



Provided by the author(s) and University of Galway in accordance with publisher policies. Please cite the published version when available.

Title	Rehabilitation approaches in dementia: an evaluation of three interventions from an occupational therapy perspective
Author(s)	Dolan, Orla
Publication Date	2017-01-25
Item record	http://hdl.handle.net/10379/6266

Downloaded 2024-04-25T07:02:03Z

Some rights reserved. For more information, please see the item record link above.



Title:

Rehabilitation approaches in Dementia:

An evaluation of three interventions from an
Occupational Therapy perspective

Volume: One

Orla Dolan, BSc (Hons) Occupational Therapy,
Senior Occupational Therapist.

Supervisor: Prof. Agnes Shiel.

School of Health Sciences

Discipline of Occupational Therapy, National
University of Ireland, Galway.

January 2017.

Table of contents:

Acknowledgement _____	11
Abstract _____	12
1.Introduction_____	14
2. Literature Review Chapter _____	19
3. Methodology chapter _____	71
4 Results chapter _____	129
5 Discussion Chapter _____	192
6 Conclusion _____	242
Reference List _____	244

Table of Figures:

Figure 1	20
Figure 2	79
Figure 3	111
Figure 4	131
Figure 5	132
Figure 6	136
Figure 7	138
Figure 8	139
Figure 9	140
Figure 10	141
Figure 11	173
Figure 12	174
Figure 13	175
Figure 14	161
Figure 15	178
Figure 16	185
Figure 17	186
Figure 18	187

List of tables

Table 1	83
Table 2	85
Table 3	93
Table 4	102
Table 5	104
Table 6	111
Table 7	115
Table 8	120
Table 9	121
Table 10	130
Table 11	130
Table 12	132
Table 13	134
Table 14	143
Table 15	144
Table 16	146
Table 17	146
Table 18	154
Table 19	155
Table 20	157
Table 21	158
Table 22	161
Table 23	163
Table 24	165
Table 25	168
Table 26	171
Table 27	172
Table 28	179
Table 29	181
Table 30	183

Table 31.....	184
Table 32.....	188
Table 33.....	195
Table 34.....	323
Table 35.....	324
Table 36.....	325
Table 37.....	326
Table 38.....	326
Table 39.....	327
Table 40.....	329
Table 41.....	330
Table 42.....	331
Table 43.....	332
Table 44.....	333
Table 45.....	333
Table 46.....	335
Table 47.....	351
Table 48.....	353
Table 49.....	367
Table 50.....	368
Table 51.....	368
Table 52.....	369
Table 53.....	370

Table 54.....	371
Table 55.....	372
Table 56.....	373
Table 57.....	374
Table 58.....	377
Table 59.....	380
Table 60.....	381
Table 61.....	385
Table 62.....	387
Table 63.....	388
Table 64.....	390
Table 65.....	392
Table 66.....	393
Table 67.....	394
Table 68.....	397
Table 69.....	393
Table 70.....	400
Table 71.....	401
Table 72.....	403
Table 73.....	404
Table 74.....	405
Table 75.....	406
Table 76.....	406

Table 77.....	409
Table 78.....	411
Table 79.....	412

List of Appendices:

- 1: Dementia an overview, p281
- 2: Screening checklist, p283
- 3: CAPE, relevant components, p287
- 4: Participant information leaflet, p288
- 5: Consent form, p292
- 6: Next of kin/family information leaflet, p295
- 7: Permission for use of SMMSE, p298
- 8: Joint consent forms, p299
- 9: Permission ADCS-ADL, p302
- 10: Permissions NPI, p303
- 11:Permissions CAPE, p304
- 12: Personal communication by e mail, p305
- 13: Session details, p306
- 14: Baseline assessments, p321
- 15: CST Baseline results, p323
- 16: Sonas Baseline results, p328
- 17: ADCS-ADL Baseline results, p336
- 18: QOL-AD Baseline results, p339
- 19: Holden Communication Scale Baseline results, p342
- 20: NPI Baseline results, p346
- 21: EL intervention technique, p349
- 22: Participant one, B phase, Chaining list, p351
- 23: Participant two, B phase, Chaining list, p353
- 24: Orientation board, p354
- 25: Shopping list, p355
- 26: To do list, p356
- 27: Cooker Sign, p357
- 28: Checklist when leaving the house, p358

- 29: Sign for keys, p359
- 30: Sign for glasses, p360
- 31: Ethics letters, p361
- 32: Letter of indemnity, p367
- 33: Medication analysis, p368
- 34: Relationship between variables at baseline, p370
- 35: OTTOS analysis, p372
- 36: Results chapter, supplementary analysis, question 3, p373
- 37: Phase two, case study one, session 2-5, p374
- 38: Phase two, case study one, session 7-10, p385
- 39: Phase two, case study one, sessions 12-15, p392
- 40: Phase two, case study two, session 2-5, p397
- 41: Phase two, case study two, session 7-10, p403
- 42: Phase two, case study two, session 12-15, p408
- 43: Phase two, participant information leaflet, p415
- 44: Phase two, participant consent form, p418
- 45: OTTOS baseline assessment, p421
- 46: CST monitoring progress form, p425
- 47: Sonas Group session evaluation tool, p426

Declaration regarding work

I Orla Dolan (formerly Orla Brady), PhD candidate, certify that the thesis is all my own work and I have not obtained a degree in this University, or elsewhere, on the basis of this work.

Acknowledgement

To my husband Robbie, you have been a wonderful support and encouragement in every possible way throughout this PhD. You are a wonderful man, it is a privilege to be your wife and I am eternally grateful for your love, support and kindness. Thank you from the bottom of my heart.

To my parents Jimmy and Pauline, you have always said that I can do and be anything if I put my mind to it. You have supported me with my education all my life and instilled the belief and drive in me that I can achieve anything. Thank you for everything.

To Prof. Agnes Shiel, you are an inspiration as a supervisor. You have supported me in achieving my limits, given me many opportunities and have believed in my abilities even when I struggled to. I would like to thank you for your honesty, kindness, professionalism and encouragement.

To the multidisciplinary team in the psychiatry of later life department and the occupational therapy department in Longford and Westmeath. You all have been a true inspiration and support throughout this PhD. Thank you.

To all the individuals who participated in this research; without you this would not be possible. Thank you.

Finally, to my unborn baby you have been very kind to your mammy as she finished this PhD. I hope in years to come that this piece of work inspires you to achieve your hopes and dreams. Your daddy and I cannot wait to meet you and we love you dearly.

Abstract

Dementia is a complex, progressively degenerative condition resulting in loss of cognitive and functional capabilities, along with a significant increase in degree of dependency.

In recent years a number of non-pharmacological interventions for individuals with Dementia have been developed and this has coincided with the reduction in the use of pharmacological interventions (Spector et al, 2008). Similarly, there has been an increase in good quality research to support these non-pharmacological interventions (Copper, 2012), (Logsdon, 2007). This study aims to build on this evidence base through its research into three rehabilitation approaches in dementia.

This study was carried out in two phases. Phase one was a single blind prospective controlled trial which examined and compared two group intervention approaches, Cognitive Stimulation Therapy (CST) and Sonas - with 28 participants with moderate dementia. Significance levels were set at 0.05. Parametric tests used were the t test (t), ANOVA (F) and Pearson correlation coefficient (rho). Non-parametric tests used were the Mann-Whitney U test (U), the Wilcoxon signed rank test (W), the Kruskal-Wallis test (K) and the Spearman's rank order correlation (rho). Results of phase one supported CST to a greater extent than Sonas with participants in the CST group showing significant changes in cognition ($p=.032$), and communication ($p=.006$). Both groups had significant changes in carer rated quality of life (CST $p=.019$; Sonas, $p=.035$) and occupational performance within a group setting (CST $p=.005$, Sonas $p=.002$).

Phase two presents two single case studies which examine the impact of goal focused Errorless Learning (EL) interventions combined with compensation and modification of the environment with two community dwelling participants. Results supported the use of the interventions in both cases with significant changes in the participants' abilities to carry out their desired occupations as a result of intervention. Specifically, the numbers of errors made during the task were reduced for both participants and both participants were more efficient with the tasks.

The outcomes of this study are positive. This study provides evidence that OT intervention can impact on the trajectory of the condition with people with dementia and demonstrates clearly that they do have rehabilitation potential. Participants responded to

all three interventions tested to varying degrees. These interventions could be implemented immediately within existing services and have potential to have a significant impact on the lives of people with dementia and their carers.

1. Introduction

Dementia is a neurodegenerative disorder characterised by progressive cognitive deterioration and associated decline in activities of daily living (ADL) (Razani et al, 2011). Deterioration is likely to occur in all domains which include memory, language, communication, mood and personality (Cahill et al, 2012). As a result, individuals present with a range of symptoms which are collectively known as Behavioural and Psychological Symptoms of Dementia (BPSD). In Ireland, it is estimated that the number of people with dementia is set to rise from an estimated 41,447 in 2006 to 147,000 in 2041 (Cahill et al, 2012). Internationally, the WHO recognises dementia as a pending international epidemic (ADI, 2009).

The impact of dementia on an individual is devastating with loss of cognitive, social and behavioural functioning; leading to a gradual loss of independence, increasing and demanding care needs and death. Dementia is not a natural part of the aging process and there is currently no cure. Therefore, dementia has a profound impact not only on the individual but on the lives of those around the individual with the condition.

In recent years there has been an increased use of non-pharmacological interventions for individuals with Dementia and this has coincided with the reduction in the use of pharmacological interventions (Spector et al, 2008). Similarly, there has been an increase in good quality research to support these non-pharmacological interventions. In addition, there are an increasing number of Cochrane reviews evaluating the current evidence base for some non-pharmacological interventions (Clare and Woods, 2008), (Woods et al, 2009), (Woods et al, 2012). This study aims to build on this evidence base through its research into three rehabilitation approaches in dementia.

Cognitive Stimulation Therapy (CST) and Sonas are two types of interventions for individuals with dementia. CST is suitable for those with mild to moderate impairment and Sonas is suitable for those individuals with moderate to severe impairment. CST has an established evidence base and Sonas lacks an evidence base (Spector et al, 2003). However, implementation figures of Sonas in Ireland remain high (Sonas aPc, 2011). Therefore, phase one of this study is required to compare the impact of the two group interventions for those individuals with moderate dementia in order to inform clinical practice.

Errorless learning (EL) is a rehabilitation approach that is not embedded in clinical practice in dementia care to date. The rationale for the second phase of the study is to examine an individual approach (EL) to rehabilitation in dementia care in order to target specific client centred purposeful and meaningful occupations; where the group interventions in the literature and in phase one have been shown not to have specific treatment effects. In addition, EL has the potential for individuals with dementia to acquire meaningful skills and engage in worthwhile activities which have the potential to maintain an individual's independence in the community and delay admission to residential care (de Werd et al, 2013).

This study is presented in two phases. Phase one of this study presents the first single blind prospective controlled study of its kind that has been completed with this population. It examines and compares two types of group therapies, namely Cognitive Stimulation Therapy (CST) and Sonas for individuals with moderate cognitive impairment. It contributes to the existing evidence base for CST and for the first time presents a preliminary evidence base for the use of Sonas.

A total of 570 participants were screened and 28 participants were included from three sites, two inpatient sites and one community. Participants were recruited from an open caseload of the Psychiatry of Later Life (PLL) team Longford and Westmeath.

Participants were assessed pre and post intervention using the Standardised Mini Mental State Examination (SMMSE), the Alzheimer's Disease Cooperative study Activities of Daily Living assessment (ADCS-ADL), the Holden Communication scale, the Quality of Life in Alzheimer's disease scale (QOL-AD) and the Neuropsychiatric Inventory (NPI). Participants were assessed at the end of every session using the Occupational Therapy Task Observation Scale (OTTOS), the CST monitoring progress evaluation form and the Sonas group session evaluation form. Analysis of the results was completed using the Statistical package for Social Sciences (SPSS) and results were presented in the form of hypotheses and secondary questions.

The main findings of phase one of the study supported the use of CST intervention to a greater extent than the Sonas. The CST group only demonstrated statistically significant differences in cognition using the SMMSE and in communication using the Holden Communication Scale. There were no changes of statistical significance in ADL or NPI total scores as a result of either intervention. The NPI showed statistically significant

changes on three individual components of the NPI for the CST group only. The QOL-AD data showed statistically significant positive improvements in carer rated QOL-AD scores only for both CST and Sonas groups.

Both groups were found to have statistically significant changes within the group sessions as measured by the OTTOS. Participants who received Sonas demonstrated statistically significant improvements in more areas assessed than the CST condition when assessed using the Sonas group session evaluation form. Participants who received CST demonstrated statistically significant improvements in more areas assessed than the Sonas condition using the CST monitoring progress evaluation form.

Phase one results are discussed in the context that dementia has a progressive nature with deterioration expected through the natural course of the disease. Therefore, maintenance on outcome measures is a positive outcome. On the SMMSE, both groups demonstrated changes in cognition that were more than maintenance of cognition but only the CST group reached statistical significance.

Neither group outcomes reached statistical significance in terms of total scores on the QOL-AD but the CST group demonstrated a trend towards significance. In other studies cognitive stimulation was associated with a significant benefit to well-being and quality of life compared with no treatment (Woods et al, 2012). Groups demonstrated statistically significant changes on the QOL-AD in terms of the carer rated scores which acknowledged that carers experienced changes in QOL as a result of both groups but participants themselves did not.

Evidence for the use of CST only in terms of targeting communication was found on the Holden communication scale. Participants in the CST group are considered to have greater opportunities to express their opinions and make contributions in the group reinforcing positive communication.

There were no significant differences in outcomes for either groups on the NPI total scores. However, both groups demonstrated a trend towards significance which is greater in the CST than the Sonas group. A small change on the NPI that makes a participant more or less agitated or aggressive has significant implications on their care irrelevant of the setting and overall their ability to function on a daily basis is considered clinically significant and therefore the outcome of this study is of major importance to

this population as a reduction in neuropsychiatric symptoms is a priority goal for non-pharmacological interventions. These groups have the potential to reduce carer burden/stress which ultimately leads to increased care needs and possible nursing home admission for community participants and similarly staff stress and levels of positive interactions with individuals (Coen et al, 1997).

Phase two of the study was informed by the findings of phase one. It examines a different approach through individual therapy with two individuals who have dementia. An ABA single case experimental design was used. These are the first single case studies which examine the impact of goal focused Errorless Learning (EL) interventions, delivered in combination with compensation and modification of the environment.

Two participants participated in the study. Participants were community dwelling individuals. Assessments consisted of pre and post assessments using the Addenbrooke's Cognitive Examination III (ACE-III), the Holden communication scale, the ADCS-ADL scale, the Barthel Index (BI) and the QOL-AD. Activity analysis and error measurement was completed using repeated measurement within each of the 15 sessions by the PI. Results of this phase of the study were analysed using visual inspections and comparison of pre and post assessment scores.

Results supported the use of the intervention in both case studies. Case study one found a reduction in the number of errors, a reduction in the number of steps required to complete the task, a change in the level safety for the occupation, statistically significant changes in QOL and clinically significant changes in communication. Case study two found a small reduction in the number of errors and the number of steps required to complete the task.

There was a small improvement (not clinically significant) which suggests maintenance of cognition for participant one and a four point reduction for participant two suggesting no effect on cognition.

Positive outcomes for participant 1 were found in communication and maintenance of communication for participant two. Clinically significant changes that potentially have an impact on the person and their interactions through communication with others are found for both participants supporting the use of the intervention in terms of communication.

The QOL-AD outcome for participant 1 indicated a significant change for the participant but little change for the carers/families. There were no differences in outcomes on pre to post assessment for participant 2, suggesting maintenance of QOL. The literature suggests that there appear to be significant differences between an individual and a carers/families perspective into what constitutes QOL which may explain the differences in outcomes between participants and their carers/families (O'Rourke et al, 2015).

Both participants in phase two had a significant reduction in the number of errors as a result of intervention, therefore the benefits of EL for both participants are clear. In particular the type of errors that the participants continued to experience were found to be clinically relevant as they did not impact on the overall completion of the goals or the safety.

This research is presented in four chapters. A literature review will examine and present the existing evidence base and provide context for the research. The methodology will examine how the research was conducted. The data, the statistical treatment and mechanics of analysis will then be presented in the results chapter. A discussion will then present interpretations and opinions, explain the implications of this research, and make suggestions for future research and clinical practice. Finally, a conclusion will summarise the main findings and implications of this research for this population.

2. Literature Review Chapter

2.1 Introduction

A review of the current literature which formed the basis for the study will now be examined and presented. This will position this study in the context of the literature currently available. The search of published literature for the review included electronic databases of papers in peer reviewed journals and library sources. The search terms used (with and/or throughout) were dementia Alzheimer's disease, vascular dementia, dementia with lewy bodies, mixed dementia, parkinson's related dementia, frontotemporal dementia, cognitive impairment and/or mild, early-stage, early onset, moderate, middle-stage, severe, advanced and/or disability, impairment, ailment, injury, defect and/or rehabilitation, improvement, recovery and/or occupational therapy, psychology, medicine, nursing and/or cognitive stimulation, cognitive training, multisensory stimulation, sensory stimulation, non-pharmacological approaches, non-drug therapies, group therapies, individual therapies and/or patients, individuals, carers, people and/or quality of life, neuropsychiatric symptoms, behaviour, cognition, activities of daily living, communication, speech, interactions with others, group interactions.

2.2 Occupational Therapy (OT) framework

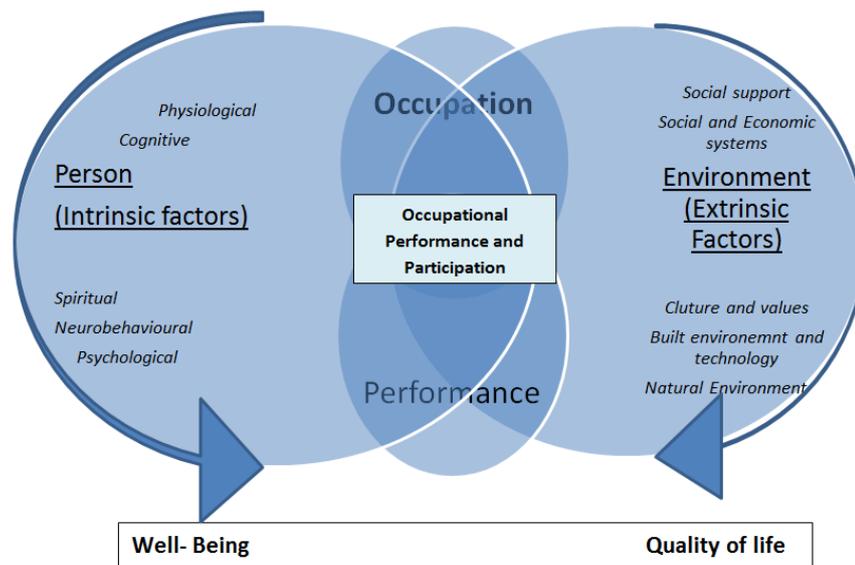
Occupation is at the core of Occupational Therapy (OT). OTs have

'a unique perspective, that of enabling people to engage in occupation when health conditions, societal conditions or disabilities impair or threaten their ability to do that which is important and has meaning for them'

(Christiansen & Baum, 2005, p243).

The practice framework relevant to this research study with consideration of this perspective is the Person- Environment- Occupation- Performance (PEOP) Model (Christiansen & Baum, 2005). This model is illustrated in the following diagram (Figure 1):

Title of figure 1: PEOP Model.



(Adapted from Christiansen & Baum, 2005, p243)

Figure 1

In this model of practice, OT intervention enables a group or an individual to use or develop their resources for successful performance of the chosen occupations using a broad range of purposeful client centred strategies. This model has four major components as outlined in the illustration above. **Occupation** is said to be ‘*what people want or need to do in their daily lives*’ for example, the goal to prepare breakfast. This, combined with, ‘*the actual act of doing the occupation*’ which is the occupational task of actually preparing the breakfast, termed **Performance**. Together with the consideration of the **Person** factors, such as how psychological, physiological, neurobehavioral, cognitive and spiritual factors for example a dementia, combine with the places at which the occupations are undertaken for example, the home or the day care centre, termed the **Environment** influence success (Christiansen & Baum, 2005, p245). The rationale for the use of this PEOP model of practice in this research project is that it is client centred, not impairment centred. It directs the OT to broaden their understanding of the client and it identifies importance of the environments in which people function. For example, an EL and a dementia friendly environmental modification combined can be viewed as purposeful client centred strategies to engage an individual in a goal orientated occupation such as preparing breakfast. Full application of the model to this study will be discussed later in more detail in the discussion chapter.

A client centred approach is central to the process of OT, irrelevant to what model of practice is chosen. It is defined as

'An approach to providing occupational therapy which embraces a philosophy of respect for and partnership with people receiving services. It recognises the autonomy of individuals, the need for client choice in making decisions about occupational needs, the strengths clients bring to an occupational therapy encounter and the benefits of the client therapist partnership and the need to ensure that the services are accessible and fit for the context in which a client lives' (Law et al, 1995, p 253).

Client centred practice can be used with any client group. When implementing it with a person with dementia the method of implementing client centred practice may have to be adapted depending on the level of cognitive impairment. This should include four extended areas: enhanced client assessment which includes clinical capacity assessment and extended history taking, graded decision making and advocacy on behalf of the individual (Sumsion, 2006). This is particularly relevant to clinical research studies which include persons with dementia as it reinforces the need to include family members, relevant others and carers in the assessment, intervention and evaluation process. These factors are particularly relevant to this research study as this approach guided the research planning process and used a tool which is central to the practice of OT.

This literature review incorporates the PEOP model though its presentation and critique of information in the following sections:

- Personal factors: These are known as the intrinsic enablers of performance are discussed through an overview of dementia which incorporates neurobehavioural factors, physiological factors, cognitive factors, psychological, emotional and spiritual factors.
- Environment: participation is known to be influenced by the nature and characteristics of the environment which it occurs (Christiansen & Baum, 2005). This literature review incorporates sections on dementia friendly environments, compensation and modification of the environments to illustrate the position of the environment in dementia.

This review of the literature encompasses the person factors and the environment factors. This facilitates an understanding of the context of occupational performance and participation for the person with dementia which is dealt with in the methodology and results. This sets the scene for the rationale for this study. The relevance of this approach to this study will be discussed in more detail in the methodology and discussion chapter.

2.3 Dementia – an overview

Dementia is a biomedical, psychological and social disability characterised by a collection of symptoms including loss of cognitive and social functioning as well as behavioural changes. Currently, dementia is used as an umbrella term used to describe a number of conditions that cause damage to brain cells and impairment in a large number of domains. It is progressive in its nature and is age-related; the incidence and prevalence increases significantly with advanced years. Prevalence is reported to double every 5 years from the age of 65 (Cahill et al, 2012).

The word dementia originated in the 18th Century from the Latin word ‘demens’ meaning without mind. Medical use of the term evolved in the 19th century and the term dementia was used to describe individuals whose mental disability was secondary to some form of Acquired Brain Damage which was noted to be degenerative and occurring mostly in old age. One of the initial studies of dementia by Marcē (1863) describes specific changes at post mortem that were not seen in non-demented individuals; this included cortical atrophy, enlarged ventricles, and softening of the brain tissue. Further research initially speculated that this softening was caused by a disorder of the blood supply to the brain. However, later research identified more degenerative and subtle changes associated with nerve cell death. Dr. Alois Alzheimer reported abnormal lesions in the form of senile plaques and neurofibrillary tangles in the brain of a female individual and detailed her symptoms to include progressive memory failure, language difficulties, agitated and aggressive behaviours at the age of 51. This led to our understanding of Alzheimer’s disease (AD) as being the most common form of dementia (Cantley, 2001).

The term dementia is now used as an umbrella term to describe a group of syndromes all of which are characterised by a progressive decline in cognitive function reaching a level of severity which interferes in occupational functioning and ultimately leads to complete dependence and death. To date over 200 subtypes of dementia have been defined

(Downs & Bowers, 2008, p11). For the purpose of this literature review a summary of the most commonly encountered subtypes in clinical practice will be presented in terms of their various courses, pattern of presentation and neuropathology. A summary of the relevant neuropathology of dementia can be found in appendix (1).

AD is thought to cause over half of all cases of dementia. AD is defined by a characteristic loss of hippocampal and cerebrocortical neurons (Lublin & Gandy, 2010). These regions control memory, thought, language, attention, perception and consciousness. AD is recognised by the accumulation of protein called beta-amyloid (which deposits outside the neurones) forming together on the brain which cause plaques and neurofibrillary tangles (NFTs) (which accumulate inside the neurones) that inhibit brain functioning (Shan, 2013). Memory loss is one of the first symptoms of this disease in the majority of cases and it is the most striking feature; however there are a range of early signs and symptoms including word finding difficulties, misplacing things regularly, losing track of time, changes in mood and behaviour and difficulty in finding the way, even in familiar places. AD is slightly more prevalent in women and age is the most common risk factor (Cantley, 2001). A range of behavioural and psychological symptoms of dementia (BPSD) associated with AD are recognised as a major component of the syndrome, BPSD are said to occur in 90% of all cases of Dementia (Robert et al, 2005). The most common emotional disorders in AD include apathy, anxiety and depression (Robert et al, 2005). In 40% of people with AD, anxiety and depression are present in the early stages of the disease arising from individual's awareness of the condition and its prognosis (Herbert et al, 2013). The rate of progression is variable and, on average, a person's scores on cognitive testing will deteriorate by 10% every year. As the illness progresses and self-awareness diminishes, the likelihood of depression decreases (Herbert et al, 2013). Life expectancy ranges from 2-20 years from onset of symptoms with an average of ten years. Management strategies for BPSD in AD include adopting a comprehensive biopsychological approach, including counselling, individual and family education, pharmacological interventions, carer support, respite and legal advice (NICE-SCIE 2007), (Haberstroh et al, 2010).

Vascular dementia (VaD) - The second most common type of dementia is vascular dementia. This accounts for between 15% and 20% of all cases. Estimations of the true incidence of VaD cases is said to be difficult to define (Jacoby & Oppenheimer, 2002, p533). This is illustrated in one community-based clinicopathological study of

individuals with dementia where it was found that a clinically defined prevalence of VaD was 9% but on post mortem examination of the same group, infarction was present as a primary pathology in 14% and as a secondary pathology in a further 15% (Holmes et al, 1999). VaD occurs when the blood supply to the brain is compromised. VaD represents a group of conditions that includes all dementia syndromes that result from ischaemic, anoxic or hypoxic brain damage (Downs & Bowers, 2010). There are two main types of VaD; one caused by stroke and the other by small vessel disease/cerebrovascular disease. Increasingly, people are being diagnosed with a mixed form of dementia, caused by both AD and VaD (Cahill et al, 2012). The symptoms of VaD are summarised to be in the form of poor attention/concentration, communication and physical symptoms such as paralysis or weakness in limbs (Downs & Bowers, 2010, p12). Similar to AD, VaD is progressive, is associated with poor life expectancy and its disease course can be highly variable (Downs & Bowers, 2010).

Mixed Dementia -The third most common type of dementia is mixed dementia. Estimates for the numbers of examined brains with mixed brain pathology have varied from 4 to 23 per cent (O'Brien, 1994). The precise population based prevalence is unknown. Later estimates based on retrospective and prospective autopsy studies suggested a wide range from 2 to 58 per cent with a reasonable mean range from 6-12 per cent (Jellinger, 2008). Kitwood (1997) made a rough generalisation stating that the older a person with Alzheimer's disease is at the point of death, the more likely the brain will show signs of vascular pathology (Kitwood, 1997). As outlined earlier, stroke and cerebrovascular disease are the hallmarks of VaD, while senile plaques and neurofibrillary tangles typify AD. It is the combination of the two pathologies that define mixed dementia (Ames et al, 2010). Mixed dementia symptoms are variable, depending on the types of brain changes involved and the brain regions affected. A study by Dang et al, (2013) suggests that the neuropsychological profile of individuals with mixed dementia of mild to moderate severity is characterised by poorer global cognitive performance when compared to those with AD. In contrast, symptoms in some cases may be similar to or even indistinguishable from symptoms of AD or another dementia type. In other cases, individuals' symptoms may suggest that more than one type of dementia is present. The Neuroepidemiology Branch of the National Institute of Neurological Disorders and Stroke and the Association Internationale pour la Recherche et l'Enseignement en Neurosciences (NINDS-AIREN) diagnostic criterion is

recommended to diagnose this complex pathology of mixed dementia clinically and accurately (Ames et al, 2010).

Dementia with Lewy bodies (DLB) is a type of dementia that shares characteristics with both AD and Parkinson's disease (PD). Lewy bodies are abnormal aggregates of protein that develop inside nerve cells in the brain. On examination, Lewy bodies appear as spherical masses that displace other cell components. They are occasionally surrounded by NFT's. Estimates of persons with DLB in the community vary. It is estimated that clinically only 2-5 % of cases referred for specialist assessment are given the diagnosis, suggesting an under detection (Ames et al, 2010). DLB accounts for just fewer than 20% of all cases of dementia referred for neuropathological autopsy (McKeith et al, 2005). The central characteristics to DLB are fluctuating cognitive impairment which is found in up to 90% of all cases with periods of increased confusion and windows of relative lucidity (Downs & Bowers, 2010). Similar to AD, symptoms progress gradually over time. The person will experience many of the signs and symptoms of AD and may also experience complex visual hallucinations, decreased visuospatial functioning, attention deficits, muscle stiffness, trembling of the limbs and a tendency to shuffle when walking. Visual hallucinations and sleep disorientation are found in 80% of cases (Clare et al, 2013). Recent memory function is not as severely impaired as in AD, this is possibly because pathological changes are not so focused on the hippocampus. Motor impairment usually develops after cognitive impairment differentiating it from PD (Wilcock, 2003). Studies suggest that the life expectancy of DLB is seven to eight years, with a few cases of DLB deteriorating very rapidly and dying within one to two years of presentation (Downs & Bowers, 2010, p13).

Parkinson's related Dementia- in PD, dementia develops in between 30% and 70% of cases, depending on duration and age (Aarsland et al., 2003). PD is a common neurodegenerative disorder affecting about 1.5% of people aged 65 years and older (Ames et al, 2010). The risk for developing dementia in PD is almost six times higher than in non PD individuals (Aarsland et al, 2001). It is not yet understood how dementia occurs in PD. It is suggested that an abnormal protein or a Lewy Body accumulates inside neurons in deep brain structures known as the substantia nigra. Lewy bodies are also seen outside the deep brain structures, in people with PD, as they do in DLB. In addition, plaques and tangles are found in most cases at autopsy (Jellinger et al, 2002). Dementia associated with PD is very similar to DLB. The main difference is that

problems with movement occur before cognitive symptoms appear in dementia associated with PD (Alzheimer's society, 2014). Symptoms of dementia associated with PD vary depending on the individual. The most common are memory, attention, visuospatial function, executive function and visual hallucinations. The person's symptoms may fluctuate. The most frequent emotional problems for those with PD are depression, anxiety and psychosis. Depression is the most common disorder and is reported in 40% of cases (Stocchi & Brusa 2000). In a USA 12 year population study by Butler et al (2008), a total of 233 PD individuals were included. They concluded that 140 individuals had developed dementia by the end of the study period. They found that the cumulative incidence of dementia increases with age and duration of PD. In addition, depending on survival, this incidence increases to 80% to 90% by the age of 90 years. Women were found to live longer with PD than their male counterparts and spend more years with dementia. A man with PD at 70 years but no dementia has a life expectancy of 8 years, of which 5 years would be expected to be dementia free and 3 years would be expected to be with dementia.

Alcohol-related dementia and Wernicke Korsakoff syndrome (WKS)- Many conditions may give rise to cognitive impairment in association with alcohol abuse and dependence and therefore a wide spectrum of neuropathological changes may be found in the brains of those who have had prolonged high intake of alcohol. Korsakoff syndrome is also referred to as wet brain, Korsakoff psychosis, and alcoholic encephalopathy. It is often but not always, preceded by an episode of Wernicke encephalopathy. This is an acute brain reaction to the deficiency of thiamine (vitamin B1). Wernicke encephalopathy is a medical emergency with death occurring in 20% of all cases. It causes life-threatening brain disruption, confusion, staggering and stumbling, lack of coordination, and abnormal involuntary eye movements. The chronic memory loss of Korsakoff syndrome often follows an episode of Wernicke encephalopathy. Both are seen as having a close relationship and as a result the chronic disorder is sometimes known as Wernicke-Korsakoff syndrome. Korsakoff syndrome can also develop in individuals who have not had a prior episode of Wernicke encephalopathy (Ames et al, 2010).

Alcohol related dementia in this form lacks a clear clinical pathology and usually affects recent episodic memory in particular. Other cognitive domains are relatively preserved. This is thought to occur because of a nutritional deficiency of vitamin B1 (thiamine)

caused by heavy sustained drinking, it is known to be reversible in the early stages by appropriate vitamin supplementation (Downs & Bowers, 2010). It is not yet known why heavy drinking causes severe thiamine deficiency in some alcoholics, while others may be affected primarily by alcohol's effects on the liver, stomach, heart, intestines or other body systems. Diagnosing alcohol-related dementia can be difficult due to the wide range of symptoms and a lack of specific brain pathology. Korsakoff syndrome can also be caused by uncontrolled vomiting, AIDS, kidney dialysis, chronic infection, anorexia, overly-stringent dieting, fasting, starvation or weight-loss surgery, or cancer that has spread throughout the body. Treatment recommendations for this type of dementia are under experiment presently. Recommendations are to target the cause with behavioural management of cognitive impairment and alcohol dependence, B vitamin therapy and thiamine therapy (Ames et al, 2010). Specific prevalence studies are lacking in this area.

Creutzfeld-Jacob Dementia (CJD) is a rare and rapidly progressive multifocal dementia often progressing to death within six months to one year. One third of cases have prodromal features such as fatigue, insomnia, depression, weight loss, headaches, general malaise and poorly defined pain sensations (Ames et al, 2010). Frequent additional neurological signs include extrapyramidal signs (movement disorders), cerebellar ataxia (inability to coordinate balance, gait, extremity and eye movements), pyramidal signs (spasticity, weakness, slowing of rapid alternating movements, hyperreflexia and Babinski sign) and cortical blindness. CJD is transmitted by a brain protein called prion, appendix (1). There are no known causes for the 80% of cases of sporadic CJD. CJD may occur because of inherited or spontaneous mutations of the gene that carries the code for the protein. This accounts for 15% of cases with 5% of the cases being iatrogenic cases linked to human to human transmission following transfer of infected material from one individual to another. CJD has a worldwide distribution and incidence of 0.5 to 1.0 cases per million populations per year. CJD also is known to be possible through eating of infected material from beef for genetically susceptible individuals (Downs & Bowers, 2010). In 1995, a new form of CJD was described in the UK in two teenagers (Bateman et al., 1995), (Britton et al., 1995) known as variant CJD or vCJD (Will et al, 1996). The emergence of vCJD was linked to the bovine spongiform encephalopathy (BSE) in cattle and vCJD appears to have arisen through the consumption of BSE infected animal products. vCJD individuals tended to be younger

that those with sporadic CJD and were found to have a longer duration of their illness which was associated with psychiatric presentations and sensory impairments.

Huntington's disease (HD)- HD is an autosomal dominant genetic neurodegenerative disease causing abnormal writhing movements of the trunk and limbs, problems with coordination, emotional disorders, together with cognitive impairment that gets progressively worse over time (Ames et al, 2010). The specific symptoms and progression of HD can be related to its neuropathology, which is characterised by loss of specific neuronal populations in many brain regions. Therefore, the course of the disease varies for each person and dementia can occur at any stage of the illness. Bates et al (2002) agrees that the description of the cognitive symptoms in HD in the form of dementia is appropriate as it denotes that the changes are progressive and encompass more than one area of cognitive function. Symptoms of dementia associated with HD are noted to encompass specific and characteristic cognitive deficits with other areas of cognitive function being well preserved. This form of dementia differs from AD in that those with the condition continue to recognise people and places until the very late stages of the illness. The dementia associated with HD is characterised by memory deficit, psychomotor slowing, apathy and depression. The psychiatric symptoms associated with HD are more variable than the cognitive and motor changes and do not follow the same progressive course (Bates, et al, 2002). HD usually begins mid-life and has a protracted course of 15-20 years. The cognitive domains affected include executive, language, perceptual, spatial skills and memory (Ames et al, 2010). Fifty per cent of HD family members are at risk of developing the disease (Cantley et al, 2001). It is suggested that genetic factors play a role in the age of onset of HD and the presentation of the disease (Bates, Harper & Jones, 2002, p29). There is no preventative or curative treatment for HD. The current goals in management of HD are

'To reduce symptoms, decrease disability and improve quality of life' (Bates et al, 2002, p475).

Frontotemporal dementia (FTD) - FTD is a clinical term that encompasses a spectrum of disorders. FTD is the most common of a group of clinical syndromes associated with degeneration of the temporal and frontal lobes of the brain with no AD pathology. The group of clinical syndromes are collectively referred to as Frontotemporal lobar degeneration (FTLD). For the purpose of this literature review the most common forms

of FTD will be discussed. FTD is described as not being clinically or pathologically uniform. The clinical presentation is primarily in relation to behavioural change at its onset and throughout its course in the form of alteration in personality and social conduct. Cognitive changes particularly in language and executive functions occur. Progressive non-fluent aphasia (PNFA) affects mainly language output with a non-fluency and variable loss of grammar and phonemic word substitutions. Those with semantic dementia (SD) have poor comprehension of words and pictures and pronounced anomia (Jefferies, 2011). The language speed of an individual with SD remains fluent, with normal use of grammar, normal digit span and memory is well preserved initially. However, there is known to be hesitation in word finding, loss of vocabulary and semantic paraphrases and speech becomes 'empty' through loss of its content with gradual deterioration in the structure of conceptual knowledge (Jefferies, 2011). SD has a late age of onset, slower rate of progression and a less frequent family history. Behavioural variant (bv-FTD) affects behaviour primarily but also affects executive skills, and the person presents with apathy and disinhibition. By-FTD has the earliest age of onset; highest reported family history and most rapid progression (Hardiman and O' Doherty, 2011).

The prevalence data for FTD is limited for those over 65; it is most often diagnosed between the ages of 45 and 65. Younger or older people can also be affected. This is much younger than the age at which people are most often diagnosed with the more common types of dementia such as AD. This early diagnosis is said to be difficult as a result of the initial symptoms being non-specific behaviour disorders such as disinhibition and apathy (Meyniel, 2005). Prevalence studies show varied results. Rosso et al, (2003) reported estimates of 3.6 persons per 100,000 at age 60-69 and increasing to 3.8 per 100,000 at 70-79 years in a Netherlands population-based study. In a 2002, UK based prevalence study the prevalence for early onset dementia was 15 per 100,000 for individuals aged 45-64 years. This makes it equivalent to AD for the younger age group. In this study they suggested that while FTD is by no means rare in the under 65 age group, it still only represents a minority of cases (Ratnavalli et al, 2002). In FTD, bv-FTD is the most common variant affecting 55% of all cases, PNFA accounts for 25% of cases and SD for 20% of cases. A positive family history is said to be present in 40% of cases, with an equal incidence in men and women and the onset of symptoms is from 45-65 years (Ames et al, 2010). Familial history of early onset dementia in first degree

relatives is thought to be found in 5-10% of cases. The length of illness varies from 2-20 years with a median of 6 to 8 years (Snowden et al, 1996). The presence of motor involvement is associated with shortened survival (Hardiman & O' Doherty 2011).

Picks disease (PiD) - In recent years there has been a difference of opinion when it came to defining PiD. Current opinion is that the term FTD should be used as an umbrella term for the overall clinical syndrome which includes PiD. PiD once represented a class of clinical syndromes with symptoms attributable to frontal and temporal lobe dysfunction. It is now understood by professionals to mean a specific pathology with characteristic clinical features that is one of the causes of FTD (Rossor, 2001). It is extremely difficult to diagnose (Bigio, 2013). The genetic mutations found in AD, HD and motor neuron disease have not been found in FTD or PiD, defining its specific pathology (Jacoby & Oppenheimer, 2002), appendix (1). PiD presents clinically in the form of a speech and thinking disorder, behavioural disorder and affective disorder. Clinical markers of the disease include depression, anxiety and excessive sentimentality, hypochondriasis and bizarre somatic complaints, emotional bluntness, apathy and lack of empathy, Amimia (loss of the power to give facial expression to emotion), progressive reduction of speech output, stereotypy of speech, perseveration, late mutism, loss of insight, loss of personal and social awareness, disinhibition and lack of judgement (Jacoby & Oppenheimer, 2002). PiD is rare and has a prevalence of 1-2% in post-mortem studies of dementia. Its onset is about the age of 60 and death is said to occur within 10 years (Gauthier, 1999) and unlike AD individuals present before 65 years of age and is relatively uncommon after 70 years of age (Coleman, 2002).

In summary, this section outlined the different types of dementia all of which have similar symptomology, differences within them and common manifestations. It is clear that Dementia in its mild to moderate stages is not expressed by an overall deterioration affecting all cognitive functions but may affect certain specific processes or cognitive systems and leave other aspects of cognitive functioning intact. The clinical research studies which form this thesis included all types of dementia. It is clear that there is a window of opportunity for interventions within the mild to moderate stages in terms of rehabilitation using a person centred approach to treatment. This window of opportunity in the mild to moderate stage requires establishment of routines, the use of compensatory measures and memory aids in order to be able to deal with the more complex issues as the disease progresses. Exploiting cognitive and functional capacities is a core goal for

maintaining individuals' autonomy in their daily lives and for the learning of instrumental activities of daily living. Additionally, it is clear from this examination of the various clinical pathologies that the goals of rehabilitation are different for the more severe stages of Dementia and therefore those with severe impairment were not included in this study.

2.4 Causes of AD and Dementia Risk Factors

In order to further comprehend the varying types of dementia all of which have similar symptomology and common manifestations, it is worthwhile examining the causes of AD and the risk factors associated with dementia. This is relevant to the context of this study as this study includes all types of dementia in its inclusion criteria and this section explains the background to the manifestation of dementia. It also provides context for pharmacological and non-pharmacological treatments for dementia which will be discussed later in the chapter.

Genetic risk factors – Both early onset and late onset AD have a genetic component. To date, genetic mutations which are understood to be a permanent change in three genes are known to cause AD. Not all people who develop AD have these genes. The three AD genes are amyloid precursor protein (APP) located on chromosome 21, presenilin 1 located on chromosome 14 and presenilin 2 located on chromosome 1. These account for 1% of AD cases which are early onset, defined as symptomatic before age 60 (Higgins, 2013). First degree relatives of individuals with AD are at a lifetime higher risk of developing AD than the rest of the population (Green et al, 2002). Researchers have not found a specific gene that causes the late onset form of the disease. A genetic risk factor is a fourth gene called Apolipoprotein E (ApoE). Unlike the first three genes, the fourth gene is not actually a mutation but an allele, otherwise known as a genetic variant. This gene appears on chromosome 19 and it said to control the production of ApoE which is a substance that that plays a role in the movement and distribution of cholesterol for repairing nerve cells. ApoE is said to be the only consistently replicated risk factor for the most common form of AD which occurs in people over 65 years of age. The gene comes in 3 varieties- ApoE 2/ ϵ 2 allele, ApoE 3/ ϵ 3 allele and ApoE 4/ ϵ 4 allele. The ϵ 4 allele leads to the accumulation of AD pathology but also interacts with other risk factors to cause cognitive impairment in AD (Ames et al, 2010). Hay (2006) reported that people without the ϵ 4 allele have a 20 per cent risk of developing AD by

the time they reach 75; people with one copy of the $\epsilon 4$ allele have a 60% chance of developing AD and people with two copies have a 90% chance of contracting AD. Not all carriers of the $\epsilon 4$ allele develop AD or other dementias (Wang, 2012). The $\epsilon 2$ and $\epsilon 3$ allele appeared to have a protective effect. Theory suggests that the nerve cell structure is conserved by the $\epsilon 2$ and $\epsilon 3$ allele by holding onto a protein known as tau, which is found in the neurofibrillary tangles. They then subsequently avert tau from configuring tangles (Hay, 1996). The presence of the $\epsilon 2$ allele is associated with a 40% reduced risk of AD (Wilson et al, 2002), (Jellinger, 2006). The data is limited in this area as this $\epsilon 2$ allele is not very common (Farrer et al, 1997).

Additional genes that may be a genetic risk factor for late onset AD have been identified. These include BIN1, CLU, PICALM and CR1. Genetic research in the area of AD and Dementia is ongoing (National Institute on Aging, 2014).

Age- Age is commonly viewed as a risk factor but Ames et al (2010) suggested that it was unlikely that advancing age per se actually causes AD. It was acknowledged that age was more likely a proxy for other potential disease processes that are associated with the development of AD. Bigarella (2014) analysed a cohort study in Brazil which evaluated 104 individuals on a ten year follow up, found that those individuals with dementia were much older than those who did not have the disease. Maternal age of death was higher in the group without the disease. Both groups (those with and those without) were otherwise similar in sex distribution, education, health status, per capita income and age of father's death. It concluded with multivariate analysis that a greater risk of dementia was present in the group with maternal age of death below 60. When the same model was applied to paternal age of death it did not reach statistical significance. The limitations of this study are the high dropout rate and the fact that the residual effect of other not directly assessed covariables was not considered (hypertension, smoking, dyslipidaemias, alcoholism and physical activity).

Gender - Current data does not suggest strong sex differences in the risk of AD. Female sex has been considered as a risk factor as the prevalence of AD is more common in women than men, particularly in the age category 80 plus (Ames et al, 2010). This difference is now understood to be secondary to greater longevity amongst women. In a study by Bauer et al (2014), comorbidity and gender were examined. Findings were that males with and without dementia do not have a higher comorbidity burden than females

with and without dementia. There were limitations to this study as the observed associations found could be based on the utilisation patterns of services by the individuals involved in the study. Also, the data lacked information on dementia severity. However, the results of this study are similar to the findings in studies by Schafer et al, (2010) and Van den Bussche et al (2011) who assessed gender specific multimorbidity.

Level of Education- Evans et al, (1997) concluded from his cohort study that markers of lower socioeconomic status (education, occupational prestige and income) predict risk of developing incident AD. The mechanism was concluded to be uncertain. He recommended that the possibility that it reflects unidentified and potentially reversible risk factors for the disease deserved careful investigation (Evans et al, 1997). In a study of the links of education to cognitive decline with aging, Zahodne (2011) concluded that education was related to cognitive performance but unrelated to cognitive decline, supporting the hypothesis of passive cognitive reserve with aging. However, this study included an under-representation of males (however, this was controlled for in the analysis) and non-Caucasians and a high mean educational attainment in the sample. Passive cognitive reserve may be defined as the brain's resilience and ability to cope with increasing damage while still functioning adequately. This passive, threshold model presumes the existence of a fixed cut-off which, once reached, would inevitably herald the emergence of the clinical presentation of dementia (Robertson, 2014).

Race and Ethnicity- Ames et al, (2010) suggests that data on the association of race/ethnicity should be interpreted with great caution as both race and ethnicity have potentially confounding effects and are entangled with socioeconomic and cultural variables that strongly influence cognitive test performance.

Personality- In a study by Terracciano et al (2014), consistent evidence was found that personality traits such as neuroticism, openness, and conscientiousness predict incidence in AD. In a discussion on this article, it was suggested that these associations between personality and AD could be explained by the link between personality and health related behaviours, lifestyle factors and clinical conditions. It also suggested that personality traits were associated with coping skills and chronic stress over one's life span. However, the number of tests performed in the study increased the risk of false positive results and the authors warn that before reaching firm conclusions that the

findings need to be replicated in independent samples. In a study by Johansson et al (2012), correlations were found between midlife self-reports of female psychological stress and moderate to severe white matter lesions and temporal lobe/ central brain atrophy.

Alcohol Intake- In a literature review by Panza (2012), protective effects of moderate alcohol consumption against cognitive decline are suggested to be more likely without the presence of the AD-associated apolipoprotein E e4 allele and where wine is the beverage. They concluded that there are no signs that light to moderate alcohol intake would be damaging to cognition and dementia. A definition of beneficial levels of alcohol intake in terms of cognitive performance was seen as highly taxing and debatable (Panza, 2012). In a German study by Weyerer et al (2011), 3,202 individuals free of dementia were studied at baseline, 1.5 years and 3 years later by means of structured clinical interviews including detailed assessment of current alcohol consumption and DSM-IV dementia diagnoses. In their results they suggested that light-to-moderate alcohol consumption is inversely related to incident dementia among individuals aged 75 years and older. However, there is potential sampling bias in this study as large groups of individuals were considered ineligible for various factors such as consent. In contrast, in a Brazilian community-based cross-sectional study, where a sample of 1,145 older people was examined in 2 phases by Lopes et al (2010), results suggest that alcohol use does not have a linear relationship with cognitive decline. There were some methodological limitations to this study. The variables relating to alcohol were reported directly by the individual or an informant, which might have led to inaccuracies with the information.

Finally, in a (2014) publication on the health retirement study (HRS) which is a USA nationally representative longitudinal survey of Americans aged 50 years or older with biannual interviews, they concluded that smoking, not drinking and low income predict incident ADL limitation and had larger absolute effects on ADL onset among individuals with high dementia probability than among cognitively normal individuals. Similarly the limitations to this study are the self-report methods of measurement which are subject to bias (Rist et al, 2014).

Hypertension- Virta et al, (2013) examined cardiovascular risk factors and late cognitive impairment and concluded that multiple midlife cardiovascular risk factors

increase the risk of cognitive impairment in later life. Hypertension, midlife obesity and low leisure time physical activity increased the risk of cognitive impairment on follow up. Similarly, the limitations of the study are the self-report assessment. The assessment of cognitive function was based on a telephone interview which may have some inaccuracies. Nordstrom et al, (2013) examined the association and found a link with hypertension in midlife with increased rates of AD and dementia. However, this was in men and early onset dementia only. In the Hoorn Study, Reijmer et al (2012) found that hypertension in later life was associated with reduced rates of AD and dementia and that this relationship attenuated with increasing age. The strengths of this study were the long 15 year time period, the detailed recording of the vascular and metabolic determinants at multiple time points and the comprehensive assessment of cognition. However, because of the long follow up period response rate on follow up assessment was 60-70% and on the final sample, stratified samples of the original cohort were invited to participate. In a 35 year follow up study in Norway, Strand et al (2013) found midlife blood pressure was not found to be significantly associated with death in dementia. One of the limitations in this study was the possible underreporting of dementia in the earlier years of the study as awareness of dementia increased in the later years of the study. Joas et al (2012) in a longitudinal study of women found that regardless of treatment for blood pressure or not, there was a steeper decline in blood pressure towards later life in those who developed dementia (Rooney, 2014). However, survival bias was considered as a limitation in this study.

Diabetes Mellitus (DM) - Growing epidemiologic evidence has suggested that people with diabetes mellitus are at an increased risk for the development dementia. Evidence within the subtypes of dementia and its association with DM is limited and inconsistent. There is an association between midlife diabetes and cognition (Kaffashian et al, 2013), (Reijmer et al 2012). According to Vlassara et al, (1992) advance glycation end products, metabolic oxidation products associated with diabetes and hyperglycaemia have been found in association with NFT's and neuritic plaques in AD. It is suggested that this may highlight an association between AD and diabetes (Stewart & Liolitsa, 1999). Burns et al, (2010) in functional imaging studies in cognitively normal individuals demonstrated that there was hyperglycaemia- associated cerebral hypometabolism in regions linked to AD. Diabetes mellitus is associated with a 1.5- to 2.5-fold greater risk of dementia among community-dwelling older people. The

mechanisms underpinning the association continue to be unclear. It is suggested that they are multifactorial in nature, involving factors such as cardiovascular risk factors, glucose toxicity, changes in insulin metabolism and inflammation (Ninomiya, 2014).

Down syndrome (DS) – This group of people are at particular risk of dementia. The life expectancy of people with intellectual disabilities (ID) has increased from 20 years in the 1930's to 60 years today, with many living as long as those in the general population (Coppus, 2013). DS is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21/ trisomy 21 in 95 per cent of all cases. In rare cases it is caused by translocation (rearranged chromosome material) or mosaicism (two cell lines, one with the normal number of chromosomes, and one with an extra number 21) (Coppus, 2013). Most people with DS develop early onset AD in middle age (Alzheimer's Society, 2014). There is a large body of research evidence that suggests that those with DS have higher prevalence rates for dementia than that of the general population (Bittles & Glasson, 2004). The mean age of onset in DS of AD is 54.7 years. It is reported that all people with DS will eventually develop AD if they live long enough (Tyrell et al, 2001). Typical neuropathological markers of AD (neuritic amyloid plaques and neurofibrillary tangles) are universally present on post-mortem studies in the brains of all people with trisomy 21 by the age of 40 years (Wisniewski et al, 1985) and their location and progression mirrors that observed in non-trisomic adults with AD (Ness et al, 2012).

Stroke and TIA- In a recent cohort study by Yang et al (2014), the risk factors for incidence of dementia after stroke or TIA were age, history of DM, white matter change severity and the presence of medial temporal lobe atrophy. They also found that approximately 30% of individuals with stroke and TIA with incident dementia harboured AD like pathology, and that this frequency was significantly greater than those without incident dementia. It is suggested elsewhere that there is a close complex relationship between stroke and primary degenerative changes in the brain underlying many cases of apparent VaD and that the stroke itself may be a relatively late event in the progressive nature of the primary cognitive decline (Jacoby & Oppenheimer, 2002, p534).

Anaesthesia and surgery- Chen et al, (2014) found an almost doubled risk of development of dementia within 3-7 years of anaesthesia and surgery. The study cohort comprised individuals aged 50 years and older who received anaesthesia for the first

time since 1995 between 1 January 2004 and 31 December 2007, and a control group of randomly selected individuals who were equivalent in age and gender. Individuals were followed until three years later to identify whether they developed dementia. The findings in this cohort study suggest a significant association between anaesthesia and surgery and subsequent dementia (Chen et al, 2014). The limitations of this study are the lack of investigation into risk factors (for example, genetic, smoking or education) on the outcomes.

Weight- In a 26 year study, Tolppanen et al (2014) found higher midlife BMI to be associated with higher risk of dementia and AD independent of obesity related risk factors and co-morbidities. They also found that steeper decrease of BMI and low later-life BMI are associated with her risk of dementia and AD. The use of BMI as a health measure is said to have limitations and it is suggested that a simple measure like waist circumference would have been of interest in the evaluation of bodyweight and body composition in relation to dementia (Ross, 2008). Dahl et al (2013) found a decrease in BMI to be associated with impairment/ higher risk of dementia and AD. Similarly, the limitations of this study were in relation to BMI. They acknowledged that although BMI is associated with fat mass; it is not an assessment for body fat distribution. Also, the study participants self-reported height and weight and the impact of inaccuracies with this method need to be considered (Dahl, 2013). Virta et al (2013) found weight gain in overweight individuals to be associated with impairment and similar to other studies the limitations of the study were the assessment through self-report. A weight change in either direction in overweight individuals is also associated with impairment (Lo et al, 2012), (Ravona-Springer, 2013). In a meta-analysis by Anstey et al (2011), it was concluded that there was a significant increase in AD/VD or any dementia associated with being overweight in midlife. They also concluded that low BMI was associated with AD risk.

Depression- Kessing et al (2012) concluded that while early onset and recurrent depression may constitute long term risk factors for dementia, symptoms developing later in life may be early symptoms of dementia. He also concluded that long term treatment with antidepressants may decrease the risk of developing some types of dementia but warned of the preliminary findings of the results that require further confirmation. In an evaluation of 19 different risk factors, Boot (2013) found that individuals with DLB were more likely to have a history of depression than those with

AD or the controls in the study. They found that depression was associated with an increased risk of ADL limitations. They also found that the interactions between depression and dementia suggested that depression may be less harmful in terms of functional independence amongst the cognitively impaired (Rist et al, 2014).

Osteoporosis- In a (2013) Taiwan based retrospective population analysis, it was concluded that there was an increased rate of Dementia in individuals with osteoporosis in Taiwan. They also noted that estrogen supplementation and bisphosphonate treatment are associated with reduced risk of dementia amongst the individuals included in the study. The limitations of this study are the potential for the underdiagnoses and undertreatment of osteoporosis in individuals with advanced dementia which may impact on the study results (Jilka et al, 1992). The need for further larger double blind RCT are required to confirm these results (Chang et al, 2014).

2.5 Incidence and Prevalence

Globally, the number of people in 2010 estimated to have dementia was 35.6 million (Prince, 2009). The United Nations population projections estimated that worldwide dementia prevalence rates would approximately double every 20 years with 42 million by 2020 and 81 million by 2040 (Cahill et al, 2012). There has been some agreement that Western Europe has the highest number of people with dementia compared to other parts of the world, (Ferri et al, 2005), (Prince, 2009). In Europe the estimated figure is estimated to be 7.7 million people living with dementia (Alzheimer's Europe, 2009). Ireland has an ageing population of 41,700 people with Dementia and this is set to increase (Cahill et al, 2012). In keeping with other European countries Ireland is known to have a gender bias in the age groups of 75 and over with women having higher prevalence rates, secondary to the disproportionate number of women in the Irish population at older ages .

The incidence within the most common subtypes of dementia has been discussed in previous sections where the data have been available. The overall incidence of dementia in Ireland is estimated to be approximately 4,000 new cases in the general Irish population every year (Cahill et al, 2012). Incidence of dementia rises rapidly with age and with more and more people living into the older age groups, the incidence continues to increase. In addition, with an improvement in overall medical treatment, individuals

with dementia are surviving for longer. The number of people in Ireland with dementia is therefore set to increase to 47,600 in 2016 and 66,600 by 2026.

Calculating the incidence of dementia is said to be problematic (Alzheimer's Scotland, 2000). Ferri et al, (2005) have estimated an incidence rate of 8.8 cases per 1,000 people over 60 per year in Western Europe. International studies have varied amongst their results with rates ranging from between 2.5 new cases per 1,000 people over 65 to 26 new cases per 1,000 people over 65 (Alzheimer's Scotland, 2000).

2.6 Economic cost of Dementia

This incidence rate has implications for care burden, public expenditure and care provision (Cahill et al, 2012). Dementia is a costly condition. Wilmo and Prince (2010) in the World Alzheimer's report estimate the worldwide cost of dementia to be \$604 billion. Of this 42% accounted for informal or unpaid care provided by family and friends in the community and 42% accounted for formal care in residential settings with 16% related to dementia related direct health care costs (Cahill et al, 2012). The European estimate of total cost of dementia is €160 billion (Wilmo et al, 2011). In Ireland, the estimated overall cost of dementia in Ireland is estimated to be just over 1.69 billion per annum with the estimated cost of €22,000 per year per person; 48% of this total cost in Ireland is attributed to family and friends for persons living in the community, 43% for medical long stay care and 9% being the contribution of formal and social care costs (Cahill et al, 2012). This highlights the heavy burden of costs that rely on family and caregivers in the community and strengthens the argument for a focus of services in this area.

The costs for people with dementia globally amount to more than 1% of gross domestic product (GDP) (Wilmo & Prince, 2010). There is a growing gap between budget allocation and the associated burden of dementia especially in higher income countries (World Health Organisation, 2008). Cahill et al, (2012) speculates the cost of dementia care has increased over the past decade when comparing previous studies to present ones which estimated the cost of dementia care in Ireland. The economic burden of dementia care ranks higher than stroke, heart disease and cancer combined; however Trepel (2010) reports that health care allocations for dementia continue to be substantially lower than each of these individual disease groups.

2.7 Pharmacological interventions for dementia

Interventions for persons with dementia may be pharmacological, non-pharmacological or both. The pharmacological treatment of a person with dementia is complex with a pharmacological focus on maintaining function, delaying the course of the disease and managing symptoms. Two primary types of medication are used to treat AD - cholinesterase inhibitors and NMDA receptor antagonists, each of which work in different ways. Cholinesterase inhibitors work by attempting to help stop the brain chemical neurotransmitter acetylcholine from breaking down. This aims to slow down the progression of AD but doesn't prevent the disease related degeneration. Cholinesterase inhibitors comprise of donepezil hydrochloride (Aricept), rivastigmine (Exelon) and galantamine (Reminyl). The NMDA receptor antagonist is Memantine (Ebixa). This works by blocking the effects of a messenger chemical known as glutamate. Glutamate is released in excessive amounts when brain cells are damaged by AD and this causes brain cells to be damaged further. These drugs were developed specifically to treat AD. The evidence base has not fully defined whether they can be helpful for people with other forms of dementia. Rivastigmine is licensed for dementia with Lewy bodies and dementia related to Parkinson's disease, but there is some evidence that acetylcholinesterase inhibitors may be useful. Acetylcholinesterase inhibitors are supported by the NICE guidelines for people with Lewy body or Parkinson's disease dementia if they have distressing symptoms or behaviours that challenge (NICE, 2006). There have been several trials with limited benefits reported in outcomes examining cholinesterase inhibitors for the treatment of vascular dementia, except in those individuals with a combination of AD and vascular dementia (Erkinjuntti et al, 2002), (Schneider et al, 2007). Cholinesterase inhibitors are not licensed for the treatment of vascular dementia (Rodda & Carter, 2012). These pharmacological interventions are used primarily to delay progression and improve the behavioural and psychological symptoms of dementia (BPSD). However, the main emphasis of treatment of BPSD is on non-pharmacological approaches. According to Ames et al (2010) non-pharmacological approaches should be first line treatment. They should include a search for delirium or pain and then management of same. This should then be followed by, examining environmental causes and matching them with social and environmental interventions that capitalise on the person's residual strengths. The use of psychotropics is recommended for cases where other simple interventions as outlined have been

attempted but have not worked or are deemed inadequate. The traditional psychotropics used fall into the category of antipsychotic medication and include Haloperidol, Thioridazine and Thiothixene. The atypical antipsychotics include Clozapine, Olanzapine, Quetiapine, Risperidone, Aripiprazole and Ziprasidone (Loy et al, 1999). Evidence suggests that antipsychotics as a group can show benefit for agitation associated with psychotic features but with the risk of side effects. There is some evidence for the use of antidepressants for agitated behaviours but evidence continues to be limited (Ames et al, 2010). Benzodiazepines are used for anxiety associated with dementia. Since, anxiety and depression tend to present side by side in individuals with dementia, many physicians choose an antidepressant rather than a benzodiazepine if medication is needed. Benzodiazepines used in Dementia include Alprazolam, Lorazepam and Oxazepam.

2.8 Dementia services in Ireland

This section outlines the context of dementia care in Ireland. Individuals with dementia are usually managed in the community by the GP and associated multidisciplinary teams in the community or primary care services. This community care is often complemented by voluntary or non for profit organisations such as the Alzheimer's society and the Carers association. However, dementia service provision may come under specialist teams such as the Community Mental Health services or Old Age Psychiatry team despite the aetiology and manifestations of dementia. The multidisciplinary composition of such teams varies considerably across geographical areas as highlighted in 'A Vision for Change' document in 2006. Individuals with dementia can account for a very significant proportion of the workload on these teams (Cahill, 2012). The individual with dementia may also be referred to other specialist services such as memory clinics, neurology, geriatricians and general physicians depending on the geographical region. At present, there is no clear clinical care pathway for individuals throughout the stages of dementia.

The Irish National Dementia strategy was published in December (2014) by the Department of Health, Ireland. The aim of this strategy is

'to improve dementia care so that people with dementia can live well for as long as possible, can ultimately die with comfort and dignity, and can have services

and supports delivered in the best way possible’ (Department of Health, 2014, p8).

The strategy was developed following a research review, a review of international dementia policies/plans/strategies, two workshops with individuals with dementia and their carer's, the National Dementia strategy advisory group, a review of Irish policy contexts, public consultation process and two clinicians’ roundtables on the National Dementia Strategy.

The Irish National Dementia strategy has a number of guiding principles and priority actions which aim to impart to and strengthen services, supports and initiatives across all health and social care sectors for individuals with dementia, their carer's and families (Department of Health, 2014). The strategy considers the priority action to be central to execution of the strategy within current resources or by reorganising these resources.

These priority actions include:

- *‘Better awareness and understanding*
- *Timely diagnosis and intervention*
- *Integrated services, supports and care for people with dementia and their carers*
- *Training and education*
- *Research and information systems*
- *Leadership*’ (Department of Health, 2014, p3)

It is acknowledged that like any strategy especially one seeking such culture change, that time must be allowed for the strategy to embed and the desired outcomes to feed through. However, the government has set out clear implementation and monitoring of the strategy (Department of Health, 2014, p4).

2.9 Intervention approaches in Dementia

This section of the chapter relates to the ‘person’ and ‘environment’ aspect of PEOP model of practice. Their unique interaction which impacts on wellbeing and QOL and ultimately how occupational performance and participation is impacted as a result.

Prior to a full analysis on intervention approaches, a short summary of some of the relevant behaviour features relevant to dementia that have not previously been outlined will be discussed. The rationale for this is that these behaviours which are influenced by the person and the environment also have an impact on the success of an intervention. A review of dementia and disability will then set the scene for rehabilitation in dementia and then specific intervention approaches will be examined.

Passive Behaviours- Passive Behaviour (PB) is

‘A lessening of mental processes associated with thinking and knowing, a decrease in the ability to experience or respond to human emotions, fewer interactions with others and surroundings, and a decrease in motor activity’
(Colling, 1999, p117).

Colling (2004) recognises that PB occurs on a daily basis for individuals with Dementia and is often resistant to interventions. Such PB included decreased verbalization, withdrawal, decreased activity levels and less socialization. He also outlines two hypotheses on PB, that PB is inescapable and the result of irreparable disordered physiological processes associated with disease and that PB occurs because of the qualities of environmental stimuli. PB is reported to put individuals at risk of further cognitive and functional decline (Kolanowski & Buettner, 2008). Colling (2004) revealed the creative manner in which caregivers of cognitively impaired older individuals in the community have developed successful caregiver interventions for PBs which included behavioural and environmental strategies rather than a reliance on activities alone.

Cohen-Mansfield and Wirtz (2009) in their study of the reasons for nursing home entry in an adult day care population found that depressed affect, the number of psychiatric diagnoses (most often included depression), a diagnosis of dementia, and age were significant predictors of nursing home entry. Colling (2004) acknowledged substantial difficulties in the identification of PB because medical problems were given priority and

that clinicians underappreciated the impact of lack of motivation and initiative which contributes to mortality and morbidity (Shulman, 2000). He stated that

'Failure to recognize the emergence of an amotivational state may lead to perceptions that the person is lazy, shy, quiet, or clinically depressed' (Colling, 2004, p118).

Therefore, one hypothesis is that if PB is being misunderstood as psychiatric diagnosis they are predictors for the need for nursing home care.

Thomas et al (2004) completed the Pixel study, which examined the reasons of informal caregivers for institutionalising dementia individuals who were previously living at home in France. Data were collected from 109 questionnaires concerning 75 females and 34 males with dementia. Cognitive disorders were not found to be the main basis for institutionalising individuals. The most frequently identified caregiver rationales at the time of institutionalisation were incontinence and withdrawal. Given that withdrawal is considered to be a PB and is outlined as the second most important reason for institutional care, it must be considered as an important area of intervention especially for those individuals living in the community where the aim of therapeutic interventions are commonly to keep the person living safely at home for as long as possible.

In summary, PB in dementia is common. They appear to be misunderstood and lack good quality evidence on their impact on individuals. They can contribute to the need for admission from the community into nursing home care and place individuals at risk of further cognitive and functional decline.

Pain in Dementia- One of the outcome measures that will be discussed in the methodology chapter of this study is the Neuropsychiatric Inventory (NPI) which examines neuropsychiatric symptoms such as aggression, agitation and occupational disruptiveness. These neuropsychiatric symptoms are commonly known as behaviours that challenge. Recent studies and literature reviews have identified pain and behaviours that challenge to be correlated (Scott et al, 2011), (Kovach et al, 2005). Some symptoms of pain such as verbalisations/vocalisations, facial expressions, noisy breathing, strained or restless body expressions resistance to care, agitation and aggressiveness are commonly miss-identified as a symptom of dementia and not pain (Pieper et al, 2013). Pain is also highly prevalent. Literature suggests that individuals with dementia are

consistently untreated for pain (Achterberg, 2007). A very high prevalence of persistent pain which often exceeds 50% of community dwelling older adults and 80% of nursing home residents has been demonstrated in some studies (Achterberg et al, 2010; Boerlage et al, 2008; Gibson, 2007; Sawyer et al, 2007; Takai et al, 2010, Zwakhalen et al, 2009). In a systematic review by Pieper et al (2013) it was concluded that pain interventions targeting behaviour and behavioural interventions targeting pain are successful in reducing pain and behavioural symptoms in dementia.

2.10 Dementia and Disability

Dementia is one of the leading causes of disability in a non-fatal form in the developed world and by 2030 it is predicted that dementia will be the third leading cause of years of life lost to death and disability (Downs & Bowers, 2010, p9). In order to form a concept of dementia within the framework of a disability model one must identify the differences between

‘The underlying impairment, resulting from pathological changes, and the resulting limitations on engaging in activity (disability) and restrictions on social participation (handicap)’ (Clare et al, 2013, p2).

Disability amounts to a withdrawal from the usual in terms of occupational performance of the individual concerned. The concept of disability is characterized by,

‘Excesses or deficiencies of customarily expected behaviour or activity, and these may be temporary or permanent, reversible or irreversible, and progressive or regressive’ (World Health Organisation, 1980, p28).

This concept of dementia as a disability leads to consideration of the rehabilitation approaches that may be applied in the context of working with an individual with dementia.

Clare et al, (2013), p2 regards activity limitation and participation restrictions to be

‘Not solely determined by the degree of impairment, but are subject to a range of personal, social and environmental influences’ (Clare et al, 2013).

Both positive and negative personal social and environmental influences are known to have the potential to impact on the level of functional disability. This may not

necessarily correspond to the degree of neurological impairment (Clare et al, 2013). Kitwood earlier discussed these influences and includes personality, biographical experience, social relationships, communication and interaction and environmental context as significant mediators, (Kitwood, 1997). Woods and Clare, (2008) suggest that in the context of mild impairment with sufficient time, appropriate support and conditions, people with dementia still have the ability to learn and retain some information and skills despite their memory difficulties. It is suggested that in order to improve and sustain everyday functioning and well-being, and reduce excess disability, for the person with dementia and the strain on their family caregivers; interventions should focus on the individuals strengths i.e. their preserved areas of cognitive functioning and develop ways of compensating for impairments in those aspects of cognition that are significantly affected (Woods & Clare, 2008).

Interventions that aim to reduce functional disability by focusing on activity and participation, drawing on retained strengths to support adaptive behaviour, are typically described as forms of rehabilitation. Rehabilitation as described by McLellan, (1991), p785 is said to

'Enable people who are disabled by injury or disease to achieve their optimum physical, psychological [and] social well-being'.

Clare et al, (2013) define the rehabilitation of people who have cognitive, as opposed to purely physical impairments as 'cognitive rehabilitation' stating that

'Although rehabilitation is most often associated with nonprogressive conditions such as brain injury, it is equally applicable to people with chronic and progressive conditions' (Clare et al 2013, p2).

Advances in the understanding of the pathophysiology of dementing illness have changed the management of individuals with dementia from a conservative and symptomatic approach to a biological, medically specific rehabilitative one. This is an evolving concept and will be discussed in detail in the next section.

2.11 Rehabilitation and dementia

Psychosocial approaches or non-pharmacological interventions with a focus on cognition have been used in Dementia Care and Rehabilitation for some time. There is considerable evidence for the efficacy of cognitive rehabilitation with a range of clinical groups including those with other neurodegenerative conditions and those with traumatic and acquired brain injury (Mitolo et al, 2015). Rehabilitation interventions are generally highly individualised, as clients have a diverse range of impairments, needs, circumstances and preferences. They usually involved an approach which was used parallel to sensory stimulation (Woods, 1977). Rehabilitation approaches are increasingly being utilised in the management of dementia. While the notion that psychosocial interventions can be effective in the management of this disease is certainly not a new one, a review by the European Commission (1997), found only a paucity of ‘gold standard’ randomised controlled studies which varied in quality (Moniz-Cook & Wang, 1998). Much progress has been made however over the last decade with increasing evidence within the literature demonstrating that psychosocial interventions can be as effective as pharmacological therapies (Olazaran et al, 2010). In Ireland, the Health Information and Quality Authority (HIQA) advocate non-pharmacological therapies such as reminiscence and reality orientation to enhance communication and stimulation needs of residents in dementia-specific care homes (HIQA, 2008, pg. 58). The core of rehabilitation is the identification of purposeful, realistic and meaningful client centred rehabilitation goals and the development of evidence based bespoke interventions to address goals. Goal-based approaches have been used in a broad range of conditions

‘Including brain injury, stroke, neurological illness, physical disability and chronic pain, as well as for frail older people’ (Clare et al, 2013, p2).

Where possible the therapist negotiates the person centred goals with the individual; where this is not fully possible therapy goals are devised with families, caregivers or relevant others. It has been suggested that rehabilitation provides a useful overarching conceptual framework for the care and support of people with dementia and for the design of interventions to meet their needs. Early examples of interventions that addressed meaningful person centred goals relating to self-care or activity participation supported the possible utility of this approach (Clare et al, 2013). In progressive

conditions such as dementia, however, the goals of rehabilitation necessarily change over time as impairments become more severe (Woods & Clare, 2008).

A Cochrane review (2008) by Woods and Clare reviewed Cognitive rehabilitation and cognitive training for early-stage Alzheimer's disease and vascular dementia; it clarified the types of rehabilitation applicable to the early stages of two types of dementia. They were noted to be the following methods:

- Cognitive Stimulation
- Cognitive Training
- Cognitive Rehabilitation

2.12 Rehabilitation Approaches in Dementia

Cognitive Stimulation- This is defined as

'Engagement in a range of activities and discussions (usually in a group) aimed at general enhancement of cognitive and social functioning' (Clare, 2004, p3).

The advantages of non-specific stimulation of cognitive domains for individuals with dementia are well respected, and

'are reflected in the demonstrated efficacy of general cognitive stimulation and reality orientation approaches in producing improvements in cognition and, in some cases, behaviour (Spector 1998), primarily for people with a moderate degree of dementia' (Woods and Clare, 2008, p3).

The NICE guidelines (2006) recommend that

'People with mild/moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme ... provided by workers with training and supervision ... irrespective of any anti-dementia drug received ...' (NICE, 2006, p29).

Reality Orientation (RO) was developed in the USA in the late 1950's in a response to confusion and disorientation in older people in hospital units and Woods et al, (2012) recognise this as the prototype of the cognitive stimulation approach. The first controlled evaluation of RO was completed in the UK by Brook et al, (1975); individuals attending

RO sessions for 30 minutes once or twice per day, five days per week for four months were found to have positive gains on intellectual functioning. This was in comparison to a control group who visited a special RO room daily but were not given any encouragement to engage with each other or any of the materials (Woods et al, 2012). In 2000, Spector completed a Cochrane review specifically examining reality orientation and it concluded that in respect of both cognition and behaviour there was some evidence that RO had benefits for people with dementia. A criticism was that that outside of a few countries, RO had been little practiced or researched since 1990 and for the RO approach was being applied in a

'Mechanical, inflexible, insensitive and confrontational manner' (Woods et al, 2012, p3).

One set of guidelines on the management of dementia cautioned against RO's use with the possibility of a negative impact on the person's well-being that outweighed any small improvements (Woods et al, 2012).

In a Cochrane review of Cognitive Stimulation to improve Cognitive Functioning in People with Dementia, Woods et al (2012), discussed the most striking finding of the review to be the effects of Cognitive Stimulation on performance in tests of cognitive function. He later went on to discuss the understanding that changes in cognition alone are not sufficient to justify intensive programmes of intervention, unless they are accompanied by other changes in behaviour and well-being. He then summarised the positive findings of cognitive stimulation in the Cochrane review to be the following:

- Results from 4 randomised controlled trials (RCT) with 223 participants indicated that positive changes were reported by staff outside of the context of the cognitive stimulation group sessions in the areas of communication and social interaction.
- Results from 4 RCT's with 219 participants identified a positive impact on quality of life (QOL) and well-being associated with cognitive stimulation (Woods et al, 2012).

In recent years, a theory has emerged that lack of cognitive activity hastens cognitive decline in normal ageing as well as in dementia (Brueil, 1994). This view in conjunction with an attempt to implement the positive aspects of RO whilst ensuring that they are utilised in an appropriate and sensitive manner and the evidence base on cognitive

stimulation has led to the development of a specific manualised programme called Cognitive Stimulation Therapy (CST) (Spector et al, 2003).

CST is a treatment that involves 14 or more sessions of themed activities. Sessions were originally designed to run twice a week over a seven week period. However, they can be run once a week and offer a longer-term programme, which involves repeating sessions and offering new sessions as outlined in the treatment manual. This once a week schedule was the chosen approach for this study which will be outlined in the methodology chapter. Sessions aim to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group (Spector, 2011). CST is a manualised programme that does not entail formal training, although opportunities for some are spontaneously available can be completed as required. The manuals include the key principles of CST, a session-by-session plan, details of the equipment required and methods of monitoring sessions (CST Dementia, 2014).

There is increasingly strong evidence for CST and its effectiveness from a number of RCT's. The first randomised controlled trial of this manualised intervention programme involving 201 participants with mild to moderate dementia, as determined by their score between 10 and 24 on the Mini-Mental State Examination (MMSE), recruited from 23 residential and day centres reported significant improvements in cognition and quality of life outcomes, which compared favourably with trials of cholinesterase inhibitors (Spector et al, 2003). This study addressed a clearly focused issue in terms of its population studies, the intervention and control group and the outcomes. The assignment of individuals to treatment was randomised. There are limitations identified here as the randomisation was completed by staff who were part of the research team and not by external independent members of staff. Similarly, the enrolment into the trial and allocation to group were not completed by external independent members of staff. The control group did not consistently mean doing an activity as normal as for some individuals this meant doing nothing. All individuals included in the trial were appropriately accounted for at its conclusion. Some of the assessments which were completed via questionnaire format through staff assessment allowed room for staff biases in the questionnaires.

An evaluation of the cost-effectiveness of the CST programme (from the Spector et al 2003 study), showed that the intervention was relatively inexpensive and more cost-effective than when compared to treatment as usual (Knapp et al, 2006). There were limitations in this study as the power calculation for the study was considered not to be large enough to test the cost effectiveness hypothesis. Forty people included in the study did not have cost effectiveness data collected. There was a short follow up period of 8 weeks which therefore failed to provide information on the longer term cost implications. The study failed to examine the cost implications for people living in the community as its primary focus was in care homes. The CST was provided by trained researchers, it was acknowledged that the cost implications may have been lower if it was considered to be delivered by care home staff.

A number of studies have examined the longer-term benefits of CST and related interventions. For example, Orrell et al (2005) found that 16 weekly sessions of maintenance following the initial CST programme resulted in significant improvements in cognitive functioning compared to a control group (usual care) and to those who only received the initial CST programme. The limitations to the study are that the sample size was small and may not have been representative of the CST sample. Blinding of staff to group allocation was not fully achieved for some of the outcome measures. Consistency among staff in completing assessments was often not possible. Randomisation of Care homes in recruitment was not achieved, thus introducing the potential for bias. Finally, the authors acknowledged that the small sample size

'lacks power to detect potential differences between the groups so there is the possibility of a type 2 statistical error, particularly for outcomes such as quality of life which had been found to significantly improve with CST' (Spector et al, 2003, p449).

To date CST has not been compared to any other non-pharmalogical treatment for dementia. Additionally, CST has not been evaluated based on the severity of the cognitive deficits. It has been evaluated in terms of mild to moderate cognitive impairment but not for each cognitive stage individually. This research study addresses the gaps in the current evidence base.

A reflection of the proposed plans for future and ongoing research in this area is presented in a study proposal by Aguirre et al, (2010) which aims to assess the

effectiveness and cost effectiveness of maintenance CST groups for dementia by comparing an intervention group who receive CST for 7 weeks followed by the maintenance CST programme once per week for 24 weeks with a control group who receive CST for 7 weeks followed by treatment as usual for 24 weeks. Similarly, an individualised CST (iCST) programme has been developed to incorporate implicit learning techniques, stimulate a series of cognitive skills, and stimulate the creation of ideas (Yates et al, 2015). This was created for use by a friend or family member to cater for those unable to attend groups for a particular reason. A large scale multicentre RCT is planned to evaluate iCST (Yates et al, 2015).

Brooker et al, (2007) explored the use of purposeful activity as a non-pharmacological intervention for people with dementia through an Enriched Opportunities Programme. This showed promising benefits in the areas of quality of life (QOL) and reduction of behaviours such as agitation and a reduction in the levels of depression. There was a statistically significant increase in the number of positive staff interventions but no change in the number of negative staff interventions overall (Brooker et al, 2007). This research was limited in the fact that the Hawthorne effect was a high probability in this type of study design. There was also a risk of researcher and assessment bias throughout the study as there was no blinding. Research demonstrates that specific activities tailored to a person's own interests and functional level generates better level of engagement (Kolanowski et al, 2005; Kolanowski et al, (2011). This aligns with the work of Kitwood (1997), where he commented on the relevance of maintaining personhood by meeting the unique needs of each individual to be occupied and that with the relevant occupation comes an enhanced feeling of self-worth (O'Connor et al, 2014). In other words he acknowledged the importance of engaging people in their interests and roles which is now acknowledged to be at the core of non-pharmacological interventions in dementia care (Cohen-Mansfield, 2016).

Interventions with a cognitive focus have been developed alongside approaches emphasising the stimulation of the senses (Woods, 1977). Sonas is a Multisensory stimulation intervention. In contrast to other Multisensory stimulation interventions which will be discussed later in this chapter, Sonas is not completed in a specific multisensory environment (MSE). Sonas was developed by Threadgold, a speech and language therapist in Ireland and is described as a system to assist people in realizing whatever potential they have (Jones & Miesen, 2004). The background concept is that an

environment is created within a group or individual session (known as Sonas Individual Multisensory Sessions/ SIMS) that provides both sensory stimulation and communicative partners. The programme is structured, manualised, requires training in order to be a registered Sonas Licensed Practitioner (SLP) and annual practice development days to maintain a SLP licence (Sonas aPc, 2014). To date, there is little published research on Sonas and its effectiveness and its evidence base relies on pilot studies, unpublished studies, feedback and anecdotal evidence (Connors, 2001), (Parrish, 2005). In 2012, Sonas aPc had trained more than 6,200 people in Ireland and the UK and train about 450 people every year. A 2006 survey of all 526 residential care facilities in Ireland by Sonas aPc indicated that of the 325 who replied (representing a 62% response rate) 43% were implementing the programme. (Sonas aPc, 2011). Sonas believe that this implementation figure is now higher. The National Advocacy and Programme Alliance (NAPA), documented structures in residential care centre services through questionnaires (NAPA, 2013). Sonas is one of six quality programmes included and it was found that more than 50% of residential centres which had completed their questionnaires reported that they were implementing the Sonas programme (Sonas aPc, 2011). One must discuss bias in the context of the Sonas information as the above figures were obtained from the Sonas CEO (2011) and from their website. The first small scale pilot study published which included 39 people and investigated the feasibility and effectiveness of Sonas and concluded that Sonas sessions did not lead to improvements in QOL and behavioural and psychological symptoms of dementia (Hutson et al, 2014). This RCT study addressed a clearly focused issue that being in a Sonas group as an intervention in dementia care was found to have statistically significant changes on validated standardised outcome measures in comparison to treatment as usual group. Recruitment was completed in an acceptable way from 4 private nursing homes in the UK and eligible participants were required to meet inclusion/exclusion criteria. Randomisation was achieved. The limitations of this study are that blinding was not fully achieved. The participants were not blind. The assessors were blind to the conditions. However, for ethical reasons it may have not been considered appropriate to blind the participants. The QOL-AD was not completed fully; they used the caregiver component of the measure and did not take into account the participants report. The study was completed in the U.K.; much of the program incorporates Irish poetry and music which UK participants are unlikely to be familiar with. The authors recommended adaptations to the Sonas approach in terms of its

applicability and feasibility of intervention and suggested that benefits may only occur within sessions and this recommendation was made for future research. Considering the high levels of training and implementation of Sonas, there is need for further robust research into its effectiveness in clinical practice.

2.13 Cognitive training

This is defined as

‘Guided practice on a set of standard tasks designed to reflect particular cognitive functions; a range of difficulty levels may be available within the standard set of tasks to suit the individual’s level of ability. It may be offered in individual or group sessions, with pencil and paper or computerised exercises’ (Woods et al, 2012, p3).

Cognitive training consists of facilitation of training on a set of standard activities designed to reflect particular cognitive duties, such as memory, attention, or problem-solving/ executive function. The understanding is that practice has the potential to protect or advance performance in the given domain and that any outcomes of practice will be applicable outside of the practice training setting (Claire & Woods, 2003).

The first and most well-known single blind multicentre RCT which examined the effects of cognitive training in older adults is known as the Advanced Cognitive Training for Independent and Vital Elderly study (ACTIVE), (Ball et al, 2002). This study addressed a clearly focused issue that being to determine if cognitive training had an effect on daily function and cognitive abilities. There were 2802 individuals involved. The outcomes of the study demonstrated that cognitive training interventions helped normal elderly individuals to perform cognitively in the specific cognitive domains they were trained (memory, reasoning and speed) but that this did not transfer to daily function. The limitations of this study were that the individuals were not impaired in their daily function and therefore the lack of transfer of training to daily function was not expected. A 5 year follow up to this study later concluded that reasoning training resulted in less functional decline in self-reported IADL and compared to the control group the outcomes of the cognitive training continued 5 years after the intervention begun (Willis et al, 2006). In a review of Cognitive-focused interventions in early-stage dementia, no significant effects were found for cognitive training, the evidence was reported to be

weak and many of the programmes reviewed lack direct relevance to everyday life and did not address issues of generalization and maintenance (Clare, 2003).

A systematic review of the literature by Frank and Konta (2005) reported that

'cognitive training methods at early forms of the dementia seem to show as little success as those methods for a heavy form of dementia in which rather more complex methods like the reality orientation are used' (Frank & Konta, 2005, p5).

They found that cognitive training can sustain the mental flexibility and competence very well in healthy older people and not in those with dementia at any stage. They concluded that the successful cognitive training methods were ones which simulated actual problem solving situations, which are similar to real functional situations as well as training which uses coaching. This review was found to have some limitations, it failed to give precise results for the outcomes reviewed and there were no cost benefit publications found (Frank & Konta, 2005).

In a Cochrane review on cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia (Bahar-Fuchs et al, 2013); it was concluded that there was no evidence for the efficacy of cognitive training in improving cognitive functioning, mood or ADL's in people with mild to moderate Alzheimer's disease or vascular dementia and that the evidence from cognitive training interventions to date was generally judged to be of low to moderate quality.

Finally, a small feasibility study including ten participants which examined the use of the BrightBrainertm, which is an interactive cognitive rehabilitation system for older people with dementia concluded that in this small sample it was possible to improve cognitive function in older lower functioning dementia patients through games combining cognitive and physical elements and that this was enjoyable for this population. They also concluded that the severity of depression in the relative subjects can be reduced though virtual reality bimanual games. However, given the study design and small size, further research is required into this specific approach (Burdea et al, 2014).

2.14 Cognitive Rehabilitation (CR)

This is described as

'An individualised approach where personally relevant goals are identified and the therapist works with the person and his or her family to devise strategies to address these', (Woods et al, 2012, p3).

The emphasis is on improving performance in purposeful and meaningful occupations in everyday life rather than on cognitive tests, building on the person's strengths and developing ways of supporting and compensating for impairments. (Woods et al, 2012, p3).

CR interventions aim to tackle those tasks considered most purposeful and meaningful by the individual with dementia and his or her family members/carers directly and target every-day situations in the real-life context. Goals for intervention are selected collaboratively and interventions are usually conducted on an individual basis. Clare and Woods (2004), state that the CR approach is enhanced for individuals with mild to moderate dementia by education through supportive discussions on cognitive strengths and weaknesses and links with other resources. They also report the goal of application of CR in the care of people with more advanced dementia to facilitate enhancement of basic skills (Camp, 1997) or reduction in behaviours regarded as problematic (Bird 2000), (Bird, 2001).

Montessori principles in CR- Montessori activities for people with dementia originated from the Montessori teaching method used with children. In Montessori teaching in dementia, individuals are presented with graded information based on their level of functioning. Materials in the environment are designed to be tools to enhance independence for individuals. Similar to activity analysis in OT, tasks are broken down into steps. Montessori activities involve

'Immediate feedback, high probability of success and repetition' (Camp et al, 1997, p689).

In (2006), Montessori based activities brought about high levels of engagement and pleasure in a small study of nursing home individuals with dementia (Camp et al, 2006).

In (2009), a modest fall in agitation was found in a trial using this approach with predetermined activities (Lin et al, 2009). In a (2013) randomised crossover trial which included 44 individuals in Australia. Personalized one to one activities were delivered using Montessori principles and compared with a non-personalized activity to control for the non-specific benefits of one to one interaction. They concluded that even non-personalised social contact in the control group improved agitation in the individuals. However, they found tailoring activities using the Montessori approach elicited more positive interactions and are especially suitable for people who have lost language fluency (Van der Ploeg, 2013). There were limitations to this study in terms of the assessors. They were not blind to the groups but they did have excellent interrater reliability. Randomisation was compromised and completed on a case by case basis. It is acknowledged that further high quality evidence is required regarding the Montessori approach in dementia care.

In summary, CR techniques aim to use multiple techniques to enhance or maintain everyday functioning and well-being and reduce excess disability for the person with dementia and to reduce strain for family caregivers (Bahar- Fuchs, 2013). A systematic review of the literature also demonstrated that caregivers of participants in CR groups had improved social relationships following the interventions relative to the control condition. It also demonstrated that additional RCT's of individualised cognitive rehabilitation are needed in order to support the tentatively promising results (Baher-Fuchs, 2013).

Errorless Learning (EL) is a form of CR which allows learning exclusively by repeated exposure to correct information. It is based on the principle if errors are made during a learning task, that establishment of correct future cognitive responses are then interfered with (Baddelely & Wilson, 1994). EL is described as a teaching technique whereby individuals are prevented as far as possible from errors when they are learning information or new skills (Wilson, 2013). Donaghey and McMillan (2009), p196 reported in their randomised control design study that it is predicted,

‘That a strategy that prevents errors occurring will lead to more efficient learning than treatment as usual which allows the individual to make errors and is then corrected’.

EL principles originated in behavioural psychology in the 1960's where a similar approach was used to teach visual discrimination to pigeons and to children with intellectual disabilities. EL learning differs from the errorful or trial and error method, in which individuals must guess the correct answer or perform the task without appropriate support (Schmitz, 2014). In recent years, errorless learning has been applied to the restoration of premorbid knowledge and the development of procedural skills in an acquired brain injury work setting (Parkin et al, 1998). Whilst many studies on EL have focused on amnesic individuals, errorless learning has also been shown to be successful in facilitating performance in individuals suffering with moderate degree of memory impairment (Hunkin et al, 2008). Schmitz et al (2014) examined the serial reaction time performance in the acquisition of a 6 element perceptual motor sequence by individuals with AD and healthy older adults in a control group. The results concluded that EL allows for faster automation of a procedure than errorful learning in both AD and healthy older adults. Donaghey and McMillan (2009) investigated whether EL is superior to treatment as usual (trial and error), when teaching people with amputations and 42% with additional cognitive impairment. The EL group recalled more correct steps than the control group and made fewer errors than controls. There were some limitations to this study however; there were no available power calculations, it lacked details on who exactly completed the randomisations and the outcomes were rated by the primary researcher who utilised an independent rater who was blind. This study is relevant to the context of this literature review as it provides evidence for the use of EL for practical skill learning with a population who were 42% cognitively impaired. It is not specific to dementia care however and it was completed in a clinical setting and not in the home or community environment.

Middleton and Schwartz (2012) in their examination of learning theory state that the most powerful learning is obtained when training involves opportunities for individuals to practice retrieving information from long-term memory. They suggest that this is at odds with the majority of the EL practices where retrieval attempts are largely pre-empted or discouraged. They also suggest that treatment conditions that increase difficult retrieval or errors which in turn decrease performance in training actually promote the best long term retention of training effects. Therefore, they summarised that EL techniques failed to make the most of this powerful learning principle as they prioritise errorless performance during training.

EL is not embedded in clinical practice to date. Several studies with low numbers of participants examined EL in functional outcomes/ life skills and were shown to have positive outcomes, such as Cohen et al, (2010), Donaghey et al, (2010) and Lekeu et al, (2002). The literature has generally been focused on studies not focused on functional outcomes, small studies, not dementia specific studies or with low numbers. For example, in Clare et al, (2000) multiple single case experimental design study there were 6 individuals with controls being the individuals themselves. In Clare et al, (2002) quasi experimental pre-test post-test design/ multiple single case experimental design study there were 12 individuals with the controls again being the individuals themselves. In Haslam et al, (2006) quasi experimental pre-test post-test / within participant design study there were 11 individuals with the controls being 8 healthy individuals. Finally in Bier et al, (2008) quasi pre-test post-test/ within participant design there were 30 individuals and the control was 15 healthy individuals. This study used mixed experimental interventions. In a study by Warmington and Hitch (2013) involving 47 individuals, two experiments compared the efficacy of EL and errorful training procedures in the acquisition of novel words in typical adults. In both studies the EL method led to significantly better learning, reductions of errors and maintenance on 3-4 day follow up. The types of EL treatment that have been examined in the studies have been mainly experimental rather than occupationally focused clinical experiments. Specifically there is no published literature on the use of EL on specific occupational goals in clinical practice and Dementia. In a literature review by Li and Liu (2012), they suggested that the efficacy of EL may be dependent on the type of information registered and the manner in which the EL intervention was carried out. Therefore, a need for research in this area of EL is identified.

Chaining is another method used in CR. Chaining is useful for relearning tasks with various steps, such as making the bed, making breakfast or playing a game. Early research into chaining was completed in education; it then evolved into individuals with ID and now in brain injury and dementia care (Caffo, 2014). A user of this technique usually completes an activity analysis at each stage of the activity to identify the components of the task and the requirements of the individual at each stage. Intervention is then provided in the form of prompts whether they be verbal or non-verbal. Users of this technique fade back prompts until each step can be carried out independently with a consensus to teach the activity as a chain of behaviour so that each step becomes a

prompt for the next (Kelly & O' Sullivan, 2015). There are two forms of chaining forward chaining and backward chaining. In forward chaining the participant is firstly fully prompted through each component of the activity. The next session, all steps are prompted except prompts are faded back for the first step until it becomes independent and is fully mastered. Then the work continues forward successively through steps until the participant can complete the entire task independently. Backward Chaining is the same concept only users work backwards successively through steps until the participant can complete the entire task independently i.e. in the reverse order in which they are usually performed. Sensitivity to which type of chaining method is said to be appropriate to the participant and the task and this is usually judged by the clinician (Slocum, 2011).

Action based encoding is when the participant physically engages in completing the activity along with the verbal instruction at the time of encoding. In this method, the participant is provided with verbal cues at the time of retrieval where they are expected to initiate an incorrect response (Kelly & O'Sullivan, 2015). There is little evidence to support this approach (Schouenborg, 2008). This method is most commonly seen as an integrated component of EL, chaining or modification of the environment and is rarely used in isolation.

2.15 The Environment

Compensation and modification of the environment is a component of CR. The term compensation is understood to be a cluster of behaviours and processes that are designed to overcome or mitigate cognitive declines or deficits (Dixon et al, 2003). Memory rehabilitation strategies can be considered in two different but related aspects, internal and external. Internal strategies involve some sort of internal mental manipulation; this focuses on enhancing encoding and the retrieval process. Strategies typically involve one of three main features: focusing attention, adding meaning to the information to be remembered and reducing the amount of information to be remembered. For example, internal strategies may be used for face name recall, number recall, story recall or list/object recall.

External strategies involve use of an external aid or spatial cue as it is otherwise known. They reduce the demand on the person's verbal and episodic memory and may involve written reminders, assistive technology or reminders from other people (Ames et al, 2010). Memory rehabilitation strategies such as objects of long-term significance to

individuals used as spatial orientation cues to help with orientation of a bedroom was found by Namazi et al (1991) to have no effect in those individuals with severe impairment and to be most effective with individuals with mild impairment who were also found to have equal effects with use of non-familiar cues.

In more recent years, modification and compensation of the environment has evolved and now the practice of dementia friendly environments in providing external physical and cognitive strategies for all aspects of cognitive impairment associated with dementia (not just memory rehab) is emerging into dementia care. The importance of the physical and social environments in supporting the person to live with dementia has therefore gained a much higher profile in dementia care (Davis et al, 2009). An emerging body of evidence has provided detailed recommendations on dementia friendly environments which are acknowledged as part of the rehabilitation process which supports the person with Dementia. These are described as

'a cohesive system of support that recognises the experiences of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way' Davis et al (2009, p187).

It is acknowledged that the need to express feelings, make choices and continue with a familiar lifestyle remains in individuals with dementia even though the ways in which such expression occurs may change (Sifton, 2005). Therefore a safe, well designed living space is a key part of providing the best care for people with dementia. Good design can help people with dementia to be as independent as possible for as long as possible. It can also compensate for impairments in memory, learning and reasoning skills and can reduce BPSD. The individual experiences living with dementia, it is acknowledged that they do not experience themselves and the physical and social environment as separate. The physical environment can force dependency or allow for maximum independence. It can obstruct or support social interaction and a sense of self (Davis et al, 2009). The principles of dementia friendly environments as outlined by Marshall et al, (1998, p16) indicated that design in care settings should:

1. *'compensate for disability*
2. *maximise independence*
3. *enhance self-esteem and confidence*

4. *demonstrate care for staff*
5. *be orientating and understandable*
6. *reinforce personal identity*
7. *welcome relatives and local community*
8. *allow control of stimuli'*

The quality of the environment has the greatest impact on those with more significant levels of impairment. Therefore, good design may compensate for such impairment (McManus & McClenaghan, 2010). Research on dementia friendly design informs methods of compensation and modification of the environment to include evidence on the use of colour' with people with dementia. The impact of age on our need for more light to see clearly has been acknowledged. It is recommended that lighting levels should be at least double the normal standards which are set for people in their mid-forties (NcNair, 2010). In general, the ability to discriminate colour decreases with age due to the yellowing of the lens in the eye. Therefore, greens, violets and blues are less identifiable in the aging person (Pinheiro & Da Silva, 2012). The visual & cognitive impairments for a person with dementia can make it more difficult to interpret their environment as persons with dementia have difficulty with contrast sensitivity, visual attention and colour (Ross, 2000). The blues/greens become more difficult to distinguish and the oranges/reds/yellows continue to be recognisable. It should also be noted that the height of signage and compensatory cues in the environment should be adapted to the downward gaze of many older people (Namazi & Johnson 1991). Unnecessary clutter should be removed and/or located discretely (Pollock & Fuggle, 2013).

Initiatives from agencies such as the Centre for Excellence in Universal Design (CEUD) which was established by the National Disability Authority (NDA) in January 2007 under the Disability Act (2005) in Ireland have added to the evolving practice in this area of dementia care by providing standards, education and professional development opportunities and in creating awareness on not only universal design but dementia specific design. Agencies such as the NDA and the emerging evidence base as outlined above provides significant resources for modifying the environment so as to maximise independence for the person with dementia.

Another use of the environment is in Multi-Sensory Environments (MSE). MSE are used extensively for people with dementia and are generally delivered in an unstructured format. Collier et al (2010) completed a randomized single-blind study to explore the efficacy of sensory stimulation on functional performance which had not been previously examined. Although initial sample size calculations were not reported in this study, interim results supported the use of MSE for people with moderate to severe dementia who have difficulty participating in conventional activities. It also highlighted the individual sensory needs of the individuals and recommended the Pool Activity Level (PAL) and the Adult Sensory Profile (ASP) to plan and facilitate activity within the MSE (Collier et al, 2010). The limitation of this study is the fact that they are interim results and at the time of publication 30 participants had been recruited which was 60% of the proposed number (n50) from power analysis; therefore this did not meet the power criteria. Promising results were also found in a RCT with 18 individuals with severe dementia observed on either active or passive behaviour during a 24-week Snoezelen programme (Milev et al., 2008). Two treatment groups showed significant improvements on apathetic behaviour compared to the control group; they also showed more improvement when they were given three sessions per week in comparison to one. The positive effects lasted for 12 additional weeks after cessation of the multisensory treatment sessions. The limitations of this study were the small sample size, a lack of true randomisation, insufficient power to statistically confirm the differences between the 2 groups and that the main outcome measure DOS was not performed in a blinded fashion (Milev et al, 2008). Similarly, Van Weert et al (2005) found positive effects on apathetic behaviour, depression and appropriate behaviours during a pre- and post-test quasi-experimental study among 61 individuals with moderate to severe dementia with the Snoezelen group showing less apathetic behaviour in comparison to the control group. However, this study must be interpreted with caution as the groups were not similar at baseline in terms of their behavioural difficulties. In addition, the observation assessments were not blind and therefore subject to bias and randomisation was not achieved (Van Weert et al, 2005).

However in contrast, Baker et al (2001) compared a multisensory stimulation group (MSS group), (otherwise known as Snoezelen which is completed in a MSE) with a control group that participated in puzzle activities in a RCT among 50 individuals with moderate to severe dementia. Both groups improved on the outcome measures related to

physical activity: initiating more activities, enjoying themselves, more active or alert, and less bored. However, there were no differences in the MSS group and the control group on outcome and no long-term effects were found. The limitations of this study were that the sample size was small (n=50) and there were baseline differences between groups.

In summary, the literature generally reports limited benefits in the use of MSE to support BPSD in people with dementia with only several studies with methodological limitations as outlined demonstrating promising benefits. A Cochrane review by Chung and Lai (2002) on the use of Snoezelen environments suggests that they have little effect on the behaviours that challenge associated with dementia. However, individuals with dementia may have some degree of sensory deprivation, as a result of a lack of stimulation in their environments. Individuals with dementia also may show a decline in sensory acuity which is said to be exacerbated by a decline in perception, attention and information processing (Yan & Dick, 2006). Extra stimulation through activity and/or sensory interventions as outlined in this section may allow individuals to become engaged and focused on the environment around them and thus allow the environments to enable their occupations. With consideration of the PEO model, this literature example explains the interactions between the person (with sensory deficits as a result of dementia) the environment (enabling and stimulating or not) and the result on occupational performance and participation (for example, engagement with occupations or decrease in BPSD).

Another non-pharmacological intervention which considers the impact of the environment on occupation (amongst others) is the tailored activities programme (TAP). This was developed in the United States. It involves an OT working with both the person with dementia and the caregiver in order to tailor and adapt ADLADL to the specific needs of the individual. It uses a combination of approaches, one of which is compensation to tailor activities to the physical, sensorimotor, and cognitive abilities of the person, which engages and motivates the individual to participate in activity. Research suggests that for this population

'Activity may fill a void, maintain social roles, enable positive expression, reduce frustrations, and enhance continuity of self-identity and feelings of connectedness' (Gitlin et al, 2009, p429).

Research with individuals living in nursing homes has supported the use of purposeful activity in reducing agitation, decreasing restraint and pharmacological use and enhancing QOL for this population (Gitlin et al, 2009). TAP focuses on strengths and provides an environment understanding of these strengths. Unlike other activity interventions the TAP approach does not focus on new learning, and some procedural learning is used if appropriate. Therapists use activities that support individuals' preserved strengths and do not rely on cognitive domains most impaired such as memory. In order to reduce errors task were simplified. The environment was modified to provide tactile, auditory or visual cues to guide recall and prompt initiation and sequencing. Activities were graded to match capabilities, decrease stress and external demands. For example,

'High-functioning individuals are introduced to goal-directed and multistep activities to achieve a just right challenge; lower functioning individuals are introduced to activities based on repetitive motion (e.g., washing windows, folding towels) and that integrate multisensory stimulation (e.g., soft music, objects pleasant to touch)' (Gitlin et al, 2009, p436).

The results of this study found that

'Out of 170 prescribed activities, 81.5% were used, for an average of 4 times for 23 min by families between treatment sessions for a period of months. Caregivers reported high confidence in using activities, being less upset with behavioural symptoms (86%) and enhanced skills (93%) and personal control (95%). Interventionists observed enhanced engagement (100%) and pleasure (98%) in individuals with during sessions' (Gitlin et al, 2009, p428).

These results suggested that this could be a non-pharmacological rehabilitation approach for dementia (Gitlin et al, 2009). O Connor et al, (2014) suggest that TAP has the potential to delay admission into long term care and maintain the ultimate goal of rehabilitation for some individuals which is staying at home.

A limitation of TAP is that formal training is required for the OT delivering the programme that was not available in Ireland at the time of completing the research. Unlike CST or Sonas one limitation of TAP is that it cannot be implemented by those who are not OT's because of the specific skills required to complete the assessments and

activity prescriptions. This adds to the cost of the programme and future research plans to address this concern, by assessing outcomes if the activities were prescribed by an OT but implemented by activity therapists (Gitlin et al, 2009).

Graff et al, (2007) completed a study in the Netherlands which involved OT home visits to complete an assessment of the individual's abilities, train family caregivers in skills such as problem solving and coping strategies and to engage people with dementia in meaningful activities by implementing environmental and compensatory strategies. They concluded that community OT was a highly effective non-pharmacological therapy for older people with dementia and their care givers. It was found to improve the ADL of older people with dementia, provide their care givers with a sense of competence and improve QOL, mood, and health status of both individuals and care givers. All of these are noted to be recommended as major outcomes in therapeutic research in dementia. As this community OT intervention was noted to be cost effective, it was highly recommended that it be offered in all community health services primary care services, and outpatient services for people with dementia and their care givers (Graff et al, 2007). There were limitations in this study as it was not blinded in terms of assessment. The individuals were recruited from a specific clinic and were not thought to be a true representation of the population in the region. In contrast to previous studies examined in this literature review, this study included both the caregiver and the individual with dementia in the community only. Group interventions discussed earlier can be provided to individuals living in residential units or in the community in a group or individual format. In addition, this programme does not include an active cognitive rehabilitation component in conjunction with the compensatory and modification of the environment whereas techniques such as EL discussed earlier has this opportunity.

Behaviours that challenge occur across various stages of the disease and dementia types and cannot be attributed to cognitive impairment alone. Emerging conceptual frameworks for understanding BPSD suggested that such behaviours are an outcome of the interaction of individuals and their environments and should be addressed using non-pharmacological approaches (Gitlin et al, 2009). In a randomised trial of a non-pharmacological intervention for targeting and managing behavioural symptoms in individuals with dementia Gitlin et al, (2010) concluded that targeting behaviours upsetting to caregivers by an in home programme and modifying potential triggers improves symptomatology in people with dementia and their caregiver's skills and well-

being. There were limitations to this study which include an inability to determine active treatment components. Another limitation is study generalisability. Because caregivers volunteered for participation, they may have been more motivated to learn skills and more aware of their role than non-volunteers. A concern may be the placebo condition. Controls received information tailored to their needs, but less time than the treatment group, making it not a true control group. In a systematic review with meta-analysis by Brodaty and Arasaratnam (2012), it was concluded that community based non-pharmacological interventions delivered by family caregivers reduce BPSD in people with dementia and improve care giver responses to BPSD. They provided additional evidence that concluded that effective interventions were multicomponent and client and carer centred which were delivered individually in the home over 3-6 months with periodic follow ups. The limitations of this study were that the sample sizes varied and the nonpharmacological intervention studies recruited individuals with less severe behavioural disturbances therefore the true representation of the sample population is questionable. The effect size or the sustainability of outcomes was not provided. The specific elements of interventions that were effective for behaviours were not clear and finally not all interventions reviewed targeted behaviours.

Assistive technology in the environment of an individual with dementia has the potential to support the performance of that individual. As outlined in the PEO model of practice this impacts on the individual's mastery of tasks and achievement of personal and meaningful goals. Electronic assistive technology (AT) is increasingly being integrated into health and social care as an intervention to support an individual with dementia to live within their environments whether this is a residential care setting or in the community. The purpose of AT is to enhance functional independence and quality of life by giving the highest possible degree of autonomy and independence. This is achieved by directly enabling individuals, informing service providers/family members or both (Davis et al, 2009). An example of this type of technology would be an environmental control system such as a monitored smoke alarm, gas detector or flood monitor. Other types would be a social alarm such as a pendant system where a person can summon help at the press of a button if there have fallen or are in some difficulty (Doughty, 2003). Research in this area is limited. In a study by Lancioni et al (2013) where he compared two AT orientation systems, verbal cues to light cues (strobe lights), he found that in the small number of participants involved (5) in daily interventions over 5 months

that there was a 60-70% mean increase in the participants abilities to locate target rooms irrespective of the methods used. In a small qualitative study by Gibson et al (2015), which explored the everyday use of AT with individual's with dementia. They concluded that a mixed economy landscape of private and public provision of AT was in place and that research is required to determine the best model of practice in delivery of AT services for those with dementia. Models of provision of AT for individuals with dementia are emerging in Ireland, for example in south Tipperary a memory technology library funded by the Genio trust provides a large range of products and space where they can be seen a tried out with professions on an individual or group basis. Short terms loans of the equipment are also available to check for suitability before the individual purchases the AT equipment privately (Five steps programme, 2016). In summary, AT is used to restore, maintain, or improve functional abilities by individuals with physical and/or intellectual disabilities and is a very useful emerging tool in dementia care (Caffo, 2012).

With the majority people with dementia living at home in their communities, research in relation on the environment outside of the home and care settings is equally important; internationally, planners have historically developed public spaces for the young and able-bodied. In a discussion paper published by Alzheimer's Australia NSW (July 2011), this was described as a planning bias where assumptions are made about a person's mental and physical ability to interact with their environment in certain ways. They discussed the fact that older persons and those with cognitive and physical disabilities experience public spaces as inaccessible and inhospitable. This is said to impact on feelings of isolation and exclusion. The WHO (2007) acknowledge that one of the determinants of active ageing is the physical environment and they acknowledge eight domains of an age friendly environment to be outdoor spaces and buildings, transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, community support and health services. In a UK study by Mitchell et al, (2004) the six major requirements of outdoor dementia friendly environments are familiar, legible, distinctive, accessible, comfortable and safe. This research investigated the perceptions, experiences and use of the outdoor environment by older people with dementia and identified design factors that influence their ability to successfully interact with their local communities. The findings have enabled the researchers to provide some preliminary recommendations for a range

of different types of designers, from urban design to the design of street furniture (Mitchell & Burton, 2006). Finally, in an Innovations in Dementia report in the UK (2011) the needs of the persons with dementia in their communities were researched and the authors reported that people with dementia regard dementia friendly environments as

'where they can find their way around and be safe, access the local facilities that they are used to and where they are known and maintain their social networks so they feel they continue to belong' (JRF Joseph Rowntree Foundation, 2012, p4).

Finally, the rehabilitation process is not complete without addressing the psychosocial needs of the individual and their carers through education and support which address the needs of the persons with dementia and support their coping mechanisms. These coping mechanisms are reported by Clare (2002, p2) to be in the areas of

'Holding on by trying harder or maintaining routines and also used compensating by relying on partners, strategies and devices. Fighting the disease by focusing on the good things in life, seeking additional information, and talking about the disease', (Davis, 2005).

It is acknowledged that individuals, depending on the stage of dementia, have an awareness of their changing skills and are grieving their loss (Davis, 2005). Education and support should be provided in a sheltered and supportive environment. Individuals can benefit from education regarding the disease, preventative measures to maintain and preserve QOL and functional independence as long as possible, the importance of social activities, planning for end of life care and long term care (Davis, 2005), the caregivers' health (Moinz-Cook et al, 1998), community resources, legal issues and opportunities for sharing of feelings and emotions (Zarit et al, 2004).

The research questions and hypothesis that this literature review leads to, will now be outlined to conclude this chapter. The overall research question is to examine the impact of OT rehabilitation in dementia. Within this overarching research question, two individual questions exist.

- Firstly, the potential impact of two separate manualised group interventions delivered to those individuals with mild to moderate cognitive impairment through examining and comparing the impact of CST or Sonas on cognition, occupational

performance within a group sessions, neuropsychiatric symptoms, communication, QOL and ADL.

- Secondly, then to examine the impact of an individual client centred intervention known as EL used on specific occupation focused goals in combination with modification of the environment and compensatory methods using a single case study design.

Specifically, table 5 outlines the individual hypothesis and the rationales for secondary questions for phase one. The rationale for completing a second phase to the study is to examine an individual approach to rehabilitation in dementia care in order to target specific purposeful and meaningful occupations where the group interventions have in the literature be shown not to have specific treatment effects.

Finally, the next chapter in this thesis is the Methodology which will outline in detail the processes used to plan, collect and analyse data to inform the results of this study.

3. Methodology chapter

3.1 Introduction

The research questions and hypothesis that originated in the literature review will now be discussed. The methodology for phase one will be described first and this will be followed by phase 2. This study originated as a clinical question for the primary investigator in her work as a Senior OT in a Psychiatry of Later Life (PLL) setting in Ireland.

The literature review established a lack of an evidence base for the use of Sonas group sessions within clinical practice with participants who have moderate to severe cognitive impairment. Despite this lack of evidence there is a high level of popularity, training and use of Sonas as reported from the Sonas aPc organisation (Sonas aPc, 2011). A good evidence base for the use of CST group sessions in Dementia care in the mild to moderately impaired participant was also identified. This study will compare the two interventions for individuals in the moderate stages of dementia. Therefore, the research question for phase one of this study is that if participants are assigned to both CST and Sonas groups will they both show statistically significant differences on Cognition, Neuropsychiatric symptoms, Occupational performance within a group setting, ADL and Communication.

Phase one of the study was completed in conjunction with a psychologist in clinical trainings study. The same participants that were recruited to this study were also used in another parallel study. The other study was entitled, An evaluation of the efficacy of Cognitive Stimulation Therapy and Sonas group interventions for people with moderate dementia, and examined specifically cognitive function. The tests used were the SMMSE, the Repeatable Battery for Assessment of Neuropsychological Status (RBANS), the Token test (TT), WAIS digit span test, the trail making test (TMT), the Boston naming test (BNT), the Victoria Stroop test (VST) and the D-KEFS verbal fluency test. Both studies used the SMMSE as an outcome measure but there were no other overlaps. The thesis was submitted in May 2012 to the National University of Ireland in fulfilment of the requirements for the degree of D Psych Sc (Clin Psych), in the department of Psychology, National University of Ireland, Galway.

Phase two of the study was developed following analysis of the results of phase one. Phase one results demonstrated that there were no statistically significant changes in ADL as a result of either Sonas or CST group. Therefore, it was questioned that in order to target a specific ADL within the rehabilitation process in dementia care that firstly the PI would have to work individually with a participant in a client centred fashion. Secondly, the evidence base for dementia friendly environments and the use of a method called EL was emerging and that specific clinical research on the application of EL and dementia friendly environments with participants with dementia was justified in order to develop its evidence base. Therefore the hypothesis for phase two was to evaluate the application of EL with compensation and modification of the environment through the use of dementia friendly environment principles with older adults with all types of dementia when applied to a specific occupational goal.

This methodology chapter will outline how the hypotheses for phase one and two of the study were investigated and how supplementary analysis was therefore completed as a result of this primary research hypothesis and then the results will be presented in the results chapter accordingly.

Phase one

3.2 Context of sample

Participants were recruited from the PLL service in Ireland, and a Care Centre/public nursing home. The PLL service accepts all new referrals to the Mental Health Service for individual's aged 65 years and over. In recent years this service has expanded to accept specific referrals to PLL for individuals as young as 55 years of age. The service is accessible to individuals in the community, inpatients in PLL long stay and respite wards and residents in nursing homes irrespective of whether they are private or public. The Care Centre was a registered residential care centre for older people, which provided rehabilitation and continuing care services for the older population within its catchment area. Since completing this research, both the PLL and the care centre have been relocated to one building. The governing structures have not changed despite the new buildings.

3.3 Sample size

Sample size was calculated using formal power analysis, G*Power software (Faul et al, 2007). Parametric sample sizes were calculated. At this stage of the research there was no reason to assume that the data was not normally distributed and therefore, non-parametric analysis was not completed.

Based on Cohen's (1988) guidelines for small ($r=0.1$), medium ($r=0.3$), and large ($r=0.5$) effects, formal power analysis was completed using G*Power software (Faul et al, 2007). Two-tailed alpha of .05 was assumed for all tests. For a 2 (pre and post-test) x 2 (CST, Sonas) mixed ANOVA, with an estimated effect size of 0.80, and with a 0.05 (two-tailed) level of significance, a sample size of 42 was required to achieve 80% power.

However, the group number changed to 2 groups (CST and Sonas) after elimination of the control group which will be discussed in the following sections. Therefore, the G*Power analysis was revised to meet this change in group number. Based on Cohen's (1988) guidelines for small ($r=0.1$), medium ($r=0.3$), and large ($r=0.5$) effects, Two-tailed alpha of .05 was assumed for all tests. For a 2 (pre and post-test) x 2 (CST and Sonas) t test, with the difference between two dependent means (matched pairs), with an

estimated effect size of .80, and with a 0.05 (two tailed) level of significance, a sample size of 34 is required with a critical t of 2.034515 and DF 33 equals actual power of 0.807778.

For a 2 (pre and post-test) x 2 (CST and Sonas) t test, with the difference between two independent means (2 groups), with an estimated effect size of .80, and with a 0.05 (two tailed) level of significance, a sample size of 52 is required with a critical t of 2.008559 and DF 50 equals actual power of 0.807487.

3.4 Inclusion Criteria

The inclusion criteria for this study were as follows:

- Having a diagnosis of Dementia (of any type) according to the DSM-IV-TR (APA, 2000), and recorded in the individual's medical charts.
- Moderate cognitive impairment as classified by the Standardised Mini-Mental State Examination (SMMSE), (Molloy et al, 1991), score ranging from 10-20.
- Some ability to communicate and understand communication, determined by a score of 1 or 0 on questions 12 and 13 of the Clifton Assessment Procedures for the Elderly-Behaviour Rating Scale (CAPE-BRS), (Pattie & Gilleard, 1979).

The rationale for the above inclusion criteria is that the DSM is one of the most widely established systems for classifying mental disorders along with the International Classification of Diseases (ICD-10) produced by the WHO (DSM IV, 2000). Since completing the research the DSM is now in its fifth edition, DSM-5, published on May 18, (2013). This was the method used by the psychiatrist involved in the study.

Similarly, the SMMSE is a tool that is used extensively in clinical and research settings and is well established for use in this population (Folstein & McHugh, 1975). The SMMSE will be discussed later in detail in the outcome measure section. Finally, the CAPE question 12 identifies if the participant understands what you communicate to them through speaking writing or gesturing and 13 identifies if they can communicate in any manner by speaking writing or gesturing. A score of 0 or 1 was deemed appropriate for the participant to take part in the assessment process and group sessions (Pattie & Gilleard, 1979).

3.5 Exclusion Criteria

The exclusion criteria for the study were as follows:

- Scores <10 or >20 on the SMMSE, (Molloy et al, 1991).
- Inability to communicate and understand communication, as determined by the CAPE-BRS, (Pattie & Gilleard, 1979).
- A significant physical health problem or illness that could impact on the individuals' ability to attend and participate in the intervention and/or assessment process (e.g. an acute or chronic physical illness).
- Exposure to CST or Sonas in the six months prior to the study.
- A sensory impairment (including hearing or vision), which would impact on the individual's ability to participate in the intervention and/or assessment process, as determined by the consultant psychiatrist(s) and/or senior nursing staff.
- Significant uncontrolled disruptive behaviours (e.g. aggression, delusions, hallucinations and agitation) that could interfere with the intervention and/or assessment process; as determined by the consultant psychiatrist(s) and senior nursing staff.
- A premorbid diagnosis of a learning disability.
- Recent onset of a depressive episode or acute anxiety which is likely to affect individual's participation in the assessment and/or intervention process; as determined by the consultant psychiatrist(s) and senior nursing staff.
- A change of antipsychotic and/or antidepressant medication in the month prior to the study's recruitment stage, or the addition of benzodiazepines during the week prior to the recruitment stage, as these would likely impact on the participants performance.

Where any changes to these medications were made when the participant was undergoing the intervention or assessment process, they were able to complete the study; however, their assessment results were not included in the final interpretation of the study's findings.

The rationale for the exclusion criteria was that scores on the SMMSE outside of the <10 or >20 range indicated that the participants had mild or severe cognitive impairment and therefore could not be included. The group treatment were suitable to be compared in the moderate category only, as the CST group treatment was appropriate for mild to moderate impairment and the Sonas group treatment was appropriate for the moderate to severe impairment category. The participant was required to have certain abilities to

participate in the assessments and group sessions in order to determine that they were able to satisfactorily complete a true representation of their abilities in the assessment process, receive the treatment appropriately and allow other group members to receive the treatment appropriately. The group treatments were not designed for those with a learning disability. Finally, medication changes could have been a potential reason for change on outcome measures and therefore this was included as a criterion.

3.6 Participants

Five hundred and seventy participants were screened for phase one of this study. This consisted of 40 in the PLL inpatients wards (n = 40), community-dwelling (n = 460) and a Care Centre (n = 70) who were screened. A checklist of the inclusion/exclusion criteria was completed for each potential participant by the PI and two co-investigators (Appendix 2). For the reasons of confidentiality, no details on the participants who were screened for the study but not included in the study were retained. Where there was no CAPE-BRS completed in the participants chart, the relevant components of this assessment was completed by the PI or relevant co-investigator when screening (Appendix 3). Identification of participants suitable for the study was based on the clinical judgement of the consultant psychiatrists and MDT in each centre working in collaboration with the PI and with consideration to the study's inclusion and exclusion criteria. Where there was any doubt about the suitability of participants for the study, the Standardised Mini-Mental State Examination (Molloy et al, 1991) was administered by the Senior OT in the PLL service and in the Care Centre. Figure (2) illustrates the screening phase and the journey to the final number of participants included in the study.

Twenty six out of the twenty eight participants also participated in a parallel study, by a psychologist in clinical training. Therefore, for ethical reasons (Appendix 8) joint consent forms and information leaflets were used.

Since completing the research, the Assisted Decision-Making (capacity) Act 2015 has been enacted into Law on the 30th December 2015. At the time of the research the Lunacy Regulations (Ireland) Act of 1871 was the capacity legislation that was adhered to. The main differences of relevance to this study in the legislation are that individuals are now facilitated in making decisions in some areas of their lives but not in others

(Assisted Decision- Making (Capacity) Act 2015, no 64). Future research will adhere to the relevant act.

3.7 Recruitment of inpatient participants

Nine participants in the long stay psychiatry of later life wards and sixteen participants in the care centre were invited to participate in the study by the PI and a Senior OT in the care centre. The purpose of the study was explained and an information leaflet was provided (Appendix 4). Two to three days later the participants were asked if they would be willing to meet with a co facilitator to discuss the study further. All participants reported that they were willing to meet with the co facilitator. The opinion of the participant was ultimately respected in all sites (whether or not they wanted to participate) irrespective of their capacity. However, for those who wanted to participate but lacked capacity the following procedures applied. The participants' capacity to give informed consent to participate in the study was evaluated by one of the co-facilitators who was a psychologist in clinical training using the MacArthur Competence Assessment Tool for Clinical Research (Mac-CAT-CR), (Appelbaum & Grisso, 2001), and in consultation with the Consultant Psychiatrist on the team. Written consent was required from participants who had the capacity to give informed consent (Appendix 5). If a person was considered unable to give informed consent about whether or not they would like to participate in the study, their next of kin/significant other was contacted by the PI to seek consent. All aspects of the study was explained to the next of kin/significant other. An information leaflet (Appendix 6) and consent form (Appendix 5) was posted with a stamped addressed envelope. A follow-up call was made by the co facilitator 4-5 days later to discuss the study further and answer any questions/concerns they may have. An optional appointment to meet with one of the study's investigators was also offered. Many of the family members did not request a follow-up call from the researcher as they reported that they were happy with the information provided. Written consent once obtained was stored securely. Throughout the research process if a participant wanted to withdraw from the study or the groups at any stage this was respected and facilitated. All individuals were informally asked at the start of each session if they were happy to participate in the group therapies and the assessments that were going on. Nine inpatients in the PLL wards and 16 in the nursing home agreed to participate.

3.8 Recruitment of Community Participants

There were nineteen PLL community-dwelling individuals identified as suitable for the study. The purpose of the study was explained to them and their next-of-kin/significant other during attendance at the day-hospital or during home visits appointments. Information leaflets for both the participant themselves and their next-of-kin/significant other were provided. A follow-up call was made by the PI to the next-of-kin/significant other. The purpose of the study (including what participants would be doing as part of the study, the possible benefits and disadvantages of participation, and the right to refuse/withdraw consent) was explained to them. If the next of kin/ significant other agreed that they would like their relative to take part and had spoken with their family member with dementia about the study, an appointment was arranged to meet with the PI. These appointments were arranged in the PLL office or in the persons own home (when requested by the family). Capacity to give informed consent to participate in the research was conducted by the psychologist in clinical training at this initial appointment (using the Mac-CAT-CR), (Appelbaum & Grisso, 2001) and if appropriate part of the pre-assessment battery was also administered on the same day. Throughout the research process if a participant wanted to withdraw from the study or the groups at any stage this was respected and facilitated. All individuals were informally asked at the start of each group session if they were happy to participate in the group therapies and the assessments that were going on.

Across the three sites (PLL inpatients, PLL Community-dwelling and the care centre/public nursing home), forty-two individuals or their next-of-kin/significant other agreed to be approached by the PI about the study. Of the 36 participants for whom consent was obtained to participate in the study, 6 participants were removed from the study prior to the pre-assessment phase. Five participants were withdrawn from the study due to physical illness. Three of these participants were from a Care Centre/public nursing home; two participants were from the PLL service residing in the community. One other participant from the community withdrew from the study due to a transfer to a residential care home. Thirty participants completed the pre-assessment phase, of which twenty eight completed the post-assessment phase. With compliance to these inclusion and exclusion criteria, a total of 28 participants were included in the study.

Title of Figure Two: Screening phase flowchart.

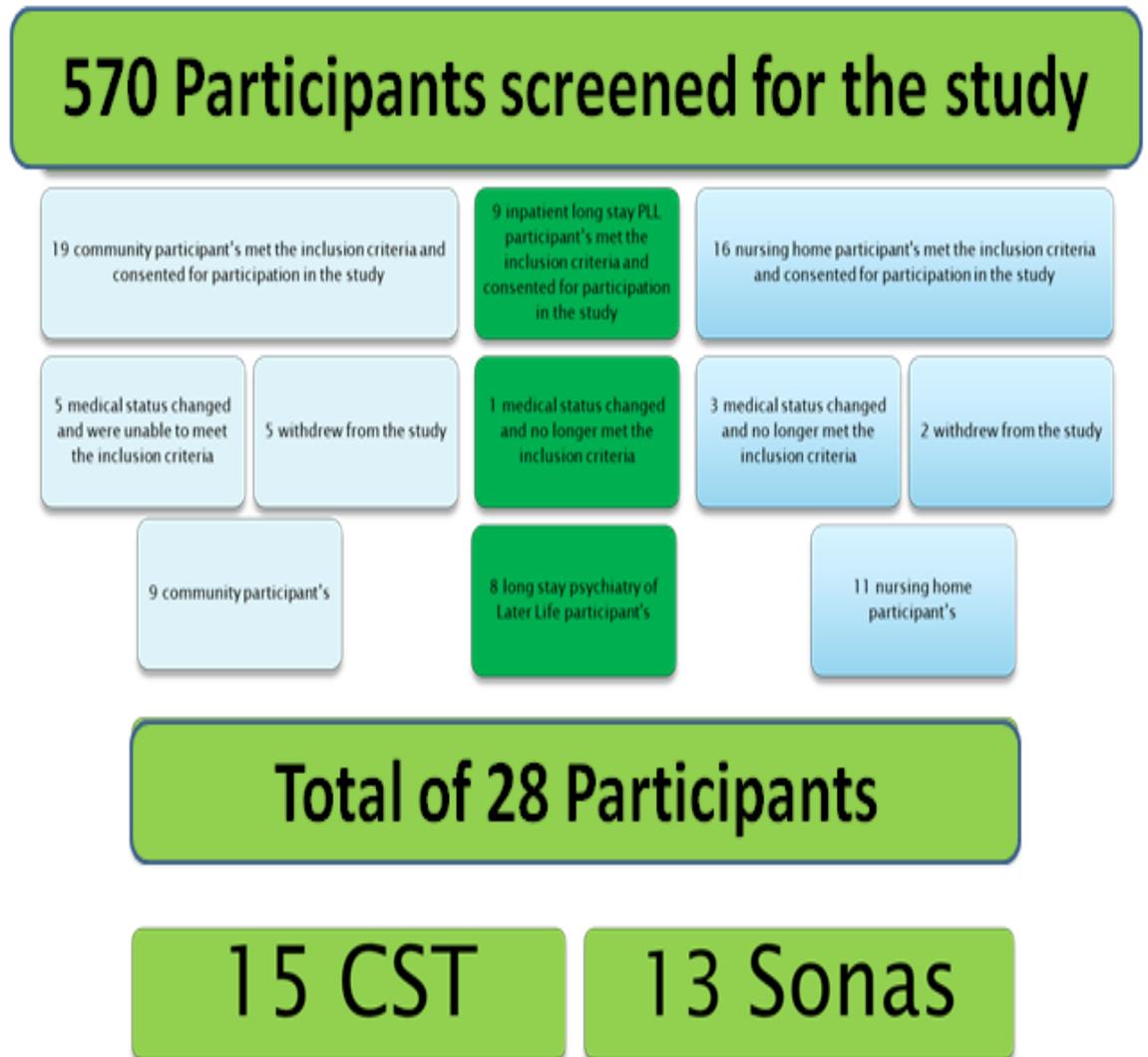


Figure 2

3.9 Study Design

The initial plan was to use a randomised control trial design (RCT). A RCT is considered the ideal design for evaluating interventions (Kaur, 2013). This design was proposed as it is considered one of the most valid methods to increase knowledge through research, because the design minimises human and environmental bias and the risk of false conclusions (Hakama et al, 2012). It is described as being at the top of the pyramid of evidence (Baldi et al, 2014). This design was considered the most appropriate to answer the research question as firstly it is quantitative and this facilitates the testing the objective hypothesis surrounding the two types of group questions by

examining the relationship amongst variables (Creswell, 2014). Secondly, it relates variables for example, site of residence and SMMSE scores, in hypothesis which inform the utility of the group intervention in that specific site for that specific outcome (cognition). Thirdly, it observes and measures information numerically which allows researchers to apply statistical approaches to make conclusions regarding the effectiveness of a type of group intervention or the best predictor of outcomes. The advantage of a RCT design was that it reduces the chance of selection bias as a threat to internal validity. This design was proposed as it is viewed as traditionally the gold standards for judging the benefits of treatments.

Due to issues with recruitment and randomisation described below, the design was changed to a prospective controlled trial. Similar to the RCT design as outlined above, the advantages of this type of design were that it is also quantitative and this facilitates the testing the objective hypothesis. It relates variables in hypothesis and it observes and measures information numerically. However, it has limitations. This design did not use full randomisation which threatens internal validity of the study as selection bias may have been present. Theoretically the RCT is the most appropriate method to answer the study question; however this research method was the appropriate to the actual population sample.

This initial proposal was to have three groups. It was proposed to have one treatment group of CST, one treatment group of Sonas and a treatment as usual control group who continued with activities as normal. For ethical reasons the PI planned to offer a treatment group to the controls once the study was complete.

There was difficulty with recruiting appropriate numbers (figure 2). The main recruitment difficulties are outlined below. The community group was subject to transport biases. There was no funding associated with this study and there was no opportunity to provide a taxi or bus service for those who did not have access to transport, the financial means to pay for their own transport or who chose not to pay for their own transport to the group. This meant that potential participants for inclusion in this study could not be recruited. Where the participant happened to live in an area that the day hospital taxi service was passing (so it did not incur additional costs to the service) transport was offered. On review of the recruitment statistics, of the 5

community participants who withdrew from the study, there were only 2 who cited this transport as a reason for withdrawal. The PI did not probe which component of transport was the cause and this was overlooked at the time.

Five community participants and two nursing home participants withdrew from the study. Informal feedback based on two/five other community participants suggested that there were some issues around the stigma of dementia coming from the participants and their families themselves. It was informally reported in 2 cases in conjunction with the issues of stigma that some participants disliked the idea of group therapies and home programmes were requested by participants themselves and by family members. This was not delivered at the time of the study as it was outside the scope of the study. They were advised to contact their local OT or psychologist for advice on relevant home programmes. To address this, the methodology was changed. It was decided to abandon the control group and allocate participants to either CST or Sonas. In total, 28 participants were recruited and completed the study.

As outlined earlier, the numbers required for power was 34 for parametric within group analysis of two groups. The PI considered the power of the study and if the control group were to be included with the final number of 28 it would have decreased the number of participants who received treatment and the numbers needed in each site for an appropriate size group which reflected standard group sizes. If the control group were included, with a two-tailed alpha of .05 was assumed for all tests, a 2 (pre and post-test) x 2 (CST, Sonas) mixed ANOVA, with an estimated effect size of 0.80, and with a 0.05 (two-tailed) level of significance, a sample size of 42 was then required to achieve 80% power. Finally, when the final number of 28 was obtained and the fact that it was close to the number needed (34), the PI and co-facilitators considered a further recruitment phase to the study in private nursing homes. However, there were logistical issues regarding this extension to the study in terms of resources, approval by ethics and time restrictions which impacted on the decision not to extend the study to private nursing homes. Therefore, this elimination of the control group was unavoidable.

3.10 Randomisation

Random allocation means that all participants have the same chances of being assigned to either treatment group (Kaur, 2013). Random allocation was planned for all participants but this proved impossible. Therefore randomisation, pseudo randomisation and convenience allocation were used as outlined below. The figures for each group in each site are presented in table (1).

In the care centre site, random allocation was completed by a clinical psychologist who was a clinical supervisor of one of the co investigators of the study using a computer-generated number system (RANDBETWEEN Command on Microsoft Excel).

In the long stay inpatient psychiatry site randomisation was done on a group basis. In this setting there were two wards, in which historically participants had never been mixed. One was a male only ward and the other was a female only ward. The wards were located in close proximity to one another. The original proposal was to randomise the participants to either CST or Sonas group and mix the participants based on the outcomes of the randomisation. The intervention was to be carried out in a communal group room and participants would be transported to the group room by staff and PI. Following consultation with management, this was not supported as a result of potential risks around management of participants off the wards. There were also logistical issues with staff's abilities to transport participants and collect them. Therefore, participants were not randomised to either condition. The full ward group of individuals were randomly allocated to either CST or Sonas conditions. This was completed by the same clinical supervisor as detailed for the care centre site, who was unaware of the gender of each ward by Tossing a coin (Head = Treatment A CST. Tail =Treatment B Sonas). This was pseudorandomisation. This method was understood to have all the properties of a random sequence following some probability distribution but not to be truly random because it is determined by a small set of initial values.

Finally, convenience allocation was used instead of randomisation for the community group. This was completed by the PI. The community group were found to have issues around transportation which was as a barrier to attendance at group sessions which were being delivered twice a week. With consideration to these difficulties it was necessary to

combine one of the group interventions into one weekly session for the seven weeks to help alleviate issues regarding transportation and participant recruitment. Due to the repetitive nature of the Sonas sessions, it was considered inappropriate to deliver two Sonas sessions in one day. Conversely, given the nature and variety of task in the CST programme, it was considered more appropriate that the CST intervention would be delivered once per week with a break in between sessions as is commonly completed with CST sessions. Those participants with transport issues and who had furthest to travel were automatically allocated to the CST groups. A 20-minute break between the two sessions for the community CST group was included to eliminate risks of fatigue. The Sonas sessions were delivered individually on a Tuesday and Thursday as planned. The allocation of participants to either group per site of residence is outlined in table one.

Title of table 1: Group numbers per site of residence

Site of Residence			
Group		Frequency	Percent
CST	Long Stay inpatient Psychiatry	4	26.7
	Care centre	6	40.0
	Community	5	33.3
	Total	15	100
Sonas	Long Stay inpatient Psychiatry	4	30.8
	Care centre	5	38.5
	Community	4	30.8
	Total	13	100

Table 1

Double blinding (or masking as it is otherwise known) is the gold standard in RCT's (Hakama et al, 2012). This is based on the premise that prior knowledge of intervention to clinicians, investigators or participants may impact on the study outcome. Therefore the identity of the treatment is concealed. In a single blind study only participating participants or the assessors do not know what intervention has been given. In a double blind study neither participating participants, nor the study investigators know what intervention was given (Kaur, 2013).

This study used a single blind method. In this study, the assessors were blind to which group the participants were assigned to. The participants themselves were not blind to which group they were attending. This is now illustrated in table (2) in the following

pages. All of the primary outcome measures were conducted under single blind conditions. The secondary outcomes were not under blind conditions. The PI was the senior OT who delivered the group interventions; the three assessments that were not completed under blind conditions as outlined in the table below were all assessments that were completed directly after the individual sessions were completed based on the observations of the PI within the sessions. The PI completed all the assessments in all sites. The co-facilitators of the group sessions were never an OT and therefore it was not appropriate to request that they complete the OTTOS which need to be completed by an OT. In addition, the co-facilitators were variable from week to week and with consideration of interrater reliability they were not asked to complete the CST monitoring progress or the Sonas group session evaluation form. This will be discussed in detail in the discussion chapter.

Title of table 2: Blinding and assessors for outcome measures.

Name of assessment	Primary outcome or secondary outcome measure	Who completed the assessment	Assessor blind
SMMSE	Primary outcome measure	Title: Psychologist in clinical training. Role: co-investigator. Completed assessment in all sites.	Yes
ADCS-ADL	Primary outcome measure	Title: CNM2, PLL. Role: research assistant. Completed all assessments in the community group and the inpatient PLL group.	Yes
		Title: Senior OT, St. Marys Care Centre. Role: research assistant. Completed all assessments in the care centre site.	Yes
QOL-AD	Primary outcome measure	Title: psychologist in clinical training. Role: co-investigator. Completed assessment in all sites.	Yes
Holden communication scale	Primary outcome measure	Title: Senior registrar, PLL. Role: co-investigator Completed assessments in all sites.	Yes
NPI	Primary outcome measure	Title: Senior registrar, PLL. Role: co-investigator Completed assessments in all sites.	Yes
OTTOS	Secondary outcome measure	Title: Senior OT Role: Primary Investigator. Completed assessment in all sites.	No
Sonas group session evaluation form	Secondary outcome measure	Title: Senior OT Role: Primary Investigator. Completed assessment in all sites.	No
CST monitoring progress	Secondary outcome measure	Title: Senior OT Role: Primary Investigator. Completed assessment in all sites.	No

Table 2

3.11 Assessments

This section of the Methodology outlines all the relevant assessments used in the study.

The Standardised Mini Mental State Examination

The SMMSE is a frequently used assessment tool that provides strict guidelines for administration and scoring (Molloy et al, 1991). It is a reliable tool which was amended from the original MMSE; when both tools were compared in 48 older adults who had the tests administered by university students on three different occasions to assess the interrater and intrarater reliability of the tests. The SMMSE had significantly better interrater and intrarater reliability compared to the MMSE: The interrater variance was reduced by 76% and the intrarater variance was reduced by 86%. The estimated percentage diagnostic accuracy is excellent; original MMSE (0.90) and SMMSE (0.94), (Molloy et al., 1996). Finally, it demonstrates equivalent reliability when administered in the clinic or the participants' home (Bedard et al., 1995). It takes an average time of 10.5 minutes to administer the SMMSE (Molloy et al, 1997). Permission was received from Prof. D. William Molloy to use the outcome measure in this study (Appendix 7).

The SMMSE was administered as a screening tool to meet the inclusion/exclusion criteria where a recent assessment was not present within the clinical chart. It was administered within 2 weeks pre and 2 weeks post the treatment phase of the study by an assessor who was blind to which group the participants were attending.

Occupational Therapy Task Observation Scale

The OTTOS is a 15 item rating scale incorporating occupational performance components which facilitates evaluation and documentation of OT intervention outcomes with individuals who have psychiatric illness including dementia. This assessment evaluates individual's performance during OT groups for the purpose of this study was used directly after each group session which did not require any individual direct time (Margolis et al, 1996). Development of the OTTOS was clearly justified by being created in response to the clinical need for a simple, quantitative and rapid method of evaluating task performance (Margolis et al, 1996).

The measure is based on the Model of Human Occupation (MOHO) (Keilhofner, 1995) and was designed to audit improvements in adults with significant performance issues (Schnell et al, 2008). The scale is known to be sensitive to changes in functional

performance during task groups (Schnell et al, 2008). The scale contains 10 items for evaluation of specific task functions and 5 items for rating general behaviour. Jones et al (1998) state that the OTTOS has good inter-rater reliability and validity. Scoring was completed in approximately 2-4 minutes for each individual.

The rationale for use of the OTTOS was that it met the objectives of the assessment need of the population of the study within a group setting. This is to observe task function and general behaviour of individuals. The Goal Attainment Scale (GAS) (Kiresuk et al, 1994) and the Canadian Occupational Performance Measure (COPM) (Law et al, 1994) are two commonly used instruments in this area, but they use individualised goal setting and are well suited to higher functioning clients and not the population of this study. It is acknowledged that there are other appropriate outcome measures cited within the literature; for example, the Assessment of Motor and Process Skills (AMPS) which is widely used and was recommended as an appropriate outcome measure (Pan and Fisher 1994). However, the training costs eliminated its use within this current study (Fuller, 2011). One limitation in the choice of the OTTOS is that it lacks further evidence of validity and reliability outside of the primary development of the tool and primary studies (Fuller, 2011). Permission to use the OTTOS was requested via e mail correspondence, but it was not received as contact was unable to be made to its authors.

The OTTOS was administered after every group session by the therapist leading the group which is acknowledged to have been the primary investigator of the study.

The Holden Communication Scale

The Holden Communication Scale is an indirect individual assessment which includes items assessing social behaviour and communication variables including, conversation, awareness, pleasure, humour and responsiveness and is completed by either a clinician or staff member if in a nursing home and family caregivers in the community where appropriate (Holden and Woods, 1995). This assessment takes approximately 5 minutes to complete. Higher scores indicate greater difficulty with communication. It is recommended for serial assessments, and has been shown to be sensitive to changes brought about by reality orientation (Brewer, 1984).

This rationale for the use of this assessment scale is that it has been used in various research articles by Spector in her research into CST (Spector et al 2003), Orrell (Orrell

et al, 2005) and Woods (Woods et al, 2012). This was chosen because of its potential to be used for comparative analysis of this study. There are limitations to the validity and reliability data outside of the original development of the tool, therefore limiting its strength. Permission for inclusion in this study was requested via email correspondence but no reply to this request was received.

This assessment was administered by one of the co-investigators who were blind to which group the participant had been allocated to. It was administered pre and post-test. Where required the co-investigator completed the tool as a joint assessment with the participants' primary nurses or care givers in the community. The group that the participant was allocated to was not disclosed by the primary nurse or care givers throughout this assessment process.

Quality of Life in Alzheimer's disease

This QOL-AD assessment consists of 13 items covering areas such as: physical health, energy, mood, friends, fun, self, and life as a whole (Logsdon et al, 2002). The scale obtains separate ratings of the individual's QoL from both the participant and the caregiver. Caregivers complete the measure as a questionnaire about the participant's QOL, while participants complete it in interview format about their own QOL. The measure consists of 13 items, rated on a four-point scale, with 1 being poor and 4 being excellent. Total scores range from 13 to 52 (Logsdon et al, 1999).

The QOL-AD has been found to have an internal reliability of 0.94 (Edelman et al, 2005) and a one-week test-retest reliability coefficient of 0.76 (Logsdon et al, 1999). Internal consistency of the scale is also noted to be good (Burns et al, 1999). Selwood et al. (2005) found that in a sample of older people with dementia with an average MMSE score of 10, more participants were able to complete the QOL-AD than other QOL tools.

Thorgrimsen et al. (2003) and Hoe et al. (2006) both reported successful use of the QOL-AD with persons with scores as low as 3 on the MMSE. In instances where QOL assessments are sought from participants with more advanced cognitive impairment and, to a lesser extent, functional impairment, it may be most favourable to employ the QOL-AD questionnaire. In addition, the QOL-AD is reported by Logsdon et al (2002) to have a good completion rate, psychometric robustness and the potential for a shorter completion time also promote the use of this measure further. Its use is recommended by

the European consensus on outcome measures for psychosocial interventions in dementia (Moniz et al, 2008). Permission was requested via e mail but no communication was received in return from the authors of the tool to include the QOL-AD in the study.

It took caregivers approximately 5 minutes to complete the measure about the participant; for participants, the interview took approximately 10 to 15 minutes to administer, this is in line with the published information (Logsdon et al 2002). The rationale for choosing this assessment over other QOL assessments was that it took into account both the individual and the caregiver, it was specific for the study population and in comparison to the Dementia Quality of Life Instrument (DQoL) (Brod et al, 1999) which only takes in the individuals account and it only suitable for mild to moderate impairment, this is a tool that could be used in future research which could include severe dementia (Brod et al, 1999). This assessment was administered pre and post assessment by a co-investigator who was blind to which group the participant was allocated to.

Activities of Daily Living

ADL were assessed using the Alzheimer's Disease Co-operative Study - Activities of Daily Living Inventory (ADCS-ADL) (Galasko et al, 1997). The ADCS-ADL is a structured questionnaire which was developed to assess functional capacity over the range of dementia severity. Both sensitivity and reliability have been established and it has comparison data, good test re-test reliability and is sensitive to dementia (Galasko et al, 1997). In Galasko et al, (1997) study, where exceptional circumstances occurred and relatives were unable to attend the clinic this test has been administered to relatives/ next of kin over the phone.

The rationale for inclusion of this assessment is based on the theory that treatment that enhances cognitive function should lead to improvements in performance of ADL (Galasko et al, 1997). A dementia specific clinical rating scale of ADL function is being used in this study. There is extensive literature regarding concerns about how the level of cognitive impairment of the individual affects ability to give an accurate report through an interview format (Frank et al, 2011). Using individual rated ADL outcome measures is reported to be a challenge, even with those with MCI and this study includes mild to moderate cognitive impairment. These concerns relate to the value of self-report

with reference to the differing levels of insight, opinions, under and over estimations of abilities and viewpoints (Kalbe et al, 2005). A version of this assessment has been developed for use with MCI, the ADCS ADL-MCI, which considers both informant- and individual-completed sections (Galasko et al, 2006). Therefore, this proxy assessment has been chosen. This proxy report for this assessment was obtained from a caregiver, key worker or relative as was appropriate.

This assessment took approximately 30-45 minutes to administer and was administered by one of the co facilitators who were a senior Nurse in PLL and a Senior OT in the care Centre. This time line was similar to the published evidence (Galasko et al, 1997). Formal permission was received from the authors of the ADCS-ADL scale (Appendix 9).

The rationale for not using direct observations to assess ADL, as is core to OT practice, was due to the time limitations that would be encountered as a result. This was considered to be a more appropriate assessment for the management of time within the study. Consideration was given to the use of the Barthel index of daily living (Collin et al, 1987) and the Katz ADL assessments (Katz, 1970) which are known to have robust psychometric properties and are long established in research and clinical practice (Collin 1988; Mahoney 1965; Wade 1988; Katz 1970). However, it was concluded that a dementia specific ADL assessment was more appropriate because it was sensitive to the characteristics of a participant with dementia in terms of how the dementia potentially impacts on their ADL.

Neuropsychiatric Inventory

The NPI assesses a variety of behavioural disturbances including: delusions, hallucinations, dysphoria, agitation/aggression, euphoria, disinhibition and apathy (Kaufer et al, 1998). Both the frequency and the severity of each domain are rated. The following psychometric approaches to the NPI have been studied: test-retest reliability, inter-rater reliability, concurrent Validity, convergent validity, differential validity and trial-related validity (Cummings, 1994), (Woods et al, 2012).

A questionnaire version of the NPI (NPI-Q) has been developed and validated and this was used for the purpose of the community group in this study. A version of the NPI has been developed and validated for use in nursing homes (NPI-NH), where information is

collected from professional caregivers. This was used in the care centre and long stay psychiatry inpatient setting (Cummings, 1997). The NPI-Q and the NPI- NH version of the NPI has been developed and cross validated with the standard NPI in clinical practice settings (Cummings, 1994). These versions are proxy assessments and they were completed by a co facilitator, who was blind to which group the participant attended and who was a Senior Registrar in Psychiatry. Both versions of this proxy assessment took approximately 15 minutes to complete. They were administered pre and post assessment. Permission was granted from the authors of the tool for use in this study, (Appendix 10).

The CST monitoring progress form

There is limited background information available regarding the development of the CST monitoring progress form. This is a tool that is included with the CST manual that records the names of the members and if they attended (Appendix 46). It then rates their performance within each session on a scale of 1 to 5 with 1 being the lowest and 5 being the highest. The areas of rating are interest, communication, enjoyment and mood.

The PI contacted the authors on the 14/02/2014 and the 19/06/2014 and the PI received feedback that

‘The tool was developed quite informally by the authors of the manual and has not been formally evaluated. It is more of a process tool than anything else’

(Aimee Spector, personal communication by e mail), (Appendix 12).

The Sonas group session evaluation form

The Sonas group session evaluation form contains 14 items. These are Eye contact, Holding Gaze, Following with Gaze, Smiling, Vocalising, Speaking, Appropriate Touch, Exercises, Singing, Rhythmic Movements, Contribution, Using Instruments, Using Gesture and Interactive Posture. The user rates each area on the form on a scale of 0 to 5 with 0 indicating no evidence, 4 indicating frequent evidence and 5 indicating that it was not applicable within the session (Sonas aPc 2012) (appendix 47).

As with the CST monitoring progress evaluation form, there is limited background information on the development of this form. The CEO of Sonas was contacted on the 14/02/2013 in relation to further information on the form and a copy of the research

proposal was provided outlining the plan to use the tool in the study. No answer to the request for further information was received and no disagreement with using the tool in the study. Similar to the CST monitoring progress form, these were both forms that were part of the manual and pack for users of the programme. Therefore, the PI chose to use them in the study.

Since completing the research, the Sonas group session evaluation tool has been named the 'Threadgold communication Tool' and its psychometric properties have been evaluated for the first time (Strom et al, 2016). The study concluded that the tool is a reliable and valid instrument, suitable for measuring communication for individuals with dementia. However, this study has limitations in terms of sample size, mainly female participants, it was only tested on individuals with moderate to severe dementia and it was not validated against another dementia specific communication assessment (Strom et al, 2016).

Clifton Assessment Procedures for the Elderly- Behaviour Rating Scale

The CAPE evaluates the presence and severity of impairment in mental and behavioural functioning. It was intended for elderly long-term psychiatric individuals and consists of two components: the Cognitive Assessment Scale (CAS) and the Behaviour Rating Scale (BRS). The CAS includes a 12-item information and orientation subtest, a brief mental abilities test, and a psychomotor performance test that involves tracing a line through a maze. The BRS contains 18 items and is completed by relatives or staff familiar with the individual's behaviour. It assesses physical disability including ADL, apathy, communication difficulties and social disturbance (Pattie and Gillard, 1979). Validity of the BRS and CAS has been demonstrated in terms of correlation with other neuropsychological tests and with longitudinal studies. The BRS has good inter-rater reliability and the test retest reliability on the CAS is high (Pattie, 1981). The full assessment was not completed in this screening phase. This full assessment (BRS and CAS) takes approximately 30 minutes to complete. Permission was granted to use this tool in this study (Appendix 11). For the purpose of this study's screening and inclusion process, question 12 and 13 was used (Appendix 3).

A summary of the validity and sensitivity data on all the assessments is presented below in table 3 to conclude this section.

Title of Table 3: Assessment validity and sensitivity data

Assessment	Validity and Sensitivity Data
SMMSE	When compared to the MMSE; the intrarater variability is significantly lower with the SMMSE (86%, $p < 0.003$) and the interrater variance was reduced by 76%, compared to the MMSE. Interclass correlation for the MMSE was 0.69 compared to 0.90 for the SMMSE (Molloy et al, 1991), (Molloy, 1999).
OTTOS	The scale is known to be sensitive to changes in functional performance during task groups (Schnell et al, 2008). Correlation coefficients were .89 for task behaviour scores, .76 for general behaviour scores, and .92 for the total scores { $p < .0005$ for each comparison} (Margolis, 1996).
The Holden Communication Scale	There are limitations to the validity and reliability data outside of the original development of the tool, therefore limiting its strength.
Quality of Life in Alzheimer's disease	The QOL-AD has been found to have an internal reliability of 0.94 (Edelman et al, 2005) and a one-week test-retest reliability coefficient of 0.76 (Logsdon et al, 1999). Internal consistency of the scale is also noted to be good (Burns et al, 1999). Selwood et al. (2005) found that in a sample of older people with dementia with an average MMSE score of 10, more participants were able to complete the QOL-AD than other QOL tools.
Alzheimer's Disease Co-operative Study - Activities of Daily Living Inventory	Both sensitivity and reliability have been established and it has comparison data, good test re-test reliability between baseline and 1 and 2 months and is sensitive to dementia (Galasko et al, 1997).
Neuropsychiatric Inventory	The following psychometric approaches to the NPI have been studied: test-retest reliability, inter-rater reliability, concurrent Validity, convergent validity, differential validity and trial-related validity (Cummings, 1994), (Woods et al, 2012).
The CST monitoring progress form	No Available data.
The Sonas group session evaluation form	No available data at the time of the research. However, since completing the research it has been renamed the Threadgold Communication Tool. Based on this one study, there was good internal consistency and test retest reliability.
Clifton Assessment Procedures for the Elderly- Behaviour Rating Scale	The BRS has good inter-rater reliability (Pattie, 1981).

Table 3

3.12 CST and Sonas group sessions

All CST group sessions across the three sites were led and completed by a Senior OT who was the PI of the study. The sessions were co facilitated by OT assistants (OTA) and healthcare assistants (HCA) in the care centre, Nursing staff in the mental health unit and a combination of OT student/volunteer and Nursing staff for the community group.

Both CST and Sonas groups are manualised programmes. The within session details of these manualised programmes that were applied can be found in appendix (13).

The sessions were completed twice a week on two separate days in the care centre and the mental health hospital. The community group completed two groups with a half an hour break between the group for toileting and refreshments. There were no more than 7 participants in a group at any one time. Records of attendance were kept.

Both CST and Sonas groups were completed in therapeutic group rooms within the relevant settings. Both groups had similar environmental conditions in all setting. Both groups were completed with strict adherence to the relevant manual for CST and Sonas CD and pack.

3.13 Statistical methods used

Baseline data normality was assessed using the explore command in the Statistical package for Social Sciences (SPSS) version 20. Normality was considered under the following assumptions:

- Confidence intervals (confidence intervals are typically stated at the 95% confidence level) to be accurate, the estimate must come from a normal distribution especially in smaller samples.
- For significance tests of models to be accurate the sampling distribution of what is being tested must be normal. Therefore, the shape of the data was considered to potentially impact on the significance tests based on the central limit theorem as the sample was small.
- For the estimates that define a model to be optimal the residuals in the population must be normally distributed (Field, 2013).

In summary, with consideration of the above bullet points it was specifically important to establish normality in this sample of data as the sample size was small (n=28). The reason for this was because of the central limit theorem which impacted on the data. In larger sample sizes the less the assumption of normality matters because the sample distribution will be normal regardless of what the data looks like (Field, 2013).

The pre score/baseline score from each outcome measure was the score used for examination in order to determine if the participant was normal in terms of that variable for example, in cognition measured by the SMMSE. The variables that were considered at baseline were the group (CST or Sonas), the site of residence (Long stay inpatient psychiatric, community or care centre), residence type (Inpatients or community), dementia type (AD and non-AD), dementia diagnosis type (AD, VaD, Mixed AD and VaD, FTD and not specified/other) and sex (male or female). These variables were examined in terms of mean pre scores for the SMMSE, the Holden Communication scale, the QOL-AD, the NPI, the ADCS-ADL scale, the OTTOS, the CST monitoring progress form and the Sonas group session evaluation form.

Potential sources of bias in baseline data were then statistically examined in the following ways:

- 1) Outliers: These are potential sources of bias which impact on the mean scores. These were examined visually on boxplots and on examination of the mean score and the 5% trimmed mean score to examine change as a result of extreme scores.
- 2) Linearity: To see if the model being fitted in this study represents reality. This assumption needs to be true and the relationship between the outcome variable and any predictors can be summed up by a straight line. This assumption was visually examined in the data.
- 3) Normality was examined in graphs:
 - Histograms. The normality of the outcome at each unique level of the predictor variable (for example, within Sonas or CST groups) was examined in the graphs. They were visually inspected to determine if the distribution of the data was bell shaped, symmetrical and did not appear too pointy or too flat.
 - P-P plots. This plots the cumulative probability of a variable against the cumulative probability of a normal distribution. These were examined to determine

if the data points fell close to the ideal diagonal line, and to examine if there were clusters around the scale

Q-Q plots. These show the same thing as P-P plots, only that they are expressed as quantiles. These were examined in the same way as P-P plots (Field, 2013).

Normality was examined numerically:

Values of skew and kurtosis. These were presented numerically on SPSS in the form of z scores. The value of zero was considered normal in a normal distribution. Positive values of skewness and kurtosis were understood as indicating a pile up of scores on the left of the distribution with a pointy and heavy tailed distribution and negative values were considered as indicating a pile up on the right of the distribution with a flat and light tailed distribution. The distance from zero was considered relevant with the further away the value was from zero the more likely the data is not to be normally distributed (Field, 2013).

3) Normality was examined through significance tests:

Kolmogorov- Smirnov test and the Shapiro-Wilk test of the normality of the distribution were completed through SPSS (Field, 2013). A significance value of less than 0.05 was considered to indicate a deviation from normality. A non-significant value of greater than 0.05 was considered to be probably normal. The degrees of freedom (df) D score and the significance p score was reported.

Homogeneity of variance:

Similar to normality this was examined in graphs (though scatterplots), numerically (values of the variances in each group can be simply looked at) and significance tests (Levene's test: significant results indicate violation of the assumption and not to be significant results indicate that the assumption is accepted and the variances are roughly equal).

An in depth description of the examination of normality and results for each outcome measures can be found from appendix (14) to (20). if groups were normal in normality results, groups were compared on baseline scores on all outcome measures using parametric independent t-test that determined whether there is a statistically significant difference between the means in two unrelated groups and therefore to establish

differences between variables on outcome measures baseline scores. If groups were not normal on normality tests then the Mann Whitney U non-parametric test was used to compare the outcome measures mean scores. This is outlined in table (3) in the results section.

If it was concluded that the data did meet the normality assumption at baseline then parametric assessments were used in the analysis. If it was concluded that the data did not meet the normality assumption non-parametric assessments were used in the analysis.

Both CST and Sonas groups were examined in two ways. A between group analysis on post assessments, to examine if the groups were significantly different at outcome and a within group analysis (i.e. pre intervention T1 to post intervention T2) to evaluate if there were significant changes within groups.

Where the analysis of the primary hypothesis concludes that on an outcome measure, both CST and Sonas groups improved significantly or did not improve significantly (it could be therefore, argued that both interventions were equally effective or not effective). The supplementary analysis was completed with the aim to examine the impact of other variables/factors these results on two outcome measures the OTTOS and the ADCS-ADL scale. A table was included to summarise findings where relevant. Other variables included in this supplementary analysis leading to secondary hypothesis were site of residence (Inpatient psychiatry of later life, care centre and community), residence type (inpatient and community), dementia type (AD and Non-AD), dementia diagnosis type (AD, Vascular, FTD, mixed AD and vascular and not specified/other), capacity to give informed consent and sex (Male and Female). In the supplementary analysis, where both group conditions improved significantly, a bivariate correlation using the Spearman's rho was completed to examine any relationship between age, length of stay in residence (inpatients) and number of group sessions attended.

Significance levels were set at 0.05. Parametric tests used were the t test (t), ANOVA (F) and Pearson correlation coefficient (rho). Non-parametric tests used were the Mann-Whitney U test (U), the Wilcoxon signed rank test (W), the Kruskal-Wallis test (K) and the Spearman's rank order correlation (rho).

The occupational performance within a group setting was evaluated on 14 occasions through the use of the OTTOS, the CST monitoring progress evaluation tool and the Sonas group session evaluation form. These assessments were completed at the end of every session. Non-parametric statistical tests were used to compare pre and post scores and visual inspection of the data on graph formats. Table (4) below details each hypothesis, the tests used and the rationale for the choice of tests.

Title of table 4: Hypothesis, test used and rationale.

Hypothesis	Test	Rationale
1. Participants assigned to both the CST and Sonas conditions will show improvements from pre-intervention to post-intervention on the SMMSE.	Comparison of pre-test (T1) and post-test (T2) SMMSE scores across both Groups using a split file paired samples t-test. An independent samples t-test was used to examine the differences in mean score between groups on the post SMMSE scores.	Data was normal at baseline. Therefore parametric t test was used to compare pre and post scores on the groups. This parametric t-test allowed comparison on whether two groups have different average values. The independent t-test is used in this experiment as there are two conditions (CST and Sonas) and different participants have been used in each condition.
2. Participants assigned to the CST group will demonstrate greater improvements in total score and task behaviour than Sonas group on the OTTOS. Both groups will demonstrate similar improvements in general behaviour.	Between groups- The Mann Whitney U test. Within groups- related samples Wilcoxon Signed	Data was not normal at baseline therefore non-parametric tests were used. The Mann Whitney U test which tested for differences between the groups on all between group analyses. The related samples Wilcoxon Signed Rank

	Rank test was used on all within group analysis.	test was used to test if population mean ranks are different.
3. Participants will demonstrate consistent gradual improvements in performance as measured by total OTTOS score over a 14 session period in both groups. There will be differences dependant on the group.	Visually inspected and displayed on a graph. Mathematical calculation of the number of decreases in mean scores.	Graph presentation to demonstrate the gradual improvements over the 14 sessions. Mathematic calculation was appropriate to obtain the number of sessions with increases or decreases in mean scores.
4. Participants in both groups will demonstrate statistically significant improvements in all areas of the Sonas group session evaluation form assessment.	Between groups- A Mann Whitney U test. Within groups- The Wilcoxon Signed Rank test	This non-parametric test was used on the individual sessions of the form and presented in table format to display results. There was no total score on this outcome measure. The Mann-Whitney U test was used to compare differences between two independent groups when the dependent variable is either ordinal or continuous, but not normally distributed. Wilcoxon Signed Rank test was used to test if population mean ranks are different.
5. Participants in both groups will demonstrate statistically significant improvements from	Between groups- A Mann Whitney U test.	This non-parametric test was used on the individual sessions of the form and presented in

<p>session one to session fourteen in all areas of the CST monitoring progress assessment.</p>	<p>Within groups- The Wilcoxon Signed Rank test</p>	<p>table format to display results. There was no total score on this outcome measure. The Mann-Whitney U test was used to compare differences between two independent groups when the dependent variable is either ordinal or continuous, but not normally distributed.</p> <p>Wilcoxon Signed Rank test was used to test if population mean ranks are different on each individual component of the test.</p>
<p>6. There will be significant change in ADL as a result of either CST or Sonas intervention.</p>	<p>Between groups- A Mann Whitney U test.</p> <p>Within groups- The Wilcoxon Signed Rank test</p>	<p>The Mann-Whitney U test was used to compare differences between two independent groups when the dependent variable is either ordinal or continuous, but not normally distributed.</p> <p>The related samples Wilcoxon Signed Rank test was used to test if population mean ranks are different.</p>
<p>7. There will be statically significant positive improvements in total QOL-AD scores, participant rated scores and carer rates scores in both groups.</p>	<p>Between groups- A Mann Whitney U test.</p> <p>Within groups- The Wilcoxon Signed Rank</p>	<p>The non-parametric Mann Whitney U test examined differences between the groups,</p> <p>This Wilcoxon signed rank test is used when</p>

	test.	comparing two repeated measurements i.e. pre and post scores. This is to assess to assess whether their population mean ranks differ.
8. There will be statistically significant improvements in the CST group only. There will be no differences in outcomes in terms of the individual components of the Holden Communication scale assessment.	Between groups- A Mann Whitney U test. Within groups- The Wilcoxon Signed Rank test.	A nonparametric test was required to compare differences between two independent groups when the dependent variable is either ordinal or continuous. This Wilcoxon signed rank test is used when comparing two repeated measurements i.e. pre and post scores.
9. There will be statistically significant improvements in total scores and individual components of the NPI assessment in both CST and Sonas groups. There will be no difference between groups.	Between groups- A Mann Whitney U test. Within groups- The Wilcoxon Signed Rank test.	A nonparametric test was required to compare differences between two independent groups when the dependent variable is either ordinal or continuous. This Wilcoxon signed rank test is used when comparing two repeated measurements i.e. pre and post scores.
Supplementary Analysis leading to secondary questions		
1. Both CST and Sonas groups improved significantly on the OTTOS. Did sex, site of residence, residence type, dementia type, dementia diagnosis type and	A related samples Wilcoxon signed rank test was completed on each of the variables.	The file was split to compare the groups and variables. Then the test was completed. This Wilcoxon signed rank test is used when comparing two repeated

capacity to give informed consent have an influence on change in the primary results?		measurements i.e. pre and post scores.
2. Neither CST nor Sonas groups improved significantly on the ADCS-ADL scale. Dis Sex, site of residence, residence type, dementia type, dementia diagnosis type and capacity to give informed consent have an influence on the primary results?	A related samples Wilcoxon signed rank test was completed on each of the variables.	The file was split to compare the groups and variables. Then the test was completed. This Wilcoxon signed rank test is used when comparing two repeated measurements i.e. pre and post scores.
3. Both CST and Sonas groups improved significantly on the OTTOS. Was there a relationship between outcome on the OTTOS and number of years in residence, age and number of group sessions attended which influenced the primary results?	Spearman's rank order Correlation (rho)	A nonparametric measure of statistical dependence between two variables was required. The Spearman's rank order Correlation (rho) was chosen.

Table 4

The rationale for each hypothesis and secondary question will now be presented in table format (table 5).

Title of table 5: Hypothesis and secondary question rationale.

Hypothesis	Rationale
Participants assigned to both the CST and Sonas conditions will show improvements from pre-intervention to post-intervention on the SMMSE.	There is a good evidence base for the use of CST and Sonas is a widely used intervention in Ireland that is claimed to be effective. Therefore, the rationale for this hypothesis is that both will be similar in the primary outcome measure for cognition.

<p>Participants assigned to the CST group will demonstrate greater improvements in total score and task behaviour than Sonas group on the OTTOS. Both groups will demonstrate similar improvements in general behaviour.</p>	<p>There is documented evidence that participants in cognitive stimulation groups have positive changes in social interaction which would affect their scores on the OTTOS. In a Cochrane review by Woods et al, (2012), four RCTs (with 223 participants) indicated that positive changes in communication and social interaction were evident in staff ratings outside the context of the cognitive stimulation group sessions. It is hypothesised here that if the positive changes are seen outside the group sessions for participants in cognitive stimulation groups that they will also be seen within the groups. In contrast, there is no evidence base to suggest that Sonas participants will have changes in any components with a group session.</p>
<p>Participants will demonstrate consistent gradual improvements in performance as measured by total OTTOS score over a 14 session period in both groups. There will be differences dependant on the group.</p>	<p>It is suggested that any improvements seen in session one in either group, will be built on in the subsequent sessions. It is hypothesised therefore, that improvements over the 14 sessions will be consistent and gradual. Given the difference in intervention sessions between the two manualised programmes, it is hypothesised that there will be differences dependant on the type of group.</p>
<p>Participants in both groups will demonstrate statistically significant improvements in all areas of the Sonas group session evaluation form assessment.</p>	<p>This evaluation form was designed for use with Sonas and therefore it is suggested that the evaluation form will be sensitive to the Sonas condition. As outlined in hypothesis 3, there is an established evidence base for CST. Therefore, this hypothesis expects both groups to demonstrate improvements.</p>
<p>Participants in both groups will demonstrate statistically significant improvements from session one to session fourteen in all areas of the CST monitoring progress assessment.</p>	<p>There are similarities in the themes in the outcome measures in hypothesis 3 and in hypothesis 4. Therefore, the hypothesis is the same.</p>
<p>There will be no significant change in ADL as a result of</p>	<p>There is no evidence base to support changes in ADL as a result of either group.</p>

<p>either CST or Sonas intervention.</p>	
<p>There will be statically significant positive improvements in total QOL-AD scores, participant rated scores and carer rates scores in both groups.</p>	<p>There is a documented evidence base to suggest that CST has positive improvements in QOL (Spector et al, 2003). In the only published study on Sonas which used the QOL-AD, they only used the caregiver ratings and not the participant's ratings combined (Hutson, 2014). Therefore, it is hypothesised that if the QOL-AD was used fully in this study (combining the two ratings) that there would be positive outcomes.</p>
<p>There will be statistically significant improvements in the CST group only. There will be no differences in outcomes in terms of the individual components of the Holden communication scale assessment.</p>	<p>In Spector et al (2003) study there was a trend towards improvements in communication in the CST group (P=0.09). In a qualitative study by Spector et al, (2011) one third of carers said that their relatives were showing improvements in their verbal skills outside the CST groups, more willingness to engage in conversation and more fluency in conversations. Therefore, it was hypothesised that the improvements in communication would be seen on the CST group only. There is no evidence to support improvement in communication as a result of Sonas.</p>
<p>There will be statistically significant improvements in total scores and individual components of the NPI assessment in both CST and Sonas groups. There will be no difference between groups.</p>	<p>The literature suggests that positive changes in communication and social interaction are present for those involved in cognitive stimulation group sessions (Woods et al, 2012). It is hypothesised that these improvements would be transferrable to neuropsychiatric symptoms in the CST groups. Sonas aPc claim that there are improvements in mood and behaviour as a result of this intervention (Sonas aPc, 2015). Therefore, this hypothesis expects that there will be improvements in both CST and Sonas.</p>

Table 5

3.14 Phase two

Phase two aimed to build on the findings of phase one and examine a different approach; this involved the application of EL interventions with individuals rather than in a group to target the areas of ADL, Cognition, QOL and Communication. The rationale was to examine those areas where firstly the group interventions were shown to not have a treatment effect and to examine different types of interventions to address these areas in order to address rehabilitation goals.

3.15 Context of Sample

In phase two, participants were recruited from the community PLL service only across the two counties of Longford and Westmeath. The intervention completed in the participant's home and therefore there were no issues with travel for the participants involved.

3.16 Participant selection

Participants were selected from an active caseload of the PLL team. This is the same team and catchment areas as outlined phase one. Participants were selected under the supervision and with permission from of the two consultant psychiatrists in this area.

The Senior OT/ PI liaised with the consultant Psychiatrist and senior nursing staff in the PLL service. Participants identified as suitable for the study was based on the relevant professional's clinical judgement with consideration to the study's inclusion and exclusion criteria.

Where there was any doubt about the suitability of participants for the study, the SMMSE, a frequently used cognitive screening tool was administered by psychiatrist, OT or nursing staff. The results of this clarified whether a person was suitable for the study (i.e. present with relevant cognitive impairment). Individuals with dementia are assessed regularly with the SMMSE. It took approximately less than 10 minutes to administer.

The initial screening phase identified participants who consented to the study. Those identified then were screened further to ensure that they met the inclusion/exclusion criteria.

3.17 Inclusion criteria

1. Diagnosis of Dementia of any type according to the DSM V (DSM V, 2013) criteria as recorded in their medical notes (American Psychiatric Association, 2013).
2. Mild to moderate cognitive impairment as classified by the SMMSE of score range 10-24 (Folstein & McHugh, 1975).

The rationale for the inclusion criteria is that this pilot study would include participants with any type of dementia was that this was a pilot that sought an evidence base for an intervention across the diagnostic spectrum of dementia. Following the literature review, the rationale for including the mild to moderate stage of cognition was that studies which examined effects of EL demonstrated greatest effects with those with mild to moderate difficulties and not severe impairment (Middleton & Schwartz, 2012). Similarly, studies exploring the role of compensatory measures in the environment found greatest improvements in those with mild impairment, with reductions seen as cognition deteriorated (Namazi et al, 1991).

3.18 Exclusion criteria

1. Severe scores of 10 or less on the SMMSE (Molloy et al, 1991).
2. A significant physical health problem such as a major physical illness that could impact on the individuals' attendance of the programmes.
3. Sensory impairment including inadequate hearing and Vision which would impact on their ability to participate in an individual treatment
4. Significant uncontrolled disruptive behaviours (e.g. aggression, delusions, hallucinations and agitation) that could interfere with the intervention and/or assessment process
5. A diagnosis of a premorbid intellectual disability.
6. Recent onset of a depressive episode or acute anxiety which is likely to affect individual's participation in the study.
7. A change of antipsychotic and/or antidepressant medication in the month prior to the study and the addition of benzodiazepines during the week prior to the commencing of the study, as these are likely to impact on an participant's performance. Where changes

to these medication are made when the participant has already engaged with the study; this will be noted. Participants will be able to complete the intervention but will not be included in the study results

8. Previous exposure to EL in the last 6 months.

The rationale for these exclusion criteria was that control measures were required to ensure that the participants could participate in the intervention with the PI and that the intervention was suitable for their level of impairment. In addition, to eradicate any lasting effects from previous EL studies if previous exposure had occurred participants were not included in the research.

3.19 Consent

Both participants were assumed to have capacity to consent to the study. There were no concerns from the participants, the PI or the family members regarding the participant's ability to give informed consent. Should there have been any issues regarding consent, the consultant psychiatrist was available to complete relevant assessments as outlined in phase one of the study. A participant information leaflet (Appendix 4) was provided to the participants and the details of the study explained directly to them by the PI. The participants were then given one week to consider their decision. The PI then returned to the participants and the consent form was completed (Appendix 5). There were clear lines of communication with the participant's families at this stage of the process and the PI's contact details were clearly provided on all information sheets and consent forms. This consent form was completed on the same day as the initial assessments.

The initial assessment administered the assessments of cognition, communication, QOL and ADL. This assessment also introduced the goal setting and this was subsequently followed up by another interview were required before the A phase of the study.

3.20 Design

Phase 2 of the study also used a quantitative approach. The type of design chosen for phase two was an ABA single case experimental design. This measured the participant participants over three phases; A= baseline assessments, B= Intervention assessments and A= Post intervention baseline assessments. In this type of design, individual participants served as their own controls with individual differences/characteristics

making no contribution to the variance. In single participant designs no comparisons are made across or between participants. A participant's behaviour is compared with their behaviour in a different stage of the experiment and not with others. Therefore, the question is whether the participant's behaviour has changed relative to their own baseline (Morgan & Morgan, 2001).

Single case experimental designs are often thought of as non-rigorous and are the most basic design in single case research. In comparison, RCT's are put at the top of the evidence rigor. In a striking assertion by Guyatt et al (2000), they put single case experimental designs at the top of the hierarchy of evidence arguing that the single case has greater generalisability to individual participants. This assertion is not generally accepted. It was acknowledged that variability and heterogeneity across individuals is a problem in any group research design and they stated that the aim of evidence based practice is to inform decisions about individuals.

There are many different single case experimental designs. The ABA design was chosen because of its strengths. It allows for the measurement of behaviour through multiple repeated measures taken over prolonged observational periods i.e. 15 sessions in this study. This allowed the PI to examine the development of behaviour of the individual over time and develop confidence that the behaviour is a true representation of the participant under the experimental conditions (Morgan & Morgan, 2001). It is easily replicated in clinical practice with its 3 phases. The fact that participants act as their own controls and comparisons made across experimental conditions and not across participants add strength to this design. When this is considered under the concept of client centred practice, and when a clinician is determining the potential effectiveness of an intervention for an individual this design is useful as it answers the question if a participant has changed relevant to their own individual baseline and not to that of others.

The weaknesses of this ABA design are related to how it is analysed, there is a general consensus of an,

'Uneasy fit between conventional inferential statistics and the data generated by single-participant studies' (Morgan & Morgan, 2001, p121).

This lack of fitting between statistics and ABA design remains debated with some researchers considering inferential statistics useful to single participant researchers and others justifying that visual inspection of data is as strong as inferential statistics when under well documented experimental conditions (Morgan & Morgan, 2001). Another weakness of this design is the threat to external validity, the issue of generalisability because the characteristics of the home environment setting cannot generalise to participants in other settings, the narrow characteristics of participants does not allow the PI to generalise to individuals who do not have the same characteristics.

This ABA design was suitable to answer the research question as it allowed repeated measurement over time of an unfolding changing goal focused behaviour as a result of intervention. It allowed for detailed observer ratings by the PI which is a direct measurement of behaviour change as a result of intervention.

The measure chosen to use within this ABA design was activity analysis. Activity analysis is viewed as a multifaceted process (Cynkin & Robinson, 1990; Hopkins & Smith, 1988; Lampion et al, 1982; Mosey, 1986). Christiansen et al (2005) describe it as a process where performance demands of the activity are defined. This is done by breaking the activity down into its component parts. This involves an analysis of each of the components in terms of

'Contextual, temporal, psychological, social, cultural and meaning dimensions'
(Christiansen et al, 2005, p220).

Cultural and environmental context were considered for the activity/occupation, for example the impact of familiarity of the home environment. The meaning of the occupation was established through goal setting. The impact of dementia on performance was fully considered prior to the B phase. The properties of the activity/occupation such as steps, tools used and safety were all documented. The characteristics of the activity related to the PEOP model of practice were considered. The activity/occupation was directly observed in the A phase as it is normally performed by the participant with a record of observations and numerical and descriptive records of errors documented by the PI. It was then modified through intervention in the B phase. This measure is suitable for frequently repeated administration. Barker et al (2002) reported that the two most common types of measures are observer ratings such as the one which was chosen for use in this study and the clients own ratings from self-

monitoring. The frequency of measurement was dictated by the individual client centred nature of the study and this was mutually agreed by the participant and PI. The assessments were approximately every 2 weekdays for participant one and every weekday for participant two, with weekends not being included for either participant.

For both participants, performance met the basic assumption of the design which is that it would stabilise in the A phase. Baseline measurements were stabilised after 5 sessions of direct baseline observations, then the first experimental treatment began at session 6 to 10. Baseline measurements recommenced in the post A2 phase which was from sessions 11 to 15 for both participants.

Single-case researchers traditionally have relied on visual analysis of the data to determine (a) whether evidence of a relation between an independent variable and an outcome variable exists and (b) the strength or magnitude of that relation (Kratochwill et al, 2010). Single case design is a collection of experimental methods classed to document three things.

- 1. If there is an observable and important change in some dependant variable.*
- 2. If the observed change in the outcome data post application of the independent variable is a result of the application of the independent variable*
- 3. If this change is something that is generalisable across time, setting and target'* (Riley-Tillman & Burns, 2009, p9).

Visual analysis was displayed on a graph. Morley and Adams (1991) discuss that the success or failure of the intervention is usually clearly obvious from the graph presentation. It is also helpful to show relevant participants their graphs in order to enable them to monitor their progress and demonstrate clearly that the intervention is working; this approach was not used in this study as self-monitoring was not relied on in the assessment phases and it may have impacted on the participant rated outcome measures (Barker et al, 2002). An example of how the ABA design might be presented is presented in figure (3) below.

Title of figure 3: ABA design example.

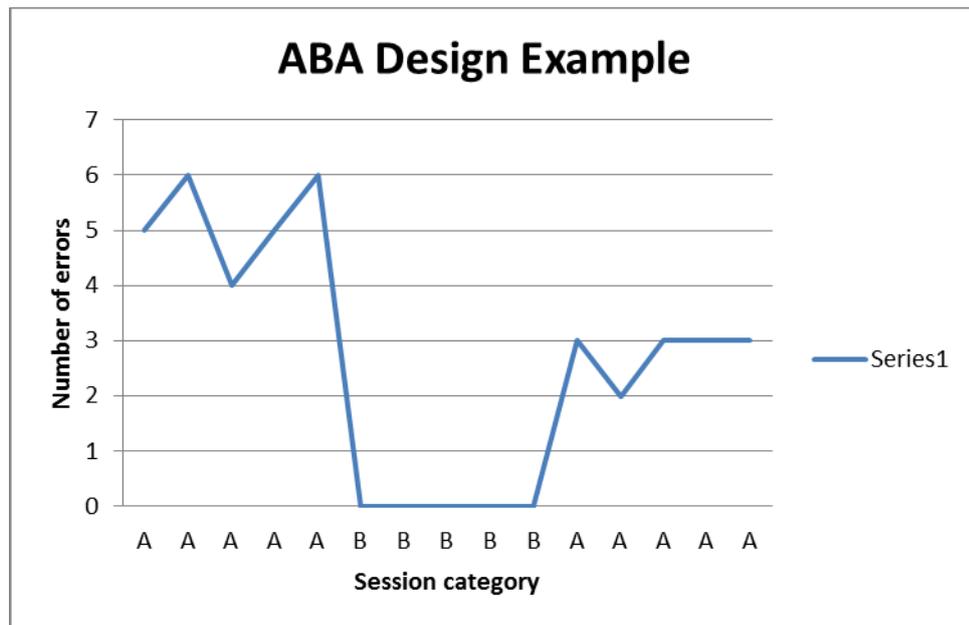


Figure 3

Tate et al (2008) devised criteria to evaluate single case experimental design and the design was assessed against these. This is shown in Table (6) below and all but two criteria were met.

Title of table 6: Tate et al criteria (SCED).

Criteria	Met / Not met
Clinical history - Age, Sex, Aetiology Severity reported	Yes
Target behaviours	Yes
At least 3 phases	Yes
Data points reported	Yes
Inter rater reliability of behaviour observation	No
Independent assessors	No but standardised validated assessments were used.
Statistical analysis	No – not appropriate
Replication	Yes
Evidence for generalisation	No

Table 6

It was planned to recruit 4-9 participants from an open caseload of the Psychiatry of Later Life team in Longford and Westmeath. There were difficulties with recruitment. There were 28 potential participants approached who met the inclusion/exclusion criteria. 26 of the 28 participants refused to consider participation in the study. Reports from these 26 participants were not formally maintained. This was overlooked. A checklist similar to phase one of the study would have been suitable. However, informal reports to the PI from participants suggest that the 26 participants who refused to participate did not acknowledge any difficulties to the PI which they would like to work on in this fashion and they wished to continue with their normal routines in which this intervention would cause possible disruption. There were 2 participants recruited. Upon initial analysis of results of both single cases, they were unequivocal with clear with reductions seen in error measurement and ADL goals attained under the conditions of the study. The repeated measurement allowed for the process of change to be closely monitored (Barker et al, 2002). The limitations of this small number were considered and these were around the topic of establishing typicality or general laws (Barker et al, 2002). However, valuable information on the participants' behaviours as a result of interventions was measured without the need for comparison with other participants as participants acted as their own controls.

3.21 Goal Setting

The use of goal setting was completed with both participants. The goals were SMART. The acronym "SMART" stands for Specific, Measurable, Attainable, Relevant and Time Related. SMART goals were written from the client's perspective, using language that was understandable to the Participant. An example of a goal was, 'to be able to independently and safely prepare a poached egg, toast and coffee as breakfast in my own kitchen within the 15 sessions with the OT'. The goals were agreed upon between the participant and the PI. The goals were established at the baseline assessment before the A phase in an interview with the participants and their families where required. When the PI involved the families (this was completed in both cases after the initial meeting with the participant) she considered the possible differences in goal domain priorities that may be present in comparison to the participants themselves (Bogardus, 1998).

The goals were observed to need further definition to the participants, they were further defined by the PI in simple language as the aim, plan, intention of the work together or what the participant would like to work on to improve their life at that particular time.

3.22 Assessments

The assessments used in phase two of the study will now be outlined.

Activities of Daily Living

Activity analysis as described earlier in this chapter was used for assessment of ADL. This activity analysis was then documented in a table format as seen in the individual session's tables in the results chapter.

Recording of errors was used as a measure of ADL. This was completed both numerically and descriptively. The PI used an A4 sheet of paper and a pen and took notes as appropriate throughout the occupation/activity. On these notes errors were recorded. These notes were later transcribed into table format which formed the basis for the individual session tables as seen in the results chapter. The errors were highlighted and numbers counted.

Alzheimer's Disease Cooperative Study- ADL assessment

This was used pre and post assessment. This was completed by the PI with family members in both participant one and two. The rationale and background for the use of the ADCS-ADL assessment has been outlined previously (Galasko et al, 1997). It was concluded that this would be an appropriate assessment for the single case experimental design as it was dementia specific assessment and analysed the feedback from family members/carers which was felt to be most reliable in this case. It also minimised the amount of time the participants themselves spend doing assessments.

The Barthel Index

This was used in phase two of the study only. The Barthel Index (BI) was originally described in 1955 by Mahoney and Barthel is a 10-item measure of activities of daily living. The BI is used in clinical practice to assess baseline abilities, to quantify functional change after rehabilitation, and to inform discharge planning with specific relevance to stroke medicine (Duffy et al, 2013). The participants' performance was established by the PI by using the best available evidence. The PI Asked the participants

and their relatives. However, direct observation by the PI from the intervention phase added to the post scale assessment. The rationale for the use of this assessment was that it is a generic ADL assessment routinely used in clinical practice (Mahoney, 1965). It was considered one that would be useful to compare outcomes of the single case studies to other interventions in the area of dementia care (Wade, 1988). The participants were community dwelling and it was considered suitable to their perceived levels of function. It may be used freely for non-commercial purposes and therefore permissions were not obtained for use in this study (Mahoney, 1965 b). This scale took less than 5 minutes to complete.

Communication

The Holden communication scale was used (Holden & Woods, 1995). The details of this scale are outlined previously. There are no formal psychometric properties published for this tool (Hutson, 2014). This was used pre and post assessment and was completed by the PI. The rationale for using this scale in phase two was similar to phase one but in addition it allowed comparison to the work of the authors of CST who also used the scale in their studies (Orrell et al, 2005), (Spector et al, 2003).

Cognition

The ACE-III was used as a pre and post assessment (Mathuranath, 2000). This assessment is a more recent version of the earlier ACE-R assessment which was updated in light of weaknesses of certain components of ACE-R, such as repetition, comprehension, visuospatial and copyright changes with the MMSE (Velayudhan et al, 2014). It a test of 61 individuals with dementia (frontotemporal dementia, FTD, n = 33, and Alzheimer's disease, AD, n = 28) and 25 controls. ACE-III cognitive domains correlate significantly with standardize neuropsychological tests used in the assessment of attention, language, verbal memory and visuospatial function. It also compared positively with the ACE-R, with similar levels of sensitivity and specificity (Hsieh et al, 2013). The test is free and comes with written instructions on administration and scoring which add to it reliability. The rationale for the use of this assessment in this study was that it is a commonly used assessment tool in clinical practice that is rapid (average 15 minutes) and practical which limits the demand on the participants in terms of assessment time (Moishi et al, 2006). It also has good standards in terms of reliability

and validity based upon standard criteria for evaluating a dementia screening test (Gifford & Cummings, 1999).

The copyright is held by Professor John Hodges who is happy for the test to be used in clinical practice and research projects. Therefore a formal letter of approval for inclusion in the research was not requested. The anonymous results of the study will be sent to Professor Hodges as available in order to honour the request that they are interested to hear about research projects that it is involved in. An online training programme for the administration and scoring of the ACE-III has been developed at the University of Glasgow in conjunction with NHS Education for Scotland. The programme is accessible on the internet (University of Glasgow, 2015). The rationale for not using the SMMSE as used in phase one was that a more extensive examination of cognition was required and time frames with individual participants allowed for this examination in comparison to phase one. This was used to train the PI in its use. Administration of the ACE-III takes, on average, 15 minutes and scoring takes about 5 minutes.

Quality of Life (QOL)

The QOL-AD was used as outlined in phase one methodology. The rationale for its use in phase two was similar to phase one in terms of validity and reliability of the instrument. The perceptions of QOL may differ between ratings of carers and PWD (Orgeta, 2014) and that the QOL-AD accounted for both reports on QOL.

3.23 Intervention Technique

The PI completed a guide for the intervention for the PI (appendix 26) which was referred to as required. A summary table (table 7) of the three phases is outlined below.

Title of table 7: Three phase table.

A phase: Multiple baseline assessments by an OT of the occupation of interest with a session by session record of errors and clinical notes.
B phase: Treatment by an OT using EL Therapy with error assessments of the occupation of interest in every session and clinical notes.
A phase: Multiple post treatment assessments of the occupation of interest by an OT. The final assessment re administered the assessments of cognition, communication, QOL and ADL.

Table 7

Participant one: Initial assessment of the specific task (to plan, prepare and organise a cooked breakfast) with participants in the A phase included a full activity analysis which detailed step by step the procedure or methods the participant used to complete her activity were recorded, notes were recorded regarding the number of errors observed and the number of prompts or where assistance was provided. The ideal sequence of the task for participant one is illustrated in the following table (8). The task of making coffee, poaching an egg and cooking toast was considered to be three different tasks that could be done in the ideal order of poaching an egg first, then cooking toast and then coffee preparation so as all items were warm when eating or drinking. Variation within the sequence of the activity was accounted for given the normal clinical conditions of the study and the client centred perspective of this study. For example, the participant may choose to have coffee before her egg and toast or similarly, she may wish to have toast separate to the egg or she may have particular habits that she fulfils that would be outside the ideal. This variation was accounted for and is highlighted in green in table (8).

Title of table 8: Ideal sequence.

Ideal sequences/ chaining list					
Poaching and egg		Cooking toast		Making coffee	
<ul style="list-style-type: none"> • Open fridge to retrieve eggs • Remove eggs from fridge and place on the counter securely • Open cupboard and remove pot or take from draining board at sink if required • Place pot on electric cooker and either fill with water from the sink tap or from the electric kettle • Turn on cooker at main switch • Turn on 	<p>Variation allowed for here, she may choose to have the pot boiling first, then organise eggs from fridge</p>	<ul style="list-style-type: none"> • Obtain toast from the bread bin, the freezer or the counter top. • Place into electric toaster • Turn on toaster by plugging it in, turning on switch at wall and then pulling down the lever to activate the heat. • Observe it cooking or consider the timer setting it 	<p>Variation allowed for here. The toaster may already be plugged in, and the lever may be the only action required. If the individual completes a quality check of the bread in her bread bin she may need to take further actions i.e. take toast from bread bin, place in the waste bin and then take it from the freezer too. She may wish not to remove the toast from the toaster</p>	<ul style="list-style-type: none"> • Turn on kettle to boil. (plug in/turn on switch at wall or flick switch at the base of the kettle) • Boil kettle • Obtain coffee from cupboard or worktop. • Obtain spoon from drawer • Obtain spoon from cupboard or from draining board at sink • Spoon coffee into cup • Re boil kettle if needed • Pour boiling water into cup • Stir with spoon 	<p>Variation allowed for here. The sequence may change, she may wish to have all items prepared before boiling the kettle</p>

<p>cooker ring using small knobs</p>		<p>is on</p> <ul style="list-style-type: none"> • Remove from the toaster and place on a plate • Open fridge and retrieve butter • Obtain a knife from the cupboard or the counter top if it had been used for another component of the activity • Use knife to butter toast 	<p>until required as this method may maintain its heat. She may choose to have or not to have butter on a particular day.</p>	<ul style="list-style-type: none"> • Obtain milk from the fridge • Pour milk into cup • Stir with spoon • Add hermesetas • Stir with spoon 	
--	--	--	---	---	--

<ul style="list-style-type: none"> • Remove salt from the press and place into boiling water in the pot • Take a knife from the drawer and break egg into a cup (then place egg into water from cup) or directly into the pot • Observe the egg poaching and maintain correct heat by adjusting knobs if the water were to boil over • When observed to be cooked remove pot from heat • Turn off 	<p>Variation allowed for here. She may choose not to have salt on any particular day. She may choose to break egg at side of pot. She may choose to turn off small knobs and at a later time in the exercise turn off the main cooker switch.</p>				
--	---	--	--	--	--

knobs <ul style="list-style-type: none"> • Turn off main cooker • Take a plate from the press 					
<ul style="list-style-type: none"> • Take a spoon from the cupboard • Transfer egg onto plate by spoon 	Variation allowed for here, she may use any appropriate kitchen utensil to transfer the egg onto a plate				

Table 8

Participant two- The specific task for participant two was to plan and organise herself in order to mobilise into her local community to complete a shopping activity. The initial assessment similarly used activity analysis which detailed the step by step method the participant used to complete the activity, the errors were recorded and where verbal or non-verbal cues were required from the PI these were provided as reported in the results chapter. The chaining method theory was the same as participant one but utilised within the context of participant two where the task varied considerably in comparison. The ideal sequences/chaining list is now illustrated in table (9).

Title of table 9: Ideal sequence participant 2.

Participant two- Ideal sequences/ chaining list	
Plan and organise herself in order to mobilise into her local community to complete a shopping activity	
<ul style="list-style-type: none"> • Agree the task for that particular day • Decide if the task requires specific items to be taken with her such as an example of a produce she requires. • Check that she has all the essential items required for going out • Go out to the shop, the town or the local chemist and complete all activities agreed at the start of the session. 	<p>Variation allowed for in terms of the task.</p> <p>Variation allowed for here in terms of sequence of which items she chose to organise first before going out .</p>

Table 9

Therefore, the chaining list for both participants was table (8) and table (9) this list allowed for variations as outlined as long as the goal was achieved. The chaining list was broad in terms of sequence but as long as the participant completed all the essential components of the chain, she achieved the whole task and ultimately her goal. The participant, in line with EL techniques, was not allowed to make errors where possible or errors were minimised by the PI where possible by subtle interruption of the task with verbal prompts or non-verbal cues.

Chaining breaks a task down into small steps and then teaches each step within the sequence by itself. For example, a participant cooking breakfast independently on an electric cooker may start with learning to turn on the cooker safely. Once this skill is learned, the next step may be monitoring the cooker and turning it off, this next step would be added sequentially to the first step etc. This technique is helpful teaching a routine task that is repetitive. This EL task was more variable because of the client centred nature of the study. Therefore, whilst chaining was used a ‘whole task training’ was completed every time to facilitate a full occupational sequence in one session which in turn provided positive feedback to the participant in the form of successful completion of the occupation/goal. This was different in comparison to other studies that have used training techniques by working on one step of the chain at different period of times and then adding other sequential steps at later times to make a full chain of events to lead to the occupation or goal.

There are two type of chaining techniques. Firstly, the forward chaining technique moves a participant from the first part of the task to the end. The benefits of forward chaining are its practical, sequential process where each step must be mastered before the next step in the skill series is added. The limitations of forward chaining are not clearly reported in the literature but from clinical observations of its use one concern with this method is that should a component of the chain not be mastered participants may become stuck on that component of the chain. In practice, where components of a chain are not accomplished assistance may be provided to ensure successful completion of the task in order to achieve the overall goal.

The backward chaining technique involves the same process, except in reverse. The backward chaining procedure was not used in either case study. The benefits of the backward chaining technique are seen as equal to forward chaining in the work with individuals with developmental and intellectual disabilities. For example, in Slocum and Tiger (2011) work, there were no preferences over which technique with both demonstrating the same effects. The limitations of the backward chaining technique are that it is not always naturally practically possible in a functional goal. For example, if participant one were to have used the backward chaining technique the completed poached egg, toast and coffee would have had to be presented first (made by the PI) and then all the steps re traced in order to fulfil the requirements of backward training which is confusing and not practically appropriate or possible.

Both participants were trained using a forward chaining procedure. For example, participant one commenced the activity of breakfast preparation with a single item such as turning on the kettle to have it pre boiled for her hot water for her coffee, if she chose to do this at a later stage it was not necessarily an error, it was a choice she made in her sequencing but as long as she achieved the goal she had not broken the chain of events. In contrast, for the task of poaching an egg, if she could not find a pot in order to poach the egg, an extended amount of time was allowed and then the PI identified relevant prompts on the spot that ensured success. The PI then prompted the participant in order to facilitate successful completion of the chain of events so that the activity could continue successfully. In summary, chaining was based on analysis of the task within that specific session. All the sub-behaviours were recognised as requirements to master the full activity. In the context of the ABA design of this study, where ever possible no

prompts were provided in either of the A phases. However, with respect to safety there were occasions where verbal or non-verbal prompts or cues were provided.

Cues in the environment were introduced in both case studies in the intervention B phase based on the baseline assessments in the A phase. Both participants were trained to use the dementia friendly environmental cues as part of the EL approach. These cues then amended the chaining list in the B phase; the cues were integrated into the chain as outlined in appendix (22) and appendix (23).

The environmental cues for participant one:

- Dementia friendly signage in the colours of red, yellow and orange on the orientation board, which was located at the door way from the main hall into the kitchen (Ross, 2000). This was a location that she walked by regularly and it was placed at her eye level height (Namazi and Johnson 1991). An example of this can be found in Appendix (24)
- A shopping list fixed to a table beside her telephone (which she used regularly). This was in a dementia friendly colour of yellow and the participant was prompted to use it by the PI. The PI also taped a pen to a string which was then taped to the shopping list booklet. An example of this can be found in appendix (25).
- A 'to do list' taped to her kitchen island on a corner location that she walked by regularly. An example of this can be found in appendix (26). The PI also taped a pen to a string to the 'to do list'.
- Vascular dementia information was provided to her family to support them in understanding her condition and how it presented itself; this information was taken from the Alzheimer's society UK website (Alzheimer's UK, 2013).
- A dementia friendly sign in the colour of red placed adjacent to the knobs on her electric cooker. This sign illustrated in bold a visual cue on which knob operated each ring on the cooker. A copy of this can be found in appendix (27). Four copies of the visual cue were placed at each of the four knobs. The participant was guided towards the sign when required or a demonstration of its use was completed by PI as reported in the results chapter.
- Education was completed with the participant and her family with regards to use of the dementia friendly signs, orientation boards and a brief background to dementia friendly environments. This education was presented in verbal format informally

through a feedback session and the key areas covered were: colour, signage, noise, light and technology. The PI provided a website to the main carer who was familiar with use of the internet (Enabling Environments, 2013).

The environmental cues for participant two were:

- Dementia friendly signage in the colours of red for the checklists (2) one on the press at the exit of her kitchen and one at her main doorway (appendix 28), yellow sign for the prompt on the keys on the hall table (appendix 29) and sign of the glasses in the main living area (appendix 30) and on the to do list (appendix 26), which was taped to the corner of her kitchen table with a fixed pad with removable sheets on it, with a pen on a string that could not be removed. These items were all at locations that she walked by regularly and all was placed at her eye level height.
- Education was completed with the participant and her family with regards to use of the dementia friendly signs, orientation boards and a brief background to dementia friendly environments. This education was presented in verbal format informally through a feedback session and the key areas covered were: colour, signage, noise, light and technology. The PI provided a website to the main carer who was familiar with use of the internet (Enabling Environments, 2013).
- The participants' family purchased a digital orientation calendar and this was placed on the kitchen counter top again at a location that was regularly visible to the participant as she walked by it regularly. It was not fully dementia friendly in terms of its colour which was grey and black. It digitally updated the time, date, season and weather. The participant herself continued to use her familiar church calendar to record PI visits and general appointments on which was routine to her. This was left in its regular location as this was familiar to the participant.

In the case of participant one, after session three was completed and in order to prepare for the intervention phase in a timely fashion in the B phase. The PI liaised with the participant's main carer and requested that excess clutter was removed from the presses and fridge and that a routine for doing this on a regular basis was devised. Her main carer reported that he regularly does this and that the participant continues to purchase new household items, kitchen accessories and excess food when shopping. PI provided advice regarding this in the context of distant supervision and subtle prompts where

required to remind her of what items she already has in her home when she attempts to purchase new ones. The participant's main carer was happy to accept this continuing role for the entire phase of this study.

For both participants, the occupational tasks were similar from session 1-15, but not exactly the same on every session. However, the agreed occupational goal was consistent throughout. Therefore, for both participants, cues in the environment were used as relevant to the task on the day and possibly outside the sessions themselves but this was not measured.

3.24 Ethics

Ethical approval was granted from the Midlands Research Ethics Committee for both phases of the study prior to commencing the relevant phases of the studies (Appendix 31). For phase one, further information was requested from the ethics committee and this was provided (Appendix 31).

The PI of this study adhered to the Association of OTs of Ireland Code of ethics (2013) and ensuring as a Member she is took responsibility to contribute to the development of her own professional standards and that of her profession by critical evaluation, audit and research.

There was no deception or withholding of information and there are no risks including psychological risk of note to the participants. Advice regarding disadvantages of treatment is provided on the information leaflet for participants should same have arisen (Appendix 4).

There have been no documented harmful side effects from participating in CST, Sonas groups or EL. There was potential for participants to experience fatigue when completing the assessments as well as during the group or individual sessions. The assessment process for participants with dementia took approximately 1 hr to complete in both phase one and two and these were completed over two or more sessions if required. It was acknowledged that participants may possibly also feel fatigued during the group or individual sessions. However, it was acknowledged that some participants were familiar with attending group sessions of a similar nature and length. Similarly, it was acknowledged that participants were familiar with individual sessions of similar nature, but not in length. Benefits have been consistently reported by participants in

CST including enjoyment, feelings of validation, and self-worth (Spector et al, 2003). The PI liaised with the relevant participant and their carers/family members of care staff re: any potential side effects from the group or individual sessions throughout the programme. There were none documented.

Participants were required to reveal information of a sensitive nature as they would in a standard psychiatry of later life assessment. This information was necessary to establish a baseline level of cognition, neurobehavioural symptoms, communication and occupational performance prior to treatment and compare to changes post treatment. It was essential that this information is obtained to measure any change and thus measure the impact of CST, Sonas and EL. Potential distress by such disclosures were monitored by family, key worker or next of kin/carer (as per guidance in the information leaflet) and where difficulties arise, the researchers contact details were available in the information leaflet for guidance.

No issues of personal safety for researchers were noted. The therapist and clinicians were the primary and research assistants in this study. They continued to work within their professional boundaries and standard operating procedures. The legal liability of NUI Galway is covered by Employers & Public Liability and Professional Indemnity policies and a letter of indemnity has been obtained from NUI Galway regarding same (Appendix 32). The research team ensured confidentiality by following the standard operating procedures locally, relevant professions guidelines and HSE national procedures for confidentiality.

Control groups were eliminated in phase one as outlined earlier. However, prior to elimination it was planned that therapeutic intervention through Sonas and CST would not initially be provided to any of the 3 control groups in phase one; requiring participants to abstain from this therapeutic intervention in the initial intervention period. The PI had planned to offer these individuals a follow up treatment programme of CST or Sonas when the intervention phase of the study was completed. In the care centre group an agreement was made with the director of nursing that a follow up programme be offered to the control group locally after the intervention phase has been completed. The decision on which type of intervention the control group would have received was planned to be based on the OT analysis of the OTTOS; detailed analysis of OTTOS results was planned to be completed 4 weeks after the treatment phase of the study.

There were no controls in phase two, as outlined with the ABA design the participant acted as their own control.

Participants were informed that they can withdraw from the study at any point; this was communicated to the participants via the information leaflet. Participants were not compensated for expenses incurred as part of their participation in this research project; this research was integrated into their standard Occupational Therapy treatment programme in Longford/ Westmeath.

With reference to the Freedom of Information Act (1997), the freedom of information amendment act (2011) and the Data Protection Act (1988) all data files associated with the study were stored in a secure filing cabinet in the Psychiatry of Later Life nursing and Occupational Therapy office. Computerised data is password protected and printed documents were stored in secured filing cabinets as detailed above.

This study complied with the NUI Galway Research Ethics Committee Data Retention Policy (2006). Data will be securely retained for a period of five years following completion of the study. The research team will ensure that such data is completely anonymous. Researchers who are leaving the institution and wish to retain data/copies of data for their personal use must get permission from the head of the department of Psychiatry of Later Life to do so. Where data of a personal nature is involved this request will be refused unless it is clear that any future use will be consistent with the terms of consent.

The consultant psychiatrist or psychologist were both part of the research team in this study. Where they deemed the individual to have the capacity to consent on initial screening, this was noted (British Psychological Society, 2008). A person will be noted to consent if he/she agrees by choice, and has the freedom and capacity to make that choice. Capacity is used to refer to a person's ability in law to make a decision with legal consequences (Law reform commission, 2005). This part of the research was completed in 2012, therefore the relevant legislation was utilised.

Where an individual has been judged not to have capacity and a guardian or next of kin has been appointed the guardian or next of kin must give consent; this was given through an assent form (Appendix 5) and they had an opportunity to read the information leaflet specifically for next of kins/carers (Appendix 6). However, there was also an

opportunity for the person to express assent. Where assent is documented as not given, the guardian will be informed and given the opportunity to re-examine the decision to consent (Law reform commission, 2005).

Participants were informed of the procedures they will encounter during the research study via an information leaflet (Appendix 4) and asked to complete the consent form (Appendix 5). There were opportunities for discussion with the research team by phone prior to the assessment phase and also opportunities for questions throughout the study. At the start of every intervention session, participants were asked if they continued to consent to the study (in informal suitable language).

2.25 Conclusion

In conclusion, this chapter outlined the methodological actions within both phase one and two of this study. Phase one of this study was completed using a single blind prospective controlled trial group design across three sites of residence. Phase two of the study was completed using a single case experimental ABA design with individual participants. In phase one, this methodology was the most appropriate one for the procedure of investigating group treatment approaches for this specific population sample. The single case experimental design was the most appropriate method for the individual case studies in phase two as it relied on the client centred approach applied throughout to demonstrate the effects of goal focused treatment with participants acting as their own controls. This methodology meets the overall objective of the research projects which is to investigate the impact of rehabilitation in dementia delivered by an OT. The results will now be presented in the next chapter.

4 Results chapter

4.1 Introduction

In this chapter the results of the study are presented. Phase one of the study is presented first. Phase one's results will be presented in a sequence of hypothesis on all outcome measures. Each section follows the following format:

- Differences between and within CST and Sonas groups at baseline
- Differences between and within CST and Sonas groups at outcome.

These primary results are followed by a table summarising the primary hypothesis and a conclusion on acceptance of the hypothesis. A supplementary analysis with secondary research questions and tables as relevant is then presented.

Case study one and then case study two are then presented. This is followed by a conclusion based on both phases of the study.

4.2 Phase one of research

4.3 Characteristics of the Sample

In total, 28 participants participated in this study. 15 participants were allocated to the CST condition (53.6%) and 13 participants were allocated to the Sonas condition (46.4%). There were 11 male (39.3%) and 17 female (60.7%). Seven males and eight females attended the CST group condition. A total of four males and nine females attended the Sonas group condition.

There were two types of residence 19 inpatients (67.9%) and nine community dwelling (32.1%). There were three sites of residence; eight participants in long stay inpatient psychiatry of later life (28.6%), 11 participants in the care centre (39.3%) and nine community dwelling participants (32.1%). Table (10) and table (11) illustrates the mean number of years in residence, the mean age and relevance to CST or Sonas condition.

Title of table 10: Demographics, years in residence.

Mean Number of years in residence:	
Inpatients	12.47 years
Inpatient psychiatry of later life	17.75 years
Care centre	8.64 years
CST	9.20 years, with a minimum of 2 years and a maximum of 40 years in residence.
Sonas	16.11 years, with a minimum of 2 and a maximum of 50 years.

Table 10

Title of table 11: Demographics, age.

Mean Age	
Overall	80.29 years
Inpatient psychiatry of later life	81 years
Care centre	81.36 years
Community	79 years
CST Participants	81.13 years, minimum 68, maximum 92 years.
Sonas Participants	79.62 years, minimum 65, maximum 92 years.

Table 11

The primary diagnoses were as follows: eight participants with Alzheimer's disease (25%), eight where the diagnosis was not specified/other (28.57%), seven with mixed Alzheimer's disease and vascular dementia (25%), five Vascular dementia (17.86%) and one frontal temporal dementia (FTD) (3.57%) (figure 4). Diagnosis was then sub divided

into Alzheimer's and Non-Alzheimer's; thus there were seven Alzheimer's participants and 21 non-Alzheimer's participants.

Title of figure 4: Types of Dementia

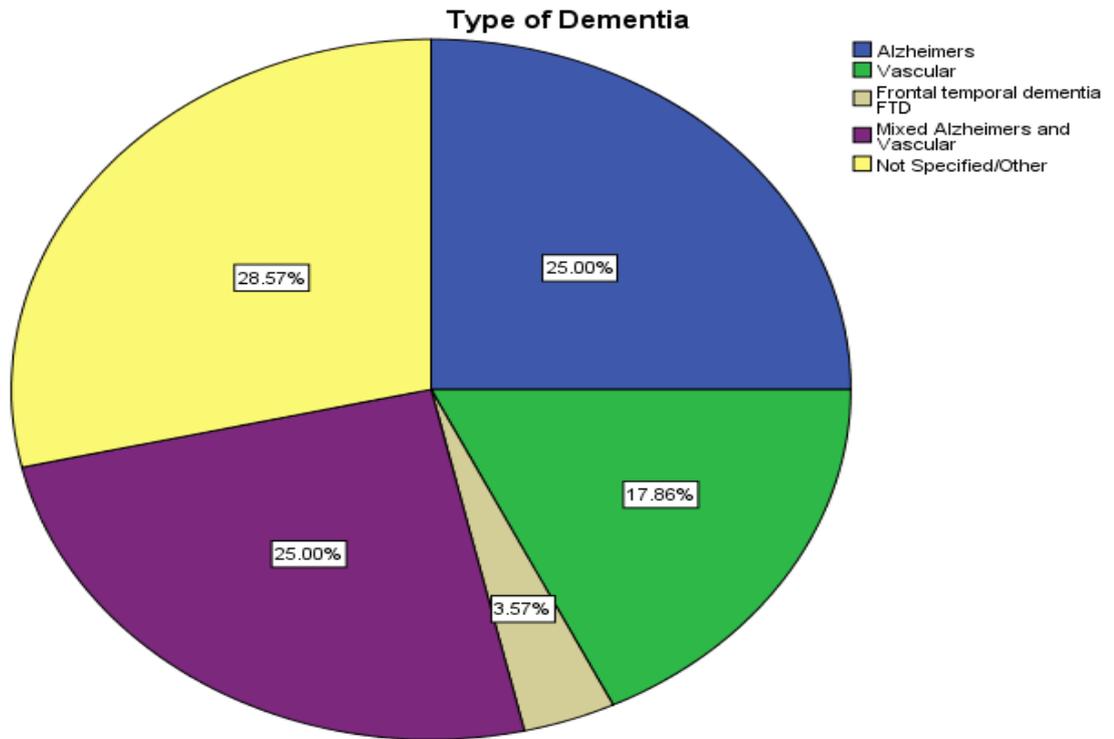


Figure 4

Title of figure 5: Type of dementia/group.

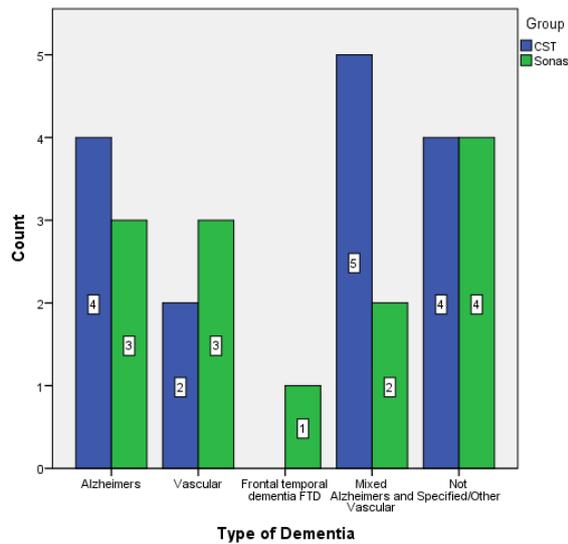


Figure 5

There were some differences in diagnoses between groups. The number of AD participants in the CST group is 4 and in the Sonas group is 3, the number with VaD in the CST group is 2 and the Sonas group is 3, the number with FTD is 0 in the CST group and 1 in the Sonas, the number with Mixed AD and VaD is 5 in the CST group and 2 in the Sonas group. Both CST and Sonas had 4 in the not specified/other group (Figure 5).

Alternative and secondary diagnoses were also examined. There were four participants with schizophrenia (14.3%), seven with depression (25%), two with epilepsy (7.1%), three with stroke/CVA (10.7%), 10 with cardiovascular conditions (35.7%) and two (7.1%) were recorded to have none of the above. These diagnoses were further examined in terms of CST and Sonas conditions. This is shown in Table (12).

Title of table 12: Alternative and secondary diagnoses

Group	Diagnosis	Frequency	Percent
CST	Schizophrenia	3	20.0
	Depression	1	6.7
	Stroke/CVA	3	20.0
	Cardiovascular	7	46.7
	Total	14/15	93.3
Sonas	Schizophrenia	1	7.7
	Depression	6	46.2
	Epilepsy	2	15.4
	Cardiovascular	3	23.1
	Total	12/13	92.3

Table 12

An examination of the types of medication participants were being actively treated with, found the following results: 15 were on Acetylcholinesterase Inhibitors (53.6%) and 13 were not on Acetylcholinesterase Inhibitors (46.4%). Seven participants (25%) were on Anti-Psychotic medication and 21 were not on Anti-Psychotic medication. 10 participants (35.7%) were on anti-depressant medication and 18 (64.3%) were not. eight participants (28.6%) were on benzodiazepines and 20 participants (71.4%) were not. Further analysis of which types of medication participants were on dependant on group are presented in appendix (33). There were differences in terms of group for those participants on Acetylcholinesterase Inhibitors (yes 9 CST, 6 Sonas), those who were on anti-depressant medication (yes 3 CST, 7 Sonas) and those who were not (no CST, 6 Sonas) and those on benzodiazepines (yes 2 CST, 6 Sonas), (no 13 CST, 7 Sonas).

Session attendance records were examined and found that the overall mean attendance rate was 11.32 (maximum 14 sessions). This was further examined in relation to CST and Sonas conditions; CST was found to have a mean attendance rate of 11 out of 14 sessions and Sonas was found to have a mean attendance rate of 10.85 out of 14 sessions.

The relationships between variables at baseline were examined using the Pearson's product-moment correlation coefficient and Dichotomous variables were examined using a Spearman's test. The rationale for this was to establish if there were relationships between variables at baseline which might impact on the results. Results showed significant relationships between variables. Full details are available in Appendix (34). A full detailed analysis of baseline assessments across all variables can be found in appendix (15-20).

One of the ways in which normality was assessed was through normality tests as outlined in the methodology section. Table 13 outlines the outcome measures, test used and the rationale as mentioned in the methodology chapter.

Title of table 13: Outcome measures, test and rationale.

Outcome measure and test statistics between CST and Sonas groups	Test	Rationale
SMMSE: No significant difference between CST and Sonas groups at baseline $t(26) = 1.231, p = .229, NS$.	Independent samples t test	Parametric test to examine any differences between groups baseline scores. The equal variances assumed score was used for the SMMSE outcome measures as normality assessments indicated that the data was otherwise normal at baseline. The equal variance not assumed score was used for all other outcome measures.
OTTOS: No differences of statistical significance between CST and Sonas groups on baseline OTTOS data ($U=81.000, p=.894, NS$). No differences between task behaviour ($U=80.500, p=.894$) or general behaviour sub scores ($U=74.000, p=.852, NS$).	Mann Whitney U test	Non-parametric test of the null hypothesis that two samples come from the same population against an alternative hypothesis.
Sonas monitoring progress: based on appendix (16) outcomes, significant differences found at baseline		
CST Monitoring progress form: based on appendix (15). Significant differences found at baseline.		
ADCS_ADL scale: no differences of statistical significance ($U=85.000, p=.571, NS$).		
QOL-AD: no significant differences ($U=104.000, p.786, NS$).		
Holden Communication scale: no significant difference ($U=95.000, p=.928, NS$).		
NPI: no statistically significant differences were found in total pre NPI score, ($U=77.500, p=.363, NS$).		

Table 13

4.4 Baseline data examination

4.5 The SMMSE

An exploration of baseline SMMSE data was completed. The SMMSE formed a component of the inclusion and exclusion criteria and therefore it was expected that there would be no differences between the groups at baseline.

Between groups- There was no significant difference between CST and Sonas groups at baseline $t(26) = 1.231$, $p = .229$, NS. The shape of the data, the distribution of the data and normality assessments were all examined and concluded to be normal (appendix 14).

4.6 Hypothesis 1

Participants assigned to both the CST and Sonas conditions will show improvements from pre-intervention to post-intervention on the SMMSE.

Between Groups-An independent samples t-test was used to examine the differences in mean score between groups on the post SMMSE scores; there were no differences between CST and Sonas Groups ($t(26) = 1.332, p=.195, NS$) on post assessment.

Within Groups- On comparison of pre-test(T1) and post-test (T2) SMMSE scores across both the Groups using a split file paired samples t-test a statistically significance difference was observed in the CST group only ($t(14)= -2.385, p= 0.032$) in comparison to the Sonas group ($t(12)=-1.923, p=.079, NS$).

Title of figure 6: CST and Sonas SMMSE T1, T2.

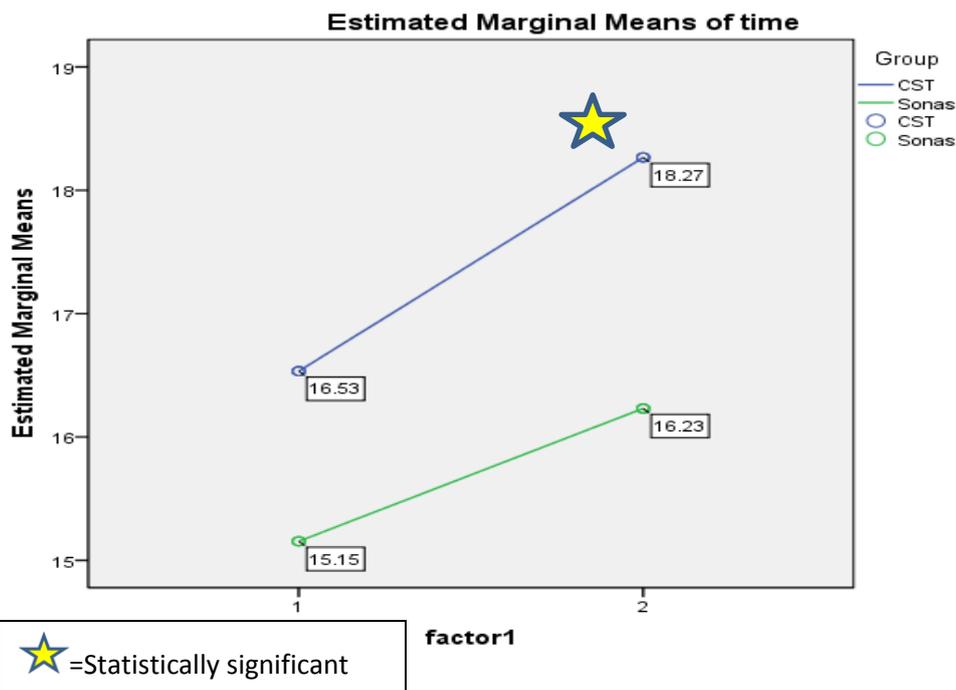


Figure 6

In summary, the CST group was found to have statistically significant improvements in pre-test to post-test SMMSE scores. There were no significant differences between post SMMSE scores in either group. Therefore the hypothesis is rejected as participants assigned to the CST group only demonstrated improvements of statistical significance on the SMMSE.

4.7 Occupational Performance within a group setting

OTTOS

4.8 Baseline data examination

An exploration of baseline session one OTTOS data was completed. An independent samples Mann Whitney U test found no statistically significant differences between CST and Sonas groups total scores on baseline OTTOS data ($U=81.000$, $p=.894$, NS). There were no differences between task behaviour ($U=80.500$, $p=.894$) or general behaviour sub scores ($U=74.000$, $p=.852$, NS).

The shape of the data, the distribution of the data and normality assessments were all examined and concluded not to be normal. A full detailed description of baseline analysis can be found in Appendix (45).

In conclusion the data were assumed not to be normal at baseline and non- parametric test were used in data analysis.

4.9 Hypothesis 2

Participants assigned to the CST group will demonstrate greater improvements in total score and task behaviour than Sonas group on the OTTOS. Both groups will demonstrate similar improvements in general behaviour.

Between groups- The OTTOS was examined using a Mann Whitney U test which tested for differences between the groups; no significant differences were found between CST and Sonas on their post OTTOS assessment ($U= 51.000$, $p=.141$, NS).

Within groups- The related samples Wilcoxon Signed Rank test was used to test if population mean ranks are different; both CST ($W=75.000$, $z=2.828$, $p=.005$) and Sonas ($W= 78.000$, $z=3.061$, $p=.002$) demonstrated statistically significantly improvement on pre (session one/baseline) to post (session 14/end of programme) on the OTTOS (figure 7). This rejects the hypothesis that participants assigned to the CST group will demonstrate greater improvements total score than Sonas group.

Title of figure 7: OTTOS, session one- fourteen.

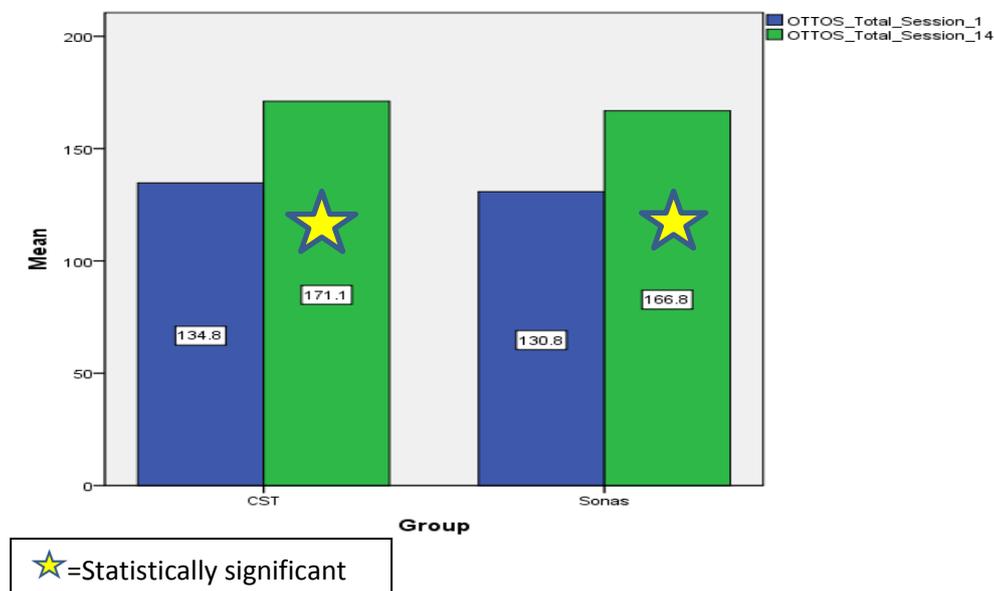


Figure 7

Groups were compared on Task behaviour.

Between groups- There were no differences between CST and Sonas groups Task behaviour on their final session (number 14) on a Mann- Whitney U test ($U=51.4$, $p=.146$, NS).

Within groups- Both CST ($W= 74.000$, $z=2.747$, $p=.006$) and Sonas ($W= 77.000$, $z=2.983$, $p=.003$) showed statistically significant improvement when tested using a Wilcoxon signed rank test (figure 8). Thus the hypothesis that participants assigned to the CST group will demonstrate greater improvements in task behaviour than Sonas group is rejected as both groups were found to be have changed significantly.

Title of figure 8: Task Behaviour, session one-fourteen.

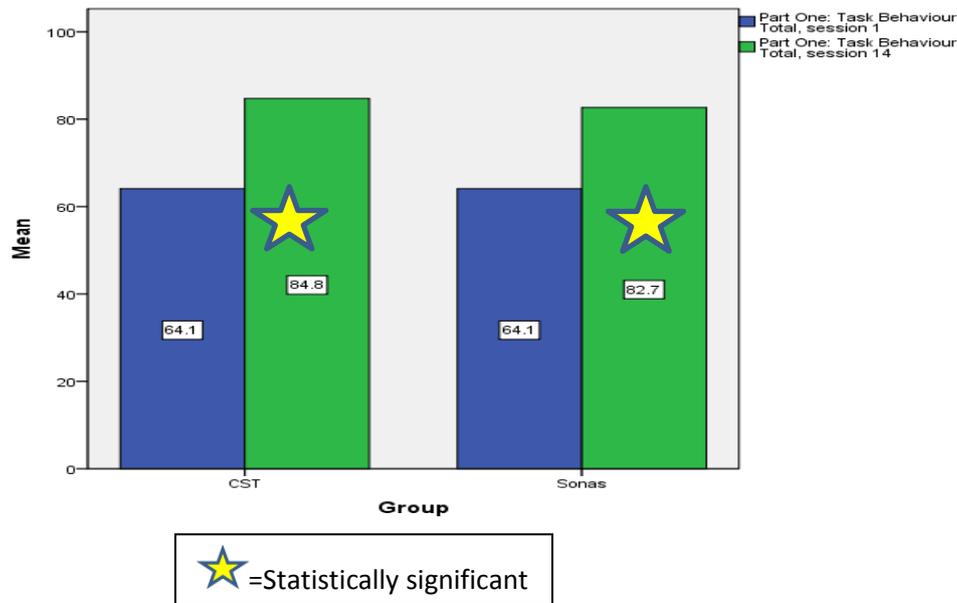


Figure 8

Groups were compared on general behaviour.

Between groups- There were no statistically significant differences between groups general behaviour on session 14 using a Mann-Whitney U test ($U=51.000$, $p=.134$, NS).

Within Groups- The Wilcoxon signed rank test which was used to examine means between groups and it showed statistically significant improvement from session one to session fourteen in general behaviour in both CST ($W=49.000$, $z=2.199$, $p=.028$) and Sonas ($W=76.500$, $z=2.944$, $p=.003$). This is illustrated with the mean scores in figure 9.

Title of figure 9: General behaviour session one- fourteen.

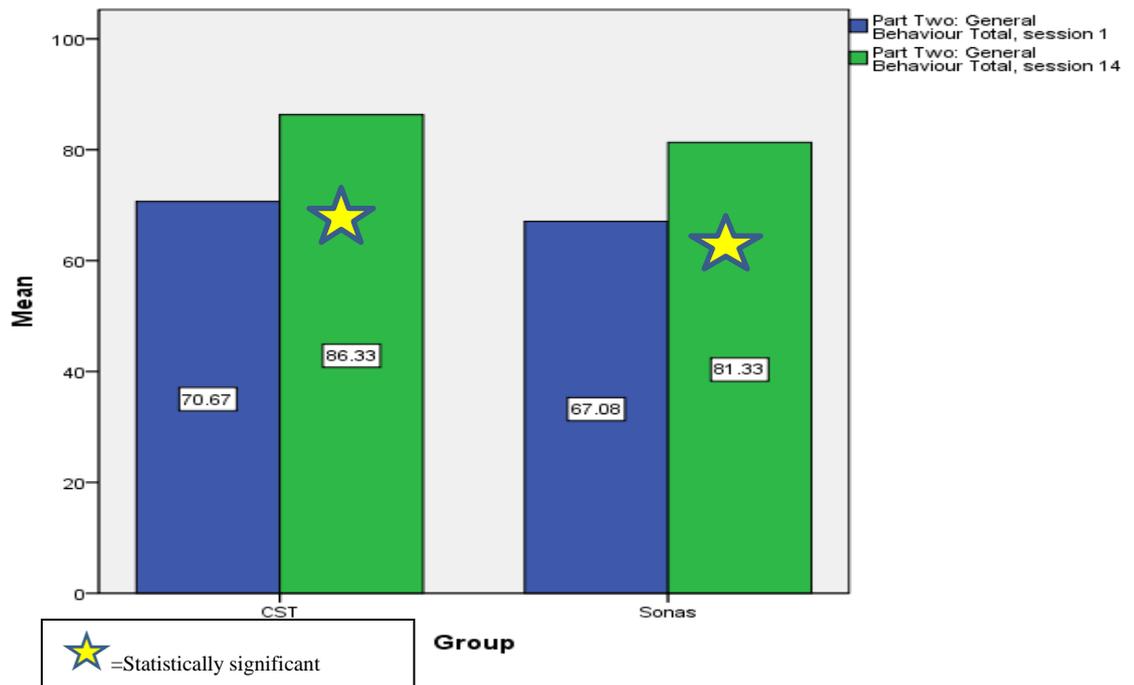


Figure 9

In summary, the hypothesis is rejected as both the CST and Sonas groups showed statistically significant improvement on their total scores, task behaviour scores and general behaviour scores. However, while there were no significant differences between the groups either at baseline or outcome, both groups showed improvement indicating that for this parameter, both CST and Sonas groups benefited equally from the intervention.

4.10 Hypothesis 3

Participants will demonstrate consistent gradual improvements in performance as measured by total OTTOS score over a 14 session period in both groups. There will be differences dependant on the group.

The stages of improvements in both CST and Sonas group's total scores on the OTTOS over the treatment period of 14 sessions are demonstrated in figure (10). This provides visual evidence that there are consistent gradual improvements in participant's performance in both the CST and Sonas groups.

Title of figure 10: Fourteen session visualisation OTTOS.

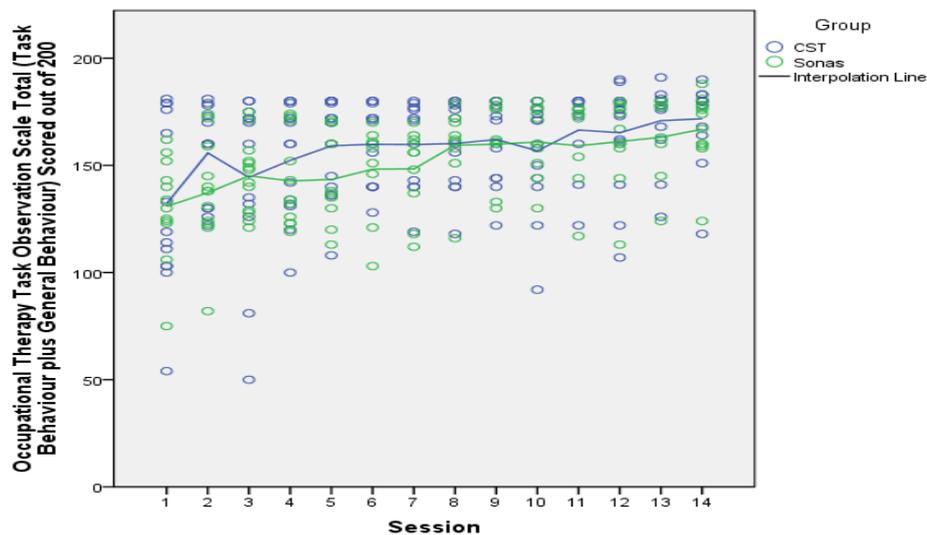


Figure 10

In order to examine which sessions were most influential interval assessments were measured and compared. It is noted that the CST group had four sessions where there were decreases in mean scores; session three, seven, ten and twelve respectively. In the Sonas group there are two sessions where decreases in mean scores; session four and eleven. This is illustrated in figure 10 and more detail in appendix (35).

In conclusion, the hypothesis is accepted as the OTTOS demonstrate consistent gradual improvements in participant's performance in both CST and Sonas groups. There were variances in intervals of improvements dependant on the group with the Sonas group having fewer sessions with decreases in mean scores.

4.11 Sonas Group Session Evaluation Form

4.12 Baseline Data Examination

An exploration of baseline (session one) Sonas group session evaluation form data was completed. This assessment was completed in 14 separate sections. Details of the full baseline analysis can be found in appendix (16).

The data were found to violate the assumption of normality at baseline and non-parametric data analysis was used in the analysis.

4.13 Hypothesis 4

Participants in both groups will demonstrate statistically significant improvements in all areas of the Sonas group session evaluation form assessment.

Between groups- A Mann Whitney U test was used to examine outcomes between groups. This is illustrated in table 14 below. Three assessment sections of the outcome measure were found to have differences within groups on session 14/post assessment. The three sections are exercises, rhythmic movements and using instruments.

Title of table 14: Assessment components, between group assessment.

Mann Whitney U test	
Between Groups (CST and Sonas)	
Eye contact	U=78.000, p=1.000, NS
Holding Gaze	U=83.500, p=0.7689, NS
Following with Gaze	U=83.500, p=0.7689, NS
Smiling	U=84.000, P=0.7689, NS
Vocalising	U=78.000, p=1.000, NS
Speaking	U=84.000, P=0.7689, NS
Appropriate Touch	U=91.000, P=0.5033
Exercises	U=29.000, P=0.0066
Singing	U=84.000,

	P=0.7689, NS
Rhythmic Movements	U=28.500, P=0.0055
Contribution	U=84.500, P=.7283, NS.
Using Instruments	U=11.000, P=.000
Using Gesture	U=78.000 P=1.000, NS
Interactive Posture	U=78.000 P=1.000, NS

Table 14

Within groups- The Wilcoxon Signed Rank test was utilised to examine the data. Results of this statistical analysis are summarised in Table (15) below.

Title of table 15: Assessment components within groups.

Wilcoxon Signed Rank test		
	Group	
	CST	Sonas
Eye contact	W=17.000 Z=1.382 P=0.167, NS	W=15.000 Z=2.121 P=0.034
Holding Gaze	W=15.000 Z=2.060 P=0.039	W=15.000 Z=2.121 P=0.034
Following with Gaze	W=15.000 Z=2.060 P=0.039	W=15.000 Z=2.121 P=0.034
Smiling	W=10.000 Z=1.841 P=0.066, NS	W=15.000 Z=2.070 P=0.038
Vocalising	W=21.000 Z=2.251 P=0.024	W=32.000 Z=2.111 P=0.035
Speaking	W=21.000 Z=2.271 P=0.023	W=28.000 Z=2.530 P=0.011
Appropriate Touch	W=10.000 Z=.707 P=0.480, NS	W=10.000 Z=1.890 P=0.059, NS
Exercises	W=6.000 Z=1.732 P=0.083, NS	W=21.000 Z=2.449 P=0.014

Singing	W=10.000 Z=1.857 P=0.063, NS	W=15.000 Z=2.070 P=0.038
Rhythmic Movements	W=6.000 Z=1.604 P=0.109, NS	W=10.000 Z=1.857 P=0.063, NS
Contribution	W=15.000 Z=2.060 P=0.039	W=21.000 Z=2.449 P=0.014
Using Instruments	W=1.000 Z=1.000 P=0.317, NS	W=3.000 Z=1.414 P=0.157, NS
Using Gesture	W=19.000 Z=.879 P=0.380, NS	W=15.000 Z=2.236 P=0.025
Interactive Posture	W=26.000 Z=2.081 P=0.037	W=6.000 Z=1.732 P=0.083, NS
Statistically significant		

Table 15

Within groups- The CST group had statistically significant changes from session one to session fourteen in six out of fourteen areas: holding gaze, following with gaze, vocalising, speaking, contribution and interactive posture. In comparison, Sonas is found to have statistically significant changes from session one to session fourteen in ten out of fourteen areas: eye contact, holding gaze, following with gaze, smiling, vocalising, speaking, exercises, singing, contribution and using gesture.

The hypothesis is rejected. Participants assigned to both CST and Sonas conditions both demonstrated statistically significant improvements in some areas. However, participants who received Sonas demonstrated statistically significant improvements in more of the areas assessed than the CST condition. Neither CST nor Sonas demonstrated statistically significant improvements in all areas.

4.14 CST Monitoring Progress

4.15 Baseline Data examination

An exploration of baseline (session one) CST Monitoring progress assessment tool data was completed. The distribution of the CST Monitoring progress assessment data was found not to be normal at baseline. This assessment was completed in 4 separate sections (there was no total score in this assessment). A full detailed analysis at baseline across all variables can be found in appendix (15-20).

The data were found to violate the assumption of normality in various areas at baseline and non-parametric data analysis was used in the analysis.

4.16 Hypothesis 5

Participants in both groups will demonstrate statistically significant improvements from session one to session fourteen in all areas of the assessment.

Between groups- A Mann Whitney U test demonstrated no statistically significant differences between CST and Sonas groups on session 14/post assessment as outlined in table (16).

Title of table 16: CST monitoring progress between group assessments.

Mann Whitney U test	
Between Group	
Interest	U=72.000, p=.7689, NS
Communication	U=71.500, P=.7283, NS
Enjoyment	U=77.000, p=.7762, NS
Mood	U=71.000, p=1.000

Table 16

Within groups- The Wilcoxon Signed Rank test was utilised to examine the data. Results of this statistical analysis are summarised in Table (17) below.

Title of table 17: CST monitoring progress within group.

Wilcoxon Signed Rank test		
	Group	
	CST	Sonas
Interest	P= .006 Z=2.739 W=45.000	P= .041 Z=2.041 W= 15.000
Communication	P=.004 Z=2.879 W=55.000	P=.066, NS Z= 1.838 W=14.000
Enjoyment	P= .004 Z=2.889 W=55.000	P=.020 Z=2.333 W=21.000
Mood	P= .004 Z=2.889 W=55.000	P= .023 Z= 2.271 W=21.000
Statistically significant		

Table 17

Both groups are found to have statistically significant changes from session one to session fourteen in the areas of interest, enjoyment and mood. The CST group only were found to have statistically significant changes in communication.

In summary, the hypothesis is rejected as the CST group was found to have statistically significant changes in four areas of the assessment. In comparison, the Sonas group was found to have statistically significant changes in 3/4 areas of the assessment

4.17 ADL

ADCS-ADL assessment

4.18 Baseline data examination

An examination of the baseline data of the ADCS-ADL assessment was completed. An independent samples Mann Whitney U test was used to compare groups at baseline; there were no differences of statistical significance between both CST and Sonas at baseline ($U=85.000$, $p=.571$, NS). On examination of the baseline ADCS-ADL data, they did not meet the normality assumptions at baseline. Full baseline analysis is detailed in Appendix (17), therefore non-parametric tests were used to examine the data.

4.19 Hypothesis 6

There will be no significant change in ADL as a result of either CST or Sonas intervention.

Between groups- A Mann Whitney U test was used to examine the differences between CST and Sonas on post assessment, $U=99.000$, $p=1.000$, NS. There were no differences between groups on post assessment.

Within groups- The Wilcoxon signed rank test was completed at T1 and T2 across both CST and Sonas groups. There are no statistically significant differences within groups, CST ($W=19.500$, $Z=-.357$, $p=0.721$, NS) and Sonas ($W=40.000$, $Z=1.277$, $p=0.201$, NS).

In summary, no statistically significant differences were identified between or within the two groups CST and Sonas. Therefore the hypothesis is accepted.

4.20 Quality of Life

QOL-AD

4.21 Baseline Data Examination

An examination of baseline QOL-AD data was completed. An independent samples Mann Whitney U test was used to establish any differences at baseline, in terms of CST and Sonas Groups, it concluded that there was no significant difference between groups at baseline $U=104.000$, $p.786$, NS.

However, differences were found in terms of the shape of the distributions which indicated variances across variables at baseline. Full detailed analysis of variables can be found in appendix (18).

In conclusion that the data did not meet the normality assumption and non-parametric assessments were used in the analysis.

4.22 Hypothesis 7

There will be statistically significant positive improvements in total QOL-AD scores, patient rated scores and carer rates scores in both groups.

Between Groups- a Mann Whitney U test was used to examine differences between CST and Sonas groups. There were no statistically significant differences on post assessment total score, $U=92.000$, $p=.8207$, NS. There were no statistically significant differences on post assessment patient rated scores, $U=64.500$, $p=.1300$, NS. There were no differences on carer rated scores on post assessment, $U=131.000$, $p=.1300$, NS.

Within groups- On examination of the data through a related samples Wilcoxon signed rank test, in terms of group there were no significant differences in total scores CST groups ($W=63.000$, $Z= 1.888$, $p=0.059$, NS) and Sonas groups ($W=55.500$, $Z=1.296$, $p=0.195$, NS). The CST group demonstrates a trend towards significance.

On examination of patient rated scores, through a related samples Wilcoxon signed rank test, there were no significant differences in CST groups ($W=.805$, $Z=42.000$, $p=.421$, NS) and Sonas groups ($W=.670$, $Z=40.500$, $p=.503$, NS).

On examination on the Carer rated QOL-AD scores, through a related samples Wilcoxon signed rank test; both CST groups ($W=79.000$, $Z= 2.344$, $p=.019$) and Sonas groups ($W= 2.104$, $Z=56.500$, $p=.035$) improved significantly.

In summary, the Hypothesis is rejected as the examination of the QOL-AD data shows statically significant positive improvements in carer rated QOL-AD scores only for both CST and Sonas groups.

4.23 Communication

Holden Communication Scale

4.24 Baseline Data analysis

An exploration of baseline Holden communication scale data was completed. An independent samples Mann Whitney U test concluded that there was no significant difference between CST or Sonas groups at baseline $U=95.000$, $p=.928$, NS.

Differences were found in terms of the shape of the distributions and normality assessments at baseline. A full detailed baseline analysis across all variables can be found in Appendix (19).

In conclusion, the data did not meet normality assumption at baseline and non-parametric tests were used in the data analysis.

4.25 Hypothesis 8

There will be statistically significant improvements in the CST group only. There will be no differences in outcomes in terms of the individual components of the Holden communication scale assessment.

Between groups- A Mann Whitney U test demonstrates no differences between CST and Sonas groups on post assessment total scores $U=127.000$, $p=.1846$, NS.

Between groups- A Mann Whitney U test was completed to examine differences between groups on individual assessment variables. The results are summarised in table (18) below. In the communication section, there is a significant difference between CST and Sonas groups in the 'Interest in past events' subsection, $U=148.000$, $p=.0195$.

Within groups- Statically significant improvements were found in the CST groups only ($W= 6.500$, $Z=-2.736$, $p=.006$) and the Sonas group was found not to be statistically significant ($W= 17.500$, $Z= -1.391$, $p=.164$, NS).

Title of table 18: Holden communication results summary.

Holden Communication Scale	
Between groups	
Conversation	
1a. Response	U=102.000, p=.8562, NS.
1b. Interest in past events	U=148.000, p=.0195
1c. Pleasure	U=81.000, p=.4672
1d Humour	U=99.500, p=.9278, NS.
Awareness and Knowledge	
2a. Names	U=117.000, p=.3874, NS.
2b. Orientation	U=121.000, p=.2945, NS.
2c. General Knowledge	U=121.000, p=.2945, NS.
2d. Ability to do join in games etc.	U=97.500, p=1.000, NS.
Communication	
3.a Speech	U=99.500, p=.9278, NS.
3b. Attempts at communication	U=105.000, p=.751, NS.
3c. Interest and Response to objects	U=121.500, p=.2737, NS.
3d.Success in communication	U=98.000, p=1.000, NS.
Statistically significant	

Table 18

Within groups- an examination of the individual assessment components of the Holden Communication Scale recorded in nominal format (5 values) was completed as per Table (19), with comparisons based on groups using the Wilcoxon Signed Rank test.

Title of table 19: Holden communication scale within groups.

Holden Communication Scale						
Conversation	CST			Sonas		
	(Pre T1 and Post T2 assessment) Z score	W	Sig. (2 tailed)	(Pre T1 and Post T2 assessment) Z score	W	Sig. (2 tailed)
1a. Response	-1.857	.000	.063	.000	1.5	1.000
1b. Interest in past events	.000	18.000	1.000	.447	9.000	.655
1c. Pleasure	-.832	20.000	.405	-.577	2.000	.564
1d Humour	-1.764	.000	.078	-1.300	1.500	.194
Awareness and Knowledge						
2a. Names	-.250	20.500	.803	-.378	6.000	.705
2b. Orientation	-1.387	15.000	.166	.000	22.500	1.000
2c. General Knowledge	-1.508	8.000	.132	-1.732	6.000	.083
2d. Ability to do join in games etc.	-1.651	6.500	.099	-1.890	.000	.059
Communication						
3.a Speech	.000	1.500	1.000	-1.414	.000	.157
3b. Attempts at communication	-1.414	.000	.157	-1.414	.000	.157
3c. Interest and Response to objects	-1.414	2.500	.157	-.707	5.000	.480
3d.Success in communication	-.756	3.000	.450	.000	.000	1.000

Table 19

There were no statistically significant changes within the individual components of the Holden Communication Scale assessment.

In summary, there were statistically significant improvements in the total scores of the CST group only. There were no differences within CST or Sonas groups in terms of the individual components of the assessments. The Hypothesis is accepted; the Holden Communication Scale total scores showed statistically significant improvements in the CST group only.

4.26 Neuropsychiatric Symptoms

NPI

4.27 Baseline Data examination

An independent samples Mann Whitney U test was used to test for differences between groups at baseline. No statistically significant differences were found between groups in total pre NPI score $U=77.500$, $p=.363$, NS. Differences were found in terms of the shape of the data, the distribution of the data and normality assessments; which indicated variances at baseline across variables. A full detailed baseline analysis on all variables can be found in Appendix (20).

In summary, on examination of the baseline data on the NPI pre assessment scores there are variances at baseline. Therefore, it can be concluded that the data did not meet the normality assumption at baseline and a non-parametric data analysis was used.

4.28 Hypothesis 9

There will be statistically significant improvements in total scores and individual components of the NPI assessment in both CST and Sonas groups. There will be no difference between groups.

Between groups- A Mann Whitney U test found that there were no differences between CST and Sonas groups on total NPI post assessment scores, $U=88.000$, $p=.6832$, NS. A Mann Whitney U test was completed on the individual components of the NPI assessment between CST and Sonas groups, the results are illustrated in table (20) below. There were no statistically significant differences between groups on the individual components of the post NPI assessment.

Title of table 20: NPI between groups.

Individual components of the NPI. Between group differences.	
Delusions	U=97.000, p=1.000, NS
Hallucinations	U=97.000, p=1.000, NS
Agitation/ Aggression	U=62.500, p=.108, NS
Depression/Dysphoria	U=107.500, p=.650, NS
Anxiety	U=88.000, p=.683, NS
Elation/Euphoria	U=91.500, p=.786, NS.
Apathy/ Indifference	U=101.500, p=.856, NS
Disinhibition	U=99.000, p=.964, NS
Irritability/ Lability	U=82.000, p=.496, NS
Abberant Motor Behaviour	U=77.500, p=.363, NS
Occupational Disruptiveness	U=50.000, p=.720, NS
Carers Stress	U=11.500, p=.730, NS
Sleep and Night time Behaviour Disorders	U=91.500, p=.786, NS
Appetite/ Eating changes	U=102.000, p=.856, NS.

Table 20

Within groups- the related samples Wilcoxon signed rank test was used to examine the comparison of pre and post Total NPI scores in terms of CST and Sonas groups. There were no statistically significant differences between the CST ($W= 21.5, Z=-1.951, p=.051, NS$) or Sonas ($W= 12.0, Z=-1.871, p=.061, NS$) groups on this assessment. Both groups show a trend towards significance.

On examination of the individual components of the NPI assessment using the related samples Wilcoxon signed rank test, the following differences illustrated in Table (21) were found between groups:

Title of table 21: Within group individual components.

	CST Group	Sonas Group
Delusions	W=2.5, Z=-1.951, p=.051, NS	W=5.0, Z= -.680, p=.496, NS
Hallucinations	W=15.0, Z=.171, p=.864, NS	W= 4.0, Z=-.378, p=.705, NS
Agitation/ Aggression	W=11.5, Z=-1.655, p=.098, NS	W=3.0, Z=.000, p=1.0, NS
Depression/Dysphoria	W=.0, Z=-2.060, p=.039	W=6.5, Z=-1.620, p=.105, NS
Anxiety	W=12.0, Z=-.849, p=.396, NS	W=4.0, Z=.535, p=.593, NS
Elation/Euphoria	W=2.0, Z=-.535, p=.593, NS	W=.0, Z=-1.342, p=.180, NS
Apathy/ Indifference	W=28.0, Z=.051, p=.959, NS	W=7.0, Z=-.740, p=.459, NS
Disinhibition	W=4.00, Z=-1.378 p=.168, NS	W=2.0, Z=-1.134, p=.257, NS
Irritability/ Lability	W=6.5, Z=-1.279, p=.201, NS	W=6.0, Z= .378, p=.705, NS
Abberant Motor Behaviour	W=3.0, Z=-1.236, p=.216, NS	W=.0, Z=-1.000, p=.317, NS
Occupational Disruptiveness	W=2.0, Z= -2.459, p=.014	W=14.0, Z=-.566, p=.572, NS
Carers Stress	W=3.5, Z=-1.089, p=.376, NS	W=.000, Z=-1.342, p=.180, NS
Sleep and Night time Behaviour Disorders	W=20.0, Z= 1.033, p=.302, NS	W= 1.5, Z=1.837, p=.414, NS
Appetite/ Eating changes	W=0.0, Z=-2.459 , p=.014	W=4.5, Z=-.813 p=.416, NS
Statistically significant *		

Table 21

The CST group was found to have statistically significant changes between pre and post assessment in the areas of:

1. Depression/ Dysphoria (W=.0, Z=-2.060, p=.039) in comparison to the Sonas group which was found to have no statistically significant changes (W=6.5, Z=-1.620, p=.105, NS)
2. Occupational Disruptiveness (W=2.0, Z= -2.459, p=.014) in comparison to the Sonas group who similarly had no statistically significant changes (W=14.0, Z=-.566, p=.572, NS).
3. Appetite and Eating changes (W=0.0, Z=-2.459, p=.014) in comparison to the Sonas group who had no statistically significant changes (W=4.5, Z=-.813 p=.416, NS).

In summary, no differences were found on statistical analysis between the groups in total scores. However, statistically significant changes were found within three of the components of the NPI assessment in the CST group only rejecting the hypothesis, as the CST group only was found to have statistically significant differences within three individual components of the NPI assessment.

A summary of the primary hypothesis results on all outcomes measures will now be presented in table format (table 22).

Title of table 22: Summary of hypothesis.

Summary of primary Hypotheses: Comparison of CST and Sonas group conditions on all outcome measures			
Hypothesis	Result within groups T(1) to T(2)	Result between groups. Post assessment	Conclusion
1: Participants assigned to both the CST and Sonas conditions will show improvements from pre-intervention to post-intervention on the SMMSE.	CST group (t (14) = -2.385, p= 0.032) Sonas group (t (12) =-1.923, p=.079, NS).	No differences (t (26) = 1.332, p=.195, NS)	Reject Hypothesis. CST group only demonstrated statistically significant differences on SMMSE.
2: Participants assigned to the CST group will demonstrate greater improvements in total score and task behaviour than Sonas group on the OTTOS. Both groups will demonstrate similar improvements in general behaviour.	Total score: CST (W=75.000, z=2.828, p=.005) Sonas (W= 78.000, z=3.061, p=.002) Task behaviour: CST (W= 74.000, z=2.747, p=.006) Sonas (W= 77.000, z=2.983, p=.003) General behaviour: CST (W=49.000, z=2.199 p=.028) Sonas (W=76.500, z=2.944, p=.003).	Total score: No differences (U= 51.000, p=.141, NS). Task behaviour: No differences (U=51.4, p=.146, NS). General behaviour: No differences (U=51.000, p=.134, NS).	Reject Hypothesis. Both the CST and Sonas groups demonstrated statistically significant changes in total score, task behaviour and general behaviour.
3: Participants will demonstrate consistent gradual improvements in performance as measured by total OTTOS score over a 14 session period in both groups. There will be differences dependant on the group.	A multiple line chart demonstrated consistent gradual improvements over the 14 session period. CST: four sessions with decreases in mean scores Sonas: two sessions with decreases in mean scores		Accept Hypothesis. Both CST and Sonas groups showed consistent gradual improvements. Variances in intervals of improvements dependant on the group with the Sonas group having fewer sessions with decreases in mean scores.
4: Participants in both groups will demonstrate statistically significant improvements in all areas of the Sonas group session evaluation form	CST: seven out of fourteen areas Sonas: ten out of fourteen areas	Three sections showed differences between groups: exercises, rhythmic movements and using instruments.	Reject hypothesis. Both CST and Sonas conditions both demonstrated statistically significant improvements in

assessment.			some areas. Participants who received Sonas demonstrated statistically significant improvements in more areas assessed than the CST condition. Neither CST nor Sonas demonstrated statistically significant improvements in all areas.
5: Participants in both groups will demonstrate statistically significant improvements from session one to session fourteen in all areas of CST monitoring progress the assessment.	CST: statistically significant changes in four areas of the assessment. Sonas: statistically significant changes in 3/4 areas of the assessment.	No differences between groups.	Reject hypothesis. The CST group only were found to have statistically significant changes all areas
6: There will be no significant change in ADL as a result of either CST or Sonas intervention.	CST (W=19.500, Z=-.357, p= 0.721, NS) Sonas (W=40.000, Z=1.277, p= 0.201, NS).	No differences. U=99.000, p=1.000, NS.	Accept Hypothesis. No change of statistical significance in ADL as a result of either CST or Sonas intervention.
7: There will be statically significant positive improvements in total QOL-AD scores, patient rated scores and carer rates scores in both groups.	Total scores: CST groups (W=63.000, Z= 1.888, p=0.059, NS) Sonas groups (W=55.500, Z=1.296, p=0.195, NS). Patient rated scores: CST groups (W=.805, Z=42.000, p=.421, NS) Sonas groups (W=.670, Z=40.500, p=.503, NS). Carer rated scores: CST group (W=79.000, Z= 2.344, p=.019) Sonas group (W= 2.104, Z=56.500, p=.035)	Total score: No difference U=92.000, p=.8207, NS. Patient rated scores: U=64.500, p=.1300, NS. Carer rated scores: No difference. U=131.000, p=.1300, NS.	Reject Hypothesis. The examination of the QOL-AD data shows statically significant positive improvements in carer rated QOL-AD scores only for both CST and Sonas groups.
8: There will be statistically significant improvements in the CST group only in the Holden communication scale. There will be no	CST groups (W= 6.500, Z=-2.736, p=.006) Sonas group (W= 17.500, Z= -1.391,	No differences on total scores. U=127.000, p=.1846, NS.	Accept Hypothesis. Statically significant improvements were found in the total scores of the CST group only.

differences in outcomes in terms of the individual components of the assessment.	p=.164, NS). Individual assessment components: No changes between groups.	Individual assessment component: communication section, significant difference between CST and Sonas groups in the 'Interest in past events' subsection, U=148.000, p=.0195.	No differences between CST or Sonas groups in terms of the individual components of the assessments.
9: There will be statistically significant improvements in total scores and individual components of the NPI assessment in both CST and Sonas groups. There will be no difference between groups.	Total scores: CST (U= 21.5, p=.051, NS) Sonas (U= 12.0, p=.061, NS) Individual components: Depression/ Dysphoria CST group (U=.000 p=.039) Sonas group (U=6.5 p=.105, NS) Occupational Disruptiveness: CST (U=2.000 p=.014) Sonas (U=14.0 p=.572) Appetite and Eating changes: CST (U=.000 p=.041) Sonas group (U=4.500 p=.416, NS).	Total scores: No differences, U=88.000, p=.6832, NS. Individual components: No differences	Reject Hypothesis. No differences in total scores in either group. CST group only: statistical changes on three individual components of the NPI.

Table 22

4.29 Supplementary Analysis

The analysis of the primary hypotheses concludes that on two outcome measures both CST and Sonas groups improved significantly or did not improve significantly. It could be therefore, argued that both interventions were equally effective or not effective. The supplementary analysis aims to examine the impact of other variables/factors on these results. This will be presented in question format and a summary table will be included within the questions in sections to summarise findings where relevant.

4.30 Question 1:

Both CST and Sonas groups improved significantly on the OTTOS. Did sex, site of residence, residence type, dementia type, dementia diagnosis type and capacity to give informed consent have an influence on change in the primary results?

The variable assessed, the outcome and the summary result is presented in table (23).

Title of table 23: OTTOS secondary question.

OTTOS		
Variable	Outcome	Summary
Sex	<p>CST: A related samples Wilcoxon signed rank test demonstrated that Males (W=21.000, Z=2.201, p=.028) in the CST group had statistically significant changes in comparison to females (W=6.000, Z=1.604, p=.109, NS).</p> <p>Sonas: In contrast, Males in the Sonas group (W=18.000, Z=1.577, p=.115, NS) did not have any statistically significant changes in comparison to Females who demonstrated statistically significant changes for the Sonas group (W=45.000, Z=2.668, p=.008).</p>	<p>CST- Males were significantly different</p> <p>Sonas- Females were significantly different</p>
Site of residence	There were no differences of statistical significance.	

Residence type	<p>CST: Inpatients (W=28.000, Z=2.366, p=.018) and community (W=36.000, Z=2.524, p=.012) residence types were found to have statistically significant outcomes.</p> <p>Sonas: No statistically significant outcomes for Inpatients (W=12.000, Z=1.219, p=.223, NS) or community (W=10.000, Z=1.826, p=.068) residence types.</p>	<p>CST- significantly different results for inpatients and community.</p> <p>Sonas – no significant outcomes.</p>
Dementia type	There were no differences of statistical significance.	
Other diagnosis	<p>CST: no statically significant changes</p> <p>Sonas: Those participants with another diagnosis of depression had statistically significant changes (W=15.000, Z=2.023, p=.043).</p>	<p>CST: No significant outcomes</p> <p>Sonas: Depression had significant changes. (Note that at baseline- higher no of participants with depression in the Sonas group).</p>
Capacity to give informed consent	<p>CST: There were statistically significant changes for the yes group (W=20.000, Z=1.997, p=.046) and no changes of significance for the no group (W=3.000, Z=1.342, p=.180, NS).</p> <p>Sonas: There were statistically significant changes for both yes (W=20.000, Z=1.992, p=.046) and no (W=55.000, Z=2.805, p=.005) groups.</p>	<p>CST: Yes group only had significant changes.</p> <p>Sonas: Both yes and no groups had statistically significant changes.</p>

Table 23

On the OTTOS a further supplementary examination revealed that in the CST group males only were found to have statistically significant outcomes. In comparison, females only in the Sonas group were found to have statistically significant outcomes. In the CST group only, statistically significant results were found for both inpatients and community. In the Sonas group only, those who had another diagnosis of depression had statistically significant outcomes. In relation to the capacity to give informed consent variable; those who had capacity defined by yes, only had statistically significant

changes. In contrast, both yes and no variables were found to have statistically significant changes.

4.31 Question 2:

Neither CST nor Sonas groups improved significantly on the ADCS-ADL scale. Did Sex, site of residence, residence type, dementia type, dementia diagnosis type and capacity to give informed consent have an influence on the primary results?

All variables were examined and there were no differences of statistical significance in either of the CST and Sonas groups in any of the variables.

4.32 Question 3:

Both CST and Sonas groups improved significantly on the OTTOS. Was there a relationship between outcome on the OTTOS and number of years in residence, age and number of group sessions attended which influenced the primary results?

A Spearman's rho was completed to examine the relationships between the variables. There were found to be no relationships of significance. The details of these results can be found in appendix (42).

4.33 Cost analysis

A basic cost analysis was completed for phase one of the study. The cost of a 14 session full programme delivered by a Senior Occupational Therapist and healthcare assistant (HCA) or multitask attendant (MTA) or OT assistant (OTA) in a HSE setting (three of whom are noted to be all on the one pay scale), was costed as outlined in table (24) (HSE, 2013).

Title of table 24: Cost analysis details.

	CST	Sonas
Initial set up costs (once off)	£13.50 plus postage of £5 (€25.24) for training manual one. Cost of group materials (reminiscence items, photocopying, tasting materials etc.) €50	Sonas course Attendance Fee €320. A Sonas kit costs €50. Cost of all materials €50.

Equipment and material costs full programme	Refreshments for all 3 CST programmes €36 (extra refreshments provided as two groups completed together with break in between), each programme costed €12 for refreshments.	Cost of refreshments for all 3 Sonas programmes €15. €5 per session for refreshments.
Costs of facilitators	<p>Senior OT Salary (as at 01/01/2010) for a senior OT midpoint on the HSE pay scale is €54,578 per year which currently equates to €28.27 per hour.</p> <p>The following time period was used: 14 hours of direct OT time = €395.78, 7 hours of indirect OT time= €197.89. Total cost of time= €593.67</p> <p>Healthcare assistant (HCA)/multitask attendant (MTA)/ OT assistant (OTA) midpoint on HSE pay scale is €29, 809 which equates to €15.28 per hour.</p> <p>The following time period was used: 14 hours of direct HCA/MTA/OTA time = €213.92, 3.5 hours of indirect HCA/MTA/OTA time= €53.48. Total cost of time= €267.4.</p> <p>Total cost of OT and HCA/MTA/OTA per group programme= €816.07</p>	
Cost of facilities	The group programmes were delivered in the participants' group activity rooms for those who were inpatients and community participants received their programmes in the PLL day hospital which was also free of charge once the participant was a service user.	
Total cost	CST total cost per programme (including initial set up costs) €816.07+€87.24 = €903.31.	Sonas total cost per programme (including initial training and set up costs) €816.07 + €425 =€1,241.07

Table 24

In summary, the total cost of the CST programme including initial set up costs is €903.31. If the initial set up cost were not included, it would cost €816.07 to deliver the CST programme. The Sonas programme has an initial set up cost of €1,241.07. If the initial set up costs were not included, it would cost €425 to deliver the programme. However, the Sonas has an ongoing annual cost of €100 for practice development days to maintain a SLP licence. Therefore, this fee would have to be added to the annual cost.

4.34 Phase two of research

4.35 Case study one

The results of the analysis of case study one will now be presented. As described in the methodology and literature review the goal of EL intervention was identified through collaboration with PI. The goal was to be able to prepare her own breakfast independently and safely in her own home. She reported that she found her cooker difficult to comprehend and that she lacked motivation to prepare a breakfast as a result of her mistakes through the process of breakfast preparation in the past.

4.36 Demographics

Participant one was female. She was a widow, she lived alone and her family locally were her main carers (daughter and son in law). She had a Diagnosis of Mixed Alzheimer's/Vascular Dementia. She was 80 years of age at time of the study.

4.37 Table presentation of results

Assessment was carried out using an activity analysis and recording of errors as described in the methodology. The results of the analysis are now presented session by session in table format. Errors are highlighted in yellow. Where two tasks were completed in isolation, they are presented side by side in table format. Where tasks were completed in an integrated sequence, they are presented in this sequence. Three tables will be presented to illustrate the results obtained, one from the baseline, one from the intervention phase and one from the post baseline. Full details of all sessions can be seen in Appendix (37, 38, 39). Table (25) details the records from session one.

Title of table 25: Session one records.

Table of Observations, Session one:	
Participant forgot to close press door and left it open in her path on one occasion (Note on safety).	
Session 1: Assessment Phase. Task was to prepare a poached egg and hot coffee.	
Poached Egg	Hot coffee
Searched for a pot and retrieved it successfully.	Initially unable to find cups, despite an increased amount of time for searching. Error
Filled pot with water from the tap on the sink.	Found 2 cups
Turned on the oven at the main switch on the wall.	Found spoon
Checked the cooker to see it was on and turned on a ring (there appeared to be no choice in the ring that participant 1 turned on), she used the first one she noticed was on by its red colour.	Unable to find coffee jar, despite checking all presses, found pot after some time and some distress. Error.
Retrieved salt from the press and placed it into the saucepan.	
Retrieved an egg from the fridge.	Spooned coffee from jar into cups.
Retrieved knife and spoon from the press.	Turned on electric kettle to boil
Used knife to crack egg into water which was starting to boil on the cooker and then used.	Found bread for toast and toaster. Toasted bread.
Unable to locate where her bin was and what she would do with the egg shells, she placed them into a storage container at the sink for soap and cleaning sponges. Error.	Found butter and buttered toast.
Turned down saucepan to a lower level on the knob as she became aware of the risk of the pot boiling over	Unable to find plate. Error. Prompt given after a search and an extended amount of time. Needed specific prompt to recall what she was looking for after an extended amount of time. Error.
Removed excess egg from the	Transferred egg onto toast

top of the water by her spoon and placed it in the sink.	
Removed excess water from the poached egg at the sink.	Checked if electric kettle was boiled.
Placed pot with egg and no water back on the hob where it began to burn. Error.	Obtained coffee, spooned coffee into cups
PI provided prompt at this stage.	
It appeared that participant 1 was distracted by her plans to make her coffee at the same time and forgot to complete the task safely. Error.	Retrieved milk and filled coffee with milk
	Retrieved hermesetas and placed into coffee
	Moved toast with eggs and coffee to pre set-up table and did not use the table mat she had set up prior to PI arriving in the home and used a book instead. Error.
Total number of errors: 8	
Total number of deviations from sequence: 0	

Table 25

4.38 Summary of activity analysis participant one A phase

From activity analysis throughout initial assessment in the baseline A phase, the difficulties with this particular task were:

- Orientation to her kitchen environment: Participant 1 was observed to have difficulty in recalling which items were stored in particular presses and her kitchen presses/cupboards appeared to lack organisation which impacted further on the disorientation. Participant one's main carer reported on initial meeting that Participant 1 was a hoarder and he regularly de cluttered the kitchen to allow her to function.
- Scanning of fridge: On assessment it was identified that Participant 1 presented with difficulties in scanning of her fridge (which was located above waist height). On searching for an item if it were not immediately clear, she would give up.
- Safe use of the cooker: The cooker was an electric cooker in built into the work top, with 4 knobs located to the right hand side of the knob. The 4 rings lit up red when heated and there was an on/off switch to the right hand side of the wall at the rear of the cooker with a red electrified light when it was turned on. From initial assessment

the difficulties with the cooker appeared to be with correct use of controls and the on/off switch at the rear. There were also difficulties with the setup of the environment for example, participant one forgot to turn on the light in the room making the visual inspection of the controls difficult, she also forgot to wear her glasses similarly making visual inspection of the cooker and the presses more difficult. It was noted that the participant moved from the UK to Ireland approximately 8 years prior to this study to a newly built home with modern appliances and therefore the cooker she used most of her life may have been quite different to the modern electric one she used in this study. This was not clarified with the participant.

- Inability to multitask: It was clear that participant one was distracted by making coffee at the same time as preparing breakfast or if she engaged in conversation with PI she became distracted from her task
- Difficulties with planning. It was observed that participant one had difficulties with planning her shopping for breakfast and whilst she was supported with her shopping she lacked choice in what she would buy. There were no shopping lists present in the home.
- General orientation: EL was planned for every second week day by PI. It was recommended and a dementia friendly orientation board was installed on a wall that participant one walked by regularly in order to prompt her on the schedule of intervention by PI and also for her general daily routine. The PI involved the participants' family in daily maintenance of the orientation board. An example of the orientation board used is found in appendix (24).

4.39 Table presentation of B phase

One session of the B phase of the study will now be presented in table format (table 26). All other sessions can be examined in Appendix (38).

Title of table 26: Session 6, participant one.

Table of Observations, Session 6:
Introduced compensatory dementia friendly signage and orientation board. Education completed with participant and her family prior to commencing errorless intervention. Both the participant and her family were open and happy to engage with this.
Session 6: Intervention (B) Phase. Task was to prepare a poached egg, toast and hot coffee.
Coffee, Poached egg and toast
<ol style="list-style-type: none"> 1. Searched for Pot, took out pot, sieve and lid. 2. PI provided prompt place excess items back into the press. 3. Filled pot with cold water from the tap and placed on electric hob. PI provided prompt to turn on the hob using the dementia friendly signage adjacent to the knobs. 4. Turned on cooker and appropriate knob successfully. 5. Reached for eggs from fridge, placed eggs into water. Error. 6. PI provided prompt that her plan was to poach eggs and not to boil them. 7. Removed eggs from water 8. Searched for knife and retrieved it successfully 9. Simultaneously, filled electric kettle with water from the tap and accurately placed on to boil. 10. Observed water boiling very slowly. PI provided prompt to turn up hob to allow water to boil a little quicker (her usual speed of boiling). 11. Put salt in water (this was a new activity, not previously observed) 12. Sourced bread and put in the toaster. 13. Checked toast. 14. Broke eggs (2) into boiling water using a knife 15. Observed egg cooking. 16. Cooked eggs and removed water from the eggs at the sink. 17. Removed eggs from pot to a plate by using a spoon 18. PI provided a prompt to turn off the cooker 19. PI prompted on next sequence ‘would you like to make a cup of coffee?’ 20. She reported yes she would 21. Searched for milk in unmarked press opposite to fridge 22. Self-corrected and commenced searching in fridge for milk

23. Retrieved coffee and spooned into 2 cups using a spoon
24. Poured hot water
25. Poured milk
26. Stirred coffee
27. Remembered to take Hermesetas (new activity)
28. Retrieved knife successfully
29. Retrieved butter successfully from fridge
30. Buttered toast
31. Carried all prepared items to the table
32. PI provided prompt to return and take cutlery with her for use.
Total errors: 1
Total prompts provided by PI to provide EL intervention: 7
Total no of deviations from sequence: 0

Table 26

4.40 Table presentation of results post A phase

The results from the post A phase will now be presented in table format (table 27).

Title of table 27: Session 11, participant one.

Table of Observations, Session 11:
There was a dirty frying pan found in the participants press. PI notes there was a weekend period between last session in B phase and this session. Table pre-set up prior to PI arrival.
Session 11: Assessment (A) Phase. Task was to prepare an omelette, toast and hot coffee.
1. The participant reported that she would like to prepare an omelette and a coffee
2. She was unable to recall the ingredients for an omelette. Error.
3. After sometime was allowed to elapse, PI provided full prompting on ingredients required for an omelette. Error.
4. She searched for her pan and retrieved it successfully
5. She searched for her oil in her press and not in her fridge where she usually stores it. Error.
6. Prompt required from PI. Error.
7. She was unable to locate her bowl for mixing. Error.
8. Verbal prompt required from PI. Error.
9. Unable to recall mixing technique. She attempted to place all the items on the pan without mixing the ingredients together first. Error.
10. Verbal prompts given by PI to support independence with same. Error.
11. Operate the electric hob independently and safely using the dementia friendly signs

12. Forgot to use her fish knife to lift off, appeared bewildered on how to remove omelette from pan. Error.
13. PI provided non-verbal prompt via demonstration of fish knife. Error.
14. Used fish knife to remove omelette and placed on plate.
15. Turned off her cooker independently.
16. Boiled electric kettle independently
17. Retrieved coffee and Hermesetas
18. Spooned coffee
19. Placed one Hermesetas into cup
20. Poured hot water
21. Retrieved milk from fridge
22. Poured milk into coffee
23. Transported all items to her table
Total Number of Errors: 10
Total Number of Interventions: 5
Total Number of Deviations from sequence: 0

Table 27

4.41 Error measurement results

Title of figure 11: Error measurement, participant one.

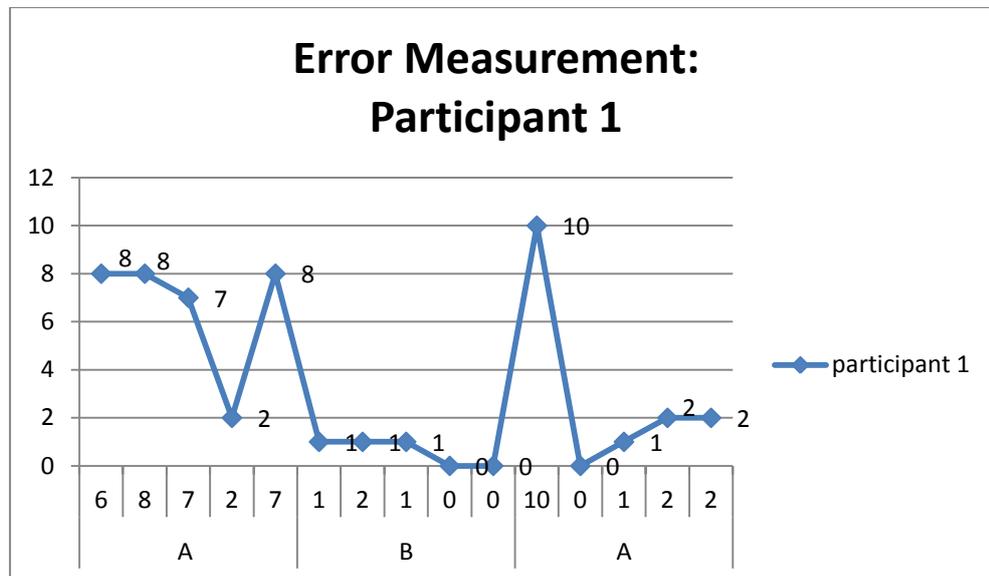


Figure 11

The error measurement over the 3 phases (ABA) is illustrated in figure (11) above. It is observed that there are significant errors in the initial A phase ranging from 2 to 8 errors. There is a large decrease in errors in the B phase (where errorless intervention was applied) and finally there is a large increase in the first assessment in post A phase where EL intervention was removed but environmental cues were in place, however this quickly plateaus and stabilises at 2 errors in the post A phase.

Safety: It must be noted that prior to the EL intervention in the B phase, participant one was observed to be unsafe with the breakfast preparation activity. It is noteworthy that in the Post A phase she was safe with the use of the cooker and independent with her activity which is a significant occupational outcome. At the end of the study, it was recommended that she was independent with supervision for her breakfast preparation.

4.42 Deviations from sequence

The following figure (12) illustrates the participants' deviations from the task sequence. In the A phase there were 2 deviations from the sequence in session 5. There were no other deviations from task sequence.

Title of figure 12: Deviations from sequence, participant one.

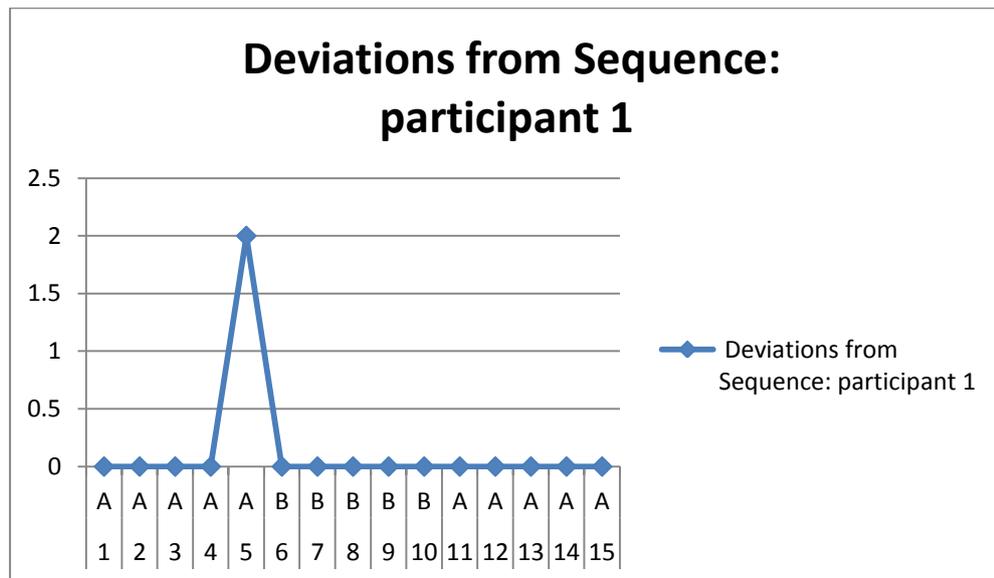


Figure 12

4.43 Number of steps used in order to complete the task

The following figure (13) illustrates the number of steps the participant used in order to complete the task. In the pre A phase the average numbers of steps are 30.6 steps. The B intervention phase has an average of 29.6 steps. The post A phase has an average of 19.2 steps in order to complete the activity. Whilst there is a slight reduction in the number of steps in the intervention phase B which indicates that the task was completed more efficiently even with the introduction of compensatory steps and use of dementia friendly environment cues, the task itself varied somewhat within the context of each session and therefore there is no clear value in comparing the overall phases. It is notable to report that the participant did appear to perform the task of preparing a poached egg more efficiently. For example, in the pre A phase it took a max of 44 and a min of 30 steps to poach an egg, prepare toast and coffee. While in the post A phase it took a maximum of 23 and a minimum of 14 steps to specifically poach an egg, prepare toast and coffee.

Title of figure 13: number of steps to complete task, participant one.

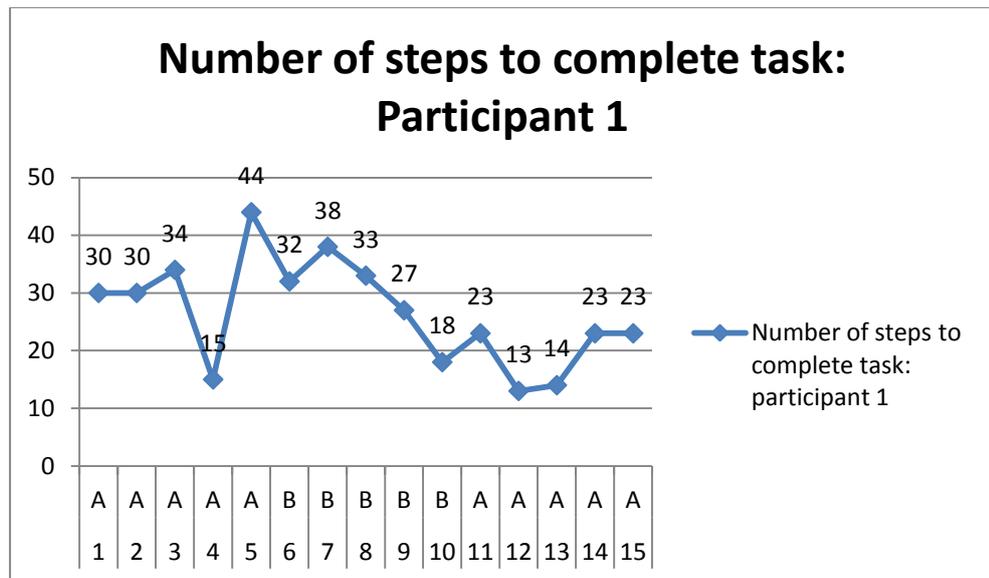


Figure 13

In summary, the number of steps the participant used to complete the task reduced. This will be discussed later in the discussion chapter.

4.44 Pre and post Assessments

The following series of assessments were completed pre the ABA phase and post the ABA phase interventions as outlined in the Methodology chapter.

Addenbrooke's Cognitive Examination-III

Participant one scored 61/100 on her ACE-III on pre assessment and 66/100 on her post assessment demonstrating little change on this cognitive assessment.

Within the individual components of the ACE-III assessment, participant one was found to have a one point decline in attention pre and post, and 6 point increase in memory from pre to post and all other areas of the assessment remained the same from pre assessment to post assessment.

Alzheimer's Disease Cooperative Study ADL Scale

Participant one was found to have no changes of relevance in the ADCS-ADL scale, with a score of 60 pre assessment and 61 post assessment.

The Barthel Index

The BI was found to have no changes from a pre assessment score of 95 to a post assessment score of 95.

The Holden Communication Scale

There were small changes on the Holden communication scale (note the lower the score indicates the higher the communication function). The total score changed from 9 to 7. Within the components of the assessment as indicated in figure (14) below there was a one point decrease in conversation in the specific component 'humour' (positive change), a one point decrease in the specific component 'ability to join in games' (positive change) and a one point increase in communication in the specific component speech (negative change). As outlined in the methodology chapter, it is a 4 point scale and the humour component changed from 'enjoying comic situations or stories' to 'creates situation or tells funny story on own initiative'. The ability to join in games component changes from 'requires careful instructions but joins in' to 'joins in games and activities with ease'. The speech component changed from 'no known difficulty' to a 'slight hesitation or odd wording'.

Title of figure 14: Holden communication scale, individual components and total score.

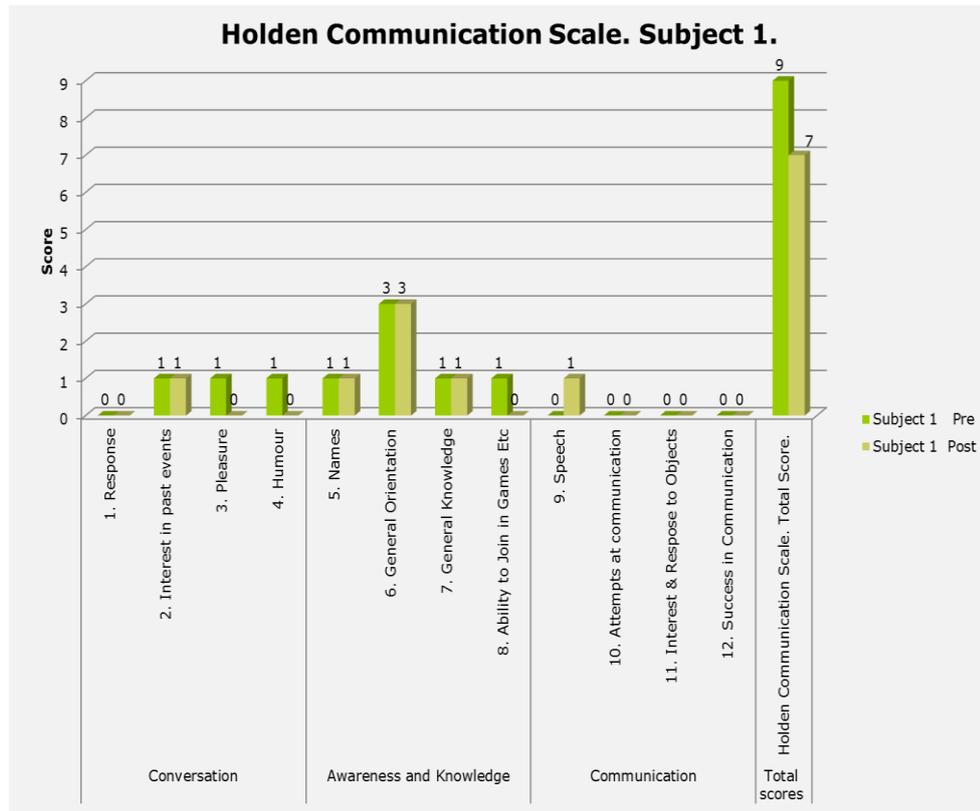


Figure 14

Quality of Life- Alzheimer's Disease

As outlined in the methodology, the QOL-AD is made up of the carer's assessment and the patient assessment combined to give a total score. The Total Patient score pre was 23 and the total patient score post was 35 which was a significant increase in score. The total carer score pre was 25 and post was 26 indicating little change as a result of intervention. The total combined score pre was 48 and the total combined score post was 61 indicating a change in quality of life which is of clinical significance. All areas of the patient assessment were found to have a type change post assessment whereas this was not the case on the carer rated assessment. This is illustrated in figure (15).

Title of figure 15: QOL-AD Participant 1.

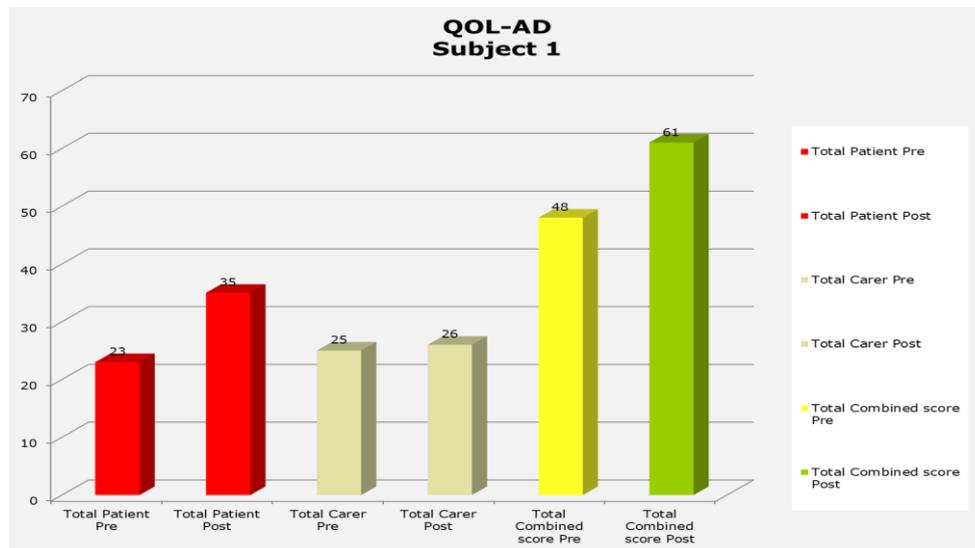


Figure 15

4.45 Cost analysis participant one

The following table (28) illustrates the comparative results of a simple cost analysis which examined the cost of OT intervention, the cost of home help intervention for the period of the intervention and contrasted this with the cost of a nursing home for the period of intervention.

Title of table 28: Cost analysis.

Cost Analysis:			
OT delivering EL intervention.	Pay of personnel	Travel costs	Equipment Costs
Total cost: €1,108.649	Senior OT midpoint on the HSE pay scale (as at 01/01/2010) would be €54,578 per year which currently equates to €28.2698 per hour. The following time period was used: 15 hours of direct PI time = €423.9	The travel cost of a return journey using a diesel car from the PI base to the participants' home was €7.80. There were 15 journeys, total = €117. The travel time was approximately 30 minutes each way, a total of one hour in total. The distance was 30 km. 15 hours	Cost of dementia friendly coloured sheets of paper, selotape and laminated pockets €2.50. Cost of OT time in preparing dementia friendly signage and education to the family on use of same €141.349.

		of OT travel time= €423.9	
<p>Home Help supporting breakfast preparation in the home for the period of the intervention:</p> <p>Total cost = €555.36</p> <p>Home help 1 hr, twice per week for one year.</p> <p>Total cost = €6,888.96</p>	<p>Midpoint on the home help pay scale is €28,494. The average is €14.61 per hour.</p> <p>15 hours of direct home help time =€219.18</p>	<p>The travel cost of a return journey using a diesel car from the home help base to the participants' home was €7.80. There were 15 journeys, total = €117.</p> <p>Travel time was approximately 30 minutes each way, a total of one hour in total. The distance was 30 km. 15 hours of home help travel time= €219.18</p>	
<p>Nursing home in Ireland for the duration of the intervention.</p> <p>Total cost= €4,670</p> <p>Nursing home in Ireland for one year.</p> <p>Total cost= €60,710</p>	<p>The average weekly cost of a public nursing-home bed in Westmeath is €1,089 and Longford is €1,246 (HSE, 2015). Average cost Longford/Westmeath is €1167.5</p> <p>The weekly cost of private nursing-home care is €875 but it can be as high as €1,344. (Irish independent, 2015).</p>		

Table 28

In summary, the intervention cost delivered by a senior OT was €1,108.649. If a Home Help supported breakfast preparation in the home for the period of the intervention this would cost €555.36. The comparable cost of a nursing home for the period of the intervention is €4.670 and for one year is €60,710.

4.46 Case Study Two

As outlined in the methodology and literature review the goal of EL intervention was identified through collaboration with PI. The Goal of EL intervention was to be able to plan and prepare to go out into the local town and complete an activity of shopping or leisure independently.

4.47 Demographics

Participant two was a female, a widow, she lived alone and her son and daughter locally were her main carers. She had a diagnosis of Alzheimer's disease and was 78 years and the time of the study.

4.48 Assessment participant two

Assessment was carried out using an activity analysis as described in the methodology. Examples of the results of the analysis are detailed in the following tables (Table 29, 30, 31). One result table example of the A phase, one example of the B phase and a final example of the post A phase. The sessions from 2-5, 7-10 and 12-15 can be found in appendix (40, 41, 42) respectively.

Title of table 29: Table of observation Participant two.

Table of Observations, Session 1:
Participant engaged in conversation with PI and deviated from one topic to another. The participant reported that she had 3 jobs to do whilst out shopping today. 1. Take her bank card to her daughter who works in a café in the town, 2. Leave medicines at chemist, 3. Visit phone shop regarding her partially working mobile phone. The participant said that she had tried to learn from previous experiences where when she got to the shop she forgot what she had to do, forgot her wallet and she allowed tasks to build up as a result of her history of errors. It was noted that her handbag was a small hand held one rather than one with a long strap and the risk of forgetting this when out was queried at this point. The participant reported that she has a spare set of keys with her neighbours as she regularly gets locked out and/or misplaces her keys. The participant was observed to have increased shortness of breath on return to the home; she reported a fall in the frost the previous Christmas with a soft tissue injury to her ribs.
Session 1: Assessment Phase. Task was to go walk to the town and complete 3 tasks.
1. The participant made attempts to organise herself prior to leaving the home. She used her coat and her handbag to store items such as her glasses, wallet, keys, medication for return to the chemist and carrier bag.
2. On the way out to the shops she lifted her house keys off the hall table

3.	The participant was fully orientated to her local town and walked pass the chemist, then after the visual prompt that she had passed the chemist she recalled that she had some business to do there, so turned around and proceeded to enter. Error.
4.	When inside the chemist, she appropriately recalled what she had to do i.e. return the medication she had placed in her handbag. She completed the return and exited the shop.
5.	The participant then exited the chemist.
6.	She proceed to walk through the town and passed the mobile phone shop, this time she did not receive a visual cue by passing the shop. She proceeded on past the shop and after some time there was no evidence of recall. OT provided verbal prompt and the participant then returned to the phone shop. Error.
7.	She returned to the phone shop after verbal prompt by PI that she had some business to do there.
8.	She was unable to recall what type of business she had to do there and exited the shop. Error.
9.	The participant then passed her daughters place of work, she walked passed with no recollection that she had business with her. Error.
10.	PI provided verbal cue and the participant returned to the cafe. Error.
11.	The participant was unable to recall that she had some business with her daughter. Error.
12.	OT provided verbal cue on what she had originally planned to give to her daughter. Error.
13.	The participant then proceeded to open her handbag loosely in the street and obtain her bank card. PI note on safety.
14.	The participant then entered the shop
15.	She gave her bank card to her daughter.
16.	The participant then exited the shop.
17.	She seeked cue from OT to examine if she had any other tasks to do. Error.
18.	The participant then mobilised to her home using her walking stick.
19.	The participant did not place her keys back on the hall table on return to the home
20.	The participant used her calendar when she returned home to orientate herself.
Total number of errors: 8	
Total number of deviations from sequence: 0	

Table 29

4.49 Summary of activity analysis, assessment A phase

Activity analysis throughout initial assessment identified that the difficulties with this particular task were:

- Organisation of essential requirements to travel out of the home in order to complete a task in the local town. It was identified that she regularly left the home and returned to collect the items she forgot or that she would travel out into the town and then be unsuccessful with the tasks she had planned as a result of her poor recall. It was also identified that she had general difficulties with organising herself in a timely fashion and that going out took a considerable amount of time in preparation for same.

4.50 Table presentation of B phase

One example of the B phase of the study is now presented in table 30.

Title of table 30: Observations, participant two, B phase.

Table of Observations, Session 6:
Introduced compensatory dementia friendly signage and orientation board. Education completed with participant and her family prior to commencing errorless intervention. Both the participant and her family were open and happy to engage with this.
Session 6: Intervention (B) Phase. Task was to travel to the local chemist and pick up her blister pack of medication.
1. The participant was orientated to the purpose of PI visit and it was clear that she had the time and date of PI visit on her church calendar. She also used her digital orientation clock to check the time.
2. The participant was advised to review her checklist which was taped to a press in her kitchen to check what she needs to organise for going out. In addition, she had used her to do list on her kitchen table to write down her task for today. She was advised to put this in her handbag.
3. The participant used the checklist and the yellow signs in the home to find her keys and glasses.
4. The participant then travelled out to the town and completed the task without any difficulty. The local chemist was on her 'loop of the town' which she completed when out in the town.
5. She was provided with a verbal cue to check her to do list on two occasions when out, which she was happy to do and satisfied that she had achieved what she set out

to do.
6. On return to the home she was advised to put the medication away where she always kept it.
7. She was advised to return the keys to their fixed location on the hall table
8. She was advised to return her glasses to the fixed location in the living room.
9. A date was organised for the next PI visit and the participant proceeded to write this up on her calendar.
Total errors: 0 Total prompts provided by PI to provide EL intervention: 7 Total no of deviations from sequence: 0

Table 30

4.51 Table presentation of results post A phase

The results of a single session in the post A phase, baseline assessment will now be presented in table 31.

Title of table 31: Observations, participant two, post A phase.

Table of Observations, Session 11:
The participant was orientated to PI arrival to the home.
Session 11: Assessment (A) Phase. Task was to travel to her daughters Café and give her a bank card.
1. The participant reported that she would like to travel to her daughter café and give her a bank card.
2. The participant had this written on her 'to do list', pick it up and placed it in her bag.
3. The participant then proceeded to get herself organised, when she felt she had herself organised she then checked the checklist in the kitchen and made sure that she had not forgotten anything. This involved removing some items from her bag to recheck that they were there.
4. The participant collected her keys from their labelled location on the hall table.
5. A verbal prompt was provided to use the second checklist at the door prior to exiting the home. Error.
6. The participant exited the home and proceeded to travel to her daughters' café along a familiar route.
7. The participant arrived at the café, checked her to do list which gave her a written prompt and gave her bank card to her daughter with verbal instructions on how she would like her to check her balance and withdraw cash for grocery shopping.
8. The participant travelled home with PI.
9. She failed to place the keys back in their appropriate location and instead left them on the kitchen table. Error.
10. PI provided verbal prompt regarding her fixed location and the benefits of placing them there. Error.
11. The participant failed to return her glasses to their appropriate location. PI provided verbal cue on same and the benefits of placing them there. Error.
12. The participant questioned PI on when she would return for the next session
13. She then wrote the date and time on her calendar.
Total Number of Errors: 4
Total Number of Interventions: 3
Total Number of Deviations from sequence: 0

Table 31

4.52 Error measurement results participant two

The results of the error measurements recorded in the ABA phases are now presented in figure (16).

Title of figure 16: Participant two error measurement.

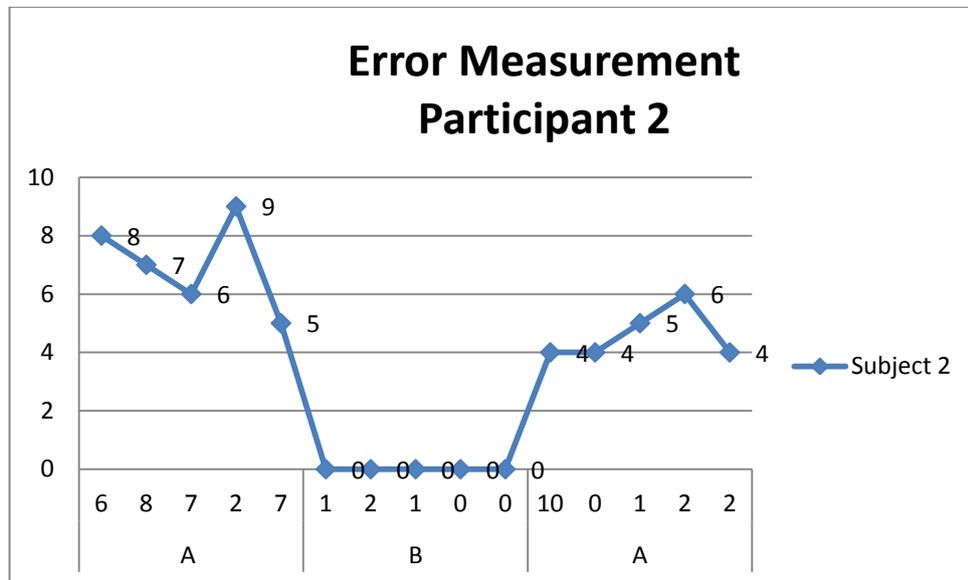


Figure 16

Figure (16) above illustrates the error measurement over the 3 phases (ABA). It is observed that there are significant errors in the initial A phase ranging from 5 to 9 errors. There is an elimination of errors in the B phase (where errorless intervention was applied) and finally there are a small number of errors ranging from 4 to 6 in post A phase where EL intervention was removed but environmental cues were in place.

Safety: The safety issues that arose were in relation to handbag security, the alternatives were discussed with the participant's daughter and the participant herself when the issue came up and when the EL was complete. The recommendations were to use a long handled handbag that could be strapped across the body in future and for the family to continue to work with the participant in developing her awareness in relation to opening wallets/handbags on the street.

4.53 Number of steps used in order to complete the task

The following figure (17) illustrates the number of steps the participant used in order to complete the task. In the initial A phase the average number of steps is 14.2 steps. The B intervention phase has an average of 9.6 steps. The post A phase has an average of 15.8 steps in order to complete the activity. Whilst there is a significant reduction in the number of steps in the intervention phase B which indicates that the task was completed more efficiently in the B phase, the task itself varied the context of each session and therefore there is no clear value in comparing the phases. The average number of steps taken rose by 1.6 steps from the pre A phase to the post A phase. This will be discussed later in the discussion chapter.

Title of figure 17: Number of steps to complete task, participant 2.

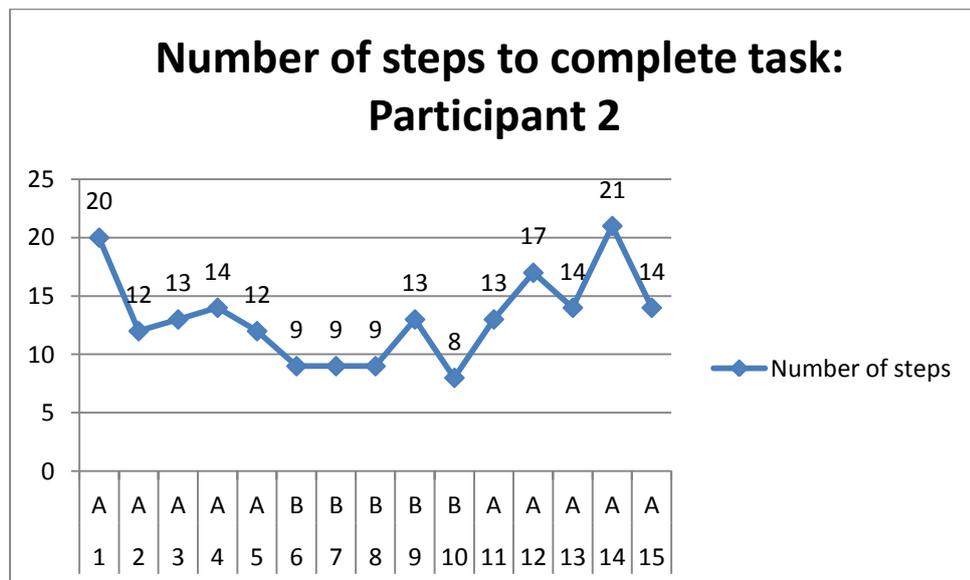


Figure 17

4.54 Deviations from sequence

The following figure (18) illustrates the participants' deviations from the task sequence. In the A phase there were 2 deviations from the sequence in session 2-5. There were no other deviations from task sequence. The relevance of this will be discussed later in the discussion chapter.

Title of figure 18: participant two, deviations from sequence.

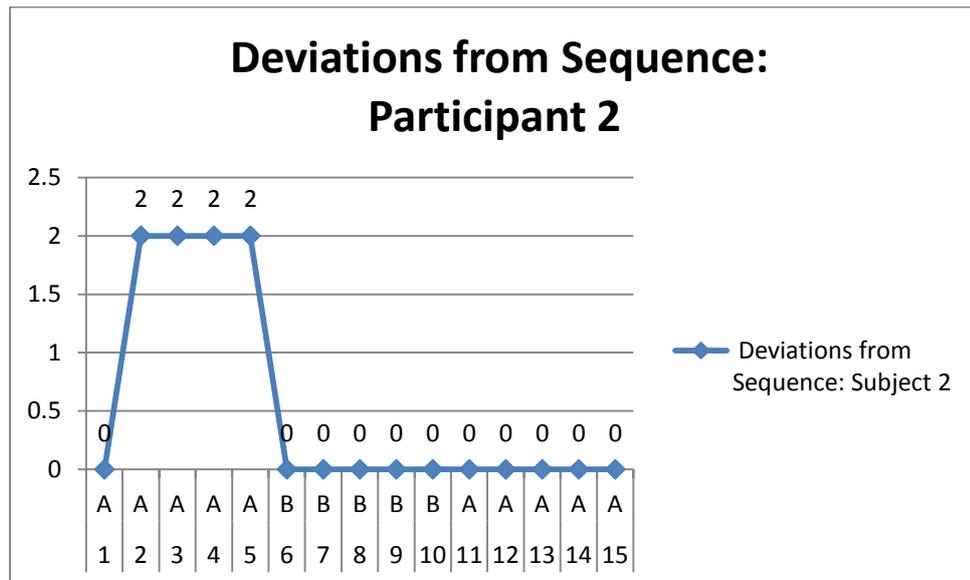


Figure 18

4.55 Pre and Post assessments

The following series of assessments were completed pre and post interventions as outlined in the Methodology chapter.

Addenbrooke's Cognitive Examination-III

Participant two scored 50/100 on her ACE-III on pre assessment and 46/100 on her post assessment demonstrating little change on this cognitive assessment.

Within the individual components of the ACE-III assessment, participant 2 was found to have a no changes in attention pre and post, and 5 point decline in memory and a 2 point increase in fluency, a 1 point increase in language and a decrease of 2 points in visuospatial function.

Alzheimer's Disease Cooperative Study ADL scale

Participant two was found to have no changes of relevance in the ADCS-ADL scale, participant one was found to have a score of 70 in both pre assessment and post assessment.

The Barthel Index

The BI was found to have no changes from a pre assessment score of 100 to a post assessment score of 100.

The Holden Communication Scale

There were no changes on the Holden communication scale. Participant 2 had a total score of 5 pre and post.

Quality of life in Alzheimer's Disease

There was no change in the QOL-AD total patient scores, carer's assessment scores or total scores.

4.56 Cost Analysis

The following tables illustrates the comparative results of a cost benefit analysis which examined the cost of OT intervention, the cost of home help intervention for the period of the intervention and the cost of a nursing home for the period of intervention. Extensive discussion can be found on these comparative figures in the discussion chapter.

Title of table 32: Cost analysis, participant two.

Cost Analysis:			
OT delivering EL intervention	Pay of personnel	Travel costs	Equipment Costs
Total cost (600.2188): €600.22	Senior OT midpoint on the HSE pay scale: €54,578 per year which currently equates to €28.2698 per hour. The following time period was used: 15 hours of direct PI time = €423.90	The travel cost of a return journey using a diesel car from the PI base to the participants' home was €0.28. There were 15 journeys, total = €4.20. The travel time was approximately 2 minutes each	Cost of dementia friendly coloured sheets of paper, selotape and laminated pockets €2.50. Cost of OT time in preparing dementia

		way, a total 4 minutes for a return journey. The distance was .97 km. 1 hour of OT travel time= €28,2698.	friendly signage and education to the family on use of same €141,349.
Home Help supporting breakfast preparation in the home for the period of the intervention: Total cost = €237.96 Home help twice per week for one year. Total cost = €1,722.032	Midpoint IS 28,494. The average is €14.61 per hour. 15 hours of direct home help time =€219.15	The travel cost of a return journey using a diesel car from the home help base to the participants' home was €0.28. There were 15 journeys, total = €4.20. The travel time was approximately 4 minutes each way, a total of one hour in total. The distance was km. 1 hour of home help travel time= €14.61	
Nursing home in Ireland for the duration of the intervention. Total cost= €4,240. Nursing home in Ireland for one year. Total cost= €64, 740	The average weekly cost of a public nursing-home bed in Westmeath is €1,089 and Longford is €1,246 (HSE, 2015). Average cost Longford/Westmeath is €1167.5 The weekly cost of private nursing-home care is €875 but it can be as high as €1,344. (Irish Independent, 2015).		

Table 32

In summary, the intervention cost delivered by a senior OT was €600.22. If a Home Help supported breakfast preparation in the home for the period of the intervention this would cost €237.96. The comparable cost of a nursing home for the period of the intervention is €4,240 and for one year is €60,740.

4.57 Conclusion

This results chapter commenced with a presentation on the results from phase one of the study. This included the primary hypothesis and supplementary analysis with summary tables. Phase two of the study was then presented with case study one being presented initially then followed by case study two.

In summary, phase one's primary hypothesis results found the following:

- Participants assigned to the CST group condition only demonstrated statistically significant differences on SMMSE.
- Both the CST and Sonas group conditions demonstrated statistically significant changes in total score, task behaviour and general behaviour scores on the OTTOS.
- Both CST and Sonas groups showed consistent gradual improvements on the OTTOS. The Sonas group having fewer sessions with decreases in mean scores.
- On the Sonas group session evaluation tool, both CST and Sonas conditions both demonstrated statistically significant improvements in some areas. Participants who received Sonas demonstrated statistically significant improvements in more areas assessed than the CST condition. Neither CST nor Sonas demonstrated statistically significant improvements in all areas.
- In the CST monitoring progress form the CST group only were found to have statistically significant changes all areas with the Sonas group having changes in three out of four areas.
- In the ADCS-ADL scale, there was no change of statistical significance in ADL as a result of either CST or Sonas intervention.
- The QOL-AD data showed statically significant positive improvements in carer rated QOL-AD scores only for both CST and Sonas groups.
- In the Holden communication scale, statically significant improvements were found in the total scores of the CST group only.
- In the NPI, there were no differences in total scores in either group. In the individual components section the CST group only had statistical changes on three individual components of the NPI.

Therefore, phase one demonstrated greater treatment effect for the CST condition than the Sonas condition.

Phase two comprised of two case studies completing goal focused occupations. Case study one was found to have a reduction in the number of errors, the number of steps required to complete the task reduced, change in the level safety for the occupation, statistically significant changes in QOL and clinically significant changes in communication. Case study two was found to have a small reduction in the number of errors and the number of steps required to complete the task.

The results as outlined in this chapter will now be discussed in the next chapter, the discussion chapter.

5 Discussion Chapter

5.1 Introduction

In this chapter, the discussion of phase one, phase two and then topics that are applicable to both phases will be presented. This will be followed by a conclusion, recommendations for future research and recommendations for changes in clinical practice.

Phase one of this study examined, compared and contrasted two different types of group interventions for people with moderate dementia, namely CST and Sonas for the first time in a prospective controlled trial. CST has an extensive research base and Sonas is a popular intervention in Ireland but little evidence to support its use. The outcome measures used were the SMMSE (Molloy et al, 1991), the Holden Communication scale (Holden & Woods, 1995), the NPI (Kaufer et al, 1998), the ADCS-ADL scale (Galasko et al, 1997), the QOL-AD (Logsdon et al, 1999), the OTTOS (Margolis et al, 1996), the Sonas group session evaluation form (Sonas aPc, 2012) and the CST monitoring progress evaluation form (Spector et al, 2006).

Phase two of this study was informed by the results of phase one. Neither group showed any effect of the intervention on ADL. ADL were a secondary outcome and were not specifically targeted with the group interventions, but they remain a core focus of OT interventions. In addition, the level of dependency an individual with dementia experiences with their ADL has significant implications on their ability to remain at home in the community. For example, if an individual were able to be safe and independent with their meal preparation activities for as long as possible, it would reduce the amount of formal and informal care/support they required in the community. This prolongs their level of independence whilst living at home and ultimately keeps them living at home for longer and out of a nursing home. As the group intervention had no impact on ADL and on review of the literature, it was hypothesised that an individual rather than a group intervention was required. Therefore, this individual approach was chosen to provide client centred goal focused interventions which would target specific ADL as outlined by the participant themselves and/or their family and the PI. Every OT process is unique and must be considered with the context of the individuals' life which backed up this individual approach (Hagedorn, 2000).

The rehabilitation approach chosen was Errorless Learning (EL). The model of practice used was the PEOP model which has four major elements; the person, the environment, the occupation and the performance. The use of the EL approach was combined with a client centred intervention on the persons environment to target the specific occupations of the person as outlined in goal setting. The outcomes used in phase two were activity analysis, error measurement, the ACE-III, the Holden communication scale, the QOL-AD, the ADCS-ADL scale and the BI.

5.2 Person Environment Occupation Performance (PEOP) Model of practice

The PEOP model was used throughout both phases of the study. Models used in OT practice

‘Organise concepts, provide terms and definitions for labelling practice-related activities and situations, and help define problems, thus leading to strategies for problem solving’ (Christiansen and Baum 2005, p244).

There are many different models of OT practice that could have been used with this research study. The Model of Human Occupation (MOHO) (Kielhofner, 1995, 2002), the Person-Environment Occupation model (Law et al, 1996) and the Canadian Model of Occupational Performance (CMOP) (Canadian Association of Occupational Therapists, 1997) were all considered because of their central elements; the person, the occupation and the environment. The rationale for the selection of the PEOP model in this research study was that one of the core features of the model is that situations in which people experience success (for example, EL conditions) help them feel good about themselves through mastery of tasks and achievement of personal meaningful goals and this therefore motivates them to face new challenges with greater confidence (for example, continues to complete such occupations like going out shopping into the community), (Christiansen & Baum 2005). In addition, occupational performance and participation are central concepts in the model and reflect the act of doing which was facilitated in both phases of this study through participation in group or individual occupations.

This model of OT practice generates an approach from the OT which incorporates a client centred strategy. The model facilitated in determining, with the participant, their perception of their occupational performance difficulties, complete an assessment of factors that may be interfering with or supporting performance as well as identifying

factors that may serve as enablers or barriers to performance. In summary, this model facilitated an enabling process by considering the intrinsic factors of the participants (physiological, cognitive, spiritual, neurobehavioral and psychological) and their transaction between this and the environment (social, economic systems, culture and values, built environment and technology and natural environment). This in turn is reflected in occupational performance when participating in the act of doing. This approach guided the PI's clinical reasoning, assessments and interventions throughout both phases of this study.

5.3 Phase one

5.4 Methodology

Theoretically the RCT is the most appropriate method to answer the study question. This research method was planned but difficulties were encountered with regard to the recruitment of the sample as discussed earlier. Consequently, the methodology was adjusted. Nonetheless, this is the first prospective controlled study comparing two interventions which has been completed with this population. The strengths of using a prospective controlled trial are that it is quantitative and this facilitates the testing the hypothesis objectively. It relates variables in hypotheses and it observes and measures information numerically. However, this methodology also has limitations. This design did not use full randomisation which threatens the internal validity of the study as selection bias may have been present. The groups were treated equivalently apart from the experimental variables (CST and Sonas), they all received the same length of treatment, and the primary therapist was consistent across all three sites. They all completed the same primary outcome measures and secondary outcome measures with assessors who were blind to which experimental condition/variable the participants were exposed to. The study had strict inclusion and exclusion criterion which were fully adhered to and ensured that the participants were all from a specific group i.e. individuals with moderate dementia. There was a low attrition rate in this study; this was attributed to the strict inclusion/exclusion criteria.

Another study limitation is the sample size. Power analysis initially identified a sample size of 42 required to achieve 80% power. This was calculated for a three group study (CST, Sonas and Control). As outlined in the methodology the control group had to be abandoned and so the power analysis was re calculated for a two group study (CST and

Sonas). This identified that a sample size of 34 was required to achieve 80% power. In the end, 28 participants were recruited. The implications of this on the study are that Type 2 errors may be present with the study failing to detect an effect that is actually present. For example, the Sonas group SMMSE score change ($t(12) = -1.923, p = .079, NS$) shows a trend towards significance, the NPI total scores showed a trend towards significance for both groups, CST ($W = 21.5, Z = -1.951, p = .051, NS$) Sonas ($W = 12.0, Z = -1.871, p = .061, NS$). If the study had the desired number of participants, these results may have reached significance or equally may not have been indicative of a trend clarifying the finding. A summary of the sample size number in this study in comparison to similar studies that have been reviewed in the literature review is presented in table 33. This study does not compare favourably to other sample sizes in other quantitative CST studies. Therefore, future studies with larger sample sizes are required.

Title of table 33: Comparison of studies

Study	Number of participants	Type of study
Brady et al, 2012	28	Quantitative
Spector et al, 2003	201	Quantitative
Aguirre et al, 2012	272	Quantitative
Spector et al, 2011	38	Qualitative

Table 33

The lack of an appropriate control group is a limitation to this study as it allows potential for the Hawthorne effect. The control group (completing treatment as usual) would have been a valuable comparison in order to discuss the potential Hawthorne effect in the study.

Recruitment to phase one was problematic. Problems with recruitment of older people to RCT's are acknowledged in the literature. Clegg et al (2015) reported widespread evidence of under-recruitment of older people to research studies, noting specifically that there were issues with RCTs of interventions. He reported that possible explanations for this under-recruitment included study exclusion criteria, ethical dilemmas, individual preference, risk of bias and challenges for treatment comparisons. In this study, the community group was subject to transport biases. There was no funding so there was no opportunity to provide a taxi or bus service for those who did not have access to transport, the financial means to pay for their own transport or who chose not to pay for

their own transport to the group. This excluded potential participants for inclusion in this study. Therefore, it raises the question of how truly representative of the population this community group actually was. Where the participant happened to live in an area that the day hospital taxi service was passing (so it did not incur additional costs to the service) transport was offered. On review of the recruitment statistics, of the 5 community participants who withdrew from the study, only 2 who cited transport as a reason for withdrawal. No further details were given. The service in PLL where the groups ran is located in a central town in the county of Westmeath. However, recruitment was completed from the adjacent county of Longford. Some participants had longer distances to travel than others which may have impacted on their levels of fatigue and with participation in the assessments and group sessions. This may have affected the outcomes. On the other hand it can be argued that this is a true representation of the sample population in the context of the fact that all the participants had to avail of transport in some form to access the group.

Future studies especially in rural settings where transport is essential, should consider this in recruitment of individuals and consider funding options to address the issue and control for this variable with a minimum and maximum transport time to and from the group.

In order to further minimise disruption to the participants and their families in phase one, two CST sessions were grouped into one afternoon with a break in between sessions. This is commonly the case with CST sessions and is not a deviation from the protocol. Participants with transport issues were automatically allocated to the CST groups. The Sonas sessions were delivered individually twice a week. This allocation to CST based on transport issues alone is a limitation as these participants were not randomly allocated. Given the strict inclusion/exclusion criteria the community participants should have had similar baseline characteristics and in fact there were no significant differences at baseline which limits but does not remove any effect on study outcomes. However, this lack of full randomisation does not affect unanticipated or even unknown factors that might influence the outcome measures.

Withdrawals were also high in the context of the overall numbers. In phase one, five community participants and two nursing home participants withdrew from the study. Two cases reported informally that, in conjunction with issues of stigma, they disliked

the idea of group therapies. Home programmes were requested by participants themselves and by family members as an alternative to the group therapies. This should be considered in clinical practice as not all individuals are comfortable participating in group therapies and alternatives should be made available. In clinical practice, the Sonas Individual Multi-sensory Session (SIMS) can be offered as an alternative for Sonas and individualised CST (iCST) for CST can be offered in the future pending the results of a current clinical trial on iCST (Yates et al, 2015). To do this was outside the scope of this study. Phase two of the study was completed in the home and one a 1:1 basis which eliminated the issues around group therapies.

It was not possible to complete a double blind or triple blind study for ethical and practical reasons. Firstly, it was clear to the participants from the manualised programmes what they were receiving and to conceal this would have been practically impossible. The therapist was also aware of the intervention being delivered. The need for a double blind study in this case may be questioned, as there is little possibility with the participants involved in this study that the results will be affected by conscious or unconscious bias on the part of participants as both types of group treatments were previously unknown to them, were not delivered as part of routine care in the healthcare settings involved in the study and when consent was being obtained it was clear to the researchers that the participants or their families did not have a prior knowledge of the group therapies.

Another methodological limitation was the difficulty with randomisation in the inpatient psychiatry of later life group. As outlined in the methodology chapter, this setting had two wards, where historically, participants had never been mixed in terms of sex. Therefore, instead of participants being randomised, a ward group of participants were randomly allocated to either CST or Sonas conditions. This pseudorandomisation has all the properties of a random sequence following some probability distribution but is not truly random because it is determined by a small set of initial values. This might have affected the results of the study. The participants were familiar with each other on the ward and this could have impacted positively or negatively on how they interacted with each other within the groups and on outcome measures. If the participants had been randomised as proposed, the fact that they may have not known every participant in the group may have impacted on their levels of stimulation as a result of their interactions.

This could have an impact on those results which were analysed in terms of sex and therefore interpretation of those results should consider this methodological limitation.

Six participants in the Sonas group in comparison to one in the CST group had a comorbid diagnosis of depression at baseline. In this study participants were not randomised based on their comorbidities but it is not known whether this impacted on findings. As the numbers were small more sophisticated statistical analysis (such as multiple regression) which could evaluate this was inappropriate.

No follow up sessions were completed; this was outside the scope of this study. If this were possible it may have added valuable information to the study regarding maintenance of gains and should be considered in future studies.

5.5 Results – phase 1

Cognitive Function - SMMSE

Hypothesis 1: Participants assigned to both the CST and Sonas conditions will show improvements from pre-intervention to post-intervention on the SMMSE.

This hypothesis was rejected. The CST group demonstrated statistically significant changes in comparison to the Sonas group on a within group analysis. There were no differences on outcome on a between group analysis.

Dementia is a degenerative and progressive condition. Therefore, changes were not expected in this area. Maintenance in cognitive functioning is a positive outcome and there were no differences in outcome between groups. However, there were differences within groups; the participants assigned to the CST group demonstrated statistically significant changes in SMMSE scores changing from a mean 16.53 to 18.27 points with a mean 1.74 point increase in post SMMSE scores. Whilst the Sonas group did not demonstrate a statistically significant change, they did demonstrate an improvement in scores by 1.08 which is more than just maintenance of cognitive function. Clinically there appears to be little difference between the two outcomes and the change is considered clinically significant. Given the fact that the number of participants was less than expected, this finding could be explained partially by a type 2 error.

On the other hand, it must be considered whether the improvement can be explained by a practice effect. The SMMSE is the most widely used screening test for cognitive function for older adults (Molloy et al, 1991). There may have been recent exposure to the test, familiarity with the test and / or similar tests, and/or the impact of procedural learning having previously completed such tests. However, should a practice effect have had impact on the outcome of the SMMSE it would be expected that this would have been the case in both groups. That the statistically significant outcome was on the CST group alone discounts this theory of practice effect as otherwise it would have been demonstrated in both groups. In addition, this finding for the SMMSE is similar to that of Spector (2003). The mean improvement in the CST group is similar where the mean group differences between the CST treatment group and the control group in Spector's work was +1.14. If there was a result of a practice effect it would be unlikely that this work would be similar to Spector's work. In addition, Aguirre et al (2013) who investigated which factors may predict response to CST also found statistically

significant changes on SMMSE with a pre mean score of 15.8 to a post score of 18.5, indicating a 2.7 point change which was statistically significant.

Another explanation may be the content of the group activities. Spector et al (2010) suggest that for the CST programme change in outcome measures may partially be because cognitive stimulation involves a more general approach whereby cognitive functions such as memory are not used in isolation. These functions are integrated with other functions such as language, attention and executive functioning. This is completed through various activities from week to week such as games, quizzes and RO. There is also active engagement between participants in these components of the group sessions. This may explain the reasons for the change in the CST group only in this study. The Sonas group does not offer this level of active component in its approach; the Sonas group relies on structure and repetition and whilst participants are facilitated in giving a contribution to the group in one section on the programme and they may naturally engage with others in the group, there is less structured and facilitated active engagement with other participants through activities in the Sonas approach and less opportunity for active stimulation of attention and executive functioning through activities.

In conclusion, on the basis of the findings above, the CST group was found to have the greatest impact on the participants SMMSE scores. Clinically, this is significant and this CST group approach is the most suitable of the two interventions in order to target cognitive functioning.

5.6 Occupational Performance

Hypothesis 2: Participants assigned to the CST group will demonstrate greater improvements in total score and task behaviour than Sonas group on the OTTOS. Both groups will demonstrate similar improvements in general behaviour.

This hypothesis was rejected. Both groups demonstrated statistically significant changes on the OTTOS total score, task behaviour and general behaviour sub scores.

The OTTOS was completed by the Senior OT who carried out the group programmes, she was not blind to intervention and she was also the PI of the study. This may have had an impact in terms of bias. However, this bias was minimised by the use of a standardised tool. The tool has good interrater reliability in experienced therapists only

as was the case for this study, which ensures compliance with this reliability requirement (Fuller, 2011). The tool also has known validity but only for the task behaviour subsection. This showed high correlation with two standardised and validated scales: the Bay Area Functional Performance Evaluation cognitive subscale and the Comprehensive Occupational Therapy Evaluation Scale (Margolis et al 1996). There are no validity data available for the general behaviour and total score on the assessment which is a limitation to the tool and must be considered when interpreting the results.

Supplementary analysis questions, identified differences in terms of residence type between groups with the CST group having significantly better outcomes than the Sonas group. The inpatients and community residence types improved significantly for the CST group only and there were no significant outcomes in either residence type for the Sonas groups. There are a number of possible explanations for this finding. The three sites involved all had different daily routines and levels of natural stimulation in their environments with some having more activity programmes or opportunities for 1:1 intervention with staff than others. It is not known whether the long stay inpatient psychiatry of later life group had different environmental stimulation and compensatory measures in comparison to those living in the community or in the care centre. The physical and social environment may or may not have enabled and encouraged participation in group sessions. The potential impact on outcomes may have been in terms of the general behaviour subsection, for example if participants were familiar or were not familiar with engaging with similar groups on the ward, they all may have had or not have had prior knowledge and experience of group sessions. Group therapy assists participants to learn how to explore and alter maladaptive interpersonal patterns of relating and behaving (Lloyd & Maas, 1997). Levels of group therapy experience can impact on how people generally behave within the groups. This can impact on the specific outcomes of activity levels, expression, cooperation and socialisation mainly secondary to familiarity of group dynamics, structures, familiarity with other participants and boundaries within groups. In future studies, this baseline environmental stimulation level should be accounted for in greater detail. For example, the activity programmes running regularly in each site, the compensatory measures in place, the natural stimulators that are lacking in some sites in comparison to others that could have meant that some participants were under stimulated resulting in greater response to intervention. These factors have potential to influence the outcome and need to be

captured in future studies. Therefore the results of this secondary analysis should be interpreted with caution but add valuable questions which should be considered in future studies.

Hypothesis 3: Participants will demonstrate consistent gradual improvements in performance as measured by total OTTOS score over a 14 session period in both groups. There will be differences between groups.

This hypothesis was accepted. Both CST and Sonas groups showed consistent gradual improvements. Variances in intervals of improvements were different between groups with the Sonas group having fewer sessions with decreases in mean scores.

The OTTOS examined how participants performed within each session for both CST and Sonas groups in order to test this hypothesis. This 14 session analysis assesses their performance on the task (task behaviour) and their general behaviour, which is then combined to give a total score. This component of the study has never been carried out with either group intervention. The fluctuations in mean scores are not consistent, at regular intervals and there are sessions in which the participants peaked and then declined briefly. The exact details of the mean scores in relation to the individual session numbers and themes are presented in Appendix (35). For example, In the CST group there were four sessions with decreases in mean scores, session 3 which was childhood games, session 7 which was word associations, session 10 which was orientation and session 12 which was number games. Possible questions could be drawn to whether there were particular components to a particular session that explained a decrease in mean scores (i.e. the participants didn't respond to that session). Similarly, this could be questioned for the improvements seen over the 14 sessions (i.e. that the participants did respond to components of that session). Future studies should examine the impact of individual components in more detail.

These fluctuations on the OTTOS were also seen in the Sonas group but they were seen 50% less frequently and there was less deterioration between sessions as outlined in appendix (35). It is questioned whether the fact that the Sonas sessions were more repetitive in nature with less variation between sessions led to this outcome.

Alternatively, one may question that the outcome (i.e. an increase or decrease in mean scores) was not immediately seen on the OTTOS assessment at the end of the group

session (one of the 14 assessments); in other words, that the outcome of one session was not seen until the subsequent session was completed. For example in the CST group sessions, did session four 'food' have a compounding effect on the outcome of session 5 'current affairs' and session 6 'faces and scenes'? (Appendix 35). This would be an interesting area for more detailed examination in future studies. In a future study there may be some sessions in both groups that participants will respond to more than others. What is not clear is whether this effect will be on an individual or group basis and this should be examined in more detail.

In a pilot RCT study by Hutson et al (2014), where there were no statistically significant outcomes on the Rating Anxiety in Dementia (RAID) Scale, the Cornell Scale for Depression in Dementia, the NPI-Q, the QOL-AD and the Holden communication scale as a result of Sonas. They suggested that the results of Sonas may only be seen within the group sessions and not outside of the group sessions. This is in partial agreement with this particular finding in this study where independent evidence for the usefulness of Sonas was found within sessions as measured by the OTTOS.

Hypothesis 4: Participants in both groups will demonstrate statistically significant improvements in all areas of the Sonas group session evaluation form assessment.

This hypothesis was rejected. The Sonas group session evaluation was a standard evaluation form that was provided to Sonas practitioners in their training pack. Neither CST nor Sonas groups demonstrated statistically significant improvements in all areas of the evaluation form. Those who received Sonas demonstrated statistically significant improvements in more areas than the CST group. However, given that the tool was specifically designed for evaluating Sonas sessions this was an expected outcome as one may hypothesise that if the tool was specific to Sonas that it would be also sensitive to Sonas. These results are suggestive of some evidence for Sonas in the areas of eye contact, holding gaze, following with gaze, smiling, vocalising, speaking, exercises, singing, contribution and using gesture which are all key elements of the Sonas programme. These results suggest evidence for within group changes in both conditions (Sonas greater than CST) which similar to the OTTOS, is in agreement with the suggestions made by Hutson et al (2014).

However, this tool is neither reliable nor valid. Therefore, these results have significant limitations. The PI acknowledges that this is a tool that is used by Sonas practitioners

and therefore it was felt appropriate to report these results. These results suggest that the tool has some sensitivity to the Sonas condition. The authors of this tool should evaluate it to determine its reliability and validity.

Hypothesis 5: Participants in both groups will demonstrate statistically significant improvements from session one to session fourteen in all areas of the CST monitoring progress assessment.

This hypothesis was rejected. As expected the CST group was found to have statistically significant changes on all four areas of the assessment in comparison to the Sonas group which was found to have statistically significant changes on three areas of the assessment. The CST monitoring progress evaluation form is not a standardised tool and has never been evaluated in terms of validity and reliability. It is acknowledged that this tool was provided as part of a CST manual and therefore it may be expected that it would be more sensitive to the CST condition. The results of this hypothesis should therefore be interpreted with caution. The results are within the components of the session. Future studies should consider follow up assessments of individuals within the sessions to determine if the gains seen within the sessions are maintained on follow up assessments. Future studies should also test this tool for validity and reliability.

Both the CST monitoring progress evaluation form and the Sonas group session evaluation form appear to assess similar areas that are commonly observed within CST and Sonas groups. The CST monitoring progress form appears to group these observations into more sections than the Sonas form for example; there are 4 sections on the CST monitoring progress form, interest communication enjoyment and mood.

All components of the Sonas group session evaluation form could be fitted into the four categories on the CST form. For example, interest could be determined by any of the fourteen areas on the Sonas form. Communication could be determined by eye contact, holding gaze, following with gaze, smiling, vocalising, speaking, appropriate touch, singing, contribution, using instruments, using gesture and interactive posture. Enjoyment and mood could be determined by smiling, vocalising, speaking, singing, contribution, using instruments and using gesture. However, these are suggestions that demonstrate potential overlap of the two forms, but this should comparison should be evaluated formally in order to make any conclusions. This potential overlap of the two forms may provide some explanation to why the Sonas condition demonstrated some

changes on the CST monitoring progress form. Similarly, it explains why the CST condition demonstrated some changes on the Sonas group session evaluation form. Both form appear to be more useful in their relevant conditions.

5.7 ADL scales phase one

Hypothesis 6: There will be no significant change in ADL as a result of either CST or Sonas intervention.

This hypothesis is accepted. There were no statistically significant changes for either CST or Sonas group. The use of the ADCS-ADL allowed for changes to be compared to the previous research in CST such as the work of Aguirre et al (2013) who also used the measure. It was also a scale that was completed by carers/staff working with the participants with dementia therefore from a research perspective it did not impact on the direct time of the participant who was asked to complete a series of alternative assessments.

No significant differences were found for either group. This generated questions about the use of the tool. Spector et al (2011) reported an improvement in alertness and concentration following CST. Participants reported improvements in concentration and memory. Most carers

'reported improvement in terms of the person with dementia's concentration skills, as well as a change in their alertness and brightness. There was also a consensus that participants were engaging in more activities such as personal care, conversations and watching television' (Spector et al, 2011, p948).

Therefore the ADL tool should have been sensitive to these changes such as an increase in engagement in or attempts at personal care, communication or leisure pursuits. However, no such improvement was identified. Two considerations will be further discussed. If the ADCS-ADL scale was not sensitive to changes or if there was no effect on ADL as a result of the intervention. For example question six A asks, regarding dressing, in the past 4 weeks: Did the participant select his/her first set of clothes for the day? If yes, which best describes his/her usual performance: without supervision or help, with supervision or with physical help (Galasko et al, 1997). If the changes in ADL abilities as a result of CST or Sonas were considered to be similar to Spector et al (2011) work as outlined above, an ADL assessment should have possibly questioned the within

task components of selecting their first set of clothes for the day, i.e. levels of prompting or cueing required or time spent at the activity. This suggests that the tool was not sensitive to the change rather than no effect.

The authors of this tool report limitations in its test re-test after 12 months. Participants in Galasko et al (1997) study showed a decline in performance from baseline to 12 months in only 20% of AD individuals. However, 90% of participants demonstrated good test-retest reliability between baseline and 1 and 2 months which is the time frame applicable to this study. This supports the use of the tool in this study and contrastingly suggests no effect on ADL in this study rather than issues with sensitivity to change (Galasko et al, 1997).

The findings of this study support the findings of Aguirre (2012) who also used the ADCS-ADL scale in their study on CST in dementia and found no statistically significant changes in ADL as a result of CST. Finally, the results of this study are similar to those in four other studies examined in a Cochrane review ‘Cognitive stimulation to improve cognitive functioning in people with dementia (Review)’ that evaluated cognitive stimulation in terms of ADL and found no statistically significant outcomes in four studies, involving 160 participants (Woods et al, 2012).

In conclusion, this study found no evidence for the use of CST or Sonas in terms of ADL. Arguments were made over the sensitivity of the tool but given that other studies using cognitive stimulation found no significant results in terms of ADL, no agreement on sensitivity could be reached and the sensitivity of this tool to detect changes in ADL should be explored in future studies.

5.8 Quality of Life phase one

Hypothesis 7: There will be statistically significant positive improvements in total QOL-AD scores, patient rated scores and carer rates scores in both groups.

This hypothesis was rejected in terms of total QOL-AD scores only. There were no differences between CST groups ($p=0.059$) and Sonas groups ($p=0.195$) in terms of outcomes and neither group showed significant change. However, the CST group showed a trend towards significance. The impact of a type two error is considered here. In a Cochrane review (2012), Baines (1987) used the Life Satisfaction Index and Spector (2003), Buschert (2011) and Coen (2011) used the QoL-AD. Cognitive stimulation was

associated with a significant benefit to well-being and quality of life compared with no treatment (Woods et al, 2012); this supports the suggestion of a type two error and the trend towards significance in this study for CST. Hutson (2014) found no changes in QOL as a result of Sonas intervention supporting the non-significant findings of this study.

The QOL-AD has two other scores which were examined - patient rated scores and carer rated scores. In a cross sectional study by Beer et al (2010) involving 351 participants, factors associated with self and informant ratings of the QOL of people with dementia living in care facilities showed that most people with dementia living in a residential setting can rate their own QoL, and that informant ratings of QoL substantially underestimate self-ratings. These findings by Beer et al (2010) are in contrast to the outcomes of this study. In the patient rated subsection, there were no differences in outcomes in either group. Beer et al (2010) suggested that carers' scores are expected to be an underestimation of this individual rated outcome which was not found to be the case in this study. In fact, both groups improved significantly on the carer rated scores only. The impact of bias is considered on the carer rated scores, patients and carers were not blind to which group the participants were attending and therefore, this should be considered when interpreting the results. However, it is argued that there was limited familiarity and prior knowledge of the group interventions in all sites with no evidence of either group running in any site and therefore these conflicts to the argument of bias.

Woods et al, (2006) in his article on 'Improved quality of life and cognitive stimulation therapy in dementia' found that there was an association between the female gender and change in QOL. However, this is in disagreement with phase one of this study. As outlined earlier in the results, there were relatively equal numbers of females in both the CST (9) and Sonas (9) conditions.

In conclusion, there were no significant differences in total scores or patient rated scores on the QOL-AD. However, there were significant changes in terms of the carer rated scores for both groups suggesting that carers observed changes in QOL as a result of both groups.

5.9 Communication phase one

Hypothesis 8: There will be statistically significant improvements in the CST group only. There will be no differences in outcomes in terms of the individual components of the Holden communication scale assessment.

This hypothesis was rejected. The Holden Communication Scale (Holden & Woods, 1995) was completed by staff in the inpatient sites and facilitated by an investigator through families for community sites. This assessment was also complemented by the observation of the participant by the investigator in baseline assessments. Whilst there were significant difference in the CST group only as hypothesised, the CST group also demonstrated significant differences in the communication section, ‘Interest in past events’ subsection.

One possible explanation for the findings is that participants in the CST group more so than the Sonas group, are given greater opportunities to express their opinions and make contributions in the group reinforcing positive communication. This works against the ‘malignant social psychology’ explained by Kitwood (1997), which refers to a social environment in which interactions and communications occur which diminish the personhood of participants experiencing that environment. Both groups reinforced interaction and created an enjoyable social experience, positively supporting the personhood of participants. The CST group positively reinforced questioning and thinking to a greater extent than the Sonas group.

This finding supports the work of Spector et al (2003), where positive trends in communication that did not reach significance were found. Other studies have also found similar outcomes using different approaches. Bourgeois and Maison (1996) used memory wallets containing limited personal factual information on cards and reported an increase in the quality of verbal output. Arkin and Mahendra (2001) paired language intervention with volunteer work and physical exercise. Results from both studies suggest that structured language intervention may have a positive effect on the quality of communication

Future studies should consider the potential outcomes of a multifaceted therapeutic approach to address communication deficits for individuals with dementia. For example, would a combination of a CST group intervention and a 1:1 memory wallet intervention

reveal more significant outcomes in communication than CST alone? Similarly, would a CST group intervention and a paired language intervention with volunteer work and physical exercise produce greater outcomes in communication than CST alone? Therapeutic approaches to address communication in this multidisciplinary format should be considered in future studies.

In conclusion, the CST group only had significant differences in communication. This supports the use of CST in addressing communication deficits in those with moderate dementia.

5.10 Neuropsychiatric Inventory

Hypothesis 9: There will be statistically significant improvements in total scores and individual components of the NPI assessment in both CST and Sonas groups. There will be no difference between groups.

This hypothesis was rejected. There were no significant differences in outcomes on the NPI total scores between or within groups. However, both groups demonstrated a trend towards significance. This trend is greater in the CST than the Sonas group. As with previous outcome measures, the role of a type two error is considered here. In addition, on examination of the individual components, the CST group only was found to have statistically significant changes between pre and post assessment in the areas of depression/ dysphoria, occupational disruptiveness and appetite and eating changes.

These findings need to be considered in the clinical context as well as statistically. A small change on the NPI that makes a participant more or less agitated or aggressive has significant implications on their care irrelevant of the setting and overall their ability to function on a daily basis. Future qualitative studies need to be carried out to explore this issue further.

The outcome of this study is of major importance to this population. Lyketsos et al (2002) and (2000) report that clinically significant neuropsychiatric symptoms are found in two-thirds of individuals with more severe impairment and in an even higher proportion of individuals with dementia in residential care (Livingstone et al, 2005). This acknowledges that a reduction in neuropsychiatric symptoms is a priority goal for non-pharmacological intervention. With the type 2 error considered, both group therapies have trends towards significance which is a positive outcome in terms of the

NPI. These groups have the potential to reduce carer burden/stress which ultimately leads to increased care needs and possible nursing home admission for community participants and similarly staff stress and levels of positive interactions with individuals (Coen et al, 1997). Future studies should consider the impact that these changes on the NPI have on carers' and staff level of stress.

Two studies found significant positive effects on neuropsychiatric symptoms similar to the outcomes of this study. The first was an abilities-focused program which was an educational program to staff on delivering abilities-focused morning care which involved 84 participants. It was found that the intervention had 'statistically significant effects on (a) residents' personal attending and calm/functional behaviours, level of agitation, and levels of overall and social function, and (b) caregivers' verbal relevance and personal attending, relaxed, and social/flexible behaviours' (Wells et al, 2000, p1). The evidence suggested that both residents and caregivers benefit from morning care that is oriented toward the abilities of people with dementia.

A second study carried out a program evaluation of education on communication skills for nursing assistants. Results suggested that participation in the programme resulted in significant reductions in the depressive symptoms experienced by residents at both 3 and 6 months after intervention. The results from this study suggest that participation in the programme by nursing assistants (who were acknowledged to spend the most time with the study participants) also had an impact on their ability to manage verbally aggressive behaviours such as yelling, physically nonaggressive behaviours such as wandering, and aggressive behaviours such as hitting (McCallion et al., 1999). The National Dementia Strategy in Ireland outlines a priority action for training and education and national dementia awareness programmes have been introduced to meet such a need (Department of Health, 2014). Future studies should evaluate participant's neuropsychiatric symptoms following a combination of a CST programme with staff education on dementia care such as the national dementia awareness programme in Ireland (National Dementia Awareness Programme, 2015).

The two groups were different at baseline in terms of alternative and secondary diagnosis (Table 12). The fact that there were differences in alternative diagnosis may suggest that the presentation of neuropsychiatric symptoms at baseline were different for the two groups. For example, the CST group had one person with depression and the

Sonatas group had six. The groups were not randomised based on diagnosis so this difference was unanticipated. However, this difference at baseline between groups needs to be considered when interpreting the NPI results.

In conclusion, there were no significant outcomes found in either group total NPI scores. Both groups demonstrated a trend towards significance. The CST group demonstrated significant changes in three individual areas of the NPI assessment. The findings of this study support the use of both groups, with the CST only demonstrating effect on individual components. However, further larger scale studies need to be completed to conclude these findings.

5.11 Medication

Medications were recorded at baseline from a chart review and re checked at post assessment to ensure that participants met the inclusion/exclusion criteria in terms of medication. Medication type was recorded in terms of participants either being on it (yes) or not being on it (no).

Chapman et al (2004) examined the effects of Cognitive- Communication Stimulation for Alzheimer's Disease Individuals Treated with Donepezil. The study outcomes were that the groups did not differ significantly on the MMSE at baseline; however, the mean baseline ADAS-Cog scores showed the donepezil-plus-stimulation group to be less impaired ($M = 18.56$, $SD = 5.72$) than the donepezil-only group ($M = 21.92$, $SD = 5.57$) $t(47) = 2.08$, $p = .0431$. Similar outcomes were found in terms of maintenance over one year (Chapman et al, 2004).

Future studies similar to the study presented here should consider a full evaluation of medication and its relationship with outcome measures. This was outside the scope of this study. Future studies similar to this study, should also consider recording maintenance effects for those participants who are on particular categories of medications.

5.12 Mechanisms for change in group sessions

There are a number of possible mechanisms of change in outcome measures related to the group interventions as outlined by Spector et al (2003). The learning environment during CST and Sonas sessions was designed to be optimal for people with dementia, for example by focusing on implicit memory, providing cues to aid memory retrieval, integrating reminiscence, client centred practice and multi-sensory stimulation throughout the programmes. The CST environment created an optimal learning environment through the use of the RO board, the use of the personalised group name and song and the same warm up activities. The Sonas learning environment was even more repetitive in its nature from session to session which fostered familiarity to the programme and it is acknowledged that this characteristic supports the more severely impaired participants who undertake the Sonas programme. There were also consistencies achieved which led to familiarity. The lead therapist and assistants were consistent throughout the programme, the time and location was consistent and the environmental set up was consistent.

Stimulation within the groups themselves may have impacted on findings (Stein and Tallant, 1988). The participants may have responded to the presence of others in the group setting or the therapeutic relationship formed with the therapist facilitating the groups. McDermott (1988) researched the effects of various group structures on interaction patterns. He concluded that task groups had more positive social-emotional communication and more interaction between group members. This indicated that variations in group format did have an effect on interaction patterns between participants. CST and Sonas have different formats, with CST being more task based than Sonas. This suggests, based on McDermott's (1988) work that this would have had a greater impact on positive communication and interaction (Lloyd and Maas, 1997) which would, in turn, impact on the outcomes of the group. Both groups allowed interactions with other participants who had similar characteristics and this fostered a sense of acceptance and normality amongst peers (Spector et al, 2008).

Finally, groups positively reinforced questioning, thinking and interacting with other people, objects and the environment. This was greater in the CST group than the Sonas. This effect might have extended beyond the groups, with people communicating more

effectively and responding to the environment and to others and could be considered as a potential mechanism for change.

5.13 Cost of Intervention phase one

A basic cost analysis was completed for phase one of the study. The cost of a 14 session full programme delivered by a Senior Occupational Therapist and HCA/MTA/OTA in a HSE setting was costed at €903.31 for the CST programme and €1,241.07 for the Sonas programme.

This is the first time a cost analysis was completed for the Sonas programme; there is no published literature on the cost of the Sonas group intervention, nor are there any publications on its cost in comparison to other types of interventions. The CST group is noted to be more cost effective in this study than Sonas; the major difference in cost is the cost of training in Sonas. Therefore, CST is not only more cost effective but its use is supported by the UK NICE guidelines which state that ‘People with mild-to-moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care staff with appropriate training and supervision, and offered irrespective of any drug prescribed for the treatment of cognitive symptoms of dementia’ (NICE, 2006, p29).

In addition to the initial training cost, any person who completed the 2-day Sonas workshop since (2002), will, on completion of the Sonas Practical Skills Day (€100), become approved as a Sonas Licensed Practitioner (SLP). Those who were Sonas-trained prior to (2002) must attend the 3-day Sonas course for approval as an SLP. The Sonas programme also has additional online training via Moodle that is needed to maintain a licence to practice Sonas at a fee of €40 every two years. These training requirements are reported to maintain the quality standards for Sonas, give access to Sonas programme resources, give access to useful dementia articles and videos and allow SLP’s to use the SLP and tutor forums to talk to other SLPs and tutors (Sonas aPc, 2015). However, given the resource limitations in health and social care, these training requirements are demanding in comparison to the CST programme where training is optional and the manual cost is cheap in comparison.

CST cost effectiveness has been examined. In a UK study, Knapp et al (2006) investigated the cost effectiveness of CST as part of a RCT costed CST intervention at £90 sterling per session, this equates to €126.73. This cannot be compared to the basic cost analysis completed in this study as it gave consideration to many other factors such as accommodation. In addition, apart from the initial cost of the manual, the delivery of CST could be an effective use of current resources in a healthcare facility and based on the work of Knapp et al (2006) participants taking part in CST group programme made little difference to the costs for the participants relative to people who received care as usual.

This basic cost measurement could have been improved upon in this study by using a standardised tool. It would have been appropriate to use the validated Client Services Receipt Inventory (CSRI) and adapt it for this study. It is used 'extensively in studies of mental health and dementia, the CSRI gathers comprehensive data on accommodation, medication and services received' (Aguirre et al, 2010, p7). This would have also allowed comparisons to be made in more depth to other studies. Future studies should consider the cost of delivering CST and Sonas in more detail in the context of Irish healthcare system.

Some participants expressed the preference for individual rather than group based interventions in the screening phase of the study. Group therapies are less expensive than individual therapies generally because an intervention is delivered in the same time frame to a number of participants but it is acknowledged that they do not suit everyone's needs and preferences. Therefore, when considering cost, the clinician needs to consider the limitations of service delivery in terms of delivery individual therapies and balance that with the more cost effective method which is group interventions. Future studies should examine the cost of individual therapies (iCST and SIMS) and their benefits in order to formally compare those to the alternative group therapies (CST and Sonas). Finally with the tough financial climate at present, OTs need to make to make a strong case for investment in their services and this is achieved through good quality cost analysis (Morley & Smyth, 2013).

5.14 Phase Two

Phase two is a novel study in the context of EL. This study focused on using a client centred, goal focused approach in order to maximise independence and occupational performance on a sequence of tasks that led to the completion of an entire occupational sequence. Most previous studies in the literature which examined functional tasks focused on teaching participants the use of devices such as a mobile phone, answering machine, coffee maker, or microwave in isolation to the full occupational sequence/process that the participant would use the device in (de Werd et al, 2013). In addition, this study used dementia friendly environmental compensatory strategies which were guided by the unique understanding of the transactions between the person, environment, occupation and performance (PEOP model). The participants were then trained in the use of the dementia friendly environmental strategies by using an EL approach.

5.15 Methodology discussion

This phase of the study used single case study approach. Tate et al (2008) developed criteria for single case experimental design (SCED) as applied to this study (table 6) in the methodology chapter. The SCED Scale is a reliable and valid instrument that provides a brief yet pertinent evaluation of methodological quality of single-subject designs (Tate et al, 2008). It is an eleven-item rating scale for single-subject designs. Ten items are used to assess methodological quality and the use of statistical analysis. The methodology will now be discussed through the items on this scale.

Clinical history (Age, Sex, Aetiology Severity) was all reported in the single case studies. The target behaviours were all reported, defined and specified through the development of the hypothesis and the use of the repeated error measurement. The design was ABA which had at least three phases. The data points in all the phases were reported and analysed. Inter-rater reliability was not established for measures of observations of target behaviours. The assessor was not independent from senior OT who provided the intervention. However, standardised validated assessments were used to measure outcomes as outlined in the methodology chapter. There was no evidence provided to generalisation the results beyond specific target behaviour.

Internal Validity of this design was considered and evaluated. Replication of the error measurement assessments were used across participants ABA phases. Findings of

causality depend on the internal validity of the research design. When repeated measurements are taken during the baseline phase, several threats to internal validity are controlled. Specifically, problems of maturation, instrumentation, statistical regression, and testing may be controlled by the repeated measurement because patterns illustrative of these threats to internal validity should appear in the baseline. When baseline measures are stable lines, these threats may be ruled out, but it is more difficult to rule out some threats if the pattern is a trend, particularly if the trend is in the desired direction (Engel & Schutt, 2013). The trend observed on baseline assessments for participant 1 was not in a desired direction; for example with participant 1 a trend in baseline was variable. With participant 2 it was a stable line, which rules out the threat to internal validity. Therefore, there are no patterns that illustrate threats to internal validity evident at baseline assessments.

A multiple baseline design was considered; this involves the careful measurement of multiple behaviours in one setting or one target behaviour in several independent settings. Similar interventions targeted at each behaviour (or in each setting) are introduced sequentially and their impact on all the target behaviours is measured (Barker et al, 2002). It has several advantages over ABA designs which only measure a single phase. These advantages are that because treatment is staggered/ started at different time it rules out the chance factor. Also, because data are gathered from several participants, inferences can be made regarding generalisability. But given that there were two participants in the study and the difficulties with recruitment as outlined in this chapter a multiple baseline design was not used.

In some ABA cases, where changes are less obvious or clear cut from visual analysis on a graph, researchers have used statistical methods to analyse single case designs. On initial examination of the results, it was not appropriate to complete statistical analysis and effect sizes were not described. However, visual inspection in this design is most frequently applied and it is a valid method to use (Parker & Brossart, 2003). Visual inspection has been shown to have considerable agreement with statistical procedures (Park et al, 1990). Visual inspection allowed for consideration of immediacy of treatment effects, understanding of the behavioural processes, the presence of trends and the variability of data within and between phases (Horner et al, 2005).

The intention was to recruit as many participants for phase 2 as possible with an initial goal of 5-9 participants seen as realistic within the resources of this study. Future studies may consider a clinical replication series in order to acknowledge the limitations in this pilot in making such generalisations for the population included. This could be achieved by replicating this study on several individuals with similar goals and baseline cognitive and functional abilities in order to make generalisations beyond the participants included in this pilot study (Barker et al, 2002). However 2 single cases were recruited and completed. Recruitment stopped at the 2 single cases. The rationale for this was that the results of both single cases are clear with reductions seen in error measurement and ADL goals attained under the conditions of the study. More single case studies may have had different results. However, it was felt that the next appropriate step in this process was not to continue with single case studies but to complete a multiple baseline design to examine target behaviours in different settings or to measure several target behaviours. Alternatively an extension of this could be completed, known as a clinical replication series with replication across multiple participants to allow the PI to generalise the results. Finally, future studies similar to this one should be larger in scale and consider a comparison of the approach used in this study with a different type of intervention. This was outside of the scope of this study.

One limitation of this study is that there no follow up assessments were completed. This was outside the scope of this study. However, this would have added valuable information on maintenance of gains. Clare et al (2001) demonstrates stable maintenance of gains on trained face name associations in year one and a modest decline for both trained and previously known items for year 2 in a participant with early dementia. Future studies replicating this one, should consider if the full approach applied i.e. not just EL alone has an impact on maintenance of gains. In addition, given that the participants in this study are at a moderate stage of dementia, it would be interesting to see the maintenance of gains given the natural progression of the illness. In a (2013) review of EL of everyday tasks in people with dementia by de Werd et al, 20 of 26 studies reviewed carried out follow up evaluations and 17 of those studies showed maintenance of EL effects after one week review and up to 9 months. Future studies replicating this approach should examine the participants at 3, 6, 9, 12 and 24 months follow up to determine if the gains were maintained by the participants involved.

Finally, future studies should consider the potential to maintain gains if a follow up home programme or refresher session were conducted with the specific occupational goals by a home help/formal carer service or OT assistant. In the literature, studies have shown positive effects of refresher sessions but failed to describe the number or duration of sessions in detail. For example, one study by Clare et al (2002), describes follow up as practice sessions by the participant with a written home programme up to one month post the last session and then three follow up refresher sessions. Future studies should consider the cost of such home programmes and follow up sessions in addition to their outcomes on follow up assessments.

5.16 Insight

Insight is considered as the ability to judge both the presence (symptoms) and the severity (functional impairment) of illness (Babinski, 1914; Critchley, 1953; DeBettignies et al., 1990; Fisher, 1989; Gainotti, 1972; Mangone et al., 1991). Awareness or insight is defined as ‘the capacity to discern the true nature of the situation, or as applied to dementia, the recognition of the fact, degree, and implications of one's own illness’ (Foley, 1992, p33). It may be that participants with insight agreed to participate in the study and those who lacked insight into their needs choose to withdraw from the study or not to participate. Anosognosia (organic unawareness of deficits) occurs frequently in dementia and affects 30–50% of individuals with mild and moderate stages of Alzheimer’s disease (Starkstein, 2006). This was not considered in this study should be considered in future studies.

5.17 Experimental condition

The client centred occupational goal remained consistent for both participants in phase two for example, the goal of planning and organising oneself to go into the community to perform a shopping task. However, the specific occupations changed within the real life clinical context and the natural home environment conditions of the study. To give a specific example from the second case study, when a day was wet the participant may get an environmental cue from the sound of the rain outside to remember to wear their coat. The experimental condition may have changed within the context of the overall goal, for example on some days the participant wished to complete her shopping in a supermarket. On another day, the participant may have wished to go to the chemist. The goal remained the same but the context of how the goal was achieved was variable.

This study illustrates the difficulties of controlling the experimental conditions in completing clinical research. The participants are humans who live in their own home environments, which while every effort can be made to ensure that the environment is controlled as much as possible, for example taking the phone off the hook or making sure the lights were on, the environment cannot be fully controlled. For example, participant 1 in session 4 decided that she did not want to poach the egg and that she wanted to prepare coffee and have that alone for breakfast. The participant reported that she had eaten prior to OT arrival. On another occasion she reported that she would like to scramble rather than poach her eggs. This reflects the real life natural clinical conditions of human research in their own homes where a person has choice and control over their environment and is in contrast to laboratory conditions. However, while the task may have changed slightly that the approach used (EL and dementia friendly environment) remained constant.

Finally, in the literature the experimental conditions are fully controlled in terms of interventions. In this study, flexibility in the intervention phase was required. Given the real life condition, participants required various error reducing methods depending on how they performed on a particular goal in a given session. These methods were ready for implementation and were chosen specifically to meet the client centred needs of the participants. They ranged from not allowing the participant to guess, modelling, verbal instruction, visual instruction and vanishing cues. As the experimental condition could not be controlled fully, the PI had to be flexible in the intervention approach. This contrasts with the previous studies where the goal such as operating the cassette desk (Bier et al, 2008) was controlled, isolated had little variation in approaches to attainment of the goal.

Finally, it is not beneficial for participants with dementia to learn a skill that is only carried out in laboratory conditions as the transfer of that skill into the own home or real life circumstances may be difficult as a result of their cognitive impairment. This is acknowledged in the literature by Tailby and Haslam (2003) where this limitation to EL is of particular relevance especially to those with severe cognitive impairment. In addition, this study utilised compensatory strategies in the environment that would have not been suitable if the skill had been carried out in laboratory conditions and this study allowed the use of the compensatory strategies outside of the sessions which embedded their use into daily life. For example, the use of the orientation board with participant

one was used for more than just the EL sessions with the PI. The participant was supported in its use by her family for a series of appointments and general orientation throughout the day.

5.18 Cognitive functioning

Phase two of the study examined participants cognitive functioning objectively on the ACE-III. This assessment tool was considered more comprehensive than the SMMSE, has a higher sensitivity (82%) and predictive value than the SMMSE for a wide range of dementia prevalence (Mathuranath et al, 2000), (Hsieh et al, 2013). It is a detailed screening assessment used by multidisciplinary teams which added to the clinical relevance of the study. Participant one, who had a diagnosis of mixed AD / VaD, had a score of 61/100 at baseline assessment and 66/100 on post assessment on her ACE-III. The second participant, who had a diagnosis of AD and had a pre score of 50/100 and 46/100 on her post ACE-III assessment. Both participants were noted clinically as having moderate cognitive impairment and there was a no change on these. This lack of change on global cognitive functioning was expected as interventions did not specifically target this area. However, changes were expected in the orientation sections as a secondary outcome, as the participants both had a form of RO by the use of either an orientation board, a calendar (manual and electronic). This was not the case for either participant. Participant 2 maintained scores on orientation and participant 1 dropped one point. RO interventions have a mixed evidence base as outlined in a systematic review by Spector et al (2000). This study suggests that RO intervention was successful in orientation to routine and appointments in this study, it did not impact on retrieval of orientation answers on standardised assessments. There is a limitation to the use of this assessment tool in this study. It is not recommended that the ACE-III is re-administered within a 6 month period to prevent individuals from recalling components of the assessment. It was re administered in this study within a six month period. However, if this re-administration within the time period were to have an impact on the results one would have expected that the participants would have improved. Nonetheless, these cognition results must be interpreted with caution.

5.19 Communication

The Holden communication scale was used to assess communication in phase two. It is completed by member of staff or relative from their observation of the person with dementia over a specified period. This was adhered to in the study. With participant 1 the total score went from 9 pre to 7 post which indicated a positive outcome. With participant 2, there was no change in scores suggesting maintenance. It is not clear whether the change in score for participant 1 is as a result of the intense assessment and intervention by the OT having completed the 15 sessions with the participant, whilst on pre assessment the communication skills were known and assessed with families but not observed over such an intense period of time by PI. Bias is also possible. If the assessments pre and post were completed by an individual blind to the intervention, this would not have been the case.

There have been important outcomes reported in the literature in terms of communication, speech and language in EL (Middleton & Schwartz, 2012). The outcomes are not secondary outcomes in comparison to what was measured in this study. These are direct outcomes as a result of targeted EL interventions on communication. For example, Clare et al (2000) used an EL approach to demonstrate positive effects in familiar face name associations when specifically targeting this goal. Clare et al (2003) then used an EL approach successfully to teach participants to learn the names of members of a support group. Another example is in the work of Conroy et al (2009) where an EL approach specifically for verb and noun naming in aphasia was as effective as errorful/hierarchical cueing methods. No EL studies present evidence for improvement in communication when it was not the direct target of intervention through EL. Therefore, these findings in this study are novel.

In summary, there were positive outcomes for participant 1 and maintenance of communication for participant two. There are no published guidelines on clinical significance for this scale. The rationale for concluding that there were clinically significant changes is that the sections where change was observed on the scale have an impact on the person and their interactions through communication with others. For example, the humour subsection changed from *'enjoying comic situations or stories'* to *'creates situation or tells funny story on own initiative'*. This change alone would permit the participant to become an active communicator rather than a passive one. The ability

to join in games component changes from *'requires careful instructions but joins in'* to *'joins in games and activities with ease'* which again has an impact on how the participant interacts with games and activities. This secondary outcome as a result of EL has not been previously reported. It appears that this secondary outcome is a positive one, but from a review of the literature, communication needs to be specifically targeted to maximise the impact of EL for individuals.

5.20 QOL

The QOL-AD was used as an outcome measure in phase two of the study. The QOL-AD outcome for participant 1 indicated a significant change for the participant but little change (1 point) for the carers/families. There were no differences in outcomes on pre to post assessment for participant 2, suggesting maintenance of QOL. For the first participant, it is not clear why she and her family had different views. Ducharme and Geldmacher (2011) examined family assessment of QOL in dementia. The most significant care issues raised by families of individuals with dementia that contributed to family QOL were disability support and medical care. The family sample studied placed less emphasis on family interaction, emotional well-being, and direct care/ADL issues. This is similar to the result reported here where there were no changes in family/carer rated QOL as a result of no direct intervention in the area of disability support or medical care. This study focused on ADL which may have a lesser priority in terms of QOL for families/carers and therefore no changes were reported on the family/carers section of the QOL-AD.

Black et al (2012) in their research to identify correlates of self-rated and caregiver rated QOL in community-residing PWD, suggested that PWD's perceptions of their own QOL are influenced by a different set of factors than those that influence caregiver perceptions of the PWD's QOL, even when both assessments are based on the same set of items (QOL-AD). They suggested that these factors included characteristics of the PWD such as their level of cognitive functioning or insight, caregiver factors such as carers stress, carers own QOL, relationship dynamics and differences in opinions to what constitutes QOL. Similarly, in a metasynthesis of the factors that affect QOL from the perspective of people with dementia by O'Rourke et al (2015) relationships, agency in life today, wellness perspective and a sense of place influenced QOL. Within these four factors, the experience of connectedness or disconnectedness influenced QOL according to people

with dementia. This highlights the fact that some people with dementia can rate their own QOL. Given that QOL is personal and is influenced by personal value systems it may be that there was goal focused occupational meaning to the person with dementia which might have contributed to the four factors outlined by O'Rourke et al (2015).

In summary, from a review of the literature, there appear to be significant differences between an individual's and a carer's/families perspective into what constitutes QOL. This may explain the differences in the outcome on the QOL-AD scale for participant 1.

5.21 ADL scales phase 2

For Participant 1, there were no changes measured on the ADCS-ADL scale from pre to post assessment. For participant 2, there was a small increase which was not clinically significant from 60 to 61 on the ADCS-ADL scale. There was no change in ADL assessments despite participants learning through intervention and demonstrating change in terms of occupational performance with less errors and steps required to complete the task.

Consideration should be given to the possibility that the scale used was not sensitive enough to detect within task occupational changes which was captured in the activity analysis. For example, the section on the ADCS-ADL which examines meals or snacks at home asks 'In the past 4 weeks, did {S} make him/herself a meal or snack at home? If yes, which best describes his/her highest level of food preparation:

- 4 cooked or microwaved food, with little or no help
- 3 cooked or microwaved food, with extensive help
- 2 mixed or combined food items for a meal or snack, without cooking or microwaving (e.g., made a sandwich)
- 1 obtained food on his/her own, without mixing or cooking it' (Galasko, 1997).

Consideration should be given to the fact that a participant may not change on this scale but have experienced considerable changes within the quality of the task performed or the ease at which it was performed which can only be measured by direct observation. In addition, the answers were from the main carers and it may be questioned how accurately they are able to report changes or how sensitive to change they were, as again

they did not directly observe the occupational activity and were reporting on the participant's level of assistance with the ADL activity. Direct observation of behaviour in an everyday environment allows for assessment of behavioural subtleties (such as use of switches on a cooker) and long term changes that might otherwise be overlooked in a proxy measure (Schmitter-Edgecombe & Parsey, 2014).

Similarly, the BI which was rated by the PI pre and post intervention identified no change in either participant. This was expected by the PI after the goals were set as the BI does not assess those areas which would reflect changes in IADL such as shopping or DADL such as breakfast preparation.

In summary, it is argued that the natural observation of ADL that was completed in phase two of this study is the most valid determination of functional status (Marcotte et al, 2010). ADL deficits have been mostly demonstrated with the use of informant-rated IADL measures in the past (Razani et al, 2011). However, studies have revealed that carers tend to over- or underestimate the individual's capabilities when using rating measures primarily due to the nature of the relationship and/or the level of burden being experienced by the caregiver (Razani et al, 2011 and La Rue, 1992). Consideration to this should be given in future studies which may plan on relying on proxy measures alone. Such considerations to direct observation would allow researchers and clinicians to draw more informed conclusions about everyday functioning from assessment data. This would pose considerable difficulty in terms of resources for large groups of participants possibly in RCT's and appears to suit the single case study design better.

5.22 ADL, dementia process and type of EL goals

ADL are divided into basic activities of daily living (BADL) and instrumental activities of daily living (IADL). BADL include self-maintenance skills such as bathing, getting dressed or eating, and IADL consist of more complex activities such as using public transportation, planning, organising and completing a shopping task or managing finances. The nature of the dementia process suggests that participants will firstly lose skills in the area of IADL which requires executive functions and explicit memories processes and are generally more complex in nature. Then, as disease progression occurs they will potentially lose skills in the area of DADL which rely more on implicit and procedural memory. Nygard (2003) suggested that IADL can be impaired even before the onset of dementia and should be included in the diagnosis of MCI. Prior to reviewing

the results of the cognitive assessment it was expected that participant 2 had mild cognitive impairment as she was still engaged in IADL. The most common functioning deficit in participants with mild cognitive impairment is a decreased ability to manage IADL (Jekel et al, 2015). Participant one's goal in the area of DADL reflected her level/stage of the disease process and participant two's goal in the area of IADL did not.

Tailby and Haslam (2003) suggested that EL learning may be supported by different cognitive processes for different participants. They suggested that EL learning relies on implicit processes in those with severe impairment that lack explicit memory abilities, but relies more on explicit processes for those participants with only mild impairment. This suggestion by Tailby and Haslam (2003), when applied to this study for the occupation of preparing breakfast or going out shopping, indicates that the participants may have relied on their previous experiences to aid the performance of a task without conscious awareness of these previous experiences. But components of the occupation such as learning to use a checklist or a regular place for items may have relied more on explicit memory processes (which enable the conscious monitoring and elimination of errors) in combination with environmental cues such as signs, their locations and dementia friendly colours. The key learning from the comparison of the two different types of goals and their relationship with the level of the dementia process i.e. mild or moderate is that whilst this is a guide for the clinician in forming goals in collaboration with individuals, that Dementia may affect participants very differently and not be fully dependant on their type of dementia or stage of the disease and that participants' goals are dictated by client centred practice and participants occupational functioning.

5.23 Environmental modification and compensation

Phase 2 of the research study sought to examine the application of EL in the home by using it in combination with environmental modification and compensation. The consideration of the environment is central to OT practice and was considered in both phases of the study.

There are further environmental recommendations which were not considered at the time. Light was a requirement for the task with participant one and the impact of the kitchen spotlights on the participant performance could have been considered. The participant had visual acuity difficulties and she regularly forgot to wear her glasses. The modifications to the environment could have been in the area of environmental controls

such as a sensor light for such lighting on the work surface to avoid the need to recall the need to turn on the light and to provide even lighting and avoid shadows. It is recommended in the literature that ‘Spotlights should be generally avoided as they produce highly directional light in pools with dark shadowy areas around the beams, which could be visually confusing for the person with dementia. Work surfaces such as table tops and kitchen work tops need to be especially well and evenly lit. It is important to provide good levels of light to suit the particular tasks being undertaken’, (Pollock & Fuggle, 2013, p440). In the case of the second participant the PI could have improved the dementia friendly signage in the home by using real life pictures for the signage rather than the computer generate pictures used (appendix 29, 30). An actual picture of her bunch of keys or glasses could have been used. This would have given familiarity to the pictures and placed them in real life context. This should be considered in the future when employing such signage strategies.

5.24 Error measurement

Errors were recorded numerically and descriptively. Error measurement is important as it records quality of occupational performance and levels of independence when used in both the numerical and descriptive format. If errors were recorded numerically only, it may not reflect independence accurately as several minor errors may not impact on safety but one major error would. In both participants there was a significant reduction in the number of errors on the post A phase. However, the reason for this is not altogether clear. The participant may have responded to the stimulation of the presence of the OT, the routine established and the interpersonal relationship formed rather than the EL intervention itself. In addition an increased level of arousal and alertness by the participants may have had an impact on their performance of the task. This same theory could be relevant to phase one of the study, as the participants could have been more stimulated and aroused by other members of the group intervention, than the intervention itself. Further research incorporating control participants receiving no EL but just the presence of a therapist when completing a task and a control group in phase 1 receiving a non-standardised group activity has potential to provide some answers to these questions and should be considered for future studies.

For participant 1 session 15, the errors are not components of the task that have significant impact on the successful completion of the task. For example, the two errors

that were in session 15 were ‘forgot Hermesetas’ and ‘forgot salt in the water’ when poaching her egg. This had little effect on the overall outcome and the success of the occupation. Participant two had errors associated with failing to use fixed locations for items such as glasses. This had no direct impact on that particular occupation on that day but could have impacted on later occupations where these items were needed. There are no safety risks associated with these error types.

In summary, both case studies demonstrated a significant reduction in errors as a result of intervention. The errors that were observed in the post A phase were observed to have little effect on the overall occupational sequence of that particular goal, which facilitated successful completion of the task and had no associated safety risks which were particularly relevant considering the vulnerability’s of the participants living in the community alone.

5.25 Trial and error learning by comparison

Jones et al (2010) who studied healthy university students, concluded that people who retain the ability to monitor and detect errors (possibly those with normal or very mild levels of impairment) and to update knowledge of their performance on the basis of feedback, may have better outcomes with a rehabilitation intervention based on trial-and-error principles (Kessels et al, 2007). Wilson et al (1994) demonstrated in a series of single case studies, that EL methods were superior to trial-and error methods in teaching a number of different tasks to neurologically impaired participants. This included learning object names, items of general orientation, names of people, orientation items, and learning how to programme an electronic aid. Evans et al (2000), in their examination of memory impaired participants supported the hypothesis in their conclusion that preventing participants from making errors during learning will improve learning, *‘but only for tasks in which the retrieval situation facilitates the expression of implicit memory for the learned information’* (Evans et al, 2000, p100). They also stated that the beneficial gain from EL is greater for more severely memory impaired participants and that this benefit may only apply over short periods of time (Evans et al, 2000).

This study did not address trial and error learning and from a review of the literature there is limited evidence for the use of trial and error learning with moderately or severely impaired participants (Evans et al, 2000). Future research could examine trial

and error methods with a combination of approaches such as environmental modification for those with cognitive impairment to establish if the outcomes of trial and error learning are improved by a combination of approaches.

5.26 Full restriction of errors in B phase

In session 6, session 7 and session 8 in the intervention phase, the PI did not manage to prevent the participant from making an error. In session 6, the participant ‘reached for eggs from fridge, placed eggs into water’. It appeared that she was attempting to use a boiling method to poach instead of a poaching method as planned. Similarly, in session 7 she mixed up the methods of poaching an egg and ‘retrieved spoon instead of a knife from drawer and it appeared that she planned to spoon the egg into the pot for a boiled egg’. Finally, in session 8 ‘she used the dementia friendly sign for her cooker but made one error by turning it down too low, which was corrected with assistance. In an ideal circumstance, no errors should have occurred in this intervention phase of the study. However, given the natural clinical conditions of the study this proved impossible.

It is not clear if the steps of poaching an egg or cooker use should have been individually trained with EL through the provision of correct information regarding use of the cooker or over multiple learning trials with the participant repeating or writing down the information as required. There may have been a difference in outcome if this was done in isolation initially and then integrated into the full procedure of cooking breakfast. The published studies on EL tend to target functional tasks in isolation rather than a full occupational sequence (de Werd et al, 2013). This should be considered for future studies.

Previous knowledge regarding cooking may also be important. This participant had cooked eggs throughout her lifetime and may have had an idiosyncratic way of doing it all her life. If so, this individualised way of doing things would then remain. This was considered but not explored further at the time of the study. Individual’s distinctive ways of doing things should be given more in depth consideration for future studies.

The benefits of EL for both participants are clear. The question remains as to which component of the EL technique facilitated the participant’s performance most. Any one or combination of verbal and non-verbal cues, modelling, the dementia friendly environment with compensatory aids and cues may have been critical? In addition the

contribution of active responses and engagement to the goal focused task by the participant may have facilitated active encoding of the information without error. Evans et al (2000) suggest that EL may only be beneficial in implicit memory and may be ineffective when explicit recall of information is required. Participant two's explicit recall of all items required to go out were supported by compensatory strategies such as 2 checklists on a wall that she walked by regularly demonstrating the combination of approaches applied to this single case. It is suggested that it is a combination of all of the techniques applied that facilitated the successful outcome.

5.27 Routine

Routines consist of behavioural or occupational patterns which organise the timing, duration and order of activities (Zisberg et al, 2006). In both phases of this study, routines were of importance. Did the participants respond to routine? In phase one, significant structure and routine was provided in both manualised programmes. There was consistency every week with the day, time, location and group facilitators. Kielhofner (2002) states that the consistency of routines depends on one's environment; families/carers in the participants environments supported the community participants with their routines outside of the group setting and the inpatients were supported by the nurses on their wards. In phase 2, did the participants respond to the routine of the PI calling to the home and how did this routine impact on the overall outcome? Participant one had items ready such as the table set and coffee made for breakfast prior to arrival of the PI which may have been in response to the routine established by PI. However, this may have not been in relation to routine alone as it was used in combination with the compensatory dementia friendly orientation board to structure the weekly routine. The evidence base on routine in dementia care is sparse and appears to be reliant on theoretical models, qualitative evidence and descriptive studies (Zisberg, 2006).

In a review of the neurofunctional approach in Traumatic Brain Injury (TBI) by Clark-Wilson et al (2014), they discuss the development of retraining programmes designed to foster the development of habitual routines and automatic functional competencies in areas identified as important by the client. They support the importance of routines in this structured, multi-dimensional, rehabilitation process, designed for people with severe impairments following TBI. They emphasise the repetitive training of functional skills in situ, and encourage adaptive routines and habits. A specific good quality

evidence base on the use of routines is also lacking in TBI and whilst one can hypothesise that if they are useful in the NFA as outlined above, they could prove to be a useful intervention in dementia rehabilitation. Evidence to support such a hypothesis is lacking at present.

Kline et al (1991) examined the use of 2 routines by special education teachers in giving feedback to enhance the performance of students with intellectual disabilities (ID) with positive outcomes on both routines examined. A “supported routines” approach in individuals with ID as outlined by Saunders et al (1996) where variables associated with task design, instructional strategy, and the reinforcement contingency are adjusted to match the learning characteristics of the individual demonstrated positive effects. Neither of the studies used routines solely as an intervention strategy, nor did they evaluate the use of routine, but they simply used it as part of the overall approach which is similar to what was completed in both phases of this study.

In summary, routines were observed to be important in both phases of this study, they are used as part of dementia care, care of those with TBI and ID but the evidence base is lacking to support their use. Therefore, future research is required to examine the nature of routine and its potential in managing and promoting health, and in providing dementia care.

5.28 Length of intervention phase

The possibility that participants may have required a longer intervention phase to learn multiple new strategies was considered in terms of outcomes for both participants. For example, with participant 2, she was eventually trained to use the second dementia friendly checklist in the home using EL which is noted to be a new skill and addition to the home. On review of sessions 13-15, where errors persisted, one must consider here that these new locations for items such as keys and glasses were habitually never consistent over her life time as a reason why this area was difficult to learn or that she just had not had a long enough intervention phase to learn the skill/strategy. Future research should consider varying lengths of intervention phases in order to inform clinical practice.

The intervention phase was chosen to be 5 sessions long from a review of the published literature in EL and the realistic transferability of the 5 session intervention to clinical

practice (de Werd et al, 2013). In a review by Bahar- Fuchs et al (2013) of cognitive training and cognitive rehabilitation for persons with mild to moderate dementia of the Alzheimer's or vascular type, the intervention periods ranged from 5-24 weeks, the time in individual sessions ranged from 30-60 minutes and the number of sessions over the weeks ranged from 6- 72 sessions. Therefore, there are variations across studies which were considered. Given that this study implemented client centred practice and completed the intervention in the participants' home, the 5 sessions were over a time period mutually agreed with the participant. For example, for participant one the sessions were 2-3 times per week, whereas with participant two the sessions were daily on weekdays. The different intervention intensities have the potential to impact on outcomes and should considered for future studies. The length of the intervention sessions were dictated by the goal chosen, which for both participants worked out at one hour on average, with some variation where the task took a shorter or longer time to complete. For example, with participant one session 4, she chose one day to not have breakfast and to prepare hot coffee which took less time to complete. An intervention phase of up to 24 weeks was considered as this could that have had a better outcome on the error measurement. However, this length of an intervention phase would be unrealistic in clinical practice and therefore was avoided. Future studies should examine if longer intervention phases further decreased errors and thus impacting on the overall outcome of the intervention.

In summary, the variation of training intensity in the literature prevents conclusions from being drawn about the minimal training intensity required to produce a clinically relevant effect. However, this study highlights the goal focused nature of client centred delivery of EL in this fashion which considers the independent variables of each participant and this dictates its own training intensity needs. This suggests that there is no one formula to fit all participants but future studies should be completed to examine this.

5.29 Cues by the PI

Participant two was allowed to have an extended amount of time searching for items. The PI questions if this extended amount of time would have led to further errors and negative encoding of information. In the post assessment phase, cues were provided by the PI after an extended amount of time had elapsed. The role of this cue is considered in this post assessment phase, did this cue further train the participant to use the strategies even though the intervention phase was over. This should be considered in future studies.

5.30 Environmental cues alone

In phase 2, for both participants when EL intervention was removed, dementia friendly environmental cues remained in place in both home environments. These cues were used outside of this direct intervention with PI when the participants were carrying out their regular activities in the home reflecting the natural clinical conditions of this study. To what extent they were used outside of the study was not fully determined. It is not known whether an application of environmental cues with standard education on their use alone would have generated similar improvements in the post A phases of both studies. Future studies should examine the impact of environmental cues and standard education alone. Alternatively, a further participant having environmental cues and standard education alone and no EL may have provided an answer.

5.31 Number of steps required to complete task

Participant 1 showed less variation in the task/goal performed within the sessions. This varied from preparing coffee to poaching and scrambling an egg but all within the same kitchen environment. Overall the number of steps completed by the participant in performing the desired tasks remained the same, but within the tasks there were a reduction in the time required to perform specific tasks. In the pre A phase it took a max of 44 and a min of 30 steps to poach an egg, prepare toast and coffee while in the post A phase it took a maximum of 23 and a minimum of 14 steps to specifically poach an egg, prepare toast and coffee. It is suggested that the participant was specifically more efficient in this specific task as a result of EL intervention.

For Participant 2 there was considerable variation in the types of the tasks within each session some of which required more steps to complete and others requiring fewer steps.

For example, the task in session 4 was to travel to her local supermarket and to purchase all items on her shopping list. In contrast, in session 7 the task was to go to her daughter's café for lunch, a less complex task requiring fewer steps. Both reflect the clinical nature of the research and the client centred choice in task/goal that was facilitated by the PI throughout the study. It is therefore, impossible to conclude whether participant 2 was more or less efficient with the tasks overall as a result of the EL intervention. In addition, new environmental cues were introduced in the B phase which added steps to the task in the B and post A phase. This should be considered in future studies where there is less variation in the task and no introduction of environmental cues into the steps required to complete the task successfully. It is noted that even with the introduction of the new environmental cues/compensatory steps the average number of steps only increased by 1.6 steps.

5.32 Cost of Intervention phase two

There is a lack of published evidence on the cost effectiveness of EL interventions. A study protocol for a single blind randomised controlled trial by Clare et al, (2013) plans to confirm the benefits and cost-effectiveness of cognitive rehabilitation in a study which commenced in (2012) which will contribute to the evidence base once published. A cost analysis was completed for phase 2 of the study; the total cost for participant 1 for the 15 sessions delivered by an OT was €1,108.649. The comparable cost of a nursing home for same period would be €4,670. The cost of a home help delivering support in the area of IADL for the same duration of the intervention was found to be €555.36. The total cost for participant 2 for the 15 sessions delivered by an OT was €600.22. The comparable cost of a nursing home for same period would be €4,670. The cost of a home help delivering support in the area of breakfast preparation was found to be €237.96. It should be noted that the cost for both home help assistance and nursing home care would be continuous whereas the cost of the OT intervention is not. Future research should cost out the delivery of such interventions in comparison to their benefits for the participants involved.

Future studies should also consider if EL applied in this fashion reduces the carer burden on professional and non-professional carers and whether the therapeutic role of professional caregivers such as home helps or non-professional carers such as family members would contribute to the cost effectiveness of this approach. It could be argued

that it is more cost effective for a formal home help to deliver such interventions. However, the quality of such interventions in comparison to a professional such as an OT or a combination of approaches where the formal home help or an OT assistant is supported closely by the OT in delivering such interventions must also be considered.

Finally, group interventions are more cost effective as seen in phase one. Both group interventions and individual intervention that are presented in this study are successful in their own ways depending on the site of residence. For community participants, the goal of keeping an individual living in the community for longer and out of residential care by using individualised interventions is achievable as seen in the success of EL in phase two. For example, participant one was not safe at cooking her breakfast pre intervention and she was safe post intervention. Therefore, the choice of groups or individualised interventions depends on the goal of intervention and the setting.

5.33 Topics relevant to both phases of the study

5.34 Passive Behaviours

A factor that was not initially considered in either phase of this study was the concept of PB. On review of the literature and on inspection of the results and accompanying assessment notes, it was found to be both relevant and important to both.

In phase one, some participants were observed to behave passively outside of the group interventions and this was reported by staff and/or families. In phase 2, informal reports on participant 1 from her family reported more active behaviours in the home such as reading and more requests to go to the local library. Oil paints were observed out on the table on one of the sessions, with evidence that the participant had actively reengaged with her leisure pursuits suggesting that there was less PB than pre intervention.

Future studies should consider a PB as an outcome measure. They should additionally enamine the impact of environmental dementia friendly cues or ward/home environments alone on PB, especially given that PB may be influenced by the nature of the environmental stimuli (Thomas et al, 2004).

5.36 Recruitment

There were recruitment difficulties in both phases of the study as presented previously. Informal feedback suggested that the stigma of dementia was one of the reasons for participants not participating in either phases of the study. This came from the participants and their families themselves. Stigma is ‘an attribute, behaviour or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one’ (Alzheimer’s Disease International, 2012, p7). Some evidence suggests that stigma promotes a reluctance to seek help and social exclusion which may explain the rationale for those who informally reported stigma around their dementia (UN joint programme on HIV/AIDS, 2010). However, another aspect of stigma came from the participants’ relatives and families who reported informally that they didn’t want others knowing that their loved one had dementia by attending such a group and that they were protecting their loved one by keeping them away from such group therapies. This was the case in one community case, phase one. This concurs with the Alzheimer’s Disease International (2012) study where they reported that stigma not only affects the people with dementia but extends to those around them which include family members. The effects of stigma on recruitment should be considered in future studies. This would be an interesting and worthwhile qualitative piece of research.

5.37 Client centred practice

Both CST and Sonas are manualised programmes. Within these programmes, multiple individual perspectives needed to be considered and therefore a truly client centred focus on individual values and interests was not fully achievable. Full implementation of client centred practice in this group treatment approach posed greater difficulty. The group of clients who were included in phase one of the study all shared a diagnosis of dementia with mild to moderate impairments. The collective group goals/aims of intervention were clearly defined in the information sheets and the on initial meeting with the participants and/or their families. These were that ‘this study will examine the effectiveness of two group interventions aimed at improving a person's memory and in general their overall quality of life. We are interested in assessing whether these treatments are beneficial for people who are experiencing difficulties in these areas’ (appendix 4). When questions arose within the sessions, the goal of the group was described as ‘to potentially improve memory and thinking abilities’ rather than medical

terminology to facilitate greater understanding of the purpose of the group. When an individual's interests and hobbies were discovered through discussion in the CST or Sonas groups, the group facilitator strove to include such themes where appropriate in future sessions so as to facilitate purposeful and meaningful engagement. On reflection, there could have been more effort to include client centred practice within the group settings through a more in depth initial interview with the participants and/or their families prior to intervention. At the time, there was a significant time requirement to complete baseline assessments and therefore every effort was made to minimise the time for the participants in order to minimise fatigue and disruption on the client. Client centred practice in a group setting may have been easier to facilitate if it were not a research study with extensive baseline assessment and it were in clinical practice.

In contrast, the single case study approach used in this study relies on client centeredness. Both case studies were client centred as is central to OT practice. This type of practice was implemented in the case studies by providing clear information to the participant and their families throughout the study. The goals were mutually agreed upon by the PI and the participants, with active participation in and negotiation of goals by the participant. The participant took an active role throughout the study with active choice and autonomy in decision making. Examples include, participant 1 session 4 where she chose not to have breakfast one day and to have hot coffee, in session 9 where she chose to make an omelette rather than poach an egg and in session 12 where she prepared fried tomatoes, toast and hot coffee. Therefore, the participant and her needs were at the centre of the study at all times. The study was completed in full partnership with the participant and their families. The positive impact that such an approach may have had on the study outcome warrants further investigations.

The limitations of this client centred approach were considered also. The participants were facilitated in making decisions on changing the session task based on their personal preference that day. This has a potential impact on the outcome as participants received EL through different varying clinical conditions but the intervention approach remained the same regardless of the task and this is what was being assessed in the study. If the clinical conditions varied less, then this could potentially have had a positive impact on the outcome.

5.38 Pain and dementia

People with dementia may experience physical pain. This is for the same reasons as everyone else. However, people with dementia are at increased risk of experiencing pain because they are at increased risk of causes of pain, such as falls, accidents or medical conditions that can cause pain. However, because of their declining cognitive abilities, they may be less well able to communicate to their carers that they are in pain. One of the exclusion criteria for these studies was: ‘A significant physical health problem or illness that could impact on the individuals’ ability to attend and participate in the intervention and/or assessment process (e.g. an acute or chronic physical illness)’. This may have included an illness that caused pain. No ongoing monitoring of pain was undertaken and the care that was being provided to the person via the health service they were attending was relied upon to have screened and managed pain effectively. The participants were not screened to evaluate whether pain was causing some of their perceived neuropsychiatric symptoms. Such screening is most relevant to those participants with severe cognitive impairment who were not included in this study but it those with moderate impairment may also benefit. This should be considered for future studies in this area in order to eliminate pain as a cause for either positive or negative change in neuropsychiatric symptoms or other relevant outcome measures.

5.39 Conclusion

In this chapter discussion points relating to phase one of the study were discussed followed by phase two of the study and finally points relevant to both phases of the study were discussed.

This study makes significant contributions to research in the area of Dementia. For the first time two different types of interventions were examined, compared and contrasted. Evidence was found for both CST and Sonas interventions justifying their use with individuals with moderate cognitive impairment. Greater evidence was found for the use of CST which indicated that this is a more effective group intervention for individuals with moderate cognitive impairment.

Phase two of the study demonstrated significant findings novel to the area of dementia care. For the first time, a client centred goal focused task was examined, not in isolation or in laboratory conditions, but within a natural home environment as is encountered in clinical practice. The intervention considered the unique transactions between the person, the environment, the occupation and the performance. Interventions were introduced specifically in the area of dementia friendly environments and participants trained to use the changes in the environments using EL. This enabled the participants to maximise their transactions between the environments and their occupational performance within it. The outcome of this phase of the research demonstrated that this is an effective intervention for participants with moderate cognitive impairment with dementia.

5.40 Recommendations for future research

The primary questions for future studies are now considered.

- CST and Sonas interventions appear to target different areas. Whilst more evidence was found for the use of CST in this study, it could be argued that there is a place for both interventions in clinical practice. Future studies, especially those evaluating Sonas should examine the areas targeted by Sonas in more detail and research Sonas in those participants with severe cognitive impairment where CST is not suitable.
- Dementia is a progressive condition with deterioration expected. The question for all three types of interventions assessed in this study, especially Sonas (where there is no published evidence on maintenance) is if maintenance of any gains occurs, to what extent and at what stage of a maintenance programme do participants eventually deteriorate. Future studies should consider this.
- Environmental stimulation: A baseline level in each site of residence should be completed. For example, the activity programmes running regularly in each site and the natural environment stimulators that are lacking in some sites. These factors have potential to influence the outcome and need to be captured in future studies.
- Mechanisms for change: Future group studies should evaluate the mechanisms for change. For example, using the 14 sessions on the OTTOS the sessions where change occurred and the mechanism for that change i.e. which session on the group intervention impacted on that change should be examined. This would allow developers of the programmes improve the content to maximise the benefits for participants.
- Routine: This study supported the use of routines in its organisation of groups and individual sessions. An evidence base for the use of routines in dementia care is not present. Future studies should examine the impact of routines on occupational performance in participants with dementia.
- The strength of environmental modification and dementia friendly environments alone should be considered. This study used both techniques in conjunction with EL. Phase two of this study could be replicated (eliminating EL) and a study completed of the impact of environmental modification and dementia friendly environments alone
- Client centred practice: This was a core component of both studies and is central to OT practice. In order to investigate the impact of this approach on study outcomes,

client centred and non-client centred approaches should be considered and compared in future studies.

There are some issues that arose, which future researchers should generally consider when completing research in the area of dementia care. These are travel in rural settings (Travel times, funding for travel and controls for this variable), screening for pain, family/carer health outcome measures, lengths of intervention phases, cost analysis and relationship with outcomes of intervention and medication.

5.41 Recommendations for changes in clinical practice

A summary of the recommendations for change in clinical practice will now be presented.

- The evidence from this study supports the continued implementation of CST groups over Sonas groups especially in the current economic climate of clinical practice. However, it acknowledges that there is a role for Sonas groups. The use of Sonas should be accompanied by outcome measures which justify its use in practice in order to continue to support its use.
- Currently EL approaches are not a core component of clinical practice. Evidence now exists for their role in combination with environmental modification using dementia friendly principles and therefore, they should be implemented in case studies similar to the ones presented in phase two of this study.
- This study highlights the role and place of multifaceted approaches with multidisciplinary teams to address individual goals for individuals. Outcomes in all areas have the potential to be improved as a result of multifaceted approaches and this should be considered when developing programmes using CST, Sonas or EL clinically.
- Stigma: The impact of stigma was considered, especially through the recruitment phase of both studies. All staff should be engaged in and promoting an enabling society for people with dementia in order to reduce stigma and encourage the use of services by individuals with dementia and their families. This concurs with the priority actions and objectives outlined in Ireland's National dementia strategy 2014.

5.42 Dissemination

The author plans to write two journal articles one for phase one and another for phase two. The plan for dissemination of phase one would be to write a journal article to target the International Journal of Geriatric Psychiatry (Impact Factor 2.699) or Aging & Mental Health (Impact Factor 1.861)

For phase two the target journals are Neuropsychological Rehabilitation (Impact Factor 2.082) or Journal of Geriatric Psychiatry and Neurology (Impact Factor 2.127).

However, at the time of publication of both journal articles the most relevant journal will be considered.

To date the research has been presented at the following:

- The 1st COTEC ENOTHE Congress, NUI Galway June 2016.
- OT Special Interest Group in PLL, September 2015
- Annual PhD presentations NUI Galway, 2013, 2014, 2015.
- 10th conference of the Neuropsychological Rehabilitation Special Interest Group of the World Federation for Neurorehabilitation (WFNR), Netherlands, 2013.
- The annual neuroscience group meeting in NUI Galway on 6th December 2013.
- The AOTI annual conference, June 2012.

The author plans to continue to disseminate the results at relevant conferences and meetings.

The future plans for research have been discussed in detail in the discussion chapter. However, the plan for phase one of the study is for replication of the original study in a larger geographical area to obtain a suitable sample size.

The plans for phase two is a clinical replication series in order to make generalisations beyond the participants included in this pilot study with consideration of the relevant intervention phase based on the complexity of the goal.

6 Conclusion

In conclusion, a diagnosis of dementia is devastating for both the individual and their family and generally creates negative perceptions and associations (Alvira, 2014). In contrast, the outcomes of this study are positive. This study provides evidence that OT intervention can impact on the trajectory of the condition with people with dementia demonstrating that they do have rehabilitation potential by responding to treatment and improving and maintaining their abilities as they progress through the condition.

Group interventions are a cost effective way of targeting the areas of communication, QOL, cognition, behaviour within a group session and neuropsychiatric symptoms. However, neither group in this study had outcomes that generalised into daily life through their ADL which is a core focus for the work of the OT and a common priority goal for individuals with dementia and their families. This study demonstrated that whilst EL in conjunction with provision of a dementia friendly environment delivered in an individual session format rather than as a group is less cost effective it has significant benefits for the individual with dementia living in the community and the role of EL has been shown to have a place in rehabilitation in dementia.

The main findings of phase one of the study supported the use of CST intervention to a greater extent than the Sonas. These findings build on the evidence base for CST and present preliminary evidence for the use of Sonas. The CST group only demonstrated statistically significant differences in cognition, communication and with three areas of neuropsychiatric symptoms. Both groups had statically significant improvements in carer rated QOL. Both groups were found to have statistically significant changes within the group sessions.

Phase two of the study was informed by the findings of phase one and presented the first single case studies which examined the impact of goal focused EL interventions, delivered in combination with compensation and modification of the environment. It examined a different approach to phase one though individual therapy with two individuals who have dementia.

The main findings of phase two supported the use of the intervention in both case studies. Case study one showed a reduction in the number of errors, a reduction in the number of steps required to complete the task, a change in the level safety for the

occupation, statistically significant changes in QOL, maintenance of cognition and clinically significant changes in communication. Case study two showed a small reduction in the number of errors, maintenance in communication, maintenance in QOL and the number of steps required to complete the task. Therefore the benefits of EL for both participants were clear.

Finally, major investments and advances in development of pharmacological treatments for dementia have been achieved and research in this area is ongoing; however, none are at a stage yet where they can make a difference to people with established dementia by impacting on their functional status and QOL (Schneider et al, 2013). In contrast, the interventions researched in this study have been shown to have an impact on cognition, QOL, functional status, communication and neuropsychiatric symptoms demonstrating that, contrary to common belief, people with dementia do have rehabilitation potential. The results showed that participants responded to all three interventions tested (albeit to different degrees). Even within the current financial constraints, these interventions could be implemented immediately within existing services and have potential to have a significant impact on the lives of people with dementia and their carers.

Reference List

- Aarsland, D., Hutchinson, M., & Larsen, J. P. (2003) 'Cognitive, psychiatric and motor response to galantamine in Parkinson's disease with dementia'. *International Journal of Geriatric Psychiatry*, 18: p937–941.
- Aarsland, D., Andersen, K., & Larsen, J.P. (2001) 'Risk of Dementia in Parkinson's disease: a community-based, prospective study'. *Neurology*, 56, p730-6
- Achterberg, W.P., Gambassi, G., Finne-Soveri, H., Liperoti, R., Noro, A., Frijters, D.H., Cherubini, A., Dell'aquila, G., & Ribbe, M.W., (2010) 'Pain in European long term care facilities: cross national study in Finland, Italy and The Netherlands'. *Pain* 148, p70-74
- Achterberg, W.P., Scherder, E., Pot, A.M., & Ribbe, M.W. (2007) 'Cardiovascular risk factors in cognitively impaired nursing home individuals: a relationship with pain?' *European Journal of Pain*, 11 (6), p707–710.
- Aguirre, E., Hoare, Z., Streater, A., Spector, A., Woods, B., Hoe, J., & Orrell M. (2013) 'Cognitive stimulation therapy (CST) for people with dementia—who benefits the most?' *International Journal of Geriatric Psychiatry*, 28, p284-290.
- Aguirre, E., Spector, A., Hoe, J., Russell, I. T., Knapp, M., Woods, R. T., & Orrell, M. (2010) 'Maintenance Cognitive Stimulation Therapy (CST) for dementia: A single-blind, multi-centre, randomized controlled trial of Maintenance CST vs. CST for dementia'. *Trials*, 11, p46.
- Alvira, M.C., Risco, E., Cabrera, E., Farré, M., Hallberg, I.R., Bleijlevens, M.H.C., Meyer, G., Koskeniemi, J., Soto, M., & Zabalegui, A. (2014) 'On behalf of the Right Time Place Care Consortium (2014) 'The association between positive–negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: a cross-sectional study'. *Journal of Advanced Nursing* 71(6), p1417–1434.
- Alzheimer's Association (2010) 'Alzheimer's disease facts and figures'. *Alzheimer's & Dementia*, 6(2), p158–194.
- Alzheimer's Disease International (ADI) (2012) *World Alzheimer's Report: Overcoming the stigma of Dementia*. ADI, London.
- Alzheimer's Disease International (ADI) (2009) *World Alzheimer's Report*. ADI, London.

- Alzheimer's Europe (2009) 'Estimated figures of people living with dementia' Available at: <http://www.alzheimer-europe.org/> (Accessed: 10 August, 2015)
- Alzheimer Knowledge Exchange (2011) 'Noise Part 2 – Social Design Interventions' <http://elderfriendlydesign.pbworks.com/f/AKE+Noise+Pt2.pdf> (Accessed 19th July, 2013).
- Alzheimer's Scotland (2000) 'Incidence of Dementia' Available at: <http://www.alzscot.org/campaigning/statistics> (Accessed: 01 August, 2015)
- Alzheimer's Society (2014). 'Information sheets' Available at: <http://www.alzheimers.org.uk/dementia2014> (Accessed: 01 August, 2015).
- Alzheimer's Society (2010) 'Keeping Active and Staying Involved'. Available at: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=115 (Accessed 23rd September 2015).
- Alzheimers UK (2013) 'Assistive Technologies' Available at: http://www.alzheimers.org.uk/site/scripts/google_results.php?q=assistive+technologies (Accessed 19/07/2013).
- Alzheimer's UK (2013) 'Vascular Dementia' Available from: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=161 Accessed: 01/09/2014.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). APA: Washington, DC.
- American Psychiatric Association. (2000) *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.) APA: Washington, DC.
- Ames, D., Burns, A. & O'Brien, J.T. (2010) *Dementia* (4th ed.) London: Hodder Arnold.
- Anstey, K. J., Cherbuin, N., Budge, M. & Young, J. (2011) 'Body mass index in midlife and late-life as a risk factor for dementia: a meta-analysis of prospective studies'. *Obesity Reviews*, 12: p426–437.
- Applebaum, P.S., & Grisso, T. (2001), 'MacCAT-CR: MacArthur Competence Assessment Tool for Clinical Research'. Sarasota, FL: Professional Resource Press.
- Arkin, S., & Mahendra, N. (2001) 'Insight in Alzheimer patients: Results of a longitudinal study using three assessment methods'. *American Journal of Alzheimer's Disease*, 16(4), p211–224.
- Association of Occupational Therapists of Ireland (AOTI) (2013) *Code of Ethics and Professional Conduct*. AOTI: Dublin.

- Babinski, M.J. (1914). 'Contribution e l'etude des troubles mentaux dans rhemiplegie organique cerebrale (anosognosie) [Contribution to the study of mental disorders in hemiplegia (anosognosia)]'. *Revue Neurologique (Paris)*, 12, p845-848.
- Baddeley, A., Wilson, B.A. (1994) 'When implicit learning fails: Amnesia and the problem of error elimination'. *Neuropsychologia*, 32 (1), p 53–68
- Bahar-Fuchs, A., Clare, L., Woods, B. (2013) 'Cognitive training and cognitive rehabilitation for persons with mild to moderate dementia of the Alzheimer's or vascular type: a review'. *Alzheimer's research and therapy*. 5 (35), p3
- Baines, S, Saxby, P., & Ehlert, K. (1987) 'Reality orientation and reminiscence therapy A controlled cross-over study of elderly confused people'. *British Journal of Psychiatry* , 151, p222–231.
- Baker, M., & Seifert, L. (2001). 'Syntagmatic-paradigmatic reversal in Alzheimer-type dementia'. *Clinical Gerontologist*, 23(1/2), p65-79.
- Baldi, I., Dal Lago, E., De Bardi, S., Sartor, G., Soriani, N., Zanotti, R., & Gregori, D. (2014) 'Trends in RCT nursing research over 20 years: mind the gap'. *British Journal of Nursing*, 23(16), p895-899.
- Barker, C., Pistrang, N. & Elliot, R. (2002) *Research methods in clinical psychology. An introduction for students and practitioners*. Second edition. England: John Wiley and sons LTD.
- Barker, W.W. (2002) 'Relative frequencies of Alzheimer disease, Lewy body, vascular and frontotemporal dementia, and hippocampal sclerosis in the State of Florida Brain Bank'. *Alzheimer Disease Associated Disorders*. 16(4), p203–12.
- Bateman, A. W., & Holmes, J. (1995) *Introduction to Psychoanalysis- Contemporary Theory and Practice*. Routledge: London.
- Bateman, D., Boughey, A.M., Scaravilli, F., Marsden, C.D., & Harding, A. (1992) 'A follow-up study of isolated cases of suspected Huntington's disease'. *International neural network*, 31, p293-298.
- Bates, J., Boote, J. & Beverley, C.A. (2003) 'Psychosocial interventions for people with milder dementing illness: A systematic review'. *Journal of Advanced Nursing*, 45 (6), p644-658.
- Bates, G.P., Harper, P.S., & Jones, A.L., (2002) *Huntington's Disease*. (3rd ed). Oxford: Oxford University Press.

- Bauer, M. (2014) 'We need to know what's going on': views of family members toward the sexual expression of people with dementia in residential aged care'. *Dementia*, 13 (5) p571 -85.
- Baum, C. M, & Christiansen, C. H. (2005) 'Person-environment-occupation-performance: An occupation-based framework for practice'. In Christiansen, C.H., Baum, C.M. & Bass-Haugen, J. (Ed) (2005) 'Occupational therapy: Performance, participation, and well-being' (3rd ed.). Thorofare, NJ: SLACK Incorporated.
- Bédard, M., Molloy, D.W., Standish, T., Guyatt, G.H., D'Souza, J., Mondadori, C., & Darzins, P.J. (1995) 'Clinical trials in cognitively impaired older adults: home versus clinic assessments'. *J Am Geriatric Society*, 43(10), p1127–1130.
- Beer, C., Flicker, L., Horner, B., Bretland, N., Scherer, S., Lautenschlager, N. T., Almeida, O. P. (2010). 'Factors Associated with Self and Informant Ratings of the Quality of Life of People with Dementia Living in Care Facilities: A Cross Sectional Study'. *PLoS ONE*, 5(12), p15621.
- Bigarella, R. L., Schumacher-Schuh, A. F., da Silva, E., & Chaves, M. L. F. (2014) 'Sex Differential Effect of Parental Longevity on the Risk of Dementia'. *Journal of the American Geriatrics Society*, 62, p393–395.
- Bier, N., Van der Linden, M., Gagnon, L., Desrosiers, J., Adam, S., Louveaux, S., SaintMleux, J. (2008) 'Face name association learning in early Alzheimer's disease: a comparison of learning methods and their underlying mechanisms'. *Neuropsychological Rehabilitation*, 18, p343-371.
- Bigio, E.H. (2013). 'Making the Diagnosis of Frontotemporal Lobar Degeneration'. *Archives Of Pathology & Laboratory Medicine*, 137(3), p314-325.
- Bird, M. J. (2001) 'Behavioural difficulties and cued recall of adaptive behaviour in dementia: Experimental and clinical evidence'. *Neuropsychological Rehabilitation* 11 (3/4), p357-375.
- Bird, M. J. (2000). 'Psychosocial rehabilitation for problems arising from cognitive deficits in dementia'. In R. D. Hill, L. Backman & A. S. Neely (Eds.), 'Cognitive rehabilitation in old age'. Oxford: Oxford University Press.
- Bittles, A. H. & Glasson, E. J. (2004) 'Clinical, social, and ethical implications of changing life expectancy in Down syndrome'. *Developmental Medicine and Child Neurology*. 46 (4), p 282 -286

- Black, B., Johnston, D., Morrison, A., Rabins, P., Lyketsos, C., & Samus, Q. (2012) 'Quality of life of community-residing persons with dementia based on self-rated and caregiver-rated measures'. *Quality of Life Research*, 21 (8), p1379-1389.
- Boerlage, A.A. Van Dijk, M., Stronks, D.L., de Wit, R., Van der Rijt, C.C. (2008) 'Pain prevalence and characteristics in three dutch residential homes'. *European Journal of Pain*, 12, p910-916.
- Bogardus, S. T., Jr, Bradley, E. H., & Tinetti, M. E. (1998) 'A Taxonomy for Goal Setting in the Care of Persons with Dementia'. *Journal of General Internal Medicine* 13(10), p675–680.
- Boot, B. (2013) 'The incidence and prevalence of dementia with Lewy bodies is underestimated'. *Psychological Medicine* 43 (12), p2687-8.
- Bourgeois, M. S. & Mason, L. A. (1996) 'Memory wallet intervention in an adult day-care setting'. *Behav Intervent*, 11, p3–18.
- Brawley, E. (1997) *Designing for Alzheimer's disease: Strategies for Creating Better Care Environments*. Brisbane: John Wiley and Sons
- Brewer, P. (1984) 'Brief assessments for the elderly mentally infirm', *The British Journal of Occupational Therapy*, Vol 47(6), Jun, p168-171.
- British Psychological Society (2008) *Generic Professional Practice Guidelines* (2nd edn.) Leicester: Author.
- Britton, J. W. (1995) 'hereditary late-onset chorea without significant dementia: genetic evidence for substantial phenotypic variation in Huntington's disease'. *Neurology*, 45(3), p443 -447.
- Brod, M., Stewart, A., Sands, L. & Walton, P. (1999) 'Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DQOL)'. *The Gerontologist*, 39, p25–35.
- Brodaty, H. & Arasaratnam, C. (2012) 'Meta-analysis of nonpharmacological interventions for neuropsychiatric symptoms of dementia'. *The American Journal of Psychiatry*, 169 (9) p946-953.
- Brook, P., Degun, G. & Maher, M. (1975) 'Reality orientation, therapy for psychogeriatric patients: a controlled study'. *British Journal of Psychiatry*, 127 , p45
- Brooker, D.L., Woolley, R.J. and Lee, D. (2007) 'Enriching opportunities for people living with dementia in nursing homes; an evaluation of a multi-level activity based model of care'. *Ageing and mental health*, 11, p361-370.

- Brueil, V., De Rotrou, J., & Forette, F. (1994) 'Cognitive stimulation of patients with dementia: preliminary results'. *International Journal of Geriatric Psychiatry*, 9, p211-217.
- Burdea, G., Polistico, K., Krishnamoorthy, A., House, G., Rethage, D., Hundal, J., Damiani, F., Pollack, S. (2014) 'Feasibility study if the BrightBrainertm integrative cognitive rehabilitation system for elderly with dementia'. *Disability and rehabilitation, Assistive Technology*, p1-12.
- Burns, C.M., Chen, K., & Kaszniak, A.W. (2013) 'Higher serum glucose levels are associated with cerebral hypometabolism in Alzheimer regions'. *Neurology*; 80: p1557-1564
- Burns, J.M., Johnson, D.K., Watts, A., Swerdlow, R.H., & Brooks, W.M. (2010) 'Reduced lean mass in early Alzheimer disease and its association with brain atrophy'. *Arch Neurol.* 67, p428–433.
- Burns, I., Cox, H. & Plant, H. (2000) 'Leisure or therapeutics? Snoezelen and the care of older persons with dementia'. *International Journal of Nursing Practice*, 6, p118–126.
- Burns, A., Lawlor, B., Craig, S. (1999) '*Assessment scales in old age psychiatry*' London, England: Martin Dunitz.
- Buschert, V.C., Friese, U., Teipel, S.J., Schneider, P., Merensky, W., Rujescu, D. et al. (2011) 'Effects of a newly developed cognitive intervention in amnesic mild cognitive impairment and mild Alzheimer's disease: a pilot study'. *Journal of Alzheimer's Disease*, 25, p679–94.
- Butler, T.C., van den Hout, A., Matthews, F.E., Larsen, J.P., Brayne, C., Aarsland, D. (2008) 'Dementia and survival in Parkinson disease. A 12-year population study'. *Neurology.* 70 (13), p1017-1022
- Caffò, A. O., Hoogeveen, F., Groenendaal, M., Perilli, A.V., Picucci, L., Lancioni, G.E., Bosco, A. (2014) 'Intervention strategies for spatial orientation disorders in dementia: A selective review', *Developmental Neurorehabilitation*, 17(3), p200-209
- Caffò, A.O., De Caro, M.F., Picucci, P.L., Notarnicola, A., Settanni, A. Livrea, P. Lancioni, G.E. Bosco, A. (2012) 'Reorientation Deficits Are Associated With Amnesic Mild Cognitive Impairment'. *American Journal of Alzheimer's Disease & Other Dementias.* 27(5), p321-330

- Cahill, S., O'Shea, E. & Pierce, M. (2012). *Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy*. Living with Dementia Research Programme, Trinity College Dublin, and Irish Centre for Social Gerontology, National University of Ireland, Galway: Dublin and Galway.
- Calkins, M. & Connell, B. (2003) 'Mary quite contrary: how do you get people to use your garden?' Presentation at American Society on Aging/National Council on Aging Annual Conference, Chicago.
- Camp, C.J., et al, (2006) *Montessori based activities for persons with dementia*. Volume 2. Beachwood, OH: Menorah Park Centre for senior living.
- Camp, C.J., Judge, K.S., Bye, C.A., Fox, K.M., Bowden, J., Bell, M., Valencic, K., Mattern, J.M. (1997) 'An Intergenerational Program for Persons With Dementia Using Montessori Methods'. *The gerontologist*. 37 (5), p688-692.
- Camp, C.J., Foss, J.W. (1997) 'Designing ecologically valid memory interventions for persons with dementia'. In: Payne, D.G., Conrad, F.G., (ed) (1997) *Intersections in basic and applied memory research*. Mahwah, NJ: Lawrence Erlbaum and Associates, p 311–325.
- Canadian Association of Occupational Therapists (1997). *Enabling occupation: An OT perspective*. Ottawa, Canada: CAOT publications.
- Cantley, C. (2001) *A handbook of dementia care*. Buckingham England: Open University Press
- Chang, K.H., Chung, C.J., Lin, C. L., Sung, F. C., Wu, T. N., & Kao, C.H (2014) 'Increased risk of dementia in patients with osteoporosis: a population based retrospective cohort analysis' *Age*, 36, p967-975.
- Chen, P.L., Yang, C.W., Tseng, Y.K., Sun, W.Z., Wang, J.L., Wang, S.J., & Oyang, Y.J., (2014) 'Risk of dementia after anaesthesia and surgery'. *The British Journal of Psychiatry*, 204, p188-193.
- Christiansen, C.H., Baum, C.M., & Bass-Haugen, J. (2005) *Occupational Therapy Performance, Participation, and Well-Being*. USA: SLACK incorporated.
- Chung, J.C.C. & Lai, C.K.Y. (2002) 'Snoezelen for dementia'. *Cochrane Database of Systematic Reviews*, 4.
- Clare, L., Whitaker, C. J., Nelis, S. M., Martyr, A., Markova, I. S., Roth, I., Woods, R. T. & Morris, R. G. (2013) 'Self-concept in early stage dementia: profile, course,

correlates, predictors and implications for quality of life'. *International Journal of Geriatric Psychiatry*, 28, p494–503.

- Clare, L., Bayer, A., Burns, A., Corbett, A., Jones, R., Knapp, M., Kopelman, M., Kudlicka, A., Leroi, I., Oyebode, J., Pool, J., Woods, B., & Whitaker, R. (2013) 'Goal-oriented cognitive rehabilitation in early-stage dementia: study protocol for a multi-centre single-blind randomised controlled trial (GREAT)'. *Trials*, 14, p152.
- Clare, L., Linden, D.E., Woods, R.T., Whitaker, R., Evans, S.J., Parkinson, C.H., van Paasschen, J., Nelis, S.M., Hoare, Z., Yuen, K. S., Rugg, M.D. (2010) 'Goal-orientated cognitive rehabilitation for people with early stage Alzheimer's disease: a single blind randomised controlled trial of clinical efficacy'. *American Journal of Geriatric Psychiatry*, 18, p928- 939.
- Clare, L. (2004) 'The construction of awareness in early stage AD: a review of concepts and models'. *British Journal of Clinical Psychology*, 43, p155-175
- Clare, L. (2003) 'Cognitive training and cognitive rehabilitation for people with early-stage dementia'. *Reviews in Clinical Gerontology*, 13, pp 75-83.
- Clare, L., & Woods, R. (2004) 'Cognitive training and cognitive rehabilitation for people with early-stage Alzheimer's disease: A review'. *Neuropsychological Rehabilitation*, 14, p385–401.
- Clare L, Woods B. (2003) 'Cognitive rehabilitation and cognitive training for early-stage Alzheimer's disease and vascular dementia'. *Cochrane Database of Systematic Reviews*, 4.
- Clare, L., Wilson, B.A., Carter, G., Roth, I., & Hodges, J.R. (2002) 'Relearning of face-name associations in early-stage Alzheimer's disease'. *Neuropsychology*, 16(4), p538–547.
- Clare, L. (2002) 'We'll fight it as long as we can: coping with the onset of Alzheimer's disease'. *Aging Mental Health*. 6(2), p139-148
- Clare, L., Wilson, B.A., Carter, G., Hidges, J. R., & Adams, M. (2001) 'Long term maintenance of treatment gains following a cognitive rehabilitation intervention in early dementia of Alzheimer's type: a single case study'. *Neuropsychological Rehabilitation* 11, p477-494.
- Clare, L., Woods, R. T. (2001) *Cognitive Rehabilitation in Dementia*. Hove, UK: Psychology Press.

- Clare L, Wilson BA, Carter G, Gosses A, Breen K, & Hodges JR. (2000) 'Intervening with everyday memory problems in early Alzheimer's disease: an errorless learning approach'. *Journal of Clinical and Experimental Neuropsychology*, 22, p132-146.
- Clark-Wilson, J., Giles, G. M., & Baxter, D.M. (2014) 'Revisiting the neurofunctional approach: Conceptualizing the core components for the rehabilitation of everyday living skills'. *Brain Injury*, 28(13–14), p1646–1656
- Clegg, A., Relton, C., Young, J., & Witham, M. (2015) 'Improving recruitment of older people to clinical trials: use of the cohort multiple randomised controlled trial design'. *Age and Ageing* 44, p547–550
- Coen, R.F., Flynn, B., Rigney, E., O'Connor, E., Fitzgerald, L., Murray, C., et al. (2011) Efficacy of a cognitive stimulation therapy programme for people with dementia. *Irish Journal of Psychological Medicine*, 28(3), p145–7.
- Cohen, M., Ylvisaker, M., Hamilton, J., Kemp, L., & Claiman, B. (2010) 'Errorless learning of functional life skills in an individual with three aetiologies of severe memory and executive function impairment'. *Neuropsychological rehabilitation*, 20 (3), p355-376.
- Cohen, J. (1988) *Statistical power analysis for the behavioural sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.
- Cohen-Mansfield, J. (2016) 'Non-pharmacological interventions for agitation in dementia: various strategies demonstrate effectiveness for care home residents; further research in home settings is needed'. *Evidenced Based Nursing*, 19(31).
- Cohen-Mansfield, J. & Wirtz, P.W. (2009) 'The reasons for nursing home entry in an adult day care population: caregiver reports versus regression results'. *Journal of geriatric psychiatry and neurology*. 22(4), p274-81.
- Coleman, L.W., Digre, K.B., Stephenson, G.M., & Townsend, J. T. (2002) 'Autopsy-Proven, Sporadic Pick Disease with Onset at Age 25 Years'. *Archives of Neurology*. 59(5), p856-859.
- Collier, L., McPherson, C., Ellis-Hill, C., Staal, J., & Bucks, R. (2010) 'Multisensory stimulation to improve functional performance in moderate to severe dementia-interim results'. *American journal of Alzheimer's disease and other dementias*. 25(8), p698 -703.

- Collin, C. Wade, D.T. Davies, S. Horne, V. (1988) 'The Barthel ADL index: a reliability study'. *International disability study*, 10 (2), p61-63
- Collin, C., Wade, D., Davies, S., Horne, V. (1987) 'The Barthel ADL index: a reliability study'. *Int Disability Study*, 10, p61-63.
- Colling, K.B. (2004) 'Caregiver interventions for passive behaviours in dementia: links to the NDB model'. *Aging & Mental Health*, 8(2), p117-125.
- Colling, K.B. (1999) 'Passive behaviours in dementia: clinical applications of the Need-driven Dementia comprised Behaviour Model'. *Journal of Gerontological Nursing*, 25 (9), p27-32.
- Connolly, S., Gillespie, P., O'Shea, E., Cahill, S., & Pierce, M. (2013). 'Estimating the economic and social costs of dementia in Ireland'. *Dementia: The International Journal of Social Research and Practice*, 11(3), p1.
- Connors, T.F. (2001) 'SONAS aPc in the hospital, impact on resident functioning. Executive summary of results'. Unpublished, Sonas aPc.
- Conroy, P., Sage, K.E., & Lambon, R. (2009) 'Errorless and errorful therapy for verb and noun naming in aphasia'. *Aphasiology*, 23(11), p1311-1337.
- Cooper, C., Mukadam, N., Katona, C., Lyketsos, C.G., et al (2012) 'Systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia' *International Psychogeriatrics*, 24 (6), p856-870.
- Coppus, A.M.W. (2013) 'People with Intellectual Disability: What Do We Know about Adulthood and Life Expectancy?' *Developmental disabilities research reviews* 18 (1) p6 -16.
- Creek, J., & Bullock, A., (2008) 'Planning and Implementation'. In: Creek, J. and Lougher, L., (4th Edition). *Occupational Therapy and Mental Health*. Edinburgh: Churchill Livingstone, p109 -131.
- Creswell, J.W. (2014). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches* (4th ed.). Thousand Oaks, CA: Sage.
- Creswell, J.W., Plano-Clark, V. L. (2011) *Designing and conducting mixed methods research*, (2nd ed.). Thousand Oaks, CA: SAGE.
- Critchley, M. (1953) *The parietal lobes*. London: Edward Arnold.
- CST Dementia (2014) Available at: <http://www.cstdementia.com/> (Accessed: 14 June 2014).

- Cummings, J.L. (1997) 'The Neuropsychiatric Inventory: Assessing psychopathology in dementia patients'. *Neurology*, 48, p10-16.
- Cummings, J., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., & Gornbein, J. (1994) 'The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia'. *Neurology*, 44, p2308-2314.
- Cynkin, S., & Robinson, A.M. (1990) *Occupational therapy and activities health: Towards health through activities*. Little Brown and Company, Boston
- Dahl, A.K., Hassing, L.B., & Fransson, E.L. (2014) 'Body mass index across midlife and late life as a risk factor for dementia: results from a prospective population based cohort'. *Journal of Alzheimer's disease*; 38, p201-209
- Dahl, A.K. Hassing, L.B. (2013) 'Obesity and cognitive aging'. *Epidemiol Rev* 35, p22–32.
- Dang, T.N.T., Dobson-Stone, C., Glaros, E.N., Kim, W.S., Hallupp, M., Bartley, L., Piguët, O., Hodges, J.R., Halliday, G.M., Double, K.L., Schofield, P.R., Crouch, P.J., & Kwok, J.B. (2013) 'Endogenous progesterone levels and frontotemporal dementia: modulation of TDP-43 and Tau levels in vitro and treatment of the A315T TARDBP mouse model' *Disease Models & Mechanisms*, 6, p1198-1204
- Data protection act (1998) Available from: <http://www.dataireland.ie/About/Pages/Data-Protection-Policy.aspx#.Vgl5zTZdF2E> Accessed: 28/09/15.
- Data protection act (1988) Available from: <https://www.dataprotection.ie/viewdoc.asp?DocID=796> Accessed: 01/09/2012.
- Davis, S., Fleming, R., & Marshall, M. (2009) *Environments that enhance dementia care: issues and challenges*, 3rd ed, Elsevier, Australia, p372-390
- Davis, L.A. (2005) 'Educating individuals with dementia: perspectives for rehabilitation professionals'. *Topics in Geriatric Rehabilitation*. 21 (4), p304-314.
- Davis, J.D., Stern, R.A., & Flashman, L.A. (2003) 'Cognitive and neuropsychiatric aspects of subclinical hypothyroidism: significance in the elderly'. *Current Psychiatry Reports*. 5 (5), p384-90.
- de Werd, M.D., Boelen, D., Olde Rikkert, M.G.M., & Kessels, R.P.C. (2013) 'Errorless learning in people with dementia: A review towards a clinical manual for (re)learning meaningful activities of daily living'. *Clinical Interventions in Aging*, p1177-1190.

- DeBettignies, B.H., Mahurin, R.K., & Pirozzolo, F.J. (1990) 'Insight for impairment in independent living skills in Alzheimer's disease and multiinfarct dementia'. *Journal of Clinical and Experimental Neuropsychology*, 12, p355-363.
- Delacourte, A., Robitaille, Y., Sergeant, N., Buee, L., Hof, P.R., Wattez, A., Laroche-Cholette, A., Mathieu, J., Chagnon, P. & Gauvreau, D. (1996) 'Specific pathological Tau protein variants characterize Pick's disease'. *J. Neuropathology*. 55, p159-168.
- Department of Health (2014) *The Irish National Dementia Strategy*. Dublin: Department of Health.
- Dixon, R., A., Hopp, G. A., Cohen, A.L., de Frias, C.M., & Backman, L. (2003) 'Self-reported memory compensation: similar patterns in Alzheimer's disease and very old adult samples'. *Journal of Clinical and Experimental Neuropsychology*. 25 (3), p382-390.
- Donaghey, C.L., McMillan, T.M., & O'Neill, B. (2010) 'Errorless Learning is superior to trial and error when learning a practical skill in rehabilitation: a randomized controlled trial'. *Clinical rehabilitation*, 24, p185-201.
- Donaghey, C., O'Neill, B., & McMillan, T. (2009) 'Errorless learning is superior to trial and error when learning a practical skill in rehabilitation: A randomised control trial'. *Clinical Rehabilitation*, 24 (3), p195-201.
- Doughty, K., & Burton, L. (2003) 'Assistive technologies to assess and support dementia suffers in the community'. Occupational therapy for elderly people workshop/ 15-16 July 2002. Available from: <http://64.233.179.104/scholar?hl=en&lr=&client=safari&q=cache:s6iiliH6mD8J:www.northern-consortium.org.uk/reports/Dementia.pdf+social+alarms+and+dementia> (accessed 2nd November 2007).
- Downs, M., & Bowers, B. (2010) *Excellence in Dementia care, research into practice*. UK: McGraw-Hill.
- Downs, M., & Bowers, B. (2008) 'Caring for people with dementia' *BMJ*; 336, p225
- Drunker, A.K.; Lawson, J.D.; Brown, C.J.; Williams, R.M.; Romero, P; Oh, J.S.; Oldfield, C.J.; Campen, A.M.; Ratliff, C.M.; Hipps, K.W.; Ausio, J; Nissen, M.S.; Reeves, R; Kang, C; Kissinger, C.R.; Bailey, R.W.; Griswold, M. D.; Chiu, W;

- Garner, E.C.; & Obradovic, Z (2001) 'Intrinsically disordered protein'. *Journal of molecular graphics & modelling*, 19 (1), p26–59.
- DSM-IV (2000). In American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
 - Ducharme, J.K., & Geldmacher, D.S. (2011) 'Family quality of life in dementia: a qualitative approach to family-identified care priorities', *Quality of Life Research*, 20 (8), p1331-1335.
 - Duffy, L., Gajree, S., Langhorne, P., Stott, D.J., & Quinn, T.J. (2013) 'Reliability (inter-rater agreement) of the barthel index for assessment of stroke survivors: systematic review and meta-analysis'. *Stroke* 44(2), p462-8
 - Edelman, P., Fulton, B.R., Kuhn, D. & Chang, C. (2005) 'A comparison of three methods of measuring dementia-specific quality of life: perspectives of residents, staff, and observers'. *The Gerontologist*, 45, p27–36.
 - Enabling Environments (2013) 'Enabling Environments' Available at: <http://www.enablingenvironments.com.au/AdaptaHome/Colour/ColourPerceptionandContrast.aspx> Accessed: 01/09/2013.
 - Engel, R.J., & Schutt, R.K. (2013) *The practice of research in social work*. (third edition) California: Sage publications Inc.
 - Erkinjuntti, T., Kurz, A., Gauthier, S., Bullock, R., Lilienfeld, S., & Damaraju, C.V. (2002) 'Efficacy of galantamine in probable vascular dementia and Alzheimer's disease combined with cerebrovascular disease: a randomised trial'. *Lancet*; 359, p1283-1290
 - Evans, J., Wilson, B., Schuri, U., Andrade, J. Baddeley, A., Bruna, O, et al. (2000) 'A comparison of 'errorless' and 'trial and error' learning methods for teaching individuals with acquired memory deficits'. *Neuropsychological rehabilitation*, 10, p67-101.
 - Evans, D.A., Hebert, L.E., Beckett, L.A., Scherr, P.A., Alber, M.S., Chown, M.J., Pilgrim, D.M., & Taylor, J.O. (1997) 'Education and other measures of socioeconomic status and risk of incident Alzheimer's disease in a defined population of older persons'. *Archives of Neurology*, 54 (11), p1399-405
 - Farrer, L.A., Cupples, L.A. & Haines, J.L. (1997) 'Effects of age, sex and ethnicity on the association between apolipoprotein E genotype and Alzheimer's disease. A

Meta-analysis. APOE and Alzheimer's disease Meta-Analysis Consortium'. *Journal of the American Medical Association*, 278, p1349-56

- Faul, F., Erdfelder, E., Lang, A.G., & Buchner, A. (2007). 'G*Power 3: A flexible statistical power analysis for the social, behavioural, and biomedical sciences'. *Behaviour Research Methods*, 39, p175-191.
- Ferri, C.P., Prince, M., Brayne, C., et al (2005) 'Global prevalence of dementia: a Delphi consensus study'. *Lancet*, 366, p2112-7.
- Field, A.P., (2013) *Discovering statistics using SPSS: and sex drugs and rock 'n' roll*. (4th edition). London: Sage.
- Fisher, C.M. (1989). 'Neurologic fragments n. Remarks on anosognosia, confabulation, memory and other topics and an appendix on self-observations'. *Neurology*, 39, p127-132.
- Five steps programme (2016) '5 steps to living well with Dementia in South Tipperary' Available from: www.southtipperarydementia.ie Accessed on: 23/11/16.
- Foley, J.M. (1992) *The experience of being demented*'. In R. H. Binstrock, S. G. Post, & P. J. Whitehouse (Eds.), *Dementia and aging: Ethics, values, and policy choices* (pp. 30-43). Baltimore: Johns Hopkins University Press.
- Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975) 'Mini-mental state. A practical method for grading the cognitive state of patients for the clinician'. *J Psychiatr Res.* 12(3), p189–198.
- Frank, L., Lenderking, W.R, Howard, K. & Cantillon, M. (2011) 'Patient self-report for evaluating mild cognitive impairment and prodromal Alzheimer's disease'. *Alzheimer's Research & Therapy*, 3, p35
- Frank, W., & Konta, B. (2005) 'Cognitive Training for Dementia'. *GMS Health Technol Assess.* 2005; 1: Doc10.
- Freedom of Information Act (2011) 'Amendment act', Available at: <http://www.irishstatutebook.ie/eli/2014/act/30/enacted/en/html> (Accessed: 23/09/2015).
- Freedom of Information Act (1997) 'Freedom of information' Available at: <http://www.irishstatutebook.ie/eli/1997/act/13/enacted/en/html> Accessed: 23/09/2015
- Fuller, K. (2011) 'The effectiveness of occupational performance outcome measures within mental health practice'. *British Journal of OT*, 74(8), p399-405.

- Gainotti, G. (1972) 'Emotional behaviour and hemispheric side of lesion'. *Cortex*, 8, p41-55.
- Galasko, D., Bennett, D.A., Sano, M., Marson, D., Kaye, J., Edland, S.D. (2006) 'ADCS Prevention Instrument Project: assessment of instrumental activities of daily living for community-dwelling elderly individuals in dementia prevention clinical trials'. *Alzheimer Dis Assoc Disord*, p152–169.
- Galasko, D., Bennett, D.A., Sano, M., Ernesto, C., Thomas, R., Grundman, M., et al. (1997). An inventory to assess activities of daily living for clinical trials in Alzheimer's disease-the Alzheimer's Disease Cooperative Study. *Alzheimer's Disease and Associative Disorders*, 11(Suppl 2), p33-39.
- Gauthier, S. (1999) *Clinical diagnosis and management of Alzheimer's disease*. Second edition. UK, Martin Dunitz LTD.
- Gibson, G., Dickinson, C., Brittain, K., Robinson, L. (2015) 'The everyday use of assistive technology by people with dementia and their family carers: a qualitative study' *BMC Geriatrics*, p1-10.
- Gibson, S.J., (2007) 'IASP global year against pain in older persons: highlighting the current status and future perspectives in Geriatric pain'. Expert review. *Neurother*, 7, p627-635.
- Gifford, D.R., & Cummings, J.L. (1999) 'Evaluating dementia screening tests—methodological standards to rate their performance'. *Neurology* 52, p224–227.
- Gitlin, L.N., Winter, L., Dennis, M. P. Hodgson, N., & Hauck, W.W. (2010) 'Targeting and managing behavioural symptoms in individuals with dementia: a randomised trial of a non pharmacological intervention'. *The American Geriatric Society*. 58 (8), p1465- 1474.
- Gitlin, L., Winter, L., Vause Earland, T., Adel Herge, E., Chernett, N., Piersol, C., & Burke, J. (2009) 'The tailored activity program to reduce behavioral symptoms in individuals with dementia: feasibility, acceptability, and replication potential'. *Gerontologist*, 49(3), p428-439.
- Graff, M.J.L., Vernooij-Dassen, M., Thijssen, M., Dekker, J. Hoefnagels, W., Olderikkert, M. (2007) 'Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial'. *The journals of gerontology*. Series A, Biological sciences and medical sciences, 62 (9), p 1002-9

- Green, R.C., Cupples, L.A., & Go, R. et al (2002) 'Risk of dementia among white and African American relatives of patients with Alzheimer disease'. *JAMA*, 287, p329-336.
- Guyatt, G.H., Haynes, R.B., Jaeschke, R.Z., Cook, D.J., Green, L., Naylor, C.D., Wilson, M.C. & Richardson, W.S. (2000) 'Users guide to the medical literature XXV. Evidence-based medicine: Principles for applying the users guides to patient care'. *JAMA* 284, p1290–1296.
- Guyatt, G.H., Meade, M.O., Jaeschke, R.Z., Cook, D.J. & Haynes, R.B. (2000) 'Practitioners of Evidence-based Care' *British Medical Journal* 320, p954-55.
- Haberstroh, J., Hampel, H., Pantel, J, (2010) 'Optimal management of Alzheimer's disease patients: Clinical guidelines and family advice'. *Neuropsychiatry. Dis. Treat.* 6, p243-253
- Hagedorn, R. (2000) *Tools for practice in OT: a structured approach to core skills and processes*. Churchill Livingstone, Edinburgh.
- Hakama, M., Malila, N., & Dillner, J. (2012) 'Randomised health services studies'. *International journal of cancer*, 131 (12) p2898-2902.
- Hardiman, O., & Doherty, C.P. (2011) *Neurodegenerative disorders: a clinical guide*. London, Springer- Verlag.
- Haslam, C., Gilroy, D., Black, S., & Beesley, T. (2006) 'How successful is errorless learning in supporting memory for high and low level knowledge in dementia?' *Neuropsychological Rehabilitation*, 16, p505-536.
- Hay, J., Moscovitch, M., & Levine, B. (2002)' Dissociating habit and recollection: Evidence from Parkinson's disease, amnesia and focal lesion patients'. *Neuropsychologia*, 40, p1324–1334.
- Hay, J. (1996) *Alzheimer's and Dementia: questions you have- answers you need*. USA: People's medical society.
- Herbert, P. L., McBean, A. M., O'Connor, H., Frank, B., Good, C. & Maciejewski, M. L. (2013) 'Time until incident dementia among Medicare beneficiaries using centrally acting or non-centrally acting ACE inhibitors'. *Pharmacoepidem. Drug Safe*, 22, p641–648.
- Higgins, J. J. (2013). 'Dementia diagnostics: preparing for a pending healthcare epidemic'. *MLO: Medical Laboratory Observer*, 45(7), p52-53.

- Hoe J., Hancock G., Livingston G., Orrell M. (2006) 'Quality of Life of people with dementia in residential care homes'. *British Journal of Psychiatry*, 188, p460-464.
- Holden, U.P. & Woods, R.T. (1995) *Positive Approaches to Dementia Care* (3rd edn). Edinburgh: Churchill Livingstone
- Homes, C., Cairns, N., Lantos, P., & Mann, A. (1999) 'Validity for current clinical criteria for Alzheimer's disease, Vascular dementia and dementia with Lewy bodies'. *British Journal of psychiatry*, 174, p45-50.
- Hopkins, H. L., & Smith, H. D. (Eds.). (1988) *Willard and Spackman's occupational therapy* (7th ed.), Philadelphia: Lippincott Williams and Wilkins.
- Horner, R.H., Carr, E.G., Halle, J., McGee, G., Odom, S., & Wolery, M. (2005) 'the use of single subject research to identify evidence based practice in special education', *Exceptional children*, 71, p165-179.
- Hunkin, N.M., Squires, E.J., Parkin, A.J., & Tidy, J.A. (1998) 'Are the benefits of errorless learning dependent on implicit memory?' *Neuropsychologia*, 36, p25–36
- Hutson, C., Orrell, M., Dugmore, O., & Spector, A. (2014) 'Sonas: a pilot study investigating the effectiveness of an intervention for people with moderate to severe dementia'. *American Journal of Alzheimer's disease and other dementias*. 29(8), p696-703.
- HSE (2013) 'Staff pay scales' Available at: http://www.hse.ie/eng/staff/Benefits_Services/pay/nov13.pdf (Accessed: 01/12/13).
- Hsieh, S., Schubert, S., Hoon, C., Mioshi, E. & Hodges, J. R. (2013) 'Validation of the Addenbrooke's Cognitive Examination III in Frontotemporal Dementia and Alzheimer's Disease'. *Dementia and Geriatric Cognitive Disorders*, 36, p242–250.
- International Classification of Impairments, Disabilities and Handicaps. Available at: http://whqlibdoc.who.int/publications/1980/9241541261_eng.pdf (Accessed, 01, July 2014).
- Irish Independent (2015), Available at: <http://www.independent.ie/irish-news/hses-nursing-homes-charging-2139-a-week-26734255.html> (Accessed: 17/05/2015).
- Jacoby, R., & Oppenheimer, C. (2002) *Psychiatry in the elderly*. Third edition. Oxford University Press. Oxford. p535.
- Jefferies, E., Bott, S., Ehsan, S., Lambon, R., & Matthew, A. (2011) 'Phonological learning in semantic dementia'. *Neuropsychological*, 49(5), p1208-1218

- Jekel, K., Damian, M., Wattmo, C. et al (2015) 'Mild cognitive impairment and deficits in instrumental activities of daily living: A systematic review' *Alzheimer's Research and Therapy*, 7(1).
- Jellinger, K.A. (2008) 'The pathology of 'vascular dementia'; a critical update'. *Journal of Alzheimer's disease*, 14, p107-23
- Jellinger, K.A. (2006) 'Alzheimer 100- highlights in the history of Alzheimer's research'. *Journal of Neural transmission*, 113, p1603-23
- Jellinger, Kurt (2002) 'The pathology of ischemic-vascular dementia: An update'. *Journal of the neurological sciences*, 203, p153 -157.
- Joas, E., Backman, K., & Gustafson, D. (2012) 'Blood pressure trajectories from midlife to late life in relation to dementia in women followed for 37 years'. *Hypertension*, 59, p796-801
- Johansson, L., Skoog, L., & Gustafson, D.R. (2012) 'Midline psychological distress associated with late life brain atrophy and white matter lesions: a 32 year population study of women'. *Psychosom Med*, 74, p120-125
- Jones, R. S. P., Clare, L., MacPartlin, C., & Murphy, O. (2010) 'The Effectiveness of Trial-and-Error and EL in Promoting the Transfer of Training'. *European journal of behaviour analysis*, 1.
- Jones, G., Miesen, M., & Bere, M.L. (2004) *Care-Giving in Dementia: research and applications*. Vol 3. Psychology press.
- Jones, B. N. Jayaram, G., Samuels, J., & Robinson, H. (1998) 'Relating competency status to functional status at discharge in patients with chronic mental illness'. *Journal of the American Academy Of Psychiatry And The Law*, 26(1), p49-55.
- JRF Joseph Rowntree Foundation (2012). Available from: <http://www.jrf.org.uk/sites/files/jrf/dementia-communities-york-full.pdf> (Accessed 14/06/2014).
- Kaffashian, S., Dugravot, A., & Elbaz, A. (2013) 'Predicting cognitive decline: a dementia risk score vs the Framingham vascular risk scores'. *Neurology*, 80, p1300-1306
- Kalbe E, Salmon E, Perani D, Holthoff V, Sorbi S, Elsner A, Weisenbach S, Brand M, Lenz O, Kessler J, Luedecke S, Ortelli P, & Herholz K. (2005) 'Anosognosia in very mild Alzheimer's disease but not in mild cognitive impairment'. *Dementia and Geriatric Cognitive Disorders*, 19, p349–356.

- Katz, S., Down, T.D., Cash, H.R., & Grotz, R.C. (1970) 'Progress in the development of the index of ADL'. *The Gerontologist*, 10(1), p20-30
- Kaufer, D. I., Cummings, J. L., Christine, D., et al (1998) 'The impact of neuropsychiatric symptoms in Alzheimer's disease: the Neuropsychiatric Inventory Caregiver Distress Scale'. *Journal of the American Geriatrics Society*, 46, p210–216.
- Kaur, R., Casey, J.R., & Pichichero, M.E. (2013) 'Relationship with original pathogen in recurrence of acute otitis media after completion of amoxicillin/clavulanate: bacterial relapse or new pathogen'. *Pediatric Infectious Disease Journal*, 32(11), p1159-62.
- Kelly, M. E., & O' Sullivan, M. (2015) *Strategies and techniques for cognitive rehabilitation. Manual for healthcare professionals working with individuals with cognitive impairment*. Dublin: The Alzheimer's society of Ireland, Trinity College Dublin and NEIL.
- Kessels, R. P. C., van Loon, E., & Wester, A.J. (2007) 'Route learning in amnesia: A comparison of trial-and-error and EL in patients with the Korsakoff syndrome'. *Clinical Rehabilitation*, 21, p905-911.
- Kessing, L. (2012) 'Depression and the risk for dementia'. *Current opinion in psychiatry*, 25 (6) p457-61.
- Kielhofner, G. (1995) *A model of human occupation: theory and application* (2nd edition). Baltimore, M.D. Williams and Wilkins.
- Kielhofner, G. (2002) 'A model of human occupation: theory and application' (3rd edition). Baltimore, MD: Lippincott Williams and Wilkins.
- Kim, S.Y., Yoo, E.Y., Jung, M.Y., Park, S.H., & Park, J.H. (2012) 'A systematic review of the effects of occupational therapy for persons with dementia: a meta-analysis of randomized controlled trials'. *Neurorehabilitation*. 31(2), p107-15.
- Kiresuk, T.J., Smith, A. & Cardillo, J. E. (1994) *Goal Attainment Scaling: Applications Theory, and Measurement*. Hillsdale, NJ: Lawrence Erlbaum Associates.
- Kitwood, T. (1997) 'The experience of dementia'. *Aging & Mental Health*, 1(1), p13-22.
- Kline, F. M., Schumaker, J. B., Deshler, D.D. (1991) '1990 Winner of CLD's Award for Outstanding Research: Development and Validation of Feedback Routines for

Instructing Students with Learning Disabilities'. *Learning Disability Quarterly*. 14 (3), p. 191-207.

- Klunk, W. E., Engler, H., Nordberg, A., Wang, Y., Blomqvist, G., Holt, D. P., Bergström, M., Savitcheva, I., Huang, G.-F., Estrada, S., Ausén, B., Debnath, M. L., Barletta, J., Price, J. C., Sandell, J., Lopresti, B. J., Wall, A., Koivisto, P., Antoni, G., Mathis, C. A. & Långström, B. (2004) 'Imaging brain amyloid in Alzheimer's disease with Pittsburgh Compound-B'. *Ann Neurol*, 55, p306–319.
- Knapp M, Thorgrimsen L, Patel A, et al. (2006) 'Cognitive stimulation therapy for people with dementia: cost effectiveness analysis', *British Journal of Psychiatry*, 188, p574–580.
- Kolanowski, A., & Buettner, L. (2008) 'Prescribing activities that engage passive residents: an innovative method', *Journal of Gerontological Nursing*, 34(1), p13-18.
- Kolanowski, A., Litaker, M., Buettner, L. (2005) 'Efficacy of theory based activities for the behavioural symptoms of dementia in nursing home residents'. *Journal of the American Geriatric Society*, 59, p1032-1041.
- Kolanowski, A., Litaker, M., Buettner, L., Moeller, J. & Costa, P. T. (2011) 'A randomised clinical trial of theory based activities for the behavioural symptoms of dementia in nursing home residents'. *Journal of the American Geriatric society*, 59, p1032-1041.
- Kovach, C.R., Noonan, P.E., Schlidt, A.M., & Wells, T. (2005) 'A model of consequences of need-driven, dementia-compromised behaviour'. *J Nurs Scholarsh*, 37, p134-140.
- Kratochwill, T.R., Hitchcock, J., Horner, R.H., Levin, J.R., Odom, S.L., Rindskopf, D.M. & Shadish, W.R. (2010). Single-case designs technical documentation. Available from: http://ies.ed.gov/ncee/wwc/pdf/wwc_scd.pdf. (Accessed: 23/09/2015).
- La Rue, A. (1992) *Aging and Neuropsychological Assessment*. New York, NY: Plenum Press.
- Lamport, L., Shostak, R., & Peas, M. (1982) 'The Byzantine generals problem' *.ACM Trans Prog. Lang. Syst.* 4(3), p382-401.
- Lancioni, G.E., Perilli, V., O'Reilly, M.F., Singh, N.N., Sigafoos, J., Bosco, A., Caffo, A.O., Picucci, L., Cassano, G., & Groeneweg, J. (2013) 'Technology-based orientation programs to support indoor travel by persons with moderate Alzheimer's

disease: Impact assessment and social validation'. *Research in Developmental Disabilities* 34, p286–293.

- Law, M., Cooper, B.A., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996) 'The Person-Environment-Occupation Model: A transactive approach to occupational performance'. *Canadian Journal of OT*, 63 (1), p9-22.
- Law, M., Baptiste, S., & Mills, J. (1995) 'Client centred practice: what does it mean and does it make a difference?' *Canadian Journal of Occupational Therapy* 65 (5), p250-257
- Law, M., Polatjko, H., Pollock, N., McColl, M.A., Carswell, A., & Baptiste, S. (1994) Pilot testing of the Canadian Occupational Performance Measure: Clinical and measurement issues. *Can J Occupational Therapy*. 61(4), p191-97.
- Law reform commission (2005) Available from: <http://www.lawreform.ie/news/2005.224.html> (Accessed: 23/09/2015).
- Lekeu, F., Wojtasik, V., Van der Linden, M., & Salmon, E. (2002) 'Training early Alzheimer's patients to use a mobile phone'. *Acta Neurology Belgium*, 102, p114-121
- Li, R., & Liu, K. (2012) 'The use of errorless learning strategies for patients with Alzheimer's disease: a literature review'. *International Journal of rehabilitation research*. Vol.00.
- Lin, L.C., Yang, M.H., Kao, C.C., Wu, S.C., Tang, S. H. & Lin, J.G. (2009) 'Using acupuncture and Montessori based activities to decrease agitation for residents in dementia: a cross-over trial'. *Journal of the American Geriatric Society*, 57, p1022-1029.
- Livingstone, G., Johnson, K., Katona, C., Paton, J. & Lyketos, C. (2005) 'Systematic Review of Psychological Approaches to the Management of Neuropsychiatric Symptoms of Dementia', *Am J Psychiatry*, 162, p1996–2021
- Lloyd, C. & Mass, F. (1997) 'Occupational Therapy Group Work in Psychiatric Settings', *British Journal of Occupational Therapy*, May, 60(5), p226-230.
- Lo, A.H., Pachana, N.A., & Byrne, G.J., (2012) 'Relationship between changes in body weight and cognitive function in middle aged and older women'. *International Journal of Geriatric Psychiatry*, 27, p863-872

- Logsdon, R, McCurry, S., Teri, L. (2007) 'Evidenced based interventions to improve quality of life for individuals with dementia' *Alzheimer's Care Today*. 8 (4), p309-318.
- Logsdon, R.G., Gibbons, L.E., McCurry, S.M., & Teri, L. (2002) 'Assessing quality of life in older adults with cognitive impairment'. *Psychosomatic Medicine*, 64, p510-519.
- Logsdon, R.G., Gibbons, L.E., McCurry, S.M., & Teri, L. (1999). 'Quality of life in Alzheimer's disease: Patient and caregiver reports'. *Journal of Mental Health & Aging*, Volume 5, Number 1, p21-32.
- Lopes, M., Furtado, E., Ferrioli, E., Litvoc, J., & de Campos Bottino, C. (2010). Prevalence of alcohol-related problems in an elderly population and their association with cognitive impairment and dementia. *Alcoholism: Clinical & Experimental Research*, 34(4), 726-733.
- Loy, J.H., Merry, S.N., Hetrick, S.E., & Stasiak, K. (2012) 'Atypical antipsychotics for disruptive behaviour disorders in children and youths'. *Cochrane Database Systematic Reviews*. 9.
- Loy, C. T., Hayen, A., & McKinnon, C. (1999) 'Protocol for REducing Anti-Psychotic use in residential care-Huntington Disease (REAP-HD): a pilot cluster randomised controlled trial of a multifaceted intervention for health professionals' *BMJ Open*, 4: p6151
- Lublin, A.L., & Gandy, S. (2010) 'Amyloid-beta oligomers: possible roles as key neurotoxins in Alzheimer's Disease', *Mt Sinai J Med*, 77(1):p43-9.
- Lyketsos, C.G., Lopez, O., Jones, B., Fitzpatrick, A., Breitner, J., & DeKosky, S. (2002) 'Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment', *JAMA*, 288, p1475–1483
- Lyketsos, C.G., Steinberg, M., Tschanz, J.T., Norton, M.C., Steffens, D.C., Breitner, J.C.S. (2000) 'Mental and behavioural disturbances in dementia: findings from the Cache County Study on Memory in Aging'. *Am J Psychiatry*, 57, p708–714.
- Mahoney, F.I., & Barthel, D.W. (1965) 'Functional evaluation: The Barthel Index'. *Med. J.* 14, p61–65.
- Mahoney FI, Barthel D. (1965) 'Functional evaluation: the Barthel Index' *Maryland State Med Journal*, 14, p56-61.

- Mangone, C. A., Hier, D. B., Gorelick, P. B., Ganellen, R. J., Langerberg, P., Boarman, R., & Dollear, W. C. (1991) 'Impaired insight in Alzheimer's disease'. *Journal of Geriatric Psychiatry and Neurology*, 4, p189-193.
- Mathuranath, P. S., Nestor, P.J., Berrios, G.E., Rakowicz, W., Hodges, J.R. (2000) 'A brief cognitive test battery to differentiate Alzheimer's disease and frontotemporal dementia'. *Neurology*, 55(11), p1613-20.
- Marcotte, T. D., Scott, J. C., Kamat, R., & Heaton, R. K. (2010). 'Neuropsychology and the prediction of everyday functioning'. In T. D. Marcotte, & I. Grant (Eds.), *Neuropsychology of everyday functioning* (p 5–38). New York, NY: Guilford Press.
- Marcé, L.V. (1863) 'Recherches cliniques et anatomo-pathologiques sur la démence senile et sur les différences qui la separent de la paralysie générale'. *Gazette Médicale de Paris*, 34, 433–5; 467–9; 497–502; 631–2; 761–4; 797–8; 831–3; 855–8.
- Margolis, R. L., Harrison, S.A., Robinson, H.J., & Jayaram, G. (1996) 'Occupational Therapy Task Observation Scale (OTTOS)©: A Rapid Method for Rating Task Group Function of Psychiatric Patients'. *Am J Occupational Therapy* 50(5), p380-385.
- Marshall, M. (2001) 'Environment: How it helps to see dementia as a disability', In *Care Homes and Dementia* (ed S Benson). The Journal of Dementia Care, 6, p15-17.
- Marshall, M. (1998) (ed) 'Design for Dementia London'. *The Journal of Dementia Care*.
- Martin, S., Kelly, G., Kernohan, W.G., McCreight, B., & Nugent, C. (2009) 'Smart home technologies for health and social care support (review)'. *Cochrane Database of Systematic Reviews*, Issue 4.
- Mattson, M.P. (August 2004) 'Pathways towards and away from Alzheimer's disease'. *Nature*, 430 (7000), p631–9.
- McCabe, L. F. (2011) 'Alcohol, ageing and dementia: A Scottish perspective'. *Dementia*, 10(2), p149-163.
- McCallion, P., Toseland, R. W., Lacey, D. & Banks, S. (1999) 'Educating nursing assistants to communicate more effectively with nursing home residents with dementia'. *Gerontologist*, 39, p546–558.
- McDermott, A. A. (1988) 'The effect of three group formats on group interaction patterns'. *Occupational Therapy in Mental Health*, 8, p69–89.

- McKeith, I. (2005) 'Dementia with Lewy bodies'. *Psychiatry*, 4 (1), p52 -55
- McLellan, D.L. (1991) 'Functional recovery and the principles of disability medicine'. In Swash M, Oxbury J. (1991) *Clinical Neurology* Vol 1. London: Churchill Livingstone; p768–790.
- McManus, M., & McClenaghan, M. (2010) *Hearing. Sound and the Acoustic Environment for people with dementia*. University of Stirling. Stirling.
- McNair, D. (2010) *Light and Lighting Design for People with Dementia*. University of Stirling. Stirling.
- Meyniel, C., Rivaud-Pechoux, S., Damier, P., & Gaymard, B. (2005) 'Saccade impairments in patients with fronto-temporal dementia'. *J Neurological Neurosurgical Psychiatry*, 76, p1581–1584.
- Middleton, E.L., & Schwartz, M.F. (2012) 'Errorless learning in cognitive rehabilitation: a critical review'. *Neuropsychological Rehabilitation*, 22 (2), p138-168.
- Milev, R.V., Kellar, T., McLean, M., Mileva, V., Luthra, V., Thompson, S., & Peever, L. (2008) 'Multisensory stimulation for elderly with dementia: a 24-week single-blind randomized controlled pilot study'. *American Journal of Alzheimer's Disease & Other Dementias*, 23, p372 – 376.
- Mitchell, L., & Burton, E. (2006) 'Neighbourhoods for life: Designing dementia-friendly outdoor environments', *Quality in Ageing and Older Adults*, 7 (1), pp.26 – 33
- Mitchell, S.L., Kiely, D.K., Hamel, M., Park, P.S., Morris, J.N., & Fries, B.E. (2004) 'Estimating Prognosis for Nursing Home Residents With Advanced Dementia'. *JAMA*. 291(22), p2734-2740.
- Mitolo, M., Venneri, A., Wilkinson, I.D. & Sharrack, B. (2015) 'Cognitive rehabilitation in multiple sclerosis: A systematic review'. *Journal of the Neurological Sciences*, 354(1–2), pp. 1–9.
- Moniz-Cook, E., Elston, C., Gardiner, E., & Agar, S., (2008) 'Can training community mental health nurses to support family carers reduce behavioural problems in dementia? An exploratory pragmatic randomised controlled trial'. *International Journal of Geriatric Psychiatry*, 23(2), p185-191.
- Moishi, E., Dawson, K., Mitchell, J., Arnold, R., & Hodges, J.R. (2006) 'The Addenbrooke's Cognitive Examination Revised (ACE-R): a brief cognitive test

battery for dementia screening' *International Journal of Geriatric Psychiatry*, 21, p 1078–1085.

- Molloy, D.W., & Standish, T.I. (1997) 'A guide to the standardized Mini-Mental State Examination'. *Int Psychogeriatric*, 9 (1), p87–150.
- Molloy, D.W., Silberfeld, M., Darzins, P., Guyatt, G.H., Singer, P.A., Rush, B., Bédard, M., & Strang, D. (1996) 'Measuring capacity to complete an advance directive'. *J Am Geriatr Soc*, 44(6), p660–664.
- Molloy, D.W., McIlroy, W.E., Guyatt, G.H., & Lever, J.A. (1991) 'Validity and reliability of the Dysfunctional Behaviour Rating Instrument'. *Acta Psychiatr Scand*. 84(1), p103–106.
- Molloy, D.W., Alemayehu, E., & Roberts, R. (1991) 'Reliability of a standardised Mini-Mental State Examination compared with the traditional Mini-Mental state Examination'. *American Journal of Psychiatry*, Vol. 14, p102-105.
- Moniz-Cook, E.D., Elston, C., Gardiner, E., Agar, S., Silver, M., Win, T. & Wang, M. (2008) 'Can training Community Mental Health Nurses to support family carers reduce behavioural problems in dementia? An exploratory pragmatic randomised controlled trial'. *International Journal of Geriatric Psychiatry*, 23, 2, p185-191
- Moniz- Cook, E., Agar, S., Gibson, G., Win, T., & Wang, M., (1998) 'A preliminary study of early intervention with people with dementia and their families in a memory clinic'. *Aging mental health*. 2 (3), p199-211.
- Moreton, I. (1999) 'person centred approaches to dementia care'. UK: Speechmark Publishing Ltd.
- Morgan, D. L., & Morgan, R. K. (2001) 'Single-participant research design. Bringing science to managed care'. *The American psychologist*, Vol.56(2), p119-27
- Morley, M., & Smyth, G. (2013) 'Are occupational therapy interventions for service users with mental health problems cost-effective?' *British Journal of Occupational Therapy*, 76(10), p470–473.
- Morley, S., & Adams, M. (1991) 'Graphical analysis of single case time series data'. *British journal of clinical psychology*, 28, p1-18.
- Mosey, A. C. (1986) *Psychosocial components of occupational therapy*. New York: Raven Press.
- Murphy, F., Brady, O., O'Halloran, J., Hogan, M. Shiel, A., O' Cuill, M. (2013) 'A qualitative evaluation of CST and Sonas' (in progress).

- Namazi, K., & Johnson, B. (1991) 'Physical environmental cues to reduce the problems of incontinence in Alzheimer's disease units'. *The American Journal of Alzheimer's Care and Related Disorders & Research*, 6 (6), p22–28.
- Namazi, K.H., Rosner, T.T., & Rechlin, L. (1991) 'Long-term memory cuing to reduce visuo-spatial disorientation in Alzheimer's disease patients in a special care unit'. *American Journal of Alzheimer's Care and Related Disorders and Research*. 7, p10–15.
- NAPA (2013) 'My home from home', Available at: <http://www.myhomefromhome.ie> (Accessed 01/01/2013).
- National Dementia Awareness Programme (2015) Available at: <http://www.hse.ie/eng/services/Publications/corporate/NursingMidwifery%20Services/dementia.html> (Accessed: 23/08/2015).
- National Institute for Health and Clinical Excellence (NICE), Social care institute for excellence (SCIE), (2007). Dementia: A NICE- SCIE guideline on supporting people with dementia and their carer's in health and social care. Available at: www.nice.org.uk/nicemedia/ (Accessed 09/04/2014).
- National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (NICE-SCIE), (2006) 'Dementia: supporting people with dementia and their carers in health and social care. Clinical Guideline 42'. London: NICE-SCIE.
- National Institute on Aging (NIH) (2014). Available at: www.nia.nih.gov/alzheimers/publication/alzheimers-disease-genetics-fact-sheet#genetics (Accessed 09/04/2014).
- National University of Ireland Galway (2006) *Research Ethics Committee Data Retention Policy*. NUI Galway: Galway.
- Ness, S., Rafii, M., Aisen, P., Krams, M., Silverman, W., & Manji, H. (2012) 'Down's syndrome and Alzheimer's disease: towards secondary prevention'. *Nature reviews. Drug discovery*, 11(9), p655 -6
- Ninomiya, T. (2014) 'Diabetes Mellitus and Dementia'. *Current Diabetes Reports*, 14, p487
- Nordström, P., Nordström, A., & Eriksson, M. (2013) 'Risk factors in late adolescence for younger onset dementia in men: a Nationwide cohort study'. *JAMA Intern Med.* 173, p1612-1618

- Nygård, L. (2003) 'Instrumental activities of daily living: a stepping-stone towards Alzheimer's disease diagnosis in participants with mild cognitive impairment?' *Acta Neurol Scand Suppl.* 179, p42–46.
- Office of the Attorney General, 'Assisted Decision-Making (Capacity) Act 2015', no 65 of 2015.
- Olazaran, J., Reisberg, B., Clare, L., & Cruz, I., (2010) 'Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy'. *Dementia and Geriatric Cognitive Disorders*, 30(2), p161-78.
- Orgeta, V., Qazi, A., & Spector, A.E. (2014) 'Psychological treatments for depression and anxiety in dementia and mild cognitive impairment'. *Cochrane Database of Systematic Reviews*, Issue 1.
- Orrell, M., Woods, B., & Spector, A. (2012) 'Should we use individual cognitive stimulation therapy to improve cognitive function in people with dementia?' *BMJ*, 344, p633
- Orrell, M., Spector, A., Thorgrimsen, L., & Woods, B. (2005) 'A pilot study examining the effectiveness of maintenance cognitive stimulation therapy (MCST) for people with dementia'. *International Journal of Geriatric Psychiatry* 20 (5), p446–451.
- O'Brien, M.D. (1994) 'Vascular dementia: Problems with nomenclature, definition, and classification Source', *Journal of stroke and cerebrovascular diseases*, vol:4 (1), p52 -56
- O'Brien, J.T., Eagger, S., Syed, G.M., Sahakian, B.J., & Levy, R. (1992) 'A study of regional cerebral blood flow and cognitive performance in Alzheimer's disease'. *J Neurol Neurosurg Psychiatry.* 55(12), p1182–1187.
- O'Connor, C.M., Clemson, L., Brodaty, H., Jean, Y.H., Moishi, E., Gitlin, L.N. (2014) 'Use of the tailored activities programme to reduce neuropsychiatric behaviours in dementia: an Australian protocol for a randomized trial to evaluate its effectiveness'. *International Psychogeriatrics*, 26 (5), p857-869.
- O'Rourke, H.M., Duggleby, W., Fraser, K.D., & Jerke, L. (2015) 'Factors that affect quality of life from the perspective of people with dementia: A metasynthesis'. *Journal of the American Geriatrics Society*, Vol.63(1), p24-38
- Panza, F., Frisardi, V., Seripa, D., Logroscino, G., Santamato, A., Imbimbo, B., Solfrizzi, V. (2012) 'Alcohol consumption in mild cognitive impairment and

dementia: harmful or neuroprotective?' *International Journal of Geriatric Psychiatry*, 27(12), p1218-1238.

- Park, S., Marascuilo, L., & Gaylord-Ross, R. (1990) 'Visual Inspection and Statistical Analysis in Single-Case Designs', *The Journal of Experimental Education*, 58 (4), p 311-320
- Parker, R.I., & Brossart, D.F. (2003) 'Evaluating single case research data: a comparison of seven statistical methods', *Behaviour Therapy*. 34, p189-211.
- Parkin, A. J., Hunkin, N. M., & Squires, E. J. (1998). 'Unlearning John Major: The use of errorless learning in the reacquisition of proper names following herpes simplex encephalitis'. *Cognitive Neuropsychology*, 15(4), p361–375.
- Parrish, J., Wilshaw, J. & Baker, J. (2005) 'That was lovely dear, evaluating the effectiveness of Sonas' *Journal of Dementia Care*, p36-37.
- Pattie, A.H., & Gilleard, C.J. (1979) *Manual of the Clifton Assessment Procedures for the Elderly (CAPE)*. Sevenoaks, Kent, UK: Hodder and Stoughton.
- Pieper, M.J.C., Van Dalen-Kok, A.H., Fancke, A. L., van der Steen, J.T., Sherder, E.J.A., Husebo, B.S., & Achterberg, W.P. (2013) 'Interventions targeting pain or behaviour in dementia: A systematic review'. *Ageing research reviews* 12, p1042-1055
- Pinheiro, C., & Da Silva, F.M. (2012) 'Colour, vision and ergonomics'. *Work* 41 (suppl.1), p5590-5593.
- Pollock, A., & Fuggle, L. (2013) 'Designing for dementia: creating a therapeutic environment'. *Nursing and Residential Care*, June, Vol 15, no6.
- Prince, M. (2009) 'The 10/66 dementia research group - 10 years on'. *Indian Journal of Psychiatry*, vol:51 (5), p8 -15
- Ratnavalli, E., Brayne, C., & Dawson, K. (2002) 'The prevalence of Frontotemporal dementia'. *Neurology* 58, p1615-21
- Ravona-Springer, R., Schnaider-Beerli, M., & Goldbourt, U. (2013) 'Body weight variability in midlife risk for dementia in old age'. *Neurology*, 80, p1677- 1683.
- Razani, J., Kakos, B., & Orieta-Barbalace, C. (2007) 'Predicting caregiver burden from daily functional abilities of patients with mild dementia'. *J Am Geriatric Soc.* 55 (9), p1415-1420.
- Razani, J., Bayan, S., Funes, C., Mahmoud, N., Torrence, N., Wong, J., Alessi, C., & Josephson, K. (2011) 'Patterns of Deficits in Daily Functioning and Cognitive

Performance of Patients with Alzheimer Disease'. *Journal Of Geriatric Psychiatry And Neurology*, 24(1), p23-32

- Reifler, B.V., & Larson, E. (1990) 'Excess disability in dementia of the Alzheimer's type'. In *Alzheimer's Disease Treatment and Family Stress*. Edited by Light E, Lebowitz BD. New York: Hemisphere
- Reijmer, Y.D., Van den Berg, E., & Dekker, J.M. (2012) 'Development of vascular risk factors over 15 years in relation to cognition: the hoorn study'. *Journal of the American Geriatric Society*, 60, p1426-1433.
- Riley-Tillman, C., & Burns, M.K. (2009) 'Evaluating Educational Interventions: Single-Case Design for Measuring Response to Intervention'. New York: The Guilford press.
- Rist, P.M., Capistrant, B.D. Wu, Q., Marden, J.R., & Glymour, M.M. (2014) 'Dementia and dependence, do modifiable risk factors delay disability'. *Neurology* 82, p1543-1550
- Robert, P.H., Verhey, F.R.J., Byrne, E. J., et al, (2005) 'Grouping for behavioural and psychological symptoms in dementia: clinical and biological aspects. Consensus paper of the European Alzheimer disease consortium'. *Eur. Psychiatry*, 20, p490-622
- Robertson, I. (2014) 'A right hemisphere role in cognitive reserve'. *Neurobiology of Aging*, 35(6), p1375-1385.
- Rodda, J., & Carter, J. (2012) 'Cholinesterase inhibitors and Memantine for symptomatic treatment of dementia'. *BMJ*; 344, p2986
- Rooney, R.F.E. (2014) 'Preventing Dementia: how lifestyle in midlife affects risk. Current opinion psychiatry'. March, 27 (2), p149-157
- Ross, R., Janaszewski, P.M. (2008) 'Is weight loss the optimal target for obesity related cardiovascular disease risk reduction?' *Canadian Journal of Cardiology*. 24(D), p25-31.
- Ross (2000), cross reference: <http://dementialelevator.ie/training-programmes/dementia-awareness-training/level-3-dementia-awareness-training-for-health-and-social-care-workers/>. (Accessed: August, 2015).
- Rosso, S.M., Donker Kaat, L., & Baks, T. (2003) 'Frontotemporal dementia in the Netherlands: patient characteristics and prevalence estimates from a population-based study'. *Brain*, 126, p2016-22.

- Rossor, M. N. (2001) 'Pick's disease: a clinical overview'. *Neurology*, 56(11) Supplement 4, p3-5.
- Saunders, R. & Spradlin, J. (1996) 'A supported routine approach to active treatment for enhancing independence, competence and self-worth', *Behavioural Interventions*, 11 (2), P 59–86.
- Sawyer, P., Lillis, J.P., Bodner, E.V., & Allman, R.M., (2007) 'Substantial daily pain among nursing home residents'. *J. Am. Med. Dire. Assoc.* 8, p158-165.
- Schafer, I., Von Leitner, E. C., Schon, G., Koller, D., Hansen, H., Kolonko, T., Kaduszkiewicz, H., Wegscheider, K., Glaeske, G., & Van den Bussche, H. (2010) 'Multimorbidity patterns in the elderly: a new approach of disease clustering identified complex interrelations between chronic conditions'. *PloS One* 5(12), p15941
- Schmitz, X., Bier, N., Joubert, S., Lejeune, C., Salmon, E., Rouleau, I., & Meulemans, T. (2014) 'The benefits of errorless learning for serial reaction time performance in Alzheimer's disease' *Journal of Alzheimer's Disease*, 39 (2), p287-300.
- Schmitter-Edgecombe, M., & Parsey, C.M. (2014) 'Cognitive Correlates of Functional Abilities in Individuals with Mild Cognitive Impairment: Comparison of Questionnaire, Direct Observation, and Performance-Based Measures', *The Clinical Neuropsychologist*, 28(5), p726-746
- Schnell, G. (1998) 'Monitoring the progress of young people's occupational performance in an inpatient mental health setting'. *New Zealand Journal of OT*, 55 (2), p4-10.
- Schneider, L.S., Mangialasche, F., Andreasen, N., Feldman, H., Giacobini, E., Jones, R., Mantua, V., Mecocci, P., Pani, L., Winblad, B., & Kivipelto, M. (2013) 'Clinical trials and late-stage drug development for Alzheimer's disease: an appraisal from 1984 to 2014 (Key Symposium)', *J Intern Med*, 275, p251–283.
- Schneider, J.A., Arvanitakis, Z., Bang, W., & Bennett, D.A. (2007) 'Mixed brain pathologies account for most dementia cases in community-dwelling older persons'. *Neurology*, 69, p2197-2204
- Schouenborg, J. (2008) 'Action-based sensory encoding in spinal sensorimotor circuits'. *Brain research reviews*, 57 (1), p111-117.

- Scott, S., Jones, L., Blanchard, M.R., & Sampson, E.L. (2011) 'Study Protocol: The Behaviour and Pain in Dementia Study (BePAID)'. *BMC Geriatrics* 11, p61.
- Selwood, A., Thorgrimsen, L., & Orrell, M. (2005) 'Quality of life in dementia, a one year follow up study'. *International Journal of Geriatric Psychiatry*, 20, p232-237.
- Shan, Y. (2013) 'Treatment of Alzheimer's disease'. *Primary Health Care*, 23(6), p32-38.
- Shulman, K.I. (2000) 'Clock-drawing: is it the ideal cognitive screening test?', *Int. J. Geriatric Psychiatry*, 15, p548–561.
- Sifton, C. (2005) 'So What Does Typical Mean Anyway?' *Alzheimer's care quarterly*. July/September, Vol. 6 (3), p173-175
- Slocum, S.H., & Tiger, J.H. (2011) 'An assessment of the efficiency of child preference for forward and backward chaining'. *Journal of applied behaviour analysis*, 44 (4), p793–805
- Snowden, J.S., Neary, D., & Mann, D.M.A. (1996) *Frontotemporal lobar degeneration: Frontotemporal dementia, progressive aphasia, semantic dementia*. London: Churchill Livingstone
- Sonas aPc (2015) 'Cost of attendance' Available at: <http://sonasapc.ie/sonas-training-course/> (Accessed: October 2015).
- Sonas aPc (2014) Available at: www.sonasapc.ie. (Accessed: August 2014).
- Sonas aPc (2012) *Sonas group session evaluation form*. Dublin: Sonas aPc.
- Sonas aPc (2011) 'NAPA figures' Email from Sinead Grennan, CEO, July, 2011.
- Spector, A., Gardner, C., & Orrell, M. (2011) 'The impact of Cognitive Stimulation Therapy groups on people with dementia: views from participants, their carers and group facilitators'. *Ageing & Mental Health* 15 (8), p945-950.
- Spector, A., Woods, B., & Orrell, M. (2008) 'Cognitive stimulation for the treatment of Alzheimer's disease'. *Expert Review of Neurotherapeutics* 5, p751–757.
- Spector A, Thorgrimsen L, Woods B, & Orrell M. (2006) *Making a Difference: An Evidence-Based Group Programme to Offer Cognitive Stimulation Therapy (CST) to People with Dementia*. Hawker Publications: UK.
- Spector A, Thorgrimsen L, Woods B, Royan L, Davies S, Butterworth M, et al. (2003) 'Efficacy of an evidence-based stimulation therapy programme for people with dementia'. *British Journal of Psychiatry* 183(24), p248–254.

- Spector, A., Davies, S., Woods, B., & Orrell, M. (2000) 'Reality Orientation for Dementia: A Systematic Review of the Evidence of Effectiveness from Randomized Controlled Trials' *The Gerontologist*, 40 (2), p206–21.
- Spector, A., Orrell, M., Davies, S., & Woods, B. (1998) 'Reality Orientation for dementia: a review of the evidence for its effectiveness'. In the Cochrane Library, Issue 4. Update Software: Oxford.
- Starkstein, S.E., Jorge, R., Mizrahi, R., & Robinson, R.G. (2006) 'A diagnostic formulation for anosognosia in Alzheimer's disease'. *Journal of Neurology, Neurosurgery and Psychiatry*, 77, p719–725.
- Stein, F., & Taliant, B. (1988) 'Applying the group process to psychiatric occupational therapy. Part 2: a model for a therapeutic group in psychiatric occupational therapy'. *Occupational Therapy in Mental Health*, 8, p29-51.
- Stewart, R., & Liolitsa, D. (1999) 'Type 2 diabetes mellitus, cognitive impairment and dementia'. *Diabetes Med.* Feb; 16(2), p93-112.
- Stocchi, F., & Brusa, L., (2000) 'Cognition and emotion in different stages and subtypes of Parkinson's disease'. *J. Neurology*, 247(2), p114-121.
- Strand, B.H., Langballe, E.M., & Hjellvik, V. (2013) 'Midlife vascular risk factors and their association with dementia deaths: results from a Norwegian prospective study followed up for 35 years'. *Journal of Neurological science*, 324, p124-130
- Strom, B.S., Engedal, K., Grov, E. K. (2016) 'A psychometric evaluation of the Threadgold Communication Tool for Persons with Dementia', *Dementia and Geriatric Cognitive Disorders Extra*, 6, p150-160.
- Sumsion, T. (2006). *Client- Centred Practice in Occupational therapy: a guide to implementation*. Second edition. London, Churchill Livingstone Elsevier.
- Tailby, R. & Haslam, C. (2003) 'An investigation of errorless learning in memory-impaired patients: Improving the technique and clarifying theory', *Neuropsychologia*, 41, p1230–1240 .
- Takai, Y., Yamamoto-Mitani, N., Okamoto, Y., Koyama, K., & Honda, A., (2010). 'Literature review of pain prevalence among older residents of nursing homes'. *Pain management Nursing*. 11, p209-223.
- Tate, R., Mcdonald, S., Perdices, M., Togher, L., Schultz, R., & Savage, R. (2008) 'Rating the methodological quality of single-subject designs and n-of-1 trials:

Introducing the Single-Case Experimental Design (SCED) Scale'

Neuropsychological Rehabilitation, 18, p385–401.

- Terracciano, A., Sutin, A. R., An, Y., O'Brien, R. J., Ferrucci, L., Zonderman, A.B., & Resnick, S.M. (2014) 'Personality and risk of Alzheimer's disease: New data and meta-analysis'. *Alzheimer's and Dementia*, 10, p179-186
- Thomas, P., Ingrand, P., Lalloue, F., Hazif-Thomas, C., Billon, R., Vieban, F., & Clement, J.P. (2004) 'Reasons of informal caregivers for institutionalising dementia patients previously living at home: the Pixel study'. *International Journal of Geriatric Psychiatry*. 19, p127–135.
- Thorgrimsen, L, Selwood, A, Spector, AL, Royan, L, Lopez, MM, Woods, B, & Orrell, M (2003) 'Whose quality of life is it anyway? The validity and reliability of the Quality of Life-Alzheimer's Disease (QoL-AD) scale'. *Alzheimer Disease & Associated Disorders*, 17(4), p201-8.
- Tolppanen, A.M., Ngandu, T., & Kareholt, I. (2014) 'Midlife and late life body mass index and late life dementia: results from a prospective population based cohort'. *Journal of Alzheimer's disease* 38, p201-209
- Trepel, D., (2010) 'Valuing Informal Caregiving in Ireland by the Replacement Cost in 2010'. Unpublished, 2010.
- Tyrell, J., Cosgrave, M., McCarron, M. et al (2001) 'Dementia in people with downs syndrome'. *International journal of geriatric psychiatry*. 16, p1168-1174.
- UN joint programme on HIV/Aids (2010), Available at: <http://www.unaids.org/> Accessed (October 2015).
- University of Glasgow (2015) 'ACE III trainer', Available at: <https://www.fom.gla.ac.uk/aceiiitrainer/> (Accessed 23/09/2015).
- Van den Bussche, H., Schon, G., Kolonko, T., Hansen, H., Wegscheider, K., Glaeske, G., Koller, D. (2011) 'Patterns of ambulatory medical care utilisation in elderly patients with special reference to chronic diseases and multimorbidity- results from a claims data based observational study in Germany'. *BMC Geriatrics*, 11, p54.
- Van der Ploeg, E.S., Eppingstall, B., Camp, C.J., Runci, S.J., Taffe, J., & O'Connor, D.W. (2013) 'A randomised crossover trial to study the effect of personalized, one to one interaction using Montessori-based activities on agitation, affect, and engagement in nursing home resident with dementia'. *International Psychogeriatrics*, 25 (4), p565-575.

- Van der Ploeg, E.S., Bax, D., Boorsma, M., Nijpels, G., & van Hout, H. P. (2013). 'A cross-sectional study to compare care needs of individuals with and without dementia in residential homes in the Netherlands', *BMC Geriatrics*, 13, p51.
- Van Weert, J., van Dulmen, A., Spreeuwenberg, P., Ribbe, M., & Bensing, J. (2005). 'Behavioural and mood effects of Snoezelen integrated into 24-hour dementia care'. *Journal of the American Geriatrics Society*, 53(1), 24-33.
- Virta, J.J., Heikkila, K., & Perola, M., (2013) 'Midlife Cardiovascular risk factors and late cognitive impairment'. *Eur J Epidemiol.* 28, p405-416
- Vlassara, H., Fuh, H., Makita, Z., Krungkrai, S., Cerami, A., & Bucala, R. (1992). 'Exogenous advanced glycosylation end products induce complex vascular dysfunction in normal animals: a model for diabetic and aging complications'. *Proceedings of the National Academy of Sciences of the United States of America*, 89(24), p12043–12047.
- Wade D.T. & Collin C. (1988) 'The Barthel ADL Index: A standard measure of physical disability?' *Int. Disability. Studies.* 10, p64–67.
- Wang, H., Weili, X., Jin-Jing, P. (2012) 'Leisure activities, cognition and dementia. Imaging Brain Aging and Neurodegenerative Disease' 1822 (3), p482 -491
- Warmington, M., & Hitch, G. J. (2013) 'enhancing the learning of new words using an errorless learning procedure: Evidence from typical adults'. *Memory*
- Warmington, M., Hitch, G. J., & Gathercole, S. E. (2013) 'Improving Word learning in Children using an Errorless Technique'. *Journal of Experimental Child Psychology*, 114, p456-465.
- Wells, D.L., Dawson, P., Sidani, S., Craig, D. and Pringle, D. (2000) 'Effects of an abilities-focused program of morning care on residents who have dementia and on caregivers'. *Journal of the American Geriatrics Society*, 48, p442–449.
- Weyerer, S., Schäufele, M., Wiese, B., Maier, W., Tebarth, F., van den Bussche, H., & ... Riedel-Heller, S. (2011). 'Current alcohol consumption and its relationship to incident dementia: results from a 3-year follow-up study among primary care attenders aged 75 years and older'. *Age and Ageing*, 40(4), p456-463.
- Wilcock, G. K. (2003) 'Dementia with Lewy bodies'. *The Lancet*, 362 (9397), p1689 -1690

- Will, R. G., Ironside, J. W., Zeidler, M., Cousens, S. N., Estibeiro, K., Alperovitch, A., Poser, S., Pocchiari, M., Hofman, A., & Smith, P. G. (1996) 'A new variant of Creutzfeldt-Jakob disease in the UK'. *Lancet*, 347, p921-925.
- Wilson, B.A. (2013) 'Neuropsychological rehabilitation: State of science'. *South African Journal of Psychology*, 43 (3), p267-277
- Wilson, R.S., Bienias, J.L., & Berry-Kravis, E. (2002) 'The apolipoprotein E epsilon 2 allele and decline in episodic memory'. *Journal of Neurology, Neurosurgery and Psychiatry*, 73, p672-677
- Wilson, B., Baddeley, A., Evans, J. & Shiel, A. (1994) 'Errorless learning in the rehabilitation of memory impaired people', *Neuropsychological Rehabilitation*, 4(3).
- Wimo, A., Jönsson, L., Gustavsson, A., McDaid, D., Ersek, K., Georges, J., Gulácsi, L., Karpati, K., Kenigsberg, P., & Valtonen, H. (2011) 'The economic impact of dementia in Europe in 2008-cost estimates from the Eurocode project'. *International Journal of Geriatric Psychiatry*, 26, p825-832.
- Wilmo, A., & Prince, M. (2010) *World Alzheimer Report 2010: The Global Economic Impact of Dementia*. ADI: London, p. 56-56.
- Wisniewski, K.E., Dalton, A.J., & McLachlan, C. (1985) 'Alzheimer's disease in Down's syndrome: clinicopathologic studies'. *Neurology* 35, p957-61.
- World Health Organisation (WHO) (2008) 'Mental health Gap Action Programme (mhGAP)'. WHO.
- World Health Organization. (2008) 'The global burden of disease 2004 update. Geneva: World Health Organization'. Available at: http://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_coverTOC.pdf (Accessed: 13/10/2015).
- World Health Organisation. (2007) *Global age-friendly cities: A guide*. Geneva: World Health Organisation Press.
- World Health Organisation. (1980) *International Classification of Impairments, Disabilities, and Handicaps*. Geneva: World Health Organisation.
- Woods, R.T., Aguirre, E., Spector, A.E., & Orrell, M. (2012) 'Cognitive stimulation to improve cognitive functioning in people with dementia'. *Cochrane Database of Systematic Reviews*, Issue 2.

- Woods, B., & Clare, L. (2008) Psychological Interventions with People with Dementia, in *Handbook of the Clinical Psychology of Ageing*, Second Edition (eds B. Woods and L. Clare), John Wiley & Sons, Ltd, Chichester, UK.
- Woods, R.T., Moniz-Cook, E., Iliffe, S., Champion, P., Vernooij-Dassen, M., Zanetti, O., & Franco, M. (2003) 'Dementia: issues in early recognition and intervention in primary care' *J R Soc Med.* Jul, 96(7), p320–324.
- Woods, R.T. (2002) 'Reality orientation: A welcome return?' *Age & Ageing*, 31, 1–2, Editorial.
- Woods, R.T. (2001) 'Discovering the person with Alzheimer's disease: Cognitive, emotional and behavioural aspects'. *Ageing & Mental Health*, 5, p7–16.
- Woods, R.T. (1979) 'Reality orientation and staff attention: a controlled study'. *British Journal of Psychiatry*, 134, p502-507.
- Woods, R.T. (1977) 'Psychological approaches to the treatment of the elderly'. *Age and Ageing* 6, p104-12
- Yan, J.H., Dick, M.B. (2006) 'Practice effects on motor control in healthy seniors and patients with mild cognitive impairment and Alzheimer's disease'. *Ageing Neuropsychol C.* 13(3-4), p385-410.
- Yang, J., Wong, A., Wang, Z., Liu, W., Xiong, Y., Leung, E., Chen, S., Lau, C., Chan, A.Y., Lau, A.Y., Fan, F., Soo, Y., Leung, T., Ho, C., Wong, L.K., Mok, V. (2014) 'Risk factors for incident dementia after stroke and transient ischemic attack'. *Alzheimers Dementia.* Jan; 11(1), p16-23.
- Yates, L.A., Leung, P., Orgeta, V., Spector, A., & Orrell, M. (2015) 'The development of individual cognitive stimulation therapy (iCST) for dementia' *Clinical interventions in aging*, 10, p 95-104
- Zahodne, L.B., Glymour, M.M., Sparks, C., Bontempo, D., Dixon, R.A., Macdonald, S.W.S., Manly, J.J. (2011) 'Education does not slow cognitive decline with aging: 12 year Evidence from the Victoria Longitudinal study'. *J Int Neuropsychological Soc.* November; 17 (6), p1039-1046.
- Zarit, S.H., Femia, E.E., Watson, J., Rice-Oeschger, L., & Kaos, B. (2004) 'Memory club: a group intervention for people with early stage dementia and their care partners', *Gerontologist*, 44 (2), p262-269
- Zuidema, S.U., de Jonghe, J.F., Verhey, F.R., & Koopmans, R.T., (2007). 'Neuropsychiatric symptoms in nursing home patients: factor structure invariance of

the Dutch nursing home version of the neuropsychiatric inventory in different stages of dementia'. *Dement. Geriatric. Cognitive. Disorders.* 24, p169-176.

- Zhukareva, V., Shah, K., Uryu, K., Braak, H., Del Tredici, K., Sundarraj, S., Clark, C., Trojanowski, J.Q. & Lee, V.M. (2002) 'Biochemical analysis of tau proteins in argyrophilic grain disease, Alzheimer's disease, and Pick's disease: a comparative study'. *Am. J. Pathol.*, 161, p1135–1141.
- Zwakhalen, S.M.G., Koopmans, R.T.C., Geels, P.J.E., Berger, M.P.F., & Hamers, J.P.H. (2009) 'The prevalence of pain in nursing home residents with dementia measured using an observational pain scale'. *European Journal of Pain* 13, p89–93.

Appendix 1: Dementia- an overview

AD- AD is recognised by the accumulation of protein called beta-amyloid (which deposits outside the neurones) forming together on the brain which cause plaques and neurofibrillary tangles (NFTs) (which accumulate inside the neurones) that inhibit brain functioning (Shan, 2013). Until recently Beta-amyloid could only be quantified on autopsy but it can now be examined in PET imaging (Klunk et al, 2004). It comes from a larger protein found in the fatty membrane surrounding nerve cells which is an intrinsically disordered protein (IDP), which lacks a fixed or ordered three-dimensional structure (Drunker et al, 2001). Beta-amyloid is chemically "sticky" and gradually builds up into plaques. The most damaging form of beta-amyloid may be groups of a few pieces rather than the plaques themselves. These are known as reactive oxygen species (ROS) which are chemically reactive molecules containing oxygen (Mattson et al, 2004). The small clumps may block cell-to-cell signalling at synapses through depolarization of the synaptic membrane, excessive calcium influx and mitochondrial impairment (Mattson et al, 2004). They may also activate immune system cells that trigger inflammation and devour disabled cells (Shan, 2013). A protein called Tau collapses into twisted strands called tangles. NFTs destroy a vital cell transport system made of proteins. Nutrients and other essential supplies can no longer move through the cells as a result and the cells eventually die. Plaques and Tangles are known to be found initially in the neocortex and become widespread in the brain with disease progression (Downs & Bowers, 2010, p12).

CJD- CJD is transmitted by a brain protein called prion. Prions are misfolded proteins that replicate by converting their properly folded counterparts to the same misfolded structure they possess. These altered prion proteins are remarkably resistant to inactivation by standard chemical, thermal and other means of inactivating microorganisms. This causes spongiform change which is an infinite number of tiny holes that appear in the cerebral cortex causing it to appear like a sponge, neuronal loss which is a loss of nerve cells that processes and transmits information through electrical and chemical signals and astrocytosis which is an abnormal increase in the number of astrocytes (neuroglial cells with fibrous or protoplasmic processes frequently observed in an irregular area adjacent to degenerative lesions) as a result of the demolition of nearby neurons from the central nervous system. Astrocytes are known to play a critical role in energy provision, regulation of blood flow, homeostasis of extracellular fluid,

homeostasis of irons and transmitters, regulation of synapse function and synaptic remodelling (Ames et al, 2010).

PiD- Cortical atrophy in PiD is severe, circumscribed with a knife blade appearance of the gyri (a ridge on the cerebral cortex), more often asymmetrical and also involving the striatum (a subcortical part of the forebrain) and hippocampus in the brain. There is marked neuronal loss, mainly in the upper cortical layers. The defining characteristics of the disease are a build-up of tau proteins in neurons, accumulating into silver-staining, spherical aggregations known as "Pick bodies". This is in addition to large dark-staining aggregates of proteins in neurological tissue as well as swollen cells, which are called Pick cells. Immunoelectrophoresis (a number of biochemical methods for separation and characterization of proteins based on electrophoresis and reaction with antibodies) and Western blotting of fractions enriched with abnormal filaments have shown two main bands of 55 and 64 kDa (used for indicating mass on an atomic or molecular scale), mostly consisting of 3-repeat tau but also of 4-repeat tau in significant amounts (Delacourte et al., 1996), (Zhukareva et al., 2002).

Appendix 2: Screening checklist.

Patient Name: _____

Date of Birth: _____

Name of Centre: _____

Name of Consultant: _____

Criteria (please tick appropriate column)	Present	Absent/Not applicable
Inclusion Criteria		
Diagnosis of Dementia (of any type)		
Moderate cognitive impairment as classified by the Mini-Mental State Examination(MMSE); score ranging from 11-20: Date of last administered MMSE: _____ Score: _____		
Some ability to communicate and understand communication, which will be determined by a score of 1 or 0 in questions 12 and 13 of the Clifton Assessment Procedures for the Elderly-Behaviour Rating Scale (CAPE-BRS see below)		
Exclusion Criteria	Present	Absent/Not applicable
Scores <11 or >21 on the Standardised Mini-Mental State Examination		
Inability to communicate and understand communication, as determined by the (CAPE-BRS see below)		
A significant physical health problem or illness that could impact on the patients' ability to attend and participate in the intervention and/or assessment process (e.g. an acute or chronic physical illness)		
Inadequate sensory impairment including hearing or vision		
Exposure to CST or Sonas in the six months prior to the study.		
Significant uncontrolled disruptive behaviours (e.g. aggression, delusions, hallucinations and agitation) that could interfere with the intervention and/or assessment process		
Recent onset of a depressive episode or acute anxiety which is likely to affect patient's participation in the assessment and/or intervention process		
A diagnosis of a learning disability		
A change of antipsychotic and/or antidepressant medication during the previous month or the addition of benzodiazepines during the previous week		

The Clifton Assessment Procedures for the Elderly' Behaviour Rating Scale (CAPE-BRS): Please circle correct response

The above named patient understands what you communicate to him/her (you may use speaking, writing, or gesturing)

- understands almost everything you communicate 0
- understands some of what you communicate 1
- understands almost nothing of what you communicate 2

The above named patient communicates in any manner (by speaking, writing, or gesturing)

- well enough to make him/herself easily understood at all times 0
- can be understood sometimes or with some difficulty 1
- can rarely or never be understood for whatever reason 2

This form is to be signed by the Consultant Psychiatrist or member of Senior Nursing Staff

With consideration and reference to the outlined inclusion and exclusion criteria for the study involving the evaluation of the Sonas and CST group interventions, I consider the above named patient to be (please tick):

Suitable* Not suitable for the study.

Signed: _____ Title: _____

Date: _____

*For patients deemed suitable for the study please complete page 2.

Site Name (please tick): Psychiatry of Later Life (PLL) A Care Centre

If patient of PLL are they: Inpatient Community Dwelling

Type of Dementia:

Dementia of the Alzheimer's Type

Vascular Dementia

Mixed Alzheimer's and Vascular Dementia

Dementia not otherwise specified

Other dementia (not listed here) _____ (please name)

Other significant past medical history: _____

Is the patient on any of the below listed medications? (Please tick if so):

Acetylcholinesterase inhibitors

Name of medication _____

(Trade Names- *NOT A DEFINITIVE LIST*): ACCUPPRO, ACEOMEL, BELLISIN, BELLRAMIL, BYRITE, CAPOTEN, CAPTOR, CIBACEN, COVERSYL, ARGININE, ENAP, INNOVACE, LESTACE, LISOPRESS, LISPRIL, LOAVEL, PENDREX, PERCARNIL, PRINDACE, RAMIC, RAMLO, RAMTACE, RAMYTE, TRITACE, VASCACE, ZESGER, ZESTAN, ZESTRIL, ACCUPRO, ACCURETIC, ACEOMEL, ACERYCAL.

Patient Name: _____

Date of Birth: _____

Antipsychotic medication

Name of medication _____

(Trace Names-*NOT A DEFINITAVIVE LIST*): STELAZINE, STESOLID, UCERAX, VALIUM, XANAX, ABILIFY, CLONACTIL, CLOPIXOL, CLOZARIL, DENZAPINE, DEPIXOL, DOLMATIL, GOEDON, INVEGA, MODECATE, NOZINAN, ORAP, PERDAMEL, RISPAL, RESDAL, RISPEREDAL, RISPERGER, RISPEVA, RISPONE, SERDOLECT, SERENACE, SEROQUEL XR, SOLIAN, STELAZINE, STEMETIL, ZYPADHERA, ZYPREXA.

Antidepressant medication

Name of Medication _____

(Trace Names-*NOT A DEFINITAVIVE LIST*): ABILIFY, AFFEX, ANAFRANIL, BELLCITAL, BELLSERT, BELLZAC, BIOZAC, CALMAX, CAMCOLIT, CIPRAGER, CIPRALAM, CIPRAMIL, CIPRAPINE, CIPROTAN, CITALOPRAM TEVA, CITROL, CYMBALTA, DEPREGER, DOTHEP, EDRONAX, EFAXIL XL, EFFEXOR XL, EPILIM, FAVERIN, FLUNAXOL, FLUZAC, GAMANIL, GEODON, GERICARB SR, GEROZAC, IREVEN, LAMICTAL, LAMORO, LAMOTRIGINE RANBAXY, LARIG, LEXAPRO, LUSERT, LUSTRAL, MANERIX, MIRAP, MIRTALL, MIRTAZ, MIRTAZAPINE, MIRZATEN, MOLIPAXIN, NORZAC, PARNATE, PAROSER, PAROX, PRIADEL, PROTHIADEN, PROZAC, PROZAMEL, PROZATAN, PROZIT, SERETRAL, SERIMEL, SERLAN, SERLO, SEROQUEL XR, SEROXAT, SURMONTIL, TEGRETOL, VALDOXAN, VEDIXAL, VEDIXAL XL, VENEX XL, VENLAFAXINE TEVA, VENLAFEX XL, VENILIFT, VENLOFEX, VENSIR XL, XANAX, ZISMIRT, ZISPIN.

Benzodiazepines

Name of Medication _____

(Trace Names-*NOT A DEFINITAVIVE LIST*): ANXICALM, ATIVAN TABLET, CALMAX, CENTRAX, DIAZEMULS, FRISIUM, GERAX, LEXOTAN, LIBRIUM, STESOLID, UCERAX, VALIUM, XANAX, DALMANE, DALMAPAM, HALCION, INSOMNIGER, MOGADON, NOCTAMID, NORTEM, ROHYPNOL, TENOX.

Name of next of kin/ significant other: _____

Relationship to patient (e.g. spouse, child) _____

Home Address of Patient/Next of Kin:

Contact number of next of kin/significant other: _____

Name of patient's keyworker (if applicable): _____

Contact telephone number of keyworker: _____

To be completed by the Principal Investigator or Co-Investigator of the study (participant recruitment stage)

Does the person have the capacity to give informed consent: Yes No

If so, do they wish to participate in the study: Yes No

If the person does not have the capacity to give informed consent and assent is sought, does the next of kin/significant other wish their family member to participate in the study: Yes No

Signed: _____

Date: _____

To be completed by the Principal Investigator or Co-Investigator of the study (at the end of the post-assessment stage)

Has there been any change in the participants antipsychotic and/or antidepressant medications, or the addition of benzodiazepines during the intervention or assessment procedure? Yes No

Signed: _____

Date: _____

To be completed by the Principal Investigator or Co-Investigator of the study

Participant Reference Number: _____

Appendix 3: CAPE BRS, relevant sections.

12. He/she understands what you communicate to him/her (you may use speaking, writing or gesturing):

- understands almost everything you communicate 0
- understands some of what you communicate 1
- understands almost nothing of what you communicate 2

13. He/she communicates in any manner (by speaking, writing or gesturing):

- well enough to make him/herself easily understood at all times 0
- can be understood sometimes or with some difficulty 1
- can rarely or never be understood for whatever reason 2

Appendix 4: Participant information leaflet

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

PARTICIPANT INFORMATION LEAFLET

Study Title: Evaluating the effectiveness of group sessions for people with memory and thinking difficulties.

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. This leaflet will tell you about the purpose of the research, and what are the possible benefits and disadvantages of taking part in the research. If you agree to take part, we will ask you to sign a Consent Form. You should only consent to participate in this research when you feel that you understand what is being asked of you, and you have had enough time to make a decision.

What is the purpose of the study?

This study aims to examine whether group sessions designed for people who experience memory, concentration and communication difficulties are helpful.

What happens in the group sessions?

The sessions will involve a group of 6-8 people with memory, concentration and communication difficulties. During sessions you will do things like: singing, tasting food, word games, music, art and gentle exercise. Each group session will last about 45 minutes. The sessions will take place twice a week for 7 weeks. They will be run by two members of staff in A.

Do I have to take part?

It is up to you to decide whether or not you would like to take part. If you do decide to take part you will be given this information leaflet to keep and be asked to sign a consent form. If you decide to take part you are still free to change your mind and withdraw from the study at any time. If you decide you do not wish to take part in the study or you withdraw from the study this will not affect the standard of care that you receive.

What will happen to me if I take part?

If you agree to take part in the study you may or may not be chosen to attend one of the group sessions. The fairest way to decide whether or not people will attend the group sessions is by chance. This will be done using a computer which will not contain any personal information about you. If you are not chosen to attend a group session initially, you will be invited to attend a group session after the study has been completed.

Following discussion of any questions you may have with a researcher, and signing the consent form, all participants will be asked to:

Meet with a researcher for between one/one and a half hours to answer questions and complete some tests about your general memory and thinking abilities as well as your mood and satisfaction with life. During these tests you may take as many breaks as you want, and we can meet for more than 2 sessions to finish these.

Either attend twice weekly group sessions or receive your usual care for 7 weeks.

Meet with a researcher again to answer the same questions as before.

The researcher will also meet with a member of staff or a member of your family who knows you well. They will be asked questions about your memory and thinking abilities, mood and overall quality of life.

What are the benefits and disadvantages for me? How does it affect me?

Studies which have examined the effectiveness of these sessions report promising benefits for individuals, including improved memory, concentration and satisfaction with life. However, it is possible that not everyone will experience improvements in these areas. Participation in the study will require your time and energy. You may feel some tiredness. However there are no other expected disadvantages to participating in this study. The assessments completed before the group starts and after it ends will be explained and you will receive as much help completing them as possible. Participation in this study will not impact any other treatments or medication you may be having.

When is the study happening and who else is involved?

The study is due to commence in November 2011 and will be completed in April 2012. It is expected that between 60 and 70 people will participate in the study.

What will happen to the results?

The results of your assessment measures will be held securely in a locked filing cabinet in the HSE office of the study's investigator's. They will not contain any information which will make you identifiable.

The results from this study will be written-up as part of the investigator's academic requirements [REDACTED]. The results of the study will be published in a reputable journal and presented at conferences. You will be invited to attend a presentation of the study's results after it has been completed. A written summary of the study will also be provided to you.

IF YOU REQUIRE FURTHER INFORMATION

For additional information now or any time in the future please contact either of the Principal Investigator's:

Name: [REDACTED]

Address: [REDACTED]
[REDACTED]

Telephone Number: [REDACTED]

Name: [REDACTED]

Address: [REDACTED]
[REDACTED]

Telephone Number: [REDACTED]

Appendix 5: Consent forms.

[REDACTED]

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

ASSENT FORM

Evaluating the effectiveness of group interventions for people with memory and thinking difficulties.

PLEASE CIRCLE OR TICK THE APPROPRIATE ANSWER

I confirm that I have read and understood the Next of kin/significant other Information Leaflet dated _____.

Yes **No**

I have had sufficient opportunity to ask questions. **Yes** **No**

All of my questions have been satisfactorily answered. **Yes** **No**

I understand that my relative's participation in this study is entirely **voluntary** and that I may withdraw their participation at any time, without giving reason, and without this decision affecting my future treatment or care.

Yes **No**

I understand that their identity will remain confidential at all times.

Yes **No**

I understand that neither my relative nor I will receive individual results on their performance in this study.

Yes **No**

I agree to my relative taking part in this study.

Yes **No**

I have been given a copy of the Next of kin/Significant Other Information Leaflet and this Consent Form for my own records.

Yes **No**

Signed by:

_____	_____	_____
Next of kin/significant other	Date	Name in block capitals

_____	_____	_____
Witness	Date	Name in block capitals

To be completed by the Principal Researcher or Co-Investigator.

I the undersigned, have taken the time to fully explain to the Next of Kin/Significant Other of _____ the nature and purpose of this study in a manner that he/she could understand. I have explained the purpose of the study, the possible benefits and disadvantages of participating and have invited him/her to ask questions on any aspect of the study that concerned them.

Signature

Title/Qualification

Name in block capitals

Date

Appendix 6: Next of kin/family information leaflet

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

NEXT OF KIN/SIGNIFICANT OTHER INFORMATION LEAFLET

Research Title:

Evaluating the effectiveness of group interventions for people with memory and thinking difficulties.

Your relative _____ is invited to take part in a research study carried out at [REDACTED]. Before you decide, it is important for you to understand why the research is being done and what it will involve. This Information Leaflet will tell you about the purpose of the research, and its possible benefits and disadvantages. You should only consent to your relative taking part in this research study when you feel that you understand what is being asked of you and your relative, and you have had enough time to think about your decision. You can withdraw your relative from the study at any time without having to justify the reasons for doing so. Your decision will have no impact on the care that your relative receives.

What is the purpose of the study?

This study aims to examine the effectiveness of group interventions designed for people who are experiencing memory, concentration and communication difficulties. We are interested in assessing whether these treatments are beneficial for people who are experiencing difficulties in these areas. Approval for this study has been granted from the

Do I have to agree to my relative taking part in the study?

It is up to you to decide whether or not you would like your relative to take part in the study. If you do agree to your relative taking part, you will be given this information leaflet to keep and be asked to sign a consent form. You are also free to change your mind and withdraw your relative from the study at any time. If you decide you do not wish your relative to take part in the study this will not affect the standard of care that they receive.

What will my relative have to do if they take part in the study?

Each group intervention will last about 45 minutes. The sessions will take place twice a week for 7 weeks. They will be run by two members of staff in [REDACTED]. The sessions will involve a group of 6-8 people with memory, concentration and communication difficulties. During sessions the participants will do things like: singing, tasting food, word games, music, art and gentle exercise.

If you agree to your relative participating in the study they will be chosen to either attend one of the group interventions, or they may continue to participate in normal care activities. The fairest way to decide whether or not people will attend the group sessions is by chance. This will be done using a computer which will not contain any personal information about your relative. If your relative is not chosen to attend a group intervention initially, they will be invited to attend a group intervention after the study has been completed.

Your relative will be also required to complete some tests and answer questions which will enquire about their memory and thinking abilities, as well as their mood and overall satisfaction with life. These assessments with your relative will last approximately 60-80 minutes and will take place before the first group session meets as well as after the last session has been completed. Nursing staff who know your relative well or a family member will also be asked to answer some questions about your relative's mood, activities of daily living and general well-being.

What are the benefits and disadvantages for my relative?

Initial studies which have examined the effectiveness of these interventions report promising benefits for individuals, including improved memory, concentration and satisfaction with life. However, it is possible that not everyone will experience improvements in these areas. Participation in the group intervention will require your relative's time and energy, however there are no expected risks to participating in these interventions. As explained earlier, your relative will be asked to complete assessments on two occasions. These will be explained fully to them and they will receive as much help completing them as possible. Participation in this study will not impact any other medication or treatments they may be having.

When is the study happening and who else is involved?

The study is due to commence in November 2011 and will be completed in April 2012. It is hoped that between 60-70 people will participate in the study.

What will happen to the results?

The results of the assessment measures will be held securely in a locked filing cabinet in the Principal Investigator's offices in the HSE. The investigators who will have access to the results of the assessment measures will only know your relative by a number. They will not have access to any information which will make them identifiable.

The results from this study will be written-up as part of the study's principal investigator's academic requirements to the [REDACTED]. It is hoped that the results of the study will be published in reputable journals and presented at conferences. Feedback to participants and their relatives as well as a written executive summary will be provided at the end of the study should you wish to attend. You will receive notification of this by letter from the study's investigator after the results of the study have been submitted to the [REDACTED].

IF YOU REQUIRE FURTHER INFORMATION

For additional information now or any time in the future please contact:

Name [REDACTED]

Address: [REDACTED]

Telephone: [REDACTED]

Signed by:

[REDACTED]

Senior Occupational Therapist

Appendix 7: Permission to use SMMSE.

Communication attached is an e mail correspondence.

You have my permission to use the SMMSE
Perhaps you should think about including the QMCI as well
I have attached some materials for you.
Best wishes
W
Prof. D. William Molloy,
Centre of Gerontology and Rehabilitation
University College Cork
St. Finbarr's Hospital
Douglas Road
Cork City
Ireland

Appendix 8: Joint consent forms.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

ASSENT FORM

Evaluating the effectiveness of group sessions for people with memory and thinking difficulties.

PLEASE CIRCLE OR TICK THE APPROPRIATE ANSWER

I confirm that I have read and understood the Next of kin/significant other Information Leaflet (dated _____) .

No

Yes

I have had sufficient opportunity to ask questions all of which have been satisfactorily answered.

Yes **No**

I understand that my relative's participation in this study is entirely **voluntary** and that I may withdraw their participation at any time, without giving reason, and without this decision affecting my future treatment or care.

Yes **No**

I understand that their identity will remain confidential at all times.

Yes **No**

I agree to my relative taking part in this study.

Yes **No**

I have been given a copy of the Next of kin/Significant Other Information Leaflet and this Consent Form for my own records.

Yes **No**

Signed by:

Next of kin/significant other Date Name in block capitals

Witness Date Name in block capitals

To be completed by a Principal Researcher (PR) or a nominee.

I the undersigned, have taken the time to fully explain to the Next of Kin/Significant Other of _____ the nature and purpose of this study in a manner that he/she could understand. I have explained the purpose of the study, the possible benefits and disadvantages of participating and have invited him/her to ask questions on any aspect of the study that concerned them.

Signature Title/Qualification

Name in block capitals Date

Appendix 9: Permission to use ADCS-ADL



M E M O R A N D U M

Alzheimer's Disease Cooperative Study

(858) 622-5895

Fax: (858) 452-0573

8950 Villa La Jolla Drive, Suite C-121 • La Jolla, CA 92037

Date: January 12, 2017

From: ADCS Clinical Operations

To: [REDACTED]

Re: ADCS-Activities of Daily Living Inventory

Per your request, enclosed please find the following materials relating to ADCS-generated instruments:

ADCS - Activities of Daily Living Inventory (ADCS-ADL)

- Sample case report forms
- Administration instructions
- Instruction card for the rater to use when administering the scale
- Article describing the development of this instrument
-

We ask that you include the following two items on the ADCS-ADL form:

- A. The statement: "Used with permission from the NIA Alzheimer's Disease Cooperative Study (NIA Grant AG10483)".
- B. The following reference for the ADCS-ADL:

Galasko, D.; Bennett, D.; Sano, M.; Ernesto, C.; Thomas, R.; Grundman, M.; Ferris, S.; and the ADCS. "An Inventory to Assess Activities of Daily Living for Clinical Trials in Alzheimer's Disease." *Alzheimer's Disease and Associated Disorders*, 1997. Volume 11(2): S33-S39.

If you have the need for training in the administering of this instrument, for example at an investigator meeting for a clinical trial, please contact Douglas Galasko, M.D. at dgalasko@ucsd.edu.

Thank you for your inquiry. If you have any questions regarding the administration or scoring of this instrument, please contact Dr. Douglas Galasko at dgalasko@ucsd.edu.

cc: Douglas Galasko, MD
Steven Ferris, PhD

Appendix 10: Permission to use NPI in phase one.

Thank you for your interest in the Neuropsychiatric Inventory (NPI-NHNPI-Q). You have my permission to use the NPI in your research without charge.

You have accessed the NPI from the website portal that indicates that your research does not use the NPI in an industry-sponsored clinical trial. There is a charge for use of the NPI in a clinical trial. If you inadvertently used the academic portal when you intended to use the industry portal, please return to the [NPI website](#) and use the [industry portal](#). You will receive the NPI, permission letter, and an invoice.

██████████ you may download the NPI-NHNPI-Q here: <http://npitest.net/download.html>

You can [contact me](#) through the website with questions.

Thank you.

Regards,

Jeffrey Cummings, MD, PhD (Hon)
Director, Cleveland Clinic Lou Ruvo Center for Brain Health
Andrea and Joseph Hahn Professor of Neurotherapeutics
Cleveland Clinic Neurological Institute
Las Vegas, Nevada; Cleveland, Ohio; Weston, Florida

www.npiTEST.net

Appendix 11: Permission to use CAPE in the study.

Hodder *Education*

338 Euston Road
London NW1 3BH
Tel: 0207 873 6000
Fax: 0207 873 6299



27th September 2011

RE: CAPE Assessment

Dear 

Thank you for your enquiry concerning permission to reproduce material from the above publication.

I am afraid that we have been unable to locate any contractual information on this publication and are therefore not in a position to grant you permission. We have no objection to your use of this material in the manner indicated in your application but, were you to do so, it would be entirely at your own risk. If you do choose to use this material it is customary to acknowledge the author, the title and the publisher of the publication concerned.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Rosanna'.

Rosanna Arenare
Permissions & Rights Assistant

Appendix 12: Personal communication by e mail

Spector, Aimee	25/06/2014
to me	
<p>Dear [REDACTED]</p> <p>The tool was developed quite informally by the authors of the manual and has not been formally evaluated. It is more of a process tool than anything else. Hope that helps.</p> <p>With kind regards,</p> <p>Aimee</p> <p>Dr Aimee Spector Senior Lecturer in Clinical Psychology</p>	

Appendix 13: session details

COGNITIVE STIMULATION THERAPY: THE MANUAL FOR GROUP LEADERS

SESSION ONE (PHYSICAL GAMES)

Introductions (10 minutes)

Welcome all members individually to the group, by name.

Involve everyone in a discussion about giving the group a name.

Select a theme song for the group and then sing it together.

Discuss day, month, year, season, weather, time, name and address of the centre (use whiteboard).

Discuss something currently in the news (use newspapers or photographs).

Offer refreshments.

Main Activity (25 minutes)

Level A

Throw a soft ball around, asking people to say something about themselves as they catch the ball, for example, their name, where they come from, their former occupation, favourite food or colour.

Level B

Play a physical game, such as skittles or indoor bowls, which involves teamwork. This should be a relaxed activity incorporating movement touch and score calculations.

Closing (10 minutes)

Thank everyone individually for attending and contributing.

Sing theme song again.

Remind everyone of the time and content of the next session.

Say farewells.

SESSION TWO (SOUNDS)

Introductions (10 minutes)

Welcome all members individually to the group, by name.

Draw attention to the name of the group (on the whiteboard).

Remind everyone of the activity in the last session.

Play soft-ball for a few minutes. When throwing the ball, people may state their name, or for the more able, the name of the person to whom they are throwing the ball. Vary this by asking people their favourite food, colour, sport, country, singer and so on).

Sing together the group's theme song.

Discuss day, month, season, year, time, name and address of the centre (use whiteboard).

Discuss options of recent events in the centre, for example, recent meals or the weather yesterday or today. Discuss something currently in the news (use newspapers).

Main Activity (25 minutes)

Level A

Play sound effects tapes that include different categories such as 'indoor sounds; and 'outdoor sounds' (e.g. animal noises) and invite members to match the sounds with pictures. Alternatively, play selected tracks from a compilation CD from the appropriate era and invite members to name the song or singer.

Level B

Give percussion instruments (e.g. spoons, combs with paper) to each person in the group. And use them to play along to familiar music.

Closing (10 minutes)

Summarise today's discussion and seek feedback about the session. Thank everyone individually for attending.

Sing theme song.

Remind everyone of the time and content of the next session.

Say farewells.

SESSION THREE (CHILDHOOD)

Introductions (10 minutes)

As per Session Two.

Main Activity (25 minutes)

Level A

Ask members to fill out a printed sheet with their name, father's name, mother's names, school attended and so on to form the first page of a memory diary. Invite members to make a drawing of their childhood bedroom, or even create a reconstruction of it on the board.

Level B

Ask members to demonstrate the use of old-fashioned childhood toys, for example, a spinning top. Talk about childhood sweets (e.g. pear drops, barley). Bring a selection to try and enjoy.

Closing (10minutes)

As per Session Two.

SESSION FOUR (FOOD)

Introductions (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Level A

Using real groceries or miniature grocery replicas that have been priced, give people a budget and as scenario to plan (e.g. dinner for four).

Categorise the groceries into foods for different mealtimes, special occasions, savoury/sweet.

Level B

Taste food which acts as memory triggers or have personal meaning (e.g. Bovril, bread pudding).

Brainstorm food categories on the whiteboard, such as soups, meats puddings etc. List as many as possible in each category.

Complete names of food items, for example, Yorkshire....., Bakewell....., and self-raising..../

Ask people to name foods with a particular letter.

Closing (10 minutes)

As Per Session Two.

SESSION 5 (CURRENT AFFAIRS)

Introductions (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Level A

Discuss issues from a selection of recent national and local newspapers and magazines. Have multiple copies of interesting articles so everyone has a piece to look at.

Level B

Use questions on cue cards to stimulate conversation on news, views, attitudes, dreams and aspirations. Some examples of opening questions may be:

- Should men and women have different roles? Should men do the cooking, cleaning and laundry?
- Who in the world do you most admire?
- Where is your favourite place in the world?
- Are mobile phones a good thing?

Closing (10 minutes)

As Per Session Two.

SESSION SIX (FACES/SCENES)

Introduction (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Level A

Prepare multiple copies of laminated photographs of famous faces or of local scenes so that everyone can look at the same picture. Give people one or more cards and ask them to identify the scene or person. Allow discussion of people's memories of these people or places to flow.

Level B

Use the same type of prepared cards as in Level A, but ask people for their opinion on questions such as:

- Who is the oldest or youngest?
- Who is most attractive?
- What do they have in common?
- How are they different?
- Offer choices of names for each. Attempt to use opinions to generate memories for names.

Closing (10 minutes)

As Per Session Two.

SESSION SEVEN (WORD ASSOCIATION)

Introductions (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Level A

Ask group members to supply the missing word in a number of phrases. These could be about quantities (a cup of ...), famous couples (Laurel and), or proverbs (A stitch in time). List of examples provided in manual.

Level B

Present the first few words of a song (e.g. 'we'll meet again...') and ask the group to sing a few lines.

Closing (10 minutes)

As Per Session Two.

SESSION EIGHT (BEING CREATIVE)

Introductions (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Levels A and B

In this session, do a creative activity such as:

- Cookery e.g. make an apple crumble. Split the activity into separate tasks (greasing the bowl, mixing ingredients, making crumble mixture) so that everyone can participate.
- Making a seasonal collage: use natural items (e.g. leaves and flowers) and pictures to create the collage.
- Clay modelling: make animals or sculptures out of clay.
- Gardening: plant bulbs or seeds and check their progress in a few weeks.

Closing (10 minutes)

As Per Session Two.

SESSION NINE (CATEGORISING OBJECTS)

Introductions (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Level A

Ask people to think of words beginning with a certain letter (e.g. 'a') in a particular category (say 'boys' names'). Write letters and categories on separate cards and use the cards to prompt the game. Alternatively, simply write the category on the board and invite people to think of as many examples as possible.

Level B

Place 20 or so objects or coloured pictures of objects on a table. Ask people to group the objects in different ways, for example, by use, colour or initial letter. This can be done as an 'odd one out' game, that is, by asking which of the three objects is the odd one out.

Closing (10 minutes)

As Per Session Two.

SESSION TEN (ORIENTATION)

Introductions (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Level A

Construct a map of Ireland, the local area or the centre on whiteboard. Fill in the map by asking the group to suggest different places or landmarks (e.g. dining room on plan of the centre). Stimulate discussion.

Level B

Mark on a large map where members originate from. Discuss whether people have moved from area to area, and if so, where from and to. Use a map of the world if people have travelled abroad. Discuss how long journeys take, how far apart places are.

Closing (10 minutes)

As Per Session Two.

SESSION ELEVEN (USING MONEY)

Introductions (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Level A

Prepare laminated cut-outs of common objects from a catalogue (or have actual objects) with prices marked on the back. Ask people to guess the prices of items, add up prices, or match the price tag with the object.

Level B

Show examples of both old and new coins and compare these. Discuss changes in prices and values using questions such as:

How much was your first pay packet?

How much did people used to earn?

How much did a loaf of bread cost?

Closing (10 minutes)

As Per Session Two.

SESSION TWELVE (NUMBER GAMES)

Introductions (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Level A

Play games involving the recognition and use of numbers, for example, bingo or dominoes.

Level B

Play 'snap' with cards.

Go around the group, with each person in turn taking the next card of a pack of cards and guessing whether it will be higher or lower than the previous card.

Guess how many items are in a container (for example, cents in a small jar). Count them out to check whose guess is closest.

Closing (10 minutes)

As Per Session Two.

SESSION THIRTEEN (WORD GAMES)

Introductions (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Level A

Play a word identification game such as 'hangman' which involves the recognition and use of letters and words.

Level B

Prepare a large-size crossword or word search puzzle on A3 paper at a difficulty level geared to the group.

Closing (10 minutes)

As Per Session Two.

SESSION FOURTEEN (TEAM QUIZ)

Introductions (10 minutes)

As Per Session Two.

Main Activity (25 minutes)

Levels A and B

Play team games: divide the group into two teams, ask them to choose a team name and then play a trivia quiz, or another game that the group enjoyed previously. Give prizes to everyone in the group.

Bring back materials created in previous sessions and display them for all to see.

Have a special group tea with cakes, special treats and so on.

Discuss people's views on the group.

Closing (10 minutes)

Summarise today's discussion and seek feedback about the overall group experience.

Thank everyone individually for attending and contributing.

Sing theme song again.

Say farewells.

The Sonas Group Session (Taken from the Sonas workshop booklet (p. 27-29) and User guide (p10) and used with permission from Sonas aPc 2011)

'The **Signature tune** introduces the session.

1. It should be playing as the participants arrive and if necessary play it a second time. As the tune becomes familiar it alerts the participants to the session (memory being triggered by association). Retain this association by not playing this music at other times.
2. When arranging the seating –
 - leave space behind the chairs so that you have room to move behind the participants
 - make sure the chairs are not so close together as to interfere with movements, but close enough so that people can make physical contact if they wish.

The **opening song** gives a personal touch.

1. The leader remains seated for the general greeting and moves from person to person for the individual greetings. Each person is addressed by name and greeted with a handshake to emphasise the interactive value of the item. Make sure that the name used is the one preferred by the individual. The helper remains seated throughout.
2. Only one person should be addressed at a time by the leader. The song allows for nine names so that the helper can be included.
3. Make eye-contact, ensuring that you are on a level with each person and not towering above.
4. Participants should be addressed by name frequently during the session.
5. The leader should tell the group his/her name.

Exercises to music encourage group participation and it is thought that increasing the physical activity of older people increases sociability and may improve cognition.

It is important to note –

The exercises should be encouraged and assistance can be offered to participants. However, it should not be thought that group members *have* to do the exercises. There are certain conditions that need careful consideration when offering help and these are referred to under Safety Considerations, **Pgs 22-25** of this booklet.

Smell The sense of smell can be stimulated by the use of pleasant-smelling items e.g. soap, flowers or baking spices. If essential oils are used it is important that you seek expert advice with each individual participant in mind. Some units have a policy that prohibits the use of essential oils so be guided by this. In general, be aware of any condition that would contra-indicate the use of topical lotions, creams or oils.

Link music plays between some of the items, giving a brief rest and allowing a change of mindset from the focus on one item and the focus to the next.

Singalong 1 allows for expression through song. Some people who may not have any speech are able to sing.

1. Songs may well trigger memories
2. Rhythm can stimulate participation
3. Interacting with people at every opportunity eg., holding and moving people's hands and arms while making eye contact facilitates interaction
4. Dancing is not encouraged during this item - it is better left until the music and percussion section. However, if people get up spontaneously and dance or move this should, within reason, be accepted as a form of expression.

Relaxing music is played while the senses of taste and touch are stimulated.

1. The taste item given can be anything which is safe (see Safety Considerations **Pgs 22-25**) and suitable. It is only a small trigger for this sense and is not a refreshment break.
2. Always tell or show what the item is and ask the person if s(he) wants it.
3. Rubbing the shoulders and back is carried out as demonstrated and keeping to this routine preserves the familiarity that comes from repetition. Again permission to touch should be sought.

Music with percussion instruments emphasises rhythm. Participants can be encouraged to express themselves through:-

1. The use of instruments.
2. Dance/movement.

Proverbs are rote learned and often the first part of the proverb will act as a trigger so that some people may be able to complete it even if they have a speech difficulty.

Poetry is there to be listened to rather than learned, but people may become familiar with it and join in.

Contributions from members of the group are encouraged at this point, but no-one is pressured to take part. There are suggestions which could be introduced on Page 26 but you will find ideas of your own that suit your group members.

Singalong 2 allows for vocal expression and further interaction through holding hands and moving to the music. By this time in the session members may well be more aware of each other and able to interact in a closer way.

The **Closing song** is similar to the opening one and members are again affirmed by use of their names and farewell handshakes by the leader. If singing the opening or closing song is felt to be inappropriate a spoken greeting or farewell can be used in time to the music.

The **Signature tune** provides closure to the session and the participants can

1. be escorted from the room while the music is playing or
2. stay and chat with perhaps a cup of tea. If the potential for communication has been activated try to provide opportunity for it. Above all try to be consistent.

Outline of Group Session

The session outline is in the Sonas Kit and it is recommended that it is visible as a reminder of the order of the session for the group leader and helper.

Signature tune – should be playing as participants arrive as its association with Sonas alerts people to the nature of the session.

Greeting song – only the leader should greet the participants using their preferred names, shaking hands and making eye contact. The helper remains seated during this activity.

Exercises – should be demonstrated by the leader, and assistance and encouragement offered by the helper, bearing in mind any safety considerations. Group members are not expected to do all the exercises.

Sense of smell – can be stimulated by a variety of items, such as flowers, spices, perfume or coffee beans but care should be taken regarding allergies and preferences.

Link music – is played between some items to give participants a rest and allow time for the change of focus.

Singalong 1 - allows for expression through singing. People can be encouraged to hold hands or copy accompanying gestures/signs.

Relaxing music – as this plays, a small taste item is offered and touch is introduced by rubbing participants' shoulders and back – permission should always be asked before this touch routine is carried out¹.

Lively music - participants can be encouraged to express themselves through using percussion instruments or, where safe and appropriate, through dancing.

Proverbs – are partially said on the CD/cassette with the opportunity for participants to complete them. **Poetry** – can be listened to or joined in with if participants wish.

Personal contributions – participants should be encouraged but not pressured, to contribute to the session. Any contributions should be accepted and acknowledged.

Singalong 2 – again, allows for vocal expression and interaction through holding hands.

Closing song - again only the leader interacts with each group member.

Signature tune – provides closure to the session and participants can either be escorted from the session area or can stay for further communication.

Appendix 14: Baseline Assessment SMMSE

The SMMSE baseline data examination included a Kolmogorov-Smirnov test of normality which was found not to be significant indicating normality across groups (CST $p=0.154$ and Sonas $p=0.200$) and sites (inpatient psychiatry of later life $p=0.200$, care centre $p=0.090$ and community dwelling $p=0.200$). In terms of dementia type, there were no significant differences on the Kolmogorov-Smirnov test between Alzheimer's (.134, $p=0.200$ NS) and non-Alzheimer's dementia types indicating normality. Similarly, in terms of sex, the Males were found to be normal on the Kolmogorov-Smirnov test of normality .182, $p=0.200$, NS; in comparison to the females, who were found to violate normality with a significant result of .224, .024. In terms of capacity to give consent, no significant differences were found between those who were marked (yes) as having capacity to consent .230, $p=.144$, NS to those who were marked (no) as not having capacity to consent .167, $p=.197$, NS.

An examination of the Skewness (CST -0.448 and Sonas 0.550) and Kurtosis (CST -1.142 and Sonas -0.430) values indicate limited deviation in any direction across groups. Similarly across sites, the Skewness (Long stay inpatient psychiatry of later life 0.295, care centre 0.186 and community dwelling -0.466) and Kurtosis (Long stay inpatient psychiatry of later life -1.428, care centre 0.229 and community dwelling -1.789) indicate limited deviation from a normal score of 0. In terms of dementia type, the Alzheimer's group -.573 and non- Alzheimer's group .089 were found to have limited Skewness in any direction. The Kurtosis values of -.547 in the Alzheimer's group and -1.451 in the non-Alzheimer's group was limited in any direction. Similarly, in terms of sex; the male Skewness value of -.650 and kurtosis value of .100 indicates limited deviation in any direction across sexes. The female Skewness value of .087 and kurtosis value of -1.746 indicate limited deviation in any direction. Finally, in terms of capacity to give consent, those marked yes has a Skewness of -1.088 and Kurtosis of .033 which was limited in any direction. Those marked no, had a Skewness of .557 and Kurtosis of -.494 which again was limited in any direction.

An examination of all boxplots no outliers were found at baseline and on examination of the mean score and the 5% trimmed mean score there is little change as a result of extreme scores in terms of groups (CST mean 16.53, 5% trimmed mean 16.65 and Sonas mean of 15.15 and 5% trimmed mean of 15.12) and sites (inpatient psychiatry of later

life 15.38 mean and 5% trimmed mean of 15.36, care centre mean of 15.64 and 5% trimmed mean of 15.65 and community dwelling mean of 16.67 and 5% trimmed mean of 16.74) indicating normality at baseline. The mean scores were examined in terms of dementia types and little change is noted between the Alzheimer's mean score of 15.57 and the 5% trimmed mean score of 15.63 and the non-Alzheimer's mean score of 16.00 and 5% trimmed mean score of 16.05. In terms of sex, both the male mean score of 15.73 and 5% trimmed mean of 15.81 and the female mean of 16.00 and 5% trimmed mean of 16.06 were found to have little difference as a result of extreme scores. Finally, in terms of capacity to give consent, those marked yes had a mean score of 17.10 and a 5% trimmed mean of 17.28, and those marked no had a mean score of 15.22 and a 5% trimmed mean of 15.19 indicating little change as a result of extreme scores. Normal Q-Q plots and Detrended normal-Q plots were additionally examined and were found to have a normal distribution at baseline across groups, residence types, dementia types, sex and capacity; with some mild differences across sites which were not found to be clinically significant. On inspection of the shape of the distribution of the bell shaped curve in the histograms at baseline, variances were found across residence types, sites, groups, dementia types, sex and capacity.

No significant difference between inpatients and community participants at baseline $t(14.199) = -.901$, $p = .383$, NS. No differences between site of residence $F(2, 25) = .444$, $p = .646$, NS. No differences in SMMSE baseline scores dependant on the type of dementia $F(4, 23) = .406$, $p = .803$, NS. No differences in SMMSE baseline scores dependant on sex, $t(25.744) = -.250$, $p = .804$, NS and finally no difference between those who had/had not capacity to give consent $t(16.989) = 1.590$, $p = .130$, NS.

In conclusion, despite some variance at baseline, the data was found to be normal at baseline and parametric test were used in the data analysis.

Appendix 15: CST monitoring progress baseline assessments

An exploration of baseline (session one) CST Monitoring progress assessment tool data was completed. The CST Monitoring progress assessment data was found to be abnormal at baseline. This assessment was completed in 4 separate sections (Similar to the Sonas group assessment tool, one notes was no total score in this assessment, therefore individual section analysis was completed). This baseline exploration of data included an examination and comparison of the Skewness and kurtosis values in both groups; Enjoyment and Mood in both groups have positive kurtosis indicating that the distribution of their data is rather peaked or clustered in the centre indicating abnormalities in these sections at baseline. In terms of group, all other areas were found to deviate from a value of 0. However, this was found to be acceptable in this case. Similarly across site of residence as indicated in table below, the Skewness and Kurtosis indicated deviation from a normal score of 0 in the community site, again this was found to be acceptable. In the Inpatient Psychiatry of Later Life site, positive kurtosis is found in communication, enjoyment and mood. In the care centre site negative kurtosis is found indicating that the distribution of the data is relatively flat with too many cases in the extremes.

Title of table 34: Skewness and Kurtosis

	CST		Sonas		Inpatient Psychiatry of Later Life		Care centre		Community		Inpatients		Community	
	Skewness (S)	Kurtosis (K)	S	K	S	K	S	K	S	K	S	K	S	K
Interest	0.498	-1.399	-0.604	-1.523	1.440	0.000	-0.286	-1.984	-0.606	-0.286	0.355	-1.650	-0.606	-0.286
Communication	0.307	-1.282	-0.812	-1.650	0.644	-2.240	-0.644	-2.240	-0.284	-0.040	0.000	-2.308	-0.254	-0.040
Enjoyment	-1.46	4.014	0.00	-2.3	-1.00	3.51	0.00	-2.80	0.000	-0.28	-0.812	1.84	0.000	-0.28

nt	2		0	33	2	6	0	0		6		1		6
Mood	-1.462	<i>4.014</i>	0.000	-2.333	-1.002	<i>3.516</i>	0.000	-2.800	0.000	-0.286	-0.812	1.841	0.000	-0.286

Table 34

Bold +italics= extremes (not close to 0)

Title of table 35: Skewness and Kurtosis, dementia type and sex

	Alzheimer's		Non Alzheimer's		Male		Female	
	Skewness (S)	Kurtosis (K)	S	K	S	K	S	K
Interest	-.909	-.150	.243	<i>-2.027</i>	-.484	<i>-2.277</i>	.059	-1.055
Communication	-.347	<i>-2.800</i>	.243	<i>-2.027</i>	.000	<i>-2.571</i>	-.274	-1.499
Enjoyment	.000	-1.200	-.985	<i>2.418</i>	-1.054	1.619	.437	-1.229
Mood	.000	-1.200	-.985	<i>2.418</i>	-1.054	1.619	.437	-1.229

Table 35

Bold +italics= extremes (not close to 0)

In the Alzheimer's dementia type, negative kurtosis in an extreme is found in communication indicating that the distribution of the data is relatively flat with too many cases in the extremes. In the Non Alzheimer's dementia type negative Kurtosis in extreme is found in interest and communication and positive kurtosis in enjoyment and mood. In the male sex, negative Kurtosis to the extreme is found in Interest and communication only.

This baseline data examination included a Kolmogorov-Smirnov test of normality which was found to be statistically significant in all areas of groups and residence type. In terms of site of residence, one area was found not to be significant in the community

sites interest section; indicating a violation of the normality assumption across groups as detailed in table attached.

Title of table 36: Normality

	<u>Kolmogorov-Smirnov test of Normality: Statistical Significance</u>						
	CST	Sonas	Inpatient Psychiatry of Later Life	Care centre	Community	Inpatients	Community
Interest	0.005	0.000	0.000	0.018	0.054	0.000	0.001
Communication	0.040	0.000	0.001	0.001	0.021	0.000	0.000
Enjoyment	0.002	0.008	0.001	0.013	0.044	0.000	0.001
Mood	0.002	0.008	0.001	0.013	0.044	0.000	0.001

Table 36

Bold +italics= statistically significant

Title of table 37: Normality, dementia type and sex

	<u>Kolmogorov-Smirnov test of Normality: Statistical Significance</u>				
	Alzheimer's	Non-Alzheimer's		Male	Female
Interest	.200	<i>.000</i>		<i>.000</i>	<i>.017</i>
Communication	<i>.007</i>	<i>.000</i>		<i>.003</i>	<i>.012</i>
Enjoyment	.200	<i>.001</i>		<i>.030</i>	<i>.009</i>
Mood	.200	<i>.001</i>		<i>.030</i>	<i>.009</i>

Table 37

The Alzheimer's dementia type was found to have non significant results in the areas of interest, enjoyment and mood indicating a violation of the assumption of normality. In terms of sex, all areas were normal.

Further inspection of the shape of the distribution through examination of the bell shaped curve in the histograms at baseline summarised that variances were found across sites, residence type, groups, dementia type and sex indicating violation of the assumption of normality at baseline. This however was expected given the short range of scores.

Title of table 38: Mean and 5% trimmed mean, site of residence

	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score		
	CST		Sonas		Long stay Inpatient Psychiatry of later life		Care centre		Community		Inpatients		Community	
Interest	3.77	3.74	4.08	4.15	3.50	3.44	3.88	3.92	4.33	4.37	3.69	3.71	4.33	4.37
Communication	3.85	3.83	4.33	4.37	3.75	3.72	4.25	4.28	4.22	4.25	4.00	4.00	4.22	4.25
Enjoyment	3.38	3.48	4.00	4.00	2.66	2.90	4.00	4.00	4.00	4.00	3.47	3.57	4.00	4.00
Mood	3.38	3.48	4.00	4.00	2.86	2.90	4.00	4.00	4.00	4.00	3.47	3.57	4.00	4.00

Table 38

Title of table 39: mean and 5% trimmed mean, dementia type and sex

	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score		Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score
	Alzheimer's		Non Alzheimer's			Male		Female	
Interest	4.00	4.06	3.89	3.88		4.20	4.22	3.73	3.76
Communication	4.57	4.58	3.89	3.88		4.00	4.00	4.13	4.15
Enjoyment	4.00	4.00	3.53	3.64		3.50	3.61	3.79	3.76
Mood	4.00	4.00	3.53	3.64		3.50	3.61	3.79	3.76

Table 39

On examination of boxplots outliers were found at baseline in the groups, sites and residence type only. They were retained in the data following examination of the mean score and the 5% trimmed mean score as summarised in the tables. One notes there was little change as a result of extreme scores in terms of groups, sites, residence type, dementia type and sex indicating normality at baseline.

Normal Q-Q plots were additionally examined and were found to have a normal distribution at baseline across groups, sites, residence type, dementia type and sex. Detrended normal Q-Q plots were examined to find some clustering of points and uneven distribution in the groups, site of residence, resident type, dementia type and sex. This indicates further abnormalities at baseline.

In summary, not all variables were fully examined including further Mann Whitney U tests. This was based on the extreme abnormalities on baseline data as presented in the tables and in the text. The data was found to violate the assumption of normality at baseline and non-parametric data analysis was used in the analysis.

Appendix 16: Sonas group session evaluation form normality/baseline

An exploration of baseline (session one) Sonas group session evaluation form data was completed. The Sonas group session evaluation data was found to be abnormal at baseline. This assessment was completed in 14 separate sections (note was no total score). This baseline data examination included a Kolmogorov-Smirnov test of normality which was found to be significant indicating a violation of the normality assumption across groups as detailed in the table. In terms of group; components of two out of 14 sections, vocalising and speaking were found to have no significant results and to be normal at baseline. This correlates with the inclusion/ exclusion criteria using the CAPE where individuals were required to have a score of 0 or 1 on the CAPE indicating their ability to participate in a group. In terms of site of residence, no significant results were found in appropriate touch section in the care centre and community site, in the inpatient psychiatry of later life exercise section, in the inpatient psychiatry of later life singing, rhythmic movements, contribution and using instruments section. These non significant results indicate normality in eleven out of fourteen sections. In terms of dementia type and sex, significant results were found dispersed across categories which indicated violation of the assumption of normality.

On examination and comparison of the Skewness and kurtosis values in both groups detailed in the relevant table; appropriate touch (CST 2.775 only) and using instruments (CST 11.703 and Sonas 6.242) sections of the assessment appear to have positive kurtosis indicating that the distribution of their data is rather peaked or clustered in the centre indicating abnormalities in these sections at baseline. All other areas were found to deviate from a value of 0. However, this was found to be acceptable in this case. Similarly across sites as indicated in the relevant table, the Skewness and Kurtosis indicated deviation from a normal score of 0 in most areas with the greatest in the community site indicating abnormality at baseline. In terms of dementia type, the Alzheimer's dementia type was found to have extremes. In terms of sex, extremes were found dispersed unevenly in both males and female categories again indicating abnormalities at baseline.

Title of table 40: Skewness and Kurtosis, group and site of residence

	CST		Sonas		Inpatient Psychiatry of Later Life		Care centre		Community		Inpatients		Community	
	Skewness (S)	Kurtosis (K)	S	K	S	K	S	K	S	K	S	K	S	K
Eye Cont act	-0.704	-0.718	- 0.719	-0.792	0.00 0	- 2.8 00	1.11 3	0.29 1	- 3.00 0	9.0 00	- 0.19 2	- 0.6 75	- 3.00 0	9.000
Hold ing gaze	-1.119	0.436	- 0.719	-0.792	- 1.67 5	3.1 36	- 1.11 3	0.29 1	- 3.00 0	9.0 00	- 0.84 1	0.6 28	- 3.00 0	9.000
Follo wing with Gaze	-1.119	0.436	- 0.719	-0.792	- 1.67 5	3.1 36	- 1.11 3	0.29 1	- 3.00 0	9.0 00	- 0.84 1	0.6 28	- 3.00 0	9.000
Smil ing	-1.190	0.421	- 0.719	-0.792	- 0.97 0	1.8 72	- 1.11 3	0.29 1	- 3.00 0	9.0 00	- 0.82 8	0.3 61	- 3.00 0	9.000
Voca lisin g	-0.979	0.927	- 0.478	-0.868	- 0.63 3	1.7 37	0.06 8	0.74 1	- 3.00 0	9.0 00	- 0.96 7	2.3 52	- 3.00 0	9.000
Spea king	-0.979	0.927	- 0.478	-0.868	- 0.97 0	1.8 72	0.40 4	- 0.22 9	- 3.00 0	9.0 00	- 0.96 7	2.3 52	- 3.00 0	9.000
Appr opria te Touc h	-1.583	2.775	- 1.068	0.352	- 1.75 8	3.9 39	- 0.27 7	- 1.39 2	- 0.27 7	- 1.3 92	- 1.42 1	3.2 04	- 0.31 8	0.520
Exer cises	-1.042	-0.163	- 0.735	-0.190	- 0.76 4	0.8 75	0.28 8	- 1.74 6	- 0.27 1	- 2.5 71	- 0.27 1	- 2.5 71	- 0.94 7	1.610
Singi ng	-1.287	1.588	- 0.179	-0.792	- 1.14 0	1.6 52	0.27 7	- 1.39 2	- 3.00 0	9.0 00	- 0.94 7	1.6 10	- 3.00 0	9.000
Rhyt hmic Mov eme nts	-1.256	-0.329	- 1.048	-0.906	- 0.18 2	- 2.1 90	- 0.10 5	- 1.92 2	- 0.27 1	- 2.5 71	- 0.60 1	- 0.8 93	- 0.271	-2.571
Cont ribut ion	-0.421	-0.677	- 0.735	-0.190	- 0.76 4	0.8 75	0.00 0	0.00 0	- 3.00 0	9.0 00	- 0.52 2	- 0.9 67	0.443	-0.967
Usin g Instr ume nts	-3.384	11.703	- 2.555	6.242	- 1.93 6	4.1 75	- 1.48 6	2.97 3	- 0.27 1	- 2.5 71	- 1.96 1	- 0.9 67	4.413	-0.967
Usin g	-0.136	-1.041	- 1.068	0.352	- 0.38	- 0.4	0.40 4	- 0.22	- 3.00	9.0 00	0.34 3	- 1.4	- 0.738	-1.421

Gest ure					6	48		9	0			21		
Inter activ e Post ure	0.000	-1.942	- 0.661	-1.964	0.31 2	- 2.3 58	- 0.06 8	0.74 1	- 2.82 8	8.0 00	0.00 0	- 0.2 71	- 1.467	-0.271

Table 40

Bold +italics= extremes (not close to 0)

Title of table 41: Skewness and Kurtosis, sex and dementia type.

	Male		Female		Alzheimer's		Non Alzheimer's	
	S	K	S	K	S	K	S	K
Eye Contact	-272	-896	-1.074	-1.106	1.258	.312	-1.376	1.302
Holding gaze	-772	-125	-1.074	-1.106	-552	.868	-1.376	1.302
Following with Gaze	-772	-125	-1.074	-1.106	-889	1.339	-1.376	1.302
Smiling	-801	-378	-1.074	-1.106	-744	.284	-1.376	1.302
Vocalising	-1.020	2.256	-1.074	-1.106	-1.369	2.500	-771	.744
Speaking	-1.020	2.256	-1.074	-1.106	-1.369	2.500	-771	.744
Appropriate Touch	-1.338	1.864	-1.085	.398	-1.375	2.355	-1.205	.328
Exercises	-563	-471	-210	-1.118	-1.375	2.355	-1.205	.328
Singing	-1.323	2.816	-1.632	1.320				
Rhythmic Movements	-754	-1.441	-744	-671	.000	-3.333	-739	-.433
Contribution	-487	.552	-1.335	.471	-1.498	3.603	-1.376	.524
Using Instruments	-2.654	7.545	-1.127	1.957	-2.449	6.000	-1.119	2.442
Using Gesture	.661	-.709	-1.792	2.625	.523	-1.875	-1.205	.328
Interactive Posture	.687	-1.043	-1.067	-1.034	.523	-1.875	-1.205	.328

Table 41

Bold +italics= extremes (not close to 0)

Title of table 42: normality assessment, group, residence type and site of residence

	<u>Kolmogorov-Smirnov test of normality: Statistical Significance</u>						
	CST	Sons	Inpatient Psychiatry of Later Life	Care centre	Community	Inpatients	Community
Eye Contact	.008	.003	0.013	0.062	0.000	0.066	0.000
Holding gaze	.021	.003	0.065	0.062	0.000	0.020	0.000
Following with Gaze	.021	.003	0.065	0.062	0.000	0.020	0.000
Smiling	.001	.003	0.147	0.062	0.000	0.016	0.000
Vocalising	.107	.028	0.046	0.012	0.000	0.016	0.000
Speaking	.107	.028	0.147	0.109	0.000	0.011	0.000
Appropriate Touch	.034	.000	0.002	0.200	0.200	0.000	0.000
Exercises	.000	.002	0.200	0.013	0.002	0.068	0.002
Singing	.021	.003	0.200	0.200	0.000	0.041	0.000
Rhythmic Movements	.000	.000	0.072	0.200	0.002	0.062	0.002
Contribution	.045	.002	0.200	0.200	0.000	0.090	0.000
Using Instruments	.000	.000	0.023	0.013	0.002	0.000	0.002
Using Gesture	.049	.000	0.200	0.109	0.000	0.031	0.000
Interactive Posture	.028	.000	0.022	0.012	0.000	0.080	0.000

Table 42

Bold = Not significant

Title of table 43: Normality, sex and dementia type.

	<u>Kolmogorov-Smirnov test of normality:</u> Statistical Significance			
	Male	Female	Alzheimer's	Non Alzheimer's
Eye Contact	.200	.000	.046	.000
Holding gaze	.200	.000	.200	.000
Following with Gaze	.200	.000	.200	.000
Smiling	.185	.000	.200	.000
Vocalising	.065	.000	.036	.000
Speaking	.065	.000	.036	.000
Appropriate Touch	.139	.000	.077	.000
Exercises	.200	.076	.077	.000
Singing	.027	.000	.168	.000
Rhythmic Movements	.061	.002	.056	.000
Contribution	.143	.000	.003	.000
Using Instruments	.001	.001	.000	.000
Using Gesture	.037	.000	.200	.000
Interactive Posture	.010	.000	.200	.000

Table 43

Bold = Not significant

Further inspection of the shape of the distribution through examination of the bell shaped curve in the histograms at baseline summarised that variances were found across sites, residence type, groups, dementia type and sex indicating violation of the assumption of normality at baseline.

Title of table 44: Mean and 5% trimmed mean group, site of residence and residence type

	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score
	CST		Sonas		Long stay Inpatient Psychiatry of later life		Care centre		Community		Inpatients	Community
Eye contact	3.08	3.14	3.33	3.37	2.50	2.50	3.13	3.19	3.89	3.93	2.81	2.85
Holding Gaze	2.91	3.03	3.33	3.37	2.25	2.23	3.13	3.19	3.89	3.93	3.89	3.93
Following with Gaze	2.92	3.03	3.33	3.37	2.25	2.33	3.13	3.19	3.89	3.93	2.69	2.76
Smiling	3.00	3.11	3.33	3.37	2.38	2.42	3.13	3.19	3.89	3.93	3.89	3.93
Vocalising	2.85	2.94	3.25	3.28	2.25	2.28	2.88	2.86	3.89	3.93	2.69	2.76
Speaking	2.85	2.94	3.25	3.28	2.38	2.42	2.75	2.72	3.89	3.93	3.89	3.93
Appropriate Touch	3.08	3.20	3.50	3.56	2.63	2.69	3.13	3.14	3.13	3.14	2.75	2.83
Exercises	3.77	3.91	3.42	3.46	2.50	2.56	3.63	3.64	4.56	4.56	3.89	3.93
Singing	3.00	3.11	3.33	3.37	2.63	2.69	2.88	2.86	3.89	3.93	3.89	3.93
Rhythmic Movements	3.69	3.82	3.42	3.46	2.38	2.36	3.63	3.64	4.56	4.56	3.00	3.06
Contribution	2.62	2.68	3.42	3.46	2.50	2.56	2.50	2.50	3.89	3.93	2.50	2.56
Using Instruments	4.54	4.76	3.75	3.83	3.75	3.89	4.13	4.19	4.56	4.56	3.94	4.10
Using Gesture	3.46	3.46	3.50	3.56	3.75	3.78	2.75	2.72	3.89	3.93	3.25	3.22
Interactive Posture	3.00	3.00	3.64	3.65	2.88	2.86	3.13	3.14	3.89	3.92	3.89	3.93

Table 44

Title of table 45: Mean and 5% trimmed mean, sex and dementia type

	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score	Mean Score	5% Trimmed Mean Score
	Male		Female		Alzheimer's		Non Alzheimer's	
Eye contact	2.80	2.83	3.47	3.52	2.60	2.56	3.37	3.46
Holding	2.60	2.67	3.47	3.52	2.20	2.22	3.37	3.46

Gaze								
Following with Gaze	2.60	2.67	3.47	3.52	2.33	2.37	3.37	3.46
Smiling	2.70	2.78	3.47	3.52	2.50	2.56	3.37	3.46
Vocalising	2.40	2.44	3.47	3.52	2.00	2.06	3.37	3.41
Speaking	2.40	2.44	3.47	3.52	2.00	2.06	3.37	3.41
Appropriate Touch	2.90	3.00	3.53	3.59	2.50	2.56	3.53	3.58
Exercises	3.20	3.28	3.87	3.91	2.50	2.56	3.53	3.58
Singing	2.50	2.56	3.60	3.67	2.17	2.24	3.47	3.53
Rhythmic Movements	3.10	3.17	3.87	3.91	2.50	2.50	3.89	3.94
Contribution	2.20	2.22	3.53	3.59	1.83	1.87	3.37	3.46
Using Instruments	4.20	4.39	4.13	4.20	4.17	4.35	4.16	4.23
Using Gesture	3.20	3.17	3.67	3.74	3.33	3.31	3.53	3.58
Interactive Posture	2.70	2.67	3.71	3.74	2.23	2.31	3.61	3.68

Table 45

On examination of boxplots outliers were found at baseline in the groups, sites, residence type, dementia type and sex. They were retained in the data following examination of the mean score and the 5% trimmed mean score as summarised in Table _ where there was little change as a result of extreme scores in terms of groups, sites, residence type, dementia type and sex indicating normality at baseline.

Normal Q-Q plots were additionally examined and were found to have a normal distribution at baseline across groups, sites, residence type, dementia type and sex. Detrended normal Q-Q plots were examined to find some clustering of points in the sonas groups, uneven distribution in the residence type, sites, dementia type and sex. Given the range of scores in the clustering this was found to be not clinically significant.

Independent samples Mann Whitney U tests were used to compare groups mean scores at baseline. There were two differences between mean scores at baseline between CST and Sonas groups.

Title of table 46: Comparison of CST and Sonas groups

	Comparison of CST and Sonas groups
Eye contact	(U=87.000, p=.650, NS)
Holding Gaze	(U=88.000, p=.611, NS)
Following with Gaze	(U=88.000, p=.611, NS)
Smiling	(U=83.000, p=.810, NS)
Vocalising	(U=91.000, p=.503, NS)
Speaking	(U=91.000, p=.503, NS)
Appropriate Touch	(U=92.000, p=.470, NS)
Exercises	(U=55.000, p=.225, NS)
Singing	(U=29.000, .007)
Rhythmic Movements	(U=44.500, p=.068, NS)
Contribution	(U=105.000, p=.152, NS)
Using Instruments	(U=17.000, p=.000)
Using Gesture	(U=79.000, p=1.000, NS)
Interactive Posture	(U=99.500, p=.106, NS)

Table 46

In summary, the initial analysis of the data in terms of normality was found to violate the assumption of normality at baseline. The Mann Whitney U tests showed two differences between individual components of the assessment (and there were no total score on this assessment). Therefore no further statistical analysis at baseline was warranted on all variables and non-parametric data analysis was used in the analysis.

Appendix 17: Baseline data examination ADCS-ADL

On examination of the baseline data of the ADCS-ADL assessment, variances across sites and groups were found which violated the normality assumption at baseline. The Kolmogorov- Smirnov assessment of normality found non-significant results across all sites ($p=0.200$), both groups ($p=0.200$), both Alzheimer's and non-Alzheimer's dementia types ($p=.200$), all Dementia diagnosis type ($p=.200$), both sexes ($p=.200$) and capacity to give informed consent ($p=.200$) at baseline. This indicates that the assumption of normality is true.

Skewness values were examined to find that the data was not particularly skewed in any direction in terms of sites (Inpatient psychiatry of later life 0.535, care centre 0.599 and community dwelling -0.081), residence types (Inpatients 1.495 and community -1.166), in terms of group (CST 0.540 and Sonas -0.219), in terms of dementia type (Alzheimer's .203 and non-Alzheimer's .691), in terms of dementia diagnosis type (Alzheimer's .698, Vascular .229, mixed Alzheimer's and Vascular .411, not specified/other .055), in terms of sex (Male .126 and female .442) and capacity to give informed consent (yes .609, no .114).

Kurtosis values were examined in terms of site and found to be (Inpatient psychiatry of later life $p= -1.182$, Care centre $p= 0.203$ and community $p=1.504$) limited. In terms of residence types (inpatients 2.927 and community 2.109) kurtosis values deviate largely over a score of 0 indicating abnormalities. In terms of groups (CST $p=-0.882$ and sonas $p= 1.210$), dementia type (Alzheimer's and non-Alzheimer's .022), dementia diagnosis type (Alzheimer's -.739, Vascular -2.608, mixed Alzheimer's and Vascular -1.758 and not specified/other -.252) limited Kurtosis was noted. Finally, in terms of sex (Males -1.136 and Females -.558) and capacity to give informed consent (yes -.652, no -.947) limited kurtosis is noted. This positive and negative kurtosis was noted not to be clinically significant therefore; this was found not to violate the assumptions of normality at baseline.

On inspection of box plots in terms of group, residence type, site of residence, dementia type, dementia diagnosis type, capacity to give informed consent and sex there are no outliers or extreme scores. In addition, on comparison of the CST mean of 27.86 and the CST 5% trimmed mean of 27.06, there appears to be limited changes in the mean as a result of the extreme scores. On comparison of the Sonas mean of 23.21 and the 5%

trimmed Sonas mean of 23.29, there appears to be little change in the mean as a result of the extreme scores. On comparison of the Long Stay Inpatient psychiatry of Later Life Site mean of 16.67 and the Long Stay Inpatient Psychiatry of Later Life 5% trimmed mean of 16.35, there appears to be limited changes in the mean as a result of any extreme scores. On comparison of the Care centre mean of 18.89 and the 5% trimmed Care centre mean of 18.49, there appears to be little change in the mean as a result of the extreme scores. Finally, on comparison of the community mean of 39.50 and the 5% trimmed community site mean of 39.56, there also appears to be little change in the mean as a result of extreme scores indicating normality at baseline. On comparison of the residence type inpatient mean of 20.21 and 5% trimmed mean of 18.73 and resident type community mean of 39.50 and the 5% trimmed mean of 39.56, limited change is noted. On comparison of dementia type mean, the Alzheimer's mean of 27.71 and 5% trimmed mean of 27.68 and the non Alzheimer's mean of 24.81 and 5% trimmed mean of 23.88 again represents little change as a result of extreme scores. The dementia diagnosis type mean of 28.57 and the 5% trimmed mean of 27.86 in the Alzheimer's group, the mean of 19.60 and 5% trimmed mean of 19.50 in the Vascular group, the mean of 25.14 and 5% trimmed mean of 24.83 in the mixed Alzheimer's and Vascular group, the mean of 26.25 and 5% trimmed mean of 26.17 in the not specified/other group all represent little change as a result of extreme scores. On comparison of the sex mean of Males 22.00 and 5% trimmed male mean of 21.94, and the female mean of 27.82 and 5% trimmed mean of 27.03; little change is noted as a result of extreme scores. On comparison of the capacity to give informed consent mean of 27 and 5% trimmed mean of 26.28 for the yes group, mean of 24.72 and 5% trimmed mean of 24.36 for the no group, little change is noted. Furthermore, following an inspection of the values in all the remaining distributions in all the variables, these cases were retained in the data file and this data was found to be normal.

On inspection of normality plots in terms of site, residence type, group, dementia type, dementia diagnosis type and sex, limited deviation from the straight line is noted, indicating a normal distribution at baseline. On inspection of the Detrended Normal Q-Q plots in terms of site and group there appears to be clustering of data in both groups indicating abnormalities of distribution of the data at baseline. Variances are noted in the shape of the curve in the histograms in terms of site, group, dementia type, dementia

diagnosis type, capacity to give informed consent and sex, again indicating abnormalities at baseline.

An independent samples t-test was used to compare groups at baseline; it concluded that there were no differences of statistical significance between both CST and Sonas at baseline ($t(23.148) = .780, p = .443, NS$). Statistically significant differences were found between residence types ($t(21.692) = -3.370, p = .006$). A one way Anova concluded that there were statistically significant differences between sites of residence ($F(2,25) = 10.797, p = .000$) but no differences between dementia diagnosis type ($F(4, 23) = .251, p = .906, NS$). An independent samples t-test was used to examine the differences between the dementia types at baseline; it concluded that there were no differences of statistical significance on the ADCS-ADL baseline assessment ($t(11.359) = .442, p = .666, NS$). The t test concluded that there were no differences between sex ($t(25.232) = -1.022, p = .317, NS$). The t test concluded there were no differences between those participants who had or did not have the capacity to give informed consent ($t(13.462) = .323, p = .752, NS$).

In conclusion, ADCS –ADL data did not meet the normality assumptions at baseline and therefore non-parametric tests were used to examine the data.

Appendix 18: QOL-AD baseline assessments

An examination of baseline QOL-AD data was completed.

Significant results in the Kolmogorov- Smirnov indicate that the distribution of QOL-AD scores in that variable at baseline was not normal and therefore the assumption of normality is violated. Non- significant results indicate normality. The Kolmogorov- Smirnov assessment of the normality of the distribution of the baseline QOL-AD scores per site indicate a significant result of $p=0.001$ in the Long stay inpatient psychiatric site, $p=0.000$ in the care centre site and $p=0.021$ in the Community dwelling site indicating abnormalities. In terms of group, the Kolmogorov- Smirnov assessment indicates a significant result of $p=0.001$ in the CST group and $p=0.000$ in the Sonas group indicating abnormalities at baseline. In terms of dementia type, the Kolmogorov- Smirnov assessment indicates no significant results in either dementia types (Alzheimer's $p=.200$, NS and non-Alzheimer's $p=.093$, NS) indicating normality at baseline in terms of dementia type. In terms of dementia diagnosis type, there were no significant results (Alzheimer's $p=.200$, NS, Vascular $p=.079$, NS, Mixed Alzheimer's and Vascular $p=.200$, not specified/other $p=.051$, NS). In terms of sex, the Kolmogorov- Smirnov assessment indicates no significant results for either sex (Male $p=.139$, NS and female $p=.200$, NS). In terms of capacity to give informed consent, there were no significant results (yes $p=.200$, no $p=.087$, NS).

The Skewness value of 0.644 in the Inpatient Psychiatry of Later Life site, -0.661 in the Care centre site and 0.254 in the community dwelling site indicate that the scores are not particularly skewed in any direction. The Kurtosis value of -2.240 in the Inpatient Psychiatry of Later Life site, -1.964 in the care centre site and -.040 in the community site indicating that the distribution in the psychiatry of later life is abnormal and relatively flat. In terms of group, 0.312 was found in the CST group and -0.175 in the Sonas group indicate that the scores are not particularly skewed in any direction. The Kurtosis value of -0.404 in the CST group and -2.364 in the Sonas group again indicate limited Kurtosis in any direction. Skewness values in terms of Dementia type Alzheimer's -.547 and non-Alzheimer's group .615 were not skewed in any direction. The Kurtosis value of -1.021 in the Alzheimer's and .080 in the Non Alzheimer's group indicate limited Kurtosis in any direction. The Skewness values in the dementia

diagnosis type variable (Alzheimer's .696, Vascular .531, Mixed Alzheimer's and Vascular .106 and not specified/other 2.004) indicate limited skewness in any direction .The Kurtosis values (Alzheimer's 1.093, Vascular -3.146, Mixed Alzheimer's and Vascular -1.181 and not specified/other 4.953) indicate abnormalities in the Vascular and not specified/other variable .In terms of sex, Male's 1.099 and females .460 were not skewed in any direction. Kurtosis values in Male's 1.755 and females -.331 indicated limited Kurtosis in any direction. In terms of capacity to give informed consent, Skewness values of .730 in the yes group and .692 in the no group indicate limited skewness in any direction. The Kurtosis values of 1.880 in the yes group and .393 in the no group indicate limited kurtosis in any direction.

On inspection of the group box plot in terms of outliers and extreme scores, there appears to be no outliers. In addition, on comparison of the CST mean of 2.67 and the CST 5% trimmed mean of 2.63, there appears to be limited changes in the mean as a result of the extreme scores. On comparison of the Sonas mean of 2.54 and the 5% trimmed Sonas mean of 2.54, there appears to be little change in the mean as a result of the extreme scores.

On inspection of the site box plot there appears to be no outliers at baseline in any site. On comparison of the Long Stay Inpatient psychiatry of Later Life Site mean of 2.38 and the Long Stay Inpatient Psychiatry of Later Life 5% trimmed mean of 2.36, there appears to be limited changes in the mean as a result of any extreme scores. On comparison of the Care centre mean of 2.64 and the 5% trimmed Care centre mean of 2.65, there appears to be little change in the mean as a result of the extreme scores. On comparison of the community mean of 2.78 and the 5% trimmed community site mean of 2.75, there also appears to be little change in the mean as a result of extreme scores. On inspection of the dementia type box plot in terms of dementia type's outliers and extreme scores, there appears to be no outliers. In addition, on comparison of the Alzheimer's mean of 54 and the CST 5% trimmed mean of 54.17, there appears to be limited changes in the mean as a result of the extreme scores. On comparison of the Non-Alzheimer's dementia type mean of 63.70 and the 5% trimmed mean of 63.39 there again is little change as a result of extreme scores. The dementia diagnosis type mean and 5% trimmed mean have little change as a result of extreme scores (Alzheimer's 58.14 and 5% trimmed mean of 57.83, Vascular 63.60 and 5% trimmed mean of 63.50, Mixed Alzheimer's and Vascular 60.71 and 5% trimmed mean of 60.74 and not

specified/other 62.75 and 5% trimmed mean of 62.06). On examination of dementia diagnosis type box plots, outliers were retained in the data file. On inspection of the sex box plot, outliers were found but they were later retained in the data file following examination of the mean scores; Male mean 59.82 and 5% trimmed mean of 59.24 and female mean of 61.82 and 5% trimmed mean of 61.75. On inspection of the capacity to give informed consent yes mean of 56.50 and 5% trimmed mean of 56.22, no mean of 63.56 and 5% trimmed mean of 63.23, little changes are noted in terms of extreme scores. On examination of box plots, outliers were retained in the data file.

The Normal probability plots (Normal Q-Q plots) in both groups, all sites, in terms of dementia type, dementia diagnosis type, capacity to give informed consent and in terms of sex have limited deviation from the straight line which indicates a normal distribution at baseline. On inspection of the Detrended Normal Q-Q plots; there appears to be no major clustering of points in either group and site of residence with varied distributions. There appears to be clustering of points in the Non Alzheimer's Dementia type, in both the Male and Female sex, in the no group of the capacity to give informed consent variable and in all dementia diagnosis types.

On inspection of the shape of the distribution in the histograms; one notes a deviation from a bell shaped curve in dementia types, dementia diagnosis types (apart from Alzheimer's which was normal), residence types, all 3 sites and groups indicating a varied distribution at baseline. Both sexes and capacity to give consent variables are noted to have a bell shaped curve indicating normal distributions.

An independent samples t-test was used to establish any differences at baseline, in terms of CST and Sonas Groups, it concluded that there was no significant difference between groups at baseline $t(23.669) = -.101$, $p = .920$, NS. In terms of type of dementia, statistically significant differences between dementia type were found at baseline, $t(20.856) = -3.089$, $p = .006$. In terms of sex, there were no statistically significant differences between groups, $t(16.787) = -.495$, $p = .627$, NS. In terms of residence type, it was concluded that that was no significant difference between inpatients and community participants at baseline $t(11.722) = -1.060$, $p = .310$, NS. Finally in terms of site of residence a one-way between groups ANOVA test showed no statistically significant differences between the long stay inpatient psychiatry of later life, the care centre site

and the community site $F(2, 25) = 1.072$ $p = .358$, NS. Similarly, it showed no differences between dementia diagnosis types $F(4, 23) = .318$, $p = .863$, NS).

In Conclusion, on examination of the baseline data on the QOL-AD assessment scores at baseline there appears to be variances across sites, residence type, groups, dementia type, dementia diagnosis types, capacity to give informed consent and sexes. It was concluded that the data did not meet the normality assumption and non-parametric assessments were used in the analysis.

Appendix 19: Holden Communication Scale baseline data examination

An exploration of baseline Holden communication scale data was completed. The Kolmogorov- Smirnov assessment of the normality of the distribution of the baseline Holden Communication Scale scores in terms of site indicates a result which is not significant of 0.239 ($p=0.199$) in the Long stay inpatient psychiatric site, 0.161 ($p=0.200$) in the care centre site and 0.210 ($p=0.200$) in the Community dwelling site. This indicates that the distribution of the Holden Communication scores between sites was normal at baseline and therefore the assumption of normality is not violated. In terms of group the Kolmogorov- Smirnov assessment indicates a non- significant result of 0.151 ($p=0.200$) in the CST group and a significant result of 0.244 ($p=0.033$) in the Sonas group. This indicates that the distribution of QOLAD scores between groups at baseline was not normal in the Sonas group and therefore the assumption of normality violated between groups. Similarly, in terms of dementia type the Alzheimer's dementia type was found not to have a significant result of .144, $p=.200$ in comparison to the non- Alzheimer's group who was found to have a significant result of .188, $p=.050$ indicating changes between dementia type. In terms of sex, the male sex was found not to be significant with a result of .114, $p=.200$ in comparison to the female sex who were found to have a significant result of .212, $p=.040$.

In terms of site, the Skewness value of 0.600 in the Inpatient Psychiatry of Later Life site, 0.319 in the Care centre site and -0.369 in the community dwelling site provide information regarding the symmetry of the distribution in Holden Communication scores in relation to a normal score of 0. This indicates that the scores are not particularly skewed in any direction. The Kurtosis value of -0.066 in the Inpatient Psychiatry of Later Life site, -1.532 in the care centre site and -1.373 in the community site again indicate limited differences in Kurtosis in any direction. In terms of group, the Skewness value of the CST group is 0.325 and 0.139 in the Sonas group. This indicates that the scores are not particularly skewed in any direction. The Kurtosis value of 0.726 in the CST group and -1.899 in the Sonas group again indicate limited Kurtosis in any direction. In terms of dementia type, the Alzheimer's group has a Skewness value of -.104 and a kurtosis value of -.548, the non- Alzheimer's group has a Skewness value of .254 and a kurtosis value of -1.600 again demonstrating limited Skewness or kurtosis in any direction. In terms of sex, the Skewness value of .333 in the male sex and .074 in the

female sex identify limited Skewness in any direction. The Kurtosis value of .074 in the male sex and -1.764 in the female sex identify limited kurtosis in any direction.

On inspection of the group box plots, there are no outliers. In addition, on comparison of the CST mean of 12.67 and the CST 5% trimmed mean of 12.57, there is limited changes in the mean as a result of the extreme scores. On comparison of the Sonas mean of 12.46 and the 5% trimmed Sonas mean of 12.46, there is no change in the mean as a result of the extreme scores. Furthermore, following an inspection of the values in the remaining data distribution, these cases were retained in the data file for analysis.

On inspection of the site box plots there are no outliers at baseline in any site. In addition, on comparison of the Long Stay Inpatient psychiatry of Later Life Site mean of 12.13 and the Long Stay Inpatient Psychiatry of Later Life 5% trimmed mean of 11.17, there appears to be limited changes in the mean as a result of any extreme scores. On comparison of the Care centre mean of 12.00 and the 5% trimmed Care centre mean of 11.94, there appears to be little change in the mean as a result of the extreme scores. Finally, on comparison of the community mean of 13.67 and the 5% trimmed community site mean of 13.69, there also appears to be little change in the mean as a result of extreme scores. Furthermore, following an inspection of the values in the remaining distribution, these cases were also retained in the data file.

On inspection of the Dementia type box plots there are no outliers at baseline. On comparison of the Alzheimer's dementia types mean of 13.57 and 5% trimmed mean of 13.58, and the non Alzheimer's mean of 12.24 and 5% trimmed mean of 12.21; there is little change as a result of extreme scores. On inspection of the sex box plots there are no outliers at baseline. On comparison of the male mean score of 12.64 and the 5% trimmed mean of 12.54 there appears to be little change as a result of extreme scores. Furthermore, following an inspection of the values in the remaining distribution, these cases were also retained in the data file.

On inspection of the Normal probability plots (Normal Q-Q plots) in both CST and Sonas groups, there is limited deviation from the straight line which indicates a normal distribution at baseline. Similarly, on inspection in all sites, residence types and dementia types there are limited deviation from the straight line which indicates a normal distribution at baseline. In terms of group, sites, residence type and dementia type, detrended Normal Q-Q plots were found to have no major clustering of points in

either group, sites, residence types, dementia types or sex with varied distributions throughout.

On inspection of the shape of the distribution in the CST and Sonas histograms; a deviation from a bell shaped curve in both groups was found indicating a varied distribution in both groups at baseline. In terms of sites and residence types, one notes variances in the bell shaped curve in all sites indicating variances in scores baseline across the 3 sites and two residence types. In terms of dementia types, variances are noted in the bell shaped curve indicating variances in scores at baseline across the two dementia types. Finally, in terms of sexes; the male sex were found to have a normal bell shaped curved histogram in comparison to the female sex who are noted to have a varied shape histogram indicating variances in the distribution at baseline.

An independent samples t test concluded that there was no significant difference between CST or Sonas groups at baseline $t(25.576)=.111$, $p=.913$, NS. No differences between sexes $t(14.555)=.050$, $p=.961$, NS. No differences between $t(6.945)=.438$, $p=.675$, NS. No differences between those who did have or did not have the capacity to give informed consent $t(15.945)=-.053$, $p=.958$, NS. No differences between inpatient and community groups (residence types) $t(24.011)=-.958$, $p=.348$. A one way ANOVA indicates that there are no differences between residence types $F(2,25)=.316$, $p=.732$, NS. It also indicated that there are no differences between dementia diagnosis types $F(4,23)=.819$, $p=.526$, NS.

Therefore, one can conclude that the data did not meet normality assumption at baseline and non-parametric tests were used in the data analysis.

Appendix 20: NPI Baseline normality assessment

In terms of group, the Kolmogorov- Smirnov assessment indicates a non- significant result of .164, $p=0.200$, NS in the CST group and .135, $p= 0.200$, NS in the Sonas group. This indicates that the distribution of NPI scores between groups at baseline was normal and therefore the assumption of normality is true across groups. The Kolmogorov- Smirnov assessment of the normality of the distribution of the baseline NPI scores in terms of site as above indicates a non- significant result of .119, $p=.200$, NS in the Long stay inpatient psychiatric site, a significant result of .289, $p=.011$ in the care centre site and a result which is not significant of .170, $p= .924$, NS in the Community dwelling site. This indicates that the distribution of NPI scores between sites at baseline was different at baseline and therefore the assumption of normality is violated. In terms of residence type, the Kolmogorov- Smirnov assessment indicates a non-significant result in inpatients .172, $p=.143$, NS and community .170, $p=.200$, NS indicating normality. In terms of dementia type, the Kolmogorov- Smirnov assessment indicates a non-significant result of .239, $p=0.200$, NS in the Alzheimer's group and .151, $p= 0.200$, NS in the non-Alzheimer's group. This indicates that the distribution of NPI scores between dementia types at baseline was normal and therefore the assumption of normality is true across groups. In terms of dementia diagnosis type, the Kolmogorov- Smirnov assessment indicates a non- significant result (Alzheimer's .197, $p=.200$, Vascular .325, $p=.092$, mixed Alzheimer's and Vascular .128, $p=.200$, not specified/other .173, $p=.200$) indicating normality. In terms of sex, the Kolmogorov- Smirnov assessment indicates a non- significant result of .173, $p=.200$ in Males and .153, $p=.200$ in females. This indicates that the distribution of NPI scores between sexes at baseline was normal and therefore the assumption of normality is true across groups. In terms of capacity to give informed consent, the Kolmogorov-Smirnov assessment indicates a result of .101, $p=.200$, NS for the yes variable and .166, $p=.200$, NS for the no variable.

In terms of group, the Skewness value of 1.124 in the CST group and 0.320 in the Sonas group indicates that the scores are not particularly skewed in any direction. The Kurtosis value of 1.451 in the CST group and -0.721 in the Sonas group again indicate limited Kurtosis in any direction. The Skewness value of 0.260 in the Inpatient Psychiatry of Later Life site, 2.403 in the Care centre site and -0.992 in the community dwelling site provide information regarding the symmetry of the distribution in NPI scores in relation to a normal score of 0. This indicates that the scores are positively skewed and

demonstrates changes at baseline. The Kurtosis value of 0.118 in the Inpatient Psychiatry of Later Life site, 6.329 in the care centre site and 1.256 in the community site again indicates Kurtosis which demonstrates differences across sites. The Skewness value of inpatients 2.003 and community -.992 indicate positive Skewness in the inpatient group, demonstrating variances at baseline. The Kurtosis value of 5.225 in the inpatient group and 1.256 in the community group indicate extreme kurtosis in the inpatient group indicating variances at baseline. The Skewness value of 1.458 in the Alzheimer's dementia type and .258 in the non Alzheimer's dementia type indicate limited Skewness. The Kurtosis value of 2.150 in the Alzheimer's dementia type and -1.048 indicates positive kurtosis and demonstrates inequalities at baseline. The capacity to give informed consent variable indicated limited Skewness (Alzheimer's -.246, Vascular .652, mixed Alzheimer's and Vascular .260 and not specified/other 1.368) and limited Kurtosis (Alzheimer's -.992, Vascular -2.830, mixed Alzheimer's and Vascular .069 and not specified/other 1.945). In terms of sex, the Male Skewness value of .429 and the female value of 1.015 indicate limited Skewness. The Male kurtosis value of -1.033 and female value of 1.375 indicate limited kurtosis. The capacity to give informed consent Skewness (yes -.278, no 1.881) value indicate limited Skewness and kurtosis value (yes -1.012, no 4.753) indicates significant kurtosis in the no group demonstrating inequalities at baseline.

On inspection of the group box plot there appears to be no outliers. In addition, on comparison of the CST mean of 15.93 and the CST 5% trimmed mean of 15.09, there appears to be limited changes in the mean as a result of the extreme scores. On comparison of the Sonas mean of 11.62 and the 5% trimmed Sonas mean of 11.61, there appears to be little change in the mean as a result of the extreme scores. Furthermore, following an inspection of the values in the remaining distribution, these cases were retained in the data file. On inspection of the site box plot there appears to be one outlier at baseline in the care centre site. In addition, on comparison of the Long Stay Inpatient psychiatry of Later Life Site mean of 11.50 and the Long Stay Inpatient Psychiatry of Later Life 5% trimmed mean of 11.39, there appears to be limited changes in the mean as a result of any extreme scores. On comparison of the Care centre mean of 11.82 and the 5% trimmed Care centre mean of 10.52, there appears to be a change in the mean as a result of the extreme score. Finally, on comparison of the community mean of 18.67 and the 5% trimmed community site mean of 19.07, there also appears to be little change

in the mean as a result of extreme scores. Furthermore, following an inspection of the values in the remaining distribution, these cases were retained in the data file. On inspection of the residence type box plot, outliers are noted in the inpatient group. However, on inspection of the inpatient mean of 11.68 and 5% trimmed mean of 10.54 and the community mean of 18.67 and 5% trimmed mean of 19.07 outliers were retained in the data file. On inspection of the dementia type box plot, there is an outlier in the Alzheimer's group only. However on examination of the impact of same on the Alzheimer's mean score of 16.86 and 5% trimmed mean score of 16.12 it was retained in the data file. The non-Alzheimer's mean score of 12.95 and 5% trimmed mean of 12.83 indicate little change as a result of any extreme values. On inspection of the dementia diagnosis type box plot, there are no outliers. The mean scores (Alzheimer's 18.57, 5% trimmed mean of 18.75. Vascular mean of 8.80, 5% trimmed mean of 8.61. Mixed Alzheimer's and Vascular mean of 10.43 and 5% trimmed mean of 10.37. Not specified/other mean of 16.88 and 5% trimmed mean of 16.08) and 5% trimmed mean scores show little differences as a result of extreme scores. On inspection of the sex box plot, there is one outlier in the female sex at baseline. However on examination of the mean female score of 11.45 and 5% trimmed mean of 11.23 there is little change as a result of such extreme scores. In addition, the male mean score of 11.45 and 5% trimmed mean score of 11.23 indicates little change as a result of any extreme values; all values were retained in the data file. On inspection of the capacity to give informed consent box plot, there is an outlier in the no variable. However, little impact is noted on mean scores (yes mean 14.40, 5% trimmed mean 14.50. No mean 12.82, 5% trimmed mean 11.69).

On inspection of the Normal probability plots (Normal Q-Q plots) in both CST and Sonas groups, in all sites, residence types, dementia types, dementia diagnosis types, sex and capacity to give informed consent groups; there appears to be a limited deviation from the straight line which indicates a normal distribution at baseline.

On inspection of the Detrended Normal Q-Q plots in terms of group, sites, residence types, dementia types, dementia diagnosis types, sex and capacity to give informed consent; there is evidence of clustering of points in some sections with varied distributions relative to the 0 line indicating abnormal distributions.

On inspection of the shape of the distribution in terms of group, site, residence type, dementia type, dementia diagnosis type, sex and capacity to give informed consent; in

all histograms one notes a deviation from a bell shaped curve indicating a varied distribution in all sections at baseline.

An independent samples t-test was used to statistically test for differences between groups, site of residence, residence type, sex and type of dementia at baseline. In terms of groups, no statistically significant differences were found in total pre NPI score $t(25.253)=1.188$, $p=.246$, NS. A one way ANOVA test found no statistically significant differences in total pre NPI score between sites $F(2,25)=1.593$, $p=.223$, NS or dementia diagnosis types $F(4,23)=1.256$, $p=.316$, NS. In terms of residence type, no statistically significant differences were found, $t(19.486)=-1.973$, $p=.063$, NS. In terms of sex no statistically significant differences are noted at baseline in total pre NPI score $t(25.776)=-1.153$, $p=.259$, NS. No statistically significant differences are noted at baseline between Alzheimer's and non-Alzheimer's dementia types $t(7.523)=.704$, $p=.503$, NS. No statistically significant differences are noted between those the yes and the no groups in the capacity to give informed consent variable $t(21.083)=.417$, $p=.681$, NS.

In summary, on examination of the baseline data on the NPI assessment scores there are variances at baseline. Therefore, one can conclude that the data did not meet the normality assumption at baseline and a non-parametric data analysis was used.

Appendix 21: EL Intervention Technique

1. Identify and teach the desired behaviour using an appropriate method.
2. Identify prompts that will ensure success. This may include verbal prompts, environmental modification or compensatory cues in the environment.
3. Have the patient begin to perform the response.
4. Provide prompts to make sure the patient performs the desired behaviour correctly. (Errors give negative responses).
5. If behaviour/response is incorrect, increase prompts to make the patient successful.
6. Repeat the trial several times (B phase) until the patient appears to be able to demonstrate the desired behaviour correctly and independently.
7. Following a specified number of non-prompted behaviour, conduct a trial to assess the patient's correct or incorrect learned behaviour in the post A phase.
8. Finish the intervention phase B on a successful trial with appropriate reinforcement.

Appendix 22: Individual one, B phase, chaining list.

Title of table 47: Individual one, B phase, chaining list.

Ideal sequences					
Poaching and egg		Cooking toast		Making coffee	
<ul style="list-style-type: none"> • Open fridge to retrieve eggs • Remove eggs from fridge and place on the counter securely • Open cupboard and remove pot or take from draining board at sink if required • Place pot on electric cooker and either fill with water from the sink tap or from the electric kettle • Turn on cooker at main switch • Turn on cooker ring using small knobs and dementia friendly signage. 	<p>Variation allowed for here, she may choose to have the pot boiling first, then organise eggs from fridge. Prompts may be needed for the environment; turn on the lights, retrieve glasses, use the dementia friendly signage at the cooker etc.</p>	<ul style="list-style-type: none"> • Obtain toast from the bread bin, the freezer or the counter top. • Place into electric toaster • Turn on toaster by plugging it in, turning on switch at wall and then pulling down the lever to activate the heat. • Observe it cooking or consider the timer setting it is on • Remove from the toaster and place on a plate • Open fridge and retrieve butter • Obtain a knife from the cupboard or the counter top 	<p>Variation allowed for here. The toaster may already be plugged in, turned on and the lever may be the only action required. If the individual completes a quality check of the bread in her bread bin she may need to take further actions i.e. take toast from bread bin, place in the waste bin and then take it from the freezer too. She may wish not to remove the toast from the toaster until required as this method may maintain its heat. She may choose to have or not to have butter on a particular day.</p>	<ul style="list-style-type: none"> • Turn on kettle to boil. (plug in/turn on switch at wall or flick switch at the base of the kettle) • Boil kettle • Obtain coffee from cupboard or worktop. • Obtain spoon from drawer • Obtain spoon from cupboard or from draining board at sink • Spoon coffee into cup • Re boil kettle if needed • Pour boiling water into cup • Stir with spoon • Obtain milk from the fridge • Pour milk into cup • Stir with spoon • Add hermesetas • Stir with spoon 	<p>Variation allowed for here. The sequence may change, she may wish to have all items prepared before boiling the kettle</p>

<ul style="list-style-type: none"> Remove salt from the press and place into boiling water in the pot Take a knife from the drawer and break egg into a cup (then place egg into water from cup) or directly into the pot Observe the egg poaching and maintain correct heat by adjusting knobs if the water were to boil over When observed to be cooked remove pot from heat Turn off knobs Turn off main cooker Take a plate from the press 	<p>Variation allowed for here. She may choose not to have salt on any particular day. She may choose to break egg at side of pot. She may choose to turn off small knobs and at a later time in the exercise turn off the main cooker switch.</p>	<p>if it had been used for another component of the activity</p> <ul style="list-style-type: none"> Use knife to butter toast 			
<ul style="list-style-type: none"> Take a spoon from the cupboard Transfer egg onto plate by spoon 	<p>Variation allowed for here, she may use any appropriate kitchen utensil to transfer the egg onto a plate</p>				

Table 47

Appendix 23: Participant two. Chaining list, phase B

Title of table 48:Participant two. Chaining list, phase B

Participant two- Ideal sequences/ chaining list	
Plan and organise herself in order to mobilise into her local community to complete a shopping activity	
<ul style="list-style-type: none"> • Agree the task for that particular day • Decide if the task requires specific items to be taken with her such as an example of a produce she requires. • Use the checklist before leaving the house and check for the following: <ul style="list-style-type: none"> ➤ Coat or jumper ➤ Scarf, Hat or gloves ➤ Walking Stick ➤ Handbag (Wallet- money, bank card) ➤ Reading Glasses (is it sunny, do you need your sun glasses?) ➤ ‘Shopping list’ or ‘to do list’ ➤ House Keys ➤ Turn pendant alarm system to the Away mode ➤ Mobile phone ➤ Shopping bag • Train the participant using the EL techniques to use the checklists and obtain the items in the home using the dementia friendly signs that highlighted where items were located i.e. glasses, keys etc. • Go out to the shop, the town or the local chemist and complete all activities agreed at the start of the session. • Use the shopping lists or to do lists when out of the home 	<p>Variation allowed for in terms of the task.</p> <p>Variation allowed for here in terms of sequence of which items on her checklist she chose to organise first but the checklist remained the same every day.</p> <p>Variation allowed for in terms of her route in the town, she usually completed a loop of the town when out and this could be completed in forward or reverse loop order. Otherwise, the route to the chemist, her daughters café and the local Tesco supermarket were all the same.</p>

Table 48

Appendix 24: Orientation board.

Dementia friendly colours were used on this board to highlight days and headings. On reflection the PI should have taken a photograph of the orientation board in the home (with consent from the participant). This was overlooked at the time.

Title of figure 14: orientation board.

WEEKLY PLANNER						
Week of: 						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
						
NOTES:						

Figure 14

Appendix 25: Shopping list.

This list was printed on dementia friendly coloured paper.

Shopping list:

Place book here

Appendix 26: 'To do' list.

This list was printed on dementia friendly coloured paper.

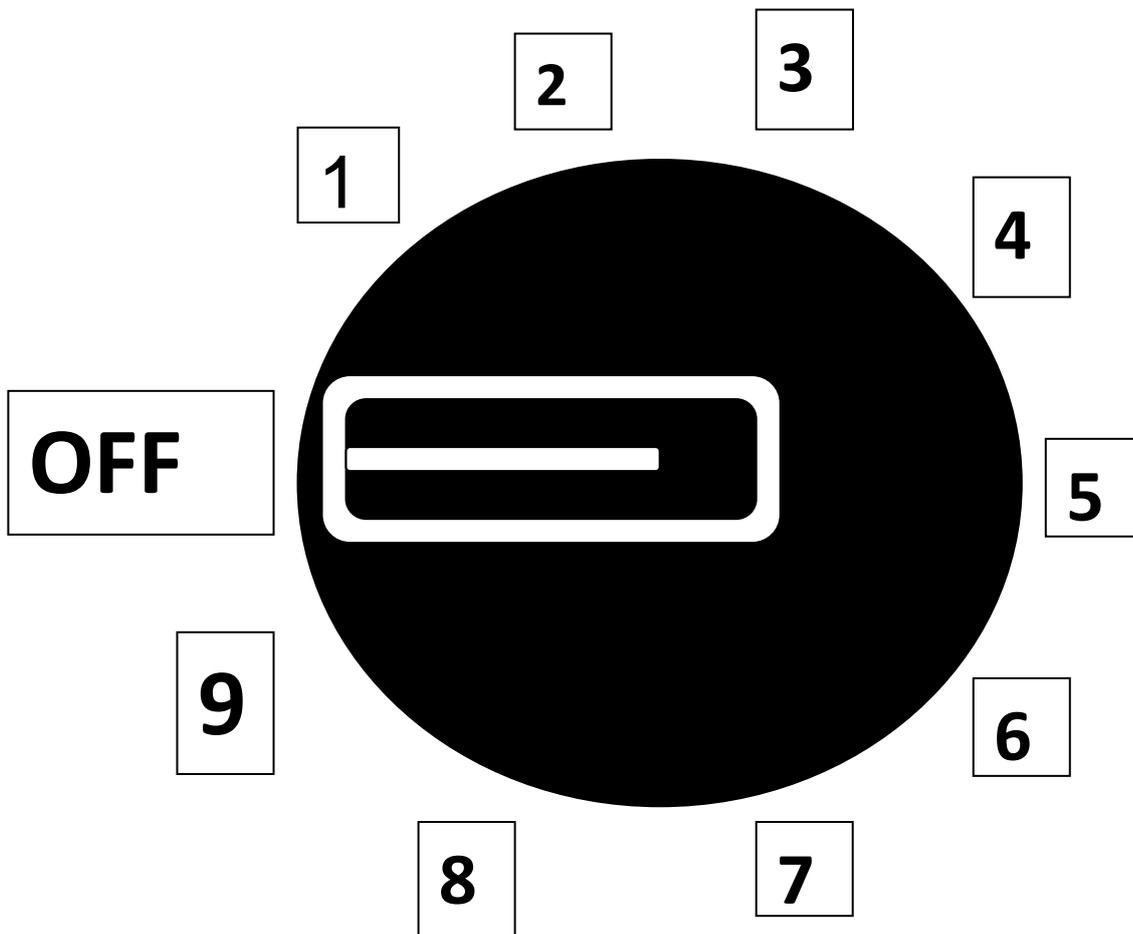
'To do' list:

Place book here

Appendix 27: Dementia friendly signage.

This page was printed in a high tone red colour.

ELECTRIC HOB SWITCH



Appendix 28: Checklist when leaving the house.

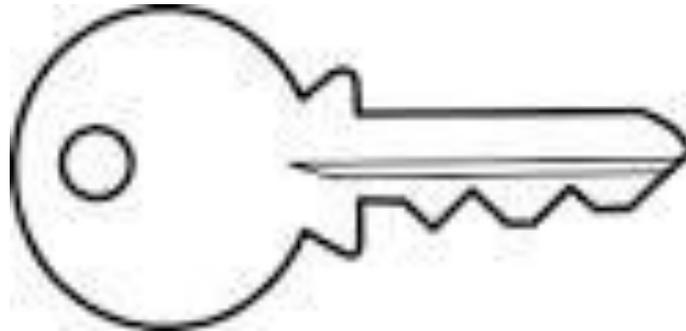
This sign was printed in the high tone dementia friendly colour of red.

Checklist when leaving your house:

Do you need any of the following?

- **Coat or jumper**
- **Scarf, Hat or gloves**
- **Walking Stick**
- **Handbag (Wallet- money, bank card)**
- **Reading Glasses (is it sunny, do you need your sun glasses?)**
- **'Shopping list' or 'to do list'**
- **House Keys**
- **Turn pendant alarm system to the Away mode**
- **Mobile phone**
- **Shopping bag**

Key's



Glasses



Glasses



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

20th October 2011

Ref: 051011OB



Re: Evaluating the effectiveness of Sonas and Cognitive Stimulation Therapy (CST) on Quality of life, Activities of Daily Living, Communication, Group participation and the Behavioural and Psychological Symptoms of people with moderate Dementia

Dear [REDACTED]

The above research proposal came before the Research Ethics Committee (REC) on the 12th of October 2011.

The REC has provided a provisional favourable opinion (B) with regard to this research proposal but would like some additional information.

- It was noted by the REC that your research was proposing to recruit the same participants as the research proposal of [REDACTED] with slight differences in methodology. This was discussed by the committee. The burden on participants is not negligible and the REC request that the researchers be mindful of this while conducting their research.
- Using two consent forms for the two different studies for one patient versus one consent form, was also discussed. We don't feel there is a definitive answer to what is best here. It is up to the wider research team to decide what is in the best interests of the patient.
- Informed consent was discussed. The National Disability Authority published guidelines recently on conducting research on persons with disability (link below). The concept of continuous informed consent or assent is introduced, communicating the information in different ways and a move away from proxies. It may be necessary to introduce these based on capacity assessment of participants.

<http://www.nda.ie/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/232F61AE5397A93D802576650052B3B9?OpenDocument>

- It was felt that the language in your participant information sheets and informed consent forms may be difficult for the client group you wish to recruit for your research. Please amend with more appropriate language – a review of the National Adult Literacy Agency website may be a useful resource for this.
- The REC was of the opinion that for some participants reviewing childhood as per session three of the Cognitive Simulation Therapy may be distressing. These comments were made in the context of the possibility of participants experiencing difficult childhoods for one reason or another. Please be aware of this during your research.
- It is recommended that only HSE mobile numbers and workplace landlines should be recorded on research literature.

The Chairperson will review your clarifications and respond promptly.

Yours Sincerely,

A large black rectangular redaction box covers the signature area, obscuring the name and any handwritten notes or dates.

Title: Copy of e mail with clarifications, phase one.

Dear [REDACTED],

I am writing to you to respond to the recent ethics committee decisions regarding the above applications. As both [REDACTED] and [REDACTED] this on behalf on both applications. I have outlined below the comments which required further clarification and/or consideration from the committee and our response to same.

Comment: *It was noted by the REC that your research was proposing to recruit the same participants as the research proposal of [REDACTED] with slight differences in methodology and this was discussed by the committee. The burden on participants is not negligible and the REC request that the researchers be mindful of this while conducting their research.*

Response: [REDACTED] and I met on Friday 21st October to clarify our methodology. The discrepancy on our applications were as a result of some adjustments made in my application in the days prior to the submission deadline. [REDACTED] had submitted her application the week prior to the submission deadline and was on holidays when I was making these adjustments in my own application. [REDACTED] and I have agreed that the methodology (as submitted in my application 051011JOH) will be followed. We are both mindful of the number of assessments involved for the participants and the potential burden this may have on them. Those involved in the assessment process will work collaboratively to ensure that these assessments are conducted over a number of sessions. Staff in the services will also be notified in advance of assessment times, appointments etc to ensure effective and smooth delivery of same.

Comment: *Using two consent forms for the two different studies for one patient versus one consent form, was also discussed. We don't feel there is a definitive answer to what is best here. It is up to the wider research team to decide what is in the best interests of the patient.*

Response: The issue of whether or not to use different participant information leaflets and consent forms has been discussed further. We have also consulted with our academic supervisor's in the National University of Ireland, Galway. In consultation, we have agreed that one information leaflet and consent form (for participants and next of kin) is the most appropriate option.

Comment: *Informed consent was discussed. The National Disability Authority published guidelines recently on conducting research on persons with disability (link below). The concept of continuous informed consent or assent is introduced, communicating the information in different ways and a move away from proxies. It may be necessary to introduce these based on capacity assessment of participants.*

Response: The NDA and other relevant guidelines were referred to on the issue of obtaining informed consent. Participants will be reminded that they can withdraw from the research throughout the study should they report any discomfort/disinterest at any stage. A person's capacity to give informed consent can fluctuate and/or change. Due to

the relatively short time frame of this study it is not envisaged that this fluctuation and/or change will occur to a significant degree. The Principal Investigator's are mindful of assuring the ongoing consent of participants. Where there are concerns that a participant's capacity to give informed consent has changed, this will be discussed with the Principal Investigators, The Consultant Psychiatrist, [REDACTED] and the Senior Clinical Psychologist, [REDACTED]

Comment: *It was felt that the language in your participant information sheets and informed consent forms may be difficult for the client group you wish to recruit for your research. Please amend with more appropriate language – a review of the National Adult Literacy Agency website may be a useful resource for this.*

Response: Please see attached amended information sheets and consent/assent forms for the participant and next-of-kin. These forms have been shortened and simpler language used where possible. The main way this has been done is to remove the reference to the names of the two group interventions. This has helped reduce the amount of information on the forms. It is not felt that omitting information about the groups (e.g. name of group intervention) causes any deception. The information provided in the leaflets still contains all necessary information as recommended by the International Association for the Scientific Study of Intellectual Disability (IASSID) and the NUIG Guidelines on writing Participant Information and Consent Forms (e.g. what is the purpose of the study, the risks and benefits, able to withdraw from the study, what will happen to the study results).

Comment: *The REC was of the opinion that for some participants reviewing childhood as per session three of the Cognitive Simulation Therapy may be distressing. These comments were made in the context of the possibility of participants experiencing difficult childhoods for one reason or another. Please be aware of this during your research.*

Response: The group [REDACTED] will be mindful of this. The presence of a co-facilitator who is present during the group sessions as an 'observer role' will help identify any discomfort participants may feel in the session.

Comment: *As the participants in this research are clients of the HSE and are cared for in facilities of the HSE no letters, information leaflets or consent forms should have NUI Galway logos on them.*

Response: This has been changed. Only HSE headed paper will be used on documentation.

Comment: *It is recommended that only HSE mobile numbers and workplace landlines should be recorded on research literature.*

Response: This has been changed. Only HSE work landline numbers will be included in the documentation.

We trust this is to your satisfaction. We look forward to hearing from you.

Kind regards

12th June 2013

100413OB

Re: Evaluating the effectiveness of an Occupation Therapy application of an errorless learning technique in older adults with dementia

Dear [REDACTED]

Thank you for your clarifications received on the 9th of May. The amended informed consent form and information leaflet were circulated to the REC for review via email and was discussed again at the REC meeting held on the 5th of June.

The REC has provided a **Favourable Opinion** but please note the following:

- The REC was not completely satisfied with the amended information leaflet. It is too long and detailed for the proposed participants. However, you as a researcher have a duty of care to ensure that potential participants can understand the proposed research and give informed consent to participate. The REC does not wish to review it again.
- The other modifications are satisfactory.

Best wishes with your research

Yours Sincerely,

[REDACTED]
Secretary – Research Ethics Committee

Appendix 32: NUI Galway legal liability.



Insurance Brokers
Reinsurance Brokers
Actuaries and Consultants
Risk Management Consultants

WILLIS
CRESCENT COURT, ST. NESSANS
ROAD, DOORADOYLE
LIMERICK

T: +353 61 218 900
F: +353 61 218 901
E: info@willis.ie
W: www.willis.com/ireland

Our Ref **CB**

Your Ref

Date 01st October 2010

Ms. Robyn Cunningham,
Buildings & Estates Department,
National University of Ireland,
Newcastle Road,
Galway.

TO WHOM IT MAY CONCERN:

We are insurance brokers to the National University of Ireland, Galway and confirm cover presently in place, details as follows:-

Employers Liability Policy No. 0747

Limit of Indemnity: €13,000,000 any one accident.
Insurer: Irish Public Bodies Mutual Ins. Co. Ltd.
Period of Cover: 12 months from 1st October 2010.

Public Liability Policy No. X/5675

Limit of Indemnity: €6,500,000 any one accident.
Insurer: Irish Public Bodies Mutual Ins. Co. Ltd.
Period of Cover: 12 months from 1st October 2010.

Professional Indemnity Policy No. EX92868588

Limit of Indemnity: €6,000,000 any one accident / aggregate.
Insurer: Irish Public Bodies Mutual Ins. Co. Ltd.
Period of Cover: 12 months from 1st October 2010.

Subject to policy terms and conditions.

Trusting this is the information you require. If you have any further queries, please do not hesitate to contact us.

Yours sincerely,

CAROLINE BOND
Client Service Executive, Corporate Risks
DD +353 (0) 61 218502
F +353 (0) 61 218501
E caroline.bond@willis.ie

Appendix 33: Medication analysis types per group

This appendix outlines the medication types the participants were on dependant on the CST or Sonas conditions.

Title of table 49: Acetylcholinesterase inhibitors

Acetylcholinesterase Inhibitors				
Group			Frequency	Percent
		Yes	9	60.0
CST	Valid	No	6	40.0
		Total	15	100.0
		Yes	6	46.2
Sonas	Valid	No	7	53.8
		Total	13	100.0

Table 49

Title of table 50: Anti-depressant medication

Anti-Depressant Medication				
Group			Frequency	Percent
		Yes	3	20.0
CST	Valid	No	12	80.0
		Total	15	100.0
		Yes	7	53.8
Sonas	Valid	No	6	46.2
		Total	13	100.0

Table 50

Title of table 51: anti-psychotic medication

Anti-Psychotic Medication				
Group			Frequency	Percent
		Yes	4	26.7
CST	Valid	No	11	73.3
		Total	15	100.0
		Yes	3	23.1
Sonas	Valid	No	10	76.9
		Total	13	100.0

Table 51

Title of table 52: Benzodiazepines

Benzodiazepines			Frequency	Percent
Group				
		Yes	2	13.3
CST	Valid	No	13	86.7
		Total	15	100.0
		Yes	6	46.2
Sonas	Valid	No	7	53.8
		Total	13	100.0

Table 52

Appendix 34: Relationships between variables at baseline.

The relationships between variables at baseline were examined using the Pearson's product-moment correlation coefficient and Dichotomous variables were examined using a Spearman's test to establish if there were relationships between variables at baseline. Statistically significant results are presented in the following tables:

Title of table 53: Spearman's rank order correlations

Spearman's Rank order Correlation:		
Dementia type	Residence type	r=.397, p=.036, N=28 medium strength positive correlation
	Sex	r=.549, p=.002, N=28 large strength positive correlation
Residence type	Acetylcholinesterase inhibitors	r=-.487, p=.009, N=28 medium strength negative correlation

Table 53

Title of table 54: Pearson's product moment correlation

Pearson's product moment correlation:		
Sex	Age	r=.467, p=.012, N=28 medium strength positive correlation
	Other diagnosis	r= .434, p=.027 medium strength positive correlation
Site of Residence	Type of dementia	r= -.540, p=.003 large strength negative correlation
	Residence type	r=.861, p=.000 large positive correlation
	Other diagnosis	r=.739, p=.000 large positive correlation

	Acetylcholinesterase inhibitors	r=-.594, p=.000 large negative correlation
Residence Type	Other diagnosis	r=.658, p=.000, N=28 Large positive correlation
Other Diagnosis	Acetylcholinesterase inhibitors	r= -.465, p=.017 medium negative correlation
	Benzodiazepines	r=.429, p=.029 medium positive correlation
Number of years in inpatient residence	Site of residence	r=-.568, p=.011 large negative correlation
	Type of Dementia	r=.543, p=.016, N=28 Large positive correlation
	Benzodiazepines	r=-.572, p=.011 large negative correlation

Table 54

In addition, the relationship between baseline SMMSE scores, ADCS-ADL, OTTOS, QOL-AD, NPI scores and Holden communication scale scores were examined using a Pearson's product-moment correlation coefficient. There were no correlations of statistical significance. The CST evaluation tool and the Sonas evaluation tool were not examined as they did not have total scores to compute correlations.

Appendix 35: OTTOS

In order to examine which sessions were most influential interval assessments were measured and compared, it is noted that CST was found to have four sessions where there were decreases in mean scores; session three, seven, ten and twelve respectively. In the Sonas group there are two sessions where decreases in mean scores; session four and eleven. This table shows the fourteen session intervals:

Title of table 55: OTTOS 14 intervals

	CST	CST Session Title	Sonas	Sonas Session Title
Session 1	132.08	Physical Games	130.83	Sonas
Session 2	155.75	Sounds	137.25	Sonas
Session 3	144.42	Childhood	145.15	Sonas
Session 4	152.29	Food	142.73	Sonas
Session 5	159.14	Current Affairs	143.40	Sonas
Session 6	159.83	Faces and Scenes	148.22	Sonas
Session 7	159.73	Word Associations	148.30	Sonas
Session 8	160.17	Being Creative	159.40	Sonas
Session 9	162.08	Categorising objects	159.88	Sonas
Session 10	156.79	Orientation	160.89	Sonas
Session 11	166.50	Using Money	159.14	Sonas
Session 12	165.21	Number games	161.10	Sonas
Session 13	170.85	Word Games	163.13	Sonas
Session 14	171.77	Team Quiz	166.83	Sonas

Table 55

 = Positive increase in mean score.

 = Negative decrease in mean score

Appendix 36 :Results chapter. Supplementary analysis, question three.

Title of table 56: Supplementary analysis question 3.

Spearman's rho	Correlations	Conclusion
Number of years in residence (inpatients only) and OTTOS post assessment.	Correlation Coefficient -.143 Sig. (2-tailed) .598, NS. N 16	Not significant
Age and OTTOS post assessment.	Correlation Coefficient .070 Sig. (2-tailed) .741, NS. N 25	Not significant
Number of group sessions attended and OTTOS post assessment.	Correlation Coefficient -.012 Sig. (2-tailed) .953, NS. N 25	Not significant

Table 56

Appendix 37: Phase 2

This appendix presents the results from the A phase in a table format from session 2-5.

Title of table 57, session 2.

Table of Observations, Session 2:	
On arriving to participant's home she presented as disorientated to date and was unaware of the pre scheduled appointment. She stated 'I thought it was Saturday'. The table was pre-set prior to OT arrival indicating orientation to breakfast time. Note on safety, later in the task she forgot to turn off the electric cooker.	
Session 2: Assessment Phase. Task was to prepare a poached egg, toast and hot coffee.	
Poached egg and toast	Hot coffee
1. On commencing the task at the kitchen, she had failed to turn on the light which inhibited her ability to see around her kitchen. Prompt was required. Error.	a) Found cups with no difficulties.
	b) Boiled electric kettle
2. Searched for a pot and retrieved it successfully.	c) Found coffee
3. Prompt was sought from PI 'what do I do next', prompt provided after an extended amount of time had passed and she was unable to problem solve	d) Used spoon to fill cup with coffee

herself. Error.	
4. Filled pot with water from the tap on the sink.	e) Poured boiling water into coffee
5. Turned on the oven at the main switch on the wall.	f) Stirred with spoon
6. Checked the cooker to see it was on and turned on a ring (there appeared to be no choice in the ring that participant 1 turned on), she used the first one she noticed was on by its red colour.	g) Opened fridge and obtained milk
	h) Poured milk into coffee
7. Retrieved an egg from the fridge.	i) Found her Hermecetas (artificial sweetener) and placed one into her coffee.
8. Placed egg into pot to boil. Error.	j) Transported coffee to table
9. She was attempting to poach an egg not boil. Prompt provided after she did not notice same. Error.	
10. Unable to successfully remove egg with spoon. Assistance sought and provided. Error.	k) Reported that she had made the coffee too weak and did not drink her coffee. Error.
11. Retrieved knife and	

spoon from the press.	
12. Used knife to crack egg into water which was starting to boil on the cooker.	
13. Stirred egg with knife	
14. Tilted pot to observe	
15. Moved saucepan to sink	
16. Used spoon to secure egg in pot and poured excess water off the egg into the sink	
17. Observed cooker for red light on ring to indicate if it were on or off, no red light therefore she presumed it was turned off. Error.	
18. Moved to table with pot in left hand, found plate pre-set on table with toast cooked earlier and placed egg on toast. She forgot to turn off her cooker, prompt provided after approximately 4 minutes. Error.	

19. Turned off cooker.	
Total number of errors: 8	
Total number of deviations from sequence: 0	

Table 57

Title of table 58: session 3.

Table of Observations, Session 3:	
On arriving to participant's home she presented as disorientated to day and the purpose of PI visit. She was unaware of the pre scheduled appointment.	
Session 3: Assessment Phase. Task was to prepare a poached egg, toast and hot coffee.	
Poached egg and toast	Hot coffee
1. On arriving to patients home, she presented as disorientated to day and was unaware of our pre scheduled appointment. Error.	a) Found cups with no difficulties.
2. While it was clear that PI was familiar, she asked 'what should we do today' and after a period of time PI responded 'let's prepare your breakfast'. Error.	
3. Participant 1 recalled that she liked to cook a poached egg and toast for her breakfast.	b) Found coffee
4. She searched for the egg in the fridge and	

found it successfully.	
5. She removed it from the fridge and placed it on the counter	
6. Searched for a pot and could not find one. Error.	c) Used spoon to fill cup with coffee
7. After an extended amount of time, PI provided prompt in order to assist her in finding a pot. Error.	
8. Placed kettle on to boil	d) Poured boiling water into coffee
9. Filled pot with water from the tap on the sink.	e) Stirred with spoon
10. Turned on the oven at the main switch on the wall.	f) Opened fridge and obtained milk
11. Made attempts to turn on cooker, turned on incorrect knob and turned it off again.	g) Poured milk into coffee
12. Made multiple attempts to put on cooker, turned on incorrect knob again. Error.	
13. PI provided verbal and non-verbal prompt for safety.	

Error.	
14. Use cooker correctly with prompt from PI.	h) Took coffee to table
15. Allowed water to commence boiling and observed.	
16. Cracked egg and observed egg poaching.	i) Forgot Hermesetas. Error.
17. Retrieved spoon and plate.	
18. Lifted egg from boiling water onto plate.	
19. Turned off cooker.	
20. Obtained bread from bread bin	
21. Placed on in toaster to toast appropriately.	
22. Searched for butter in fridge with an extended amount of time required, retrieved same.	
23. Buttered toast using knife	
24. Took all items to her table successfully.	
25. Ate her breakfast.	
Total number of errors: 7	
Total number of deviations from sequence: 0	

Table 58

Title of table 59, session 4 observations.

Table of Observations, Session 4:	
<p>The PI noticed that the participant had no glasses on, which she required because of poor visual acuity.</p> <p>Her mood was observed to be good and there was evidence on a table that she had been completing her painting which her family reported in initial interview that she had not completed in a long time as she felt her skills had diminished in this area. Participant reported to have taken toast prior to PI arrival to her home.</p>	
Session 4: Assessment Phase. Task was to prepare hot coffee.	
Participant did not wish to have a poached egg this morning.	Coffee Preparation
	a) Turned kettle on to boil
	b) Reached for two mugs and obtained same successfully
	c) Poured boiled water into cups
	d) Noticed there was not enough water in the kettle and re filled kettle at the sink. (Not considered an error as she self-corrected in a timely manner).
	e) Placed kettle on the counter and tried to turn on, emptied water from kettle slightly (not considered an error as she self-corrected efficiently).
	f) Tried to turn on again and then realised that the kettle was not on its base and then found based
	g) Turned on successfully without assistance
h) Searched for coffee and was unable to obtain after an extended	

	amount of time. Error.
	i) Prompt required and provided by PI. Error.
	j) Poured coffee granules into mug
	k) Retrieved milk from fridge
	l) Poured water
	m) Poured milk
	n) Stirred using spoon which was on the counter top
	o) Sat and drank coffee
Total number of errors: 2	
Total number of deviations from sequence: 0	

Table 59

Title of table 60: Observations session 5

Table of Observations, Session 5:	
<p>Appeared orientated to PI and the task of poaching an egg and making coffee. The participant reported midway through the session that she did not sleep well last night.</p>	
<p>Session 5: Assessment Phase. Task was to prepare a poached egg, toast and hot coffee.</p>	
Poached egg and toast	Hot coffee
1. Lifted kettle off stand	A) Obtained two cups for coffee
2. Lifted it to sink and filled with water at the sink.	B) Reached into appropriate drawer for spoons
3. Placed back on kettle stand	
4. Turned on switch to boil.	C) Reached to appropriate area for coffee
5. Pursued general tidying	D) Checked that kettle was boiled

of kitchen prior to preparing breakfast	E) Spooned coffee into cups
	F) Poured boiling water into cups
6. Questioned PI on 'what are we doing again', PI allowed time for participant to process same herself but she did not come up with an answer. Error.	G) Removed milk from fridge
	H) Poured Milk into coffee
	I) Appropriately questioned PI if she took sugar
	J) Sat and drank her coffee with PI
7. Required a verbal prompt to re-orientate participant to task. Error.	
8. Retrieved toast and placed in toaster accurately	
9. Tidied kitchen sink	
10. A delayed amount of time was allowed for participant to process what she might do next. She did not come up with an answer to what the next step of the process was or if there was a next step in the process. Error.	
11. PI provided verbal cue 'what are we doing next'? Error.	
12. She removed eggs from the fridge	
13. She took a pot from the	

press	
14. Filled pot with cold water from tap	
15. Placed on electric hob to boil	
16. Allowed water to boil and supervised it	
17. Distracted by a stray cat that arrived into the kitchen environment	
18. Re-orientated herself to the task	
19. Removed toast from toaster	
20. Placed on a plate she successfully retrieved from the press.	
21. Searched for butter in fridge	
22. Opened drawer to get knife	
23. Buttered bread	
24. Attempted to poach egg by boiling it. Error.	
25. PI provided prompt verbally on the technique for poaching.	
26. Poached egg	
27. Placed egg on toast	
28. Moved over to labelled compost bin to scoop off excess egg	

29. Poured excess water from pot into sink	
30. Placed pot in sink for washing	
31. She began to move to the table with her items to begin eating breakfast	
32. She forgot to turn off her cooker. Error.	
33. Verbal prompt provided by PI to turn off cooker. Error.	
34. She took three extra spoons to the table. Error.	
<p>Total number of errors: 8</p> <p>Total number of deviations from sequence: 2</p>	

Table 60

Appendix 38: Phase 2. Table presentation of results from the B phase, sessions 7-10.

Title of table 61: Observations session 7.

Table of Observations, Session 7:
Increased word finding difficulties noted in participants language throughout session. On PI arriving into the kitchen to commence the intervention with the participant. She has a pot pre prepared with cold water on the electric hob ready to commence indicating orientation to task and purpose of PI visit.
Session 7: Intervention (B) Phase. Task was to prepare a poached egg, toast and hot coffee.
<ol style="list-style-type: none">1. She turned on her cooker using the dementia friendly signs independently and accurately.2. She boiled her electric kettle simultaneously3. Opened fridge4. PI prompted on the activity that we were completing5. Took out her eggs from the fridge and removed one egg from a pack of 66. Retrieved spoon instead of a knife from drawer and it appeared that she planned to spoon the egg into the pot for a boiled egg. Error.7. PI provided a prompt that she wished at the start of the intervention to complete a poached egg.8. Prompt for salt provided by PI.9. Sprinkled salt into boiling water10. Split egg using knife and put egg into boiling water11. Observed the egg to be vigorously boiling12. PI prompted to turn down cooker using the dementia friendly signs to prevent it from boiling over13. She turned down the cooker14. PI provided a question to participant ‘what else shall we do while we wait?’15. She suggested toast16. Removed bread from bread bin

<p>17. Placed toast in toaster</p> <p>18. Turned on</p> <p>19. She requested prompt from PI ‘anything else I’ve missed’</p> <p>20. Visual cue provided in the form of a point towards the coffee</p> <p>21. Boiled kettle</p> <p>22. Found tea spoons</p> <p>23. Found the coffee</p> <p>24. Used the tea spoon to spoon the coffee into the mugs</p> <p>25. Poured water</p> <p>26. Moved cups to the counter edge</p> <p>27. Retrieved milk and poured milk</p> <p>28. PI provided a prompt ‘do you usually take a sweetener’</p> <p>29. Reply, ‘yes I do’.</p> <p>30. Found Hermesetas sweetener and used same.</p> <p>31. PI provided a prompt ‘what else would you like to take on your toast’</p> <p>32. She found butter in fridge and then forgot to take the butter with her to the counter. Error.</p> <p>33. PI prompted again on butter</p> <p>34. She obtained butter and buttered toast</p> <p>35. Placed egg on toast using a spoon</p> <p>36. Turned off cooker</p> <p>37. Transported breakfast to her table which was pre-set with cutlery.</p> <p>38. She then ate her breakfast.</p>
<p>Total number of errors: 2</p> <p>Total number of prompts by PI: 8</p> <p>Total number of deviations from sequence: 0</p>

Table 61

Title of table 62: Observations session 8.

Table of Observations, Session 8:
There were four books on the kitchen table, OT questioned if the participant was reengaged with her reading activity. She reported that she and her family had been to the library and that she was actively reading. This was backed up by her family. This was an activity that she had not requested to do in some time.
Session 8: Intervention (B) Phase. Task was to prepare a poached egg, toast and hot coffee.
1. Prompt provided regarding planned activity prior to commencing intervention
2. Prompt given regarding first step
3. She removed the saucepan from the press
4. Filled with water from the tap
5. Used knobs on electric cooker safely to turn on ring
6. Placed water on to boil
7. Removed eggs independently from fridge
8. Found knife and spoon accurately
9. Verbal cue provided by PI to use knife to break egg into pot of boiling water
10. Broke egg into water
11. Turned on electric kettle safely
12. Found coffee.
13. Found mugs (2).
14. Found spoons.
15. Spooned coffee into mugs
16. Poured water and made coffee with milk from fridge
17. Checked eggs
18. She used the dementia friendly sign for her cooker but made one Error by turning it down too low to cook, which was corrected with assistance from PI.
19. PI provided prompt regarding her sweetener for her coffee

20. Found location of sweetener with ease and used same.
21. Prompt given by PI to use spoon to lift egg from pot
22. Prompt given to prepare a plate to put the egg onto before using the spoon
23. She turned off the cooker independently
24. Recalled independently the activity of preparing toast.
25. Got bread and placed in toaster
26. Put on toast
27. Checked toast
28. Put on for a second time
29. She observed it to be slightly overcooked but satisfactory
30. Found butter in fridge
31. Buttered toast
32. Transported all items to the table
33. Ate her breakfast
Total number of errors: 1
Total number of prompts provided: 7
Total Number of deviations from sequence: 0

Table 62

Title of table 63: observations session 9.

Table of Observations, Session 9:
OT set up environment for the participant with assistance with putting on the lights in the kitchen. On arrival to the home, the kitchen was pre-set up for breakfast preparation which indicated to OT that the participant was orientated to the PI's arrival and task to be completed. There was a pan and oil on it on an appropriate ring on the electric cooker and there was a mixing pot out for the omelette. OT provided a verbal prompt to obtain her glasses; she mobilised up the stairs and obtained her glasses successfully.
Session 9: Assessment Phase. Task was to prepare an omelette, toast and hot coffee.
1. On initial discussion with the participant. She had decided that she

would like to prepare and cook an omelette
2. She removed a frying pan and placed oil on it on a ring on the electric hob.
3. She took out a mixing pot
4. She chose her ingredients for the omelette with some verbal prompts from PI on the items required.
5. Chopped and mixed ingredients with prompts from PI on techniques
6. Used cooker appropriately and able to verbalise the correct use of it.
7. Placed mixture on pan by pouring from bowl and cooked it
8. Prompt by PI to use fish knife to lift mixture off pan
9. Assistance provided by PI in finding fish knife.
10. PI prompted on how to tilt pan to assist in removing the omelette from the pan to a plate
11. Independently recalled that she uses Hermecetas sweetener and retrieved it from the press in anticipation of making her coffee.
12. Placed kettle on to boil
13. Searched for toast, she noticed her toast was gone off
14. PI prompted to dispose of it, which was completed in the compost bin
15. Found toast accurately in the fridge freezer
16. Assistance provided by PI in braking same in order to split the slices
17. She then toasted the bread appropriately
18. She retrieved butter from counter (it was already out as she used it for the omelette ingredients, she recalled same) and spread it using a knife
19. She placed the buttered toast on the plate with the omelette
20. She retrieved two cups
21. She retrieved the coffee
22. She checked that the kettle was boiled

23. She then spooned the coffee into the cups
24. She poured the hot water into the cups
25. She used the milk that was on the counter from the previous omelette prep
26. She transported all items to the table
27. She ate her breakfast
Total number of errors: 0 Total number of interventions provided: 9 Total Number of deviations from sequence: 0

Table 63

Title of table 64: Observations, session 10.

Table of Observations, Session 10:
PI turned lights on in kitchen environment and verbalised this action to participant. General multitasking proved to be difficult throughout the session. PI provided prompt to put on glasses, she successfully found them. The coffee for two was fully pre prepared prior to PI arrival again suggesting orientation to PI's schedule. PI noted that there was poor lighting in the press where she searched for her pan.
Session 10: Intervention (B) Phase. Task was to prepare an omelette, toast and hot coffee.
1. Prepared environment for omelette prep with verbal cues from PI
2. Increased time required to find pan in press
3. PI provided prompt in order to find pan
4. Prompting from PI on the location of ingredients in the fridge was completed after time had elapsed and she was unable to find them
5. Mixed all ingredients in bowl
6. Poured oil on the pan
7. Turned on cooker with assistance from PI and verbal cues on how to use dementia friendly signage
8. Cooked omelette and observed it cooking
9. Found plate appropriately

10. Placed omelette on a plate independently
11. PI provided prompt to turn off cooker
12. PI prompted on 'what would you like with this?'
13. She replied 'toast'
14. She obtained the toast
15. She used the toaster appropriately to toast it
16. Buttered toast and placed on the same plate as the omelette
17. Transported items to the table
18. Ate breakfast
Total number of errors: 0
Total number of interventions: 6
Total number of deviations from sequence: 0

Table 64

Appendix 39: Phase 2.

Table presentation of results from the post A phase.

Title of table 65, observations session 12.

Table of Observations, Session 12:
There was a dirty frying pan found in the participants press. PI notes there was a weekend period between last session in B phase and this session. Kitchen and table pre-set up prior to PI arrival.
Session 12: Assessment (A) Phase. Task was to prepare fried tomatoes, toast and hot coffee.
1. PI provided prompt to put on glasses; she successfully found them but decided not to wear them.
2. She was observed to be fully orientated to items in her fridge
3. She was observed to be independent with locating her items such as her tomatoes and her bread
4. She located her pan and oil independently
5. Turned on cooker independently using dementia friendly signage
6. Chopped her tomatoes independently, retrieving all items successfully
7. Cooked fried tomatoes independently
8. Sourced place appropriately and placed tomatoes on a plate independently
9. Independently turned off cooker
10. She obtained the toast and used the toaster appropriately to toast it
11. Retrieved butter from fridge, buttered toast and placed on the same plate as the omelette
12. Transported items to the table
13. Ate breakfast
Total number of errors: 0 Total Number of interventions: 0 Total Number of deviations from sequence: 0

Table 65

Title of table 66: observations, session 13

Table of Observations, Session 13:
Kitchen and table pre-set up prior to PI arrival. Coffee for two was pre prepared prior to PI arrival.
Session 13: Assessment (A) Phase. Task was to prepare a poached egg, toast and hot coffee.
1. She was observed to be fully orientated to items in her fridge
2. She was observed to be independent with locating her items such as her eggs and her bread
3. She located her pot independently
4. Filled with water from tap
5. Turned on cooker independently using dementia friendly signage
6. Broke her eggs into the boiling water using a knife independently
7. Forgot to use her salt in her water. Error.
8. Observed cooking
9. Found plate appropriately and removed poached eggs using a spoon from pot and placed on her plate
10. Independently turned off cooker
11. She obtained the toast and used the toaster appropriately to toast it
12. Retrieved butter from fridge, buttered toast and placed on the same plate as the omelette
13. Transported items to the table
14. Ate breakfast
Total Number of Errors: 1
Total Number of Interventions: 0
Total number of deviations from Sequence: 0

Table 66

Title of table 67: Observations session 14 and 15.

Table of Observations, Session 14:
Kitchen and table pre-set up prior to PI arrival. Coffee for two was pre prepared prior to PI arrival.
Session 14: Assessment (A) Phase. Task was to prepare a poached egg, toast and hot coffee.
1. She boiled her electric kettle
2. She retrieved her coffee, spoon and her 2 cups independently
3. Forgot Hermecetas. Error.
4. Spooned coffee into cups
5. Poured boiling water into two cups and stirred coffee
6. She was observed to be fully orientated to her fridge
7. She was observed to be independent with locating her items such as her eggs and her bread
8. She located her pot independently
9. Filled with water from tap
10. Turned on cooker independently using dementia friendly signage
11. Broke her eggs into the boiling water using a knife independently
12. Forgot to use her salt in her water. Error.
13. Observed cooking
14. Found plate appropriately
15. Removed poached eggs using a spoon from pot
16. Placed on her plate
17. Independently turned off cooker
18. She obtained the toast and used the toaster appropriately to toast it
19. Got butter from fridge
20. Buttered toast
21. Placed on the same plate as the omelette
22. Took all required items to the table
23. Ate breakfast

Total number of errors: 2
Total Number of interventions: 0
Total Number of deviations from sequence: 0

Table of Observations, Session 15:	
	Kitchen and table pre-set up prior to PI arrival. Coffee for two was pre prepared prior to PI arrival.
	Session 15: Assessment (A) Phase. Task was to prepare a poached egg, toast and another hot coffee for two.
1.	She boiled her electric kettle
2.	She retrieved her coffee
3.	She retrieved spoon
4.	Retrieved her 2 cups independently
5.	Forgot Hermecetas. Error.
6.	Spooned coffee into cups
7.	Poured boiling water into two cups and stirred coffee
8.	She was observed to be fully orientated items in to her fridge
9.	She was observed to be independent with locating her items such as her eggs and her bread
10.	She located her pot independently
11.	Filled with water from tap
12.	Turned on cooker independently using dementia friendly signage
13.	Broke her eggs into the boiling water using a knife independently
14.	Forgot to use her salt in her water. Error.
15.	Observed cooking
16.	Found plate appropriately and removed poached eggs using a spoon from pot and placed on her plate
17.	Independently turned off cooker
18.	She obtained the toast and used the toaster appropriately to toast it

19.	Got butter from fridge.
20.	Buttered toast
21.	Placed on the same plate as the omelette
22.	Took items to the table
23.	Ate breakfast
Total number of errors: 2	
Total number of interventions: 0	
Total number of deviations from sequence: 0	

Table 67

Appendix 40: Phase 2, case study 2. Sessions 2-5.

Title of table 68: Observations session 2.

Table of Observations, Session 2:
PI orientated the participant to the rationale for PI visit. On PI arrival the participant was appropriately organising her home, she was disposing of an old lamp which no longer worked, she placed it in a location in the kitchen for disposal, she then removed a lamp from her music room and moved it into the location in the kitchen where the old lamp originally sat.
Session 2: Assessment Phase. Task was to go out to a chemist in the local shopping centre.
1. The participant identified that she wanted to go to a specific chemist in a local Tesco shopping centre to get 'ear cleaning product'.
2. The participant could not recall the name of the product and she had not recorded it anywhere.
3. She identified that she had kept the empty bottle of the product for the purpose of replacing it and she began an extensive search of the home for same. After approximately 10 minutes of searching, the participant retrieved the item she was looking to replace. Error.
4. The participant repeated the earlier task of lifting the broken lamp up from the location she had left it for disposal and then searching for a new lamp to replace it. Error.
5. OT prompted her that she had already organised her lamp. Error.
6. In preparation for going out, the participant organised her wallet, coat, shoes and house keys. The participant forgot the bottle she had earlier found which she wanted to take with her to the chemist as a prompt. Error.
7. It then transpired that she was unable to recall what he purpose of going out was and PI provided a verbal cue in the form of 'you said the place you wanted to go to was in the local Tesco shopping centre' in order to prompt recall. This was unsuccessful. Error.
8. After some time was allowed to elapse (3 minutes approximately),

<p>PI provided the answer to the participant and reported that she planned to go to the chemist in the local Tesco shopping centre and replace an ear cleaning product, the PI then lifted the empty bottle and showed her the product she wanted to replace. Full recall was then achieved by the participant and she placed the bottle in her coat pocket. Error.</p>
<p>9. The participant demonstrated clear place orientation to her home and the location of the local Tesco shopping centre. She commented how lucky she was that it was so close and there were no difficulties with route finding to and from the shopping centre.</p>
<p>10. On leaving her home, once on the footpath outside her home she recalled that she must return to the home as she had forgotten her stick and her hat. Error.</p>
<p>11. The participant returned to her home and retrieved the items she had forgotten</p>
<p>12. The participant then travelled to the chemist, showed the empty bottle to the chemist, purchased a replacement item, used her money appropriately, appropriately interacted with staff and returned to her home.</p>
<p>Total number of errors: 7 Total number of deviations from sequence: 2</p>

Table 68

Title of table 69: Observations session 3.

<p>Table of Observations, Session 3:</p>
<p>On PI arriving to the participants' home she was engaged in rechecking behaviours in preparation for going out. She was orientated to the purpose of PI's visit to the home. The weather was cold outside, it was early January.</p>
<p>Session 3: Assessment Phase. Task was to travel to her daughters' place of work, to ask her daughter to check her bank balance and to request her daughter to take a sum of money out for her in order to prepare her for planned shopping activities.</p>
<p>1. The participant clearly articulated her planned task for the session</p>

with the PI.
2. The participant began to prepare her items for going out; she began checking her coat pockets, her bag, her kitchen table. The participant appeared a little confused as to what she required for going out into the community.
3. She then began re checking the same items. Error.
4. The participant was unable to recall the items she required for going out and took the items that were visible to her, which included her coat, her bag and her keys. Error.
5. On exiting the home, OT provided a verbal cue on the requirement of her stick for mobility and her bank card for the task she had planned to do. Error.
6. Verbal cue was successful and the participant retrieved the items.
7. The participant forgot her hat. Error.
8. The participant recalled that she had forgotten her glasses on the footpath outside her home, paused and thought about it and then proceeded without them. Error.
9. The participant mobilised to her daughters' place of work (café) appropriately and safely
10. She appropriately communicated her needs to her daughter.
11. The participant then decided that she would stay for lunch with her daughter, despite having reported on route down that she had taken her usual lunch.
12. She was unable to recall what in fact she had taken for her lunch. Error.
13. Session ended.
Total number of errors: 6 Total number of deviations from sequence: 2

Table 69

Title of table 70: Observations session 4.

Table of Observations, Session 4:
On arriving to the participants' home, the PI observed that the participant was not dressed. She had her shopping list ready and clearly reported her plans for the session with OT. When dressing She was disorganised and moved around the home allot searching for items.
Session 4: Assessment Phase. Task was to travel to her local Tesco supermarket and purchase all items on her shopping list.
1. The participant was prompted by PI to commence getting dressed in order to travel out to the supermarket. Error.
2. The participant needed a further prompt by PI to initiate this task Error.
3. It was observed to take her at least 30 minutes to get dressed appropriately.
4. The participant got fully organised with her coat, wallet in her handbag, hat, stick and keys
5. She then proceeded to leave the home without her shopping list. Error.
6. OT provided verbal cue and the list was retrieved. Error.
7. The participant mobilised to the Tesco supermarket independently with her stick, openly discussing her love of music on the way.
8. On arriving to the Tesco supermarket (her local supermarket which she frequents a number of times a week) she was unable to locate the shopping baskets. She proceeded with her list and began clumsily carrying items. Error.
9. OT provided verbal cue on location of shopping baskets. Error.
10. An increased amount of time was required. The participant lacked planning abilities in order to assist her in what way she would mobilise around the supermarket; she proceeded to travel in a disorganised fashion overlapping where she had previously been on several occasions. Error.

11. The participant found all items on her list and paid for them appropriately.
12. The participant pulled her own shopping bag from her coat pocket.
13. The participant paused outside of the supermarket to check her cash. Concern here over safety. Error.
14. The participant mobilised back to her home with her stick and then recalled that she had forgotten to use her clubcard vouchers when checking out. Error.
Total number of errors: 9 Total number of deviations from sequence: 2

Table 70

Title of table 71: observations session 5.

Table of Observations, Session 5:
The participant was well orientated to on the arrival of PI to the task at hand. She was neatly dressed. The participant reported that she had left a spare set of keys with her next door neighbours as she regularly forgets her house keys.
Session 5: Assessment Phase. Task was to go to the Holland and Barrett health food shop and purchase cod liver oil.
1. The participant showed PI an empty bottle, indicating that she required a top up of these supplements and spoke of where the shop was and that she would like to walk there.
2. The participant then proceeded to organise herself in order to walk to the shop. This took a considerable amount of time.

3. The participant retrieved her coat, hat, handbag with wallet inside, stick and house keys.
4. The participant forgot the bottle she originally wanted to take with her to the shop. Error.
5. A verbal cue was provided by PI and she retrieved the item. Error.
6. When the participant was outside the home with the door appropriately closed, she panicked and re checked that she had her house keys. She found them in her bag.
7. The participant then stated that she always wore prescription sunglasses when outside as she had sensitivity to glare in her eyes. On this occasion she had forgotten the glasses and returned inside to retrieve them. Error.
8. The participant then left the house, was fully orientated to her locality and travelled on the same route she takes daily (a loop of the town so to speak), when she was required to turn off this loop to the Holland and Barrett store. She did not and proceeded to walk by the turn for it heading in the direction of her daughters café which was a regular stop for her. Error.
9. OT allowed the participant to travel into the café to greet her daughter. She then came outside and OT provided verbal prompt on the planned task. Error.
10. The participant then travelled to the health store, retrieved the bottle from her person and then asked at the counter appropriately a staff member for the item.
11. She purchased it appropriately.
12. She returned to her home with PI and the session ended.
Total number of errors: 5 Total number of deviations from sequence: 2

Table 71

Appendix 41: Phase two. Case study two. Sessions 7-10, B phase.

Title of table 72: observations session 7.

Table of Observations, Session 7:
The participant was orientated to the purpose of PI visit and was dressed on PI arrival to her home. It was clear that the participant had commenced using her to do list to record relevant messages for her telephone, which she reported to have found helpful.
Session 7: Intervention (B) Phase. Task was to go to her daughters' café for lunch.
1. The participant was orientated to the purpose of PI visit and it was clear that she had the time and date of PI visit on her church calendar. She also used her digital orientation clock to check the time.
2. The participant was advised to review her checklist which was taped to a press in her kitchen to check what she needs to organise for going out. In addition, she had used her to do list on her kitchen table to write down her task for today.
3. She was advised to put this in her handbag.
4. The participant used the checklist and the yellow signs in the home to find her keys and glasses.
5. The participant then travelled out to the town and entered her daughters café where she proceeded to have her lunch in the company of PI.
6. She was provided with a verbal cue to check her to do list on two occasions when out, one before the lunch and one after the lunch; which she was happy to do and satisfied that she had achieved what she set out to do.
7. On return to the home, she was advised to return the keys to their fixed location on the hall table
8. She was advised to return her glasses to the fixed location in the living room.

9. A date was organised for the next PI visit and the participant proceeded to write this up on her calendar.
Total number of errors: 0
Total number of prompts by PI: 6
Total number of deviations from sequence: 0

Table 72

Title of table 73: observations session 8.

Table of Observations, Session 8:
Prior to the intervention commencing the PI introduced a new dementia friendly yellow sign adjacent to her phone. It consisted of a yellow sign entitled 'phone messages' with a removable paper pad attached to the A4 sign and a pen on a string that cannot be easily removed.
Session 8: Intervention (B) Phase. Task was to go to the local Tesco store for Milk and bread.
1. The participant was orientated to the purpose of PI visit and it was clear that she had the time and date of PI visit on her church calendar. She also used her digital orientation clock to check the time.
2. The participant was advised to review her checklist which was taped to a press in her kitchen to check what she needs to organise for going out. She was prompted to use her to do list on her kitchen table to write down her task for today. She was advised to put this in her handbag.
3. The participant used the checklist and the yellow signs in the home to find her keys and glasses.
4. The participant then travelled out to the local Tesco store which was close to her home.
5. She was provided with a verbal cue to check her to do list on two occasions when out, which she was happy to do and satisfied that she had achieved what she set out to do.

6. On return to the home she was advised to put the milk and bread away where she always kept both items.
7. She was advised to return the keys to their fixed location on the hall table
8. She was advised to return her glasses to the fixed location in the living room.
9. A date was organised for the next PI visit and the participant proceeded to write this up on her calendar.
Total number of errors: 0
Total number of prompts provided: 7
Total Number of deviations from sequence: 0

Table 73

Title of table 74: observations session 9.

Table of Observations, Session 9:
The participant was welcoming and open to PI visit. The participant was orientated to the purpose of PI visit and it was clear that she had the time and date of visit on her church calendar. She also used her digital orientation clock to check the time.
Session 9: Assessment Phase. Task was to go to her daughters' café for her lunch.
1. The participant was advised to review her checklist which was taped to a press in her kitchen to check what she needs to organise for going out.
2. She had used her to do list on her kitchen table to write down her task for today. She was advised to put this in her handbag.
3. The participant used the checklist and the yellow signs in the home to find her keys and glasses.
4. The participant then travelled out to the town and arrived at her daughters Café without any difficulty.

5. She was provided with a verbal cue to check her to do list on two occasions when out, which she was happy to do and satisfied that she had achieved what she set out to do.
6. She arrived at her daughters café independently
7. She ordered her lunch independently
8. She ate her lunch independently
9. She finished her lunch and returned to her home environment independently
10. She sourced her keys from her handbag and opened her main door
11. She was advised to return the keys to their fixed location on the hall table
12. She was advised to return her glasses to the fixed location in the living room.
13. A date was organised for the next PI visit and the participant proceeded to write this up on her calendar.
Total number of errors: 0
Total number of interventions provided: 7
Total Number of deviations from sequence: 0

Table 74

Title of table 75: observations session 10.

Table of Observations, Session 10:
The participant was orientated to the PI visit, was welcoming and engaged in lengthy discussion with OT on general local topics. She also mentioned that she had missed a church service over the weekend as she forgot it was on and she was disappointed about same. It was clear that she had the time and date of PI visit on her church calendar. She also used her digital orientation clock to check the time.
Session 10: Intervention (B) Phase. Task was to travel to the local

chemist to return unused medication.
1. The participant was advised to review her checklist which was taped to a press in her kitchen to check what she needs to organise for going out. In addition, she had used her to do list on her kitchen table to write down her task for today. She was advised to put this in her handbag.
2. The participant used the checklist and the yellow signs in the home to find her keys and glasses.
3. The participant then travelled out to the town and completed the task without any difficulty. The local chemist was on her 'loop of the town' which she completed when out in the town. Prior to arriving at the local chemist she was provided with a verbal cue from PI.
4. She was provided with a verbal cue to check her to do list on two occasions when out, one before the chemist stop and one after; which she was happy to do and satisfied that she had achieved what she set out to do.
5. On return to the home she was advised to put the medication away where she always kept it.
6. She was advised to return the keys to their fixed location on the hall table
7. She was advised to return her glasses to the fixed location in the living room.
8. A date was organised for the next PI visit and the participant proceeded to write this up on her calendar.
Total number of errors: 0
Total number of interventions: 8
Total number of deviations from sequence: 0

Table 75

Appendix 42: Phase 2. Case study two. Sessions 12-15, post A phase.

Title of table 76, observations session 12.

Table of Observations, Session 12:
On arriving to the participants' home she appeared orientated to PI. Prior to PI arrival, she was busy reading a letter she had received and had a reply letter partially prepared.
Session 12: Assessment (A) Phase. Task was to go to the shop to purchase a stamp.
1. The participant reported that she would like to travel to the shop in the local Tesco to purchase a stamp.
2. The participant had this written on her 'to do list'; she picked it up and placed it in her bag. She also had the cue of her partially written reply letter on her kitchen table.
3. The participant then proceeded to get herself organised.
4. When she felt she had herself organised she then checked the checklist in the kitchen and made sure that she had not forgotten anything. This involved removing some items from her bag to recheck that they were there and reminding herself of the task verbally.
5. The participant collected her keys from their labelled location on the hall table.
6. The participant uses the second checklist at the door prior to exiting the home.
7. The participant exited the home
8. She proceeded to travel to shop café along a familiar route previously travelled with PI.
9. The participant arrived at the shop, checked her to do list which gave her a written prompt
10. She then proceeded to purchase 3 stamps, she decided that it would be best to have more than one as she had in fact a couple of letters to reply to.

11. The participant travelled home with PI.
12. She failed to place the keys back in their appropriate location and instead left them on the kitchen table. Error.
13. PI provided verbal prompt regarding her fixed location and the benefits of placing them there. Error.
14. The participant failed to return her glasses to their appropriate location. Error.
15. PI provided verbal cue on same and the benefits of placing them there. Error.
16. The participant questioned PI on when she would return for the next session.
17. She wrote the date and time on her calendar.
Total number of errors: 4 Total Number of interventions: 2 Total Number of deviations from sequence: 0

Table 76

Title of table 77, observations session 13.

Table of Observations, Session 13:
On arriving to the participants' home she appeared orientated to PI.
Session 13: Assessment (A) Phase. Task was to travel to the local post office to post 3 letters.
1. The participant had written her plans on her 'to do list', pick it up and placed it in her bag.
2. The participant then proceeded to get herself organised, when she felt she had herself organised she then checked the checklist in the kitchen and made sure that she had not forgotten anything. This involved removing some items from her bag to recheck that they were there. It also involved re reading addresses on the envelopes of her letters, searching for an address book which took considerable time to find and re checking that the addresses were correct.
3. The participant collected her keys from their labelled location on the

hall table.
4. A verbal prompt was provided to use the second checklist at the door prior to exiting the home. Error.
5. The participant exited the home and proceeded to travel to the post office which was along a familiar route.
6. The participant arrived at the post office, checked her to do list which gave her a written prompt and posted the letters into the post box.
7. She questioned herself and PI on if she had anything else to do while out and failed to reuse the 'to do list' for same. She proceeded to return home having concluded that she had done her task as planned.
8. The participant travelled home with PI.
9. She failed to place the keys back in their appropriate location and instead left them on the kitchen table. Error.
10. PI provided verbal prompt regarding her fixed location and the benefits of placing them there. Error.
11. The participant failed to return her glasses to their appropriate location. Error.
12. PI provided verbal cue on same and the benefits of placing them there. Error.
13. The participant questioned PI on when she would return for the next session.
14. She wrote the date and time on her calendar.
Total Number of Errors: 5
Total Number of Interventions: 3
Total number of deviations from Sequence: 0

Table 77

Title of table 78: observations, session 14.

Table of Observations, Session 14:
The participant engaged in warm open discussion with PI regarding her grandchildren and their musical achievements.
Session 14: Assessment (A) Phase. The task was travel to her daughter's café and have lunch.
1. The participant reported that she would like to travel to her daughter café to have lunch.
2. The participant had not this written on her 'to do list'; therefore she did not use it. Error.
3. The participant then proceeded to get herself organised.
4. When she felt she had herself organised she then checked the checklist in the kitchen and made sure that she had not forgotten anything.
5. This involved removing some items from her bag to recheck that they were there.
6. She then went to the checklist and back to her bag.
7. She repeated this step of going to the checklist and back to her bag and she appeared satisfied that she was organised.
8. The participant collected her keys from their labelled location on the hall table.
9. A verbal prompt was provided to use the second checklist at the door prior to exiting the home. Error.
10. The participant exited the home
11. She then proceeded to travel to her daughters' café along a familiar route.
12. The participant arrived at the café, greeted her daughter
13. She proceeded to order her lunch.
14. When lunch was complete she collected all her items.
15. The participant travelled home with PI.

16. She failed to place the keys back in their appropriate location and instead left them on the kitchen table. Error.
17. PI provided verbal prompt regarding her fixed location and the benefits of placing them there. Error.
18. The participant failed to return her glasses to their appropriate location. Error.
19. PI provided verbal cue on same and the benefits of placing them there. Error.
20. The participant questioned PI on when she would return for the next session, she was provided with the answer by PI.
21. She wrote the date and time on her calendar.
Total number of errors: 6
Total Number of interventions: 4
Total Number of deviations from sequence: 0

Table 78

Title of table 79: observations session 15.

Table of Observations, Session 15:
The participant was engaged in attempting to operate her modern wood chip burner stove on OT arrival. She was frustrated with the controls and reported that she had been given it as a present from her son but was unable to figure out yet how to turn it on when she wanted some heat.
Session 15: Assessment (A) Phase. Task was to travel to her daughters' café for lunch.
1. The participant reported that she would like to travel to her daughter café and have some lunch.
2. The participant had this written on her 'to do list', pick it up and placed it in her bag.

3. The participant then proceeded to get herself organised, when she felt she had herself organised she then checked the checklist in the kitchen and made sure that she had not forgotten anything. This involved removing some items from her bag to recheck that they were there and having an open discussion with herself on what she needed whilst referencing the checklist.
4. The participant collected her keys from their labelled location on the hall table.
5. The participant used the second checklist at the door prior to exiting the home.
6. The participant exited the home and proceeded to travel to her daughters' café along a familiar route.
7. The participant arrived at the café, checked her to do list which gave her a written prompt and then realised that she had nothing on it apart from lunch in her daughters café and she proceeded to have her lunch.
8. The participant ordered her lunch without difficulty.
9. The participant travelled home with PI.
10. She failed to place the keys back in their appropriate location and instead left them on the kitchen table. Error.
11. PI provided verbal prompt regarding her fixed location and the benefits of placing them there. Error.
12. The participant failed to return her glasses to their appropriate location. Error.
13. PI provided verbal cue on same and the benefits of placing them there. Error.
14. The participant questioned PI on when she would return for the next session, PI reported to her that it was the last active session together but that she should be encouraged to go out by herself just like she had done with PI.
Total number of errors: 4
Total number of interventions: 2

Total number of deviations from sequence: 0

Table 79

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

PARTICIPANT INFORMATION LEAFLET

Title: Evaluating the effectiveness of an Occupational Therapy application of an errorless learning technique in older adults with Thinking and Memory Difficulties.

Principal Investigator's Name [REDACTED]

Principal Investigator's Title: Senior Occupational Therapist

Telephone Number [REDACTED]

You are being invited to take part in a clinical research project carried out at the [REDACTED]. The type of treatment we propose to use is called 'errorless learning'; this is a treatment that is known to help with learning or relearning of things that you specifically might be having difficulty remembering. Some people have used it to help remember their daily routine or people's names. The treatment will be specific to your needs and will be provided by a senior Occupational Therapist. Similar research in this area has shown benefits to having this type of treatment in terms of a person's memory and thinking skills, how a person communicates, the person's quality of life and how they manage on a daily basis. The purpose of this research project is to examine how effective and beneficial this type of treatment is for you.

This leaflet provides information on the project. Please take time to consider all that is involved, ask questions and discuss it with your family or friends. It is important that you understand the possible benefits and disadvantages of participating in the study so that you can make a decision that you are satisfied with and that is right for you – this process is known as Informed Consent. You can change your mind at any time before, during or even after the study. You can withdraw from the study without having to

justify the reasons for doing so. Your decision to participate or not will have no impact on the care that you receive.

What is the purpose of the study and what does it involve?

The purpose of this research project is to examine how effective and beneficial this type of treatment is for you and for other people who are having difficulties similar to yours.

The project will look at how the treatment impacts on you in the following areas:

1. Everyday difficulties that you may or may not be experiencing. These are known as activities of daily living.
2. Communication.
3. Cognition: this is your thinking and memory skills.
4. Quality of Life: this is your overall satisfaction with life in general.

The treatment sessions involve an approach used by the Occupational Therapist known as cognitive rehabilitation. The specific technique used is called errorless learning. This is a relatively recent rehabilitation approach. It developed in behavioral psychology in the 1960's and was used to teach children who had learning disabilities. In recent years, errorless learning is used to restore knowledge and skills with people who have had a brain injury (Parkin et al, 2008) and (Andrews et al, 1999). Errorless learning has also been shown to be successful in improving performance in people suffering from a moderate degree of memory impairment (Hunkin et al, 2008).

You will be required to complete a range of assessment measures which will enquire about your memory, how you communicate, activity levels and overall satisfaction with life. Family members or nursing staff who know you well may also be asked questions or to fill in similar questionnaires about you only with your permission. These assessments will take approximately 50 min and will take place before the first treatment session begins as well as after the last session has been completed. Additionally, you will be assessed completing a specific occupation (that you have identified as previously having difficulty with) a number of times before the treatment, when the treatment is happening and after the treatments are complete. An example of this occupation may be having a cup of tea, remembering names or your daily routine.

What are the benefits and disadvantages for me? How does it affect me?

Initial studies which have examined the effectiveness of this type of treatment report promising benefits for people, including improved memory and thinking skills,

communication, quality of life and improvements in the specific daily occupations they identified for treatment for example remembering medication.

Potential disadvantages may be that you are tired after the assessments and treatment sessions are complete. The times and length of the assessment or treatment sessions can be changed to suit your needs.

Participation in this study will not impact any other treatments or medication you may be having. Should you agree to participate in this study, the principal investigator will support and advise you where needed on any distress, discomfort associated with the group interventions.

When is the project happening and who else is involved?

The research project is due to commence in April 2013 and will be completed in December 2013. It is expected that 5-9 people will participate in the study.

What will happen to the results?

The results of the assessment measures will be held securely in a locked filing cabinet in [REDACTED]

[REDACTED] All participants in the study will initially be given a number. The investigators in this study who will have access to the results of the assessment measures will only know you by your number. They will not have access to any information which will make you identifiable.

The results from this study will be written-up as part of the academic requirements of the Principal Investigator's [REDACTED]. It is hoped that the results of the study will be published in a reputable journal and presented at conferences. We will be happy to give feedback to the group at the end of the study should you wish to attend.

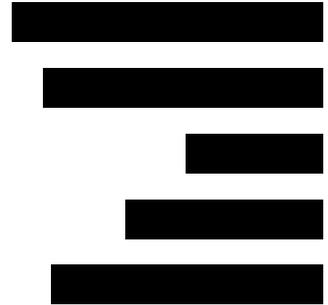
IF YOU REQUIRE FURTHER INFORMATION

For additional information now or any time in the future please contact:

Name: [REDACTED]

[REDACTED]

[REDACTED]



PARTICIPANT CONSENT FORM

<p>Title:</p> <p>Evaluating the effectiveness of an Occupational Therapy application of an errorless learning technique in older adults with Dementia.</p>
--

Please tick or circle the appropriate answer

I confirm that I have read and understood the Participant Information Leaflet dated _____.

Yes **No**

I have had sufficient opportunity to ask questions all of which have been satisfactorily answered.

Yes **No**

I understand that my participation in this study is entirely **voluntary** and that I may withdraw at any time, without giving reason, and without this decision affecting my future treatment or care.

Yes **No**

I understand that my identity will remain confidential at all times.

Yes **No**

I am aware of the potential risks of this research study.

Yes

No

I agree to take part in this study.

Yes

No

I have been given a copy of the Participant Information Leaflet and this Consent Form for my own records.

Yes

No

Signed by:

Participant
Name in block capitals

Date

Witness
Name in block capitals

Date

To be completed by a Principal Investigator (PI) or a nominee.

I the undersigned have taken the time to fully explain the nature and purpose of this study in a manner that the above named participant could understand. I have explained the purpose of the study, the possible benefits and risks of participating and have invited him/her to ask questions on any aspect of the study that concerned them.

Signature

Title/Qualification

Name in block capitals

Date

2 copies to be made: 1 for participant and 1 for PI.

Appendix 45: OTTOS Baseline assessment

An Exploration of baseline data was completed.

The Kolmogorov- Smirnov assessment of the normality of the distribution of the baseline OTTOS scores per group indicates a non-significant result of 0.200 in the CST group and 0.181 in the Sonas group. This indicates that the distribution of SMMSE scores between groups at baseline was normal. In terms of site, the Kolmogorov- Smirnov assessment of the normality of the distribution of the baseline OTTOS scores per site as above indicates a non-significant result of 0.200 in all three sites. This indicates that the distribution of SMMSE scores across sites at baseline was normal. In terms of residence type, the Kolmogorov- Smirnov assessment indicates a non-significant result of .200 for inpatients and .200 for community indicating normality. In terms of capacity to give informed consent, the Kolmogorov- Smirnov assessment indicates a non-significant result of .200 in the yes and .200 in the no, indicating normality. In terms of type of dementia, a not to be significant result of .200 for all types indicates normality at baseline. In terms of Alzheimer's and non-Alzheimer's group, the Kolmogorov-Smirnov result of .200 in both groups indicate normality. In terms of sex, the Kolmogorov-Smirnov assessment indicates a not to be significant result of .200 in the yes and .200 in the no, indicating normality.

The Skewness value of -0.197 in the CST group and -1.084 in the Sonas group provide information regarding the symmetry of the distribution in OTTOS scores in relation to a normal score of 0. This indicates that the scores are not particularly skewed in any direction. The Kurtosis value of -0.801 in the CST group and 1.813 in the Sonas group again indicate limited Kurtosis in any direction. The Skewness value are 0.127 in the Inpatient Psychiatry of Later Life site and -1.138 in the Care centre site and -.756 in the community dwelling. This indicates that the scores are not particularly skewed in any direction. The Kurtosis value of -0.557 in the Inpatient Psychiatry of Later Life site, -0.860 in the care centre site and -1.109 in the community site again indicate limited Kurtosis in any direction. In terms of residence type, -.687 for inpatients and -.756 for community participants indicate limited Skewness in any direction. The Kurtosis of .820 for inpatients and -1.109 for community indicate limited Kurtosis in any direction. In terms of type of dementia, the Alzheimer's group have a Skewness value of -.207 and Kurtosis value of -1.567. The vascular group have a Skewness value of -.267 and

Kurtosis value of .110. The mixed Alzheimer's/vascular group have a Skewness value of .078 and a Kurtosis value of -1.702. The not specified or other have a Skewness value of 1.299 and a kurtosis value of 1.682. The type of dementia groups, have therefore limited skewness and kurtosis indicating normality. The Alzheimers group has a Skewness value of -.207 and Kurtosis value of -1.567. The non-Alzheimer's group has a Skewness value of -.338 and Kurtosis value of .129. These values indicate limited Skewness or kurtosis in any direction. In terms of capacity to give informed consent the Skewness value of .052 and Kurtosis value of -1.520 in the yes group and Skewness value of -.436 and Kurtosis of .240 indicate limited Skewness and Kurtosis in any direction. In terms of sex, the Skewness value of -.634 in males and -.418 in females indicate limited skewness. The Kurtosis of 1.559 in males and -.445 in female also indicate limited kurtosis.

Outliers and Extreme scores:

On inspection of the group box plot there appears to be one outlier as baseline in the Sonas group; this is noted not to be an extreme outlier and therefore no changes to outlier cases was completed. In addition, on comparison of the CST mean of 132.08 and the CST 5% trimmed mean of 133.70, there appears to be limited changes in the mean as a result of the extreme scores. On comparison of the Sonas mean of 130.83 and the 5% trimmed Sonas mean of 132.20, there appears to be little change in the mean as a result of the extreme scores. Furthermore, following an inspection of the values in the remaining distribution, these cases were retained in the data file. On inspection of the site box plot below there appears to be no outliers as baseline in any site. In addition, on comparison of the Long Stay Inpatient psychiatry of Later Life Site mean of 121.25 and the Long Stay Inpatient Psychiatry of Later Life 5% trimmed mean of 121.22, there appears to be limited changes in the mean as a result of any extreme scores. On comparison of the Care centre mean of 109.88 and the 5% trimmed Care centre mean of 110.42, there appears to be little change in the mean as a result of the extreme scores. Finally, on comparison of the community mean of 159.78 and the 5% trimmed community site mean of 160.64, there also appears to be little change in the mean as a result of extreme scores. Furthermore, following an inspection of the values in the remaining distribution, these cases were retained in the data file. On inspection of the capacity to give informed consent, sex, residence type, type of dementia, Alzheimer's and non-Alzheimer's group box plot there appears to be no outliers as baseline in either

group. In addition, on comparison of the mean and 5% trimmed mean, there appears to be limited changes in the mean as a result of any extreme scores. Furthermore, following an inspection of the values in the remaining distribution, these cases were retained in the data file.

On inspection of the Normal probability plots (Normal Q-Q plots) in both CST and Sonas groups, in all sites, in terms of capacity to give consent, sex, residence type, type of dementia, Alzheimer's and non-Alzheimer's group there appears to be a limited deviation from the straight line which indicates a normal distribution at baseline.

On inspection of the Detrended Normal Q-Q plots; there appears to be no major clustering of points in either group with varied distributions, with the most collecting around the zero line on the Sonas Group more than the CST group. On inspection of the Detrended Normal Q-Q plots in terms of the sites; there appears to be no major clustering of points in any site with varied distributions relative to the 0 line. In terms of residence type, there is clustering in the inpatient site and well distributed for the community site, indicating abnormalities at baseline. In terms of type of dementia, the Alzheimer's group are well distributed, the vascular group are unevenly distributed, the mixed Alzheimers/Vascular group are unevenly distributed, and the not specified /other is clustered. These variances suggest abnormalities at baseline. The Alzheimer's group is well distributed and non-Alzheimer's group is clustered indicating abnormalities. In terms of capacity to give informed consent, the data is well distributed for the yes and clustered for the no indicating abnormalities at baseline. In terms of sex, it is unevenly distributes indicating variances at baseline.

On inspection of the shape of the distribution in the CST and Sonas histograms, a reasonably bell shaped curve in both groups indicating a normal distribution. On inspection of the shape of the distribution in the histograms in every site, variances in the bell shaped curve are present in all sites indicating variances in OTTOS scores baseline. In terms of residence type, inpatients have a bell shaped curve and community residents have variance in the shape, this indicates abnormalities at baseline. In terms of type of dementia and Alzheimer's and non-Alzheimer's groups, all histograms have abnormal shaped curves indicating abnormalities at baseline. In terms of capacity to give informed consent, variances in the normal curve are seen for the yes and a normal shape for the

no, indicating abnormalities at baseline. In terms of sex, the males have a normal bell shaped curve while the female curve is abnormal, indicating abnormalities at baseline.

The OTTOS data were found to have differences at baseline between inpatients and community residences ($t(19.187)=-4.437, p=.000$) and site of residence ($F(2,22)=9.273, p=.001$). No differences were found between sex ($t(20.326)=-1.911, p=.070, NS$), diagnosis type (Alzheimer's and non-Alzheimer's) ($t(11.935)=1.891, p=.083, NS$), type of dementia ($t(4, 20)=1.233, p=.328, NS$) and capacity to give consent ($t(16.989)=1.592, p=.130, NS$).

Conclusion

In Conclusion, the OTTOS scores were found not to be normal at baseline.

Appendix 46: CST monitoring progress form

Making a difference

Monitoring progress

It is important to keep a session by session record of each member's response to and involvement in the sessions to enable you to adapt and plan the programme for future sessions. Photocopy this page to keep a record of the whole group programme.

Session number.....

For each member, rate their interest, communication, enjoyment and mood shown in today's session with a number from 1 to 5 as follows (use 2s and 4s to reflect ratings in between the descriptions given):

Names of members	Attended? Yes/No	Interest	Communication	Enjoyment	Mood
1.					
2.					
3.					
4.					
5.					
6.					

Interest: 1 = No interest
3 = Shows some interest
5 = Shows great interest

Communication: 1 = Little or no communication
3 = Some response
5 = Communicates well

Enjoyment: 1 = Does not show enjoyment of the session today
3 = Shows some enjoyment
5 = Enjoys the session greatly

Mood: 1 = In low mood today, appears depressed or anxious
3 = Some signs of good mood
5 = Appears happy and relaxed today

Activities used today:

Comments:



This page may be photocopied

Making a difference

13

Appendix 47: Sonas group session evaluation form

**Sonas Group Session Evaluation Form A
(Covering 4 sessions)**

Name: _____

Note: Evidence of the various signs of communication should be noted below the session date.

Signs	Session Dates			
Eye Contact				
Holding gaze				
Following with gaze				
Smiling				
Vocalising				
Speaking				
Appropriate touch				
Exercises				
Singing				
Rhythmic movements				
Contribution				
Using instruments				
Using gesture				
Interactive posture				

Numeric value: No evidence = 0, Very little evidence = 1, Some evidence = 2, Good evidence = 3, Frequent evidence = 4

Evaluated by: _____ Date: _____