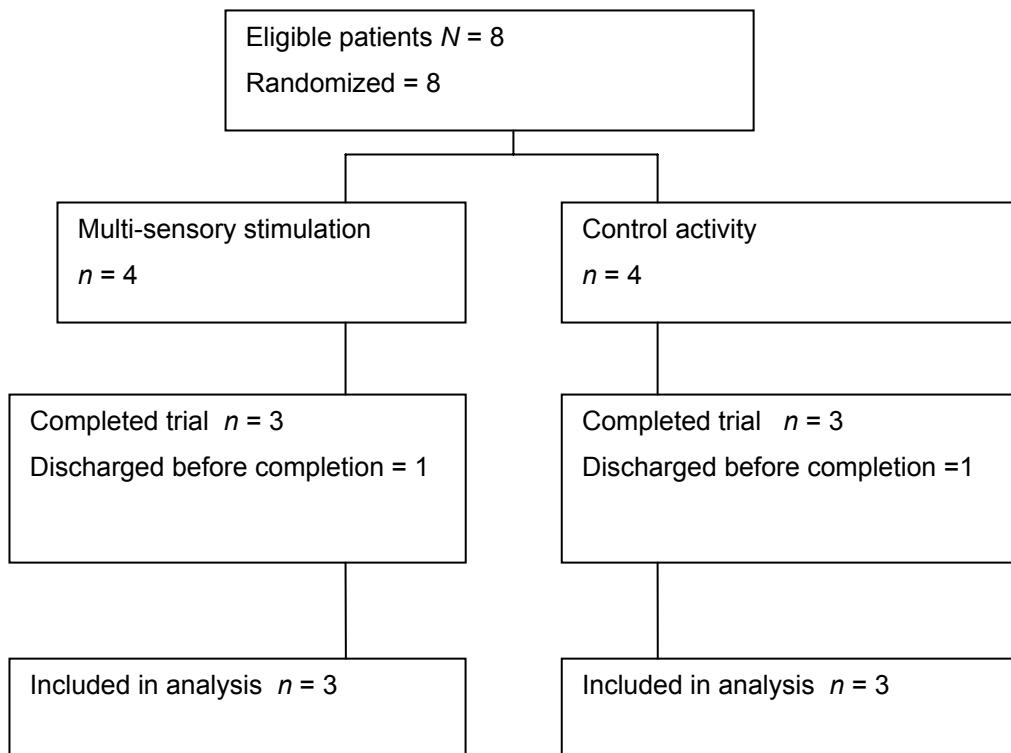
Consent was obtained by approaching the participant, with their key worker present, to explain what the study was for and what their involvement would entail. If it was clear that the participant was aware of what was required of them, they were asked to sign the consent form. Awareness of consent was confirmed by the key worker. Of the eight people identified, five were able to give informed consent. All participants' relatives were informed of the study and given information sheets. The relatives of the remaining three people who were unable to give informed consent were approached and assent was obtained.

7.2.2   Procedure

The eight participants were allocated to two assessment periods for ease of study management. Four participants were assessed during week one, followed by two consecutive weeks of intervention. The second group of four participants were baseline assessed three weeks later followed by two weeks of intervention. It was hoped that during the two weeks of intervention each participant would attend their selected activity three times each week. The planned research period for each participant was estimated at three weeks for the pilot study (figure 11)

Figure 11: Study outline

```
┌──────────────┐     ┌────────────┐        ┌────────────┐     ┌──────────────┐
│ Baseline     │     │            │      ┌─│    MSE     │───┐ │ Post activity│
│ Assessment   │────▶│  Random    │─────▶└─────────────┘   └▶│ Assessment   │
│ Period       │     │  Allocation│      ┌─────────────┐   ┌▶│ Period       │
└──────────────┘     └────────────┘      └▶│  Activity  │───┘ └──────────────┘
┌─────────────────────────────────────────────────────────────────────────────┐
│  Week 1                                        Weeks 2 – 3                     │
└─────────────────────────────────────────────────────────────────────────────┘
```
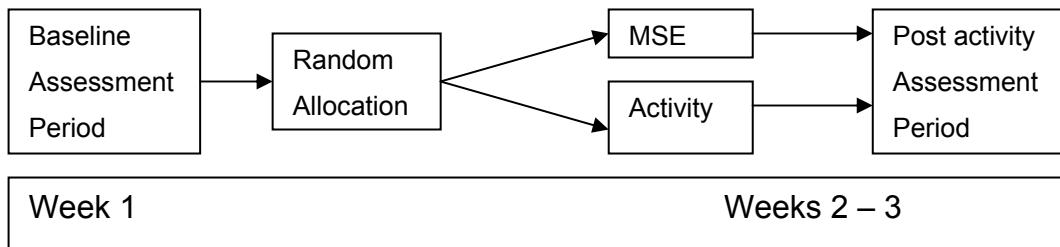
Note. MSE – Multi-sensory environment

7.2.3   Assessment period

Baseline - Each participant was assessed by the researcher. The SMMSE and GBS scale were used to describe the participant's level of dementia and to describe their signs and symptoms. The PAL Occupational Profiling tool was used to identify the most suitable format for the MSE and activity groups. The Adult Sensory Profile was used to identify the sensory preferences of the individual. Activity performance was assessed using the AMPS assessment and the Neurobehavioural Rating Scale. Following the baseline assessment period and random allocation each participant was assessed pre and post activity.

Pre and post session assessment – Each participant was again assessed by the researcher using the AMPS and the Neurobehavioural Rating Scale. Responses to the MSE were recorded by the Occupational Therapist running the intervention group using the Interact Rating Scale. The intervention period continued for two weeks during the pilot phase. On completion of the intervention period (two weeks) each participant was assessed using the follow up assessment tools.

Follow up assessment – During the final assessment period each participant was assessed again using the AMPS assessment, the Neurobehavioural Rating Scale.and the Adult Sensory Profile. The assessment tools used have been described in Chapter 6.

7.3   Results

The results will be discussed using the framework identified in the pilot study aims.

7.3.1   Suitability of the assessment tools

Overall the assessments selected were easy to administer and were acceptable to the participants. However, methodological challenges such as motivating the participant to take part in the assessment and to concentrate sufficiently to complete the assessment were identified. Further details of strategies used to manage these problems are listed below.

7.3.2   Methodological challenges not anticipated in the initial research design

The pilot study raised several methodological and ethical considerations that needed to be considered in order to refine the main study. Each issue will be considered in the order that they occurred.

Therapist compromising blinding.

During the initial design of the study it was recognised that participants may give away which group they had attended, therefore, compromising the blinding of the study. Participants were asked by their nurse / therapists not to discuss which activity they had attended. This proposal worked during the pilot study. However, little consideration was given to reminding the therapists running the activity groups. Consequently one therapist informed the researcher of the success she had with a participant in the activity before the researcher had time to stop her. In discussion with the occupational therapists running the interventions it was decided the solution would be to leave a notice on the door reminding the occupational therapists of the blinding procedure. During the remainder of the pilot study this system was effective.

Initiating AMPS assessment procedure.

Some difficulties arose in encouraging participants to take part in the AMPS assessment activity. AMPS activities were selected to reflect the time of day at which the activity would be taking place. Eating a meal (coded P1) was assessed at breakfast time when the participants would be expecting to eat. This maintained some ecological validity in terms of appropriateness of the assessment and in the participant's commitment to the activity. Post AMPS activities were harder to place in context due to their timing and the range of appropriate activities for that time of day. Pouring a cold beverage (coded A1) appeared to be the most appropriate activity but the

researcher found that more encouragement to take part in the activity was required which compromised the robustness of the assessment. Possible solutions included incorporating a series of prompts which would be allowed in order to encourage participation in the AMPS activity, or, recognition that failure to participate in the AMPS assessment activity constituted a fail, and that in itself was an indicator of the effects of the intervention on the individual. It was decided that contact with the AMPS organisation may clarify the use of failure to complete as part of an AMPS assessment and help inform the researcher of the best solution. The AMPS organisation suggested a failure to complete the assessment be recorded as missing data. Therefore, it was decided that if a participant refused to participate in the AMPS assessment following one prompt a missing data code would be given for an incomplete assessment.

Problems maintaining participant involvement throughout the study period

Due to the nature of the dementia process and the ages of the participants, periods of ill health were considered to be serious threats to gaining sufficient data. It was decided that the use of 'Intention to treat' analysis in the main study would accommodate this problem. Intention to treat means both groups (MSE and control) would be included in analysis regardless of whether all 12 sessions were completed.

Sustaining same nurse / therapist throughout the assessment / intervention period

The initial protocol stated that the same nurse / therapist would be used in order to capitalise on the therapeutic relationships already established. However the pilot phase revealed that, at times, this was unfeasible due to annual leave, sick leave and occasionally, staffing shortages. This resulted in several activity groups being cancelled. In light of such problems it was decided to approach the ethics committee to ask permission to include a practitioner who could step in to cover staffing gaps where necessary. One 3rd year Occupational Therapy student was recruited. Training and supervision was provided by the researcher. This idea was keenly accepted by the therapists on site as a way of maintaining regular contact with the participants, as well as keeping to the study protocol. The researcher submitted an ethics amendment form and followed up the requirements for an honorary contract. Whilst such an arrangement would address some of the problems experienced in the pilot, there may be other effects such as the loss of some of the benefits of using staff who are familiar with the participants, a reduction in skill level given the hospital based therapists have several years experience between them whereas the student has understandably limited experience.

7.3.3   Opportunity for therapy staff to practice following the research protocol

Staff involved in the research found that they had not anticipated the time needed to run the activity sessions nor had they considered the problems of ensuring the researcher remained blinded to the activity attended by the participant. Running a pilot allowed them to identify feasible timeframes to prepare and run the activity sessions. It also allowed them to practice how best to warn participants not to reveal which group they attended. The staff requested that the activity sessions be run first thing in the morning to capitalise on alertness of the participants and to fit in with established therapy programmes. This also allowed the researcher to use eating tasks from the AMPS assessment during breakfast time.

7.3.4   Length of time required for data collection procedures

The pilot study also allowed the researcher to calculate how much time was needed for pre and post assessment. It was important that the assessment time was kept to a minimum in order to maintain the concentration and co-operation of the participant. Assessment time was calculated to be fifteen minutes pre-activity, a short break of five minutes before the activity commenced was also scheduled.

7.3.5   Sample size and power calculations

Primarily, descriptive analysis was used due to the limited number of participants in the pilot study. As described in Chapter 5, power calculations were conducted on the AMPS pilot results and were compared with power calculations from other suitable published studies using the AMPS.

As participants presented with fluctuating mental and physical health, sample size calculations were conducted on an intention to treat basis. One participant had missing data due to their refusal to take part in the pre-activity assessment; however, they willingly took part in all subsequent assessments. Eight participants took part in the pilot study but only six completed all sessions (Table 13). Power calculations are presented in Chapter 5.3.3.

Table 13: Description of participants in the pilot study

Demographic characteristics		*M* (*SD*), range
Participants (pilot phase)		8
Gender (Male : Female)		5 : 3
Age (years)		83.50 (11.85), 61 - 94
SMMSE		9.83 (5.00), 4 - 15
GBS		
	Intellect	44.17 (10.30), 32 – 63
	Emotion	8.67 (4.37), 6 – 17
	ADL	14.00 (8.79), 8 - 31
AMPS		
	Motor	0.88 (0.71), -.42 – 1.68
	Process	0.13 (0.84), -1.55 - .68
PAL		
	Planned activity level	1
	Exploratory activity level	1
	Sensory activity level	5
	Reflex activity level	1
Sensory profile		
	Low registration	0
	Sensory seeking	5
	Sensory sensitive	0
	Sensation avoidance	3

Note. SMMSE – Standardised Mini-mental State Examination. GBS – Gottfries, Bråne and Steen scale. ADL – Activities of Daily Living. PAL - Pool Activitiy Levels.

Results of the AMPS are presented here and were also used to calculate power (see Chapter 4; Table 2).

7.4   Summary of key issues covered during the pilot phase

A number of key issues were identified during the pilot phase. The process of applying to Ethics committees, Trust Research and Development committees required organisational communication skills; particularly in answering explicit questions about the design of the study. Alongside this, a valid argument was required to justify why routine guidelines for consent forms were unsuitable for the participant group. The Ethics committee questioned why national guidelines were not followed explicitly, but accepted the argument that the format suggested would not be suitable for people with severe dementia given their limited cognitive abilities.

The pilot phase also allowed the opportunity to trial the research design to ensure that all components of a randomised controlled study had been considered. Although many of the problems had been anticipated, one or two were not expected. As noted, a particular problem was that of maintaining blindness with the nurse or therapist, who found it hard not to divulge information about the intervention they had just facilitated.

The next chapter will present the results of the main study under each of the research questions.

Chapter 8 Efficacy of intervention group on older people with dementia

This chapter presents the findings of the following research questions.

1. To what extent, if any, do MSEs influence functional performance?

2. To what extent, if any, does the control activity (gardening) influence functional performance?

3. In what way are mood and behaviour affected by MSEs compared with the control activity (gardening)?

4. To what extent is the sensory profile of the individual associated with the response to the MSE compared to the control activity (gardening)?

Initially, demographic and clinical characteristics of the participants will be described. The results will then be presented under each research question.

8.1   Demographic and clinical characteristics

The researcher intended to recruit 50 participants (see Chapter 5 Methodology). However, due to changes in service provision this was not achieved. Therefore, the results should therefore be considered as interim analyses, with discussion regarding the reasons for insufficient numbers in Chapter 9.

8.1.1   Randomisation

Fifty-four participants were identified for inclusion in the study (Figure 12) of whom 31 were considered suitable following baseline assessments. One participant completed baseline assessment but became too unwell to continue in the study. Seventeen participants were randomised to receive the MSE intervention and 13 to receive the control intervention.

Figure 12: CONSORT Diagram showing the passage of participants through the study

Number of participants referred to study $n = 54$

Reasons for exclusion
Discharged before start of study $n = 7$
Too unwell to start study $n = 8$
Refused to participate $n = 8$

Eligible participants $n = 31$

Reason for exclusion
Discharged $n = 1$

Number of participants randomised $n = 30$

MSE group baseline $n = 17$

Control group baseline $n = 13$

Completed trial to session 12 $n = 5$

Completed trial but not to session 12 (LTS) $n = 12$

Completed trial but not to session 12 (LTS) $n = 10$

Completed trial to session 12 $n = 3$

Reason for non-completion
Died $n = 2$
Refused to participate $n = 2$
Discharged $n = 8$

Reason for non-completion
Died $n = 1$
Refused to participate $n = 1$
Discharged $n = 8$

Completed to follow up $n = 5$

Completed to follow up $n = 3$

Note. MSE – Multi-sensory Environment. LTS – last treatment session.

All participants randomly assigned to the intervention or control group completed the baseline assessments and at least one session. Table 14 shows the number of participants completing each number of possible treatment sessions and follow up.

Table 14: Frequency scores for last assessment and last treatment session

Number of participants for whom this was the last assessment

Session	MSE n = 17	Control n = 13	Total n =30
3	3 (18%)	2 (15%)	5 (17%)
5	2 (12%)	2 (15%)	4 (13%)
6	1 (6%)	3 (23%)	4 (13%)
7	-	1 (8%)	1 (3%)
8	3 (18%)	-	3 (10%)
9	1 (6%)	-	1 (3%)
10	1 (6%)	-	1 (3%)
11	1 (6%)	1 (8%)	2 (7%)
12	-	-	-
Follow up	6 (35%)	2 (15%)	8 (27%)

Number of participants completing this session

Session	MSE n = 17	Control n = 13	Total n =30
1 - 3	17 (100%)	13 (100%)	30 (100%)
5	15 (88%)	11 (85%)	26 (87%)
6	13 (76%)	9 (69%)	22 (73%)
7	-	6 (46%)	6 (20%)
8	12 (71%)	-	12 (40%)
9	9 (53%)	-	9 (30%)
10	8 (47%)	-	8 (27%)
11	7 (41%)	5 (39%)	12 (40%)
12	6 (35%)	4 (31%)	10 (33%)
Follow up	6 (35%)	2 (15%)	8 (27%)

Note. Some participants refused assessment but took part in their allocated intervention.

8.1.2 Description of participants

Table 15 contains the descriptive details of the two groups. There were no significant differences between the two groups in age, distribution of gender, of recruitment sites or of diagnosis, in SMMSE, PAL occupational profiling, GBS, or in AMPS scores: age, t (28) = - 1.03, p = .314; gender distribution, χ^2 (1, N = 30) = 3.83, p = .050; distribution of recruitment sites, χ^2 (3, N = 30) = 0.56, p =1.0, Fishers Exact test; diagnosis, χ^2 (2, N = 30) = 1.35, p = .811, Fishers Exact test; SMMSE score, t (28) = -0.56, p = .579; distribution of sensory profile, χ^2 (3, N = 30) = 3.90, p = .275, Fisher's Exact test; PAL occupational profiling, χ^2 (3, N = 30) = 4.93, p =.189 Fisher's Exact test; GBS score, intellect, U ($N1$ = 17, $N2$ = 13) = 75.00, p = .137, emotion, t (28) = 1.17, p = .252, ADL, U ($N1$ = 17, $N2$ = 13) = 95.00, p = .390; AMPS motor, t (28) = -0.47, p = .641, AMPS process, t (28) = -1.04, p = .308; NRS, t (28) = 1.49, p = .148, equal variances not assumed.

Table 15: Demographic and clinical characteristics

		MSE *n* = 17	Control *n* = 13
Age (years)		80.00 (7.2), 60 - 91	83.08 (6), 70 - 95
Gender (Male : Female)		7:10	10:3
Recruitment site	Day hospital	4 (23%)	4 (31%)
	Continuing care	6 (35%)	4 (31%)
	Nursing Home	2 (12%)	1 (8%)
	Assessment ward	5 (29%)	4 (31%)
Diagnosis	Alzheimer's disease	13 (77%)	9 (69%)
	Vascular dementia	4 (23%)	3 (23%)
	Lewy Body disease	0 (0%)	1 (8%)
SMMSE		9.53 (5.08), 1 - 17	10.54 (4.61), 4 - 17
Sensory profile	Low registration	6 (35%)	4 (31%)
	Sensation seeking	8 (47%)	3 (23%)
	Sensory sensitive	1 (6%)	4 (31%)
	Sensation avoiding	2 (12%)	2 (15%)
PAL	Planned level	3 (18%)	4 (31%)
	Exploratory level	5 (29%)	4 (31%)
	Sensory level	2 (12%)	4 (31%)
	Reflex level	7 (41%)	1 (8%)
GBS	Intellect	43.88 (12.73), 26 – 62	33.77 (15.49), 11 – 63
	Emotional	7.12 (4.19), 1 – 17	5.15 (4.99), 0 – 17
	ADL	18.82 (12.19), 2 – 40	14.23 (10.86), 0 – 36

(Higher score = more severe impairment)

Note. SMMSE - Standardised Mini-Mental State Examination, < 14 = moderate to severe dementia;
PAL - Pool Activity Levels; GBS - Gottfries Bråne Steen scale; ADL – Activities of Daily Living.

8.2　Effect of intervention on functional performance

This section will explore research questions 1 and 2. That is, to what extent functional performance is affected by the MSE and control activity.

8.2.1　Analysis of baseline to last treatment session

Analysis was carried out for AMPS motor scores. There was a significant main effect of intervention, $F(1,27) = 8.63$, $p = .007$. There was no significant interaction, $F < 1$, that is the intervention did not affect the groups differently, and no main effect of group, $F < 1$. Given the main effect of intervention, a paired comparison was undertaken. This revealed a weak trend for an effect of intervention on the MSE group from baseline to last treatment session, $t(16) = -2.8$, $p = .013$, even adjusting for multiple testing[5], but not on the control group, $t(11) = -1.5$, $p = .162$. Further more, there were no differences between groups at baseline, $t(28) = -0.5$, $p = .641$ or at last treatment session, $t(27) = -0.1$, $p = .913$ (Table 16).

This analysis was repeated for AMPS process scores. There was a significant main effect of intervention, $F(1,27) = 4.56$, $p = .042$. Again, no significant interaction, $F < 1$, and no main effect of group, $F < 1$ were found. However, a paired comparison revealed no effect of intervention either for the MSE group or the control group, $t(16) = -1.9$, $p = .067$, $t(11) = -1.2$, $p = .261$ respectively. There were no differences between groups at baseline, $t(28) = -1.0$, $p = .308$ or at last treatment session, $t(25.5) = -0.5$, $p = .593$, equal variances not assumed (Table 16).

8.2.2　Analysis of baseline to session 3 and session 6

Given that other studies using MSEs had used fewer intervention sessions (Baillon et al., 2004; Baker et al., 1997; Kragt, Holtkamp, van Dongen, van Rossum, & Salentijn, 1997) 3, 3 and 8 sessions respectively, and the shortened hospital admissions which have been implemented as part of changes in service provision, variable end points were analysed. The data revealed that the majority of participants reached session 3 and 70% achieved 6 sessions

The number of participants who improved from baseline (session 1) to session 3 on the AMPS assessment was explored using a mixed ANOVA of group (MSE, control) by session (baseline, session 3) for AMPS motor scores (see Table 16). There was no significant main effect of intervention, $F(1,27) = 2.99$, $p = .095$, no significant interaction, and no main effect of group, both

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[5] Bonferroni Correction to account for 2 comparisons within group and 2 between group on same data set, thus acceptable p value becomes $p < .0125$

F < 1. This analysis was repeated for AMPS process scores. There was no significant main effect of intervention, no significant interaction, and no main effect of group, all *F* < 1.

The number of participants who improved from baseline (session 1) to session 6 on the AMPS motor assessment was also explored (see Table 16). There was a significant main effect of intervention, $F(1,19) = 9.67$, $p < .006$. There was a significant interaction between intervention type and group, $F(1,19) = 7.07$, $p = .016$, but there was no main effect of group, *F* < 1. The interaction term was decomposed to check where the intervention effect occurred. A significant effect of intervention was found for the MSE group from baseline to session 6, $t(11) = -5.8$, $p < .001$, even adjusting for multiple testing, but not for the control group, $t(8) = -0.2$, $p = .816$. Furthermore, there were no differences between groups at baseline, $t(28) = -0.5$, $p = .641$ or at session 6, $t(19) = 0.8$, $p = .443$.

This analysis was repeated for AMPS process scores. There was no significant main effect of intervention, $F(1, 19) = 3.76$, $p = .069$. There was a significant interaction, $F(1,19) = 11.90$, $p < .003$, but there was no main effect of group, *F* < 1. The interaction term was decomposed. There was a significant effect of intervention in the MSE group, $t(11) = -3.7$, $p = .004$, even adjusting for multiple testing, but not in the control group, $t(8) = 1.2$, $p = .254$. There were no differences between groups at baseline, $t(28) = -1.0$, $p = .308$, or at session 6, $t(19) = 0.8$, $p = .439$.

Inferential analysis of baseline to session 12 and baseline to follow-up was not carried out due to the small number of participants who completed to session 12 ($n = 10$). However, summary statistics are available in Appendix 7.

Table 16: AMPS scores for Baseline, last treatment Session, Session 3 and Session 6.

M (*SD*), range	MSE	Control (Gardening)
Baseline	*n* =17	*n* = 12
Motor	0.32 (1.22), -3.00 - +1.69	0.51 (0.89), -0.54 - +2.04
Process	-0.44 (1.10), -3.00 - +0.70	-0.09 (0.61), -1.55 - +0.80
Last treatment session	*n* = 17	*n* = 12
Motor	0.98 (1.41), -1.66 - +2.89	1.03 (1.16), -1.20 - +2.99
Process	-0.02 (1.21), -3.00 - +1.17	0.17 (0.65), -1.42 - +0.83
Session 3	*n* = 17	*n* = 12
Motor	0.84 (1.58), -3.00 - +3.23	0.58 (1.15), -1.66 – +2.79
Process	-0.20 (1.07), -3.00 - +1.22	-0.10 (1.06), -3.00 - +0.91
Session 6	*n* = 12	*n* = 9
Motor	1.27 (1.12),-1.08 - +2.67	0.87 (1.54), -1.27 - +3.00
Process	0.11 (0.92), -1.20 - +1.60	-0.17 (0.64), -1.26 - +0.69

Note. AMPS - Assessment of Motor and Process Skills.

8.2.3   Sessional analysis

Sessional analysis was conducted to explore whether a benefit may be gained after each session or over a period of sessions. The effect of each session, across individual participants was explored first.

8.2.3.1 The effect of each session on AMPS motor scores across participants

To explore the effect of each session on AMPS motor scores the mean change (delta) scores across participants was calculated for each session, for each intervention. A positive score indicates an improvement in motor performance. A delta score greater than or equal to +0.5 logits indicates significant improvement. Figure 13 shows mean delta scores over the 12 sessions for the MSE and control groups.

Figure 13: Mean delta AMPS motor scores over 12 sessions for treatment groups
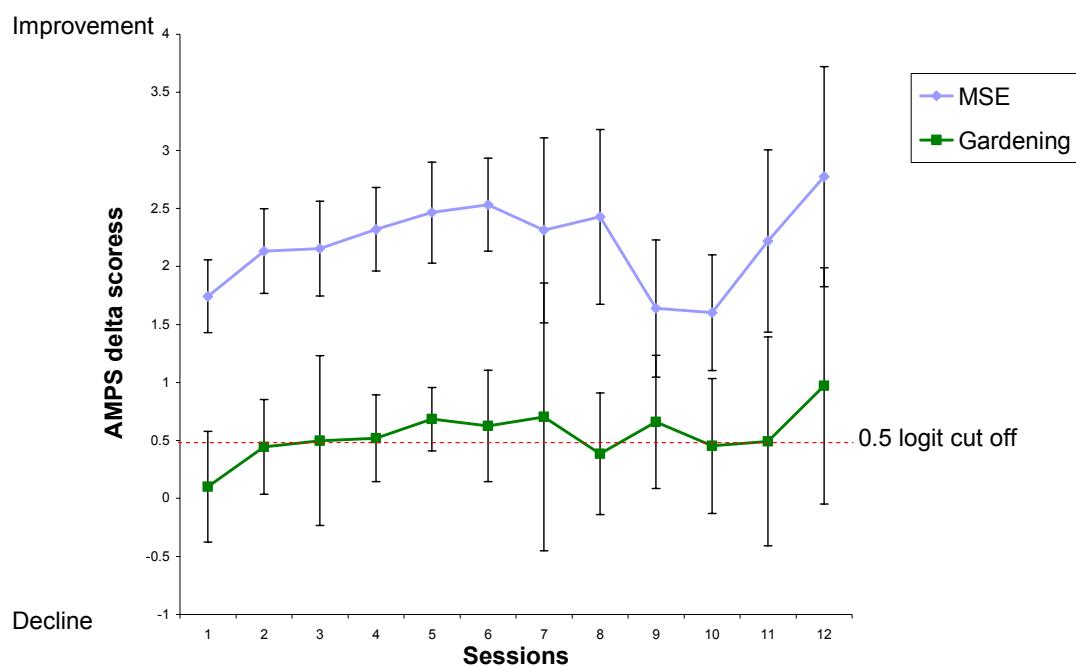
Note. Error bars = 95% Confidence intervals. Different numbers of participants are entered into the mean score recorded for each session.

This figure shows that the majority of MSE participants improved by 0.5 logits or more after each session. Improvements amongst the control group were more variable and closer to the 0.5 logit cut-off with only three overlapping confidence intervals (CI) between the two groups.

8.2.3.2 The effect of each session on AMPS process scores across participants

To explore the effect of each session on AMPS process scores mean delta scores were calculated. A positive score indicates an improvement in process performance. As reported for motor scores, a delta score greater than or equal to +0.5 logits indicates significant improvement. Figure 14 shows mean delta scores over the 12 sessions for both the MSE and control groups.

Figure 14: Mean delta AMPS process scores over 12 sessions for treatment groups
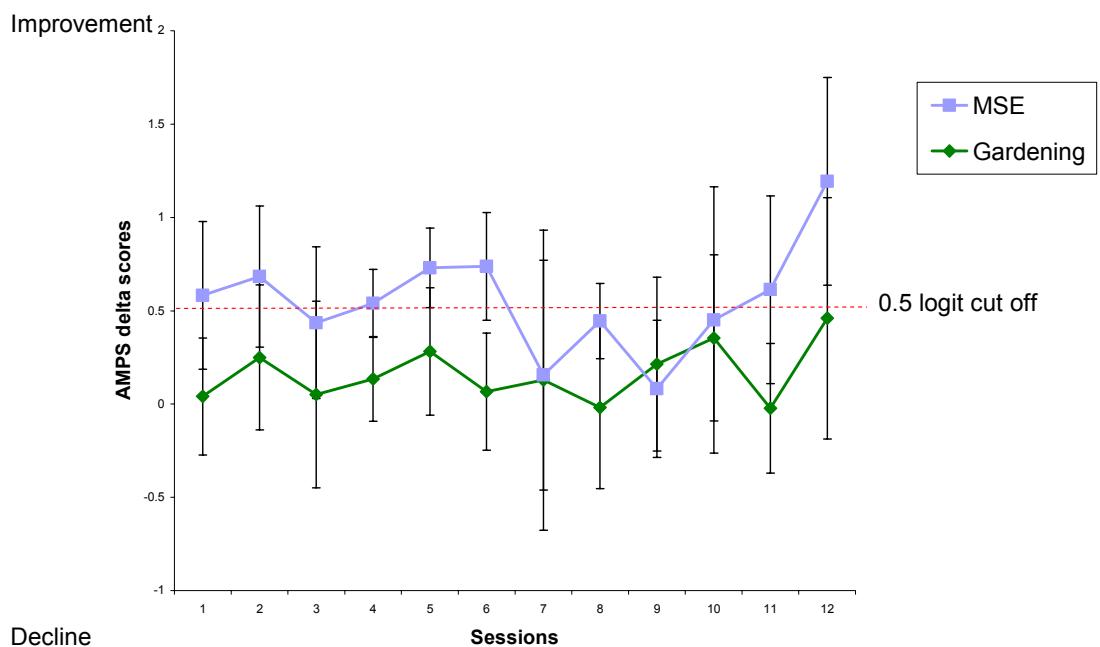
Note. Error bars = 95% Confidence intervals. Different numbers of participants are entered into the mean score recorded for each session.

This figure reveals that improvement in logit scores across the two groups was more variable, with the majority of the control group falling below 0.5 logit improvement and no clear pattern of result for the MSE group. Furthermore, the overlap in CIs suggests no difference between the groups in sessional outcome.

8.2.3.3 Number of sessions for which improvement was made

Next, the effect of the interventions over a period of sessions was explored by examining the mean percentage sessions in which a participant improved. For example, if a participant attended five sessions and improved by ≥ 0.5 logits on four of them then the percentage of sessions in which improvement was made was 80. Figure 15 shows the mean percentage of sessions for which an improvement in motor and process skills, ≥ 0.5, was achieved in each group.

Figure 15: Percentage of sessions for which a participant made an improvement ≥ 0.5 logits in AMPS motor and process scores
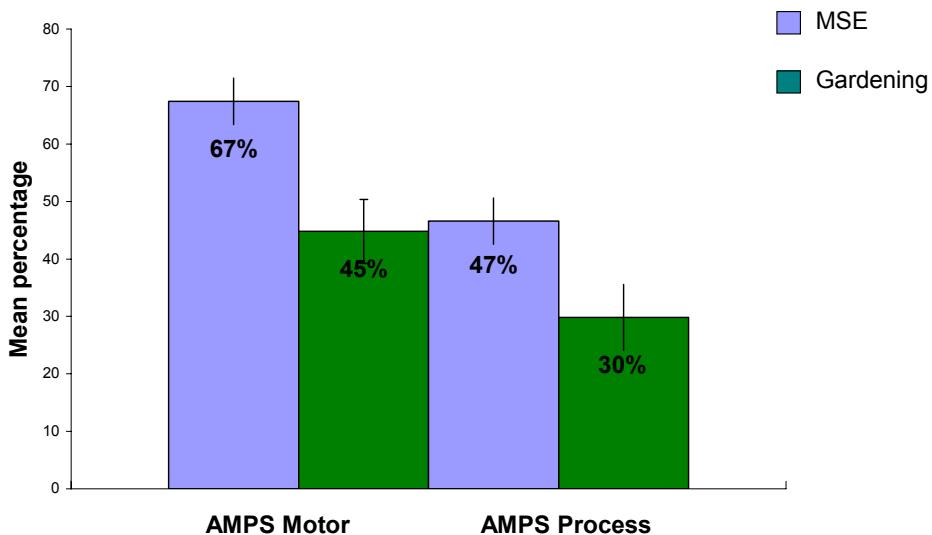
Note. Error bars = Standard errors of mean percentages.

A t-test was used to explore group differences in the percentage of sessions for which an improvement was made. There were significantly more sessions in which improvement was made in motor performance in the MSE group (M = 67.39, SD = 24.61) compared with the control group (M = 44.80, SD = 29.66), t (28) = 2.28, p = .030. There was no statistical difference between the MSE (M = 46.55, SD = 24.64) and control group (M = 29.82, SD = 30.63) for process scores, t (28) = 1.66, p = .108.

This analysis was repeated using logit scores ≥ 0.3 as this score has been proposed to represent clinically significant change (Fisher, 2003). Figure 16 shows the percentage of sessions for which an improvement in motor and process skills was achieved.

Figure 16: Percentage of sessions for which a participant made an improvement ≥ 0.3 logits
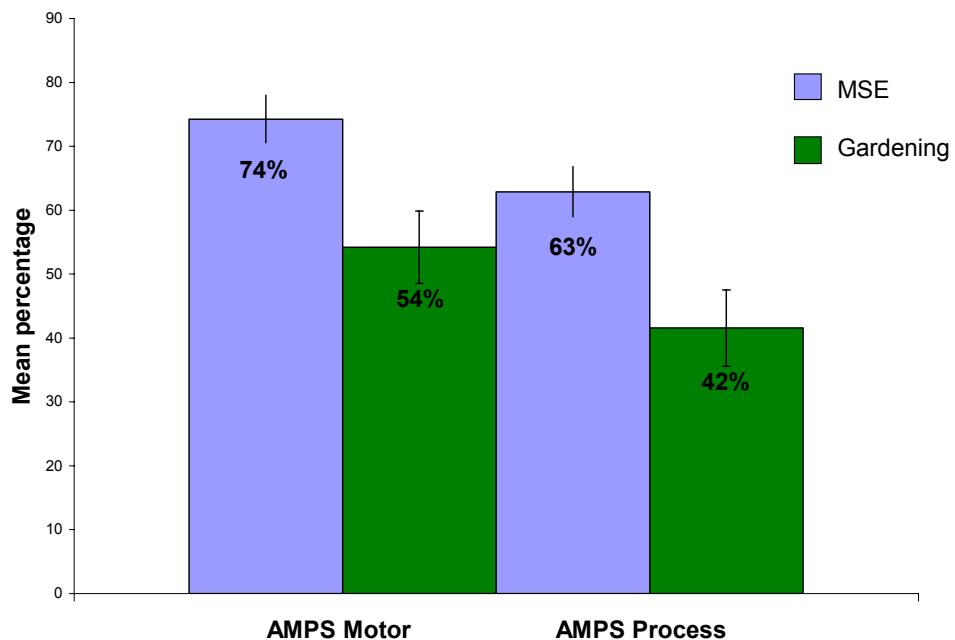
Note. Error bars = Standard errors of mean percentages.

There were significantly more sessions for which improvement in motor performance was made in the MSE group (M = 74.26, SD = 22.77) compared with the control group (M = 54.22, SD = 30.33), t (30) = 2.1, p = .046. This outcome was repeated with the process scores, MSE group (M = 62.89, SD = 23.95) compared with the control group (M = 41.55, SD = 32.01), t (30) = 2.1, p = .048. Despite these differences, it was also noteworthy that the control group improved significantly in over half of their sessions.

8.3   Effect of MSEs on mood and behaviour

This section considers question 3. That is in what way are mood and behaviour affected by multi-sensory environments compared with the control activity group?

8.3.1   Analysis of baseline to last treatment session

Firstly, the number of participants who improved from baseline (session 1) to last treatment session on the NRS was explored. There was a significant main effect of intervention, $F_{(1,28)} = 23.24$, $p < .001$, but no interaction, $F_{(1,28)} = 2.16$, $p = .153$, and no effect of group, $F < 1$. Given the main effect of intervention, a paired comparison was undertaken. This revealed an effect of intervention on the MSE group from baseline to last treatment session, $t_{(16)} = 3.4$, $p = .003$, and on the control group, $t_{(12)} = 3.6$, $p = .004$ even adjusting for multiple testing. Further more, there were no differences between groups at baseline, $t_{(27.3)} = 1.5$, $p = .148$, equal variances not assumed, or at last treatment session, $t_{(28)} = 1.4$, $p = .184$.

8.3.2   Analysis of baseline to session 3 and to session 6

Next, the number of participants who improved from baseline (session 1) to session 3 on the NRS was explored (see Table 17).There was a significant main effect of intervention $F_{(1,27)} = 27.12$, $p < .001$, but no interaction, $F_{(1,27)} = 2.64$, $p = .116$, and no main effect of group, $F < 1$. Paired comparisons revealed an effect of intervention on the MSE group from baseline to session 3, $t_{(16)} = 4.9$, $p < .001$, even adjusting for multiple testing, but the significant control group difference did not survive a Bonferroni correction, $t_{(11)} = 2.7$, $p = .021$, There were no differences between groups at baseline, $t_{(27.3)} = 1.5$, $p = .148$, equal variances not assumed, or at session 3, $t_{(27)} = 0.2$, $p = .812$.

The number of participants who improved from baseline (session 1) to session 6 on the NRS was explored (see Table 17). There was a significant main effect of intervention $F_{(1,19)} = 24.98$, $p < .001$, no interaction, $F_{(1,19)} = 1.30$, $p = .268$, and no effect of group, $F < 1$. Paired comparisons revealed an effect of intervention on the MSE group from baseline to last treatment session, $t_{(11)} = 4.5$, $p = .001$, and for the control group, $t_{(8)} = 2.7$, $p = . 027$. As in the baseline to session 3 comparison, the latter was not significant if one accounted for multiple comparisons. There were no differences between groups at baseline, $t_{(27.3)} = 1.5$, $p = .148$, equal variances not assumed, or at session 6, $t_{(19)} = 0.2$, $p = .860$.

Inferential analysis of baseline to session 12 and baseline to follow-up was not carried out due to the small number of participants who completed to session 12 (n = 10). However, summary statistics are available in Appendix 8

Table 17: NRS scores for baseline, last treatment session, session 3 and session 6

M (*SD*), range	MSE	Control (Gardening)
Baseline	*n* =17 38.41 (18.31), 12 - 69	*n* = 13 30.23 (11.71), 8 - 51
Last treatment session	*n* = 17 28.82 (18.99), 8 - 66	*n* = 13 20.92 (9.82), 10 - 44
Session 3	*n* = 17 22.53 (18.02), 2 - 70	*n* = 12 21.08 (12.43), 6 - 47
Session 6	*n* = 12 20.00 (18.48), 5 - 63	*n* = 9 18.78 (9.90), 9 - 39

Note. NRS Neurobehavioural Rating Scale; a higher NRS score indicates deterioration in mood and behaviour.

8.3.3   Sessional analysis

8.3.3.1 Effect of each session on NRS scores

To explore the effect of each session on NRS scores, mean change (delta) scores were calculated. A negative score indicates an improvement in mood and behaviour. A delta score greater than or equal to -1.3 was taken to indicate significant improvement (McCauley et al., 2001). Figure 17 shows mean delta scores over the 12 sessions for both MSE group and the control group.

Figure 17: Mean delta NRS scores over 12 sessions
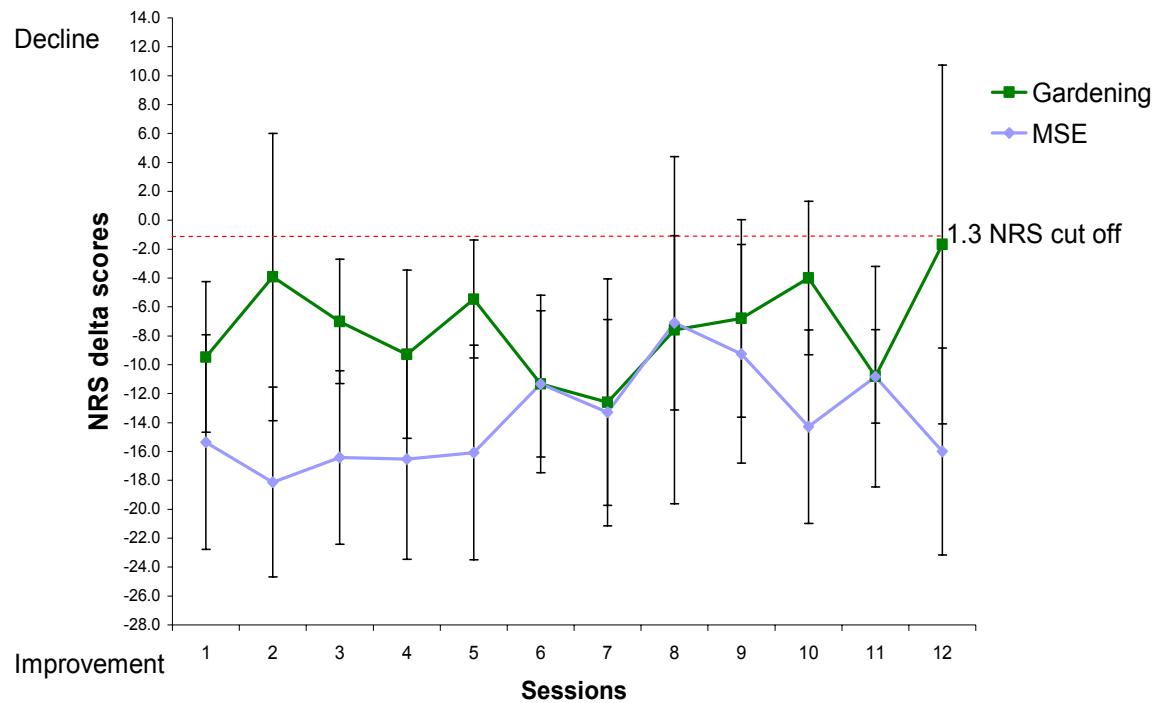
Note. Error bars = 95% Confidence intervals. Different numbers of participants are entered into the mean score recorded for each session.

The graph shows a drop in scores in all sessions for both groups, suggesting mood and behaviour improved for all participants.

8.3.3.2 Number of sessions for which improvement occurred

This was investigated by looking at the mean percentage of sessions for which a participant improved in mood and behaviour, defined as a change ≥1.3 (McCauley et al., 2001). Figure 18 shows the mean percentage of sessions for which an improvement in mood and behaviour was achieved.

Figure 18: Percentage of sessions for which a participant made an improvement ≥1.3 in NRS scores.
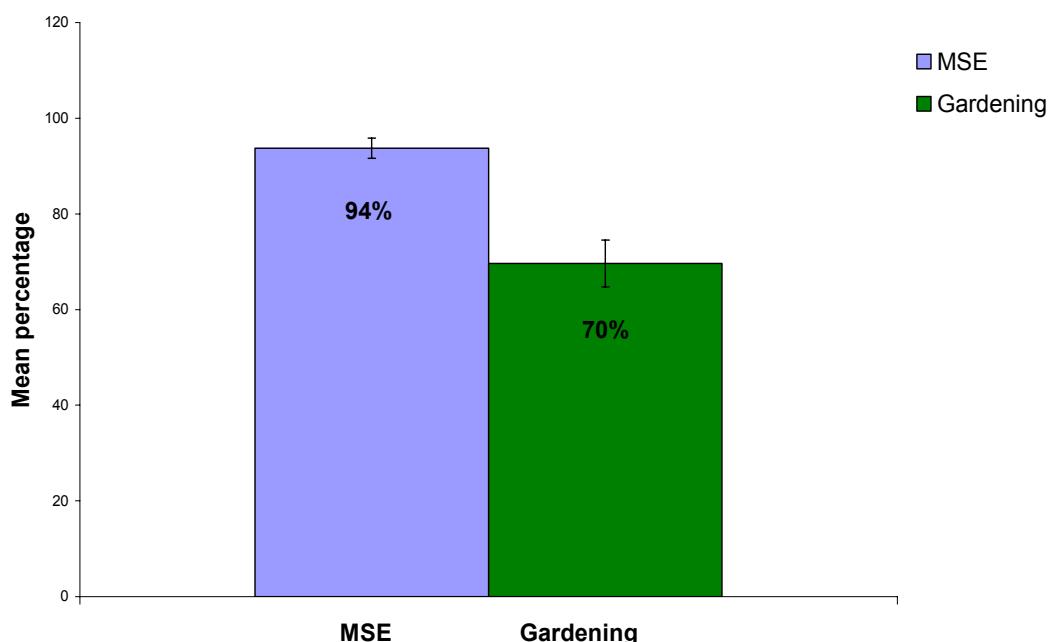
Note. Error bars = Standard errors of mean percentages.

There were significantly more sessions in which improvement in mood and behaviour occurred in the MSE group (*M* = 93.72, *SD* = 12.74) compared with the control group (*M* = 69.61, *SD* = 26.33), *t* (16.3) = 3.0, *p* = .008, albeit both groups showed improvement.

8.4 The association of an individual's sensory profile in response to activity

This section will explore research question 4. That is, to what extent is the sensory profile of the individual associated with the response to the MSE compared to the control activity?

8.4.1 Association between sensory profile, improvers and non-improvers

As the AMPS score was used as the primary outcome measure, the percentage of sessions for which improvement occurred on AMPS motor and process scores was compared against the sensory quadrants that constitute a sensory profile. This is illustrated by the cross tabulation table below (Table 18).

Table 18: Percentage of sessions for which improvement was made on AMPS motor and process scores within each sensory quadrant

		Sensory profile quadrants			
		Low registration	Sensation seeking	Sensory sensitivity	Sensation avoidance
MSE group					
AMPS motor		$n = 6$	$n = 8$	$n = 1$	$n = 2$
	Improvers	5 (83%)	1 (13%)	1(100%)	2 (50%)
	Non-improvers	1 (17%)	7 (88%)		2 (50%)
AMPS process		$n = 4$	$n = 8$	$n = 1$	$n = 2$
	Improvers	2 (50%)	2 (25%)		1 (50%)
	Non-improvers	2 (50%)	6 (75%)	1(100%)	1 (50%)
Control group					
AMPS motor		$n = 4$	$n = 3$	$n = 4$	$n = 2$
	Improvers	1 (25%)	2 (67%)	1 (25%)	2 (100%)
	Non-improvers	3 (75%)	1 (33%)	3 (75%)	
AMPS process		$n = 4$	$n = 3$	$n = 4$	$n = 2$
	Improvers	3 (75%)	1 (33%)	1 (25%)	
	Non-improvers	1 (25%)	2 (67%)	3 (75%)	2 (100%)

Note: Percentages may add up differently due to rounding.

There was no association between sensory quadrant and the distribution of participants who improved or not within the MSE group on AMPS process scores, χ^2 (2, N = 14) = 1.36, p = .778. Nor were there associations between AMPS process scores, χ^2 (3, N = 13) = 3.39, p = .450, or AMPS motor scores, χ^2 (2, N = 13) = 3.82, p = .364, Fisher's Exact Test in each case for the control participants. However, there was a significant association between sensory quadrants and the distribution of improvers and non-improvers in the MSE group on AMPS motor scores, χ^2 (3, N = 17) = 7.99, p = .017. That is more improvers fell within the low registration quadrant and more non-improvers fell within the sensation seeking quadrant.

This analysis was repeated with the NRS scores (see Table 19).

Table 19: Percentage of sessions for which improvement was made on NRS scores within each sensory quadrant

	Sensory profile quadrants			
	Low registration	Sensation seeking	Sensory sensitivity	Sensation avoidance
MSE group				
NRS	n = 4	n = 8	n = 0	n = 2
Improvers	3 (75%)	5 (63%)		2 (100%)
Non-improvers	1 (25%)	3 (38%)		
Control group				
NRS	n = 4	n = 3	n = 4	n = 2
Improvers	4 (100%)	2 (67%)	3 (75%)	1 (50%)
Non-improvers		1 (33%)	1 (25%)	1 (50%)

Note: Percentages may add up differently due to rounding.

There was no association between sensory quadrant and the distribution of improvers or non-improvers on the NRS scores within the MSE group, χ^2 (2, N = 14) = 0.98, p = 1.000, or within the control group, χ^2 (3, N = 13) = 2.63, p = .720, Fisher's Exact Tests reported.

8.5   Comments in the research log

A research log was kept for the duration of the study to record any incidences or events that occurred. The log was used to record any challenges to the blinding system, any untoward events

during the interventions and any major changes to the participants' medical or social management, including changes in medication.

A single blind system was used whereby the researcher was blind to the intervention allocation of each participant. However, given the difficulties of ensuring participants did not divulge intervention allocation, a research log was kept of any incidences recorded during the assessment period. This included any information given inadvertently by the participant or any suspicions of the researcher regarding intervention allocation. Any suspicions noted were compared with participant allocation once the allocation code had been broken. On completion of the study, no incidents had been noted; no participants had revealed their group allocation and of five suspicions noted only one proved accurate (muddy hands of a participant who had taken part in a gardening activity).

The key nurse or therapist was responsible for noting in the log any major change to medical or social management. During the study no significant changes were recorded.

8.6 Post-hoc analysis for sample size and power calculation using main study data

Initial sample size calculations for the main study were carried out using motor scores from the pilot data and published studies using the AMPS with older people with dementia (Doble et al., 1997; Nygard et al., 1993). As a result, the proposed sample size identified was 50 participants in total, 25 in each condition (see Chapter 4.3.3). Accordingly, pot-hoc power calculations were carried out, using the Power and Sample Size Programme (Version 2.1.31; Dupont, 1990), with the main study data to explore the power of the study at this point and to inform the future development of this study (see Chapter 9.5.1).

8.6.1 Sample size calculations using main study data

In total, 17 participants were recruited to the MSE condition and 12 to the control (gardening condition). Using the change values for the AMPS motor scores given in Table 20, this revealed power of 49% and 67% for the conditions, respectively (power for AMPS process scores also given in Table 20). Clearly, the current recruitment levels mean the study was underpowered. In order to calculate the number of participants needed to achieve 80% power, the difference between AMPS data at baseline (before session 1) and after last treatment session were also used to calculate a new sample size for which 80% power could be achieved (see Table 20).

Table 20: Difference between baseline and last treatment session for the MSE and control (gardening) group, with sample size

	MSE group *M*(*SD*), current power, required sample size per group	Control (gardening) group *M*(*SD*), current power, required sample size per group
Amps Motor	0.65(1.31), 49%, 34	0.77(1.03), 67%, 16
AMPS Process	-0.23(1.16), 12%, 197	0.04(0.63), 5%, 2067

Note. MSE – Multi-sensory environment; AMPS – Assessment of Motor and Process Skills.

The sample size for the MSE group motor skills was found to be 34 participants. The sample size for the control (gardening) group motor skills was found to be 16. The sample sizes for both groups' process skills were very large, which suggest that many participants would be needed to detect an effect, even if an effect were there to be detected. As the results so far have shown that motor skills improve following the MSE and control interventions it would be appropriate to use the AMPS motor scores to calculate how many more participants would be needed to find a significant effect in either intervention. Therefore, the higher figure of 34 in each group will be used as the sample size for the main study. So far 30 participants have been recruited, therefore, a further 38 participants will be recruited to complete the study. As the sample size was not achieved within a reasonable timeframe for a PhD (over two years full-time data collection), it is proposed that the data collection continues until an appropriate sample size has been achieved. Discussion regarding the reasons for failure to achieve the proposed sample size is included in Chapter 9.

8.7   Summary

The results from each of the research questions can be summarised thus.

The analysis of AMPS scores from baseline to last treatment session revealed a significant improvement in motor and process scores for both groups. Analysis of AMPS scores from baseline to sessions 3 revealed no significant change in either motor or process scores. Analysis of AMPS scores from baseline to sessions 6 revealed a significant improvement in motor and process scores for the MSE group only. However, this was following a stringent Bonferroni correction and there may be an effect in the control group in a properly powered study.

Analysis of AMPS delta scores for individual sessions revealed that all participants in the MSE group significantly improved in motor skills whereas just over half of the participants in the control group significantly improved in motor skills. Half of the participants in the MSE group significantly improved in process skills with only three participants in the control group significantly improved in process skills. However, the overlapping CIs suggest no difference between the groups in sessional outcome.

Analysis of the number of sessions for which an improvement was made revealed that there were significantly more sessions for which improvement in motor skills was made in the MSE group, compared with the control group. There was no significant difference between groups for process skills. When clinical significance was explored, there were significantly more sessions for which improvement in motor and process skills were made in the MSE group, compared with the control group.

Analysis of NRS scores from baseline to last treatment session revealed that participants significantly improved in mood and behaviour in both groups. Comparisons between session 3 and session 6 revealed significant improvements in both interventions. However, those of the control (gardening) group were no longer significant following adjustment for multiple comparisons. This will be discussed further in Chapter 9.

NRS delta scores for individual sessions revealed that three quarters of all participants in both groups significantly improved in mood and behaviour. Analysis of the number of sessions for which an improvement was made revealed that there were significantly more sessions in which improvement occurred amongst the MSE group compared with the control group. However, both groups showed improvement with 9 out of 10 sessions resulting in improvement for the MSE group and 7 out of 10 sessions for the control group.

Analysis of the association of an individual's sensory profile with response to activity was explored and revealed there was a significant association between sensory quadrant and AMPS motor skills. That is, of those participants who were allocated to the MSE group, and fell within the low registration quadrant, 83% improved in motor skills, whilst, of those who fell within the sensation seeking quadrant, 88% did <u>not</u> improve in motor skills. There was no association between sensory quadrant and NRS scores for either group.

These results will be discussed with reference to the facilitation of activity in people with moderate to severe dementia, current clinical practice and service provision, and recommendations for further research.

Chapter 9 Discussion

9.1   Introduction

This study investigated the effects of multi-sensory environments (MSEs) and control activity on functional performance of older people with moderate to severe dementia. Changes in motor and process skills, mood, and behaviour were primary outcome measures. A secondary aim investigated how the sensory profile of the individual was associated with the response to the MSE compared to a control using the Adult Sensory Profile tool.

The complex problems presented in the 'final common pathway' of dementia were accommodated within the study design. Standardised assessments were used to collect data. Interventions were structured using the PAL (Pool Activity Level) occupational profiling tool. Support staff in environments that were familiar to the participants administered these interventions

Results will be discussed as they relate to each of the research questions with reference to theoretical frameworks to explain outcomes; these include the role of sensory processing in motor control, the effects of stimulus enhancement on performance, and environmental demands through sensoristasis. Guidelines will be suggested for how activity may be selected and facilitated with this client group in clinical practice. Finally, results will be considered in light of the strengths and limitations of the methodological design, with reference to plans for future research.

9.2 Statistical and clinical relevance of findings

9.2.1 Description of participants

There were no statistically significant differences between the groups with respect to age, gender distribution, diagnosis, cognitive state as measured by the SMMSE, functional performance as measured by AMPS or mood and behaviour. The equal distribution of men to women does not reflect the current population distribution of this age group of 85 men to 100 women aged 50 years and over (National Statistics, 2007). Population projections indicate that the gender ratio amongst older people will balance out in the future (National Statistics, 2007); therefore the distribution in this study is appropriate for drawing conclusions on future management of this population. The difference in gender distribution does not affect the study outcomes.

Participants were recruited from day hospitals, wards and nursing homes; this is representative of locations in which this client group is cared for. The diagnostic categories of the sample population reflected the distribution of these types of dementia in the population; the majority having a diagnosis of Alzheimer's disease or vascular dementia.

The overall description of the participants therefore indicates that they are representative of a population of people with moderate to severe dementia.

9.2.1 Effect of intervention on functional performance

The following research questions will be discussed:

> To what extent, if any, do MSEs influence functional performance?
> To what extent, if any, does the control activity (gardening) influence functional performance?

Analysis of AMPS motor scores from baseline to last treatment session revealed both groups' functional performance in activities of daily living improved significantly. This effect was greater in the MSE group compared to the control group using the stringent Bonferroni correction. This suggests that multi-sensory stimulation may have been more effective in improving motor performance than the control activity, but that both are beneficial. When this analysis was repeated with the AMPS process scores, a significant improvement for both groups was also found.

Data taken baseline to session 6 revealed a greater improvement for both motor and process scores in the MSE group. As the results for each session fluctuated over time, individual scores

were analysed. Changes in mean delta scores over 12 sessions were detected with nearly two thirds of participants in the MSE group showing an improvement in motor skills after each individual session compared with less than half of the participants in the control group. In comparison, not quite half of the MSE group and less than a third of the control group showed improvements in process scores, but these proportions did not differ significantly.

When clinical significance was explored (change of ≥ 0.3), nearly three-quarters of MSE sessions attended by participants resulted in significant improvement in motor skills in contrast with around half of control activity sessions. Two-thirds of MSE sessions attended by participants resulted in clinically significant improvement in process skills in contrast with around 4 in 10 of control activity sessions, and these proportions were significantly different. Jacobson, Follette & Revenstorf (1984) defined clinical significance as the extent to which the intervention moved the participant outside of the dysfunctional population. Normally, treatment effects are described on the basis of statistical analysis of two or more treatments (Jacobson & Truax, 1991) and whilst statistical significance suggests a robust response to treatment, it does not account for the individual variability of response to treatment which may be considered as pertinent to clinicians. As the majority of the MSE group showed clinically significant change after the intervention, it would seem appropriate to accept this clinically significant result as a positive outcome even though statistically significant differences were found in smaller numbers

The results for process skills, which include cognition, are unsurprising as an improvement in this area was considered to be unlikely given the normal rate of decline (Boller et al., 2002; Binetti, Locascio & Corkin et al., 2000; Roman, 2003). Also, decline in cognition is known to increase with severity of dementia (Mitnitski, Graham, & Rockwood, 1999). The results for process skills indicate that participants in both the MSE and control groups did not worsen in cognitive performance, rather cognitive performance remained static. However, motor skills did improve in both groups, often to a greater extent in the MSE group. As motor skills are essential for participation in daily life, this outcome may benefit other activities of daily living such as self care and feeding. The association between maintenance of motor skill and activity performance was explored by Kolanowski (2006) who found that people who are physically frail take part in less activity. Although the causal association between physical ability and activity remains unclear, it would appear that by offering a suitable activity, such as the MSE, there is the potential to maintain or enhance physical ability. The improvements in motor skills seen after participation in the MSE are consistent with this view. These results are also consistent with the findings of a number of other correlation studies (Wang, Larson, Bowen, & van Belle, 2006; Whittle & Goldenberg, 1996), all of which have shown a relationship between motor performance and participation (Aguero-Torres, Fratiglioni, Guo et al., 1998). By maintaining or improving motor skills there is the potential to influence a person's ability to participate in activity, whether that is activities of daily living or social activities. These are areas of care highlighted in government reports '*Our health, our care, our say*'

(Department of Health, 2006) and *'A new ambition for old age. Next steps in implementing the National Service Framework for Older People'* (Philp, 2006).

Ayres' model of Sensory Integration offers one explanation for why motor performance may have improved in the MSE group (Ayres, 1979). Sensory Integration suggests that the way the brain processes sensory information has a direct impact on motor performance and learning (see Chapter 4 for a detailed introduction to the model). Ayres suggests that poor motor performance is related to problems with organisation and interpretation of sensory information. People in the later stages of dementia are known to have problems processing sensory information from the environment, which leads to physical limitations and changes in mood and behaviour (Kovach, 2000). These sensory processing problems may be due to over or under stimulation. Studies exploring the problem of over or under stimulation suggest that by modifying the level of environmental stimulus, mood and behavioural problems and motor performance may be managed (Eslinger & Damasio, 1986; Kolanowski, Litaker, & Buettner, 2005; Kovach, 2000). Activities such as the MSE, properly delivered, should modify the level of environmental stimulation received. This modified level of stimulation, target to the needs and preferences of the individual may assist in sensory processing by reducing sensory overload for the participant thus explaining the improvement seen in motor performance.

This decline in sensory processing ability was also discussed by Yan & Dick (2006) in relation to motor performance in people with dementia. They acknowledged that as people age they show a decline in sensory acuity which is exacerbated by a decline in perception, attention and information processing (Yan & Dick, 2006). This decline is particularly noticeable in people with moderate to severe dementia. Previous studies (Dick et al., 2000; Eslinger & Damasio, 1986; Willingham, Peterson, Manning, & Brashear, 1997) also discuss the relationship between motor performance and dementia, showing that motor learning remains intact in people with Alzheimer's disease, suggesting preservation of neural structures that integrate sensory and kinaesthetic information. Therefore, loss of motor performance seen in moderate to severe dementia may not be due to neural damage, but rather to the cognitive deficits which create 'noise' within the central nervous system. This 'noise' is thought to impede sensory processing and motor response (Petersen et al., 2000). Feldman (1980) also hypothesised that a decline in motor performance amongst people with neurological damage could be attributed to reduced ability to process sensory information and access appropriate motor programs. Therefore, by controlling the sensory stimulus present in the environment, as seen in MSEs, and facilitating participation to accommodate problems in perception, attention and information processing using the PAL activity profiling tool, it may be possible to reduce cognitive 'noise' and improve the person's ability to process sensory information. The control activity (gardening) may also be modified to take into account perceptual and cognitive limitations but it is harder to modify the level of sensory stimulation in the same way as the MSE. These limitations may reflect the lower performance scores achieved by the control group.

Another aspect of motor control theory is that of environmental context. Motor activity is known to be influenced by the environment in which it is performed (Weber & Easley-Rosenberg, 2001). For example, performing a complex motor task such as weighing cooking ingredients is easier to do if it is performed within a kitchen rather than a busy day room. Weber described these environments as being either a stable or variable environment. A stable environment is a familiar environment appropriate for the task. The stable environment simplifies the demands of motor control by being in context with the activity to be performed. A variable environment, by contrast, is an unfamiliar setting out of context with the activity to be performed. The variable environment may also have competing stimuli which increase the demands on the central nervous system (CNS). The variable environment requires a greater level of motor control in order to allow the person to adapt to the changing environment. The person with dementia may not be able to adapt to a variable environment due to attention deficits and problems with information processing. Therefore, motor performance in this situation would be expected to decline. Indeed, research with older people has indicated that by focussing selective attention to visual or auditory stimuli enhances neural activity in the corresponding sensory cortices, however, if task-irrelevant information is not suppressed interference may occur leading to a loss of focused attention (Alain & Woods, 1999). The MSE may offer a more stable environment due to the reduction in competing stimuli and its similarity to a sitting room or bedroom. This stable environment, therefore, has the potential to positively influence motor control. Although these motor improvements may be small in terms of the ADL tasks achieved, being able to sustain simple activities may improve a sense of well-being for people with dementia, as well as increasing their levels of independence (Dick et al., 2000).

Stimulus enhancement may also assist in the filtering of competing stimuli. An environment offering weakened proximal stimuli may contribute to the confusion experienced by the person with dementia, thereby leading to an increase in cognitive and behavioural impairments (Gilmore, Cronin-Golomb, Neargarder, & Morrison, 2005). As mentioned above, competing stimuli increase the demand on the CNS leading to slowing in information processing. By enhancing the sensory signal the demand on the CNS is reduced and performance may be enhanced. Multi-sensory environments may be modified to control the number of competing stimuli and the intensity of stimulation by matching sensory preferences to individual need. For example, a single enhanced stimulus, such as optic fibres, may be presented until attention and engagement of the participant are obtained. The contrast between this piece of equipment and the surrounding environment is often sufficient to gain attention and engagement in the participant. This suggestion is consistent with the findings of Cronin-Golomb, Gilmore & Morrison et al. (2004), Dunne, Neargarder & Cipolloni et al. (2004), Kovach (2000) and Lawton & Nahemow (1973), who demonstrated an increase in performance by enhancing the stimulus presentation to match the information processing ability of the individual. Also, the secure environment of the MSE may reduce the demands on the person's cognitive reserves, allowing them a sense of security and the opportunity to explore in a failure free environment. Other activities could be introduced within the MSE to take advantage of on the quiet environment and minimal stimulation. This improvement in functional

performance seen in this study may be a reflection of the enhanced stimulation available in the MSE. The control group also improved but to a lesser extent. This may have been due to the more complex, competing stimuli experienced by the participant during this activity.

9.2.2   Effect of activity on mood and behaviour

The following research question will be discussed.

> In what way are mood and behaviour affected by multi-sensory environments compared with the control activity group?

Mood and behaviour were measured using the NRS, which assesses attention, engagement, sense of well-being and motivation (Sultzer et al., 1992). Participants in both groups improved significantly from baseline to last treatment session and from baseline to sessions 3 and 6. However, changes to session 3 and session 6 in the control group were found to be no longer significant following adjustment of the significance level for multiple comparisons. It seems likely that, in a larger sample, these benefits would be found more robustly. When the mean percentage of sessions for which a participant improved in mood and behaviour was explored, there was found to be significantly greater proportions of sessions amongst the MSE group than the control group. However, it should be noted that the percentage of sessions for which improvement was made was considerable for both groups.

These results are consistent with other studies exploring the effect of MSEs on mood and behaviour with older people with dementia (Kragt, Holtkamp, van Dongen, van Rossum, & Salentijn, 1997) and people with learning disabilities (Singh et al., 2004). In particular, Baker et al. (Baker et al., 2003) conducted a large scale, international study. Participants with moderate to severe dementia were recruited from British and Dutch wards and nursing homes, and randomly assigned to either eight multi-sensory or general activity sessions. These activities took place twice a week for four weeks. The results suggest that there were no statistically significant differences between the two groups, although some improvements were made. Participants in both groups related better to other people and were less inactive after sessions. Mood and behaviour remained stable but deteriorated once the sessions had stopped. These results suggest that mood and behaviour may be stabilised by regular activity which may explain the improvement seen in both groups.

Although Baker's study suggests some benefit in terms of stabilisation of mood, the results must be treated with caution. As described in Chapter 3, Baker et al. identified validity issues that may have influenced the outcome of the study. Firstly, the reliability of the assessment tools used to measure mood and behavioural change was questioned and, secondly, there was variation in selection and

facilitation of activities at each site. For example, the definition of what constituted as general activity was different for the two locations.

The stabilisation of mood and behaviour seen in both this study and Baker's study may be explained by several hypotheses, but the causal association, as yet, is still unclear. The sensory deprivation hypothesis suggests that neural atrophy, as seen in dementia, goes some way to explain the difficulty in processing sensory information. This in turn may lead to changes in mood, behaviour and cognitive functioning (Lindenberger & Baltes, 1994; Valentijn et al., 2005). If regular participation in activity is sustained the person may be at less risk of sensory deprivation and hence mood and behaviour may be stabilised. Several studies have alluded to this hypothesis, suggesting sensory stimulation treatment may significantly improve engagement, attention and communication, and reduce negative behaviours such as anger and disapproval through the modulation of sensory input (Hope et al., 2004; van Weert et al., 2005).

Lawton's ecological model (1973) provides a theoretical framework from which to understand the relationship between sensory deprivation and the individual's behaviour. This model suggests positive mood and behaviour is dependent on the relationship between individual competence and the demands of the environment (environmental press). This theoretical framework is also supported by sensoristasis (Kovach, 2000), as described in Chapter 4. Both models propose a delicate balance between individual capabilities and environmental demands in order to engage successfully with activity. If environmental demands are exceeded, as in an increase in noise levels, the individual may move from performing at maximum potential to being unable to perform adequately. Subsequently, they may become frustrated and disengaged from the activity. Conversely, if environmental demand drops too low the individual may lose interest and, again, engagement will be lost (Lawton et al., 1973). A basic tenent of this model is the concept of 'environmental docility' (Lawton, 1986). This concept suggests that as personal competency decreases, as in dementia, the environment becomes a more potent determinant of engagement. If the demands of the environment are matched to the competencies of the individual, engagement will be maximised, behavioural problems such as frustration and disinterest will be reduced, and mood will improve. The environmental demands within MSEs may be modified to match individual competencies.

In conclusion, mood and behaviour improved during both activities and this may have been due to the attention given to structuring the activities to match skill level and environmental demand. The MSE was more successful at improving mood and behaviour. This was probably due to the ease in which the environment could be modified to provide a suitable challenge.

9.2.3　The association of an individual's sensory profile with response to activity

The following research question will be discussed.

> To what extent is the sensory profile of the individual associated with the response to the MSE compared to the control activity (gardening)?

There was a significant association between sensory quadrant and AMPS motor skills. That is, of those participants who were allocated to the MSE group, who fell within the low registration quadrant, more than 4 in 5 improved in motor skills. Amongst those who fell within the sensation seeking quadrant, nearly 9 in 10 did not improve in motor skills. There were no associations between the sensory quadrants and the AMPS process scores for either group, or with the AMPS motor scores for the control group. There was also no association between sensory quadrant and NRS scores for either group.

These results suggest that participants in the MSE group who improved may have benefited from the enhanced sensory stimulation. This is evident from the high AMPS scores found in those who fell within the 'low registration' quadrant and the low AMPS scores found in those who fell within the 'sensation seeking' quadrant. These patterns of response indicate that participants have a high neurological threshold requiring high levels of sensory stimulation in order for them to respond to the environment. The MSE may be more successful in offering a higher level of intense stimulation than the control group (gardening). These findings are congruent with results of other studies exploring the sensory profiles of older people (Chung, 2006; Pohl et al., 2003). Chung, in particular, noted that 'due to the lower levels of registration and awareness of sensory information, participants with dementia do not fully register and perceive environmental stimuli', therefore they are less likely to engage in purposeful behaviours and also unable to avoid unpleasant stimuli (Chung, 2006; p. 653).

Those participants with low registration may have responded better in the MSE due to the intense sensory stimulation and lack of distraction from stimuli external to the activity. As the mechanisms of sensory processing are closely linked with other neural functions, sensory profiles may also influence other behaviours. Dunn (2001) speculated that those who fell within the low registration quadrant experienced higher levels of threat, such as accelerated heart rate, when in unfamiliar surroundings; which is indicative of a link between sensory processing and autonomic response. Participants in the study who fell within the low registration quadrant possibly did better in the MSE as it provided a relaxing environment without stressful, competing stimuli, this may have evoked a feeling of security and relaxation, compared with the general environment which may have been perceived as bewildering and disorienting.

Finally, the inability to reach the sensory threshold may be due to 'cognitive noise' as described earlier (Petersen et al., 2000). The person with dementia who falls within the 'low registration' quadrant may not have the ability to filter out competing stimuli and will, therefore, require a higher level of intense stimulation in order to reach their sensory threshold. Other diminishing sensory acuities such as visual tracking deficits may also lead to less efficient sensory processing, especially when stimulus intensity is weak or overwhelming therefore giving supplementary challenges to processing ability (Chung, 2006; Corcoran et al., 1987; Gilmore, Cronin-Golomb, Neargarder, & Morrison, 2005; Valentijn et al., 2005).

In conclusion, there was a significant association between those who improved in functional performance and those who attended the MSE. Many of these participants were found to fall within the 'low registration' and sensory seeking quadrant. Participants with these sensory processing patterns require higher levels of stimulation in order to reach their neural threshold. The MSE may have been more successful than the control activity at achieving this threshold due to the intense stimulation provided by the equipment. This may have reduced cognitive noise, reduced competing stimuli, and resulted in greater relaxation and security. These features may all contribute to improvement in functional performance.

9.2.4   Application to clinical practice

These results lead to a number of recommendations for facilitating activity with people in the later stages of the dementia disease process and these will be discussed below.

Firstly, assessment is essential in identifying and preparing a person for activity in the later stages of dementia. The Pool Activity Level occupational Profiling Tool and the Adult Sensory Profile propose guidelines for sensory processing patterns and facilitation of activity. Using these assessments, it is argued that suitable activity can be selected and presented in a manner in which the person with dementia will be able to participate. The Assessment of Motor and Process Skills provides a standardised measure of functional performance which is sensitive to change. Functional performance is an outcome of interaction between health and contextual factors such as the environment within the International Classification of Functioning, Disability and Health (WHO-ICF, 2002). This assessment allows the therapist to monitor these contextual factors in order to maximise opportunities for independent functioning.

Secondly, specific, scheduled activities of a sensory nature, such as MSEs and gardening, would appear to improve functional performance (motor and process skills) in a significant proportion of individuals with moderate to severe dementia. However, due to small numbers at follow-up, this study offers no evidence of a maintenance effect in either MSEs or gardening. Therefore, since the long term effects of multi-sensory activity are not established, it would appear that sensory activity

should be engaged with on a regular basis in order to gain an effect. It may be that continued engagement in sensory activity is required to assist in the processing of sensory stimulation and assist in reducing the 'cognitive noise' that is induced by busy hospital environments. Furthermore, management of sensory changes in the person's everyday environment may also assist sensory processing. Activities such as multi-sensory stimulation may help the clinician identify sensory preferences that can then be incorporated into the everyday environment and personal space, such as bedrooms. For example, a reduction of environmental demands and removal of distractions during other activities, such as personal activities of daily living and other social activities, may also improve engagement with the task and enhance mood and behaviour.

Finally, the sensory profile provides an indication of those participants who may be more likely to benefit from MSEs. Given that, currently, many MSE sessions are not structured to reflect personal need, negative opinions regarding the value of this intervention for people with dementia may have resulted from offering them to people to whom they are not suited. The use of the Adult Sensory Profile may assist in identifying those who would benefit from the MSE, i.e. those who fall within 'low registration ' and 'sensory seeking' quadrants, and those who may do better with an alternative activity i.e. sensory avoiders. By matching activity to sensory profiles it should be possible to enhance sensory attention and engagement.

This study has highlighted some key points for clinical practice; however, there are limitations to the study. Therefore, these results should be considered within the context of the following limitations.

9.3 Critique of trial design and methodological considerations

Randomised controlled trials (RCT) are thought to provide the most robust evidence of effectiveness of an intervention, which may lead to development of services that offer effective treatment and reduce possible hazards (Dean, 2006). Randomised controlled trials to evaluate more complex interventions such as occupational therapy, with participants with complex problems such as dementia, are recognised to be more challenging to design (Creek, 2003). This RCT was designed to measure outcomes that are particularly relevant to patients, carers and healthcare professionals. Indeed, reduced function is a diagnostic feature of dementia (McKhann et al., 1984; World Health Organisation, 2003).

Particular challenges faced with this study included achieving a feasible sample size with sufficient power, selecting the most suitable randomisation method, management of the blinding procedures, standardisation of the interventions given the different skill levels of the therapists and variable locations in which interventions were carried out, timing of the study in relation to the most suitable number of sessions, and selection of a suitable study design. These will be discussed below.

9.3.1 Power and effect size

In order to calculate the number of participants required for this study a sample size calculation was made based on 80% power. As only 30 participants were recruited, thereby achieving 60% of the proposed recruitment, the probability of correctly rejecting the null hypothesis was reduced. As 80% power is considered the common, but arbitrary choice, the power achieved could be considered to be insufficient. However, it could also be argued to be acceptable given the low risk of the interventions in terms of negative side effects, and the potential pleasure experienced by the participant. None of the participants experienced negative side effects and all demonstrated either stability or some improvement.

As no specific *a priori* prediction*s* of the hypotheses were stated, paired comparisons were used to decompose any interactions identified. In order to account for this multiple testing a Bonferroni correction was used to interpret the level of significance achieved. This correction adjusts the significance level to account for the number of tests carried out on the data, therefore, controlling the family wise error rate (type 1 error) (Field, 2000). Although the trade off is a loss of statistical power, the Bonferroni correction is suited for small samples sizes. A small sample size was evident towards the end of this study where participant numbers may have been insufficient for the ANOVA statistic.

This study fell short of the proposed sample size due to changes in service provision, staffing problems and limits of the study time-frame. Therefore, results should be treated with a degree of caution. A small sample size means there is a greater risk of a false-negative result (Type II error), that is an effect may not be detected. This may lead to a clinically important effect being ignored.

Therefore, data collection will continue in order to reach a suitable sample size. Post hoc analysis has revealed that 38 additional participants will be needed to power the study to 80% for motor skills. However, this will not be sufficient to identify a change in process scores given that a minimum of 364 additional participants may be required.

9.3.2 Randomisation and blinding

Participants were independently, randomly allocated to one of two groups using stratified randomisation. Due to the small sample size and need to ensure sufficient participant numbers were included in each strata, only two were included (location and gender). Participants were randomised by an independent occupational therapist as staff referred participants to the study. Participants were allocated to the interventions over a 24 month period. This was longer than anticipated but was due to changes in service provision. It was also found that data collection sites could not accommodate more than four participants at a time, due to staffing levels and facilities available. This process of stratified randomisation could have been considered to be less than robust given the problems with recruitment and, in retrospect, a system of Minimisation may have been more appropriate. Minimisation allocates each participant to either group depending on the characteristics of those already enrolled (Altman & Bland, 2005). The aim is to minimise the imbalance across the two groups. This differs from the randomisation system used as only the first participant would have been randomly allocated. From then on, allocation would have been based on achieving a good balance between groups. This system would have accommodated the slow referral rate and small sample size achieved.

A single blind system was used for this study, but the researcher was aware that participants with moderate to severe dementia may divulge their intervention allocation. Therefore a research log was used to document any suspicions or incidents. No participants revealed their group allocation and of five suspicions noted only one proved to be accurate. Therefore, it was assumed the single blind procedure employed was robust.

9.3.3 Standardisation of the intervention

This study was designed to standardise the delivery of the interventions based on the needs of each individual participant using the PAL occupational profiling tool (Pool, 2002). However, variables such as the experience of the nurse or therapist who facilitated the intervention and the different locations in which interventions were conducted could not be controlled for. This meant there was a potential to introduce bias to the results. For example, one therapist may have been more skilled at engaging participants in activity than another either due to skill, experience, or indeed personality. As the study relied on the good will of the therapists or nurses working in each location, level of competence could not be adjusted for even if such adjustment were possible. However, an attempt to manage this problem was undertaken by training of staff in the facilitation of the activities. These training sessions included strategies to encourage engagement and communication skills. Also some locations were able to offer purpose built multi-sensory rooms, whilst others had quiet spaces with equipment lent from the supplier (Rompa UK). Despite this being a confounding variable, these contextual differences accurately reflect current clinical practice, and as such were considered acceptable.

One other variable that was recognised as being a feature in current clinical practice was the influence of co-interventions. Where-ever possible other medical and social interventions were kept as constant as possible. However, the client-centred nature of many of the hospitals and day services meant that treatment plans were adapted on a regular basis to reflect participants' needs. Any changes were documented in the research log by the key nurse or therapist and reviewed after data input was complete. No significant changes to treatment were noted for any of the participants.

9.3.4 Timing of the study

The study was designed to run for 12 sessions, 3 sessions a week for 4 weeks. This figure was based on previous multi-sensory studies which varied from 6 sessions to 12 sessions (Baker et al., 2001; Chung et al., 2002). Twelve sessions proved difficult to sustain with participants being discharged from hospital, becoming too unwell, and some dying. Although there was variability in the end points, intention to treat analysis was used. The data revealed that the majority of participants reached session 3 and 70% achieved 6 sessions. Given the shorter lengths of hospital stay coupled with the move toward community care, shorter periods of intervention would appear to be more realistic. Also, given the number of participants lost to follow-up, a community based study may have been more successful in maintaining participant numbers.

Where-ever possible sessions were run in the morning to fit in with the hospital or nursing home routine. This also maximised the potential of accessing participants at their 'best time of day'.

Diurnal variation is a recognised feature of dementia, with deterioration in mood and behaviour later in the day (Mccann, Gilley, Bienias, Beckett, & Evans, 2004). However, there were two participants for whom an earlier session was not achievable due to the time constraints of their key nurse or therapist. Their results may have been influenced by diurnal variation; however, as they fell within the same intervention group, made some improvement over the sessions and their sessions were consistently at the same time of day, their results fitted in with the rest of their group.

9.3.5 Alternative study designs

Other study designs were considered at the initial planning stage and are discussed below.
A cross over design allows participants to act as their own controls. Participants would have been allocated to one of the two interventions then, after a wash out period, they would have swapped to the other intervention. There are inherent difficulties which rendered this design unsuitable for this study. Firstly, given the progressive nature of the disease it would be likely that functional performance in people with dementia would deteriorate over such a long period of time. Secondly, the time-frame for the study would have been too long with participants first receiving 12 sessions of one intervention, a wash out period, then 12 weeks of the second intervention. Given that the majority of participants did not make session 12 it would seem unlikely many would have made it to the end of a cross over trial.

A Zelen design allows participants to choose their preferred intervention. This design endeavours to address the problems of participants dropping out of the study or complying with the study protocol. People with severe dementia would not necessarily have the cognitive abilities to make an informed choice about which activity to select. In addition, both activities were recognised to have benefits in terms of possible enjoyment and sense of well-being (Volicer, Hurley, & Camberg, 2000). Therefore, benefits could be achieved regardless of intervention allocation. Finally, the advantages, to the study design, of true randomisation would have been lost.

The final design considered was that of a multiple base-line using a single case design.
An AB experimental design where A is the baseline and B is the intervention was considered. The multiple base-line conditions would allow the intervention to be applied at different points in time to different base-line conditions across participants. This design was used by Moffat et al. (1993) for their pilot study investigating the outcomes from using MSEs with people with dementia. However, this method would have meant there was a delay in the participants starting the baseline period before progressing on to the allocated activity, thereby leading to a long data collection period. Given the progressive nature of the disease, the participant may have demonstrated poor functional performance at the end of the trial due to deterioration in the disease progress rather than due to the lack of effectiveness of the intervention. Also, having found some positive findings from single case series, the RCT was arguably the next step.

9.3.6   Conclusion

Where-ever possible, internal validity was maintained through the study. However, there were some examples such as therapist experience and timing of the interventions that were beyond the control of the researcher. These features may influence the results of this study, but do represent the normal clinical environment in which these interventions may take place. Regardless of how robust a RCT may be, investigating complex interventions with people with complex problems will always offer challenges for the researcher in achieving accurate results (Bond et al., 2001). Therefore the limitations of this study are acknowledged as a balance between clinically relevant research and the reality of clinical practice.

9.4 Clinical guidelines in current health provision and recommendations for best practice for people with moderate to severe dementia

Establishing best practice guidelines has been at the fore-front of development for professional and governmental bodies, creating a standard from which the management of people with dementia can be addressed. In particular, guidelines can provide a benchmark from which new research can be assessed to expand and update the evidence base. This study is no different and will be compared against the clinical guidelines from the Alzheimer's Society, National Services Framework for Older People (NSF; Department of Health, 2001), NICE-SCIE guidelines Dementia: supporting people with dementia and their carers (National Institute for Health and Clinical Excellence, 2007), the Scottish Intercollegiate Guidelines Network (Scottish Intercollegiate Guidelines Network, 2006) and the College of Occupational Therapists (Creek, 2003), and build on what we understand as best practice for people with moderate to severe dementia.

9.4.1 Assessment of people with moderate to severe dementia

Clinical guidelines for people with dementia refer to assessment as a method to prompt provision of care (Department of Health, 2001; Scottish Intercollegiate Guidelines Network, 2006), with a particular focus on mental status as measured by assessment tools such as the Mini-Mental State Examination (MMSE; Folstein et al., 1975). However, NICE acknowledge that formal cognitive testing using instruments such as the MMSE only goes so far and care plans should include assessment of independent functioning; mobility and level of support (National Institute for Health and Clinical Excellence, 2007). An assessment highlighted by NICE as being sensitive to these areas of competency is the AMPS (Fisher, 2003). This focus on assessment of function is also supported by the College of Occupational Therapists. The College recommends the use of the World Health Organisation International Classification of Functioning, Disability and Health (World Health Organisation, 2002) as an assessment framework in order to bridge the organisational divides of NHS, social care and the private sector, as well as medical and social models of healthcare. This study utilised the AMPS and the International Classification of Functioning, Disability and Health as tools and frameworks which embrace current clinical practice.

Complex problems presented by people with dementia require analysis from a variety of perspectives beyond conventional neuropsychological assessments. This study measures levels of competency using the Standardised Mini-Mental State Examination (Molloy et al., 1997) and the AMPS (Fisher, 2003), but goes further by assessing ability to participate in activity using the PAL Occupational Profiling Tool (Pool, 2002) and sensory processing abilities using the Adult Sensory Profile (Brown et al., 2002). This range of assessments identifies the level of facilitation needed for successful participation depending on each person's sensory needs and performance levels. Given

that participants had limited cognitive ability, all these assessments were appropriate as data were gathered from carers and relatives, or participants were observed whilst engaged in everyday tasks such as eating breakfast. All assessments, except the SMMSE, focus on ability and participation rather than impairment and disability, reflecting the key terms used by the ICF-2 (World Health Organisation, 1997). This change of focus on ability and participation reflects the NSF strategy of reducing disability and maximising independent living and social functioning, enabling people with moderate to severe dementia rather than disabling them. These assessments underpin the selection of appropriate activity for people with dementia.

9.4.2   The use of activities for people with moderate to severe dementia

Occupational therapy is concerned with the impact of illness, disability, or environmental factors on a person's ability to carry out desired occupations and activities (Creek, 2003). As such occupational therapists are well placed to facilitate activity with people who are normally unable to access activity independently. The need to maintain activities with people in late stage dementia is supported by the Alzheimer's Society (Recommendations for end of life care strategy for adults, 2006), NICE Therapeutic interventions for people with dementia (National Institute for Health and Clinical Excellence, 2007), and SIGN Management of people with dementia (Scottish Intercollegiate Guidelines Network, 2006), with a particular focus on interventions that are tailored to individual preferences, skills and abilities. The Royal College of Psychiatrists: Guidance for the management of behavioural and psychiatric symptoms in dementia (Royal College of Psychiatrists, 2004) goes further by suggesting non-pharmacological approaches should always be used first, using a client centred approach respecting the individual. Unfortunately many people in the late stages of dementia are left un-stimulated, with few opportunities to participate in activity and with few staff who are able to facilitate participation (Alzheimer's Society, 2006).

The two activities selected for this study were identified as suitable for people with moderate to severe dementia as they could be adapted to accommodate different abilities levels. This adaptation was achieved by tailoring activity demands to the remaining abilities of the individual, such as task performance skills using the PAL Occupational Profiling Tool (Pool, 2002) and the ASP (Brown et al., 2002). Both activities revealed positive outcomes in relation to participation, motor performance, cognitive performance, mood and behaviour, as measured by the AMPS (Fisher, 2003), and the NRS (Sultzer, 1992). As such these two activities were found to be suitable for people with moderate to severe dementia when adapted using guidance from the PAL and the ASP. The PAL and ASP provide a robust system from which clinicians can tailor interventions for people with moderate to severe dementia.

Other activities may also prove to be suitable for people at the later stages of dementia when adapted using the assessment tools listed above. However, multi-sensory activities such as MSE

and gardening particularly address the information processing abilities by the modulation of sensory input. This has not been identified as an activity feature in clinical guidelines, possibly due to the lack of research in this area.

In conclusion, this study has embraced many of the guidelines and recommendations made by statutory bodies such as NICE and the NSF for older people. As such the findings may help clinical staff identify and use appropriate assessment tools that will guide selection of activities to match individual need. The activities used in this study have revealed themselves to be suitable for people with moderate to severe dementia, a group who have previously been challenging to engage. However, this study has revealed many areas for future research, particularly with this group of people. Therefore, recommendations for future research will be discussed.

9.5   Recommendations for future research

Suggestions for future research will be discussed under two headings; extension of the current study in light of the problems in achieving sufficient participant numbers, and proposals for further research in this field.

9.5.1   Extension of the current study

As this study did not recruit the number of participants needed to achieve a sufficient sample size, data collection will continue. It is anticipated that a further eighteen months of data collection will achieve this number of participants. An application has been made to the relevant ethics committees to seek approval to extend this study. A number of hospital and nursing home locations have been approached regarding participation in the extension of this study and have offered their support. It is proposed, that in the short term, feedback presentations will be given to hospitals and nursing homes who participated in the study to inform them that both interventions were shown to be beneficial and to request opportunities for further data collection. Further detailed feedback sessions will be given once the full participant numbers have been achieved and the analysis repeated. However, it is clear from the initial analysis that further research is required. This will be explained in more depth.

8.5.2   Further research in this field

There have been limited studies exploring the use of activity with people who are in the later stages of the dementia disease process; however, the few that have been published reveal the benefits that can be gained (Baillon et al., 2004; van Weert et al., 2006). This study used specific assessment tools to design individual programmes for participants engaging in either the MSE or a control activity. The study revealed further questions which could be explored in further research.

It would be pertinent to explore further the use of the Adult Sensory Profile with people with moderate to severe dementia, with the aim of gaining a clearer understanding of their ability to process sensory information and provide normative data for this client group. The Adult Sensory Profile has recently been extended to explore sensory processing in more depth (Dunn, 2006). Results from such a study may help explain the variable success of activities used with this group and provide a framework to assist with problem solving in order to target effective interventions. Having an understanding of sensory processing may also assist with environmental design of facilities for people with dementia. It would also be relevant in identifying whether people with

moderate to severe dementia fall within specific sensory profiles as a result of the dementia process, or whether these are trait profiles.

Sensory processing abilities are also relevant to environmental design. Environmental design has been highlighted as a key feature of the 'Recommendations for end of life care strategy for adults' (Alzheimer's society, 2006), the Scottish Intercollegiate Guidelines Network (2006) and the NICE-SCIE guidelines 'Dementia: supporting people with dementia and their carers (2007). Given the importance of environmental design and the sensory processing abilities of people with dementia, Initial discussions have been made with Professor Paul Chamberlin, Sheffield Hallum University regarding a collaborative study with the aim to explore the use of therapeutic environmental design for people with moderate to severe dementia.

Other studies exploring the efficacy of MSE have claimed that no carry over effect has been achieved (Baillon et al., 2004; Chung et al., 2002; McKee, Harris, Rice, & Silk, 2007). However, the assessment tools used in these studies lacked the sensitivity of AMPS to detect change; therefore, the effect may have been missed. Previous studies have also focussed on mood and behaviour rather than functional performance. As functional performance is a diagnostic indicator of dementia (National Institute for Health and Clinical Excellence, 2007; Overshott et al., 2005) it may be a more appropriate measure of outcome. As this study did not explore the carry over effects of MSEs an extension of the current methodology to explore carry over effects at one month would be appropriate. A carry over period of more than one month may not be appropriate given the normal pattern of decline seen in dementia.

The MSE would appear to offer an activity that can be accessed by people who have moderate to severe dementia and has an impact on functional performance. These outcomes would benefit from being explored in more depth, in particular the number of sessions required before effect is gained. This may be achieved by evaluating the effect of intervention at different time frames, for example, 1 session, 3 sessions, 6 sessions and 10 sessions. This aim could be incorporated within such as the one above.

Given the success of the ASP and PAL in constructing activity profiles for people with moderate to severe dementia, further exploration could be made of other activities used with this group. NICE, SIGN and the Alzheimer's Society all support the use of activity for all people with dementia but current research gives little guidance on how to construct and facilitate activity. Most activities are aimed at those with mild to moderate dementia but have had limited success with those with the later stages of the disease. The AMPS could be used to explore the efficacy of other activities, such as music and movement or taking part in domestic activity, whilst the use of the MSE could be explored with those with mild to moderate dementia using a research design similar to the one used for people with moderate to severe dementia.

9.6 Conclusion

This study explored the efficacy of two multi-sensory activities (MSE and gardening) on the functional performance (motor and process skills) and mood and behaviour of people with moderate to severe dementia. A subsequent aim was to investigate whether those who improved as a result of participating in either group fell within specific sensory profiles.

The results revealed that both groups improved in functional performance, mood and behaviour after attending between 6 and 12 sessions. Further analysis revealed a greater improvement in motor performance than process skills (cognition), but this is not unsurprising given the pattern of cognitive decline seen in dementia. Analysis of individual sessions revealed there were significantly more sessions in the MSE for which improvement in motor skills were made than the control group. Analysis of an individual's response to activity revealed a significant association between sensory profile and improvement in functional performance. That is those participants allocated to the MSE who fell within the low registration quadrant were more likely to improve in motor skills. Those within the same group who fell within the sensation seeking quadrant were less likely to improve in motor skills.

However, when accepting these conclusions there are a number of caveats to be considered. This study did not achieve the proposed sample size therefore the results must be treated with caution. Further data collection will be carried out. This study did not explore the effect of other activities that were part of everyday routine within the locations used and there clearly remain many other important questions.

Despite these comments, this novel study does offer promising results and supports the use of activity for people with moderate to severe dementia. As such, it may offer solutions for improving functional performance and improving mood and behaviour for a group who are known to be difficult to engage in activity. The study makes recommendations for the use of two assessment tools, the ASP and the PAL, to design and construct activity to meet the specific needs of people in the later stages of the disease, as well as the AMPS to detect any treatment effects. The study also highlights the problems of sensory processing and maintenance of activities of daily living with this patient group. Recommendations are also given for implementing activity and the use of MSEs. These recommendations are supported by the National Service Framework for Older People (Department of Health, 2001) and the NICE-SCIE guidelines (National Institute for Health and Clinical Excellence, 2007). In keeping with those guidelines, results will be published and feedback will be given to the hospitals and nursing homes who participated in the study to assist in the development of good practice.

Appendices

PATIENT INFORMATION SHEET

Title of study: Does stimulation of the senses help with concentration and mood?

You have been invited to take part in this study. Before you decide whether you wish to take part please read this information sheet. If you have any questions please ask.

Thank you for reading this.

What is the purpose of the study?

I am looking at how different activities effect how people feel in themselves and how they concentrate.

Do I have to take part?

It is up to you whether or not you wish to take part in the study. You can change your mind at any time. Even if you decide to take part, you can change your mind later. You do not have to give a reason.

What do you want me to do?

I am asking you to take part in an activity. There are 2 activities. The first is gardening, the second is a sensory room where you can touch and feel different objects.

Gardening activity

Sensory room

To find out if the activity is helping I will need to ask some questions. I will ask you how you are feeling before and after you do the activity, to see if there is any change. I will not ask you which activity you are doing because I'm not supposed to know!

The activities happen 3 times a week and usually last about half an hour. We will offer the activities for 4 weeks.

Are there any side effects?

Very rarely some people do not like doing these activities. For example they may not like getting their hands dirty with gardening or find that the lights in the sensory room give them a headache. If you decide you do not like the activities, we will stop immediately.

What are the benefits?
We hope that both activities will help you. We find that most people enjoy them.

What happens when the study ends?

When the study ends you will still be able to participate in the activities. The results of the study will be used by other nurses and therapists to help others.

Who is organising this study?

The hospital and the University are working together on this study. The study was funded by the Department of Health.

- Have you any questions?

- If you would like to be part of this study, please sign the consent form?

Thank you

Name of Researcher: Lesley Pinkney

Address: School of Health Professions and Rehabilitation Sciences, University of Southampton.

Telephone number: 023 80595284

Please keep this sheet for your information.

Ethics number: 238/03/w

INFORMATION SHEET

(For carers, relatives, spouse and key workers)

Title of study: A study of sensory stimulation for people with memory dysfunction.

Your relative / spouse / client has been invited to take part in the above study. It is important that they and yourselves understand why the study is being undertaken and what it will involve. Please take time to read the following information and discuss it with the researcher if you wish. If there is anything that is not clear, or if you require more information, please do not hesitate to ask. Take time to decide whether or not it is suitable that your relative / spouse / client takes part.

Thank you for reading this.

What is the purpose of the study?

This study aims to explore the effect of sensory stimulation on ability to perform functional activities i.e. your ability to do a task in the right order, how to work out a problem.

Why has my relative / spouse / client been chosen?

Your relative / spouse / client has been selected as they have problems with memory and thinking skills. These activities have been found to work best with these kinds of problems.

Do they have to take part?

It is up to them whether or not they take part. They can withdraw at any time during the study without giving a reason. This decision will not affect their standard of care in anyway.

What will happen to them if they take part?

Once they have completed some initial assessments, which look at their current level of dementia, they will be randomly allocated either to a gardening activity or a multi-sensory room. They will take part in this activity 3 times a week for 4 weeks (12 sessions). Before and after each activity they will meet with me (Lesley Pinkney) to answer some more questions and complete some further assessment forms.

The study is called a single blind study as the researcher (Lesley Pinkney) will not know to which group the participant has been allocated. It is important that every effort is made not to discuss which activity an individual is attending so that the researcher is not influenced by the results.

What are the activities that are being tested?
There are two activities; 1. Gardening activity which will involve planting some bulbs; 2. The multi-sensory room which will involve handling and looking at objects.
These two activities (gardening and multi-sensory room) are groups which already run in the hospital / nursing home. For the study, they will be run in a particular way and if your relative / spouse / client is allocated to a particular activity they will be unable to take part in the other until the end of the study.

Are there any side effects?
It is very rare for any side effects to occur. People may find the lights in the multi-sensory room give them a headache or they might not like getting their hands dirty in gardening. The activities will be run on a one-to-one basis so if any difficulties are noted the activity will be stopped.

What are the possible benefits of taking part?
Most people enjoy taking part in these activities. We hope that they will benefit from taking part, for example, with an improvement of concentration, mood and behaviour. However, this cannot be guaranteed. The information we obtain from the study should help us treat patients better in the future.

What happens at the end of the study?
On completion of the study, the results will be published to inform other healthcare staff. All data will remain anonymous and any paper data collection will be destroyed. Both activities will be available to the person on completion of the study.

What happens if something goes wrong?
If you have any concerns please contact the researcher (details below) or the manager of the service. Someone familiar with the participant will carry out all activities so that they may respond to any problem that may arise. If necessary, the activity will be stopped if the participant appears to be distressed or uncomfortable.

Will their taking part in this study be kept confidential?
All information collected during the course of the study will be kept strictly confidential. Information strictly related to the study may be collected from the participant's notes and the participant's GP will be notified about their inclusion in the study.

Who is organising and funding the research?
This study is organised by the University of Southampton and is a collaboration between the researcher (Lesley Pinkney), her supervisors at the University (Dr. R Bucks & Dr. K McPherson) and the hospital / nursing home. Funding has been provided by the Department of Health.

Who has reviewed the study?
The study has been reviewed by the Southampton and South West Hampshire, and East Dorset Local Research Ethics Committees, REC 238/03/w.

Contact for further information.
If you have any questions please contact:
Lesley Pinkney
School of Health Professions and Rehabilitation Sciences
University of Southampton
Tel: 023 80595284

If you agree with your relative / spouse / client taking part please complete the Assent form.

Thank you for taking the time to read this information sheet.

Appendix 2 Staff Training Programme

9.30 Introduction

    My background and development of the research question

    Introduction to the study

9.45 Study methodology (what I'm going to do)

    Passing on information to perspective participants and their families

    Identifying suitable participants

    Gaining consent

    The baseline assessments

    Maintaining blindness

    Ensuring ongoing consent

10.15 Running the activities (what you need to do)

    Using the PAL occupational profile

    Running the activities

    Managing unforeseen circumstances

    Using the research log

10.45 Question and answer time

11.00 Finish

Appendix 3 Letter introducing researcher

Ethics number: 238/03/w

Dear

My name is Lesley Pinkney and I am an Occupational Therapist at the University of Southampton. I am currently carrying out a study exploring the effects of sensory stimulation for people with dementia.

I would like to invite you to take part in this study. I would also like to ask you and your relative to meet with me to talk about why the study is being undertaken and what it will involve. I have attached an information sheet for you both and will ask your key nurse or therapist to contact you to see if you would be interested in the study. If you agree to take part in the study, you may withdraw at any stage without giving us an explanation.

Yours sincerely,

Lesley Pinkney
Occupational Therapist

Appendix   4   Consent form

Patient identification number:

CONSENT FORM

Title of study: Does stimulation of the senses help with concentration and mood?

Name of Researcher: Lesley Pinkney

Please circle answer

1.   Have you read the information sheet?   Yes / No
      (Version 1; 16/07/03)
      Have you had the chance to ask questions?

2.   Do you understand;
      Taking part in this study is up to you.
      You can change your mind about taking part.   Yes / No
      You do not have to give a reason.

3.   Do you understand that your medical notes
      will be looked at by the researcher?   Yes / No

4.   Do you agree to take part in this study   Yes / No

Name of participant……………………………………………………..
Signature……………………………………………………………….
Date…………………………………………………………………….
Researcher's signature…………………………………………………

1 for person giving consent   1 for researcher   1 to be kept with hospital notes

Ethics number: 238/03/w

Appendix   5   Assent form

Participant identification number:

ASSENT FORM

Title of study: A study of sensory stimulation for people with memory dysfunction.

Name of Researcher: Lesley Pinkney

Please initial box

1. I confirm that I have read and understood the information
    Sheet (Version 1; 16/07/03) for the above study and have had the
    opportunity to ask questions.

2. I understand that my relative / spouse / client's (*please delete
    as appropriate*) participation is voluntary and they are free to
    withdraw at any time, without giving any reason, without their
    medical care or legal rights being affected.

3. I understand that sections of any of their medical notes may
    be looked at by the researcher or from regulatory authorities
    where it is relevant to the participant taking part in the research.

4. I agree to their taking part in the above study.

Name of person giving assent…………………………………………………………….
Signature……………………………………………………………………………………….
Date……………………………………………………………………………………………
Researcher's signature……………………………………………………………………

1 for person giving assent   1 for researcher   1 to be kept with hospital notes
Ethics number: 238/03/w

Appendix   6   Pool Activity Level guidelines

Pool Activity Level Guidelines for Multi-Sensory Environment group

Planned activity level.

Activity objectives

To enable the person to take control of the MSE Activity and master
the steps involved.

Position of the equipment

Place the equipment in the same place for each session. Orientate the person to the room on each
occasion. Ask the person to select preferred pieces of equipment, ensuring that the selection
includes stimulus for all the senses.

Verbal directions

Explain the task in short sentences and repeat directions as necessary. If the person is new to the
MSE then demonstrate to them what is available. Demonstration will also help prevent errors in
selection.

Communication and activity characteristics

Allow the person time to settle before focusing on the sensory aspects. Start with main room lights
on and slowly dim the room. The session may last up to 30 minutes but end the session when the
person is no longer able to concentrate on the experience. The ideal session should be 1:1 but a
group of up to 3 people may be accommodated.

Allow the person time to explore and handle equipment. Focus any conversation toward what is
happening, what the effect is, how it feels, likes and dislikes, what it reminds you of. Encourage the
person to reflect on the sensory qualities of the session with those around them.

Ending the session

Slowly brighten the room and return the conversation to everyday discussion. Encourage the
person to tidy the equipment away.

Pool Activity Level Guidelines for Multi-Sensory Environment group

Exploratory activity level

Activity objectives

To enable to person to experience the sensation of the activity.

Position of the equipment

Lay out the selection of equipment that is suitable for the person based on sensory preferences and needs, but allow for some element of choice. Ensure the equipment is in the line of vision and is easily accessible. Ensure the selection provides stimulus for all the senses.

Verbal directions

Explain the task in short sentences. If the person is new to the MSE then demonstrate what is available. Demonstration will also prevent errors in selection.

Communication and activity characteristics

Allow the person time to settle before focusing on the sensory aspects. Start with main room lights on and slowly dim the room. The session may last for up to 20 minutes but end the session if the person is no longer able to concentrate on the task or if they fall asleep (this approach is designed to stimulate rather than relax).
The ideal session should be 1:1 but a group of two may be accommodated.

Break each activity down into 2 - 3 steps at a time and limit the stimulus to no more than three pieces of equipment operating at anyone time. If the person appears distracted by the number of items operating limit them to two.

Allow the person to explore and handle the equipment. Do not enforce any instructions on how to use or handle the equipment unless the person is placing himself or herself in danger. Allow an element of creativity and spontaneity. Encourage the person to reflect on the sensory qualities of the session and use the opportunity to reminisce about sensory activities that the person may have enjoyed in the past.

Ending the session

Slowly brighten the room and return the conversation to everyday discussion.

Pool Activity Level Guidelines for Multi-Sensory Environment group

Sensory activity level

Activity objectives

To enable the individual to experience the effect of the activity on their senses.

Position of the equipment

Having established a sensory profile select equipment that stimulates all the senses. Stimulate the preferred senses first then move on to those senses that receive little or no stimulus through everyday activity. Make sure the person is aware of the equipment by making bodily contact.

Verbal directions

Reinforce any verbal directions with guided movements. Use body language to help the person to settle and explore the equipment. If the person is new to the MSE consider introducing them to the equipment outside of the room.

Communication and activity characteristics

Allow the person to settle in the room and explore any equipment. Start with main room lights on and slowly dim the room. The session may last for up to 20 minutes but end the session if the person is no longer able to concentrate on the task or if they fall asleep (this approach is designed to stimulate rather than relax).
The ideal session should be 1:1 but a group of two may be accommodated.

Break each activity down into 2 steps at a time and limit the stimulus to no more than two pieces of equipment operating at anyone time. If the person appears distracted by the number of items operating limit them to one.

Allow the person to explore and handle the equipment. Do not enforce any instructions on how to use or handle the equipment unless the person is placing himself or herself in danger. Ensure that the person is able to access the sensory qualities of each piece of equipment and use the opportunity to discuss how the sensory activity feels. Repeat the activity for as long as the person wishes to reinforce the sensory component.

Ending the session

Slowly brighten the room and return the conversation to everyday discussion.

Pool Activity Level Guidelines for Multi-Sensory Environment group

Reflex activity level

Activity objectives

To arouse conscious awareness of self and the immediate environment.

Position of the equipment

Make available to the participant equipment that stimulates all of the senses. Directly stimulate the area of the body to be targeted i.e. touching the palm of the hand / arms / feet, shining visual stimuli into the line of vision, placing aromas directly under the nose for olfactory stimulation. Ensure all the senses are stimulated equally. Look for signs that the person is aware of the equipment such as eye / head / hand movement, verbal responses, moving parts of their body.

Verbal directions

Help the person to settle and explore the equipment. Guide all movements and reinforce with simple one word verbal directions. If the person is new to the Snoezelen room ensure they are settled with each piece of equipment before exploring its sensory components. Maintain eye contact and reinforce the activity with appropriate body language and gestures.

Communication and activity characteristics

Bring the person into the room and settle them in a comfortable chair. If they are in a wheelchair transfer them to an easy chair. Start with main room lights on and slowly dim the room. The session may last for up to 10 minutes but end the session if the person is no longer able to concentrate on the task or if they fall asleep (this approach is designed to stimulate rather than relax).
The session should be 1:1.
Break each activity down into 1 step at a time and limit the stimulus to one piece of equipment operating at anyone time. Repeat the activity for as long as the person is able to tolerate it. The activity is in direct response to the level of stimulation needed to arouse.
Guide the person by touch to explore and handle the equipment. Do not enforce any instructions on how to use or handle the equipment unless the person is placing himself or herself in danger. Ensure that the person is able to access the sensory qualities of each piece of equipment, and use your body language and tone of voice to enhance the level of stimulation.

Ending the session

Slowly brighten the room and allow the person to become accustom to the everyday environment. Adapt tone of voice and body language to the new environment

Pool Activity Level Guidelines for gardening group

Planned activity level.

Activity objectives
To enable the person to take control of the gardening activity and master
the steps involved.

Position of the equipment
Place the equipment in the same place for each session. Orientate the person to the room on each
occasion. Ask the person to select preferred task, for example, planting seeds, pruning roses.
Ensure that the activity includes stimulus for all the senses.

Verbal directions
Explain the task in short sentences and repeat directions as necessary. If the person is new to the
task then demonstrate to them what is available. Demonstration will also help prevent errors in
selection.

Communication and activity characteristics
Bring the participant into the room and settle them in a comfortable chair. If they are in a wheelchair
transfer them to an easy chair. Allow the person time to settle before focusing on the sensory
aspects of the task. The session may last up to 30 minutes but end the session when the person is
no longer able to concentrate on the activity. The ideal session should be 1:1 but a group of up to 3
people may be accommodated.

Allow the person time to explore and handle equipment (soil, flowers, oasis). Focus any
conversation toward what is happening, what the effect is, how it feels, likes and dislikes, what it
reminds you of. Encourage the person to reflect on the sensory qualities of the session with those
around them.

Ending the session
Return the conversation to everyday discussion. Encourage the person to tidy the equipment away
and clear up any mess.

Pool Activity Level Guidelines for gardening group

Exploratory activity level

Activity objectives

To enable to person to experience the sensation of the activity.

Position of the equipment

Lay out the selection of tasks that are suitable for the person based on sensory preferences and needs, but allow for some element of choice. Ensure the different tasks are presented one at a time. Ensure the selection provides stimulus for all the senses.

Verbal directions

Explain the task in short sentences. If the person is new to the activity then demonstrate what is available. Demonstration will also prevent errors in selection.

Communication and activity characteristics

Bring the participant into the room and settle them in a comfortable chair. If they are in a wheelchair transfer them to an easy chair. Allow the person time to settle before focusing on the sensory aspects. The session may last for up to 20 minutes but end the session if the person is no longer able to concentrate on the task. The ideal session should be 1:1 but a group of two may be accommodated.

Break each activity down into 2 - 3 steps at a time. If the person appears distracted by the number of stages in the activity limit them to two.

Allow the person to explore and handle the equipment (soil, flowers, oasis). Do not enforce any instructions on how to use or handle the equipment unless the person is placing himself or herself in danger. Allow an element of creativity and spontaneity. Encourage the person to reflect on the sensory qualities of the session and use the opportunity to reminisce about sensory activities that the person may have enjoyed in the past.

Ending the session

Pack the equipment and materials away and inform the participant that the activity is over. Reflect on the sensory qualities of the activity i.e. the compost was cold wasn't it?

Pool Activity Level Guidelines for gardening group

Sensory activity level

Activity objectives

To enable the individual to experience the effect of the activity on their senses.

Position of the equipment

Make available equipment that has been identified by the participant. Make sure they are aware of the equipment and materials by guiding the participant's hands, for example, identify the flower pot, compost and bulbs. Look for signs that the participant is aware of the equipment such as eye / head / hand movement, verbal responses, moving parts of their body.

Verbal directions

Help the person to settle and explore the equipment. Break down the activity into one step at a time, for example, waiting until the person has filled the flower pot with compost before giving the next instruction to select a bulb. Maintain eye contact and reinforce the activity with appropriate body language and gestures.

Communication and activity characteristics

Bring the participant into the room and settle them in a comfortable chair. If they are in a wheelchair transfer them to an easy chair. Repeat elements of the activity if they are enjoyed by the participant; for example, plant more than one bulb. The session may last for up to 15 minutes but end the session if the person is no longer able to concentrate on the task. The ideal session should be 1:1 but a group of two may be accommodated. Guide the participant to explore and handle the equipment and materials by limited spoken directions to explanations of movements required to carry out the tasks.

Ending the session

Pack the equipment and materials away and inform the participant that the activity is over. Reflect on the sensory qualities of the activity i.e. the compost was cold wasn't it?

Pool Activity Level Guidelines for gardening group

Reflex activity level

Activity objectives

To arouse conscious awareness of self and the immediate environment.

Position of the equipment

Having established sensory profile, select an activity that stimulates all the senses. Directly stimulate the area of the body to be targeted i.e. touching the palm of the hand with leaves, holding a flower in the line of vision, placing aromatic herbs directly under the nose for olfactory stimulation. Ensure all the senses are stimulated equally. Look for signs that the person is aware of the equipment such as eye / head / hand movement, verbal responses, moving parts of their body.

Verbal directions

Help the person to settle and explore the activity. Guide all movements and reinforce with simple one word verbal directions. If the person is new to the activity ensure they are settled before exploring the sensory components of the activity. Maintain eye contact and reinforce the activity with appropriate body language and gestures.

Communication and activity characteristics

Bring the person into the room and settle them in a comfortable chair. If they are in a wheelchair transfer them to an easy chair. The session may last for up to 10 minutes but end the session if the person is no longer able to concentrate on the task.
The session should be 1:1.

Break each activity down into 1 step at a time and limit the stimulus to one step of the activity at a time. Repeat the activity for as long as the person is able to tolerate it. The activity is in direct response to the level of stimulation needed to arouse.

Guide the person by touch to explore and handle the equipment. Do not enforce any instructions on how to use or handle the equipment unless the person is placing himself or herself in danger. Ensure that the person is able to access the sensory qualities at each stage of the activity, and use your body language and tone of voice to enhance the level of stimulation.

Ending the session

Allow the person to become accustom to the everyday environment. Adapt tone of voice and body language to the new environment.

Appendix 7 Summary statistics from baseline to session 12 and baseline to follow-up for AMPS motor and process skills scores.

AMPS scores	MSE	Control
M(SD), range	*n* = 5	*n* = 2
Baseline to session 12		
AMPS Motor baseline	0.55(0.68), -3.00 – 1.69	0.64(0.69), -0.54 – 2.04
AMPS Process baseline	-0.48(1.07), -3.00 – 0.70	0.02(0.72), -1.55 – 0.80
AMPS Motor post-session 12	1.71(0.64), 0.71 – 2.32	1.10(0.64), 0.60 – 1.51
AMPS Process post- session 12	0.41(0.62), -0.57 – 1.06	0.04(0.03), 0.02 – 0.06
Baseline to one month follow-up	*n* = 8	*n* = 2
AMPS Motor baseline	0.46(0.54), -3.00 – 1.69	0.64(0.69), -0.54 – 2.04
AMPS Process baseline	-0.43(0.83), -3.00 – 0.70	0.02(0.72), -1.55 – 0.80
AMPS Motor follow-up	1.21(0.93), -0.81 – 1.95	0.58(0.04), 0.60 – 0.58
AMPS Process follow-up	0.10(0.58), -0.70 – 1.06	0.04(0.03), 0.06 – 0.04

Note. AMPS – Assessment of Motor and Process Skills

Appendix 8 **Summary statistics from baseline to session 12 and baseline to follow-up for NRS scores.**

NRS scores	MSE	Control
M(SD), range		
Baseline to session 12	*n* = 5	*n* = 2
NRS baseline	8.41(18.31), 12 - 69	30.23(11.71), 8 - 51
NRS post-session 12	11.20(4.76), 7 - 19	23.67(9.87), 17 - 35
Baseline to one month follow-up	*n* = 8	*n* = 2
NRS baseline	8.41(18.31), 12 - 69	30.23(11.71), 8 - 51
NRS follow-up	21.88(17.55), 7 - 59	27.00(5.20), 24 - 33

Note. NRS – Neurobehavioural Rating Scale

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