

# The use of Digital-Touch Screen Technology in Reminiscence Work with People with Dementia in Jordanian Care Homes: A Feasibility Study

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#### Abstract

**Background:** Dementia is progressive degenerative illness is synonymous with cognitive and behavioural decline. Dementia cannot be cured. However, several pharmacological and nonpharmacological approaches can be used to address the symptoms of dementia. Reminiscence therapy (RT) is a non-pharmacological intervention utilising of written, oral, or both accounts of historical events to improve psychological well-being utilising of written, oral, or both accounts of historical events evoke the long-term memories of the people with dementia (PwD), and improve psychological well-being. Using digital-touch screen technology to deliver RT content is new in the care home activities. The digital RT application contains a wide range of stimuli to prompt reminiscence amongst PwD in the care homes. This is the first study to evaluate the feasibility and acceptability of using digital-touch screen technology to deliver RT for PwD in Jordanian care homes.

**Aims:** The primary aim of this study was to explore the feasibility and acceptability of a digital RT intervention for PwD. The secondary aim was to determine the likelihood of changes in outcome measures including cognitive function, communication, depression, anxiety, and quality of life (QoL).

**Methods:** Concurrent mixed methods research was conducted in two care homes in Jordan using outcome measures and semi-structured interviews for data collection. A single group pre-post-intervention quantitative study was conducted with 60 residents with dementia using the Arabic Version of Saint-Louis-University-Mental-Status (SLUMS) for memory; Older People's Quality of Life questionnaire (OPQoL) brief-13 for QoL; Arabic version of Hospital Anxiety and Depression Scale (HADS) for anxiety and depression; and Holden Communication Scale for persons with dementia (HCS) for communication. Qualitative semistructured interviews were conducted with 14 residents with dementia and seven care home staff purposively sampled from both care homes to explore the feasibility and acceptability of a digital RT intervention for PwD. Quantitative data was analysed to determine whether certain outcomes are sensitive to change after completion of the digital RT intervention. Thematic analysis was used to analyse the qualitative data using Nvivo. Statistical Package

for the Social Science Version 25.0 (IBM SPSS 25.0) was used to analyse quantitative measures.

**Results:** The recruitment process and response rate, retention rate and adherence to the intervention indicated the feasibility of the research processes. The response rate was 100%. There was a loss to follow up at post-intervention (25%). For adherence, the median of session attendance for those who received the intervention was 80%. No adverse health impacts were observed as a consequence of taking part, although emotional distress was reported on five occasions by participants who subsequently withdrew from the study.

Thematic analysis of the interview data revealed four themes relating to the necessary features of a digital RT application to be used successfully with the PwD. These included being easy to use, having a facilitative environment, having interesting content and having a positive impact in QoL that participants recognise. The resident participants perceived several positive changes including enhancing communication and cognitive abilities, enhancing relationships, and positive changes in psychological and emotional aspects after completion of the digital RT intervention which led to improving their QoL. There was a positive, statistically significant and clinically relevant difference on all outcome measures from pre to post-intervention: means of cognitive ability (3.7; SD=2.4; t (45) =10.43; p=0.000), communication (6.2; SD= 4.2; t (45) = -9.9, p=0.000), anxiety (4.4; SD= 2.9; t (45) = -10.1, p=.000), depression (3.7; SD= 2.6; t (45) = -9.6; p=.000), and QoL (6.2; SD= 4.8; t (45) =8.6; p=0.000).

**Conclusion:** Using digital-touch screen technology to deliver RT may be feasible and acceptable among PwD and their staff in care homes in Jordan. The statistically significant changes in outcome measures demonstrate that a digital RT intervention may be a promising intervention for PwD in care homes to improve their cognition, communication, QoL, depression, and anxiety for residents PwD. This thesis offers exciting avenues of future research, including a definitive trial to evaluate the efficacy and long-term effectiveness of

the digital RT for PwD. However, the digital RT and research processes in their current form require simple adaptations to optimise their potential efficacy.

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# **Table of Contents**

Chapter 1		Introduction17			
	1.1	Dementia17			
	1.2	Reminiscence Therapy33			
	1.3	Digital-Touch Screen Technology for People with Dementia56			
	1.4	Digital-Touch Screen Technology in Reminiscence Work for People with			
	Demen	tia59			
Chapter 2 Technolog	y: a Sys	The Impact of Reminiscence Therapy Delivered via Digital-Touch Screen tematic Review61			
	2.1	Introduction61			
	2.2	Review aims62			
	2.3	Methods62			
	2.4	Results			
	Include	ed70			
	Identif	ication70			
	Screen	ing70			
	Eligibility				
	2.5 Q	uality Assessment of Included Studies81			
	2.6	Discussion			
	2.7	Conclusions			
	2.8	Significance and Research Questions of the Study			

Chapter 3		Intervention Development87
	3.1	Introduction
	3.2	Method
	3.3	Conclusion128
Chapter 4		Methodology and Methods129
	4.1	Introduction
	4.2	Aim and Objectives129
	4.3	Methods130
	4.4	Procedure133
	4.5	Ethical Consideration156
Chapter 5		Psychometric Properties of Arabic Holden Communication Scale for
Chapter 5 people wit	:h den	Psychometric Properties of Arabic Holden Communication Scale for nentia Questionnaire160
Chapter 5 people wit	:h den 5.1	Psychometric Properties of Arabic Holden Communication Scale for nentia Questionnaire
Chapter 5 people wit	:h den 5.1 5.2	Psychometric Properties of Arabic Holden Communication Scale for nentia Questionnaire
Chapter 5 people wit	:h den 5.1 5.2 5.3	Psychometric Properties of Arabic Holden Communication Scale for nentia Questionnaire
Chapter 5 people wit	:h den 5.1 5.2 5.3 5.4	Psychometric Properties of Arabic Holden Communication Scale for nentia Questionnaire
Chapter 5 people wit	:h den 5.1 5.2 5.3 5.4 5.5	Psychometric Properties of Arabic Holden Communication Scale for nentia Questionnaire
Chapter 5 people wit	:h den 5.1 5.2 5.3 5.4 5.5 5.6	Psychometric Properties of Arabic Holden Communication Scale for nentia Questionnaire
Chapter 5 people wit	th den 5.1 5.2 5.3 5.4 5.5 5.6 5.7	Psychometric Properties of Arabic Holden Communication Scale for nentia Questionnaire

Chapter 6		Quantitative Results170
	6.1	Introduction170
	6.2	Recruitment170
	6.3	Response Rate170
	6.4	Follow-up
	6.5	Baseline Characteristics of the Sample173
	6.6	Intervention Uptake and Adherence174
	6.7	Missing Data175
	6.8	Data Checking175
	6.9	Normality and Outliers176
	6.10	Outcome Measures at Pre and Post Intervention
	6.11	Effect Size
	6.12	Impact of the Intervention on Outcome Measures
	6.13	Summary185
Chapter 7		Qualitative Findings186
	7.1	Introduction186
	7.2	Interviewee Characteristics186
	7.3	Themes, Sub-themes and Codes189
	7.4	Summary
Chapter 8		Process Evaluation of the Feasibility Study214

	8.1	Introduction 214
	8.2	Process Evaluation Method215
	8.3	Research Process
	8.4	Intervention Process: Intervention Implementation
	8.5	Conclusions
Chapter 9		Discussion231
	9.1	Introduction
	9.2	Participants Characteristics232
	9.3	Overview of the Findings232
	9.4	The Feasibility and Acceptability of Digital RT for PwD234
	9.5	The Feasibility of Outcomes to Change241
	9.6	Strengths and Limitations of the Study248
	9.7	Implications of the Study254
	9.8	Recommendations for a Future Trial257
	9.9	Conclusion259
Chapter 10	)	References261
Chapter 11	L	Appendices288

# List of Tables

Table 1: The information about Jordanian care homes which was adopted from The Jordanian
Ministry of Social Development (Ministry of Social Development (MOSD)) (2017) 27
Table 2: Nonpharmacological approaches and their effects on PwD       30
Table 3: Details of the SRs for nonpharmacological that were used in Table 2 Error!
Bookmark not defined.
Table 4: The essential elements and contents of the RT approach adapted from Schweitzer
and Bruce (2008)
Table 5: Table demonstrating the attempts to categorise the various functions of
reminiscence
Table 6: Summary of Search Strategy (Search Terms)       66
Table 7: A Summary of the Characteristics of Included Studies       72
Table 8: Characteristics of Participants    77
Table 9: A summary of measures and findings    80
Table 10: Quality score of included studies based on the JBI-MAStARI (2017) critical appraisal
tool for non-RCTs
Table 11: Challenges and management of Using Technology with PwD         112
Table 12: The guiding list of questions in the exploratory research stage       120
Table 13: Screenshot of the first two RT sessions
Table 14: Topic guides for residents and staff interviews       148
Table 15: The six phases of thematic analysis, adapted from Braun and Clarke (2006)150

Table 16: Summary of interventions to establish trustworthiness         155
Table 17: Demographic characteristics of the participants in the pilot study         166
Table 18: Correlated item to total correlation and Cronbach's coefficient alpha of item deleted
from Arabic HCS scale
Table 19: Reliability testing for Arabic HCS scale       168
Table 20: Baseline characteristics of participants in both care homes         174
Table 21: SPSS output for Kolmogorov-Smirnov and Shapiro-Wilk tests of normality177
Table 22: Mean Scores and SDs for Main Outcome Measures       182
Table 23: Effect size for all used outcome measures       183
Table 24: Individual resident participants' characteristics       187
Table 25: Individual staff participant's characteristics         188
Table 26: Overview of themes, sub-themes and codes       190
Table 27: Process evaluation components and related process measures of an intervention
adapted from Reelick et al. (2011)216

# **List of Figures**

Figure 1: Jordan Statistical Profile ((United Nations (UN), 2015)
Figure 2: PRISMA 2009 Flow Diagram 70
Figure 3: The MRC framework adapted from Craig et al. (2012)
Figure 4: The selection and recruitment of care homes134
Figure 5: The study settings135
Figure 6: Pictures of study settings136
Figure 7: The recruitment of the participants140
Figure 8: The recruitment process of the participants140
Figure 9: Flow chart of recruitment participants through the study172
Figure 10: Histogram of intervention adherence175
Figure 11: Change in SLUMS scores between pre and post intervention
Figure 12: Change in HCS scores between pre and post intervention179
Figure 13: Change in OPQoL scores between pre and post intervention180
Figure 14: Change in anxiety scores between pre and post intervention180
Figure 15: Change in depression scores between pre and post intervention181

# **List of Appendices**

Appendix 1: A common classification scheme for bias
Appendix 2: JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized
experimental studies)
Appendix 3: Quality Score of Included Studies Based on JBI-MAStARI Critical Appraisal Tool
Appendix 4: Characteristic of Interventions and Comparators of SR
Appendix 5: Characteristic of Interventions of SR294
Appendix 6: Designing and Prototyping Phase295
Appendix 7: PPI meeting minutes 20th October 2017296
Appendix 8: Peer Review Form
Appendix 9: Poster Advertising Study Participation
Appendix 10: Semi-structured interviews questions with residents and staff in Jordanian care homes 310
Appendix 11: Questionnaires (Arabic and English versions)
Appendix 12: Ethical Approval Process
Appendix 13: Participant Information Sheet (Arabic and English versions)
Appendix 14: Consent forms for residents and care home staff (Arabic and English versions)
Appendix 15: Consultee Assent Form (Arabic and English versions)
Appendix 16: Permission to Translate HCS scale for PwD into Arabic
Appendix 17: Histograms of Pre and Post Intervention Scores of Outcome Measures
Appendix 18: Screenshot of all digital RT sessions

# List of abbreviation

WHO	World Health Organization
PwD	People with dementia
RT	Reminiscence therapy
QoL	Quality of life
ADLs	Activities of daily living
CART	Computer Assisted Reminiscence Therapy project
CIRCA	Computer Interactive Reminiscence and Conversation Aid project
DRT	Digital reminiscence therapy
MRC	Medical research council
NHS	National health service
AD	Alzheimer's disease
VD	Vascular dementia
LBD Association	Lewy Body Dementia Association
DLB	Dementia with Lewy bodies

ΑΡΑ	American Psychiatric Association
FTD	Frontotemporal dementia
YHEC	York Health Economics Consortium
RYCT	Remembering Yesterday, Caring Today
RFS	Reminiscence Functions Scale
ACH	Acetylcholine
ONS	Office for National Statistics
SR	Systematic review
MRC	Medical Research Council
RCTs	Randomised controlled trials
Non-RCTs	Non-randomised controlled trials
SST	Socioemotional Selectivity Theory
ТАМ	The Technology Acceptance Model
PEOU	Perceived Ease of Use

PU	Perceived Usefulness				
PPI	Patient and Public Involvement				
MMR	Mixed Method Research				
SPIRIT	Standard Protocol Items: Recommendations for Interventional Trials				
SLUMS	Saint-Louis-University-Mental-Status				
OPQOL-brief- 13	Older People's Quality of Life questionnaire				
Arabic HADS	Arabic version of Hospital Anxiety and Depression Scale				
HCS	Holden Communication Scale for persons with dementia				
NIHR NETSCC	National Institute for Health Research- Evaluation, Trials and Studies Coordinating Centre				
SPSS	Statistical Package for the Social Science				

#### Chapter 1 Introduction

Dementia is considered a public health priority (World Health Organization (WHO), 2012, 2017a). It is a chronic syndrome that is caused due to the disease of the brain in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (World Health Organization (WHO), 2012). Also, it can have a negative impact on people with dementia's (PwD's) family, friends, and caregivers (Alzheimer's Society, 2018d; WHO, 2017a).

This chapter will introduce and evaluate the key topics relating to PwD and their participation in reminiscence therapy (RT) delivered via digital technology. This chapter illustrates different types of dementia, their pharmacological and nonpharmacological treatments, and the use of RT as a specific form of nonpharmacological treatment for PwD. The justification for promoting the use of digital technology to deliver RT will be provided. An existing digitaltouch screen technology to support RT is introduced.

#### **1.1 Dementia**

This section introduces dementia, different types of dementia, the social context of dementia in Jordan, and the pharmacological and nonpharmacological treatments of dementia.

#### **1.1.1 Introduction**

Dementia is a progressive degenerative illness characterised by cognitive decline and deterioration of behavioural functions (Abraha et al., 2017; Elshahidi, Elhadidi, Sharaqi, Mostafa, & Elzhery, 2017; WHO, 2017a). In 2017, the prevalence of dementia in the world was estimated at 50 million (WHO, 2017a) and it is predicted to be around 141 million by 2050 (Prince et al., 2013; WHO, 2017a). The global cost of treating and caring for PwD is more than six hundred billion dollars per year (£380 billion) (Alzheimer's Society, 2018d; WHO, 2017a). In the UK, it has been estimated that there are around 850,000 PwD in 2014 and dementia costs £26 billion a year (The British Psychological Society, 2016).

Different types of dementia can affect PwD in different ways, and everyone will experience symptoms in their way (Alzheimer's Society, 2018d; National Health Service(NHS), 2017a). Generally, PwD experience memory loss, problems with communication, mood changes, poor quality of life (QoL), and neuropsychiatric symptoms including depression and anxiety.

#### **1.1.2 Types of Dementia**

Dementia is an umbrella term which is used to describe a number of conditions affecting the brain, including Alzheimer's disease (AD), dementia with Lewy bodies (DLB), Frontotemporal dementia, and very rare types of dementia such as Creutzfeldt-Jakob disease, and Young-onset dementia (Alzheimer's Society, 2018d; Dening & Sandilyan, 2015).

#### 1.1.2.1 Alzheimer's Disease (AD)

Alzheimer's disease (AD) is reported to be the most common type of dementia (Bademli, Lok, & Selcuk-Tosun, 2018; NHS, 2018). It is estimated to be around 60-80% of all dementia cases in the world (Garre-Olmo, 2018). There are two specific proteins thought to cause impairment in the brain of a person with AD called amyloid and tau (Furcila, DeFelipe, & Alonso-Nanclares, 2018). The amyloid protein is deposited to form plaques that build up around brain cells. Additionally, the tau protein is broken down to form tangles within brain cells (Alzheimer's Society, 2018a; Furcila et al., 2018; Hampel et al., 2018; NHS, 2018). The amyloid plaques and tau protein tangles collect between neurons and disrupt brain cell function (Andrade-Moraes et al., 2013; Furcila et al., 2018; Hampel et al., 2018). To date, researchers do not fully understand how these proteins are involved in AD, but this is an active research area now (Hampel et al., 2018; Korolev, 2014; NHS, 2018).

Two neurotransmitters are considered to affect the brain in an individual with AD: acetylcholine and glutamate (Murley & Rowe, 2018). Acetylcholine (ACH) and glutamate have an important role in short-term memory formation and learning (Hasselmo, 2006; Murley & Rowe, 2018). Additionally, ACH is usually involved in synaptic transmission between nerve

cells around the brain (Hampel et al., 2018; Kracmarova, Drtinova, & Pohanka, 2015; Picciotto, Higley, & Mineur, 2012).

Research suggests that too much acetylcholinesterase, an enzyme which is involved in breaking down ACH, is released within the synapses of people with AD (Ferreira-Vieira, Guimaraes, Silva, & Ribeiro, 2016). The excess amounts of acetylcholinesterase are accompanied by a progressive decline in ACH levels (Ferreira-Vieira et al., 2016; Garcia-Ayllon, Small, Avila, & Saez-Valero, 2011). As a consequence, the availability of ACH at synapses in the brain is decreased and synaptic transmission is not transmitted as effectively, which contributes to the symptoms of AD (Alzheimer's Society, 2018d; Garcia-Ayllon et al., 2011; Hampel et al., 2018).

Moreover, people with AD release excess amounts of glutamate (Ferreira-Vieira et al., 2016). Excessive activation of glutamate receptors can result in neuronal dysfunction and death in a process called excitotoxicity neuronal death (Ferreira-Vieira et al., 2016; Murley & Rowe, 2018; Zhou & Danbolt, 2014).

It has also been found in AD that the hippocampus (structures with key roles in working memory in the limbic system) and its connected structures will be the first area affected and damaged (Alzheimer's Society, 2015; Toda, Parylak, Linker, & Gage, 2018). As such, commonly, initial symptoms include short term memory problems typically expressed through repeated statements within conversations and difficulty in remembering events occurring within the same day (Alzheimer's Society, 2015; Watchman, 2017).

In addition, in AD, the amygdala (structures with key roles in emotions) is generally affected much later than the hippocampus (Alzheimer's Society, 2015; Gupta, Koscik, Bechara, & Tranel, 2011). So, people with AD often remember their emotional aspects of something even if they cannot recall other details about it. Therefore, those people may respond more according to their feelings about something rather than in a more logical way (Alzheimer's Society, 2015).

Moreover, as AD is progressive, additional areas and lobes in the brain will become affected (Alzheimer's Society, 2018a, 2018d). The brain gradually shrinks and the cortex will become thinner. This cerebral cortex is the part of the brain that functions to make human beings unique (Watchman, 2017). It is responsible for higher brain functions including higher thought, language, and human consciousness, i.e. the ability to think (Henry, Beeson, & Rapcsak, 2008; Watchman, 2017). Therefore, a person with AD will often experience memory loss; asking their questions repetitively; mood swings; difficulty carrying out ADLs which leads to dependence on another person to assistance the completion of daily tasks totally; loss in confidence; reduction in communication skills; becoming withdrawn; confusion; and disorientation (Alzheimer's Society, 2018a; NHS, 2018).

## 1.1.2.2 Vascular Dementia (VD)

Vascular dementia (VD) is considered as the second most common type of dementia (Alzheimer's Society, 2018a, 2018c; NHS, 2018). It is estimated to be around 15% of dementia cases (O'Brien & Thomas, 2015). VD is generally caused due to diseased blood vessels which decrease blood supply to the brain resulting in brain tissue death (Alzheimer's Society, 2018c). Several conditions can result in diseased blood vessels including heart problems, strokes, diabetes and high blood pressure (Alzheimer's Society, 2014b). As treatment of the underlying problem may slow down the progression of dementia, it has been found that early diagnosis of VD is preferable (Alzheimer's Society, 2014b). There are three different types of VD and they differ according to the part of the brain that is affected and the cause of the damage (Alzheimer's Society, 2014b, 2018c; NHS, 2017a; O'Brien & Thomas, 2015):

1. Stroke-related Dementia: a stroke happens when the blood supply in a large vessel to a part of the brain is suddenly cut off. This sudden interruption may have occurred due to blockage of the vessel by a clot or the vessel bursts and bleeds into the brain, resulting in brain tissue death. VD can often occur after one infarct forms in an important part of the brain and this causes dementia (single infarct dementia), or after a series of mini-strokes or transient ischaemic attack lead to a number of infarcts

spread around the brain (multi-infarct dementia) (Alzheimer's Society, 2014b; NHS, 2017a; O'Brien & Thomas, 2015).

- Mixed Dementia: a combination of both VD and AD (Alzheimer's Society, 2014b, 2018c; O'Brien & Thomas, 2015).
- Subcortical VD: caused by diseases of the very small blood vessels that lie deep in the brain. They develop thick walls and become stiff and twisted, meaning that blood flow through them is reduced (Alzheimer's Society, 2014b, 2018c; O'Brien & Thomas, 2015).

The symptoms of VD are similar to the symptoms of other types of dementia. A person with VD may experience common cognitive symptoms such as problems with making decisions, solving problems, planning or organising and concentrating, as well as difficulties following instructions involving a series of steps and a slower speed of thought (O'Brien & Thomas, 2015). In addition, people with VD may have problems with their visuospatial skills in perceiving objects in three dimensions, recent memory, or language (Alzheimer's Society, 2014b, 2018c; O'Brien & Thomas, 2015). The progression of the VD symptoms is more abrupt in onset and has a stepwise deterioration rather than the continuous steady slow decline in other types of dementia (Karantzoulis & Galvin, 2011; Potocnik, 2013).

## 1.1.2.3 Dementia with Lewy Bodies (DLB)

Dementia with Lewy bodies (DLB) is caused by tiny abnormal protein deposits (alphasynuclein) that appear within the synapse in the brain (Alzheimer's Society, 2018b; Colom-Cadena et al., 2017; Lewy Body Dementia Association (LBD), 2017). DLB accounts for at least 4.2% of all diagnosed dementias in the world (Abeysuriya & Walker, 2015; Donaghy, O'Brien, & Thomas, 2015).

Consequently, few studies of DLB exist compared with other forms of dementia (Rongve et al., 2016). However, It has been found that DLB is linked to two factors:1) low levels of ACH and dopamine neurotransmitters that transmit signals between nerve cells and 2) a loss of connections between nerve cells, which then die (Alzheimer's Society, 2018b).

The progression of the DLB is similar to AD, however, DLB sometimes may progress rapidly (Galasko, 2017). A person with DLB may often experience cognitive problems associated with motor dysfunction, perceptual disturbances, and sleep/or wake cycle alterations (LBD Association, 2017). Unlike AD, DLB is characterised by a fluctuating of cognitive functioning over time (Galasko, 2017). Also, people with DLB may experience visual and auditory hallucinations, and delusions (Alzheimer's Society, 2018b).

## 1.1.2.4 Frontotemporal Dementia (FTD)

Fronto-temporal dementia (FTD), which is called also Pick's disease or frontal lobe dementia, occurs when the frontal and/or temporal lobes nerve cells die, and the pathways that connect the lobes change (Alzheimer's Society, 2016; Bang, Spina, & Miller, 2015; McGinley, 2015; Murley & Rowe, 2018). It is estimated to be around 2.7% of all cases of dementia in the world (Hogan et al., 2016). FTD accompanied by loss of pre-synaptic dopaminergic neurons, reduced dopamine levels, reduced dopamine transporter binding, and abnormal dopamine receptor binding (Murley & Rowe, 2018). Over time, as more and more nerve cells die, the brain tissue in the frontal and temporal lobes shrinks (Alzheimer's Society, 2016; Murley & Rowe, 2018). The frontal lobe is predominantly responsible for executive functions such as the planning of actions and the learning of new tasks, regulation of behaviours, motivation, and emotional responses (Alzheimer's Society, 2014; Garcia-Madruga, Gomez-Veiga, & Vila, 2016; Otero & Barker, 2014). The temporal lobe is mainly responsible for memory (Alzheimer's Society, 2014; Lech & Suchan, 2013).

A person with FTD may often have personality and behavioural changes (it can make them appear selfish), language difficulties in finding the right word (aphasia dysarthria), and problems with mental abilities (getting distracted easily, struggling with planning and organisation) (Bang et al., 2015).

Unlike AD, people with FTD may retain memory but demonstrate pronounced personality and emotional changes in the early stage of FTD (Hughes, Shuman, Gould, & Wiener, 2017). However, the disease progression of FTD in the later stages becomes similar to those of AD

(Alzheimer's Society, 2016; Hughes et al., 2017). Research shows that people with FTD may live on average for about six to eight years after symptoms start (Alzheimer's Society, 2016; Bott, Radke, Stephens, & Kramer, 2014).

# 1.1.3 The Social Context of Dementia in Jordan

#### 1.1.3.1 Health Care Systems in Jordan

The Hashemite Kingdom of Jordan is located in the Eastern Mediterranean region. The population of Jordan is estimated to be approximately 9.942 million (United Nations (UN), 2018). Life expectancy at birth has increased to 72 years in men and 76 years in women (UN, 2015). The public health care systems in Jordan are represented by two major public programs: the Ministry of Health (MOH) and Royal Medical Services (RMS). In addition, there are smaller public programs including: private sectors; non-for-profit organizations such as United Nation Relief and Works Agency (UNRWA) and The King Hussein Cancer Centre (KHCC); and several university-based programs, such as Jordan University Hospital in Amman and King Abdullah Hospital in Irbid (Jordan's National Human Resources for Health Observatory (NHRHO), 2017). The MOH operates 102 comprehensive centres, 380 primary centres, 194 village clinics, 464 maternal and child health centres and 405 oral health clinics. There are also 31 MOH hospitals distributed over the 12 governorates of Jordan with 37.7% of the total beds in the country. The military's RMS runs 15 hospitals with 21.2% of the total beds in Jordan; UNRWA delivers primary health care services through 25 primary health care facilities which deal with over two million visits each year; KHCC with about 1% of the total beds; two university hospitals with 4.4% of the total beds in Jordan; and private hospitals distributed among 59 hospitals with about 33.2% of the total beds in Jordan (Jordan's NHRHO, 2017). Figure (1) explains some demographic data about Jordan.



Figure 1: Jordan Statistical Profile ((United Nations (UN), 2015)

# 1.1.3.2 Dementia in Jordan

The total number of people in Jordan over the age of 60 increased from 100,000 in 1994 (Hweidi, Gharaibeh, & Al-Obeisat, 2018) to 582,141 in 2017 (WHO, 2017b). It has been estimated that this number will increase to 1.107 million by 2030 (Hweidi et al., 2018) and to 1.853 million by 2050 (UN, 2015). It is estimated that this percentage will increase over the coming years during which time the availability of younger people to care for them will decrease (Al-Makahmreh, 2010; Hweidi et al., 2018).

Few studies have been undertaken in Jordan to identify the most common health problems among older people over 60 years old. For example, Hamdan-Mansour (2016) suggests that physical and motor problems comprised 33% of problems; visual, speech and hearing problems comprised 10-16%; paralysis as a result of stroke comprised 10.5%; developmental disabilities comprised 3.7%; and 7-15% of problems were other chronic diseases.

To date, the exact number of PwD in Jordan is not known because there are no epidemiological studies of dementia there (Bhalla et al., 2018; Karam & Itani, 2013). However, according to some regional studies in nearby countries, the percentages of PwD are varied. For instance, the prevalence is reported to be between 2% and 5% in Egypt

(Elshahidi et al., 2017), 6.4% in Saudi Arabia (Alkhunizan, Alkhenizan, & Basudan, 2018), 7.9% in Iran (Sharifi et al., 2016) and 10.5% in Lebanon (Phung et al., 2014). Jordan's cultural and economic context closely resembles that of the region, so it is reasonable to suggest that the percentage of PwD in Jordan will be more or less around what is proposed in the other regions. In addition, as with other parts of the world, given that the strongest risk factor for dementia is age, the incidence and prevalence of dementia are likely to rise substantially, constituting a significant challenge and emotional burden to families, and a significant social and economic burden. Moreover, this demographic development has important implications in terms of the demands made upon social institutions that provide care and support for older people (Al-Makahmreh, 2010).

The prevalence of dementia is 5.1% for the North Africa and the Middle East region, which is lower than for Western Europe (15.9%), North America (10.2%), East Asia (20.9%), South Asia (11%) and the developed Asian Pacific region (7.8%); and higher than all of Latin America (0.7% at Andean, 3.3% at Central, and 1.6% at southern), and the rest of Africa (0.3% to 1.5%) (Wimo, Gauthier, & Prince, 2018). Furthermore, it has been highlighted that the predicted proportionate increase in dementia prevalence in North Africa and the Middle East was 329%, substantially greater than the increase of 92% predicted for Western Europe between 2015 and 2050 (Prince et al., 2015).

Few attempts have been made to collect data about the incidence or prevalence of caring for PwD in the Arab world (Al-Makahmreh, 2010). The reason for this is likely that the number of specialised centres for the assessment and treatment of dementia is very limited, Moreover, that family has a pivotal role in Jordanian society in which elderly parents, including PwD, gain a high status within the family structure; and that the delivery of care for PwD within the family is an essential characteristic of both the culture and religion in Jordan (Al-Makahmreh, 2010).

However, in recent years, economical changes are having an impact on Jordanian society (Al-Makahmreh, 2010; Salameh, Ananzeh, & Daradkah, 2018). Therefore, many sons and

daughters who would normally live close to their older relatives are increasingly likely to be working abroad and leaving them to manage on their own (Al-Makahmreh, 2010). Importantly, the main concern in Jordan is the increased proportion of older people because of the recent fast growth in nuclear families and the prevalence of individualism (Hweidi et al., 2018). Therefore, Jordanian society does not have sufficient awareness nor the resources to meet the needs of the health and social care issues associated with older people (Abyad, 2015; Al-Khateeb, 2009; Al-Makahmreh, 2010).

#### 1.1.3.3 Care Homes in Jordan

Recently, there has been acceptance of care homes by communities in Jordan, and there are now nine registered care homes in Jordan (Ministry of Social Development (MOSD), 2017). Eight of them were located in the capital of Jordan (Amman) (MOSD, 2017). Table 1 lists the information about Jordanian care homes which was adopted from The Jordanian Ministry of Social Development (MOSD, 2017). The Jordanian MOSD covers the expenses of some residents who do not have enough money to pay for their care (Al-Khateeb, 2009; Almomani & Bani-Issa, 2017; MOSD, 2017). Some of these care homes are supported by public charity organizations with very limited financial recourses, and others are worked by the private sector (Al-Makahmreh, 2010; Almomani & Bani-Issa, 2017).

No	Nursing homes	Location	Year of opening	Residents	Gender
1	Dar Aldiafeh Nursing homes	Amman- Aljwideh	1979	150 ( Male 95, Female 55)	Male Female
2	Her Highness Princess Muna of Nursing home	Zarqa Directorate	1965	35 female	Female only
3	Dar Alsalam Nursing homes	Amman	1970	40 (Female 25, Male 15)	Male Female
4	Al Ziarah Nursing homes	Amman	1992	For Elder female nurses only	Male Female
5	House of nuns human caring	Amman	1999	30 (Male & female)	Male Female
6	Hope Elder Nursing homes	Amman	1996	40 (Female 25, Male 15 )	Male Female
7	Darat Samir shama Nursing homes	Amman	2001	Not Available	Male Female
8	Dar Al-zahraa Elder 10 Nursing homes	Amman	2000	30 (Female 15, Male 15)	Male Female
9	Wadi Al sheta Old Ages Nursing homes	Amman	2007	10 (Female 1, Male 9)	Male Female

Table 1: The information about Jordanian care homes which was adopted from The Jordanian Ministry of Social Development (MOSD)) (2017)

# 1.1.3.4 Treatment of Dementia in Jordan

In his book about dementia in Jordan, Sarhan (2017), a consultant psychiatrist-chief editor of the Arab journal of psychiatry, identified that both American Psychiatric Association (APA) Practice guidelines and National Institute for Health and Care Excellence (NICE) guidelines are used to treat and care PwD in Jordan (Sarhan, 2017, pp. 40-47). The treatments of dementia in Jordan are almost the same as in the UK including pharmacological, alternative treatments, and psychotherapies. The pharmacological treatments include the management of cognitive and non-cognitive symptoms. The management of cognitive symptoms includes cholinesterase inhibitors (Donepezil, Galantamine, and rivastigmine) and Memantine. In addition, the management of non-cognitive symptoms including antipsychotic drugs (Risperidone, Quetiapine, Amisulpride, and Olanzapine), anti-depressants (Mirtazapine, Sertraline, Escitalopram, Venlafaxine, and Duloxetine), and muscle relaxants (Lorazepam or Bromozepam).

The alternative treatments include acupuncture, aromatherapy, massage, bright light therapy, herbal medicine, and transcutaneous electrical nerve stimulation. Psychotherapies include reality orientation, reminiscence, dementia care mapping, music therapy, 'Quran-Kareem' listing therapy, and physical exercise. However, while these treatments of dementia were mentioned in Sarhan (2017) book, there are no empirical studies or articles specifically discussing the treatments for dementia utilised in Jordan.

#### **1.1.4 Treatments for Dementia**

It is generally accepted that dementia cannot be cured (Alzheimer's Society, 2018d). However, several pharmacological and nonpharmacological approaches can be used to address the symptoms (Abraha et al., 2017; D'Onofrio et al., 2016; Gitlin, Kales, & Lyketsos, 2012).

#### 1.1.4.1 Pharmacological Treatment of Dementia

The National Institute for Health and Care Excellence (NICE) recently issued revised guidance on prescribing of medication for the treatment of dementia (Alzheimer's Society, 2018e; NICE, 2018b). The pharmacological treatments will be according to the presence of these symptoms (NICE, 2018b). These treatments include:

- 1. Management of cognitive symptoms:
  - Acetylcholinesterase Inhibitors (or cholinesterase inhibitors): they will maintain the existing supplies of the ACH by preventing the enzyme acetylcholinesterase from breaking it down. There are three different types of inhibitor including Donepezil (Aricept), Galantamine (Reminyl), and rivastigmine (Exelon) (Alzheimer's Society, 2018e; NICE, 2018b).
  - Memantine (Ebixa): It protects the brain cells against the effects of the excess glutamate released when cells are damaged by AD (Alzheimer's Society, 2018e; NICE, 2018b).

- 2. Management of non-cognitive symptoms:
  - a. Antipsychotic drugs (NICE, 2018b).
  - Acetylcholinesterase inhibitors and Memantine to manage non-cognitive symptoms in all types of dementia except people with VD, they are not recommended for people with VD (NICE, 2018b).

It has been found that the pharmacological approaches outlined can temporarily alleviate symptoms for between six months and a year (Abraha et al., 2017; Bishara, Sauer, & Taylor, 2015; Yiannopoulou & Papageorgiou, 2013). However, in some cases a pharmacological approach can make the symptoms worse, for instance, it can increase aggression among people with FTD (Bishara et al., 2015). Also, pharmacological treatments for PwD may have the potential to cause harmful side effects as well (Hsieh et al., 2010; Li et al., 2017).

Therefore, PwD will be offered pharmacological treatment combined with nonpharmacological approaches for the management of cognitive symptoms (Backhouse, Killett, Penhale, & Gray, 2016; Scales, Zimmerman, & Miller, 2018). Nonpharmacological approaches might be used as a first-line treatment to avoid the need for medication for non-cognitive symptoms (D'Onofrio et al., 2016; Gitlin et al., 2012; NICE, 2018a).

# 1.1.4.2 Non-pharmacological Treatment of Dementia

Nonpharmacological approaches include cognitive behavioural therapy (CBT) (addresses the interaction between people's thoughts, feelings and behaviour), reality orientation (reminding PwD of facts about themselves and their environment), validation therapy (empathizing with expressed emotions), reminiscence therapy (RT), bright-light therapy (exposure to daylight or specific wavelengths of light), touch therapy (including massage or therapeutic touch) and music therapy (engagement in a musical activity) (Ballard, Khan, Clack, & Corbett, 2011; D'Onofrio et al., 2016; de Oliveira et al., 2015; Douglas, James, & Ballard, 2004; Scales et al., 2018). See Table 2 for an overview of the effectiveness of these nonpharmacological approaches across various outcomes for PwD from different systematic reviews (SRs). Table 3 discusses these SRs in details and their results.

### Table 2: Nonpharmacological approaches and their effects on PwD

Types	Outcomes
Cognitive Behavioural Therapy (CBT)	<ul> <li>It can reduce depressive symptoms for PwD (Orgeta, Qazi, Spector, &amp; Orrell, 2014; Spector et al., 2015).</li> <li>There was no effect on anxiety, quality of life, and cognition (Orgeta et al., 2014).</li> </ul>
Reality Orientation	<ul> <li>It is not effective in improving cognitive functioning among PwD.</li> <li>It has limited or not found effects on daily functioning, and depression (Carrion, Folkvord, Anastasiadou, &amp; Aymerich, 2018).</li> </ul>
Touch Therapy	<ul> <li>PwD experienced a statistically significant effect in reducing behavioural symptoms only (de Oliveira et al., 2015).</li> </ul>
RT	<ul> <li>RT has positive effects on PwD in the domains of QoL, cognition, communication, and mood (Woods, O'Philbin, Farrell, Spector, &amp; Orrell, 2018).</li> <li>The results showed improvement in most variables including cognition and depression (D'Onofrio et al., 2016).</li> <li>These outcomes will be discussed more in this chapter section 1.2.4.</li> </ul>
Bright Light Therapy	<ul> <li>There are positive results in improving night-time sleep, reduction in agitation, and improvement in cognitive performance (de Oliveira et al., 2015).</li> <li>There is limited evidence of a reduction in agitation and aggression among PwD (D'Onofrio et al., 2016).</li> </ul>
Music Therapy	• It is effective in reducing agitation, anxiety, and apathy in moderate and severe dementia in the short term (de Oliveira et al., 2015).
Validation Therapy	<ul> <li>There is insufficient evidence about the efficacy of validation therapy for PwD (Abraha et al., 2017).</li> </ul>

Nonpharmacological approaches aim to reduce family and caregiver distress by managing the behavioural and cognitive impairments of PwD (Cohen-Mansfield et al., 2010; de Oliveira et al., 2015; Gitlin et al., 2012; Subramaniam & Woods, 2012). It has been found that these nonpharmacological interventions are safe and effective (Scales et al., 2018; Staedtler & Nunez, 2015). In general, these interventions have the potential to reduce apathy (Brodaty, 2012); improve cognition (Bademli et al., 2018; Cammisuli, Danti, Bosinelli, & Cipriani, 2016; Fang, Ye, Huangfu, & Calimag, 2017; Li et al., 2017; Mileski et al., 2018; Subramaniam & Woods, 2012); social interaction (Chiang et al., 2010; Choi & Jeon, 2013; Mileski et al.,

2018); quality of care and QoL for PwD (Backhouse et al., 2016; Cabrera et al., 2015; D'Onofrio et al., 2016; Huldtgren, Mertl, Voromann, & Geiger, 2017); manage dementiarelated sleep problems (Gibson, Gander, Dowell, & Jones, 2017) ; and decrease symptoms of depression, anxiety, and agitation (Cammisuli et al., 2016; D'Onofrio et al., 2016; Huldtgren et al., 2017; Scales et al., 2018; Staedtler & Nunez, 2015).

Table 2 shows outcomes of different SRs into the nonpharmacological approaches; Orgeta et al. (2014) conducted their SR of CBT for PwD, which utilised a meta-analysis of randomised controlled trials (RCTs) to assess the effects of CBT on PwD. The review showed evidence from six RCTs that CBT has positive effect on depression but there was no effect on anxiety, quality of life, and cognition. Carrion et al. (2018) conducted their SR of reality ortientation for PwD. The review showed evidence from 40 RCTs that reality orientation is not effective in improving cognitive functioning among PwD and it has limited or not found effects on daily functioning, and depression. de Oliveira et al. (2015) in their SR showed evidence from 20 RCTs that PwD experienced a statistically significant effect in reducing behavioural symptoms only after completion of touch therapy, there were positive results in improving night-time sleep, reduction in agitation, and improvement in cognitive performance after completion of bright light therapy, and reducing agitation, anxiety, and apathy in moderate and severe dementia in the short term after music therapy. Woods et al. (2018) conducted their Cochrane review of RT for PwD, which utilised a meta-analysis of randomised controlled trials (RCTs) to assess the effects of RT on PwD. The review showed evidence from 22 RCTs that RT can improve cognition, communication, QoL and potentially mood in PwD. Abraha et al. (2017) conducted their SR of SRs of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. This review showed evidence from 38 SRs (156 RCTs) that there is insufficient evidence about the efficacy of validation therapy for PwD, music therapy was effective in reducing agitation and anxiety, and home-based behavioural management techniques, caregiver-based interventions or staff training in communication skills, person-centred care or dementia care mapping with supervision during implementation were found to be effective for symptomatic and severe agitation.

However, as mentioned in Table 2, systematic reviews of outcome studies have indicated that studies into these nonpharmacological approaches, except RT, do not consider all potential outcomes of cognitive, communication, depression, anxiety, and QoL. However, compared to other nonpharmacological approaches for PwD, RT has been suggested to be of great potential for the enhancement PwD in all domains of QoL, cognition, communication and mood (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007; Lazar, Thompson, & Demiris, 2014; Li et al., 2017; Subramaniam & Woods, 2012; Woods et al., 2018). Also, RT is very easy to perform and deliver by anyone with some level of training, and require some expertise to work effectively with someone with moderate to severe dementia (Li et al., 2017).

Moreover, RT is considered to be less challenging than all other approaches for those with impaired cognitive function; it can be used with different levels of cognition, including those who have lost the ability to verbalize (Douglas et al., 2004; Lazar et al., 2014). Moreover, it is age-appropriate as it utilises the memories to improve psychological well-being (Cohen-Mansfield et al., 2010; Subramaniam & Woods, 2012; Woods, Spector, Jones, Orrell, & Davies, 2005). In addition, RT has a great deal of flexibility as it can be adapted either to the individual or groups (Douglas et al., 2004).

# **1.1.5 Conclusion**

This section has demonstrated that dementia is considered a public health priority. Dementia is a progressive degenerative illness is synonymous with cognitive and behavioural decline. Dementia symptoms include memory loss, problems with communications, mood changes, poor quality of life (QoL), and psychiatric symptoms including depression and anxiety. Moreover, there is a number of different types of dementia including AD, DLB, FTD, and other very rare types such as Creutzfeldt-Jakob disease, and Young-onset dementia. Dementia cannot be cured. Therefore, pharmacological and nonpharmacological approaches are recommended for use alongside to treat PwD. There are many types of nonpharmacological approaches include behavioural therapy, validation therapy, RT, art therapy, and music

therapy. However, this research suggests that RT has many advantages to be used as a great potential to treat PwD.

To date, the exact number of PwD in Jordan is unavailable. In addition, to treat and care for PwD, both the American Psychiatric Association (APA) Practice guidelines and NICE guidelines are used in Jordan. The effort for PwD in Jordan requires more strategic attention all at levels within society. Moreover, their human rights demand that consideration be focused on improving their health and social circumstances to improve their QoL.

In summary, this thesis will focus on using RT in PwD as means to be used to improve the psychological well-being of PwD. The next section seeks to identify RT for PwD.

#### **1.2 Reminiscence Therapy**

# **1.2.1 Introduction**

This section introduces reminiscence therapy (RT), implementation of RT, application in dementia, RT sessions, RT functions, RT types, and impact of RT.

#### 1.2.1.1 Reminiscence Therapy Definition

The RT can be defined as a nonpharmacological treatment that utilises written and/or oral accounts of historical events to improve psychological well-being (Abraha et al., 2017; Dempsey et al., 2014; Scales et al., 2018). The main aim of RT for PwD is to improve their well-being by evoking discussion of memories through using tangible triggers including music, objects, photos, and videos (Abraha et al., 2017; Gundogdu, Bejan, Kunze, & Wolfel, 2017; Woods et al., 2018).

## 1.2.1.2 Reminiscence Therapy Implementation

Reminiscence work is a well-established approach that has been promoted in practice for over fifty years (Dempsey et al., 2014). In the 1960s, Butler's early work, Life Review, proposed the idea that reminiscing intervention could have the potential to lead to successful ageing by the increasing realization of mortality and impending death as a dynamic process of adjustment (Dempsey et al., 2014; Hallford & Mellor, 2013; Klever, 2013; Subramaniam & Woods, 2012; Woods et al., 2018). This work contributed to the change in professional perspectives on reminiscence (Woods et al., 2018). As a result, the idea of looking back at and reflecting on one's own life gained support (Dempsey et al., 2014; Hallford & Mellor, 2013; Klever, 2013; Woods et al., 2018).

Reminiscing is considered as a healthy natural occurrence (Dempsey et al., 2014; Subramaniam & Woods, 2012; Woods et al., 2018). It is evident that reminiscence is an important cognitive development activity throughout the lifespan, with people utilising it at various stages in their life for different purposes (Alea, Bluck, & Ali, 2015; Hallford & Mellor, 2013; Henkel, Kris, Birney, & Krauss, 2017; Westerhof & Bohlmeijer, 2014). Reminiscence therapy can be performed individually or within a group (Duan et al., 2018; Woods et al., 2018). Whilst group RT is associated with benefits for communication (Amieva et al., 2016; Charlesworth et al., 2016; Sarkamo et al., 2014; Woods et al., 2012; Woods et al., 2018), it has been found that individual RT is associated with more improvements in cognition, mood and QoL than when it is delivered in a group (Morgan & Woods, 2012a; Subramaniam, Woods, & Whitaker, 2014).

## 1.2.1.3 Application to Dementia care

Reminiscence therapy has become one of the most popular nonpharmacological interventions to promoting older people's mental health especially in dementia care (Bazooband, Baghbanian, & Torkfar, 2016; Duan et al., 2018; Gonzalez, Mayordomo, Torres, Sales, & Melendez, 2015). Whilst PwD tend to have intact long term memory (remote memory) for many years after dementia diagnosis (Scales et al., 2018), they have impairments in short term memory leading to problems with their communications, mood, QoL, and ADLs (Alzheimer's Society, 2018d; Scales et al., 2018; Yamagami, Oosawa, Ito, & Yamaguchi, 2007).

During reminiscence work, PwD are encouraged to engage in recalling and sharing their memories, through using the five senses to stimulate the retrieval of memories which provide the basis of conversations for them (Astell, Ellis, Alm, Dye, & Gowans, 2010; El Haj et al.,

2016; Woods et al., 2018). These processes may enhance their communication, and allow them to talk confidently about their earlier life and experiences (Woods et al., 2018).

There have been extensive empirical studies investigating the beneficial effects of RT on a wide range of outcomes for PwD. They suggested that RT has a pivotal role in maintaining a person's sense of identity and self-esteem, maintaining problem-solving, promoting communication and wellbeing, and aiding with death preparation for PwD (Cappeliez, Guindon, & Robitaille, 2008; Dempsey et al., 2014; Hsieh et al., 2010; Klever, 2013; Westerhof, Bohlmeijer, & Webster, 2010). In addition, RT has the potential to increase social interaction; improve mood, cognition, and behaviour; reduce social isolation; offer an enjoyable and stimulating activity; promote self-worth; and improve QoL (Cotelli, Manenti, & Zanetti, 2012; Egan et al., 2007; NICE, 2018a; Woods et al., 2018; Yamagami et al., 2007).

#### 1.2.1.1 Reminiscence Therapy Sessions

It has been found that reminiscence work may take several different forms such as psychotherapy and environmental redesign (Woods et al., 2018). It utilises familiar prompts that include household familiar items and artefacts from the past such as photographs, video, music, smells, tastes and old objects to evoke memories (Abraha et al., 2017; Gonzalez et al., 2015; Gundogdu et al., 2017; Woods et al., 2018). These triggers aim to simulate all five senses (Siriaraya & Ang, 2014). It works best when these familiar triggers are suitable and appropriate to the audience's age, culture, and interests (Dempsey et al., 2014; Tolson & Schofield, 2012).

Reminiscence work can be undertaken using generic or personalised items (Cohen-Mansfield, Marx, Thein, & Dakheel-Ali, 2010; Subramaniam & Woods, 2012). It has been found that generic items could be more effective prompts and spark off multiple recollections that enrich the reminiscence process, whereas the personal materials could be less effective and are perceived as a memory test (Astell, Ellis, Bernardi, et al., 2010). In addition, the use of generic materials will put all PwD on an equal footing with a healthy conversation and

emphasizing community membership over illness (McFadden & McFadden, 2011; Purves, Savundranayagam, Kelson, Astell, & Phinney, 2011).

There are a wide variety of RT sessions in terms of structure (Stinson, 2009; Woods et al., 2018). It has been suggested in some studies the need for structured RT sessions to meet the needs of individuals (Adhikari, 2013; Parker, 2006; Stinson & Long, 2014). For example, Jopling and Mousley (2017) have published their book 'The Multi-Sensory Reminiscence Activity Book: 52 Weekly Group Session Plans for Working with Older Adults'. This book contains 52 multi-sensory reminiscence group session plans incorporating a range of activities (Jopling & Mousley, 2017). These group session plans provide cognitive stimulation and can be used with PwD (Jopling & Mousley, 2017). It will provide a comprehensive guide to enable group facilitators to run an enjoyable and interactive multi-sensory group (Jopling & Mousley, 2017).

Schweitzer and Bruce (2008) have published their book 'Remembering Yesterday, Caring Today, (RYCT), Reminiscence in Dementia Care: A Guide to Good Practice'. The RYCT approach has been developed by the European Reminiscence Network and was used and studied in various European countries during the last 15 years. Moreover, this RYCT approach is person-centred and very structured (Eggers, 2012) and it can be used in a group or individual care (Schweitzer & Bruce, 2008). It was developed as a 12-week intervention with various stimuli such as video, artwork, and music (Eggers, 2012; Schweitzer & Bruce, 2008). Additionally, this approach will focus on a different theme each week and aims to help PwD and their caregivers to remember the individual's life before being diagnosed with dementia (Eggers, 2012). Table 3 explains the essential elements and contents of this RT approach adapted from (Schweitzer & Bruce, 2008).
Table 3: The essential elements and contents of the RT approach adapted from Schweitzer and Bruce (2008).

Week	Session	Themes	Session content
1	1	Warm up	<ul><li>Introduction of program and rules.</li><li>Introduction to the principal researcher.</li></ul>
	2	Childhood and family life	<ul> <li>Sharing memory about parents and brothers</li> </ul>
2	3	Schooldays	<ul><li>Sharing the dream about future</li><li>Sharing the success and frustration</li></ul>
	4	Working lives	<ul> <li>Sharing the memories and feelings about success and frustration.</li> </ul>
3	5	Going out and having fun	<ul> <li>Sharing the feeling about recalling the past pleasures, common experiences, hobbies, interest, and travel.</li> </ul>
	6	Wedding	<ul> <li>Sharing the feeling about a partner at first meeting</li> <li>Sharing process of marriage</li> </ul>
4	7	The next generation, babies and children	Sharing the birth of the first baby
	8	Food and cooking	<ul> <li>Sharing the feeling about recalling good feelings associated with food and eating.</li> </ul>
5	9	New understanding of parents and recognition of value about oneself - Having pride in solving the problem	<ul> <li>Sharing the experience of pleasure and difficulty in the process of rearing of children</li> <li>Sharing about mind to leave on the children</li> <li>Sharing the most difficult experience</li> <li>Sharing the successful experience</li> </ul>
	10	Stage of senescence: successful agedness and positive recognition about proceeding of agedness	<ul> <li>Sharing the experience of grandparents in childhood</li> <li>Sharing opinion about successful agedness</li> </ul>
6	11	Death preparation	<ul><li>Sharing opinion about death in mind.</li><li>Sharing opinion about an ideal death</li></ul>
	12	Positive reconstruction about the life	Reminiscence of whole life and sharing     wish about the future

# **1.2.2 Reminiscence Therapy Functions**

Reminiscence work is considered as a multidimensional, multigenerational, and multidisciplinary process (Afonso, Serrano Selva, & Latorre Postigo, 2015). Therefore, there are various functions and taxonomies of RT (Afonso et al., 2015; O'Rourke, Carmel, Chaudhury, Polchenko, & Bachner, 2013). According to Coleman (1974), there are two types of reminiscence functions: simple reminiscence and informative reminiscence. Simple reminiscence is the spontaneous and significant past events that can be a resource for the balance of the self. Whereas informative reminiscence is the application of past experiences to the present as a way to teach others.

Watt and Wong (1991) proposed the following six types of reminiscence functions: (Afonso et al., 2015).

- Integrative reminiscence function: a process involving acceptance of the self and others, reconciliation about one's past, a sense and meaning of personal value, and integration of the past and present.
- 2. *Instrumental reminiscence function*: remembering past plans and attempts to aid the solving of problems currently being experienced.
- 3. *Transmissive reminiscence function*: storytelling their memories with the intention of teaching or informing future generations. Moral instruction is usually included.
- 4. *Narrative reminiscence function*: allowing old people to share their memories in descriptive or factual accounts of the past to provide the biographical information.
- Escapist reminiscence function: a defensive process that helps the person relieve boredom resulting from the present stress by glorifying the past and deprecating the present.
- 6. Obsessive reminiscence function: based on a failure to integrate problematic past experiences in positive aspects of life. This type of reminiscence is evidenced by feelings of guilt, shame, resentment, and despair. Therefore, it leads to the person ruminating on memories, with intending to justify the feelings of bitterness.

However, Webster (1993, 2003) identified, through using Reminiscence Functions Scale (RFS),that there are eight functions of reminiscence: identity, problem solving, teach-inform, conversation, boredom reduction, bitterness revival, death preparation, and intimacy maintenance (Afonso et al., 2015; El Haj & Antoine, 2016; Hofer, Busch, Polackova Solcova, & Tavel, 2016; Ros et al., 2016; Webster, 1993, 2003; Westerhof et al., 2010). In RFS, the first six functions of reminiscence have corresponded with the reminiscence functions which were identified by Watt and Wong (1991). Whereas, death preparation and intimacy maintenance were initially identified using the RFS. However, Watt and Wong

(1991) considered death preparation is part of the integrative (identity) function, whereas Webster (1993, 2003) considered it to be a function in its own right.

It has been identified that there is a general agreement between Watt and Wong (1991) and Webster (1993, 2003). The categories functions of reminiscence according to this agreement will be: identity (integrative), problem-solving (instrumental), teach-inform (transmissive), conversation (narrative), boredom reduction (escapist), bitterness revival (obsessive), death preparation, and intimacy maintenance (Cappeliez et al., 2008; Hofer et al., 2016; Westerhof & Bohlmeijer, 2014).

Hofer et al. (2016), Ros et al. (2016), and Webster (2003) identified that functions of reminiscence can be arranged in a model defined by two dimensions: self-versus social; proactive/growth-oriented versus reactive/loss-oriented. These two dimensions include four categories compromising two functions of reminiscence each: self-proactive/growth (identity and problem-solving); social-proactive/growth (teach/inform and conversation); self-reactive/loss (boredom reduction and bitterness revival); social-reactive/loss (death preparation and intimacy maintenance). Table 4 demonstrates the attempts to categorise the various functions of reminiscence.

		Identity	Problem solving	Boredom reduction	Bitterness Revival	Teach- inform	Conversation	Intimacy maintenance	Death preparation
Self-	proactive/growth	A & B	A & B						
Self-	reactive/loss			A & B	A & B				
Social	proactive/growth					A & B	A & B		
Social-	reactive/loss							В	В
A: Watt and Wong (1991) B: Webster (1993, 2003)									

Table 4: Table demonstrating the attempts to categorise the various functions of reminiscence

1.2.2.1 Self-proactive/growth

# 1.2.2.1.1 Identity (Integrative)

Identity is one of self-proactive/growth reminiscence function that uses of the past to explore or crystallise a clear feeling of who we are (El Haj & Antoine, 2016; Hofer et al., 2016; Webster, 2003; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014). It assists people to identify a pattern of coherence in one's living, and find meaning and continuity in life (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2006; Cappeliez, Rivard, & Guindon, 2007; Ros et al., 2016). Additionally, it has been suggested that engaging in reminiscence for identity purposes will be important for personal development and well-being (Cappeliez & O'Rourke, 2006) The main aspect of identity reminiscence functions is the re-evaluation and transformation of negative memories into good outcomes (Cappeliez & O'Rourke, 2006; Watt & Wong, 1991). Through the use of identity as a part of integrative functions, the reminiscer is encouraged to reconcile and accept the past that has a positive influence on wellness (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2006; Watt & Wong, 1991). In cases where integrity is achieved, life satisfaction is increased, higher levels of self-esteem, then a sense of life coherence and better mental health are achieved (Cappeliez & O'Rourke, 2006; Watt & Wong, 1991).

It has been evident that there is a negative association between identity reminiscence functions and depression (Cappeliez & O'Rourke, 2006). Therefore, engaging in reminiscence work for identity functions could be able to treat depression symptoms during a structured clinical intervention (Cappeliez & O'Rourke, 2002; Cappeliez et al., 2007; Watt & Cappeliez, 2000).

## 1.2.2.1.2 Problem-solving (Instrumental)

Reminiscence work for problem solving functions is defined as the use of past memories as a constructive coping mechanism for managing current problems by remembering experiences of successful past problem-solving (Cappeliez & O'Rourke, 2006; Cappeliez et al., 2007; Dempsey et al., 2014; Ros et al., 2016; Watt & Cappeliez, 2000; Watt & Wong, 1991; Webster, 2003). Additionally, problem-solving reminiscence functioning revives strategies used to successfully cope during difficult and stressful life events allowing them to be implemented in the present situation (Cappeliez, O'Rourke, & Chaudhury, 2005; Cappeliez & O'Rourke, 2006; Westerhof et al., 2010).

It has been suggested that the use of instrumental reminiscence for problem-solving purposes could help people to view themselves as capable, competent and self-efficacious leading to an increase in self-motivation self-esteem, and morale (Cappeliez & O'Rourke, 2006; Cappeliez et al., 2007; Watt & Wong, 1991). Also, a problem-solving function of reminiscence can be seen to act as a buffer to emotional distress that decreases feelings of

anxiety (Hallford & Mellor, 2013; Korte, Bohlmeijer, Westerhof, & Pot, 2011; Watt & Wong, 1991).

#### 1.2.2.2 Self-reactive/loss

## 1.2.2.2.1 Boredom reduction (Escapist)

Sometimes, elderly people have very difficult lives in an environment which is considered under-stimulating that includes multiple traumas and periods of illness (Cappeliez et al., 2007; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014). Reminiscence for the boredom reduction purposes involves thinking back about the past to return to the good old days by expressing nostalgia, and escaping from monotonous situations by reflecting on the past (Cappeliez et al., 2005; Cappeliez et al., 2007; El Haj & Antoine, 2016; Hofer et al., 2016; Watt & Wong, 1991; Westerhof et al., 2010). In addition, it can be observed as an easy technique to distract elderly people from current problems, and fill time or simply to create ease of conversation (Cappeliez et al., 2005; Dempsey et al., 2014; El Haj & Antoine, 2016). There are three main elements of the boredom reduction function of reminiscence involving a magnified view of the past, contrasting of the past with the present, and a desire to return to an idealised past (Cappeliez et al., 2008; Watt & Wong, 1991). In addition, older people could utilise self-esteem protection strategies (escapism technique) by which they re-imagine themselves as the hero of a specific situation when confronted with the natural impairment associated with older age (Watt & Wong, 1991).

However, using of boredom reduction function of reminiscence provide a feeling of instant relief, it can have a negative effect on a person if it is used on a long term basis (Cappeliez et al., 2008; Cappeliez et al., 2005; Cappeliez & O'Rourke, 2006; El Haj & Antoine, 2016; Watt & Wong, 1991). It can lead to an increase in negative feelings, particularly those related to apathy (Cappeliez et al., 2008; Cappeliez et al., 2005; Cappeliez & O'Rourke, 2006). Therefore, it is important to ensure that it can be used in the short term only.

#### 1.2.2.2.2 Bitterness Revival (Obsessive)

Bitterness revival is also known as obsessive reminiscence which can be defined as a process by which ruminating on past memories about unjust treatments providing justification for maintaining negative feelings and thoughts (Cappeliez et al., 2008; Cappeliez et al., 2005; El Haj & Antoine, 2016; Hofer et al., 2016; Watt & Wong, 1991). It has been found that reminiscence for the purposes of bitterness revival is the opposite of the identity function of reminiscence, demonstrating a failure to integrate previous life experiences that represent problematic events (Cappeliez et al., 2007; Watt & Wong, 1991). Additionally, the reminiscence for bitterness revival purposes can demonstrate a fragmented and lacking meaning self (Cappeliez et al., 2007). It is associated with weaker goal setting, emotional vulnerability, and psychological distress (Cappeliez et al., 2005).

Mainly, older people who live with depression will often focus on the negative memories and ignoring the positive experiences to support their dysfunctional review of their life (Gonzalez et al., 2015). Therefore, using bitterness revival function of reminiscence may lead to an increase in the problem in which this person will continue to ruminate on negative experiences, which will have a detrimental effect on their health and well-being (Cappeliez et al., 2008). It has been found that reminiscence for bitterness revival may induce a sense of depression, agitation, panic and suicide (Cappeliez et al., 2008; Watt & Wong, 1991).

#### 1.2.2.3 Social-proactive/growth

#### 1.2.2.3.1 Teach-inform (Transmissive)

The reminiscence for teach-inform purposes involves the passing on and sharing of personal experiences and life lessons of older people to younger generations (Cappeliez et al., 2008; Hofer et al., 2016; Watt & Wong, 1991; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014). It has been found that the old generations want to leave their mark on the world and ingrain their important values and ideas (Watt & Wong, 1991). As such, these memories often will have evaluative or instructive purposes about general life (such as moral lessons), or oneself (Watt & Wong, 1991; Webster, 2003; Westerhof et al., 2010; Westerhof &

Bohlmeijer, 2014). It has been expected that reminiscence for teach-inform functions is used more frequently by older generations than younger people due to the greater experiences held by older people when compared to the young (Webster, 1993).

Reminiscence for the teach- inform purposes could be often linked with social functioning (Cappeliez & O'Rourke, 2006) that could be associated with positive emotions within a social context (Cappeliez et al., 2007). In addition, this type of reminiscence could be used to convey an image of older people as self-enhanced, wise and experienced (Cappeliez & O'Rourke, 2006; Cappeliez et al., 2007) that could lead to an elevated mood in the person, and an increased sense of respect and admiration from others (Cappeliez & O'Rourke, 2006). The reminiscence for teach-inform functions is often associated with intergenerational interactions (Cappeliez et al., 2007). It can provide opportunities for the bond between the old and the younger to be strengthened (Chung, 2009), and give the younger something to build on in the future (Cappeliez et al., 2007). Therefore, the reminiscence for teach-inform functions can have a positive effect on the social adaptation of older adults (Chung, 2009; Watt & Wong, 1991). Additionally, it is a valuable social function for oral histories that will enhance self-esteem (Watt & Wong, 1991).

# 1.2.2.3.2 Conversation (Narrative)

Reminiscence for conversation functions involves the informal use and recounting of memories in order to connect or reconnect to others with no instructive or evaluative purposes (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2006; Hofer et al., 2016; Watt & Wong, 1991; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014). It tends to be descriptive in nature including providing personal information (such as name, place, and date of birth) and the sharing of the stories that could be considered to be relevant to the listener (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2006; Watt & Wong, 1991). It is often associated with socialisation by either re-connecting with old friends or fostering new friendships (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2006; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014). In addition, this type of reminiscence could be used to

convey an image of older people as a communicative, pleasant, and entertaining person in a social environment (Cappeliez et al., 2007), which can have a positive effect on the mental health and emotions of older people especially in social situations (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2006; Cappeliez et al., 2007). In addition, it has been found that this type of reminiscence provides opportunities to share these positive emotions in social situations that improve their mood and leads to successful ageing (Cappeliez et al., 2005; Cappeliez & O'Rourke, 2006).

#### 1.2.2.4 Social-reactive/loss

## 1.2.2.4.1 Intimacy maintenance

The intimacy maintenance function of the reminiscence is defined as a process of resurrecting cognitive and emotional memories of important someone departed in one's life physically (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2002, 2006; Hofer et al., 2016; Webster, 2003; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014). It is used as a method to maintain a closeness with someone who is no longer part of our lives due to death (Cappeliez et al., 2008; Cappeliez et al., 2005; Cappeliez & O'Rourke, 2006; Cappeliez et al., 2007), and to ensure these memories will remain accessible to present the faithful image of themselves to the departed person (Cappeliez et al., 2005; Cappeliez et al., 2007).

It has been suggested that this type of reminiscence function can be the starting point of the self-evaluation process and a reconsideration of one's life trajectory (Cappeliez & O'Rourke, 2006). In addition, it can be indicative of an incomplete grieving process that leads to unresolved grief feelings with negative psychological outcomes (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2006; Cappeliez et al., 2007). However, this type of reminiscence function could encourage the participants in accepting their loss, and aid them in accepting attitude towards not having someone who is no longer part of their lives anymore (Cappeliez et al., 2007).

It is evident that using the reminiscence for intimacy maintenance function purposes can lead to psychological distress and negative affect (Cappeliez et al., 2008; Cappeliez et al., 2005;

Cappeliez & O'Rourke, 2006). This type of reminiscence function is highly associated with increased levels of depression (Cappeliez et al., 2005; Cappeliez et al., 2007).

## 1.2.2.4.2 Death preparation

The reminiscence for death preparation functions involves helping a person to arrive at a calm, and accepting attitude towards approaching the end of their life (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2006; El Haj & Antoine, 2016; Hofer et al., 2016; Webster, 1993, 2003; Westerhof & Bohlmeijer, 2014). It has been used as a method to allow older people to approach their mortality with a feeling of wholeness, and completeness with feelings of closure on their life (Cappeliez & O'Rourke, 2006; Webster, 2006; Webster, 2003).

Several studies have suggested that the function of this type of reminiscence is to be used for a positive function rather than a negative one (Cappeliez et al., 2005; Cappeliez & O'Rourke, 2006; Cappeliez et al., 2007; El Haj & Antoine, 2016). It can be used to predict levels of life satisfaction that can lead to a more constructive approach to the end of their life, as well as, promoting a sense of meaning (Cappeliez et al., 2005; Cappeliez & O'Rourke, 2006; Cappeliez et al., 2007; El Haj & Antoine, 2016).

On the other hand, it is suggested that using the reminiscence for death preparation purposes can have a negative effect on the psychological functioning of older people and is correlated with depression (Cappeliez et al., 2005; Cappeliez & O'Rourke, 2006; El Haj & Antoine, 2016). This can then contribute to higher levels of anxiety and fear (El Haj & Antoine, 2016; Webster, 2003).

#### **1.2.3 Types of Reminiscence Approach**

There has been much discussion relating to the main modalities of reminiscence. It has been identified that there are three main forms of reminiscence: simple reminiscence, life review, and life review therapy (Gaggioli et al., 2014; Pinquart & Forstmeier, 2012; Webster, Bohlmeijer, & Westerhof, 2010; Westerhof et al., 2010).

## 1.2.3.1 Simple Reminiscence

Simple reminiscence involves unstructured autobiographical storytelling and spontaneous reminiscence (Pinquart & Forstmeier, 2012; Webster et al., 2010). This type of reminiscence

is appropriate for older adults who consider the sharing of their memories is a meaningful activity, as well as, those who are in good mental health (Gaggioli et al., 2014). It aims to recollect their positive past events, enhance social contacts and short-term well-being, and foster their positive emotions and feelings (Pinquart & Forstmeier, 2012). The Social-proactive/growth dimension of reminiscence functions, which includes teach/inform and conversation, are most common in this form (Webster et al., 2010). Simple reminiscence can be often conducted within a relational context among friends and family (Webster et al., 2010). It is often applied in reminiscence groups in care homes to increase the life satisfaction of care home residents, reducing the anxiety among them, improving their mood, and enhancing intergenerational bonding (Hallford & Mellor, 2013; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014). This type of reminiscence corresponds with socioemotional selectivity theory (SST) (Hernandez-Rubio, Meneses-Viveros, Mancera-Serralde, & Flores-Ortiz), as this type will focus on emotional functioning and strengthens the positivity bias in memory (Webster et al., 2010) (SST will be discussed later in Chapter 3, section 3.2.2).

# 1.2.3.2 Life Review

Life review is an approach that is used systematically to undertake a retrospective critical analysis of one's life history and evaluating and integrating the memories in a one-to-one format that gaining insight into one's development and reflecting on one's life (Dempsey et al., 2014; Gaggioli et al., 2014; Hallford & Mellor, 2013; Pinquart & Forstmeier, 2012). Compared with simple reminiscence, it is much more structured and focuses on both positive and negative memories to invoke the identity function of reminiscence (Gaggioli et al., 2014; Pinquart & Forstmeier, 2012; Subramaniam et al., 2014; Webster et al., 2010; Westerhof et al., 2010). Moreover, it can be successfully conducted with people with mild psychological distress who have difficulties in coping with transitions and struggling to find meaning in life (Webster et al., 2010; Westerhof et al., 2010).

Life review reminiscence corresponds with continuity theory that finds the continuity between past and present (Webster et al., 2010). This continuity in one's life between past and

present makes older people maintain similar patterns of behaviours and lifestyles across time, changing only slowly (Cooper & Beehr, 2015). Therefore, a new meaning for memories in the present can be created, and a psychological balance can be gained by using this type of reminiscence (Gonzalez et al., 2015). Therefore, life review intervention is shown to be effective at enhancing older people's life satisfaction, improving mastery and self-acceptance, and encouraging the sense of cohesion and continuity in one's life to achieve their ego integrity (Gaggioli et al., 2014; Hallford & Mellor, 2013; Westerhof et al., 2010).

#### 1.2.3.3 Life Review Therapy

Life review therapy is defined as highly structured approach that is applied mainly in psychotherapeutic settings to treat mental health problems such as depression or anxiety (Gaggioli et al., 2014; Hallford & Mellor, 2013; Pinquart & Forstmeier, 2012; Webster et al., 2010; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014). Life review therapy aims to improve adaptive functioning, alleviate the symptoms of mental illness of recipients, induce self-change, and enhance their feelings of meaning and identity cohesion (Hallford & Mellor, 2013; Westerhof et al., 2010). Therefore, life review therapy is not only focusing on the feelings of cohesion and continuity in one's life, but also, on reducing boredom and bitterness revival that will promote a positive view on one's past (Pinquart & Forstmeier, 2012; Webster et al., 2010; Westerhof et al., 2010).

The protocol of life review therapy intervention must have guidance in which negative memories will be directed towards a more positive self-identity (Webster et al., 2010; Westerhof et al., 2010). Therefore, it aims to reframe and re-evaluate negative memories, and feelings of guilt or worthlessness in a positive way to improve their coping skills and enhance their feelings of meaning and identity cohesion (Gaggioli et al., 2014; Hallford & Mellor, 2013). Moreover, it emphasises changing individuals' perceptions of themselves positively and increasing their feeling of self-efficacy to improve adaptive functioning and reduce depressive symptoms (Hallford & Mellor, 2013).

It has been evident that there are four factors contributing to an effective life review therapy for optimizing this approach (Dempsey et al., 2014; Gaggioli et al., 2014; Subramaniam et

al., 2014). These factors are time, structure, individuality, and evaluation. It has been implied that the time of this intervention should last six weeks or longer; with guided, structured and targeted sessions. The individual should be trained to guide this therapy to support older people who require support and they are unable to conduct the process independently (Cotelli et al., 2012; Dempsey et al., 2014; Gaggioli et al., 2014; Hallford & Mellor, 2013; Subramaniam et al., 2014).

## **1.2.4 Impacts of Reminiscence Therapy**

There have been extensive empirical studies investigating the beneficial effects of RT on a wide range of outcomes for PwD. Whilst the results of some empirical studies remain inconclusive on the beneficial effects of RT on wide range of outcomes for PwD (Azcurra, 2012; Cotelli et al., 2012; Hsieh et al., 2010; Tadaka & Kanagawa, 2004; Tolson & Schofield, 2012; Woods et al., 2018), it has been suggested in other studies that RT may have mutual benefits to both the PwD and their care-givers (Gonzalez et al., 2015; Jo & Song, 2014; Mulvenna et al., 2011; Okumura, Tanimukai, & Asada, 2008).

Woods et al. (2018) conducted their Cochrane review of RT for PwD, which utilised a metaanalysis of RCTs to assess the effects of RT on PwD. The review showed evidence from 22 RCTs that RT can improve cognition, communication, QoL and potentially mood in PwD. However, they found there were inconsistencies across the studies relating to the study setting (care homes versus community), sample size (small versus large size), and treatment modalities (individual versus group). In addition, O'Philbin, Woods, Farrell, Spector, and Orrell (2018) reported similar results in their Cochrane systematic review of the evidence from 16 RCTs.

In order to establish more robust, valid, and consistent conclusions about the effectiveness of RT as an intervention, it has been concluded that there is a clear need for better-designed studies (Woods et al., 2018). RT needs to be tested for effectiveness using RCTs (Dempsey et al., 2014; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014; Woods et al., 2018), with large sample size (Woods et al., 2018; Woods et al., 2005), using a more clear and exact

definition of RT (Dempsey et al., 2014; Westerhof et al., 2010), and more consistent outcome measurements (Woods et al., 2018; Woods et al., 2005).

There are many factors making RT a popular intervention, such as it has a simple nature to implement, it is non-stigmatising, age-appropriate, and has non-harmful effects (Azcurra, 2012; Hsieh et al., 2010; Subramaniam & Woods, 2012; Subramaniam et al., 2014; Woods et al., 2018; Woods et al., 2005). However, it is important to recognise that RT may have the potential to evoke negative and positive memories (Dempsey et al., 2014; Subramaniam et al., 2014). Therefore, it is important to use the experiencing of these negative emotions should be addressed by supporting the individual appropriately (Dempsey et al., 2014; Mulvenna et al., 2011).

The ongoing use of RT is recommended due to its anecdotal evidence of benefit and popularity which helps PwD retain a sense of self-worth, identity, and individuality (Dempsey et al., 2014; Woods et al., 2005). Therefore, this section will discuss the impact of RT on cognitive, communication and interaction, QoL, behaviour, and mental health including depression and anxiety.

## 1.2.4.1 *Cognitive Impact*

The decline in cognitive functioning is a well-documented symptom associated with dementia (Jo & Song, 2014). There are many studies that demonstrate a significant improvement of this cognitive decline after engaging in RT (Duru Asiret & Kapucu, 2016; Fang et al., 2017; Lin, Yang, Cheng, & Wang, 2017). However, the evidence for the effectiveness of RT on cognitive decline is still inconsistent and is described as controversial (O'Philbin et al., 2018; Woods et al., 2018).

Recent evidence suggests that engaging PwD in RT can lead to a statistically significant improvement in cognitive functioning (Astell, Smith, Potter, & Preston-Jones, 2018; Bademli et al., 2018; Choi & Jeon, 2013; Duru Asiret & Kapucu, 2016; Fang et al., 2017; Huang et al., 2015; Kim et al., 2016; Lin et al., 2017; Lopes, Afonso, Ribeiro, Quelhas, & Almeida, 2015; Subramaniam & Woods, 2012). However, there are other studies which have demonstrated no change in cognitive function (Amieva et al., 2016; Bahar-Fuchs, Clare, & Woods, 2013; Huang, Li, Yang, & Chen, 2009; Su, Wu, & Lin, 2012; Tadaka & Kanagawa,

2007; Woods et al., 2012). Although some of these studies have demonstrated no improvement in cognitive function, they have suggested that RT could prevent a decline in cognitive function when they found that PwD conditions have stabilised compared with control groups who have experienced a deterioration (Chung, 2009; Thorgrimsen, Schweitzer, & Orrell, 2002).

In addition, it has been found that structured RT for PwD could be able to improve both engagement and levels of attention significantly (Azcurra, 2012; Chung, 2009; Tolson & Schofield, 2012). Moreover, it has been found RT can lead to an increase in the number of recalled words for PwD in RT (Kim et al., 2016; Okumura et al., 2008).

The large number of previous studies showing that cognitive function can be improved through RT implies that it is a beneficial intervention for PwD. However, in all of the studies, the sample size is reasonably small. Therefore, further studies are required in order to assess whether participation in RT can have a measurable effect on PwD.

## 1.2.4.2 Communication and Interaction

The decline in communication and interaction also is one of the main symptoms associated with dementia (Jo & Song, 2014). It has been suggested that RT can be used to improve communication for PwD (Astell et al., 2018; Woods et al., 2018; Woods et al., 2005). However, there was an inconsistency between studies related to RT modality (group versus individual) (Woods et al., 2018). In particular, the effects were uncertain with very low-quality evidence for individual RT, and moderate-quality with slight benefit for group RT. However, several studies testing RT have demonstrated a statistically significant improvement in communication and interaction skills for PwD (Chiang et al., 2010; Choi & Jeon, 2013; Chung, 2009; Jo & Song, 2014; Tadaka & Kanagawa, 2007; Thorgrimsen et al., 2006; Okumura et al., 2008). Research conducted by Kim et al. (2016) suggested that the significant increase in conversational fluency was due to an increased number of words recalled after engaging in just three sessions of RT. Furthermore, RT could have a pivotal role in fostering the bond between PwD and their caregivers and encouraging greater levels of interaction (Dempsey et al., 2014; Subramaniam et al., 2014; Westerhof &

Bohlmeijer, 2014), through building a greater rapport with them(Baillon et al., 2005; Mackinlay & Trevitt, 2010).

#### 1.2.4.3 Quality of Life (QoL)

As a result of declining capacities experienced by PwD associated with cognitive decline and loss of autonomy, PwD can also experience a decline in their levels of well-being resulting in poorer QoL (Jo & Song, 2014). However, it has been cited that RT can be a potential solution to manage and improve this (Astell et al., 2018; Choi & Jeon, 2013; Fang et al., 2017; Jo & Song, 2014; Kim et al., 2016; Li et al., 2013; Subramaniam et al., 2014). It is suggested that improving memory plays an important role in improving QoL about the construction and maintenance of self-image and leading them to become the person they are today (Dempsey et al., 2014). However, the evidence for RT effectiveness on minimising QoL decline is still inconsistent mainly related to the study setting (Haslam et al., 2010; O'Philbin et al., 2018; Woods et al., 2018).

Recent evidence suggests that engaging PwD in RT can improve their QoL statistically (Astell et al., 2018; Azcurra, 2012; Choi & Jeon, 2013; Fang et al., 2017; Jo & Song, 2014; Kim et al., 2016; Li et al., 2013; Subramaniam et al., 2014). However, the evidence of QoL improvements is not strong because these studies have only looked at this in small samples (Woods et al., 2018; Woods et al., 2005). On the other hand, there are other studies with small samples that have demonstrated no change in QoL scores (Charlesworth et al., 2016; Haslam et al., 2010; Yousefi, Sharifi, Tagharrobi, & Akbari, 2014). In general, the evidence that RT is effective at improving the QoL of PwD is inconclusive.

## 1.2.4.4 Behavioural Impact

One of the main symptoms associated with PwD is a reduction in behavioural functioning (Stiadle, Zarit, & Bangerter, 2013). This reduction in behavioural functioning includes social disturbance behaviours, withdrawal from social interactions and a reduced friendship base (Chung, 2009; Stiadle et al., 2013; Tadaka & Kanagawa, 2007). RT provides a basis for new connections and aiding in the maintenance of existing relationships, through the sharing of memories, the establishment of common ground, and the provision of mutual support (Chung, 2009; Dempsey et al., 2014; Tadaka & Kanagawa, 2007). However, there were no

clear and consistent effects of RT on behavioural challenges (Woods et al., 2018; Woods et al., 2005).

Many studies have demonstrated a significant improvement in behavioural functioning after engaging in RT (Duru Asiret & Kapucu, 2016; Jo & Song, 2014; Lopes et al., 2015). However, while there are many studies that have tended towards a positive outcome of RT for PwD, other studies have not demonstrated a statistically significant outcome (Cotelli et al., 2012; Wang, Yen, & OuYang, 2009).

The previous studies which have found that behavioural functioning was improved through RT imply that it is a beneficial intervention for PwD. However, in some of these studies, the RT effects were only experienced in the short-term. Therefore, future study is required in order to assess whether participation in RT can have a measurable effect on PwD.

# 1.2.4.5 Mental Health

The mental health of PwD can be seriously affected due to the experience of cognitive decline, and disturbed self-perception and emotions (Alzheimer's Society, 2017; Coleman, 2005; Dempsey et al., 2014; Westerhof & Bohlmeijer, 2014). Anxiety and depression frequently occur in older people and is often observed as a co-morbidity to dementia (Alzheimer's Society, 2017). Research has suggested that RT can be utilised to support and improve the mental health of PwD (Coleman, 2005; Hallford & Mellor, 2013; Westerhof & Bohlmeijer, 2014).

It has been suggested that RT may provide PwD with potential solution to manage and alleviate depression and anxiety in PwD (Dempsey et al., 2014; Hallford & Mellor, 2013; Jo & Song, 2014; Subramaniam & Woods, 2012; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014). It has been suggested that the act of recollecting enjoyable pastime memories can lead to an increase in positive emotions, decreasing anxiety and depression and feeling happier (Okumura et al., 2008; Westerhof & Bohlmeijer, 2014).

Huang et al. (2015) conducted a meta-analysis of RCTs to evaluate the effectiveness of RT on depression in PwD. This review demonstrated that RT is effective in improving depression in

PwD. In addition, there are many studies have demonstrated a significant improvement in depression scores of PwD following engaging in RT (Chiang et al., 2010; Choi & Jeon, 2013; Fang et al., 2017; Hars, Herrmann, Gold, Rizzoli, & Trombetti, 2014; Hsieh et al., 2010; Lopes et al., 2015; Musavi, Mohammadian, & Mohammadinezhad, 2017; Song, Shen, Xu, & Sun, 2014; Subramaniam & Woods, 2012; Testad et al., 2014).

Several studies have obtained a significant improvement in depression scores at follow up period but not directly at the end of the intervention (Woods et al., 2018; Woods et al., 2005). On the other hand, there are other studies which have demonstrated no statistically changes in depression scores at follow up period (Huang et al., 2009; Jo & Song, 2014; Kim et al., 2016).

No previous meta-analysis of RCTs to evaluate the effectiveness of RT on anxiety in PwD was conducted. However, many studies have demonstrated a significant improvement in anxiety scores of PwD subsequent to engaging in RT (Fang et al., 2017; Hallford & Mellor, 2013; Hars et al., 2014; Lopes et al., 2015; Musavi et al., 2017; Testad et al., 2014; Yousefi et al., 2014; Yousefi, Sharifi, Tagharrobi, & Akbari, 2015). Conversely, there are other studies that have not demonstrated any statistically significant changes in anxiety scores and/or any clear effects of RT on anxiety (Charlesworth et al., 2016; Woods et al., 2012; Woods et al., 2018). The previous studies which have found that mental health was improved through RT imply that it is a beneficial intervention for PwD. However, in some of these studies, the RT effects were only experienced in the short-term. Therefore, further research is required in order to assess whether participation in RT can have a measurable effect on PwD.

## **1.2.5 Conclusion**

This section has suggested that there are eight functions of reminiscence in four categories including self-proactive/growth (identity and problem-solving); social-proactive/growth (teach/inform and conversation); self-reactive/loss (boredom reduction and bitterness revival); and social-reactive/loss (death preparation and intimacy maintenance). For the purpose of this study, the dimensions of self-proactive/growth and social-proactive/growth

dimensions will be utilised. In order to reduce the likelihood of the program having a detrimental effect on the PwD, the dimensions of self-reactive/loss and social-reactive/loss dimensions will be avoided as well.

It has been found that there are three main types of reminiscence: simple reminiscence, life review, and life review therapy. This research will aim to utilise the simple therapy and life review therapy types of reminiscence to ensure the PwD is successfully guided through their life stages history.

There have been extensive empirical studies investigating the effects of RT on a wide range of outcomes for PwD. This section has listed that there are five main groups of RT impacts for PwD: cognitive functioning, communication and interaction, QoL, behavioural functioning, and mental health. However, there are problems with these studies that include small samples, and a limited number of studies, therefore it is difficult to draw a firm conclusion.

It has been suggested that the traditional RT that uses real materials of memories can have limitations (Gowans et al., 2004; Subramaniam et al., 2014). These limitations can be time consuming and requiring organisation and planning (Gowans et al., 2004). Additionally, RT can be repetitive and stressful for PwD, and requires a supportive environment to implement the intervention (Gowans et al., 2004; Subramaniam et al., 2014).

With advances in technology, the flexibility of digital- touch screen technology can assist and support RT to provide an easy start and user-friendly alternative to traditional RT approaches (Alm & O'Mara, 2001; Gowans et al., 2004; Lazar et al., 2014; Subramaniam et al., 2014). Furthermore, it can facilitate PwD to participate in RT sessions (Sarne-Fleischmann & Tractinsky, 2008b); and help them to engage in meaningful conversation (Alm et al., 2003; Astell et al., 2018; Yasuda, Kuwabara, Kuwahara, Abe, & Tetsutani, 2009). Using digital-touch screen technology to support RT could result in improvements to traditional practices, reduce demands on caregivers, provide a more dynamic reminiscence experience, and improve methods of access to RT content on a more user friendly interface (Lazar et al., 2014; Subramaniam et al., 2014; Yasuda et al., 2009). Moreover, using multimedia in digital-touch screen technology to deliver RT content can produce a great deal of interest and motivation in PwD (Matos, Rocha, Cabral, & Bessa, 2015). Therefore, the next

section will discuss the approach of using digital-touch screen technology to deliver RT for PwD.

## **1.3 Digital-Touch Screen Technology for People with Dementia**

#### **1.3.1 Introduction to Digital-Touch Screen Technology**

For the purpose of this study, digital-touch screen technology can be considered as an electronic visual display that the user can control through simple gestures by touching the screen with one or more fingers (Ros et al., 2016; Sweta, 2015), rather than using a mouse, touchpad, or any other intermediate device. It is sensitive to the touch of a human finger, hand, pointed fingernail and passive objects like a stylus. Users can simply move things on the screen, scroll them, and make them bigger. The popularity of smartphones, tablets, and many types of information appliances is driving the demand and acceptance of common digital portable and functional electronics (Meyyarasu, Dalton, & Abinaya, 2015).

Digital-touch screen technology can have advantages and disadvantages when compared with other input devices that use a mouse or keyboard (Caprani, O'Connor, & Gurrin, 2012). It is easy to learn; requires little thinking, has easier hand-eye coordination than mouse or keyboard; no extra workspace is required as with other pointing devices; and it is durable in public access and high-volume usage (Caprani et al., 2012). In addition, it is more easily available than traditional computers and highly adaptable to personal preferences (Hitch, Swan, Pattison, & Stefaniak, 2017; Joddrell & Astell, 2016). On the other hand, digital-touch screen technology screens need to be used at a lower viewing position and tilted to reduce arm fatigue, there can be some reduction in image brightness, and they tend to be more costly than alternative devices (Caprani et al., 2012).

## **1.3.2 Digital-Touch Screen Technology for Older People**

In recent years, digital technologies are increasingly available and are developing at an accelerated pace (Iancu & Iancu, 2017). However, there are many demographic factors such as ageing which may influence the speed of digital-touch screen technology use (Damodaran

& Olphert, 2015). It has been found that older generations have been relatively slow to adapt to digital-touch screen technology; and have less comfort, efficacy, and control over digital technologies compared to younger generations (Vaportzis, Clausen, & Gow, 2017). In addition, older people may struggle to use these technologies because of their lack of understanding of, and confidence with, how they work, and anxieties about doing something wrong (Age Concern England, 2009; Czaja, 2005; Goodwin, 2013).

In Jordan, no statistical reports on the use of digital-touch screen technology among older people are available. However, 18% of UK citizens are aged over 65 in 2017 (Office for National Statistics (ONS), 2017), and around 78% of people aged 65-74 and 44% over 75, have used digital technologies in particular smartphones (to go online) in 2018 (ONS, 2018). It has been cited that having access to use digital-touch screen technology will help those older people to be socially included in terms of their ability to successfully negotiate the built environment, and independently live and function (Czaja, 2005; Reneland-Forsman, 2018).

Digital-touch screen technology can have many additional advantages for older people, it can support many day-to-day activities such as connecting with friends and family to be socially involved; keeping healthy; living and functioning independently; and financial planning (Czaja, 2005; Iancu & Iancu, 2017; Kerssens et al., 2015; Vaportzis et al., 2017). In addition, it can be used for in-home monitoring and within the health care settings for interactive communication between patients and their physicians (Czaja, 2005; Iancu & Iancu, 2017).

#### **1.3.3 Digital-Touch Screen Technology for People with Dementia**

There is a growing interest in using digital-touch screen technology for PwD. Several studies have shown that the use of digital-touch screen technology is widely accepted by PwD when it has beneficial effects on their communication and QoL (Haron, Sabri, & Ali, 2017; Klein & Uhlig, 2016; Roupa et al., 2010; Subramaniam & Woods, 2016). It can offer sophisticated services that are widely expected to have a role to play in responding to the challenges posed by dementia (Damodaran & Olphert, 2015). In addition, it has been demonstrated that PwD

can participate and provide useful feedback on digital-touch screen technology (Kerssens et al., 2015).

Even though PwD have experience of multiple impairments, they are called upon to adapt to new technology to meet the demands of modern society (Haron et al., 2017). There have been innovative advances in technology that can be used with PwD to support interaction, such as through gaming devices (Lazar et al., 2014). It has been found that using digitaltouch screen technology for PwD will support them to be more socially included within modern society, reduce family stress, and reduce stigma (Hitch et al., 2017; Meiland et al., 2017; Owuor et al., 2018). In addition, digital technologies have many applications that are available to be customised to match personal interests, pursuits, and skills (Hitch et al., 2017).

It is noteworthy that using digital-touch screen technology for PwD can improve their psychological well-being, support engagement in meaningful activities, improve the interaction and relationships between them and their caregivers, and support independent living (Hitch et al., 2017; Lorenz, Freddolino, Comas-Herrera, Knapp, & Damant, 2017; Tyack & Camic, 2017).

However, as mentioned previously, PwD may have some limitations which will influence the access and use of digital-touch screen technology (Joddrell & Astell, 2016; Meiland et al., 2017). Therefore, suitably designed interfaces should be considered during the development of digital-touch screen technology for PwD (Ancient & Good, 2013; Joddrell & Astell, 2016). This designing should consider usability features, accessibility features, and user experience (Ancient & Good, 2013). These issues will be discussed in Chapter 3, section 3.2 as a guideline to develop a suitable interface for PwD.

# 1.4 Digital-Touch Screen Technology in Reminiscence Work for People with Dementia

With improved portability of digital technologies and increases in their capacity, they potential to support reminiscence work (Ancient & Good, 2013; Laird et al., 2018; Subramaniam & Woods, 2016).

The use of digital approaches to delivering RT can provide PwD with opportunities to access, rich and engaging multimedia reminiscence materials (Astell, Ellis, Bernardi, et al., 2010; Elfrink, Zuidema, Kunz, & Westerhof, 2017; Hamel, Sims, Klassen, Havey, & Gaugler, 2016; Ryan et al., 2018), facilitating them to take ownership of conversations, and decreasing the barriers to using technology due to motor deficits during interactions with media (Kerssens et al., 2015; Lazar et al., 2014).

It important to note that PwD may have several limitations experienced when they are using RT applications such as negative attitudes; inaccurate perceptions about digital RT applications; and lack of digital literacy and skills (Kerkhof, Bergsma, Graff, & Droes, 2017; Lorenz et al., 2017; O'Connor, Bouamrane, O'Donnell, & Mair, 2016; Span, Hettinga, Vernooij-Dassen, Eefsting, & Smits, 2013). Therefore, it has been recommended that these RT applications have to be well planned and executed to address these barriers (Lorenz et al., 2017; O'Connor et al., 2016; Ryan et al., 2018).

Although there are many existing applications, software systems, and online websites for social networking provide opportunities to search, gather, and share multimedia resources (Lorenz et al., 2017), there is very little research into the usability of digital-touch screen technology systems for the purpose of reminiscing between PwD (Gibson et al., 2016).

Ryan et al. (2018) have cited that there are few existing projects which have previously used digital-touch screen technology to facilitate RT with PwD. Lazar et al. (2014) and Ryan et al. (2018) have listed these existing projects: the Alive! Project (n.d); Computer Interactive Reminiscence and Conversation Aid (CIRCA) (Alm et al., 2004b); the Computer Assisted

Reminiscence Therapy (CART) project (Pringle & Somerville, 2013); Story Frame (Chen, Lin, & Liang, 2013); lifelogging (Sellen & Whittaker, 2010); and Reminiscence Enhanced Material Profiling in Alzheimer's and other Dementias (REMPAD) (Yang, 2013). These projects will be discussed more in Chapter 3, section 3.1.

These existing RT applications considered only cognitive and communication outcomes. They do not consider other health benefits outcomes such as QoL and psychological wellbeing for PwD; and they do not implement a theory-based RT programme using a digital device for use inside the care home environment.

## Chapter 2 The Impact of Reminiscence Therapy Delivered via Digital-Touch Screen Technology: a Systematic Review

## **2.1 Introduction**

In Chapter 1, theoretical and empirical evidence was presented that supported the need to deliver reminiscence therapy (RT) for people with dementia (PwD) using digital-touch screen technology. In this chapter, a systematic review (SR) will be conducted to review the available evidence of the effects of digital RT on cognitive, communication, depressive symptoms, anxiety, and quality of life (QoL) of PwD. According to the Medical Research Council (MRC) guidance, a systematic review is recommended during the development of an intervention to collate the existing evidence (Craig et al., 2012). Until recently, no systematic review on the impact of RT delivered via digital-touch screen technology for PwD had been published.

Only one SR was conducted by Lazar et al. (2014) that reviewed randomised controlled trial (RCT) and non-randomised control trial (non-RCT) studies of the use of technology for RT, with a focus on different types of information and communication technology (ICT) to examine the applications of ICT to RT. This review suggested that ICT could be used to facilitate RT. In addition, it had some benefits for both PwD and their caregivers including the enjoyment derived by PwD through using multimedia materials; reducing session preparation time; and making available materials possible for a therapist to find on his or her own. However, information may have been missed regarding the description of how RT was delivered in the included interventions and the potential health outcomes to individuals at different stages of dementia. Thus, a synthesis of evidence from other study designs on the impact of RT delivered via digital-touch screen technology on cognitive, communication, depressive symptoms, anxiety, and quality of life (QoL) for PwD is warranted. The significance and research questions of the study will be provided at the end of this SR.

#### 2.2 Review aims

The impact of RT delivered via digital-touch screen technology in PwD is still unclear. Thus, this chapter aims to review the synthesised evidence from RCTs and non-RCTs of the impact of digital RT on PwD. this SR aims to:

- 1. Examine and synthesise the existing interventions using digital RT for PwD
- Examine the impact of RT delivered via digital-touch screen technology on cognitive, communication, depressive symptoms, anxiety, and QoL outcomes for PwD.
- 3. Generate recommendations for the future delivery of digital RT.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Moher, Liberati, Tetzlaff, & Altman, 2009) has guided the undertaking and reporting of this review.

## 2.3 Methods

This section describes the methods used to conduct this review, including the eligibility criteria, data sources and search strategy, study selection, a summary of search strategy, data extraction procedure, quality assessment procedure, data synthesis, and dealing with missing data. This SR was conducted in accordance with Cochrane guidelines (Higgins & Green, 2011).

## 2.3.1 Eligibility Criteria

The eligibility criteria of the study are reported in accordance with the PICOS principles for systematic reviews (Petticrew & Roberts, 2008); Population, Intervention, Comparison, Outcomes, and Study designs.

## 2.3.1.1 Inclusion Criteria

## 2.3.1.1.1 Type of participants

This review includes studies targeting all people with mild, moderate or severe; early or lateonset dementia. Additionally, there was no limitation on participant age to avoid inclusion bias and reduce the selection bias (Torgerson, 2003).

# 2.3.1.1.2 Type of interventions

This review includes the use of digital-touch screen technology to deliver RT– this included tablets, iPads, smartphones, touch screen computer utilising photographs, music, and videos. The interventions are delivered in care homes, day care facilities, social care facilities or people's own homes.

# 2.3.1.1.3 Comparison

This review includes studies that were eligible if comparison groups involved PwD who were not using digital-touch screen technology in RT. Digital RT is compared with any other care methods for dementia.

## 2.3.1.1.4 Outcomes

This review includes cognition, communication, depression, anxiety, and QoL are considered of interest.

# 2.3.1.1.5 Study Designs

This review includes RCTs, quasi-experimental controlled trials, intervention development/pilot testing studies, and non-controlled studies. RCTs refer to studies including an interventional group with digital RT, in which participants were randomly assigned to their group at the beginning. Quasi-experimental controlled trials refer to a controlled or comparison group with no randomisation. Non controlled trials refer to single group studies without a control group. Studies published in peer-reviewed journals. Available in English, with no limitation on the year of publication or length of follow-up is included.

# 2.3.1.2 Exclusion Criteria

The following exclusion criteria were applied:

- Populations with a diagnosis of a mental health disorder or learning disability.
- Digital RT as co-intervention studies whereby RT formed part of a larger treatment package.
- Published in other languages rather than English

## 2.3.2 Data Sources and Search Strategy

An electronic search was conducted using the following databases: CINAHL Plus, PsycINFO, Web of Science, SCOPUS, Cochrane Library, and MedlineS. The final searches were conducted in December 2018. The reference lists of review articles and included studies were also handsearched for eligible studies.

# 2.3.3 Study Selection

Study selection occurred in two phases: Phase 1– Study titles and abstracts were screened for eligibility using the criteria outlined above; Phase 2 – Full texts were obtained for all studies whereby eligibility was either confirmed or unable to be ascertained at Phase 1. All full texts were then checked against the eligibility criteria. The reference lists of included studies were checked for relevant studies.

#### 2.3.4 Search Strategy (Search Terms)

As per guidance Centre for Reviews and Dissemination (CRD) (2009), the search terms were identified through consultation with experts in the topic area. Each term was inserted into the database separately, for example, dementia was inserted alone, then reminiscence alone. According to De Brun and Pearce-Smith (2011), this strategy helps to track the resulting

number of each key term and ease the editing if needed. Then terms were linked by the Boolean operator 'OR' between each element in PICO and the main result of each PICO element was combined with 'and' to reach the final number of articles, titles, and abstracts to be scanned. Table 5 explains the summary of a search strategy that was used in this SR.

# Table 5: Summary of Search Strategy (Search Terms)

PICOS frame work	Population		Intervention		Comparison		Outcome
Key compo nent	people with dementia		Digital technology in reminiscence work		Other care for dementia		Improvement of cognitive impairments Improvement of communication Improvements in depression and anxiety scores Improvements in quality of life
Search terms	exp Dementia/ dementias.mp. (OR) dementias.m_titl. exp (OR) Alzheimer Disease/ Alzheimer.mp. (OR) Alzheimer.m_titl. (OR) Alzheimer's disease.m_titl. (OR) exp Dementia, Vascular/ (OR) Vascular dementia.mp. (OR) Vascular dementia.m_titl. (OR) exp Lewy Body Disease/(OR) Dementia with Lewy bodies.mp. (OR) Dementia with Lewy bodies.m_titl. (OR) exp Frontotemporal Dementia/(OR) Frontotemporal dementia.mp. (OR) Frontotemporal dementia.m_titl. (OR) exp Creutzfeldt-Jakob Syndrome/(OR) Creutzfeldt-Jakob disease.mp. (OR) Creutzfeldt-Jakob disease.m_titl. (OR) exp Korsakoff Syndrome.mp. (OR) Wernicke-Korsakoff Syndrome.mp. (OR)	AND	reminiscence.mp. (OR) reminiscence.m_titl. (OR) reminiscence therapy.mp. (OR) reminiscence work.mp. (OR) reminiscence therapy.m_titl. (OR) reminiscence work.m_titl. (OR) reminisce.mp. (OR) reminisce.m_titl. (OR) memories.mp. (OR) memories.m_titl. (OR) remembrances.mp. (OR) remembrances.mp. (OR) remembrances.m_titl. (OR) recall.mp. (OR) Mental Recall/(OR) recall.m_titl. (OR) Story telling.mp. (AND) exp Technology/(OR) touch screen.mp. (OR) digital.mp. (OR) touch screen.m_titl. (OR) digital.m_titl. (OR) exp Tablets/(OR) tablet.mp. (OR) tablet.mp. (OR) tablet.mp. (OR) tablet.mp. (OR) tablet.mp. (OR) tablet.mp. (OR)	AND		AND	Cognitive (OR) Cognition (OR) Cognitive competence (OR) Cognitive functioning (OR) Memory (OR) Communication (OR) Conversation (OR) Depression (OR) Anxiety (OR) Quality of life

#### 2.3.5 Assessment of Eligibility

In line with the Centre for Reviews and Dissemination (CRD) (2009) guidance, two reviewers, the principal researcher (AA) and a research assistant (MA) independently reviewed abstracts of potentially relevant articles identified from the search in order to improve the reliability of inclusion decisions. When the abstract suggested potential eligibility, the full article was retrieved. Full text eligibility was based on mutual agreement between reviewers (AA and MA) and reasons for exclusion were recorded. Disagreements were presented to a third reviewer (the principal supervisor), who made the final decision to include or exclude the article.

## **2.3.6 Assessment of the Methodological Quality of the Literature**

Appraising the methodological quality of the included studies is essential in SRs (Torgerson, 2003). In order to obtain reliable conclusions from SRs, the reviewers should carefully consider the potential limitations of the included studies by appraising them. This appraising aims to identify the risk of bias and errors of the results, to determine the validity of the research methods, and to evaluate the intervention (Higgins et al., 2011). Using biased studies might provide misleading conclusions (Deeks et al., 2003). Appendix 1 illustrates the major methodological biases adapted from Higgins et al. (2011). In line with Higgins and Green (2011), two reviewers (AA and MA); independently assessed the quality of the studies included within the review in order to avoid bias and improve the reliability of decisions.

## 2.3.7 Data Extraction and Appraisal

Extracted data from primary studies included explicit details about the interventions, comparator, measurement tools, populations, study methods and outcomes of importance to the SR objectives. In order to reduce reviewers' subjectivity in the interpretation of findings and errors, two independent researchers (AA and MA) extracted the data (Higgins & Green, 2011).

#### 2.3.8 Data Synthesis

Data synthesis involves the collation, combination, and summary of the findings of individual studies included in the SR (Boland, Cherry, & Dickson, 2013). Synthesis can be done quantitatively through using formal statistical techniques such as meta-analysis, or if formal pooling of results is inappropriate, through a narrative (CRD, 2009).

The SR encompasses text and tables to provide an initial descriptive summary and explanation of the characteristics and findings of the included studies. Analysis of the relationships within and between studies and an overall assessment of the quality of the evidence is provided. Narrative synthesis is inherently a more subjective process than metaanalysis due to heterogeneity; therefore, the approach used should be rigorous and transparent to reduce the potential for bias (CRD, 2009).

## 2.3.9 Dealing with Missing Data

The authors were contacted twice via email by the principal researcher for clarification of data wherever there was data missing or insufficient detail provided in the report.

#### 2.4 Results

## 2.4.1 Search Results

The search yielded 1250 primary studies. 635 studies were retrieved after duplicates were removed. Of these, 488 were deemed to be irrelevant, and removed following critical examination of titles and abstracts. A full text review of the remaining 148 studies was carried out and a total of 143 studies were consequently excluded because they are not eligible as identified out in Figure 2. Thus, a final selection of 5 studies was identified as suitable for inclusion. A flow chart of this process is presented in Figure 2 by adapting the PRISMA 2009 flow diagram.

When a high level of heterogeneity is observed across the included studies, meta-analyses of studies is not feasible (Haidich, 2010). Therefore, relevant findings, interpretation, and implications for clinical practice and research are presented in narrative form.



#### 2.4.2 Study Design

Four studies used a comparative quasi-experimental design (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010; Laird et al., 2018; Williams et al., 2011) and one used a mixed-method design (Subramaniam & Woods, 2016).

## 2.4.3 Characteristics of Included Studies

A summary of the characteristics of the included studies is given in Table 6. Two of the included studies were conducted in care homes only (Subramaniam & Woods, 2016; Williams et al., 2011), two in both daycare and residential facilities (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010), and one article in social care trust setting (Laird et al., 2018). Four of the included studies shared the aim of looking at the impact of using digital-touch screen technology to deliver RT on the communication abilities of PwD (Astell et al., 2011). One study looked at the impact of using digital-touch screen technology to deliver RT on cognitive competences (Subramaniam & Woods, 2016). One study looked at the impact of using digital-touch screen technology to deliver RT on the included studies looked at the impact of using digital-touch screen technology to deliver RT on QoL (Laird et al., 2018; Subramaniam & Woods, 2016). Four of the included studies were undertaken in the UK (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2018; Subramaniam & Woods, 2016) and one study was conducted in the USA (Williams et al., 2011).

Author (year)	Title	Study Design	Study Aims Setting	Country
Williams, Harris, Lueger et al. (2011)	Visual Cues for Person- centered Communication	Single group pre- post design, non- controlled designs	<ol> <li>To test the feasibility and effects of using automated photo displays to improve staff-resident communication and related outcomes.</li> </ol>	United States of America Kansas City, KS, USA
Astell, Ellis, Alm, Dye, Gowans, Campbell (2005)	Using hypermedia to support communication in Alzheimer's disease: The CIRCA project	Quasi- experimental controlled trial	<ol> <li>To systematically evaluate the usefulness of CIRCA by comparing it with individual RT sessions conducted using traditional reminiscence stimuli.</li> <li>Daycare and residential facilities.</li> </ol>	United Kingdom Scotland
Astell, Ellis, Bernardi et al. (2010)	Using a touch screen computer to support relationships between people with dementia and caregivers	Quasi- experimental controlled trial	<ol> <li>Further explore the utility of CIRCA by examining its impact on:</li> <li>The behaviour of people with dementia,</li> <li>The behaviour of caregivers</li> <li>The interaction between the two.</li> </ol>	United Kingdom Scotland
Subramaniam, Woods (2016)	Using information and communication technology to help older adults with dementia to engage in reminiscence work	Single group pre- post design, non- controlled designs	<ol> <li>To establish an evidence-base for the acceptability and efficacy of using multimedia digital life storybooks with people with dementia in care homes, in comparison with conventional life storybooks, taking into account the perspectives of people with dementia, their relatives, and care staff.</li> </ol>	United Kingdom Wales, Bangor University

# Table 6: A Summary of the Characteristics of Included Studies
Laird et al. (2018)	Using Mobile Technology to Provide Personalized Reminiscence for People Living With Dementia and Their Carers: Appraisal of Outcomes From a Quasi-Experimental Study	Single group pre- post design, non- controlled designs	To measure the effect of technology-enabled reminiscence on mutuality (defined as the level of "closeness" between an adult living with dementia and their carer), quality of carer and patient relationship, and subjective well-being.	A large health and social care trust in a region of the United Kingdom.	UK
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#### **2.4.4 Characteristics of Participants**

A total of 71 participants were enrolled across the included studies all of whom had a clinical diagnosis of dementia. A summary of the participants' characteristics is shown in Table 7. Appendix 4 and Appendix 5 will summarise the characteristics of interventions and comparators. Sample sizes were as follows: six (Subramaniam & Woods, 2016; Williams et al., 2011); 11 (Astell, Ellis, Bernardi, et al., 2010); 18 (Astell et al., 2005); and 30 (Laird et al., 2018). In all studies, the age of participants with dementia ranged from 60 to 95 years. All studies included both men and women.

#### **2.4.5** Characteristics of Intervention

#### 2.4.5.1 Recruitment and Intervention Settings

Residents were recruited from care homes in two studies (Subramaniam & Woods, 2016; Williams et al., 2011), from both daycare and residential facilities in two studies (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010), and from a social care setting in one study (Laird et al., 2018). Three studies reported on recruitment methods by letter invitation and face-toface in the care home (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010; Williams et al., 2011). All interventions in all studies were delivered under supervised conditions.

#### 2.4.5.2 Duration

The duration of the digital RT ranged from a 2-hr recording session (Williams et al., 2011) to 3 days per week for 12 weeks (Laird et al., 2018). Three studies used single group, noncontrolled designs (Laird et al., 2018; Subramaniam & Woods, 2016; Williams et al., 2011); and two studies were controlled studies (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010).

#### 2.4.5.3 *Time and Frequency*

Digital RT sessions varied from 12 minutes (Subramaniam & Woods, 2016) to 2-hr (Williams et al., 2011). The number of sessions was reported in two studies which was 3-4 times

session per week for 4 weeks (Subramaniam & Woods, 2016); and five sessions, 3 days per week for 12 weeks (Laird et al., 2018). While, the other three studies did not report the number or frequency of sessions (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010; Williams et al., 2011).

#### 2.4.5.4 *Type of Reminiscence Therapy*

The interventions included automated digital displays of resident photographs (Williams et al., 2011), Digital Life Storybooks (DLS) (Subramaniam & Woods, 2016), InspirD app (Laird et al., 2018), and Computer Interactive Reminiscence and Conversation Aid (CIRCA) (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010). In all studies, the intervention was personalised, by recollecting personal memories that can be prompted by various stimuli including photographs. Participants could choose their own photographs, which should optimise engagement, and promote person-centred communication (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2018; Subramaniam & Woods, 2016; Williams et al., 2011). In the two studies with a control group, the control participants received traditional RT delivered face-to-face without digital-touch screen technology (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010).

## 2.4.5.5 Fidelity, Adherence, and Acceptability

Fidelity of the intervention, in terms of the delivery of the content, was not mentioned in all studies included in this review. Adherence to digital RT was not reported in any of these five studies (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010; Laird et al., 2018; Subramaniam & Woods, 2016; Williams et al., 2011). Also, the acceptability of digital RT was mentioned only in one study (Subramaniam & Woods, 2016).

## 2.4.5.6 Theoretical Underpinning

No study included in this review referred to any specific theoretical underpinning.

## 2.4.5.7 Adverse Effects

No study included in this review reported any adverse effects of digital RT.

## Table 7: Characteristics of Participants

Author (year)	Sample Size	Age (in years)	Dementia Severity	Inclusion criteria	Intervention Control group	
Williams, Harris, Lueger et al. (2011)	N = 6	70 - 90	MMSE not mentioned	Adequate vision and hearing to allow communication with staff and visualization of the photo frame display and the availability of photographs of historical significance to the resident	Interventional group N= 6 Pre-intervention assessment N= 6	
Astell, Ellis, Alm et al. (2005)	N= 18	65–95	NINCDS-ADRDA criteria for probable Alzheimer's Disease MMSE score 9-23 Average 15.9	Who met the NINCDS-ADRDA criteria for probable Alzheimer's Disease (McKhann et al., 1984)	CIRCA sessions N= 9	traditional reminiscence sessions (TRAD) N= 9
Astell, Ellis, Bernardi et al. (2010)	N= 11	65-95	NINCDS-ADRDA criteria for probable Alzheimer's Disease MMSE score 9-23 Average 15.9	Who met the NINCDS-ADRDA criteria for probable Alzheimer's Disease (McKhann et al., 1984)	CIRCA sessions N= 11	traditional reminiscence sessions (TRAD) N= 11
Subramaniam, Woods (2016)	N= 6	73-89 Average: 82.2	mild to moderate dementia according to Clinical Dementia Rating (CDR)	Mild to moderate dementia living in care homes	Interventional group N= 6 Pre-interventional assessment N= 6	
(Laird et al., 2018)	N= 30	61-94 Mean age : 79	Mild to moderate dementia	Had a diagnosis of early to moderate dementia, Were able to communicate and understand conversations, Were aware of their dementia diagnosis	Pre-post intervo N= 30	ention

## 2.4.6 Effect of Intervention

## 2.4.6.1 Summary of Measures

A summary of the measures and findings of the included studies is given in Table 8.

## 2.4.6.1.1 Engagement and Interpersonal Communication

Three studies measured engagement and interpersonal communication as an outcome of the digital RT (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010; Williams et al., 2011). Williams et al. (2011) used the Minimum Data Set Activities of Daily Living scale. Astell, Ellis, Bernardi, et al. (2010); and Astell et al. (2005) measured the difference in means of Minimum Data Set Activities of Daily Living scale to identify the effects of using CIRCA to enhance communication and relationships by coding the verbal and observational measures. These measures aimed to evaluate the utility of CIRCA in providing an engaging shared activity for PwD and caregivers.

#### 2.4.6.1.2 Memory and Depression

Memory and depression were measured in one study only (Subramaniam & Woods, 2016). Using the Autobiographical Memory Interview (AMI) and Geriatric Depression Scale (Residential) (GDS-12R) respectively.

## 2.4.6.1.3 QoL

QoL was measured in two studies (Laird et al., 2018; Subramaniam & Woods, 2016). Laird et al. (2018) used the World Health Organization–Five Well-Being Index (WHO-5). Subramaniam and Woods (2016) used the Quality of Life-Alzheimer's Disease Scale (QOL-AD).

#### 2.4.6.2 *Summary of Findings*

#### 2.4.6.2.1 Engagement and Interpersonal Communication

Astell, Ellis, Bernardi, et al. (2010) and Astell et al. (2005) reported there was a statistically significant difference between CIRCA and traditional reminiscence sessions mean scores (TRAD), (t(10) = 2.191, p < .05); (z(9) = 2.19, p < .05). However, Williams et al. (2011) reported that there was no statistically significant, clinically meaningful increase in resident engagement, person-centred communication, and reminiscence at two weeks or three months follow-up (z(6) = .85, .73; p = .40, .46).

#### 2.4.6.2.2 Memory and Depression

In Subramaniam and Woods (2016), five of the six participants showed statistical improvement in measures of autobiographical memory (the mean change in AMI =+8.92), and all participants showed improvement in measures of depression scores (the mean change in GDS-12R=-1.84).

## 2.4.6.2.3 QoL

In Subramaniam and Woods (2016), reported that five of the six participants showed statistical improvement in measures of QoL (the mean change in QOL-AD=+3.17). Laird et al. (2018) reported there was a statistically significant increase in subjective QoL scores from baseline to endpoint (P<.001).

## Table 8: A summary of measures and findings

Author (year)	Outcome measure	Outcome measure/ instrument	Analysis techniques	Main Results/ Overall Performance Score	Conclusion
Williams, Harris, Lueger et al. (2011)	Engagement and interpersonal communication	Minimum Data Set Activities of Daily Living scale	Wilcoxon signed ranks test	No statistically significant difference between the task-focused and interpersonal focus group. Clinically meaningful increases in resident engagement, person-centred communication, and reminiscence also occurred (z (6) = .85, .73; p = .40, .46).	Automated photo displays are an easily implemented, low-cost intervention to promote person- centred communication.
Astell, Ellis, Bernardi et al. (2005)	Communication and interaction with caregivers	Observations measures	Wilcoxon signed ranks test	There was statistical difference between the groups. (z(9) = 2.19, p < .05).	The results suggest that CIRCA is engaging and enjoyable for people with dementia and caregivers alike and provides a supportive interaction environment that positively benefits their relationships.
Astell, Ellis, Bernardi et al. (2010)	Communication and interaction with caregivers	Observations measures	T-test	There was statistical difference between the groups. (t(10) = 2.191, $p < .05$ ).	The results suggest that interacting with the touch screen system is engaging and enjoyable for people with dementia and caregivers alike and provides a supportive interaction environment that positively benefits their relationships.
Subramaniam, Woods (2016)	quality of life, autobiographical memory, depression scores,	using the autobiographical memory interview (AMI)	Descriptive analysis	<ul> <li>Five of the six participants showed additional improvement in measures of quality of life and autobiographical memory.</li> <li>All participants showed improvement or stability in depression scores <ul> <li>The mean change in AMI =+8.92)</li> <li>The mean change in GDS-12R=-1.84</li> <li>The mean change in QOL-AD=+3.17)</li> </ul> </li> </ul>	The results suggest that life story movie can reinforce and augment the effects of life review and conventional life storybooks, and that quality of life and autobiographical memory are appropriate outcome measures to consider.
(Laird et al., 2018)	To identify the level of quality of wellbeing (QoL)	World Health Organization– Five Well-Being Index (WHO-5).	ANOVA test	A statistically significant increase in subjective well-being (P<.001) from baseline to endpoint.	Individual-specific reminiscence supported by an iPad app may be efficient in the context of early to moderate dementia

#### 2.5 Quality Assessment of Included Studies

Joanna Briggs Institute (JBI) (2017) was used to ascertain study quality and reflect the most major methodological bias that should be considered while evaluating the quality of studies (see Appendix 2). This tool utilizes nine questions to assess the quality of the methodology design. Although JBI did not define the scoring or weighting of each item (Torgerson, 2003), this review used each item in the critical appraisal tool to help provide better decisions as a novice researcher. Each question is answerable by "yes", "no" or "unclear", every "yes" was allocated one mark, and every "no" or "unclear" with no mark. A total score below five indicates poor quality design, a score of more than five "yes" responses indicates moderate quality, and seven or more "yes" responses indicate high quality.

All studies were judged to be at an unclear answer at least one domain. Four studies were rated moderate quality (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010; Laird et al., 2018; Williams et al., 2011), whereas, one study was rated high quality (Subramaniam & Woods, 2016). Table 9 provides a summary of the risk of bias of selected articles. In addition, Appendix 2 explains the quality score of included studies based on the JBI-MAStARI critical appraisal tool for non-RCTs.

Table 9: Quality score of included studies based on the JBI-MAStARI (2017) critical appraisal tool for non-RCTs

Authors (year)	Astell et al. (2005)	Astell, Ellis, Bernardi, et al. (2010)	Williams et al. (2011)	Subramaniam and Woods (2016)	Laird et al. (2018)
Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Yes	Yes	Yes	Yes	Yes
Were the participants included in any comparisons similar?	Yes	Yes	No	No	No
Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	NO	No	Yes	Yes	Yes
Was there a control group?	Yes	Yes	No	No	No
Were there multiple measurements of the outcome both pre and post the intervention/exposure?	No	No	Yes	Yes	No
Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	Unclear	Yes	Yes	Yes	Yes
Were the outcomes of participants included in any comparisons measured in the same way?	Yes	Yes	Unclear	Yes	Yes
Were outcomes measured in a reliable way?	Yes	Yes	Yes	Yes	Yes
Was appropriate statistical analysis used?	No	No	Yes	Yes	Yes
Total	5	6	6	7	6

**Note**: Rating score is from 1 (lowest) to 9 (highest); Y=Yes; N=No; U=Unclear The quality score was categorized into three groups: Low: 1-4 Moderate: 5-6 High: 7-9

#### 2.6 Discussion

# 2.6.1 The Impact of Using Digital RT on Cognitive, Communication, Depressive Symptoms, and QoL Outcomes for PwD

Four studies found statistically significant improvements in at least one health outcome following digital RT (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010; Laird et al., 2018; Subramaniam & Woods, 2016), with only one study reporting no statistically significant health outcomes (Williams et al., 2011).

It is important to acknowledge these findings, even with bias issues, in order to inform future research. However, interpretation of theses finding must be considered with caution because bias was present in all included studies. The small number of studies, the heterogeneity in measures/outcomes and interventions; and the lack of information about the nature of the interventions mean that it is difficult to draw any firm conclusions.

#### 2.6.2 Characteristics of Existing Studies using Digital RT with PwD

The characteristics of the included studied varied greatly, making synthesis difficult. Interventions varied with regards to the type of RT performed, duration of the intervention, recruitment, frequency, and length of each session.

In all studies, the intervention was personalised, by recollecting personal memories that can be prompted by various stimuli including photographs. The potential for digital RT interventions to promote constant changes in cognitive, communication, depression scores, and QoL outcomes for PwD remains inconclusive, as three studies in this review involved pre and post-intervention evaluation (Laird et al., 2018; Subramaniam & Woods, 2016; Williams et al., 2011).

No study included in this review reported that the intervention had a theoretical underpinning. Without a theoretical underpinning, it is difficult to target the key processes

involved in digital RT (Heath, Cooke, & Cameron, 2015; Wadensten & Hagglund, 2006). In addition, no study mentioned the fidelity, adherence rate to use of digital RT, and adverse effects of intervention delivery.

Additionally, there was heterogeneity in study design and methods. Two studies were controlled studies (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010) and single group pre-post design, non-controlled designs (Laird et al., 2018; Subramaniam & Woods, 2016; Williams et al., 2011).

## 2.6.3 Acceptability of Using Digital RT for PwD

Although it is outside of the scope of this SR to explore the acceptability of using digital touch screen technology to deliver RT, this adds additional context to this study as it uses mixed method research approach. Acceptability and experience of using digital RT were expolred in two included studies (Laird et al., 2018; Subramaniam & Woods, 2016).

In Subramaniam and Woods (2016) found that that using digital touch screen technology to deliver RT was acceptable. This study used semi structured interviews to explore the experience of using digital life storybooks for resident participants, relatives, and care home staff. Thematic analysis showed that all of them viewed digital RT (digital life storybooks) as a very useful tool triggering memories and positive emotions. The main themes were stimulating, triggers memories, enjoyment and feeling good, and encourage conversation. In Laird et al. (2018) reported that using digital touch screen technology to deliver RT was acceptable. However, this study did not mention the the methods of qualitative design, qualitative analysis and themes.

#### **2.6.4 Recommendations for Future Research**

This review found no RCTs exploring the impact of digital touch screen-based RT for PwD. Moreover, there is limited data on acceptability presented and there is substantial variability of settings and ages of participants across the few included studies. Therefore, the findings from this review are summarised into the following recommendations for future research:

- Larger studies are needed to determine whether these interventions have a
  positive effect on cognitive impairment, communication, QoL, memory and
  depression for PwD. Longitudinal research is recommended to focus on collecting
  rigorous outcome data over a significant period of time.
- Interventions should be theory-driven to include elements known to be associated with health outcomes, and QoL improvements and help explain how interventions bring about change. According to Heath et al. (2015), theory-driven interventions will lead to better outcomes. In addition, theories can provide tentative explanations for interventions to be of higher quality when they address more key related factors (Heath et al., 2015).
- Maintenance follow-up data are required to explore whether changes in important outcomes are sustained beyond the intervention period. The principal researcher would recommend doing this in a future RCT beyond the feasibility study.
- The fidelity, adherence rate to use of digital RT, and adverse effects of intervention delivery should be monitored and reported.

## 2.7 Conclusions

Digital RT may have benefits in health and QoL outcomes, but firm conclusions cannot be drawn from the few studies that have been conducted to date. Moreover, this review has found that no RCTs have been undertaken, very little or no data on acceptability presented, the variability of settings and ages of participants. Moreover, heterogeneity in study design and methods remains a barrier to fully understanding the effectiveness of using digital RT for PwD. As such, well-designed RCTs are required to test for effectiveness on health and QoL outcomes.

In conclusion, to the author's knowledge, no previous study has used an evidence-based and theoretically-driven digital RT for PwD. There has also been no previous research into the promotion of sustained digital RT for PwD or the specific factors that influence participation in digital RT in the target population. This thesis will seek to address these shortcomings.

Therefore, there is an urgent need for more research to explore this area. The next chapter of the thesis will illustrate the intervention development to be used in this study.

## 2.8 Significance and Research Questions of the Study

There are many research studies on RT for dementia, and digital-touch screen technology for PwD, however, there are very few studies reporting on the delivery of digital-touch screen RT in PwD, and none have been undertaken in Jordan. Additionally, the existing studies do not consider other psychosocial health benefits outcomes such as QoL and psychological wellbeing for PwD. There is a need to explore the feasibility and acceptability of digital RT with PwD before testing of its clinical effectiveness on health outcomes that include cognitive, communication, depression, anxiety, and QoL.

Therefore, the research questions of this study are as follows:

- 1. Can digital RT be delivered as planned in the care of PwD in Jordanian care homes?
- Is digital RT acceptable/tolerable to PwD and care home staff in Jordanian care homes?
- 3. What are the most appropriate outcome measures to evaluate the delivery of digital RT to PwD in Jordanian care homes to be used in a subsequent definitive trial?

#### Chapter 3 Intervention Development

#### **3.1 Introduction**

The systematic review in the previous chapter demonstrated that regarding the use of theory-based digital-touch screen technology reminiscence therapy (RT) for people with dementia (PwD) to date: none have been implemented in Jordan or Arab countries; few studies have tested the using of digital-touch screen technology to facilitate RT as an intervention for PwD; previous studies have failed to explore the long-term effects of the intervention; no study has been explicitly underpinned by theory; and little attention has been given to potential cognitive function, communication, depression, anxiety, and quality of life (QoL) outcomes for PwD following the delivery of a RT via digital-touch screen technology. Therefore, this research aims to explore the feasibility and acceptability of a theory-based digital-touch screen technology reminiscence intervention for PwD.

The UK Medical Research Council (MRC) guidance emphasises the importance of performing process evaluations alongside the effect evaluation (Craig et al., 2012). In addition, it points to the special challenges that evaluation of complex interventions poses for evaluators (Craig et al., 2012; Datta & Petticrew, 2013). Therefore, this research aligns with the MRC framework for developing and evaluating complex interventions as new guidance (Craig et al., 2012). The MRC will provide guidance on the development, evaluation and implementation of the complex intervention through adherence to the framework below:

**I**. Phase 1 is 'developing a complex intervention phase'. It is important to establish an empirical and theoretical understanding of the given behaviour in the population of interest to the point where it can reasonably be expected to have a worthwhile effect. In this research, Phase 1 will involve:

1. Identifying the evidence base to explore the engagement of PwD with digital-touch screen technology in RT and existing digital reminiscence interventions.

- 2. Identifying the potential appropriate theory in relation to digital-touch screen technology in RT for PwD.
- 3. Modelling process and outcomes which can provide important information about the design of both the intervention and evaluation by qualitative studies with PwD and caregivers to explore the experience of digital-touch screen technology in RT.

II. Phase 2 is 'assessing the feasibility and piloting methods' which is important to test procedures regarding the acceptability and feasibility of recruiting and retaining participants, delivering the intervention, determining sample size, and conducting an evaluation. Figure (3) illustrates the elements of the development and feasibility process.



## Figure 3: The MRC framework adapted from Craig et al. (2012)

Therefore, in order to follow MRC guidance, this chapter aims to develop a digital application to deliver RT for PwD. This chapter illustrates the existing digital reminiscence interventions for PwD, the guidelines to develop a digital interface for PwD, then identifying the potential appropriate theory in relation to digital-touch screen technology in RT for PwD. In addition, this chapter will report the design of developing the RT application. The next section will discuss the existing digital RT application projects before starting the development process to identify the gaps in these RT applications.

#### 3.1.1 Existing Technologies to Support Reminiscence Therapy

As mentioned in Chapter 1; section 1.4, Ryan et al. (2018) and Lazar et al. (2014) have reviewed the existing projects which have previously used digital-touch screen technology to facilitate RT with PwD. These existing projects include the Alive! Project (n.d); Computer Interactive Reminiscence and Conversation Aid (CIRCA) (Alm et al., 2004b); the Computer Assisted Reminiscence Therapy (CART) project (Pringle & Somerville, 2013); Story Frame (Chen, Lin, et al., 2013); lifelogging (Sellen & Whittaker, 2010); and Reminiscence Enhanced Material Profiling in Alzheimer's and other Dementias (REMPAD) (Yang, 2013). This section highlights these projects which could be related to the outcomes of this project and evaluate them to identify the gaps in these digital RT applications.

## 3.1.1.1 Lifelogging System

The lifelogging system project utilised a wearable sensor in order to produce a digital archive of personal daily interactions to support memory for PwD (Sellen & Whittaker, 2010; Whittaker et al., 2012). There are two main classes of lifelogging system: total capture, and situation-specific capture (Sellen & Whittaker, 2010). Total capture involves a camera that takes regular images, videos, and sounds throughout the day to record everyday life (Sellen & Whittaker, 2010). In contrast, situation-specific capture will be only taking photographs when particular conditions are met to record of specific activities in particular places (Sellen & Whittaker, 2010). From reminiscence purposes, it could help PwD to re-live past experiences by evoking memories which are stored in the long-term memory for PwD (Sellen & Whittaker, 2010; Whittaker et al., 2012).

#### 3.1.1.2 The Computer Interactive Reminiscence and Conversation Aid Project (CIRCA)

The CIRCA project is an interactive multimedia software application was developed to implement RT via using a desktop touch screen device in order to support and promote communication between PwD and their caregivers in Dundee, and Scotland (Alm et al., 2004a; Astell et al., 2018; Smith & Astell, 2018). This CIRCA project utilised generic memory prompts including photographs, video and music recordings that could support PwD to participate in meaningful social interactions with caregivers within care homes (Astell et al., 2009; Astell et al., 2018).

An iterative design process with PwD was utilised to develop this application (Alm et al., 2004b; Astell et al., 2009). This iterative design process helped to produce a well-developed programme at each iteration to increase its impact (Alm et al., 2007; Astell et al., 2009). This project highlighted the importance of ease of use regarding touch screen technology to deliver RT for PwD to become actively involved in the reminiscence process (Pringle & Somerville, 2013).

It has been found that PwD enjoyed physically interacting on their own even they did not have any technical skills on computer technology in the CIRCA project (Astell et al., 2018; Gowans et al., 2004). However, this CIRCA project was associated with ergonomic problems such as loss of engagement which could occur when setting in a wrong position while using the touch screen (Gowans et al., 2004). In addition, this project was associated with problems of lack of portability (Pringle & Somerville, 2013).

#### 3.1.1.3 The Computer Assisted Reminiscence Therapy project (CART)

Building on the CIRCA project, the CART project used a mobile tablet computer technology to deliver both generic and personalised RT sessions for four PwD in Nottinghamshire care settings (Pringle & Somerville, 2013). This project eliminated the problem of lack of portability associated with the CIRCA project to be done in any care setting with PwD.

It has been found that using the digital-touch screen technology to deliver RT encouraged PwD to be engaged in conversations and improved their ability to recall information about the memory prompt (Pringle & Somerville, 2013). However, this project demonstrated that it is possible to deliver RT via a mobile tablet device, the effect of using digital-touch screen technology to deliver RT was not considered. In addition, this intervention was not a theorybased.

## 3.1.1.4 Story Frame

Story Frame project utilised digital-touch screen technology to deliver RT by sharing the recorded audio-photos of the past (Chen, Lin, et al., 2013). It has been found that this project can trigger further conversations by establishing self-identity, improving social connectedness and creating feelings of well-being.

This research employed a two-year qualitative approach to obtaining an in-depth and holistic understanding of reminiscing in the elderly. However, there is little consideration for the effect that it has on especially for PwD. In addition, this intervention was not theory-based. Moreover, this project did not consider the quantitative results to measure the effects of digital RT on communication and interactions.

# 3.1.1.5 *Reminiscence Enhanced Material Profiling in Alzheimer's and other Dementias* (*REMPAD*)

REMPAD is a software system designed to facilitate group RT for PwD (Yang, 2013). This project utilised the publicly accessible videos from the Internet (e.g. YouTube) based on the group participants' profile, interests and hobbies. It has been found that this project can indicate high user satisfaction when using the system, and a strong tendency towards repeated use in the future. This project was designed in 3 phases: exploratory interview, lowfidelity prototype test, then the field evaluation (Yang, 2013). However, this intervention was not theory-based. In addition, there is no consideration for the effects that it has on the PwD and their caregivers.

#### 3.1.1.6 *The Alive Project*

The Alive project is the UK's leading charity enriching the lives of older people living in care homes and training their caregivers (n.d). This project established the potential for using iPad images, music and multi-sensory prompts to encourage the conversation and help older people living in care homes to reconnect with their interests (n.d). However, the focus of the project was to deliver RT via iPads for older people in general, rather than with PwD. In addition, this intervention was not theory-based. Moreover, it lacks a grounding in research.

#### 3.1.2 Gap in Existing Digital Reminiscence Projects

Most of the existing projects which are discussed in this section have implemented RT using digital devices; however, little attention has been given to potential cognitive function and communication outcomes for PwD following the delivery of RT via digital-touch screen technology. Moreover, they do not consider other health benefits outcomes such as QoL and psychological wellbeing for PwD. Moreover, these projects did not mention the issues which need to be considered when developing technological interventions for older people. Furthermore, these projects do not implement a theory-based RT programme using a digital device. The explicit use of theory-based intervention may offer a number of advantages, such as designing interventions, providing a generalisable framework for predicting and interpreting behaviour and explaining how interventions bring about change (Clemson et al., 2018; Foy et al., 2007). Moreover, using theories can provide tentative explanations for interventions to be of higher quality when they address more key related factors (Heath et al., 2015).

In this project, a theory-based approach will be used to develop a RT programme that will be implemented on a digital device. The aim of utilising this theory-based approach is to support the engagement of PwD and caregivers in RT activities inside the care home environment. It is asserted that theory-driven intervention will lead to better outcomes, and can provide tentative explanations for interventions to be higher quality when they address more key related factors (Heath et al., 2015). In addition, PwD's special needs will be considered when

developing technological interventions for older people in this project. Thus, the next section will discuss the method of the development process.

## 3.2 Method

This section will illustrate the method of the development process. Firstly, the guidelines to develop a digital interface for PwD will be explained, then the potential appropriate theories in relation to digital-touch screen technology in RT for PwD will be identified. In addition, the design of developing the RT application will be reported.

#### 3.2.1 Guidelines to Develop Interface for PwD

In order to ensure that the digital RT application is usable for PwD, the specific needs for PwD must be considered when developing technological interventions. The following section will focus on the requirements that must be considered throughout the development process for interaction design. Four areas of requirements include: accessibility, user experience, usability, and user acceptance will be demonstrated in this chapter.

#### 3.2.1.1 Accessibility

Many changes that may affect older people should be considered during designing digital interfaces (Diaz-Bossini & Moreno, 2014; Hertzum & Hornbk, 2010). It has been reported that the mental and physical condition of older people will be impaired as they age (Boontarig, Chutimaskul, Chongsuphajaisiddhi, & Papasratorn, 2012; Chou, Lai, & Liu, 2013; Guthrie et al., 2018; Hwang, Hong, Hao, & Jong, 2011). These challenges need to be considered to address when developing and implementing a digital interface for older people in general and PwD in particular as interaction can be negatively affected (Chou et al., 2013; Diaz-Bossini & Moreno, 2014; Hertzum & Hornbk, 2010; Wallace, Graham, & Saraceno, 2013; Wandke, Sengpiel, & Sonksen, 2012).

The sensory and cognitive abilities of older people which change are often broadly categorised into four impairment areas: cognitive, motor, auditory, and visual (Albers et al.,

2015; Caprani et al., 2012; Guthrie et al., 2018; Thompson & Mayhorn, 2012). This section discusses the key factors relating to each of the four impairment areas. In addition, suggestions for interaction adaptations to have potential benefits for older people will be made.

#### 3.2.1.1.1 Motor Impairment

Motor skills become increasingly impaired for older people as they age (Hoogendam et al., 2014; Mohadis & Ali, 2014; Seidler et al., 2010; Wallace et al., 2013; Wandke et al., 2012; Wong, Thwaites, & Khong, 2010). This motor skills impairment with ageing occurs due to a decrease in circulatory capacity accompanied by a degenerative loss of skeletal muscle performance resulting in a reduction in motor coordination (Tieland, Trouwborst, & Clark, 2018). In addition, a person's motor abilities in older people will be further reduced by many physical conditions such as Parkinson's disease and arthritis (Bouca-Machado, Maetzler, & Ferreira, 2018; Charness & Boot, 2009; Piper, Campbell, & Hollan, 2010; Taveira & Choi, 2009; Wallace et al., 2013). This restriction in motor abilities can have a detrimental effect on the using of and interaction with technology by older people (Charness & Boot, 2009; Chen & Chan, 2013; Chen & Chan, 2011; Piper et al., 2010; Taveira & Choi, 2009; Wallace et al., 2013). PwD will experience the natural motor abilities decline which is associated with ageing.

Motor skills are broadly classified into gross and fine skills (Bremer & Cairney, 2018). Gross motor skills use the large muscles in the body and include broader movements such as walking and jumping (Bremer & Cairney, 2018). Whereas, the fine motor skills are those that require a high degree of control and precision in the small muscles of the hand (Bremer & Cairney, 2018). A reduction in the fine motor abilities is often associated with ageing (Hwang et al., 2011; Piper et al., 2010; Taveira & Choi, 2009; Taylor et al., 2014; Wallace et al., 2013; Wong et al., 2010). These fine motor impairments make it difficult for older people to perform precise movements, particularly when using a mouse (Meza-Kubo & Moran, 2013; Taveira & Choi, 2009; Taylor et al., 2010). In order to alleviate this

problem, it has been suggested that designs operating should not require any precise mouse movements (Wagner, Hassanein, & Head, 2010). Furthermore, it is recommended that buttons should not share a common boundary to reduce the number of missed presses as a result of impaired fine motor control (Biswas, Robinson, & Langdon, 2011).

In addition to a decline in fine motor ability, older people will also experience a reduction in steadiness hand dexterity with aging (Caprani et al., 2012; Hart, Chaparro, & Halcomb, 2008; Martin, Ramsay, Hughes, Peters, & Edwards, 2015; Williams, UI-Alam, Ahamed, & Chu, 2013; Wong et al., 2010). This decline can lead to difficulty with finding and using the small buttons on digital interfaces (van-Veldhoven, Vastenburg, & Keyson, 2008). Therefore, it has been suggested that the buttons should be designed to be bigger to avoid this problem (Biswas et al., 2011; Charness & Boot, 2009; Mohammed, Ibrahim, & Cavus, 2018; Wong et al., 2010). Furthermore, it is recommended to increase the target area in which the person is required to press for the click (Lam & Chung, 2009).

Moreover, a person's muscle strength and control will decline as a result of the ageing process (Barnard, Bradley, Hodgson, & Lloyd, 2013; Charness & Boot, 2009; Lam & Chung, 2009; Taveira & Choi, 2009). These declines can lead to difficulty with controlling movement (Chen & Chan, 2011; Wallace et al., 2013); slower response times (Pijukkana & Sahachaisaeree, 2012; Taveira & Choi, 2009; Wallace et al., 2013); and a reduced ability to control the forces they apply (Naumann, Wechsung, & Hurtienne, 2010). There is a distinct lack of discussion relating to how these problems can be alleviated through the interface or interaction design. However, this study will aim to use user-paced, or have longer time out periods to mitigate any negative effects due to slower response times.

## 3.2.1.1.2 Cognitive Impairment

Older people generally experience a decline in their cognitive skills (Chou et al., 2013; Higgins & Glasgow, 2012; Li, Rau, Fujimura, Gao, & Wang, 2012; Miller, Gagnon, Talbot, & Messier, 2013; Mohadis & Ali, 2014). In addition, this decline is accentuated by a dementia condition for PwD (Higgins & Glasgow, 2012). This cognitive impairment makes using and

interacting with technology very difficult (Boontarig et al., 2012; Or & Tao, 2012; Williams et al., 2013).

Older people often experience a decline in their memory (Charness & Boot, 2009; Chou et al., 2013; Higgins & Glasgow, 2012; Pijukkana & Sahachaisaeree, 2012; Piper et al., 2010; Wallace et al., 2013). For PwD, the memory impairments will be worsened due to the nature of the dementia condition (Mahmud et al., 2010). Thus, this decline in memory needs to be mitigated to support PwD to interact with new technology (Mahmud et al., 2010). In order to achieve that, it is recommended to reduce the memory load (Hwang et al., 2011) by using cognitive cues (Etcheverry, Terrier, & Marquie, 2012; Wagner et al., 2010), or transferring the need to remember items from the person to the technology (Higgins & Glasgow, 2012). These things will reduce the reliance on memory impairments, and allow older people to successfully interact with the technology.

Short term memory loss is considered to be one of the primary symptoms associated with dementia (Langdon & Thimbleby, 2010), which makes interacting with and using technology very challenging for PwD (Mahmud et al., 2010). This decline in short term memory will lead to users having difficulty in recalling whether they have encountered information previously (Etcheverry et al., 2012). Therefore, in order to reduce the short term memory load, it is recommended to minimise the amount of information which is required to be remembered (Or & Tao, 2012).

It has been found that older people can store fewer items in working memory than those who are younger (Chevalier, Dommes, & Martins, 2013; Wong et al., 2010), and this limits the number of steps which could be remembered by the user (Higgins & Glasgow, 2012; Wong et al., 2010). Therefore, it is suggested that all information relating to manipulation is displayed on the screen to aid the users (Higgins & Glasgow, 2012).

Moreover, the processing speed by which older people can process information will decrease with ageing due to limited resources for processing (Burns, Jones, Iverson, & Caputi, 2013; Chen & Chan, 2011; Wallace et al., 2013; Wandke et al., 2012). This results in increased

reaction time between a stimulus and the response (Chou et al., 2013; Mertens, Brandl, Przybysz, Koch-Korfges, & Schlick, 2012; Pijukkana & Sahachaisaeree, 2012). In order to mitigate the deteriorated processing speed effect, it is recommended to leave adequate time between the end of instruction and the beginning of the task (Reeder, Zaslavksy, Wilamowska, Demiris, & Thompson, 2011; Wong et al., 2010).

However, there is a large diversity in the abilities of older people that makes deciding on an appropriate time allowance difficult (Ancient & Good, 2013; Miller et al., 2013; Wallace et al., 2013). To manage this challenge, it has been suggested to eliminate the need for a specific time to complete a task by using a user-paced system (Ancient & Good, 2013).

Moreover, the way that an older person can interact with technology will be affected by a reduced ability to inhibit irrelevant information (Ancient & Good, 2013; Chevalier et al., 2013; Higgins & Glasgow, 2012; Hwang et al., 2011). This will increase the dependence on selective attention in order to compensate for their inability to ignore any distracting details (Chen & Chan, 2011). In general, it has been suggested that interfaces should be simplified with a simple and plain background (Ancient & Good, 2013; Hwang et al., 2011).

Another consequence of ageing is the difficulty to distinguish between relevant and irrelevant details (Ancient & Good, 2013; Chen & Chan, 2011; Wandke et al., 2012). This may lead them to remember the irrelevant details and thus minmise the effect of RT (Wandke et al., 2012). Thus, it has been suggested that any irrelevant details for the current task should be removed from the view (Higgins & Glasgow, 2012), and those relevant stimuli should be made more salient (Chevalier et al., 2013; Hara & Kashimura, 2010).

Furthermore, older people may experience a reduced learning speed and the ability for skills accomplishment (Higgins & Glasgow, 2012; van-Veldhoven et al., 2008; Wallace et al., 2013; Wandke et al., 2012). Moreover, the plasticity of the brain for older people will be reduced, making it is difficult to integrate new learning with existing knowledge (Wandke et al., 2012). However, it has been highlighted that the capacity to learn does not decrease (Renaud, Karen, Biljon, & Judy, 2008). Therefore, it is recommended that the interfaces should be

planned and designed to provide a quick to learn and easy to understand interaction to compensate for the reduced learning speed for older people (Piper & Hollan, 2013; Wagner et al., 2010).

#### 3.2.1.1.3 Visual Impairment

As the natural ageing process, older people can have conditions which have a detrimental effect on the visual abilities of a person, such as age-related macular degeneration (Zhou, Rau, & Salvendy, 2012). Therefore, older people will also experience a decline in their visual abilities (Chen & Chan, 2011; Hart et al., 2008; Mohadis & Ali, 2014; Or & Tao, 2012; Pijukkana & Sahachaisaeree, 2012; Taylor et al., 2014; Wallace et al., 2013; Zhou et al., 2012). This visual impairment makes interacting with technology difficult for older people (Chou et al., 2013; Pijukkana & Sahachaisaeree, 2012; Renaud et al., 2008). With most devices often relying on graphical or text-based interfaces (Chen & Chan, 2011). Therefore, it is important to consider the needs of older people with regards to their decline in visual abilities when designing interfaces for them (Chou et al., 2013; Mohadis & Ali, 2014; Pijukkana & Sahachaisaeree, 2012; Renaud et al., 2013; Mohadis & Ali, 2014; Pijukkana & Sahachaisaeree, 2012; Renaud et al., 2013; Mohadis & Ali, 2014; Pijukkana & Sahachaisaeree, 2012; Renaud et al., 2013; Mohadis & Ali, 2014; Pijukkana & Sahachaisaeree, 2012; Renaud et al., 2013; Mohadis & Ali, 2014; Pijukkana & Sahachaisaeree, 2012; Renaud et al., 2013; Mohadis & Ali, 2014; Pijukkana & Sahachaisaeree, 2012; Renaud et al., 2008; Tseng, Hsu, & Chuang, 2012).

Ageing will be associated with a decline in visual acuity in which the person is able to perceive small details (Charness & Boot, 2009; Chen & Chan, 2011; Chiu & Liu, 2017; Mohadis & Ali, 2014; Taveira & Choi, 2009; Tseng et al., 2012; Vetter, Butzler, Jochems, & Schlick, 2012; Wallace et al., 2013; Wandke et al., 2012; Williams et al., 2013; Wong et al., 2010). Therefore, in order to counteract the effects of this problem, it is recommended that the interfaces should be designed to provide the ability to make the interface items larger (Chen, Lin, et al., 2013; Hou, Dong, Ning, & Han, 2018; Mohadis & Ali, 2014; Or & Tao, 2012; Vetter et al., 2012; Williams et al., 2013; Wong et al., 2013; Nong et al., 2010). In addition, the users could be provided with the opportunity to resize objects to suit their vision (Hou et al., 2018; Reeder et al., 2011).

As a result of increasing age, older people will also experience a reduced in the sensitivity to contrast (Burns et al., 2013; Crossland & Rubin, 2012; Piper et al., 2010; Williams et al.,

2013; Wong et al., 2010; Zhou et al., 2012). This results in older people struggling to distinguish the different elements and buttons on an interface (Ali, Norizan, & Shahar, 2013). In addition, it results in difficulties to read the text (Crossland & Rubin, 2012). Therefore, in order to alleviate this problem, it is recommended to increase the size of the elements and buttons (Ali et al., 2013; Hou et al., 2018; Hwang et al., 2011; Mohammed et al., 2018; Santa-Rosa & Fernandes, 2012). Moreover, it is recommended to choose the used colours carefully to ensure a high contrast between the background colour and the foreground text (Fromme, Kenworthy-Heinige, & Hribar, 2011; Wong et al., 2010). This will improve the readability of the interface (Ali et al., 2013; Fromme et al., 2011; Hwang et al., 2011; Wong et al., 2010).

Moreover, the lens in people's eyes will turn slightly yellow and darken as they age (Fromme et al., 2011). This darkening and yellowing of the lens result in older people struggling to distinguish the colours which only have differences in the blue content (Chou et al., 2013; Fromme et al., 2011). Therefore, a reduction in ability to perceive differences in colour is also experienced as a result of increasing age (Ali et al., 2013; Chen & Chan, 2011; Fromme et al., 2010; Vetter et al., 2012; Wallace et al., 2013; Wong et al., 2010). In order to ensure colour differences are easily recognisable, it is suggested to utilise the primary colours in interface design with a focus on reds and yellows (Fromme et al., 2011). In addition, it is recommended to use bright colours instead of dark colours which are considered tiring by older people (Ali, Shahar, Kee, Norizan, & Noah, 2012)

#### 3.2.1.1.4 Auditory Impairment

Older people will also experience a decline in their auditory abilities (Chen & Chan, 2011; Mohadis & Ali, 2014; Williams et al., 2013; Wong et al., 2010). Their hearing abilities will decrease as they age (Burns et al., 2013; Chen & Chan, 2011; Mahmud et al., 2010; Mohadis & Ali, 2014; Pijukkana & Sahachaisaeree, 2012; Piper et al., 2010; Taylor et al., 2014; Wallace et al., 2013; Williams et al., 2013). Therefore, it is important to consider the needs of older people with regards to their hearing loss when designing interfaces for them (Burns

et al., 2013; Mohadis & Ali, 2014; Pijukkana & Sahachaisaeree, 2012; Taylor et al., 2014; Wong et al., 2010). In order to counteract the effects of this problem, it is recommended to utilise the ability to increase the volume sound of any interaction elements (Chen & Chan, 2013; Williams et al., 2013). In contrast, other research found that older people are less tolerant and more sensitive to loud sounds (Ali et al., 2013; Wallace et al., 2013). Therefore, it is recommended that the older users should be able to adjust the volume levels to suit them, which could consider the careful balance needs to be struck between a volume which is sufficiently loud enough to be heard, whilst not proving uncomfortable (Williams et al., 2013).

Moreover, older people will start their auditory decline with higher frequency tones as they age (Charness & Boot, 2009; Chen & Chan, 2011; Wallace et al., 2013; Williams et al., 2013), then gradually move to the middle range frequencies (Langdon & Thimbleby, 2010). Therefore, it is prefered to utilise lower frequency tones (Lam & Chung, 2009).

Furthermore, hearing in older people is further reduced in a noisy environment (Charness & Boot, 2009; Chen & Chan, 2011; Wong et al., 2010). Thus, they will be unable to differentiate between the foreground sound and background distractions that make the inability to keep up with conversations for older people (Ali et al., 2013; Wong et al., 2010). For PwD, keeping up with conversations will be worsened due to the nature of the dementia condition. Therefore, it is recommended that background noises should be minimised where possible such as wearing headphones in order to block out the unnecessary sounds, encouraging the person to focus on the interface, and supporting their conversations (Charness & Boot, 2009; Wallace et al., 2013; Waniek, 2008; Wong et al., 2010).

#### 3.2.1.2 Usability

Usability can be defined as the extent to which a system or product can be used to achieve specified goals with efficiency, effectiveness and satisfaction by specified users in a specified context of use (Bevan, Carter, Earthy, Geis, & Harker, 2016; Holthe, Halvorsrud, Karterud, Hoel, & Lund, 2018). Therefore, the focus of this section is to ensure that PwD are able to use the developed system with efficiency, effectiveness and satisfaction. Holthe et al. (2018)

in their systematic review found there is now a greater emphasis on developing designs to be usable and useful which matches the needs of PwD. It has been found that poor design leads PwD to encounter difficulties (Castilla et al., 2013). Therefore, these difficulties can be alleviated and, in some cases eliminated through considering the usability of a design.

#### 3.2.1.2.1 Ease of Use

It has been found that older people tend to struggle with using digital-touch screen technology easily compared to younger generations (Naumann et al., 2010; Or & Tao, 2012; Vaportzis et al., 2017). These difficulties include text messaging (Ji et al., 2010), turning the device on and off (Barnard et al., 2013), and interactions being more challenging to work out than perform (Piper et al., 2010). Therefore, it is recommended to use the interfaces which are easy to operate (Hwang et al., 2011; Taylor et al., 2014) and provide simple layouts to reduce the demands on older people users (Charness & Boot, 2009; Chou et al., 2013; Hart et al., 2008; Hwang et al., 2011; Lam & Chung, 2009; Or & Tao, 2012; Williams et al., 2013).

In order to simplify the interface, it has been suggested to ensure that each screen should only complete one task if it is to be used by PwD (Chan, Wong, Lee, & Chi, 2009; Orpwood et al., 2009). Whilst this could be a useful idea, it would be only effective in circumstances where the task to be completed that allowed this. However, this one control per screen suggestion would not be possible to implement and achieve the desired functionality in situations where the user can either go forwards or backwards in the interface. Therefore, whilst simplicity is an important point, it is important to ensure that users are still able to complete all the tasks they need and wish.

## 3.2.1.2.2 Ease of Understanding

It has been found that older people may have difficulties to understand technology particularly in relation to applications (Arning & Ziefle, 2009; Chen & Chan, 2014; Chiu & Liu, 2017; Hwang et al., 2011; Xue et al., 2012). Therefore, it is recommended to develop

interface applications to be easy for beginner users to understand (Langdon & Thimbleby, 2010). This can be achieved by presenting the information on the system in a manner which is easy to understand and eliminates any ambiguity for the user (Taylor et al., 2014). Furthermore, it is recommended to provide the users with visibility of the actions carried out by the digital-touch screen technology in order to make the system more transparent to them (Ali et al., 2012). In order to complement the system transparency, it is suggested to provide the user with information relating to the functionality provided by buttons (Hwang et al., 2011).

It has been found that the utilising unfamiliar technological terminology was a major source of difficulty in understanding technology for older people (Ancient & Good, 2013; Castilla et al., 2013; Or & Tao, 2012; Wandke et al., 2012). This results in increasing intimidation feelings (Hakkarainen, 2012), and increasing levels of confusion (Barnard et al., 2013; Williams et al., 2013). Therefore, in order to overcome this problem, it is recommended to use the plain, simple, and non-technical language during the interaction process (Ali et al., 2012; Miller et al., 2013; Williams et al., 2013). This simple language will provide beginner older users the opportunity to understand the function easily (Ali et al., 2012; Waniek, 2008).

As mentioned before, PwD have difficulty in finding the most appropriate word and understanding the new technical terminology (Ancient & Good, 2013). Therefore, it is recommended to use familiar and simple words rather than unfamiliar and complicated terminology when designing and developing interface applications for PwD (Castilla et al., 2013).

#### 3.2.1.2.3 Intuitiveness

Intuitiveness means the use of familiar design which is easy to understand, regardless of the user's knowledge, experience, concentration level or language skills (Rowland, Goodman, Charlier, Light, & Lui, 2015). It is suggested that utilising the intuitive interface will counteract an older person's unfamiliarity with technology (Barnard et al., 2013; Langdon & Thimbleby, 2010; Meza-Kubo & Moran, 2013). In addition, it results in the required action to

be easily and naturally presenting itself to the user (Barnard et al., 2013; Israel et al., 2009). Therefore, the use of intuitive interface will improve the usability of the device (van-Veldhoven et al., 2008). In addition, the users will be able to know exactly how to interact with the system from the moment they see the screen subconsciously (Gudur, Blackler, Popovic, & Mahar, 2014; Israel et al., 2009).

It has been suggested that through using intuitive interface, the technology device becomes invisible to the users allowing them to focus on the required task to complete (Castilla et al., 2013). In addition, older people can become distracted easily, therefore, using an intuitive interface will be particularly important for them to reduce the possibility of distractions from the interface (Chevalier et al., 2013; Hart et al., 2008; Li et al., 2012; Williams et al., 2013). Moreover, it has been suggested to match between the interfaces and the real world to increase the intuitiveness for the user (Or & Tao, 2012). As an example, placing the previous button on the right-hand side of the screen and the next on the left would match interfaces to the real world and increase the intuitiveness (Money, Fernando, Lines, & Elliman, 2009).

## 3.2.1.2.4 Task Performance

Older people often experience that there is very little time between the end of an instruction and the beginning of the task commencing (Reeder et al., 2011), resulting in an increase in time taken to complete the task (Chen, Chan, & Tsang, 2013; Chevalier et al., 2013; Li et al., 2012; Reeder et al., 2011; Wagner et al., 2010). In addition, they tend to prioritise accuracy over speed (Piper et al., 2010). These points lead them to experience poorer task performance in comparison with younger people (Chen, Chan, et al., 2013; Miller et al., 2013; Wagner et al., 2010). However, in order to counteract this effect, it is recommended to allow older people to control the pace of their interaction and process information which results in improving their performance as well as younger people (Gilly, Celsi, & Schau, 2012). Additionally, in order to allow older people to interact at their own rate, it has suggested that no responses are time-limited (Ancient & Good, 2013).

It has been suggested that well-defined tasks should be utilised when designing technology interactions that lead to slower completion speeds (Chevalier et al., 2013). Therefore, it is recommended to slow down the interaction speed through an increase the amount of time required can be catered for (Chan et al., 2009; Piper et al., 2010).

A large number of cognitive resources are required to search for information and process the results (Chevalier et al., 2013). Therefore, older people tend to struggle with diminished search performance (Chevalier et al., 2013; Miller et al., 2013), including regular unsuccessful attempts to find the information they need (Hart et al., 2008) and slower speeds of search (Hasegawa, Miyao, Matsunuma, Fujikake, & Omori, 2008). In addition, older people are at increased risk of forgetting the information already gained, and ultimately, the purpose of their search (Chevalier et al., 2013). This will be particularly challenging for PwD, as short term memory loss is one of the primary symptoms associated with dementia (Langdon & Thimbleby, 2010). Therefore, it is recommended to clearly display all required information within the interface to alleviate this effect to improve their search performance (Hwang et al., 2011).

## 3.2.1.2.5 Readability

Readability means how readable materials can be read and understood for a sustained period (Zamanian & Heydari, 2012). It will depend on several factors including the visual abilities (Castilla et al., 2013; Chen, Chan, et al., 2013); the number of new words contained and the average sentences length (Zamanian & Heydari, 2012); the size and shape of a font (Chen, Chan, et al., 2013; Hou et al., 2018; Lam & Chung, 2009), and density of text (Ancient & Good, 2013; Hwang et al., 2011). Therefore, older people will often encounter readability issues with text (Castilla et al., 2013; Chen, Chan, et al., 2013), resulting in a higher likelihood of errors (Hasegawa et al., 2008).

It has been often found that older people find that text is too small for them to read easily (Ali et al., 2012; Chen, Chan, et al., 2013; Hasegawa et al., 2008; Wagner et al., 2010). In addition, the high density of text will increase an older person's response times because it will

interfere with the fluency of reading (Hwang et al., 2011). Therefore, in order to combat these issues, it has been suggested that large fonts should be used (Ali et al., 2012; Chen, Chan, et al., 2013; Hasegawa et al., 2008; Mohammed et al., 2018; Wagner et al., 2010), and reducing the density of text to improve the readability (Ancient & Good, 2013; Hwang et al., 2011). Furthermore, it is suggested that limiting the number of words per page (Hwang et al., 2011), and appropriate use of colour and headings (Burns et al., 2013) should be used to maximise the benefit for older adults.

#### 3.2.1.2.6 Navigation

Older people tend to struggle with using navigation during interface interaction, particularly when the navigation requires the use of spatial abilities which decline in old age (Hwang et al., 2011; Lin, Neafsey, & Strickler, 2009; Vetter et al., 2012). Therefore, it is recommended to design the navigation to be easy for older people to use (Wallace et al., 2013). In addition, it should be intuitive to support interaction with the system (Ji et al., 2010).

It has been listed that navigation styles could be hierarchy-based or tag-based systems(Lee et al., 2018; Pak, Price, & Thatcher, 2009). The hierarchy-based system which uses navigating through clustered topics, can hamper performance and counter-productive for older people (Arning & Ziefle, 2009; Lee et al., 2018). Tag-based systems which use free search, utilises the crystallised intelligence and vocabulary which has increased rather than diminished as people aged (Chevalier et al., 2013; Lee et al., 2018; Pak et al., 2009).

The hierarchy-based system can result in becoming distracted from the correct navigation task for users (Arning & Ziefle, 2009; Zhou et al., 2012). Therefore, they will take a longer time to find the location they were aiming for and increased cognitive requirements (Arning & Ziefle, 2009; Chevalier et al., 2013). In order to decrease the amount of time and cognitive requirements to operate interfaces, it has been suggested to avoid hierarchical navigation and utilise tag-based system navigation which is easy for older adults to use (Chou et al., 2013; Lee et al., 2018; Pak et al., 2009; Wallace et al., 2013). Additionally, it has been found

that using the tag-based model will improve older people's performance when compared to hierarchical systems (Pak et al., 2009).

## 3.2.1.2.7 Complexity

The performance of older people when interacting with technology will be affected when they are using extremely complex interfaces (Castilla et al., 2013; Stamato & Moraes, 2012). It has been found that complexity is considered a central feature that influences the successful task completion for older people when interacting with technology (Li et al., 2012). The more complex interface will increase demand on working memory and cognitive requirements that declines in old age (Chen, Chan, et al., 2013; Higgins & Glasgow, 2012; Li et al., 2012; Vetter et al., 2012; Zhao, Rau, Zhang, & Salvendy, 2009). Therefore, interaction by older people can be supported by designing an appropriate interface which considers complexity (Vastenburg, Visser, Vermaas, & Keyson, 2008).

It has been suggested that to improve the ease and quality of interaction with technology, an interface complexity should be reduced (Lorenz & Oppermann, 2009; Vastenburg et al., 2008). Through reducing the complexity of the interface, older people will perform the required tasks quicker and more efficiently (Li et al., 2012). In order to reduce the complexity of the interface, it has been recommended to include the only the relevant functions to the designed application (Chevalier et al., 2013; Hwang et al., 2011; Wandke et al., 2012; Williams et al., 2013), including providing critical features, basic functions, and frequent commands (Chen, Chan, et al., 2013).

## 3.2.1.3 User Experience

It has been implied that user experience should complement both usability and accessibility issues (Barnard et al., 2013; Ji et al., 2010). It is recognised that user experience is an important consideration when designing interfaces (Meza-Kubo & Moran, 2013; van-Veldhoven et al., 2008). User experience is defined as a person's perceptions and emotional

responses for using of a technology product, system or service in the real world (Barnard et al., 2013; Dirin, 2018; Zarour & Alharbi, 2017).

User experience aims to consider the system characteristics, the subjective views of the user and the environment within which the technology needs to work (Barnard et al., 2013). Furthermore, user experience is used to give the user an experience that goes beyond pure functionality and elicit an emotional response (Barnard et al., 2013; Dirin, 2018; Hernandez-Encuentra, Pousada, & Gomez-Zuniga, 2009), which aim to produce an enjoyable, pleasurable and entertaining experience (Chen & Chan, 2014; Stelmaszewska, Fields, & Blandford, 2004; van-Veldhoven et al., 2008).

It has been concluded that a more enjoyable experience could motivate older people to overcome any barriers to interaction encountered (Ramon-Jeronimo, Peral-Peral, & Arenas-Gaitan, 2013). Therefore, it is important to ensure there is a positive experience during older people interaction with technology to improve their acceptance of the technology. Moreover, when an application is designed to be used by older people, it is important to consider the user preferences to present the user with an easier technology experience (Ortiz Nicolas & Aurisicchio, 2011; Page, 2014; Williams et al., 2013).

The choosing of a favourite colour is considered an important area in the context of user experience (Ancient & Good, 2013). It has been recommended to use the coordinated, classy and high saturation colours within the interface (Ji et al., 2010; Kim, Kang, Yang, & Kim, 2009). However, it is important to avoid bright colours which can cause a lack of comfort for older people (Ali et al., 2013). Thus, it has been suggested to use calm and peaceful colours to avoid lack of comfort for older people (Pijukkana & Sahachaisaeree, 2012).

## 3.2.1.4 User Acceptance

User acceptance is defined as a person's verifiable willingness to accept, adopt and continue using technology which is newly introduced to them (Wahdain & Ahmad, 2014). It has been found there is conflict as to whether older people are willing to accept and adopt new

technologies (Golant, 2017). Some researchers found the elderly averse to use new technologies (Chen & Chan, 2011; Chen & Chan, 2014), whilst other researchers found the opposite (Arning & Ziefle, 2009; Chou et al., 2013; Wallace et al., 2013). Therefore, it is recommended to consider a person's acceptance of new technologies carefully to increase avoid failure of the product (Chen & Chan, 2014).

This section will focus on the following elements which influence the acceptance and adoption of new technologies by older people: introduction to technology, the technology acceptance model, and attitude towards technology.

#### 3.2.1.4.1 Introduction to Technology

Older people have been relatively slow to adopt the new digital-touch screen technology (Vaportzis et al., 2017) and they have a lack of experience to use this new technology (Barnard et al., 2013). Therefore, the introduction of older people to technology is a vital consideration. It has been recommended to introduce older people to technology before retirement as part of their job within the workplace can lead to a person actively adopting the technology (Barnard et al., 2013).

Furthermore, to increase the likelihood of the technology being adopted, it is suggested to give the opportunity for potential users to physically interact with technology and show them how to use this technology before purchasing it (Barnard et al., 2013; Braun, 2013; Gilly et al., 2012; Pan, Bryan-Kinns, & Dong, 2017). This will allow users to prove that they are able to control the device (Saariluoma, 2008). Additionally, it is important to inform older people about the value of technology and potential technology benefits to improve their adoption rates (Berkowsky, Sharit, & Czaja, 2018).

Familiarity with technology is considered as a predictor of technology adoption with older people (Ji et al., 2010; Pan, Miao, Yu, Leung, & Chin, 2015; Taylor et al., 2014). Therefore, this will improve the satisfaction and adoption of technology (Pan et al., 2015). In order to increase familiarity with technology and their acceptance, it is recommended to use existing
interface design elements (Higgins & Glasgow, 2012). Additionally, it is recommended for older people to bundle new devices with existing products that are already adopted to improve their acceptance (Young, Willis, Cameron, & Geana, 2014). Also, it has been found that regular use of technology will improve the adoption of technology to be used into everyday life (Braun, 2013).

Older people grew up in an era where they have very limited exposure to modern technologies (Barnard et al., 2013; Chen & Chan, 2013). Thus, they have lack of experience in technology (Castilla et al., 2013; Hakkarainen, 2012; Ji et al., 2010; Or & Tao, 2012; Taveira & Choi, 2009; Zhou et al., 2012) and enjoyment of it (Gatto & Tak, 2008). In order to counteract this lack of experience, it has been suggested to increase the dependency and usability of the technology in their lives (Hwang et al., 2011).

A lack of understanding of technology will reduce the motivation of older people to start using it, and decrease their confidence with how it works (Age Concern England, 2009; Chen & Chan, 2014; Czaja, 2005; Hwang et al., 2011; Xue et al., 2012). Therefore, this lack of technology understanding may deter the purpose of technology uses which is designed to support older people (Chen & Chan, 2014). In addition, enthusiasm of older people for technology can be affected by their fear of breaking the device (Barnard et al., 2013; Ji et al., 2010), being unsure of what to do when something wrong occurs (Barnard et al., 2013; Chen & Chan, 2014), and their feelings of possibility of losing work (Dickinson, Eisma, & Gregor, 2010). Therefore, it is recommended to support older people during the technology adoption process and throughout the times when they are unsure how to proceed (Barnard et al., 2013).

Furthermore, it has been identified that motivation and enjoyment experiences of using technology are considered important elements to achieve the satisfaction of older people's needs (Chou et al., 2013; Patel, 2007; Wang, Rau, & Salvendy, 2011). This will increase the likelihood of adoption and increase the possibility for acceptance of technology (Patel, 2007; Rosenthal, 2008).

A person's self-image can be incompatible with the technology adoption for older people (Young et al., 2014). This can lead to a loss of self-confidence in the technology device (Karlsson, Axelsson, Zingmark, & Savenstedt, 2011), rejection of technology which is perceived to be too difficult for them to use (Wandke et al., 2012), and believing that they do not need technology (Abdullah, Salman, Razak, Noor, & Abdul Malek, 2011). Therefore, it is recommended that older people should use and interact with technology through regular, successful ways to build their self-confidence with technology (Wild et al., 2012).

#### 3.2.1.4.2 Attitude towards Technology

It has been identified that the attitude of a person towards technology tends to have determinal effects on their acceptance of the device (Hakkarainen, 2012). People who have positive perceptions of technology are more likely to adopt technology than those who negative perceptions of technology (Hakkarainen, 2012; Wagner et al., 2010). It has been suggested that older people will have a more negative perspective in relation to their using computers with age (Hakkarainen, 2012). However, in order to counteract these negative perspectives for older people, it is recommended to expose those older people to technology regularly and successfully (Wild et al., 2012).

In addition to negative attitudes towards technology, older people tend to have anxieties about doing something wrong with using computers (Abdullah et al., 2011; Goodwin, 2013; Hart et al., 2008). However, in order to reduce this fear of technology and improve their acceptance of the device, it has been recommended that an interface should be designed to be used easily when interacting with technology (Abdullah et al., 2011). Moreover, through the use of supported interactions, the levels of anxiety will be reduced (Wild et al., 2012), and improve their performance and acceptance of the device (Wagner et al., 2010).

#### 3.2.1.5 Conclusion

This section aimed to establish a set of guidelines that should be followed when developing interfaces for PwD. The natural ageing process should be considered in addition to the needs

of PwD. This section focused on the requirements which must be considered throughout the development process for interaction design that include: accessibility, usability, user experience, and user acceptance. Table 10 summarises the challenges that are PwD will face during their interacting with technology and the guidelines on how to manage these challenges. These guidelines will be utilised when implementing the theory-based RT application on a digital device in the next section.

Table 10	: Challenges ar	d management o	of Using <sup>-</sup>	Technology	with PwD
		· · · · · · · · · · · · · · · · · · ·			

	Challenge	Guideline management		
Accessibility	Decline in muscle strength	Provide a system which is user-paced		
	Reduced processing speed			
	Reduced learning speed			
	Decline in dexterity	1		
	Decline in working memory	Encourage interface simplicity and minimise complexity		
	Motor impairments	Develop an easy-to-use system, which takes into account the possible impairments experienced Provide options for interface customisation Where possible, avoid the use of hierarchical navigation structures Choose input and output modalities appropriate to the users and the tasks to be performed		
	Cognitive impairments			
	Visual impairments			
	Auditory impairments			
	Reduced learning speed	Provide an interaction which aims to be intuitive, but with provision for training and postadoption support		
Usability	Decline in task performance	Provide a system which is user-paced		
	Lack of familiarity with technology	Encourage interface simplicity and minimise complexity		
	Reduced performance, due to complexity			
	difficulty managing complex interactions			
	Decline in task performance too many functions and features			
	Need interfaces to be easy to use	Develop an easy-to-use system, which takes into account the possible impairments experienced		
	Lack of familiarity with technology			
	Difficulties with navigation	Provide an interaction which aims to be intuitive, but with provision for training and postadoption support		
		Where possible, avoid the use of hierarchical navigation structures		
		17		

		Enhance available resources, whilst supporting those which have declined	
	Reduced readability, due to font sizes	Provide options for interface customisation	
	Small device form factor	Choose input and output modalities appropriate to the users and the tasks to be performed	
User Acceptance	Lack of familiarity with technology	Encourage interface simplicity and minimise complexity	
		Develop an easy-to-use system, which takes into account the possible impairments experienced	
		Provide an interaction which aims to be intuitive, but with provision for training and postadoption support	
	Reduced exposure to technology	Provide an interaction which aims to be intuitive, but with provision for training and postadoption support	
	Poor introduction to technology	Provide support to adopt new technologies	
		Ensure the introduction to technology is appropriate to the person,	
		their self-image, and the task to be carried out	
	Negative attitude to technology	Provide support to adopt new technologies	
	Reduced availability of appropriate support and training		
	Reduced comfort levels		

#### **3.2.2 Theoretical Framework**

According to Heath et al. (2015), theory-driven interventions will lead to better outcomes. Theories can provide tentative explanations for interventions to be of higher quality when they address more key related factors (Heath et al., 2015). Therefore, it has been recommended in the systematic review chapter of this study that interventions should be theory-driven to provide tentative explanations for interventions to be higher quality when they address more key related factors.

There are number of theories can be used in RT studies such as Socioemotional Selectivity theory (SST), Continuity Theory, and Disengagement Theory. SST focuses on emotional functioning and strengthens the positivity bias in memory (Webster et al., 2010). Continuity theory finds the continuity between past and present (Webster et al., 2010). The continuity in one's life between past and present makes older people maintain similar patterns of behaviours and lifestyles across time, changing only slowly (Cooper & Beehr, 2015). However, there are three degrees of continuity; too little, too much, and optimal. Too little continuity produces an unsettled feeling that one's life is too unpredictable. Too much continuity is boring and totally predictable. The optimal amount of continuity provides sufficient challenge for change but not so much challenge that the person is overwhelmed (Cech & Martin, 2011; Gonzalez et al., 2015). Disengagement Theory suggested that aging people turned inward as a means of withdrawal from family and society (Cech & Martin, 2011). Therefore, SSTwill be used to base this work.

This study will use SST as it was previously used in other RT studies and it was effective (Subramaniam et al., 2014). Technology Acceptance Model (TAM) was previously used in developing digital RT application and it was very useful (Ancient & Good, 2013). Thus, this section will focus on the following theoretical frameworks that will be used in this research project: SST, and TAM.

#### 3.2.2.1 Socioemotional Selectivity Theory (SST)

It has been proposed that frequent rehearsal and rumination will be evoked by emotional memories (Allen, Schaefer, & Falcon, 2014). In addition, the repetition of emotional memories will make them more deep-rooted in the memory of the individual (Coluccia, Bianco, & Brandimonte, 2010). The practice of using memories will make it easier for PwD to recall them as the more of using memory, the better of remembering things. Therefore, they will have the ability to fully participate in the RT programme (Coluccia et al., 2010). Moreover, using memories that induced positive emotions could be considered as an effective intervention to eliminate or alleviate feelings of negative emotions and sadness (Chen, Takahashi, & Yang, 2015; Seebauer et al., 2016), therefore, it may support PwD to manage their mood (Chen et al., 2015).

Often, the memories that induced positive emotions could be helpful and have positive consequences on the physical health of the person, well-being, and support the maintenance of social and emotional bonds, thus, these positive emotions could be described as functional (Chen et al., 2015; Shiota et al., 2014). People will gain a positive bias towards their memories when they grow older (Cappeliez et al., 2008; Otake, 2015), this positive bias towards their towards their memories is called the positivity effect as described in SST (Westerhof et al., 2010).

SST was proposed by Carstensen, Isaacowitz, and Charles in 1999 (Carstensen, 2006; Carstensen, Isaacowitz, & Charles, 1999; Subramaniam et al., 2014; Westerhof et al., 2010). It has proposed that people have two important motives in their life: information gain, and emotion regulation (Carstensen, 2006; Carstensen et al., 1999; Westerhof et al., 2010). SST predicts that different types of goals are prioritized by people of different ages (Carstensen, 2006). Older people increasingly perceive time as finite as they age, then they attach greater importance to goals from which they derive emotional regulation and meaning and less importance to goals about information gain (Carstensen, 2006; Westerhof et al., 2010). Therefore, in later life, motivational priorities shift from information gain to the emotions

regulation in order to gain a sense of well-being (Cappeliez & O'Rourke, 2006; Carstensen, 2006; Westerhof et al., 2010).

Older people will be more selectively biased towards personal memories which have positive emotions as the result of the positivity effect (Cappeliez et al., 2008; Carstensen, 2006), it has been found that older people who have experienced depression will tend towards negative personal memories (Gonzalez et al., 2015; Hallford & Mellor, 2013). Therefore, the positivity effect can be applied with depressed older people through the process of creating idealised positive memories by adapting to forget any negative past events selectively in order to distance themselves away from negative memories (Dempsey et al., 2014). This SST has applied in Subramaniam et al. (2014) study, PwD in this study actively selected to escape any details and information of distressing events in the creating of their life story books.

#### 3.2.2.2 The Technology Acceptance Model (TAM)

The Technology Acceptance Model (TAM) was proposed by Fred Davis in 1986 (Davis, Bagozzi, & Warshaw, 1989; Lai, 2017). The TAM model aims to illustrate and predict the main factors of technology acceptance that lead to facilitating design changes before users have experience with the new system that influences their adoption of it (Davis et al., 1989; Lai, 2017). The basic TAM model included two major beliefs: Perceived Ease of Use (PEOU) and Perceived Usefulness (PU) (Davis et al., 1989; Kanwal & Rehman, 2017; Lai, 2017; Tang & Chen, 2011).

The PEOU can be defined as the degree to which the potential user believes the technological device to be free of effort (Davis et al., 1989; Tang & Chen, 2011). When the PEOU is significantly high, it makes the target system easy to use, it could result in the prospective user adopting the new technology (Greengard, 2009; Roupa et al., 2010). In using technology with PwD, many challenges will be considered to have a free effort target system. These challenges and how can consider them were explained in the previous section, Table 10.

It has been found that both age and interface design of the new system could have a detrimental effect on the PEOU (Xue et al., 2012). Frequently, older people experience a lower PEOU than younger people which could consider as a barrier to adoption (Or & Tao, 2012; Zhou et al., 2012). In addition, poorly designed interfaces and interaction principles will hinder the individual's perception of the ease of using technology (Kuo, Chen, & Hsu, 2012a). Therefore, in order to support older people in the adoption process, a well-designed interface and appropriate interaction principles that include ease of use, and intuitiveness which were discussed in the previous section should be used (Chen & Chan, 2011).

The PU can be defined as the degree to which the potential user expects that using a particular system would improve their performance (Davis et al., 1989; Tang & Chen, 2011). It has been found that technology is often perceived as useless by older people (Chen & Chan, 2013; Hakkarainen, 2012; Hanson, 2010; Zhou et al., 2012). In addition, they have experienced obstacles to identify the advantages of adopting new technology (van-Veldhoven et al., 2008). However, the adoption rate will increase when the new technology fulfils perceived needs (Reeder et al., 2011). Additionally, the PU will be affected negatively by the level of incompatibility between the user's needs, wants, and expectations with the features included in the system (Or & Tao, 2012). Therefore, in order to improve the acceptance of the new technology, the designers throughout their development process must ensure that possible user's expectations, wants, and needs are met.

It is essential to clearly demonstrate the potential benefits of adopting new technologies for older people (Lam & Chung, 2010; Zhou et al., 2012). Older people's motivation to learn how to utilise new technologies will be reduced by a lack of perceived benefits which could have a negative impact on their life, and new technologies will be seen as not worth adopting (Wandke et al., 2012). Therefore, in order to overcome this effect, the benefits of new technologies over existing ones for older people adopting should be shown clearly (Logue & Effken, 2012). In addition, to improve the acceptance of new technologies, the advantages should outweigh the costs associated with adoption (Zhou et al., 2012).

Various considerations need to be undertaken into account in order to apply a TAM framework in which researchers need to be acutely aware of the multiple limitations which are inherent in attempting to do so. One of the limitations of the TAM concerns the variable which pertains to the behaviour of users, which is inevitably evaluated through subjective means such as behavioural intention and interpersonal influence (Ajibade, 2018). These subjective means cannot be reliably quantified in an empirical investigation, owing to a number of different subjective factors such as the norms and values of societies and personal attributes and personality traits (Ajibade, 2018; Ang, Ramayah, & Amin, 2015). Hence, the argument that a relative, friends could influence the acceptance of and willingness to use technology through exacting social pressure (Ang et al., 2015) is highly falsifiable.

Moreover, TAM does not consider the external factors that influence PU such as age and education (Zahid, Ashraf, Malik, & Hoque, 2013). These external variables could influence acceptance of and willingness to use technology (Zahid et al., 2013). Accordingly, potential users of technology may not necessarily base their acceptance of and willingness to use new technology on their perceptions of the usefulness of IT and how easy it is to use, although the model does suggest that there may be other external factors which could be responsible for their acceptance of the technology.

#### 3.2.3 Design

In the previous section, the guidelines to develop a digital interface for PwD were illustrated, then the potential appropriate theories in relation to digital-touch screen technology in RT for PwD were identified. In this section, the design of developing the RT application will be reported.

# 3.2.3.1 Introduction

There is a consensus relating to the components of the process of RT (Dempsey et al., 2014). In order to develop a high quality, robust, and flexible framework digital theory-based RT program, an Agile approach will be adopted and utilised. The Agile approach describes a set

of principles for software development under which requirements and solutions evolve through the collaborative effort of self-organizing cross-functional teams (Aydin, Harmsen, & Stagwee, 2005). The Agile approach has been used in e-learning development (Boyle, 2003; Boyle et al., 2007). In addition, it can be used for non-educational digital resources. For example, it was used in the development of RT digital application to allow the functional prototype to be created early in the development lifecycle, with testing for usability and modification taking place throughout the development process (Laird et al., 2018). It was found that this method will balance the necessities for flexibility to fit pressurised work environment with the need to facilitate the development of high-quality resources (Aydin et al., 2005; Boyle et al., 2007). As well as, it is structured but adaptable to local circumstances (Boyle et al., 2007).

The development process will be carried out by a collaborative group of the principal researcher and software developers, in which the principal researcher will be responsible for the conceptual design of the theory-based RT, while the multimedia developers will provide expertise in helping with the building the programme.

There are three main functions that are essential to be covered in the development process. These functions include exploratory phase (analysis of needs); designing and prototyping phase; and testing phase. Therefore, the application development study was split into these three main sections.

# 3.2.3.2 Exploratory Phase

This phase involved consultation work from health care professionals in dementia and caregivers who work with PwD regularly. It was used to explore and identify the needs of both the health care staff and the PwD when developing and designing an application in order to assess requirements for a system.

Two health care professionals and two caregivers who have direct contact with PwD in the Jordanian care homes were contacted twice by email to provide their expert opinions on the application based on their professional and personal experience of dementia. The principal

researcher used a semi-structured questionnaire. Table 11 lists the guiding list of questions in the exploratory research stage.

Reminiscence	1. Do they thoughts about the past	If yes, is there any particular		
(RT)	events?	things that trigger this past		
		event?		
		If no, is there any cause?		
	2. How do they currently store			
	memory triggers such as			
	photographs video and music?			
	3. Have they been in RT in the past?	Did they enjoy them?		
		If no, what didn't make it		
		enjoyable?		
		If yes, what made it		
		enjoyable?		
	4. Have they established a memory	If yes, do they use it		
	book?	frequently?		
Technology	1. Do they have personal technologies such as mobile phones /			
	tablet computers/ smart phones/ computers?			
	If they have personal technologies:	Do they use them		
		frequently?		
		Did they incorporate them		
		into their life?		
	If they don't have personal	Is there a cause?		
	technologies			
		How can they overcome this		
		reluctance?		
	2. Have they faced any obstacles	Tablet- / Smartphone-related		
		1		
	using these technologies?	obstacles		

Table 11: The guiding list of questions in the exploratory research stage

		How did they overcome
		these obstacles?
		Did they refer to anyone for
		additional assistance?
Reminiscence	1. Would they be happy in adopting	If no, is there any specific
Application	a digital-touch screen technology to	doubt?
	manage the viewing and storing of	
	triggers for speaking about the past?	
	2. How do they accept the idea of	
	involving multiple triggers together,	
	e.g. a piece of music and a	
	photograph together?	
	3. How do they accept the usage of	
	group recollections together, e.g.	
	grouping all wedding pictures	
	together to recall that day in detail?	
	4. Are there any specific wants or	
	expectations PwD have for the	
	system?	

# 3.2.3.3 Designing and Prototyping Phase

The RT application was designed based on the findings of the guidelines that were discussed in the previous section (3.2.1) regarding the development of the interface for PwD. Once the application has been developed, participants were given the opportunity to use tablet computers with potential designs for the application installed in this phase. Four participants (2 health care professionals and 2 caregivers) were provided with a prototype application and were asked to use and interact with the system. In this phase, participants were encouraged to voice their opinions on the designs, together with any improvements. Therefore, they were given boxes to fill in based on the following headings: I dislike; I like; I would remove; and I would add. It was designed to obtain the participant's likes and dislikes for aspects of the prototype (see Appendix 6). Each prototyping session lasted for one hour. The principal researcher did the stakeholder consultation by direct contact with the four people across two care home.

# 3.2.3.4 *Testing Phase*

An initial assessment of the usability involved individual evaluation of participant's ideas and thoughts on the outcome. This testing stage had two different evaluation methods: firstly, through engagement with the significant PPI activities (Dementia, Frail Older People and Palliative Care Public and Patient Involvement Workshop) (see Appendix 7); secondly, through pilot testing of the digital intervention through individual evaluation of expert review and service user testing to support a rigorous development process for the digital intervention.

In PPI activities, accessibility, usability, and problems PwD have with both were discussed. An overview of RT was given. Then, the group started their discussion about each session, its component, and what should be included in each session. In piloting testing, the principal researcher provided the participants with a sheet of paper to record the assistance they would require in the delivery of RT. This would ensure that possible user's expectations, wants, and needs were met. The digital RT application was given to four health care professionals who are helping in the prototyping in their own home over the course of a week for use. These four participants were encouraged to fill the peer review form to explore their experience of using the digital RT application (see Appendix 8).

# 3.2.4 Users' Results and Recommendation

#### 3.2.4.1 Exploratory Phase

During this phase, it became apparent that the participants had the perception that the RT sessions system would be utilised as face to face; individual; and structured sessions for a specific amount of time. Participants suggested using RT based on the key stages in life which most people have experienced. In order to achieve the needs of both the health care staff and the PwD when developing and designing an application, the contents and elements

of these RT sessions were adapted from Schweitzer and Bruce (2008) which was explained in Chapter 1, section 1.2, Table 3.

Participants in this phase suggested that the optimal types of stimulus which should be included within the developed application are photographs, audios, and videos. They also identified that visual prompts would be more effective than textual memories on evoking memories. In addition, they suggested using generic memories associated with the area in which the research was conducted (Jordan) in order to put all the PwD on a more equal footing with a healthy conversation. Therefore, all of the included generic memories were obtained by free download from the internet without copyright infringement.

Furthermore, participants explained that PwD may struggle to use the touch screen device. They suggested that PwD may have many challenges in using technology. Therefore, they suggested using a special management guideline to consider these challenges during the development of interfaces.

## 3.2.4.2 Designing and Prototyping Phase

The application has been designed to reduce the volume of information which needs to be remembered due to the declining short term memory of PwD. In addition, it is desirable to reduce the amount of unnecessary effort placed on the brain, as this capacity is in decline. Therefore, in order to develop a RT application which is appropriate for PwD, it was suggested to provide a system which was user-paced and encourage interface simplicity and minimise complexity. Furthermore, it was recommended to develop an easy-to-use system by taking into consideration the possible impairments experienced, provide an interaction that aims to be intuitive, and avoid the use of hierarchical navigation structures.

The main issue identified by all the participants in the prototyping phase was the colour system. They did not have a problem with the brightness of the white background; they felt that it was an unexciting colour structure. They suggested using light green and light yellow colours instead of white colour in order to make the interface appear more cheerful.

Moreover, the users struggled to identify the volume buttons in the interface. Therefore by adding a label to the volume buttons, this would allow the users to quickly identify their use. However, the users felt that the system was easy to use.

## 3.2.4.3 Testing Phase

The participants in both PPI activities and piloting testing felt that the application would be beneficial to them for facilitating RT. The participants in PPI activities suggested that PwD lose the ability to use the technology, so this application needed to be guided. Moreover, some of those participants in PPI activities suggested removing the session of death preparation because it is not part of RT.

The participants in piloting testing found the RT application was easy to use and navigate, and the content of each session was clear, audible and engaging. They felt the background colour had a calming effect. However, they suggested to include the volume and zoom buttons included on the interface. In addition, they suggested the need to deal with the tablet 'sleeping' after a period of inactivity.

# 3.2.5 Interface Design

The following section will view the final interface design of the application, with a particular focus on how the guidelines developed in section 3.2.1 have been applied. Moreover, this final interface design is based on the results and recommendations of the previous section. In this section, an example of the first two sessions of both Arabic and English versions will be viewed as a screenshot of each session in Table 12. The screenshot of all digital RT sessions will be found in Appendix 18.

# Table 12: Screenshot of the first two RT sessions

Arabic version	English version
للفلاريات (Reminiscence Therapy) العلاج بالذكريات اعاد الباث علم اعد العرد علم اعد العرد بنه الغرم السحة بنه الغرم السحة بنه الغرم السحة بنه الغرم السحة بنه الغرم السحة بنه الغرم السحة	Reminiscence Therapy   Prepared by   Asem Ahmed Abdalrahim   School of Health Sciences   University of Nottingham   Copyright: Asem Ahmed Al-Hmoud
لتعلاج بالذكريات ولا المراجعين المراجعين ولا المراجعين والمراجعين ولا المراجعين والمراجعين ولا المراجعين ولا لا لمراجعين ولا المراجعين ولا لمراجعين ولا المراجعين ولا المراجعين ولا المراجعين ولا لمراجعين ولا المراجعين ولا المراجع ولا لمراجعين ولا المراجعين ولا المراجعين ولو المراجعين ولا المراجعين ولو المراح	Berneiniscence Therapy   Duroduction   Dementia is a condition that describes a wide range of symptoms associated with a decline in memory or person's ability to perform everyday activities. Therefore, we need to be thinking about ways in which to alleviate some of the symptoms for any of the provide state of the symptom of the symptoms. With the introduction of touch screen technology, there is the potential to produce a program capable of holding arrange of objects such as photos, music, and videos to facilitate reminiscence therapy that it might be easier to use and more functional   Back Sessions Page





#### 3.3 Conclusion

This chapter focused on the development of theory-based RT application for PwD. It discussed the existing RT application projects in order to summarise the gaps within these existing applications. Moreover, it focused on the guidelines which must be considered throughout the development process for interaction design that include: accessibility, usability, user experience, and user acceptance. These guidelines were utilised when implementing the theory-based RT application on a digital device for PwD.

This chapter has presented the theoretical framework that would be used in the development process of theory-based RT application that includes SST, and TAM. The development process of theory-based the RT application has also been presented. The development of the application was divided into three main phases: exploratory phase; designing and prototyping phase; and testing phase. In the exploratory phase, it was suggested that the RT sessions system would be utilised as face to face; individual; and structured sessions for a specific amount of time. Moreover, special guideline management to consider these challenges during the development of interfaces should be used.

In the designing and prototyping phase, it was suggested to provide a system which is userpaced, encourage interface simplicity and minimise complexity, develop an easy-to-use system by taking into consideration the possible impairments experienced, provide an interaction which aims to be intuitive, and avoid the use of hierarchical navigation structures. The participants in the piloting testing phase found the RT application was easy to use and navigate, and the content of each session was clear, audible and engaging. However, it is important to assess the feasibility and acceptability of the theory-based RT application for PwD. Therefore, the next chapter will illustrate the methodology to assess the feasibility and acceptability of the RT application for PwD.

#### Chapter 4 Methodology and Methods

# 4.1 Introduction

The previous chapter aimed to develop a theory-based digital application to deliver reminiscence therapy (RT) for people with dementia (PwD). This chapter presents the methodology and procedure that were used in the study in order to assess the feasibility and acceptability of this theory-based RT application for PwD.

This chapter begins by presenting the overall aim and objectives of the study. Subsequently, a discussion of the philosophical underpinning of the research that led to the research design of the study is presented. This is followed by a description and discussion of the study procedure and ethical considerations.

# 4.2 Aim and Objectives

The aim of this study was to explore the feasibility and acceptability of a theory-based digital application to deliver RT for PwD. This PhD study is an important stage prior to the subsequent testing of the clinical effectiveness of this intervention on health outcomes including cognitive function, communication, depressive symptoms, anxiety, and QoL. The objectives of this study are:

- To determine whether digital RT can be delivered as planned in the care of PwD in Jordanian care homes.
- 2. To determine whether digital RT is acceptable/tolerable to PwD and care home staff in Jordanian care homes
- To identify the most appropriate outcome measures to evaluate the delivery of digital RT to PwD in Jordanian care homes to be used in a subsequent definitive trial.

#### 4.3 Methods

In order to achieve the aim of this study, mixed-method research (MMR) single group feasibility study approach was used. Data were collected on cognitive function, communication, depression, anxiety, and QoL from residents and staff in Jordanian care homes through questionnaires and interviews. This section begins by outlining the philosophical underpinning that led to the study design.

#### 4.3.1 Philosophical Underpinning

It is well established that there are concerns generated from the mixing of two apparently contradictory paradigms underpinning quantitative and qualitative standpoints in MMR (Guba & Lincoln, 1994).

The Positivism paradigm asserts the truthfulness of study findings because these findings will be presented in an objective, valid way (Crotty, 1998). The positivist paradigm has the traditional notion of the absolute truth of knowledge. However, post-positivist philosophy asserts that positivists face challenges for this traditional notion when they study the behaviours and actions of humans due to the absolute truth of knowledge as positivists attempt to identify causes which influence outcomes (Clark, 1998; Creswell & Clark, 2007). Post-positivists seek to understand causal relationships; thus, quantitative studies are used. However, more than sense-data is collected, participants' perspectives are often sought. Furthermore, as knowledge is tentative, hypotheses are not proved but simply not rejected (Creswell & Clark, 2007).

On the other hand, interpretivism suggests that reality is based on people's unique perspectives of the world, so multiple realities will exist (Guba & Lincoln, 1994). One of the aims of interpretivist research is to be in-depth, contextual and flexible findings (Lincoln & Guba, 1985a).

However, each one of these paradigms offers a very limited view of understanding the world and a limited view to explore or enhance new knowledge (Clark, 1998). In addition, it is

unable to examine an intervention in a complex context that needs more in-depth explanation and causation (Clark, 1998).

A MMR approach merges quantitative and qualitative methods into a single study to develop a better understanding of the research problem than would be achieved using either approach alone (Boswell & Cannon, 2014; Creswell & Clark, 2011). Creswell and Clark (2007) explain that MMR is a research design with philosophical assumptions as well as methods of inquiry. So, this methodology is in a different position to the interpretivist or positivist assumptions alone (Teddlie & Tashakkori, 2009). Thus, by taking a MMR approach, it is important to explain how this incompatibility between qualitative and quantitative research paradigms will be overcome (Johnson & Onwuegbuzie, 2004).

Pragmatism has been recognized as one of the most appropriate epistemologies for MMR (Teddlie & Tashakkori, 2009). Pragmatism will judge the importance of an evaluation by the extent to which the evaluation is practical and useful (Johnson & Onwuegbuzie, 2004). Moreover, pragmatists believe that the choice of research design will be determined by the research inquiry rather than focusing on methods or paradigms (Johnson & Onwuegbuzie, 2004).

Pragmatism will arise out of actions, situations, and consequences rather than antecedent conditions (Creswell, 2012). Pragmatism provides researchers with the opportunity to use any or all approaches and methods to understand the problem and address the research question at hand (Greene & Caracelli, 1997). Thus, it is appropriate to the nature of this study to employ the pragmatist standpoint to open the door to multiple methods, different assumptions, and different forms of data collections and analysis.

However, there are many criticisms of pragmatism. These criticisms include: 'for whom is a pragmatic solution useful?', and 'what is meant by usefulness?' (Mertens, 2003, p. 501). So, to answer the first question within this research study, the desired end and useful application is in assessing the feasibility of digital RT for the benefit of PwD on cognitive, communication, depression, anxiety, and QoL outcomes. There is a strong focus on the practicality of the

results and testing the feasibility enables a thorough evaluation of whether this intervention is acceptable and attractive for this population. Then, to clarify what is meant by useful, there are two different ways to consider this research approach useful:

- This approach will be useful for the development of an effective intervention by using a mixture of methods in order to gather the best possible knowledge to inform the adaptation and delivery of the intervention
- 2. This approach will be useful for the participants because the desired end and motive for using a pragmatic approach is to develop an intervention that elicits some beneficial health changes such as cognitive function, communication, depression, anxiety, and QoL outcomes in PwD.

#### 4.3.2 Study Design

There are a number of typologies asserting several variations of MMR throughout the literature (Creswell & Clark, 2011; Greene & Caracelli, 1997). MMR is divided into three advanced designs (intervention design, multistage evaluation design and social justice design) and three basic designs (exploratory sequential design, explanatory sequential design and convergent parallel design) (Creswell, 2015). In this study, the convergent parallel MMR single group feasibility study approach was used to achieve the aim of this study. The protocol of this study was prepared according to Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) (Chan et al., 2013). As the digital RT intervention was determined to be 10 sessions; twice a week in Chapter 3, section, 3.2.4, this study was a five weeks single group feasibility trial (pre-post individual intervention). A MMR evaluation was ongoing and explored the rate of recruitment, adherence to the intervention, retention, data completion and adverse events. Qualitative interviews were undertaken with study residents and staff working within the care homes to explore: satisfaction with the intervention; barriers and facilitators of the intervention; the perceived impact of the intervention, and potential changes and necessary improvements. The qualitative and quantitative components will be illustrated later in this chapter.

#### 4.4 Procedure

This section will discuss the procedure of this study including study settings, participants, recruitments, intervention delivery, quantitative methods, qualitative methods and data synthesis.

# 4.4.1 Study Settings

At the time of the study, there were only nine care homes listed by the Jordanian Ministry of Social Development (MOSD) with 400 resident older adults (MOSD, 2017). MOSD was contacted by the researcher to get formal agreement to conduct the study in their care home centres. MOSD was unable to support the study due to the unavailability of specialised centres in caring for older people under the direct supervision of them (see Appendix 12, b). MOSD suggested contacting directly with care home managers. Jordanian care homes were contacted individually by the researcher. The letters were sent to care home managers. The researcher selected two care homes which have the largest number of PwD. Figure 4 explains the selection and recruitment of care homes.



## Figure 4: The selection and recruitment of care homes

This study was conducted in two care homes in Amman: Dar Aldiafeh Nursing Home which provided care for both female and male older people; and Darat Samir Shama Nursing Home which was a private setting providing care for both male and female older people. Figures 5 and 6 show the study settings in Jordan.

Firstly, Dar Aldiafeh Nursing Home is the largest care home in Jordan that contains 43 rooms; it was founded in 1979. It is open for 24 hours; the total number of residents is 120, while employees are amounted to 62 workers from different specialized professions and categories like administrators, nurses, technicians, physical therapists, cooks and mail servants. The services offered, like food, drinks, all types of health care. In addition, there is a club where participants spend their free hours during day time and meet with each other, talking or playing some games entertaining or exercise walking in the garden of a club or practicing some hobbies' like reading (MOSD, 2017). Secondly, Darat Samir Shamma Nursing Home is a non-profit organisation, accommodating senior residents and offering homes especially constructed to cater to the needs of the retired. It was founded in 2001 and located on the hill in the area of Shafa Badran, Amman. It contains six Villas and 61 studios which are built in conformity with international standards to give the maximum comfort along with physical ease and relaxation for the residents. It is open for 24 hours for a full security system and house-keeping service; and two hours per day for medical and nursing services. The services offered food, drinks, health club, and the library. The total number of residents is 65, while employees are amounted to 60 workers from different specialized courses and categories like administrators, nurses, technicians, physical therapists, cooks and mail servants (Sammir Shamma Homes, 2019).



Figure 5: The study settings



# Figure 6: Pictures of study settings

# 4.4.2 Participants

PwD residents from the selected Jordanian care homes were recruited. Formal sample size calculations were not necessary for a feasibility study (Billingham, Whitehead, & Julious, 2013), but the study aimed to recruit 60 PwD and 15 staff caregivers. This proposed sample size is based on feasibility and pilot studies to recruit 40-50 participants, in the National Institute for Health Research- Evaluation, Trials and Studies Coordinating Centre (NIHR NETSCC) glossary (NHS, 2017b).

There were around only 185 residents living in both selected care homes and 120 staff during the period of study. Older adults and staff who could participate in this study were selected according to the eligibility criteria. This section explains these eligibility criteria that include inclusion criteria and exclusion criteria.

#### 4.4.2.1 Inclusion Criteria

Residents were included if they:

- 1. Were clinically diagnosed with dementia determined by a psychiatrist in the selected care homes. The diagnosis was recorded in their care home notes.
- 2. Were residents in the designated care home and they were anticipated to be resident in the care home for the coming year.
- 3. Had the capacity to understand and consent to participate in the study (including those who can consent in the moment), OR they had a consultee who could be approached for their assent if they were not able to consent in the moment but met the eligibility criteria.

# 4.4.2.2 Exclusion Criteria

Participants were excluded if they:

- 1. Were deemed too unwell to participate determined by care home staff.
- 2. Had a diagnosis of an additional psychiatric disorder other than those identified in the inclusion criteria (e.g. schizophrenia, MDD) as determined by care home staff.

# 4.4.3 Recruitment

One week before collecting data, the care home managers and staff were contacted to explain the purpose and the procedure of the study. They were asked to assist with screening for eligible residents. The care home managers and staff verified that the resident/or their consultee was happy to be approached by the study researcher from those who fulfilled the eligibility criteria. Moreover, an advertisement (Appendix 9) was put out during care home meal times in both care homes in order to increase the response rate and reach to at least an estimated value for the recruitment (Davies & Nolan, 2006; Morrison, Winter, & Gitlin, 2016).

The researcher visited the care homes and distributed the invitation letter and introductory leaflet to care home residents and staff caregivers once the consent to be approached was

verified. Then, the full participant information sheets were provided to care home staff and residents. The opportunity was given to ask the researcher any questions about the research. Informed consent then was taken by the researcher.

If there were any residents without the capacity to consent, the researcher asked the care home managers to identify someone to act as a consultee on the potential participant's behalf, by approaching their next of kin. Once a consultee was identified the researcher organised to meet with them and discuss the involvement of the potential participant in the study. Study documentation supported this discussion. This documentation emphasised that the consultee acted as an informant to a best interest's decision, taking account of the potential participant's currently and previously stated views about whether they should be enrolled in the study. In addition, the consultee was asked to provide assent on behalf of the potential participants opposed to consent. If a participant no longer wished to be included within the study this was respected and they were removed from the study, the data collected to date were not erased and were used in the final analysis. Also, for those who could not consent for themselves; or their capacity to consent changed during the study, the researcher repeated the process of assent because ongoing assent is a vital requirement. A decision 'not to participate' did not affect the care offered to potential participants (Toth-Allen, 2013).

According to the Mental Capacity Act (2005), if there were any residents without capacity and no consultee could be identified, an independent consultee was used to determine whether it is in their best interests to participate (Department of Health, 2005). This was a chosen individual approved by care home managers. There was no financial incentive or other benefits to the care home or any staff within it of providing assent for a potential participant. Figure 7 explains the recruitment of the participants.

Since the number of PwD in Jordanian care homes was relatively low (see Chapter 1, section 1.1.3), it was intended to recruit every eligible PwD in both care homes. A pragmatic sample strategy was used to select all available eligible residents with dementia. The recruitment

process for this study was implemented to recruit 60 PwD (35 from Dar Aldiafeh Nursing Home, and 25 from Darat Samir Shamma Nursing Home) and 20 staff of caregivers (12 from Dar Aldiafeh Nursing Home, and eight from Darat Samir Shamma Nursing Home). This convenience sampling ensured that all participants met the inclusion criteria. Study participants were participating in the study for around five weeks duration. The recruitment process was begun on 1st December 2017 and ended on 21st December 2017. In this study, 43 PwD were identified that they had their capacity to consent and eight independent staff were identified by care home managers to act as independent consultees on behalf of 17 PwD.

In qualitative research, there are various approaches to select a sample (e.g. purposeful sample: Marshall, 1996). In order to generate a more comprehensive understanding of the research phenomena, a purposive sampling approach provided a rich source of data (Creswell, 2012; Sandelowski, 1995). Therefore, this study used a purposive sampling to ensure that resident and staff participants who met the inclusion criteria and objectives of the study and had experiences with the phenomena of interest.



Figure 7: The recruitment of the participants

Recruited to the intervention

Baseline data collection

# 4.4.4 Data Collection and Intervention Delivery

Following the consent and recruitment procedures, 60 residents in both care homes were assessed and invited to complete study questionnaires as baseline data collection by two independent researchers. Participants were invited to undertake an individual digital RT programme that was run at the care home they were resident within. As mentioned in Chapter 3, there are 10 sessions of digital RT sessions were adapted from Schweitzer and Bruce (2008). Therefore, the intervention was delivered for 10 sessions undertaken twice a week, for five weeks, for up to an hour at a time (this depended on the participant's ability and willingness to participate). The digital RT sessions were face to face; individual; and structured sessions based on the key stages in the life which most people had experienced. Figure 8 shows how this intervention was delivered. Consent was given for these pictures to be taken and included in this thesis and published report.



Figure 8: Examples of intervention delivery

PwD who completed the intervention delivery were asked to complete outcome measures at post-intervention. In addition, those PwD and 15 staff caregivers in both care homes were invited to take part in the semi-structured interviews. This allowed for all the participants' experiences to be captured and maximum variation in responses to be collected. Each interview lasted between 30–60 mins and was audio-recorded and transcribed verbatim. The last post-intervention assessment was conducted on 28th February 2018.

# 4.4.5 Quantitative Method

#### 4.4.5.1 Research Objective

The objective of the quantitative study was to determine the likelihood of changes in outcome measures and to identify the most appropriate outcome measures to evaluate the delivery of digital RT to PwD in Jordanian care homes to be used in a subsequent definitive trial. In order to achieve this objective, a single group (pre-post individual intervention) was used.

# 4.4.5.2 Population and Sample

It was intended to recruit 60 PwD in both selected care homes in order to adequately describe the characteristics of this population, and identify the most appropriate outcome measures to evaluate the delivery of digital RT to PwD in Jordanian care homes to be used in a subsequent definitive trial. This recruitment process was according to the inclusion and exclusion criteria that mentioned before in this chapter, section, 4.4.3.

# 4.4.5.3 Data Collection Method

Quantitative data were collected via questionnaires to compare cognitive function, communication, depression, anxiety, and QoL outcomes before and after the delivery of the intervention to explore whether certain outcomes are sensitive to change. In addition, the rate of recruitment, adherence to the intervention, retention and data completion were collected in the quantitative data. The outcome measures that were used to collect data in this study consists of four questionnaires, as described below.

#### 4.4.5.3.1 Personal Demographic Characteristics

The demographic characteristics questionnaire included age, setting, the severity of dementia, gender, level of education, and marital status.

# 4.4.5.3.2 Arabic Version of Saint-Louis-University-Mental-Status (Arabic SLUMS;

Abdelrahman & El Gaafary, 2014)

Cognitive function in PwD was measured by the Arabic Version of SLUMS (Abdelrahman & El Gaafary, 2014). The Arabic Version of SLUMS was first created by Tariq, Tumosa, Chibnall, Perry, and Morley (2006), and it has been tested and used extensively among mild cognitive impairment and dementia worldwide. Arabic Version of SLUMS consisting of an 11-item questionnaire with scores ranging from 0 to 30. It is a one-page screening test administered in 10 minutes to identify elderly people with cognitive impairment through measuring orientation, memory, attention, and executive functions. The score interpretation depends on the level of education; High school education: Normal: 27-30; Mild neuro-cognitive disorder: 21-26; Dementia: 1-20. Less than high school education: Normal: 25-30; Mild neuro-cognitive disorder: 20-24; Dementia: 1-19 (Abdelrahman & El Gaafary, 2014).

For testing validity and reliability of Arabic-SLUMS tool, the Arabic version of SLUMS has been tested for its reliability and validity on 90 elderly group. It has been found there is statistically significant agreement that was evident between SLUMS Examination and Mini Mental State Examination MMSE (Kappa 0. 826, P <0.001) (Abdelrahman & El Gaafary, 2014). It was found that the sensitivity of Arabic SLUMS Examination was 94% (31/33) while the specificity was 96% (55/57). Arabic SLUMS Examination was also found to be reliable by test-retest. (McNemar P>0.05, Kappa 0.806 P<0.001). The internal consistency of the Arabic version of SLUMS examination on the main items of cognitive function showed a Cronbach's alpha of 0.723 with a significant item-to-item and item-to-total correlation.

# 4.4.5.3.3 Older People's Quality of Life questionnaire (OPQOL-brief-13; Bowling, Hankins, Windle, Bilotta, & Grant, 2013)

Quality of life in older people was measured by OPQOL-brief-13 (Bowling et al., 2013). OPQOL-brief-13 was developed from prioritizing the most important items from the OPQOL-35. It has been tested and used extensively among older people. OPQOL-brief-13 consisting of 13-items with the participant being asked to indicate the extent to which he/she agrees with each item by selecting one of five possible options ("strongly disagree", "disagree", "neither agree nor disagree", "agree" and "strongly agree", each with a score of 1–5). Higher scores represented higher QOL. The total score ranges from 13 (worst possible QOL) to 65 (best possible QOL). The 13 items of OPQOL-brief will take 5 minutes to complete. The OPQOL-brief was found to be highly reliable (Cronbach's alpha = 0.856, p < 0.001). Moreover, it was found to be moderately and highly valid (Bowling et al., 2013).

# 4.4.5.3.4 Arabic version of Hospital Anxiety and Depression Scale (Arabic HADS; Al Aseri et al., 2015).

Depression and anxiety in PwD were measured by the Arabic Version of HADS (Al Aseri et al., 2015). It contains seven self-report items related to anxiety, as well as seven self-report items related to depression which can take 2 - 5 minutes to complete. Participants were asked to rate symptoms of anxiety and depression by indicating how often they have experienced each symptom in the past week on a Likert-type scale that ranges from 0 to 3. Scores for each subscale (anxiety and depression) range from 0 to 21 with scores categorized as follows: normal 0–7, mild 8–10, moderate 11–14, and severe 15–21.

Arabic HADS was found to be highly reliability and validity. The overall Cronbach alpha were (0.73) and (0.77) measures of internal consistency for anxiety and depression, respectively. Also, it was found to be a valid tool by obtaining two-factor solution according to HADS subscales (anxiety, and depression) using factor analysis, the result was a statistically significant correlation (r = 0.57; p < 0.0001) between the two subscales (Al Aseri et al., 2015).
# 4.4.5.3.5 Holden Communication Scale for persons with dementia (HCS; Strom, Engedal, & Grov, 2016)

Communication was measured by using HCS (Strom et al., 2016) after translation and back translation to Arabic (Arabic HCS). The details of the development psychometric properties of the Arabic HCS Scale are provided in Chapter 5. It comprises 12 items assessing conversation, awareness and knowledge, and communication which can take 2 - 5 minutes to complete. Each Arabic HCS item is assigned a score on a Likert-type scale from 0 to 4. Scores for the entire scale of all 12 items rang more difficulties with communication from 0-48, with a higher rating indicating a greater degree of communication difficulty. HCS was found to be highly reliable and valid. The internal consistency (Cronbach's a)=0.94, test-retest reliability was r=0.71, and the corrected item-total correlation ranged from 0.63 to 0.79 (Strom et al., 2016).

#### 4.4.5.4 *Quantitative Data Analysis Strategy*

Quantitative data were analysed using the Statistical Package for the Social Science Version 25.0 (IBM SPSS 25.0). In order to retrieve pieces of missing information, the researcher started by reviewing data for completeness and legibility. In addition, outliers were checked before entering and recording data in order to clean the data (Freeman & Walters, 2006). Additionally, the researcher selected 20% of the computerised data files randomly to proof against the original file to ensure the accuracy of the data file (Tabachnick & Fidell, 2001).

Descriptive statistics (means, standard deviations and frequency distributions) were used to identify the characteristics of the sample; the number of sessions attended; and the number of drop-outs (Polit & Beck, 2012). For each outcome measure, the distribution of the data was assessed for normality required for parametric statistical analyses. All data were checked for extreme values and boxplots were scanned for outliers. Non-parametric analyses were used if data were deemed to depart from normality.

In feasibility studies, it is not typical practice to conduct statistical tests (Arain, Campbell, Cooper, & Lancaster, 2010). However, tests were conducted to compare the differences between baseline scores and post-intervention scores of depression, communication, cognition, anxiety, and QoL in order to achieve the quantitative objective of this study. The significance level was set at p<.05. In accordance with the provisions of the UK Data Protection Act (1998), data will be stored for a minimum of seven years after the completion of the study at the University of Nottingham in order to be readily available to a licensing authority on request.

## 4.4.6 Qualitative Method

## 4.4.6.1 Research Objectives

The objectives of the qualitative study were to explore the participant's experiences of using digital RT in Jordanian care homes; and to explore the acceptability of the digital RT intervention in Jordanian care homes and suggestions for improvement.

## 4.4.6.2 Research Design

The qualitative process evaluations allowed for the investigation of participant's views on the intervention, the examination of any contextual factors and determination of processes that might have mediated any observed intervention effects (Wight & Obasi, 2002). In order to explore and understand peoples' perceptions and experiences of healthcare interventions, the use of qualitative methods using semi-structured interviews have been recommended to gain more understanding about the dynamics of participation (Riddoch, Puig-Ribera, & Cooper, 1998).

# 4.4.6.3 Sampling and Selection of the Cases

Residents and care home staff were included in this branch of the study with the aim of obtaining data from multiple perspectives that matched with the inclusion of two stakeholder groups (Cassar & Kiger, 2005). In order to generate a more comprehensive understanding of

the research phenomena, the purposive sampling technique provided a rich source of data (Creswell, 2012; Procter & Allan, 2006). Therefore, purposive sampling was used to select eligible residents and care home staff from each care home that met the objectives of the study and had participated in the study.

It has been suggested that there are no definitive parameters for the appropriate sample size in qualitative research; the selection of sample and size should be appropriate to answer the research question (Procter & Allan, 2006). However, it has been suggested that using sample 10 participants sample size might be considered as an adequate sample size to provide a rich source of data in order to generate a more comprehensive understanding of the research phenomena (Sandelowski, 1995). Therefore, 10-15 of residents and staff in Jordanian care homes were invited to be interviewed by using semi-structured interviews to have an adequate sample for certain kinds of to generate a more comprehensive understanding of the research phenomena and reach a data saturartion.

## 4.4.6.4 Data Collection Method

A qualitative process evaluation consisting of follow-up interviews had predetermined topics and open-end questions laid down in an interview schedule (Tod, 2006). This type of interview retains the flexibility necessary to follow issues raised by participants that had not been anticipated (Tod, 2006).

In relation to this study, semi-structured interviews were conducted to explore the feasibility and acceptability of the digital RT for PwD, and explain why the intervention might or might not work. This process used individual semi-structured interviews with residents and staff in Jordanian care homes. The feasibility was tested through the analysis of the following:

- Whether digital RT is delivered as planned in the care of PwD in Jordanian care homes.
- The number of PwD in two care homes who are eligible to participate in digital RT session.
- The willingness of people to participate.

- Whether the inclusion criteria are appropriate to recruit the target population.
- Whether participants complete the full programme (adherence).
- Whether any adverse events related to the intervention occur.
- Follow-up response rates (retention) and the level of missing data.
- Whether outcome measures are sensitive to change and their suitability for the evaluation of this intervention.
- The perceived burden to participants.

Topic guides for the two different types of participants (residents and staff in Jordanian care homes) were developed as explained in Table 13. Appendix (10) shows the semi-structured interview schedule for residents and staff in Arabic and English versions.

# Table 13: Topic guides for residents and staff interviews

	Topic guides for staff interview		Topic guides for PwD interview
٠	Whether staff thought the intervention was	•	Whether PwD enjoyed the
	beneficial, useful and easy to incorporate into the		intervention
	daily routine.	•	The barriers to participation in the
•	Perceived reasons for changes in outcomes.		digital RT programme, including
•	The willingness of healthcare professionals to		reasons for non-adherence, attrition
	recruit and suitability of the clinic for recruitment.		and missing data.
•	Whether the inclusion criteria were deemed	•	Perceived reasons for changes in
	appropriate.		outcomes.

The interviews took place one week after the post-intervention quantitative measures were taken. Each interview took approximately 30 to 60 minutes. It was audiotaped, with due regard for confidentially (discussed in the ethical considerations section).

# 4.4.6.5 Qualitative Data Analysis Strategy

A thematic analysis approach was utilised to identify key themes and NVivo (version 12) was used to organise the data. Qualitative data were coded and analysed by the principal researcher with guidance from expert researchers in qualitative research from the University of Nottingham (supervisors: PC, TC and HB). This thematic analysis followed guidelines suggested by Braun and Clarke (2006) (see Table 14). Thematic analysis was used to analyse and report the data thematically in order to organise and describe the data in rich detail (Braun & Clarke, 2006). All interviews in this study were conducted in Arabic language, audio recordings needed to be transcribed verbatim, and then translated into the English language after the analysis in order to preserve cultural nuances in the data during analysis (Chen & Boore, 2010). However, in order to get feedback from supervisors for academic purposes about the interview process itself, the principal researcher translated the transcripts of the first two interviews from Arabic to English. Two bilingual independent reviewers were consulted to compare the transcripts and translations in order to enhance the quality of the translating process and recognise inconsistencies that may need clarification as Cruz, Padilla, and Agustin (2000) suggested. After transcription, thematic analysis followed through the six phases of analysis of Braun and Clarke (2006) guideline. These six phases were: familiarisation with the data; generation of initial codes; searching for themes; reviewing themes; defining and naming themes in a code book; and producing the report. Table 14 summarises these six phases of Braun and Clarke (2006) guideline. Usually, both deductive (derived primarily from theory-driven) and inductive (derived primarily from the data) approaches were valued in the analysis of interview transcripts (Gale, Heath, Cameron, Rashid, & Redwood, 2013). An inductive approach arose purely from the data and thus was not anticipated in advance of data analysis. Therefore, there were all themes were derived inductively from the data in this study.

Table 14: The six phases of thematic analysis, adapted from Braun and Clarke (2006)

Phases	Process
Phase 1: Familiarisation with the data	The researcher was familiar with the depth and breadth of the content through reading; re-reading in an active way, and searching for meanings; note-taking or marking ideas for coding that the researcher then went back to in subsequent phases. Transcripts were read while listening to the recordings. A list of initial ideas was created based on common threads and patterns in the data.
Phase 2: Generating initial codes	The researcher organised data into meaningful groups as the process of coding. These initial codes were organised into potential themes which are broader. This process was done both manually and through a software programme. Generating initial codes manually was by using highlighters or coloured pens to indicate potential patterns. In using a software programme for generating code, the coding was by tagging and naming selections of text within each data item. In this process, data were initially coded & collated, and the researcher had a long list of the different codes were identified across the data set.
Phase 3: Searching for themes	This phase re-focused the analysis at the broader level of themes, rather than codes, involved sorting the different codes into potential themes, and clustering all the relevant coded data extracts within the identified themes. This phase included analysing codes and considering how different codes may combine to form an overarching theme; and starting thinking about the relationship between codes, between themes, and between different levels of themes and then organised into main themes and sub-themes. This phase was ended with a collection of candidate themes, and sub-themes, and all extracts of data that have been coded in relation to them.
Phase 4: Reviewing potential themes	In this phase, internal homogeneity and external heterogeneity were considered. Data within themes needed to cohere together meaningfully to achieve internal homogeneity. In addition, themes needed a clear distinction from each other to achieve external

	heterogeneity. This phase involved two levels of reviewing and refining themes.
Phase 5: Defining and naming themes	In this phase, the researcher defined and further refined the themes by identifying the essence of what each theme is about (as well as the themes overall), and determining what aspect of the data each theme captured. For each individual theme, the researcher reviewed names and definitions in order to ensure whether these themes generate clear names and definitions.
Phase 6: Final analysis and Producing the report	In this phase, the researcher provided a concise, coherent, logical, no repetitive, and interesting account of the story within and across themes.

# 4.4.6.6 *Trustworthiness in Qualitative Research*

In qualitative research, trustworthiness is important to evaluate its quality and worth (Lincoln & Guba, 1985a). It involves establishing credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985a). Each of these issues are noted in Table 15, along with a definition offered by (Lincoln & Guba, 1985a; Morse, 2015), and a summary of strategies employed to satisfy criteria. In order to demonstrate rigour in these parameters, this study has applied various strategies in order to demonstrate rigour in these parameters as described below.

# 4.4.6.6.1 Credibility

Credibility in qualitative research has been related to the concept of internal validity in quantitative research (Baxter & Eyles, 1997; Lincoln & Guba, 1985a; Morse, 2015). It concerns how well the research represents the participants, data, and actual phenomenon

under consideration (Morse, 2015). Moreover, it focuses more on the richness of information rather than the quantity of data (Morse, 2015).

Various strategies can be used to demonstrate credibility, including persistent observation, prolonged engagement with participants, time sampling, triangulation, member checking, and peer debriefing (Hadi & Closs, 2016; Krefting, 1991; Lincoln & Guba, 1985a; Morse, 2015). Many strategies have been applied in this study to increase the credibility of the research, including prolonged engagement with study participants, triangulation and peer debriefing.

Prolonged engagement with study participants has been recommended to gain their trust and establish rapport between the researcher and participants (Creswell, 2006; Hadi & Closs, 2016). It is important to enabling the researcher to get more in-depth data and explore the research phenomena comprehensively (Creswell, 2006; Hadi & Closs, 2016). In order to ensure that the researcher gained participants' trust and established rapport with the researcher in this research, the principal researcher implemented the intervention, did the qualitative interviews and participated in social activities in the care homes during the data collection period in this study.

Triangulation has been also recommended to ensure the credibility of qualitative studies (Creswell, 2006; Hadi & Closs, 2016). Triangulation in qualitative studies aims to reduce inherent bias associated with a single source, method or researcher (Hadi & Closs, 2016). It refers to using two or more related data sources, data collection methods or investigators to answer one research question (Krefting, 1991; Morse, 2015). In order to enhance the quality of the research, this study has applied the triangulation of data sources from residents and care home staff. In addition, the data from different sources were cross-checked throughout the data analysis and interpretation.

Peer debriefing is a method in which the researcher discusses the research methodology, data analysis and interpretations continuously throughout the research process with his/her peer (Hadi & Closs, 2016; Lincoln & Guba, 1985a). It is important to prevent bias throughout the study development, particularly for new researchers (Morse, 2015). Moreover, the peer

debriefing could provoke critical thinking, synthesise and see the pattern of the data and provide alternative/additional perspectives and explanations (Given, 2008; Hadi & Closs, 2016). In this study, the process of peer debriefing was applied and manifested in supervision meetings that held regularly around every month during data collection, in person and by Skype, WhatsApp messages and emails. The complete transcripts of two participants were read and discussed during the process of data collection and data analysis by the supervisors (second coder).

Member checking has also been recommended to ensure the credibility of qualitative studies (Creswell, 2006; Hadi & Closs, 2016). It might be conducted throughout the process of data collection to check that the researcher understands and interprets the participant responses correctly to get reliable results (Lincoln & Guba, 1985a; Morse, 2015). In order to enhance the quality of the research, this study has applied member checking by sending out a summary of the findings to participants for their comments prior to publication and dissemination.

## 4.4.6.6.2 Transferability

Transferability refers to the degree in which the research findings can have applicability in other contexts where the same phenomenon is found (Lincoln & Guba, 1985a; Morse, 2015). Transferability in qualitative research has been related to the concept of external validity in quantitative research (Lincoln & Guba, 1985a; Morse, 2015). It has been suggested that transferability can be achieved by providing thick and rich descriptions of the research context (Creswell, 2006; Hadi & Closs, 2016; Lincoln & Guba, 1985a). It requires the researcher to give sufficient and rich details about settings, sample characteristics and inclusion/exclusion criteria, data collection and analysis methods (Hadi & Closs, 2016). In order to achieve in-depth information of understanding on the group of people who experienced the phenomenon of interest, a purposive sampling strategy could be used (Hadi & Closs, 2016). In this study, the process of transferability was applied by adopting a purposive sampling strategy to select residents who had been clinically diagnosed with

dementia and care home staff who had at least six months experience of working in a care home.

# 4.4.6.6.3 Dependability

Dependability in qualitative research involves ensuring that the research findings would be consistent fashion and the same when conducting another study in a similar context (Lincoln & Guba, 1985a). It has been related to the concept of reliability in quantitative research (Lincoln & Guba, 1985a; Morse, 2015), being concerned with the consistency of the findings (Krefting, 1991).

It has been suggested that various strategies can be used to demonstrate dependability, including external audit, triangulation, stepwise replication, member checking, peer examination or code-recode procedure (Hadi & Closs, 2016; Krefting, 1991; Lincoln & Guba, 1985a). In this study, the process of dependability was applied and manifested in supervision meetings and triangulation. The findings from two perspectives (residents and care home staff) were compared during the data analysis to make sure both sources give the same results.

#### 4.4.6.6.4 Confirmability

Confirmability is referred to how the study findings are supported by the data collected to be logical (Morse, 2015). Confirmability in qualitative research has been linked to the concept of objectivity in quantitative research (Lincoln & Guba, 1985a; Morse, 2015). It has been suggested that there are various strategies can be used to establish confirmability in qualitative research, including audit trail, reflexivity, triangulation or external review (Krefting, 1991; Lincoln & Guba, 1985a). In this study, the process of confirmability was applied and manifested in using open coding and categories rather than pre-determined coding. Moreover, the study findings showed multiple quotations from many interviews to illustrate each category. Furthermore, confirmability was applied in using external review throughout data collection and data analysis by supervision meetings.

#### Table 15: Summary of interventions to establish trustworthiness

Criteria	Definition	Strategies employed to satisfy criteria	
Credibility	It concerns how well the research represents the participants, data, and actual phenomenon under consideration	<ul> <li>Prolonged engagement with study participants</li> <li>Triangulation</li> <li>Peer debriefing</li> <li>Member checking</li> </ul>	
Transferability	The degree in which the research findings can have applicability in other contexts where the same phenomenon is found	<ul> <li>A purposive sampling strategy</li> </ul>	
Dependability	Ensuring that the research findings would be consistent fashion and the same when conducting another study in a similar context	<ul><li>Supervision meetings</li><li>Triangulation</li></ul>	
Conformability	How the study findings are supported by the data collected to be logical.	<ul> <li>External review</li> <li>Data analysis by supervision meetings</li> </ul>	

# 4.4.7 Data Synthesis

Quantitative and qualitative data were collected concurrently and were analysed independently, so, merging data analysis through data comparison was applied in this study (Creswell & Clark, 2011). Summary tables will be used to present the findings of the quantitative, qualitative data in the next two chapters. Quantitative results will be first presented followed by the supporting findings of the qualitative analysis. Then, the process evaluation of the feasibility study chapter will be presented.

# 4.4.8 Reflexivity and conducting of data collection

Reflexivity refers to an awareness of the influence that the researcher has on the research process and outcomes, in terms of their actions, feelings and perceptions (Darawsheh, 2014). The principal researcher was consciously aware of the issues of reflexivity that could arise in this study as a researcher working among older people residing in care homes. As a researcher with extensive experience of carrying out RT for PwD, I have a variety of assumptions based upon my personal experiences and practice. For example, I am aware of the dementia conditions and the impact such conditions have upon an individual's quality of life. Residents tended to perceive me as a health care professional rather than a researcher due to my visits to the care homes prior to data collection, which could inhibit their participation in the study or which could make them reticent to voice critical experiences they feel may be disparaging to professionals or institutions. They also may perceive that negative information during their participation may affect the care they receive. However, the principal researcher has explained the details of the research and data collection to all participants and made sure that they understood that they could withdraw from the study at any time without giving any reasons, and participations, non-participation or withdrawal would not affect the service and care provided by care home staff.

In order to decrease the data collection bias in the quantitative part, two independent researchers (MO and KY) were recruited to collect the outcome measures at baseline and post-intervention (Schensul, Schensul, & LeCompte, 1999; Smith & Noble, 2014a). They are mental health nurses and were given sufficient description of all outcome measures. In addition, they were trained well by the principal researcher to use the study questionnaires for data collection in order to decrease the measurent bias (Smith & Noble, 2014a).

## 4.5 Ethical Consideration

It is essential to address ethical considerations when conducting research on humans, particularly the vulnerable groups who are at risk of psychological and physical harm (Polit & Beck, 2012). People with mental health problems, the terminally ill and frail older adults are considered as such (Gerrish & Lacey, 2006). Therefore, the researcher consciously avoided any risk of harm to study participants and also other care home residents, caregivers or relatives of people residing in care homes. The processes for doing so are outlined below.

#### 4.5.1 Ethical Approval Process

Ethical approval was obtained from the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of Nottingham (Ref: 110-1709). In addition, the Jordan

Ministry of Social Development Institutional Review Board (MSOD's IRB) was contacted to solicit permission to conduct research in the aforementioned institutions in the MOSD care homes, Jordan. Upon receiving permission to conduct the study from both ethical committees, the researcher contacted care home mangers for approval to conduct the study at each site. Without permission from the Research Ethics Committees, no data collection was undertaken and no people were approached (See Appendix 12; a, b, c and d).

# 4.5.2 Informed Consent

In introducing the study to the possible participants, the researcher stressed that no one should feel obliged or coerced to take part. The researcher distributed the participant information sheet to all participants (see Appendix 13). This sheet explained full details about the aim of the study, the data collection process, major potential benefits and ethical protocols, including anonymity and the right of participants to freely withdraw their totally voluntarily participation at any time without giving any explanation and without this affecting their care. Voluntarily participation was verbally restated prior to conducting the interviews. Furthermore, participants were provided with opportunities to ask questions or discuss queries related to the study before starting the interview.

The researcher used a consent form (see Appendix 14) to record consent to participate in this study. The potential benefits of participating in this study were declared to participants, such as this intervention might enhance their cognitive function, communication, depressive and anxiety symptoms, and QoL. Moreover, the researcher used the consultee assent for residents without capacity (see Appendix 15).

#### 4.5.3 Confidentiality and Data Protection

Confidentiality was emphasised by maintaining anonymity all through the research process. To achieve confidentiality by maintaining anonymity, the consent form and personal demographic data sheet were maintained separately. Participants' names and identities were coded as a unique code in quantitative data and transcribed as pseudonyms in qualitative

data. Therefore, the names and identities of participants were not be disclosed throughout the study and the researcher could not match up the codes and pseudonyms.

The researcher was the only person who had access to all participants' personal information. However, research data will be kept for a minimum of five years, the personal identifying information will be destroyed after the study end. All electronic data in softcopy from audio files and interview transcripts were made anonymous with participant identifiers stored in password-protected computers and files and all information collected during the data collection were stored in a secure and locked office. The data was used only for academic purposes, including discussion during supervision and conferences.

The researcher sent out a summary of the findings of quantitative and qualitative parts to participants for their comments prior to publication and dissemination. Any wording that may potentially identify individual staff or care homes were modified and removed from any publications.

Although the data from the interview was confidential, PwD who live in care homes who were at any risk of psychological distress or imminent harm to self or others may require a referral by the researcher to care home administrator and staff in order to administer appropriate care or manage their issue (Yin, 2014). The information sheet and consent forms explained any risk situations to self or others in which the principal researcher needed to disclose identifying information to health departments and other authorities. The number of residents who reported with emotional distress was reported in five residents in both care homes.

# 4.5.4 Emotional Distress

It is vital to secure the safety of and protect from harm vulnerable groups such as older adults or children when carrying out the research (Silverman, 2014). Therefore, the researcher considered the major potential risks which might influence the participants during the time of the intervention and data collection process. These risks included emotional or psychological distress during the intervention (Silverman, 2014). In an effort to minimise the

risk of emotional distress during this time, participants were encouraged to only recall positive memories and avoid negative memories. If participants found this intervention very stressful, they were encouraged to pause or stop the intervention and they were informed that they had the right to withdraw from the study at any time without reason. Then, the researcher assessed PwD if they were becoming distressed, anxious or low in mood. This could be indicated through changes in behaviour, or changes in co-operation with the study processes (Slaughter, Slaughter, Nichols, Holmes, & Martens, 2001). Moreover, the researcher observed the negative consequences after the intervention, such as feeling depressed or experiencing emotional distress in PwD. Five residents in both care homes were referred to care home staff and administrators for appropriate care as agreed with participants at the beginning of the study process. The researcher worked closely and collaborated with staff members in all both care homes to enhance access to the research settings and participants via rapport with gatekeepers, and to observe the consequences during and after the data collection processes.

In addition, it was important to consider the issues of confidentiality and safeguarding among participants who were being abused by a member of staff, family member or another resident. The results of their participation in the study, they will not be put in any undesirable position (Yin, 2014). Therefore, the researcher clarified with the participants at the beginning of the interview process when obtaining consent that, as a registered nurse, there was a responsibility to pass on such information to an appropriate professional who was involved in the organisation of the care arrangements i.e. potential risks to participants such as having moderate or severe depressive symptoms which was reported by the researcher to an administrator or staff of the care homes in order to provide an appropriate care. The next chapter of the thesis will present the psychometric testing of the translated Arabic HCS scale to measure communication among PwD.

# Chapter 5 Psychometric Properties of Arabic Holden Communication Scale for people with dementia Questionnaire

# 5.1 Introduction

The aim of the psychometric properties study is to confirm that the study tools are standardised and calibrated to assess the intended phenomena (Thabane et al., 2010). The general aim of this chapter was to test the psychometric properties of the Arabic version of Holden Communication Scale for people with dementia (PwD) (Arabic HCS).

This chapter discusses the objective of this psychometric properties study, the Arabic HCS scale, the process of cross-cultural adaptation of HCS, methods and procedure of development psychometric properties of the Arabic HCS, measure outcome, data analysis, results and discussion.

# 5.2 Objective of the Psychometric Properties Study

This chapter aimed to test the quality of the translated Arabic HCS Scale. This psychometric study aimed to validate and cross-culturally adapt the Arabic HCS scale.

# 5.3 Arabic version of Holden Communication Scale for PwD

In this study, the communication for PwD was assessed using the Arabic version of the HCS scale (Strom et al., 2016). The original HCS consists of 12 items designed to assess the conversation, awareness and knowledge, and communication (Strom et al., 2016). Each HCS item is assigned a score on a Likert-type scale from 0 to 4. Scores for the entire scale of all 12 items range from 0-48, with a higher rating indicating a greater degree of communication difficulty. The original HCS was found to be highly reliable and valid. The internal consistency (Cronbach's a)=0.94, test-retest reliability was r=0.71, and the corrected item-total correlation ranged from 0.63 to 0.79 (Strom et al., 2016). This section illustrates the process of cross-cultural adaptation of HCS, methods and procedure of development psychometric properties of the Arabic HCS.

#### 5.3.1 The Process of Cross-Cultural Adaptation of HCS

In order to develop the Arabic version of the HCS scale to measure communication for PwD, three phases were involved: obtaining copyright permission, the translation process, and the validation of the reliability of the translation scale (Beaton, Bombardier, Guillemin, & Ferraz, 2000). The researcher started by contacting the author of this scale (Benedicte Sorensen Strom) in order to obtain copyright permission for using the HCS scale and translating it into an Arabic version (see Appendix 16). After getting this permission, the translation process was started. According to the fact that the guideline aims to minimise the issues of translation and cultural adaptation of the scale, the guideline for the stages of cross-cultural adaptation by Beaton et al. (2000) was used as a guideline to translate the HCS scale into Arabic version.

There were five stages of cross-cultural adaptation adapted from Beaton et al. (2000) including initial translation by two or more people, synthesis of the translations, back translation, expert committee and testing reliability of the Arabic version HCS scale.

# 5.3.1.1 Stage 1: Forward translation

In order to start the forward translation stage and produce the two independent translation reports, it is recommended to include at least two bilingual translators whose mother tongue is the target language (Arabic), and they also should have different profiles and academic backgrounds (Beaton et al., 2000). This stage involved two independent bilingual translators, one of whom is aware of the concepts of the communication scale (Dr Shaher Hammaideh) and the other translator is a professional expert in English and Linguistics (Associate Professor Baker Bani-kahir). They both worked independently and separately to translate the scale from English to Arabic version. Then, they produced two written reports of the translation that they completed (T1) and (T2).

#### 5.3.1.2 Stage 2: Synthesis of the translation

The two Arabic initial translations (T1 and T2) were then compared by the principal researcher. If there was any inconsistency, a third translator was consulted, Mr. Abdullah Abu-keet, a bilingual translator (Beaton et al., 2000). After the synthesis, the common translation (T-12) version of the scale (Arabic version) was produced.

#### 5.3.1.3 Stage 3: Back translation

This stage focused on working with the T-12 Arabic version of the HCS scale and, totally blinded to the original version, to translate it back into the original language (English). It is recommended that the back translation stage should include at least two bilingual translators whose mother tongue is the original language of the scale (English) (Beaton et al., 2000). The back translation in this study was undertaken by Associate Professor Ali Jamil, whose mother tongue is Arabic and has lived in the UK since 1990, who specialises in the area of dementia care. The second translator was Mr Mike Forum, whose mother tongue is English and who specialises in the Arabic culture and linguistics. Both translators have no knowledge of the wording on the HCS scale from the original English version. They both worked independently and separately to back translate the scale from Arabic to English. Consequently, the back-translations (BT1 and BT2) were produced by two translators.

## 5.3.1.4 Stage 4: Expert committee

The expert committee comprised four bilingual translators (forward and back translators), and the researcher. This expert committee aimed to review the Arabic translation of the scale and reach a consensus and agreement on any inconsistency. The committee reviewed all materials including the original HCS tool, and each translation (T1, T2, T12, BT1, BT2) together with corresponding written reports to reach a consensus on any inconsistency. The prefinal Arabic version of HCS was produced for pretesting of reliability of the scale.

#### 5.3.1.5 Step 5: Pretesting

The prefinal Arabic HCS scale was tested for test-retest reliability (between two to nine days) and internal consistency using Intraclass Correlation Coefficient (ICC) and Cronbach's alpha respectively with 15 older people. Misspellings and other minor discrepancies were corrected before field-testing.

## 5.3.2 Methods

#### 5.3.2.1 Setting and Population

The pilot study was conducted in two care homes, more details on which are provided in Chapter 4. The pilot study was conducted over approximately one week before starting the actual data collection between 27<sup>th</sup> November 2017 and 4<sup>th</sup> December 2017.

During the pilot study, there were 95 residents living in the two care home when the data were collected. The inclusion criteria of PwD who can participate in the pilot study were based on the inclusion criteria used in the main study as described in chapter four. A purposive sampling of fifteen residents participated in the pilot study in order to test the internal consistency of the scales.

# 5.3.2.2 Data Collection

One week before the beginning of the pilot data collection, the researcher contacted the care home managers by phone to inform them about the purpose of the pilot study, the research procedure and the eligibility criteria of the participants, the time period for conducting a pilot study and the main study.

Subsequently, 15 eligible residents, who first expressed their interest to participate in the pilot study to the researcher were approached to explain all information related to the pilot study purpose and procedures. They were also informed that without giving a reason, they could withdraw or refuse to participate in this study at any time.

The researcher then asked them to sign a consent form to show their willingness to participate (see Appendix 14). After receiving informed consent, the participants were interviewed (face-to-face) by the researcher for approximately 10 minutes using the Arabic HCS scale. Participants of the pilot study were deemed eligible to be included in the main study only if there were no revisions required to the Arabic HCS measures.

#### 5.3.2.3 Ethical Considerations

The researcher consciously followed the same ethical considerations that described under ethical considerations in Chapter 4, section 4.5. These ethical considerations included the ethical approval process, informed consent, data protection and confidentiality and emotional distress.

## 5.4 Measure Outcome

## 5.4.1 Internal Consistency

Reliability in statistics is defined as the ability of study measurement to consistently measure the concept under study (Coughlan & Ward, 2007; Polit & Beck, 2012). Internal consistency is one of the tests that is frequently used to assess the reliability and consistency of results across items within a test (Polit & Beck, 2012). It is assessed by using Cronbach's alpha coefficients (Polit & Beck, 2012). The reliability of the Arabic version of HCS scale in this pilot study was assessed by evaluating internal consistency using the Cronbach's alpha coefficients. It aimed to determine the degree to which related items of a questionnaire measure the same concept. The normal range of Cronbach's alpha coefficients is between 0.00 to +1.00 (Polit & Beck, 2012). A high Cronbach's alpha coefficients value reflects a higher internal consistency (Polit & Beck, 2012). It has been suggested that a Cronbach's alpha coefficient value 0.7 or more is considered to indicate good internal consistency in a questionnaire (Rattray & Jones, 2007).

#### 5.4.2 Test-retest Reliability

Test-retest reliability is one of the tests frequently used to assess the reliability of a scale (Coughlan & Ward, 2007; Polit & Beck, 2012). Test-retest reliability is measured by calculating the correlation between the two scores that conducted by the same person on two different occasions using the intraclass correlation coefficient (Pallant, 2013). A high testretest value reflects a more reliable scale (Pallant, 2013). This pilot study assessed the reliability of the Arabic HCS scale by conducting the test-retest reliability between two to nine days after the recruitment process in the pilot study.

#### 5.5 Data Analysis

The data of the pilot study was analysed using the Statistical Package for the Social Science Version 25.0 (IBM SPSS 25.0). Descriptive statistics (means, standard deviations and percentages) were used to summarise the demographic data from the pilot study (Polit & Beck, 2012). The intraclass correlation coefficient was calculated to assess test-retest reliability (Weir, 2005). Cronbach's alpha coefficient was calculated to determine the internal consistency reliability (Rattray & Jones, 2007). This statistic was used to determine whether constituent items are measuring the same domain (Rattray & Jones, 2007).

#### 5.6 Results

#### 5.6.1 Demographic Data

Demographic data were collected from 15 participants. The characteristics of participants in the pilot study within both care homes are shown in Table 16. PwD in the pilot study had a mean age of 62.27 years (SD=4.682 years and range= 55-70 years). Gender distribution was approximately equal (53.3% female). The sample included participants with dementia of varying degrees of severity (73.3.7% mild; 13.3% moderate and 13.3% severe). The level of education was approximately equal in both care homes (53.3% less than high school education).

Characteristic	Value
Age (years), mean (SD), range	62.27 (4.682), 55-70
Gender, n (%)	
Male, n (%)	7 (46.7%)
Female, n (%)	8 (53.3%)
Severity of Dementia	
Mild, n (%)	11 (73.3%)
Moderate, n (%)	2 (13.3%)
Severe, n (%)	2 (13.3%)
Level of education,	
Less than high school education, n (%)	8 (53.3%)
High school education and more, n (%)	7 (46.7%)
Care home,	
Dar AlDiafeh nursing home, n (%)	10 (66.7%)
Darat Samir Sahmma nursing home, n (%)	5 (33.3%)

Table 16: Demographic characteristics of the participants in the pilot study

# 5.6.2 Reliability of the Scale

The Arabic HCS scale was reported to have an acceptable level of internal consistency with an overall Cronbach's alpha of 0.89. High levels of internal consistency were evident in most sub-scales, with Cronbach's alpha values of 0.94, 0.95, and 0.96 for conversation, awareness and knowledge, and communication respectively.

Table 17 shows the results of the correlated item to total correlation and Cronbach's alpha coefficient with the deletion of items from the translated scale (Arabic HCS). All subscales were reported with high internal consistency, comprising conversation, awareness and knowledge, and communication, with Cronbach's alpha coefficients of 0.94, 0.95, and 0.96 respectively.

Table 17: Correlated item to total correlation and Cronbach's coefficient alpha of item deleted from Arabic HCS scale

			Cronbach's
			Alpha if
		Corrected Item-Total	Item
Items		Correlation	Deleted
	Conversation sub-total scor	re, Cronbach's alpha = 0.941	
1.	Response	0.868	0.888
2.	Interest in past events	0.844	0.889
3.	Pleasure	0.813	0.889
4.	Humour	0.874	0.887
	Awareness and knowledge sub-to	tal score, Cronbach's alpha = (	0.956
5.	Names	0.887	0.887
6.	General orientation	0.913	0.888
7.	General knowledge	0.913	0.888
8.	Ability to join in games etc	0.954	0.886
	Communication sub-total sc	ore, Cronbach's alpha = 0.963	
9.	Speech	0.849	0.889
10	. Attempts at communication	0.854	0.888
11	. Interest and response to objects	0.904	0.889
12	. Success in communication	0.919	0.888

In addition, the internal consistencies and test-retest reliability (after two to nine days) of the entire scale of the Arabic HCS revealed high levels of internal consistency with reporting a split-half coefficient of 0.94 and ICC of 0.97. The results of reliability testing for the Arabic HCS scale are shown in Table 18.

#### Table 18: Reliability testing for Arabic HCS scale

	Internal			
	consistency	Internal	Test-retest	
	(Cronbach's	consistency (split-	reliability	
Items	alpha)	half coefficient)	(ICC)	
Arabic HCS entire scale	0.89	0.94	0.97	
Conversation sub-total score	0.94		0.96	
Awareness and knowledge	0.95		0.97	
sub-total score				
Communication sub-total	0.96		0.94	
score				

#### 5.7 Discussion

The HCS scale was blind back translated into the Arabic language by four bilingual translators and then tested for its psychometric properties. The findings showed that the Arabic HCS scale had acceptable internal consistency for the entire scale, with a reported Cronbach's alpha of 0.89. All subscales were analysed for internal consistency reliability. The results revealed the reliability between 0.89 and 0.96. Moreover, the results of test-retest reliability after two to nine days demonstrated a higher value of internal consistency, with a reported ICC of 0.94 to 0.97. A high level of reliability was also reported in the original study of psychometric evaluation of a HCS scale, with the internal consistency (Cronbach's alpha)=0.94, test-retest reliability was r=0.71, and the corrected item-total correlation ranged from 0.63 to 0.79 (Strom et al., 2016). Overall, the Arabic HCS scale was found to have a high level of internal consistency and test-retest reliability. These results of reliability were comparable with the original study of HCS.

In this pilot study, there is a limitation that needs to be undertaken into account. It has been suggested that the number of participants to be included in the pilot study will depend on the parameters to be estimated (Lancaster, Dodd, & Williamson, 2004). They suggested using a general rule of thumb to take 30 participants or more to adequately estimate parameters in the pilot study (Lancaster et al., 2004). However, the sample size in this pilot study is very small, consisting of only fifteen PwD in order to test the reliability of the Arabic HCS scale due to the limited time available. This will limit the representativeness of the findings.

#### 5.8 Conclusion

The Arabic HCS scale was found to be highly reliable and valid. The translation of the HCS scale showed a high acceptable level of internal consistency of the scale, comparable to the original version. In addition, it demonstrated high reliability and validity for measuring communication among PwD residing in Jordanian care homes. Therefore, this scale was appropriate to apply in order to measure the communication among PwD residing in Jordanian care homes multiply and presiding in Jordanian care homes in the main study. The next chapter of the thesis will present the quantitative results of the main study.

#### Chapter 6 Quantitative Results

#### 6.1 Introduction

The previous chapter presented the psychometric testing of the Arabic Holden Communication Scale (HCS) questionnaire for people with dementia (PwD). This chapter will present the quantitative results of the study. The chapter begins with an overview of the recruitment, response rate, and follow up rate. Subsequently, a discussion of an overview of participant baseline characteristics, intervention uptake and adherence are presented. This is followed by a discussion of the missing data, data checking, normality and outliers, and outcome measures at pre and post-intervention, followed by effect size and a summary of quantitative results.

## 6.2 Recruitment

The participants were recruited from two care homes in Amman (Dar Aldiafeh nursing home and Darat Samir Shamma care home). The recruitment was undertaken between 1st and 21st December 2017. The total number of participants that were assessed for eligibility by the researcher was 95. There were 35 residents not eligible to participate. Reasons for noneligibility included they were deemed too unwell to participate as determined by care home staff (n=17), and they had a diagnosis of an additional psychiatric disorder: schizophrenia (n=10), MDD (n=8) as determined by a consultant psychiatrist and care home staff.

## 6.3 Response Rate

In total, 60 participants were approached to take part in the study and all 60 agreed to take part and were recruited into the study (response rate =100%, see discussion on this in Chapter 9, section 9.4.1). All of whom were recruited and identified by care home managers and staff. The majority of participants were recruited following a referral from a care home manager (60%), with the remaining participants recruited by GPs or nurses in both care homes, 30% and 10% respectively. Thirty five residents were from Dar Aldiafeh nursing home, and 25 were from Darat Samir Shamma care home.

#### 6.4 Follow-up

Of the 60 participants who agreed to take part 45 completed the intervention (75%). Fifteen participants were not available for post-intervention data collection and were subsequently excluded from the analysis due to unavailable data. Specifically, six residents left the care homes and were transferred to other care homes, four residents died during the intervention delivery process and five were reported with emotional distress and withdraw from the study. At post intervention, the total lost to follow-up was 25%. Figure 9 shows the participants' flow through the study.



Figure 9: Flow chart of recruitment participants through the study

#### 6.5 **Baseline Characteristics of the Sample**

Baseline data were collected from all 60 participants. This is shown in Table 19. Study participants (PwD) had a mean age of 66.9 years (SD=7.4 years and range= 55-85 years). Gender distribution was approximately equal (51.7% female). The sample included participants with dementia of varying degrees of severity (46.7% mild; 33.3% moderate and 20.0% severe). The level of education for almost two-thirds of the study participants in both care homes was less than high school education (63.3%). The representativeness of the sample will be discussed more in Chapter 9, section 9.2.

The two settings were compared and p values were calculated to indicate whether there was a statistically significant difference between them with regard to participant demographics and characteristics. The sample characteristics of participants in the two care homes were compared using Chi-squared tests. There were no statistically significant differences in any of the demographic characteristics between care home residents who lived in Dar AlDiafeh nursing home and Darat Samir Shamma nursing home (please see Table 19).

Characteristic	Value	Differences between two care homes (P value)
Age (years), mean (SD), range	66.9 (7.4), 55-85	.320
Gender, n (%)		.275
Male, n (%)	29 (48.3%)	
Female, n (%)	31 (51.7%)	
Severity of Dementia		.731
Mild, n (%)	28 (46.7%)	
Moderate, n (%)	20 (33.3%)	
Severe, n (%)	12 (20.0%)	
Level of education,		.124
Less than high school education, n (%)	38 (63.3%)	
High school education and more, n (%)	22 (36.7%)	
Care home,		
Dar AlDiafeh nursing home, n (%)	35 (58.3%)	
Darat Samir Sahmma nursing home, n (%)	25 (41.7%)	

#### Table 19: Baseline characteristics of participants in both care homes

## 6.6 Intervention Uptake and Adherence

Of the 60 participants, three, representing 5% of the sample, did not receive the intervention (attended no digital RT sessions) after the baseline data was taken. The reasons for this were that two participants died before starting the intervention and one participant was transferred to another care home.

Of the 57 participants who attended at least one session, 12 participants (21.1%) dropped out. Session attendance was used as a measure of intervention adherence. Median session

attendance for those who received the intervention was 80% (median=8, IQR=4). Figure 10 presents the histogram of intervention adherence.





# 6.7 Missing Data

All returned questionnaires were checked for missing data. In cases where forms were returned with items missing, the independent researchers were contacted as soon as the questionnaires were received, chased up the item response with residents and asked them to complete the missing items. In one case where a single item was missing from one of the measures (OPQoL) at pre-intervention and the independent researcher was unavailable to complete this item, then the principal researcher calculated the mean of the responses and added it as a response item (Strube, 1985).

# 6.8 Data Checking

Quantitative data were input into Statistical Package for the Social Science Version 25.0 (IBM SPSS 25.0). The researcher selected 20% of the computerised data files randomly to proof against the original file to ensure the accuracy of the data file (Tabachnick & Fidell, 2001).

When errors were identified, they were highlighted and changed. Additionally, outliers were checked before entering and recording data in order to clean the data (Freeman & Walters, 2006). No outliers were identified at baseline and post-intervention. The raw data was subsequently checked to confirm accuracy.

# 6.9 Normality and Outliers

The principal researcher assessed the distribution of the variables by checking for statistical tests for normality and visual methods at pre and post-intervention time. These included continuous variables of the study: cognition, quality of life (QoL), communication, depression and anxiety.

For the statistical test, the Kolmogorov-Smirnov and Shapiro-Wilk were used to test the assumption that the sample data was drawn from a normally-distributed population (Polit & Beck, 2012). The results of this statistical test are shown in Table 20. Total scores of SLUMS, HCS, OPQoL and HADS (anxiety and depression) were used for cognition, communication, QoL, anxiety and depression respectively.

# Table 20: SPSS output for Kolmogorov-Smirnov and Shapiro-Wilk tests of normality

# **Tests of Normality**

	Kolmogorov-Smirnov <sup>a</sup>		Shapiro-Wilk			
	Statistic	df	P value	Statistic	df	P value
At Pre-intervention						
SLUMS**	.166	45	.003	.936	45	.015
HCS	.183	45	.001	.913	45	.002
OPQoL	.147	45	.016	.947	45	.038
Anxiety (HADS)	.154	45	.009	.941	45	.023
Depression (HADS)	.152	45	.010	.908	45	.002
At Post-intervention						
SLUMS	.146	45	.018	.899	45	.001
HCS	.166	45	.003	.914	45	.003
OPQoL	.108	45	.200*	.938	45	.018
Anxiety (HADS)	.170	45	.002	.950	45	.052
Depression (HADS)	.122	45	.091	.935	45	.014
Changes in scores betwe	en pre an	d post inte	ervention			
SLUMS	.116	45	.155	.951	45	.057
HCS	.139	45	.030	.972	45	.339
OPQoL	.084	45	.200*	.977	45	.514
Anxiety (HADS)	.132	45	.046	.972	45	.336
Depression (HADS)	.113	45	.183	.933	45	.012

\*. This is a lower bound of the true significance.

\*\*. SLUMS: Saint Louis University Mental Status; HCS: Holden Communication Scale for persons with dementia; OPQoL: Older People's Quality of Life questionnaire; HADS: Hospital Anxiety and Depression Scale.

a. Lilliefors Significance Correction

The Shapiro-Wilk and the Kolmogorov-Smirnov were statistically significant (p< 0.05) for all questionnaires at pre-intervention, and for cognitive function, communication and anxiety at post-intervention. As such this indicated violation of the assumption of normality. However, the Shapiro-Wilk and the Kolmogorov-Smirnov tests showed non-statistical significance in the change scores between baseline and post intervention (p>0.05) for all questionnaires except communication, indicating that all of these scores except communication were normally distributed.

In addition, normality was checked visually via the frequency distributions (histograms) of pre, post and change scores. This method may provide a visual judgment about gaps in the data and outliers outlying values and about whether the distribution is bell-shaped curve (Ghasemi & Zahediasl, 2012). A bell-shaped curve has the greatest frequency of score in the middle with smaller frequencies towards the extremes, this is described as a normal distribution curve (Pallant, 2013, 2016). Furthermore, if scores are skewed to the left or right, the variables are not normally distributed. The histograms in Appendix 17 provide information about the distribution of scores on the continuous variables of the study; cognition, quality of life (QoL), communication, depression and anxiety respectively at pre and post-intervention. Figures (11-15) provide information about the distribution of change scores on the study variables.



# • The change in scores between pre and post-intervention









Figure 13: Change in OPQoL scores between pre and post intervention



Figure 14: Change in anxiety scores between pre and post intervention


Figure 15: Change in depression scores between pre and post intervention

In summary, all variables including cognition, QoL, communication, depression and anxiety are reasonably normally distributed as histograms showed that most variable scores occurred in the centre with tapering out towards the extremes. These results were discussed with Dr Andrea Venn, medical statistician and considered as normally distributed. Repeated Measures (T-test) were conducted to investigate the impact of using digital RT (pre and postintervention) on cognitive function, communication, anxiety, depression, and QoL. Outliers were assessed by checking the tails of the distribution curves, comparing means with the 5% Trimmed Mean, checking at the extreme values and observing the box plot. There were no outliers were found to have a significant effect on the results of the analysis tests and no cases needed to be removed.

#### 6.10 Outcome Measures at Pre and Post Intervention

The mean scores and standard deviations (SD) for all main outcome measures are displayed in Table 21.

Table 21: Mear	Scores	and	SDs	for Main	Outcome	Measures
					0.0000	

Measure		Pre- intervention Mean (SD)	Post- intervention Mean (SD)	Difference in mean change at 95% CI (SD)	t-value	p value
SLUMS		14.6 (4.9)	18.3 (5.8)	3.7 (2.4)	10.4	.000
OPQOL-brie	ef-13	38.4 (12.8)	44.6 (12.9)	6.2 (4.8)	8.6	.000
HCS		27.5 (10.9)	21.4 (12.9)	-6.2 (4.2)	-9.9	.000
HADS	Anxiety:	12.3 (4.4)	7.9 (4.7)	-4.4 (2.9)	-10.1	.000
	Depression:	12.2 (4.5)	8.5 (4.8)	-3.7 (2.6)	-9.6	.000

# 6.11 Effect Size

Effect size aims to understand the magnitude of differences found in the findings (Schafer & Schwarz, 2019; Sullivan & Feinn, 2012). This study uses Cohen's d (1988) in order to detect the effect size. The effect size can be classified according to Cohen (1988) into:

- Small effect size if Cohen's d between 0 to .3
- Moderate if it is between .3 to .7
- Large effect size if Cohen's d between .7 to 1
- Very large effect size if Cohen's d more than 1

Cohen's d (1988) The effect size Cohen's d can be calculated directly from the t-value and the number of participants using the formula provided by Rosenthal (1991):

# Cohen's $d = t/\sqrt{n^1}$

Cohen's d for all outcome measures are presented in Table 22 which illustrates the effect sizes for all used outcome measures.

	t-value	n	Cohen's d
SLUMS for cognition	10.4	45	1.5: very large effect size
HCS for communication	-9.9	45	1.5: very large effect size
OPQOL-brief-13 for QoL	8.6	45	1.3: very large effect size
HADS for anxiety	-10.1	45	1.5: very large effect size
HADS for depression	-9.5	45	1.4: very large effect size

Table 22: Effect size for all used outcome measures

It was found that all outcome measures have a very large effect size. These effect sizes for all used outcome measures will be discussed more in Chapter 8, section 8.6.2.

# **6.12 Impact of the Intervention on Outcome Measures**

In order to determine the likelihood of changes in outcome measures, the difference in mean scores from baseline to post-intervention were calculated using repeated measures t-tests.

# 6.12.1 Cognitive Function

Of the 45 PwD who completed the pre-intervention SLUMS scale to measure cognitive function, the mean SLUMS was 14.6 (SD= 4.9). At post-intervention, the mean SLUMS was

<sup>&</sup>lt;sup>1</sup> t: t value, n: number of sample size

18.3 (SD= 5.8). Although, there are no standard definitions for this parameter to identify the cut-off score for cognitive decline, there was a statistically significant increase in mean SLUMS scores between pre and post-intervention 3.7 (SD= 2.4; t (45) =10.4; p=0.000), suggesting improvements in cognitive functioning.

#### 6.12.2 Quality of Life

Of the 45 PwD who completed the pre-intervention OPQOL brief-13 scale to measure the QoL, the mean OPQoL was 38.4 (SD= 12.8). At post-intervention, the mean OPQOL-brief-13 was 44.6 (SD= 12.9). Although, there are no standard definitions for this parameter to identify the cut-off score for poor QoL, there was a statistically significant increase in the mean OPQOL-brief scores between pre and post-intervention 6.2 (SD= 4.8; t (45) =8.6; p=.000), suggesting improvements in QoL after using digital RT for PwD.

## 6.12.3 Communication

Of the 45 PwD who completed the pre-intervention HCS scale to measure the communication, the mean HCS was 27.5 (SD= 10.9). At post-intervention, the mean HCS was 21.4 (SD= 12.9). Although, there are no standard definitions for this parameter to identify the cut-off score for communication decline, there was a statistically significant decrease in the mean HCS scores between pre and post-intervention 6.2 (SD= 4.2; t (45) = -9.9, p=.000), suggesting improvements in communication skills after using digital RT for PwD.

## 6.12.4 Anxiety

The results suggest that there is a statistically significant reduction of anxiety after using digital RT for PwD. The cut-off score for anxiety according to the HADS is 10 and above (Al Aseri et al., 2015). Of the 45 PwD who completed the pre-intervention HADS scale to measure anxiety, the mean HADS for anxiety was 12.3 (SD= 4.4) which indicated mild anxiety. At post-intervention, the mean HADS for anxiety was 7.91 (SD= 4.7) which indicated non-clinical levels of anxiety. There was a statistically significant decrease in the

mean HADS for anxiety between pre and post-intervention 4.4 (SD= 2.9; t (45) = -10.1, p=.000), suggesting reductions in anxiety symptoms.

# 6.12.5 Depression

The results suggest that there was a statistically significant reduction of depression after using digital RT for PwD. The cut-off score for depression according to the HADS is 10 and above (Al Aseri et al., 2015). Of the 45 PwD who completed the pre-intervention HADS scale to measure depression, the mean HADS for depression was 12.2 (SD= 4.5) which indicated mild depression. At post-intervention, the mean HADS for depression was 8.5 (SD= 4.8) which indicated non-clinical levels of depression. There was a statistically significant decrease in the mean HADS for depression between pre and post-intervention 3.7 (SD= 2.6; t (45) = -9.6; p=.000), suggesting reductions in depression symptoms.

# 6.13 Summary

This study provides preliminary evidence supporting the value of a digital RT to improve cognitive function, communication, QoL and anxiety and depression scores. There were statistically significant improvements in scores of cognitive function, communication, anxiety, depression, and QoL from pre to post-intervention of using digital RT. This chapter explored that all these outcomes are sensitive to change after using digital RT for PwD. These quantitative results will be discussed in details in Chapter 9. The next chapter will present the qualitative findings.

#### Chapter 7 Qualitative Findings

## 7.1 Introduction

The previous chapter in this thesis demonstrated preliminary evidence supporting the feasibility of a digital reminiscence therapy (RT) to improve cognitive function, communication, quality of life (QoL), anxiety and depression scores. This chapter will present the qualitative findings which begins with giving details about the characteristics of the people who participated in this aspect of the study. Subsequently, themes and sub-themes are outlined. This is followed by a summary of the qualitative findings.

#### 7.2 Interviewee Characteristics

Qualitative interviews were conducted with 21 participants from the two care homes in Jordan, comprising 14 residents (eight residents from Dar AlDiafeh Nursing home, and six residents from Darat Sammir Shamma) and seven care home staff (four staff from Dar AlDiafeh Nursing home, and three staff from Darat Sammir Shamma). Half of the resident participants were male (7/14). The mean age of the resident participants was 65.8 years (SD = 5.8, range 58-75 years). Of the resident participants, two-thirds of recruited resident participants have mild dementia and one-third of them have moderate dementia. The mean Saint Louis University Mental Status (SLUMS) score for the resident participants was 20.8 (SD = 2.4, range 17-24) which indicated dementia of mild severity (see the classification of SLUMS in Chapter 4). All resident participants reported using informal reminiscence in their lives. The triggers that were used for their informal reminiscence include seeing old photos (5/14), talking about the past (3/14), watching old films on the TV (3/14), listening old songs (1/14) and listening to Quran Kareem (2/14). In terms of storing these triggers, half of the resident participants stored these memories using their phones (3/14), paper-based albums (3/14), and using audiotape recordings (1/14). The other half did not store these memories (7/14)

More than half of the care home staff participants were female (4/7). Their mean age was 42.4 years (SD = 4.7, range 35-50 years). All staff participants were married. The staff

participants were nurses (4/7), social worker (1/7), and managers of the care homes (2/7). The individual descriptive information is presented in Table 23 for resident participants and in Table 24 for care home staff participants. All names used for both resident and staff participants are pseudonym names.

Resident name (ID)	Gender	Age	Severity of dementia
R01: Ahmed	Male	65	Mild, SLUMS*=24
R02: Khalid	Male	70	Mild, SLUMS=23
R03: Ali	Male	72	Moderate, SLUMS=18
R04: Sham	Female	66	Mild, SLUMS=21
R05: Suzan	Female	75	Moderate, SLUMS=18
R06: Aref	Male	60	Mild, SLUMS=21
R07: Zinab	Female	58	Mild, SLUMS=22
R08: Ashraf	Male	60	Mild, SLUMS=23
R09: Asyia	Female	71	Moderate, SLUMS=19
R10: Maysa	Female	70	Moderate, SLUMS=18
R11: Hadel	Female	60	Mild, SLUMS=21
R12: Sami	Male	60	Mild, SLUMS=23
R13: Abed	Male	62	Mild, SLUMS=23
R14: Hiba	Female	72	Moderate, SLUMS=17

Table 23: Individual resident participants' characteristics

\*SLUMS: Saint Louis University Mental Status

# Table 24: Individual staff participant's characteristics

Staff name (ID)	Gender	Age	Marital status	Occupation
S01: Omar	Male	35	Married	Registered nurse
S02: Salem	Male	50	Married	Manager of care home
S03: Farah	Female	45	Married	Registered nurse
S04: Hanan	Female	44	Married	Manager of care home
S05: Mohammad	Male	42	Married	Registered nurse
S06: Manal	Female	41	Married	Social worker
S07: Sana	Female	40	Married	Registered nurse

#### 7.3 Themes, Sub-themes and Codes

The qualitative study in this thesis aimed to explore the participant's experiences of using digital RT in Jordanian care homes; and to explore the acceptability of the digital RT intervention and suggestions for improvement. In order to achieve these aims, thematic analysis as outlined by Braun and Clarke (2006) in Chapter 4, section 4.4.6.5 was used to analyse the qualitative data set from both staff and resident participants together. A total of four themes were generated from 11 sub-themes applied to the data. These four themes outline the necessary features of the digital RT application to be used successfully to the PwD and their caregivers (easy to use, having a facilitative environment, having interesting content and having a positive impact on perceived QoL). The descriptions and explanations of the themes, sub-themes and codes are supported by verbatim quotes from interview participants. All quotes are anonymised and referenced by the participant's ID number. The key findings are summarised in Table 25.

Themes	Sub-themes	Codes
Easy to use	The flexibility of the intervention delivery	Using many properties in technology
		Sitting for a long duration of time
		Capacity to reschedule missed sessions
	Simple format	Easy transitions between pages
		Background colours
		Similar format for all pages
Facilitative	Influence of distractions	
environment	Getting to grips with digital- touch screen technology Availability of guidance	Using unfamiliar technology
Interesting	The structure of the content	
content	Variety in format	
	The familiarity of the generic content	
Positive impact on QoL	Enhancing communication and cognitive abilities	
	Enhancing relationships	
	Positive changes in psychological and emotional aspects	

# Table 25: Overview of themes, sub-themes and codes

#### 7.3.1 Theme 1

## Easy to Use

Cognitive and physical impairments occurring in dementia were associated with difficulties when using digital-touch screen technology. However, through considering the concept of ease of use design as mentioned in Chapter 3, these difficulties can be alleviated and, in some cases eliminated. In this study, resident and staff participants felt that digital RT sessions were developed and delivered in a design that was easy to use in order to match the needs of PwD. They reported that these difficulties were alleviated by allowing flexibility of the intervention delivery and using a simple format.

#### 7.3.1.1 *The Flexibility of the Intervention Delivery*

Considering the changes and declines that affect PwD, the delivery of the digital RT application is very important. Overall, the majority of residents and staff participants expressed positive feelings about the design which accommodated a broad range of individual preferences and abilities. This sub-theme brings together the codes of using many properties in technology to counteract the effects of physical impairments occurring in dementia, sitting for long duration time, and the capacity to reschedule missed sessions.

#### 7.3.1.1.1 Using Many Properties in Technology

It was observed that the resident participants had experienced declines in their visual and auditory abilities as a result of ageing. However, it is very important to consider these declines during designing and implementing the digital RT application. Some resident participants tended to articulate positive feelings about using many properties in technology which were used to counteract the effects of physical impairments occurring in dementia. Ahmed, a male resident, expressed how he felt about having the ability to use 'zoom in' property to counteract his visual impairment: 'I really liked the fact that I could zoom in and widen the screen size so that I could see things because I can't see unless I zoom. I don't have good eyesight so I used it in all the sessions' (R01).

Alongside, Suzan, a female resident, expressed a similar view about having the ability to use 'volume button' to counteract her auditory impairment:

'It was great that I could put up the volume because my hearing isn't so good' (R05).

Likewise, Hadel, a female resident, expressed a similar view about using these properties in technology to meet her needs:

There are so many really perfect things in it [this programme] like being able to zoom into the screen, put up or down the volume, look at good quality pictures...I could see and hear everything so well' (R11).

The previous quotations in this section illustrate the capacity of the technology to be used easily in order to meet the needs of PwD with regards to their physical impairments occurring in dementia. Likewise, some staff participants expressed a similar view about using these properties in technology to meet the resident's needs. Sana, a female staff member, stated:

'It was really good that you thought of some of the issues residents have and helped them overcome these when using the application; like being able to zoom in and out, for example, and still enjoy good picture quality. The fact that they could lower and increase the volume; these things really helped' (S07).

# 7.3.1.1.2 Sitting for a Long Duration of Time

Due to many physical and mental changes that happen to PwD, some residents and staff participants commented on how the resident participants felt about the long duration of the intervention. Maysa, a female resident, stated:

*'I don't like it when there is a long session time. The more time that is needed the more concentration required and that is difficult'* (R10).

Hiba, a female resident, expressed a similar view about having long duration time of intervention, and had noticed that it made her tired:

'Sessions two times a week is too much work, I felt tired after that' (R14).

Moreover, Omar, a male staff member, expressed a similar view about delivering the session twice a week and having a long session time:

'I think it makes them tired when they have to sit down for a long time, so I think it's better when the sessions are shorter in length' (S01).

As a result of these concerns, some participants felt that it would be better if the length of the intervention was shorter and less frequent. Maysa, a female resident, expressed this opinion:

'Sometimes, the duration was long, I think is better to just use shorter clips... If it is just a short clip, it's much easier to concentrate...' (R10).

Some resident participants felt decreasing the number of digital RT sessions to one session per week would help to increase their commitment to the sessions. Abed, a male resident stated:

'I think one session every week would be enough because there's so much in each session [pictures, audios, and videos]. I also have other things to do and I have to plan beforehand and prioritize things' (R13).

This quotation illustrates the importance of considering the needs of PwD to have usable digital RT application for PwD. Interestingly, it appears that the majority of proposed modifications to the digital RT intervention were regarding having fewer sessions per week and less time at each session.

# 7.3.1.1.3 Capacity to Reschedule Missed Sessions

Some of the resident participants were keen to have any missed sessions rescheduled. They tried to highlight how the sessions were positive and they tried not to miss any benefits of these sessions. Suzan, a female resident, illustrated the positive feelings about being able to reschedule missing sessions:

'I missed one session because I was sick but I was able to take it again once I was well. They [the sessions] gave me a great feeling of confidence' (R05).

In summary, the flexibility of the intervention delivery is considered to be an important aspect in determining how resident participants are able to use digital RT sessions easily. Most resident and staff participants in this study expressed the positive feeling about the flexibility of the intervention delivery.

## 7.3.1.2 *Simple Format*

It has been found that PwD have difficulties in understanding how to use technology as mentioned in Chapter 3. Therefore, eliminating any ambiguity and complexity of the digital RT application for the resident participants is very important. Overall, the majority of both resident and staff participants expressed positive feelings about the format of the technology used to deliver the RT. They found the design easy to use and understand, regardless of the user's experience, knowledge, language skills, or current concentration level. This sub-theme brings together the codes of simple transitions, the use of calm background colours, visually interesting format, and using a similar format for all pages.

# 7.3.1.2.1 Easy Transition between Pages

There was an acknowledgment from residents and staff participants that the digital RT application used simple transitions between pages. Some of the resident participants felt the transition between pages was very easy and logic. Suzan, a female resident, perceived this easy transition between the application pages:

`To me, the sessions were very easy and straightforward and I could take part without any problems...I don't need anything needs to be changed about the sessions' (R05).

Moreover, some resident participants performed the required tasks more quickly and efficiently because of the simple transition between the pages. Abed, a male resident stated:

'It was really easy and simply take part in the sessions. I could even understand the information on my own. I really enjoyed the sessions and feel like I achieved

something. Listen!! Now I know how to use it [application] and it is really simple' (R13).

Moreover, the majority of staff participants expressed a similar view about having a simple transition feature between pages as it improved the ease and quality of interaction with technology. Farah, a female staff member, described how the transition between pages was so simple:

'The application's format is very easy to use and follow, I found it easy to move and go from page to page in it' (S03).

# 7.3.1.2.2 Similar Format for all Pages

There was acknowledgment from one resident and one member of staff about using the same format for all pages of the session. They felt that using of similar format for all pages decreased the demand on working memory and cognitive requirements that declines in PwD. Sami, a male resident, expressed the opinion that using a similar format for all pages improved his engagement in the session:

'Another thing I really liked it, all parts had the same format. This made it very easy and straightforward to understand and I enjoyed the sessions much more as a result' (R12).

Similarly, Manal, a female member of staff, tried to highlight how the using similar format for all pages was positive as it encouraged residents' participation:

'I saw how you used the same format in all of the pages that we looked at in the sessions...I think it really helped them [residents] to understand how to use the application better and they could remember how to do it more easily' (S06).

Overall, the use of a simple format was an important aspect in determining how the digital RT application was developed and delivered in order to meet the needs of the PwD. The majority of residents and staff in this study expressed the positive feelings about this. The simple transitions between pages, calm background colours and similar format for all pages were important issues contributing to the appealing and simple format.

# 7.3.1.2.3 Background Colours

Some residents and staff participants appreciated the readability of the interface because of the very calm background colours of the digital RT application. They expressed valuing the background colours of the digital RT application to improve its readability. Hadel, a female resident, told the researcher how she felt about using very calm colours:

*The programme was perfect. Really easy to read and lovely use of colours in the background'* (R11).

Moreover, Salem, a male care home manager expressed a similar view about using very pleasant background colours of the digital RT application:

'I really liked using this technology in the sessions. Everyone could use the application quite easily. The colours used in the background and all the images were really, really nice' (S02).

In summary, ease of use is outlined as one of the necessary features of the digital RT application to be used with efficiency, effectiveness and satisfaction by resident participants in both care homes. The flexibility of the intervention and simple format were notably important issues contributing to the ease of use aspects in order to match PwD needs.

#### 7.3.2 Theme 2

## **Facilitative Environment**

It has been suggested that a supportive environment is very important to implement and deliver the digital RT intervention to enhance their engagement (Gowans et al., 2004; Subramaniam et al., 2014). Overall, the majority of residents and staff participants expressed positive feelings about the environment in which the sessions were delivered. This theme brings together the subthemes of the influence of distractions, using unfamiliar technology and the availability of guidance.

## 7.3.2.1 Influence of Distractions

Residents and care home staff in this study suggested that the setting was crucial for making the digital RT application simple to use. Whilst some resident participants expressed positive feelings about the environment in which the sessions were conducted, the other of resident participants had negative feelings about it. Suzan, a female resident, told the researcher how she felt about the environment of the delivery:

'There was a lovely atmosphere and it was great to take part in the session' (R05). Omar, a male member of staff, also expressed a similar point-of-view:

'I really enjoyed these sessions. It was a great area [environment] for taking part' (S01).

All of the previous quotations in this section illustrate the positive feeling towards the appropriate setting to facilitate session delivery by using a comfortable environment and a professional researcher involvement who support them to use the intervention.

Whilst a majority of residents and staff participants expressed positive feelings about the session environment, some resident participants in the study had negative feelings about being distracted and having a lot of interruptions in the care home. Asyia, a female resident,

clearly complained about the distraction sources in terms of giving medications during the session delivery:

'I really liked all of the sessions with you. The only complaint I have is that there were a lot of distractions during the meetings because we're in a care home. Like, sometimes, the staff nurses were going around handing out medication and things like that' (R09).

Alongside, Maysa, a female resident, added other sources of distraction:

'Sometimes there were sounds and noises that interrupted the sessions, mostly coming from around in the care home. Like, people were talking loudly or there were noises from staff doing different jobs around the place' (R10).

Likewise, Farah, a female member of staff, expressed a similar view about having a lot of interruption during the delivery of the sessions:

'There were a lot of distractions in the care home that disrupted the sessions...usually the distractions were due to medication being given to residents, staff walking around, and staff and visitors chatting loudly nearby where we gathered' (S03).

# 7.3.2.2 Getting to Grips with Digital-Touch Screen Technology

Whilst PwD had difficulties understanding technology, this was compounded when the technology was unfamiliar to them (Ancient & Good, 2013; Castilla et al., 2013; Or & Tao, 2012; Wandke et al., 2012). The sub-theme of getting to grips with digital-touch screen technology was relevant to residents and care home staff in both care homes in this study. This sub-theme brings the code pertaining to participants' reflections on the intervention in terms of using unfamiliar technology.

## 7.3.2.2.1 Using Unfamiliar Technology

The majority of residents and care home staff in this study expressed negative attitudes about learning how to use the unfamiliar digital-touch screen technology as it needed a lot of concentration and effort to understand it. Some resident participants highlighted how this affected their participation. Suzan, a female resident, explained her feelings about using unfamiliar technology:

'I think we [residents] need a lot more concentration, it [using digital-touch screen technology in the sessions] makes me feel quite tired' (R05).

Whilst some resident participants mentioned the negative feelings towards using this unfamiliar technology. Khalid, a male resident, added some physical problems associated with this issue:

' this [using new technology] gives me a headache...Doesn't it?!! I really want to learn and know more... but my brain can't handle it... two sessions every week made me tired...it was a job to remember everything' (R02).

# 7.3.2.3 Availability of Guidance

The availability of guidance during using digital RT was appreciated by residents and staff in both care homes in this study. The participants appreciated the guidance that was provided by the researcher. Some resident participants perceived that the availability of guidance during using digital RT was helpful and played an important part in supporting them not to skip any sections of the sessions. Maysa, a female resident, told the researcher how she felt about the availability of guidance during using digital RT:

'I enjoyed the sessions [guided reminiscence sessions] from the beginning. The guidance I got in the sessions was really helpful, as I am a beginner and I needed help. No sections are skipped...I learned that it is really important to go through all the sections correctly' (R10).

Moreover, some resident participants in the study tried to highlight how the involvement of the researcher in the session delivery was positive because it normalised their experience and encouraged participation. Aref, a male resident, expressed his feeling about the researcher involvement in the session delivery that: 'I really enjoyed the person-to-person chatting in the sessions. It made me remember my things from my life. You were so friendly to talk to and we always had great chats that made me enjoy taking part so much' (R08).

Similarly, some staff in the study expressed a similar view about the researcher involvement in the session delivery. Mohammad, a male staff member, stated:

'It was very easy to understand and use all of the app information. When I had a question or didn't understand something, I could ask you directly' (S05).

Moreover, some resident participants felt that the availability of guidance during using digital RT influenced their attendance, causing them to not miss out of any benefits of digital RT application. Hadel, a female resident, reflected her appreciation toward the availability of guidance during using digital RT:

'I liked it [guidance] because the support during these sessions was great. You don't miss out on one good thing you provided [benefits] when there's supervision' (R11).

Additionally, some resident participants added that the availability of guidance for them while using digital RT potentially motivated them to use and adhere to the technology correctly. Ashraf, another male resident, identified the importance of guidance and support during using digital RT:

'I felt there was enough support during the sessions and this helped me participate...technology was difficult to use...I knew I had the help of a supervisor (you) throughout the sessions and this helped me take part well...I also knew that I could contact you if I needed to' (R08).

Similarly, Omar, a male member of staff, expressed a similar view, mainly relating to having adequate guidance and support during the delivery of the sessions made the technology easy to use:

'It was easy to understand how to use the technology because there was a lot of help at hand...I knew I could ask you if I had a problem or didn't understand something' (S01). Particularly, some staff participants discussed the importance of guidance and support to facilitate overcoming difficulties experienced in gaining access to the technology as resident participants struggled to cope with the digital-touch screen technology. Farah, a female member of staff, explained her perception of the help offered to resident participants during the delivery of the sessions:

'You are trying to help residents who all understand things in different ways and have different levels [of ability]. So, some of them are well able to do many things and others aren't. Those are the ones who need a lot of help' (S03).

In addition, Sami, a male resident, reflected the importance of supervision them to facilitate overcoming difficulties experienced in which the device kept going to sleep. He would have liked the duration of the showing time to have been longer:

'It kept going to sleep. You helped me during that but I wish that this could be fixed, it would be so much better if it could last longer' (R12).

However, while some resident participants perceived the guidance and support during the session's delivery as one factor helping them feel able to use the technology easily, other resident participants commented that it did not help. They identified that the problem was with their memory decline. Hiba, a female resident, described this difficulty:

'You showed me how to use it [application] and you helped me. I learned how to use it, but I keep forgetting how to use it when I haven't used it for a week' (R14).

In summary, a facilitative environment is outlined as one of the necessary features of the digital RT to be used successfully by both PwD and their caregivers in care homes and enhancing their engagement with the intervention. The majority of residents and staff in this study expressed positive feelings about this aspect. The influence of distractions, getting grips to the technology, and availability of guidance were notably important issues contributing to the facilitative environment aspect in order to match the PwD needs.

## 7.3.3 Theme 3

## **Interesting and Relevant Content**

Overall, the majority of residents and staff in the study felt that they were willing to use digital RT intervention because it had interesting and relevant content. The resident participants in both care homes felt that the content of the intervention was relevant to them. This theme brings together the sub-themes pertaining to participants' reflection on the intervention in terms of the structure of the content, the method of delivery, the familiarity of the generic content, the relevance to the personal life and memories of the residents and innovative approach.

## 7.3.3.1 The Structure of the Content

There was an acknowledgment from participants that the content was organised and structured reflecting the life stages of the participants. Some resident participants highlighted how this aspect of the sessions was positive as it encouraged their participation and adherence to the sessions. Sami, a male resident, illustrated his experience of using organised and structured sessions:

'I really liked the way that I could see all of the past memories in the order of my life, starting with my childhood and throughout my family life up to now in my elder years...Really, it was a great experience. All of my life stages were organised together based on how I have lived...I realised at the end that I had a great life. Really, the sessions were great' (R12).

Likewise, Salem, a male care home manager, expressed a similar view about having structured and organised sessions as it stimulated the resident's participation:

'The sessions were organised around their [resident participants] life and the experiences they have had. This was what they went through in all the sessions...I really liked them [the sessions]' (S02).

The participants, on the whole, demonstrated the positive feelings towards having structured and well-prepared sessions according to the life stages of the resident participants.

# 7.3.3.2 Variety in Format

Overall, participants noticed and for the most part appreciated that the content was delivered via different forms of multimedia. Some resident participants had positive feelings about using this multimedia. Ahmed, a male resident, told the researcher how he felt about this:

'I liked that I could...listen to music, change the size of images and remember all of the different parts of my life again...There were lots of pictures and lots of other features used which help older people like me [people with dementia] and this helped me really enjoy it all' (R01).

Additionally, some resident participants felt that the variety of presentations added interest to the content. One example of this was Ali, a male resident, who stated:

'It [the delivery of content] was lovely to look at because of all the pictures' (R03).

Similarly, Mohammad, a male staff member, commented:

'All of the different types of media used in the sessions meant that everyone [resident participants] really enjoyed them and had a great time. As a result, the app is really lovely to look at and use.' (S05).

Moreover, Hiba, a female resident, alluded to the notion of the benefits of using multimedia to deliver RT sessions:

'I liked all the different photos and clips we saw when we were looking at my life history...it [using multimedia] made me feel so happy and I wasn't sad anymore' (R14).

This quotation illustrates there were positive benefits of using multimedia to deliver RT sessions which enhanced the adherence to the sessions. The participants, on the whole, demonstrated positive feelings towards using multimedia to deliver RT sessions.

# 7.3.3.3 The Familiarity of the Generic Content

Some participants were happy to use generic yet familiar content during their RT sessions. They highlighted how familiar generic content was positive as it encouraged their participation. Zinab, a female resident, demonstrated the positive feelings towards having familiar generic content during RT sessions:

*'I really prefer well-known everyday pictures and music because I am so familiar with them, it's easy to fall back to them'* (R07).

Moreover, Sami, a male resident, highlighted how this aspect of the sessions was positive as it encouraged their participation and adherence to the sessions:

'Using familiar pictures, music and videos made it really enjoyable. It was great fun and easy to understand and taking part in the sessions' (R12).

Many staff members expressed a similar view concerning the use of familiar generic RT content. Farah, a female staff member, expressed how the using familiar content encouraged the resident participants' participation:

'all of the material was easy to understand and I could relate to it...I think the familiarity of pictures and music encouraged more people to take part' (S03).

Moreover, Manal, a female staff member, illustrated the positive feelings of resident participants towards having familiar generic content during RT sessions as it encouraged their remembering:

*The memories were so commonplace and general that everyone could relate to them. Using material like this improves the experience for the participants and helps them remember more'* (S06).

Whilst the previous participants of residents and staff mentioned their positive feelings about using familiar generic content, other resident participants suggested that the use of their personal memories would make it more attractive. Khalid, a male resident stated:

'The sessions [RT content] used a lot of familiar pictures, music and videos. All of the material was well-known to me...it helped knowing what was expected from me when I took part in these sessions. I really liked the content but I think it would be better if some personal memories were also included.. I think this would make it look great' (R02).

Moreover, Omar, a male staff member, supported this view:

'It would be better if they [residents] could have some personal memories to put in so that these sessions could be more effective... I suggest using personal items (photos, videos).' (S01).

This quotation illustrates the importance of using personal memories of resident participants to have a more attractive digital RT application for them. Although some resident participants expressed the positive feelings of using familiar and generic memories, others proposed modifications to the digital RT intervention were regarding the ability to upload personal memories to this digital RT.

## 7.3.3.4 Innovative Approach

There was an agreement from staff participants that using digital-touch screen technology to deliver RT sessions was a new and novel way which was not used before. There was an acknowledgment from most of them about the value of using this way to deliver RT sessions. Omar, a male staff member described that about using of digital-touch screen technology deliver RT:

' using this type of technology was totally new to me and I wasn't sure what to expect...I wanted to come just to see what other people were dealing with and coping with...It turned out to be great fun and I was really comfortable; I really liked it. I have always loved things are new and technical' (S01).

Alongside, Manal, a female staff member, supported this view:

'I love the idea of using past memory digital technology with past memories and I think it will really help them [resident participants] and improve their lives...I saw it helped them with their memories, it was amazing' (S06).

In summary, using interesting and relevant content is considered as one necessary feature of a digital RT intervention to be successful to both PwD and their caregivers. The majority of residents and staff in this study expressed positive feelings towards this aspect. This aspect can be contributed by many issues including using a very structured and organised way to deliver familiar generic content of memories by using multimedia.

# 7.3.4 Theme 4

## **Positive Impact on QoL**

Previous studies found that many of the PwD experienced poor quality of life (Alzheimer's Society, 2018d; Monroe, Herr, Mion, & Cowan, 2013; NHS, 2017a; Nowrangi, Lyketsos, & Rosenberg, 2015). Residents and staff in the study were asked to reflect on any changes or impact that they had noticed either during or since completion of the intervention. Most of them reported enhancements in their cognitive function, communication, relationships between staff and residents, and emotions which finally have a positive impact in their QoL. Therefore, this theme comprises the sub-themes that are related through the specific aspects of the intervention that were particularly valued by participants in terms of enhancing their cognitive function and communication abilities, enhancing relationships, and positive changes in psychological and emotional aspects.

# 7.3.4.1 Enhancing the Cognitive Function and Communication Abilities

Resident and staff participants reported positive changes that were broadly encapsulated under the umbrella of enhancing abilities. These positive changes included enhancements in cognitive function and enhancing communication skills.

## **Improvements in Memory**

Most of resident and staff participants tended to articulate that the digital RT appeared to improve their cognitive function in that it stimulated and triggered their past memories. They told the researcher how they felt about using life stages in the digital RT session. Ahmed, a male resident, described his feeling about that:

'That stuff made me think about some memories I had and I could remember some things I couldn't before, like some places, names and even people. It really helped me to remember' (R01).

These quotations illustrate the positive feeling towards using digital RT which improved their remembering things. Similarly, Ali, a male resident, also reflected that the improved cognitive function they experienced may have acted as a catalyst to improvements in other areas he was having difficulty with:

' Really, I felt so much better because I could remember things I did well in life' (R03).

Moreover, Hanan, a manager of one of the care homes, expressed a similar view:

'This application could really help residents with memory problems because they have trouble talking to people and remembering what was said. This could really help them to remember and communicate' (S04).

Alongside, Sana, a female staff member, expressed that digital RT usage had improved residents' memory which led to improving in their quality of life:

'I think that the application gave them [resident participants] the chance to..... improve their memories .. Overall, it improves their quality of life so we will definitely use it again in our routine care for them.' (S07).

# **Enhancing Communication**

Most residents and care home staff participants tended to articulate positive feelings towards using digital RT to address this decline. Khalid, a male resident, explained that digital RT usage had increased his desire to be more engaged with fellow residents and staff to be more talkative and resulted in more frequent contacts by his staff in his care home. He pointed out that:

'Now, when I am sitting with someone, I'm different; I'm more talkative. I want to talk with people here' (R02).

Moreover, Ali, a male resident, also reflected that the improved communication he experienced may have acted to improve other areas he was having difficulty with,

'Now, when I come into the sitting room, I'm happy to talk to people...I'm not afraid to talk and can chat more easily. I'm calmer now that I can chat' (R03).

In addition, Zinab, a female resident, commented on how the photos and videos encouraged her communication and interaction:

'Looking at everything really made me want to try to speak to everyone and I realised I could speak to everyone more easily. The different things we looked at [pictures and clips] really helped me to understand and I could chat more easily than before' (R07).

In the same way, most of the staff participants noted that using this digital-touch screen technology to deliver RT improved residents' communication skills and conversations. Omar, a male staff member, stated:

'I saw that they [resident participants] spoke more when they were using the smart technology because it gave them a structured topic of conversation. So it was clear to me that this process helped them communicate' (S01).

Alongside, Sana, a female staff member, expressed that digital RT usage had improved residents' communication which led to improve their quality of life:

'I think that the app gave them [resident participants] the chance to have better and more enjoyable conversations with other people.... Overall, it improves their quality of life so we will definitely use it again in our routine care for them.' (S07).

# 7.3.4.2 Enhancing Relationships

Care home managers in both care homes tended to articulate positive feelings about using digital RT in enhancing the mutual respect between staff and residents. Salem, a care home manager, reported seeing PwD in a new light since completion of the intervention:

'Once I finished going to these sessions, I realised that I knew a lot more about residents and I understood them now differently. I know now that this type of technology can help to improve the lives of them [resident participants] and benefit their relationships' (S02). Furthermore, Hanan, a care home manager, also reflected that facilitating enjoyable shared memories and experiences by using digital-touch screen technology may have acted to encourage mutual respect between them and residents:

'Once the sessions were over, I realised that staff and residents [participants] to have better relationships and more respect for each other by helping them [resident participants] remember good memories and times in their lives would improve their life quality.' (S04).

This quotation tended to articulate the positive feelings towards using digital RT in improving residents' quality of life since the completion of the intervention by enhancing the relationships between residents and staff in the study.

# 7.3.4.3 Positive Changes in Psychological and Emotional Aspects

Residents and staff in the study reported positive changes that were broadly encapsulated under the umbrella of psychological and emotional changes. These positive changes included improvements in mood, optimism and feeling enjoyment.

# **Improvements in Mood**

Most resident participants in both care homes tended to report positive feelings about using digital RT in improving their moods. Ashraf, a male resident, expressed his feeling after completing the digital RT sessions:

'Once I had finished the sessions...I remember using it [application]...[and] it makes me happy. I feel rested and I can sit down feeling happy and relaxed. I'm feeling more positive and can have more fun...I guess it's just changed my mood from being depressed and sad to feeling happy most of the time. At the moment, I am able to laugh and see the humour in things' (R08).

In addition, some resident participants experienced that the improvements in mood during the delivery of sessions could have increased their involvement with the sessions. Zinab, a female resident, stated about that:

'I'm feeling so relaxed and I have a great feeling of accomplishment that I achieved something in my life. The whole experience kind of motivated me to taking part. I'm in a great mood and I feel very positive about things' (R07).

Interestingly, some resident participants experienced that the improvements in mood during the delivery of sessions could have increased their attendance at the sessions. They typically associated this increasing their adherence to the sessions with attending them again. Aref, a male resident, stated:

'I will use it again because I feel so much better these days. I didn't miss one session and attended them all because they were so interesting; so many nice pictures that made me feel good to look at... It makes me feel happy and I want to do it again so that I can feel happy again' (R06).

Moreover, Hadel, a female resident, typically associated with the improvement of her mood after taking part in the sessions with the feeling of peace and more expressing her feelings:

'Once I finished the sessions, I was happy and calm and could deal with things better. I also felt more relaxed and at peace in myself because I had talked about happy memories from my life...I could go into a room and feel good...That makes me happy because I can enjoy talking now and express myself. It really relaxed me' (R11).

In the same way, most of the staff participants expressed a similar view about residents' mood improvement since completion of the intervention. Manal, a female staff member, expressed that digital RT usage had improved residents' mood:

'After we finished these sessions, they [resident participants] were a lot calmer and could deal with things more easily. The sessions could really help to reduce their anxiety and depression and could help them [resident participants] feel a lot more secure in themselves; help them feel safe and content' (S06).

Alongside, Sana, a female staff, expressed that digital RT usage had improved residents' mood which led to improving their quality of life:

'I think that the application gave them [resident participants] the chance to...reduce anxious and depressed feelings that they have. It improves their quality of life so we will definitely use it again in our routine care for them.' (S07).

# **Feelings of Accomplishment and Enjoyment**

Some resident participants described that taking part in the digital RT sessions provided them with feelings of accomplishment. Zinab, a female resident, typically associated this feeling of accomplishment with feeling much better about herself:

'I was more and more relaxed after each session because I felt I had really done something with my life. I feel so much better because I talked about all the great things I did in my life' (R07).

Moreover, some resident participants felt a sense of accomplishment through what they had accomplished at the sessions. With Asyia, a female resident, reflected that her feelings that she can use and attend the sessions easily,

'The sessions were easy and only twice a week, so I really gained something out of them. It felt great having something to do...I guess, I really looked forward to the sessions. They were easy to follow and take part in, like talking but with different pictures and songs' (R09).

Some resident participants also reflected their feelings of accomplishment and enjoyment by doing and achieving something that they never did that before. Aref, a male resident, commented on how talking about something never talked before,

'It was a different type of experience, coming to the sessions and looking at your tablet and talking about the past. I could sit down and talk about things I didn't remember talking about before. I felt really happy and could enjoy things afterwards...it felt great that I could do it' (R06).

Furthermore, some resident participants experienced feelings of accomplishment as a result of what they had achieved at the sessions. Maysa, a female resident, reflected:

'I really liked the sessions because I got the chance to take part in something that helped me remember the past...Probably after the fourth or fifth session, I was going to bed feeling so good and I was feeling much more relaxed. It was really great to feel so good again' (R10). Alongside, Khalid, a male resident, typically associated this feeling of enjoyment with feeling pleasure and relaxed,

'I really enjoyed it and I was relaxed most of the time. I wasn't as tense or worried anymore...it [the content] made me feel happy and relaxed because it was so good to talk about things I had achieved in my life' (R02).

In summary, a positive change in QoL is an important aspect that participants had noticed after completion of the intervention. Most residents and staff in this study stated that they were positively affected by their participation in the intervention. Enhanced communication and cognitive abilities, relationships, and positive changes in psychological and emotional aspects were important issues contributing to a positive change in QoL.

#### 7.4 Summary

The objectives of the qualitative study were to explore the participant's experiences of using digital RT in Jordanian care homes; and to explore the acceptability of the digital RT intervention and suggestions for improvement in Jordanian care homes.

Although there were some minor challenges with using the unfamiliar technology, the majority of participants were very positive about the digital RT intervention in terms of ease of use, having a facilitative environment, having interesting content, and a positive impact in their QoL that participants recognise. The findings implied that digital RT is acceptable for this sample of PwD and was delivered as planned in the care of PwD in Jordanian care homes. Chapter eight will present the process evaluation of this feasibility study.

**Note**: all interviews were conducted in the Arabic language and the analysis was conducted in the English language. Conducting data analysis in the different languages in which it was collected could interrupt the flow of conversation and be distracting for the respondent and interviewer (Smith, Chen, & Liu, 2008; van Nes, Abma, Jonsson, & Deeg, 2010). In addition, some of the quotes in this are perhaps not as might be expected with regards to the language used (van Nes et al., 2010). Therefore, it is acknowledged that some qualitative

findings might have been misinterpreted through the analysis process as a result of the translation process. This will be discussed more in Chapter 9, section 9.6.2.

#### Chapter 8 Process Evaluation of the Feasibility Study

#### 8.1 Introduction

Previous chapters in this thesis have highlighted the development of a theory-based digital application to deliver reminiscence therapy (RT) for people with dementia (PwD), the methodology and the procedure that were used in the study in order to assess the feasibility and acceptability of this theory-based RT application for PwD. The primary aim of this thesis was to explore the feasibility and acceptability of a theory-based digital application to deliver reminiscence therapy (RT) for people with dementia (PwD). This is the first study to evaluate the feasibility of using digital-touch screen technology to deliver RT for PwD in Jordanian care homes. In addition, the secondary objective of this feasibility study was to determine the likelihood of changes in outcome measures and to identify the most appropriate outcome measures to evaluate the delivery of digital RT to PwD in Jordanian care homes to be used in a subsequent definitive trial.

Feasibility studies play an important role in the next generation of intervention development (Jago & Sebire, 2012). It has been emphasised the importance of performing process evaluations alongside the effect evaluation in the Medical Research Council (MRC) frameworks (Craig et al., 2013). Process evaluation of the intervention documents each research process in detail and can help to explain why an intervention did or did not work and how it can be optimised (Reelick, Faes, Esselink, Kessels, & Olde Rikkert, 2011). Moreover, it allows appropriate interpretations and conclusions to be drawn about negative or positive results and can explain the discrepancies between expected and observed outcomes (Reelick et al., 2011).

This chapter begins by discussing details about the process evaluation method of the feasibility study and its components in order to evaluate both the intervention and the research processes. Then, evaluation and conclusions are presented.

#### 8.2 Process Evaluation Method

According to Moore et al. (2015), there is agreement that guidance is required and necessary for the conduct of process evaluations for complex intervention to understand why it was or was not successful. However, there is no one size guideline that fits all methods and frameworks which have been used (Moore et al., 2015).

In order to conduct this process evaluation for this study, Reelick et al. (2011) standardised framework was chosen for the current study. This framework provides comprehensive and systematic guidance for process evaluations at the development and feasibility evaluation stages (Reelick et al., 2011). This process evaluation used mixed-methods to evaluate both the intervention and the research processes. There are three main components are evaluated by this framework including the study sample; the data collection process; and the way the complex intervention was carried out (Reelick et al., 2011). These components appropriately addressed the current research objectives to focus on the acceptability of the intervention and its evaluation by examining the quality and quantity of what is delivered, rather than making conclusions about the effectiveness of the intervention (Moore et al., 2015). Table 26 shows each main evaluation component and its related measures and variables assessed adapted from Reelick et al. (2011).

# Table 26: Process evaluation components and related process measures of an intervention adapted from Reelick et al. (2011).

Process	Process	Process Variables
Components	Measures	
Research	Recruitment rate	Number of eligible residents in target
processes:		population
Study sample		Number of participants from the sample of
		eligible PwD
		Number of participants versus aimed number
	Facilitators and	<ul> <li>Motivation for participation</li> </ul>
	barriers to	<ul> <li>Reasons for non-participation</li> </ul>
	recruitment	• Experience of recruitment: time taken to recruit
	process	
	Follow-up rate:	Number of participants completing follow-up
	Attrition rate	versus number started
	Barriers and	Reasons for drop-out
	facilitators for	<ul> <li>Motivation for continued participation</li> </ul>
	follow-up	
Research	Completeness of	Number and characteristics of missing data
Processes:	data collection	Reasons for missing data
Data collection		Feasibility of outcome measures to detect
process		change over time
	Barriers and	Rate of questionnaire completion
	facilitators for	<ul> <li>Time needed to collect and analyse data</li> </ul>
	data collection	
Intervention	Delivery of the	Participant satisfaction
processes:	intervention	
Intervention	Barriers and	Reasons for diverging from, or applying
implementation	facilitators for	(planned) components
	delivery of	Experience of implementation: researcher
	interventional	reflections
	components	
	Adherence to	Number of sessions followed
	interventional	Intervention components (partly) followed
	components	Compliance to individual recommendations
	Barriers and	Motivation for compliance and attendance
	facilitators for	Reasons for lack of compliance and/or
	adherence to	attendance
	interventional	
	components	
	Experience of the	Participants' satisfaction
	interventional	Perceived acceptability
	components	Perceivea benefit
		Kecommendations for implementation of the digital PT appriance
		uigital KT Sessions
		Strong and weak aspects of the intervention
		Adverse events
#### 8.3 Research Process

Evaluation of the research process gives insight into the success rate of recruitment and the quality of the study population, and the data collection process (Reelick et al., 2011). Therefore, this section will discuss these research components in order to understand why the research process was or was not successful.

#### 8.3.1 Study Sample

The study sample has been described in details in Chapter 6, from section 6.3 to section 6.6. These sections described the same sample, with particular consideration to details relevant for the process evaluation. The success of the research participant selection process can be determined by conducting the evaluation of the study sample. It gives insight into the quality of the recruitment and response rate, barriers and facilitators to the recruitment process, retention rate, and barriers and facilitators for follow up.

# 8.3.1.1 Recruitment and Response Rate

Recruitment rate is defined as the number of eligible resident participants who enrolled on the study from those who were recruited by care home managers and staff or self-referred via the expression of interest form. Earlier within Chapter 4, section 4.4.6, it has been mentioned that one of the feasibility outcomes of this study was to assess the feasibility of the strategies used to recruit participants. In order to achieve this aim, a purposive sampling method was implemented to recruit 60 PwD (35 from Dar Aldiafeh nursing home, and 25 from Darat Samir Shamma care home) and 20 staff of caregivers (12 from Dar Aldiafeh nursing home, and 8 from Darat Samir Shamma care home). This purposive sampling ensured that all participants met the inclusion criteria. Study participants were participating in the study for around five-week intervention duration. This recruitment process was undertaken by using direct recruitment approach (face-to-face strategy) and using an advertisement (Appendix 9) which was put out during care home meal times in both care homes.

The total number of resident participants that were assessed for eligibility by the researcher was 95 in both selected care homes. There were 35 residents not eligible to participate. Reasons for non-eligibility included they were deemed too unwell to participate as determined by care home staff (n=17), and they had a diagnosis of an additional psychiatric disorder: schizophrenia (n=10), major depressive disorder (n=8) as determined by a consultant psychiatrist and care home staff. Therefore, 60 participants were approached to take part in the study and all 60 agreed to take part and were recruited into the single group study. Therefore, the inclusion criteria were appropriate to recruit resident participants. In this study, 43 PwD were identified that they had the capacity to consent and eight independent staff were identified by care home managers to act as independent consultees on behalf of 17 PwD. The response rate was 100%. This will be discussed more in Chapter 9, section 9.4.1.

# 8.3.1.2 Barriers and Facilitators to Recruitment Process

Understanding what motivates participants to be involved in research can help towards engaging those who are less likely to enrol onto research studies. Being motivated by the personal relevance of the intervention facilitated the recruitment process. Interviews with resident participants and their caregivers explored their motivation for participation in the study. Some resident participants displayed their personal motivation and they were not being pressured to take part in the study and they perceived it was a useful way in improving their mood. Zinab, a female resident participant, described her recruitment:

'I was not to get pushed to come and participate. I felt relaxed and I can do it...' (R07)

Farah, a female member staff, expressed a similar viewpoint:

'No force to take part in the study, it was all by choice... I have attended because I have received the letters at home and I want to participate.'

In addition, some staff participants indicated that using an innovative approach in this study encouraged resident participants to come and participate in the study. Omar, a male staff member described that about using of digital-touch screen technology to deliver RT:

' using this type of technology was totally new to me and them [residents] and I wasn't sure what to expect...I wanted to come just to see what other people were dealing with and coping with...It turned out to be great fun and I was really comfortable; I really liked it. I have always loved things are new and technical' (S01).

As all resident participants were approached to take part in the study, and all agreed to take part, there were no refusals, and as such, no reasons for refusal to report.

#### 8.3.1.3 Retention Rate and Barriers and Facilitators for Follow-up

Retention is defined as the number of participants completing post-intervention assessments compared to the number who started the intervention. The retention rate was 75%, losing n = 15 or a 25% rate of attrition. This will be discussed more in Chapter 9, section 9.4.2.

The barriers to follow up to the digital RT sessions were explored in Chapter 6, section 6.4 (Figure 10). Reasons for attrition rate were due to co-morbidity and mortality (i.e., death, transferred to other care homes, and emotional distress).

Understanding what motivates participants to complete the intervention can help towards staying those who are less likely to retain throughout research studies. Interviews with resident participants and their caregivers explored the reasons which improved their attendance and retention during using digital RT. These included the easy to use design, letting the resident participants take the time they need, availability of guidance, using many properties in digital-touch screen technology which were used to counteract the effects of physical impairments occurring in dementia such as zooming in and out the photos and putting up or down the volume.

## 8.3.2 Data Collection

Evaluation of the data collection process aimed to explore the appropriateness of the outcome measures, the completeness of the data and the feasibility of outcome measures to detect change.

#### 8.3.2.1 *The Appropriateness of the Outcome Measures*

Five outcome measures were collected via using five questionnaires which have been described in Chapter 4 (Section 4.4.5). All of the measures had robust psychometric properties and their suitability for use with resident and staff participants has been demonstrated previously in Chapter 4, section 4.4.5. These questionnaires were successfully collected by two independent researchers as mentioned in Chapter 4, section 4.4.4 in order to reduce bias in the study and to ensure that the research is the highest quality possible for a single group study.

#### 8.3.2.2 Completeness of Data Collection and Barriers and Facilitators for Data Collection

Questionnaires were checked for completeness and reasons for missing data were explored. Frequency counts of missing items were conducted at all data collection periods for all questionnaire outcome measures. The criterion for feasibility was met if less than 10% of items on each of the questionnaires were missing (As in Quirk, Glazebrook, & Blake, 2018); the likely threshold for imputation in a definitive trial. All returned questionnaires were checked for missing data. In cases where forms were returned with items missing, the independent researchers were contacted as soon as the questionnaires were received, chased up the item response with residents and asked them to complete the missing items. At preintervention, a single item in one case was missing from one of the measures (OPQoL) and the independent researcher was unavailable to complete this item, then the principal researcher calculated the mean of the responses and added it as a response item (Strube, 1985).

#### 8.3.2.3 *Feasibility of Outcome Measures to Detect Change*

Evaluation of data collection also explored the ability of the outcome measures to detect the change in outcomes over time. All outcome measures have been described in Chapter 4 (Section 4.4.5). These outcome measures included Arabic Version of Saint-Louis-University-Mental-Status (Arabic SLUMS; Abdelrahman & El Gaafary, 2014) for memory; Arabic version

of Older People's Quality of Life questionnaire (OPQOL-brief-13; Bowling et al., 2013) for QoL; Arabic version of Hospital Anxiety and Depression Scale (Arabic HADS; Al Aseri et al., 2015) for anxiety and depression; and Holden Communication Scale for persons with dementia (HCS; Strom et al., 2016) for communication (see Appendix 11). The changes in all outcome measures between pre and post-intervention have been described in Chapter 6, section 6.12. There were statistically significant and clinically relevant improvements in scores of cognitive function, communication, anxiety, depression, and QoL from pre to postintervention of using digital RT (see Table 21, Chapter 6). The qualitative findings are used in this section to reinforce the quantitative results regarding improving the outcomes following completion of digital RT intervention for PwD.

Within this feasibility study, a statistically significant and clinically relevant increase in mean by 3.7 (SD=2.4; t (45) =10.43; p=0.000) for cognitive function and 6.2 (SD= 4.8; t (45) =8.6; p=.000) for QoL were observed. Addiitonally, a statistically significant and clinically relevant decrease in mean scores of 6.2 (SD= 4.2; t (45) = -9.9, p=.000), 4.4 (SD= 2.9; t (45) = -10.1, p=.000) and 3.7 (SD= 2.6; t (45) = -9.6; p=.000) were observed for communication and anxiety/ depression respectively. These changes in mean represent the difference between pre and post intervention thus suggesting improvements in cognitive functioning, QoL, communication, anxiety and depression.

In terms of cognitive function, it has been especially insightful to consider the qualitative data gathered during this feasibility work alongside the results of the quantitative data analysis. Some resident and staff participants experiencing improvements in residents' cognition and memory after completing the intervention. As mentioned in Chapter 7, resident participants described the positive feeling towards using digital RT which improved their remembering things. They reported that the digital RT content was stimulating and triggered their past memories. Other resident participants felt improvements in other areas they were having difficulty with as a result of cognition improvement following completion of the digital RT intervention.

In terms of communication, the qualitative data which was gathered during this feasibility work showed that some resident and staff participants experiencing improvements in residents' communication after completing the intervention. As mentioned in Chapter 7, resident participants described the positive feeling towards using digital RT which improved their communication. They reported that the digital RT content was increasing their desire to be more engaged with other fellow residents and staff to be more talkative and resulted into more frequent contacts by their staff in their care homes. Other resident participants felt improvements in other areas they were having difficulty with as a result of communication following completion of the digital RT intervention.

In terms of anxiety, as mentioned in Chapter 7, resident participants described the positive feeling towards using digital RT which decreased their anxiety. They reported that the digital RT content could have increased their involvement with the sessions. Other resident participants felt improvements in their adherence to the sessions. Moreover, others felt of peace and more expressing her feelings after taking part in the sessions.

In terms of depression, the qualitative data which gathered during this feasibility work showed that some resident and staff participants experiencing improvements in residents' mood after completing the intervention. As mentioned in Chapter 7, resident participants described the positive feeling towards using digital RT which decreased their depression. They reported that the digital RT content could have increased their involvement with the sessions. Other resident participants felt of peace and more expressing her feelings after taking part in the sessions.

In terms of QoL, the qualitative data which gathered during this feasibility work showed that some resident and staff participants experiencing improvements in residents' QoL after completing the intervention. They reported that their QoL was improved because of enhancements in their cognitive function, communication, relationships between staff and residents, and emotions.

In summary, it appears that the convergence of quantitative and qualitative data suggest that the quantitative results could be reinforced by qualitative findings regarding improving cognitive, communication, anxiety, depression and QoL following completion of digital RT intervention for PwD.

Although the results should be interpreted with caution, the study suggests that the SLUMS, OPQOL brief -13, HSC, and HADS scales were able to detect a highest positive, statistically significant and clinically relevant difference on all outcome measures in cognitive function, QoL, communication, anxiety, and depression respectively between pre and postintervention. Furthermore, future research would need to incorporate some follow-up measures in order to explore the effect of digital RT in maintaining outcomes in the longterm. These will be discussed more in Chapter 9, section 9.8.

#### 8.4 Intervention Process: Intervention Implementation

The evaluation of the intervention processes involved exploring whether the digital RT intervention was delivered as per the research protocol and whether it was feasible and acceptable for participants involved. The processes evaluation included delivery of intervention components, barriers and facilitators for delivery of the intervention, adherence to intervention components, barriers and facilitators for adherence to the intervention and experience of the intervention. All intervention components were delivered as intended and will now be discussed in turn.

#### 8.4.1 Delivery of the Intervention, and Barriers and Facilitators for Delivery

The evaluation of the delivery of the intervention aimed to explore whether each session of the digital RT programme was delivered as intended and identify reasons for deviating from the study protocol. Moreover, this evaluation aimed to explore successful sessions of the intervention perceived by resident and staff participants and their recommendations for future implementation. The intervention delivery has been described in Chapter 4 (Section 4.4.4). The digital RT intervention was delivered in accordance with the research protocol and methods approved by the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of Nottingham. No breaches of the study protocol were reported during the conduct of the study which would suggest this intervention was delivered according to the study protocol. All resident participants received the digital RT sessions as planned. All sessions of individual digital RT were planned and delivered to the majority of them (see Chapter 6, section 6.6 for attendance).

As mentioned in Chapter 7 (section 7.3), interviews with resident and staff participants sought that digital RT sessions were delivered successfully which was determined by it being considered easy to use (flexibility of the intervention delivery and simple format), availability of guidance, interesting content (step by step structured content, variety of format and the familiarity of the content), and positive impact in residents' QoL (enhancing their memory and communication, enhancing their relationships and positive changes in psychological and emotional aspects).

Whilst being feasible in this small-scale study context, using unfamiliar technology for PwD and the distractions in the care homes may limit the extent to which in-depth digital RT sessions are possible. According to the resident and staff participants interviewed, some of them highlighted that the rooms and the environment, where the intervention was delivered, were not deemed a suitable environment for the digital RT due to a lot of interruptions in the care home and noises. Therefore, it is better for future implementation of digital RT intervention to be delivered in a quiet rooms and minimise distraction sources such as medication administration, psychologists visits, and initiation of conversations unrelated to the sessions.

Moreover, some resident and staff participants expressed their negative feelings about keeping forgetting how to use the digital RT application because their memory decline. A future implementation may therefore use step-by-step instruction cards to the resident

participants, or need to be delivered with the support of a care worker, informal caregiver or nurse.

Additionally, some of resident and staff participants expressed their negative feelings about the long duration of the intervention, number of sessions per week and using generic memories. Future implementation could consider that caregivers could upload personal memories (images, videos and audios) and they could be trained to deliver the RT, and decreasing the time duration in each session and the number of sessions each week to one session.

# 8.4.2 Adherence to the Intervention and Facilitators and Barriers for Adherence to the Intervention

Session attendance was used as a measure of intervention adherence. The data of this study showed that acceptable adherence was achieved with using digital RT for PwD. The median of session attendance for those who received the intervention was 80%.

As mentioned in Chapter 7 (section 7.3), interviews with resident and staff participants aimed to explore their motivation for compliance and attendance and the reason for non- adherence to the digital RT sessions.

# The facilitators for adherence to the intervention

The facilitators for adherence to the intervention were grouped into four main reasons: i) the flexibility of the intervention delivery, ii) Everything for digital RT is in one place, iii) simple format, iv) availability of guidance, and v) interesting content.

## *i)* The flexibility of the intervention delivery

Some resident participants expressed that the reason for their adherence to the digital RT was the ease of use of these sessions including the flexibility of the intervention delivery by accommodating a broad range of individual preferences and abilities. This included using many properties in technology which were used to counteract the effects of physical

impairments occurring in dementia and its capacity to reschedule the missed sessions. In addition, the digital-touch screen technology is easy to carry around with them, so they always have it available. Moreover, this digital RT is relatively simple to learn, and needs less dexterity, so residents are still able to take part in RT sessions using just their fingers.

# *ii)* Everything of digital RT is in one place

The digital-touch screen technology is a suitable way of bringing everything together as resident participants do not have to have lots of different resources or stack of papers, for example, CDs, craft equipment and DVDs. They can do everything from it rather than needing lots of real resources.

# iii) Simple format

Using the simple format of digital-touch screen technology to deliver RT was generally perceived as a facilitator for attendance, adherence and engagement with intervention by resident and staff participants. They suggested that eliminating any ambiguity and complexity of the digital RT application was very important to motivate them for compliance to the sessions. They described how using easy transitions between pages, the use of calm background colours, visually interesting format, and using a similar format for all pages had played an important part in motivating them for compliance to the sessions.

#### *iv)* Availability of guidance

The availability of guidance also considered as another facilitator for attendance and adherence by resident and staff participants. They suggested that it was very helpful and played an important part in supporting them not to skip any sections of the sessions, and causing them to not miss out of any benefits of digital RT application. Moreover, it facilitated overcoming difficulties experienced during using this digital RT.

# v) Interesting content

The more simple an intervention, the more easy it is to ensure high adherence (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004). The nature of the intervention components and how clearly they are defined to determine simplicity (Hasson, 2010). The majority of

residents and staff in the study felt that they were willing to use and adhere to digital RT intervention because it had interesting and relevant content. They described how using step by step structured content, variety of multimedia format and the familiarity of the content had played an important part in motivating them for compliance and adherence to the digital RT sessions.

#### The barriers to adherence to the intervention

However the study sample of resident participants was comprised primarily of people with mild or dementia, reasons for non-adherence to the digital RT sessions were explored. As mentioned in Chapter 7, reasons for non-attendance were purely logistical (i.e., health condition and getting to grips with unfamiliar digital-touch screen technology) rather than anything to do with the appeal of the digital RT sessions. The resident and staff participants offered reasons for poor attendance at sessions, and believed that the resident participants' attendance was dependent on their 'health condition' and 'getting to grips with unfamiliar digital-touch screen technology':

# i) Health conditions

Some resident participants expressed that the reason for their non-adherence to the digital RT was their health condition. Some of them were sick and being in hospital or health centres. Others described that these sessions needed sitting for long duration time which made them physically or mentally tired.

ii) Getting to grips with unfamiliar digital-touch screen technology Getting to grips with unfamiliar digital-touch screen technology was supported by resident participants' own account of barriers to intervention adherence. Some of the resident participants implied negative feelings about getting to grips with digital-touch screen technology due to its lack of familiarity meaning that it needed a lot of concentration and effort to understand it which negatively affected their adherence to the digital RT.

#### **8.4.3 Experience of the Intervention**

It is important to understand the experience of the intervention for a number of reasons. It aims to give the researcher a better understanding of what exactly it is that motivates participants to take part in digital RT sessions. Participants' experiences of the intervention were explored through interviews with resident and staff participants. Interviews aimed to explore participants' satisfaction, perceived acceptability, perceived benefits, and recommendations for implementation of the digital RT sessions. Strong and weak aspects of the digital RT intervention and adverse events experienced as a result of participation in the intervention were also evaluated.

# *i)* Participants' satisfaction

Most resident and staff participants indicated that they satisfied with being involved in the digital RT sessions. The findings from the interviews with them provided evidence for the influence of resident participants' satisfaction in their participation and adherence to the digital RT sessions. They suggested that digital RT components were feasible and satisfactory.

# *ii)* Perceived acceptability

The acceptability of the digital RT sessions was assessed via interviews with resident and staff participants. The findings from the interviews with resident and staff participants suggested that digital RT sessions have been shown to be acceptable and feasible. Moreover, the staff participants suggested being used the digital RT in their routine care for PwD in the care homes.

# *iii)* Perceived benefits

Interviews with resident participants and staff enabled the potential benefits of the digital RT sessions. These benefits also measured quantitatively to be identified. Most resident and staff participants indicated that they benefitted from being involved in the digital RT sessions or noticed benefits in the resident participants. As mentioned in Chapter 7, section 7.3.4, the perceived benefits were categorised into three benefits: a) enhancing memory and

communication abilities, b) enhancing relationships and c) positive changes in psychological and emotional aspects. These are discussed more in this chapter, section 8.2.1.2.3.

# *iv)* Recommendations for implementation of the digital RT sessions

The digital RT sessions were particularly valuable for resident and staff participants to gain an insight into how the residents' QoL were improved. The findings from the interviews with resident participants and staff suggested that future implementation of the digital RT sessions would benefit from firmly to promote their QoL by enhancing their memory, communication, relationships with staff and other residents, and positive changes in psychological and emotional aspects. The recommendations for implementation of the digital RT sessions are presented within the recommendations for future research trial section.

# v) Adverse events

No adverse health impacts were observed as a consequence, although emotional distress was reported on five occasions, by patients who subsequently withdrew from the study after referral to care home staff as agreed with them at the beginning of the study process as mentioned in Chapter 4, section 4.5.4.

# 8.5 Conclusions

This chapter focused on the process evaluation for digital RT intervention. The standardised framework by Reelick et al. (2011) was chosen for the current study. The use of a standardised framework for the evaluation of complex interventions enhances the methodological rigour of this study. Combining quantitative and qualitative data were collected from resident and staff participants in two Jordanian care homes during the conduct of the feasibility study underpinned by a pragmatic philosophy and a MMR design. The MMR has been combined in a way which enables a gradual accumulation of knowledge (Moore et al., 2015).

The process evaluation showed that the digital RT intervention and research process were feasible and acceptable to resident and staff participants in Jordanian care homes. The

process evaluation for the digital RT captures details about how the intervention is delivered and received by resident and staff participants. This will enable relevant stakeholders to adapt the intervention to maximise the chances of success in any future trial. Moreover, this process evaluation highlighted the evaluation of the research process which gave insight into the success rate of recruitment and quality of the study population, and data collection process.

The process evaluation for digital RT suggests that there is no significant difficulties in recruitment that were experienced throughout the duration of this study. Moreover, it highlighted a variety of facilitators and barriers to the implementation of digital RT for PwD, retention for follow up and adherence to the intervention. Possible mechanisms for overcoming these barriers for these aspects were addressed.

The findings of this chapter imply that a future definitive trial would be appropriate. In addition, it has offered recommendations to help optimise its delivery in a future definitive trial. However, lots of limitations and bias sources were identified during the process evaluation of this feasibility study. The limitations and recommendations will be discussed later in Chapter 9.

#### Chapter 9 Discussion

#### 9.1 Introduction

The primary aim of this thesis was to explore the feasibility and acceptability of a theorybased digital application to deliver reminiscence therapy (RT) for people with dementia (PwD). In addition, the secondary objective of this feasibility study was to determine the likelihood of changes in outcome measures and to identify the most appropriate outcome measures to evaluate the delivery of digital RT to PwD in Jordanian care homes to be used in a subsequent definitive trial. In chapter two, the systematic review for quantitative studies regarding the use of digital-touch screen technology to deliver RT identified that on the whole, no RCTs have been undertaken, with very little or no data on acceptability presented, and variability of delivery settings and ages of participants. Therefore, heterogeneity in study design and methods remains a barrier to fully understanding the effectiveness of using digital RT for PwD.

Mixed-method research (MMR) was applied to explore the research questions related to the feasibility and acceptability of a theory-based digital RT. Sixty participants were recruited and 45 completed the intervention. The process evaluation of the feasibility study and the qualitative findings found that digital RT is feasible and acceptable for this sample of PwD and was delivered as planned in the care of PwD in Jordanian care homes. The quantitative findings provide preliminary evidence supporting the value of a digital RT to improve cognitive function, communication, QoL and anxiety and depression scores.

This chapter will present a detailed and critical discussion of the findings and methods presented in the thesis. This chapter begins by discussing details about the characteristics of the sample who participated in the feasibility study and how they relate to samples within other studies evaluating the use of digital-touch screen technology to deliver RT. Subsequently, the feasibility and acceptability outcomes including recruitment and response rate, retention and attrition rate, delivery of the intervention, adherence to the intervention and the experience of the intervention are discussed. Then, a discussion of the feasibility

outcomes to change is discussed. Following this, the chapter discusses the strengths and limitations of the study then the implications of the study for practice and a future definitive trial are presented. This is followed by recommendations for a future trial and conclusion of the study.

#### 9.2 Participants Characteristics

The mean age of residents in this sample (66.9 years, SD= 7.4, range: 55-85) was broadly comparable with that observed in the population of PwD living in care homes in Jordan (MOSD, 2017; 68.3 years, SD=6.2, range: 50-95). In Jordan, life expectancy is 72 years in men and 76 years in women (UN, 2015).

Moreover, the percentages of dementia severity of resident participants in quantitative part in this study (46.7% mild; 33.3% moderate and 20% severe) were broadly comparable with that observed in the population of PwD living in care homes in Jordan (MOSD, 2017; 45% mild; 35% moderate and 20% severe). This suggests that the sample in this study is a representative sample of PwD who live in Jordanian care homes.

# 9.3 Overview of the Findings

#### 9.3.1 Quantitative Results

In total, 60 participants were recruited into a single group (pre-post individual intervention). The recruitment process and response rate were successful as the recruitment was undertaken two care homes in Amman and the response rate was 100%. There was a loss to follow up at post-intervention (25%). The response and retention rates will be discussed more in this chapter, section, 9.4.

Due to the small feasibility sample size single group (pre-post individual intervention), a descriptive analysis of the quantitative data was conducted. In addition, inferential analysis was also conducted in order to determine the likelihood of changes in outcome measures and identify the most appropriate outcome measures to evaluate the delivery of digital RT to PwD

in Jordanian care homes to be used in a subsequent definitive trial. There was a positive, statistically significant and clinically relevant difference on all outcome measures; means of cognitive, communication, anxiety, depression and QoL scores changed between pre and post-intervention. The outcome measures will be discussed in details in this chapter, section 9.5.

#### 9.3.2 Qualitative Findings

In order to explore the experience of the intervention, qualitative interviews were conducted with 21 resident and staff participants from two Jordanian care homes. The analysis of the qualitative data was carried out by the principal researcher, with guidance from the expert panel in qualitative research from the University of Nottingham according to the strategy described earlier within section 4.4.6.5. In order to protect the identity of the participant, all participants have been allocated a pseudonym.

It is possible that the qualitative findings related to the feasibility and acceptability of the digital RT, particularly as thematic analysis of the interview data revealed that there are four themes outlined the necessary features of the digital RT application to be used successfully to the PwD and their caregivers. This is certainly in keeping with the Technology Acceptance Model (TAM) which suggests the necessary features of the digital RT application to be used successfully to the PwD and their caregivers (Davis et al., 1989; Lai, 2017). The TAM model is consistent with the themes identified during the post-intervention interviews reported here. The post-intervention interviews provide some data relating to the easy to use, having a facilitative environment, having interesting content and having a positive impact in QoL that participants recognise. In addition, the resident participants perceived a number of positive changes in their QoL are certainly in keeping with Socioemotional Selectivity Theory (SST) which suggests that older people gain their sense of well-being and high QoL as the result of the positivity effect in which they selectively biased towards personal memories which have positive emotions (Cappeliez et al., 2008; Carstensen, 2006). The positive changes in their QoL including enhancing communication and cognitive abilities, enhancing relationships, and

positive changes in psychological and emotional aspects after completion of the digital RT intervention which led to improving in their QoL. These will be discussed more and linked to the theory used in the next section of this chapter, 9.5.

# 9.4 The Feasibility and Acceptability of Digital RT for PwD

The primary objective of this feasibility study was to explore the feasibility and acceptability of a theory-based digital application to deliver RT for PwD in Jordanian care homes to be used in a subsequent definitive trial. In order to achieve this aim, this section will discuss the recruitment and response rate, retention and attrition rate, delivery of the intervention, adherence to the intervention and the experience of the intervention.

#### 9.4.1 Recruitment and Response Rate

Results from the evaluation of the study population indicate that it is possible to recruit PwD and their caregivers onto the use of digital-touch screen technology to deliver RT. The recruitment process was faster than expected using a direct recruitment approach (face-toface strategy) and having support from the care home staff for recruitment and identifying participants. It is common for research among PwD to demonstrate slow uptake. Booth (2017) reported that it took 5 weeks to recruit 10 eligible PwD for an intervention study. However, there is no previous study that has mentioned the recruitment rate for PwD in a digital intervention study. The face-to-face recruitment approach has previously been identified as a beneficial recruitment strategy in PwD intervention (Tremont et al., 2015). Moreover, using an advertisement (Appendix 9) which was put out during care home meal times in both care homes could facilitate and accelerate the recruitment process (Davies & Nolan, 2006; Morrison et al., 2016).

According to Bartlett, Milne, and Croucher (2018), there could be a number of barriers which prevent PwD from participating in studies such as a lack of awareness about research opportunities because they are being overprotective from those around them, including care home staff and ethics committees or the recruitment processes are so inadequate that care

home staff are not aware of the research opportunities themselves. Therefore, in order to counteract these barriers and reduce the time invested by researchers, the principal researcher discussed and explained the purpose and the procedure of the study with resident and staff participants well. Furthermore, study documentation including invitation letter and participant information sheets were distributed to support this discussion.

As all of the resident participants who were approached to take part in the study were agreed to participate into the study, the response rate was 100%. This is a very high response rate when compared to other studies of using mobile technology to deliver RT for PwD by Laird et al. (2018) where the response rate from PwD was 96.6% which was conducted in the UK. This is the only previous study which reported the response rate of using digital RT for PwD as mentioned in Chapter 2. The higher response rate in this study may have been due to using a variety of strategies for improving the response rate including the previous strategies of Bartlett et al. (2018) mentioned previously. Moreover, being motivated by the personal relevance of the intervention facilitated the recruitment process as mentioned in Chapter 8, section 8.2. This is consistent with results from a previous study, which found that PwD were motivated to enrol onto a research study when the intervention was perceived as a useful way to have a positive outcome (Bartlett et al., 2018). As all resident participants were approached to take part in the study, and all agreed to take part, there were no refusals, and as such, no reasons for refusal to report.

The sample size was good and reasonable for this feasibility study and comparable with similar research in this field (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010; Laird et al., 2018; Subramaniam & Woods, 2016; Williams et al., 2011). This sample size was sufficient as it addressed the study aims and it was according to the National Institute for Health Research- Evaluation, Trials and Studies Coordinating Centre (NIHR NETSCC) glossary (NHS, 2017b). Although the data is relatively limited as it only represents a small number of the resident participants approached, these data indicated that they have a good interest in the research and they have the willingness to participate. However, it is possible that a greater number of resident participants would have changed the data observed during

feasibility. This point will be discussed in the limitations of the study in this chapter, section, 9.6.

# 9.4.2 Retention and Attrition Rates

While high dropout is a common problem in studies of using digital-touch screen technology with PwD (30%-50% in Hartin et al. (2014); Ramsey, Wetherell, Depp, Dixon, and Lenze (2016) respectively), the data of this study showed that acceptable retention rate was achieved with using digital RT for PwD. The retention rate was 75%, losing n = 15 or a 25% rate of attrition which is lower than attrition rates found in other studies of using digital-touch screen technology with PwD.

The barriers to follow up to the digital RT sessions were explored in Chapter 6, section 6.4 (Figure 10). Reasons for attrition rate were due to co-morbidity and mortality (i.e., death, transferred to other care homes, and emotional distress) not due to the intervention itself.

Mody et al. (2008) identified that there are numerous modifiable challenges to successful attendance and retention of PwD in research studies, however, these challenges can be overcome by obtaining a variety of strategies for improving the attendance and retention of PwD such as;

- Encourage and reassure PwD during enrolment and data collection
- Shorter length questionnaires
- Let PwD take the time they need
- Enlist caregivers' assistance, as appropriate
- Use large, bold name tags
- Use large, bold fonts
- Allow PwD to respond verbally and have someone record responses, if appropriate
- Separate tasks into smaller sections, allowing for breaks
- Identify and address PwD specific concerns
- Listen to and address the specific concerns of potential PwD concerning privacy issues

 Plan to address motivations such as monetary stipends, meal vouchers, and newsletters.

Particularly, Huldtgren et al. (2017) identified that there are a variety of strategies for improving the attendance and retention during using technology with PwD such as,

• Design for familiar and self-directed interactions with artefacts because they have limited capacity to learn new interactions with digital user interfaces.

• Match the design to the level of dementia and be sensitive to the individual user. Moreover, Smith, Crete-Nishihata, Damianakis, Baecker, and Marziali (2009) added these strategies for improving the attendance and retention during using technology to deliver RT for PwD:

- Personal media such as photographs frequently elicited positive responses from participants.
- Selecting meaningful music and songs to increase their engagement.
- Enhancing and improving the interface design according to PwD and caregivers' suggestions.

The results of this study demonstrate good adherence and retention rates and the reasons for attrition were not due to the digital RT intervention itself. However, it is possible that retention rates could have been further improved in future studies upon with the methods which advocated by (Huldtgren et al., 2017; Mody et al., 2008; Smith et al., 2009), particularly the use of personal media and enhancing the interface design according to PwD and caregivers' preferences. These will be discussed more in this chapter, section 9.8.

#### 9.4.3 Delivery of the Intervention

The digital RT programme was delivered successfully and as intended. The digital RT intervention was received well by the resident participants. The digital RT sessions were face to face and individual sessions. This is in line with previous digital RT intervention studies of PwD (Astell, Ellis, Bernardi, et al., 2010; McFadden & McFadden, 2011; Purves et al., 2011; Subramaniam & Woods, 2016). Moreover, the digital RT intervention was structured sessions

based on the key stages in life which most people had experienced. This is in line with the theory of using memories that induced positive emotions (Carstensen, 2006).

The digital RT intervention enabled the researcher to elicit resident and staff participants' satisfaction around using digital-touch screen technology to deliver RT and gain insight into their perceived barriers and facilitators to goal attainment. The evaluation of the barriers and facilitators for delivery of intervention aimed to explore resident and staff participants' perceptions of the digital RT programme, including what helped and hindered its delivery. However, there were unknown confounding variables, for example: age, health condition, the time of intervention delivery and early or late onset of dementia type. These confounding variables could have an impact on the adherence to the intervention (Dukart, Schroeter, & Mueller, 2011) and on the outcome measures.

The facilitators for digital RT delivery which discussed in Chapter 8, section 8.2.2 were in accordance with the majority of the previous digital RT projects (Chen, Chan, et al., 2013; Laird et al., 2018; Pringle & Somerville, 2013; Yang, 2013). However, some of the barriers during intervention delivery which were reported in Chapter 8, section 8.2.2 could be overcome by the suggestions from many studies (Chen, Chan, et al., 2013; Laird et al., 2018; Pringle & Somerville, 2013; Sarne-Fleischmann & Tractinsky, 2008a; Subramaniam & Woods, 2016; Yang, 2013; Yasuda et al., 2009). These will be discussed more in this chapter, section 9.8.

# 9.4.4 Adherence to the Intervention

Attendance at the digital RT sessions was good as anticipated. The sessions were well attended, the median of session attendance for those who received the intervention was 80%. Reasons for non-attendance were logistical (i.e., session timing and location) rather than the appeal of the session. No previous study reported the rates of adherence in using digital RT intervention for PwD so it is not possible to make a direct comparison. However, this attendance rate is comparable to rates of adherence in technology-based exercise

interventions in older people in which the median attendance has been shown to be around 90% (Valenzuela, Okubo, Woodbury, Lord, & Delbaere, 2018).

It is appeared that the flexibility of the intervention delivery in relation to the fact that everything in digital RT is in one place and the simple format have been noted as substantial facilitators to improve adherence in similar research exploring the use of iPads in care homes with PwD (Evans, Bray, & Evans, 2015). Furthermore, the availability of guidance to use the digital-touch screen technology was considered as facilitators for improving the adherence of older people to digital intervention (Kuo, Chen, & Hsu, 2012b; Reeder et al., 2011). In addition, the availability of guidance has positively influenced the adherence of participants in the intervention (Chee, Gitlin, Dennis, & Hauck, 2007).

However, getting to grips with unfamiliar digital-touch screen technology has been noted as extremely challenging in similar research exploring the feasibility of technology-based exercise interventions in older people (Hopkins et al., 2018; O'Rourke, 2016; Valenzuela et al., 2018). In addition, late cancellation or non-attendance by participants due to their health condition has been also reported in this feasibility study as common in a similar digital technology intervention study in the care home (Valenzuela et al., 2018).

# 9.4.5 Experience of the Intervention

The digital RT sessions were evaluated positively by resident participants who attended and their caregivers. Most resident and staff participants indicated that they benefitted from being involved in the digital RT sessions or noticed benefits in the resident participants. As mentioned in Chapters 7 and 8, the perceived benefits were categorised into three benefits: a) enhancing memory and communication abilities, b) enhancing relationships and c) positive changes in psychological and emotional aspects. These perceived benefits of the digital RT sessions have been noted in similar previous studies included the opportunity for PwD to have positive impact in enhancing their memory (Cohene, 2006; Damianakis, Crete-Nishihata, Smith, Baecker, & Marziali, 2010; Pringle & Somerville, 2013; Subramaniam & Woods, 2016), communication and relationships with staff and other residents (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010; Chen, Chan, et al., 2013; Pringle & Somerville,

2013; Sarne-Fleischmann & Tractinsky, 2008a), positive changes in psychological and emotional aspects (Damianakis et al., 2010; O'Rourke, 2016; Subramaniam & Woods, 2016) and improving their QoL (Chen, Chan, et al., 2013; Laird et al., 2018; Subramaniam & Woods, 2016).

Digital RT sessions were considered very valuable and enjoyable by resident and staff participants as found in similar previous studies (Alm et al., 2004b; Damianakis et al., 2010; O'Rourke, 2016; Yang, 2013). However, these sessions require supervised caregivers to deliver as noted in similar previous studies (Evans et al., 2015; O'Rourke, 2016; Yang, 2013). The format and structure of the digital RT sessions were considered simple, easy to use and understand, using many properties in technology to counteract the effects of physical impairments occurring in dementia, and flexible to reschedule missed sessions (Chen, Chan, et al., 2013; Evans et al., 2015). The content of sessions was considered very interesting, relevant, useful, structured, used a variety of format, familiar and novel (Pringle & Somerville, 2013; Subramaniam & Woods, 2016). However, some participants suggested to use personal memories and decease the time duration and frequency of sessions per week to be more attractive and tolerable. Therefore, these issues were notably important issues contributing to having a usable and acceptable digital RT session.

Using generic memories was in accordance with the previous digital RT which were created with a generic focus (Astell, Ellis, Bernardi, et al., 2010; McFadden & McFadden, 2011; Purves et al., 2011). However, the approach was contrary to some studies that used personalised materials (Chen, Chan, et al., 2013; Laird et al., 2018; Pringle & Somerville, 2013; Sarne-Fleischmann & Tractinsky, 2008a; Subramaniam & Woods, 2016; Yang, 2013; Yasuda et al., 2009). Participants' experiences clearly support the personalised approach in person to person setting as producing beneficial effects. The individual person to person approach was preferred by most resident and staff participants. This is certainly in linking with SST which suggests that older people gain their sense of well-being and high QoL as the result of the positivity effect in which they selectively biased towards personal memories

which have positive emotions (Cappeliez et al., 2008; Carstensen, 2006). This will be discussed more in the next section of this chapter.

Overall, it is feasible to use digital for delivering RT for PwD which was consistent with previous feasibility and developmental studies (Lim, Wallace, Luszcz, & Reynolds, 2013; Pringle & Somerville, 2013; Subramaniam & Woods, 2016). Moreover, this digital RT intervention was well accepted by resident and staff participants in Jordanian care homes which was consistent with previous feasibility and developmental studies (Alm et al., 2004b; Smith et al., 2009; Subramaniam & Woods, 2016). However, this digital RT intervention in its current form requires simple alteration to optimise its efficiency and potential efficacy. These recommendations for the implementation of the digital RT sessions are presented within this chapter, section 9.8.

#### 9.5 The Feasibility of Outcomes to Change

The secondary objective of this feasibility study was to determine the likelihood of changes in outcome measures and to identify the most appropriate outcome measures to evaluate the delivery of digital RT to PwD in Jordanian care homes to be used in a subsequent definitive trial. In order to achieve this aim, this section will discuss the findings of both quantitative and qualitative data together. The quantitative results were used to determine the likelihood of changes in outcome measures and identify the most appropriate outcome measures to evaluate the delivery of digital RT to PwD in Jordanian care homes to be used in a subsequent definitive trial. The qualitative findings were used to reinforce the quantitative results regarding improving the outcomes following completion of digital RT intervention for PwD.

# 9.5.1 Cognitive Function

There was a statistically significant and clinically relevant increase on Saint Louis University Mental Status (SLUMS) mean score to by 3.7 (SD=2.4; t (45) =10.43; p=0.000) between

pre and post-intervention suggesting improvements in cognitive functioning as mentioned in Chapter 6 and Chapter 8.

The systematic review in Chapter 2 reported that there is only one study which has previously reported that cognition is sensitive to change after implementing digital RT sessions (Subramaniam & Woods, 2016). Subramaniam and Woods (2016) used the Autobiographical Memory Interview (AMI) scale to measure the cognitive function. Subramaniam and Woods (2016) reported that the mean of AMI was increased by 8.9 (SD=3.04). The finding of this study is congruent with the finding of Subramaniam and Woods (2016) study. However, Subramaniam and Woods (2016) used a different tool to measure the cognitive function for the resident participants, it is possible that such data could relate to the result of this study. This study provides preliminary evidence supporting that the digital RT intervention appeared to have an impact on overall cognitive function at postintervention.

The qualitative findings in Chapter 7 in this study reported that residents' communication was improved. There is some similar qualitative data in several developmental projects reporting that digital RT improved memory and cognition of PwD (Pringle & Somerville, 2013; Sellen & Whittaker, 2010; Smith et al., 2009; Subramaniam & Woods, 2016; Upton et al., 2011; Whittaker et al., 2012). As such, resident participants may have been accepting the digital use to deliver RT for memory decline change. This is certainly in linking with SST theory which suggests that the practice of using past memories during positivity effect will make it easier for PwD to recall them as the more of using memory, the better of remembering things (Carstensen et al., 1999; Charles, Mather, & Carstensen, 2003; Gorenc-Mahmutaj et al., 2015; Mark, 2012). Therefore, they will have the ability to fully participate in the RT programme (Coluccia et al., 2010).

# 9.5.2 Communication

There was a statistically significant and clinically relevant increase on the mean Holden communication Scale (HCS) 6.2 (SD= 4.2; t (45) = -9.9, p=.000) between pre and post-

intervention, suggesting improvements in communication skills after using digital RT for PwD as mentioned in Chapter 6 and Chapter 8.

The systematic review in Chapter 2 reported that the previous studies that have investigated the effect of digital RT on communication in PwD have reported mixed results (Astell et al., 2005; Astell, Ellis, Bernardi, et al., 2010; Williams et al., 2011). Williams et al. (2011) found is not sensitive to change after using digital RT sessions at 2 weeks or 3-month follow-up (z(6) = .85, .73; p = .40, .46) by using Minimum Data Set Activities of Daily Living scale. Astell et al. (2005) and Astell, Ellis, Bernardi, et al. (2010) have suggested that communication is sensitive to change after using digital RT sessions ((z(9) = 2.19, p < .05; (t(10) = 2.191, p < .05)) respectively). The finding of this study is consistent with the findings of Astell et al. (2005) and Astell, Ellis, Bernardi, et al. (2010) which were presented in Chapter 2. However, Astell et al. (2005) and Astell, Ellis, Bernardi, et al. (2010) which were presented in the tool was used, it is possible that such data could relate to the result of this study. This study provides preliminary evidence supporting that the digital RT intervention appeared to have an impact on overall communication at post-intervention.

The qualitative findings in Chapter 7 in this study reported that residents' communication was improved. There are some similar qualitative researches and projects reporting that digital RT improved communication following completion of the digital RT intervention for PwD (Chen, Chan, et al., 2013; Klein, Uhlig, & Will, 2018; Sarne-Fleischmann & Tractinsky, 2008a; Upton et al., 2011). As such, resident participants may have been accepting digital use to deliver RT for communication improvements. Particularly, there is some research reporting that using digital RT is more likely to yield communication improvements for people with mild to moderate severity of dementia (Lim et al., 2013; Meiland et al., 2012). This in line with the RT for teach-inform purposes which suggests that older people want to leave their mark on the world and ingrain their important values and ideas (Watt & Wong, 1991). In addition, It can provide opportunities for the bond between the old and the younger to be strengthened (Chung, 2009), and give the younger something to build on in the future (Cappeliez et al., 2007). Therefore, the reminiscence for teach-inform functions can have a positive effect on

the social adaptation of older adults (Chung, 2009; Watt & Wong, 1991). Moreover, this supports the RT for conversation purposes which associated with socialisation by either reconnecting with old friends, or fostering new friendships (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2006; Westerhof et al., 2010; Westerhof & Bohlmeijer, 2014).

Additionally, this aligns with SST theory which suggests that positivity effect can induce positive emotions which could be helpful and have support the maintenance of social and emotional bonds (Chen et al., 2015; Shiota et al., 2014). PwD tend to choose an emotionally close social partner as a result of positivity effect which enhancing their communication and interactions with others (Carstensen, 2006; Carstensen et al., 1999; Mark, 2012).

# 9.5.3 Anxiety

There was a statistically significant and clinically relevant decrease on the mean Hospital Anxiety and Depression Scale (HADS) for anxiety between pre and post-intervention 4.4 (SD= 2.9; t (45) = -10.1, p=.000), suggesting reductions in anxiety symptoms after using digital RT for PwD as mentioned in Chapter 6 and Chapter 8.

Nevertheless, there have been no previous quantitative studies incorporating an outcome measure relating to anxiety after using digital RT as mentioned in the systematic review in Chapter 2. Although, this is the first study used to measure anxiety to identify the changes in anxiety between pre and post digital RT intervention, other studies have used HADS scale to measure anxiety and depression of PwD in care homes (Drageset, Dysvik, Espehaug, Natvig, & Furnes, 2015; Haugan & Drageset, 2014; Smith, Samus, et al., 2008). This study provides preliminary evidence supporting that the digital RT intervention appeared to have an impact on overall anxiety at post-intervention.

The qualitative findings in Chapter 7 in this study reported that residents' anxiety was improved. However, no qualitative research into the experiences of anxiety between PwD engaging in digital RT has previously been reported. The qualitative data which gathered

during this feasibility work showed that some resident and staff participants experiencing improvements in residents' mood after completing the intervention.

As this is the first study exploring the experiences of anxiety between PwD engaging in digital RT, it is argued that all the quantitative and qualitative findings are novel and contribute to new knowledge in this under researched area. This supports the RT function for teach-inform purposes which suggests that could be associated with positive emotions within a social context (Cappeliez et al., 2007) that convey an image of older people as self-enhanced, wise and experienced (Cappeliez & O'Rourke, 2006; Cappeliez et al., 2007). This could lead to an elevated mood in the person, and an increased sense of respect and admiration from others (Cappeliez & O'Rourke, 2006). Moreover, this links with the RT for conversation purposes which could be used to convey an image of older people as a communicative, pleasant, and entertaining person in a social environment (Cappeliez et al., 2007), which can have a positive effect on the mental health and emotions of older people especially in social situations (Cappeliez et al., 2008; Cappeliez & O'Rourke, 2006; Cappeliez et al., 2007).

# 9.5.4 Depression

There was statistically significant and clinically relevant on the mean Hospital Anxiety and Depression Scale (HADS) for depression between pre and post intervention 3.7 (SD= 2.6; t (45) = -9.6; p=.000), suggesting reductions in depression symptoms after using digital RT for PwD as mentioned in Chapter 6 and Chapter 8.

The systematic review in Chapter 2 reported that there is only one previous study also suggested that depression is sensitive to change after using digital RT sessions (Subramaniam & Woods, 2016). Subramaniam and Woods (2016) used the geriatric depression scale (Residential) (GDS-12R) scale to measure the depression. Subramaniam and Woods (2016) reported that the mean of GDS-12R was decreased by 1.84 (SD=-1.9). The finding of this study is congruent with the finding of Subramaniam and Woods (2016) study. However, Subramaniam and Woods (2016) used a different tool to measure the depression for the resident participants, it is possible that such data could relate to the result

of this study. This study provides preliminary evidence supporting that the digital RT intervention appeared to have an impact on overall depression at post-intervention.

The qualitative findings in Chapter 7 in this study reported that residents' depression was improved. There is some similar qualitative study reporting that digital RT improved depression following completion of the digital RT intervention for PwD (Alm et al., 2004a; Sarne-Fleischmann & Tractinsky, 2008a; Subramaniam & Woods, 2016). This aligns with SST theory which suggests that the positivity effect can be applied with depressed older people through the process of creating idealised positive memories by adapting to forget any negative past events selectively in order to distance themselves away from negative memories which improving their mood (Cappeliez & O'Rourke, 2006; Carstensen, 2006; Knight & Durbin, 2015; Westerhof et al., 2010).

#### 9.5.5 Quality of Life

The conceptualisations of QoL in dementia vary with the progression of the disease (Ettema et al., 2005). For example, while in the early stages of dementia, enjoyment of activities is relevant however it becomes less relevant typically in severe dementia (Ettema et al., 2005). For the purpose of this study, the aspects QoL included cognitive function, mood, interpersonal relationships and the ability to participate in meaningful activities. There was statistically significant and clinically relevant increase on the mean Older People's Quality of Life questionnaire (OPQOL-brief-13) between pre and post-intervention 3.7 (SD= 2.6; t (45) = -9.6; p=.000), 6.2 (SD= 4.8; t (45) = 8.6; p=.000), suggesting improvements in QoL after using digital RT for PwD after using digital RT for PwD as mentioned in Chapter 6 and Chapter 8.

The systematic review in Chapter 2 reported that there are only two previous studies also highlighted that QoL is sensitive to change after using digital RT sessions (Laird et al., 2018; Subramaniam & Woods, 2016). Subramaniam and Woods (2016) used the same OPQOL brief-13 scale to measure the QoL. Subramaniam and Woods (2016) reported that the OPQOL brief-13 scale was increased by 3.2 (SD=1). Laird et al. (2018) used World Health

Organization–Five Well-Being Index (WHO-5) to measure QoL. They reported that the WHO-5 was increased by 1.9 (SD=1). The finding of this study is congruent with the finding of Subramaniam and Woods (2016) study. Subramaniam and Woods (2016) used the same tool which was used in this study to measure the QoL, therefore, it is possible that such data could relate to the result of this study. This study provides preliminary evidence supporting that the digital RT intervention appeared to have an impact on overall QoL at post-intervention.

The qualitative findings in Chapter 7 in this study demonstrate that residents have a better QoL after completion of the digital RT session because of enhancements in their cognitive function, communication, relationships between them and the staff, and mood. There are some similar qualitative data in other developmental qualitative studies reporting that digital RT improved QoL following completion of the digital RT intervention for PwD (Klein et al., 2018; Pringle & Somerville, 2013; Upton et al., 2011). This is in linking with SST theory which suggests that the RT that induced positive emotions could be helpful and have positive consequences on the mood, memory, well-being, and support the maintenance of social and emotional bonds (Chen et al., 2015; Shiota et al., 2014). Moreover, SST suggests that PwD seek out positive experiences, avoid the negative and spend quality-time with loved ones in smaller social networks as a result of the positivity effect which enhances their QoL (Carstensen, 2006; Carstensen et al., 1999; Mark, 2012).

In summary, the quantitative and qualitative findings of this feasibility study demonstrate that many positive changes may be experienced by PwD following completion of the digital RT intervention. However, there were five resident participants out of 60 left the study due to emotional distress. Therefore, it is difficult to determine the changes in outcomes between pre and post intervention for them as they were outside of this feasibility study in order to link that with SST theory. Moreover, there is a possibility that the small feasibility sample size single group used in this study had different outcomes to the wider population of PwD, which warrants replication in a larger randomised control group study.

# 9.6 Strengths and Limitations of the Study

#### 9.6.1 Strengths of the Study

In chapter two, the systematic review has demonstrated no studies have been implemented in Jordan or Arab countries; no studies has tested the using of digital-touch screen technology to facilitate RT as an intervention for PwD; previous studies have failed to explore the long-term effects of the intervention; no study have been explicitly underpinned by theory; and little attention has been given to potential cognitive, communication, depression, anxiety, and QoL outcomes for PwD following the delivery of RT via digital-touch screen technology. Therefore, this study has assessed the feasibility and acceptability of a novel using digital-touch screen technology to deliver for PwD in Jordanian care homes which may be used to shape the design of a future study.

This study is one of the first in this research area using a theory-driven intervention in order to include elements known to be associated with health outcomes, and QoL improvements and help explain how interventions bring about change. It is suggested that the explicit use of theory-based intervention may offer a number of advantages, such as designing interventions, providing a generalisable framework for predicting and interpreting behaviour and explaining how interventions bring about change (Clemson et al., 2018; Foy et al., 2007). Moreover, using theories can provide tentative explanations for interventions to be higher quality when they address more key related factors (Heath et al., 2015).

The next major strength of this study was using patient and public involvement (PPI) which provided a maximal contribution of PwD and their caregivers in order to consider their preferences. It is suggested that PPI plays a crucial role in the design of the study materials and the subsequent feasibility study (Green, 2016; Oliver, 1995; RCN, 2007). PPI has been shown to increase the possibility of research being implemented and acknowledged into routine care (RCN, 2007). Moreover, PPI could achieve equilibrium in order to address power imbalances between researchers, health care staff and patients (Green, 2016).

Moreover, it is one of the first in this research area to report the adherence, retention, adverse events, and acceptability of digital RT for PwD as recommended in the systematic review in Chapter 2. In addition, no previous research has explored facilitators and barriers to the use of digital-touch screen technology to deliver RT for PwD. Overall this study adds a novel contribution to the body of knowledge regarding the feasibility of digital RT for PwD which is particularly relevant to the Hashemite Kingdom of Jordan context and expansion to nursing practice. Further details regarding implications and recommendations as a result of this feasibility study will be found within the sections which will be discussed later.

A further strength of the study was the exceptionally high response rate from the resident participants (100%) which is higher than the previous research conducted using personalised digital RT for PwD (96.6%) (Laird et al., 2018). It is suggested the response rate in questionnaire research should be reached at least 60% (Fincham, 2008). Low response rate could reflect nonresponse bias which results in the study findings not necessarily being representative of the total sample and thus the wider population (Fincham, 2008; Wallander, Tikkanen, Mannheimer, Ostergren, & Plantin, 2014).

This primary research data could be used for comparing with other studies aiming to explore the feasibility of digital RT for PwD. The dataset of the study could also be used to run simple analyses for other academic purposes. Using the dataset for secondary analysis would reduce the cost of conducting another research and save time in conducting fieldwork for relevant research questions. In addition, a future definitive trial could be recommended beyond this feasibility study.

A further strength of the study was making significant efforts to reduce bias. Bias in research can be refered to any tendency which prevents any unprejudiced consideration of a question in research; it can occur research design planning, data collection analysis or publication phases of research (Pannucci & Wilkins, 2010; Smith & Noble, 2014b). It can affect the reliability and the validity of quantitative research which leads to misinterpretation of results (Smith & Noble, 2014b). Moreover, bias may affect the trustworthiness of qualitative

research in terms of credibility, transferability, dependability and confirmability (Smith & Noble, 2014b).

This study has applied various strategies to address potential biases throughout this study and make efforts to demonstrate rigour in the qualitative and quantitative parameters. These efforts included very clear research questions identified to guide the study design, and a MMR approach was employed consisting different types of data collection and analysis which provides a better understanding of the research problem than would be achieved using either approach alone (Boswell & Cannon, 2014; Creswell & Clark, 2011). In addition, this study addressed the feedback from expert panel and peer reviewers regarding the intervention development and research design as part of the process of confirmation review, intervention development process, and ethical permission from the ethics committees of University of Nottingham (Ref: 110-1709) and the local sites in Jordan (Morse, 2015). More details of the trustworthiness of this study are provided in Chapter 4, section 4.4.6.6.

Additionally, this study used purposive sampling in qualitative research to select participants to participate in qualitative interviews in order to reduce the risk of selection bias due to the sample being refined to meet the study aims (Smith & Noble, 2014b). Purposive sampling was applied by selecting residents who had been clinically diagnosed with dementia at least one year and care home staff who had at least six months experience of working in a care home. Moreover, the process of transferability aspect of trustworthiness could be applied by adopting a purposive sampling strategy as it provides a depth of understanding (Hadi & Closs, 2016). Furthermore, the principal researcher used semi-structured interviews as a guide during the qualitative data collection which could have produced in-depth understanding and allowed a richer analysis of the experience of participants viewing their digital RT intervention (Morse, 2015). Furthermore, the principal researcher used semi-structured used external review during data analysis of qualitative data by the process of supervision meetings, to ensure that the researcher did not overlook data inconsistencies due to personal beliefs or interests which will finally decrease bias of qualitative analysis (Morse, 2015).

In addition, this feasibility study used robust, validated and standardised measures in the quantitative study in order to address data collection bias as recommended in Smith and Noble (2014b). All questionnaire measurements used in the study (SLUMS, OPQOL-brief-13, HCS, and HADS) showed highly reliable and valid. The measurements of SLUMS, OPQOL-brief-13, and HADS have been used among Arabic older people living in the care homes (Abdelrahman & El Gaafary, 2014; Al Aseri et al., 2015; Bowling et al., 2013). The pilot study was undertaken in order to validate the Arabic HCS scale before the actual data collection which showed that Arabic HCS after the translation was a highly reliable and valid tool. Moreover, all measurements used in the study were collected by two independent researchers in order to decrease bias during quantitative data collection. Therefore, the quantitative results of the study comprise accurate information, helping to achieve the aim of the study. In summary, this study made extensive efforts to address bias in all phases of the study.

## 9.6.2 Limitations of the Study

Although there are many strengths of the study, there are some limitations should be considered carefully when analysing and interpreting the results presented throughout this thesis. First of all, this study has used a small sample size (n=45). Using small sample sizes in studies prone to greater sampling variation, undermining the internal and external validity of the study and are thus less precise (Faber & Fonseca, 2014; Higgins & Green, 2011). Therefore, any conclusions drawn from the small sample size study will be weak (Faber & Fonseca, 2014; Higgins & Green, 2011). thus there may be limits to the generalizability of the current findings.

Nonetheless, the current study was not aimed to generate inferential data regarding the effectiveness of the digital RT intervention and make generalisations of its findings. However, inferential statistics were conducted in order to determine the likelihood of changes in outcome measures and identify the most appropriate outcome measures to evaluate the delivery of digital RT to PwD in Jordanian care homes to be used in a subsequent definitive

trial. It is noted that the digital RT intervention has descriptive data relating to positive changes in levels of cognition, communication, anxiety, depression, and QoL. By further developing the interventions with the knowledge obtained during this feasibility study, it is possible that these effects could be improved. It is also possible that effects have occurred by chance alone within a feasibility study of this size. Moreover, It is possible that the effects would be reduced with a larger sample size.

The next major limitation of this study was time constraints and very tight timescale for the data collection period. Respondent validation was not taken due to this time constraint and very tight timescale. It is suggested that respondent validation is a process of involving research participants responding either to forms of initial data such as transcripts of interviews and findings were not reported back to the participants in order to check them for validation and establish the level of correspondence (Lincoln & Guba, 1985b; Torrance, 2012). In addition, it is suggested to increase the credibility of qualitative findings (Lincoln & Guba, 1985b). Therefore, it is acknowledged that some qualitative findings may have been misinterpreted through the analysis process as the researcher did not undertake the respondent validation.

This study used a single group, pre-post-test, non-controlled and non-randomised design due to time constraints and very tight timescale. The using of this design is considered another limitation of this study. The major weakness of this design is a selection threat to internal validity compared to randomised control trial studies (Spieth et al., 2016). Therefore, any conclusions inferring changes to outcomes beyond that expected by chance are weak. Also, the feasibility of randomisation has not been tested in this study. In addition, without a ranomsied control arm, confounding variables in this study, such as the effect of time alone, cannot be excluded (Evans, 2010). Thus, a future study is recommended to be conducted by using randomised control trial design.

A further limitation of the study was a very large effect size (Cohen's d= 1.5 for cognition, communication and anxiety, 1.3 for QoL, and 1.4 for depression). Effect size aims to
understand the magnitude of differences found in the findings (Schafer & Schwarz, 2019; Sullivan & Feinn, 2012). More details about effect size are provided in Chapter 6. It is suggested that a very large effect size (Cohen's d > .8) gives results slightly larger than the true population value and limits the generalizability of the current findings (Sullivan & Feinn, 2012). This may be due to the small sample size as there was a significant negative correlation between sample size and effect size (Schafer & Schwarz, 2019; Slavin & Smith, 2009). Therefore, a future study should factor in a larger sample size and using randomised control trial study.

All interviews were conducted in the Arabic language and the analysis was conducted in the English language. This can be considered as a limitation of this study. It is suggested that conducting data analysis in the different languages in which it was collected could interrupt the flow of conversation and be distracting for the respondent and interviewer (Smith, Chen, et al., 2008; van Nes et al., 2010). In addition, the translations of transcripts could be misunderstood by the other reader so this data needed to be re-translated again many times (van Nes et al., 2010). Therefore, it is acknowledged that some qualitative findings may have been misinterpreted through the analysis process as a result of the translation process. However, in order to increase the credibility and confirmability of qualitative evaluation of this study, all transcripts were re-translated by an independent bilingual translator whose mother tongue is the Arabic language, he lives in the UK for 25 years, and he also works in the UK care home.

Whilst this feasibility study is not looking for a representative sample in the qualitative evaluation, the qualitative evaluation aims to explore the views and the experiences of the use of digital RT. Almost two-thirds of recruited resident participants in qualitative interviews have mild dementia and one-third of them have moderate dementia. Therefore, views and the experiences of those with more severe dementia are not considered. This intervention has only been explored the experiences of people with mild to moderate severity of dementia. This makes the findings highly pertinent to people with mild or moderate severity

of dementia. Therefore, further research is required to explore the digital RT experiences of people with severe dementia.

All semi-structured interviews have been conducted by the same researcher who delivered the intervention sessions. Therefore, it is possible that participants could have been less likely to reveal negative experiences in their and disclose unfavourable opinions of the intervention as a result of this point (Adams, 2015; Tress, Tress, & Fry, 2005). However, several participant opinions of negative experiences with frank reflections on the research participation experience have been received suggesting that this intervention could be improved. Moreover, the credibility of qualitative studies was ensured by using two related data sources (residents and care home staff) and two data collection methods to answer the research questions.

#### 9.7 Implications of the Study

#### 9.7.1 Implications for Practice

This study is relevant to practice as it explores a novel approach to supporting RT with PwD in the care home setting. The approach uses digital-touch screen technology to improve access and efficiency of RT for facilitators and to stimulate cognition, communication, anxiety, depression and QoL of PwD.

Using digital-touch screen technology to deliver content for RT has shown that digital-touch screen technology has the ability to improve such interventions, making them less arduous for the staff and potentially more beneficial for PwD. This in turn can improve the quality of life of PwD. Therefore, it is of value to consider the types of guidance and support required to enable uptake and access to such digital-touch screen technology resources to ensure that access and benefits of the intervention are upheld, as while digital-touch screen technology did show benefits for the RT process, there were many associated risks with its delivery. Thus, using digital RT within a practice approach leads to multiple considerations for potential therapists or researchers planning to use digital-touch screen technology with PwD. There are

many factors to be considered when using digital RT in the care home setting for therapeutic practice:

- Digital-touch screen technology enabled RT needs to preserve the social component of reminiscence activity and opportunity for meaningful interaction.
- The reliability of digital-touch screen technology in the care home and the prioritisation of technology to meet the needs of staff and residents in the home.
- Digital RT should be easy to use and provide efficient, personalized, and structured content for RT, ultimately leading to successful reminiscence outcomes.
- Digital RT needs to be used over a period of time to allow participants to adjust to the technology and increase the opportunity to experience therapeutic benefits from it.
- Digital RT needs to be user-paced, encourage interface simplicity and minimise complexity, develop an easy-to-use system by taking into consideration the possible impairments experienced, provide an interaction which aims to be intuitive, and avoid the use of hierarchical navigation structures.

The findings from this feasibility study, while preliminary, suggest that depression and anxiety could be reduced, and communication, QoL and cognitive functions could be improved in the environment of care homes after completing digital RT for PwD. Furthermore, this study enhanced the development of digital RT usage for PwD in care homes and helped the dissemination of accurate information about digital RT and its usage among dementia residents to support other PwD at their home.

With a feasibility study of a small sample of participants experiencing the digital RT, it is almost impossible to make any robust claims regarding the effects noted within the study. Nonetheless, there is no evidence to suggest that digital RT interventions should be discontinued although the digital RT sessions need to be modified to encompass some form of support. Moreover, as the resident participants in this study rarely had significant or consistent carers, it is difficult to generalise these results to PwD who are outside of care home settings or in other countries where individuals within care homes are more likely to retain access to significant carers.

#### 9.7.2 Implications for a Future Definitive Trial

A feasibility study of using a novel digital-touch screen technology to deliver RT for PwD in Jordanian care homes has been conducted and reported. Although the sample size of the study was small, using one group pre-post design and using purposive sampling, much has been learned from running the feasibility study which has implications for future research and the design of a future trial.

This study was used to explore the feasibility and acceptability of the digital RT programme for PwD, which could subsequently enhance the development or improvement of the digital RT usage and improving health outcomes for PwD in care home settings. The findings from this feasibility study indicated that digital RT can be delivered in a formal evaluation across several care homes in a future definitive trial.

The key stakeholders who could directly benefit from this study are PwD residing in care homes and staff. The qualitative and quantitative data from this study showed that PwD could have improved their cognition, communication, anxiety, depression and QoL after completing digital RT intervention. It is important to improve these outcomes for PwD because these are common problems in dementia and improving these would make a difference to resident's lives. In addition, it would make a difference to the provision of health and social care services.

Moreover, the consideration should be given to the potential negative impact on resident participants during the delivery of sessions. Therefore, plans should be to implemented to minimise this effect such as using personal memories, decreasing the number of digital RT sessions to one session per week, decreasing the duration time of each digital RT session, delivering the intervention in a quiet rooms and minimise distraction, and using step-by-step instruction cards to the resident participants, or needing to be delivered with the support of a care worker, informal caregiver or nurse.

The qualitative data collected during the conduct of this study has provided valuable information regarding the acceptability and the suitability of the digital RT intervention in accordance with the recommendations contained within the MRC complex interventions framework (Craig et al., 2013). A future trial should continue to draw on the strengths of mixed methods study designs and future qualitative evaluations are warranted. This study did not interview participants with severe dementia. Therefore, a future trial should consider widening the scope of qualitative data collection in order to increase the impact these data have on our understanding of digital RT intervention used for people with severe dementia.

Overall, the duration of research and funding should consider the necessity of involving resident and staff participants to become involved in the design and conduct of the research. Timescales of the research should be sufficient to allow PwD involvement within the development of the trial and its interventions.

The data gathered and critically discussed here can only improve upon the quality of the interventions which should be developed and potentially utilised within a future study.

## 9.8 Recommendations for a Future Trial

This feasibility study highlighted many limitations to improve future research. Therefore, it makes specific recommendations in order to address these issues raised in this study, and support the development of a future definitive trial. These recommendations will focus on strategies to enhance the design, implementation, retention of the digital RT intervention. These will include:

 A future study should be conducted by using RCT design, fully powered to detect a large treatment effect on cognitive function outcome on people with mild to moderate dementia in order to determine the effectiveness of digital-touch screen technology facilitated RT for PwD.

- The future study should have sufficient time and clear timescale for the data collection period in order for recruiting participants in the RCT study and conducting respondent validation.
- In the current study, there was agreement among stakeholders (resident and staff participants) as regards the quality of the implementation of RT is vital in studying its effectiveness with PwD. Therefore, it is essential to build the procedures for evaluating the quality of research undertaken by using the best forms of training, supervision and support.
- It is suggested that training of staff and family caregivers from experts in RT is very important in implementing high quality digital RT (Haight, Gibson, & Michel, 2006; Morgan & Woods, 2012b). Moreover, the delivery of the digital RT intervention by RT experts' supervision and support (eg. psychiatric nurse and psychiatrist) may help in implementing digital RT of high quality.
- As mentioned in this chapter section 8.4.1.3.1, that using unfamiliar technology was one barrier for intervention delivery, it is suggested that training of staff and family caregivers from experts in digital-touch screen technology is very important in implementing high quality of digital RT.
- A future research should provide a system which is user-paced, encourage interface simplicity and minimise complexity, develop an easy-to-use system by taking into consideration the possible impairments experienced, provide an interaction which aims to be intuitive, and avoid the use of hierarchical navigation structures.
- A future research should consider utilising personal memories in which caregivers could upload personal memories (images, videos and audios) and they could be trained to deliver the RT.
- Using step-by-step instruction cards could be used in the future research for the resident participants who could use this digital RT alone because they keep forgetting how to use the digital RT application as a result of dementia and memory decline.
- Future evaluations of digital RT interventions for PwD should explore the digital RT experiences of people with severe dementia. This study has only been explored the

experiences of people with mild to moderate severity of dementia. This makes the findings highly pertinent to people with mild or moderate severity of dementia.

- Consideration should be given in relation to decreasing the time duration in each session and the number of sessions each week to one session in order to increase the adherence to the intervention.
- The digital RT interventions in future studies should be delivered in a quiet rooms and minimise distraction.
- To increase the retention and compliance to the digital RT intervention, a future study should encourage and reassure PwD during enrolment and data collection, and plan to address motivations such as monetary stipends, meal vouchers, and newsletters.

## 9.9 Conclusion

This study is one of the first in this research area using a theory-driven intervention in order to include elements known to be associated with health outcomes, and QoL improvements and explain how interventions bring about change. The primary aim of this study was to evaluate the feasibility of the digital-touch screen technology to deliver RT for PwD in Jordanian care homes.

This thesis has demonstrated that the research processes and digital RT are feasible and acceptable among PwD and their caregivers in care homes, and has offered recommendations to help optimise its delivery in a future definitive trial. The findings from the feasibility study demonstrated that it is possible to recruit and retain PwD to a digital RT intervention. Successful engagement and implementation of the digital RT was dependent on it's easy to use, availability of guidance and interesting content.

The secondary objective of this study was to determine the likelihood of changes in outcome measures and to identify the most appropriate outcome measures to evaluate the delivery of digital RT to PwD in Jordanian care homes. The digital RT was evaluated positively by resident and staff participants involved and the results implied that all outcome measures could be used as intended and were sensitive to change. The findings from this thesis

demonstrated that digital RT intervention is shown to be a promising intervention for PwD in care homes to improve their cognition, communication, QoL, depression and anxiety.

This thesis offers exciting avenues of future research, including a definitive trial to evaluate the efficacy and long-term effectiveness of the digital RT for PwD. The findings will continue to be disseminated among the research participants, academic and clinical audiences. However, the digital RT and research processes in their current form require simple adaptations to optimise their potential efficacy.

As this study has generated intellectual property, it is confidential and the property of the University of Nottingham and the principal researcher. No part of it may be transmitted, reproduced, published, or used by others persons without prior written authorisation from the University of Nottingham or the principal researcher. Taking even a small excerpt of someone else's intellectual property and including it in your thesis (print or digital) must be permitted in law if your work is not to infringe on anyone else's rights.

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# Chapter 11 Appendices

Type of bias	Description	Relevant domains in the Collaboration's 'Risk of bias' tool
Selection bias	Systematic differences between baseline characteristics of the groups that are compared	<ul><li>Sequence generation</li><li>Allocation concealment</li></ul>
Performance bias	Systematic differences between groups in the care that is provided, or in exposure to factors other than the interventions of interest	<ul> <li>Blinding of participants and personnel.</li> <li>Other potential threats to validity</li> </ul>
Attrition bias	Systematic differences between groups in how outcomes are determined	<ul> <li>Blinding of outcome assessment.</li> <li>Other potential threats to validity</li> </ul>
Detection bias	Systematic differences between groups in withdrawals from a study	Incomplete outcome data
Reporting bias	Systematic differences between reported and unreported findings	Selective outcome reporting

## Appendix 1: A common classification scheme for bias

Appendix 1: A common classification scheme for bias
## Appendix 2: JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized experimental studies)

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#### JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized experimental studies)

Revi	ewerDate				
Auth	orYear			Record Nu	mber
		Yes	No	Unclear	Not applicable
1.	Is it clear in the study what is the 'sauge' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?				
2.	Were the participants included in any comparisons similar?				
3.	Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?				
4.	Was there a control group?				
5.	Were there multiple measurements of the outcome both pre and post the intervention/exposure?				
6.	Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analuzed?				
7.	Were the outcomes of participants included in any comparisons measured in the same way?				
8.	Were outcomes measured in a reliable way?				
9.	Was appropriate statistical analysis used?				
Ove Com	rall appraisal: Include Exclude Seek furt ments {Including reason for exclusion}	ther info			

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Critical Appraisal Checklist 3 for Quasi-Experimental Studies

Appendix 2: JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized experimental studies)

# Appendix 3: Quality Score of Included Studies Based on JBI-MAStARI Critical Appraisal Tool

Authors (year)	Astell et al. (2005)	Astell, Ellis, Bernardi, et al. (2010)	Williams et al. (2011)	Subramaniam and Woods (2016)	Laird et al. (2018)
Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Yes	Yes	Yes	Yes	Yes
Were the participants included in any comparisons similar?	Yes	Yes	No	No	No
Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	NO	No	Yes	Yes	Yes
Was there a control group?	Yes	Yes	No	No	No
Were there multiple measurements of the outcome both pre and post the intervention/exposure?	No	No	Yes	Yes	No
Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	Unclear	Yes	Yes	Yes	Yes
Were the outcomes of participants included in any comparisons measured in the same way?	Yes	Yes	Unclear	Yes	Yes
Were outcomes measured in a reliable way?	Yes	Yes	Yes	Yes	Yes
Was appropriate statistical analysis used?	No	No	Yes	Yes	Yes
Total	5	6	6	7	6

Appendix 3: Quality Score of Included Studies Based on JBI-MAStARI Critical Appraisal Tool

Author (year)	Touch screen in RT	Comparator	Assessment measure	Assessment elements
Williams, Harris, Lueger et al. (2011)	automated digital displays of resident photographs	Pre- automated digital displays of resident photographs	Descriptive information about residents including age, gender, marital status, occupational history, diagnoses, medication. Minimum Data Set Activities of Daily Living scale	Communication Functional status
Astell, Ellis, Alm, Dye, Gowans, Campbell (2005)	CIRCA	Traditional reminiscence sessions (TRAD)	Mini-Mental State Examination (MMSE; Folstein et al., 1975). Measures of communication and relationships were mentioned by verbal measures	Communication Relationships
Astell, Ellis, Bernardi et al. (2010)	CIRCA	Traditional reminiscence sessions (TRAD)	Mini-Mental State Examination (MMSE; Folstein et al., 1975). Measures of communication and relationships were mentioned by verbal measures	Communication Relationships
Subramaniam, Woods (2016)	Using DIGITAL LIFE STORYBOOKS to help older adults with dementia to engage in reminiscence work	Pre- using information and communication technology to help older adults with dementia to engage in reminiscence work	a number of questionnaires used in the initial life storybook project were repeated: Clinical Dementia Rating (CDR) The quality of life-Alzheimer's disease scale (QOL- AD) The autobiographical memory interview (AMI) The geriatric depression scale (Residential) (GDS- 12R)	Quality of life Autobiographical memory Depression scores
(Laird et al., 2018)	Using the InspireD app	Pre-using the InspireD app	World Health Organization-Five Well-Being Index (WHO-5).	To identify the level of quality of wellbeing (QoL)

#### Appendix 4: Characteristic of Interventions and Comparators of SR

Appendix 4: Characteristic of Interventions and Comparators of SR

Author (year)	Recruitment and intervention	Duration	Time and frequency	Type of RT	Fidelity and adherence	Theoretical underpinni	Adverse effects	Limitations
	setting					ng		
Williams et al. (2011)	Residents with dementia was chosen by the nursing home administration. Intervention setting was in each resident's room.	2-hr recording session	Mini digital recorders were placed in each resident's room when staff entered the room at the start of the day shift. Recorders set to continuously record. The number of session was not	automat ed digital displays of resident photogr aphs	Fidelity: Prior to installing the photo frames in each resident's room, 2 days of baseline audio recordings were collected during morning care. Adherence was not mentioned.	Was not reported	Not mention ed	Staff and residents were aware of audio recording and the study focused on communication, natural conversation could have been altered.
Astell, Ellis, Bernardi et al. (2010)	Residents were recruited from a number of day care and residential facilities by sending out letters to people with dementia in the partner organizations and their families informing them of the study and asking if they were agreeable to the study team	two 20- min sessions	Time and frequency were not reported.	CIRCA and tradition al reminisc ence therapy.	Fidelity: The CIRCA contained 113 items comprising 80 photographs, 10 video clips and 23 pieces of music or songs. The stimuli were mainly drawn from the1930s to the 1960s and were presented in a simple visual format. The traditional: caregivers were asked to choose their own stimuli based on materials they used to run reminiscence sessions in the normal course of their work. Adherence for both were not mentioned.	Was not reported	Not mention ed	They were not reported.

#### **Appendix 5: Characteristic of Interventions of SR**

	approaching them to take part.							
Astell, Ellis, Bernardi et al. (2005)	Residents were recruited from a number of day care and residential facilities by sending out letters to people with dementia in the partner organisations and their families informing them of the study and asking if they were agreeable to the study team approaching them to take part.	two 20- min sessions	Time and frequency were not reported.	CIRCA and tradition al reminisc ence therapy.	Fidelity: The CIRCA contained 113 items comprising 53 photographs, 13 video clips and 23 pieces of music or songs. The stimuli were mainly drawn from the1930s to the 1960s and were presented in a simple visual format. The traditional: caregivers were asked to choose their own stimuli based on materials they used to run reminiscence sessions in the normal course of their work. Adherence for both were not mentioned.	Was not reported	Not mention ed	They were not reported.
Subram aniam, Woods (2016)	Six participants with dementia living in care homes were recruited from the 23 participants in a recently completed randomized controlled trial for developing a conventional life storybook.	4 weeks, The length of movies ranged from 12 minutes to 27 minutes, with an average length of	The time was not reported but frequency was three to four times in a week.	Using informa tion and commu nication technol ogy to help older adults with dementi a to engage in	Fidelity: Participatory design was used, with the participant actively involved in the decision-making process, designing and creating, and directing their own life story movie with the researcher acting as co- editor. A plan and design with timeline at "Windows Movie Maker" program was used to create a dynamic presentation. It had been developed through a structured process. It	Was not reported	Not mentio ned	There are measurement errors on each, and performance on may be influenced by a variety of extraneous factors, including the person's health and mood. Different assessors carried out the assessments at different points in time, potentially

		18 minutes.		reminis cence work	divided into six segments, eg, childhood, teenage life, career, mid-life, etc. adherence was not reported.			introducing other sources of variability, although all were trained to carry out the assessments Lack of a control group and by the lack of blinded post intervention assessments.
(Laird al., 2018)	et A purposive sampling strategy was used to recruit 30 caregiving dyads	5 reminisce nce training sessions. 12 week interventi on from 7 to 19 week of interventi on	3 days per week for the following 12 weeks.	Using Inspire D app	Fidelity: InspireD app (incorporates a logging facility for 5 canonical events. These are entry (logging in), admin (adding a photo, deleting an audio, etc), reminiscing (viewing a video, viewing a photo, etc), ecological momentary assessment (EMA) questions, and exit (logging out). A 19-week personalized reminiscence intervention facilitated by a program of training and a bespoke iPad app was delivered to people living with dementia and their family carers at their own homes. Outcome measurement data were collected at baseline, midpoint, and intervention closure. Adherence: a total of 58 participants (29 dyads) out of 60 were retained in the study at completion	Not mentioned	Not mentio ned	Cannot establish cause-and-effect relationships with certainty Cannot rule out a Hawthorne effect given the trial design and the possibility that pre- existing factors have influenced the results Underrepresentation of women among the participants living with dementia

Appendix 5: Characteristic of Interventions of SR

## Appendix 6: Designing and Prototyping Phase

#### **Prototype Number:**

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Appendix 6: Designing and Prototyping Phase

#### Appendix 7: Dementia, Frail Older People and Palliative Care Public and Patient Involvement Workshop (Palliative Care) Minutes

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Search Mail and People 🛛 🔎	⊕ New   Y      Î Delete      Archive Junk   Y Move to Y Categories Y ····
<ul> <li>Favorites</li> <li>Asem Abdalrahim</li> <li>Inbox 1238</li> <li>Drafts 55</li> <li>Sent Items</li> <li>Deleted Items 15</li> <li>2nd year supervision annual review</li> <li>Archive</li> <li>Conversation History</li> <li>data collection</li> </ul>	Bajwa Rupinder Wed 11/8/2017, 1:15 AM mascough@ntlworld.com; Alan Caswell <alan.caswell@virginmedia.com>; simcork@gmail.com; +21 more * You forwarded this message on 11/8/2017 5:13 AM Vou forwarded this message on 11/8/2017 5:13 AM Unconfirmed PPI group v 20 KB Download Save to OneDrive - The University of Nottingham Good Afternoon,</alan.caswell@virginmedia.com>
development progr	Please find attached the unconfirmed minutes from the PPI meeting held on 20 <sup>22</sup> October 2017. Please do let me know of any correction
dr.holly ethics	Kind regards, Rupinder
flight good news hadeel hhh	Rupinder Kaur Bajwa Research Assistant (PrAISED) School of Medicine University of Nottingham B114, Medical School, QMC Nottingham, NG7 2UH +44 (0) 115 82 30478   nottingham.ac.uk/medicine
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Appendix 7: PPI meeting minutes 20th October 2017

#### Dementia, Frail Older People and Palliative Care Public and Patient Involvement Workshop (Palliative Care) Minutes

#### October 2017

# 20th October 2017, 13.00 – 15.0010.30-1pm B75, Medical School, University of Nottingham, QMC, Nottingham, NG7 2UH

**Attendees:** George Wood (GW), Janet Norris (JN), Kate Hodgett (KH), Linda Hamlin(LH), Suzanne Sheils (SS), Marianne Dunlop (MD), Maureen Godfrey (MG) Kate Sartain (KS) Jay Gorecha (JG), Pushba Gorecha (PG), Lalita Bharadia (LB), Morag Whitworth (MW), Margaret Kerr (MK), Marion Sharp (MS).

Meeting Facilitators: CB (Chair), RB (minutes).

**Introductions:** CB welcomed and thanked everyone for attending the meeting, everyone introduced themselves.

#### Sarah's presentation – VOICE study

- Gave group insight to career as a nurse and a researcher.

- Gave group background to challenges with communication and language in dementia. VOICE study recorded and analysed conversations between health care professionals (HCPs) and patients. From this a dementia skills training programme was developed and 45 HCPs attended the training, with 44 out 45 attending the second day of the course. Kate, Maureen and Margaret have been involved in development of training course.

- Lots of HCPs second language is English, would like to do another study and video HCPs who first language isn't English. They may be using skills and techniques that might be better for communicating with dementia patients. The outputs and resources developed could then be included into induction programmes across the UK for HCPs from overseas.

- Discussed ideas around they participants they will look to recruit, should it be kept open to all HCPs who's second language isn't English or focus on a particular region such as India? Group raised it is not just HCPs whose first language isn't English, dementia patients too.

- Lots of HCPs whose first language isn't English, aren't very confident. SG found in VOICE study participant stated researchers wouldn't want to film the as their English is very good. Also reflected on the nurse who dropped out of the training programme after the first day and how this may be due to lack of confidence.

- MG highlighted dialect and speed can make it difficult. Group agreed, dialect is a massive issue but it can be very difficult to change. KS highlighted looking into dialect could be useful to include into introduction training for HCPs when working in certain areas.

- SG, the proposed research could be a first of its kind in the UK. GW stated it is very important to study this.

- SG and Margaret discussed recruitment. SG stated it would be easier to recruit doctors as they are looked after by an individual HR person at the university, with nurses it is more difficult as they don't have a designated HR contact. Also doctors are looking for some training like this and are very keen. Perhaps it could be rolled out to agency and care staff.

- In the VOICE study results showed, HCPs found techniques more useful 1 month after training, as opposed to immediately after.

- MS and KS highlighted phrasing is also very important and MD highlighted non-verbal communication is also very important too.

- SS feels research could spill over to older people and perhaps roll out to everybody. Linda highlighted need someone on the research team whose first language isn't English. Group feels mixed geographic locations for participants would be better than focusing on just one. Group suggested training pack could include something on dialect.

- Group thinks it is important piece of research and area willing to support it and will have a think about being a PPI co-applicant. Will contact SG if they are interested. Discussed funding, Alzheimer's and NIHR. Group suggested trying Rotary for support and contact Department of Health for more senior support.

# Asem's presentation - The use of digital-touch screen technology in reminiscence work with dementia people in Jordanian care homes: a feasibility study

- Asem's project will look at developing an app for reminiscence therapy for Jordanian care homes. The app will be in Arabic. Discussed accessibility, usability and problems patients with dementia have with both. Also gave overview to what reminiscence therapy is. Will conduct a feasibility study, testing the app in Arabic speaking countries. Talked the group through the digital resource, both on the computer and smartphone. There will be 12 sessions available on the app, will be tested mainly with patients with mild to moderate levels of dementia.

- MW highlighted as dementia progress they lose ability to use tech, so app needs to be guided. Margaret asked if app will be guided, it will.

- KS asked if app can be made personable to you. MG stressed that when using generic images, you need to be careful as it can trigger episodes and gave a personal example of where and how this happened. Group agreed, need to be careful suing generic imagery. KS, can the app include videos and pictures from family? KS spoke about Berlin conference and advanced care planning, suggested incorporating it into the app, consulting with religious advisors and medics.

- Asem asked the group whether the session of death preparation should be included. Group had mixed views, some of the group believed it may be inappropriate, whilst others thought this would be acceptable if the culture in Jordan is one that speaks openly about death in this way. If it is included in the app, needs to be sensitive and important to consult with medics, religious advisors and must be culturally sensitive. Group also highlighted this usually isn't part of reminiscence therapy, so may not be appropriate.

#### Updates

- Recap on PPI workshop – CB working on finding and independent person for the group. Also found that no need to for PPI members to get insurance as there is the UoN volunteer network.

- MW attended meeting about mindfulness and dementia

- Margaret involved in joint health and wellbeing strategy for Nottinghamshire. Also spoke about STP's being split into Nottingham, Greater Nottingham. Will be attending a meeting on 1st November at Albert hall for public update on STPs.

- KH running dementia groups and singing for the brain.

- KS went to Berlin with Professor Rowan Harwood and Rebecca O'Brien about the VOICE project. Conference was on Dementia, medical, arts building research etc. Conference highlighted participants are middle class, white females. Also discussed Alzheimer Europe magazine.

- MD workshop for last offices, training for nurses to communicate properly, with dignity with families of loved ones who have passed, will be national.

- MG has been on the radio and won Volunteer award.

- GW gave update on tax issues, HMRC and university agreement, checked online, agreement still relevant, circulated copy to group.

#### **Appendix 8: Peer Review Form**

Note: this peer review form is adopted and modified from Reusable Learning Object Peer Review (2)-Media form

#### **Reviewer's instructions**

*Please work through the DRT then complete the relevant sections of this form. You may wish to discuss the feedback with the author. Please indicate below whether this discussion has occurred.* 

Once completed, please return it by the date shown to the person named below:

#### Author's instructions

Once you receive the form completed by the reviewer, please note any amendments that you wish to make in the "Author's revisions" boxes.

Please return the form to the person named below and arrange to discuss the suggested revisions with your developer.

Name	Asem Abdalrahim	
Address	43 Tonniler road, Dunkirk	
	NG7 2RW	
E-mail	Asem.abdalrahim@nottingham.ac.uk	l

1) Is the general look & "feel" of the DRT coherent and easy to use?

2) How long would it take PwD to complete each session, in your estimation?

3) Is the content of each session clear, audible and engaging?

4) Do the audios/images/video support the RT for PwD?

5) Are the sessions appropriate and engaging?

6) Is each session effective & engaging as a test of the study objective?

7) Is the DRT easy to navigate?

8) Would this DRT be useful for a range of courses?

Have you discussed your review with the authors?

Yes No

Additional comments or continuations of above sections

Appendix 8: Peer Review Form

#### **Appendix 9: Poster Advertising Study Participation**



Appendix 9: Poster Advertising Study Participation

# Appendix 10: Semi-structured interviews questions with residents and staff in Jordanian care homes

#### The use of Digital-Touch Screen Technology in Reminiscence Work with People with Dementia in Jordanian Care Homes: A Feasibility Study

Post-intervention interview with people with dementia: interview guide

Qualitative Script: Acceptability, Desirability and Feasibility

#### People with dementia (Residents)

Aim 1: To determine whether DTR can be delivered as planned in the care of PwD in Jordanian care homes.

*Aim 2:* To determine whether DTR is acceptable/tolerable to PwD and care home staff in Jordanian care homes

- 1. Introduction
- General introduction
- Personal introduction
  - PhD researcher and nature of the research
- Recap purpose of the study
  - The interview will be recorded and then I will type it all up to use as data for my research.
  - If there's any questions you do not want to answer then that's ok and if at any time you want the interview to stop that's fine too.
    - I expect the interview to last about 30-45minutes, is that ok?

• If it's ok with you I will turn the recorder on now and everything we talk about from now on will be recorded.

#### Start recording

• Would you mind if I asked you some questions about yourself first?

Reminiscence (RT)	1. Do you often find yourself looking back on events that have happened in your life?	If yes, are there any particular things that trigger your memories? If no, do you know why this might be?
	2. How do you currently store things that give you memories about the past such as photographs, videos or music?	
	3. Have you had RT in the past?	If so, could you tell me about your experiences of RT?

		Did you enjoy it?
		If no, what didn't make it enjoyable?
Technology	1. Do you have use a mobile phone computer at all?	e or electronic tablet, or
	If yes:	What do you use?
		Do you use it/them frequently?
		What do you use them/it for?
	If no:	Why?
		Is there anything that would make using them easier or more appealing?
	2. Are there any barriers, or anything that makes it difficult	Tablet- / Smartphone- related barriers
	phones, electronic tablets or computers?	Computer-related obstacles
		Have you managed to overcome these difficulties/barriers? If so, how?
Reminiscence Application	1. How do you feel about storing photographs, videos and music that help you to remember things in your past on a digital device such as smart phone, electronic tablet or computer?	

- 1. What did you think about the sound of the research/project?
- 2. Do you remember the reminiscence application?
  - What did you think about it?
  - Why did you like / not like using it?
  - What do you think about having to use it again?
  - If appropriate: Probe why participants are interested in finding out the results?
- 3. What do you think about the guided reminiscence sessions?

- •
- Were there any sessions you did not attend? If so what were the reasons?
- What did you like about these sessions?
- What did not you like about these sessions?
- 4. I'd like you to think about the program that was used on the electronic tablet, what about it was particularly useful? (format content)
- 5. What about it was not particularly useful? How did the reminiscence application make you feel?
  - Probe perceived benefits
  - Probe perceived negative effects
- 6. What would you like to change about reminiscence application?
  - Content
  - Format
- 7. Would you recommend this intervention to other people?
  - Yes or No
  - Probe why?/ how come?
- 8. Anything else you would like to say about this intervention?
- 9. Do you have any questions?

The use of Digital Technology in Reminiscence Work with People with Dementia in Jordanian Care Homes: A Feasibility Study

Post-intervention interview with care home staff: Interview guide

Qualitative Script: Acceptability, Desirability and Feasibility

#### Care home staff

Aim 1: To determine whether DTR can be delivered as planned in the care of PwD in Jordanian care homes.

*Aim 2: To determine whether DTR is acceptable/tolerable to PwD and care home staff in Jordanian care homes* 

- 1. Introduction
  - General introduction
  - Personal introduction: PhD researcher and nature of the research
  - Recap purpose of the study
  - The interview will be recorded and then I will type it all up to use as data for my research.
  - If there's any questions you do not want to answer then that's ok and if at any time you want the interview to stop that's fine too.
  - I expect the interview to last about 30-45minutes, is that ok?
  - If it's ok with you I will turn the recorder on now and everything we talk about from now on will be recorded.

\*\* RECEIVE (ongoing) CONSENT BEFORE STARTING THE INTERVIEW \*\*

#### Start recording

- 1. Have you read the information sheet?
- 2. Do you understand why we want your feedback?
- 3. Have you had the chance to ask any questions?
- 4. Are you happy to go ahead with the interview?
- 5. What attracted you to taking part in this particular research study?
- 6. What did you think about the recruitment process?
  - Receiving a letter at home
  - Meeting Asem in care home/speaking to Asem about it
- 7. What did you think about the reminiscence application?
- 8. How was your experience of using the application? Why do you think people with dementia liked/did not like using it?
  - If appropriate: Probe why participants are interested in finding out the results?
- 9. Would you have liked to have been offered this reminiscence application as part of your usual care?
  - Yes No
  - Probe further: (if appropriate) At what stage after diagnosis would this have been useful?

10.Is there anything else you would like to say about this reminiscence application?

11. How much did you and your client use the reminiscence application? 12.

- 13. How much of the information about reminiscence did you already know?
- 14.If this was included in clinical practice, what might be the barriers to its implementation? What do you think about the reminiscence application and the things included in it (images, audios, and videos)? Did your client use it?
- 15. What about reminiscence application did you like/not like?
- 16.What about it did your client like/not like?
- 17.What messages do you think we were trying to give to people with dementia and their caregivers?
- 18. What do you think about the reminiscence session?
  - Did your client attend all of them? How many sessions your client attended?
  - Probe why they did/ did not attend (location/time..)?
  - What did you like about these sessions?
  - What did not you like about these sessions?
- 19.What did you think was particularly good about the reminiscence application?
  - Content
  - Format
- 20. What difficulties, if any, did you have with the reminiscence application?
- 21.Did the application seem beneficial to your client?
- 22.Would you like to continue using the application? If no, is there a specific cause?
- 23.Is there anything you would like to change (add, modify, remove) about the application? What would you change about the reminiscence application to improve it?
- 24. What additional information, if any, should be included?
  - Content
  - Format
- 25. How did you find the application to use in term of ease?
- 26.Did you use the application alone, or did you need someone to help you in using the application?
  - If you needed someone:
  - Who was mainly lead the application?
  - Why did you need the assistance?
- 27.What influence or effect, if any, did the reminiscence application have on your client life?
- 28.Would you recommend this intervention to other people with dementia?
  - Yes/ No
  - Probe further: why? / how come?
- 29.Is there anything else you would like to say about this intervention? 30.Do you have any questions?

END OF INTERVIEW

Appendix 10: Semi-structured interviews questions with residents and staff in Jordanian care homes

دليل المقابلة: جدوى ومدى قبول واستحسان استخدام التكنولوجيا في العلاج بالذكريات

المقيمين المصابين بالخرف

#### اهداف الدراسة:

- لتحديد ما إذا كان يمكن أن يتم تطبيق العلاج بالذكريات باستخدام التكنولوجيا التي تعمل باللمس باليد كما هو مقرر مع الاشخاص المصابين بالخرف في دور رعاية المسنين الأردنية.
- لتحديد ما إذا كان تطبيق العلاج بالذكريات باستخدام التكنولوجيا التي تعمل باللمس باليد مقبول للأشخاص المصابين بالخرف في دور رعاية المسنين الأردنية.
  - 1. المقدمة
  - مقدمه عامه
  - مقدمه خاصة
  - عن الباحث وطبيعة الدر اسة
    - التذكير بهدف الدراسة
  - سيتم تسجيل المقابلة •يحتوي وثم سوف يتم طباعتها لاستخدامها كبيانات للدر اسة.
  - إذا هناك هو أي أسئلة لا تريد الإجابة عنها لك ذلك وإذا أردت في أي توقف المقابلة لد ذلك ايضا.
    - اتوقع ان تستمر المقابلة تقريبا من 30-45 دقيقة. هل انت موافق؟
    - اذا كنت موافق على كل شىء فانه سوف ابدا بالتسجيل وكل شىء من الأن فصاعدا سيتم تسجيله.

بدء التسجيل

هل تمانع إذا طلبت منك بعض الأسئلة عن نفسك أو لأ؟

الذكريات	<ol> <li>هل غالبا ما تجد نفسك تنظر إلى</li> </ol>	إذا كان الجواب نعم، هل هناك أي أشياء معينة تحفز
	الوراء في الأحداث السابقة التي	ذلك؟
	وقعت في حياتك؟	إذا لا، هل تعلم لماذا قد يحدث هذا؟
	<ol> <li>كيف يمكنك تخزين الأشياء التي</li> </ol>	
	قد تذكرك بالماضي مثل الصور	
	أو ملفات الفيديو أوَّ الموسيقي ؟	
	<ol> <li>8. هل استخدمت العلاج بالذكريات</li> </ol>	إذا كان الأمر كذلك، هل يمكن أن تخبرني عن
	في الماضى؟	تجربتك بالعلاج بالذكريات؟
		هل استمتعت بها؟
		إذا لا، ما الذي لم يجعلها ممتعة؟
التكنولوجيا	<ol> <li>هل تستخدم الهاتف المحمول أو الشاشات التي</li> </ol>	ي تعمل باللمس، أو جهاز الكمبيوتر على الإطلاق؟
]	اذا نعم:	ماذا كنت تستخدم؟ هل كنت تستخدمها كثير ا؟
		لماذا كنت تستخدمها؟
]	اذا لا:	لماذا؟
		هل هناك أي شيء يمكن ان يجعل استخدامها أكثر
		سهولة أو أكثر جاذبية؟
	<ol> <li>٤. هل هناك أي حواجزاو صعوبات</li> </ol>	الصعوبات المتصلة بالهاتف النقال
	بالنسبة لك لاستخدام الهواتف النقالة	الصعوبات المتصلة بالكمبيوتر
	الذكية وأجهزة الكمبيوتر؟	هل تمكنت من التغلب على هذه
		الصعوبات/الحواجز؟ إذا كان الأمر كذلك، كيف؟

<ol> <li>کیف تشعر حول تخزین الصور</li> </ol>	استخدام
الفوتو غرافية وأشرطة الفيديو	التكنولوجيا في
والموسيقي التي تساعدك على تذكر	الذكريات
الأشياء في المأضبي الخاص بك على	
الهواتف الذكية أو الكمبيوتر؟	

- 10. ما هو رأيك حول هذه الدراسة؟
- 11. هل تتذكر تطبيق العلاج بالذكريات ؟
  - مارايك به؟
  - ماذا تحب/ تكرة في استخدامه؟
- ما رايك حول استخدامه مرة اخرى؟
- اذا امكن: ك(تحقيق) لماذا المشاركون مهتمون بعرفة النتائج؟
  - .12 ما رايك باستخدام المساعدة في تطبيق العلاج بالذكريات ؟
    - اي من الجلسات لم تحضر ها؟ ما هي الاسباب؟
      - ماذا احببت في هذه الجلسات؟
      - ما الذي لم تحبه في هذه الجلسات؟

13. اود ان علم ما هو رايك في هذا البرنامج الذي يستخدم الهواتف الذكيه والنقاله والتي تعمل باللمس ما اذا كان مفيدا بشكل خاص؟

- التنسيق
- المحتوى
- 14. ماذا اذا كان غير مفيد بشكل خاص؟ ما هو الشعور الذي جعلك تشعر به عند استخدام تطبيق العلاج بالذكريات؟
  - (تحقيق) ما هي الفوائد التي تم تحقيقها؟
  - (تحقيق) الاثار السلبية التي تم تحقيقها؟

.15. ما الذي ترغب بتغييره في تطبيق العلاج بالذكريات؟

- التنسيق
- المحتوى
- 16. هل تنصح بهذا التطبيق إلى أشخاص آخرين؟
  - نعم او لا
  - (تحقيق) لماذا/ كيف؟
- 17. هل هناك أي شيء آخر تود قوله حول هذا التطبيق؟
  - 18. هل لديك اسئلة اخرى؟

#### انتهت المقابلة

#### دراسة جدوى استخدام تكنولوجيا الاجهزة التي تعمل باللمس باليد في العلاج بالذكريات مع الاشخاص المصابين بالخرف في دور رعاية المسنين الاردنية

#### دليل المقابلة: جدوى ومدى قبول واستحسان استخدام التكنولوجيا في العلاج بالذكريات

#### مقدمي الرعاية للمصابين بالخرف

#### اهداف الدراسة:

- 3. لتحديد ما إذا كان يمكن أن يتم تطبيق العلاج بالذكريات باستخدام التكنولوجيا التي تعمل باللمس باليد كما هو مقرر مع الاشخاص المصابين بالخرف في دور رعاية المسنين الأردنية.
  - 4. لتحديد ما إذا كان تطبيق العلاج بالذكريات باستخدام التكنولوجيا التي تعمل باللمس باليد مقبول للأشخاص المصابين بالخرف في دور رعاية المسنين الأردنية.
    - 3. المقدمة
    - مقدمه عامه
    - مقدمه خاصة
    - عن الباحث وطبيعة الدر اسة
      - التذكير بهدف الدراسة
    - ، سيتم تسجيل المقابلة وثم سوف يتم طباعتها لاستخدامها كبيانات للدر اسة.
    - · إذا هناك هو أي أسئلة لا تريد الإجابة عنها لك ذلك وإذا أردت في أي توقف المقابلة لد ذلك ايضا.
      - اتوقع ان تستمر المقابلة تقريبا من 30-45 دقيقة. هل انت موافق؟
      - اذا كنت موافق على كل شيء فانه سوف ابدا بالتسجيل وكل شيء من الأن فصاعدا سيتم تسجيله.

بدء التسجيل

- 31. هل قرات ورقة المعلومات الخاصة بك؟
- 32. هل تعلم ما هو الهدف من اخذ تقييمك للدر اسة؟
  - .33 هل كان لديك الفرصة لطرح اية اسئلة?
  - 34. هل انت سعيد للاستمر ار في هذه المقابلة؟
  - .35 ما الذي جذبك للمشاركه فى هذه الدراسة?
- 36. ما هو رايك في عملية توظيف المشاركين بالدراسة؟
  - استلام رسالة المشاركه في دور الرعاية
- مقابلة عاصم في دار الرعاية/محادثة عاصم حول هذا التطبيق
  - 37. ما هو رايك حول تطبيق العلاج بالذكريات؟
- 38. كيف كانت تجربتك في استخدام هذا التطبيق؟ لماذا باعتقادك الناس المصابين بالخرف رغب او لم يرغب باستخدام التطبيق؟
  - اذا كان مناسبا: (تحقيق) لماذا المشاركين مهتمون بمعرفة النتائج الدراسة؟
  - 39. هل ترغب في استخدام هذا التطبيق في الرعاية الروتينيه الخاصة بالمصابين بالخرف؟
    - نعم/ لا
    - تحقيق اكثر: (اذا كان مناسبا) في اي المراحل بعد التشخيص يكون استخدامه مفيدا؟
      - 40. هل هناك أي شيء آخر تود قوله حول تطبيق العلاج يالذكريات؟
        - .41 كم مرة استخدمت انت ومريضك برنامج العلاج بالذكريات؟
        - .42 كم من المعلومات حول ذكريات ماضي كنت تعرفها بالفعل؟

- وإذا أدرج هذا التطبيق في الممارسة السريرية، ما هي العقبات المحتملة التي قد تعترض تنفيذه؟ ما رأيك .43 حول تطبيق العلاج بالذكريات والأشياء المدرجة فيه (الصور والتسجيلات الصوتية وأشرطة الفيديو)؟ هل مريضك استخدامها؟ ما الذي احببته في تطبيق العلاج بالذكريات؟ ما الذي لم تحبه؟ .44 ما الذي احبه مريضك في تطبيق العلاج بالذكريات؟ ما الذي لم يحبه؟ .45 ما هي الرسائل التي تعتقد في أننا كنا ان نحاول ايصالها للأشخاص المصابين بالخرف ومقدمي الرعاية لهم؟ .46 ما رايك بالنسبة لجلسات التطبيق: .47 هل مريضك حضر كل الجلسات؟ كم جلسة حضر مريضك؟ • (تحقيق): لماذا حضرو/ لم يحضرو ( المكان/ الوقت..) • ما الذي احببته في هذه الجلسات؟ • ما الذي لم ترغبه في هذه الجلسات؟ • ما الذي تعتقده والذي يجعل تطبيق العلاج بالذكريات جيدا بشكل خاص؟ .48 المحتوى • التنسيق ما هي الصعوبات (ان وجدت) في تطبيق العلاج بالذكريات؟ .49 هل تعتقد بان تطبيق علاج الذكريات كان مفيدا لمريضك؟ .50 هل ترغب في الاستمر ار في استخدام التطبيق؟ إذا لا، هل هناك سبب معين؟ .51 هل هناك أي شيء ترغب في تغييره في هذا التطبيق (إضافة أو تعديل أو إزالة) ؟ ما هو الذي ترغب ا .52 بتغيير هفي هذا التطبيق لتحسينه؟ ما هي المعلومات الإضافية، إذا وجدت،التي ينبغي إدر اجها؟ .53 المحتوى • التنسيق كيف تجد استخدام هذا التطبيق في مدى سهولته؟ .54 هل يمكنك استخدام هذا التطبيق لوحدك، أو هل أنت بحاجة إلى شخص ما لمساعدتك في استخدام هذا .55 التطبيق؟ إذا كنت في حاجة شخص ما:: من الذي كان يقوده غالبا؟ لماذا تحتاج الى المساعدة? ما هو تاثير او اثر ان وجد في استخدام تطبيق العلاج بالذكريات على حياة المريض المصاب بالخرف؟ .56 هل تنصح بهذا التطبيق إلى أشخاص آخرين؟ .57 • نعم او لا (تحقيق) لماذا/ كيف؟
  - 58. هل هناك أي شيء آخر تود قوله حول هذا التطبيق؟
    - 59. هل لديك اسئلة اخرى؟

انتهت المقابلة

#### Appendix 11: Questionnaires (Arabic and English versions)

#### A. Personal demographic characteristics

Participant code.....

#### 

5. Religions

#### 6. The highest qualification

1. No qualifications ( )	<ol> <li>Primary school ( ) 3. Secondary school ( )</li> </ol>
4. Diploma ( )	5. Bachelor degree ( ) 6. Master degree ( )
7. Higher than master degree ( )	8. Others ( ) please specify

#### 7. Marital status

1. Single ( )	2. Married ( )	3. Partnership ( )	4. Separated (
5. Divorced ( )	6. Widowed ( )	7. Others ( ) please specify	

#### 8. Do you have your own child or adopted child?

No ( ) 2. Yes ( ), if you answer is yes please answering the item 8a.
 Sa. How many your own child or adopted child do you have?

#### B. Hospital Anxiety and Depression Scale (HADS) **English version**

#### Hospital Anxiety and Depression Scale (HADS)

## Tick the box beside the reply that is closest to how you have been feeling in the past week. Don't take too long over you replies: your immediate is best.

D	Α		D	Α	
		I feel tense or 'wound up':			I feel as if I am slowed down:
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to			I get a sort of frightened feeling like
1		enjoy:			'butterflies' in the stomach:
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if			
1		something awful is about to			I have lost interest in my appearance:
		happen:			
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			I look forward with enjoyment to things:
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			I get sudden feelings of panic:
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			I can enjoy a good book or radio or TV program:
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:

Total score: Depression (D) \_\_\_\_\_

Anxiety (A) \_\_\_\_\_

0-7 = Normal 8-10 = Borderline abnormal (borderline case) 11-21 = Abnormal (case)

## Hospital Anxiety and Depression Scale (HADS) Arabic version

Hos	pital Anxiety Depression Scale (HADS):				، قم بإختيار الإجابة المناسبة بوضع داترة عليها:	من فضألك
Α	أشعر بالتوتر الشديد:			D	أحس بأتنى هامد ( فاقد تلطاقة ) :	
	• أكثر الوقت	3			<ul> <li>تفريباً في كل وقت</li> </ul>	3
	<ul> <li>عدة مرات</li> </ul>	2			<ul> <li>في كثير من الأحيان</li> </ul>	2
	• آجياناً	1			<ul> <li>في بعض الأوقات</li> </ul>	1
	<ul> <li>لا أشعر بذلك مطلقاً</li> </ul>	0			<ul> <li>لا أشعر بذلك مطلقاً</li> </ul>	0
D	أنا لازلت أتمتع بالأشياء التي اعتدت أن أستمتع بجا:		1	Α	يتتابني شعور بالخوف:	
	<ul> <li>بالتأكيد، كما كنت</li> </ul>	0			<ul> <li>لا، على الإطلاق</li> </ul>	0
	• ليس قاماً	1			• أحياتاً	1
	• قليلاً	2			• كثيراً	2
	<ul> <li>بالكاد، على الإطلاق</li> </ul>	3			<ul> <li>في أغلب الأوقات</li> </ul>	3
Α	أشعر بنوع من الخوف, وكأن شيئا مروعا على وشك الحدوث:			D	لقد فقدت الإهتمام بمظهري:	
	<ul> <li>بالتأكيد، وبشكل مزعج</li> </ul>	3			<ul> <li>بالتأكيد فقدت كل الاهتمام</li> </ul>	3
	<ul> <li>نعم، ولكن أقل سوءاً</li> </ul>	2			<ul> <li>أنا لا أهتم عظهري كما يُحِب أن أهتم</li> </ul>	2
	<ul> <li>قليلاً، لكنه لا يقلقني</li> </ul>	1			<ul> <li>قد لا أعتني بمظهري كما يجب</li> </ul>	1
	<ul> <li>لا أشعر بذلك على الاطلاق</li> </ul>	0			<ul> <li>أعتني بمظهري بشكل جيدكما كنت سابقا</li> </ul>	0
D	أستطيع الضحك و رؤية الجوانب المتعة في الاشياء:			Α	اشعر بالتعلمل	
	<ul> <li>کماکنت سابقا</li> </ul>	0			<ul> <li>في الواقع، كثيراً جداً</li> </ul>	3
	<ul> <li>اقل مما کنت سابقا</li> </ul>	1			• كثيراً، لاباس به	2
	<ul> <li>بالتأكيد، ليس كثيراً الآن</li> </ul>	2			<ul> <li>أشعر بذلك قليلاً</li> </ul>	1
	<ul> <li>لا أشعر بذلك على الإطلاق</li> </ul>	3			<ul> <li>لا أشعر بذلك على الإطلاق</li> </ul>	0
A	تأتيني دائما افكار مقلقة:			D	أنا أتطلع للأشياء من حولي باستمتاع:	
	<ul> <li>أغلب الأوقات</li> </ul>	3			<ul> <li>بقدر ما يمكنني فعله</li> </ul>	0
	<ul> <li>معظم الأوقات</li> </ul>	2			<ul> <li>نوعا ما أقل مما اعتدت على فعله</li> </ul>	1
	<ul> <li>من وقت لآخر، ولكن ليس كايراً</li> </ul>	1			<ul> <li>بالتأكيد أقل مما اعتدت على فعلة</li> </ul>	2
	• آجيانا	0			<ul> <li>لا، على الإطلاق</li> </ul>	3
D	أشعر بالبهجة:			A	يتتابني إحساس مفاجئ باظلع:	
	<ul> <li>لا، على الإطلاق</li> </ul>	3			<ul> <li>في الواقع، في كثير من الأحيان</li> </ul>	3
	• ليس كليراً	2			• غالباً	2
	<ul> <li>في بعض الأحيان</li> </ul>	1			• ليس كثيراً	1
	<ul> <li>في أغلب الأوقات</li> </ul>	0			<ul> <li>لا أشعر بذلك على الإطلاق</li> </ul>	0
A	يمكنني الجلوس براحة و الشعور بالاسترخاء:			D	يمكني الإستمتاع بقراءة كتاب جيد أو مشاهدة البرامج	
					التلفزيونية أو الإستماع إلى الإذاعة:	_
	<ul> <li>بكل التأكيد</li> </ul>	0			• غالباً	0
	• عادة ما	1			<ul> <li>في بعض الأحيان</li> </ul>	1
	• ليس كثيراً	2			• ليس كثيراً	2
	<ul> <li>لا يمكنني ذلك على الإطلاق</li> </ul>	3			• نادراً جداً	3

هذا الاستبيان يساعد الطبيب لمعرفة مشاعرك وقراءة أحاسيسك ، لذا يرجى إحاطة الرقم الموازي لأقضل اختيار يصف حالتك خلال الأسبوع الماضي. ليس من المطلوب الاستغراق في التفكير لإختيار الإجابة، وإنما تفضل الإجابات العفوية التلقائية.

#### **C. SLUMS Examination**

#### **English version**



SH Tariq, N Turnosa, JT Chibnall, HM Perry III, and JE Morley. The Saint Louis University Mental Status (SLUMS) Examination for Detecting Mild Cognitive Impairment and Dementia is more sensitive than the Mini-Mental Status Examination (MMSE) - A pilot study. J am Geriatri Psych (in press).

#### **SLUMS Arabic version**

جامعة سان لويس اختبار الحالة العقلية

St. Louis University Mental Status (SLUMS) Examination - Am J Geriatr Psychiatry 2006;14:900-10



ملاحظة: يمكن طرح هذا الاختبار باللغة المحلية المناسبة

#### D. The Holden Communication Scale (HCS) English version

#### The Holden Communication Scale (HCS)

The Holden communication scale (HCS) has been developed by Una Holden and includes 12 items. The score range from 0-48 and the higher score the more difficulties. Choose only **ONE** answer. The HCS was psychometric tested in 2016 (Strøm, Engedal, Saltyte Benth, & Grov, 2016).

Holden		Score
Conversation		
1.Response	0. Initiates conversation deeply involved with anyone	
	1.Good for those familiar to person	
	2.Fair response to those close by; no initiation of	
	conversation	
	3.Rather confused; poor comprehension	
	4.Rarely or never converse	
2.Interest in past	0.Long, full account of past events	
events	1.Fairly good description	
	2.Short description; a little confused	
	3.Confused or disinterested	
	4.No response	
3.Pleasure	0.Shows real pleasure in situation /achievement	
	1.Smiles and shows interest	
	2.Variable response; slight smile; vague	
	3.Rarely shows even a smile	
	4.No response of just weeps	
4.Humour	0.Creates situation or tells funny story on own initiative	
	1.Enjoys comic situations or stories	
	2.Needs an explanation and encouragement to respond	
	3.Vague smile; simply copies others	
	4.No response or negativistic	
Awareness and		
knowledge		
5.Names	0.Knows most people's names on ward	
	1.Knows a few names	
	2.Needs a constant reminder	
	3.Knows own name only	
	4.Forgotten even own name	
6.General	0.Knows day, month, weather and whereabouts	
orientation	1.Can forget one or two items	
	2.Usually gets two right but tries	
	3.Vague; may guess one	
	4.Very confused	
7.General	0.Good om current events; generally able	
knowledge	1.Outstanding events only; fair on general knowledge	

	2.No current knowledge; poor general information	
	3.Confused about many things; gets anxious and upset	
	4.Confused about everything; does not respond	
8.Ability to join	0.Joins in games and activities with ease	
in games etc.	1.Requieres careful instructions but joins in	
	2.Can only join in simple activities	
	3.Becomes anxious and upset	
	4.Cannot or will not join in	
Communication		
9.Speech	0.No known difficulty	
	1.Slight hesitation or odd wording	
	2.Very few words; mainly automatic phrases	
	3.Inappropriate words; odd wounds; nodding	
	4.Little or no verbalisation	
10.Attempts at	0.Communicates with ease	
communication	1.Tries hard to speak clearly	
	2. Tries to draw; gesticulates needs etc.	
	3.Euphoric laughter; weeping; aggressive	
	4.No attempt	
11.Interest and	0.Responds with interest and comment	
response to	1.Despite difficulties shows interest	
objects	2.Shows some interest, but rather vague	
	3.Weeps; rejects objects; shows aggression	
	4.No response; no comprehension	
12.Success in	0.Clearly understood	
communication	1.Uses gestures and sounds effectively	
	2.Understanding restricted to a few people	
	3.Becomes frustrated and angry	
	4.Makes no attempt	
Total score		
Sign		
Date		

#### References

Strøm, B. S., Engedal, K., Saltyte Benth, J., & Grov, E. K. (2016). Psychometric evaluation of the Holden Communication Scale (HCS) for persons with dementia. *BMJ Open*, 6(12), e013447. doi:10.1136/bmjopen-2016-013447

#### The Holden Communication Scale (HCS) Arabic version

#### (Strøm, Engedal, Saltyte Benth, & Grov, 2016)

يشمل هذا الاستبيان 12 بندا يقيس فيه حجم الاتصال والتواصل. مجموع نقاط هذا الاستبييان من 0-48 حيث كلما زادت مجموع النقاط زادت الصعوبات بالتواصل. الرجاء اختبار **إجابة واحدة ف**قط. تم اختبار هذا الاستبيان في عام 2016.

العلامة	Holden
	المحادثة
<ol> <li>ويدا المحادثة بشكل عميق مع أي شخص</li> </ol>	1. الاستجابة
<ol> <li>فقط مع الاشخاص المالوفين لدية</li> </ol>	
<ol> <li>یستجیب فقط للاشخاص المقربین لدیة و لا یبدا الحدیث هو</li> </ol>	
<ol> <li>عديم التركيز وكالم غير متناسق</li> </ol>	
4. قلیل جدا او ابدا لا یتحدث	
0.اهتمام كامل وطويل لاحداث الماضمي	2. الاهتمام بالأحداث
1. وصف جود الى حد ما	الماضية
2. وصف قصير، قليل التركيز	
3. غیر مرکز وغیر مرغوب فیه	
<ol> <li>بدون استجابه ورد</li> </ol>	
<ol> <li>وظهر استمتاع واقعى في المواقف والنجاحات</li> </ol>	3. الاستمتاع
1. يبتسم ويظهر المتعة	
<ol> <li>متغير الاستجابة ابتسامة طفيفة وغامضة</li> </ol>	
<ol> <li>ذاكرا ما يظهر حتى ابتسامة</li> </ol>	
4. لا يوجد زد يبخي فعط صاح التاً حدّ تا حدّ المنات	Seetty a
<ol> <li>يحلق حلله او يحكي قصبه مضحكه بمبادرة خاصبه</li> <li>م ت ت الا دراما ال</li> </ol>	هر النخبة
1. پسمنع بالاوضاع او الفصص الخوميدية جــــــــــــــــــــــــــــــــــــ	
<ol> <li>ریک از معلول از منطق الاندین (</li> <li>۲. ایک ایک ایک ایک (</li> <li>۲. ایک ایک (</li> <li>۲. ایک (</li></ol>	
د المسج عنصب المسج الحرين	
په. د ز- وسېږي	الوعي والمعرفة
<ol> <li>يعرف أسماء معظم الناس الموجودين في القسم</li> </ol>	5. الاسماء
1. يعرف بعض الاسماء	
2. بحاجة الى تذكير مستمر	
3. يعرف اسمه فقط	
4. پئسی حتی اسمه	
<ol> <li>يعرف اليوم، والشهر، والطفس وأماكن وجودهم</li> </ol>	6. التوجة العام
<ol> <li>یمکن آن پنسی و احده او اثنتین منها</li> </ol>	
<ol> <li>بالعادة يتوصل إلى اثنتين منها لكن بعد أن يحاول</li> </ol>	
3. غامض وقد يستطيع تخمين واحده	
4. غير مركز وكثير الخلط	
<ol> <li>جيد في معرفة الاحداث الجارية وبتسكل عام قادر</li> </ol>	7. المعلومات العامة
<ol> <li>فادر على معز قه الإحداث البارزة فقط؛ مقبول في المعز قه العامة.</li> </ol>	
<ol> <li>لا يوجد معرفة للوقت الحالي؛ قليل المعلومات العامة.</li> <li>جن بين كن في أقرار كانيري، جن بي بينا.</li> </ol>	
<ol> <li>عن مز در في اللارة عصبي ومحيط ٨ خد مدكر في الاقدام الاعداد ماليتماية</li> </ol>	
4 عور مز هي من ديسوء و د يوجد المنجاب. 0 داد اد ف الألمان الأنشاطة سيدانة	<ul> <li>القدة على الالية اط</li> </ul>
ن وسرت مي الالعاب والاست بسهوت. 1. بحتاج الـ. تعليمات دقيقة والكنه بنضد في النهاية	في الالعاب الخ
2. يستطيع فقط الانضمار إلى الأنشطة البسيطة	C , Q
3. يصبح مضطرب ومحيط	

	<ol> <li>لا يستطيع او لا ير غب بالمشاركة</li> </ol>	
التواصل		
و. الكلام	<ol> <li>لا يوجد صعوبة</li> </ol>	
1	<ol> <li>تردد طفيف أو كلمات غريبة</li> </ol>	
1	2 كلمات قليلة؛ و عبار ات التلقانية	
1	3 کلمات غیر مناسبة ا طأطأة ر اس	
1	<ol> <li>تعابير لفظية قليله او لا تحبير</li> </ol>	
10. محاولات الاتصال	0. يتصل بسيولة	
1	<ol> <li>يحاول بصعوبة التحدث بوضوح</li> </ol>	
1	2. يحاول الرسم؛ الاشارة الخ	
1	<ol> <li>الضحك بابتهاج البكاء العدوانية</li> </ol>	
1	4. لا محاولة	
11. المتعة والاستجابة	<ol> <li>يستجيب مع الاهتمام والتعليق</li> </ol>	
للاشياء	<ol> <li>على الرغم من الصعوبات لكنه يظهر الاهتمام</li> </ol>	
]	<ol> <li>يظهر بعض الاهتمام، ولكنه غامضا اكثر</li> </ol>	
]	3. بيكي ويرفض الاشياء ويظهر العدوانية	
	4. لا استجابة ولا وضوح	
12. النجاح في التواصل	0. مفهوم بوضوح	
]	<ol> <li>يستخدم الإيماءات والأصوات بشكل فعال</li> </ol>	
]	<ol> <li>الفهم يقتصر على بضعة أشخاص</li> </ol>	
]	3. يصبح محبط و غاضب	
	4. لا يصنع اي محاولة	
مجموع النقاط		
التوقيع		
التاريخ		

المرجع

Strøm, B. S., Engedal, K., Saltyte Benth, J., & Grov, E. K. (2016). Psychometric evaluation of the Holden Communication Scale (HCS) for persons with dementia. BMJ Open, 6(12), e013447. doi:10.1136/bmjopen-2016-013447

#### E. OPQOL-brief English version

#### **OPQOL-brief:**

#### Notes: The OPQOL-BRIEF questionnaire has 13 items, with a preliminary single item on global QoL, shown below. This single item is not scored with the OPQOL; it is coded as Very good (1) to Very bad (5). OPQOL-Brief scoring: Each of the 13 items is scored Strongly agree=1, Agree=2, Neither=3, Disagree=4, Strongly disagree=5. The items are summed for a total OPQOL-Brief score, then positive items are reverse coded, so that higher scores represented higher QoL. We would like to ask you about your quality of life:

Single item - global QoL:

#### 1 Thinking about both the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?

Your quality of life as a whole is:	Very good	Good	Alright	Bad	Very bad

#### OPQOL-Brief

## 2 Please tick one box in each row. Please select the response that best describes you/your views. There are no right or wrong answers.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1 I enjoy my life overall					
2 I look forward to things					
3 I am healthy enough to get out and about					
4 My family, friends or neighbours					

4 My family, friends or neighbours

would help me if needed			
5 I have social or leisure activities/ hobbies that I enjoy doing			
6 I try to stay involved with things			
7 I am healthy enough to have my independence			
8 I can please myself what I do			
9 I feel safe where I live			
10 I get pleasure from my home			
11 I take life as it comes and make the best of things			
12 I feel lucky compared to most people			
13 I have enough money to pay for household bills			

Thank you for your help

OPQOL: Copyrighted @ A. Bowling. This questionnaire is free to use and no permissions are needed. The request is that the source is credited:

Bowling A, Hankins M, Windle G, Bilotta C, Grant R. (2013). A short measure of quality of life in older age: The performance of the brief Older People's Quality of Life questionnaire (OPQOL-brief). Archives of Geriatrics and Gerontology, 56, 1: 181-187. <u>http://dx.doi.org/10.1016/j.archger.2012.08.012</u>
OPQOL-brief

الموجز -OPQOL						
ملاحظات: هذا الاستبيان موجز أوينكون مز	13 بند، مع عنصر	ىر واحد أولية علم	ن قل العلمية، هو	ميين أدناه. لم	بيتم اعطاء هذا	البند ای نقطه:
لكنه تم ترميزه من حسنا جدا (	إلى سينا جدا (5)					
طريقة اعطاء النقاط: كل بند من بند حمد نقاط حميد العناص الع	لينود 13 يتم تسج الاستنبان، ثم العد	بيله: انفق بشدة : ناصر الايحانية تع	= 1، أوافق = 2، طي شيف ة معاكس	لا = 3، لا اوا آه، حدّ ينکه ن	افق = 4، أعارظ الد حات العالية	س بشدة = 5. تمثل نوعية
الحياة الأعلى.		- 3439		۰۰ سی سون		730-
أود أن أسألك عن نوعية الحياة ال	اصة بك:					
بند واحد من الاستيانة العالمية:						
<ol> <li>التفكير في الأشياء الجيدة والس</li> </ol>	ة التي تشكل نوع	فية الحياة الخاصة	و یک، کیف تقیم نو	عية الحياة الذ	فاصة بك بشكل ا	عام؟
نوعية الحياة جيد بشكل علم	÷ 14	فتزد	حسنا	مىيء		سيء جدا
7 7						
الموجز-OPQOL						
2. يرجى وضع اشاره في مريع و	ند من کل صف. اا	الرجاء تحديد اجابا	تك التي تصف لك	وجهة نظرك ا	الخاصة بك. لا يو	رجد هناك
اجابات صحيحة أو خاطئة.						
		موافق شدة	موافق	محايد	غير ممافق	نخير موافق بشدة
					- <b>1</b> 0-1	
<ol> <li>انا مستمتع بحياتي بشك</li> </ol>	علم					
<ol> <li>د انا انطلع الى الاشياء</li> </ol>						
<ol> <li>انا بصحة جيدة تمكني ا</li> </ol>	، الخروج					
		_				
<ol> <li>افراد العائلة او اصدقائم</li> </ol>	او چيرانې	_	_	_	_	_
يقدمو لي المساعده اذا	عتجت					
<ol> <li>لدي انشطة اجتماعية أ</li> </ol>	الترفيهية	_		_	_	
/هو ایات اتمتع به						



Shata, El-Kady, & Ibrahim. (2015). Reliability and Validity of an Arabic Version of Quality of life - Alzheimer Disease in Alexandria, Egypt. *International Journal of* 

Behavioral Research & Psychology, 157-163. doi:10.19070/2332-3000-1500028

Appendix 11: Questionnaires (Arabic and English versions)

## **Appendix 12: Ethical Approval Process**

## a. Ethical approval from the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of Nottingham



Appendix 12: Ethical Approval Process



## Faculty of Medicine & Health Sciences Research Ethics Committee

c/o Faculty PVC Office School of Medicine Education Centre B Floor, Medical School Queen's Medical Centre Campus Nottingham University Hospitals Nottingham, NG7 2UH

Email: FMHS-ResearchEthics@nottingham.ac.uk

#### 15 September 2017

## Asem Abdalrahim,

PhD student c/o Dr Holly Blake Associate Professor of Behavioural Science B Floor, School of Health Sciences QMC Campus Nottingham University Hospitals Nottingham NG7 2YH

#### Dear Asem

Ethics Reference No: 110-1709 – please always quote					
Study Title: Use of digital technology	Study Title: Use of digital technology in reminiscence work with dementia people in Jordanian care				
homes: a feasibility study					
Short Title: Digital reminiscence for	people with dementia				
Chief Investigator/Supervisor: : Dr	Holly Blake BA(Hons), PhD, CPsychol, AFBPsS, SFHEA				
Associate Professor of Behavioural S	clence/Director of Postgraduate Research and Environment				
Lead Investigators/student: Asem Abdalrahim, BSc Nursing (The University of Jordan), MSc Nursing					
(Hon)/ Psychiatric and Mental Health Nursing (Hashemite University) , PhD Student, School of Health					
Sciences.					
Other Key Investigators: Dr Philip Clissett PhD, Lecturer, Nursing with older people, Dr Tim Carter					
PhD, Teaching and Research Associate, Mental Health Nursing.					
Type of Study: PhD Student project (PhD in Nursing studies):					
Feasibility study of acceptability and applicability of using digital reminiscence therapy, Questionnaire-					
based study, Interviews, Overseas: Jordan					
Proposed Start Date: 28/11/2017	Proposed End Date: 28/02/2018 3mths				
No of Subjects: 40-50	Age: 18+years				
School: Health Sciences					

Thank you for submitting the above application which has been considered by the Committee at its meeting on 11<sup>th</sup> September 2017and the following documents were received:

FMHS REC Application form and supporting documents version 1.0: 19.09.2017.

These have been reviewed and are satisfactory and the study has been given a favourable opinion.

A favourable opinion is given on the understanding that the conditions set out below are followed:

- All appropriate ethical and regulatory permissions are respected and followed in accordance with all local laws of the country in which the study is being conducted and those required by the host organisation/s involved.
- Please submit copies of letters/e-mails of approval/permission from the Jordan Ministry of Social Development Institutional Review Board and the 3 Jordanian Care homes for our records when these are available.
- You should follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).
- 4. You must notify the Chair of any serious or unexpected event.



An End of Project Progress Report is completed and returned when the study has finished (please request a form).

Yours sincerely

San . S. Shat of 6

Professor Ravi Mahajan Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

## b. Ethical approval from the Jordan Ministry of Social Development Institutional Review Board and selected care homes



الدت من *1 | / ۲* ۲ ۵ | التاريخ / / 1438هـ الموانق\/ / ۹ / 2017

## To Whom It May Concern

In reference to your letter dated 8 August 2017 requesting the support for the researcher Mr. Asem Abdalrahim who is enrolled in the second year as a phD student in Nursing Studies, School of health Science, University of Nottingham, Uk, and who is conducting a research on "Using of Digital Technology in Reminiscence Work with Dementia People in Jordanian Care Homes: A Feasibility Study".

The Ministry of Social Development apologize to support the researcher mentioned above to conduct his research in our care centers due to unavailability of specialized centers in caring of old people under the direct supervision of our ministry.

Sincerely, Hala Bsaisu Lattouf Minister of Scoial Development Amman Jordan

معر مالع

## c. Darat Samir Shamma ethical approval



Date: 5<sup>th</sup> October2017 No. 353/2017

To Whom It May Concern

In reference to your letter dated 20<sup>th</sup> September 20 17 requesting the support for the researcher **Mr. Asem Abdalrahim** who is enrolled in the second year as a PhD student in Nursing Studies, School of health Science, University of Nottingham, UK, and who is conducting a research on " **Using of Digital Technology in Reminiscence Work with Dementia People in Jordanian Care Homes: A Feasibility Study**".

After reviewing the protocol of the study, the Director of Darat Samir Shamma for the Elderly (Amman) is pleased to welcome and support the researcher mentioned above to conduct his research in Darat Samir Shamma for the Elderly (Amman).

Sincerely,

**General Director** 

Dr. Ehmoud Al Lasasmeh

## d. Dar Aldiafeh Nursing Home (White Beds Society) ethical approval



## e. The replying email to the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of Nottingham

<ul> <li>Favorites</li> <li>Asem Abdalrahim</li> <li>Inhor</li> <li>1216</li> </ul>	AA Abdalrahim Asem <ntxaa37@exmail.nottingham.ac.uk></ntxaa37@exmail.nottingham.ac.uk>	<b>v</b>
Inbox     1516       Drafts     63       Sent Items     15       Deleted Items     15       2nd year supervision     annual review       Archive     Conversation History	study advert_final (1).doc       Medical School Ethics C       consent form residents I       Image: Consent form residents I         Show all 12 attachments (2 MB)       Download all       Save all to OneDrive - The University of Nottingham         Dear Louise,       could you please see the attached files which contain the new version of past forms of ethical approval and the ethical approvals from Jordan if you received, them please reply me.         many thanks	nt for
data collection development progra dr.holly ethics	SL Sabir Louise ! 0 \$	V
flight good news	348 KB       139 KB         Show all 2 attachments (487 KB)       Download all         Save all to OneDrive - The University of Nottingham	
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progress qualitative qualitative part	Participant Information Sheet: "What if there is a problem" – we suggest an appropriate local body in Jordan is used for formal complaints rather than this Committee. All the above points are for advice and no additional approval is required. Please can you submit letters/e-mails confirming approval/permission from the Jordanian Ministry of Social Development Institutional review board and t care homes when these are available for our records	; he

## **Appendix 13: Participant Information Sheet**

# a. For residents (Arabic and English)English version

#### University of Nottingham, Faculty of Medicine & Health Sciences, School of Health Sciences



Title of Study: The use of Digital Technology in Reminiscence Work with People with Dementia in Jordanian Care Homes: A Feasibility Study Name of Researcher(s): Mr Asem Abdalrahim, PhD researcher Dr Holly Blake, Associate Professor of Behavioural Sciences, School of Health Sciences Dr Philip Clissett, Lecturer, School of Health Sciences Dr Tim Carter, Assistant Professor of mental health, School of Health Sciences

#### Participants Information Sheet People with Dementia (Residents)

You are being invited to take part in a research study. Before you decide whether to take part, 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 friends and relatives if you wish to. Please ask the investigator, Asem Abdalrahim if there is anything that is not clear or if you would like more information (Asem's contact information is at the end of this information sheet). Take your time to decide whether you wish to take part or not. Thank you for showing interest in this study.

#### Background

Dementia is a condition that describes a wide range of symptoms associated with a decline in memory or person's ability to perform everyday activities. Therefore, we need to be thinking about ways in which to alleviate some of the symptoms. Reminiscence therapy may provide a possible solution. The aim of reminiscence therapy is to evoke discussion of past memories by using music, objects, photos, and videos. In addition to offering an enjoyable and stimulating activity, it has the potential to improve a person's mood; increase social interaction; and reduce social isolation and depressive symptoms. With the introduction of touch screen technology, there is the potential to produce a program capable of holding a range of objects such as photos, music, and videos to facilitate reminiscence therapy that it might be easier to use and more functional.

#### What does the study involve?

This study will explore whether touch screen technology devices (such as electronic tablets) might be used to aid reminiscence for people with dementia. To do this, we would like to recruit 30-40 people with dementia who are residents in care homes as well as about 10 members of staff caregivers from these care homes.

If you agree to take part, you will be asked to complete a set of four questionnaires before being supported to take part in a six-week reminiscence therapy programme using touch-screen technology. At the end of the programme, you will be asked to complete the four questionnaires again and may be asked to take part in an interview where you will be asked about your experiences and views on taking part in the study and the reminiscence programme.

#### Why have you been chosen?

We are looking for people who live in a care home who have been diagnosed with dementia. You are being invited to take part because the care home staff have indicated that you meet this criteria.

#### Do you have to take part?

It is up to you to decide whether or not to take part. Please take your time to decide whether or not you wish to take part and discuss this with your family and friends. If you would like any further information please do not hesitate to contact Asem Abdalrahim on <a href="https://www.ntxaa37@nottingham.ac.uk">https://www.ntxaa37@nottingham.ac.uk</a>.

If you do decide to take part you will be asked to keep this information sheet and sign a consent form. You will still be free to withdraw at any time and without giving a reason.

#### What will happen to you if you take part?

If you accept to be part of this study, you will be invited to complete some questionnaires before you are supported to undertake an individual digital reminiscence therapy programme that runs at the care homes you are resident in. The intervention will run for 12 sessions, each session will last for one hour and will be taken twice a week at your convenience for six weeks. Immediately after the programme, you will complete another set of same questionnaires you filled earlier. You may be invited for an interview that will last between 30–60 mins and will be audio-recorded after completing this second set of questionnaires. The interview will be used to collect your views about intervention and its acceptability for use in Jordan.

#### Expenses and inconvenience allowance

You will not be paid or received any other incentive to participate in the study.

#### What are the possible disadvantages and risks of taking part?

The main potential disadvantage with taking part is that you may find some of the memories cause you some distress. If this happens, please inform the researcher and your caregivers. The conversation will be interrupted or postponed and any issues raised may be reported to the care home mangers should you wish this to happen.

#### What are the possible benefits of taking part?

While we hope that you will find taking part in the reminiscence programme an enjoyable experience, we cannot promise the study will help you but the information we get from the study will help us to develop and assess a touch screen reminiscence therapy programme that might be more widely used.

#### Will my taking part in this study be kept confidential?

We will take a number of actions to ensure that your taking part in this study will be kept confidential. We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**. To achieve confidentiality by maintaining anonymity, the consent form and personal demographic data sheet will be stored separately. Your name and identity will be replaced with a unique code and this will and as such your name and identity will not be disclosed throughout the study. The researcher is the only person who will have access to your personal information. Importantly, all the information collected from you will be kept for a minimum of 7 years, however, any information that could identify you will be stored in password-protected computers and files. All non-electronic data will be stored in a secure and locked office.

We would also like to seek your consent so that the data may be stored and used in possible future research during and after 7 years- this is optional (please indicate you agree to this on the consent form).

#### What will happen to the results of the research study?

The results of the study will be used by the researcher for the development of a PhD and will be published in relevant health journals. Participants will not be identifiable in any publication.

#### What will happen if you don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason and it will have no impact on your ongoing care. However, the data collected to the point at which you leave the study

## Who is organising and funding the research?

The research is organised by the University of Nottingham and funded by Al Albaxt. University, Jordan.

#### Who has reviewed the study?

All research in the University of Nottingham is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Medicine & Health Sciences (FMHS) Research Ethics Committee.

#### What if there is a problem?

If you have a concern about any aspect of this study, you should contact Golden Age Home manger, Retired Brigadier General <u>Muna Hadadin</u>, or <u>Society Samir Shamma</u>. <u>Homes</u> director, <u>Dr. Ehmoud</u> A-I <u>Lasasmeh</u>, If you remain unhappy and wish to complain formally, you should then contact the FMHS Research Ethics Committee Administrator you should contact the Chief investigator e-mail: holly.blake@nottingham.ac.uk. **Further information and contact details** 

holly.blake@nottingham.ac.uk

Investigators Name Email
Principle investigator Asem Abdalrahim ntxaa37@nottingham.ac.uk

#### Contact for Further Information

Chief investigator

If you would like to find out more about the study, please contact: Asem Abdalrahim, PhD student. E-Mail: <u>ntxaa37@nottingham.ac.uk</u> Mobile: +447449831883 **Thank you for your time.** 

Dr Holly Blake

Appendix 13: Participant Information Sheet (Arabic and English versions)

## Arabic version



#### جامعة نوتنجهام البريطانية كلية الطب والعلوم الصحية

#### عنوان الدراسة: دراسة جدوى استخدام تكنولوجيا الاجهزة التي تعمل باللمس باليد في العلاج بالذكريات مع الاشخاص المصابين بالخرف في دور رعاية المسنين الاردنية.

**اسماء الباحثين**: عاصم عبدالرحيم، الدكتورة هولي بلاك، الدكتور فيليب كليسيت، الدكتور تيم كارتر

#### معلومات الدر اسة للمشاركين ( المقيمين )

أنت مدعو للمشاركة في هذه الدراسة. قبل أن تقرر ما إذا كنت ستشارك فيها، عليك ان تنقهم ما هو هدف هذه الدراسة وماذا سنتضمن. يرجى أخذ الوقت الكافي لقراءة المعلومات التالية بعناية ومنافشتها مع الأصدقاء والأقدرب إذا كنت ترغب في ذلك. يرجى سؤال الباحث (عاصم عبدالرحيم) إذا كان هناك أي شيء غير واضح، أو إذا كنت ترغب في مزيد من المعلومات (للتواصل مع الباحث فان معلوماته توجد في نهاية هذه الورقة). خذ وقتك الكافي لتقرر ما إذا كنت ترغب في المشاركة أم لا. شكرا لك على اظهارك الرغبة في المشاركة في هذه الدراسة.

#### المقدمة

الخرف هي المالة التي تزدي عمرما إلى مجموعة واسعة من الأعراض المرتبطة بانخفاض الذاكرة أو قدرة الشخص على القيام بالأنشطة اليومية. لذلك نحن بحاجة إلى التفكير في الطرق التي يمكن بها التخفيف من حدة بعض الأعراض المرافقة لها. العلاج بالذكريات قد توفر حلاً ممكناً. يهنف العلاج بالذكريات إلى تحفيز المناقشة لاستحصار الذكريات السابقة عن طريق استخدام الموسيقي، والصور، وأشرطة الفيديو. وجد أن العلاج بالذكريات يعمل على تحصين مزاج الشخص. زيادة التقاعل الاجتماعي؛ وتقليل بعض اثار الخرف الاخري. مع إدخال تكتولو جيا الشاشات التي تعمل بالمس، هناك إمكنية. لإنتاج برنامج قادر على تسهيل العلاج بالذكريات والتي ممكن اكثر سهولة وفاعلية.

#### ماذا ستتضمن هذه الدراسة؟

تهدف هذه الدراسة الى استكشاف جدوى استخدام تكلولوجيا الإجهزة التي تعمل باللمس باليد في العلاج بالذكريات مع الاشخاص المصابين بالخرف في دور رعاية المسنين الاردنية. للقيام بهذا، نود أن نوظف 30-40 شخصا مصابين بالخرف مقيمين في دور رعاية المسنين، بالاضافة الى 10 أعضاء من مقدمي الرعاية الصحية العاملين في هذه الدور. إذا كنت موافق على المشاركة بهذه الدراسة، سيطلب منك إكمال أربعة استيرلنات قبل البده في استخدام برنامج العلاج بالذكريات باستخدام تكلولوجيا الاجيزة التي تعمل باللمس باليد لمدة ستة اسابيع. في نهاية البرنامج، سيطلب منك إكمال الاستيرلنات الأربعة مرة أخرى وقد يطلب منك العمار لماه مية الموال عن خبرتك ور آيك بشناطة من مقام برنامج العلاج برنامج العلاج بالذكريات الذكري وقد يطلب منك الضا المشاركة في مقابلة للسوال عن خبرتك ور آيك بشأن المشاركة في برنامج العلاج بالذكريات.

## لماذا تم اختيارك للمشاركة في الدراسة؟

نحن نبحث عن الناس الذين يعيشون في دور ر عاية المسنين الذين تم تشخيصهم بالخرف. أنت مدعو للمشاركة لأن موظفي دور ر عاية للمسنين قد اشاروا بانك تحقق المعايير التي تنطبق على المشاركين.

#### هل انت مجبر للمشاركة بالدراسة؟

الأمر متروك لك لاتخاذ قرار المشاركة من عدمه. الرجاء خذ وقتك لتقرر ما إذا كنت ترغب ام لا في المشاركة ومناقشة هذا الأمر مع العائلة والأصدقاء. إذا كنت ترغب في أية معلومات أخرى لا تقردد في التواصل مع الباحث عاصم عبدالرحيم على الهولله <u>ntxaa37@nottingham.ac.uk</u>.

صلة الرقوم مع العالمة والاصطلاح والمسطور بين علم الراحية في لود موروبات الحراق في التركيم في التواصيل مع الباعك عبدالرحام على المؤلم Kamajar (<u>nottingham.ac.ut</u>) إذا كلنت ترغب في المشاركة سيتطلب مناك الاحتفاظ بورقة المعلومات هذه والتوقيع على استمارة الموافقة للمشاركة في الدراسة. لذيك كامل الحرية للانسحاب من الدراسة في أي وقت ودون إبداء سبب.

## ماذا سيحدث لك إذا قررت المشاركة في الدراسة؟

إذا قررت ان تكون جزءا من هذه الدراسة، سوف تتم دعوتك لتعبنة بعض الاستبيانات قبل المشاركة في برنامج العلاج بالذكريات عن طريق استخدام تكنولوجيا الاجهزة التي تعمل باللمس باليد والتي سيتم تطبيقها في دار الرعاية التي تقوم فيها. بنامج العلاج بالذكريات سيتضمن 12 جلسة، كل جلسة ستستمر لمدة ساعة واحدة مرتين في أسبوع على راحتك لمدة ستة

1

أسابيع. بعد المشاركة في هذا البرنامج مباشرة، سوف تقوم بإكمال مجموعة أخرى من نفس الاستبيانات التي تم تعينتها قبل المشاركة في برنامج العلاج بالذكريات. ايضا قد يتم دعوتك لاجراء مقابلة مسجلة صوتيا قد تستمر بين 30-60 دقيقة، بعد الانتهاء من هذه المجموعة الثانية من الاستبيانات. ستتضمن هذه المقابلة جمع وجهات نظركم حول هذا البرنامج ومدى تقبل استخدامها في الأردن.

#### المصاريف والحوافز بدل المشاركة

لن يتم دفع أو تلقى أي حوافز أخرى للمشاركة في هذه الدر اسة.

## ما هي السلبيات والأخطار المحتملة للمشاركة في الدراسة؟

الخطر الرئيسي المحتمل للمشاركة في هذه ألدر اسة أنه قد تجد بعض هذه الذكريات قد تسبب لك بعض المضابقة. إن حدث هذا، الرجاء إيلاغ الباحث ومقدمي الرعاية الخاصة بك. في هذه الاثناء، سوف يتم توقيف أو تأجيل المحادثة، وسيتم ابلاغ ادارة دور الرعاية عن اي شيء قد يحدث إذا كنت ترغب في ذلك.

## ما هي الفواند المحتملة للمشاركة في الدراسة؟

نحن نأمل أنك ستجد تجربة المشاركة في برّنامج العلاج بالذكريات تجربة ممتعة، ولكننا لا يمكن أن نعنك بانها سوف تساعدك ولكن المعلومات التي سنحصل عليها من هذه الدر اسة سوف تساعدنا على تطوير وتقييم برنامج العلاج بالذكريات عن طريق استخدام تكنولوجياً الاجهزة التي تعمل باللمس باليد والتي من الممكن أن تستخدم على نطاق واسع.

## هل مشاركتي في هذه الدراسة ستبقى سرية؟

سوف نتخذ عددا من الإجراءات للتأكد من أن مشارَكتُكَ في هذه الدراسة ستبقى سرية. وسوف نتبع الممارسات الأخلاقية . والقانونية، وسيتم التعامل مع كافة المعلومات عنك بثقة.

إذا قررت الانضمام إلى هذه الدراسة، فإن بعض البيانات التي سبتم جمعها للدراسة سيطلع عليها فريق البحث وهم أشخاص مرخص لهم من جامعة نوتنجهام . وسيتطلع عليها ايضا اشخاص مرخص لهم التأكد من أن الدراسة تجري بالشكل الصحيح. وسيكون كل هذه الاجراءات للحفاظ على السرية لك كمشارك في البحث وإننا سوف نبذل قصاري جهدنا لتحقيق هذا الواجب.

جميع المعلومات التي سيتم جمعها منك أثناء الدراسة ستحفظ بسرية تامة. لتحقيق هذه السرية فقه سيتم تخزين نموذج استمارة الموافقة وورقة البيانات الشخصية بشكل منفصل. وسيتم استبدال الاسم والهوية الخاصة بك برمز فريد و لن يتم الكشف عن هويتك او اسمك طيلة فترة الدراسة. الباحث هو الشخص الوحيد الذي سيتمكن من الوصول إلى المعلومات الشخصية الخاصة بك. الأهم من ذلك، سوف تبقى جميع المعلومات التي تم جمعها منك لمدة 7 سنوات على الأقل، و سيتم التخلص من أي معلومات شخصية يمكن ان تؤدي الى التعرف عليك بعد الانتهام من الدراسة مباشرة. وسيتم تخزين جميع البيانات الإلكترونية في ملفات وأجهزة كمبيوتر محمية بكلمة مرور. وكما سيتم تخزين جميع البيانات غير الإلكترونية في غرفة أمنة ومغلقه.

كما نود أيضا أن نلتمس الموافقة منك على امكانية استخدام وتخزين بياناتك في البحوث المستقبلية المحتملة أثناء وبعد 7 سنوات - هذه اختيارية (يرجى الاشارة للموافقة لها في استمارة الموافقة).

#### ماذا سيحدث لنتانج الدراسة ؟

سوف يتم استخدام نتائج الدراسة من قبل الباحث للحصول على درجة الدكتوراه، وسوف يتم نشر ها في المجلات الصحية ذات الصلة. المشاركين لن يتم التعرف عليهم في أي منشور.

#### ماذا سيحدث إذا كنت لا ترغب في الاستمرار في الدراسة؟

المشاركة في هذه الدراسه هي اختبارية طوعية ولك كامل الحرية في الانسحاب منها في أي وقت، دون إعطاء أي سبب من الأسباب دون ان يكون لها تأثير على الرعاية المقدمة. الا ان البيانات االتي يتم جمعها ستستخدم إلى النقطة التي تركت الدراسة فيها.

#### من هو منظم هذه الدراسة ومن هو ممولها؟

البحث منظم من جامعة نوتينغهام البريطانية وممول من جامعة ال البيت، الأردن

#### من الذي قيم هذه الدراسة واستعرضها؟

2

جميع البحوث في جامعة نوتنغهام البريطانية تعرض على فريق المستقل ، يدعى "لجنة أخلاقيات البحوث"، لحماية المصالح الخاصة بك. وقد استعرضت هذه الدراسة وتم إعطاء رأي إيجابي من قبل "لجنة أخلاقيات البحوث كلية الطب. والعلوم الصحية- جامعة نوتنغهام البريطانية".

#### ماذا إذا حدثت هناك مشكلة؟

إذا كان لديك قلق بشأن أي جانب من جوانب هذه الدراسة، يجب عليك الاتصال بالعميد المتقاعد متى حدادين- مدير دار الضبافة للمسنين او الدكتور احمود اللصاصمة - مدير دارات سمير شما. إذا ما زالت غير سعيد وترغب في تقديم شكرى رسميا، يجب عليك الاتصال بمسؤول الدراسة على البريد الإلكتروني: holly.blake@nottingham.ac.uk.

#### المزيد من المعلومات وتقاصيل الاتصال

الأسم
عاصم عدالر حيم
الدكتورة هولى بليك

## لمزيد من المعلومات والتفاصيل

إذا كنت ترغب في معرفة المزيد عن الدراسة، يرجى الاتصال: طالب الدكتوراه : عاصم عيدالرحيم. ايمزل: <u>htxaa37@nottingham.ac.uk</u> تلغرن: 447449831883

شكرا لك على وقتك

# b. Participant information sheet for care home staffEnglish version

#### University of Nottingham, Faculty of Medicine & Health Sciences, School of Health Sciences



Title of Study: The use of Digital Technology in Reminiscence Work with People with Dementia in Jordanian Care Homes: A Feasibility Study Name of Researcher(s): Mr Asem Abdalrahim, PhD researcher

Dr Holly Blake, Associate Professor of Behavioural Sciences, School of Health Sciences Dr Philip Clissett, Lecturer, School of Health Sciences Dr Tim Carter, Assistant Professor of mental health, School of Health Sciences

#### Participants Information Sheet Caregivers of People with Dementia

You are being invited to take part in a research study. Before you decide whether to take part 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 friends and relatives if you wish to. Please ask the investigator, Asem Abdalrahim, if there is anything that is not clear or if you would like more information. Take your time to decide whether you wish to take part or not. Thank you for showing interest in this study.

#### Background

Dementia is a condition that generally leads to a progressive loss of cognitive function and behavioural ability. As there is currently no cure, we need to be thinking about ways in which to alleviate some of the symptoms. Reminiscence therapy may provide a possible solution. Reminiscence therapy aims to evoke discussion of past memories for you by using music, objects, photos, and videos. In addition to offering an enjoyable and stimulating activity, it has the potential to improve a person's mood; increase social interaction; and reduce some of the effects of dementia.

With the introduction of touch screen technology, there is the potential to produce a program capable of holding a range of objects such as photos, music, and videos to facilitate reminiscence therapy that it might be easier to use and more functional.

#### What does the study involve?

This study will explore whether touch screen technology devices might be used to aid reminiscence for people with dementia. To do this, we would like to recruit 30-40 people with dementia who are residents of care homes as well as about 10 members of staff caregivers from these care homes.

Participants who are care home residents will be asked to complete four questionnaires before being supported to take part in a six-week reminiscence therapy programme using touch-screen technology. At the end of the programme, they will be asked to complete the four questionnaires again and may be asked to take part in an interview where they will be asked about their experiences and views on taking part in the study and the reminiscence programme.

You will be invited to take part in an interview where you will be asked about your views on this approach to reminiscence therapy.

#### Why have you been chosen?

We are looking for staff caregivers who work with people with dementia regularly. You are being invited to take part to collect your views on this approach to reminiscence therapy.

#### Do you have to take part?

It is up to you to decide whether or not to take part. Please take your time to decide whether or not you wish to take part. If you would like any further information please do not hesitate to contact Asem Abdalrahim on <a href="https://www.ntsaa37@nottingham.ac.uk">ntsaa37@nottingham.ac.uk</a>. If you do decide to take part you will be asked to keep this information sheet and sign a consent form. You will still be free to withdraw at any time and without giving a reason.

#### What will happen to you if you take part?

If you accept to be part of this study, you will be invited for an interview after the digital reminiscence therapy programme with people with dementia has taken place within the care home that you work. The interview will be used to collect your views on this approach to reminiscence therapy and its acceptability for use in Jordan. This interview will last between 30–60 mins and will be audio-recorded.

#### Expenses and inconvenience allowance

You will not be paid or receive any other incentive to participate in the study.

#### What are the possible benefits of taking part?

The information obtained from the study will help to develop and assess a novel, touch screen, digital reminiscence therapy programme. As such, it will provide insight into how useful and acceptable it might be and whether it might be used more widely.

#### Will my taking part in this study be kept confidential?

We will take a number of actions to ensure that your taking part in this study will be kept confidential. We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**. To achieve confidentiality by maintaining anonymity, the consent form and personal demographic data sheet will be maintained separately. Data will be transcribed as pseudonyms. Therefore, the names and identities of participants will not be disclosed throughout the study.

The researcher is the only person who will have access to your personal information. However, research data will be kept for a minimum of 7 years, the personal identifying information will be destroyed after the study end. All electronic data in softcopy from audio files and interview transcripts will be made anonymous with participant identifiers stored in password-protected computers and files and all information collected during the data collection will be stored in a secure and locked office.

We would also like to seek your consent so that the data may be stored and used in possible future research during and after 7 years- this is optional (please indicate you agree to this on the consent form).

#### What will happen to the results of the research study?

The results of the study will be used by the researcher for the development of a PhD and will be published in relevant health journals. Participants will not be identifiable in any publication.

#### What will happen if you don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason. However, the data collected to the point at which you leave the study will not be erased and will be used in the final analysis.

#### Who is organising and funding the research?

The research is organised by the University of Nottingham and funded by Al Albaxt. University, Jordan.

#### Who has reviewed the study?

All research in the University of Nottingham is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Faculty of Medicine & Health Sciences (FMHS) Research Ethics Committee.

#### What if there is a problem?

What if there is a problem?

If you have a concern about any aspect of this study, you should contact Golden Age Home manger, Retired Brigadier General Muna Hadadin, or Society Samir. Shamma Homes director, Dr. Ehmoud A-I Lasasmeh. If you remain unhappy and wish to complain formally, you should then contact the FMHS Research Ethics Committee Administrator you should contact the Chief investigator e-mail: holly.blake@nottingham.ac.uk.

#### Further information and contact details

Investigators	Name	Email
Principle investigator	Asem Abdalrahim	ntxaa37@nottingham.ac.uk
Chief investigator	Dr Holly Blake	holly.blake@nottingham.ac.uk

#### Contact for Further Information

If you would like to find out more about the study, please contact: Asem Abdalrahim, PhD student. E-Mail: <u>ntxaa37@nottingham.ac.uk</u> Mobile: +447449831883

Thank you for your time.

## • Arabic version



## جامعة توتتجهام البريطانية – كلية الطب والعلوم الصحية

عتوان الدراسة: دراسة جدوى استخدام تكنولوجيا الاجهزة التي تعمل باللمس باليد في العلاج بالذكريات مع الاشخاص المصابين بالخرف في دور رعاية المستين الاردنية.

اسماء الياحثين: عاصم عبدالرحيم ، الدكتورة هولي بلاك ، الدكتور فيليب كليسيت ، الدكتور تيم كارتر.

معلومات الدراسة للمشاركين ( مقدمي الرعاية الصحية )

أنت مدعو للمشاركة في هذه الدراسة. قبل أن نقرر ما إذا كنت سنشارك فيها، عليك ان نتنهم ما هو هدف هذه الدراسة وماذا سنتضمن. يرجى أخذ الوقت الكافي لقراءة المعلومات الثالية بعناية ومناقشتها مع الأصدقاء والأقارب إذا كنت ترغب في ذلك. يرجى سؤال الباحث (عاصم عبدالرحيم) إذا كان هناك أي شيء غير واضح، أو إذا كنت ترغب في مزيد من المعلومات (للتواصل مع الباحث قان معلوماته توجد في نهاية هذه الورقة). خذ وقتك الكافي لتقرر ما إذا كنت ترغب في المشاركة أم لا. شكرا لك على اظهارك الرغبة في المشاركة في هذه الدراسة.

#### ائمقدمة

الخرف هي الحالة التي نؤدي عموما إلى مجموعة واسعة من الأعراض المرتبطة بانغفاض الذاكرة أو قدرة الشخص على القيام بالأنشطة اليومية. لذلك نحن بحاجة إلى التفكير في الطرق التي يمكن بها التغفيف من حدة بعض الأعراض المرافقة لها. العلاج بالذكريات قد توفي حلاً ممكناً. يهدف العلاج بالذكريات الى تحفيز المناقشة لاستحصار الذكريات السابقة عن طريق استخدام الموسيقي، والصور، وأشرطة الفيديو. وجد أن العلاج بالذكريات يعمل بعمل على تحسين مزاج الشخص. زيادة التقاط الاجتماعي؛ وتقليل بعض آثار الخرف الاخرى. مع إنخال تكنولوجيا الشاشات التي تعمل باللمس، هناك إمكانية

#### ماذا ستتضمن هذه الدراسة؟

تهدف هذه الدراسة الى استكشاف جدوى استخدام تكنولوجياً الاجهزة آلتي تعمل باللمس باليد في العلاج بالذكريات مع الاشخاص المصابين بالخرف في دور رعاية المسنين الاردنية. للقيام بهذا، نود أن نوظف 30-40 شخصا مصابين سبالخرف مقيمين في دور رعاية المسنين، بالاضافة الى 10 أعضاء من مقدمي الرعاية الصحية العاملين في هذه الدور . سبطلب من المشاركين المصابين بالخرف المقيمين في دور رعاية المسنين الى إكمال أربعة استيباتات قبل البدء في استخدام برنامج العلاج بالذكريات باستخدام تكنولوجيا الاجهزة التي تعمل باللمس باليد لمدة ستيباتات قبل البدء في سبطلب من المشاركين المصابين بالخرف المقيمين في دور رعاية المسنين الى إكمال أربعة استيباتات قبل البدء في استخدام برنامج العلاج بالذكريات باستخدام تكنولوجيا الاجهزة التي تعمل باللمس باليد لمدة ستة السابيع. في نهاية البرنامج، سبطاب منهم إكمال الاستيباتات الأربعة مرة أخرى وقد يطلب منهم الإضا المشاركة في مقابلة للسؤال عن خبراتهم وارائهم بشأن المشاركة في برنامج العلاج بالذكريات. انت مدعو للمشاركة في مقابلة حيث سيئم سؤالك عبن النهج بشار النهم بين للعلاج بذكريات.

## لماذا تم اختيارك للمشاركة في الدراسة؟

نحن نبحث عن مقدمي الرعاية الذين يعملون بانتظام مع كبار السن المصابين بالخرف. انت مدعو للمساركة لجمع آرائكم يشأن هذا النهج للعلاج بذكريات.

## هل انت مجير للمشاركة بالدر اسة؟

الأمر متروك لك لاتخاذ قرار المشاركة من عدمه. الرجاء خذ وفتك لتقرر ما إذا كنت ترغب ام لا في المشاركة ومناقشة هذا الأمر مع العائلة والأصدقاء. إذا كنت ترغب في أية معلومات أخرى لا تتردد في التواصل مع الباحث عاصم عبدالرحيم على ايميله <u>ntxaa37@nottingham.ac.uk</u>.

إذا كنّتُ تُرغب في المسّاركة سينطلب منك الأحنّفاظ بورقة المعلومات هذه والتوقيع على استمارة الموافقة للمسّاركة في الدراسة. لديك كامل الحرية للانسحاب من الدراسة في أي وقت ودون إبداء سبب.

1

#### ماذا سيحدث لك إذا قررت المشاركة في الدراسة؟

إذا قررت ان نكون جزءا من هذه الدراسة، سوف نَتَم دعونك لاجراء مقابلةً مسجلةً صونياً قد تُستَمر بين 30-60 دقيقة بعد الانتهاء من مشاركة المصابين بالخرف بيرنامج العلاج بالذكريات باستخدام تكنولوجيا الاجهزة التي تعمل باللمس باليد. سنتضمن هذه المقابلة جمع وجهات نظركم حول هذا البرنامج ومدى تقبل استخدامها في الأردن.

## المصاريف والحواقز بدل المشاركة

لن يتم دفع أو تلقى أي حوافز أخرى للمسّاركة في هذه الدراسة.

#### ما هي القوائد المحتملة للمشاركة في الدراسة؟

المعلومات المستقاة من هذه الدراسة ستساعد على تطوير وتقييم فكرة جديدة ونيرة و هي برنامج العلاج بالذكريات باستخدام تكنولوجيا الاجهزة التي تعمل باللمس باليد ، حيث ستوفر نظرة شاملة عن مدى الاستقادة من هذا البرنامج ومدى تقبله على نطاق اوسع.

## هل مشاركتي في هذه الدر اسة ستيقى سرية؟

سوف نتخذ عددا من الإجراءات للتأكد من أن مسّاركتكَ في هذه الدراسة سنّبَقى سرية. وسوف نتبع الممارسات الأخلاقية والقانونية، وسيئم التعامل مع كافة المعلومات عنك بنتة.

إذا قررت الانضمام إلى هذه الدراسة، فان بعض البيانات التي سيئم جمعها للدراسة سيطلع عليها فريق البحت وهم أشخاص مرخص لهم من جامعة نوننجهام . وسينطلع عليها ايضا اشخاص مرخص لهم للناكد من أن الدراسة نجري بالشكل الصحيح . وسيكون كل هذه الاجراءات للحفاظ على السرية لك كمشارك في البحت وإننا سوف نبذل قصاري جهدنا التحقيق هذا الواجب.

جميع المعلومات التي سيئم جمعها منك أثناء الدراسة ستحفظ بسرية نامة. لتحقيق هذه السرية فانه سيئم تخزين نموذج استمارة الموافقة وورفة البيانات الشخصية بشكل منفصل. وسيئم استبدال الاسم والهوية الخاصة بك برمز فريد و لن يئم الكثف عن هويتك او اسمك طيئة فترة الدراسة. الباحث هو الشخص الوحيد الذي سيئمكن من الوصول إلى المعلومات الشخصية الخاصة بك. الأهم من ذلك، سوف نبقى جميع المعلومات التي تم جمعها منك لمدة 7 سنوات على الأقل، و سيئم التخصية الخاصة بف الأهم من ذلك، سوف نبقى جميع المعلومات التي تم جمعها منك لمدة 7 سنوات على الأقل، و سيئم التخصية الخاصة بف الأهم من ذلك، سوف نبقى جميع المعلومات التي تم جمعها منك لمدة 7 سنوات على الأقل، و سيئم التخصي من أي معلومات شخصية يمكن ان تؤدي الى التعرف عليك بعد الانتهاء من الدراسة مباشرة. وسيئم تخزين جميع البياتات الإلكترونية في ملفات وأجهزة كمبيوتر محمية بكلمة مرور. وكما سيئم تخزين جميع البياتات غير الإلكترونية في غرفة آمنة ومغلقه.

كما نود أيضا أن نلتمس الموافقة منك على امكانية استخدام وتخزين بياناتك في البحوث المستقبلية المحتملة أنناء ويعد 7 سنوات – هذه اختيارية (برجي الاشارة للموافقة لها في استمارة الموافقة).

#### ماذا سيحدث لتتالج الدراسة ؟

سوف يدّم استخدام ننائج الدراسة من قبل الباحث للحصول على درجة الدكتوراه، وسوف يدّم نشرها في المجلّات الصحية ذات الصلة. المشاركين لن يدّم التعرف عليهم في أي منشور.

## ماذا سيحدث إذا كنت لا ترغب في الاستمرار في الدراسة؟

المسّاركة في هذه الدراسه هي اختيارية طوعية وللله كاملَ الحريَّة في الانسّحابَّ منهّا في أي وقت، دون إعطاء أي سبب من الأسباب دون ان يكون لها تأثير على الرعاية المقدمة. الا ان البيانات االتي يتم جمعها سنّستخدم إلى النقطة التي تركت الدراسة فيها.

#### من هو منظم هذه الدراسة ومن هو ممولها؟

البحت منظم من جامعة نوتينغهام البريطانية وممول من جامعة ال البيت، الأردن

#### من الذي قيم هذه الدراسة واستعرضها؟

جميع البحوث في جامعة نونتغهام البريطانية تعرّض على فريق المستقل ، يدعى "لجنة أخلاقيات البحوث"، لحماية المصالح الخاصة بك. وقد استعرضت هذه الدراسة وتم إعطاء رأي إيجابي من قبل "لجنة أخلاقيات البحوث كلية الطب والعلوم الصحية. جامعة نونتغهام البريطانية".

2

## ماذا إذا حدثت هناك مشكلة؟

إذا كان لديك قلق بنّدأن أي جانب من جوانب هذه الدراسة، يجب عليك الاتصال بالعميد المتقاعد منى حدادين۔ مدير، دار الضبافة للمسنين اوالدكتور، احمود اللصناصمة - مدير، دارات سمير، شما. إذا ما زالت غير، سعيد وثر غب في تقديم سُكوى رسميا، يجب عليك الاتصال بمسؤول الدراسة على البريد الإلكتروني: holly.blake@nottingham.ac.uk.

## المزيد من المعلومات وتفاصيل الاتصال

الايميل	الاسم
ntxaa37@nottingham.ac.uk	عاصبم عبدالبرجيم
holly.blake@nottingham.ac.uk	الدكتورة هولى بليك

## لمزيد من المعلومات والتقاصيل

إذا كنت تَرغب في معرفة المزيد عن الدراسة، يرجى الاتصال: طالب الدكتوراه : عاصم عبدالرحيم. المِدِل: <u>ntxaa37@nottingham.ac.uk</u> تلفون: 447449831883+

شكرا لك على وقتك

## **Appendix 14: Consent Form**

## a. Consent form for residents

English version

#### CONSENT FORM (Residents)

#### Title of Study: Use of digital technology in reminiscence work with dementia people in Jordanian care homes: a feasibility study

#### REC ref:

Name of Researcher: Asem Abdalrahim, Dr Holly Blake, Dr Philip Clissett, and Dr Tim Carter

#### Name of Participant:

Please init	ial box
-------------	---------

- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis.
- 3. I understand that relevant sections of my data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.
- I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports.
- I understand that all data will be anonymous and confidential with the exception of information being revealed during the interview which is of concern and may need reporting i.e. potential risks to another person or to myself
- I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred is will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed.
- 7. I agree to take part in the study and complete the associated questionnaires
- 8. I agree to take part in an interview if invited to do so

Name of Participant	Date	Signature	
Name of Person taking consent	Date	Signature	
2 copies: 1 for participant, 1 for the project	notes.		

Appendix 14: Consent forms for residents and care home staff (Arabic and English versions)

# • Arabic version

	استمارة الموافقة (متلقي الرعاية)	
	الدراسة: دراسة جدوى استخدام تكتولوجيا الاجهزة التي تعمل باللمس باليد في العلاج ات مع الاشخاص المصابين بالخرف في دور رعاية المستين الاردنية.	تقوان بالذكريا
	: حقين: عاصم عبدالرحيم ، الدكتورة هولي بلاك ، الدكتور فيليب كليسيت ، الدكتور تيم كارتر 	المرجع اسم اليا،
	سارك:	امتم المذ
¢	أؤُكَّ بأنتى قرأت ورقة المعلومات الماصنة بالدراسة نموذج رقم بتاريخ للدراسة المذكورة اعلاه وقد أتيحت لى الفرصة لطرح الأسئلة.	.1
	أعلم أن مشاركتي في هذه الدراسة هي اعتيارية ولى كامل الحرية بالانسحاب من الدراسة في أي وقت، بدور إبداء أي سبب، ودون ان تتأثر حقوقي القانونية. وأقهم أنه ينبغي على الانسحاب ثم المعلومات التي جمعت حتّ الأن لا يمكن محوها، وأن هذه المعلومات قد لا تزال تستحدم في تحليل المضروع.	.2
ن م م	أتقهم أن الأجزاء ذات الصلة من البيادات التي تم جمعها في هذه الدراسة قد تعرض على اشخاص معتمدين مر جامعة موتعهمام، ومجموعة باحثى الدراسة والجهات التنظيمية ذات الصلة في مشاركتي في هذه الدراسة. امن الموافقة لهؤلاء الأشخاص في الحصول على هذه السجلات، وجمع، وتخزين وتحليل ونشر المعلومات التي تُ الحصول عليها من مشاركتي في هذه الدراسة. وأنفهم أن بياداتي الشخصية ستبقى سرية.	.3
	أتفهم أنه سيتم تسجيل المقابلة وأنه من العمكن استحدام اقتباسات مباشرة بصبيعة العجهول من تلك المقابلة ف تقارير الدراسة.	.4
	اتفهم أن جميع البيادات سوف تكون سرية باستثناء المعلومات التي يمكن ان تكتشف حلال المقابلة والتي ق تحتاج إلى الإبلاع عنها مثل احتمالية ايذاء شخص آخر أو ايذاء نفسي.	.5
<sup>م</sup> [	اتفهم بأن المعلومات التي سجلت عنى خلال الدراسة ستحفظ في قاعدة بيانات أمنة. وان عملية نقل البيانات ستت بصيغة المجهول. وانه سيتم الاحتفاظ بالبيانات لمدة 7 سنوات بعد انتهاء الدراسة ثم تدمير ها بشكل أمن.	.6
	أوافق على المشاركة في الدراسة وإكمال الاستبيانات ذات العلاقه بالدراسة.	.7
	أوافق على المشاركة في المقابلة إذا دعيت للقيام بذلك	.8
	نرڭ التاريخ التوقيع	اسم المشا
	ص أهذ موافقة التاريخ التوقيع	اسم الشم

نسختين: نسخة للمثشرك ونسخة للدراسة

## b. Consent form for care home staff

## • English version

## CONSENT FORM (Caregivers)

## Title of Study: Use of digital technology in reminiscence work with dementia people in Jordanian care homes: a feasibility study

## REC ref:

I

Name of Researcher: Asem Abdalrahim, Dr Holly Blake, Dr Philip Clissett, and Dr Tim Carter

#### Name of Participant:

#### Please initial box

- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis.
- 3. I understand that relevant sections of my data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.
- I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports.
- I understand that all data will be anonymous and confidential with the exception of information being revealed during the interview which is of concern and may need reporting i.e. potential risks to another person or to myself
- I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred is will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed.
- I agree to take part in the above study

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes.

# • Arabic version

استمارة المواققة (مقدمو الرعاية)	
الدراسة: دراسة جدوى استخدام تكنّولوجيا الاجهزة التي تعمل باللمس باليد في العلاج ت مع الاشخاص المصابين بالخرف في دور رعاية المستين الاردنية.	عقوان ا بالذكريا
: نَشِنَ: عاصم عبدالرحيم ، الدكتورة هولي بلاك ، الدكتور فلِلِبِ كليسيت ، الدكتور تيم كارتر 	المرجع : اسم الياه
بارك:	اسم المث
أؤكد بأننى قرأت ورقة المعلومات الماصة بالدراسة نموذج رقم بتاريخ للدراسة المذكورة اعلاه، وقد أتيحت في الفرصة لطرح الأسطة.	.1
أعلم أن مشاركتي في هذه الدراسة هي احتيارية ولى كامل الحرية بالانسحاب من الدراسة في أي وقت، بدون إبداء أي سبب، ودون ان تتأثر حقوقي القانونية. وأفهم أنه ينبغي على الانسحاب ثم المعلومات التي جمعت حتى الآن لا يمكن محوها، وأن هذه المعلومات قد لا ترال تستخدم في تحليل المشروع.	.2
أتقهم أن الأجزاء ذات الصلة من البيادات التي تم جمعها في هذه الدراسة قد تعرض على اشخاص معتمدين من جامعة موتدمهام، ومجموعة باحثى الدراسة والجهات التنظيمية ذات الصلة في مشاركتي في هذه الدراسة. امتح الموافقة لهؤلاء الأشخاص في الحصول على هذه السجانت، وجمع، وتخزين وتحليل ونشر المعلومات التي تم الحصول عليها من مشاركتي في هذه الدراسة. وأتفهم أن بياداتي الشخصية ستبقى سرية.	.3
أتفهم أنه سيتم تسجيل المقابلة وأنه من الممكن استحدام اقتباسات مباشرة بصيعة المجهول من تلك المقابلة في تقارير الدراسة.	.4
اتفهم أن جميع البيادات سوف تكون سرية باستثناء المعلومات التي يمكن ان تكتشف خلال المقابلة والتي قد تحتاج إلى الإبلاع عنها مثل احتمالية ايذاء شخص آهر أو ايذاء نفسي.	.5
اتفهم بأن المعلومات التي سجلت عنى خلال الدراسة ستحفظ في قاعدة بيانات أمنة. وان عملية نقل البيانات سنتم يصيغة المجهول. وانه سيتم الاحتفاظ بالبيانات لمدة 7 سنوات بعد انتهاء الدراسة ثم تدميرها بشكل أمن.	.6
أوافق على المضاركة في المقابلة إذا دعيت للقيام بذلك	.7

التاريخ التوقيع اسم المشترك اسم الشمص أحذ موافقة التوقيع التاريخ

سختين: نسخة للمشترك ونسخة للدراسة

## **Appendix 15: Consultee Assent Form**

• English version



#### CONSULTEE ASSENT

#### Title of Study: Use of digital technology in reminiscence work with dementia people in Jordanian care homes: a feasibility study

REC ref:

Name of Researcher: Asem Abdalrahim, Dr Holly Blake, Dr Philip Clissett, and Dr Tim Carter

Name of Consultee:

#### Name of Participant:

Please	initial	box
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- 2. I understand that I can request he/she is withdrawn from the study at any time, without giving any reason, and without their care or legal rights being affected. I understand that should he/she be withdrawn from the study, then the information collected so far cannot be erased and that this information may still be used in the project analysis.
- 3. I understand that relevant sections of their data collected in the study may be looked at by the research group and by other responsible individuals from the University of Nottingham, and regulatory authorities where it is relevant to their taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from their participation in this study. I understand that their personal details will be kept confidential.
- 4. I understand that the information about him/her recorded during the will be kept in a secure database. If the data is transferred it will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed.
- 5. In my opinion he/she would have no objection to taking part in the above study.

Name of Consultee

Date

Signature

Name of Researcher

Date

Signature

2 copies: 1 for consultee, 1 for the project notes

Appendix 15: Consultee Assent Form (Arabic and English versions)

# • Arabic version

1	
استمارة المواققة (مقدمو الرعاية)	
الدراسة: دراسة جدوى استخدام تكتولوجيا الأجهزة التي تعمل باللمس باليد في العلاج ت مع الأشخاص المصابين بالخرف في دور رعاية المستين الاردنية.	عقوان ا بالذكريا
نشين: عاصم عبدالرحیم، الدکتوره هولی بلاك، الدکتور فیلیب کلیسیت، الدکتور نیم کارى د ه.	المرجع : اسم الياه اسم الم
صرت: أؤكد بأننى قرأت ورقة المعلومات الماصنة بالدراسة نموذج رقم بتاريخ للدراسة المذكورة اعلاه، وقد أتيمت في الفرصنة لطرح الأسئلة.	ميم ميني 1.
أعلم أن مشاركتي في هذه الدراسة هي اهتيارية ولي كامل الحرية بالانسحاب من الدراسة في أي وقت، بذون إبداء أي سبب، ودون ان تتأثر حقوقي القانونية. وأفهم أنه ينبغي على الانسحاب ثم المعلومات التي جمعت حتى الأن لا يمكن محوها، وأن هذه المعلومات قد لا ترال تستخدم في تحليل المشروع.	.2
أتفهم أن الأجزاء ذات الصلة من البيادات التي تم جمعها في هذه الدراسة قد تعرض على اشعاص معتمدين من جامعة موتعهام، ومجموعة باحثى الدراسة والجهات التنطيمية ذات الصلة في مصاركتي في هذه الدراسة. امنح الموافقة لهؤلاء الأضعاص في الحصول على هذه السجانت، وجمع، وتعزين وتحليل ونشر المعلومات التي تم الحصول عليها من مشاركتي في هذه الدراسة. وأتفهم أن بياناتي الشعصية ستبقى سرية.	.3
أتفهم أنه سيتم تسجيل المقابلة وأنه من الممكن استحدام اقتباسات مباشرة بصبيعة المجهول من تلك المقابلة في تقارير الدراسة.	.4
اتفهم أن جميع البيادات سوف تكون سرية باستثناء المعلومات التي يمكن ان تكتشف حلال المقابلة والتي قد تحتاج إلى الإبلاع عنها مثل احتمالية ايذاء شخص أخر أو ايذاء نفسي.	.5
اتفهم بأن المعلومات التي سجلت عنى خلال الدراسة ستحفظ في قاعدة بيانات أمنة. وان عملية نقل البيانات سنتم بصيغة المجهول. وانه سيتم الاحتفاظ بالبيانات لمدة 7 سنوات بعد انتهاء الدراسة ثم تدميرها بشكل أمن.	.6
أوافق على المضاركة في المقابلة إذا دحيت للقيام بذلك	.7
رك التاريح التوقيع	اسم المشتر

اسم الشخص أخذ موافقة

الثاريخ

التوقيع

سختين: نسخة للمثترك ونسخة للدراسة

# Appendix 16: Permission to Translate HCS scale for PwD into Arabic

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Appendix 16: Permission to Translate HCS scale for PwD into Arabic

# **Appendix 17: Histograms of Pre and Post Intervention Scores of Outcome Measures**



• Pre-intervention Scores





HCS total scores at pre-intervention



QoL total scores at pre-intervention



Anxiety total scores at pre-intervention





• Post-intervention scores



SLUMS total scores at post-intervention



HCS total scores at post-intervention



OPQoL total scores at post-intervention



Anxiety total scores at post-intervention





Appendix 17: Histograms of Pre and Post Intervention Scores of Outcome Measures

# Appendix 18: The screenshot of all RT sessions

Arabic version	English version
للفلاج بالذكريات (Reminiscence Therapy) العلاج بالذكريات أعاد الباحث عصم احمد الحمود تلبة الفرم المسحية جلسة نونتجهام البريطلية copyright: Asem Ahmed Al-Hmoud	Reminiscence Therapy Prepared by Asem Ahmed Abdalrahim School of Health Sciences University of Nottingham Copyright: Asem Ahmed Al-Hmoud
لتكثير في المذي التي يودي عمرة إلى هذان التدريج في الوظائف المرفية والترج بالذكريات ويونى من محاجه إلى المقدمة المقدوم هي المذي التي يودي عمرة إلى هذان التدريج في الوظائف المرفية والترج السلوكية. لذلك ندن بحاجه إلى المقدمة المقدوم في المذي التي يوكن بها التقنيف من حدة بعض الوظائف المرفية والترج السلوكية. لذلك ندن بحاجه إلى ممكل بهذه الذي التي يوكن بها التقنيف من حدة بعض الرعان الدامية في أورك الملح والتركيات أن يوفر حد ممكل بهذه الذي التي يوكن بها التقنيف من حدة بعض الحواز العراقة أبي يمكن للملاح والتركيرات أن يوفر حد ممكل بهذه الذي التي يوكن المان الملقية ومعان الملح الذي إذي السابقة عن طريق استخدام المربقية والتعامل. الإجتماعي وتقليل بعض الذي الذي الذي الذي المانية عن طريق استخدام المربقية والتعامل. يردامج قدر على تسبيل الملاح بالذكريات والتي سكن الكان كتي سيولة وماعلي.	Introduction           Dementia is a condition that describes a wide range of symptoms associated with a decline in memory or person's ability to perform every/day activities. Therefore, we need to be thinking about ways in which to alleviate some of the symptoms. Reminiscence therapy may provide a possible solution. The aim of reminiscence therapy may provide a possible solution. The aim of reminiscence therapy may provide a possible solution. The aim of reminiscence therapy may provide a possible solution. The aim of reminiscence therapy may provide a possible solution. The aim of reminiscence therapy is to evoke discussion of past memories by using music, objects, photos, music, and videos to facilitate reminiscence therapy that it might be easier to use and more functional           Back         Sessions Page         Next


















Appendix 18: Screenshot of all digital RT sessions