

Quality of Life and Digital Gaming Technology

The benefits of a technology based intervention for
community dwelling people with dementia

Clare Margaret Cutler

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Abstract

Community dwelling people living with dementia are often at risk of experiencing reduced Quality of Life (QoL) as a result of, but not restricted to, social exclusion, isolation and malignant social positioning. It is therefore imperative that QoL is protected, supported and maintained to ensure that people can live well with dementia. However, whilst it is acknowledged that post diagnostic dementia support is integral for the maintenance of QoL, less is known about the sort of interventions that can promote, support and maintain it, within a community setting.

The role of technology in dementia care is a growing area of research, and in recent years the use of digital gaming technology has emerged as a viable method to support health needs, care and rehabilitation. However, whilst the health and social benefits of using digital gaming technology, such as the Nintendo Wii (Nintendo Co LTD), Xbox Kinect (Microsoft Corp) and the Apple iPad, have been evidenced in other health research, there is a gap in knowledge surrounding the QoL benefits of this technology specifically for community dwelling people with dementia.

To explore the potential benefits of a digital gaming technology intervention for community dwelling people with dementia, a multi method qualitative methodology with a nested quantitative element was utilised to collect data over a six week period, across 12 two hour weekly sessions, set within two community locations. Findings of the intervention called the 'Tech Club', which had 16 participants, illustrated two significant emerging themes. Firstly, that such an intervention can support and protect selfhood through providing opportunities to address self-esteem, efficacy and agency, thereby counterbalancing the fragility of selfhood. Secondly, that engagement in lifelong learning and teaching is possible through participation with digital gaming technology. These themes indicate that the QoL of people with dementia can be protected, maintained and enhanced through a digital gaming based mechanism which supports self and agency, increases a sense of citizenship and equity within this, and provides an opportunity for active social contribution through lifelong learning and teaching.

This thesis makes an original contribution to knowledge by evidencing that a digital gaming technology intervention has QoL benefits for community dwelling people with dementia and that a psychosocial post diagnostic intervention using the Nintendo Wii, Apple iPad and Microsoft Xbox Kinect is a mechanism which can support the maintenance of QoL.

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Author's declaration

The author has nothing to declare in regards to this thesis.

Chapter One: Background

There are approximately 44.4 million people living with dementia worldwide, this is estimated to increase to 75.6 million by 2030, and 135.5 million by 2050 (Alzheimer Disease International (ADI) 2014). In the UK, an estimated 850,000 people are currently living with dementia (Alzheimer's Society 2014a). In response to the rising prevalence of this condition, dementia is seen as a public health priority worldwide (World Health Organisation (WHO) 2012) and within the UK (Department of Health (DoH) 2013).

Dementia, described as a '*set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language*' (Alzheimer's Society 2017), is an umbrella term used to label a set of symptoms that result in the cognitive impairment of those living with it, and includes conditions such as Alzheimer's dementia, frontotemporal dementia, vascular dementia and dementia with Lewy bodies. As a progressive condition, dementia is typically associated with symptoms which can affect thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (Alzheimer's Society 2014a; WHO 2012), confusion, loss of memory, disorientation, which can lead to difficulties in remembering, decision making, undertaking practical tasks, retaining and acquiring new information (Waite et al. 2008). These symptoms are believed to be out of the realms of 'normal ageing' (WHO 2012) and are expected to interfere with daily life (Derouesné 2003), social behaviour, emotional control and motivation (WHO 2012).

As people live longer, the number of those expected to develop the condition continues to rise. The increase in life expectancy is one of the greatest challenges facing dementia care (Powell et al. 2010) as it is estimated that dementia specific care costs the UK approximately £26.3 billion per annum (Alzheimer's Society 2014a). Financial strain on the public health sector has sparked an international drive towards active and healthy ageing (WHO 2012) and with approximately two thirds of people with dementia living in the community (Alzheimer's Society 2014a), it is a UK government priority (DoH 2012) to promote good quality of life (QoL) in older age to enable people with dementia to be living independently in the community for as long as possible.

Despite current efforts to develop and promote healthy ageing (Swedish National Institute of Public Health Research (SNIPHR) 2006), and initiatives such as Dementia Friendly Communities and Dementia Friends (Alzheimer's Society 2013a); Dementia Friendly Societies (Alzheimer's Society 2013b) and the Prime Minister's Challenge on

Dementia (DoH 2015; 2012), 61% of people with dementia still feel anxious or depressed, 40% feel lonely and 34% do not feel part of their community (Alzheimer's Society 2014b). Subsequently, community dwelling people with dementia are often at risk of social exclusion and isolation (Innes 2009) which can result in reduced social networks (Krause 2006; Woods 2001; Kitwood 1997) and general feelings of loneliness (Routasalo and Pitkala 2003). This can lead to a decline in physical, social and mental stimulation (Innes 2009) and therefore potentially QoL.

My journey

I have not been personally affected by dementia and I have not watched family members either live with this condition or care for someone who has it. My passion for dementia research comes from a desire to help make a difference to a societal issue which at some point is likely to have an impact on me personally.

I have always had a passion for research and at young age this passion was history. Whilst I enjoyed learning about past populations, there was always something that did not feel quite right, I wanted to undertake research which not only had an impact but had an impact on people, now. I wanted the research I undertook to be of relevance to today's society, to have a real world impact. Therefore I decided to undertake research in the social sciences where I began working as a research assistant and project manager for Bournemouth University Dementia Institute (BUDI), now the Ageing and Dementia Research Centre.

During my time in BUDI, I met many people affected by dementia, from those living with it to government lobbyists. As a result I developed a hunger to try and make a difference in this area, in any way I could. Having worked on several research projects within BUDI, one which sparked my attention was the use of digital gaming technology. I worked on several projects where the focus was the interaction of people living with dementia and this technology. One of my main observations from these projects was the ability technology had to break down barriers in a way that I had not seen in other projects. It was here that I really began to consider the potential benefits of this commercially available technology for people living with dementia. This prompted the beginning of my research journey exploring the role of digital gaming technology in relation to QoL.

Introduction to thesis

People with dementia generally experience reduced QoL (Cooper et al. 2012) and for this reason it has been argued that enhancing QoL should be the primary objective in dementia care (ADI 2010; Graff et al. 2007; Selai et al. 2000). In the absence of an effective cure, addressing QoL is seen as having the potential to make an important difference to the lives of those with the condition (Selwood et al. 2005).

It is well documented that QoL is enhanced through physical, social and mental stimulation (Swann 2012; Wang et al. 2012b; Hill and Kürüm 2010; Hall et al. 2009), but new and innovative methods to engage and support people living with dementia are required (Giebel and Sutcliffe 2017; Phinney et al. 2007; Sherratt et al. 2004). However, as people with dementia are suggested to be one of the most excluded and marginalised groups in society (Wilkinson 2002), and whilst it is acknowledge that they are becoming more involved within research, people with dementia are still excluded and underrepresented within literature (Nygård 2006; Mason et al. 2005; Hubbard et al. 2003). Therefore, our understanding of the most effective ways to support those with dementia and the services that might best serve them requires more investigation (Wilkinson 2002).

Post diagnostic support for community dwelling people with dementia is predominately medically focused, with few services or community interventions (beyond what local and national charities provide) offering alternative psychosocial support. Psychosocial interventions provide an alternative technique to support people with dementia (Moniz-Cook et al. 2011; Moniz-Cook et al. 2008) and are argued to be as effective as pharmacological treatments (Olazarán et al. 2010). Whilst there are recognised potential benefits to the use of psychosocial interventions, including reducing depression and improving self esteem (Leung et al. 2015), knowledge surrounding what interventions may help to improve QoL specifically is limited (Cooper et al. 2012).

A digital gaming technology based community intervention is a way of providing post diagnostic support in the form of a psychosocial intervention specifically for community dwelling people with dementia. Research has identified the benefits of gaming technology in general healthcare connected to health conditions such as stroke, cancer and autism (Procci et al. 2013; Rahmani and Boren 2012) and has also been identified as being beneficial for older people's cognitive training (Boot et al. 2011) and balance and physical strengthening enhancement (Maillot et al. 2012). With the potential health benefits evident for the general population including older people, gaming technologies have also been suggested to increase person centred care (Maiden et al. 2013),

enhance the sense of self (Hanson et al. 2007) and can be used to engage people with dementia in recreational therapies (Fenney and Lee 2010).

Overview of thesis

This thesis, structured in ten chapters, takes the reader on a journey from research conception to a contribution to knowledge, exploring QoL and digital gaming technology for those living with dementia. Chapter one, the background, sets the scene for this thesis by highlighting current dementia statistics and associated challenges faced when living with dementia in the community. This chapter also provides insight into my personal research journey and provides an introduction to the thesis. Chapter two builds on this background by detailing how this thesis developed and how my experience of undertaking service evaluations using digital gaming technology informed the creation of the research questions and objectives of this research.

Chapter three follows to address how the emerged research questions and objectives shaped the scope of the literature review. A review of four separate bodies of literature was undertaken, exploring the understandings of dementia and its impact on the lived experience; the concept of QoL and its significance when living with dementia; a review of post diagnostic support interventions available for community dwelling people with dementia, and finally, the role of digital gaming technology in health care and its potential application for those living with dementia. This chapter emphasises a gap in the literature and returns to the research questions of this thesis to showcase how this PhD research addresses this gap.

Chapter four, the research methodology, is split into two main sections. Firstly, it describes the research design, philosophical underpinning, methodological approach and why a qualitative methodology with a nested quantitative element was adopted. This section of the chapter also provides information into the rationale behind the applied methods and how these were used when conducting the research. Data management and analysis is the second section of chapter four, providing a detailed account of the methods used to undertake a collated data analyses.

Chapter five is the first of the findings chapters which sets the scene to the research, by providing biographies for each of the participants and an insight into how the intervention was structured and how this was adapted on a weekly basis following participant feedback. This provides the reader with an understanding of the research and its participants prior to viewing the full findings of the research in chapter's six to eight. Chapter six presents the quantitative findings of the QoL questionnaire, whilst

chapters seven and eight provide the thematic findings of the qualitative data within two main themes; ability to regain self and access to learning and teaching.

Chapter nine, the discussion, provides an overall summary of the findings before discussing them in relation to QoL and addressing the overall research question. Practical and theoretical reflections are also presented in this chapter. Finally the limitations, strengths, directions and recommendations for future research and theoretical and methodological contributions offered by this research are discussed in chapter ten, the conclusion chapter. This chapter highlights how this research has addressed the gap in literature and knowledge, a gap which is first explored and highlighted in chapter two, building on the background.

Chapter Two: Building on the Background

Thesis Development

In 2014, Bournemouth University was commissioned by a local authority to design, deliver and evaluate a service evaluation of a technology based intervention for community dwelling people with dementia. Its aim was to build on the findings of a pilot service evaluation in 2012 and a second service evaluation which took place in 2013 (Cutler et al. 2014), which explored whether digital gaming technology could promote social engagement, physical activity and mental stimulation in a social environment for those living with dementia.

Service evaluations have the potential to create important questions and emerging research areas which should be explored more thoroughly but rarely are due to funding and time constraints. Based on my knowledge of the literature and previous experience of undertaking similar projects with digital gaming technologies (Cutler et al. 2014), I was aware of the potential of this technology and wanted to explore beyond the aims and objectives of the 2014 service evaluation to truly understand the possibilities of this technology when used with community dwelling people with dementia.

I was granted approval to conduct my PhD research alongside the 2014 service evaluation where I was given permission to use the data collected as part of the service evaluation in addition to the ability to collect supplementary data for the purposes of the PhD research. When simultaneously designing the 2014 service evaluation and PhD research I was aware of the gaps in the literature regarding digital gaming technology and was able to design the aims and objectives of the PhD research around these gaps whilst also responding to the strategic aims and objectives of the service commissioner. Table 1 illustrates the research questions and objectives of this thesis which developed from emerging research themes prompted from my experience of previous service evaluations alongside evident gaps within the literature. This will now be explained in more detail.

Table 1: Research questions and objectives

Research Questions
1. What are the benefits (if any) of a technology based community intervention for people with dementia?
2. Does the use of digital gaming technology have an impact on quality of life throughout the duration of the Tech Club?
3. What are the experiences of using digital gaming technology for community dwelling people with dementia?
Research Objectives
1. To understand the benefits of participation in a community intervention for people with dementia.
2. To understand if gaming technology has an impact on the quality of life for people with dementia.
3. To collect first hand experiences, comments, feelings and opinions of quality of life from people with dementia.
4. To collect first hand experiences, comments, feelings and opinions of using gaming technology from community dwelling people with dementia.

In 2016, a peer reviewed paper (Cutler et al. 2016) was published. This work has informed the context of this thesis by providing an overview of the impact of digital gaming technologies on people living with dementia. This paper combined the findings of the 2012, 2013 and 2014 service evaluations (with one other pilot study), and, after analysis several notable recurring themes were identified, including the promotion of lifelong learning; optimisation of mental, physical and social stimulation; independence and promotion of healthy ageing. Whilst this paper is a distinct piece of work and was not envisaged as part this PhD, it illustrates emerging research themes aligned to digital gaming technology, showing how this thesis, as a separate body of work, builds on and offers new contributions to this area of knowledge. Cutler et al. (2016) is provided below.

Does digital gaming enable healthy ageing for community dwelling people with dementia?

Introduction

People with dementia have been classed as a vulnerable population (Mental Capacity Act (MCA) 2005) and their numbers are predicted to rise from 44.35 million in 2013 to 75.62 million in 2030 and 135.46 million by 2050 (ADI 2013). In 2010, the numbers of people with dementia were estimated to cost the worldwide economy \$604 billion (WHO 2012) and this will only increase as this population continues to grow. In the UK, it is estimated that around 850,000 people are living with dementia, with 720,000 in

England (Alzheimer's Society 2014a). This is likely to cost the UK around £26 billion a year in care costs and lost productivity (Alzheimer's Society 2014b). With the lack of a silver bullet cure and faced with these stark figures, it is unsurprising there has been an increased global focus on supporting and helping people with dementia to live well at home for longer, particularly as two thirds of people with dementia in the UK reside in the community (Alzheimer's Society, 2014a). The World Health Organisation (WHO 2012) and the 2013 G8 Dementia summit (DoH 2013) places dementia as a global health priority while the English National Dementia Strategy (DoH 2009) and the subsequent Prime Ministers Challenge (DoH 2012) and dementia friendly communities initiatives (Alzheimer's Society 2013a; DoH 2012;) have ensured that dementia has received national recognition.

Living with dementia poses particular challenges for the Healthy Ageing Agenda. Healthy ageing for the general older population has been defined by SNIPHR (2006) as:

“A process of optimising opportunities for physical, social and mental health to enable older people to take an active part in society without discrimination and to enjoy an independent and good quality of life.” This definition will apply to all references to Healthy Ageing throughout this paper.

This approach is supported in the dementia field where the importance of maintaining and enhancing wellbeing whilst living with dementia by keeping physically, socially and mentally active has been recognised (Swann 2012; Wang et al. 2012b; Hill et al. 2010; Hall et al. 2009). Activities promoting engagement and well-being may help to reduce the risk of dependence, further health deterioration and social exclusion for those living with dementia (Innes 2009). English policy directives (DoH 2012; DoH 2009) support research findings, for example initiatives designed to raise societal awareness of dementia (Alzheimer Society 2013a) and to reduce social isolation experienced when diagnosed with the condition (Alzheimer Society 2013c).

Lifelong learning refers to an on-going process of learning throughout one's lifetime in different environments that can contribute to personal fulfilment, active citizenship, social inclusion and employability/adaptability (The European Commission 2001), and is therefore an important element of healthy ageing. Research suggests that lifelong learning may be a protective factor for developing dementia (Foresight 2008) but it is also beneficial for the well-being of those living with the condition. For instance, the Scottish Charter advocates the right for people with dementia to access opportunities

for community education and lifelong learning for purposes of empowerment and well-being (Alzheimer Scotland 2009).

Whilst healthy ageing is an admirable ideological aspiration to apply to people with dementia it can be difficult to achieve. Recent Alzheimer's Society research (2014b) showed that 61% of people with dementia in the UK feel anxious or depressed, 40% feel lonely and 34% do not feel part of their community. This, in part, can be attributed to a lack of services for people with dementia but also to the 'jeopardy' (Innes 2003; Bowes and Wilkinson 2002; Benbow and Reynolds 2000) people with dementia may face. Multiple jeopardies (Innes 2003) including, ethnicity, gender, class, sexual orientation and physical disability lead to various forms of discrimination and the marginalisation of people with dementia. The label dementia carries with it a stigma, referred to by Goffman (1963) as an "attribute that is deeply discrediting" and that reduces the bearer "from a whole and usual person to a tainted, discounted one." Research has shown that people with dementia are stigmatised and discriminated against (Benbow and Jolley 2012; Milne 2010). This stigma weakens people's sense of self-worth and self-esteem whilst increasing their sense of being burdensome (Sabat 2010). This may create barriers to accessing services which are designed to support their healthy ageing or enable them to play an active role in wider society. Bartlett and O'Connor (2010) discuss the concept of 'social citizenship' to illustrate how society can impede people with dementia from upholding their basic rights as a citizen bestowed upon them by the state, including accessing health and social services and being socially active and connected to others. This is often detrimental to their well-being and healthy ageing by further adding to their social exclusion and marginalisation (Gilmour and Brannelly 2010; Innes et al. 2004). It is vital that people with dementia are supported to successfully achieve healthy ageing; this requires promoting public awareness and understanding to challenge on-going misconceptions and stigma of dementia reported globally (ADI 2012).

Psychosocial interventions and living well with dementia in the community

Psychosocial interventions offer an alternative way to support people with dementia to live independently for longer and are now acknowledged as a core element of dementia care research (Moniz-Cook et al. 2012; Vernooij-Dassen et al. 2011; Moniz-Cook et al. 2008). Guidelines (The National Institute for Health and Care Excellence (NICE) 2006) argue for a reduction in the use of pharmacological interventions in dementia care as psychosocial interventions have been reported to be just as effective as pharmacological treatments (Olazaran et al. 2010).

Benefits of community psychosocial interventions align well with the ideological aim of healthy ageing. These have included: reducing depression, and improving quality of life and self-esteem (Leung 2015); slowing the progression of dementia and reducing symptoms associated with the condition (McLaren 2013; Wang et al. 2010); enhancing memory (Zarit et al. 2004) and positively impacting on sociability, emotional adaptation, mood and behaviour (Camic et al. 2014; 2013; Choi et al. 2009; Rusted et al. 2006). Counselling and family support programmes have also been linked to delays in nursing home placement (Andrén and Elmståhl 2008; Spijker et al. 2008; Mittelman et al. 2006). It has been argued that delaying admission to long term care is one reason why psychosocial interventions are a cost effective approach to providing care for those living with dementia (Aguirre et al. 2014b). Therefore adopting a psychosocial approach can directly benefit a community-dwelling person with dementia and contribute to achieving the aims of a health ageing agenda while reducing societal economic burden.

As an alternative to pharmacological interventions, digital gaming technology has been used more generally in health care to support rehabilitation in conditions such as heart disease (Lieberman et al. 2010) and strokes (Saposnik et al. 2010). For older people more generally, this technology has been used to explore and promote physical activity and balance (Maillot et al. 2012; Agmon et al. 2011), cognitive training (Boot et al. 2011; Ackerman, et al. 2010; Ball et al. 2002) and prevention and reduction of cognitive decline (Basak et al. 2008). This demonstrates how this type of technology has been used to benefit the general population and its potential benefits for people with dementia. Although in the field of dementia, its use has been scarcely explored, perhaps due to the assumption that people with dementia need dementia specific technology (Astell 2013).

Living well with dementia using digital gaming technology

Technology can support the well-being of people living with dementia in the community (Mulvenna et al. 2010). However most research has focused primarily on using technology to promote safety and security for people with dementia and their informal carers (Span et al. 2013; Lauriks et al. 2007). Astell (2013) has argued that this has unduly influenced the direction of technology research and consequently other areas of well-being have been neglected. Dementia-specific technology, such as CIRCA (Computer Interactive Reminiscence and Communication Aid) (Alm et al. 2009) or Cogknow (Meiland 2007) demonstrates additional health benefits for people with

dementia, including improved communication and heightened mood and sense of well-being, through reminiscence activities. It has been argued that specifically designed technology may be more suitable than commercially produced technology for people living with dementia (Astell 2013). However the limited research exploring off the shelf technologies such as the Wii and iPad suggests health benefits for people with dementia living in the community (Leahey and Singleton 2011; Fenney and Lee 2010) and those residing in Assisted Living and nursing home environments (Chao et al. 2013; Leng et al. 2013; Padala et al. 2012; Ulbrecht 2012; Upton et al. 2011; Tobiasson 2010). Reported benefits include; improvement in scores and in the maintenance of procedural memory for the games (Leahey and Singleton 2011; Fenney and Lee 2010); transferability of learned skills to other leisure activities (Leahey and Singleton 2011); improvement in balance on the Wii Balance Board and fitness games (Chao et al. 2013; Padala et al. 2012); improvement in communication with informal and formal carers, as well as fostering intergenerational communication and supporting activities of daily living (Upton et al. 2011) and general enhancement in social interaction and well-being through engaging with fun games and applications (Leng et al. 2013; Padala et al. 2012; Fenney and Lee 2010; Tobiasson, 2010). If technology is to be used routinely within the community, it is imperative that it is affordable, user-friendly and widely available.

The limited research, conducted primarily in care home settings, suggests that digital gaming may provide a way to promote learning and mental, social and physical wellbeing for people with dementia; all of which are integral to the Healthy Ageing Agenda. This paper critically assesses the benefits of digital gaming technology available 'off-the-shelf' to support the healthy ageing and independence of people living with dementia in the community.

Study Design

This study aimed to capture the experiences and views of using digital gaming from people living with dementia. This approach reflects the emphasis in the literature of including the voices of people with dementia in research, (Murphy et al. 2014; McKeown et al. 2010; Cowdell 2008; Dewing 2008; Wilkinson 2002; Downs 1997; Goldsmith 1996), with the aim of working collaboratively with participants (Dupuis et al. 2012; Bradbury and Reason 2003) in a way that responds to individual personalities, needs and values as advocated by person centred approaches (Broker 2004; McCormack 2004). This project followed principles of participatory action research

(Israel et al. 2008; Reason and Bradbury 2008) by adapting sessions to meet the interests of the participants.

Between September 2012 and May 2014, a total of 26 technology sessions, referred to as 'Tech Clubs' (commissioned by a local authority) were delivered to 29 community-dwelling people with dementia between the ages of 65-80 years old, all of whom resided own homes with carers (who provided support) or assisted living accommodation (individual self-contained accommodation within a larger housing facility with 24 hour professional support and care if required).

The Tech Clubs were hosted in four accessible venues; all had Wi-Fi access and a large screen. Sessions were scheduled over a two hour period and ran for six to eight weeks in an English town. Groups had between three and ten participants as can be seen in the participant breakdown table:

Participant breakdown per Tech Club

	Total number	Male	Female
TC1	10	1	9
TC2	3	2	1
TC3	10	5	5
TC4	6	3	3
Total	29	11	18

This project did not follow a bio-medical approach (Lyman 1989) and so no medical information or MMSE scores were collected before or during the project to ensure participant inclusivity.

Tech Club Structure

Each session was led by two facilitators, using a range of software, games and apps for the Nintendo DS, Nintendo Wii and Apple iPad as can be seen below:

Equipment	Games and Apps
Nintendo Wii	Wii Resorts; Wii balance board and associated games; Wii Motion Play; Mario Kart
Nintendo DS	Built in camera and voice recorder; Arts games; Cooking games; Animal related games; Flip note; Card games
Apple iPad	Musical and instrumental; Google Earth; Google Maps, National Geographic; 3D planet; BBC news and weather; BBC iPlayer; You Tube; Built in camera

These technologies were chosen for this study as they are commercially available and there is evidence for their potential health and wellbeing benefits for older adults and people with dementia (Chao et al. 2013; Padala et al. 2012; Leahey and Singleton 2011; Upton 2011; Fenney and Lee 2010). As a starting point, the sessions concentrated on providing basic information and instruction for the chosen pieces of equipment and associated games and apps (Cutler et al. 2014). Repeat visual and verbal demonstrations were offered as required.

Methods

A mixed-method approach (Bryman 2008) captured the views and experiences of the participants. Three methods were used: ethnographic field notes (Holloway and Wheeler 2010) to record participant engagement and interaction with the digital gaming equipment; participant and carers self-complete questionnaires (Bryman 2012); and focus group style discussions (Kitzinger 1995) at the end of each session following a natural conversation approach to generate feedback (Flick 2014).

The self-complete questionnaire was a simple user friendly tick box sheet, which asked the participants how they enjoyed the session using a 5 point Likert Scale (Sarantakos 2005). It then asked if they had enjoyed aspects of the technology with 'Yes' and 'No' options, followed by two open ended questions asking what the participants particularly liked about the session and what they did not.

The semi structured focus groups explored the participants' experiences of using the digital gaming technology directly after the sessions. This was an opportunity to freely explore positive and negative aspects of each piece of equipment and the participants' overall feelings and opinions of the technology as part of a natural conversation. All focus groups were audio recorded and fully transcribed.

Ethics

Ethical approval was obtained from the University Ethics Committee. Information sheets and recruitment posters were distributed by local gatekeepers (the local Alzheimer Society and council) to potential participants. All participants had a diagnosis of dementia (verified by the relevant gatekeepers) but also had the ability to consent.

Consent forms confirming awareness of voluntary participation, withdrawal at any time and confidentiality and anonymity principles were completed by each participant, and

discussed verbally where required. Process consent methods (Dewing 2008) including responding to nonverbal cues of a wish to withdraw were followed during each session. A weekly registration form was used to remind participants that they were part of a study.

Data Analysis

Data was analysed thematically using NVivo10 for data management purposes. A coding framework (Bryman 2008) was used to analyse data collected from the self-complete questionnaires, focus groups and field notes. This framework was developed by one researcher and verified by another to enhance the authenticity of the analysis. The following table provides details of the group and participant identifier codes in the findings that follow. Formal carers (FC) are paid care workers. Informal carers (IC) are care partners (family or friend) who attended the sessions with the participants:

Identifier codes

Club Identifier	TC1	Tech Club 1
	TC2	Tech Club 2
	TC3	Tech Club 3
	TC4	Tech Club 4
Participant Identifier	PWD	Person with dementia
	FC	Formal Carer
	IC	Informal Carer
Data Identifier	FG	Focus Group
	SQ	Self-Complete Questionnaires
	FN	Ethnographic Field Notes

Findings

Three distinct themes relating to the benefits of digital gaming to promote healthy ageing and independence of people living with dementia emerged: promoting lifelong learning; optimising mental, physical and social stimulation; and independence. These are discussed and then brought together under the overarching theme of promoting healthy ageing.

Promoting Lifelong learning

The use of digital gaming technology supports the concept of lifelong learning as it enables participants to develop, maintain and enhance their skills and knowledge. This

is an important part of healthy ageing as it promotes the need for continual learning and engagement in new meaningful activities.

Learning agendas

Most participants had never seen or used digital gaming technology. The exception was the iPad which was more commonly recognised amongst participants in two of the groups (TC2 and TC4). Despite unfamiliarity with the gaming technology, all participants were interested in learning how to use them. Participants in three groups (TC2, TC3, TC4) held individual learning agendas, in particular how to use the iPad and the Nintendo DS;

'I want to learn more on the iPad.' TC3PWD(17) (FG)

'I'm hoping to learn more next week about the iPad.' TC2PWD(12) (FG)

TC2PWD(11) brought his own DS along to the session to be shown how to use it. (FN)

TC4PWD(26) commented when asked is there anything in particular you would like to learn, *'it's all new and I like learning new things, I would like to be shown how to use more of the iPad.'* (FN)

Interestingly, whilst the sessions concentrated on providing the basic information and instruction for the selected gaming technologies and associated games and apps, three participants wanted to learn additional aspects of using the iPad beyond the explanation provided. They wanted to learn how to physically handle the iPad, how to use it to communicate with family and friends, and how to add applications to access their hobbies and interests;

'How do you turn the screen?'... *'How can you talk to people?'*... *'Can you download Google Earth at home?'* TC4PWD(27) (FN)

TC2PWD(12) started to ask questions surrounding other features of the game and about how you can change the direction of the bowling ball. TC2PWD(13) enquired into other control features of the game, for example, reverse actions on Mario Kart. (FN)

Learning to use unfamiliar technologies, games and apps provided participants with a sense of achievement as they had learnt something completely new. This supports the

idea of people with dementia engaging in new and meaningful activities to benefit well-being (Phinney 2007). Participants reported 'learning' as one of the most enjoyable aspects of the sessions;

'Well you felt you were learning something.' TC4PWD(24) (FG)

'I learnt things I could never master before...' TC2PWD(11) (SQ)

Whilst it is apparent that learning was an enjoyable experience, participants reported that the act of learning to use the technologies made them feel that they had physically used their brains;

'This gives you a head ache doesn't it?...I'd like to learn more and know more if my brain can handle it.' [in reference to iPad] TC3PWD(21) (FN)

'I open up my mind to what's being taught to me and I can understand it. Sometimes I forget, it's the understanding of it... I know a lot more about the DS than I ever did... I've picked up something that I will hold in my brain I suppose.' TC2PWD(11) (FG)

'It has fired dad's enthusiasm for technology. It has given him a new thing to think about and aim for. He would love to learn more.' TC2IFC(3) (SQ)

Participants successfully engaging with the technologies was often unexpected and surprising to formal care workers who expected them not to want to or be able to use the technologies;

'I was surprised the clients could use some of the games on computer.' TC3FC(4) (SQ)

'Yes was quite surprised how clients embraced technology' TC3FC(5) (SQ)

A desire for continued learning was apparent in the participants, demonstrating that they were both able to and wished to maintain lifelong learning. Learning opportunities were embraced in relation to the technologies and also to the games that required mental and physical engagement.

Transferable skills

Participants of TC2 and TC4 demonstrated a desire to continue their learning beyond their attendance at the sessions. This was extended further by two participants who wanted to transfer their new skills to enable them to reinstate past hobbies and to share their learning with family and friends;

When provided with a guide to use the iPad, one participant commented *'the presentation of this is very useful and you can work through it at home.'* TC4PWD(27) (FN)

A family carer commented that while at home the participant *'wanted to play the memory game that they had in the sessions.'* TC4IFC(7) (FN)

One participant commented that they wanted to learn how to play the DS to enable them to *'play at home with the grandchildren.'* TC2PWD(11) (FN)

Participants wanted to learn new skills and apply their previous experiences. For example one participant wanted to learn how to use the iPad (due to its perceived similarity to a PC) so that they could transfer their existing skills and knowledge to this new equipment. This demonstrates that the participants were not only capable of learning new concepts but were also able to access and apply past knowledge and skills from one piece of technology to another;

'You can do the same things that you can do with a computer.' TC2PWD(13) (FN)

The Tech Clubs offered the opportunity to not only use new equipment but to learn and be taught how to use it. All participants were willing to learn, with some having a commitment to continued learning through developing their own clear learning agendas. Our data supports the argument that people with dementia can and want to learn, that learning new complex and intricate skills are possible for this community and that with support people with dementia are able to develop their learning and apply it to other areas of life. Transferability of skills to other leisure activities was also reported by Leahey and Singleton (2011). This challenges assumptions of limited capability of people with dementia and further supports the Scottish Charter (Alzheimer Scotland 2009) argument that people with dementia have a right to lifelong learning.

Optimising mental, physical and social stimulation

Digital gaming technology provided a way to optimise mental stimulation, physical activity and social interaction for participants. All of these are crucial aspects for healthy ageing.

Mental stimulation

Participants actively engaged with most of the technology for extended periods of time in all the groups. This required high levels of concentration often for thirty minutes or longer to successfully play the games and activities;

TC2PWD(11) was very involved with the brain training and was concentrating for 1/2hr. (Nintendo DS)... TC2 (FN)

The room was very quiet whilst participants were engaged in their activity. Facilitator stepped back and allowed the participants to use the iPads...This lasted for five minutes. TC4 (FN)

The technology acted as a medium to engage and mentally stimulate participants. In one group gaming technology was used to paint, draw and take photographs enabling participants to engage in previously mentioned creative hobbies. This highlights the importance of acting on knowledge of participants' interests to tailor the use of the technology. This can be particularly beneficial when first introducing new technology;

At the beginning of the session it was discovered that both participants (TC2PWD(11) and (12) were artistic and enjoyed arts, crafts and painting. Following from this it was decided that the iPads would be used...to be creative... TC2PWD(11) was very engaged and creative in taking photos of himself, and switching the camera to take photos of the facilitator and carers. TC2PWD(12) wanted to take photos of themselves with their pearl necklace. After seeing TC2PWD(11) taking photos of other people they also wanted to take photos of the carers, TC1G2(2) and co- facilitator. (FN)

Creating a Mii character on the Nintendo Wii provided participants with an outlet for creative expression. This task required concentration and skill as the participants used their imagination to create a range of characters, many of which were unlike themselves and often of a different sex. The humorous nature of this task helped participants to bond;

TC2PWD(12) created a male and TC2PWD(11) created a female. This generated much laughter but also demonstrated the participants' playful side and sense of humour...TC2PWD(12) was independent and undeterred in their choices of features, whilst TC2PWD(11) at first was led by others in the group in his decisions. After a while TC2PWD(11) decided which features they preferred. (FN)

Participants from the other groups commented on the need to use their mental abilities to engage with the digital gaming technology and this was something which appealed to them;

'...it's alright now because I'm using my brain. Yeah, I like it.' [in reference to iPad] TC3PWD(21) (FG)

'I like the way my brain had to work. I am fascinated by my brain.' [in reference to DS] TC1PWD(2) (FG)

The iPad and Google Earth application were useful digital gaming devices to encourage participants to use their mental abilities. For example, two participants from one Tech Club became noticeably engrossed with the application and began to use investigative skills to explore previous places they had visited or resided in by using their memory to establish familiar landmarks;

TC2PWD(12) was using investigative skills in trying to find old properties through elimination using memory. Seeing things on Google Earth sparked more memories for TC2PWD(12). TC2PWD(11) was looking at Cyprus and Madeira... using investigative skills to find where they were based in the army and whilst on holiday.(FN)

Digital gaming technology provides opportunities for mental stimulation, by engaging participants in activities which require them to concentrate and use mental capabilities such as memory.

Physical Activity

The Nintendo Wii and Balance Board required participants to move their body to interact with the games via the motion censored control system. It was evident through comments made and field notes, that most participants were able to undertake the

actions required of them (some of which were quite complex) and they enjoyed doing so;

'I thought that was fantastic...freedom of movement. We don't have to stand there like a stiff dummy, I will show the kids.' [in reference to Wii] TC2PWD(11) (FG)

As soon as TC1PWD(1) became familiar with the balance board and the game they were more comfortable with the movements required...Facilitator commented *'this is good exercise'*, participant replied *'of course it is'* and was very determined to beat her previous score commenting *'you've got to go faster.'* (FN)

However, participants in two of the groups appeared to find the games which were slower paced with fewer moving graphics easier to engage with and subsequently more enjoyable;

Participants seemed to respond more to the ice cream game. This may be due to the fact that the ice cream game was slower, less moving graphics and was of a slower, calmer nature. [in reference to Wii] TC1 (FN)

'I find Mario Kart too fast for my eyes.' [in reference to Wii] TC2PWD(11) (SQ)

Physically interacting with the digital games had additional benefits for the participants. For example it was noted by an informal carer, that one participant's co-ordination, balance and memory seemed to improve through engaging with the Nintendo Wii;

'Through activity; better coordination; ability to follow instructions; willingness to be directed; remembering skills: balance improved.' [in reference to Wii] TC2IFC(2) (SQ)

Participants enjoyed interacting with the Nintendo Wii and the Balance Board. It is interesting to note that when participants were given the choice of sitting or standing to interact with the games they predominantly chose the latter. On occasions, it surprised informal and formal carers when they demonstrated the necessary physical abilities to engage with the games. This highlights how digital gaming can be used as a platform for participants to challenge misconceptions of their abilities (discussed further below);

During all of the Wii games all of the participants choose to stand up whilst playing the game. TC1 and TC3 (FN)

It was also noted that all participants stood to do the bowling through choice despite some concerns from their carers. TC2 (FN)

Digital gaming allowed participants to engage in mild forms of physical exercise by taking part in activities they once enjoyed but were now no longer able to due to physical and/or practical limitations. The intuitive nature of the Nintendo Wii, meant that participants with previous experience of the activity in a real world setting could pick up the actions and movements relatively easily;

'When provided with a selection of games to play using the Nintendo Wii balance board, TC2 decided to play the slalom ski game. When TC2PWD(12) started to play this, it was mentioned that this participant frequently used to go skiing on holiday but had not been able to go now for a number of years. (FN) When this participant was later asked what they enjoyed about the session, the participant's reply was '*Skiing.*' (FG)

Having access to different technologies during each session allowed individual participants to pursue their own interests while also being part of a group. More and less physically challenging games provided the opportunity for group members to actively choose games that met their physical abilities. It also meant that if on certain weeks participants were not in the mood to physically engage with movement games they could undertake more sedentary activities and still be part of the group;

TC3PWD(21) commented '*I'm tired today, I've been tired all week*' and declined to play the Wii bowling game and instead opted to engage with the iPad. (FN)

Digital gaming technology promoted mild physical exercise via fun activities, new and old, with informal carers reporting benefits for the person with dementias co-ordination and balance. These benefits have also been reported in other studies (Chao et al. 2013; Padala et al. 2012; Tobiasson 2010).

Social interaction

Digital gaming promoted social interaction amongst participants and was particularly important for the development of group cohesion as participants got to know one another whilst learning new games and applications. The digital gaming devices acted as a catalyst for social interaction through two means: either by participants talking about the technology as they engaged with it or; participants talking about topics of conversation introduced and promoted by the use of the technology.

When the technology or games were first introduced to the participants the 'novelty factor' stimulated light hearted conversation as the game, and what was required to play, was discussed;

TC3PWD(23) and TC3PWD(16) were talking to each other about the game and laughing and chatting about their go. [in reference to Wii] (FN)

After the iPads were explained to the participants of TC1, TC1PWD(2) commented *'it's amazing what you can do'*, to which TC1PWD(9) replied *'isn't it great, very clever.'* (FN)

Social interaction between the participants suggest that they were mentally stimulated throughout the duration of the game; both when they were playing it and when they were observing others' engagement. Using the equipment can therefore increase social interaction between participants, and between participants and their informal carers;

TC2PWD(11) was teaching TC2PWD(12) how to play chequers on the I Pad. They concentrated on the game for 15 minutes. ...As TC2PWD(12) finished their turn and TC2PWD(11) came for their turn, TC2PWD(12) was telling them how to control the Kart and reminded them to keep their finger on number 2. TC2PWD(12) also did this when their carer had a turn. [in reference to Wii] (FN)

TC3PWD(16) was encouraging three other participants when using the Wii Balance Board by commenting *'you've got it there mate, well done, keep going'*; *'You've done well mate'*; *'you are doing well.'*; *'you are doing alright.'* (FN)

The technology, in particular the iPad, allowed topics of conversation to be introduced and discussed promoting social interaction within the groups. These were used successfully in one-to-one situations to increase social interaction and in a group setting to encourage general discussion;

'..iPad and Google Earth were passed around the participants were asking questions about countries, TC3PWD(20) asked 'where's Australia?', TC3PWD(21) added, 'my brother lives in Australia'. TC3PWD(20) added 'I know what Australia looks like.' (FN)

The participants were interested in You Tube as different songs and videos were played. Participants sang along to the words and watched the old music

videos. ...TC1PWD(3) was very happy to watch the horses and was talking about them extensively. TC1PWD(3) mood changed to be happy as they sat and watched the videos and told stories. They said *'they mean a lot to me.'* (FN)

TC2PWD(13) was very interested in the different applications of the iPad and enjoyed looking at the place where they used to live. This activity triggered many memories from when they were at school and used to have lunch at the Natural Museum on Sundays. (FN)

Conversations promoted by the technology predominantly focused on previous life experiences but also included current hobbies. These discussions allowed for a deeper understanding of the participants' lives to be ascertained. During these activities the dialogue flowed with ease and the participants' mood seemed to be lifted and upbeat;

One participant from TC1 commented that they *'hadn't seen TC1PWD(3) smile for ages as they are always sitting looking sad, but today they are smiling.'* (FN)

Social interaction has been a salient finding reported in many of the studies exploring the use of digital gaming technology with people with dementia (Padala et al. 2012; Fenney and Lee 2010; Tobiasson 2010) and this is consistent with the current study. The technology was an important medium to promote social interaction and subsequently group cohesion. Activities also encouraged the participants to reminisce. There are suggestions this is something which can enhance the mood of people with dementia and is therefore important for their well-being (Cotelli et al. 2005).

Independence

Gaming technology promoted independence for the participants as it offered them an opportunity to explore games, software and equipment independently away from the facilitators and carers. Whilst it is acknowledged that initial support was required, after this, participants were able to use the equipment (mainly the iPad and DS) and associated software (mainly apps of Google Earth and You Tube) alone;

TC2PWD(11) picked up the DS and started using it on their own accord. The participant went straight to the camera facility unaided to take a picture of the research team to show his grandchildren...Whilst sat alone TC2PWD(12) started to use the iPad and type in addresses to Google Earth unaided....TC2PWD(11) played the Wii tightrope game. Unlike in a previous

session 4 this participant was able to do this game completely unaided and without any advice. (FN)

Independent use of the iPad, DS and Wii actively challenged assumptions around the abilities of people with dementia to use equipment independently. For example, two participants (TC4PWD(26) and TC4PWD(27)) had informal carers who owned iPads but who would not allow the participants to use them through fear of them breaking them and an assumption they couldn't use them.

Providing opportunities to use the equipment independently in the groups allowed participants a sense of empowerment and a chance to regain their rights as an individual. Two participants in particular fought to maintain their independence in using the equipment when support was offered;

TC4PWD(25) was using the iPad but couldn't see page, after the screen was enlarged the facilitator started to help the participant with the activity but the participant said '*give it to me*' and took the iPad from facilitator. (FN)

When offered advice from facilitator when using the Wii TC3PWD(21) replied instantly with '*I know how to do it.*' (FN)

This highlights that whilst support may be offered with the best intentions it can undermine the abilities of those with dementia.

Five participants bought technologies (Wii, DS and iPad) they had been introduced to in the sessions for their personal use at home. This demonstrates a desire to continue to play independently of the group;

'Dad has talked about getting an iPad himself and has really enjoyed the possibility. It has opened up a new line of thought.' TC2IFC(3) (SQ)

'I want to buy one.' TC3PWD(17) (SQ)

The findings challenge the idea that people with dementia require continued support to use commercial digital gaming technology (Astell 2013). Although initially support may be required, overtime people with dementia can successfully engage in activities independently promoting a wider sense of empowerment contributing to healthy ageing. In fact, some participants relished the opportunity to use the technology alone

and were inspired to buy this equipment to continue with this level of independence at home.

Promoting healthy ageing

The connecting finding from this work is that digital gaming technology can promote healthy ageing in participants with dementia by enabling them to challenge their own views of their capabilities as well as that of their informal and formal carers.

Challenge own assumptions of capabilities

For some participants, interacting with the games provided them an opportunity to challenge their own perceptions of their capabilities which resulted in a sense of achievement. One participant interacting with the Nintendo Wii balance board said;

'It was great to see I could do it.' [in reference to the Wii Balance Board]
TC2PWD(11) (FG)

However these assumptions and expectations to successfully engage with a game, particularly if it was something people had once been good at, at times deterred them from taking part. This was the case with one participant who used to be a truck driver and decided not to interact with a driving game for the Nintendo Wii;

'I think with TC3PWD(19) he's been a macho man all his life, he's driven lorries and he's done all that sort of thing, and he's probably sitting there thinking, if I make a muck-up of it like all the rest of them they're going to laugh at me, and they don't like it men don't; they've got that thing about it.' [in reference to Wii]
TC3FC(4) (FN)

This example provides an instance where tailoring the activities towards a participant's interest was not beneficial for their well-being predominantly due to the assumptions they held around their abilities and the expectations they felt about the need to perform well in front of the group.

This aspect of managing expectations and challenges was also present in other participants who were engaging in games which were not associated with their previous life experience;

'The thing is that normally people like to succeed, they like to grasp at something okay, and find within a short length of time they can get some

satisfaction out of it. Not a massive leap, but the fact is I didn't find any challenge, but that was a function shall we say...Take myself. I like a challenge, okay? I don't like finding that I'm not getting the hang of it...' [in reference to iPad] TC4PWD(24) (FG)

Challenging others' assumptions of capabilities

By engaging with the digital gaming technology, participants from two Tech Clubs were able to challenge informal and formal carers perceptions of their abilities;

'Yes. No, it is good, and I'm surprised at the ladies with that iPad and they go, no, no, do that. They weren't doing it right, but they were having a go at it.' TC3FC(4) (SQ)

'I think it's a great use to those with cognitive challenges to continue, just once a week, doing these sorts of activities, it is amazing what you suddenly realise is missing and what comes back the following week and I really think that does need to be observed and recorded.' TC2IFC(2) (FG)

Following one of the Tech Clubs, a participant began to use the Nintendo Wii at home with their grandchildren and it was evident that this began to challenge their misconceptions of the participant's capabilities;

TC2PWD(11) told about playing their Wii at home with their grandchildren. They played archery, bowling, golf, darts and Mario Kart and confirmed that their grandchildren were surprised at the participant's ability to play them games and how they were good at the games. (FN)

Digital gaming technology can promote the healthy ageing agenda by challenging assumptions of the abilities of people with dementia both in those living with the condition and those supporting them. This can help people with dementia to defy the stigma associated with the condition (Benbow and Jolley 2012; Milne 2010).

Discussion

Our findings suggest that participants displayed a willingness and desire for continued learning, showing people with dementia are keen and able to partake in novel activities and learn new concepts; all of which are beneficial for their healthy ageing. This provides support for the notion that lifelong learning should continue despite a

diagnosis of dementia (Alzheimer Scotland 2009). Learning was by no means bound to activities which relied predominately on mental concentration alone. Learning was also apparent when using technologies requiring both mental and physical concentration. The findings suggest that not only did the participants learn complex movement and button combinations that relied on both mental, physical and fine motor skills, but that the participants were also able to develop this learning to acknowledge and correct mistakes, even before they were pointed out. Learning new skills enabled the participants to transfer this knowledge to other areas of their life. This has also been reported in other similar research (Leahey and Singleton 2011).

Our findings also support the idea that digital gaming technologies can be beneficial for other aspects of the Healthy Ageing Agenda. Provided they were offered the initial support, overtime some people with dementia were able to successfully engage in activities independently which provided a wider sense of empowerment, contributing to healthy ageing. This challenges the idea that people with dementia can only engage independently with technologies that have been specifically designed for them (Astell 2013). Our participants relished the opportunity to use this equipment alone which further inspired some to buy the equipment to continue with this level of independence at home.

Digital gaming technology also provides opportunities for mental, social and physical stimulation, by engaging participants in activities which require them to concentrate and use mental capabilities such as memory. This has also been found in the other similar studies (Leng et al. 2013; Padala et al. 2012; Leahey and Singleton 2011; Upton et al. 2011; Fenney and Lee 2010; Tobiasson 2010). Participants enjoyed interacting with the activities particularly when they were tailored towards their interests supporting the notion of person-centred approaches (McCormack 2004; Brooker 2003). This technology can act as a catalyst to promote social interaction either through talking about the technology itself or the topics of conversation which are generated through the use of the games and the applications; such as reminiscing about days gone by. Having multiple technologies can enable conversations to flow unabated for longer and can ensure the games and applications can be tailored towards the interests of the participants. Engaging participants in fun activities to promote mild physical exercise, using this technology may have additional benefits for their co-ordination and balance as was found in other studies using digital gaming technologies (Chao et al. 2013; Padala et al. 2012; Tobiasson 2010).

An important overarching finding was the ability for digital gaming technologies to provide a platform whereby people with dementia could challenge the perceptions and stereotypical views of their capabilities. This aligns well with the concept of 'resistance' which has recently been introduced in the dementia care field (Genoe 2010). Resistance is viewed as a struggle against power structures that spread through everyday life which can occur when social constraints and ideologies are challenged (Shaw 2006). Our findings indicate that participants, by engaging in non-stereotypical activities, showed both themselves and others what they are capable of doing and so challenged negative discourses around dementia and ageing. This suggests that digital gaming technologies can not only provide activities which promote healthy ageing in people with dementia but also provide a platform to challenge stigma and negative perceptions surrounding the condition. If practitioners can be encouraged to move away from the stereotypical activities which are often provided to people with dementia (Genoe 2010) and embrace these novel and non-stereotypical activities, it may make society more 'dementia aware' and enable those living with the condition to become more socially active and connected (Bartlett and O'Connor 2010).

Future research using digital gaming technologies may also be particularly beneficial when raising dementia awareness in the younger generation due to their intergenerational appeal (Upton et al. 2011). In addition, using digital gaming technologies as a platform for resistance to raise dementia awareness particularly within the younger generation is an area of interest.

Limitations

There were limitations to the use of particular technology during the sessions. Participants found it difficult to concentrate using certain games for the Nintendo Wii, for example, bright colours and fast moving graphics. Some of these games also acted as a barrier to participant's ability to physically engage with them due to the speed of the game. This was complicated further when speed was mixed with fast paced graphics and colour changes. Participants also found the Nintendo DS challenging due to the small size of the screen and numerous pages of instructions prior to starting the game or activity. There were general issues when using the iPad in these sessions as weak Wi-Fi signals, or using multiple iPads all accessing Wi-Fi at the same time, limited internet access to all or some of the participants, restricting what they could do and see on the iPad.

An additional limitation to this study was around participant recruitment. As participants self-selected for the study they were more likely to have an interest in the technology and so more willing to engage with it. This will have impacted on the size and characteristics of the sample and may have influenced the outcomes of the research. As such, caution must be taken when generalising the findings of the study to the wider population of community-dwelling people with dementia.

A final limitation to this study was that there was an overall preference to the iPad (potentially due to its sedentary nature) which has led to a slightly imbalanced response to the technology equipment as a whole.

Conclusion

The use of digital gaming technology enabled community-dwelling people with dementia to engage in a range of innovative and creative activities benefitting their mental, physical and social well-being, sense of independence and opportunities for life-long learning. The combined impact of this is that gaming technologies provide an opportunity to promote healthy ageing. Our data demonstrates that participants left the sessions with heightened wellbeing, increased levels of alertness, and a sense of empowerment. Participants chose to use the technology either on their own or in a group, promoting a sense of choice and independence. Participants also displayed a desire to learn more about the digital gaming technology and improve on their performances. There were also signs that this learning was transferred into everyday activities outside of the sessions to benefit well-being and promote intergenerational socialisation.

The findings from this study suggest healthy ageing for people with dementia can be achieved or enhanced through the use of digital gaming technologies. This study has also found that community-dwelling people with dementia are able to, and want to, engage with digital gaming technologies. This challenges the notion of stereotypical activities suitable for people with dementia and suggests that practitioners working in the field need to be more open to this medium as a way of promoting healthy ageing and independence for people with dementia. In addition, whilst our sample focused on community dwelling people with dementia in the South of England, the results may also be applicable to those residing in care homes and in other communities within the UK. This could be an area for future research. Further research should also focus on providing a better understanding of how to use digital gaming with people living with dementia.

As can be seen, Cutler et al. (2016) identify that digital gaming technologies can promote healthy ageing for those living with dementia. Yet as suggested, there still remain large gaps in knowledge on the potential of digital gaming technology for people living with dementia. This thesis builds on the emerging themes identified from the discussed service evaluations by exploring the QoL benefits of digital gaming technology. Chapter three now presents the literature review for this thesis, illustrating the gaps in knowledge and literature surrounding QoL and digital gaming technologies.

Chapter Three: Literature Review

Introduction

This chapter firstly explores the conceptualisation of dementia, exploring malignant social positioning, selfhood and the impact of the biomedical approach on the lived experience of dementia. The chapter then considers the concept of QoL and its significance when living with dementia especially in relation to citizenship and user involvement. This is followed by a review of post diagnostic support interventions available for community dwelling people with dementia, considering both community based and psychosocial specific interventions. The role of digital gaming technology in health care and its role in dementia specific care is then explored. Finally, the chapter will conclude with a summary of these key areas of literature highlighting a gap in knowledge.

I will first explain how these key areas were identified and why they were considered significant for this research. As explained in chapter two, the research questions (Table 1) emerged from my experience of undertaking service evaluations focused on the use of digital gaming technology and not from an initial review of the literature. Through research undertaken prior to designing, conducting and delivering each of the three service evaluations, I was aware of the major gaps in the literature concerning digital gaming technology and dementia research and built on this to develop the research questions and literature review for the PhD.

Table 1: Research questions and objectives

Research Questions
1. What are the benefits (if any) of a technology based community intervention for people with dementia?
2. Does the use of digital gaming technology have an impact on quality of life throughout the duration of the Tech Club?
3. What are the experiences of using digital gaming technology for community dwelling people with dementia?

A critical literature review, focusing on four key bodies of literature, was conducted prior to conducting this research. The review, which included peer reviewed journal articles, books and grey literature, firstly concentrated on the construction of dementia and how societal understandings of the condition impact on the treatment of those with dementia and therefore the lived experience. Secondly, QoL literature was reviewed to obtain an understanding of this theoretical concept in relation to dementia research. As the research was designed as a community intervention set within a service evaluation,

post diagnostic support in the form of community interventions was identified as an important body of literature to review, especially in relation to psychosocial interventions. The final focus of the literature review centred on technology itself. It was important to consider the emerging role of technology in dementia care and the specific use of digital gaming technology as a viable technique in psychosocial interventions.

Understanding of Dementia

As previously explained, dementia is described as a '*set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language*' (Alzheimer's Society 2017). Such symptoms are believed to interfere with daily living (Derouesné 2003), social behaviour, emotional control and motivation (WHO 2012). As an umbrella term, dementia encompasses a variety of conditions which manifest these symptoms, they include Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy bodies dementia, for example.

Our understanding of dementia as a brain disease stems from the early 20th century when a series of neurological and neuropathological breakthroughs within the field of dementia (Boller 2008) took place. This was also the period when Alzheimer's disease was 'discovered' by the German Neuropathologist, Alois Alzheimer (Holstein 1997). Whilst there was no evidence to suggest that Alzheimer's disease was different from what was observed in older adults over 65 (referred to as senile dementia), the discovery of pathological changes in a younger person paved the way for a 'new' brain disease to be introduced (Cheston and Bender 1999), termed Alzheimer's disease. However, there was no medical evidence supporting the claim that either 'senile dementia' or Alzheimer's disease was a medical condition requiring medical treatment. Despite this, by the 1920s Alzheimer's disease particularly was imbedded within medical thinking and was classified within its own disease category (Holstein 1997). As dementia was now categorised as a medical condition, this became and remains the dominate thought process and approach applied to understanding and treating the condition of dementia (Bond 1992). The biomedical approach to dementia considers the condition to be an abnormal and a pathological degenerative disease (Davis 2004). Typically, biomedical approaches to dementia tend to focus on causes and prevention of dementia but also suggest that diagnosis of the condition should be made using a biomedical approach (Lyman 1989).

In current times, dementia remains one of the key health and social care challenges of the 21st century and biomedical approaches to dementia continue to influence care,

policy and practice (Innes and Manthorpe 2013) and have continued to dominate research within this field (Doyle and Rubinstein 2013; Beard 2012). Whilst there is a need to develop medical support for those with dementia, the biomedical approach, coined the 'standard paradigm' (Kitwood 1997), has contributed to the creation of wider societal issues through the medicalisation of this condition.

The biomedical approach to dementia and dementia care, the standard paradigm, has resulted in the disempowerment of both people with dementia and their families (Bond 1992; Lyman 1989) and has increased the vulnerability of those with dementia to be exposed to treachery, infantilisation, intimidation, labelling, stigma, outpacing, invalidation, banishment and objectification, a collective, otherwise termed 'malignant social psychology' (Kitwood 1990). Kitwood (1997; 1990) suggests that those living with dementia are vulnerable to malignant positioning, not through malicious intent, but because they are considered dysfunctional as a result of their dementia. This has resulted in a 'them' and 'us' scenario, where those without dementia are considered '*sound and undamaged*' but those with dementia are regarded as '*damaged, derailed and deficient*' (Kitwood and Bredin 1992, p.272).

Malignant Social Psychology: labelling and stigma

Labelling, a component of malignant social positioning, is one result of the biomedical approach to dementia. The 'standard paradigm' has resulted in those diagnosed with dementia to be labelled as 'patients' and 'service users', for example. The labelling theory (Rosenhan 1973) analyses how social definitions are created and applied in a social context (Shulman 2005) and further considers how future perceptions of people may be influenced because of a label (Coulter 1981). This is particularly problematic for this community as labelling changes the way people interact with and treat those with dementia (Harding and Palfrey 1997). For example, the biomedical approach to dementia care has attempted to categorise the progression of dementia into stage models (Lynott 1983; Hayter 1974) to account for certain behaviours (Gubrium and Lynott 1987). This has resulted in further labelling of those with dementia as 'deviant' (Freund et al. 2003) if their behaviour and lived experience does not conform to an appropriate stage within this model. Whilst it is acknowledged there may be benefits to labelling dementia for carers and medical professionals (Kitwood 1997; Bond 1992; Lyman 1989), the beneficiaries are rarely those who live with dementia. Being labelled in such a way can have profound effects on selfhood (Herskovits 1995) and quality of life (Woods 2001; Gillies 2000) as it ultimately creates stigma (Garand et al. 2009).

Stigma can create and contribute to social isolation and social exclusion and is a significant contributor to the loss of QoL (ADI 2012). It results in a person being reduced from 'normal' to someone who has something wrong with them (Goffman 1963), labelling them incapable. This can lead to excess disability (Brody et al. 1971) and dementia becoming a self-fulfilling prophecy (Lyman 1989; Lemert 1972) where people begin to doubt themselves and become what they are expected to be. Labelling and stigma is an example of how the biomedical model is 'flawed' (Harding and Palfrey 1997) as it influences present and future perceptions of people with dementia based on a notional attempt to create order and predictability (Lyman 1989) to an otherwise disorderly and unpredictable condition. As suggested, this can have a profound impact on self and ultimately QoL.

Selfhood

The concept of selfhood is embedded in the overarching notion of identity, which despite being two individual concepts are arguably inseparable. In an attempt to understand human identity, identity research has become a significant area of interest within psychoanalysis, psychology, political science, sociology and history, therefore resulting in interchangeable definitions and meanings of identity between the disciplines (Stryker and Burke 2000), making this a complex concept to define.

Identity refers to an individual's personal and social identity. Personal identity refers to the attributes that highlight each person as being unique (McLeod 2008) and is often the focus of psychological research. Social identity, which is associated to social positioning, roles and groupings within a social structure (McLeod 2008) is the major consideration of sociologists. However, the identity theory has foundations in both sociology and psychology which has often resulted in a dual social psychological approach to this research (Schwartz 2002). With philosophical underpinnings associated with structural symbolic interactionism (Stryker 1980), which aims to explore and understand '*how social structures affect self and how self affects social behaviours*', the concepts of society and self, under the lens of identity, are increasingly researchable (Stryker and Burke 2000, p.285).

The concept of 'self' embodies two parallel views, how individuals experience their own self and how others view the self of that person (Sabat et al. 1999). As suggested by Sabat et al. (1999) and Stets and Burke (2000), the way self is experienced by an individual may change in the life course of that person, making them and their experiences unique. It is suggested that individuals develop a sense of self from '*the social categories to which they belong*' (Stets and Burke 2000, p.225), or the

knowledge that they are a member of a social category or group (Hogg and Dominic 1988). In contrast, it is suggested (Sabat et al. 1999, p.6) that the way others identify with another's self, is based on a comparison between experiences held by that person, which is a criterion for '*judging whether this is one and same person as the one who has been identified at some other time and place*', suggesting that acceptance of change within this may be limited, highlighting that self is largely dependent on others (Sabat and Harré 1992).

Whilst there is no clear definition of self (Caddell and Clare 2010), operational uses of the concept include self-identify (Cohen-Mansfield et al. 2000), personal and social self (Sabat and Harré 1992), selfhood (Sabat 2001; Sabat and Collins 1999) and personhood (Kitwood and Bredin 1992), all of which consider the role, attributes, preferences and identities of an individual. The concept of 'selfhood' will be used in this thesis and will be referred to as 'self'. This concept embodies a social psychological approach to self and applies equal validity and importance on the psychological (personal identity and self attributes) and sociological (personal persona, social positioning and role) elements of self, therefore acknowledging the difference in selves associated to personal and social identity. This is important as it has been suggested that if any one area of identity and therefore self is weakened this can result in an 'identity crisis' (Cote and Levine 2014) and therefore a potential crisis of self. For this reason, it is vital to understand and consider all elements of self in order to have an insight into this area especially when considering people living with dementia.

As explained, the concept of selfhood considers all areas of self to provide an holistic view of that person's self, for example, the selfhood concept suggests that each individual's self is a combination of three distinct selves, self1, self2 and self3 (Sabat 2001). Self1 is associated with the personal identity of an individual, often expressed as 'me', 'myself', 'my', 'mine' and 'our'. This aspect of self is not reliant on others to exist and therefore likely to be maintained when living with dementia (Sabat 2001). Self2 on the other hand, is at risk in a way that self1 is not, as it is the consideration of a person's attributes such as humour, hobbies, abilities, skills and everyday preferences. Self2 is at risk due to the assumption held by others that cognitive impairment impedes the ability to retain existing skills and abilities as well as having the ability to learn new skills (Beard 2004). The most vulnerable of the selves is self3, this self is concerned with the different personae a person has, such as a spouse, parent, teacher or artist, for example. This self is reliant on the co-operation of others to exist and is therefore increasingly vulnerable when living with dementia (Sabat 2001).

The concept of self in connection to dementia is increasingly complex due to two opposing arguments, is self lost or maintained when living with dementia? Some suggest that loss of self is an inevitable consequence of having dementia (Cohen and Eisdorefer 2002), leading to an assumption that those with it are '*drifting towards the threshold of un-being*' (Kitwood and Bredin 1992, p.285). This viewpoint is a consequence of labelling and stigma, resulting in the perceived loss of self² and therefore self³. As a result, people with dementia are restricted by others from engaging in opportunities which may maintain the health of their self attributes (Sabat 2002). Contrastingly, Sabat and Harré (1992) argue against the prevailing assumption of loss of self as a consequence of dementia, and suggest that not only does self endure when living with dementia, but loss of self is the result of the lack of co-operation of others and if societal attitudes change, self can be maintained.

The biomedical approach to dementia can result in the labelling and stigmatisation of those with the condition, consequentially leading to the perceived loss of self and therefore an exacerbation of cognitive decline, especially around skill and ability. Therefore, the maintenance of selfhood is vital to avoid lowered self esteem, anxiety and or depression (Rusted et al. 2006; Sabat 2002). A shift away from the assumption of loss of self is required (Kontos 2004) to enable society to embrace previous, existing and new self attributes of individuals with dementia in order to maintain their selfhood. There is also a recognition that the biomedical approach ignores social work and the experiences of people with dementia, produces inadequate stage models and has led to an unbalanced reliance on medicine. This illustrates that the impact of social context is being ignored (Cheston and Bender 1999) and that there is an increased tendency to make the cognitive impairment, rather than the person, the focus (Kitwood and Bredin 1992), therefore potentially threatening the stability of selfhood and QoL.

Quality of Life and Dementia

Concepts of Quality of Life (QoL) and life satisfaction emerged in the 1950s (Landesman 1986; George and Bearon 1980) and have been used in the development of theories of ageing (Havighurst 1963; Cumming and Henry 1961) and in the assessment of medical, health and social care interventions (Willcocks et al. 2005). Today, the significance of QoL is recognised in both UK and international policy. Alzheimer Disease International (ADI) has placed significant focus on QoL for people with dementia within in its World Alzheimer's reports (2014; 2013; 2013; 2011). Likewise, the UK Prime Minister's extended 2020 Dementia Challenge (DoH, 2015)

also recognised the significance of QoL and how this can support and enhance independent community living.

The term QoL is used to refer to an individual's own evaluation of their lives, encompassing social life, financial status, work or living situation (Campbell et al. 1976). All of which are affected by a person's physical health, psychological state, level of dependence, social relationships, personal beliefs and environment (WHO 1997). However, it is widely agreed that QoL is an elusive and multidimensional concept which has no defined boundaries (Bond 1999; Brod et al. 1999), making the definition difficult to establish as it is subject to change depending on the context of how it is used, for what reason and by whom (Alzheimer's Society 2010). The most widely used definition of QoL is provided by the WHO (1997):

'An Individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.'

The concept of Health Related Quality of Life (HRQoL) is also relevant when considering those living with dementia. Whilst different to general QoL definitions, HRQoL looks *'through the perspective of a person's health status and/or impact of a person's health condition or disability'* (Alzheimer's Society 2010) to obtain an understanding of an individual's QoL. This is particularly beneficial as the experience of health and its impact on an individual's QoL can differ dramatically (Alzheimer's Society 2010). As such, this concept measures the perceptions of QoL, incorporating factors such as emotional, physical, social functioning and lifestyle (Bowling 2014). However, Farquhar (1995) suggests that for community dwelling older people, there is more to QoL than health. Due to this, exploring the QoL of those living with dementia using HRQoL concepts and measures can be problematic. The Alzheimer's Society (2010) suggests that if an individual's health status is the primary focus of their QoL, the QoL of that person is likely to deteriorate if measured objectively as it will not be true to their global perspective of their life as a whole. For this reason, HRQoL concepts will not be used in this thesis.

It is also important to note the difference between QoL and wellbeing. Whilst current usage of these concepts are intertwined and interchangeable, resulting in the main distinctions between the concepts becoming lost with no meaningful distinction between them (Langlois and Anderson 2002) and often being used to define each other (De Leo et al. 1998), they are conceptually different. Originally, Smith (1973)

suggested that wellbeing is objective in nature and should be used to explore a particular population's 'life conditions', whereas QoL refers to an individual's subjective experiences and assessments of their own life. Whilst it is acknowledged that QoL can be partially objective (Langlois and Anderson 2002) and wellbeing can have a eudaimonic focus (living a satisfying and full life) and be subjective (Deci and Ryan 2008), the conceptual differences between QoL and wellbeing are still considered to be significant (Smith 1973). Despite the lack of distinction between QoL and wellbeing, as the concept of QoL can consider both objective and subjective experiences simultaneously, when referring to QoL in this thesis, the most widely used definition of QoL (WHO 1997) will be used and will not infer wellbeing.

The growing awareness surrounding the significance and importance of improving QoL for people living with dementia (Rusted et al. 2006) is acknowledged as those with dementia generally experience a lowered QoL (Cooper et al. 2012), which can be exacerbated by community living and can lead to social isolation, reduced social networks (Krause 2006; Woods 2001; Kitwood 1997), feelings of loneliness (Routasalo and Pitkala 2003), dependency and depression (Tay et al. 2014). In the absence of a cure for a condition with no effective pharmacological treatment, it has been argued that enhancing QoL should be the primary objective in dementia care (Wimo et al. 2013). This is echoed by Selwood et al. (2005) who agree that the consideration of QoL in dementia care can make a significant difference to the lives of those living with this condition.

The importance of assessing QoL in dementia care has long been recognised (Walker et al. 1998), yet it is only recently that emerging research (Robertson 2014; Sheehan et al. 2012; Miranda-Castillo et al. 2010) has considered the subjective perspectives of those with dementia in this area. Historically, research which has been conducted with people with dementia appears to have a significant focus on HRQoL (Hodgson et al. 2014; Leach et al. 2014; Tatsumi et al. 2009; Graff et al. 2007), with people with dementia rarely the sole participant or focus of the research (Leon-Salas et al. 2013; Gómez-Gallego et al. 2012; Missotten et al. 2007). Informal and formal caregivers have been relied upon to provide knowledge about the QoL of people living with dementia (Leach et al. 2014; Bartfay and Bartfay 2013; Leon-Salas et al. 2013; Gómez-Gallego et al. 2012), with limited research considering both people with dementia and carer perspectives. Despite this, the focus of QoL in dementia research tends to be on the reduction of carer burden (Black et al. 2012), improving caregiver health and wellbeing (Leach et al. 2014) and ensuring carers are coping and increasing their knowledge of community resources (Bartfay and Bartfay 2013), in addition to gaining a sense of

control (Graff et al. 2007). In addition, current QoL research appears to be targeted at a particular 'stage' of dementia, for example some research has inclusion criteria for only those with 'mild' to 'moderate' dementia (Hodgson et al. 2014; Tay et al. 2014; Luzny 2013; Black et al. 2012; Graff et al. 2007), or those diagnosed with the Alzheimer's type of dementia (Bartfay and Bartfay 2013; Leon-Salas et al. 2013; Gómez-Gallego et al. 2012; Tatsumi et al. 2009). Despite this, it is argued that people with dementia at all 'stages' can still provide meaningful insights into their QoL (Alzheimer's Society 2010).

Whilst more research is being conducted into the QoL of those with dementia, from their perspective, this section demonstrates that QoL in the dementia field needs to continue expanding and collaborating with those with dementia to increase understanding of this area, especially as QoL extends far beyond health. Overwhelmingly, what is evident from the literature is that despite calls for those with dementia to be included in research, some still may be excluded on the basis that they are living with dementia.

Citizenship and Quality of Life

Citizenship is a concept which considers a person's role as a citizen, from a civil, political and social perspective (Marshall 1950), and advocates the belief that all people should have rights and freedom (Ignatieff 1989). However, once labelled with dementia, the Mental Capacity Act (MCA 2005) categorises this community as 'vulnerable'. Whilst the MCA is designed to protect the basic rights of citizenship through the protection of capacity, choice and control, it can be used to legitimise the removal of rights of a person with dementia, where capacity is questioned simply because of the presence of dementia (Boyle 2008), thus removing the rights of citizenship. Boyle (2008) suggests that despite the MCA, the very presence of dementia reduces opportunities for decision making in those where capacity is evident and a reduction in the expression of preferences where capacity is lacking in an individual. An additional example of the misuse of the MCA is provided by McLaughlin et al. (1997) whose research suggest that when there is a discrepancy in the decisions made between a person with dementia and carer, the decision of the former can be overridden because of the presence of dementia, which can be seen to invalidate a person with dementia's response. Whilst research on the topic of citizenship has considered people with dementia in association with research (Wilkinson 2002) and care (Brannelly 2006), it is suggested that increased concentration on citizenship research is vital for those with dementia to be seen as equal citizens (Bartlett and O'Connor 2010).

Gould (1990) suggests that a citizen is defined by participation and inclusion within one's country and/or community. Marshall's (1950, p.34) definition of a citizen is having *'A status bestowed on those who are full members of a community. All of who possess the status are equal with respect to the rights and duties which the status is endowed'*. Others argue (Bartlett and O'Connor 2007; Craig 2004) that citizenship should be a practice which relates people to their communities and is something which is achieved through maintaining a sense of participation, community belonging and personal identity. Marshall's (1950) definition is arguably the most widely used definition of citizenship, yet it has been suggested to be difficult to apply to people with dementia as it is exclusionary (Bartlett and O'Connor 2010). Whilst Bartlett and O'Connor (2010, p.37) provide an overview of the many definitions of citizenship, they offer an alternative definition which takes dementia specifically into consideration; *'social citizenship can be defined as a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and social level'*. Despite the number of or variance with these definitions, they have a common factor, that participation and inclusion in the community is a requirement of, and therefore indicator of citizenship. However, due to the symptoms attached to dementia surrounding cognition and communication, people with dementia are considered as 'passive actors' (Bartlett and O'Connor 2007), resulting in them neither being seen nor treated as active and or participating citizens (Brannelly 2011).

Barnes (1997) suggests that people with dementia need to be empowered to become active citizens. Inclusion in 'normal' societal activities can provide opportunities around decision making and wider community support which are significant indicators of social inclusion (Burchardt et al. 1999). Downs (1997) argues that people with dementia have rights, one of these rights is to have access to research, whereby their experiences and insights are explored. Creating opportunities for user involvement in research and other aspects of community living will enable people with dementia to be seen as active and contributing citizens (Bartlett and O'Connor 2007), will reduce social exclusion (Phillipson and Scharf 2004) and can could potentially impact on QoL.

User Involvement and Quality of Life

As a 'silent and excluded voice' (Wilkinson 2002), people with dementia have often been seen as unreliable participants in providing insight into the condition itself (Cotrell and Schultz 1993). Whilst this view may be outdated and those with dementia are being included in research more readily (Clare et al. 2008; Steeman et al. 2007; Hancock et al. 2006; Phinney 1998), for example in the Quality Research Community Network and the Dementias and Neurodegenerative Diseases Research Network, apprehension to collaborate with people with dementia remains present, as highlighted in Pachana et al. (2015) research. This is primarily due to stigma (Hellström et al. 2007) and a sense that information provided by people with dementia is unreliable (Smebye and Kirkevold 2012; Lloyd et al. 2006). However, despite reservations surrounding the reduced reliability of the contribution of people with dementia, it is widely argued that people with dementia do have the ability to contribute to research (Cowdell 2008; Nygård 2006) and can provide important and meaningful insights about their experiences and requirements (Bartlett and O'Conner 2007; Clare et al. 2005; Beard 2004). Similarly, others argue (Hellström et al. 2007; Dewing 2002; Cotrell and Schultz 1993) that people with dementia should be active participants, not subjects, and should be given a voice (Brooker 2007; Kitwood 1993). The Prime Minister's Challenge (DoH 2015) has acknowledged the valuable contribution that people with dementia can make to research, with others acknowledging that such involvement could validate people with dementia (Murphy et al. 2015), thus proving their capacity to participate and contribute therefore potentially creating social change (Innes and Sherlock 2004; Barnett 2000). Actively involving people with dementia in research can provide a wealth of information which has the potential to reduce stigma (Wilkinson 2002), and provide an opportunity to gain access to personal experiences which could inform service provision, policy and practice (INVOLVE 2007), but more importantly could lead to enhancements within QoL and those with the condition being acknowledged as active and contributing citizens.

Post Diagnostic Support

The recent Prime Minister's 2020 Dementia Challenge (DoH 2015) states that greater awareness of the importance of post diagnostic support following a dementia diagnosis can improve QoL and reduce care costs. Despite this recognition, funding is predominately directed into pharmacological research exploring prevention, diagnosis and treatment, with little government funding made available for non-pharmacological post-diagnostic research, which has been suggested to be more effective than

pharmacological services (Olazarán et al. 2010). Whilst community dwelling people with dementia are gaining more access to non-pharmacological interventions, research into these types of interventions need to be increased and become more robust (Olazarán et al. 2010) in order to understand and evidence the true benefit of them for those living with dementia.

Community Interventions

One of the main foci of a community intervention is *'... to create change in community infrastructure and services, norms, attitudes, beliefs and policies that would result in improved health status for community residents'* (Guttmacher et al. 2010, p.12). In relation to dementia, post diagnostic support in the form of community interventions has the potential to challenge societal perceptions of dementia and has been suggested to be of benefit for those living with the condition as they provide opportunities for peer to peer support (Mason et al. 2005), can reduce depression and increase self esteem (Leung et al. 2015), as well as amplify feelings of self efficacy (Levine and Perkins 2004). A review undertaken by Olazarán et al. (2010) exploring non-pharmacological interventions found that they have the potential to delay institutionalisation and have notable benefits associated to cognitive training and activities related with daily living. This type of intervention has also been suggested to slow the progression of dementia, reduce symptoms, enhance memory (McLaren et al. 2013; Zhou et al. 2010) and have an impact on QoL (Leung et al. 2015).

However, access to community interventions can be limited for those living with dementia and of the services that are available there is a significant focus on health. For example, many community interventions concentrate on prevention of cognitive decline through physical exercise (Kamegaya et al. 2012; Maki et al. 2012) and the importance of social interaction in the prevention of dementia (Pillai and Verghese 2009). There are also many community interventions associated with dementia but intended for carers in the form of support groups (Bartfay and Bartfay 2013; Rodriguez 2013; Stern and Munn 2010), care service interventions (Reuben et al. 2010; Dias and Patel 2009) and support health monitoring, training and education (Aguirre et al. 2014a; Parker et al. 2008). This demonstrates a need to increase the range of services which are made available to people with dementia to enable them to have choice, variety and control (Mason et al. 2005). For instance, it is acknowledged that in order to improve the QoL of people living with dementia (Ballard et al. 2001; Marshall and Hutchinson 2001) approaches to dementia care need to include psychosocial interventions.

Psychosocial interventions

Psychosocial interventions, described as an interaction between people to improve psychological and social functioning, wellbeing and cognition, interpersonal relationships and everyday functional abilities such as daily living skills (Moniz-Cook et al. 2011), are a core element of dementia research (Moniz-Cook et al. 2008). Whilst less attention has been paid to the potential of psychosocial interventions over pharmacological approaches to care (Sanders and Morano 2008), there is now a growing interest in the effectiveness of this type of intervention (Kurz et al. 2013) and how communities can benefit from them (Moniz-Cook et al. 2011). Of the services which are available for some community dwelling people with dementia, creative psychosocial interventions using art (Rusted et al. 2006), music (Wong et al. 2015) and dance (Campbell et al. 2010) for example, have been suggested to be of specific benefit. These types of intervention have been found to make a positive impact on cognitive functioning, emotional adaptation and sociability (Kydd 2001; Brotons and Koger 2000; Kamar 1997) in addition to mood and behaviour (Camic et al. 2013; Choi et al. 2009; Baker et al. 2001) and reducing the risk of falls and injury whilst increasing balance and independence in mobility (Campbell et al. 2010). Despite the recent emergence of psychosocial interventions within communities, it is acknowledged that more psychosocial interventions are needed (Leung et al. 2015; Aguirre et al. 2014b; Kurz et al. 2013; McLaren et al. 2013; Moniz-Cook et al. 2011), with increased focus on alternative types of interventions that can develop skills and knowledge (Bartlett and O'Connor 2010) and ultimately support improvements in QoL (Cooper et al. 2012) for community dwelling people with dementia.

Technology and Dementia

Split into four main areas, this section of the literature review firstly provides an introduction to the role of technology within dementia care, followed by an overview of the use of digital gaming technologies within this. The second and third areas of this section specifically focus on exergaming and touch screen technologies, whereby a background to these technologies are provided, followed by two literature reviews which focus on the Xbox Kinect (Microsoft Corp), Sony PlayStation, Nintendo Wii (Nintendo Co LTD) and Apple iPad. As can be seen in Appendix 1, specific search criteria and data bases were utilised to provide a full and informed review of the literature concerning these pieces of technology in connection to how they have been used with people with dementia to date. Finally, in the last section, the potential of

digital gaming technologies as a psychosocial intervention will be presented. The introduction into the role of technology within dementia care will now be presented.

The role of technology in enabling independent living for community dwelling people with dementia has been a steady focus of research for over a decade (Edyburn 2004; Scherer 2002; Matthews and McKenzie 2000) but has more recently been of increased interest as a result of the Alzheimer's Dementia Friendly Technology Charter (Alzheimer's Society 2014c). The focus on Assistive Technologies (AT) such as prompting devices, reminiscence tools and tracking devices, for example, has increased in response to the drive to support independent community living for people with dementia (Alzheimer's Society 2014b; Alzheimer's Disease International 2012; WHO 2012). Similarly, research concentrated on Information Communication Technologies (ICT) within dementia care has largely focused on assistive devices and surveillance technology (Olsson et al. 2012), yet more recently has been explored for its potential in promoting social contact (Nimrod 2010; 2009; Lauriks et al. 2007). Whilst ICTs and AT products claim to address QoL by enabling independent living (Evans et al. 2017; Robinson et al. 2009; Sixsmith 2006), they are not sufficiently responsive to meeting needs surrounding meaningful activities, social interaction, fulfilment and achievement (Astell 2013). Whilst this illustrates a gap in literature surrounding the QoL benefits of ATs and ICTs it highlights an even wider gap in knowledge surrounding the potential benefits of alternative technologies for community dwelling people with dementia. For example, the use of digital gaming technologies in later life has been suggested to be under researched, potentially due to the accepted assumption that older people cannot and do not want to use computers (Musselwhite et al. 2016).

Digital gaming technology and dementia

Unlike many ATs and ICTs, off the shelf commercial digital gaming technologies have not been tailored for a dementia audience, yet research has explored the role and benefits of this technology within generic healthcare in connection to prevention, therapy and assessment (McCullum 2012), in association to health conditions such as stroke, cancer, asthma, mental health and autism (Procci et al. 2013; Rahmani and Boren 2012), multiple sclerosis (Taylor and Griffin 2015), cerebral palsy (Deutsch et al. 2008) and obesity (O'Donovan and Hussey 2012). An attempt to define the use of this technology in health care has resulted in two terms being developed to identify the purpose and rationale for using digital gaming technologies. Firstly, 'serious games' are games specifically designed to achieve change in the player via knowledge, attitude, physical ability, cognitive ability, health or mental wellbeing (McCallum 2012), and

secondly 'gamification', which refers to the use of video game elements in non-video games to improve user experience (Deterding et al. 2011). Whilst there is an evident use of digital gaming technologies in connection with older adults, research exploring the role of this technology and 'serious gaming' targeted at those living with dementia is limited, yet gaining momentum (König et al. 2014). For example, 'serious gaming' has been found to have the potential to increase motor skills, decrease cognitive impairment and increase social interaction in those living with dementia (Muscio et al. 2015; König et al. 2014). However, these studies have taken a medical perspective focusing on how this technology could support medical professionals, such as doctors, nurses and dementia specialists, when caring for people living with dementia.

In general the majority of research which has been conducted is largely clinical in its focus and concentrates on prevention (Wang et al. 2012a), progression (Aurilla and Arntzen 2011), pain management and diagnosis (Rahmani and Boren 2012), spatial awareness and navigational skills (Morgan 2016), cognition (Polistico et al. 2016) and working memory (Burdea et al. 2015). Whilst a medical approach to the use of digital gaming technologies with those living with dementia has been seen to provide a sense of personal control over medical care (Aurilla and Arntzen 2011), therefore contributing to a sense of self (Hanson et al. 2007) and person centred care (Maiden et al. 2013), this approach does not consider the wider social potential of this technology. Whilst it has been shown that the use of commercially available digital gaming technologies offers a means to engage people with dementia (Cutler et al. 2016; 2014; Fenney and Lee 2010), this area of research remains largely unexplored in comparison. The role of exergaming and touch screen ICTs within dementia research will now be explored.

Exergaming and motion based technology

Exergaming is the use of motion sensors and movement tracking cameras within a games console that enable a participant to stand in front of a screen and play a game based on movement alone, without the use of handheld controllers (Aurilla and Arntzen 2011). Currently, there are three main exergaming consoles on the commercial market; the Nintendo Wii (Nintendo Co LTD), Sony PlayStation and the Microsoft Xbox Kinect (Microsoft Corp).

Although the target audience for the Nintendo Wii is nine to 18 year olds (Tobiasson 2009), research into its versatility for older audiences has been explored (Lawrence et al. 2010) and has included people living with dementia. Harley et al. (2010) suggest that the use of the Nintendo Wii could have the potential to change negative

relationships between this audience and other technologies which have traditionally been unpopular with older adults, more generally. This could be attributable to the fact that the Nintendo Wii may be more enjoyable and motivating than traditional exercise (Franco et al. 2012) or more engaging than alternative activities (Dattilo and Rusch 2010).

The Xbox Kinect and Sony PlayStation have also been introduced to support health care, in particular stroke and cancer rehabilitation (Aurilla and Arntzen 2011). However, the major difference between the Xbox Kinect and the Nintendo Wii is that the Xbox Kinect has further developed the concept of exergaming and motion based technologies by tracking movements with a camera without the use of a handheld controller. Due to this, the Xbox Kinect has been used to support people with cognitive impairments to train using repetitive movement (Chang et al. 2013) as well as executive cognitive performance (Kayama et al. 2014). However, both the Sony PlayStation and Xbox Kinect are fairly new technologies and more investigation is needed as to whether the Xbox Kinect has a positive impact on physical and cognitive abilities of people with dementia (Aurilla and Arntzen 2011) and whether the Sony PlayStation is of any benefit to a dementia audience at all.

A recent literature review undertaken by Dove and Astell (2017) provides a general and comprehensive review of the use of exergaming and motion based technology with people living dementia and mild cognitive impairment. Considering only the dementia specific studies (25 out of 31) there was a significant focus on cognition (Bamidis et al. 2015; Taillon-Hobson 2014; Tarnanas et al. 2013; De Urturi et al. 2012; Chang et al. 2011; Legouverneur et al. 2011; Yamaguchi et al. 2011; Fenney and Lee 2010; Higgins et al. 2010), physical exercise and leisure when using the Nintendo Wii, Xbox Kinect and Sony PlayStation2 (Konstantinidis et al. 2016; Cutler et al. 2014; Siriaraya and Ang 2014; Taillon-Hobson 2014; Benveniste et al. 2012; Billis et al. 2011; Higgins et al. 2010; Tobiasson 2009). However, as can be seen by Dove and Astell's (2017) review, many studies sought to explore a combination of cognitive, physical and leisure aspects when using the Nintendo Wii and Xbox Kinect (Cutler et al. 2016; Tobiasson et al. 2015; Kayali et al. 2013; McCallum and Boletsis 2013; Colombo et al. 2012; Ulbrecht et al. 2012; Boulay et al. 2011; Leahey and Singleton 2011; Chilukoti et al. 2007). Of these studies, many used commercially available technologies (Cutler et al. 2016; Tobiasson et al. 2015; Kayali et al. 2013; McCallum and Boletsis 2013; Colombo et al. 2012; Leahey and Singleton 2011; Fenney and Lee 2010), whilst some utilised tailor made technologies (De Urturi et al. 2012; Boulay et al. 2011; Yamaguchi et al. 2011; Chilukoti et al. 2007). What can be seen from Dove and Astell's (2017)

review is that of the dementia specific studies which used commercially available exergaming / motion based technologies, people with dementia found this enjoyable (Cutler et al. 2016; Tobiasson et al. 2015; Kayali et al. 2013; Colombo et al. 2012), empowering (Cutler et al. 2016; Colombo et al. 2012; Leahey and Singleton 2011), engaging (Kayali et al. 2013; Colombo et al. 2012; Leahey and Singleton 2011; Fenney and Lee 2010;), useable (Cutler et al. 2016), motivating (Fenney and Lee 2010) and meaningful (Leahey and Singleton 2011). This review concluded that motion based technologies have the potential to make a positive impact on the lives of those living with dementia regarding cognitive, physical and leisure aspects, yet it also shows that the use of commercial exergaming is still limited. What should be noted is that this review includes exergaming and motion based technologies, which spans from commercially available digital gaming technology to virtual reality assistive technologies. Literature which specifically explores the use of commercial gaming technologies (Nintendo Wii, Xbox Kinect, Sony PlayStation) will now be explored as part of a wider literature review.

Nintendo Wii, Xbox Kinect and Sony PlayStation

A specific review of the literature considering the Nintendo Wii, Xbox Kinect and Sony PlayStation directly in relation to people living with dementia (search terms and criteria: Appendix 1), has identified that whilst research in this area is gaining momentum, it is still limited. In consideration of this growing area of research two papers have provided literature reviews which consider elements of digital gaming technologies (Dove and Astell 2017; McCallum and Boletsis 2013). Whilst the findings of Dove and Astell (2017) have been explained in the previous section, the findings of McCallum and Boletsis (2013) also show that this area of research needs greater investigation.

Of the studies which were not focused on literature reviews, research exploring the benefits of individual exergaming and motion based consoles has overwhelmingly been dominated by the Nintendo Wii (Table 2), which has been used in two main ways. Of the 19 research projects using the Nintendo Wii, 17 used this technology with commercially available games (Wii Fit, Wii Fit balance board, Wii Sports (bowling and tennis) and brain training games) (Padala et al. 2017; Mukerjee 2017; Cutler et al. 2016; Lee 2016; Splithof and Vries 2016; Tobiasson et al. 2015; Cutler et al. 2014; Phillippe 2013; Yoon et al. 2013; Padala et al. 2012; Ryder-Jones et al. 2012; Ulbrecht et al. 2012; Leahey and Singleton 2011; Legouverneur et al. 2011; Fenney and Lee 2010; Tobiasson 2009), and two used specifically tailored equipment using elements of the Nintendo Wii controller (Benveniste et al. 2012; Boulay et al. 2011). Participant

criteria and sampling for research concentrating on the Nintendo Wii has ranged from community dwelling participants (including those living in assisted living accommodation) (six studies), to those in formal care facilities such as hospitals, care homes or other special housing (seven studies). Of these, there is also an emphasis on diagnosis, with many criteria placed on this. Whilst four studies (Cutler et al. 2016; Splithof and Vries 2016; Cutler et al. 2014; Ulbrecht et al. 2012) appear to have only a diagnosis of dementia as a criterion, the remaining specify a requirement for a diagnosis of Alzheimer's disease (mild to moderate / mild to severe / moderate to severe dementia), having lived with dementia for a number of years, early onset dementia or specific MMSE scores. Of the community dwelling specific research, only two studies (Cutler et al. 2016; 2014) required no other criteria other than a dementia diagnosis.

Another interesting element of the literature was the motivation to undertake the research. Of the Nintendo Wii specific research, the focus was on improving cognitive function (Cutler et al. 2016; Splithof and Vries 2016; Tobiasson et al. 2015; Yoon et al. 2013; Boulay et al. 2011; Leahey and Singleton 2011; Legouverneur et al. 2011; Fenney and Lee 2010), physical function or falls prevention (Padala et al. 2017; Mukherjee 2017; Lee 2016; Cutler et al. 2016; Tobiasson et al. 2015; Yoon et al. 2013; Padala et al. 2012; Tobiasson 2009), promotion of leisure activities (Cutler et al. 2016; Tobiasson et al. 2015; Cutler et al. 2014; Benveniste et al. 2012; Ryder-Jones et al. 2012; Ulbrecht et al. 2012; Boulay et al. 2011; Tobiasson 2009), improving self-image (Padala et al. 2017; Benveniste et al. 2012), reducing behavioural symptoms (Benveniste et al. 2012), and addressing healthy ageing and QoL (Cutler et al. 2016; Lee 2016; Philippe 2013). Overall, the literature shows that the main motivation for conducting research with the Nintendo Wii and people with dementia is to test and or improve cognitive and physical function. Research aimed at improving cognitive function recognised the need to keep the brain active through brain training and the ability to learn new motor skills or play new games. Studies considering physical function were particularly focused on improving physical ability through balance and walking to reduce the occurrence of falls, as can be seen in Table 2.

Interestingly, the motivation for research focusing specifically on community dwelling people with dementia also concentrates on physical function, falls prevention (Mukherjee 2017; Padala et al. 2017; 2012) and cognitive function (Cutler et al. 2016), in addition to healthy ageing (Cutler et al. 2016), and promotion of leisure activities (Cutler et al. 2014; Ryder-Jones et al. 2012). As can be seen, the focus on community dwelling people with dementia has only been conducted by five research studies,

indicating that research on community dwelling people with dementia needs to be expanded. It should also be noted that no study considered the role of QoL for community dwelling people with dementia.

An additional element which should be highlighted is the structure of the research studies. Nine studies conducted the research using a number of individual participants alone, seven used the technologies as part of a group activity, three used a mixture of group and individual participants and one used a single research participant. Of the three studies which concentrated on group activities with community dwelling people, the main motivations were promoting healthy ageing, cognitive and physical function (Cutler et al. 2016) and leisure activities (Cutler et al. 2016; 2014; Ryder-Jones et al. 2012).

Considering the Sony PlayStation and Xbox Kinect, only two studies considered the role of the Sony PlayStation with people living with dementia (Colombo et al. 2012; ACM 2006). Both studies focused on cognitive function, with Colombo et al. (2012) also considering the promotion of leisure activities with people living with mild to moderate dementia. It is interesting to note that these studies used individual participants, highlighting how research involving the Sony PlayStation is within its infancy, and has not yet been used within a group setting in the same way as the Nintendo Wii and Xbox Kinect. Interestingly no studies considered the role of the Xbox Kinect alone. However, five studies did use the Xbox Kinect as part of the research along with the Nintendo Wii (Cutler et al 2016; Tobiasson et al. 2015; Cutler et al. 2014; Phillippe 2013; Ulbrecht et al. 2012). These studies have been discussed as part of the wider Nintendo Wii literature review. The next section will discuss the findings of these research studies.

What has been found?

As can be seen in Table 2, the review of the literature has established two main areas of findings, those associated with personal experience and those resulting from further in-depth analysis. From a personal perspective, the findings show that people with dementia found the use of the technologies to be engaging and fun (Dove and Astell 2017; Mukherjee 2017; Cutler et al. 2014; Benveniste et al. 2012; Colombo et al. 2012; Padala et al. 2012; Fenney and Lee 2010; Tobiasson 2009). In general, it is reported in many studies that people with dementia enjoyed the experience of using the technologies and what they allowed the participants to do and achieve (Dove and Astell 2017; Mukherjee 2017; Cutler et al. 2016; Tobiasson et al. 2015; Cutler et al. 2014; Benveniste et al. 2012; Colombo et al. 2012; Tobiasson 2009). It was also reported that some felt that they were empowered by the technologies (Cutler et al. 2016; Colombo

et al. 2012), motivated to engage more fully with their everyday lives (Lee 2016; Fenney and Lee 2010), and felt a level of independence as a result of using the technologies (Cutler et al. 2016).

From an analytical perspective, the literature has identified that primarily, people with dementia are able to use these technologies (Cutler et al. 2016; Cutler et al. 2014; Benveniste et al. 2012; Colombo et al. 2012; Padala et al. 2012; Ulbrecht et al. 2012; Boulay et al. 2011). It has also been established that using the technologies can help improve physical function, in particular falls prevention and reducing the fear of falling (Mukherjee 2017; Padala et al. 2017; Lee 2016; Yoon et al. 2013; Padala et al. 2012), in addition to improving physical health for fun, health promotion and general wellbeing (Cutler et al. 2016; Tobiasson et al. 2015; Tobiasson 2009). Similarly, the literature review has identified improvements to the cognitive function of people living with dementia. This includes general mental stimulation (Tobiasson et al. 2015; Colombo et al. 2012), especially through the promotion of lifelong learning and the ability to develop new skills (Cutler et al. 2016; Leahey and Singleton 2011), the acquisition of skills to use in an everyday context (McCallum and Boletsis 2013; Yoon et al. 2013), in relation to improvements to memory (Legouverneur et al. 2011; Fenney and Lee 2010; AMC 2006) and general cognitive ability (Splithof and Vries 2016; Ulbrecht et al. 2012). There was also evidence of general social stimulation as a result of engaging with the technologies (Mukherjee 2017; Cutler et al. 2016; Tobiasson et al. 2015; Ryder-Jones et al. 2012), this included encouraging conversation, the importance of being with others, and being a general catalyst for conversation. Of the studies considering group activities for community dwelling people with dementia (Cutler et al. 2016; 2014; Ryder-Jones 2012), the findings reveal that there was a general acceptability of the technologies (specifically the Nintendo Wii and Xbox Kinect), that engagement promoted mental, social and physical stimulation and empowerment, that as leisure activities they were considered fun, enjoyable and engaging, which promoted lifelong learning, and independence.

Overall, it has been found that these technologies can support and contribute to healthy ageing (Cutler et al. 2016) and generally improve the everyday lives of people living with dementia (Dove and Astell 2017). Specially, Lee (2016) used a Korean version of the Quality of Life–Alzheimer Disease Scale (KQoL-AD) to explore QoL benefits of exergaming and found that in general this technology impacted on depression and QoL through the improvement of balance and general emotion. Similarly a study conducted by Splithof and Vries (2016) also identified that the Nintendo Wii in particular showed improvements to psychosocial health and behaviour.

However, as can be seen, literature to date has not explored the wider impacts of using this technology on QoL.

In summary

To summarise, this literature review, considering the role of the Nintendo Wii, Xbox Kinect and Sony PlayStation, has provided an overview of research to date as well as highlighting gaps within the literature. In general, of the research conducted, few use more than one piece of technology in any one research project at one time, most are focused on those residing in formal care facilities, and the majority of research has criteria specifically around participants with Alzheimer's disease or with specific MMSE scores. This highlights a gap in the approach taken to this area of research, as research conducted with community dwelling people with dementia with just the criteria of dementia is limited. Therefore, this could contribute to exclusion from research if very specific criteria are required to take part in such interventions. The literature has also highlighted that overwhelmingly the Nintendo Wii is the most used piece of technology within research to date, with only two studies using the Sony PlayStation and no study solely using the Xbox Kinect. Whilst the use of motion based technology and the Xbox Kinect is gaining momentum, as illustrated by Dove and Astell (2017), this piece of technology needs to be explored and used more extensively.

Whilst the focus of the research conducted appears to be fairly extensive in terms of its scope, from cognitive and physical function to healthy ageing and self-improvement, the majority of the studies use quantitative approaches. Of the studies which are solely focused on community dwelling people with dementia, the main motivations of these studies are promoting healthy ageing, cognitive and psychical function and leisure activities. This highlights a lack of research considering QoL and the role of this technology on community dwelling people with dementia. Whilst it is acknowledged that two studies do explore QoL, these are international papers, quantitative in nature, focused on Health Related QoL (HRQoL) (Philippe 2013), and using a Korean version of the QoL-Ad (Lee 2016). Lee's (2016) work was conducted with people living with dementia in a care centre, and it is unclear where the participants resided with Philippe's (2013) research. This highlights a gap in literature as no research has been conducted into the QoL benefits of digital gaming technology specifically concerning community dwelling people with dementia at all.

The findings from this literature review highlight that people with dementia are able to use these technologies, enjoy using and engaging with them, and found them to be empowering. In general, the findings illustrate that the use of such exergames can

support physical and cognitive function, and mental, physical and social stimulation. Of the research considering group activities for community dwelling people with dementia, the findings reveal that there was acceptability of the technologies (specifically the Nintendo Wii and Xbox Kinect), that engagement with the technologies promoted mental, social and physical stimulation, and as leisure activities, they were considered fun, enjoyable and engaging, which promoted lifelong learning, independence and empowerment.

This part of the literature review has highlighted that from an exergaming perspective, with particular reference to the Nintendo Wii, Xbox Kinect and Sony PlayStation, there are gaps in the literature surrounding methods and approach to research, community dwelling people with dementia, QoL and the use of more than one technology simultaneously. The following section will now explore the role of touch screen technologies in dementia research.

Table 2: Literature Review of Digital Gaming Technologies - Exergaming

Author	Country of research	Focus and Motivation	Participant Criteria	Technology	Structure	Main findings
Benveniste et al. 2012	Undisclosed	Improve self-image / reduce behavioural symptoms / promotion of leisure activities	Hospital patients / Alzheimer's disease and other dementias (mild to moderate)	Serious Game - MINWii (Music) / elements of Nintendo Wii	Group / Individual	Participants able to use interface / strong interest in MINWii / fun / enjoyable / engaging
Boop et al. 2017	Undisclosed	Falls prevention via exercise programme	Community dwelling / Alzheimer's disease (mild)	Nintendo Wii: Wii Fit	Individual Participants	Improvements in balance and reduction in fear of falling
Boulay et al. 2011	France	Improve self-image / cognition function / promotion of leisure activities	Long term care facility / Alzheimer's disease (mild to severe)	Serious Game - MINWii (music) / elements of Nintendo Wii	Group / Individual	Useable technology / satisfaction with technology / positive interaction with caregivers / reminiscence
Colombo et al. 2012	Italy	Cognition function / promotion of leisure activities (acceptability of the technology and games)	Dementia (mild to moderate)	PlayStation2: Eyetoy	Individual Participants	Empowering / useable / enjoyable / engaging / cognitive improvement
Communications of the ACM (Riding the Brain Train)	Japan	Cognitive function (encourage brain training to improve memory)	Older people / Dementia	PlayStation: Quiz games	Individual Participants	Memory improvement
Cutler et al. 2016	UK	Healthy ageing benefits / cognition function / physical function / promotion of leisure activities	Community dwelling / Dementia	Nintendo Wii / Xbox Kinect	Group Activity	Contributes to healthy ageing / physical, mental and social stimulation / independence / empowering / useable / enjoyable / promotes lifelong learning
Cutler et al. 2014	UK	Promotion of leisure activities (acceptability of technology / enjoyment / engagement)	Community dwelling / Dementia	Nintendo Wii / Xbox Kinect	Group Activity	Technologies are understood and can be used by those with dementia / fun / enjoyable / engaging

Author	Country of research	Focus and Motivation	Participant Criteria	Technology	Structure	Main findings
Dove and Astell 2017	N/A	Literature review (motion based technology)	Dementia and MCI	Nintendo Wii / Xbox Kinect	N/A	Enjoyment / ability to engage / potential to improve lives
Fenney and Lee 2010	Canada	Cognition function (ability to learn new motor skills)	Dementia (duration 2 - 5 years)	Nintendo Wii: Wii Sports (bowling)	Group Activity	Improvements in scores and memory for the game / motivating / engaging
Leahey and Singleton 2011	Canada	Cognition function / promotion of leisure activity	Alzheimer's disease	Nintendo Wii: Wii Sports (bowling)	One Individual Participant	Access to familiar and meaningful activities and ability to master new skills / caregiver benefits
Lee 2016	Korea	Falls prevention (improve balance), emotion and quality of life. Korean version of quality of life- Alzheimer's disease (KQOL-AD)	Dementia Care Centre / MCI or Dementia (mild)	Nintendo Wii: Wii Fit (balance board) / Wii Sports	Individual Participants	Improved balance, depression and QoL / increase engagement in daily living activities
Legouverneur et al. 2011	Undisclosed	Cognition function (ability to learn to play games)	MCI and Alzheimer's disease (mild to moderate)	Nintendo Wii: Wii Sports (Bowling / Tennis)	Group Activity	Preserved memory (motor and cognitive skills)
McCallum and Boletsis 2013	N/A	Literature review (serious games)	Dementia	Nintendo Wii: Wii Fit / Wii Sports / Brain training games	N/A	Experience using dementia specific serious games are transferable to other daily activities
Mukherjee 2017	USA	Falls prevention (improve balance and gait) (Clinical Trial)	Community dwelling / Alzheimer's disease	Nintendo Wii: Wii Fit (balance board)	Individual Participants	Balance and social improvement / enjoyment / enthusiasm / engagement
Padala et al. 2012	Undisclosed	Falls prevention (improve balance and gait) exercise programme	Assisted living facility / Alzheimer's disease (mild)	Nintendo Wii: Wii Fit	Individual Participants	Improvements in balance and gait compared with traditional walking programmes / useable / engaging

Author	Country of research	Focus and Motivation	Participant Criteria	Technology	Structure	Main findings
Philippe (PI) 2013	France	HRQoL (focus on balance and gait) (Clinical Trial)	Dementia and MCI	Nintendo Wii / Xbox Kinect	Individual Participants	Under investigation
Ryder-Jones et al. 2012	Undisclosed	Promotion of leisure activities (acceptability - how Wii technology enlived a club for people living with young onset dementia)	Community dwelling / Early onset dementia	Nintendo Wii	Group Activity	Encouraged social participation
Splithof and Vries 2016	Holland	Exergames for health promotion (cognitive function)	Nursing home / dementia	Nintendo Wii	Individual Participants	Improvement in psychosocial health / cognitive ability and behaviour
Tobiasson et al. 2015	Undisclosed	Physical function (for wellbeing) / cognition function / promotion of leisure activities	Dementia care unit / Dementia (moderate to severe)	Nintendo Wii / Xbox Kinect	Group Activity	Enjoyment of games and competition / physical, social and cognitive stimulation
Tobiasson 2009	Sweden	Physical function / promotion of leisure activities	Special housing / Dementia (severe)	Nintendo Wii	Group / Individual	Access to be physically active / fun / enjoyable
Ulbrecht et al. 2012	Undisclosed	Promotion of leisure activities (acceptability / enjoyment / pleasure of games)	Nursing home / Dementia	Exergames (Nintendo Wii / Xbox Kinect)	Individual Participants	Slight cognitive improvement / general acceptability of exergames
Yoon et al. 2013	Undisclosed	Physical / cognitive function (effectiveness of cognitive activity combined with physical exercise)	Dementia diagnosis (MMSE score 16 - 23)	Nintendo Wii: Wii Fit (balance board)	Group Activity	Improve balance and strength / ability to acquire effective skills relevant to daily living

Touch Screen ICTS

As discussed, ICT technologies are usually considered assistive technologies, either as assistive devices or for surveillance (Olsson et al. 2012). However, ICT technologies have increasingly been seen to include the use of touchscreen technologies. There are many variations of ICT touchscreen technologies (Apple iPad, Apple iPod, Samsung Galaxy tablet, Motorola XOOM and Asus Eee Pad), whereby the user is able to navigate around a computer without the need of a mouse or key pad.

Whilst touchscreen ICT technologies are used in health care, and the benefits of these from a clinical and medical perspective have been noted (Joddrell and Astell 2016; Marceglia et al. 2012), benefits to those receiving care are now emerging. As touchscreen ICT technologies provide access to the internet, this medium has been used by older adults to access social network sites, family trees, photo albums, games and virtual hobbies (Nimrod 2010). Whilst it might be accepted that younger audiences are more likely to be users of touchscreen technologies, research has also shown that engagement in different activities is rewarding, satisfying and has a positive impact on health and wellbeing of older people (Singh-Manoux et al. 2003).

Touchscreen technology is suggested to be particularly accessible for people living with dementia as they are easy to use and provide access to an 'unlimited library' of resources (Lloyd-Yeates 2013b). In addition, Newall et al. (2002) suggest that ICT technologies promote QoL for people with dementia, as they enable the person to retain independence and control, remain physically and mentally active and reduces social isolation. Research has begun to explore the potential of ICT technologies. For example, Astell et al.'s (2009) created a series of computer based games which used a touchscreen called Living in the moment (LIM). This was a series of games designed and created specifically for a dementia audience. Over the years Astell et al. (2009; 2013; 2014) research has established that people with cognitive impairment (due to dementia) can learn to play these tailor made games independently. Astell et al. (2016) have also established that whilst this community are able to use and play games independently, people with dementia also enjoyed using touch screen equipment and can do so with minimal assistance. Whilst, research has explored the potential health benefits for people with dementia when engaging with such technologies (Leng et al. 2014; Upton et al. 2011), a review of touchscreen technologies in relation to people with dementia (Joddrell and Astell 2016) found that the focus of such technology is primarily for assessment and screening (as an assistive technology), and whilst the

potential of touchscreens as a leisure activity has been explored, more research is required in this area.

Apple iPads

Unlike mobile phones and other touchscreen devices, iPad touchscreens are larger, more portable and increasingly user friendly (Marceglia et al. 2012). Research focusing on iPad tablets and dementia has predominately considered this technology's role in diagnosis (Onoda and Yamaguchi 2014) and care support (Maiden et al. 2013). The creation of games or applications (apps) for the iPad, with a dementia specific audience, has become of increased interest (Astell et al. 2016; Joddrell et al. 2016; Manera et al. 2015; Memory Apps for Dementia; Alive Charity), especially in the creation of tailor made apps which focus on memory, person centred care (Lloyd-Yeates 2013a; 2013b) and cognitive exercise. Joddrell et al. (2016) noted that of the two million available apps for the iPad and in consideration of the growing repository of apps specifically for the dementia market, people with dementia find these difficult to use and find, and therefore easier navigation for apps within app stores are required. Despite this, it has been suggested that the iPad is particularly well placed to respond to people with dementia as this technology has the ability to react to personal choice, can be used independently (Lloyd-Yeates 2014), is easily adapted (Leng et al. 2014) and is versatile to any activity (Lloyd-Yeates 2013b), through one portal (Evans et al. 2017). Enabling access to the internet through this technology is also thought to be of benefit for people with dementia as it has the ability to serve and influence personal choice, addressing wellbeing needs (Nasi et al. 2012) and can act as a 'gateway' to the past, present and future (Lloyd-Yeates 2014).

A specific review of the literature considering the Apple iPad directly in relation to people living with dementia (search terms and criteria: Appendix 1) has identified that this area of research is limited. In consideration of the growing area of research three papers have provided literature reviews (Schikof et al. 2017; Tyack and Camic 2017; Joddrell and Astell 2016) which compared and synthesized general touchscreen research to date. Overall, these papers found that more research is required in this area. Of the studies which were not focused on literature reviews (Table 3), 21 research studies which have explored the Apple iPad were predominately focused on either cognitive function or the promotion of leisure activities. Ten studies (Evans et al. 2017; Groenewoud et al 2017; Astell et al. 2016; Cutler et al. 2016; Astell 2014; Cutler et al. 2014; Leng et al. 2014; Schikhof et al. 2014; Tyack et al. 2014; Upton et al. 2013) focused on the promotion of leisure activities. The potential of the iPad to promote

leisure activity considered the acceptability, familiarity, engagement potential, possibility of enjoyment and experiences of using the iPad. Some studies also used promotion of a leisure activity to explore QoL, carer wellbeing and general access to meaningful activities (Groenewoud et al. 2017; Tyack et al. 2015; Leng et al. 2014; Schikhof et al. 2014). Nine studies (Critten and Kucirkova 2017; Kong 2017; Cutler et al. 2016; Cardulla et al. 2015; Kong 2015; Pang and Kwong 2015; Tomori et al. 2015; Cho et al. 2014; AlMazura et al. 2013) focused on the cognitive function impact of using the iPad. The foci of these studies included memory stimulation, cognitive decline, cognitive exercise and rehabilitation concentrating on reminiscence, cognitive training and sensory stimulation. Finally, two studies (Cutler et al. 2016; Leng et al. 2014) identified a motivation to explore healthy ageing benefits of the iPad.

Of the 21 studies (excluding literature reviews and produced frameworks), six used dementia specific iPad apps (Cardulla et al. 2015; Tomori et al. 2015; Astell 2014; Cho et al. 2014; Schikhof et al. 2014; AlMazura et al. 2013), whilst the remaining studies utilised commercially available apps (dominoes, card games, camera, art and music, life histories, brain training). Few studies utilised apps such as BBC news, Google Earth and YouTube (Cutler et al. 2016; Cutler et al. 2014) or Skype (Evans et al. 2017). Table 3 highlights a gap in the exploration of the use of both commercially available and dementia specific apps for the iPad. Of the studies which utilised commercially available apps, eight primarily focused on the potential of the iPad as a mechanism to promote leisure activities (Evans et al. 2017; Groenewoud et al. 2017; Astell et al. 2016; Cutler et al. 2016; Tyack et al. 2015; Cutler et al. 2014; Leng et al. 2014; Upton et al. 2013), four considered cognitive functioning (Critten and Kucirkova 2017; Kong 2017; Cutler et al. 2016; Kong 2015), and two considered healthy ageing (Cutler et al. 2016; Leng et al. 2014), using general games, BBC news, Google Earth, YouTube, art and music, camera and Skype apps.

As can be seen in Table 3, similar to the findings of the exergaming literature review, participant criteria and sampling ranged from community dwelling participants (including assisted living) (nine studies), to people with dementia in formal care settings (five studies), with an emphasis on diagnosis. Whilst 11 studies (Evans et al. 2017; Groenewoud et al. 2017; Schikof et al. 2017; Astell et al. 2016; Cutler et al. 2016; Cardulla et al. 2015; Astell 2014; Cho et al. 2014; Cutler et al. 2014; Leng et al. 2014; Upton et al. 2013) appeared to require only a diagnosis of dementia, the remaining studies required specific criteria to be fulfilled. This included a diagnosis of Alzheimer's disease, (mild or early stage / early stage / moderate to mid stage / mid to moderate), a

diagnosis within four years, specific MMSE scores, certain levels of education and no serious co morbidities. Two studies (Kong 2017; Upton et al. 2017) also consider the role of carers in addition to those with dementia in their research. An additional interesting element of the literature review is the structure of the research studies. Seven studies conducted the research as activities for individuals, seven were focused on group activities, with one considering both individual and group activities and another focusing on the person with dementia and carer dyad. It should be highlighted that of these studies only four (Astell et al. 2016; Cutler et al. 2016; 2014; Leng et al. 2014) focused on group activities for community dwelling people with dementia. The main motivations for these studies were promotion of a leisure activity (Astell et al. 2016; Cutler et al. 2016; 2014; Leng et al. 2014), followed by healthy ageing (Cutler et al. 2016; Leng et al. 2014) and cognitive function (Cutler et al. 2016). This identifies a gap in research on the use of the iPad in a group setting for community dwelling people with dementia. It also highlights that there is no research focused on the potential QoL impact of the iPad.

What has been found?

As can be seen in Table 3, the review of the literature has established that the findings of these studies are also in two parts, those connected to personal experience and those the result of further in-depth analysis. From the participants' personal perspective, the findings have shown that people with dementia have found using the iPad enjoyable, fun, empowering, useable and have had an overall positive experience (Evans et al. 2017; Groenewoud et al. 2017; Kong 2017; Astell et al. 2016; Cutler et al. 2016; Cutler et al. 2014; Schikhof et al. 2014). From a more analytical perspective, the literature has highlighted that the use of iPads engage and support people with dementia (Evans et al. 2017; Schikhof et al. 2017; Cho et al. 2014; Cutler et al. 2014; Upton et al. 2013), and that people with are able to understand, and want to use and learn how to use the iPad (Joddrell and Astell 2016; Astell 2014; Cho et al. 2014; Cutler et al. 2014). In addition, literature has established that the iPad promotes independence (Cutler et al. 2016; Astell 2014; Schikhof et al. 2014), has a cognitive impact on areas including mood, memory and attention (Cardulla et al. 2015; Tyack et al. 2015), as well as promoting lifelong learning (Cutler et al. 2016), and an opportunity for social stimulation (Evans et al. 2017; Cutler et al. 2016), especially around family relationships (Tyack et al. 2015). Four studies identified that activities on the iPad are as engaging, meaningful and as effective as alternative activities (Groenewoud et al. 2017; Schikhof et al. 2017; Tomori et al. 2015; Cho et al. 2014; Leng et al. 2014). However, it has been found that familiarity of activities when connected to apps on the

iPad does not guarantee successful usage (Astell et al. 2016). Therefore careful consideration surrounding the suitability, usability and accessibility of the activity (apps) are matched to those using the technology (Groenewoud et al. 2017; Schikof et al. 2017). In addition, from a more clinical perspective, literature has found that the iPad can supplement clinical interventions such as behavioural training techniques (Kong 2017; 2015) and can encourage and enable decision making (Tomori et al. 2015). Overall, it has been highlighted that the iPad contributes to healthy ageing (Cutler et al. 2016), and whilst such technologies are less typically owned by people with dementia and therefore may contribute to a 'digital divide' in healthcare (Marceglia et al. 2012), access to iPads can also ensure digital inclusion for those with dementia (Evans et al. 2017).

Whilst healthy ageing benefits have been acknowledged (Cutler et al. 2016), what has not been considered is the impact on QoL and wellbeing despite three studies (one literature review) exploring it (Groenewoud et al. 2017; Tyack and Camic 2017; Tyack et al. 2015). Tyack and Camic (2017) found that overall, touchscreen technology in general (not solely iPads) have the potential to make an impact on the psychological wellbeing of people with dementia. Groenewoud et al. (2017) considered QoL through the promotion of leisure activities, however this study did not use any QoL measure, and found that it was challenging to determine if involvement in leisure activities made an impact on the QoL for people with dementia, therefore highlighting a gap in this area of knowledge. Similarly, Tyack et al. (2015) also considered wellbeing when using the iPad using the QoL-Ad tool. However, this tool was used to explore the QoL benefits of viewing art (using a dementia specific app) and not as a result of using the iPad more widely.

In summary

To summarise, this literature review considering the role of the Apple iPad has provided an overview of research to date as well as highlighting gaps in the literature. Overall, the review has established that the iPad has been utilised for a variety of purposes, mainly concerning the promotion of leisure activities, and the iPads role in the rehabilitation of cognitive function, using a variety of apps. However, the review has established that whilst much research has utilised commercially available apps, the range of apps used are limited. Whilst some studies have focused on the application of the iPad as a piece of technology in itself and found that in general people with

dementia can and want to use it, it is the apps on the iPad which seem to be of focus, therefore highlighting a further gap in the literature.

The review has also established that similarly to research conducted with exergames, there are few studies that require a diagnosis of dementia as the only criteria for participation. In addition, whilst research conducted with individuals and in groups is fairly equal, there is an obvious gap within research conducted with community dwelling people with dementia in a group setting. The biggest gap highlighted from this review is the lack of focus on QoL and the potential impact of the iPad on community dwelling people with dementia, further evidencing the need for research to be conducted in this area.

Gaming technology as a psychosocial intervention

Overall, this literature review highlights the potential of digital gaming technology for people living with dementia and has illustrated that whilst research into the use of such technologies for people with dementia is increasing, it is still in its infancy and is therefore fairly limited. Of the research which has been conducted, there is a significant clinical and medical focus, with limited consideration of the potential social benefits for community dwelling people with dementia. It has been demonstrated that commercially available digital gaming technologies, especially the Nintendo Wii and Apple iPad can contribute to healthy ageing (Cutler et al. 2016), which has been defined as *'the process of optimising opportunities for physical, social and mental health to enable older people to take an active part in society without discrimination and to enjoy an independent and good quality of life'* (SNIPHR 2006, p.8), yet despite this, few studies focus on computer based activity groups for people with dementia (Lauriks et al. 2007). Additionally, whilst some research has begun to delve into the QoL benefit of gaming technology (Groenewoud et al. 2017; Tyack et al. 2017; Ijsselsteijn et al. 2007), this has not progressed beyond older adults or in consideration of the wider aspect of QoL. This highlights a gap within the literature and therefore knowledge surrounding the potential QoL benefits of digital gaming technology for community dwelling people with dementia.

Table 3: Literature Review of Digital Gaming Technologies – Apple iPad

Author	Country of research	Focus and Motivation	Participant Criteria	Technology	Structure	Main findings
AlMazura et al. 2013	Undisclosed	Cognitive function (monitoring memory decline)	Alzheimer's disease	iPad (apps: dementia specific - Monitoring Memory Streams (MMS))	N/A	MMS app has potential to be a reminiscence therapy technique
Astell et al. 2016	Undisclosed	Promotion of leisure activities (acceptability / familiarity / engagement / enjoyment)	Community dwelling and Local care facilities / Dementia	iPad (apps: Solitaire and Bubble Explode)	Group activity	Enjoyable / familiarity not ensure successful playing
Astell 2014	Undisclosed	Promotion of leisure activities (engagement)	Dementia	Touchscreen (apps: dementia specific - garden, art, fairground)	Individual activity	Participants can learn to play / promotes independent play
Cardulla et al. 2015	Italy	Cognitive function (rehabilitation)	Dementia	iPad (apps: dementia specific)	Individual activity	Impact on cognition (appreciation and efficacy)
Cho et al. 2014	Taiwan	Cognitive function (rehabilitation: reminiscing, cognitive training, reality orientation, sensory stimulation)	Dementia	iPad (apps: dementia specific - Memoir Monopoly)	Group activity	Increased engagement / willingness to play iPad reminiscence games compared with paper based versions
Critten and Kucirkova 2017	UK	Cognitive function (stimulate memory)	Housing association / Dementia (mild to moderate)	iPad (apps: Our Story / camera)	Group activity	'Our Story' app enables participants to store, access and generate memories / highlights the importance of personalisation in apps

Author	Country of research	Focus and Motivation	Participant Criteria	Technology	Structure	Main findings
Cutler et al. 2016	UK	Healthy ageing benefits / cognition function / physical function / promotion of leisure activities	Community dwelling / Dementia	iPad (apps: BBC news / Google Earth / YouTube / arts and music / camera)	Group activity	Contributes to healthy ageing / physical, mental and social stimulation / independence / empowering / useable / enjoyable / promotes lifelong learning
Cutler et al. 2014	UK	Promotion of leisure activities (acceptability of technology / enjoyment / engagement)	Community dwelling / Dementia	iPad (apps: BBC news / Google Earth / YouTube / arts and music / camera)	Group activity	Technologies are understood and can be used by those with dementia / fun / enjoyable / engaging
Evans et al. 2017	UK	Promotion of leisure activities (experiences)	Care home / People with dementia / Care staff / Family	iPad (apps: art / Skype / games / film and song)	Individual and group activity	Promotes engagement and digital inclusion for in all participants
Groenewoud et al. 2017	Holland	Promotion of leisure activities (influence QoL)	Day centre / Dementia / No visual impairment, severe physical disability or apraxia	iPad (apps: Draughts / Dominoes / Solitaire / music and art / shopping / pets / soccer - some dementia specific)	Individual activity	Ability to play casual games as a meaningful activity / Importance surrounding need to match the game to the skills, interests and ambitions / Positive experiences
Joddrell and Astell 2016	N/A	Literature review (synthesize existing literature)	N/A	N/A	N/A	Ability to use touchscreen technology
Joddrell et al. 2016	N/A	Produce a shareable framework that can be used to identify available touchscreen apps suitable for people living with dementia	Dementia	Touchscreen (incl. iPads) and apps	N/A	A framework has the potential to be a valid method to identify accessible and suitable apps for people living with dementia

Author	Country of research	Focus and Motivation	Participant Criteria	Technology	Structure	Main findings
Kong 2017	USA	Cognitive function (exercise)	Community dwelling / Alzheimer's disease (mid or early stage dementia) / Level of education (High school)	iPad (apps: brain training / puzzle games / art)	Group activity	General interest, satisfaction and willingness from participants / iPad apps can be used as behavioural training techniques
Kong 2015	USA	Cognitive function (exercise)	Dementia (early stage or mild)	iPad (apps: brain training / puzzle games / art)	Individual activity	iPad can supplement clinical interventions
Leng et al. 2014	Australia	Promotion of leisure activities / healthy ageing (increase positive emotions)	Community dwelling / Dementia / No serious co-morbidities	iPad (apps: cooking and craft)	Group activity	iPad group activities can be as engaging as other conventional activities
Pang and Kwong 2015	Hong Kong	Cognitive function (rehabilitation: review of app development)	Dementia (early stage)	iPad	N/A	Apps can be developed for those living with dementia
Schikof et al. 2017	UK / Netherlands / Canada	Literature review (comparing recent reviews)	Community dwelling / Long term care / Dementia	iPad and apps	N/A	Engagement /access to meaningful activities / Overall suitability, usability and accessibility of apps need to be considered
Schikhof et al. 2014	Undisclosed	Promotion of leisure activity (meaningful activity / sense of self-achievement)	Community centre / Nursing home / Alzheimer's disease (moderate to mid stage)	iPad (apps: dementia specific)	Individual activity	Enjoyment / Enables independence
Tomori et al. 2015	Japan	Cognitive function (rehabilitation) / promotion of leisure activities	Long term care / Dementia (MMSE 0 - 30)	iPad (app: dementia specific - Aid for decision (ADOC))	Individual activity	ADOC provides an alternative activity / Encourages shared decisions

Author	Country of research	Focus and Motivation	Participant Criteria	Technology	Structure	Main findings
Tyack and Camic 2017	UK	Literature review (review of touchscreen technologies and wellbeing)	Alzheimer's disease / dementia	Touchscreen (incl. iPads)	N/A	Touchscreens can improve people with dementia's wellbeing
Tyack et al. 2015	UK	Promotion of leisure activities (increase person with dementia and carer wellbeing)	Community dwelling / Dementia (diagnosis within 4 years)	iPad (apps: art images)	Person with dementia carer dyad	Impact on cognitive stimulation (stimulating / remembering / attention / challenge / learning / reappraising / improvement / good experiences / liked aspects / familiarity / relationships / conversation) Mood (improved / lowered / range) behaviour (use of time / activation/ social)
Upton et al. 2013	UK	Promotion of leisure activities (experiences)	Dementia / Carers	iPads (used to record life histories)	Individual activity	Engaging / Supportive

Summary

To summarise, this chapter has provided insight into the biomedical conceptualisation of dementia, considering the concepts and theories of malignant social positioning and selfhood. This section has demonstrated that the biomedical approach to dementia and dementia care, termed the 'standard paradigm', has resulted in the disempowerment (Bond 1992; Lyman 1989) and increased vulnerability of those living with this condition, positioning them as '*damaged, derailed and deficient*' (Kitwood and Bredin 1992, p.272). Labelling, one of components of malignant social positing, is argued to create stigma (Garand et al. 2009) and is known to contribute to social isolation, social exclusion and is a huge contributor to the loss of QoL (ADI 2012) and selfhood (Herskovits 1995). Whilst it is suggested by some that loss of self is inevitable when living with dementia (Cohen and Eisdorefer 2002), others argue that not only does self endure when living with dementia, but loss of self is actually the result of the lack of co-operation of others (Sabat and Harré 1992). Overall, the biomedical approach to dementia results in the labelling and stigmatisation of those with the condition, consequentially leading to the potential loss of self and reduced QoL.

This chapter has also detailed the concept of QoL, its significance when living with dementia and its impact on citizenship and involvement. The importance of assessing QoL in dementia care has long been recognised (Walker et al. 1998), yet appears to be largely weighted towards health. However, it is acknowledged that people with dementia can generally experience a lowered QoL (Cooper et al. 2012), which can be exacerbated by community living and can lead to social isolation and reduced social networks (Krause 2006; Woods 2001; Kitwood 1997). Therefore it is argued that there is more to QoL than health for community dwelling people with dementia (Farquhar 1995). Whilst this section demonstrated that people with dementia are now being involved in research surrounding QoL and their perception of it, it remains largely health focused, with some still being excluded on the basis of dementia. This highlights that dementia reduces opportunities for decision making and inclusion as those with the condition are considered as 'passive actors' (Bartlett and O'Connor 2007) and no longer seen or treated as active or participating citizens (Brannelly 2011). This section identified that QoL research in the dementia field needs to be expanded to increase understanding of this area.

Post diagnostic support was also a significant area for review in this chapter, as access to community interventions can be limited for those living with dementia despite the acknowledgement that non-pharmacological interventions can be as effective as

medical based treatments (Olazarán et al. 2010). Of the services which are available there continues to be a heavy focus on health or on providing carer support. However, it has been argued that in order to improve QoL for those living with dementia (Ballard et al. 2001; Marshall and Hutchinson 2001), approaches to dementia care need to include psychosocial interventions. Although there is now a growing interest in the effectiveness of this type of intervention (Kurz et al. 2013) and how people with dementia can benefit from them (Moniz-Cook et al. 2011), it is acknowledged that more psychosocial interventions are needed (Leung et al. 2015; Aguirre et al. 2014b; McLaren et al. 2013; Kurz et al. 2013; Moniz-Cook et al. 2011), with increased focus on alternative types of interventions that may support QoL (Cooper et al. 2012).

Finally, the last focus of the literature review considered the role of technology in health care where it was evidenced that the role of digital gaming technology, whilst emerging, is largely unexplored in the area of dementia care and support. The role of technology to enable independent living for community dwelling people with dementia has been a steady focus of research for over a decade (Edyburn 2004; Scherer 2002; Matthews and McKenzie 2000), yet the consideration of gaming technologies and dementia, which include exergaming, video games and touch screen ICTs is limited. To date, most of the research which has been conducted focuses on prevention (Wang et al. 2012a), pain management and diagnosis (Rahmani and Boren 2012). Whilst the use of this commercially available technology is now growing and has been demonstrated to engage people with dementia (Cutler et al. 2014), contributing to healthy ageing (Cutler et al. 2016), the role of digital gaming technology in relation to QoL, as a post diagnostic intervention has not been explored, identifying a gap in the literature.

The below research questions will therefore address this gap in the literature surrounding QoL and a digital gaming technology based intervention for community dwelling people with dementia.

Research Questions
1. What are the benefits (if any) of a technology based community intervention for people with dementia?
2. Does the use of digital gaming technology have an impact on quality of life throughout the duration of the Tech Club?
3. What are the experiences of using digital gaming technology for community dwelling people with dementia?

Chapter four, research design and analysis, will now provide details on how this research was designed and will include its philosophical underpinning, methodological approach, data collection methods and analytical techniques used to address the research questions of this thesis.

Chapter Four: Methodology

Research Design

This chapter, divided into two main sections will provide details of the research design, data management and analysis of this research. In the first section, the research design will be presented. This will include an overview of the philosophical foundations used to underpin and inform this research, followed by details of and justification for the chosen methodological approach. Rationale for the data collection methods utilised in this research will then be highlighted followed by details of ethical processes and participant recruitment. This section will conclude by providing a detailed account of how each data collection method was used when in the research environment. The second section of this chapter, data management and analysis, will provide an overview of the approach taken to analyse the collected data and will include details of the descriptive statistics and thematic analysis undertaken, followed by details of the nominated coding process and data triangulation.

Prior to outlining the methodological approach and data collection methods used within this research, an overview of pragmatism, the philosophical foundation which underpins this research, will be provided.

Pragmatism

The main question of this research is whether there are any QoL benefits as a result of partaking in a digital gaming technology based intervention for community dwelling people with dementia. As explained in chapter two, this research was designed alongside a service evaluation, whereby some of the decisions for venue selection and methods for participant recruitment were influenced by external parties. For this reason, along with the nature of attempting to understand the QoL of people with dementia, the philosophical world view of pragmatism naturally underpins this research.

There are many interpretations of this world view, from the early works of Charles Peirce (1905), John Dewey (1931) and William James (1948), to more contemporary works of Rorty (1990), Murphy (1990) and Cherryholmes (1992). Whilst it is acknowledged that amongst these philosophers there is a general agreement that pragmatism arises out of '*actions, situations and consequences*' (Creswell 2009, p.10), these philosophers differ in their view of 'truth' and how 'truth' is gained. Peirce's (1905) pragmatism was objective and scientific in nature, whilst James's (1948) approach was

subjective and psychological in its pursuit (Rescher 2005). Contrastingly, Dewey's (1931) pragmatism does not sit in any one discipline and so is not grounded in science or psychology, but straddles both approaches considering social emphasis and ethics (Rescher 2005).

Dewey was particularly interested in how pragmatism was applied to society rather than the theories that underpinned it as he believed that philosophy should be informed by society and that under this approach social change could be instigated (Rescher 2005). Within this, Dewey also acknowledged that historical, societal and political contexts were not independent of societal challenges but inherent within (Cherryholmes 1992). There is an understanding within this stream of pragmatism that external factors have an impact on society and those living in it, therefore, individuals cannot be considered, approached or viewed in the same way, as each individual lives a different reality and so obtaining truth and understanding will differ and require alternative approaches in practice. This is supported by the wider pragmatic view that every person has their own individual view and interpretations of the world (Morgan 2007) which will be influenced by historical, societal and political contexts. This is significant for this research as the nature of dementia as a cognitive impairment will affect people in different ways. This, in addition to the lived experience of dementia, also differs between individuals based on their environment, relationships and society. The experience of dementia therefore is different for all those who live with it and when applied to a concept such as QoL this is significant as this too is subjective and may change or be influenced by the overall experience of dementia. Dewey's approach to pragmatism is especially relevant when conducting research with people living with dementia as it is both subjective and objective and considers the 'whys' and not just the facts.

The concept of QoL is closely associated to the basic philosophy of pragmatism as pragmatists believe that in order for humans to survive and thrive, they need to have a satisfied life with access to the things they need (food, security, social contact, freedom) in addition to what they desire (self-respect, companionship, sense of belonging and choice and control), and that without this people cannot experience fulfilled or satisfying lives, therefore risking their wellbeing (Rescher 2005). This aligns closely to the concept of selfhood, where people living with dementia can experience a reduction in what that they need and what they desire (selves 2 and 3), which could therefore potentially result in the loss of or reduction in QoL.

This philosophy is focused on reality and obtaining 'truth' (James 1948), pragmatists believe that the discovery of 'truth' needs to agree with the reality of the world (Rescher 2005) and that the world can only be approached and understood by being practical. It accepts that the journey to obtaining the 'truth' and therefore providing solutions to social problems (Blaikie 2007) in the real world is not perfect, is unpredictable and requires an adaptive and interchangeable approach (Morgan 2007; Tashakkori and Teddlie 1998). Therefore pragmatism places 'practice' at its centre, leading those who use this approach to regard the best that they can do as being good enough (Rescher 2005). In regards to this research, when working alongside an external party (service commissioner) which had a certain amount of influence in some areas of the research design, pragmatism acknowledges the complex nature of research conducted in the real world and pronounces that in order to obtain an understanding, problems and unpredictable solutions will be encountered but can be circumvented by being practical, adaptive and interchangeable.

Consequently pragmatism is regarded as the '*paradigm of choices*' as it discards the need to choose between extremes (Morgan 2007, p.67) and is therefore not committed to any one system of philosophy or reality, giving researchers autonomy over methods and freedom to be pluralistic in response to undertaking research in the real world (Creswell 2009). It therefore allows for flexibility and interchangeability within theories and the methods used to collect data in order to obtain the most appropriate evidence to answer the research question(s). As it is acknowledged that QoL is a multidimensional concept which can be subjective, objective and complex to measure and therefore understand, a pragmatic understanding has informed the decision to use a qualitative methodological approach for this research.

Qualitative Methodology

Qualitative methodology typically aligns to the world views of constructivism (Teddlie and Tashakkori 2009), postpositivism and feminism (Denzin and Lincoln 2008). However, this methodology has no set '*theory or paradigm that is distinctly its own*' (Denzin and Lincoln 2008, p.8) as it considers reality to be '*subjective, constructed, multiple and diverse*' (Sarantakos 2012, p.41). Therefore it is considered to be fluid and evolutionary, allowing researchers to make discoveries which contribute to knowledge (Corbin and Strauss 2008) in ways that more rigid methodologies, such as quantitative approaches, may be unable to. Whilst qualitative research is generally challenging to define (Denzin and Lincoln 2008), Nelson et al. (1992, p.4) provide this definition:

'Qualitative research is an interdisciplinary, transdisciplinary, and sometimes counter disciplinary field. It crosscuts the humanities and the social and physical sciences. Qualitative research is many things at the same time. It is multi-paradigmatic in focus and its practitioners are sensitive to the value of the multi-method approach...'

From this definition qualitative methodology is interdisciplinary, cutting across disciplines and subject areas and includes the use of multiple data collection methods. Essentially, qualitative research uses methods to gather, analyse and interpret information (Teddlie and Tashakkori 2009), allowing the researcher *'to get at the inner experience of participants'* (Corbin and Strauss 2008, p.12). As explained in Nelson et al. (1992) definition, this approach is naturally multiple method focused (Flick 2014; 2009), placing no method over another (Denzin and Lincoln 2008), therefore being flexible and respondent to what is available to the researcher.

One of the most significant elements of the qualitative methodology is that it enables the researcher to interpret what can be seen in the context within which it was generated (Braun and Clarke 2013). Braun and Clarke (2013) also suggest additional benefits of this approach are that it allows participants to provide their own perception of the issues within context, it enables a greater understanding into the meanings and experience of the participants, it embraces the imperfections of conducting research with humans and it can be flexible, enabling research to evolve and new concepts to emerge. In addition, when considering the role of this methodology when undertaking research with people living with dementia, qualitative methodologies have the potential to allow research to be driven by the participant and their experiences, therefore giving the participants *'a voice'* (Braun and Clarke 2013).

One of the main arguments against the use of this subjective methodology is that it does not provide one single answer to a research question or line of investigation as the data are interpretable in many different ways. Yet as Braun and Clarke (2013) explain, data produced by this methodology can be viewed as stories, meaning that there is more than one way to answer a question, this being a strength of the qualitative methodology. Other disadvantages have been noted by Benini (2000) who argues that as a methodology it cannot offer representativeness meaning that findings are not generalisable, that validity and reliability cannot be ensured, comparability is not possible, ethical issues are abundant, time and cost constraints are a limitation and finally some of the data it produces may not be used. However, as Sarantakos (2012, p.46) argues, these elements are *'characteristic to the nature of this research and should be seen in their context as strengths and not weaknesses'* and that many of the

areas of validity and reliability are simply '*different and not inferior*' to other methodologies.

Triangulation

Using a qualitative methodology also allows for triangulation. Triangulation permits the researcher to view the data from more than one perspective (Sarantakos 2012) which therefore '*reflects an attempt to secure an in-depth understanding of the phenomenon in question*' (Denzin and Lincoln 2008, p.7). The purpose of triangulation is to fully address the research topic by increasing the amount of data to overcome the limitations of using one method alone (Burgess 1984). Method triangulation is one of the most commonly used types of triangulation as it combines several methods in the same study to investigate different aspects of the same phenomenon (Crawford and Christensen 1995). Whilst there are concerns that triangulation does not guarantee better results (Silverman 1985), others argue that diversity within methodology should be celebrated (Denzin 2010).

Triangulation is a commonly used method in dementia research (Murphy et al. 2015; Phinney and Moody 2011; Mckeown et al. 2010). Nygård (2006) suggests that triangulation of data collected from methods such as observations and interviews may provide an insight into the lived experience of dementia which would otherwise not be possible if methods were collected and analysed in isolation. Despite the benefits of triangulation, one of the major issues faced when adopting this approach is the potential for differences within the data, whereby one method suggests one finding and another suggests an alternative (Sarantakos 2012). However, as the main goal of triangulation is to avoid researcher bias and inefficiencies of single research investigation (Denzin 1989), triangulation is seen as one of the most significant techniques in improving data analysis (Teddlie and Tashakkori 2009) adding '*rigor, breadth, complexity, richness and depth to any inquiry*' (Flick 2009, p.227).

An inductive deductive strategy

In order to address the 'what' and 'why' of research, a strategy is used to provide a logic as to how that is done (Blaikie 2009). The main strategies include deduction, induction and abduction. Deductive approaches establish logical conclusions from tangible 'phenomena' (Sarantakos 2012) and typically take a top down approach to data analysis (Boyatzis 1998). This strategy aims to directly address the heart of the research question by testing theories, hypotheses or the 'why' questions (Blaikie 2009). Contrastingly, inductive approaches generally take a bottom up approach to data

analysis (Frith and Gleeson 2004) to generate conclusions that are 'probably true' (Teddlie and Tashakkori 2009) from general 'phenomena' (Sarantakos 2012). Induction is defined as an '*approach to the relationship between theory and research in which the former is generated out of the latter*' (Bryman 2015, p.691). Inductive approaches allow for natural and significant themes within data to be brought to the surface as it is not bound to any structure which could overlook important research findings, as can be the case with a deductive strategy (Thomas 2003). In contrast, abduction is a mixture of both deduction and induction, with a stronger relationship to induction (Bryman 2015). This strategy however sees the researcher working backwards to determine the cause for events which may be considered as unexpected (Denzin 1978). However, it has been argued that all strategies need to be used together to obtain a comprehensive insight (Teddlie and Tashakkori 2009). Pragmatists believe that strategies to answer research questions fall in various places on the '*inductive-deductive research cycle*' and that the '*inductive-deductive cycle of research is an accurate description of how research is conducted*' (Teddlie and Tashakkori 2009, p.79). This ultimately means that in order to answer research questions the choice is never truly between one strategy and another, therefore justifying the use of both.

Whilst it is acknowledged that researchers who use an overarching qualitative methodology are generally aligned to the world views of constructivism, postpositivism and feminism, qualitative methodologies are also closely aligned to pragmatism, whereby those conducting research have autonomy over '*the methods, techniques and procedures of research that best meet their need and purposes*' (Creswell 2009, p.10). A qualitative methodology aligns with pragmatist philosophies as it is also acknowledges that conducting research in the real world is not perfect and requires an adaptive, interchangeable and pluralistic approach (Saraktos 2012; Creswell 2009; Morgan 2007; Tashakkori and Teddlie 1998). Similarly to pragmatism, qualitative methodological approaches recognise that when approaching and conducting research an element of practicality is required. For example, qualitative methodology endorses the use of multiple method data collection approaches as it is appreciated that more than one method may be required in order to gain insight into an area of research.

Whilst considering the significant QoL element of this research, a multi method qualitative methodology with a small nested quantitative element was considered the most appropriate methodology to address the research questions of this thesis (Table 1). Therefore, the qualitative methodological approach used in this research stems from, is shaped by and is consequently grounded in the pragmatist philosophy. A nested quantitative element was incorporated to capture data mainly in connection to

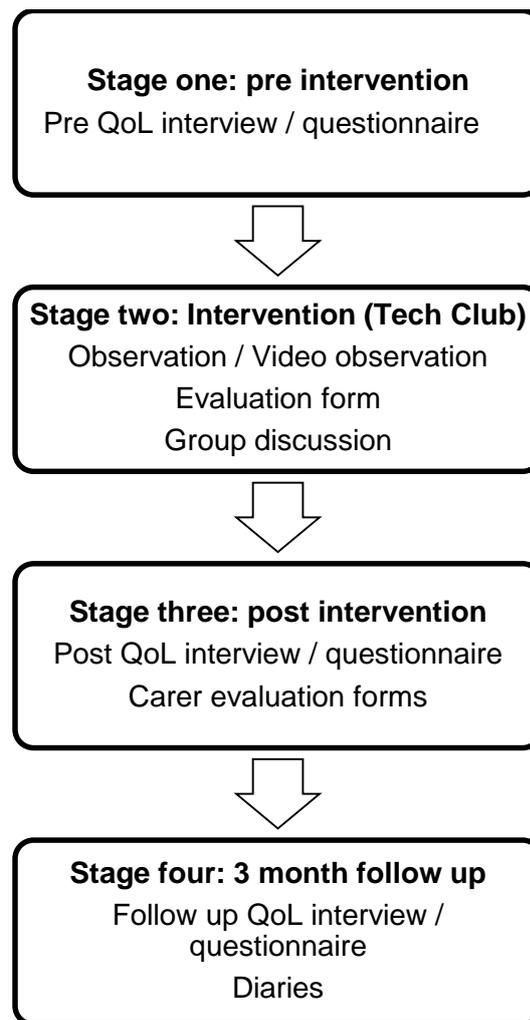
QoL tools which are quantitative in nature and a recognised method to understand and investigate QoL of people living with dementia. In addition, in line with pragmatist philosophy and qualitative methodological approaches, an inductive deductive research strategy was considered the best technique to address this research as both inductive and deductive quantitative and qualitative methods were required to address the research questions of this thesis.

A mixed methods methodology was rejected in favour of an overarching qualitative methodology on the basis that whilst it is acknowledged there is a small nested quantitative element, the majority of the data methods utilised were qualitative. The following section will now provide the rationale for the choice of data collection methods used within this research.

Methods Rationale

This section of chapter four will now provide details and justification for each data collection method utilised within this research. As can be seen in Figure 1, this research used a qualitative methodological approach, incorporating multiple methods and a nested qualitative element during four stages. This aligns with the pragmatist position that rejects having to decide between extremes associated with methods (Morgan 2007) allowing for flexibility within data collection in order to obtain the most appropriate evidence to answer the research question(s). The following section will now describe why these particular methods were selected.

Figure 1: Research design and data collection stages



Quality of Life Questionnaire Tools

As discussed earlier in the chapter, pragmatism is closely aligned to QoL as it is acknowledged that every individual has a different interpretation of their world and therefore QoL, which can be influenced by a variety of external factors (Morgan 2007) and therefore can be experienced differently by everyone. As each person's perspective of QoL differs it is necessary to gain a personal insight into each participant's QoL from their viewpoint. As pragmatism is both subjective and objective (Dewey 1931), a tool considering both the 'whys' in addition to the facts would provide a greater insight into each participant's QoL.

As explained, QoL is a multifaceted and complex concept (Bond 1999; Brod et al. 1999) making it difficult to define (Alzheimer's Society 2010) and therefore measure as there are fundamental variations in the conceptualisation of this theory (Felce and Perry 1995). As a result there is further debate surrounding what domains constitute QoL. It is generally accepted that by combining information from a mixture of domains

(the areas of a person's life which are assessed during a QoL assessment) that an insight into an individual's QoL can be produced. However, in general, there is no standard approach to the number or structure of domains required to understand QoL. For example, Birren et al. (2014) suggest three domains (social, psychological and physical) are needed to provide insight. Whereas, Lawton (1997) outlines four domains containing behavioural competence, self-assessed quality of everyday life, environment and psychological wellbeing. George and Bearon (1980) also describe four domains which differ from Lawton (1997) and consist of general health and functional status, socioeconomic status, life satisfaction and self esteem. Contrastingly Bond (1999) suggests ten domains are needed, these being, health status characteristics, clinical characteristics, physical environment factors, social environment factors, socio economic factors, personal autonomy factors, subjective satisfaction, personality and cultural factors. Lack of consensus of what and how many domains contribute to QoL supports the understanding that the meaning of QoL is different for everyone (Farquhar 1995), and therefore are underpinned by silent discourses which could impact on the objectivity and subjectivity of QoL. However, whilst striving to understand an individual's QoL through acknowledging different domains, there is further debate surrounding how QoL can be captured, measured and interpreted. Lawton's (1997; 1996; 1994) model of QoL has had significant influence on the conceptualisation of QoL in dementia research as it is argued that QoL assessment should be both subjective and objective.

Algar et al. (2016) provides a review of some QoL measures currently used in dementia research, demonstrating that within dementia research there is also no standard approach. Ready and Ott (2003) suggest that whilst approaches and implementation of dementia specific QoL measures differ, what is generally similar between them is that they all appear to be influenced by Lawton's model of QoL (et al. 1999; 1997; 1994), suggesting that QoL has both objectivity and subjectivity interacting together.

Table 4 provides an overview of the most commonly used QoL tools when undertaking research with people living dementia. They include the Activity and Affect Indicators of QoL (AAIQoL); Cognitively impaired Life Quality Scale (CILQ); Community Dementia QoL Profile (CDQ-LP); Cornell-Brown scale for QoL in dementia (CBS); Dementia QoL instrument (DQoL); QoL Alzheimer's Disease (QOL- AD); QoL assessment schedule (QoLAS); QoL in late stage dementia (QUALID). As for reasons explained, this table does not include HRQoL or wellbeing specific measures.

Table 4: Dementia specific QoL measures

	AAIQoL	CILQ	CDQ-LP	CBS	DQoL	QoL-AD	QoLAS	QUALID
Reference	Albert et al. (1996)	DeLetter et al. (1995)	Salek et al. (1999)	Ready et al. (2002)	Brod et al. (1999)	Logsdon et al. (1999)	Selai et al. (2001)	Weiner et al. (2000)
Purpose	Assessment of activity and affect	Assess those in the 'later' stages	Disease specific QoL tool exploring	Global assessment of QoL	Explore QoL from the perspective of those with dementia	Measure QoL from proxy / self-perspective	Explore QoL from the perspective of those with dementia	Assess those in the 'later' stages
Method	Observation	Questionnaire	Questionnaire	Interview	Questionnaire	Questionnaire	Interview / qualitative and quantitative	Observation
Completion	Neither	Proxy	Proxy	Proxy and self	Self	Proxy and Self	Self	Neither
No. areas considered	15	14	33	As below	29	13	10	11
Categories considered	N/A	Social interaction; Basic physical care; Appearance; Nutrition and hydration; pain / comfort	Thinking and behaviour; family and social life; physical activities and daily living	Positive affect; physical and psychological satisfactions; Self esteem; relative absence of negative effect and experiences	Positive affect; negative affect positive affect; self esteem; feeling of belonging; sense of aesthetics	Relationships; concerns; physical condition; mood; overall assessment of QoL	Physical; psychological; social/family; usual activities; cognitive functioning	N/A

As can be seen from the table above, there are many dementia specific QoL measures which address an array of objectives, using a multitude of methods, with different participant foci and a wide consideration of QoL related categories. In general what can be seen is that most of the methods incorporate subjective, objective and or observational methods in the form of self-completed reports (questionnaire or interview) conducted by the person with dementia (Selai et al. 2001; Brod et al. 1999), proxy reports (questionnaire or interview) completed by a caregiver (Salek et al. 1999; DeLetter et al. 1995), dual proxy and self-complete report (Ready et al. 2002; Logsdon et al. 1999) and direct observations (Weiner et al. 2000; Albert et al. 1996).

In critiquing these tools it is found that the DQoL and QoLAS both use self-reporting methods in isolation, relying on the person with dementia alone to provide an account of their QoL. Whilst this may be considered a benefit of this measure as it requires no proxy perspective which may complicate data collection, this feature has been argued to be a limitation of these tools as it could *'limit the group of people able to be*

evaluated as a number of measures use exclusion criteria according to cognitive or communication abilities' (Algar et al. 2016, p.834). In addition, these two measures focus on psychological based QoL domains and cognitive abilities which are not representative of the definition of QoL which is used within this research. Similarly, the CILQ and CDQ-LP require only the perspectives of the proxy, which has been used in previous research for example Rabins (2000). However, these tools do not align with the objectives of this research as the CDQ-LP is disease specific and the CILHQ is reserved for use of those in the 'later' stages of dementia. The AAIQoL and QUALID are similar in that they both rely on observation methods which may be especially beneficial when focusing on those in the 'later' stages of the condition (Volicer and Bloom-Charette 2013; Lawton et al. 1999), however, this method is used in isolation and does not seek the participation of those living with dementia. Therefore, this tool does not align with the objectives of this research. In contrast, the CBS and QoL-AD both use a dual proxy/self-approach in an interview questionnaire format and both aim to consider a global assessment of QoL. Nevertheless the CBS places significant emphasis on mood whereas the scope of the QoL-AD appears to be wider in its consideration of QoL domains. In addition, the QoL-AD has been suggested to be the QoL tool of choice when exploring QoL in this community due to its structure, sensitivity and adaptability (Moniz-Cook et al. 2008). This is evident as it has been consistently used in dementia research (Orgeta et al. 2015; Tay et al. 2014; Bartfay and Bartfay 2013; Sheehan et al. 2013; Black et al 2012; Gómez-Gallego et al. 2012; Tatsumi et al. 2009; Hoe et al. 2005).

QoL-AD (Quality of Life – Alzheimer Disease)

The QoL-AD questionnaire (Logsdon et al. 1999) is a 13 item measure specifically developed for people with dementia, which aims to assess the QoL of a person, taking into consideration both the perspectives of the individual and caregiver (proxy) (Appendix 2). The QoL-AD is intended to be used directly with the person with dementia as they are the primary source of information about their own QoL (Novella et al. 2001). This approach however places little demand on the person with dementia but assumes that they have the capacity for self-assessment and are able to provide information from their own perspective (Merchant and Hope 2004).

The validity and reliability of the QoL-Ad has been evaluated extensively (Novelli et al. 2010; Fuh and Wang 2006; Matusi et al. 2006; Shin 2006; Hoe et al. 2005; Thorgrimsen et al. 2003; Logsdon et al. 2002; 1999). A study undertaken by Merchant

and Hope (2004), which aimed to assess the reliability and validity of the QoL-AD tool found that the QoL-AD demonstrated good retest reliability over a one week interval. Similarly, the study suggested that the QoL-AD also displayed validity as the 13 domains were reviewed by those living with the condition, caregivers and gerontology experts to ensure the measure focused on QoL domains considered important by people with dementia. In addition, Thorgrimsen et al. (2003) agree that the QoL-AD has good validity as it can be completed at different 'stages' of the person's journey with dementia with no additional items required and that in general the reliability of the QoL-AD measure is strengthened by the use of two sets of assessment (person with dementia and proxy) (Ready et al. 2004), making this the 'measure of choice' for evaluating QoL in people with dementia (Moniz-Cook et al. 2008).

Although the QoL-AD tool is suggested to be accessible, reliable and have validity, there are also limitations to the use of this measure. Ready et al. (2004) suggest that because the QoL-AD relies on a conceptualisation of QoL (Lawton 1997; 1996; 1994) some may regard it as broad because of the inclusion of items concerning memory and functional abilities. Others (Selai et al. 2000; Brod et al. 1999) argue that this measure is limited in its use with those with a Mini Mental State Exam (MMSE) score <10. In addition, it is suggested (Bassett et al. 1990) that proxy ratings are influenced by the caregiver's own perceptions, expectations, belief systems, relationship with the person with dementia and levels of stress or 'burden' which can result in proxy assessments being rated lower than how the person with dementia might rate the same elements (Logsdon et al. 1999; Bassett et al. 1990).

Despite such limitations associated with the QoL-AD, these can be circumvented. The suggestion that the measure is limited as a result of the broad spectrum of domains was not considered a limitation in this research as it shows a wider QoL perspective above and beyond HRQoL. The second limitation which addresses MMSE scores can be avoided as it is also argued that the measure is reliable for people with dementia who's MMSE scores are >2 (Hoe et al. 2006; 2005; Thorgrimsen et al. 2003). As this research recruited participants who lived within the community, were able to take part in everyday life and therefore able to give informed consent, this was not an issue. The third limitation which addresses proxy reports and the potential for misguided ratings and external influence, was not a concern for this research as proxy QoL reports were used in addition to the self-reporting of those with dementia.

After investigation, the QoL-AD questionnaire was determined to be the most appropriate measure to respond to this thesis's research question 2, which seeks to explore potential QoL changes throughout the digital gaming technology intervention. This measure specifically aligns to pragmatism as to takes into consideration a wider scope of QoL to include areas which are perhaps needed, such as living accommodation and family relationships, as well as areas that are potentially desired, for example, money or hobbies. As explained, pragmatism suggests that in order for people to not only survive but thrive, they need to be satisfied with their overall QoL which considers what is wanted as well as what is needed (Rescher 2005), making it a well-placed tool to explore QoL. In addition, as this measure is deductive in nature, it provides direct quantitative answers to research question 2. As the other methods used in this research are not focused on QoL (as an inductive strategy is being taken), the QoL-AD questionnaire ensures that all possible data are captured in order to adequately address the relevant research question(s).

Observation

Within pragmatism there is the appreciation that in order to understand the world an element of practicality needs to be applied. In this research it is recognised that an understanding of the impact the intervention may not be obtainable by solely relying on what the participants say, as what people say and do are different. Therefore an element of the data collection needs to be practical and take this into consideration. Observation in the case of this research allows a level of insight that is not reliant on verbal contributions in response to direct questions. It allows data to be collected in context which presents the participants in a slightly more objective position, than when being directly asked to respond to a question, therefore providing a different insight into the research environment.

Typically, observation concerns an element of ethnography, whereby the researcher aims to capture an understanding of social processes by observing them in context. Ethnography involves the researcher participating '*overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions and collecting whatever data are available to throw light on the issues that are the focus of the research*' (Hammersley and Atkinson 1983, p.2). As suggested by Robson (2002, p.310) other advantages of observation are that the researcher is able to take note of the participants' communication and behaviours without any interference, it compliments other methods such as interviews and questionnaires and is a tool for '*getting at 'real life' in the real world*'. In addition, the use of thick

description, under an ethnographic style approach, is a method which allows the researcher to look behind the observations by adding reflective thoughts as part of the observation process (Ponterotto 2006).

Observation is a commonly used method in dementia research (Arntzen 2011; Theng et al. 2009; Tobiasson 2009) and is noted as being a particularly beneficial method to use especially when people are considered to be in the 'later' stages of the condition (Nygård 2006) as it is inclusive (Hubbard et al. 2003). This method can take a formal or informal approach. Formal observation is structured by the research agenda, whereby only the relevant is observed, whereas informal observation is unstructured and so gives the researcher freedom in what is observed and how (Robson 2002). In addition, it is also seen as an appropriate method for researchers as it focuses attention on areas which could potentially escape notice (Nygård 2006).

However, how observation is conducted is a largely debated topic. There are several ways in which observation can be conducted within the research environment, by the researcher undertaking different roles when conducting observation. Gold (1958) suggests that this role could be as a complete participant, participant observer, observer participant or complete observer. The role of complete participant conceals the researcher's agenda as they become a participant (Hammersley and Atkinson 1983), therefore becoming immersed in the research. Robson (2002) argues that this role should be avoided as it can be considered manipulative and covert (Kirby and Mckenna 1989) and therefore potentially unethical. As a participant observer, the researcher has a clear role as an observer to the participants but can establish a relationship with them by being free to explain and demonstrate areas of the research when required (Robson 2002). However, it is suggested that this role may influence the participants' reaction to the research and or researcher, therefore '*creating an artificial environment*' (Robson 2002, p.317), in addition to the researcher potentially experiencing challenges between being an insider outsider observer (Dwyer and Buckle 2009). In the role of observer participant, the researcher is known as the observer within the research and has no other role (Gold 1958). However, it is argued that by being in the room and only observing the researcher is actually not a participant of the research at all (Robson 2002). Finally, in the role of complete observer, the researcher observes only and has no contact with the research participants, limiting the researcher's ability to question or interact with the participants (Hammersley and Atkinson 1983).

The use of observation within this research is inductive as it abides by no framework or agenda, yet follows an ethnographically inspired approach by observing and recording all interactions that may provide insight into the impact of the technology on this community within the research environment, as well as collecting data which may enable the development of new concepts. As the most widely used method in social science research (Bryman et al. 2008), the role of participant observer was considered the most suitable role to engage with observation as it is the most pragmatic based on the researcher's experience of using digital gaming technology with people with dementia in similar projects. The use of observational methods will help to address research questions 1, 2 and 3.

Video Recording

As suggested above, pragmatism lends itself to the understanding that research is not perfect and therefore adaptive and interchangeable methods are required. It is acknowledged in this research that undertaking observational methods is not without its limitations. The main limitation being that it is not possible for the researcher to observe all interactions within the research environment at once. In response to this, video recording can circumvent the limitations of observational methods, ensuring that no element of the observed situation is lost.

The use of video as a data collection method is routinely used across disciplines especially associated with health research as it captures and reveals '*the ongoing interaction of people in a specific context by recording all aspects of the environment*' (Jewitt 2012, p.14). Video recording in dementia research has been found to be informative and inclusive as it enables interaction and behaviour to be captured (Wilkinson 2002).

Overall, there are advantages and disadvantages of using video recording as a data collection method (Table 5). The main advantage being that it can support an in-depth analysis by supplementing data collected by other methods (Foster 1996). When used in this way it can also reduce researcher bias (Caldwell and Atwal 2005) by allowing secondary analysis to be conducted by independent observers (Van Ort and Philips 1992). Regarding the disadvantages, there are two main concerns surrounding validity. Video cameras within the research environment are suggested to act as a deterrent or be of influence when partaking in research (Foster 1996), therefore potentially compromising the natural environment. However, this can be avoided by placing the video equipment as out of sight as possible (Jewitt 2012). Secondly, accuracy of recording the event could be compromised by researcher bias (Jewitt 2012). In

addition, this method is recognised as being vulnerable to the risks of technological failures when in the field (Foster 1996).

Table 5: Potentials and constraints of video data

Advantages	Disadvantages
Video can support an exploratory research design and extended data-discovery	Video is limited and shaped by decisions in the field
It can be 're-opened' for later analysis and capture things not noticed at the time of being present	Video data is partial: it includes and excludes elements
Participants can use the camera to extend the researcher access to their life	Video is primarily focused on the material external expression
Video is sharable-participants can be invited to reflect and discuss it	It can be edited to represent the order of events in new ways
It can be used effectively to support empirical comparison of strategies, style, and interaction across a data set	It usually provides one perspective on an event
Video enables researcher to re-visit a moment 'not as past but formerly present'	It generally records interaction over short periods of time
It can re-awaken the memories and experiences of a researcher or participants	Video takes time to watch and review and can be difficult to meaningfully summarised

Jewitt (2012, p.8)

There are also discussions regarding the appropriate number of cameras that should be used within the research environment. Heath et al. (2010) and Foster (1996) suggest that the use of more than one camera can overcomplicate the data and be problematic during analysis and so one camera is less invasive. Therefore, the use of one fixed camera is considered the most suitable for this research as it can capture the whole intervention with minimal interference or bias (Erickson 2007) and minimises the potential of participants acting in an unnatural manner.

As observational methods address research questions 1, 2 and 3 through an inductive approach, video observation provides an additional opportunity for the researcher to observe the intervention, ensuring data is not missed during the initial observation. As only one researcher observed the intervention and undertook the role of participant observer (whereby interaction within the research could span beyond observation), video recording circumvents any potential for missed data enabling a full analysis to be undertaken.

Evaluation forms, group discussions and diaries

A pragmatic approach believes that people cannot be approached, considered or viewed in the same way, as each individual's experience of a situation is different.

Morgan (2007) suggests that each person will have different interpretations of the same situation, therefore, gaining an understanding of any research focus requires alternative approaches to be used. In the case of this research, this signifies that observation and QoL questionnaire interviews are not enough to truly address the research focus of this thesis. In addition, as it is acknowledged in pragmatism that in order to gain an insight into research, adaptive and interchangeable approaches are required (Tashakkori and Teddlie 1998). Based on this, this research uses a variety of additional methods in combination to ensure that the research questions are addressed.

Aligned with pragmatism, it is also recognised that when conducting research with people living with dementia it is recommended that the most appropriate methods to collect views and opinions are through structured and semi structured interviews, observation and focus groups (Barnett 2000; Brooker 1995). The two most commonly used methods are observation and qualitative interviews (Phinney and Moody 2011; Nygård 2006; Hubbard et al. 2003). Murphy et al. (2015) suggest that an amalgamation of methods including interviews, diaries, focus groups and observations is the best approach for data collection when research is conducted with people living with dementia.

As discussed, this research uses observation as a data collection method. The QoL-AD questionnaire was conducted in an interview style environment where the questionnaire structures the interview. Additional questions were meant to be asked around the QoL-AD domains in a semi structured way to enable conversation in connection to these areas, however, for reasons discussed in the reflections of the discussion chapter, these did not form part of the QoL-Ad interview. In addition to observation and QoL questionnaire interviews, three other data collection methods were employed in this research, these will now be discussed.

Evaluation forms

This is one of the most commonly used methods within research (Robson 2002), especially healthcare (Rattray and Jones 2007). Evaluation forms are a type of survey or questionnaire that ask certain questions which are to be completed in an oral or written format (Sarantakos 2012). Whilst there are many ways a questionnaire or survey can be completed such as via email, telephone or online, the hard copy self-administer approach is one of the main formats. This process sees the participant being provided with a form or set of questions that is then returned to the researcher after completion (Braun and Clarke 2013). The advantages of using a hard copy, self-

administered approach, as suggested by Braun and Clarke (2013), is that it allows data to be collected in a group setting where the forms can be collected at the end of the session thereby maximising response rates and sample size.

Evaluation forms can be highly structured and contain a series of set questions and a number of set answers (Sarantkos 2012), or unstructured which are more flexible and use open ended questions to allow the participant to answer however they see fit (Robson 2002). However, a semi structured approach using a series of both open and closed questions is frequently used (Braun and Clarke 2013; Teddlie and Tashakkori 2009). In addition, a semi structured approach allows pictures and or images to be used, making this inclusive to those with limited literacy (Braun and Clarke 2013).

Using an evaluation form / questionnaire method can help to address research questions 1 and 3 as they can be designed to focus on the participants' experience directly after the intervention. As explained, evaluation forms can be structured in many ways, however, a semi structured format with both fixed and open ended questions is considered the best structure for this research as it ensures necessary questions are asked as well as allowing opportunity for the participants to express their opinions and feelings in a private manner. This ensures that opinions and comments are collected by both those who prefer to keep their comments private and those who are stimulated as part of a discussion.

Group discussions

The method of bringing people together in a group setting to discuss specific topics or issues is commonly referred to as focus groups (a group discussion designed to obtain feedback regarding a topic) or group interviews (a group gathering designed to collect responses to a structured set of questions). Group discussions are commonly used in healthcare research and typically form part of a multi method approach (Morgan 1996), as it is believed they encourage discussion and can address topical issues (Sarantkos 2012). Robson (2002) suggests that a group approach, such as a focus group, allows a significant amount of data to be collected from numerous people at once.

This method also has limitations, for example, it is argued that the group setting may result in participants not sharing their experiences or opinions, there is a risk of participant domination or some not taking part at all, there may be the possibility that the participants respond to questions in a way that they believe the researcher wants them to and finally the researcher may face challenges attempting to keep the discussion focused (Sarantkos 2012). In addition, Murphy (2007) suggests that

terminology, such as 'focus group', can commonly make participants feel that they are being tested. Despite all of this it is believed that this method is more valuable than individual interviews (Blumer 1970) as it instigates and develops conversation (Flick 2009) regarding a shared experience.

The use of this method, in a focus group style, helps to address research questions 1 and 3. As explained, this format may provide an environment which could instigate further thoughts and opinions stimulated as part of a natural conversation which would perhaps not be possible during discussion in the QoL interviews or within the evaluation forms. This provides a vocal opportunity for the participants to discuss their experiences, in a semi structured deductive format. In addition, this method offers an alternative technique for the expression of opinions or comments if the participant is unable or does not want to convey these thoughts in a written format.

Diaries

Diaries, defined as '*a document created by an individual who has maintained a regular, personal and contemporaneous record*', are considered to be a relatively underused technique in social science (Alaszewski 2006, p.1). However, it is acknowledged that this is an effective data collection method which can be used alongside more traditional methods when applied in healthcare and dementia research (Bartlett 2012). This method is suggested to be '*a good opportunity to elicit information about actions and emotions experienced in everyday life immediately or very soon after the evocative events*' (Välimäki et al. 2007, p.75), and is beneficial as it acts as a secondary observation in situations where observation would not be able to take place (Robson 2002), for example in the home environment. Providing diaries to record thoughts and opinions away from the research can be beneficial as it enables an element of reflection to take place which may produce alternative thoughts and feelings that were not apparent when asked immediately after the research by using evaluation forms or group discussions. In this way Nygård (2006) suggests that recounting experiences and routines is typically easier when in the home environment.

Diaries can take many forms and can include written (Braun and Clarke 2013) and oral (Hislop et al. 2005) accounts, photos (Carlson et al. 2006) or pictures (Wiseman et al. 2005). Diaries are also known to take many formats such as structured, where participants are required to report on certain activities, feelings or opinions by responding to open ended questions (Keleher and Verrinder 2003) or unstructured where participants are free to record anything they wish (Välimäki et al. 2007). An

unstructured approach is suggested to produce unique information, especially when used with carers of people with dementia (Välimäki et al. 2007).

Research which has used a diary method directly with people with dementia and carers (Bartlett 2012; Välimäki et al. 2007) has noted that this method provides the participants with an element of control over what is recorded, the method and pace at which this is done and additional control over self-representation (Bartlett 2012). Carers are noted to find this process personally satisfying and therapeutic and are subsequently more motivated to engage with this data collection method, however, it has also been noted that care givers may also lose motivation due to stress (Välimäki et al. 2007). This highlights the importance of the contribution from both the person with dementia and carers, as joint collaboration can maximise the potential for contribution.

Overall, diary methods allow the researcher to obtain additional information outside of the initial research if used as part of a multi methods approach. This method helps to address research questions 1 and 3 by providing another opportunity for the participants to record their opinions and feelings, again allowing for potential emerging concepts to develop as it is completely inductive.

Ethical Approval

Ethical approval (Appendix 3) was obtained from the ethics committee within the School of Health and Social Care at Bournemouth University. Ethical principles were taken into consideration when designing the research and were continually adhered to throughout its duration. This included participant recruitment, consent, anonymity and data protection. I was particularly cognisant of the need to observe for signs of continued consent or withdrawal of consent, therefore process consent procedures used in dementia research (Dewing 2008) were adhered to.

Participant recruitment was conducted through approved nominated gate keepers, which included local authorities and charities. Potential participants were not approached without discussion and approval from the gate keepers who were primarily the commissioners of the service evaluation (local authority), and the managers of the day centre. As discussed in chapter nine, recruitment also involved the Alzheimer's Society, in addition to the Memory Assessment Team, Memory Support Service and Community Mental Health teams in the local area and the Carers Information Service database. As recruitment was conducted by external parties associated with the service evaluation, I provided the gate keepers with a recruitment poster (Appendix 6) (Hellström et al. 2007) which were designed to be informative and to entice potential

participants. Through previous experience of working on technology related projects with this participant base, it was noted that technophobia was often a barrier to participation in such interventions. To address this, the poster was designed to be informative yet to suggest a fun and informal intervention.

I also designed and provided the gate keepers with information sheets (Appendix 4). The information sheets were designed for people with dementia in mind and were made accessible by ensuring text was kept to a minimum (with enough but not too much information), using a bold and clear font and a picture of myself (as a way to introduce me as the researcher). The information sheets were sent to potential participants prior to the start of the research as well as being provided at every session. This was to ensure that the participants were fully informed about the research, enabling them to make an informed decision regarding their participation.

Process consent methods (Dewing 2008; 2002) were also followed throughout the duration of the research. Consent forms (Appendix 5) clarified that participation was voluntary, that the participant could leave at any time and that all collected data would be kept confidential and anonymised. Both the participants with dementia and carers were asked to sign one consent form to ensure that both parties were happy to be involved in the research. Consent forms were collected at stage one of the research, during the pre QoL questionnaire interview. This was again to give the participants an opportunity to ask further questions before physically attending the intervention. To avoid the timely completion of consent forms within the Tech Club (which through experience added additional unnecessary pressure to the participants), I decided to collect verbal consent at the beginning of each session as opposed to asking the participants to physically complete additional consent forms for each session. At the beginning of each session, each participant was approached individually, whereby the research was explained to them and they were reminded that participation was voluntary and that they could leave at any time. At this point they were asked to supply their verbal consent to taking part in the research and to confirm they were happy to be filmed (taking into account that people can change their minds). This verbal consent was witnessed by two people and a registration form was completed as a paper record of who consented each week.

To ensure anonymity and confidentiality all data has been anonymised and each participant has been provided with a pseudonym. The venues hosting the intervention have also been de-identified and will be referred to as the day centre (DC) and community centre (CC) throughout this thesis. To comply with Bournemouth

University's research data management policy and data protection guidelines, all files relating to this research are stored on the university's password protected secure network. Any data held in paper format is stored in locked cupboards in a secure and locked office on the university campus. Any transcription was conducted by a Bournemouth University approved service.

Participant Sampling

Living within the community and having the condition of dementia were the only criteria for participation in the intervention. Whilst 'community' is a contested term, within the context of this thesis when referring to 'community dwelling' this will infer people with dementia who reside independently within the community. No medical history or MMSE scores were collected at any stage of the intervention. Recruitment through appropriate gatekeepers ensured that the participants accessing the intervention had a diagnosis of dementia or were in the final stages of receiving one. Upon enquiry, carers also confirmed their relative's diagnosis of dementia. There were no further limiters to participation. Similarly, age and specific diagnosis were not relevant in order to answer the research question(s) and so these data were not collected as per data collection ethical guidelines which states that only required data should be collected (Data Protection Act 1998).

The groups were delivered with an initial group size of 10 participants in each venue. Due to the nature of delivering technology based interventions, it was decided that more than 10 participants would compromise the quality of the sessions and the level of support offered. Whilst larger participant numbers would have resulted in a larger data set, lower participant numbers are not to be unexpected as this is often the reality of undertaking research within a community setting, as can be seen in other studies (Camic et al. 2013; Hochgraeber et al. 2013; Mason et al. 2005) whose participant numbers have been as low as five.

As a note, whilst the intervention was for people with dementia, family carers (FCs) and professional carers (PCs) wanted to take part in the Tech Club. Others wanting to take part in the sessions were welcome to do so but were viewed as participants and were not asked to support in the delivery of the Tech Club.

Fieldwork

This section details the preparation of each research stage and the collection of data, discussing each data collection method separately. As with any research, unexpected challenges arose in relation to data collection and conducting the research. Where

relevant, this will be identified and reflected on (if appropriate) in chapter nine. Prior to detailing how each data collection method was approached when in the research environment, a description of the venues which hosted the Tech Club is provided to give context to the situations and challenges which shaped the data collection.

The Venues

Two venues, a day centre and a community centre, were selected to host the intervention, called the Tech Club. To protect the anonymity of the participants, the names of the venues have been anonymised and will be referred to as the day centre (DC) and the community centre (CC). The DC venue was selected by the commissioners of the service evaluation. It was deemed that this was an appropriate venue due to its existing service user base of people living with dementia. In addition, this particular DC placed significant emphasis on encouraging activities which provided mental, physical and social stimulation to those with dementia, making this an attractive location to deliver the Tech Club. The second venue, the CC, also selected by the commissioners, was deemed suitable due to its central location and community facility status. The CC did not have an existing client base as it primarily supported the wider local community and faith groups. This venue was selected in the hope that it would offer the residents in the local and surrounding areas an opportunity to take part in a community intervention which may not usually be available to them.

Whilst the commissioners opted to select the venues to host the Tech Club, both were in line with Nygård's (2006) suggestion that when possible all data should be collected in an everyday context. Participants of the DC were both familiar and comfortable with the environment as the Tech Club was held in the same room that was used for daily activities. Whilst the CC participants were not familiar with this venue, the room hosting the Tech Club was arranged to be as comfortable and informal as possible and included a sofa and groups of chairs and tables, mimicking a social space such as a café.

The Tech Club took place in the same room every session when hosted in the DC. The room was in the middle of the building along a corridor in between the main activity room where the participants ate and the toilets; it was regularly used as an activity space when the clients of the day centre were separated into groups for morning and afternoon activities. Inside, the room was small and narrow with many high backed arm chairs, too many for the size of the room. The chairs were arranged in a semi-circle shape (as far as the room would allow), around the focal point of a television stand with

no television. At the back of the room French doors, with no curtains or blinds, led to a garden patio area.

Similarly, the Tech Club also took place in the same room when hosted at the CC, which was a large building on one level with many rooms and corridors. The manager of the community centre insisted that the participants accessed the building via the back door as this was closest entrance to the nominated room. The selected room was considered to be the best in the building due to the number of tables and various electrical points for the video camera and other technology equipment. The room was big and impersonal; it was rectangular in shape with a line of windows and no curtains spanning the length of the room. It also had six large tables with chairs surrounding them, an empty kitchen area and a sofa. In an effort to make the room more inviting and personal, it was rearranged to create a social area by moving the sofa around the television, rearranging some tables to the edge of the room, reorganising the remaining tables and chairs and covering them with table clothes and adding refreshments and the technologies to the tables.

This description of the research environment provides context for the following sections which explain how each data collection method was approached. The QoL-AD questionnaire interview will be described first, followed by how the observation methods, video recording, evaluation forms, group discussions and the diaries were approached when in the research field.

Quality of life questionnaire interview

A series of QoL questionnaire interviews were conducted with each participant before and after the intervention and again three months after the last session of the Tech Club. Gathering the same data at three stages provided comparable data to explore if the intervention was of any benefit to the QoL of the participants living with dementia. The questionnaire interviews took place in the DC for the participants of this venue as they were both familiar and comfortable in this environment, and either in the homes of the participants of the CC or within the venue once the participants had familiarised themselves with it.

The collection of the QoL-AD questionnaire data prior to the start of the Tech Club provided a baseline (Logsdon et al. 1999). Whilst the participants, carers and I had been acquainted and had several telephone conversations prior to the start of the intervention, the first QoL questionnaire interview provided an opportunity to physically

meet the participants. This in line with Nygård's (2006) suggestion that preceding the start of any intervention an initial meet and greet should take place. For purely pragmatic reasons based on time restrictions connected to the participants and my time, a gap of three months was deemed the most suitable option to undertake the follow up QoL questionnaire interviews. However, any period longer than this was considered to be too large of a gap for any relevant conclusions regarding QoL to be drawn using this method.

Prior to the commencement of the intervention all participants had agreed to take part in the QoL questionnaire interviews, where it was explained that the QoL-AD protocol required both the person with dementia and the carer to provide a proxy QoL perspective. Family carers (FC) agreed to provide the proxy response for participants of the community centre (CC). However, it was uncovered that FCs were unable to complete the proxy QoL questionnaires for participants of the day centre (DC), as some participants were reported to have no carer or close living family member (this will be discussed in the reflection section of chapter nine). In response to this, assigned key or health workers or professional carers (PC) who were deemed to have an in depth knowledge of the participants completed the proxy QoL questionnaires in absence of a FC.

The pre QoL questionnaire interviews were conducted in the homes of participants of the CC and within the DC for the participants of this group. These interviews were conducted, at the earliest, one week before the Tech Club and at the latest the day before. Proxy questionnaires were completed at the same time as the participants of the CC, whereas due to the working schedules of the PCs who did not attend the DC every day, proxy questionnaires took one week to be returned for the participants of the DC. All questionnaires were completed prior to the start of the Tech Club.

Post QoL questionnaire interviews were conducted on site at both the DC and CC. For the participants of the CC, these took place immediately after the last session. One participant was going on holiday and so this was the only opportunity to complete the post QoL interview as close to the end of the Tech Club as possible. Upon hearing this other participants asked if they could conduct theirs at this point too. Here, both sets (proxy and self) of questionnaires were completed. The post QoL questionnaire interview for the participants of the DC took place a week after the last session, when they were next in the DC. These interviews were conducted over two days as some participants had changed their visit days to the DC. Proxy questionnaires were

provided to the PCs (via the DC manager) at the end of the last session of the intervention and were collected whilst conducting the interviews with the participants.

Follow up QoL questionnaire interviews were conducted approximately three months after the last session of the Tech Club. The interviews for the participants of the CC were conducted in their homes, where both sets of questionnaires (proxy and self) were completed. The questionnaire interviews were held within a designated room for the participants of the DC. Proxy follow up QoL questionnaires were sent to the PCs a week before the participant questionnaire interviews took place so that they could be collected when undertaking the follow up interviews at the DC.

In general, when undertaking the QoL questionnaire interviews for the participants of the CC, both the participant and the FC (proxy) were provided with the questionnaire and a pen at the same time. I sat with the participant, explained the instructions and read through each item separately, whereby the participant then indicated their response verbally for me to physically mark the form or for them to mark the form themselves. The proxies were usually sat away at this point but were still in the room. A similar approach was used when conducting the questionnaire interviews with the participants of the DC, where verbal responses were marked on the questionnaire either by themselves or by me if requested. At this point there were no other people in the room as the questionnaires were completed. The proxy questionnaires for the participants of the DC were handed to the manager of the DC who disseminated them as the PCs came into the DC and were returned after all had been completed.

Overall, each questionnaire interview took between seven to 40 minutes and was conducted in line with guidance provided by Logsdon et al. (1999). Whilst there were no time restrictions dictating how long or short the interviews should be, whilst undertaking the interviews in the DC, some PCs rushed this process by knocking on the door and signalling that the participant needed to leave due to time schedules of the DC such as lunch or activity breaks. This will be commented on further in the reflection section of chapter nine.

Observation

As explained, the venues were selected as part of the service evaluation which meant that I had limited input as to where the interventions would be held. Due to this, the room selected to host the DC intervention was small and narrow which subsequently caused complications for the observation of the sessions.

As a participant observer I was in plain sight of the participants of both groups. The setup of the room within the CC meant that I was able to sit slightly away from the group, enabling me to see each participant fully without being in their immediate vicinity. However, due to the space restrictions of the room within the DC, I was required to sit in a semi-circle with the participants, observing them as I was sat with them. This was the only option available which enabled me to observe the participants fully. The alternative option was to observe the participants from behind where my view was restricted to the backs of the majority of the participants. Whilst this was not ideal, it was not too much of a complication as the role of participant observer allowed for this type of presence when observing, enabling more flexibility as to where and how I observed the Tech Club.

As explained, an inductive ethnographic inspired observation approach was adopted, where the aim was to capture and record all elements of engagement within the intervention. This included recording the names and details of the participants, the activities, specific individual actions, the sequence of events, feelings, interaction with others in the group and the equipment and topics of conversation and body language. There was also a particular focus on observing participants' reactions, emotions, perceptions and responses throughout the duration of the sessions directly associated to digital gaming technology. In addition, as suggested by Robson (2002), all observations should begin with a description of the environment, I therefore observed and recorded the environment which included the space (layout of rooms and furniture) and temperature (Spradley 1980), in case this contributed to the emergence of new themes and concepts within the research. I also used the method of thick description (Ponterotto 2006) when recording all observations. Whilst a large element of 'thick description' is interpretative, the use of thick description in observation within this research meant that I reported on what I saw and so undertook a full and detailed observation with reflective notes on top.

In the role of participant observer it was decided that I would have minimal involvement in the delivery of the Tech Club sessions themselves, only responding to direct questions or providing support when requested by the participants. However, the reality of this when in the field was challenged and so a new set of criteria was devised to explain my involvement in the research beyond observation and the rationale for this. The new criteria for my physical involvement in the Tech Club (where I moved away from purely observing) included being asked questions, advice or for support by the participants and or facilitator; stepping in when the facilitator was unable to

communicate instructions or explanation and this appeared to be negatively impacting on the participants; when the participants were sat without support and unable to progress with the technology; when the participants tried to undertake an activity and failed when I could see that this was a result of facilitation. My reflections surrounding the role of participant observer and the importance of communication when undertaking research involving digital gaming technology will be presented in the reflections section of the discussion chapter.

Video Recording

In response to literature (Jewitt 2012) which suggests that video cameras which are fixed to a tripod are typically the equipment of choice within research (as they allow for wider vision and can record for extended periods of time), a handheld flip camera attached to a tripod was chosen to record the Tech Club. As I would be observing the sessions and in line with suggestions that the visibility of the video camera should be kept to a minimum, this type of camera was deemed the most appropriate for this research as it could be situated in one place, capture the whole event and require minimal movement. In addition, as most participants were seated, a roaming video camera would not have been appropriate and an imposition in the Tech Club sessions. The video recording equipment was controlled and operated only by myself and was started as soon as all the participants entered the room, were seated and agreed that they were happy to be recorded, and ceased directly after the group discussion which was the end of Tech Club session. To note, whilst the visibility of video cameras within the research environment are advised to be kept to a minimum, to acknowledge potential ethical issues, I balanced the presence of the video camera to minimise intrusion with sufficient participant awareness of the equipment, to ensure continued consent.

To video record the DC sessions, the position available for the video camera was limited. The only option was for the video camera to be placed at the back of the room due to its small size and limited electrical sockets. It was not possible to arrange the room so that the participants were facing the video camera as the television stand and electrical sockets for the television screen and equipment were located at the top of the room near the patio doors, and could not be moved. However, to ensure optimal view of the participants, the video camera was placed on the tripod which was then placed on a box to provide the camera with extra height to enhance the range of what was captured. The alternative would have been to place the camera at the front of the room. However, in this position the camera would be too close to the participants to capture

the whole room, it would have not only been visible but a prominent feature within the room, and there was also a lack of electrical sockets to ensure a full charge for the duration of the each session. Jewitt (2012) acknowledges that there is no right or wrong way to position this equipment, but where possible it should be placed in a position which causes the least amount of disruption.

When recording the CC Tech Club sessions, the video camera was placed out of direct line of sight and at the back of the room where it was able to capture the full scope of the room and all of the participants. Whilst the camera was moved around the room to be in different positions at the start of some sessions, accommodating for the change in activity or requirements for electrical access, the camera was rarely in the participants' direct line of sight. As the size of the room meant that participants would move about, an additional camera would have been advantageous for this group. However, due to the restricted locations to place an additional video camera and the amount of cable which would be trailed around the room to ensure a full electrical charge, logistically this would not have been possible.

Evaluation Forms

Both participants and carers (family and professional) were asked to complete evaluation forms. The participants were invited to complete these at the end of every Tech Club session, resulting in the participants having completed six evaluation forms each by the end of the intervention. Carers were invited to complete one evaluation form at the end of the last Tech Club session.

Participant evaluation forms (Appendix 7) were a user friendly tick box sheet which consisted of a series of fixed questions such as Likert scales (supported by image cues) and 'yes' and 'no' questions, along with a series of open ended questions to ensure that all participants would be able to contribute regardless of communicative ability. To provide an alternative view of the intervention, carers were invited to complete an evaluation form (Appendix 8), these also included fixed and open questions.

The participants were provided with evaluation forms at the end of every session, along with a pen, and completed these whilst the groups were still formed and all present. As the participants completed the forms I frequently provided support if it was requested. When support was requested, each question was read to the participant with the selection of responses when referring to a fixed question or allowing the participant to

answer freely if it was an open ended question. In most cases the participants chose not to scribe their responses themselves and so they verbally provided their responses which were recorded verbatim onto the evaluation form by myself or the facilitator of the session.

At the end of the last Tech Club session the carers were provided with an evaluation form if they had attended any of the sessions. For FCs of the participants of the CC, these were completed during the last session when the participants completed their evaluation forms and were returned straight away. Evaluation forms for the PCs who attended the Tech Club within the DC were left with the team manager to disseminate as and when the PCs arrived at the DC. These were returned as soon as all of the forms were completed.

Group discussion

It was decided that a focus group style discussion at the end of each Tech Club session would provide an opportunity for conversation directly surrounding the Tech Club. As the purpose of this was to directly answer research questions 1 and 3, an informal semi structured approach was used, supported by a prompt script (Appendix 9). However, as explained, terminology can have an impact on how participants react to taking part in approaches like focus groups. As a result I decided to avoid using terminology such as focus group or group interview to describe this method as it has been known to make participants feel as if they are being tested (Mckeown et al. 2010). An informal title of group discussion was adopted to help the participants feel at ease and therefore potentially more willing to contribute.

After the completion of the evaluation forms, participants were invited to take part in a group discussion. The participants either stayed in their current seats if this was conducive to a group discussion or moved to sit around a table or in a semi-circle. I joined them at this stage and began the group discussion, which was both audio and video recorded. The group discussions took place at the end of every session and in total 12 discussions (six per group) were conducted. Whilst the focus of the group discussions was primarily to obtain the views of those with dementia, as carers were present when the discussions were taking place, they also provided their views in line with the conversation or in direct response to questions asked.

After the first sessions, the prompt script proved to be unhelpful and it was decided it was better to direct and facilitate the conversation naturally to find the answers to the questions I was seeking. It was felt that this was a more appropriate method to obtain

responses as it appeared that when asked direct questions the participants were very quiet or simply gave 'yes' or 'no' responses, which may have been a result of having just completed the evaluation forms that were solely question focused. As such the group discussions lasted no more than 15 minutes and were often much shorter than this. This was potentially attributable to the length of the session which were two hours long. By this point the participants may have been experiencing fatigue and were potentially distracted as it was obvious the session was coming to an end and so attention shifted from the session to leaving.

Diaries

Each participant was provided with a hard back purple paper book which was to be used as a diary during the period of the research. The books had nothing in them except lined pages. These were provided to the participants of the CC after the pre QoL questionnaire interview, where it was explained that the diaries were for both the participant and the carers to add and collect any valuable information, thoughts, opinions or comments they had before, after or in between each of the six sessions. The participants of the DC were informed and shown the diaries after the pre QoL questionnaire interview but it was insisted by the management team of the DC that they be handed to them after all of the pre QoL interviews had taken place. The key and health workers (PCs) who provided proxy responses for the QoL questionnaire for the DC participants were invited to contribute to the diaries. This message was relayed through the manager of the DC when the PCs attended the venue. Once all the diaries were handed out they were collected at the follow up QoL interview which was approximately three months after the Tech Club had finished.

As explained, it was communicated to the participants that the diaries were to be taken home, however, the PCs of participants of the DC decided to keep the diaries on site, where the PCs added to them weekly. It came to light that the participants of the DC did not have full access to the diaries and they were never given them to contribute to. A participant explained that he approached a PC and asked to add something to the diary but was told that it would be done on his behalf, this was never done. The diaries for the participants of the CC were semi completed, with no contributions from the participants and only one FC adding to this diary throughout the duration of the research. There were no contributions from the participants of the DC in the diaries.

This concludes the first section of chapter four which has presented the overall research design, its philosophical foundations, methodological approach, rationale for

the nominated data collection methods, an account of the approach used when using these methods to physically conduct the research and details surrounding ethical considerations and participant recruitment. The second section of the chapter will provide an overview of the analytical approach adopted to analyse the collected data.

Data Management and Analysis

This section of chapter four provides an overview of the data management strategies and analytical approaches used within this research. This section firstly provides details of the descriptive statistic methods used to analyse the quantitative data, followed by an in-depth insight into the approach used to analyse the qualitative data which includes details of the nominated coding process, the use of NVivo and triangulation.

At this point it should be noted that the pragmatist philosophy also links to and informs how the analysis has been conducted. True to the pragmatic nature which is both objective and subjective, the analytical methods used in this research align with this as descriptive statistics offer an objective view by presenting the facts based on the quantitative data; alongside thematic analysis which is more subjective and considers the 'whys' from the qualitative data. Using an objective and subjective approach to data analysis can therefore provide a greater insight into the data as a whole. Table 6 provides a visual overview of the analytical approaches used. Each phase of analysis will now be discussed.

Table 6: Analytical approach

Data Sets	Framework used	Research questions
QoL-AD Questionnaire and Evaluation Forms	Descriptive statistics	1 / 2
Evaluation Forms; Group Discussions; Diaries; QoL-AD Interview	Thematic analysis: Braun and Clarke (2006)	1 / 2 / 3
Observation and Video Observation	Thematic analysis: Braun and Clarke (2006)	1 / 2 / 3
Observation Notes	Descriptive analysis	Context Setting

Descriptive statistics

As this research used a qualitative methodology with a small nested quantitative element, I deemed it appropriate to use descriptive statistics for the quantitative aspect of this research. Therefore descriptive and frequency statistics were used to analyse data collected from the QoL-AD questionnaire and quantitative data from the evaluation forms.

QoL-AD questionnaire and Evaluation Forms

To obtain data from the QoL-AD questionnaire, the participants were invited to provide one of four responses to each of the 13 QoL domains (poor (1), fair (2), good (3), excellent (4)). Each response was converted into a corresponding number, as per the QoL-AD scoring scheme (Logsdon et al. 1999). After all 13 QoL domain responses were converted into their numeral representative they were added together to provide an overall score for the completed questionnaire. At the end of the intervention each participant had an overall score for their pre, post and follow up QoL questionnaires. A total of six questionnaires were collected for the whole QoL questionnaire process per participant (three from the person with dementia and three from the carer/proxy). In total, 84 questionnaires were completed. The numeral data were input into Microsoft Excel (10), providing a before and after quantitative view of the data for each participant and proxy. By converting these data into graph form I was able to identify any patterns or trends to respond to research question number two which asks whether the use of digital gaming technology had an impact on QoL of the participants throughout the duration of the Tech Club.

Initially, the data were to be input into SPSS19 and analysed to determine if, from a statistical perspective, participation in the Tech Club had an impact on the QoL of the participants, if there were any changes in QoL depending on which group the participant was part of and whether there were differences in QoL responses between the participants and the carers (proxy). However, for various reasons which will be discussed in chapter six, it was not possible to use the QoL-AD quantitative data in this way.

As explained earlier in this chapter, the evaluation forms for the participants and carers also included a series of quantitative based questions, which included numbered Likert scales and 'yes' and 'no' questions (frequency). This data were input into Microsoft Excel (10) as they were collected. Once within this format I was able to identify any patterns or trends within this data in order to address the research questions. However once completed, this quantitative dataset was not used as it was no longer relevant in addressing the research questions. It was identified that whilst these questions (for example, 'did you enjoy the session today?' or 'did you like using the Nintendo Wii bowling?') were originally considered important in addressing the overall research questions of this thesis, on reflection it was realised that the responses to these questions were one dimensional, offering no in-depth insight. In addition, in depth

answers to these questions were provided through the thematic analysis of the qualitative data.

Thematic Analysis

Thematic analysis is an analytical approach that identifies, analyses and reports patterns or themes within qualitative data in 'rich' detail (Braun and Clarke 2006). It has historical links to grounded theory (Cobin and Strauss 2008) and discourse analysis (Burman and Parker 2016), yet it is a distinctive method of social analysis in its own right (Braun and Clarke 2006). Above all, thematic analysis is renowned for its flexibility when compared to more established approaches as it can be used across different data collection methods (Boyatzis 1998), theoretical positions, sample sizes and can be used to address a range research questions (Smith 2015). In addition, thematic analysis can produce unanticipated findings, is accessible to researchers with limited analytical experience and can complement participatory research (Braun and Clarke 2013; 2006).

Thematic analysis is commonly used within dementia research. For example, it has been used to gather care givers' experiences of caring for a person with dementia (Melunsky et al. 2015; Park et al. 2004; Butcher et al. 2001), whereas others have used this approach to explore the experiences of living with dementia directly from those living with the condition (Innes et al. 2011; Clare et al. 2008; Phinney 1998). In addition, it is routinely used to analyse data in dementia research (Brooker et al. 2016; 2011; McParland et al. 2016; Innes et al. 2015; Camic et al. 2014; Clare et al. 2008) and it has been specifically utilised to analyse technology related dementia research (Cutler et al. 2016; 2014). However, there are recognised weaknesses within this analytical approach. It has been noted by Braun and Clarke (2013) that it can be limited if not used within a theoretical framework, guidance is inadequate for its use in the higher levels of interpretative analysis and finally participants' voices could become lost when working with large data sets.

However, this analytical approach is considered an appropriate analytical tool for this research as it aligns with the philosophical position of pragmatism in that it allows for and acknowledges the importance of flexibility. As this research uses multiple methods within a qualitative methodology (with a nested quantitative element), the data corpus produced is not only large but complex, therefore the analytical approach needs to be flexible to respond to the differences within data collection methods utilised. Although

there is an argument that there is a potential that the 'voices' of participants could be lost (Braun and Clarke 2013), the objectives of this research are focused on providing a platform for people with dementia to vocalise their opinions and comments. In addition, thematic analysis can be used to probe deep into the data, beyond a semantic level, which provides a rigorous deconstruction of the data in order to appropriately address the research questions.

Coding and NVivo

As discussed, thematic analysis involves the identification of patterns within data (Braun and Clarke 2006), whereby the patterns are coded until themes are generated (Fereday and Muir-Cochrane 2006). A code is produced when the researcher has identified something of interest or importance within the raw data (Boyatzis 1998), this is done by '*tagging*' and naming selections of text (Braun and Clarke 2006, p.86). Themes are generated when a visible pattern is identified within the generated codes, themes then help the researcher to address or understand the topic of the research (Boyatzis 1998). Within this approach there are various levels of analysis (semantic and latent). A semantic approach focuses on one level of analysis where the researcher does not delve into the data above and beyond '*what has been said or written*', whereas latent levels of analysis means that the researcher explores beyond the data to search for meanings above and beyond '*what has been said or written*' (Braun and Clarke 2006, p.84). Braun and Clarke's (2006) work is seminal in this area and is a well known and well used method for the coding of qualitative data within thematic analysis. This was the approach selected to thematically analyse the qualitative data of this research. An outline of Braun and Clarke's (2006, p.87) six phase approach to coding and theming of data and the general overview of how I approached each stage of the thematic analysis in accordance to this can be seen in Figure 2 (p.118).

In order to manage, organise and analyse the data, the management software system NVivo 10 was used. Within NVivo two main types of terminology are used to describe the data and how the data are managed (sources and nodes). Sources refer to the data collection method, for example observation, and nodes store coded data to begin the process of developing and managing themes. NVivo is the data management system used within Bournemouth University to support the management of qualitative data for all researchers. Prior to using NVivo in this research I had previously attended two training workshops on two occasions and I had prior experience of using this software within other research projects.

The first section of the analysis will detail how I undertook phases one and two of Braun and Clarke's (2006) coding process to initially approach the analysis. This will be followed by a section describing the triangulation of the data under phases three and four. Finally, the chapter will conclude with a section on how I undertook a further in-depth analysis moving away from NVivo to complete phases five and six.

Approaching the analysis

This section presents how I undertook phases one and two of Braun and Clarke's (2006) coding process. At this stage participant case nodes were created but not linked to individual data sets as this was not necessary in order to answer the research questions and the data corpus was too large at this stage to set the system up in this way. Due to the size and complexity of the data set, Figure 3 (p.119) illustrates the numerical representation of the coding process from the initial coding list to the final identified themes.

Observation

12 sets of observation notes were produced, equating to six per group. The observation notes were uploaded into NVivo10 under the source name of *observation notes* once all of the Tech Club sessions were delivered. At this stage I read and reread each set of observations, ensuring I was completely familiar with the data prior to undertaking the coding. In line with the inductive deductive approach used within this research I coded all data that appeared to be interesting and potentially informative whether this was in line with the research questions or not, this included the coding of any reflective notes I added to the observations. 107 initial codes were produced in this stage of coding. Once initial codes were generated, they were refined and grouped again at this stage to make the data more manageable prior to entering phases three to six. This stage finally resulted in 29 nodes.

Video observation

24 hours of recorded video footage underwent a thick descriptive observation as discussed earlier in this chapter (two hour video recording per session). In line with Jewitt's (2012) suggestion, I approached this by watching each two hour video twice, undertaking the observation straight away. This ensured that I was immersed in the data but also avoided missing something of interest by only noting down my observations once. As explained, the position of the video recorder and the setup of the

room meant that some of the video footage did not capture the entire room or have a clear view of all of the participants. In the situation where there was not sufficient visual material to observe, I wrote as descriptively as possible about what I was able to see and hear, directly into a Microsoft Word document. All 12 video observation files were uploaded into NVivo10 under the source name of *video observation*. This was to enable a secondary observation to take place, where new codes could be developed or identical codes supporting the original observation and coding could be observed.

When coding this data set I read and reread each set of observations, ensuring that I was completely familiar with the data prior to undertaking the coding. As above, I coded all data that appeared to be interesting and potentially informative whether this was in line with the research questions or not. Reflective notes were again recorded to ensure that any new ideas, thoughts and opinions I had were captured. 114 initial codes were produced in this stage of coding. Once initial codes were generated, they were refined and grouped at this stage to make the data more manageable prior to entering phases three to six. This resulted in 26 nodes.

Evaluation Forms

As explained, two sets of evaluation forms were completed over the duration of the Tech Club (78 participant evaluation forms; four FCs and 0 for PCs). As qualitative responses on these forms were mainly in direct response to a question, the data for each question was approached separately. This was done by taking all of the responses for each individual question and compiling them into question groups in the same Microsoft Word document which was then uploaded into NVivo10 under the source name *evaluation forms*. After reading through the responses to the questions two times, they were coded and grouped under the specific question. Additional comments that were not part of a direct question were coded independently. 45 initial codes from this data set were produced. Once initial codes were generated, they were refined and grouped at this stage to make the data more manageable prior to entering stages coding stages three to six. In this stage, responses to the questions were rearranged. For example, if the participant's response to 'what did you not enjoy about the session?' was '*nothing, I enjoyed it all, especially the company*'. I moved this response to the question enquiring what was enjoyed about the session. This stage resulted in 14 nodes. The same approach was applied to the carer evaluation forms, however, there was not enough similarity within these responses to refine them. 12

initial codes were generated and did not undergo a second refinement under phase two.

Diaries

This data collection method resulted in 11 diaries with entries, all completed by the carers. All entries were transcribed into a Microsoft Word document, one per participant, and uploaded into NVivo10 under the source name of *diaries*. After reading through the diary entries twice, the diaries were coded as one whole data set and were not coded per participant as there was not enough data to allow this. Using an inductive approach, the initial coding resulted in 47 codes being generated. After refinement and general grouping of initial patterns 13 nodes were produced.

QoL-AD Interview

A total of 42 QoL questionnaire interviews were audio recorded, each lasting between seven and 40 minutes long. Due to time constraints, the audio recordings were transcribed by myself and a Bournemouth University approved professional transcriber. Each transcribed file was uploaded into NVivo10 under the source name *QoL interviews*. Prior to coding the data, I listened to each audio recording with the transcript twice. As the QoL questionnaire interview followed a script in order to obtain quantifiable data, additional qualitative comments above and beyond the standard questionnaire script (poor, fair, good and excellent) were coded, in addition to any observations and reflections I made. I did this by coding each qualitative response and grouping it under the QoL domain which sparked the response. Any comment or conversation that fell outside of a specific question was coded individually. 134 codes were the result of the initial coding. In order to make the data manageable all the codes outside of the direct QoL questions were grouped where patterns were identified, keeping the responses provided directly to QoL questions separate. This resulted in 25 nodes.

Group Discussion

A total of 12 group discussions lasting between five and 15 minutes long were audio recorded, which I transcribed into 12 separate Microsoft Word documents, which were then uploaded into NVivo10 under the source name *group discussion*. Prior to coding I listened to and read the transcript twice to ensure complete data immersion. As with

the evaluation forms, this approach was inductive deductive in that some responses were provided to direct questions. Due to this, identified codes were grouped under the relevant question. Any conversation that was outside of a direct question was coded separately. Initial coding generated 90 codes. To make the data manageable, the codes were refined and rearranged if responses were representative of another question, as explained in the initial analysis of the evaluation forms, resulting in 10 nodes being generated.

Triangulation

In line with Braun and Clarke's (2006) coding scheme this phase of analysis represents the completion of phases three and four. This is where the nodes are collated and gathered to search for potential themes and where the developed themes were reviewed. As discussed in the first section of chapter four, multiple method triangulation was used to gain further insight into the data. This allowed individual data sets to come together, forming one overarching data corpus adding validity to the findings if similar patterns were visible across more than one data set. I undertook this phase by combining all the codes across the data sets into one main coding list, resulting in 600 codes across seven sources. Many nodes were duplicated when the data sets were brought together, for example, lack of confidence codes appeared in three data sets. When this occurred, the nodes were merged so that one node contained all references to one pattern of data. At this stage 344 nodes were categorised into 49 groups. After duplicate nodes were merged, obvious patterns categorised and nodes were searched to remove any with insufficient generalizability (two or less sources and 3-4 references) or obviously irrelevant data (for example QoL responses regarding money for example) in addition to a further round of refinement, 235 nodes were present in 13 main categories at the end of phase three.

At this stage I started to search for potential themes (phase four). All the raw data was reread and reviewed to ensure that the data was representative of the node and theme within which it was placed. After further refinement, eight initial themes were identified, which were collapsed into seven and then six main themes after one theme was removed at this stage as it was in relation to process as opposed to findings.

Figure 2: NVivo coding process

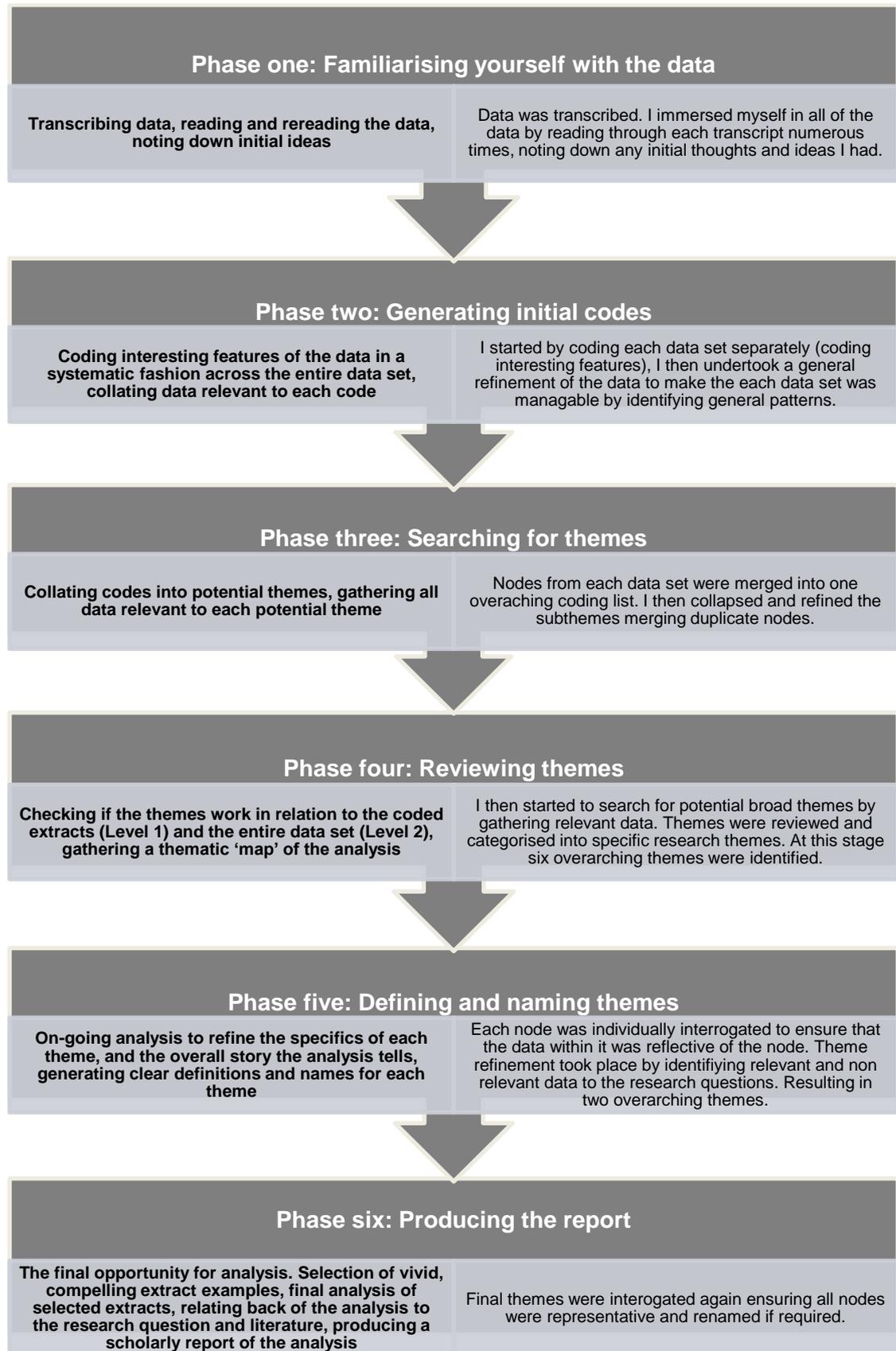
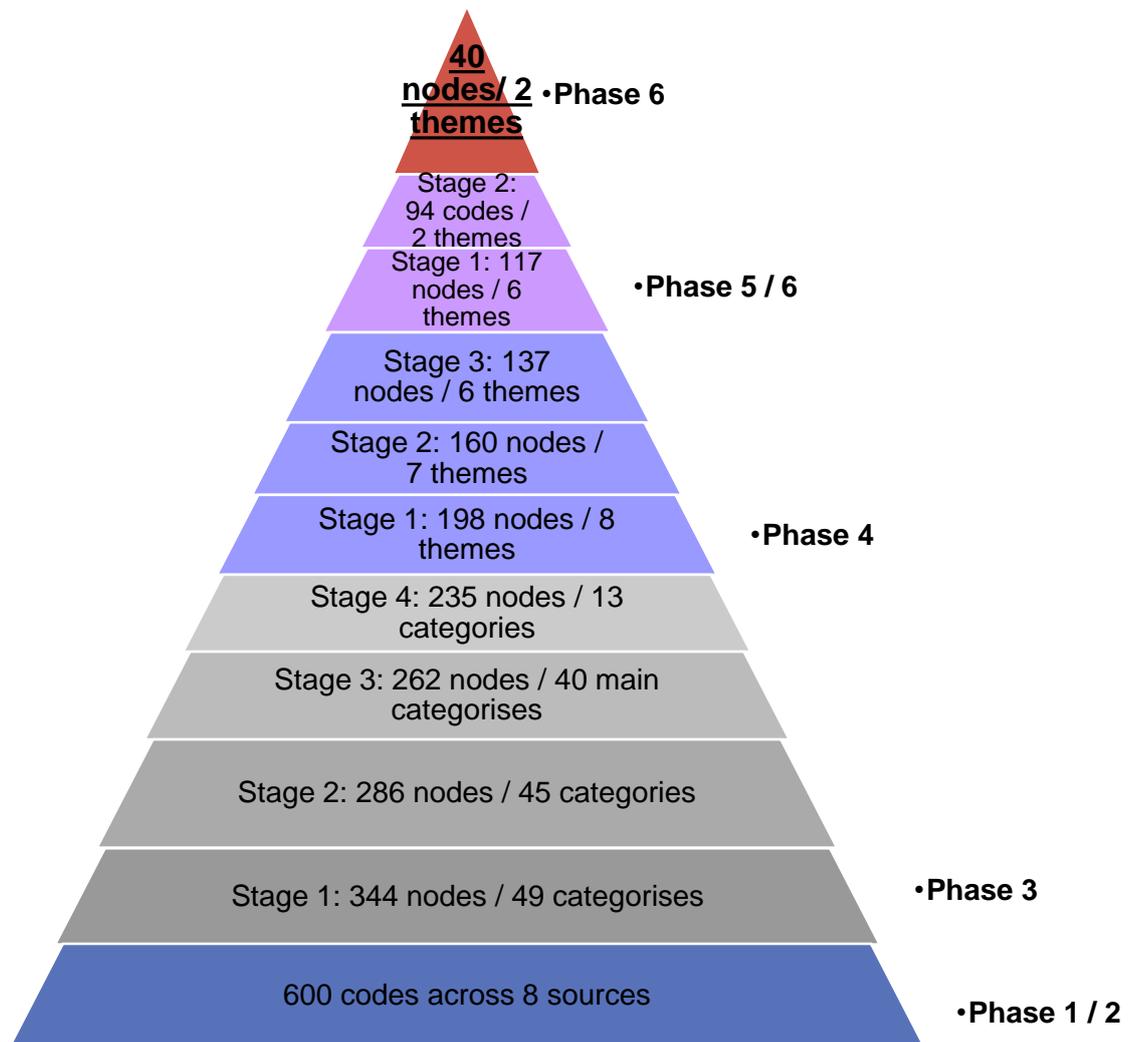


Figure 3: Coding refinement



An in depth analysis

This section represents analysis phases five and six. I provisionally placed the six themes into two categories which I believed represented two overarching themes (Appendix 12). However, there was too much data to really understand if the overarching themes I had identified were representative of the data. Following this I decided that the data needed to be reduced to understand what the main themes were. Whilst NVivo aids in the management of large data sets, I felt that at this stage I needed a different approach which was more intuitive. I decided that I would need pen and paper to really drill down into the data to refine the specifics of each theme and to identify the overall story which the data was telling.

Following this, each theme was interrogated in order to refine them. I did this by going through each node within every theme to check its relevance to the research questions

and to ensure the findings were new and making a contribution. I was therefore required to decide which themes were relevant and significant and which were not. In connection with literature, I knew that two themes I had identified were very relevant and new. I therefore designed criteria to help me understand the relevance of the other four themes (Appendix 13). To do this, I read through all the nodes of each of the six remaining themes, where I asked; What are the findings of this theme? What research question(s) does this theme answer? What is the unique contribution from this data? Is any of this data better suited elsewhere? At this point I identified that some of the themes and data within them (for example ability to remember the facilitator, gender specific references, data connected to socialisation and company), were not relevant, were not a unique contribution and or did not answer the research question, at which point they were removed. At this point it should be acknowledged that although the 'Togetherness' theme (which included three subthemes of company and companionship, friends and family and conversation) was not used within the findings of this research (Appendix 13), the importance of socialisation as a whole is an important element. Whilst it is recognised that the findings associated to socialisation were potentially relevant when addressing the research questions of this thesis, it was decided that, as these themes have already been evidenced in Cutler et al. 2016, the findings chapters would only focus on the novel findings of this research.

Following the above criteria, themes and nodes within them that were not removed were printed out and placed it on a board (Appendix 14) around the two main themes which I identified as being the prominent findings of this research. In doing so I was able to identify a natural connection to some of the nodes to the two main themes. Where there was no obvious connection, I left these nodes to one side to think where this data sat best and its importance and relevance, whilst always keeping an open mind that a new theme might be developed at this stage, ensuring that I was not moulding the nodes to fit into the two identified themes. Remaining nodes were either incorporated or removed at this stage.

Once the above process was complete, I then went back to the two themes to ensure that all of the nodes were representative, relevant and supported the claims I was making by revisiting the nodes and codes (Appendix 15). Two final themes were then identified (Appendix 16).

This concludes the second section of chapter four and this chapter as a whole. This section presented an overview of the analytical approach adopted within this research

and demonstrates the use of descriptive statistics and thematic analysis. It has illustrated the in-depth approaches adopted when undertaking the thematic analysis and how this was segmented to ensure a robust analysis of the qualitative data. Before the findings of this research are presented, chapter five sets the scene to the research, providing additional context for the findings in chapters six, seven and eight.

Chapter Five: Setting the scene

The purpose of this chapter is to set the scene to the research and data gathering by using observation notes to introduce the participants; to provide a brief introduction of the role of the carers and the difference between family and professional carers' in this setting; to describe the intervention structure and weekly session structure, showcasing its transition and development and finally to provide details surrounding the facilitation of the weekly sessions. The chapter will start by introducing the participants.

Meet the participants

Sixteen participants originally took part in the research. Table 7 provides a breakdown of the total number of participants per group. The DC had the maximum number of ten participants and the CC had a total of six. Two participants from the CC did not continue to attend the Tech Club past the first session. Margaret, a FC, confirmed that the reason that she and Jack (person with dementia) would not be attending the Tech Club any longer was due to their perceived lack of ability to be able use the technology:

'We don't have an iPad at home and we are not computer minded at all.'

(Margaret (FC): Observation notes. S1)

The second participant not to return was Emily, a person with dementia. Emily decided to withdraw participation from the Tech Club two days after the initial session. A telephone conversation confirmed that Emily believed that the Tech Club *'was not for'* her. Therefore the findings are representative of a total of 14 participants as can be seen in the table below.

Table 7: Breakdown of participant numbers

Breakdown	Male	Female	Total
Day centre (DC)	5	5	10
Community centre (CC)	2	2	4
Total	7	7	14

The following section provides short biographies for each participant. All participants have been provided with pseudonyms to maintain their anonymity.

Biographies: Day centre participants

Sylvie, now a widow, has two children and two grandchildren. She lives in a house she owns with her daughter, with whom she has a very strong relationship. Sylvie considers this relationship to be her closest now that her husband has passed away. Sylvie previously played the piano but now enjoys her pet dog and going for walks along the beach, when her daughter is free to take her. Sylvie is in her 80s and has a diagnosis of dementia along with other health conditions.

Pauline is originally from Scotland but moved to England when marrying her late husband, she has one child and two grandchildren. As a performer prior to marriage, Pauline likes to tell stories of her travels and being on stage in different countries. As a sociable person, Pauline likes to meet new people and to go out but does not have the opportunity anymore. She likes to garden and tend to plants but is unable to do this any longer as she now lives in a flat. Pauline is in her late 80s and has a diagnosis of dementia.

Evan, originally a Londoner, moved to the south of England where he now lives with his wife, with whom he has a very strong relationship, she is his best friend. Evan has a son and one grandchild. He enjoys gardening but cannot get around as much as he would like. His ability to undertake activities around the house, which he once enjoyed, are now completed by home helpers. Evan is in his 70s and has a diagnosis of dementia along with other health conditions.

Karl lives in a bungalow with his wife and has a daughter and a number of grandchildren. Karl worked in industry for over 20 years, of which he is very proud. He previously played the piano and was an avid swimmer and diver but now enjoys going to the pub with his friends once a week. Karl's wife also lives with memory problems and is often in hospital. Karl is in his 80s and has a diagnosis of dementia.

Martin lives with his wife in a house in the local area. He has a son and three grandchildren who live further away. Martin enjoys playing football with his grandchildren in the garden when they come to visit. Martin is in his 70s and has a diagnosis of dementia.

Max has many nick names from his days working abroad. He is fluent in many languages and specialises in regional dialects. Max is widely travelled and has driven across Europe in a lorry. Max is a widow and has two children, his son is now his closest relationship. Max lives alone but loves company and considers himself to be a

sociable person, however feels that he has lost most of his friends now. Max is in his 70s and has a diagnosis of dementia along with other health conditions.

Ada was previously employed by the government as a driver. However, *Ada's* passion was beauty and so retrained to be a beautician, which she continued until retiring. *Ada* is married to her husband but has no children or surviving family. They live in their own home and are supported by home help. *Ada* is in her 80s and has a diagnosis of dementia and other health conditions.

Doris lives in sheltered accommodation in the local area. She is a widow and has a daughter and grandchildren who live in another county a few hours away. *Doris* enjoys knitting and other crafts but especially gardening and feeding the birds, although she no longer has a garden to be able to do this. When her daughter visits she likes to go for walks in the fresh air. *Doris* is in her 70s and has a diagnosis of dementia among many other health implications.

Paul has lived in the south of England all of his life where he has been a local entrepreneur and ran many businesses. He is a keen performer, enjoying the arts of theatre and comedy. *Paul* is multilingual and likes to make people laugh. He lives in his own home with his son after the passing of his late wife. Whilst *Paul* is close to his son he feels alone and left out. *Paul* is in his 70s and has a diagnosis of dementia.

Maudy's main passion in life is laughing, she likes to laugh and loves to makes others laugh. *Maudy* is a people person but is now a widow and has no children, her closest relationship is with her brother. *Maudy* likes to read, sing and do things for herself around the house, however most daily chores are done for her by family members. *Maudy* is in her 70s and has a diagnosis of dementia.

Biographies: Community centre participants

William has a wife, *Abigail*, whom he lives with in their flat. *William* was an educator within higher education and takes great pride in his previous career. He is also interested in sports and politics. *William* is very close to his daughter who lives abroad, whilst they communicate often he misses her dearly. *William* is in his 70s and has a diagnosis of dementia.

Martha lives with her husband *Martin* in their own home. She has three children and four grandchildren. *Martha* was previously an educator within higher education and has

strong interests in history and crafts. Martha and her husband have no friends or family apart from a daughter living nearby. As a couple they were previously socially active and undertook lots of travel, however this has reduced heavily due to Martha's condition. Martha is in her 70s and has a diagnosis of dementia.

Florence lives with her husband Phil in their own home and has a son and a granddaughter. Florence has recently been provided with a mobility aid to help her move around the house and outside, however she feels that her independence has been comprised by the mobility aid and is striving to be able to move without it. Florence enjoys doing puzzles but her passion is animals. Florence is in her 70s and has a diagnosis of dementia along with mobility restrictions.

Henry lives with his wife Catherine in their home. He has one son who lives far away and sees once a year. Henry considers his wife to be his only family. He enjoys music of all kinds and spends much of his time listening to rock and roll. Henry was a professional technology technician but is a private person and prefers to keep himself to himself as he has a fear of being embarrassed. Henry is in his 70s and has a diagnosis of dementia.

Carers

Carers are not the focus of this research yet were involved through their contribution to the QoL questionnaire interviews and their presence during the Tech Club. Two types of carers were present, family carers (FC) of the participants of the CC and professional carers (PC) working within the DC. As explained in the fieldwork section of chapter four, in order to complete the QoL proxy questionnaire and diaries, key support and health workers were deemed the most appropriate to replace FCs for the participants of the DC, who were unavailable to take part in this research. Table 8 provides a breakdown of the formally assigned PCs for each participant of the DC, and whom therefore provided the proxy information for each participant. In addition this table also shows the participant / carer dyad for the participants of the CC. FCs were often in attendance at every session of the Tech Club for the CC, whereas there was only one PC in attendance during each session at the DC, which was rotated.

Table 8: Participants and carer dyads

Professional Carers (PC)	Participants	Family Carers (FC)
Kate	Paul (DC)	N/A
Laura	Karl (DC)	N/A
Dawn	Doris (DC)	N/A
Michelle	Sylvie (DC)	N/A
Dawn	Pauline (DC)	N/A
Michelle	Max (DC)	N/A
Michelle	Martin (DC)	N/A
Eve	Maudy (DC)	N/A
Eve	Ada (DC)	N/A
Natalie	Evan (DC)	N/A
N/A	Henry (CC)	Abigail
N/A	Martha (CC)	Martin
N/A	Florence (CC)	Phil
N/A	Henry (CC)	Catherine

Tech Club Structure

The Tech Club was structured as two six week interventions, six two hour weekly sessions at the DC and six two hour weekly sessions set within the CC. Weekly sessions followed immediately after one another unless the nominated day of the week fell on a bank holiday or was needed to be moved due to predicted mass participant absence. A maximum number of 10 participants per venue was decided as the optimal number of participants for this type of intervention due to the number of facilitators available and amount of equipment required. Each weekly session was designed around the use of various digital gaming technologies, using a range of games and apps for the Nintendo Wii (Nintendo Co LTD), Apple iPad and the Xbox 360 Kinect (Microsoft Corp). As this equipment can be considered under the 'serious games' definition as it is commercially available and has not been specifically designed to achieve change in a player, this technology will be termed digital gaming technology. Whilst it is acknowledged that the iPad is more commonly referred to as an ICT or AT, for the purposes of this research the iPad will be referred to under the definition of a digital gaming technology as it is being used as a tool above and beyond both ICT and AT purposes.

The rationale behind the selection of technologies was based on both funding restrictions and my experience gained from previous technology research projects. Using prior knowledge I was able to select the equipment to be used, which was restricted to commercially available and popular digital gaming technology equipment.

The Nintendo Wii was purchased within the BUDI research centre and had previously been utilised with this community in other projects. The selection of the Xbox Kinect was based on its limited use with this community, as supported by literature at this time. The Xbox Kinect and iPads were supplied as part of the funding for the service evaluation.

In order to be responsive to participant feedback, the session structure of the Tech Club was fluid, allowing the sessions to be influenced by the participants wherever possible. This approach allowed me to be reactive to the skills, preferences and agendas of the participants whilst maintaining the necessary structure to ensure the aims and objectives of the research were met. Table 9 demonstrates the initial planned session structure, although this was subject to change following feedback from the participants.

Table 9: Initial weekly session structure

Week	Nintendo Wii	Xbox Kinect	Apple iPad
S1	Mii Character Creation (intro)	N/A	Google
	Bowling	N/A	Google Earth
S2	N/A	Intro	Games (group & individual)
	N/A	Sports (golf, baseball)	BBC news
S3	Group game (Wheel of Fortune / Family Fortunes)	N/A	YouTube
	Motion Play	N/A	Google Earth
S4	N/A	Mindful game	Art App
	N/A	Adventure game	Music App
S5	Balance games (Skiing, Tight Rope, Hula Hoop)	N/A	BBC iPlayer
	Archery	N/A	Google Earth
S6	N/A	Karaoke	YouTube
	N/A	Group game (Carnival)	Photos of sessions

Session Structure

When designing the session structure for the Tech Club, it was envisaged that one session programme would be used for the duration of the research for both groups (Table 9). However, after undertaking the first session (S1) in both the CC and DC I realised that in order to be responsive, the programme structure needed to be adapted constantly, especially in light of the differences in preference between the groups which

was highlighted in the first session. Adaptations to the session structure for each of the venues will now be discussed.

Day centre

After the first session in the DC I decided that the session structure should change for this group based on observations I made surrounding the used frequency of the technologies within the sessions. On reflection I felt that it would be more beneficial if the iPad was used every week and either the Nintendo Wii or Xbox Kinect was used in two week blocks ensuring a level of consistency. This would enable the Nintendo Wii or Xbox Kinect to become familiar, providing the opportunity for the participants to go over learning from the previous week. After session two it was decided that the Nintendo Wii and Xbox Kinect should be used in blocks of three consecutive weeks each, enabling the participants to become even more familiar with the equipment rather than moving between them potentially causing confusion between the two. Table 9a illustrates the redesigned session structure up to session four, where it was redeveloped again.

Table 9a: DC session structure weeks 1 - 4

Week	Nintendo Wii	Xbox Kinect	Apple iPad
S1	Mii Character Creation	N/A	Google
	Bowling	N/A	Google Earth
S2	Wii Motion Play (Ice cream games)	N/A	Google Earth
	Wii Motion Play (Mole game)	N/A	Arts and Music
S3	Wii Balance Games (Tight Rope)	N/A	Arts and Music
	Wii Balance Games (Hula Hoop)	N/A	YouTube
S4	N/A	Joy riding (car game)	App Games (no internet)
	N/A		
S5	N/A	Sports (Golf etc)	BBC iPlayer
	N/A		Google Earth
S6	N/A	Karaoke (group game)	YouTube
	N/A		Photos of sessions

However, after session four and following huge complications when using the Xbox Kinect (which will be reflected on in the reflections section of the discussion chapter) I decided that only the Nintendo Wii would be used in the following sessions. This contrasts with Dove and Astell's (2017) research which acknowledge that people with

dementia enjoy using exergaming equipment by illustrating that this was not the case with regards to the Xbox Kinect within this research. Table 9b shows the redeveloped programme after session 4. This presents the final session structure for the DC participants.

Table 9b: DC session structure weeks 5 - 6

Week	Nintendo Wii	Xbox Kinect	Apple iPad
1	Mii Character Creation	N/A	Google
	Bowling	N/A	Google Earth
2	Wii Motion Play (Ice cream games)	N/A	Google Earth
	Wii Motion Play (Mole game)	N/A	Arts and Music
3	Wii Balance Games (Tight Rope)	N/A	Arts and Music
	Wii Balance Games (Hula Hoop)	N/A	YouTube
4	N/A	Joy riding (Car Game)	App Games (no internet)
	N/A	N/A	N/A
5	Carnival Games	N/A	Memory Games / Google Maps
	N/A	N/A	iPad ten point activity
6	Brain training games	N/A	iPad ten point activity
	N/A	N/A	Photos of sessions

Community Centre

Based on observations and participant comments during the first session, none of the participants had any interest in using the Nintendo Wii. Some participants had decided that they simply did not want to use it and others felt that they could not due to mobility restrictions. For this reason the Nintendo Wii was not used in the subsequent sessions, although the participants were frequently invited to use the equipment. The Xbox Kinect and iPad was then utilised following session one. Session two was redeveloped to introduce the participants to the Xbox Kinect to see if they were more inclined to use this equipment. Table 9c illustrates the redeveloped CC session structure based on participant feedback after session one.

Table 9c: CC session structure weeks 2 – 6

Week	Nintendo Wii	Xbox Kinect	Apple iPad
1	Mii Character Creation	N/A	Google Earth
	Bowling	N/A	Arts and Music
2	N/A	Joy riding (Car Game)	YouTube
	N/A	N/A	Google Earth
3	N/A	Sports games	App games
	N/A	N/A	Google Maps
4	N/A	Carnival Games	App Games
	N/A	N/A	BBC iPlayer / YouTube
5	N/A	Adventure game	App games
	N/A	N/A	Arts and Music
6	N/A	Group game	Google Earth / YouTube
	N/A	N/A	Photos of sessions

Following session 2 it was obvious that the Xbox Kinect was also not suitable to use (explored in the discussion chapter) and that the participants were not interested in this equipment either. At this point the participants had identified that their agenda was solely around the use of the iPad. Whilst the participants from both venues wanted to use the iPad, participants of the CC in particular had a wider agenda of being taught how to use the iPad rather than simply 'do things' on it. In order to facilitate this I designed a ten point activity guide (Appendix 10) for the participants to work through, in groups or alone. Supported by picture cues to help the participants identify with the required actions the activity guide supported the learning of how to use the iPad and took the participants through the basics of this equipment, from rotating the screen to finding particular apps by navigating through the iPad. Each week the guide was enhanced to make the actions more challenging and to provide the participants with further learning of this equipment. Table 9d shows the session structure following session 2.

Table 9d: CC session structure weeks 3 – 6

Week	Nintendo Wii	Xbox Kinect	Apple iPad
1	Mii Character Creation	N/A	Google Earth
	Bowling	N/A	Arts and Music
2	N/A	Joy riding (Car Game)	YouTube
	N/A	N/A	Google Earth
3	N/A	N/A	App games
	N/A	N/A	iPad ten point activity
4	N/A	N/A	Arts and Music
	N/A	N/A	iPad ten point activity
5	N/A	N/A	iPad ten point activity
	N/A	N/A	Google Earth / YouTube
6	N/A	N/A	iPad ten point activity
	N/A	N/A	Photos of sessions

Based on feedback from participants following session 4 whereby it was indicated that they wanted to use the iPads to service their own agendas associated with their interests and hobbies, it was felt across the group that they did not know how or where to start with this. A participant suggested that the available opportunities on the iPad, in line with their interests, could be communicated on a piece of paper to make the information and therefore the process manageable. Following this feedback I designed three A4 pages with three choices of activities (Appendix 11) which could be undertaken during the session using the iPad, in response to the participants individual requests, preferences and hobbies. Images were added to this sheet to provide visual cues and to respond to individual interests in an effort to individualise the activity. Table 9e illustrates the changes to the session structure following this feedback, this presents the final session structure for the CC participants.

Table 9e: CC session structure weeks 5 – 6

Weeks	Nintendo Wii	Xbox Kinect	Apple iPad
1	Mii Character Creation	N/A	Google Earth
	Bowling	N/A	Arts and Music
2	N/A	Joy riding (Car Game)	YouTube
	N/A	N/A	Google Earth
3	N/A	N/A	App games
	N/A	N/A	iPad ten point activity
4	N/A	N/A	iPad ten point activity
	N/A	N/A	Arts and Music
5	N/A	N/A	Three choice activity
	N/A	N/A	N/A
6	N/A	N/A	Three choice activity
	N/A	N/A	N/A

Tech Club Facilitation

Each of the weekly sessions were delivered by one of two facilitators and the participant observer. The facilitators, who were employees of the research centre and who had experience of working with people with dementia on similar projects, led the sessions by demonstrating, explaining and then supporting the participants to use and interact with the technologies, responding to conversations, requirements and personal agendas. Budget requirements meant that the Tech Club would physically be delivered by one facilitator. However this enabled the sessions to accurately mimic a ‘real world’ situation whereby if similar sessions were replicated, only one or two facilitators may be able to deliver them. It is recognised at this point that whilst the intervention was for people living with dementia, family and professional carers wanted to join in by using the technologies also. Carers were welcome to take part but they were treated as participants (who completed consent forms) and were not relied upon to support or help deliver the sessions. It should be noted at this point that originally the FCs of the CC participants sat amongst the participants within the sessions, however, after the second session they were asked to sit away from the participants. This was due to negative comments made by some of the carers and the display of the carers taking over the activity. It was feared that this could potentially disrupt the atmosphere of the group and negatively impact on the participants’ experience of the Tech Club.

As explained in chapter four I undertook the role of participant observer, in which I observed the sessions and undertook data collection at each research stage. As explained, whilst it was not the role of the participant observer to interfere with the

delivery of the sessions or become involved in the activities, if a situation arose where it was felt that intervention on my part was appropriate and necessary (based on my judgement), I would offer support. This included being asked direct questions or for advice; intervening if the facilitator was unable to communicate or explain instructions and this appeared to be negatively impacting on the participants; when the participants were sat without support and unable to progress with the technology. Implications of undertaking the role of participant observer within this research are reflected on in the discussion chapter.

This chapter has set the scene to the research and data gathering by introducing the reader to the participants of the research and the carer / participant dyad. This chapter has also provided insight into the weekly structure of the research and its adaptations and developments as the intervention progressed. Finally, details of how the Tech Club was facilitated were provided, identifying how and by whom the sessions were delivered. Chapter's six to eight will now present the findings of this research, starting with the findings from the QoL-AD questionnaire.

Chapter Six: QoL-AD questionnaire findings

The following three chapters (six to eight) will present the quantitative and qualitative findings of the data analysis. Chapter six will provide insight into the quantitative findings from the QoL-AD questionnaire, whilst chapters seven and eight present the thematic findings of the qualitative data which has led to findings relating to the concepts of self and learning and teaching. When relevant, quantitative and qualitative data will be used in combination to support the findings. Each chapter will address the relevant research questions. For ease, these have been provided in the table below.

Whilst chapters seven and eight are individual findings chapters highlighting unique contributions in their own right, it should be noted that there is an important connection between them, where the concept of self weaves through the findings of learning and teaching. Whilst the concept of self will be highlighted throughout chapter seven, a section discussing the relevance of this will be presented in chapter nine, the discussion.

Research questions

Research Questions	Addressed in
1. What are the benefits (if any) of a technology based community intervention for people with dementia?	Chapter six / seven / eight
2. Does the use of digital gaming technology have an impact on quality of life throughout the duration of the Tech Club?	Chapter seven and nine
3. What are the experiences of using digital gaming technology for community dwelling people with dementia?	Chapter eight

Introduction

In this chapter, findings from the QoL-AD questionnaire (Logsdon et al. 1999) will be presented to address research question 2, which asks whether the use of digital gaming technology had an impact on QoL of the participants throughout the duration of the Tech Club. This will be achieved by establishing if there were differences between the pre, post and follow up self-reported QoL scores provided by the participants, of every QoL-AD domain (Appendix 2). In order to provide a full overview of the responses to the QoL-AD questionnaire, all domain scores will also be combined at the end of the chapter to provide an insight into the impact on QoL as a whole. The chapter will then consider proxy contributions to this questionnaire and associated limitations regarding proxy data and the data set as a whole. The chapter will conclude with a

direct answer to research question 2 from the perspective of the QoL-AD questionnaire data.

QoL scores, did they change?

As explained in chapter four, participants were asked to rate their QoL using a Likert scale. Each self-reported qualitative response to all of the 13 domains on the scale was converted into a quantitative indicator as can be seen in the table below, providing a numerical score for each domain at pre, post and follow up stage, enabling comparison between them (Graphs 1 – 13). Combining the numerical scores for every domain at each stage provides an overall QoL score for each participant (Graph 14).

Whilst quantitative statistical analysis would normally assist in determining if there had been a change to an individual's QoL, as will be discussed later in this chapter, statistical analysis was not possible (mainly attributable to missing data). In light of this and in order to provide some insight into the data, descriptive statistics were used to determine if there was an impact on the participants' QoL. This was recognised by a reduction or increase between pre, post and follow QoL scores, whereby a major change in QoL was identified as a movement of more than two points on the QoL-Scale, for example from 1 – 4 or 5 – 2.

Whilst the QoL-AD questionnaire uses all three stages, including the follow up stage which is approximately three months after the intervention, I have decided to present the data directly either side of the intervention (pre and post) as any potential changes in QoL can be more closely aligned to the Tech Club during these two time periods. For this reason, the findings in this chapter will initially present pre and post QoL scores in an effort to provide an accurate representation of the participants' QoL during the timeframe of the Tech Club. Each of the self-reported 13 QoL domain scores will now be compared between pre and post Tech Club attendance, followed by a combination of all the scores providing an overview of the QoL status of each participant within this time period.

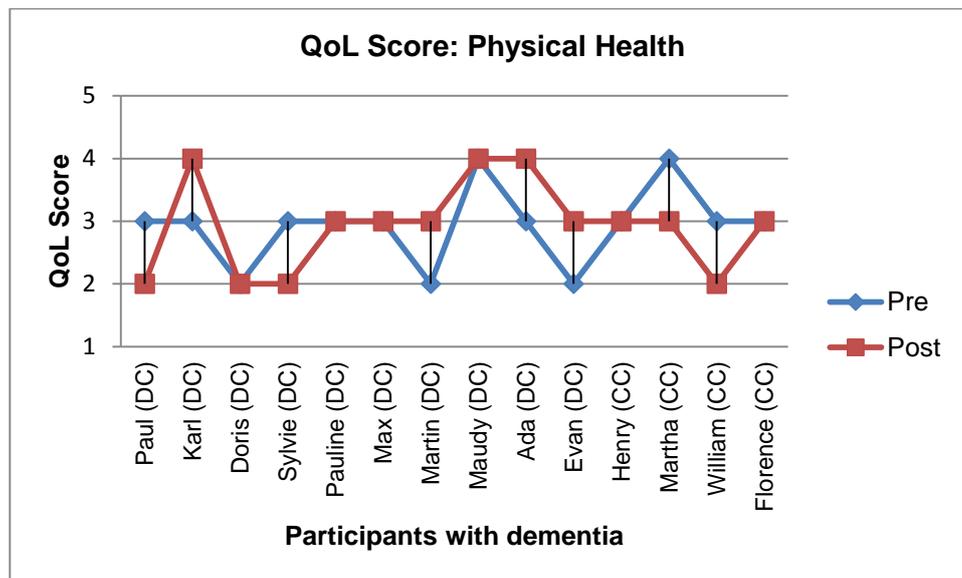
QoL score descriptors

QoL score per domain	Descriptor	Combined QoL score across 13 domains
4	Excellent	52
3	Good	39
2	Fair	26
1	Poor	13

1. Physical Health

As can be seen in graph 1, the responses provided when asked ‘*How do you feel about your physical health?*’ suggest that overall, participants considered their physical health to be between fair and excellent. Four participants’ perception of their physical health increased, four decreased and six remained the same. This suggests that the Tech Club made no considerable impact on this area of QoL for the majority of the participants.

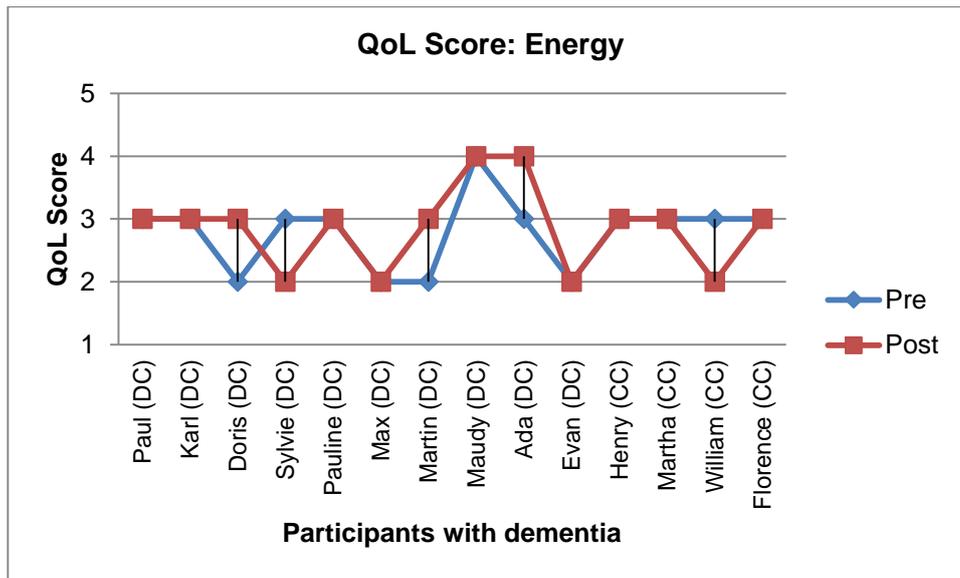
Graph 1: Pre to post QoL responses for physical health



2. Energy

Graph 2 presents the responses provided by each participant when asked ‘*How do you feel about your energy level?*’ It shows that the participants considered their energy levels to be between fair and excellent. Overall, three participants’ perception of their energy increased, two decreased and nine remained the same, suggesting that the Tech Club had no substantial impact on the majority of participants QoL in this area.

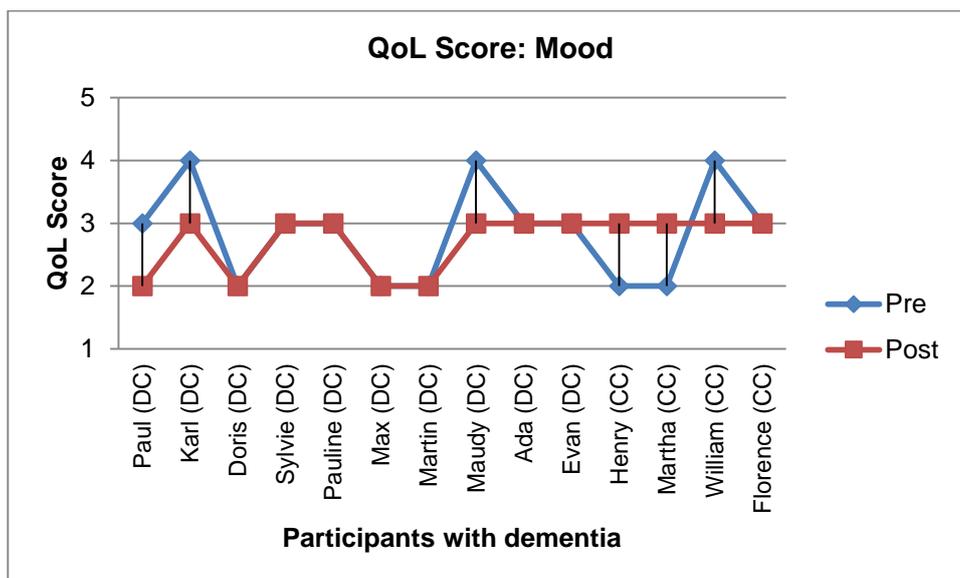
Graph 2: Pre to post QoL responses for energy



3. Mood

Graph 3 presents the responses provided by each participant when asked 'How has your mood been lately?' It shows that overall the participants considered their mood to be between fair and excellent. Two participants' perception of their mood increased, four decreased and eight remained unchanged. These findings suggest that for the majority of participants the Tech Club made no substantial impact on QoL in this area.

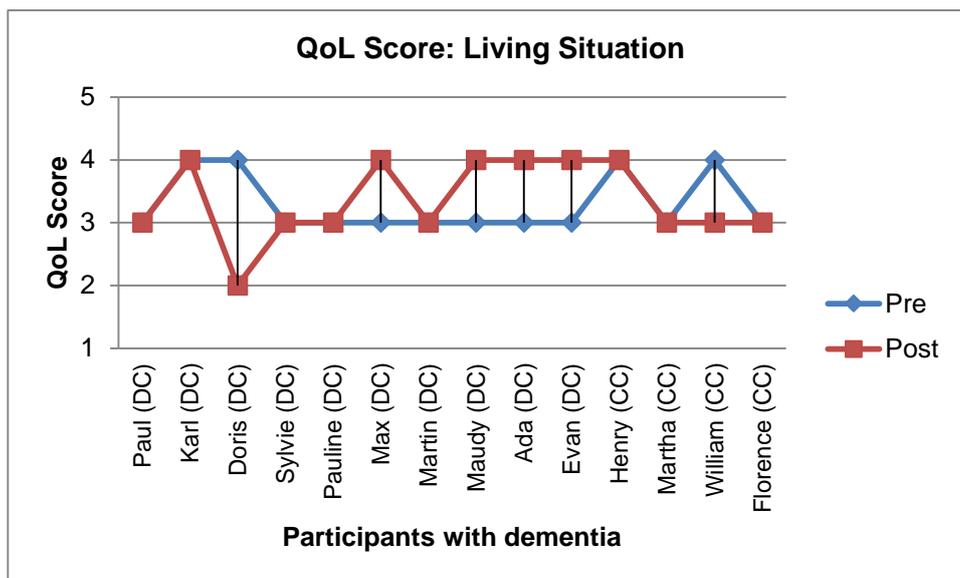
Graph 3: Pre to post QoL responses for mood



4. Living situation

When asked ‘How do you feel about the place you live now?’ graph 4 shows that overall the participants considered their living situation to be between fair and excellent, with four participants’ perception of their living situation increasing, two decreasing and eight staying the same between pre and post Tech Club, therefore suggesting the intervention had no impact on this domain of QoL for most of the participants.

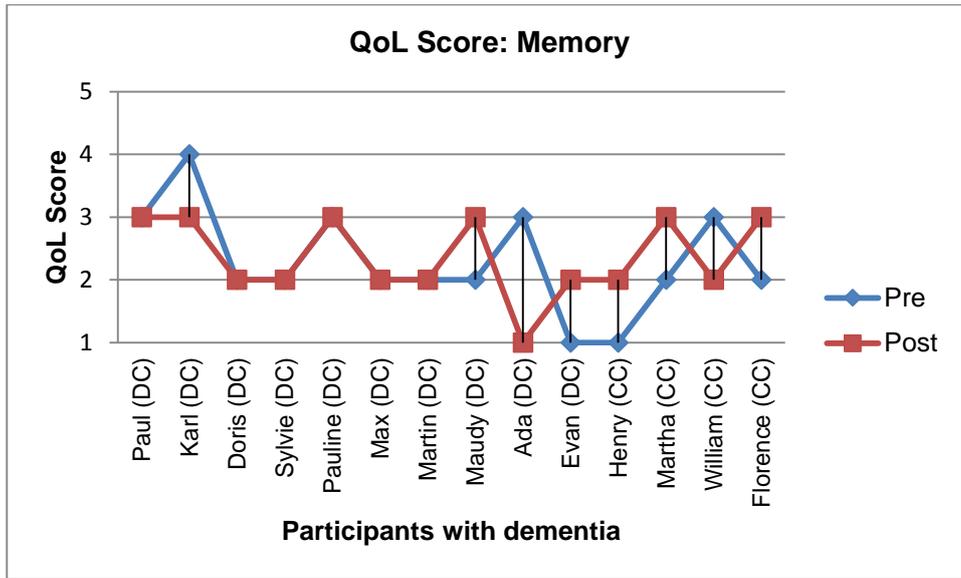
Graph 4: Pre to post QoL responses for living situation



5. Memory

As can be seen in graph 5, when asked ‘How do you feel about your memory?’ the participants considered their memory to range between poor and excellent. Overall, four participants’ feelings towards their memory increased, three decreased and six remained the same, suggesting the Tech Club had no impact on memory for most of the participants.

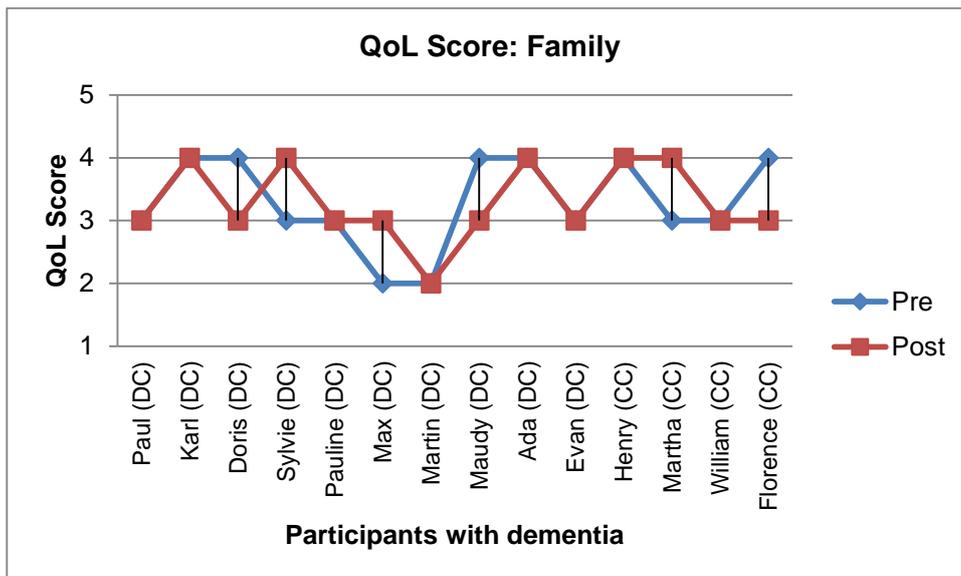
Graph 5: Pre to post QoL responses for memory



6. Relationships with family

Graph 6 presents the responses provided when asked ‘How do you feel about your relationships with your family?’ It shows that the participants considered their family relationships to be between fair and excellent. Overall, three participants’ perception of this domain increased, three decreased and eight remained the same through the duration of the Tech Club. These findings suggest that the intervention made no substantial impact on this area of QoL for the most of the participants.

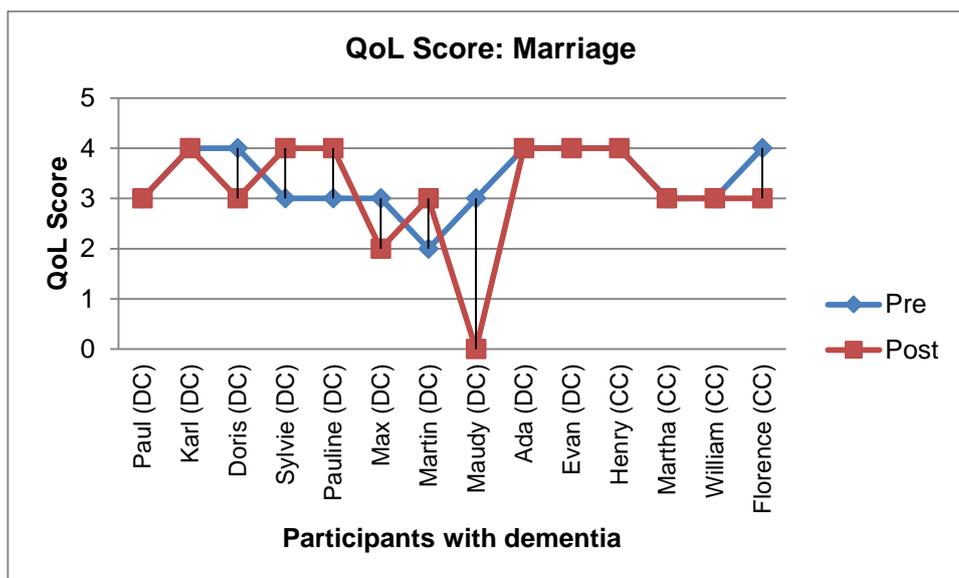
Graph 6: Pre to post QoL responses for relationships with family



7. Marriage

When asked 'How do you feel about your marriage?' some participants shared that they were widowed or not married. In line with instructions provided when conducting the QoL-AD questionnaire the participants provided a response based on their closest relationship. Graph 7 shows that overall the participants considered their marriage or closest relationship to range between fair and excellent. Whilst Maudy initially identified a relative as being her closest relationship during the pre QoL questionnaire, Maudy chose not to answer this question at the post questionnaire stage. As can be seen, three participants' perception of this domain increased, three decreased, seven remained unchanged and one participant provided no answer. These findings indicate no considerable impact was made on this domain by attendance at the Tech Club for most of the participants.

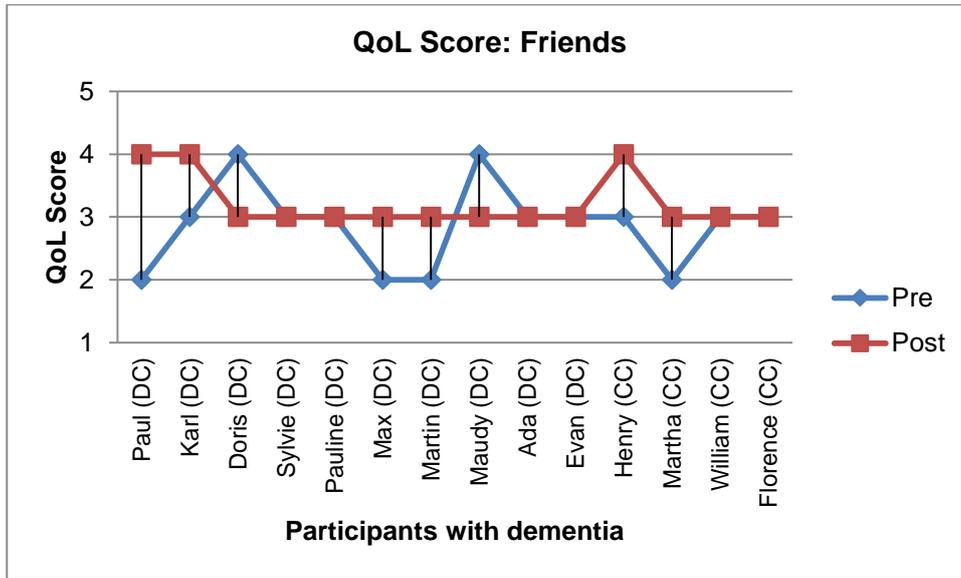
Graph 7: Pre to post QoL responses for marriage



8. Relationships with friends

As can be seen in graph 8, when asked 'How would you describe your current relationship with your friends?' the participants considered these relationships to range between fair and excellent. Over the course of the Tech Club, six participants' perception of this domain increased, two decreased and six remained the same. The findings therefore suggest that the intervention made no considerable impact on this area of QoL for the majority of participants.

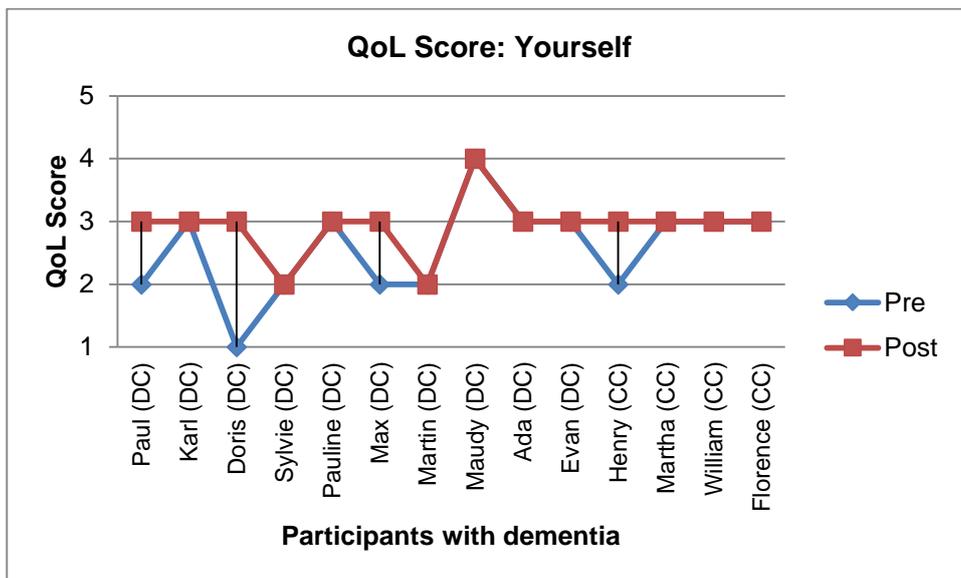
Graph 8: Pre to post QoL responses for relationships with friends



9. Yourself

Graph 9 presents the responses provided by each participant when asked ‘How do you feel about yourself?’ It shows that overall the participants considered their self to be between poor and excellent. As can be seen, four participants’ perception of their self increased and ten remained unchanged. These findings suggest that the Tech Club potentially contributed to an increase in the sense of self for four participants’, whilst for the majority, the Tech Club appears to have had no major impact on this area of QoL.

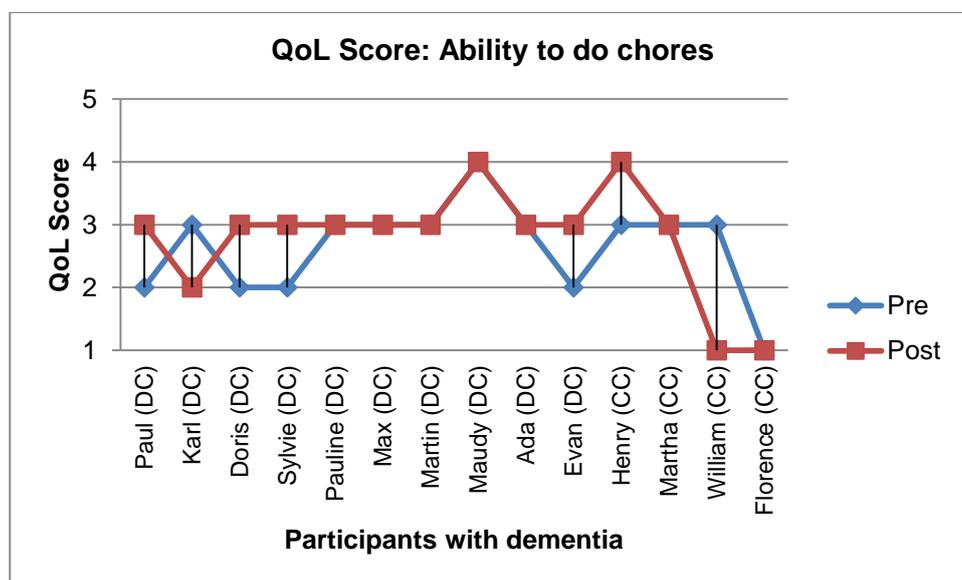
Graph 9: Pre to post QoL responses for yourself



10. Ability to do chores

When asked ‘How do you feel about your ability to do chores around the house or things you need to do?’ graph 10 shows that overall the participants considered their ability in this area to range between poor and excellent. As can be seen, five participants’ feelings towards this ability increased, two decreased and seven stayed the same between pre and post Tech Club. These findings suggest that the intervention made no substantial impact on the ability to do chores for most of the participants.

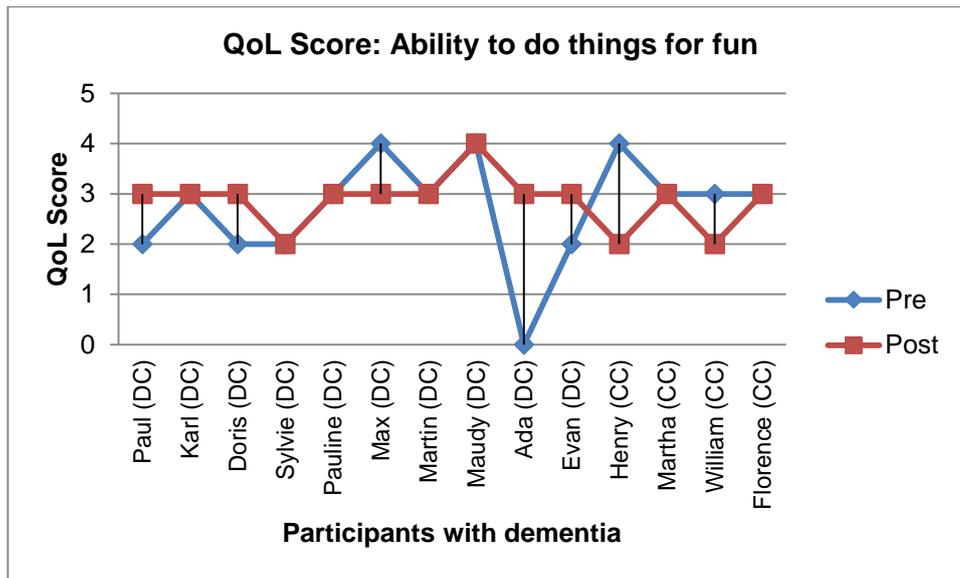
Graph 10: Pre to post QoL responses for ability to do chores



11. Ability to do things for fun

As can be seen in graph 11, when asked ‘How do you feel about your ability to do things for fun?’, overall the participants considered this ability to be between fair and excellent. Three participants’ perception of this domain increased, three decreased and seven remained the same. Ada chose not to answer this question at the pre QoL stage, no reason was provided. The findings indicate that the Tech Club made no impact on this area of QoL for the majority of the participants.

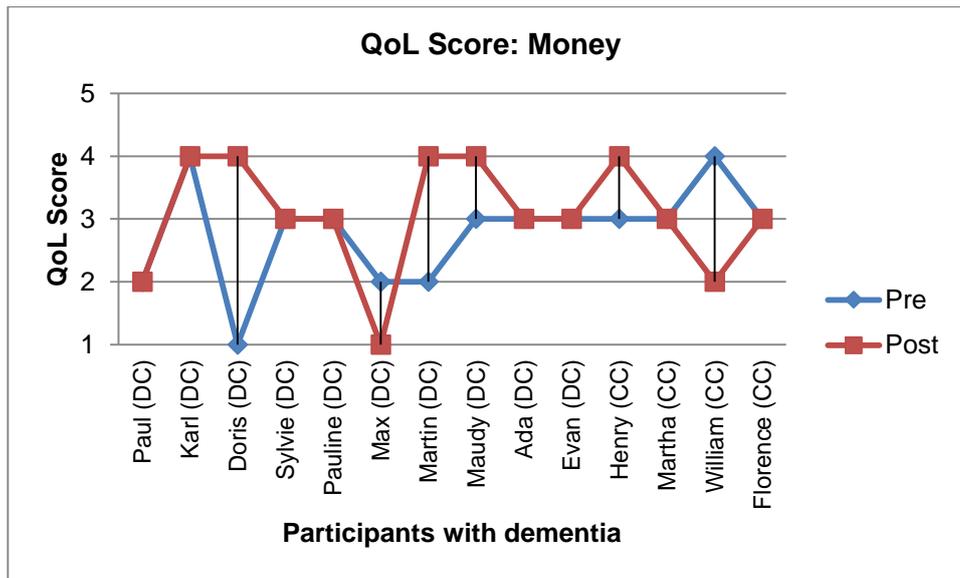
Graph 11: Pre to post QoL responses for ability to do things for fun



12. Money

Graph 12 presents the responses provided by each participant when asked ‘*How do you feel about your current situation with money, your financial situation?*’ It shows that overall the participants considered their money situation to be between poor and excellent. Overall, four participants’ perception of this domain increased, two decreased and eight remained unchanged during the period of the Tech Club. Therefore for the majority of participants the Tech Club appeared to make no impact on this area of QoL.

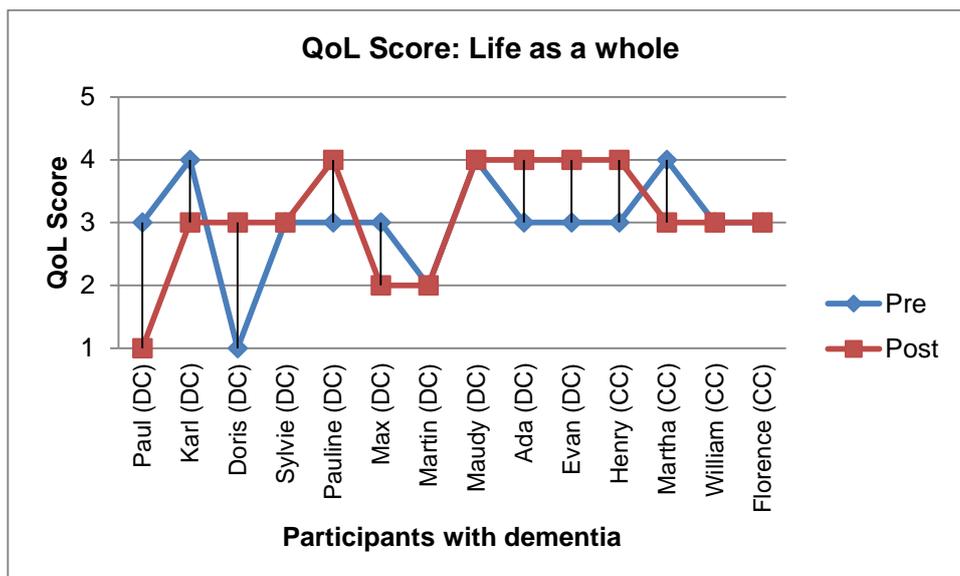
Graph 12: Pre to post QoL responses for money



13. Life as a whole

When asked 'How would you describe your life as a whole?' graph 13 shows that overall the participants considered their life as a whole to range between poor and excellent. As can be seen, five participants' feelings towards this domain increased, four decreased and five stayed the same. These findings suggest that no negative impact was made on this domain by engaging in the Tech Club, but possibly may have contributed to an increase in positive feelings towards this aspect of QoL.

Graph 13: Pre to post QoL responses for life as a whole



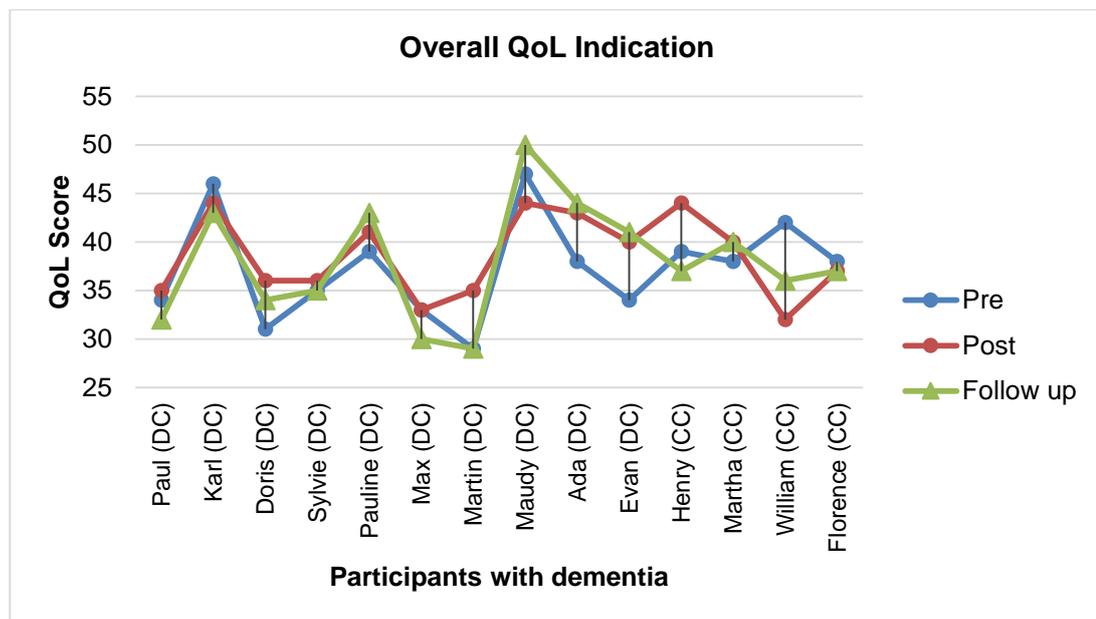
The findings from each of the 13 QoL-AD domains suggest that overall there was no substantial change, either in increase or decrease of any QoL domain, during the duration of the Tech Club. To suggest that a substantial change in QoL had taken place, a greater movement between QoL scores increasing or decreasing would be expected. Table 10 shows that the majority of participants experienced no change in their QoL at individual domain level. Only two domains (domain 8 (friends) and domain 13 (life as a whole)) indicate as many participants experiencing an increase in QoL as those that remained unchanged.

Table 10: No. participants indicating change on the QoL Scale

QoL Domain	Decreased	Remained	Increased	No answer
1. Physical Health	4	6	4	0
2. Energy	2	9	3	0
3. Mood	4	8	2	0
4. Living Situation	2	8	4	0
5. Memory	3	6	5	0
6. Family	3	8	3	0
7. Marriage	3	7	3	1
8. Friends	2	6	6	0
9. Self as a whole	0	10	4	0
10. Ability to do chores	2	7	5	0
11. Ability to do things for fun	3	7	3	1
12. Money	2	8	4	0
13. Life as a whole	4	5	5	0

As can be seen in graph 14, when individual nominal scores are combined to provide one numerical representative for pre, post and follow up QoL, an overview of the participants' QoL is produced. The graph illustrates that holistically, the participants' perspective of their QoL did not change dramatically between the three QoL time periods. Pre and post QoL data arguably provides the most insight into the impact of the Tech Club on this area, yet between these two time periods, six participants' overall QoL score increased, seven decreased and one remained the same. Whilst the graph shows both increases and decreases in some participants' QoL, this change was minimal, suggesting that from this view the Tech Club made no considerable impact on the participants' QoL during this time.

Graph 14: Pre to post total QoL scores



Limitations

This section will discuss the limitations of the data produced by the QoL-AD questionnaire as well as some of the more immediate limitations of the questionnaire itself, as highlighted by the participants. The critique of the QoL-AD questionnaire will be continued in chapter nine, the discussion. The main limitations of these findings are in relation to missing proxy data which renders this dataset as non-representative, as discussed. An additional limitation of this dataset is its inability to withstand rigorous statistical testing. Utilising tests such as Friedman's ANOVA was initially explored; however, it has been decided these could not be undertaken on account of missing data and statistical bias (one proxy providing QoL scores for more than one participant). Due to this, attempts to delve further into the data in this manner would not yield findings of any significance. Therefore, inferential statistics, which take a sample of the data to make generalisations when an examination of the overall population is not possible, were not undertaken. The potential trends identified emerged solely from descriptive statistics, which was deemed the extent of the quantitative capability of this dataset.

Complications with the QoL-AD

Completing the QoL-AD questionnaire proved challenging for some participants as they did not understand the questions or the phrasing of the question when the QoL-AD

script was followed. For example, when the participants were asked to rate a domain of QoL, questions like the below were common:

When the participant was asked *'How do you feel about your living situation, so the place where you live now? Would you say it's poor, fair, good or excellent?'* Ada responded *'Well when you say live do you mean the area, do you mean the way I live, I don't know what the question means?'* (Pre QoL Interview)

When asked *'How do you feel about your current situation with money, your financial situation?'* Evan replied *'What do you mean by that? How you use money, how much money you've got?'* (Post QoL Interview)

When asked *'How do you feel about yourself, when you think of your whole self, and all the different things about you?'* Karl said *'Well, I can't...you've confused me there because I don't know what you mean.'* (Pre QoL Interview)

The findings also suggest that the QoL-AD questionnaire forced responses into one of four categories. Some participants felt that in some cases none of the options really covered their feelings towards the domains, for example, some participants felt that their answers sat in between two of the responses such as good and excellent:

When asked to rate a QoL domain, Evan responded with *'That's a hard one, it's between good and excellent.'* (Follow up QoL Interview)

When asked to rate a QoL domain, Maudy replied *'It's between excellent and good.'* (Post QoL Interview)

When asked to rate a QoL domain William replied *'between fair and good'*, when pressed to choose one, William said *'I should say between fair and good'*. At this point Abigail (FC) said *'no you haven't to have a between, you've to have one or the other'*. William said again, *'between fair and good...well, I'm sorry...it's between fair and good.'* (Post QoL interview)

Extending on this, some participants commented that they did not believe that their feelings towards the QoL domains could fit into any of the QoL-AD categories of poor, fair, good or excellent:

When asked *'How do you feel about your family and relationships with family members? Would you describe them it as poor, fair, good or excellent?'* Paul

(G1) replied '*Well it wouldn't be the same for each person would they? I don't think I can put any one of those things into my feelings?... I can't put it into any of those categories.*' (Follow up QoL Interview)

When asked to rate an area of QoL, Henry (G2) commented '*It's very difficult to put what you want to say into your little box, you leave such a specific area that erm, that's pretty difficult...you can't make them fit easily, you're sort of balancing between one or the other.*' (Follow up QoL Interview)

These findings demonstrate that some of the difficulties the participants faced in understanding and completing the QoL-AD questionnaire was due to the construction of the questionnaire itself. The QoL-AD questionnaire and associated limitations will be explored in greater detail in the discussion chapter.

Research question 2. Does the use of digital gaming technology have an impact on QoL of the participants throughout the duration of the Tech Club?

The findings produced by the QoL-AD questionnaire address the above research question by indicating that from a quantitative perspective, there was no substantial change in the participants' QoL between pre and post Tech Club, suggesting that neither the digital gaming technology nor the Tech Club had an impact on the QoL of the participants with dementia.

In summary, these findings have provided an insight into the QoL status of every participant of the Tech Club (according to the QoL-AD) at three QoL stages. The findings have also highlighted various limitations of the data, subsequently emphasising further limitations with the QoL-AD questionnaire itself, which will be explored in the discussion chapter. Overall the findings of this chapter have illustrated that from a quantitative perspective, using the QoL-AD tool, the QoL of the participants did not undergo any substantial change, from a domain specific level or from an overall standpoint. Despite this, the findings produced from the QoL-AD are however relevant to the later discussion.

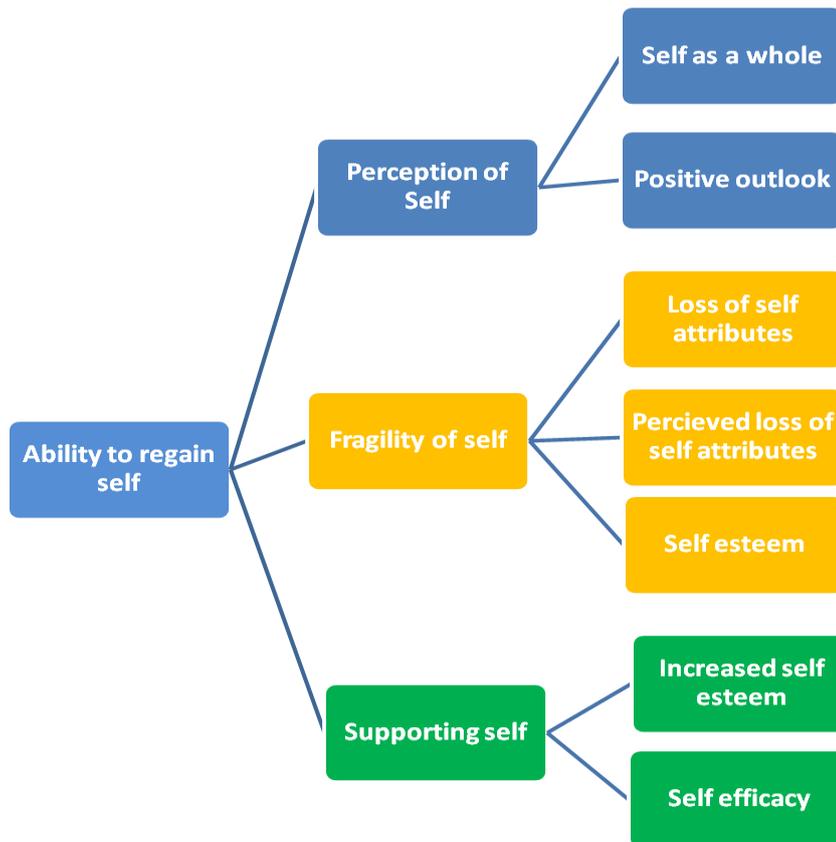
Regardless of the limited insight into QoL produced by using the QoL-AD tool, the following two chapters present the thematic findings which offer an alternative to the concluded findings of this chapter. Chapter seven will now present findings highlighting the importance of self.

Chapter Seven: Ability to regain self

The significance of self in relation to dementia has been discussed within the literature review. The literature highlights that whilst some argue that self is lost as a consequence of dementia (Cohen and Eisdorfer 2002), others (Sabat and Harré 1992; Kitwood 1990) believe that self is actually made vulnerable as a consequence of societal misunderstandings of this condition. Due to this, Sabat (2002) suggests that of a person's three selves (self1 personal identity, self2 personal attributes and self3 role); self2 is at risk, making self3 vulnerable. The findings within this chapter address research questions 1 and 2 which ask; (if any) what are the benefits of a technology based intervention for those with dementia and does the use of digital gaming technology have an impact on QoL throughout the duration of Tech Club?

The findings within this chapter are structured in three interconnected subthemes (Figure 4). Firstly, findings which illustrate the participants' perception of their own self will be presented, followed by the second subtheme which highlights the fragility of self. Finally, findings demonstrating the supporting of self through engagement with digital gaming technologies will be presented. This chapter will conclude by addressing the research questions.

Figure 4: Thematic map of Ability to regain self theme



Perception of self

Findings under this subtheme provide an insight into the participants' perception of their self through their 'self as a whole' and a 'positive outlook', therefore providing a foundation to this chapter surrounding how the participants perceive their self and how an insight into self is captured using the QoL-AD tool.

Self as a whole

Of the 13 QoL domains included in the QoL-AD questionnaire, domain 9 refers to 'self' (Appendix 2). This domain asks the participants 'How do you feel about yourself?' Apart from a prompt which slightly rephrases the question ('When you think of your whole self, and all the different things about you, how would you rate it?'), there is no definition provided to explain the concept of 'yourself' or 'whole self' in this context. It is therefore suggested that this question may actually be referring to selfhood. Due to this, from this point forward, participant responses to domain 9 on the QoL-AD questionnaire referring to 'yourself' or 'whole self' will be inferred as a response to

address how the participants feel about their self. As discussed in the literature chapter, Sabat's (2002) concept of selfhood will be used to understand self in this context.

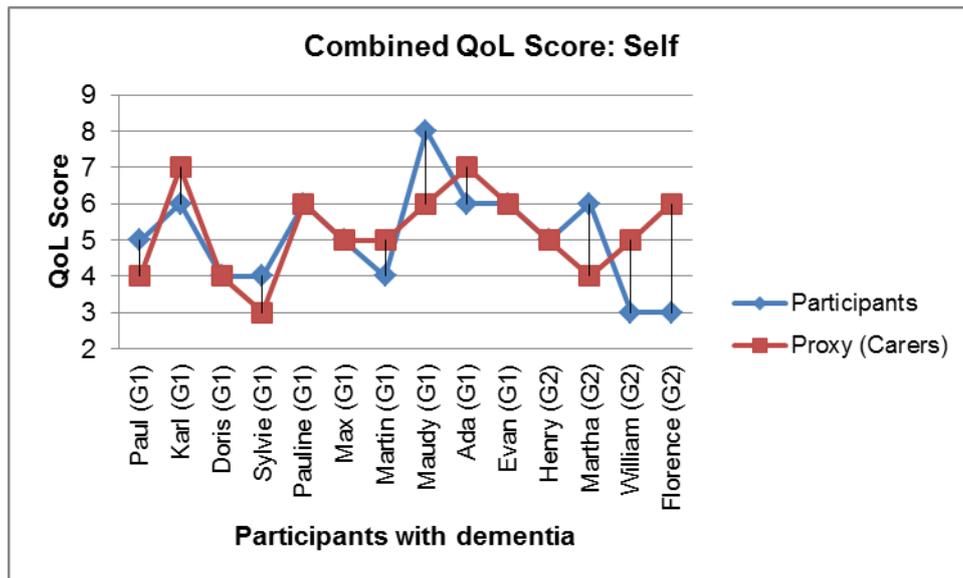
Provided in chapter six were participant responses when asked '*How do you feel about yourself?*' (Graph 9). As explained, the findings demonstrate that overall the majority of participants considered their self to be between fair and good, indicating a fairly positive perception of 'self' from the participants' perspective. Whilst carer (proxy) QoL scores have not be presented due to missing data as explained in chapter six, in connection to the theme of self, the scores are presented as they identify a possible trend.

As can be seen in graph 15, responses provided by carers regarding the participants' self overall (pre and post scores combined, table below) were similar to that of the participants. As can be seen, the responses between the individual participants differed greatly, yet were similar between carers and participants. In four cases carer scores were below that of the participants, in five cases they were the same and in five cases they were higher than the participants' perspective. PCs for Doris and Sylvie did not provide a score at the pre QoL stage and this may reduce these carers' overall score for this domain.

QoL score descriptors

Individual QoL score per domain	Descriptor	Combined QoL score for domain 9
4	Excellent	8
3	Good	6
2	Fair	4
1	Poor	2

Graph 15: Combined responses to QoL question: Self as a whole



Overall, the findings show that the participants consider their self to be fair or above, which was similar to the carers' perspective. This fairly positive response across all participants is supported by additional qualitative data where participants added to their responses during the QoL interview:

'As long as you can get about and do things but if you come to the point where you are stuck in an arm chair, I wouldn't want that. I should have a needle and go. I'm not being cruel but I mean you've got to enjoy what you've got and if you don't enjoy that you've nothing...' (Evan (DC): Post QoL interview)

'Well I'm quite happy. I mean, in some ways, I suppose, I'd prefer to be better but I'm quite happy; I don't want to change it... No I wouldn't change my life.' (Ada (DC): Pre QoL interview)

As illustrated in chapter six, most responses across all QoL-AD domains were indicated to be fair or above. When considering these individual domains against the concept of self, it could be suggested that responses to most of the QoL-AD domains are also indicators of self. For example, mood, memory, ability to do chores, ability to have fun and life as whole, are all manifestations of self² and relations within a marriage, family and friendships are indicative of both self² and 3. Considering the domains in this way would indicate that overall the participants' perception of their self, in direct relation to domain 9, as well as domains 3 – 13, is fairly positive.

Interestingly, when approaching the QoL domains in this way, the findings show a connection made by the participants, where manifestations of self are linked to age. This was particularly relevant when considering the QoL domains of memory, physical health, energy, ability to do chores and ability to have fun, where the participants suggest age related barriers when answering individual domains on the QoL scale:

'I can't remember things because I'm older.' (Maudy (DC): Follow up QoL interview)

'I get quite tired in comparison to what I used to but I am old. So I don't think I'm out of the ordinary when you get to my age, I'm in my 70s.' (Sylvie (DC): Post QoL interview)

'My memory, well, at my age now, I wouldn't say it was really poor. Well, for my age, I would say good.' (Pauline (DC): Pre QoL interview)

This is interesting as it may be expected that dementia would feature as a prominent barrier, however, these findings suggest that dementia potentially has less of an impact on self and other associated QoL domains than age does from the participants' perspective.

Positive outlook

These findings are in response to the last question (domain 13) on the QoL-AD questionnaire, *'When you think about your life as a whole, everything together, how do you feel about your life?'* Whilst there is no prompt question provided within the questionnaire instructions, it is assumed that *'thinking about everything together'* refers to a consideration of all the domains on the QoL scale. As discussed, when considering Sabat's theory (2002), elements of self are exhibited throughout all of the domains of the QoL-AD questionnaire, so responses to domain 13 are inclusive of the 'self' domain and other domains which can be considered to be indicators of self² and 3, therefore providing rationale for the use of these findings under the theme of 'self'.

As demonstrated, graph 13 illustrates the responses provided at pre and post QoL stages when the participants were asked *'How do you feel about your life as a whole?'* The findings demonstrate that overall the majority of participants considered their life as a whole to be between fair and excellent, again suggesting a fairly positive

perception of this domain. A positive outlook on life as a whole is also supported by additional qualitative data where participants added to their responses:

'Well for me I've got a good life. I'm not going to brag about it but I've got a good life.' (Pauline (DC): Post QoL interview)

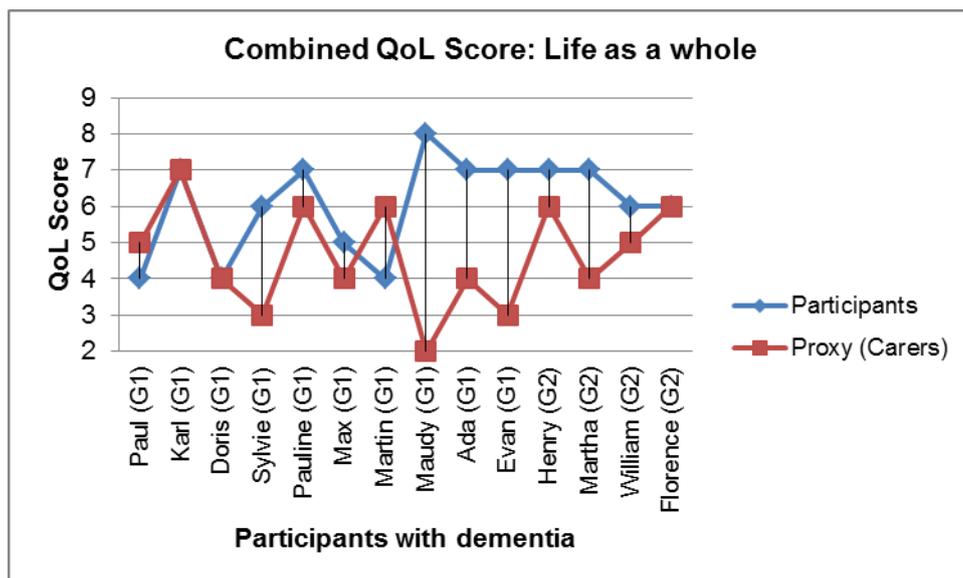
'We've had a good life and that's that.' (Henry (CC): Pre QoL interview)

'I've done everything in my life, anything, very very full of life, I have been very lucky.' (Paul (DC): Follow up QoL interview)

'I just like life really. I feel that I'm lucky, I've not got very much but I'm lucky. I think I'm very lucky.' (Ada (DC): Follow up QoL interview)

In contrast, graph 16 illustrates a greater variance between the combined scores of the individual participants as well as between the participants and carers regarding this domain. In nine cases, carers rated the participants' overall life lower than the participants. Two rated it higher and three were the same as the participants. PCs for Doris, Sylvie, Maudy, Ada and Evan did not provide a score at pre QoL stage, this may reduce these carers' overall score for this domain.

Graph 16: Combined responses to QoL question: Life as a whole



Whilst caution should be applied to these findings due to absent carer data, the findings do suggest a potential trend as the responses from the carers' in the majority of cases are much lower than those from participants. The difference between the consideration of 'self as a whole' and 'life as a whole' from the carers' perspective may be attributable to missing data but could also be a result of the lack of understanding around the concept of self and what this means.

In summary, the findings from this subtheme illustrate the participants' perception of self is largely positive, therefore providing a foundation for the rest of the chapter. This responds to Caddell and Clare's (2010) suggestion that it is important to understand how people with dementia recognise and experience self, as this enables an understanding of how this concept impacts on the lived experience of dementia. The findings also highlight the complex nature of the concept of self and potential implications when trying to capture an understanding of it. This section has demonstrated that self cannot be captured in one domain as attempted by the QoL-AD questionnaire.

Fragility of self

As explained in the literature review chapter, the very nature of being diagnosed with dementia can lead to stigma and labelling and can alter the way others see and therefore treat those living with this condition (Kitwood and Bredin 1992; Kitwood 1990; Goffman 1963). Findings highlighting the fragility of self through the potential physical loss of self2 attributes as a result of dementia will now be presented. This will be followed by the second theme which offers findings that demonstrate the perceived loss of self2 attributes as a potential consequence of societal perception. This section will conclude with findings that suggest that the self esteem of the participants may have been negatively impacted on as a result of the overall loss of self2 attributes.

Loss of self attributes

As explained, those with dementia are at risk of experiencing a twofold loss of 'self' as a consequence of dementia and societal perception. These findings illustrate the role dementia plays in connection to the loss of self2 attributes which concerns ability, preferences and hobbies. For example, the participants described difficulties associated with memory:

'That's one thing I haven't told you, my memory isn't as good as it used to be. People used to say 'Sylvie will know' but Sylvie doesn't always know now.' (Sylvie (DC): Follow up QoL interview).

'My memory is not good, it's, well I suppose its poor but not on all things you see. I remember some things ever so well and other things I can't remember so it's a bit iffy.' (Ada (DC): Post QoL interview).

Another participant described experiencing reduced communication skills which has impacted on his ability to understand information and has resulted in avoidance of conversation and evasion of social contact. Initial loss of this self2 attribute has led this participant to view his life as narrow and therefore potentially isolating:

'I find that it gets embarrassing when someone tries to tell me something and I don't understand and so I really, we steer clear. We see people to say hello to but I don't get into any conversations or things like that because I feel like an idiot...I just have to accept I am as I am... I mean really, I know I've got a narrow life... I'm frustrated that I can't do what I want to do.' (Henry (CC): Pre QoL interview)

Participants also described reductions in their self2 attributes associated with a reduced aptitude to undertake hobbies, which in some cases also resulted in additional loss of independence:

When asked what hobbies Doris liked to undertake, Doris replied *'I used to do knitting but I can't seem to do that lately.'* (Doris (DC): Follow up QoL interview). This was associated with Doris's reduced ability to comprehend knitting patterns.

During a conversation when Henry proclaimed that he didn't have any hobbies, he was asked what he would like to do, Henry replied, *'What I would like to do is what I used to do at one time in my life was televisions and things like that, repairing them.'* (Henry (CC): Pre QoL interview). Henry was unable to fix televisions due to his inability to work because of dementia.

When asked what Evan enjoyed doing, he responded, *'I used to be able to walk down the shops, and all that. I used to walk round and get my paper every morning...but I don't do that now'* (Evan (DC): Pre QoL interview). This was associated to reduced memory skills.

This is in addition to frustration which some participants experienced as a result of loss of self2 attributes. Doris (DC) for example, was engaging in a conversation but was having trouble articulating what she wanted to say. This led to Doris becoming frustrated at the loss of this ability which she directly deemed was a result of her condition:

'...See this is what happens to my damn brain, it won't work properly these days...and it annoys me.' (Pre QoL interview)

Findings in this subtheme support existing literature by suggesting that self is at risk by dementia as a degenerative condition. These findings illustrate the fragility of the participants' self2 and the impact of new self2 attributes as a result of cognitive deterioration which has resulted in lack of memory, reduction in hobbies, lowered self esteem and unsociable behaviour. The findings demonstrate that the participants are aware of their ailments, highlighting an understanding of the loss of certain skills (self2 attributes) which has led to feelings of isolation, dependence and frustration.

Perceived loss of self attributes

Whilst the above findings have identified dementia as a risk to the participants' self2, within the context of the Tech Club, the following findings suggest an additional significant risk to self2 is other people. In this section the findings demonstrate an assumption surrounding the participants' lack of the self2 attributes regarding communicative skills, information processing and decision making. Assumptions around loss of self2 attributes led to increased carer involvement within the Tech Club as some carers' held the belief that the participants lacked capability because of dementia:

'...When he [William (DC)] was normal he was very astute and very you know, grasped things right away...now he can't put a sentence together because he's forgetting what he was talking about. The trouble with Alzheimer's is that you can only take so much information in at a time...he can't take a lot in, especially as you say, all in one go. Slowly can take bits in, but the brain has got to the stage where new information can't go in.' (ESD.S1). *'You shouldn't ask people with dementia questions because their brain can't handle it.'* (Abigail (FC): QoL notes)

When asked if the carers' felt that the Tech Club were of benefit to the participants' on the evaluation form, Abigail (FC) commented *'Only if the*

participant has some memory. William had forgotten by the time we had travelled home...he is too far GONE to be of any use.' (Carer Evaluation Form)

In one situation, Abigail (FC) identified a distinct difference between the role of a carer and the participants with dementia by commenting to a participant with dementia that they were a *'cared for'* and that she was a *'carer'*. This supports the labelling concept that the participants are no longer seen as *'social beings'* but as *'patients'*, or *'service users'*.

In this case, from Abigail's perspective, William is now invalid because it is perceived that he has not only lost his ability to remember but also the skills required to construct a sentence, absorb information, process new information and answer questions. Despite William's academic background in which he was an educator within higher education, it appears that he has been stripped of his academic achievements (self2) and status to someone who now has dementia (self3). This aligns with Sabat's (2002) suggestion that new self2 attributes become the focus, with existing attributes diminished.

Here the findings show the carers' answering on behalf of the participants, therefore indicating an assumption of the loss of self2 attributes regarding ability to answer for themselves:

During the first session (S1) of the Tech Club, Florence (CC) was asked whether she had used an iPad before. Florence nodded to indicate *'Yes'*, but before she had a chance to verbalise her response, Phil (FC) replied on her behalf *'Florence hasn't really, but I have a bit.'* (Video observation notes.S1). This happened again during a QoL interview where Florence was asked to rate her ability to undertake chores around the house, Florence was about to verbally respond but Phil jumped in and replied *'I think that goes under poor'* (Post QoL interview), making the decision for Florence.

In some cases, during the QoL questionnaire interviews, carer's disagreed and overturned the participants' responses in front of them:

When asked how William felt about his memory, William answered *'Well, fair'*. Abigail instantly questioned this response by asking *'Your memory is fair?'* When William replied *'I would think so'*, Abigail commented, *'It's amazing how his answers are quite different to mine, a lot of them are, I mean, he thinks he's got a good energy or fair energy, and I would think it's non-existent...I got three*

poor's, how many poor's did he get?' When it was replied 'One?' Abigail continued 'Only one, oh...I think he said memory was fair, didn't he? I mean, he might say something to you and I can't hear him, so I pop in and say, sorry, what did you say? He says, I've forgot, it's gone, within seconds it's gone. So I'd never ever say his memory is fair.' (Pre QoL interview)

This happened consistently to William (CC) when he was willing to answer a question but being unable to do so as Abigail (FC) answered for him or challenged his response. He commented on this, showing that it was having a negative impact as he felt excluded. This comment was made when Abigail had left the room briefly and he was asked 'How are you?' :

'The only thing is occasionally, well more than occasionally, part of you is left out of the conversation...' (Pre QoL interview)

William's comment '*part of you is left out*' suggests that whilst he is physically there, the other part of him, 'self', is left out. Interestingly William does not refer to himself as 'me' or 'I' but refers to himself in the third person of 'you', also potentially suggesting a loss of self¹.

In some cases, during the QoL interviews, carers attempted to influence the participants' response in some way through pressure:

During an interview Henry was asked to comment on the marriage domain of the QoL-AD, at this point he was sat next to his wife Catherine (FC). When asked, '*How do you feel about your marriage?*' Henry turned to Catherine and exclaimed '*Stop punching me*'. Catherine then looked away and Henry then responded '*Excellent*'. (Post QoL interview)

During an interview William was asked to rate an area of QoL. William was taking his time to consider this but was being rushed by Abigail (FC) who commented '*Which will it be? You've got to make your mind up, one or the other...yes yes we know that, but, I mean, you've got to just think about it and say an answer*'. William replied '*I should say between*', Abigail interrupted '*No you haven't to have a between, you've to have one or the other...I thought that was the easiest one.*' (Post QoL interview)

The participants also experienced potential pressure to take part. Here the findings illustrate that the participants were repeatedly encouraged to take part in the activities by peers, carers and facilitators, even after they declined the offer:

Martin (DC) was asked if he would like to play on the Nintendo Wii and the reply was 'No'. 'Are you sure?' asked the facilitator. 'Yes' was the answer. The participant was then asked again at which point other participants were saying 'Come on' and then Martin got up to play the game. (Video observation.S5)

Evan (DC) was asked if he wanted to have a turn on the Xbox Kinect memory game, the reply was 'No not really'. The facilitator insisted in a friendly way and the PC in the room shouted 'Go on'. The participant stood up and said 'I ain't got no memory'. After having a turn Evan (DC) said 'Does someone want to have a go please?' At this point the participant had not finished or completed his turn. (Video observation.S6)

For participants of the CC, their FCs were present during all stages of the Tech Club, whereas FCs for the participants of the DC were not. However, both sets of participants' experienced carers (family and professional) 'taking over'. In this scenario, some carer's began the required activity on behalf of the participants without invitation, therefore illustrating the perceived loss of the participants' ability to do this for themselves:

Participants' of (CC) were invited to use the iPad to take pictures of the room using the camera app. Catherine (FC) was holding the iPad at the time and proceeded to take a picture of Henry. Catherine showed this to Henry and the other participants. Catherine pulled the iPad away from Henry so that he could see the picture only, Henry never got to use the iPad. (Video observation.S6)

Similarly participants' of the DC were invited to use the iPad to take pictures of the room, the garden or each other. The PC in the room, who was sat with some of the participants, took the iPad and asked the participant's what they wanted her to take pictures of. The carer allowed Pauline to walk around the room with her but never let her hold the iPad or take pictures for herself. (Video observation.S6)

During the session it was noticed that Florence (CC) had not used the iPad and so was asked by the facilitator 'Are you starting to get an idea about how to use the iPad?' Florence replied 'Only a little bit'. Florence was then asked, 'Have you had a chance to hold it?' Florence looked over at Phil who was holding and undertaking the allocated activity on the iPad and replied 'Not this morning no'. (Video observation.S3)

William was looking at the iPad and was attempting to play Solitaire, Abigail then took the iPad from William and completed the game alone. (Observation notes.S5)

Carers taking over was a common finding evidenced within the Tech Club, which was also suggested to happen within the home environment. This supports the findings that there is an assumption surrounding the loss of self2 attributes, despite the participants being able to undertake activities; others simply think they cannot. For example, when asked about ability to do chores around the house Maudy commented that whilst she enjoys and feels able to do the housework, it is done for her:

'I don't do them. I can do everything but I don't because they're [relatives] there you know.' When asked if Maudy could do the chores herself, Maudy replied *'Oh god yes...I could do the washing up and everything'* (Post QoL interview). *'The thing is my brother and sister-in-law they look after me and say 'I'll do that, I'll do that'...they do everything for me which I would like to do things for myself...It's always, 'I'll do this, I'll do that'.'* (FU QoL interview)

Overall, these findings illustrate that Kitwood's standard paradigm is still a dominant thought process and how this way of thinking can be a risk to self2 attributes. The findings align closely with Kitwood and Bredin's (1992) malignant social psychology theory whereby the participants of the Tech Club experienced disempowerment and infantilisation through the lack of acknowledgement of the participants' preference when answering 'no' and the use of excess care (doing it for them) resulting in excess disability; intimidation through physical coercion to answer questions in a certain way or the use of pressure; outpacing through being rushed to answer questions at a speed deemed appropriate to someone else; invalidation through reduced opportunity for involvement in activity due to an assumed inability and lack of communicative, decision making and information processing skills and labelling where participants were referred to as 'cared for'. Therefore, these findings show that there is a perceived loss of the participants' self2 attributes from the carers' perspective, especially surrounding the perceived skills required to engage in the activities of the Tech Club and QoL questionnaire interviews.

In summary the findings of this subtheme align with Sabat and Harré's (1992) research, that within the context of the Tech Club, the carers were focused on the perceived dysfunctional elements of the participants' self2. These findings also align with Brody et al. (1971) excess disability theory, which suggest the use of excessive care or reaction

to a person, beyond what is required can lead to additional losses of skills and ability. Overall, as evidenced within these findings and as Sabat and Harré (1992) suggest, self2 is significantly reliant on the cooperation of others to exist, therefore demonstrating the fragility of self2 which if at risk or lost could result in the reduction of self esteem.

Self- esteem

Within this subtheme the findings suggest that the participants may have been experiencing reduced self esteem (confidence in one's worth and abilities) through the lack of confidence in their own ability and expressions of low self-worth.

There was a general lack of confidence in ability displayed during the Tech Club when the participants first engaged with the technologies. This was especially in connection to the Xbox Kinect and the Nintendo Wii where there was an instant assumption made by the participants about their own ability (or lack of) when invited to take part:

'No, I won't be able to do it.' (Pauline (DC): Observation notes. S1)

'I would like to give it a try but I'm not capable.' (Sylvie (DC): Observation notes. S1)

Whilst there was an initial lack of confidence expressed with using the technologies, there was a greater reluctance from the participants to take part in games which potentially highlighted loss of a previous skill such as driving. When introducing driving based games to the participants of the DC, participants did not want to engage even though all participants had previously driven, with some doing it for a living. Whilst most participants eventually engaged with the game, one participant's self-confidence was very low:

It was widely known within the day centre that Max (DC) was previously a lorry driver. Max told stories of his travels and his skills as a driver across Europe to the PCs and his peers. When invited to take part in the driving game on the Nintendo Wii, Max did not want to engage in the game at all and proceeded to watch the others play. Other participant's attempted to encourage Max to have a turn and after declining several times Max decided to play the game. Max took the game very seriously and whilst others laughed during their turn, Max was quiet and maintained concentration. He walked away from the game and added *'I'm not very good'* (Video observation. S4), despite his ability to manoeuvre the vehicle and to complete the lap, potentially suggesting that Max

did not believe his performance represented his past skill. (Observation notes. S1)

Max's lack of confidence was noted by a PC who commented:

'I think with Max, he's been a macho man all his life, he's driven lorries and he's done all that sort of thing, and he's probably sitting there thinking, if I make a muck-up of it like all the rest of them they're going to laugh at me, and they don't like it men don't; they've got that thing about it.' (Dawn (PC): ESD. S4)

Lack of confidence surrounding ability was also evident by the participants' initial responses to success. When successfully completing a game or required action, there was a general disbelief that the success was a result of their ability. Instead, the participants attributed this to 'luck':

After playing Wii bowling, Henry (CC) was praised on his ability, the facilitator commented *'You did excellent then'*, Henry replied *'No, it was just luck'*. (Video observation. S1)

During a game of bowling on the Wii, Martha (CC) had many attempts to knock the skittles down, with support. After a while, Martha was able to throw the bowling ball unassisted, which resulted in some skittles being knocked down. When Martha received acknowledgements of this accomplishment, Martha commented *'That was more by luck.'* (Video observation. S1)

When using the iPad to play the memory match game, William was initially having trouble understanding what he was required to do. William then selected two of the same cards. William was commended, but he replied that this achievement was a *'fluke'*. (Video observation. S2)

In addition, there also appeared to be a sense of embarrassment displayed by some participants after succeeding in an activity, in this case when using the iPad. The below findings highlight a participant appearing to be embarrassed as a result of her success when questioned by another participant. Florence's (CC) response to this was particularly interesting as she had previously played the game independently and successfully in other sessions yet had never previously attributed her success to 'luck':

When playing the memory match game Florence got two of the same cards. Martha said *'Did she get two the same?'*, *'How did you do that?'* and Florence replied *'It was just a guess, there was no skill I'm afraid.'* Florence was quiet

and then refrained from the game slightly after this. (Video observation.S4)
Florence (CC) got a card match on the memory match game, Martha (CC) said '*You are better than this than I am*'. Florence said '*No.*' Again, Florence refrained from the game after this. (Video observation. S5)

These findings may suggest that Florence was experiencing low self-confidence and esteem in herself to the point that she was trying to stay within the boundaries of what was expected of her based on the perceived new self attributes she should be displaying (reduced memory, reduced ability and reduced skill). Florence was unable to identify with her own success or skills, highlighting that this participant may be living up to the self-fulfilling prophecy.

Despite attributing success to 'luck' and potential embarrassment around this, the participants displayed reactions of disappointment in their performance, especially when using the Nintendo Wii:

Karl (DC) found the arm action very difficult and when he sat down he said quietly '*What a load of rubbish*' in reference to his performance. (Julia (PC): Diary)

Martha (CC) got into place ready to play the Wii but then sat down and sighed after she was unable to perform the required action, commenting '*I'm not very good at this at all*', '*I'm not doing it properly, you'd better get someone else.*' (Video observation. S1)

'Paul (DC) was talking to the PC about his turn on the Wii, when the carer said '*You did well*', Paul replied '*Well? I did poor*'. He then spelt poor out for the carer '*p- o- o- r*.' (Video observation. S6)

These findings demonstrate more than disappointment in ability, they indicate that the participants actually had a desire to achieve and to do well, but when they did not perform as they wanted to, they then displayed expressions of low self-worth through the use of words and phrases such '*rubbish*', '*I'm not doing it properly*', and '*poor*' in reference to themselves. Groenewoud et al. (2017) found that perceived failure when using the iPad in particular was reported to create annoyance and insecurity in participants, however this was attributed to be a result of a mismatch between the expectations of those with dementia and their interests. The findings of research also align with this as negative experiences seem to be associated with self-expectation, but not attached to interests and closely connected to perceived lack of ability.

Whilst the cause of lowered self esteem cannot be ultimately identified, it is a fair assumption that a potential cause of this is related to the experiences of reduced self attributes and associated treatment from others. These findings demonstrate how some participants experienced low self-confidence in their current abilities to undertake the activities of the Tech Club and in their previous abilities highlighted through a reluctance to engage in activities which could potentially highlight the loss of these self attributes. They also demonstrate low self-confidence through an assumption of inevitable failure when undertaking activities within the Tech Club and lowered self-worth when not succeeding as hoped for. Even when succeeding, low self confidence and self worth restricted the participants' from identifying with this success as their own and through potential embarrassment deny their ability and skills, supporting and building on the concept of the self-fulfilling prophecy. All of which could contribute to the continued fragility of and therefore perceived loss of self attributes from others perspectives, further exacerbating those with dementia being exposed to discouragement and failure through the display of lowered self esteem (Kitwood 1990). Because of this, more research is necessary to explore how self can be supported (Kelly 2010).

Overall, the findings from this subtheme provide an alternative viewpoint of self when compared to the findings produced in the subtheme of perceptions of self. Whilst it appears that a fairly positive outlook regarding self is held by the participants, the findings within this subtheme suggest that the participants' self is at potential risk despite their own perceptions of this area of QoL. The following subtheme demonstrates what is possible when the health of self attributes of those with dementia are assumed and supported.

Supporting self

Thus far the findings have identified the fragility of the participants' self, however the findings in this subtheme highlight the supporting of 'self', whereby the participants displayed alternative self attributes when engaging with the digital gaming technologies within the Tech Club. Findings highlighting an increase in self esteem will now be presented. This will be followed by findings displaying expressions of self efficacy and the affirmation of self attributes. This chapter will conclude with a brief summary where relevant research questions will be addressed.

Increased self esteem

As identified, the participants lacked general self esteem when engaging with the digital gaming technologies. These findings of this subtheme suggest that there was a general increase in the self esteem of the participants throughout the duration of the Tech Club, where there appears to be a growth in self2 attributes of confidence, communication, pride and dignity. For example, it was observed within the second session of the Tech Club that the participants' confidence in using the Nintendo Wii and Xbox Kinect had increased:

More participants were getting up straight away when invited to have a turn on the Nintendo Wii or Xbox Kinect, for example, after the participants who wanted to have a try took their turn, those who originally said 'No' were invited again. (Observation notes. S1). In the following session, when invited to take part, most participants got up straight away when invited the first time. (Observation notes. S2)

A growth in confidence was also evident on an individual basis of those participants who initially displayed a lack of confidence. Sylvie (DC) first commented that she did not want to take part in the activities, especially using the Nintendo Wii and Xbox Kinect, as she felt she was '*not capable*'. It was later observed in subsequent sessions by a PC that there had been a shift in Sylvie's confidence in using the technologies:

'Sylvie (DC) started to build her confidence up as the sessions went on.' (Diary). Sylvie's confidence grew throughout the sessions by slowly using the technology on her own time and becoming happy to take part and have a go whenever she was invited. (Observation notes. S5)

Max (DC) also initially lacked confidence in using the technologies, especially those which may have highlighted a potential loss of skill. Again a PC observed that Max's confidence to try new games and use the technologies was increasing:

'Max's confidence was getting better the more he was playing the games.' (Eve (PC): Diary)

The findings also illustrate a growth in participant confidence surrounding communication and the use of their voice to express preferences, ideas and dissatisfaction. Henry (CC), who originally declared that he avoided conversation and socialising because of a loss of self2 attributes around his ability to retain information

and communicate effectively, grew in confidence throughout the Tech Club enabling him to confidently converse with his peers rather than avoid such interaction:

Despite Henry's lack of confidence at the beginning of the sessions and a preference to sit with his wife, after a while he gained the confidence to sit with the group alone and effectively communicate with other participants to the point where he was able to explain to others how to use some of the technology equipment. (Observation notes. S5)

Within the Tech Club, participants were encouraged to talk freely and express their thoughts, opinions, ideas and concerns. It was evident that for one participant, William (CC), this was a rarity as during the sessions he was consistently overshadowed by his carer, who answered questions for him and talked freely about him, giving the impression that William was unable to communicate effectively. At first William was selective in his replies and often remained quiet. However, during the Tech Club, William's confidence appeared to grow as he exercised his right to express himself. When doing so, William was not only capable of effective communication but he used this to aid his understanding of the Tech Club, demonstrating an increase in confidence to stand up for himself and an increase in pride and dignity. William increasingly commented on the pace of the instruction or the session indicating that he acknowledged that he needed more time to process information and was confident enough to request this:

When instruction or information was provided to the participants, William was vocal when this pace did not suit him '*You are going far too fast.*' (Video observation. S4). Also during a session where the A4 iPad activity sheet was provided to the participants as a choice to guide their activity, William was asked by the facilitator if he had any questions regarding the activity sheet. William responded with '*I need to absorb what's on the sheet before I can ask questions.*' Indicating that he acknowledged that he needed more time to process the information and was confident enough to request this (Observation notes. S5). When collecting the participants' thoughts and opinions on the Tech Club when completing the evaluation form, William was asked if he had enjoyed the session, William replied '*I'd rather have some chance to think about it.*' (Observation notes. S5)

William commented that he had not understood some instruction provided in the session, the facilitator suggested that they talk about the purpose of the iPad to aid William's understanding. To this William commented '*It's an enormous*

learning curve.' The facilitator replied '*I understand*', to which William replied '*I don't think you do actually love.*' (Video observation. S4)

It should be noted that William was much more vocal when the carers were moved to another table, away from the participants. The findings suggest that this had a positive influence on the participants. This observation was also noted by the facilitator during the session:

'The decision of separating the participants from their partners was good. For instance, William and Martha were more lively and communicative on their own, different people...' (Observation notes.S2)

Martha (CC) was in a similar position as her carer also constantly answered on her behalf. However, throughout the duration of the Tech Club Martha's confidence also grew as she began to express her thoughts about the Tech Club, demonstrating self belief in her own opinion. For example, rather than sitting quietly as was the case during the QoL interviews, at the start of the Tech Club, Martha became very vocal, especially if she did not understand an element of the instruction provided:

When information or instruction was provided regarding the technology, Martha commented '*I don't understand a word of what you said really.*' (Observation notes. S1) During session two Martha was very vocal throughout the session when there were elements which she had not understood '*I don't really understand what I am doing*', '*I still don't see what you are talking about*', '*I still don't know what you mean by look for the other card.*' (Video observation. S2)

When introducing the Xbox Kinect driving game to Martha, the facilitator said '*I think you will like it*' [in reference to the game]. Martha replied '*Well I expect that's your opinion but I will tell you if I don't.*' (Video observation. S2)

Not only do these findings suggest a growth in confidence but alongside this there appears to be an element of confrontation which may be the result of having the freedom to express themselves after potential suppression of this element of self2.

Along with a growth in confidence, the findings show that the participants also experienced pride and dignity in both what they were undertaking and the result of this. After initial lack of confidence when using the technologies, as confidence grew, so did the participants' aspiration to succeed and do well. It was not enough for the participants to simply take part; they displayed pride and dignity in what they were undertaking, particularly when using the Nintendo Wii and Xbox Kinect:

When playing the tightrope game on the Nintendo Wii balance board, Ada (DC) was asked if she would like another turn to attempt a better score. Ada replied, *'I won't be any better but I will try'* (Observation notes. S3). Again, when playing the Wii fair game ride, Ada was very close to completing the objective of the game, Ada said *'I'm trying my best'* and that she wanted to carry on and try again. (Video observation. S5)

'Martha (CC) was keen to try all games and make sure she did the right actions in order to play the game properly mastering which way to move the Wii.' (Natalie (PC): Diary). This was supported by Martha exclaiming that she was *'rubbish'* during this game but that she will *'do one more to try again.'* (Video observation notes. S1)

William (CC) explained that an aspiration to succeed is an innate feeling which most people experience and therefore seek, regardless of dementia or not:

'The thing is that normally people like to succeed, they like to grasp at something and find within a short length of time they can get some satisfaction out of it...' (ESD. S1)

This is supported by the previous findings in which some of the participants experienced feelings of disappointment around their ability when using the technologies, indicating sentiments of lowered self-worth. The below findings illustrate that as confidence grew, aspirations to succeed were identified and a sense of pride and achievement was the result:

After Doris (DC) completed her action of selecting a Mii character feature on the Nintendo Wii, the rest of the group clapped and Doris turned to face the group, smiled, took a bow and then returned to her seat smiling and giggling. (Video observation. S1)

'Martin (DC) was enthusiastic to try all the Wii games but when playing the fairground basketball game he successfully threw several balls into the net. Once the game was over he punched the air in triumph.' (Natalie (PC): Diary. S3)

When using the iPad piano app Maudy (CC) was very happy with herself after she was able to play seven keys in a controlled manner, one after the other.

Following this, Maudy turned to the facilitator and said '*You know what I did? I did seven all in a row.*' She was smiling lots. (Observation notes. S2)

These findings highlight a potential transition from a lack of self esteem surrounding confidence, to a growth in self esteem and these self2 attributes. Confidence in ability grew through more participants engaging with the technologies and through increased conversation amongst peers, by providing thoughts, opinions and asking questions. Growth in confidence also resulted in an increased sense of aspiration through wanting to do well, wanting to succeed and pride and dignity through a sense of achievement in their own performance and ability. This therefore identifies one potential benefit of a technology based intervention, as increasing self esteem can counterbalance the fragility of self2, contribute to healthy ageing (Cutler et al. 2016) and as Kitwood (1990) suggests, the maintenance of self esteem is necessary to enable learning and efficacy.

Self efficacy

The below findings build on the previous section by illustrating expressions of self efficacy (a person's belief in their own ability to succeed) as the participants' self esteem and confidence in their ability to engage with the technologies grew. Within the Tech Club, participants showcased belief in their own ability through the rejection of support when using the technologies with the clear message that they were capable of doing these activities on their own:

When completing the evaluation form Martin (DC) was being assisted by a PC to complete the form. Martin took the pen from the PC to tick the boxes and complete the form himself. (Video observation. S6)

When playing the Nintendo Wii bowling game, the facilitator asked Doris (DC) '*Do you want me to press anything?*' Doris replied '*No*'...The facilitator tried to offer Doris instruction on her second go but Doris said '*I know how to do it*' in an annoyed tone. (Video observation. S2).

When playing the Nintendo Wii ice cream balance game, the facilitator asked if Paul (DC) would like another go and he said '*Yes*', the facilitator said '*Shall we do it together?*' Paul replied '*No, I can do it on my own.*' (Video observation. S2)

This extended to belief in the participants' own capability to engage with the technologies independently but also physically alone without interference of others:

Paul (DC) suggested in the discussion that he would like to use the iPad alone in the next session, *'Paul said he would like to have had more opportunity to use the tablet himself.'* (Natalie (PC): Diary)

Catherine (FC) was using the iPad alone and not including Henry (CC) with it at all, Catherine then placed the iPad on the table and Henry picked it up. At this point Henry was not sharing it and held it directly in front of himself where he was using it alone. Catherine leant over to tell him to press a button and to lower the volume but Henry moved the iPad away from Catherine and carried on with his activity (Video observation. S5). During this session Henry was heard commenting that *'he likes to play and fiddle with the iPad himself'*, and on the evaluation form he commented that he enjoyed being left alone and when asked what was enjoyed the most about the session he replied *'Being left alone with this actually [iPad].'* (Evaluation form. S5)

After working together and supporting Martha, the facilitator suggested that Florence (CC) might prefer to go through the iPad guide and work through it herself at her own pace. Florence agreed to this and was very happy to be doing this alone. (Video observation. S4)

During a session where participants were working together the iPad was placed in between Martha (CC) and William (CC), both had their hands on it, yet Martha took the iPad and placed it in front of her for her sole use (Video observation. S4). During another session, Martha commented that she was having difficulty seeing the screen *'I'm going to find that too hard as I don't have my glasses on.'* The facilitator zoomed the page in to assist Martha but Martha exclaimed *'Give it to me'* and took the iPad from facilitator. (Observation notes. S6)

The rejection of support and therefore belief in the participants' own ability is also highlighted by the refusal of physical support when using the Nintendo Wii balance board. For example, some participants who used walking aids elected to take part in the balance games on the Wii but decided that they could do this without the use of the walking aid. In four cases walking aids were passed to the facilitator, illustrating the participants' belief in their physical ability but also showcasing self2 attributes of decision making:

Evan (DC) gave his walking aid to the facilitator and was able to play the game, understanding the movement and balance concept straight away without the support of his walking aid. (Observation notes. S3)

During several sessions when playing between the Nintendo Wii and Xbox Kinect, Paul (DC) repeatedly played these games without his walking stick. The carer encouraged Paul to use this but when the carer got up to assist Paul, he passed the walking stick to the carer (Video Observation. S1). Paul decided not to use his walking stick for support when engaging with the Nintendo Wii and Xbox Kinect at all. Paul enjoyed playing the games, during a session when he was invited to play the Wii he replied '*I would love to*'. (Video observation. S4)

When playing the Nintendo Wii ice cream balance game, Max (DC) got up and left his walking stick by the chair (Video observation. S2). He did this again during session 5. (Video observation. S5)

Karl (DC) was asked if he wanted to have a turn of the Nintendo Wii. Karl got up straight away and left his stick by the chair. (Video Observation notes. S6)

Belief in ability was also showcased by the participants' affirmation of existing self attributes, where current skills and abilities were demonstrated. This may have been a response to initial feelings of low self esteem and low confidence when first engaging with the technology, therefore potentially showcasing current talents rather than highlighting areas they perceived to be weaker. For example, the showcasing of language skills during a session when there was no natural association to this particular skill:

Max (DC) said that he could speak three languages, along with regional dialects. Doris (DC) also confirmed that she could speak fluent Greek. Paul then confirmed that he could speak Latin. (Video observation. S2)

Within this, the affirmation of self attributes which highlighted skills and ability instigated an element of competition between some of the participants with regards to their own skills and abilities:

Maudy (DC) started singing 'How much is that doggy in the window', Paul (DC) then followed by singing a song in Latin. Pauline (DC) started to sing 'Danny Boy' and the rest of the group joined in. Martin (DC) started singing 'Saints go

marching in'. Paul then started speaking in French and Max replied Arabic.
(Observation notes. S2)

This may illustrate a need for the participants to display their existing skills if they don't otherwise have the opportunity to do so. In a situation where others are sharing such talents, it appears to be a catalyst for others to showcase their talents also. The element of competition is also a self2 attribute which seems to have come alive during the Tech Club and sparked the participants to look to themselves to revive their self2 attributes, which then switches the focus of others to the highly functioning attributes of self2 opposed to the 'dysfunctional'. This is evidenced by the surprise some carers expressed after seeing the abilities of the participants:

After Paul (DC) sang a song completely in Latin, Ada (DC) added, that song was *'Come All Ye Faithful'*. Dawn (PC), the carer in the room, replied in complete shock *'How do you know that?'* Ada confirmed that she could also speak fluent Latin. Dawn sat and looked at Ada, shook her head and had looked at the other participants. At the end of the session Dawn commented *'We can probably get more from them [participants], because we don't know what they can or can't do, they know exactly what they can and can't do.'*
(Observation notes. S4)

Affirmation of current skills and ability was extended by two participants, who recalled self2 attributes associated with previous self3 roles as a teacher and lecturer. As previously identified both William (CC) and Martha (CC) initially experienced low self esteem and confidence. However, identification with previous roles indicates former status and professional knowledge which potentially shifts focus away from their perceived inability to undertake some of the activities within the Tech Club to a refocus on their expertise as educators in similar educational type situations:

After attendance at the first session and having struggled to understand the purpose of it, William (CC) commented *'Before we carry on, I was a university lecturer. So obviously I've got different levels just like everybody else.'* (ESD. S1) During a subsequent session, both William and Martha (CC) were struggling to understand the purpose of the technology, they were talking about how to keep students interested in the lesson based on their experience of working in the teaching profession. William commented on the technique of teaching, *'When I was in your situation and had a lesson planned, a framework, the onus is on let's say yourself.'* (Video observation. S3)

When both Martha and William indicated that they did not understand the facilitator's instructions, the facilitator suggested '*Shall we play a different game? Will that help?*' William (CC) replied '*How will that help because at the moment the two of us now...*' the sentence was finished by Martha who said '*...have no idea how it works.*' There was a definite tone to Martha's voice at this point. Before moving to the iPads William said '*At the moment for me, I think it's been a complete waste of time. You have not explained clearly.*' The participants then talked amongst themselves about how to teach information and that this was not being done effectively from their perspective. (Video observation. S3)

The findings of this section demonstrate the participants illustrating a sense of self efficacy through a belief in their own ability to use the technologies. The findings also illustrate a potential transition from a focus surrounding loss of ability and skills, low self esteem and reduced sense of self-worth, to the presence of self efficacy through acknowledgements of ability, a preference to do activities alone and independently, the showcasing of current skills and abilities and the recalling of self2 attributes from previous self3 roles. This therefore identifies another potential benefit of a technology based intervention.

It could be argued that the increase in self esteem (increase in confidence in skills and ability, regaining their voice and increased sense of aspiration pride and dignity) along with self efficacy has the potential to counterbalance the excess disability imposed on the participants through invalidation, disempowerment and infantilisation, intimidation and outpacing. This could therefore act as a rejection of the self-fulfilling prophecy whereby the participants have the opportunity to develop, regain, reinstate and showcase their new and existing self2 and self3 attributes. The findings from this subtheme therefore contributes new knowledge by suggesting a mechanism to support self2 attributes (counterbalancing the fragility of this self), thereby protecting self3.

Conclusion

The findings of this chapter align with and support literature which suggests that those with dementia are exposed to elements connected to Kitwood's (1990) malignant social positioning theory. This leads to the fragility of self2, illustrating that despite the participants' positive outlook on their 'self', self is fragile, with self2 being at a dual risk from the condition and societal perceptions, which have been found within this research to negatively impact on the participants' self esteem.

Here, the findings contribute to existing literature as well as adding new knowledge to this area by acknowledging the fragility of self and illustrating a potential mechanism to counterbalance this fragility and support self through a digital gaming technology based intervention. In essence, the findings highlight what is possible when the health of self² of those with dementia is assumed rather than negatively focused on, therefore responding to Sabat's (2002, p.26) argument that because people with dementia are labelled and seen as dysfunctional they are '*not given any opportunities by others in the social world to manifest remaining intact healthy abilities*'. The Tech Club offers this opportunity and therefore provides an answer to research question 1 which is presented below.

In addition, the findings also contribute new knowledge by highlighting the complex nature of self and potential implications of using the QoL-AD tool when trying to capture an insight into it. Within this research the QoL-AD attempts to address self as part of QoL yet the findings illustrate that this cannot be done using one 'self' focused domain alone. A full consideration of what self means or an acknowledgement of the significance other QoL domains play when considering the concept of self, in the context of the QoL-AD, is required.

Research question 1. What are the benefits (if any) of a technology based community intervention for people with dementia?

The findings from this subtheme identify a mechanism for the supporting of self² which could counter balance the potential fragility of this area of self. Therefore, the benefit of a community based technology intervention for community dwelling people with dementia is that it could provide an opportunity for the development, regaining, reinstating and showcasing of self² attributes. Supporting self could reduce the rate of decline in skill and dependence of those with dementia, as well as potentially safe guarding against additional health, care and support needs, therefore contributing to the QoL of the individual. These findings also address research question 2 when viewed under a QoL lens, this will be explored in the discussion chapter.

In conclusion, it is suggested that an understanding of the self when considering people with dementia can aid in the development of appropriate interventions (Caddell and Clare 2010; Cohen-Mansfield et al. 2000). Based on the findings of this chapter, interventions which use digital gaming technologies can be suggested to support self

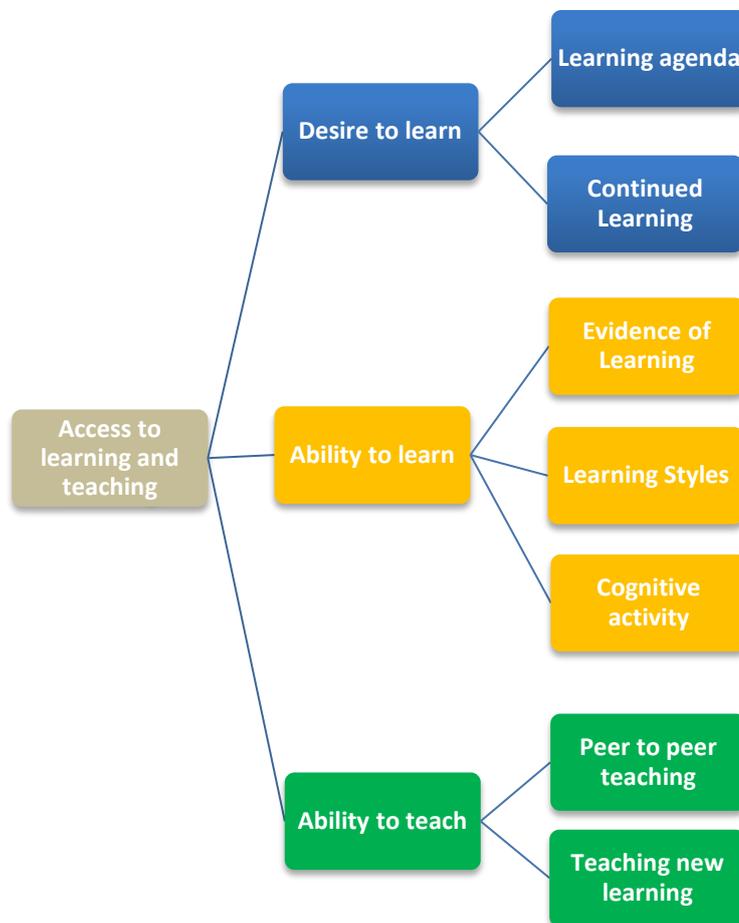
and be of benefit to those living with dementia by supporting their personal attributes (self2), therefore protecting their role (self3). Sabat (2002, p.25) suggests that '*if attention is focused on healthy self2 attributes, it is possible for the afflicted person to construct a worthy self3 persona*'. The following chapter, chapter eight, will now demonstrate the result of assuming the health of self2, as the participants of the Tech Club undertake self3 roles of students and teachers.

Chapter Eight: Access to learning and teaching

The body of literature surrounding the topic of learning and teaching is considerable and is now gaining momentum in connection to healthy and active ageing (WHO 2002). However, in connection to people living with dementia, it is extremely limited. Whilst the Scottish Charter (Alzheimer Scotland 2009) has highlighted the importance of learning for those with dementia, this area remains largely unexplored. The findings of this chapter address research questions 1 and 3 which ask; what are the benefits (if any) of a technology based community intervention for people with dementia and what are the participants' experiences of using digital gaming technology? These findings thereby contribute to the existing limited literature as well as adding new knowledge to this area.

This chapter is structured in three subthemes (Figure 5) and will begin by presenting findings in connection to the participants' desire to learn, followed by evidence in support of the participants' ability to learn. Finally, findings demonstrating the participants' capacity for teaching will be presented. As highlighted at the beginning of chapter six, the concept of self weaves through the findings of this chapter and the relevance of this will be explored in the later discussion.

Figure 5: Thematic map of Access to learning and teaching theme



Desire to learn

This subtheme showcases findings which suggest that the participants had a desire to learn through the display of participant led learning agendas and a potential aspiration to continue learning outside of the Tech Club.

Learning agendas

As described in earlier chapters, participants were introduced to the Tech Club at the pre QoL questionnaire interview stage, where its concept was explained. At this point it was noted that some participants had specific agendas for their attendance at the Tech Club which surrounded the act of learning. For example, when asked during a QoL interview what the participant wanted to get out of attending the Tech Club, Florence (CC) replied:

'To be able to learn to do things with the, what is it...iPad.' (Pre QoL interview).

The iPad was the most popular piece of technology used within the Tech Club despite the majority of participants having never seen or used one before. The findings show that both predetermined and newly developed learning agendas centred on the iPad and regardless of the participants' level of knowledge of this technology the iPad appeared to spark general interest and intrigue amongst the participants:

'If I had one of these I don't think I would ever come off it.' (Doris (DC): Observation notes. S1)

'It's interesting isn't it, you can do so much on them.' (Ada (DC): Video Observation. S1)

As the participants became familiar and comfortable with the iPad and its potential, they began to request to use the iPad to service their own personal agendas, such as looking on the internet to access hobbies and interests using apps like YouTube and BBC news. As explained in chapter five, in response to this, two activities were created to fulfil participant requirement (Appendix 10 and 11), thereby enabling choice and control, making this process person centred:

When introducing the iPad in this session each participant was invited in turn to choose what they would like to use the iPad for. William (CC) commented *'I would like to look at sports, maybe table tennis.'* Martha (CC) elected to want to *'look up history, I like history.'* and Florence (CC) suggested *'I like horses, can I see horses on that?'* (Observation notes. S4)

The findings show that there was great interest surrounding the capabilities of the iPad, which the participants then wanted to learn. For example, there were many questions around how to use the iPad to gain access to the internet and its communication ability, potentially indicating future agendas and an insight into how and why this technology may be used in the future:

'How do you use an iPad if you want to contact people? So if I do use an iPad how do you go about contacting other people?' (Karl (DC): Video observation. S2)

'If it was on the internet what could you do with it?' (William (CC): Video observation. S1)

Whilst the findings clearly demonstrate an interest and desire to learn how to use the iPad, for some, it was simply the act of learning in general that was the highlight of the

Tech Club. When asked what was enjoyed about the sessions, learning was a common response:

'It's all new and I like learning new things.' (Florence (DC): ESD.S3)

'It felt you were learning something.' (William (DC): ESD.S2)

It is acknowledged in literature that *'learning participation may become more focused on, or related to, personal interests and activities as people get older'* (Jenkins and Mostafa 2015, p.3). The findings of this subtheme both support and add to this by illustrating that this research can be extended to include older people with dementia, in addition to supporting the idea that as people become older, learning should not only be made available but should also be increasingly person centred. These findings also support and align with research which highlights the potential benefit of the iPad when used with people living with dementia as it can be tailored to individual preferences and hobbies (Lloyd-Yates 2013a; 2013b).

Overall, these findings demonstrate that in a technology focused intervention, the participants had a desire to learn how to use a specific area of digital gaming technology, the iPad. This identifies a potential benefit of a technology based intervention in that it can service the desire to learn for those living with dementia and also provides insight into the experiences of this community when using the iPad.

Continued learning

In support of the findings demonstrating the participants' desire to learn, the following findings suggest an intention for continued learning outside of the Tech Club. Specifically in relation to the iPad, some participants made comments in reference to using this technology within the home environment:

When asked by the facilitator if Henry (CC) had found the iPad activity guide useful, he replied *'The presentation of this [iPad guide] is very useful and you can work through it at home.'* Henry then asked *'Can you download Google Earth at home?'* Henry took the iPad guide home with him. (Observation notes.S2)

When talking to a PC about the iPad, Maudy (DC) suggested that she was very interested in the iPad and *'Wanted to take one home'* with her. (Julia (PC): Diary)

Abigail (FC) commented that after attendance at two sessions of the Tech Club, it had informed her decision to buy an iPad for future use in the home shared by herself and William. (Observation notes.S3)

The potential for continued learning outside of the Tech Club was supported by additional questions regarding the price of the iPad and where this equipment could be purchased:

'I do like it [iPad], are they dear to buy those?' (Doris (DC): Observation notes.S2)

Karl asked *'How much is the iPad...where do you get them?'* (Observation notes.S2)

However, some participants indicated that the price of the iPad would stop them from acquiring one:

Doris (DC) *'I'm not paying that much for that.'* (Video observation. S5)

'The problem is I probably wouldn't be able to buy the equipment. It's too expensive...it gives you a good understanding of what goes on but as I say, if you can't afford an iPad, it's a complete waste of time.' (Paul (DC): Post QoL interview)

These findings demonstrate that a potential barrier to the participants' continued learning outside of the Tech Club was the price of the equipment rather than dementia, disability or poor health. Whilst barriers to continued learning have been identified, this section has illustrated that a potential benefit of a technology based intervention is that it instigates the desire to continue learning within the home environment.

Overall, the findings of this subtheme address a gap in literature. Whilst it is acknowledged that older people in general need more access to initiatives which promote the development of new skills and knowledge (WHO 2002), research which considers what older adults say they want to learn is limited (Boulton-Lewis 2010), with research describing what people with dementia say they want to learn being non-existent. These findings address this gap by showing that the people with dementia in the Tech Club had a desire to learn and to continue learning with the focus being on the iPad.

Whilst research conducted by Purdie and Boulton-Lewis (2003) found that in general, older people identified technology as their least important learning need, they still wanted to use it despite being less confident in their ability to successfully engage with

it. The findings of this research cannot claim that technology was the most important learning need for the participants of the Tech Club, however, based on participant experience, they do demonstrate that in a technology focused intervention the participants had a desire and ability to learn how to use the technology, therefore highlighting the potential benefit of an intervention of this kind, and its additional advantage for healthy ageing (Cutler et al. 2016).

Ability to learn

Ability to learn when living with dementia is rarely discussed within literature (as explored in chapter nine), potentially aligning to Kitwood's (1997) standard paradigm theory. Consequently, in the context of having the ability to learn, it is commonly assumed and accepted that people with dementia do not have this ability (Riley et al. 2009; Orpwood et al. 2005; Bird 1998), therefore emphasising the perceived loss of self2 attributes as identified in chapter seven. The findings in this subtheme demonstrate that not only can the participants learn but they also display variation in their learning styles.

To provide context to the barriers concerning learning and those living with dementia, as demonstrated in chapter seven some carers generally perceived the participants' ability and skills negatively. To enforce how common presumptions surrounding ability to learn are, the quote provided by Abigail, carer of William (CC), underlines the potential barriers based on perception:

'...When he was normal he was very astute and very you know, grasped things right away... The trouble with Alzheimer's is that you can only take so much information in at a time...he can't take a lot in, especially as you say, all in one go. Slowly can take bits in but the brain has got to the stage where new information can't go in.' (Abigail (FC):ESD.S1)

Whilst there was is no evidence to understand the extent to which the Tech Club challenged negative assumptions around the participants' ability to learn, the findings demonstrate that the Tech Club did have an influence. For example, after the second session, Abigail (FC) indicated that she had bought an iPad to use with William (CC), suggesting a potential shift in her thought process. Another example of challenged assumption around ability to learn was when a PC was surprised about the ability of the CC participants:

'I'm surprised at the ladies with that iPad. It's amazing what they can actually learn to do isn't it...I mean, I've got my own mother in a nursing home, in a worse state than some of these, but I'm sure with a bit of encouragement they could do more, but they sit there in this awful semicircle with the blooming television. They can learn, they can.' (Dawn (PC): ESC. S4)

Common misconceptions such as these can be challenged through digital gaming technology (Cutler et al. 2016) simply by the person with dementia having access to learning opportunities. This has the potential to alter how others view those with dementia, as well as challenging how the person with dementia sees themselves (Cutler et al. 2016; Benbow 2009), subsequently impacting on self2 and self3 attributes and contributing to general healthy ageing.

Evidence of learning

The participants' ability to learn is evident in the relearning of previous skills and the learning of new skills. The findings demonstrate that the Tech Club not only provided the participants with access to their hobbies and interests through the technology but also enabled them to relearn previous skills and hobbies:

When asked if the participants had enjoyed the session, one participant replied *'... I enjoyed, you know, just getting myself refreshed about things that I had known about in the past.'* (Martha (CC): ESD.S3)

Some of the games inspired memories of previous skills. Doris (DC), when playing Nintendo Wii bowling, shared that she *'Used to be a part of a bowling group.'* Doris used the Nintendo Wii to relearn and refresh this skill (Observation notes. S1)

However, the majority of the equipment and games were completely new to the participants, where none of the participants had previously used the Nintendo Wii or Xbox Kinect and only three having seen an iPad before, demonstrating that the participants were embarking on the learning of new and complex concepts. These findings demonstrate that the participants understood the basic concept of the technologies which enabled learning into how to use them:

Karl (DC) asked to play the piano app (on the iPad) but the screen needed to be rotated. Karl was able to rotate the screen without support or prompting following initial instruction (Observation notes. S5). This shows that Karl had

learnt that the iPad needed to be rotated in order to work in the manner he wanted it to, he then demonstrated his learning further by doing this unaided.

When playing the Nintendo Wii, fairground games, Martin (DC) started to tell the facilitator what to do and how to perform the required actions (Observation notes. S2). This evidences that he had not only learnt the purpose of the game but the actions required to complete it to the extent that he was able to explain it to someone else.

These findings demonstrate that the participants were therefore able to engage in all three elements of Rösler et al. (2002) learning cycle, whereby the participants were able to take information into their memory (acquisition), store it (retention) and then retrieve it. The most striking example of this was the participants' ability to repeat the moves or actions they were shown and then to either carry on with the activity themselves or show others how to do it. This showcases acquisition and an understanding of the technology and its objective, and retention in order to be able to store the required information to enable retrieval, therefore enabling the participant to engage in the game or apps and to provide advice regarding this.

There is also evidence within the findings of continuing progression, as some participants learnt the basics of the technologies, games and apps but continued to build their skills and knowledge to more complex areas such as difficulty levels, largely in connection to apps on the iPad and the Nintendo Wii:

Florence (CC) and Martha (CC) moved up a level (from easy to medium) on the memory match game (Observation notes. S5). Florence was very fast when playing alone. It took her approximately 30 seconds to complete the game. (Video observation. S5)

When playing the bowling game on the Wii, simply bowling the ball was not enough for Doris (DC). Doris enquired about additional features on the game which would allow her to change the direction of where the ball was thrown (Video observation. S1). This demonstrates that Doris had learnt the concept and objective of the game to the point where basic control functions were not enough and so enquired about additional features which would aid her in completing the game at a suitable level.

Within the Tech Club there were also periods of obvious concentration displayed by individual participant's when they were introduced to a piece of equipment or game, and in groups when information and direction was being provided:

Paul (DC) was watching the control demonstration for another participant, he was fully concentrating on what the facilitator was saying as if he was trying to understand the button and movement combination needed. There was definitely a strong element of watching and becoming familiar with the controls.

(Observation notes. S1)

It was obvious that everyone was concentrating fully on the game as the room went quiet at some points and all were watching the screen. Everyone was concentrating. (DC. Observation notes. S2)

These findings support the work of Cutler et al. (2016) who identified that this technology engages those living with dementia in activities which require them to concentrate. Building on this, the findings of this thesis illustrate that the participants were engaged in explicit learning, whereby they were required to think about what they were doing. Within the Tech Club the participants were introduced to many elements which required learning. For example, learning the purpose of the technologies; learning their role as a player in connection to the technologies; how to use the related controller equipment (Nintendo Wii controller, nun chuck and balance board, iPad finger control, Xbox Kinect hand control); how to use a combination of control devices simultaneously (Wii nun chuck and controller); learning how to connect their movement to the television screen; how to use the Xbox Kinect without a physical controller and learn that movement was replicated on the screen; how to play various games on the Nintendo Wii and Xbox Kinect; learn the different objectives, levels, graphics, paces, control directions for each game or app; learn how to hold and navigate around the iPad and how to use individual iPad apps.

These findings show that explicit learning was especially relevant when using the Nintendo Wii and Xbox Kinect where participants were required to think about what they were doing in order to play the game. This was similar with the iPad, however, whilst explicit learning was required when using the iPad, after its initial introduction the participants were able to use their fingers unconsciously to navigate around the iPad.

Overall, these findings address a gap in the literature (as explored in chapter nine) which demonstrate that people with dementia cannot only learn but can learn new and complex concepts, can engage in explicit learning and are able to participate in all

areas of the learning cycle. The findings of this subtheme suggest that interventions like the Tech Club may be a method to challenge negative assumptions around people with dementias' ability to learn, therefore highlighting an additional potential benefit of this type of intervention.

Learning styles

Whilst it is widely acknowledged that every individual has a unique learning style, literature exploring learning the styles of people with dementia is extremely limited (chapter nine). The findings in this section address this gap by illustrating that the participants also varied in the way they learnt, showcasing variation in learning styles, method and pace.

As described in chapter five, the weekly session structure of the Tech Club altered dependent on participant feedback. One of the main areas of change was the way in which information and instruction was delivered to the participants (largely in connection to the iPad). Originally, this information was provided verbally, however the participants struggled to understand how to use the iPad, what it was for and what it could provide access to. By the recommendation of two participant's, this led to the creation of the iPad activity choices and instructional guide (Appendix 10 and 11) which contained a combination of words and picture cues and was delivered alongside auditory explanation. The findings suggest that this was more effective than verbal instruction alone as there were fewer questions after the visual guides were provided, and a strong preference to continue using them in the subsequent sessions. This therefore demonstrates that participant learning was aided through written down visual instructions and image cues:

As Henry (CC) was one of the participants who asked for an instructional style guide to help him learn how to use the iPad, when asked if he had used the provided iPad guide, Henry replied '*I prefer to use it and get stuck into it.*' Indicating a preference to use a guide rather than following verbal instruction alone (Observation notes.S2). However, in a later session Henry showcased an additional learning preference where he said he wanted to sit and listen and '*Learn that way*' (Observation notes. S6). Showing a preference for auditory learning alone in some cases.

There was however a difference in the learning styles between participants of the DC and CC. The iPad activity and instructional guide were the result of requests and a solution to aid the learning of participants of the CC, however, when used in the DC,

the participants followed the iPad activity guide to an extent but this did not appear to be such an important requirement for this group. This could suggest a difference in learning environment preference, where the sessions were slightly more formal in the CC and informal for the DC. The structure of the Tech Club in both venues was a mixture of formal and informal learning. This was a particular issue for two participants who were previously teachers and preferred the environment to be more formal so they felt that they were learning:

William (DC) was talking about the technique of teaching and commented *'When I was in your situation and had a lesson planned, a framework, the onus is on let's say yourself to ensure the learning of the students.'* Indicating a dissatisfaction in the way they were learning. Martha (DC) also agreed by saying 'Yes' and nodding at Williams's comments. William then asked *'What level do you deem this, A-Level, degree or whatever?'* (Observation notes. S3)

These findings align with adult learning literature which suggests that in general, for older people, some want their learning to be formal, some want it to be informal (Boulton-Lewis 2010). These findings suggest that a mixture of both is preferred for the participants of the Tech Club.

Kinaesthetic learning, the act of doing rather than watching, appeared to be the preference of the majority of participants who wanted to get physically involved with the Nintendo Wii and Xbox Kinect. When in connection to this technology, kinaesthetic learning was supplemented by guided learning, whereby the facilitator physically held the participant to guide their movement, showing them the required action. When using the Xbox Kinect and Nintendo Wii, guided learning appeared to be particularly effective as the participants were able to learn the required movements, especially when using the balance board and in connection with the Wii controller button and movement combination:

When playing on the Xbox Kinect golf game, William (CC) was having trouble understanding the movement which was required. The facilitator physically demonstrated the movement to William by holding his hand and raising his arm to mimic the swinging of a golf club. The facilitator then moved to face William as a mirror image and did the movement with him again. William was then able to do the required movement alone with no need for further physical support. (Observation notes. S2)

When playing bowling on the Nintendo Wii, Maudy (DC) said that she was not sure what to do, holding the controller and looking at it in a confused manner. The facilitator replicated the movement physically with Maudy by placing a hand over hers whilst she was holding the controller, so that the movement and button release were done together. The facilitator asked if Maudy now understood what was required and stood next to her with a dummy controller and mimicked what was required whilst the participant copied and did this alone. The ball was successfully released and Maudy went back to her seat smiling. (Observation notes. S1)

This suggests that kinaesthetic learning was a potentially effective method to learn how to use the Nintendo Wii and Xbox Kinect for the participants of the Tech Club.

Learning method and pace

Learning within the Tech Club was undertaken in a group/dyad or alone. The method of learning was also a strong preference for some participants who elected to learn alone:

After the session, Paul (DC) was asked if he had enjoyed the session. He replied that he would like to have had *'More opportunity to use the tablet [iPad] by himself.'* (Natalie (PC): Carer Dairy)

When asked what was enjoyed about the session, Henry (CC) replied *'Being left alone with this actually [iPad]. That's nothing against your tuition I just like to work on my own.'* (Evaluation form).

There were no findings supporting the idea that learning in a group was a major preference in the same manner that lone working appeared to be for the participants. Most participants engaged in a mixture of both solitary (lone learning) and social (group) learning but shared no major preference for one or the other. However, it was noted that when using the iPad participants appeared to be happy to learn in groups when first introduced to the equipment, yet when the participants appeared to be comfortable some then preferred to work alone:

Martha (CC) and William (CC) were sat together learning how to use the iPad, they were looking at the memory match game. The iPad was placed in the middle of them, with both of them touching the iPad and talking to each other about what to do and taking turns. They were touching shoulders and were very physically close. After a while, Martha appeared to be comfortable with the iPad and moved it and placed it in front of her. Martha also slanted her body away

from William who was leaning over to see the iPad. They were not taking it in turns at this point as Martha appeared to want to use this alone. (Video observation. S4)

Whilst there were definite learning styles and methods which appeared to be preferred by the participants, preference surrounding the pace at which information and instruction was delivered also differed between the participants. Some participants felt that instruction and information was provided at too fast a pace and that the length of the session was too short for the amount of information provided:

As the iPad activity guides were being explained, William (CC) commented to the facilitator *'You are going too fast...It's an enormous learning curve. The point is that the people, they tend to be unaware of the problems that this side of the table have...the speed that at which you are dealing with things are far quicker than mine for instance, and the thing you have to do is try and preserve what self-confidence that we have.'* (Video observation. S4) *'The time is too short to learn new things.'* (Observation notes.S3)

In conversation at the end of a session, a carer commented that based on her own thoughts along with comments made by Henry (DC), that the instruction and general pace of the session was too fast, *'I think to take it slower would be better because, as Henry said, information overload is a problem.'* (Catherine (FC): ESD)

Contrastingly, this was not the same for all participants. Florence (CC) for example, was often held back from progressing in the sessions as she had to wait for others working at different paces, in the group scenario, before she could progress, showing that Florence was learning at a faster pace than her peers:

William (CC) and Martha (CC) agreed that the facilitator was going too fast for them to absorb the information, Florence (CC) disagreed and said the pace was *'fine'* for her. (Observation notes.S4). I don't think Florence had a very good experience within these sessions as she was rarely able to do what she wanted and had to share most activities with another person who was at a different level to her and had different interests. (Video observation.S6)

Henry (CC) was in the same situation as Florence as he was now waiting for William (CC) and Martha (CC) to feel comfortable and ready to start using the

iPad, when he was ready to begin the activity (Video observation.S5). This again shows that Henry's learning pace was also faster than some of his peers.

These findings align with Bird's (1998) research which suggests that it is important to ensure that the learning cycle and completion of each element of this, from acquisition to retrieval, is at the correct pace for the person undertaking them. These findings show that this is also the case for those with dementia and that in the context of these findings information delivery should be matched to varying learning paces.

In summary, of the four main styles (visual, auditory, kinaesthetic and linguistic), the findings suggest that the participants learnt most effectively through a combination of visual, auditory and kinaesthetic (physical) styles. Kinaesthetic learning is demonstrated to be an enabler to learning in the use of the technology equipment especially around the use of the Nintendo Wii and Xbox Kinect, particularly when supplemented with guided learning. These findings support research (Cowdell 2008; Nygård 2006) which addresses user involvement and inclusion as they demonstrate that participants learnt effectively when being physically involved. Therefore these findings address a gap in literature which suggests that learning styles for older adults need to be explored (Jenkins and Mostafa 2015) by providing evidence for a variation in the learning styles and learning paces of older people living with dementia. This area is limited in general but currently unknown with regards to digital gaming technology. In addition, these findings also align with adult learning literature which suggests a preference from older people towards both formal and informal learning (Boulton-Lewis 2010), by offering findings which illustrate that both informal and formal learning environments are the preference of older people living with dementia in the context of a technology based intervention.

Cognitive activity

Older adult learning literature suggests that one of the main reasons older adults without dementia engage in the act of learning is primarily '*to keep their brains active, to enjoy the challenge*' (Boulton-Lewis 2010, p.215) and to engage in intellectual activities (Withnall 2009; Boulton-Lewis et al. 2006; Dench and Regan 2000). This is similar to the findings of this section. For example, during the QoL interviews, participants confirmed undertaking activities which specifically required the use of cognitive functioning, such as cross word puzzles and reading. However, the below findings suggest that engagement in the Tech Club potentially gave the participants an opportunity to take part in something cognitively 'different'. When asked what was

enjoyed about the sessions, replies were in connection to an alternative activity being offered:

'All of it really, it was a new experience for me and so it was all new.' (Florence (CC): Follow up QoL Interview)

'Doing something completely new which I enjoy.' (Henry (CC): Evaluation form. S2)

These findings could suggest that the participants are engaged in the same types of activity on a daily basis with little variation and therefore a new challenge could be one reason why the participants elected to engage in the Tech Club.

Off the shelf, commercially available digital gaming technology and associated games and applications were utilised in the Tech Club and were not infantilised based on the participants' diagnosis of dementia. The relative difficulty of some of the games, especially in connection to the Nintendo Wii and Xbox Kinect was commented on by a PC, supporting the general challenge of the Tech Club sessions:

As the participants were engaged in a driving game using the Xbox Kinect, whilst watching the participants playing the game, the PC commented *'It's not as easy as it looks. It's really difficult isn't it?'* (Dawn (PC): Video observation. S4)

The difficulty of the technology and associated games was also noted by the participants:

In reference to the Nintendo Wii hula hooping game, Evan (DC) commented, *'It's not as easy as you think, you know'* (Observation notes. S3). Evan also commented in subsequent sessions in connection to the Xbox Kinect driving game, *'It's easier said than done'* (Observation notes. S4). In addition, Evan commented on the complicated nature of using fingers to control the iPad by saying *'This is complicated'* after attempts to move iPad screens. (Observation notes. S5)

Pauline (DC) also commented on the difficulty of the games associated to the Nintendo Wii bowling game by saying, *'It's not as easy as it looks'* (Observation

notes. S1). Pauline again commented on the nature of the Xbox Kinect driving game by saying *'It's harder than what you think.'* (Observation notes. S4)

However, despite the perceived difficulty, these findings demonstrate that the participants understood the challenge of the activity and the associated challenge on their cognitive and physical ability. This did not appear to deter the participants as it was recognised that it was a matter of initially being shown how to use the technology so that they could understand and learn what was required:

After discussion about the use of the iPad activity guide to support the learning of the participants, Pauline (DC) commented *'You know...it's really simple when you find out how to do it.'* (Video observation.S5)

After Doris (DC) engaged with the Nintendo Wii to play bowling, after her first turn, Doris returned to her seat and commented to a participant sat next to her *'It's easy when you know how.'* (Observation notes.S1)

When playing Wii bowling, Martin returned to his seat and commented that *'It's just getting used to things like that ant it?'* in reference to his turn. (Martin (DC): Video Observation.S1)

These findings indicate that Pauline (DC) initially perceived the iPad as difficult yet this dissolved as she understood what was required and how to do it. Similarly, Doris (DC) initially considered the game or control requirement as complicated but after playing the game this perceived difficulty diminished. Martin (DC) also recognised the difficulty of the game and acknowledged it was just a case of practice in order to get used to it.

There is evidence within the findings to suggest that engaging in activities whilst using the digital gaming technologies may have encouraged executive functioning cognitive activity associated with problem solving skills, working memory and attentional control (concentration). When using the technologies, participants were required to activate these executive functioning skills in order to correctly use the equipment and play the games and apps. For example, when using the iPad, participants were required to use working memory to be able to hold the iPad (in consideration of the rotating screen) and navigate around the iPad in order to find the required apps and problem solving to play some of the games:

Florence and Martha (CC) remembered the memory match game (on the iPad) and how to play this from a previous session. Unlike the previous week when Martha needed lots of support and demonstrations to play the game, she had learnt and remembered the concept of and how to play the game unaided by holding the iPad, selecting the difficulty of the card game that she wanted to play and then playing the game without any need for instruction or support. (Observation notes. S5)

Similarly, the findings illustrate the participants using attentional control skills to concentrate for extended periods of time:

Henry (CC) used the iPad for long periods of uninterrupted time of 20 to 30 minutes, sometimes longer. (Video observation. S5)

When playing the memory match game on the iPad, participants were engaged in this for approximately 25 minutes, which was largely uninterrupted. The participants (CC) were completely engaged in the game and the only questions which were asked were about how to get back to the start of the game. (Video observation. S4)

Learning in this way was enjoyable for some participants who commented that they felt that they had physically used their brain in the session:

When using the iPad within a session Doris (DC) commented '*This gives you a headache doesn't it? I'd like to learn more if my brain can handle it.*' (Observation notes.S5). At the end of the session, Doris was asked to expand on this statement. The facilitator asked, '*Doris, earlier you said that using the iPad gives you a headache because it's...*' Doris responded in the middle of the sentence and said '*Starting off but it's alright now because I'm using my brain. Yeah I like it.*' (ESD.S5)

Overall, these findings challenge research by demonstrating that the participants had the ability to learn and that they were also capable of a higher level of learning. Therefore, aligned to literature which suggests that older people in general want to engage in learning (Boulton-Lewis 2010) to keep their brain active, these findings suggest that this can be extended to older people living with dementia. In addition, these findings add to knowledge by demonstrating that through engagement in a

technology based intervention, cognitive activity and especially executive functioning cognitive activity is encouraged, thereby highlighting a potential benefit of a technology focused community intervention.

In addition, the findings have identified that the participants were not deterred by the challenge of the activities, especially in connection to the Nintendo Wii and Xbox Kinect, whereby they confirmed that whilst initially the technologies first appeared to be complicated, it was a case of just being shown how to use them. Therefore, engaging participants in challenging activities and learning can help towards addressing how people with dementia see themselves by supporting the self2 attributes of self esteem and self efficacy, along with how others see them by challenging the perceived loss of self2 attributes surrounding the ability to learn.

Teaching

The three previous subthemes have demonstrated the participants in the role of a student. Contrastingly, this subtheme demonstrates the participants undertaking the role of teacher (someone who shares knowledge to teach and instruct others how to do something).

Peer to peer teaching

Within the Tech Club, group or dyad team work was often encouraged when using the iPad. Whilst this enabled the participants to build relationships and familiarity between themselves, this was primarily for pragmatic reasons to reduce individual support requirements, enabling the facilitator to provide equal support to the whole group. In a group or dyad, two or more participants engaged in an activity together, however, whilst support was provided to all groups, participants were often left without support for short periods of time and were unable to progress with the activity. Here the findings focus on three participants in particular who engaged in the act of peer to peer teaching as a result of this, whereby if one participant was struggling within the group or dyad, another participant provided instruction and support:

Florence (CC) remembered the memory match game and explained how to do this to William (CC) and Martha (CC). Florence was very capable as she previously used the memory match game with Martha and was able to explain the concept simply by saying, '*You need to think, where is the other one?*' in reference to choosing two of the same cards. Florence was patient in explaining the game and William was able to follow and ask questions. William did not

seem embarrassed or flustered about asking questions. Florence and Martha were leaning into one another and helping each other, with Florence teaching Martha how to get to a new page. Florence was putting a lot of time into helping Martha play the game rather than using the iPad herself. (Observation notes.S2)

Florence offered Martha the iPad saying '*Would you like to have a go?*' Martha took the iPad and whilst looking at the screen said '*Where do we go?*' This was in reference to the starting a new game. Florence replied '*I got to there but now I don't know where to go.*' Martha moved and sat next to Florence telling her what she had learnt from the facilitator. (Observation notes. S1)

William sat next to Florence in order to learn how to play the memory match game. They both had an iPad whilst Florence was explaining how to play the game. William asked Florence '*What is the aim?*' Florence replied '*To match them all up*', William replied '*Oh ok*' and continued to play the game using the instructions and explanation provided by Florence. (Observation notes. S2)

This peer to peer teaching appeared to be successful, through the findings it is suggested that a large element of this success may be attributable to the perceived commonalities that the participants believed they shared; this was especially relevant between Martha and William who paired themselves together because of this:

Martha mentioned to William that she had never played the chequers game on the iPad before, to this William responded with '*So we are in the same boat.*' (Video observation.S2)

When playing on the Nintendo Wii memory game together, William said to Martha '*We are in the same boat*', Martha replied '*Yes, we are*'. This was in acknowledgement that neither of them seemed to know what they should be doing on this game. (Video observation.S3)

For these two participants in particular, this perceived bonding led William, who questioned much of the instruction provided by the facilitator, to take the instruction from Martha without question, for example:

William found it difficult to follow the instruction from the facilitator, when sat next to Martha, William relaxed. The two participants were sat together working

out how to turn the iPad on and off. When either of these participants had a question, they looked to each other for support over the facilitator or carer. (Observation notes. S3)

When working together playing the memory card game, William looked to Martha and asked '*What am I meant to do?*' Martha responded '*You have to imagine that another card looks like that*' and pointed to two similar cards. (Observation notes.S4)

Whilst in this case William looks to Martha for instruction and support, Martha is not seen as a teacher or in a role of power because they are in the 'same boat'. Again, it is suggested that William was comfortable with Florence providing the explanation because she was also 'in the same boat'. Being taught by a peer in the same situation appeared to hold more credibility than being taught by someone with fewer commonalities. The fact that the participants identified commonalities between themselves could lead to greater respect and trust, enabling both the giving and receiving of teaching and learning.

However, the findings also suggest that whilst peer to peer teaching is successful as an informal arrangement, where no one participant has power or authority over the other, this dynamic is fragile and can be compromised if the arrangement is formalised, giving one participant the role of teacher. For example, when the facilitator noticed Florence's ability to remember previous sessions, use the iPad largely unsupported, along with the informal teaching Florence provided to Martha and William, Florence was asked more formally if she would teach William and Martha to use the iPad. In response to this and despite doing this naturally and unconsciously already, Florence replied:

'I don't think I will be able to teach anyone.' (Observation notes.S2)

Florence was able to teach, this is evidenced in the findings. Despite this, Florence expressed feelings around her ability to teach formally. These are in line with the earlier findings in the chapter on self which highlight Florence down playing her ability and success of her self2 attributes:

When playing the memory match game Florence got two of the same cards. Martha said '*Did she get two the same?, how did you do that?*' and Florence replied '*It was just a guess, there was no skill I'm afraid.*' Florence was quiet and then refrained from the game slightly after this (Video observation.S4). In a

different session Florence got a card match on the memory match game, Martha said *'You are better than this than I am.'* Florence (CC) replied *'No.'* Again, Florence refrained from the game after this. (Video observation. S5)

The findings could therefore suggest that Florence did not want to stand out as being able to do anything 'special' or having a formal role as a teacher because of her abilities. It was noticed in the sessions that William and Martha were potentially becoming disillusioned in the perceived commonalities they believed they shared with Florence as she progressed in the session, resulting in the suggestion that Florence might not be in the 'same boat' after all:

William and Martha said that the facilitator was going too fast when providing instructions. The facilitator asked other participants if they felt the same, to which Florence replied *'No'* indicating that the speed of instruction was at the right pace for her personally. Both Martha and William looked at Florence. William then turned to Martha and said *'I think we are in the same boat'* and Martha replied *'Yes I think we are in the same boat.'* (Observation notes. S4)

These findings align with Whitman and Fife's (1988, p.4) research which suggests that an important aspect of peer to peer learning is that for it to be successful it needs to be conducted between people who are in similar situations, where neither participant is in the role of teacher and *'do not have power over each other by virtue of their positions or responsibly.'* Whilst literature suggests that most peer to peer teaching takes place on an informal basis, a more formalised approach can aid learning more effectively in general (Whitman and Fife 1988). This does not appear to be the case for these participants as the findings suggest that changing the arrangement from informal teaching where no participant held power over another, to a formal arrangement where one participant was in a position of power as a teacher, could alter the way participants view each other, therefore negatively impacting on the potential of peer to peer teaching. These findings have demonstrated that the participants were able to teach others through peer to peer teaching, the following findings showcase what the participants were able to teach.

Teaching new learning

Throughout the duration of the Tech Club there was evidence of the participants teaching their peers, facilitators and carers, both current and previous skills such as puzzle games to new languages. This demonstrates a general desire for the

participants to impart their knowledge onto others but also illustrates that they were able to communicate and explain complex concepts to beginners:

During a break in the session the group was talking about travel, Max (DC) explained about his travelling days in the Middle East. This aroused interest, with one participant asking about languages. It was suggested that Max teach the group some Arabic words. Max then set about saying an Arabic word slowly two or three times and then explaining what it meant, saying it again, and then asking others to repeat. He corrected unsuccessful attempts at pronunciation. (Video observation. S2)

However, more frequently, the participants were teaching newly obtained skills as opposed to previous ones. The teaching of new learning was however only in connection to the iPad. For example, after learning how to manoeuvre the iPad and use its basic functions in a group, Max (DC), Karl and Paul had one iPad between them and were provided with a list of instructions to teach them how to use it. After a demonstration was provided, the group was left with the instruction list and the iPad:

Max took the iPad and was able to perform some the actions after reading through the instructions. After Max learnt how to move the iPad around, turn it on and off, change the size of the screen and get back to the main page, he passed the iPad to Karl, along with verbal instructions on how to increase and decreased the size of the screen. Karl then passed the iPad to Paul and then re-communicated his learning to be able to show Paul how to do this. (Observation notes. S5)

Peer to peer teaching was extended to the apps on the iPad, especially the memory match game, which required the participant to match two of the same cards on a screen out of 10 plus cards. The participants initially received general explanation from the facilitator surrounding the concept and objective of the game, as well as how to play the game using the finger to select the card. This was then passed on peer to peer:

Doris (DC), Sylvie (DC) and Pauline (DC) seemed to master the memory match game on the iPad as a group, answering questions and showing each of the members of the group how to work the game. They were able to play the game

through group problem solving. As a group they then taught Paul (DC) how to play this game. (Observation notes. S4)

Evan (DC) learnt how to play the memory match game from the facilitator. He then explained the mechanics of how to select the cards and the objective of the game to Max (DC) and Martin (DC) who had just to be shown how to play it. They each played a game independently. (Observation notes.S4)

Whilst peer to peer teaching was contained to the use of the iPad, the participants gave lots of advice and support when using the Nintendo Wii and Xbox Kinect to fellow participants and carers who took part:

When the group were taking turns to play the Nintendo Wii bowling game, when others were bowling, Evan (DC) shouted out advice about stance as a way to support the person playing the game, '*Go on the back foot.*' (Observation notes.S4)

Whilst playing a driving game on the Wii, the PC was having a turn and Pauline (DC) was providing the PC with advice as where to go in order for the carer's position in the game to increase. Pauline was shouting out advice such as '*You're second now, go to the left, and now go to the right.*' (Observation notes. S4)

Doris (DC) was advising the PC when playing the balance board game by telling her how to angle her body in order to further the character's position on the rope, by saying '*That's it, now get yourself straight.*' (Observation notes. S4)

Whilst this type of engagement is not true teaching, it is noted in literature that people with dementia are increasingly more informative, communicative and focused when asked to provide advice as it requires the fulfilling of a role (Dijkstra et al. 2006). The participants of the Tech Club were not formally invited to provide advice but did so of their own accord. This may suggest that some of the participants wanted to engage in supportive roles within the sessions, this is particularly relevant as advice was extended to carers also, thereby showcasing advice giving ability (self2 attributes). These findings also suggest that the participants were focused on the task at hand and understood the concept enough to provide advice.

It is argued that peer to peer teaching and learning should be mutually beneficial to all parties (Topping and Ehly 1998; Whitman and Fife 1988). The findings suggest this to be the case in the Tech Club as participants both reaped the benefits of being taught and then cemented their learning by teaching. Teaching the new and complex concepts of the unfamiliar digital gaming technologies in itself is further evidence in support of earlier findings showcasing the participants' ability to learn, as in order to teach, the participant needed to have a clear understanding of the taught subject in order to communicate this, therefore showing a benefit of a technology based intervention.

Noted within the findings was the way in which the participants taught others when imparting their learning surrounding the iPad, in a peer to peer scenario. The findings show that they all used the same style, direct yet calm tone and straight to the point, using both verbal instruction but always using a hands on kinaesthetic approach:

When working together playing the memory match card game, Martha (CC) explained to William (CC) how to select the cards on the iPad. To do this Martha used her fingers to point to the relevant cards to show what was required, she then used a downwards tapping movement to demonstrate how to physically select the required card. Martha continued watching William complete the task she had just learnt herself, answering questions and providing advice, yet never taking over the activity. (Observation notes.S4)

Interestingly, this is the way the participants were taught. Literature suggests that through teacher/supportive style training, people with dementia can produce the same effects as the facilitator would (Camp and Skrajner 2004). This is interesting as these results could suggest that the participants used the same methods as applied by the facilitator in order to teach, yet this was done without training and would be considered implicit learning.

These findings have identified that the participants of the Tech Club were not only able to teach but were able to teach new and complex concepts using visual and kinaesthetic teaching styles, therefore adding new knowledge to this area. Having the ability to teach also supports the findings of the earlier subthemes as in order to teach, the participants required a clear understanding of the taught subject. Therefore these findings demonstrate a mechanism to engage those with dementia in teaching using off

the shelf commercial gaming technology, again adding new knowledge to this area of research and showcasing an additional benefit of this type of intervention.

Overall, the findings from this subtheme illustrate the importance and impact of peer to peer teaching, suggesting that for some, this method has more credibility when delivered by someone who is considered to be in a similar position. The findings have identified that formal identification of a teacher between two participants could potentially alter the dynamic of a group and therefore impact on the peer to peer learning and teaching through the introduction of a hierarchy. Therefore the findings of this subtheme address a gap in research (explored in the later discussion) as there is currently limited literature exploring the role of people with dementia in a supportive educational capacity (Dijkstra et al. 2006; Camp and Skrajner 2004), and to my knowledge, these findings are the first to evidence people with dementia taking an active role of teacher in a peer to peer capacity.

Conclusion

Potentially attributable to the assumed loss of self2 attributes, learning in general does not appear to be an option made available to people living with dementia. As can be seen in these findings, engaging participants in activities which are challenging can help towards addressing the societal perception surrounding people with dementias' perceived lack of ability as it highlights learning ability and the capability of those living with this condition. Therefore, as will be discussed in greater detail in chapter nine, the act of learning can help to support and protect the participants' existing self2 attributes as well as developing new self2 attributes in skill and ability, subsequently protecting self3. Overall, these findings highlight a general gap in research concerning the learning capability of people living with dementia.

The findings from this chapter address this gap by offering evidence that suggests that older adult learning literature should be extended to include older adults living with dementia. It has been identified that people with dementia have a desire to learn and in the context of the Tech Club the iPad is the focus, and can learn to the extent that they can engage in all stages of the learning cycle and in doing so exhibit differences in learning styles, paces and methods. As well as demonstrating that people with dementia learn in different ways, in the context of the Tech Club, the findings also demonstrate that this includes a combination of visual, auditory and kinaesthetic learning methods. Kinaesthetic learning has also been found to be a particularly effective method for those with dementia in learning how to use the Nintendo Wii and

Xbox Kinect. These findings also highlight the use of specific executive functioning skills, such as working memory, problem solving and attentional control in the context of learning how to use the iPad.

In addition, the findings continue to contribute new knowledge by evidencing peer to peer teaching and that people with dementia have the ability to impart new and complex knowledge onto others through peer to peer teaching and advice giving. To my knowledge there is currently no literature which addresses people with dementia in the role of teacher (explored in greater detail in the following discussion chapter) and so this is the first to evidence people with dementia actively taking the role of teacher, is the first to evidence people with dementia teaching others with dementia and the first to address the significance of informal and formal peer to peer teaching within this community.

Therefore these findings suggest that the Tech Club may be a mechanism to instigate learning opportunities and teaching prospects for people living with dementia, thereby addressing the following research questions.

Research question 1. What are the benefits (if any) of a technology based community intervention for people with dementia?

These findings demonstrate that an intervention of this kind provides people with dementia with an opportunity and platform to learn which is acknowledged as a basic requirement for healthy and active ageing. A technology focused intervention allows access to pieces of technology which can be tailored to a person's individual preferences and can fuel personal learning agendas and continued learning. An additional benefit is that the Tech Club offered a cognitive challenge, which is acknowledged as being desired in older adults learning literature, and therefore provides an opportunity for those engaging in it to exercise and use their executive function cognitive skills.

In addition, this intervention provided the participants with a platform to teach. Teaching new and existing knowledge not only concretises personal learning and exercises cognitive functions but also supports self3, whereby those with dementia are not seen as patients or people with dementia, but as teachers. Additionally, it also allows for the opportunity to engage in peer to peer learning, which may potentially be a more effective method of learning for those with dementia.

Research question 3. What are the experiences of using digital gaming technology for community dwelling people with dementia?

The findings provide evidence which suggest that whilst all the technologies were new to the participants the iPad was by far the most popular piece of equipment. When side by side, the participants showed a much greater preference to the iPad over the Nintendo Wii and Xbox Kinect. The participants were generally intrigued by the iPad and the activities its functions could enable them to undertake. Although used in groups initially, after being shown how to use the iPad and a level of comfort and familiarity had been reached, the majority of the participants preferred to use the iPad independently, suggesting that it was servicing personal agendas regarding hobbies and interests in addition to enabling a level of independence.

This concludes the findings of this research. The following chapter, chapter nine, will begin a discussion into the findings of this research and will consider them in respect to the concept of QoL.

Chapter Nine: Discussion

As the discussion chapter, this chapter firstly starts with a summary of the findings as presented in chapter's six to eight. Following this, a discussion of the findings in direct relation to QoL will be presented. This will include a discussion surrounding the quantifiable approach to QoL and its limitations, followed by an in-depth discussion surrounding the role of self, access to learning and teaching and how these align to and impact on QoL. This chapter will conclude by presenting practical and theoretical reflections of undertaking this research and will be followed by the concluding chapter, chapter ten.

Summary of findings

To summarise, the findings of chapter six (QoL-AD questionnaire findings) have illustrated that the participants of the Tech Club did not undergo any substantial change in QoL. However, this chapter did highlight some limitations associated with the QoL-AD questionnaire itself which will be discussed later in this chapter. Based on the findings of chapter six alone, research question 2, which asks if digital gaming technology had an impact on QoL of the participants throughout the duration of the Tech Club, is addressed. Here it is indicated that there was no substantial change in the participants' QoL between pre, post and three months after the Tech Club, suggesting that, from a quantitative perspective, the Tech Club did not have an impact on the QoL of the participants with dementia.

Despite this, the thematic analysis of the qualitative data identified important findings surrounding the concept of self. Overall, Kitwood's (1990) malignant social positioning theory was supported through the findings of chapter seven (ability to regain self) whereby the participants of the Tech Club were exposed to malignant positioning despite their own positive outlook on their self as a whole. It has been identified that malignant positioning could be contributing to the fragility of 'self', leading to self2 attributes, particularly self esteem, being at potential risk. This chapter adds to knowledge by acknowledging the fragility of 'self' and contributes new knowledge by offering a possible mechanism to counterbalance this fragility through the supporting of self2 attributes of self esteem and self efficacy. Overall, the findings have highlighted the complex nature of self and potential implications of using the QoL-AD tool when trying to capture an insight into it. Based on these findings, research question 1 which asks what are the benefits (if any) of a technology based community intervention for people with dementia, is addressed. Here the findings show that interventions which

use digital gaming technologies could be a mechanism to address potential loss of self and therefore be of benefit by supporting the development and retention of self2 personal attributes and self3 role attributes.

The findings of chapter eight (access to learning and teaching) also produced important findings which has addressed gaps in literature by providing evidence that older adult learning literature should be extended to include older adults living with dementia. Therefore the findings contribute to knowledge by demonstrating that people with dementia have a desire to learn, ability to learn, that they can engage in all stages of the learning cycle but exhibit differences in learning styles which have been found to be a combination of visual, auditory and kinaesthetic learning methods, with the latter being suggested as the most effective method to learn how to use the Nintendo Wii and Xbox Kinect. Through learning, these findings highlight the use of executive functioning skills, such as working memory, problem solving and attentional control. The findings in this chapter therefore continue to contribute new knowledge by suggesting that the act of learning and teaching can support and protect the participants' existing self2 attributes as well as developing new self2 attributes, subsequently protecting self3.

The findings of this chapter thereby address research questions 1 and 3, question 1 asking; what are the benefits (if any) of a digital gaming technology intervention for community dwelling people with dementia? Here the findings demonstrate that a technology based intervention provides people with dementia with an opportunity to learn, to undertake personal learning agendas and continued learning in the home environment. The findings also show that the Tech Club offered a cognitive challenge, therefore providing an opportunity for those with dementia to exercise their executive function cognitive skills. In addition, the Tech Club provided a platform to teach, whereby teaching new and existing knowledge concreted personal learning and by default supported self3. Finally, a technology based intervention was found to enable peer to peer teaching which may be a more effective method of learning for those with dementia. In response to research question 3, the findings have identified that the iPad was the most popular piece of equipment over the Nintendo Wii and Xbox Kinect, demonstrating that the participants of the Tech Club were intrigued by the iPad and its associated functions and what this may enable them to do. Additionally, the findings demonstrate that after its initial introduction, there was a preference to use the iPad independently, suggesting that it was servicing personal agendas regarding hobbies, interests and independence.

As can be seen, the findings have directly addressed research questions 1, 2 and 3. However the following section considers the findings of this research in direct relation to QoL which further addresses research question 2.

Under a Quality of Life Lens

The following section presents a discussion of the findings directly in relation to QoL. Firstly, a discussion surrounding the ability to quantify QoL and selfhood will be presented, followed by an in-depth discussion concerning selfhood, learning and teaching, and their relation to and impact on QoL. Finally, this section will conclude with a discussion surrounding orientated reality through the connection between selfhood attributes, learning and teaching.

Quantifying Quality of Life

Implications surrounding the construction, collection of and trustworthiness of data produced by the QoL-AD questionnaire have been identified within the QoL findings of chapter six. This section provides a critique of these issues by discussing the construction of the questionnaire and its limitations, followed by a discussion surrounding the trustworthiness of the data produced by this QoL tool.

One of the main strengths of the QoL-AD questionnaire interview tool is that it was constructed in collaboration with people living with dementia (Logsdon et al. 2002; 1999). Despite this, the findings within chapter six have identified that in this research the participants with dementia found the questionnaire challenging to understand and difficult to complete as a result of its design. Question structure surrounding each QoL domain caused confusion due to the unclear nature of what was specifically being asked. For example, domain four asks the participants to rate how they feel about their current living situation, some participants questioned which living environment this referred to, home environment, their wider community or regional environment. Whilst I inferred that this referred to the home environment, it is obvious that this can be interpreted in different ways and without descriptions for each QoL domain it was difficult to be completely sure which scenario the question was referring to. This can also be extended to domain nine which asks the participants to rate how they feel about their 'self as a whole'. Many participants found this difficult to answer as it was not entirely clear what 'self' meant and therefore what this question was asking. In addition, this domain was seen to be very similar to QoL domain 13, 'life as a whole'. Again, there were no clear definitions or descriptors provided to enable an informative explanation to be offered to the participants regarding what either 'self as a whole' or

'self' meant in this context and how this differentiated from 'life as a whole'. This builds on the findings of Selai et al. (2001) research which found that in general the participants undertaking this scale had difficulty interpreting the domains of the QoL-AD in direct relation to their QoL. This thesis suggests that this may be attributable to the lack of descriptions provided for the domains, which has potentially led to confusion surrounding what the domains are referring to and therefore asking. Lack of description of the domains and what the domains are asking has also been evidenced to be an issue identified by proxy contributors when completing this questionnaire (Selai et al. 2001). This thesis has demonstrated that this is also a challenge for people with dementia, and that providing descriptors could create a stronger and more informed foundation for the completion of the QoL-AD.

An additional finding of this research is that when conducting the QoL-AD questionnaire the participants felt that the questionnaire forced an answer into one of the four options (poor, fair, good or excellent), highlighting two individual areas for critique. Firstly, there are no descriptors explaining what each of these options mean, therefore making the tool highly subjective, as one person's 'good' could be another's 'poor'. Descriptors would enable the participants, both the person with dementia and proxy, to provide a more informed and therefore accurate response based on a clear definition of what each option means in the context of this QoL tool. This would provide the researcher with a tangible insight into each response, whilst also reducing the subjectivity of this measure in both how the domains are answered in addition to how they are interpreted. Secondly, the QoL-AD questionnaire does not provide a 'not sure' or 'don't know' option, therefore forcing the participant to answer in only one of four ways. This potentially encourages the participant to provide a response which may not be an accurate reflection of their perception of their QoL as a consequence of there being no neutral option available.

Building on the above point, the findings also demonstrate that the four response options may not sufficiently capture how the participants feel about their QoL. There were many occasions where participants felt that an accurate response to any one domain fell in between two options, for example, 'poor' and 'fair'. This is supported by the reflections of Hoe et al. (2005) who commented that they believed that the participants in their research had difficulty choosing from such an 'abstract list'. The findings of this thesis confirms this to the case. Whilst the limited number of options available potentially makes the questionnaire more accessible by reducing unnecessary information, therefore making it user friendly, the findings of this research suggest that additional response options beyond the basic four are required. This

again supports Selai et al. (2001) research which found the same to be true from the proxy perspective. This thesis therefore extends on this by showing that the response domains are also too restrictive for those with dementia. Whilst others (Akpınar and Küçükgüçlü 2012) may argue that the simplicity of the scale enhances applicability and therefore could widen its scope for use, subtle enhancements to the questionnaire, by expanding its range, might increase the trustworthiness of the data being provided and could prevent participants forcing an answer into a category which may not be representative of their true feelings.

Another area for critique is the collection of proxy data. Whilst this is not a specific critique of the QoL-AD, it is a general observation of QoL questionnaires which use a dual participant and proxy approach. My experience of using the QoL-AD to obtain proxy data has been challenging. Firstly, not all people with dementia have a suitable proxy, relying on alternative proxy representatives (often professional carers) to provide the required information. In this situation, the data provided by the proxy is highly subjective in that their relationship with the person with dementia is professional. This could consequently impact on their perspective as this may be influenced by factors associated with their professional role, working environment and the dynamic between a professional and customer, and or non-family carer and person with dementia relationship. Therefore, this potentially renders this data unusable as the professional carer may not be best placed to comment on every domain of the participant's QoL. This has been shown to be of potential negative impact when professional carer proxies provide their perspective as they can often be influenced by external factors associated to their professional role (León-Salas et al. 2011). Secondly, as this thesis has demonstrated, inviting a proxy contribution has implications in itself as some carers openly disagree with the participant's perception of their own QoL as it sometimes differs from their own. Within literature, proxy contributions especially in reference to family carers, are suggested to be influenced by factors associated with the carer's living situation, the biological relationship between the carer and person with dementia, generational factors, stress and the severity of dementia (Orgeta et al. 2015). This causes potential issues as not only is the proxy contribution highly subjective due to the external factors which may influence their perception of the participant's QoL, when in the same vicinity as the participant completing the questionnaire, they may overtly or inadvertently influence the participant's own response, potentially rendering the data questionable. It is widely accepted that people with dementia rate their own QoL higher than a proxy (Hurt et al. 2008; Fuh and Wang 2006), however, if the objective is to understand the QoL status of a person with dementia surely only they can provide this,

therefore is proxy QoL data relevant or even required? Whilst the QoL-AD questionnaire was selected for this research on the basis that within literature (Wolak et al. 2015; Novelli et al. 2010; Wolak et al 2009) it is perceived that the proxy element provides a sense of enhanced reliability or 'completeness', in practice this seems to have a greater potential to delegitimise the data rather than strengthening it.

There are many elements of the QoL-AD questionnaire which potentially compromise the trustworthiness of the data produced from it. For example, in addition to what has been discussed above, when using this tool to determine if exposure to an experience has resulted in an impact on QoL, unless the research is conducted in a controlled environment, it is impossible to determine what exactly has influenced or led to a change as there are too many external factors which can impact on this. Using a pre, post and follow up approach in interventions, such as the Tech Club, divulge how the participants feel at the time of completing the questionnaire, yet reveals nothing about the influencers behind this. Whilst the follow up score provides a longitudinal perspective of QoL, when working with those with dementia, this could be irrelevant if done too far after the initial pre and post questionnaire interviews as many areas of that person's QoL may have changed during that time. In the case of this research, it is almost impossible to identify if attendance at the Tech Club played a substantial role in affecting the overall QoL of the participants by using this tool. It could therefore be argued that data produced by the QoL-AD questionnaire (unless doing a repeat and controlled longitudinal study) could be redundant if used for anything other than simply capturing QoL changes throughout different time periods.

In conclusion this critique demonstrates that in the case of this research a tool like the QoL-AD questionnaire cannot be used in isolation. This section has identified that the QoL-AD questionnaire has many implications which potentially limits the data it produces in its current format. The overall accuracy of this tool may be questioned and caution should be applied if quantitative questionnaires are used to capture an insight into the QoL of people living with dementia.

Quantifying Selfhood?

As discussed, there are a lack of definitions and descriptors explaining the context and or concept behind each of the 13 QoL domains on the QoL-AD questionnaire scale. Of which, domain nine specifically refers to 'self'. Many participants found this difficult to answer as it was not clear what self meant and how this differentiated from domain 13, 'life as a whole'. Whilst the QoL-AD tool is not solely focused on the concept of self, it

does acknowledge it as one of 13 significant areas of QoL specifically for people living with dementia. Although this is a further critique of the QoL-AD tool it does highlight a general interesting issue around the attempt to quantify a complex concept such as self.

As identified by Sabat (2001), there are three distinct areas which contribute to an individual's overall sense of self. Self1 is associated with personal identity, self2 is in reference to an individual's attributes and everyday preferences, and self3 is connected to persona. However, the QoL-AD tool addresses self as one concept rather than breaking it down. In the context of QoL, this potentially suggests that attempts to capture an understanding of self using this tool may not be adequate as the unique areas of self are not explored in depth or even acknowledged. This, along with the lack of definition as to what is meant by self, could produce notional responses that are not reflective of the person's perception of this area of QoL.

Cohen-Mansfield et al. (2000) suggest that there are many methods used to explore self, using both quantitative and qualitative tools such as observation and interviews. The findings of this research support Cohen-Mansfield et al. (2000) argument that other methods should be found by illustrating that from a quantitative perspective using the QoL-AD tool has established no tangible findings regarding the participants' self and its impact on QoL. In addition, the concept of self is highly subjective as it differs from person to person but is also changeable throughout an individual's life course and largely influenced by a biography history continuum, whereby when and where an individual was born may influence their overall sense of self. For example, depending on where a person is in their life cycle, their upbringing or their physical status can impact on an individual's experience of dementia and sense of self as these will be influenced by past and present life experiences (Bartlett and O'Connor 2010).

Overall, this research has demonstrated that a quantitative approach to self provides little information regarding an individual's sense of self and how this contributes to QoL, in the context of the Tech Club. This is further supported by the findings produced using qualitative methods which did provide interesting insights into self. Therefore, this research identifies that quantitative QoL tools especially the QoL-AD questionnaire need to be reviewed in respect of this.

Retaining Selfhood and Agency

Whilst there is no quantifiable evidence indicating that the participants' sense of self was impacted on throughout the duration of this research, the qualitative findings

illustrated in chapter seven provide an alternative perspective and greater insight into this area when reviewed under a QoL lens. The importance of self when aligned to QoL will now form the basis of this section, where the findings of this research will be discussed, with further discussion surrounding the concept of agency, and how this applies to this research and its overall importance to QoL.

When deconstructing the definition of QoL the significance of self is highlighted. The WHO (1997) definition of QoL identifies key areas considered to be imperative for an individual's QoL to be rich, meaningful and fulfilling:

'An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (WHO 1997)

When considering the role of self in the wider context of QoL Sabat's (2001) self theory is ingrained within this. The reference to position can be suggested to represent self3, an individual's persona or role. Goals, expectations, standards and concerns can be identified as aligning with Sabat's self2, personal attributes. Based on the findings of this research it has been established that in general there is a frailty to the concept of self for a person with dementia, where self2 attributes are at risk from dementia and society resulting in the vulnerability of self3. The above definition of QoL places emphasis on position, goals, expectation, standards and concerns based on the culture and value systems in which an individual lives. This is particularly significant for people living with dementia as the world in which some people live is heavily influenced by the standard paradigm and malignant social positioning, which can therefore reduce an individual's control over their sense of self and therefore overall QoL.

Position

There is a notable emphasis placed on the reference to 'position' within the WHO (1997) definition of QoL as it appears to form a foundation for other elements of QoL to connect to. However, it is not entirely clear what 'position' means and whether this is in reference to a social position, personal position or a mixture of both. There are many deconstructions of this area of self, in both identity theory and when referring to the concept of selfhood which has resulted in personal and social facing selves (Stets and Burke 2000), and inner and outer selves (Aquilina and Hughes 2005), for example. Regardless of which 'position' the definition is referring to, this area of self has been found to be particularly vulnerable. This is relevant for people with dementia as a

reduction in this area of QoL is problematic as Robertson (2014, p.540) argues that *'having a 'good' quality of life is the accomplishment of being engaged in the social world in ways that represent a person's sense of self and social identity'*, she also suggests that *'self and social identity is closely associated with the way they [people with dementia] evaluate their current life circumstances'*. This would therefore suggest that people with dementia can experience a reduction in QoL as their 'position' in the world is compromised and thereby due to the standard paradigm and malignant positioning people with dementia may have limited or no control over their 'position' in their own lives. Whilst it is evident that people with dementia can generally experience a reduction in QoL (Cooper et al. 2012), approaching QoL in this way highlights that selves 2 and 3 have a significant impact on this area and need to be protected and nurtured to ensure that the 'position' element of QoL is maintained and or developed.

Goals, expectations, standards and concerns

The additional elements of QoL, an individual's goals, expectations, standards and concerns, align with self2 personal attributes. Similarly to self3, self2 is also at risk as a result of societal perception and dementia, indicating that self2 is as socially dependant as self3. As Sabat (2002, p.26) argues, as people with dementia are labelled and seen as dysfunctional they are not given opportunities by society to exercise *'remaining intact healthy abilities'*. As a result and similarly to the discussion above, the findings of this research have identified that the participants were potentially experiencing lowered self confidence and a reduced sense of self worth, which ultimately led to a negative impact on self esteem. Consequently, their ability to develop aspiration (goals), manifest high expectations of themselves and to have a voice (standards and concerns) have been reduced, indicating that if not given the opportunity to exercise self2 attributes these areas of QoL may not be fulfilled and this could negatively impact on an individual's overall QoL.

Despite this, this research has demonstrated that engagement in a technology based intervention can support the regaining of self2 attributes such as self esteem and self efficacy, whereby supporting these areas of self can lead to an increase in confidence, communication, pride and dignity, which supports the participant's overall ability to set goals, identify with their expectations and to voice standards and concerns. As explained, self esteem (a self2 attribute), was developed and enhanced throughout the duration of the Tech Club. However, an additional element which is acknowledged to enhance self esteem and which was apparent throughout the findings was self-verification. Positive self-evaluation can boost self esteem (Hoelter 1986) due to the

personal acknowledgement of ability, performance and the appraisal of others (which can influence how we feel about ourselves) (Franks and Marolla 1976). In this research, self-verification led to increased self confidence in the participants' perceived ability to undertake the activities of the Tech Club. Self efficacy also has links to self-verification as identifying with good performance can help to gain a sense of control (Gecas and Schwalbe 1983). Burke and Stets (1999, p.233) suggest that *'self esteem and self efficacy are increased by the self verification which occurs through performing a role well'*, which in the case of this research is as a player / student. This suggests that when in a position where performance is required self-verification may not only increase self esteem and efficacy but may also develop the likelihood of those with dementia undertaking new roles.

Self esteem has also been suggested to develop from being in a group (Stets and Burke 2000). When discussing the group dynamic in this research it is not from the stance of the importance of 'being together' or having company but in recognition of what the group dynamic created and enabled. Firstly, the group dynamic gave the participants an opportunity to practice and exercise their self² skills surrounding communication and general confidence. Secondly, it instigated competition whereby participants competed to showcase their existing self² attributes or expert knowledge (self³). Thirdly, the group environment enabled the participants to speak out and provide their comments and opinions. Therefore the group environment in general contributed to the participants expressing their concerns, standards and goals, and asserting their position within the group, contributing to the maintenance of these areas of QoL. Finally and unexpectedly, the group dynamic created a scenario for self categorisation. Whilst the main commonality between the participants was dementia, further self categorisation based on perceived similarities took place, whereby some participants perceived themselves to be 'different' to others in the group but the same as each other. Stets and Burke (2000) suggest that individuals may categorise themselves to feel valuable, worthy, competent and effective. Whilst these participants initially shared a perceived inability to interact with the technologies and a general lack of confidence, when together, their ability to speak out, disapprove and question increased. As a result of having a 'group identity' confidence and esteem increased, they engaged more with the technologies yet continued to cement their position and vocally exercise their perspective on standards and concerns associated to previous self³ role and self² attributes. Overall this suggests that by supporting the development, maintenance and regaining of self² attributes, particularly self esteem and self efficacy, this can support the QoL of people with dementia as it contributes to

the maintenance of their position, goals, expectations, standards and concerns. Above and beyond this, it allows people with dementia to gain a sense of control over their self and therefore over their QoL.

This discussion has identified that people with dementia may have limited control over their QoL when considering the impact of self on this area, therefore indicating a potential loss of agency. It has been suggested that people with dementia have no sense of agency (Kontos 2004) or the '*ability to control personal life in a meaningful way, to produce, to achieve, to make some mark upon others and the world*' (Kitwood and Bredin 1992, p.283). However, it is argued that people with dementia do possess a sense of agency yet this is limited and underrepresented within the literature (Boyle 2014). This research adds knowledge to this area by illustrating that the participants demonstrated capabilities of self-reflection, through reflective practice on the impact of dementia on their life, and their QoL, in addition to evaluating their performance associated with the engagement with the digital gaming technologies of the Tech Club. This demonstrates that if agency requires self reflection (Burkitt 2008), then people with dementia are in fact capable of this, in the context of this research. As Boyle (2014) suggests, through agency people with dementia '*can influence the direction of their future lives*', therefore they are able to undertake actions which can improve or contribute to their position, goals, expectations, standards and concerns within their QoL.

This research has identified that a technology based intervention can support people with dementia to exercise agency as it provides opportunities for them to influence their own personal circumstances (Madhok et al. 2013), through regaining self² and 3 attributes, therefore challenging malignant positioning and thereby gaining more control over their QoL. Whilst it has been suggested that people with dementia find the act of 'doing' more challenging than 'being' and therefore prefer simply 'being' (Boyle 2014), this research offers an alternative perspective as it illustrates that it is not enough for people with dementia to 'be' and that whilst the act of doing may be challenging, this is how self can be regained, how position can be established and ultimately how QoL can be maintained. Therefore it can be argued that agency needs to be '*recognised and facilitated*' (Boyle 2014, p.114) for a good standard of QoL to be possible. A technology based intervention can provide an opportunity for this.

In conclusion, the unique contribution of this research is that it has evidenced that self is integral for QoL as it is embedded in the position, goals, expectations, standards and concerns that contribute to QoL, therefore without self, QoL may be reduced. It has

also established that these areas of QoL are largely out of the control of people with dementia as they are influenced by society's perceptions and understandings of dementia. Therefore, it is suggested that a technology based intervention is a potential mechanism to support self by the regaining of self esteem and self efficacy which are vital for the maintenance of goals, expectations, standards and concerns, whilst also protecting the individual's role and position. This discussion has identified that an intervention of this kind provides an opportunity for people with dementia to regain a sense of agency over their selfhood and therefore ultimately their QoL.

Lifelong Learning and Active Aging

Access to lifelong learning is recognised to be an aspect of active and healthy ageing (Alzheimer Scotland 2009; Moody 2004) which is seen to contribute to overall QoL. The importance of lifelong learning, defined as '*all purposeful learning activity, undertaken on an ongoing basis with the aim of improving knowledge, skills and competence*' (Commission of the European Communities 2000, p.3), for older adults is recognised internationally (European Commission 2010; 2006; 2001). It is a concept which has been debated since the 1970s (Dehmel 2006) and is attributed as being a key factor for 'active ageing' (Moody 2004). The concept of active ageing has direct association with the QoL of older adults and is defined as the '*process of optimising opportunities for health, participation and security in order to enhance quality of life as people age*' (WHO 2002). This concept was primarily developed in response to the economic, social and health 'burdens' associated with the increase in ageing populations, and it highlights that in order for the health and QoL of older adults to continue, engagement in physical and social activities (Jenkins and Mostafa 2015) and lifelong learning is required.

To date there have been many studies (Jenkins and Mostafa 2015; Štatiénė 2015; Jamieson 2012; Boulton-Lewis 2010; Withnall 2009; Narushima 2008; Jamieson 2007; Dench and Regan 2000) conducted into the role of learning specifically focused on older adults. The seminal work of Dench and Regan (2000) discovered that in respect to older adult learning, 80% of participants reported a positive impact on various areas of their life (enjoyment, self-confidence and coping abilities), 28% reported increased involvement in social and community activities and 42% confirmed an increase in their ability to stand up and be 'heard', as a result of learning. In addition, this research highlighted that higher proportions of people with disabilities or health problems reported positive benefits of learning when compared to those in good health. Overall, the reported benefits of engaging in the act of learning from these participants

surrounded having the opportunity to keep their brains active, enjoyment of learning new concepts and learning topics which were focused on personal interests. This research is supported by the later work of Boulton-Lewis (2010) who also suggests that access to education is essential for allowing a contribution to society. In addition, other studies have also found that when engaged in learning benefits also include mental stimulation through the acquisition of new knowledge (Withnall 2009; Jamieson 2007), general overall improvements to QoL (Jamieson 2007) and motivation to carry on with everyday life (Narushima 2008).

The importance of lifelong learning and QoL has been acknowledged in international policy (European Commission 2010; WHO 2002), whereby there are calls for the promotion of active ageing, education, learning and the development of new skills to be made available throughout each individual's life course (WHO 2002) to meet the challenge of promoting active ageing (European Commission 2010). This is alongside policies such as the Organisation for Economic Co-operation and Development (Keese 2006) which states that *'if people are to remain engaged in meaningful and productive activities as they grow older, there is a need for continuous training in the workplace and lifelong learning opportunities in the community'*. Yet despite this and along with the significant understanding of the impact that learning has on active ageing and therefore QoL, literature is largely based on older adults in general. Literature exploring the role of lifelong learning for those with dementia is stark, largely quantitative in nature, clinical in its focus and is currently limited to the understandings of implicit and explicit motor skills for everyday activities (Van Tilborg et al. 2011); retrieval skills surrounding memory (Bird 1998) and the use of familiar skills (Kessel and Hensken 2009; Cowles et al. 2003; Rösler et al. 2002). As discussed, the work of Dench and Regan (2000) starts to explore the role of learning with those in poor health and or disability yet this is the extent of the literature. This may be attributable to the fact that dementia is set within a 'tragedy' discourse (McParland et al. 2017), whereby people with the condition are seen to be outside of the boundary of 'normal' society (Bruens 2014). Due to this, people with dementia are simply considered outside the realms of learning, as is evident here. McParland et al (2017) suggest that a shift in the negative dementia discourse is required in order for social change to occur.

This illustrates that the QoL benefits of learning for those living with dementia is simply not considered despite the recognised benefits that learning has for older adults. Due to this, this thesis contributes unique knowledge to this area by adding to the understanding of older adult learning from a dementia perspective.

Building on the work of Boulton-Lewis (2010) who suggests that understanding what older people say they want to learn is limited, this thesis offers findings which add to this by demonstrating that in the context of a technology based intervention, older people (living with dementia) want to learn how to use the iPad. This thesis also builds on the work of Purdie and Boulton-Lewis (2003) who propose that whilst older people do not have an urgency to use technology there is a desire to learn how to use it, by evidencing that the iPad can be added to the repository of technologies older people (with dementia) have a desire to learn. These findings also support and align with research highlighting the potential benefits of the iPad when used with people living with dementia as it can be tailored to individual preferences and hobbies (Lloyd-Yates 2013a; 2013b), therefore acknowledging that *'learning participation may become more focused on, or related to, personal interests and activities as people get older'* (Jenkins and Mostafa 2015, p.3). In general, aligned to the concept of lifelong learning, literature has highlighted the potential of the iPad as an enabler of personal choice and control, this thesis has identified that there is a desire to use the iPad in this way to access personal interests.

Overall, this section of the discussion has highlighted a general gap in research concerning the learning capability of people living with dementia. Therefore this research adds knowledge to this area by building on the work of Dench and Regan (2000) by demonstrating the findings can be extended to older adults living with dementia. In particular they build on the suggestion that older people in poor health or with disabilities are less likely to have plans for continued learning. However, this thesis offers findings to the contrary, showing that in the context of the Tech Club people with dementia do have a desire and plan for continued learning within the home environment. Alongside this, this thesis also aligns with and adds to the known benefits of engaging in learning, being increased self esteem and self efficacy. Overall, this thesis responds to international policy agendas by identifying and providing a mechanism which can encourage active ageing for community dwelling people with dementia. Whilst it has been acknowledged within this research that a technology based intervention enables access to lifelong learning, which has been discussed to be integral for active ageing and therefore QoL, there are also additional QoL benefits evident from having an opportunity to learn within the Tech Club.

Citizenship through Lifelong Learning

This section of the discussion will explore the role of learning and its connection to the citizenship status of people living with dementia, the impact of citizenship will then be

reviewed under a QoL lens to provide insight into the role of a technology based intervention.

Lifelong learning and citizenship

Upon receiving a dementia diagnosis the citizenship status of people living with dementia can be reduced (Boyle 2008), whereby the roles and responsibilities that are indicative of being an active citizen are removed (Kelly and Innes 2013), leading people with dementia to effectively experience a 'social death' (Brannelly 2011; Sweeting and Gihooly 1997). As demonstrated and discussed throughout this thesis, people with dementia are stigmatised, discriminated against and malignantly positioned, and one consequence of this is that they are considered 'passive actors' (Bartlett and O'Connor 2007), resulting in them neither being seen nor treated as active citizens (Brannelly 2011). It is recognised that there are two types of citizen, those who contribute to the state and those who take from it. This acknowledges the 'active' citizen who contributes to the economy or democratic process and the 'passive' citizen who gets what they are entitled to on the basis of equal citizenship (Bartlett and O'Connor 2010). A demotion to 'welfare recipients' (Bartlett and O'Connor 2010, p.127) reduces people with dementia's access to not much more than health care, demonstrating an additional indication of the person with dementia's loss of position (self3), which this research has already established is of paramount importance to the maintenance of QoL.

As 'contribution', namely in connection to neoliberalism economic and political discourse (Burke 2015), is arguably the main indicator of active citizenship (Turner 2001), this highlights an inequality regarding citizenship entitlement. Citizenship entitlement and active citizenship were historically based on the three foundations of work, war and parenthood (Turner 2001). Yet despite social developments, entitlement remains heavily reliant on contribution. Bartlett and O'Connor (2010, p.99) comment that work is perhaps '*the single most important aspect of being a citizen*', which from a state perspective could suggest that economic contribution is the biggest motivation behind citizenship identification. Whilst this claim could be suggested to be unfounded, the fact that the state appears to invest in those who are seen as able to make an economic contribution now or in the future by providing opportunities for development and learning (for example to encourage entry into the workplace or ensuring longer working commitment), this investment is not extended to those who are believed to be unable to contribute. This demonstrates inequality within citizenship status as it appears that the state only invests in the future of those who can contribute to the state.

One example of such inequality surrounds lifelong learning. Developmental opportunities, such as access to education and learning are recognised as being vital for all of society, except those living with dementia. This illustrates that people with dementia are not privy to the same opportunities as everyone else despite the recognised benefits of lifelong learning. It appears that access to learning is accessible only to those in society who are considered able and worthy to learn. However, as citizenship is '*rights based not needs based*' (Bartlett and O'Connor 2010, p.35), it could be argued that access to education and learning is both a right as well as need within our society and therefore opportunities for learning engagement should be made available to everyone to ensure equality. Inclusion in everyday societal activities is indicative of social inclusion (Burchardt et al. 1999) and by creating opportunities such as access to learning, people with dementia can be seen as active and contributing citizens (Bartlett and O'Connor 2007). Therefore, creating opportunities for learning can help to address the equality balance within citizenship status to ensure that universally recognised concepts such as learning are accessible to those living with dementia. This research thereby argues that learning is an indicator of citizenship, and that the citizenship status of those with dementia can be challenged, established and protected through engagement in lifelong learning. This can validate them through their ability to learn, enable them to grow (Bartlett and O'Connor 2010), increase their sense of belonging and challenge their position in the world, thereby confirming their status as valued citizens, which is imperative for QoL to be maintained.

Citizenship and QoL

The impact of citizenship on the QoL of people with dementia is considerable. As explained in chapter three, there are many definitions of citizenship, however this research aligns to the definition which appears to be the most inclusive on the basis that it takes into consideration people living with dementia whilst acknowledging the flaws and limitations in other definitions:

'Social citizenship can be defined as a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and social level' (Bartlett and O'Connor 2010, p. 37)

Deconstructing the definition of citizenship illustrates a direct relationship with QoL (*'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'* (WHO 1997)). The first element of the definition of citizenship is in reference to 'discrimination' which essentially refers to the way in which people are treated on the basis of their condition and therefore has links to the QoL indicator of 'position', and *'have opportunities to grow and participate in life to the fullest extent possible'*, which links to the 'goals, expectations, standards and concerns' of QoL. This research suggests that if an individual with dementia has the opportunity to grow and participate in life without discrimination, which in the case of this research is through learning, they are engaging in the associated areas of QoL. Here citizenship status can be challenged, reducing discrimination and enabling people with dementia to participate, thereby contributing to the maintenance, protection and enhancement of their QoL. In addition, the same is true of the second element of the definition which refers to 'justice'. This has strong links to equality (equality within citizenship status) aligning to discrimination and therefore the position of the person with dementia. Ultimately, by providing equal opportunities, which in the case of this research is to learn, this demonstrates equal citizenship value, therefore impacting people with dementia's position in the world. Similarly, the definition also refers to personhood and *'responsibility for shaping events at a personal and social level'*. This takes into account the subjective elements of a person in line with the external world, again aligning to QoL as it is this area of a person, if supported, that can enable the person to undertake their goals, expectations, standards, concerns and have an element of agency over their self, position and ultimately their QoL. Regardless of the definition, a common factor is that participation and inclusion in the community is a requirement of, and therefore indicator of citizenship, however, it should be noted that citizenship is not included on the QoL-AD as a QoL domain. Therefore citizenship is important as it supports the maintenance, protection and enhancement of QoL through encouraging equality and justice, challenging social positioning, encouraging selfhood, agency and development, all of which address the positioning, goals, expectations, standards and concerns which are fundamental to the QoL of people living with dementia.

In summary, this research shows that there is an inequality in citizenship status and that within this people with dementia are seen as passive citizens who are considered unable to contribute and as a result have no opportunities for continued development. However, the findings of this research illustrate great benefits and potential of technology based interventions as they provide access to learning for those with

dementia. It shows that enabling access offers the ability to engage in lifelong learning and active ageing (the benefits of which have already been stated), and can provide a heightened sense of citizenship as their position has shifted from invalid and unworthy to worthy and capable, addressing the balance of equality within citizenship status.

The Act of Teaching

This section of the discussion focuses on people with dementia undertaking the role of teacher and how this thesis aligns with current research, before considering the impact of teaching on QoL.

To provide context, literature exploring people with dementia undertaking the act of teaching is extremely limited. Research on this topic is mainly associated to intergenerational schools (Whitehouse and Whitehouse 2005; Camp et al. 1997) where people with dementia act as teaching support in areas of reading; provide advice (Dijkstra et al. 2006); act as group leaders (Camp and Skrajner 2004) and dementia subject experts (Russell 2016). Camp et al. (1997) research explored people with dementia's ability to 'teach' or act as mentors when providing young children lessons based on daily living, language, mathematics, social science and social skills (Montessori programme). However, the main focus of this research is on the Montessori programme and whether it could be taught by people living with dementia after extensive training and with heavily structured guidance. Another study conducted by Camp and Skrajner (2004) explored the role of people with dementia as group leaders for activities with other people with dementia. However, this involved those with dementia being trained to lead bingo style games where there was no element of teaching. Research undertaken by Dijkstra et al. (2006) was the most significant with regards to people with dementia undertaking an active teaching role. This research saw participants relaying a cake recipe from a visually cued booklet to undergraduate students who followed their instruction and undertook the cooking of the recipe. Whilst the aim of this research was to explore if people with dementia could 'teach' this recipe, its main agenda was to identify the language which was used and how instructions were communicated. However, the participants were restricted to the instructions of the recipe card which they could not deviate from, comment on or question, even if they considered elements to be inaccurate.

The reported benefits of engaging in 'teaching' style roles from the research above suggests that people with dementia undertaking the role of dementia subject expert (Russell 2016) found this rewarding, enjoyable and interesting, and was an opportunity

for them to increase their confidence and to make a contribution to society. This is in line with the findings of this thesis, where the participants engaged in topics of interest to them through digital gaming technologies and experienced an increase in self esteem and self efficacy.

As explained, this area of research is limited and in its infancy. Whilst the above research has begun to delve into the potential teaching capacity of those living with dementia and its associated benefits, by the definition of teaching (someone who shares knowledge to teach and instruct others how to do something) current research has not in fact engaged this community in the act of teaching, but explored their capacity to take on supportive roles. In contrast, this thesis illustrates that people with dementia can naturally undertake the act of teaching without training, support or prompting to do so, extending on their own learning to impart their knowledge in an organic way, rather than a teaching environment being artificially constructed. This research therefore builds on the existing literature base as it evidences that people with dementia have the communication skills required to impart information on to others and are able to explain complex concepts to beginners, further instructing them after initial communication and explanation has been provided. To date, research has demonstrated an attempt to engage those with dementia in the act of teaching, yet this is diluted and largely one way, whereby people with dementia are provided with information and instruction and asked to comply. As there is little research to compare the findings of this thesis to, this thesis therefore adds unique knowledge by demonstrating the true act of peer to peer teaching and potential for a change in the direction of interaction, whereby people with dementia are becoming interactive selves by imparting their new knowledge onto others through teaching, showcasing their ability *'to affect as well as be affected'* (Bartlett and O'Connor 2010, p.128).

In addition, due to the limited literature on this topic, it also contributes new knowledge by not only being the first to illustrate people with dementia taking an active teaching role thereby confirming the teaching capabilities of people with dementia, but also that people with dementia can teach and learn from others with this condition. Furthermore it also provides insight into the significance of informal and formal peer to peer teaching within this community.

Whilst teaching or imparting advice is not included as a QoL domain on the QoL-AD scale, nor does it naturally align to any of the key QoL elements of the WHO (1997) definition of QoL, this thesis illustrates that QoL can be supported through undertaking

the role of teaching, therefore further contributing more new knowledge to teaching, QoL and dementia literature.

Active Social Contribution through Teaching

The role of learning and its impact on the citizenship status of those with dementia has been discussed, acknowledging that it enables individuals to have an increased sense of citizenship through access to lifelong learning. However, this discussion demonstrates a shift from inclusion and equity within citizenship to active involvement within society, a movement from passive to active citizenship. As Bartlett and O'Connor (2010, p.40) suggest, '*people with dementia must have the opportunities to grow*', this thesis suggests that this is both in terms of skills and ability as well as growing into a different kind of citizen.

As will be discussed in greater detail in the following section, there is an important connection between self and teaching. In the case of this research this is from two perspectives. Firstly, people with dementia undertaking the role of teacher instantly challenges the standard paradigm and malignant social positioning. Benbow (2009) suggests that in general when older people undertake teaching roles this can change how others see them and how they see themselves. In addition, as suggested by Bourgeois et al. (2005), engaging in specific roles (such as teaching) can lead to enhanced QoL as the person's abilities are recognised by others therefore leading to more rewarding personal relationships. Secondly, through teaching and connections to self² and self³, people with dementia are able to replace the identity of patient, service user or someone with dementia to an active member of the community. It is suggested that roles such as a teacher can strengthen self, reduce learned helplessness and contribute to increased feelings of self esteem (Liang et al. 2001).

Whilst it is acknowledged that people with dementia are becoming more actively involved in society and making a contribution through sharing their experiences and expert knowledge of dementia as well as being activists (for example the Scottish Dementia Working Group), raising awareness of the condition through conference proceedings, research, service evaluation and online website presence (Bartlett and O'Connor 2010), this research demonstrates an alternative method for social contribution which is not focused on dementia and is based purely on the skills and ability to teach.

As highlighted in the literature review, creating opportunities for people with dementia to become engaged in their community could enable them to become contributing

citizens (Bartlett and O'Connor 2007), which is an indicator of active citizenship status. This is supported by the findings of Russell's (2016) research which identified that undertaking a supportive expert role made the participants feel that they were actively contributing to society. Barnes (1997) suggests that people with dementia need to be empowered to become active citizens. This research shows a mechanism for this through providing opportunities to engage in interactional activities that nurture a sense of competence through social contribution in the form of teaching, enabling people with dementia to become legitimate 'active social agents' (Bartlett and O'Connor 2010, p.5).

Social contribution is vital for a sense of citizenship. The importance of citizenship to QoL for people with dementia has already been identified within this research where it has been established that contribution is the difference between passive and active citizenship. This discussion further builds on this as it identifies a mechanism for continued social contribution which has obvious immediate benefits for people with dementia such as increased self esteem, positive impacts on self3 attributes and QoL. Active social contribution has direct lineage to the position element of QoL which when considering the wider impact of citizenship can alter the world and the structures in which people with dementia find themselves, therefore challenging and dismantling malignant positioning. As Bartlett and O'Connor (2010, p.73) comment, '*creating a climate where participation of people with dementia is maximised and valued is a societal responsibility*', teaching is one way that people with dementia can contribute. This research evidences people with dementia making an active contribution by undertaking teacher roles, showing a shift from passive to active citizenship status.

In summary this discussion has identified that through engagement in a digital gaming technology based intervention the QoL benefits for community dwelling people with dementia is increased social contribution through teaching. Societal contribution for those with dementia could arguably be the most significant QoL benefit associated with the act of teaching as it provides a sense of contribution, redresses the balance of equity within citizenship status and challenges the positioning of people living with dementia. Therefore a sense of citizenship is integral for maintaining, protecting and enhancing QoL.

Orientated Reality

As suggested in previous chapters there is a strong interconnection between the supporting and protecting of self2 and 3 with access to learning and teaching. This section of the discussion argues that in the context of a digital gaming technology based intervention, supporting the personal attributes of self2 and protecting self3 role

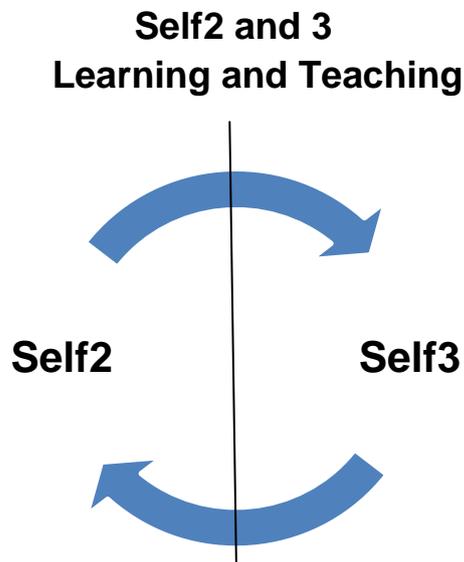
attributes are not mutually exclusive to the act of learning and teaching, they can occur at the same time and they stimulate each other.

This research has demonstrated that through engagement in the Tech Club self2 attributes of self esteem and self efficacy can be supported. The separate findings on lifelong learning and teaching have illustrated that people with dementia have the abilities to learn in addition to the abilities required to teach new and complex concepts. This demonstrates that learning and teaching are both self2 attributes, whereby the use of numerous self2 skills sets such as those associated with executive cognitive functioning, retention, retrieval and communication have been illustrated, in addition to self2 attributes related with personal hobbies and interests. With this in mind, engaging in the act of learning and teaching naturally alters social positions from a 'person with dementia' to a person engaged in education as a student and or teacher, resulting in new self3 roles. New self3 roles therefore challenge current self3 status, potentially impacting on self2 attributes of self esteem and self efficacy.

In reverse, people with dementia would potentially not engage in learning and teaching due to a reduction in or perceived loss of self2 attributes surrounding ability and lowered self esteem. However, supporting self2 attributes can be argued to enable the development of new or existing skills and attributes which facilitate learning and teaching to initially take place, therefore leading to new self3 roles. This aligns with Kitwood's (1990) suggestion that the maintenance of self esteem, for example, is necessary to enable learning and self efficacy. This has certainly been the case in this research that has identified a potential connection to the supporting of self esteem and the possibility that this enables development in other areas when using digital gaming technology. Whilst this research cannot claim that the development of self esteem in the context of the Tech Club directly resulted in the participants' ability to learn or teach, there is a link as without one, in this case self esteem, self efficacy, learning and teaching may not naturally follow.

As illustrated in the figure below, by developing new self2 attributes people with dementia are learning, whereby new skills and knowledge are then transferred to others. This therefore impacts on self3 roles in addition to the development of new self2 attributes associated to learning and teaching. The figure shows a change in direction of interaction, where people with dementia have become interactive selves as opposed to being interacted with, thereby demonstrating a mechanism where bi-directional interaction can take place (Bartlett and O'Connor 2010). However, overall, this is an ongoing process which contradicts the standard paradigm; offers an

alternative way to think about those living with dementia and offers a technology based intervention as a mechanism for those with dementia to retain a sense of self, gain a sense of agency, challenge citizenship status and make an active social contribution, simultaneously.



It should be noted that the above figure does not take into consideration the inevitable decline in self2 attributes that people with dementia will experience as a result of the condition. However, regardless of the decline in skill and ability new self2 attributes may continue to be developed as people continue to grow as people (Bartlett and O'Connor 2010). Therefore, self2 attributes in those living with dementia should be continuously supported as this protects them from becoming someone who is declining and invalidated to someone who is simply living with a condition, thereby safeguarding their selfhood, agency and citizenship status.

Reflections

This section of the discussion presents my reflections on the practical process of undertaking a digital gaming Tech Club for community dwelling people living with dementia. Firstly, barriers I faced when conducting participant recruitment will be illustrated. This will be followed by outlining the implications of the research environment and the presence of carers within this. I will then reflect on the importance of facilitator communication and how this had an impact on my role as participant observer. This section will conclude with my reflections on the limitations of the digital gaming technology equipment when used with those living with dementia.

Barriers to participant recruitment

As explained in chapter four, the process of recruitment was largely influenced by the commissioners of the service evaluation. Whilst I designed the participant information sheets and the recruitment posters, physical recruitment was conducted by the service commissioner and gatekeepers they nominated. The rationale for this was that the commissioner felt that as they had access to the target participants it would be easier for them to recruit. However, this process was ingrained with problems which lead to the recruitment process becoming complicated and in some cases awkward on a personal level.

The service commissioner elected the day centre (DC) managers to act as gatekeepers and aid the recruitment process within this venue as they were considered best placed to engage with potential participants. Whilst this approach in theory was beneficial, I felt that even though the managers were knowledgeable about the service users, they had their own perceptions of dementia and what they believed their 'clients' could and could not do. It was mentioned several times that the service users were at 'end stage'. These perceptions acted as a barrier to recruitment.

Allowing for ample time to recruit, I sent the recruitment material to the service commissioner eight weeks prior to the start date of the Tech Club. After two weeks it was discovered that the management of the DC had not disseminated the material as they disliked and disapproved of the word dementia on the recruitment poster, on the basis that they believed it would offend the service users. In response to the concerns of this gatekeeper it was requested that I adapt the poster to display that the Tech Club was '*for people with dementia and memory problems*'. The gatekeeper confirmed that their DC service was specifically for those with dementia and so the recruitment posters would only be seen by the client base that had dementia. Despite the adaptations, it was confirmed that the management of the DC were too busy to display the recruitment posters, delaying recruitment for a further week. After which the managers then decided they did not want to send the participant information sheets to the carers as they felt the carers '*would be confused*'. The commissioner investigated this and discovered that there was a dislike of the word '*institute*' (part of the name of the research centre at the University) on the participant information sheet which the managers feared would scare and make their clients may think they '*were signing themselves up to be put into an institute*'. As recruitment had still not started I arranged a meeting with the management of the DC to discuss these concerns directly. It was explained that due to ethical considerations, the research centre's logo would not be

removed. It was also agreed that as the DC was worried about family carer involvement, key workers would provide QoL information for those without family carers or in replacement of family carers of anyone who did not want to take part in the research.

Recruitment for the community centre (CC) followed the same process, where all recruitment material was sent to the commissioner to disseminate eight weeks before the start of the Tech Club. There were many delays with the recruitment to this venue as there were queries as to how to disseminate this information effectively when attempting to attract community dwelling people with dementia. The commissioner suggested that the poster should be sent to 3000 carers in the local area via post. I explained that as the Tech Club only required ten participants this would not be productive, it then took over a week for this to be agreed. It was then decided that recruitment would be targeted through an existing Carers Information Service database, however, this relied on another local authority department to respond, so there were additional delays as justification to use the database was required. Due to significant delays in this process, the start date of the research was moved by three weeks. In order to assist the recruitment process it was agreed that I could send recruitment material to the local Alzheimer's Society, in addition to the Memory Assessment Team, Memory Support Service and Community Mental Health Teams in the local area.

On reflection I believe that the management team of the DC had the best interests of the service users at heart, yet were creating unnecessary barriers based on their own judgements and assumptions. In order to successfully recruit, recruitment needs to extend beyond an information sheet and posters when working with external parties as I believe it would have been more informative and effective to have been able to visit the venue to explain the Tech Club in person to all involved, potentially alleviating any issues this gatekeeper had, allowing them to ask questions at the start of the process rather than delaying the process due to confusion or misunderstanding. Whilst I originally believed that conducting recruitment through the commissioner, with a venue with an existing user base, would make the recruitment process easier, I found that the commissioner was an unnecessary 'middle man' which complicated the process. The perceptions held by the gatekeeper posed as an additional barrier between the research and its intended participants, acting as a potential threat to the production of the research. Similarly, I considered that recruitment conducted through the commissioner for the CC participants would make the process easier due to their access to carer databases. However this complicated the process as it relied on too

many departments to undertake their part of the process. On reflection I believe it would be easier to restrict recruitment to one smaller gate keeper as outsourcing this to other departments significantly delayed the process. It also makes sending out the information again to generate interest more difficult as the same delays are experienced making it challenging to follow standard reminder processes. To conclude, I feel that the researcher needs to be involved in all areas of the research process in order to communicate the research intentions adequately to avoid unnecessary issues affecting the undertaking of research.

Implications of the research environment

As explained, two rooms within a DC and CC were selected. However, there were implications within each of these research environments'. Firstly, due to a double booking of the room initially agreed as a suitable space for conducting the Tech Club (large room, cool and plenty of space) within the DC, a smaller room, with French patio windows, as described in chapter five, was provided. Despite negotiations after the first session, where I conveyed my concerns about the suitability of this space, it was confirmed that this was the only room available and would therefore be allocated for the duration of the Tech Club. The size of the room and the environment created by the French patio doors created implications when conducting the Tech Club as it was too small to adequately video record the sessions and it restricted the participants' view of some of the activities. The size of the room was too small for the amount of and type of chairs it housed, when the participants were seated, the arms of the chairs were touching to the point that some participants could not see the television screen when the Nintendo Wii or Xbox Kinect was being used. I noticed some participants were shifting around in their seats, lifting themselves up, sitting back down and leaning forward and backwards again to be able to see the television. In response to this I moved the chairs around as much as the room would allow increasing visibility for the participants. In addition, the patio windows had no curtains or blinds so the room was uncomfortably warm as the sun shone through in the afternoon. This was particularly problematic when using the Nintendo Wii and Xbox Kinect as the use of these games made the participants even warmer than they already were. I was permitted to open the patio door once to allow breeze into the room but I was later requested to keep the doors closed and locked to avoid the participants going into the garden. On some occasions, I noted that the room was too warm, even for me, as I could see some participants starting to fall asleep towards the end of one session.

In contrast the agreed room in the CC was available and as previously explained this room was large and contained many tables, chairs and electrical points. Despite the initial observations of the room, when conducting the research issues which were not immediately obvious came to light. The size of the room, which was originally considered a highlight, became a draw back in consideration of the number of participants which were recruited. Whilst for a larger group this room would be ample, for this group it was too big and impersonal. I made adaptations in an effort to make the room more comfortable and inviting, however, the overall environment had additional challenges. The windows, which spanned the length of the room, had no curtains or blinds and so when sun was shining the light was too harsh for some participants. With no other means to reduce the light, I covered some of the windows with table cloths. In addition, as the room was large it was very cold with some participants wearing their coats and another commenting that the cold interfered with their performance within the sessions. A heater was brought into the room to increase the room temperature.

On reflection, even though I felt that I had undertaken a rigorous inspection of the venues and the rooms with regards to accessibility, toilet access, parking and electrical points for the exergaming, this was not rigorous enough. For example, potential implications with light, heat, chairs and tables were not obvious during my original inspection and therefore were not taken into consideration when selecting the rooms. Whilst the room in the DC was out of my control, these were not elements that I had considered in the initial inspection of the agreed room either. It would have been beneficial prior to the research to conduct pilot sessions in the designated rooms so that I could experience the full environment prior to the start of the research. When conducting research I have learnt that the room and the environment can have a large bearing on the participants' experience and ability to engage in the activity and so this needs to be fully considered when undertaking interventions of this kind. This also extends to the equipment used within the research.

There were also various implications to the use of the internet within both venues. Whilst internet accessibility was explored and tested prior to the start of the Tech Club, it transpired that the internet connection in both venues was not strong enough to support the usage of more than one iPad at a time. This limited what the participants were able to do on the iPads and often meant they were doing the same thing on the apps. I believe that limited access to the internet within the sessions was detrimental as it limited the amount of time the participants were able to explore their hobbies as there was only one functioning iPad. I think that the sessions were affected because of this as some of the participants were unable to engage with the iPad in the way they

wanted to. Whilst I had limited control over the chosen venues, on reflection, had I undertaken a ‘dummy’ session prior to the start of the Tech Club I may have discovered this and potentially had time to rectify it.

On reflection, there were many differences between the two groups which could have also impacted on the participants’ overall experiences. Whilst this is not the focus of the research and a comparison between the groups is irrelevant, the differences between them (table below) may have had an impact on the way the participants reacted to the technologies and how they engaged in the Tech Club.

Differing factors	Day Centre	Community Centre
Venue	Participants familiar with environment	Participants unfamiliar with environment
Time of day	Sessions held in the afternoon	Sessions held in the morning
Travel	Participants already at the venue	Participants required to travel to the venue
People	Participants familiar with peers	Participants unfamiliar with peers
Activity	Participants familiar with engaging in activities	Participants may not have been familiar with interacting with activities
Carers	Professional care staff present	Family carers present

One of the main differences between the groups which potentially impacted on how the participants engaged in the sessions was that the participants of the CC were required to travel to the sessions, whereas participants of the DC were already at the venue as part of their daily activity. It was reported by some participants of the CC that they had trouble getting to or finding the venue. This was problematic as it meant that sometimes the participants were late, which disrupted the session for the other participants’ or that the participants’ mood has been affected because of a bad experience on route to the venue.

Carer influence

As seen in the findings, despite carers not being the focus of this research, they had a significant influence within the research environment. For example, in connection to the findings associated with self regarding carer perspective and an element of taking over, on reflection, there appeared to be a level of self interest displayed by some of the carers with their engagement in the Tech Club as some openly commented that they also wanted to learn how to use the technologies. Whilst I initially considered that the presence of FCs within the Tech Club would have a minimal impact on the sessions and the participants, this was not the case as I felt that in the session’s carer presence and engagement was a potential barrier to participant involvement, evidenced by the

fact they were asked to sit away from the group. Whilst carer inclination to learn would ordinarily be positive, in the Tech Club I think this affected the participants' experience as this took away support from the participants and often took over the activities. There was also a level of interference when conducting the QoL questionnaire interviews, as identified in the findings of the research. I wonder if participant responses were affected because of the carer presence and perhaps would have changed if that dynamic was not present.

In contrast, PCs were present during some elements of the research for participants of the DC. Yet, even when they were not physically present, they still had a significant influence on the participants and the research. For example, when conducting the QoL questionnaire interviews both myself and the participants were sometimes rushed to complete this as quickly as possible by those who worked there. On many occasions, PCs stood outside of the door for extended periods of time when the QoL interviews were being conducted, proceeding to tap on the window, signalling to their watch. This added pressure to complete the interview as quickly as possible. In general, I think that carer presence within the research environment needs to be carefully considered if they are not the focus of research as their presence alone can have an impact on the participants and therefore the research.

Encouragement and pressure

As a participant observer I was able to observe and therefore reflect on the importance of communication when delivering technology based interventions. One major area for reflection is the role of encouragement verses pressure. Whilst observing I noticed that the facilitator of the session asked participants to evidence their learning regarding the use of the iPad, ensuring that the participants understood what they were meant to do and were able to do it. On reflection, I wonder if this caused an element of pressure inadvertently. In reality it made no difference if the participants were able to perform the actions or not, yet the facilitator decided to request that the participants illustrate their learning in what could have been perceived as a test, demonstrating a potential fine line between encouragement and pressure. In many of the sessions participants were invited to use the equipment, mainly the Xbox Kinect or the Nintendo Wii. In some cases the participant's answer was 'no' even after repeat encouragement was provided in order to empower the participant to try. In some cases the participants answered they did not want to use the equipment because they felt that they could not. On reflection, were the participants being disempowered by the facilitator applying 'encouragement' when the participant's answer was 'no', and how many times does a

person need to be 'encouraged' to take part before this is interpreted as pressure by the participant? When does encouragement turn into pressure and when does 'no' really mean 'no' as opposed to the participant simply being nervous, apprehensive or lacking in confidence? Are the participants being disempowered by presenting them with a task or activity which they feel they cannot do by telling them 'yes you can', does this not undermine their initial decision? On reflection, there is a fine line between encouraging someone and that encouragement unintentionally turning into pressure. This is an area of research to be explored in more detail.

Participant observer and facilitator experience

Two areas in particular made this role challenging to undertake, firstly the environment and secondly the confidence and experience of the facilitator. Due to the size limitations of the DC room, it was difficult to be sat 'outside' of the group, in order to undertake an adequate observation of participants and their activities I had no choice but to sit amongst the participants. Being so visible meant that I was often pulled into the sessions by the participants who were looking for support when the facilitator was elsewhere.

Whilst the facilitator had experience of working with people with dementia, their experience of using digital gaming technology with those with dementia was limited. There were numerous occasions when observing the sessions or undertaking the video observation that I felt the way in which the facilitator responded to certain situations could have negatively impacted on the participants' experience, especially when the facilitator appeared to be experiencing signs of tiredness, worry, confusion or impatience. This I felt could put the participants on edge or make them apprehensive and uneasy by making them feel that were doing something wrong when in fact it was the facilitator's lack of confidence and ineffective communication methods which were the issue. In many cases the facilitator requested that I provide them with support. I was required to abandon my role as participant observer on many occasions to demonstrate other methods of communicating instructions to the facilitator.

On reflection, more than one facilitator is needed for technology based interventions like this. Providing support to those who may have never used this equipment before is time consuming and cannot be rushed, especially when using the Nintendo Wii and Xbox Kinect. As a participant observer, I believe that interventions like these need to be led by experienced individuals with strong communication skills in addition to having experience of using this type of technology with this participant group.

Digital gaming technology

When undertaking the Tech Club intervention there were many limitations associated to the Xbox Kinect and the Nintendo Wii. As discussed, the Xbox Kinect was not used beyond its first introduction in both the DC and CC as it was difficult to use. One of the major limitations to the use of this technology is a consequence of the sensor. The sensor recognises the participant playing the game but only works with one person in front of the screen. As the participants required assistance when using the game, the facilitator was required to stand next to the participants, meaning that the sensor would not work properly. In one case it took 37 minutes to work before the game had started. In addition, as this technology is not reliant on a physical controller and so by default should be easy for the participant to use, on reflection I consider the opposite to be the case. Due to the lack of a physical object to hold, the relationship between the participant and the television screen was lost, potentially making interaction confusing for some participants. Whilst I believe the participants understood the concept of the Xbox Kinect, as there was no controller or physical object to hold, I think there was a disjoint between the game and the participant. One participant was unable to grasp that their movements were replicated on the screen without holding anything as with the Nintendo Wii. This impacted on user experience as some participants felt that they could not control what was on the screen and this was a result of their lack of ability, yet this was actually a consequence of the equipment.

Contrastingly one of the major reflections of using the Nintendo Wii is the display of error messages. Error messages were displayed on the screen if the technology considered the participant to have 'failed'. This could be detrimental to the participants' confidence if the participants are apprehensive of their ability to engage in technologies like this. I do not think that error messages should deter others from using this equipment with those with dementia as long as the environment in which they are being used is supportive and informal, where the error messages can be disregarded and not taken seriously.

Finally, the participants of the Tech Club requested to engage in memory games, however, this was connected to the iPad, which was usually used in small groups or individually. In general, unless they are specifically requested I think memory games should be avoided when using the Nintendo Wii or Xbox Kinect. On reflection, I do not think it is a good idea to focus on an area of the participants life which they are struggling with (unless it is specifically requested) as it can highlight this area of difficulty or annoy, agitate and frustrate them, especially in a group environment.

In conclusion, this chapter has provided an overview of the findings of this research, has presented discussions of the findings when considered in line with QoL and has provided my practical reflections of undertaking a technology based community intervention. The following final chapter of this thesis, the conclusion, will now present the final conclusion of this research, highlighting the major findings as well emphasising its unique contribution to knowledge.

Chapter Ten: Concluding Chapter

As the concluding chapter of this thesis, the limitations and strengths of this research will now be discussed, followed by directions and recommendations for future research. The chapter will conclude with a summary of the keys findings and an overview of the overall contribution to knowledge made by this research, culminating with my concluding thoughts.

Limitations of research

It could be argued that the most significant limitation to this research is that it is attached to an independent service evaluation which resulted in limited control in some elements of the research design, recruitment processes and venue selection. With regards to the limitations surrounding the research design, this was mainly in connection to available funding which restricted the duration of the research and number of facilitators to support the delivery of the sessions. However, whilst the service evaluation restricted some elements of the research design it also provided a real world scenario which has resulted in the production of research which has responded to real life limitations, challenges and obstacles.

An additional limitation of this research was that the maximum target of 20 participants was not reached. However, including the two participants who decided not to pursue the Tech Club after their initial visit, only four participant spaces remained unfilled. Therefore, I do not consider this to be detrimental to the research as the multiple methods data collection approach ensured an abundance of rich data would be collected regardless of the final number of participants.

A potential further limitation is regarding the limited experience of the facilitators when using digital gaming technology with community dwelling people with dementia. Building on the points made above, as this research was conducted alongside a funded service evaluation there were limitations as to how many facilitators could be used. Despite this, the facilitators delivering the Tech Club were experienced in working with people living with dementia and had received an element of training on the use of this technology specifically with the target group prior to the start of the intervention. In addition, as a participant observer with much experience in this area I was able to provide support if required.

Strengths of research

Despite its potential limitations, the service evaluation is one of the greatest strengths of this research as it has resulted in this thesis being a practical reflection of research conducted within the real world which has been shaped by and has responded to everyday research challenges. This highlights the accessibility of this research and potential repeatability in a real world situation. In addition, the adaptability of this research was also a major strength as through its pragmatic underpinnings and multiple methods approach, I was able to respond to changes within the research design, session structure and participant feedback in ways that may have been more restricted if using alternative methodologies and philosophical underpinnings. This ensured that the research never became stagnant and constantly evolved to produce interesting and relevant findings. The research was further strengthened and complimented by the use of thematic analytical approaches, which were also flexible and allowed unexpected findings to emerge from the data which may have been stifled if using alternative analysis methods.

In addition to building on existing research in the areas of selfhood, adult learning and the role of technology in dementia post diagnostic support, the overall main strengths of this research are the unique contributions it makes to knowledge both theoretically and methodologically. From a theoretical perspective, the research has identified key findings which contribute to knowledge and address gaps within the literature. Overall, this research has addressed the research questions and evidenced that a digital gaming technology intervention has an impact on the QoL of community dwelling people with dementia by enabling people with dementia to regain a sense of self, gain a sense of agency, challenge equality within their citizenship status and illustrate active citizenship through making a legitimate active social contribution. All of which are integral for QoL to be supported, protected and maintained.

This research has also contributed new knowledge by offering evidence to suggest that a digital gaming technology intervention is a mechanism to support self, which is of vital importance when living with dementia. It also addresses the gap in adult learning literature concerning the significance of learning and peer to peer teaching for those with dementia, the learning preferences of people with dementia and effective learning environments for this group. In addition, it has also contributed new knowledge surrounding peer to peer teaching, whereby it has been evidenced that not only can people with dementia teach, they are able to impart new and complex concepts onto others with dementia. From a methodological perspective this research has highlighted

implications in methodological approaches to QoL research and therefore challenges the use of quantitative methods in QoL based research especially concerning people living with dementia.

In essence, this research has made a unique contribution to knowledge by being the first to evidence that a digital gaming technology intervention has QoL benefits for community dwelling people with dementia.

Recommendations for future research

From a methodological perspective, whilst this research has used a pragmatist philosophy to underpin it, using a social constructionism philosophy may also yield interesting findings. Social constructionism may be an alternative philosophy to underpin future research similar to this as it directly relates to the construction of the world, society and of self, which is relevant to the understanding of dementia, QoL and selfhood. The social constructionism paradigm explores the way in which people think and talk about reality which is particularly relevant when considering those living with dementia as they may not act or behave in a manner which is considered socially acceptable based on socially constructed ideas surrounding the condition, as discussed in the earlier literature review. As found in this research, people living with dementia are exposed to malignant positioning which can be argued to develop from socially constructed perceptions of dementia, potentially attributable to the biomedical approach. Using this philosophy to underpin future research may provide an alternative insight into the QoL of those living with dementia.

When considering research design, whilst the duration of the Tech Club was optimal for this research, a longer intervention, potentially with more frequent sessions may provide an even more in-depth insight into QoL if using qualitative approaches. Based on the findings of this research which has deemed QoL may be questionable when attempting to measure it, it is suggested that QoL quantitative tools should be used with caution when attempting to gain insight into the QoL of those living with dementia.

From a process and practicalities perspective there are various learning and recommendations from undertaking this research which may be considered when designing future research based on interventions using digital gaming technology. Firstly, ensuring the chosen venue has a suitable room, which is of a good size for the group numbers, has adequate heat and light controls and has strong internet connection to support more than one iPad simultaneously is vital. Secondly, it is recommended that a test session is undertaken prior to the delivery of any intervention

to circumvent potential environmental and logistical issues prior to the start of the research. Thirdly, as found with this research, technology based interventions can be facilitated by one facilitator if this facilitator is confident, understands the equipment, understands the importance of atmosphere, has an understanding of dementia and can develop a relationship with the participants and the group as a whole, although two facilitators is optimal. In addition to this, facilitator training is highly recommended if they have never used this technology with people living with dementia before. Fourthly, technology interventions like the Tech Club should be made available to all people with all dementia regardless of ability or understanding and if the intervention is to be held in a community venue where participants do not know each other, an introduction session before the start of the research could be advantageous. Finally, clear boundaries should be established if carers of any kind are present during research concerning this type of technology to ensure the intervention is focused and tailored for those with dementia.

Finally, from a policy perspective, the role of digital gaming technology based interventions aimed at community dwelling people with dementia should be considered as a valid post diagnostic support mechanism as it has been found to support self and be an enabler of learning and teaching, both of which are of huge importance to QoL which is vital for active ageing and successful community living. Future research could consider the role of this technology on the QoL of people living with dementia who reside in hospital or fully supported care facilities.

Conclusion

This PhD thesis, underpinned by a pragmatist approach using a qualitative methodology with a nested quantitative element, has addressed the research questions which ask if participation in a technology based intervention has any benefits for community dwelling people with dementia. This research has contributed new and unique knowledge by evidencing that there are QoL benefits to participating in a digital gaming technology intervention. A technology intervention has been found to support the protection, maintenance and enhancement of QoL by providing a mechanism to support self and agency, in addition to increasing a sense of citizenship and equity within this, and by providing an opportunity for active social contribution.

This research has produced the below key findings:

1. Based on the use of and critique of the QoL-AD questionnaire scale, attempts to quantify QoL have been suggested to be questionable. QoL does not appear to be easily quantifiable, and tools such as the QoL-AD questionnaire should be used with caution when attempting to gain insight into the QoL of people living with dementia.
2. A digital gaming technology based intervention can be a mechanism to support and protect selfhood through providing opportunities to address self esteem and self efficacy thereby counterbalancing the fragility of self and potential reduction in self confidence and self worth. The findings therefore present a means, through a technology intervention, to support and protect selfhood. Through the supporting of self, this research has demonstrated that QoL can also be supported through regaining a sense of agency.
3. Engaging in lifelong learning is possible through participation in a technology based intervention and as such lifelong learning concepts should be extended to include people living with dementia. The findings have illustrated that people with dementia can learn, can engage in all stages of the learning cycle and that they exhibit different learning styles, paces and methods whilst using their executive functioning skills of working memory, problem solving and attention control. Therefore, a digital gaming technology intervention is a mechanism to instigate learning opportunities for people with dementia. Through access to lifelong long learning opportunities, equality in the citizenship status of people

with dementia can be addressed, thereby contributing to the support and maintenance of QoL.

4. People with dementia have the capability and skills required to teach newly obtained and complex knowledge through peer to peer teaching and advice giving. The findings demonstrate that for this to be successful, informal teaching arrangements are the best method for peer to peer teaching and learning for people living with dementia, as equalisation is produced through the removal of formal role hierarchy, thereby showing that a technology intervention is a method to instigate the prospect of teaching. Through having opportunities to teach, people with dementia can make a legitimate active social contribution thereby illustrating active citizenship status, which is vital for QoL to be supported and maintained.

Therefore, this thesis has directly addressed a gap in the literature and makes an original contribution to knowledge by identifying a psychosocial post diagnostic mechanism which contributes to and supports the maintenance of QoL for community dwelling people with dementia, using an intervention focused on the Nintendo Wii (Nintendo Co LTD), Xbox Kinect (Microsoft Corp) and the Apple iPad. In essence, this research has made a unique contribution to knowledge by being the first to evidence that a digital gaming technology intervention has QoL benefits for community dwelling people with dementia.

REFERENCE LIST

- Ackerman, P.L., Kanfer, R. and Calderwood, C., 2010. Use it or lose it? Wii brain exercise practice and reading for domain knowledge. *Psychology and aging*, 25 (4), 753.
- ACM., 2006. Riding the Brain Train. *Communications of the ACM*. 49 (6), 10-10.
- Agmon, M., Perry, C.K., Phelan, E., Demiris, G. and Nguyen, H.Q., 2011. A pilot study of Wii Fit exergames to improve balance in older adults. *Journal of geriatric physical therapy*, 34 (4), 161-167.
- Aguirre, E., Hoare, Z., Spector, A., Woods, R. T. and Orrell, M., 2014a. The effects of a Cognitive Stimulation Therapy [CST] programme for people with dementia on family caregivers' health. *BMC Geriatrics*, 14 (1), 1.
- Aguirre, E., Spector, A. and Orrell, M., 2014b. Guidelines for adapting cognitive stimulation therapy to other cultures. *Clinical Interventions In Aging*. 9, 1003-1007.
- Akpinar, B. and Küçükgüçlü, Ö., 2012. The validity and reliability of the Turkish version of the quality of life scale for patients with Alzheimer's disease (QOL-AD). *Journal of Neurological Sciences*, 29 (3), 554-565.
- Alaszewski, A., 2006. *Using diaries for social research*. Sage.
- Albert, S.M., Castillo-Castaneda, C., Sano, M., Jacobs, D.M., Marder, K., Bell, K., Bylsma, F., Lafleche, G., Brandt, J., Albert, M. and Stern, Y., 1996. Quality of life in patients with Alzheimer's disease as reported by patient proxies. *Journal of the American Geriatrics Society*, 44 (11), 1342-1347.
- Algar, K., Woods, R.T. and Windle, G., 2016. Measuring the quality of life and well-being of people with dementia: A review of observational measures. *Dementia*, 15 (4), 832-857.
- Alm, N., Astell, A.J., Gowans, G., Dye, R., Ellis, M.P., Vaughan, P. and Riley, P., 2009. Engaging multimedia leisure for people with dementia. *Gerontechnology*. 8 (4), 236-246.
- Almazrua, H., Al-Wabil, A., Al-Muhanna, H. and Al-Wabil, R., 2013. Technology for psychosocial interventions for individuals with Alzheimer's: Reminiscence therapy and monitoring progressive decline of cognitive abilities. *Proceedings of 2013 Science and Information Conference*, SAI 2013, 171-175.
- Alzheimer Disease International., 2014. *World Alzheimer report 2014: Dementia and Risk Reduction*. Alzheimer's Disease International.
- Alzheimer Disease International., 2013. *World Alzheimer report 2013: An analysis of long term care for dementia*. Alzheimer's Disease International.

- Alzheimer's Disease International., 2013. *The Global Impact of Dementia 2013-2050*. ADI: London.
- Alzheimer Disease International., 2012. *World Alzheimer report 2012: Overcoming the stigma of dementia*. Alzheimer's Disease International.
- Alzheimer Disease International., 2011. *World Alzheimer report 2011: The benefits of early diagnosis and intervention*. Alzheimer's Disease International.
- Alzheimer Disease International., 2010. *World Alzheimer report 2010: the global economic impact of dementia*. Alzheimer's Disease International.
- Alzheimer Scotland., 2009. *Charter of rights for people with dementia and their carers in Scotland*. Edinburgh. England.
- Alzheimer's Society., 2017. What is dementia? *Factsheet 400*. Alzheimer's Society.
- Alzheimer's Society., 2014a. 'Statistics' .Available from: <http://www.alzheimers.org.uk/statistics>. [Accessed 16/12/14].
- Alzheimer's Society., 2014b. *Dementia 2014: Opportunity for change*. Alzheimer's Society.
- Alzheimer's Society., 2014c. *Dementia Friendly Technology Charter*. Alzheimer's Society.
- Alzheimer's Society., 2013a. *Building dementia friendly communities: A priority for everyone*. Alzheimer Society.
- Alzheimer's Society., 2013b. *Dementia Friendly Societies*. Alzheimer's Society.
- Alzheimer's Society. 2013c. *Dementia 2013: The Hidden Voice of Loneliness*. Alzheimer's Society.
- Alzheimer's Society., 2010. *My name is not dementia: literature review*. Alzheimer's Society.
- Andrén, S. and Elmståhl, S., 2008. Effective psychosocial intervention for family caregivers lengthens time elapsed before nursing home placement of individuals with dementia: a five-year follow-up study. *International Psychogeriatrics*, 20 (6), 1177-192.
- Aquilina, C. and Julian, C., 2005. The return of the living dead: agency lost and found?. In: Hughes, Julian, et al. *Dementia: Mind, Meaning, and the Person*. Oxford University Press, 2006. International Perspectives in Philosophy and Psychiatry. EBSCOhost.
- Astell, A.J., Joddrell, P., Groenewoud, H., de Lange, J., Goumans, M., Cordia, A. and Schikhof, Y., 2016. Does familiarity affect the enjoyment of touchscreen games for people with dementia?. *International journal of medical informatics*, 91,1 - 8.

Astell, A., Alm, N., Dye, R., Gowans, G., Vaughan, P. and Ellis, M., 2014, July. Digital video games for older adults with cognitive impairment. In *International Conference on Computers for Handicapped*. Springer International Publishing.

Astell, A., 2013. Technology and fun for a happy old age. In *Technologies for active aging* 169-187. Springer US.

Astell, A. J., Alm, N., Gowans, G., Ellis, M., Dye, R., & Vaughan, P., 2009. Involving older people with dementia and their carers in designing computer-based support systems: Some methodological considerations. *Universal Access in the Information Society*, 8 (1), 49-59.

Aurilla, A. and Arntzen, B., 2011. Game based Learning to Enhance Cognitive and Physical Capabilities of Elderly People: Concepts and Requirements. *World Academy of Science, Engineering and Technology*. 60.

Baker, R., Bell, S., Baker, E., Holloway, J., Pearce, R., Dowling, Z., Thomas, P., Assey, J. and Wareing, L.A., 2001. A randomized controlled trial of the effects of multi-sensory stimulation (MSS) for people with dementia. *British Journal of Clinical Psychology*, 40 (1), 81-96.

Ball, K., Berch, D.B., Helmers, K.F., Jobe, J.B., Leveck, M.D., Marsiske, M., Morris, J.N., Rebok, G.W., Smith, D.M., Tennstedt, S.L. and Unverzagt, F.W., 2002. Effects of cognitive training interventions with older adults: a randomized controlled trial. *Journal of the American Medical Association*. 288 (18), 2271-2281.

Ballard, C., Fossey, J., Chithramohan, R., Howard, R., Burns, A., Thompson, P., Tadros, G. and Fairbairn, A., 2001. Quality of care in private sector and NHS facilities for people with dementia: cross sectional survey. *British Medical Journal*, (7310), 426-427.

Bamidis, P.D., Fissler, P., Papageorgiou, S.G., Zilidou, V., Konstantinidis, E.I., Billis, A.S., Romanopoulou, E., Karagianni, M., Beratis, I., Tsapanou, A. and Tsilikopoulou, G., 2015. Gains in cognition through combined cognitive and physical training: the role of training dosage and severity of neurocognitive disorder. *Frontiers in aging neuroscience*, 7.

Barnes, M., 1997. *Care, Communities and Citizens*. London. Routledge.

Barnett, E., 2000. *Including the Person with Dementia in Designing and Delivering Care: I Need to be Me!*. Jessica Kingsley Publishers.

Bartfay, E. and Bartfay, W.J., 2013. Quality-of-life outcomes among Alzheimer's disease family caregivers following community-based intervention. *Western journal of nursing research*, 35 (1), 98-116.

Bartlett, R., 2012. Modifying the diary interview method to research the lives of people with dementia. *Qualitative Health Research*, 22 (12), 1717-1726.

- Bartlett, R. and O'Connor, D., 2010. *Broadening the dementia debate: Towards social citizenship*. Policy Press.
- Bartlett, R. and O'Connor, D., 2007. From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21 (2), 107-118.
- Basak, C., Boot, W.R., Voss, M.W. and Kramer, A.F., 2008. Can training in a real-time strategy video game attenuate cognitive decline in older adults?. *Psychology and aging*, 23 (4), 765.
- Bassett, S.S., Magaziner, J. and Hebel, J.R., 1990. Reliability of proxy response on mental health indices for aged, community-dwelling women. *Psychology and Aging*, 5 (1), 127 - 132.
- Beard, R.L., 2012. Art therapies and dementia care: A systematic review. *Dementia*, 11 (5), 633-656.
- Beard, R.L., 2004. In their voices: Identity preservation and experiences of Alzheimer's disease. *Journal of Aging Studies*, 18 (4), 415-428.
- Benbow, S.M. and Jolley, D., 2012. Dementia: stigma and its effects. *Neurodegenerative Disease Management*, 2 (2), 165-172.
- Benbow, S.M. and Reynolds, D., 2000. Challenging the stigma of Alzheimer's disease. *Hospital medicine (London, England: 1998)*, 61 (3), 174-177.
- Benbow, S.M., 2009. Older people, mental health and learning. *International Psychogeriatrics*, 21 (05), 799-804.
- Benini, A., 2000. *Construction of Knowledge*. Rome. Gnome publishers.
- Benveniste, S., Jouvelot, P., Pin, B. and Péquignot, R., 2012. The MINWii project: Renarcissization of patients suffering from Alzheimer's disease through video game-based music therapy. *Entertainment Computing*, 3(4), pp.111-120.
- Billis, A.S., Konstantinidis, E.I., Ladas, A.I., Tsolaki, M.N., Pappas, C. and Bamidis, P.D., 2011. Evaluating affective usability experiences of an exergaming platform for seniors. In *Biomedical Engineering, 2011 10th International Workshop on*. IEEE.
- Bird, M., 1998. Clinical use of preserved learning capacity in dementia. *Australasian Journal on Ageing*, 17 (4), 161-166.
- Birren, J.E., Lubben, J.E., Rowe, J.C. and Deutchman, D.E. eds., 2014. *The concept and measurement of quality of life in the frail elderly*. Academic Press.
- Black, B.S., Johnston, D., Morrison, A., Rabins, P.V., Lyketsos, C.G. and Samus, Q.M., 2012. Quality of life of community-residing persons with dementia based on self-rated and caregiver-rated measures. *Quality of Life Research*, 21 (8), 1379-1389.

- Blaikie, N., 2009. *Designing social research*. Polity.
- Blaikie, N., 2007. *Approaches to social enquiry: Advancing knowledge*. Polity.
- Blumer, H., 1970. What's wrong with social theory? In: Filstead, W.J. and Filstead, W.J. eds., 1970. *Qualitative methodology: Firsthand involvement with the social world*. Chicago: Markham Publishing Company. 52 – 62.
- Boller, F., 2008. History of dementia. *Handbook of clinical neurology*, 89, 3-13.
- Bond, J., 1999. Quality of life for people with dementia: approaches to the challenge of measurement. *Aging and Society*. 19 (5), 561 – 579.
- Bond, J., 1992. The medicalization of dementia. *Journal of Aging Studies*, 6 (4), 397-403.
- Boot, W.R., Blakely, D.P. and Simons, D.J., 2011. Do action video games improve perception and cognition?. *Frontiers in psychology*, 2, 226.
- Boulay, M., Benveniste, S., Boespflug, S., Jouvelot, P. and Rigaud, A.S., 2011. A pilot usability study of MINWii, a music therapy game for demented patients. *Technology and health care*, 19 (4), 233-246.
- Boulton-Lewis, G.M. 2010. Education and learning for the elderly: Why, how, what. *Educational Gerontology*, 36 (3), 213-228.
- Boulton-Lewis, G.M., Buys, L. and Lovie-Kitchin, J., 2006. Learning and active aging. *Educational gerontology*, 32 (4), 271-282.
- Bourgeois, M.S., Dijkstra, K. and Hickey, E.M., 2005. Impact of communication interaction on measuring self-and proxy-rated depression in dementia. *Journal of Medical Speech-Language Pathology*, 13 (1), 37-51.
- Bowes, A., Dawson, A., Jepson, R. and McCabe, L., 2013. Physical activity for people with dementia: a scoping study. *BMC geriatrics*, 13 (1), 129.
- Bowes, A. and Wilkinson, H. South Asian people with dementia: research issues. In: Wilkinson, H. eds., 2002. *The perspectives of people with dementia: Research methods and motivations*, 223-241. London: Jessica Kingsley
- Bowling, A., 2014. *Research methods in health: investigating health and health services*. McGraw-Hill Education (UK).
- Boyatzis, R. E., 1998. *Transforming Qualitative information: Thematic analysis and code development*. Thousand Oaks. Sage publications.
- Boyle, G., 2014. Recognising the agency of people with dementia. *Disability & Society*, 29 (7), 1130-1144.

Boyle, G., 2008. The Mental Capacity Act 2005: promoting the citizenship of people with dementia?. *Health and social care in the community*, 16 (5), 529-537.

Bradbury, H. and Reason, P., 2003. Action research: An opportunity for revitalizing research purpose and practices. *Qualitative social work*, 2 (2), 155-175.

Brannelly, T., 2011. Sustaining citizenship: People with dementia and the phenomenon of social death. *Nursing Ethics*, 18 (5), 662-671.

Brannelly, T., 2006. Negotiating ethics in dementia care: an analysis of an ethic of care in practice. *Dementia*, 5 (2), 197-212

Braun, V. and Clarke, V., 2013. *Successful qualitative research: A practical guide for beginners*. Sage publications.

Braun, V. and Clarke, V., 2006. Using thematic analysis in psychology. *Qualitative research in psychology*, 3 (2), 77-101.

Brod, M., Stewart, A.L., Sands, L. and Walton, P., 1999. Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). *The Gerontologist*, 39 (1), 25-36.

Brody, E.M., Kleban, M.H., Lawton, M.P. and Silverman, H.A., 1971. Excess disabilities of mentally impaired aged: Impact of individualized treatment. *The Gerontologist*, 11 (2), 124-133.

Brooker, D.J., Latham, I., Evans, S.C., Jacobson, N., Perry, W., Bray, J., Ballard, C., Fossey, J. and Pickett, J., 2016. FITS into practice: translating research into practice in reducing the use of anti-psychotic medication for people with dementia living in care homes. *Aging & mental health*, 20 (7), 709-718.

Brooker, D., La Fontaine, J., De Vries, K., Porter, T. and Surr, C., 2011. How can I tell you what's going on here? The Development of PIECE-dem: An observational framework focussing on the perspective of residents with advanced dementia living in care homes.

Brooker, D., 2007. *Person-Centred dementia care. Making services better*. Jessica Kingsley publishers.

Brooker, D., 2003. What is person-centred care in dementia?. *Reviews in clinical gerontology*, 13 (3), 215-222.

Brooker, D., 1995. Looking at them, looking at me. A review of observational studies into the quality of institutional care for elderly people with dementia. *Journal of Mental Health*, 4 (2), 145-156.

- Brotons, M. and Koger, S.M., 2000. The impact of music therapy on language functioning in dementia. *Journal of music therapy*, 37 (3), 183-195.
- Bruens, M.T., 2014. Dementia: beyond structures of medicalisation and cultural neglect. *Ageing, meaning and social structure: Connecting critical and humanistic gerontology*.
- Bryman, A., 2015. *Social research methods*. Oxford University Press.
- Bryman, A., 2012. *Social research methods*. Oxford University Press.
- Bryman, A., 2008. *Social Research Method*. Oxford University Press.
- Bryman, A., Becker, S. and Sempik, J., 2008. Quality criteria for quantitative, qualitative and mixed methods research: A view from social policy. *International Journal of Social Research Methodology*, 11 (4), 261-276.
- Burchardt, T., Le Grand, J. and Piachaud, D., 1999. Social exclusion in Britain 1991—1995. *Social Policy & Administration*, 33 (3), 227-244.
- Burdea, G., Polistico, K., Krishnamoorthy, A., House, G., Rethage, D., Hundal, J., Damiani, F. and Pollack, S., 2015. Feasibility study of the BrightBrainer™ integrative cognitive rehabilitation system for elderly with dementia. *Disability and Rehabilitation: Assistive Technology*, 10 (5), 421-432.
- Burgess, R.G., 1984. *In the Field: An Introduction to Field Research*. London and New York.
- Burke, L., 2015. In: Swinnen, A. and Schweda, M. eds., 2015. *Popularizing dementia: Public expressions and representations of forgetfulness*. 6.
- Burke, P.J. and Stets, J.E., 1999. Trust and commitment through self-verification. *Social Psychology Quarterly*, 347-366.
- Burkitt, I., 2008. *Social selves: Theories of self and society*. Sage.
- Burman, E. and Parker, I. eds., 2016. *Discourse analytic research: Repertoires and readings of texts in action*. Routledge.
- Butcher, H.K., Holkup, P.A., Park, M. and Maas, M., 2001. Thematic analysis of the experience of making a decision to place a family member with Alzheimer's disease in a special care unit. *Research in Nursing & Health*, 24 (6), 470-480.
- Caddell, L.S. and Clare, L., 2010. The impact of dementia on self and identity: A systematic review. *Clinical psychology review*, 30 (1), 113-126.
- Caldwell, K., and Atwal, A., 2005. Non-participant observation: using video tapes to collect data in nursing research. Issues in Research. *The Nurse Researcher*, 13 (2), 42-54.

Campbell, D., Klages, A., Martineau, J. and Richeson, N., 2010. Dance movement: Increasing mobility and decreasing depression for persons with dementia. *Activities Directors Quarterly for Alzheimer's and Other dementia Patients*, 11 (3), 27-32.

Camic, P.M., Tischler, V. and Pearman, C.H., 2014. Viewing and making art together: A multi-session art-gallery-based intervention for people with dementia and their carers. *Aging & Mental Health*, 18 (2), 161-168.

Camic, P.M., Williams, C.M. and Meeten, F., 2013. Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*, 12 (2), 157-176.

Camp, C.J. and Skrajner, M.J., 2004. Resident-Assisted Montessori Programming (RAMP): training persons with dementia to serve as group activity leaders. *The Gerontologist*, 44 (3), 426-431.

Camp, C.J., Judge, K.S., Bye, C.A., Fox, K.M., Bowden, J., Bell, M., Valencic, K. and Mattern, J.M., 1997. An intergenerational program for persons with dementia using Montessori methods. *The Gerontologist*, 37 (5), 688-692.

Campbell, D., Klages, A., Martineau, J. and Richeson, N., 2010. Dance movement: Increasing mobility and decreasing depression for persons with dementia. *Activities Directors Quarterly for Alzheimer's and other dementia Patients*, 11 (3) 27-32.

Campbell, A., Converse, P.E. and Rodgers, W.L., 1976. *The quality of American life: Perceptions, evaluations, and satisfactions*. Russell Sage Foundation.

Cardullo, S., Valeria, P.M., Ilaria, T., Ambra, P., Gamberini, L. and Mapelli, D., 2015. Padua Rehabilitation Tool: A Pilot Study on Patients with Dementia. In *International Conference on Games and Learning Alliance*. Springer International Publishing, (292-301).

Carlson, E.D., Engebretson, J. and Chamberlain, R.M., 2006. Photovoice as a social process of critical consciousness. *Qualitative health research*, 16 (6), 836-852.

Chang, Y.J., Chou, L.D., Wang, F.T.Y. and Chen, S.F., 2013. A kinect-based vocational task prompting system for individuals with cognitive impairments. *Personal and Ubiquitous Computing*, 17 (2), 351-358.

Chang, Y.J., Chen, S.F. and Chuang, A.F., 2011. A gesture recognition system to transition autonomously through vocational tasks for individuals with cognitive impairments. *Research in developmental disabilities*, 32 (6) 2064-2068.

Cho, S.-Y., Cheng, Y.-F., Chen, H.-R., Tang, H.-H., Chu, W.-C., Chen, M.-Y. and Chen, C.-H., 2014. Memoir monopoly: A rehabilitation game for elderly living with dementia. *Gerontechnology*, 13 (2), 91-92.

Chao, Y.Y., Scherer, Y.K. and Montgomery, C.A., 2015. Effects of using Nintendo Wii™ exergames in older adults: a review of the literature. *Journal of aging and health*, 27 (3), 379-402.

Chao, Y.Y., Scherer, Y.K., Wu, Y.W., Lucke, K.T. and Montgomery, C.A., 2013. The feasibility of an intervention combining self-efficacy theory and Wii Fit exergames in assisted living residents: A pilot study. *Geriatric Nursing*, 34 (5), 377-382.

Cherryholmes, C.H., 1992. Notes on pragmatism and scientific realism. *Educational researcher*, 21 (6), 13-17.

Cheston, R. and Bender, M., 1999. *Understanding dementia: The man with the worried eyes*. Jessica Kingsley Publishers.

Chilukoti, N., Early, K., Sandhu, S., Riley-Doucet, C. and Debnath, D., 2007. Assistive technology for promoting physical and mental exercise to delay progression of cognitive degeneration in patients with dementia. In *Biomedical Circuits and Systems Conference, 2007. BIOCAS 2007*. IEEE.

Choi, A.N., Lee, M.S., Cheong, K.J. and Lee, J.S., 2009. Effects of group music intervention on behavioral and psychological symptoms in patients with dementia: a pilot-controlled trial. *International Journal of Neuroscience*, 119 (4), 471-481.

Clare, L., Rowlands, J., Bruce, E., Surr, C. and Downs, M., 2008. The experience of living with dementia in residential care: An interpretative phenomenological analysis. *The Gerontologist*, 48 (6), 711-720.

Clare, L., Roth, I. and Pratt, R., 2005. Perceptions of change over time in early-stage Alzheimer's disease: Implications for understanding awareness and coping style. *Dementia*, 4 (4), 487-521.

Cohen, D. and Eisdorfer, C., 2002. *The loss of self: A family resource for the care of Alzheimer's disease and related disorders*. WW Norton & Company.

Cohen-Mansfield, J., Golander, H. and Arnhem, G., 2000. Self-identity in older persons suffering from dementia: preliminary results. *Social science & medicine*, 51 (3), 381-394.

Colombo, M., Marelli, E., Vaccaro, R., Valle, E., Colombani, S., Polesel, E., Garolfi, S., Fossi, S. and Guaita, A., 2012. Virtual reality for persons with dementia: an exergaming experience. *Gerontechnology*, 11 (2), 402-405.

Commission of the European Communities., 2000. A memorandum on lifelong learning. *Commission staff working paper* . SEC 2000. Brussels.

Cooper, C., Mukadam, N., Katona, C., Lyketsos, C.G., Ames, D., Rabins, P., Engedal, K., de Mendonça Lima, C., Blazer, D., Teri, L. and Brodaty, H., 2012. Systematic

review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics*, 24 (6), 856-870.

Corbin, J.M. and Strauss, A.L., 2008. *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Sage publications.

Cote, J.E. and Levine, C.G., 2014. *Identity, formation, agency, and culture: A social psychological synthesis*. Psychology Press.

Cotelli, M., Manenti, R. and Zanetti, O., 2012. Reminiscence therapy in dementia: A review. *Maturitas*, 72 (3), 203-205.

Cotrell, V. and Schulz, R., 1993. The perspective of the patient with Alzheimer's disease: a neglected dimension of dementia research. *The Gerontologist*, 33 (2), 205-211.

Coulter, J., 1981. *The social construction of mind*. Studies in Ethnomethodology and Linguistic Philosophy. Macmillan press. London.

Cowdell, F., 2008. Engaging older people with dementia in research: myth or possibility. *International Journal of Older People Nursing*, 3 (1), 29-34.

Cowles, A., Beatty, W.W., Nixon, S.J., Lutz, L.J., Paulk, J., Paulk, K. and Ross, E.D., 2003. Musical skill in dementia: a violinist presumed to have Alzheimer's disease learns to play a new song. *Neurocase*, 9 (6), 493-503.

Craig, G., 2004. Citizenship, exclusion and older people. *Journal of Social Policy*, 33 (01), 95-114.

Crawford, H.J. and Christensen, L.B., 1995. *Developing research skills: A laboratory manual*. Allyn and Bacon. Boston.

Creswell, J.W., 2009. *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications.

Critten, V. and Kucirkova, N., 2017. 'It brings it all back, all those good times; it makes me go close to tears'. Creating digital personalised stories with people who have dementia, *Dementia*. London. England.

Cumming, E. and Henry, W.E., 1961. *Growing old, the process of disengagement*. Basic Books. New York.

Cutler, C., Hicks, B. and Innes, A., 2016. Does digital gaming enable healthy aging for community-dwelling people with dementia?. *Games and Culture*, 11 (1-2), 104-129.

Cutler, C., Hicks, B. and Innes, A., 2014. Technology, Fun and Games. *The Journal of Dementia Care*. 22 (4), 12-13.

Data Protection Act., 1998. Office of Public Sector Information.

Dattilo, J. and Rusch, F.R., 2010. Effects of an Interactive Video Game (Nintendo Wii (TM)) on Older Women with Mild Cognitive Impairment. *Therapeutic Recreation Journal*, 44 (4), 271.

Davis, D.H., 2004. Dementia: sociological and philosophical constructions. *Social Science & Medicine*, 58 (2), 369-378.

Deci, E.L. and Ryan, R.M., 2008. Hedonia, eudaimonia, and well-being: An introduction. *Journal of happiness studies*, 9 (1), 1-11.

Dehmel, A., 2006. Making a European area of lifelong learning a reality? Some critical reflections on the European Union's lifelong learning policies. *Comparative Education*, 42 (1), 49-62.

DeLetter, M.C., Tully, C.L., Wilson, J.F. and Rich, E.C., 1995. Nursing staff perceptions of quality of life of cognitively impaired elders: Instrumental development. *Journal of applied Gerontology*, 14 (4), 426-443.

De Leo, D., Diekstra, R.F., Lonqvist, J., Lonqvist, J., Cleiren, M.H., Frisoni, G.B., Buono, M.D., Haltunen, A., Zucchetto, M., Rozzini, R. and Grigoletto, F., 1998. LEIPAD, an internationally applicable instrument to assess quality of life in the elderly. *Behavioural Medicine*, 24 (1), 17-27.

Dench, S. and Regan, J., 2000. *Learning in later life: Motivation and impact*. Great Britain, Department for Education and Employment.

Denzin, N.K., 2010. Moments, Mixed Methods, and Paradigm Dialogs. *Qualitative Inquiry*, 16 (6), 419-427.

Denzin, N.K., 1989. *The research act* 3rd edition. New York: Prentice Hall. McGraw Hill. New York.

Denzin, N.K., 1978. *The research act: A theoretical orientation to sociological methods*. McGraw-Hill, New York. 2012, 'Triangulation', 2, 80-88.

Denzin, N.K. and Lincoln, Y.S., 2008. *The landscape of qualitative research*, (1). Sage publications.

Department of Health., 2015. *Prime Ministers Challenge on Dementia 2020*. London, UK: Department of Health.

Department of Health., 2013. *Against Dementia, Global Action*. G8 Dementia Summit.

Department of Health., 2012. *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015*. London: DH Publications.

Department of Health., 2009. *Living well with dementia: A national dementia strategy*.

London, UK: Department of Health.

Derouesné, C., 2003. What is dementia? 2. A fuzzy construct. *Psychologie & neuropsychiatrie du vieillissement*, 1 (1), 15-24.

Deterding, S., Sicart, M., Nacke, L., O'Hara, K. and Dixon, D., 2011. Gamification. using game-design elements in non-gaming contexts. In: *CHI'11 Extended Abstracts on Human Factors in Computing Systems*, 2425-2428. ACM.

De Urturi Breton, Z.S., Zapirain, B.G. and Zorrilla, A.M., 2012. Kimentia: Kinect based tool to help cognitive stimulation for individuals with dementia. In *e-Health Networking, Applications and Services (Healthcom), 2012 IEEE 14th International Conference*. IEEE.

Deutsch, J.E., Borbely, M., Filler, J., Huhn, K. and Guarrera-Bowlby, P., 2008. Use of a low-cost, commercially available gaming console (Wii) for rehabilitation of an adolescent with cerebral palsy. *Physical therapy*, 88 (10), 1196-1207.

Dewing, J., 2008. Process consent and research with older persons living with dementia. *Research Ethics Review*, 4 (2), 59-64.

Dewing, J., 2002. From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, 1 (2), pp.157-171.

Dewey, J., 1931. The Development of American Pragmatism. In: *Pragmatism: The Classic Writings*, Thayer, HS, ed,(Indianapolis, Indiana: Hackett). 1989. *First published*, 23-40.

Dias, A. and Patel, V., 2009. Closing the treatment gap for dementia in India. *Indian journal of psychiatry*, 51 (5), 93.

Dijkstra, K., Bourgeois, M., Youmans, G. and Hancock, A., 2006. Implications of an advice-giving and teacher role on language production in adults with dementia. *The Gerontologist*, 46 (3), 357-366.

Downs, M., 1997. The emergence of the person in dementia research. *Ageing and Society*, 17 (05), 597-607.

Dove, E. and Astell, A.J., 2017. The Use of Motion-Based Technology for People Living With Dementia or Mild Cognitive Impairment: A Literature Review. *Journal of Medical Internet Research*, 19 (1), 3.

Doyle, P.J. and Rubinstein, R.L., 2013. Person-centred dementia care and the cultural matrix of othering. *The Gerontologist*, 54 (6), 952-963.

Dupuis, S.L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L. and Sadler, L., 2012. Moving beyond patient and client approaches: Mobilizing 'authentic partnerships' in dementia care, support and services. *Dementia*, 11 (4), 427-452.

- Dwyer, S.C. and Buckle, J.L., 2009. The space between: On being an insider-outsider in qualitative research. *International journal of qualitative methods*, 8 (1), 54-63.
- Edyburn, D.L., 2004. Rethinking assistive technology. *Special Education Technology Practice*, 5 (4), 16-23.
- European Commission (EC)., 2010. Europe 2020: A Strategy for smart, sustainable and inclusive growth. *Working paper. COM (2010) 2020*. Publications office, Luxembourg.
- European Commission (EC)., 2006. Adult learning: It's never too late to learn. *COM (2006)*. Publications office, Luxembourg.
- European Commission (EC)., 2001. *Making a European area of lifelong learning a reality*. Publications office, Luxembourg.
- Erickson, F., 2007. Ways of seeing video: Toward a phenomenology of viewing minimally edited footage. *Video research in the learning sciences*, 145-155.
- Evans, N., Carey-Smith, B. and Orpwood, R., 2011. Using smart technology in an enabling way: A review of using technology to support daily life for a tenant with moderate dementia. *British Journal of Occupational Therapy*, 74 (5), 249-253.
- Evans, S., Bray, J. and Evans, S., 2017, The iPad project: Introducing iPads into care homes in the UK to support digital inclusion. *Gerontechnology*, 16, (2), 91-100.
- Farquhar, M., 1995. Elderly people's definitions of quality of life. *Social science & medicine*, 41 (10), 1439-1446.
- Felce, D. and Perry, J., 1995. Quality of life: Its definition and measurement. *Research in developmental disabilities*, 16 (1), 51-74.
- Fenney, A. and Lee, T.D., 2010. Exploring spared capacity in persons with dementia: What WiiTM can learn. *Activities, Adaptation & Aging*, 34 (4), 303-313.
- Fereday, J. and Muir-Cochrane, E., 2006. Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International journal of qualitative methods*, 5 (1), 80-92.
- Flick, U., 2014. *An introduction to qualitative research*. Sage. Bournemouth University Library Catalogue, EBSCOhost, viewed 1st January 2015.
- Flick, U., 2009. *An introduction to qualitative research*. Sage publications.
- Foresight., 2008. *Mental Capital and Wellbeing Project: Final Project report*. The Government Office for Science, London.

- Foster, P., 1996. Observational Research. In: Sapsford. R. and Jupp, V.eds. *Data Collection and analysis*. Sage publications.
- Franco, J., Jacobs, K., Inzerillo, C. and Kluzik, J., 2012. The effect of the Nintendo Wii Fit and exercise in improving balance and quality of life in community dwelling elders. *Technology & Health Care*, 20 (2), 95-115.
- Franks, D.D. and Marolla, J., 1976. Efficacious action and social approval as interacting dimensions of self esteem: A tentative formulation through construct validation. *Sociometry*, 324-341.
- Freund, P.E., McGuire, M.B. and Podhurst, L.S., 2003. *Health, illness, and the social body: A critical sociology*. Prentice Hall.
- Frith, H. and Gleeson, K., 2004. Clothing and embodiment: Men managing body image and appearance. *Psychology of men and masculinity*, 5 (1), 40-48.
- Fuh, J.L. and Wang, S.J., 2006. Assessing quality of life in Taiwanese patients with Alzheimer's disease. *International journal of geriatric psychiatry*, 21 (2), 103-107.
- Garand, L., Lingler, J.H., Conner, K.O. and Dew, M.A., 2009. Diagnostic labels, stigma, and participation in research related to dementia and mild cognitive impairment. *Research in gerontological nursing*, 2 (2), 112-121.
- Gecas, V. and Schwalbe, M.L., 1983. Beyond the looking-glass self: Social structure and efficacy-based self esteem. *Social psychology quarterly*, 77-88.
- Genoe, M.R., 2010. Leisure as resistance within the context of dementia. *Leisure Studies*, 29 (3), 303-320.
- George, L.K. and Bearon, L.B., 1980. *Quality of life in older persons: Meaning and measurement*. Human Sciences Press, New York.
- Giebel, C.M. and Sutcliffe, C., 2017. Initiating activities of daily living contributes to well-being in people with dementia and their carers. *International Journal of Geriatric Psychiatry*.
- Gillies, B.A., 2000. A memory like clockwork: Accounts of living through dementia. *Aging and Mental Health*, 4 (4), 366-374.
- Gilmour, J.A. and Brannelly, T., 2010. Representations of people with dementia subaltern, person, citizen. *Nursing inquiry*, 17 (3), 240-247.
- Goffman, E., 1963. *Behaviour in public place: Notes on the social organisation of gatherings*. Free Press of Glencoe. New York.
- Gold, R.L., 1958. Roles in sociological field observations. *Social forces*, 217-223.

Goldsmith, M., 1996. *Hearing the voice of people with dementia: Opportunities and obstacles*. Readers Digest.

Gómez-Gallego, M., Gómez-Amor, J. and Gómez-García, J., 2012. Determinants of quality of life in Alzheimer's disease: perspective of patients, informal caregivers, and professional caregivers. *International psychogeriatrics*, 24 (11), 1805-1815.

Gould, C., 1990. *Rethinking democracy: Freedom and social cooperation in politics, economy and society*. Cambridge University Press. Cambridge.

Graff, M. J. L., Vernooij-Dassen, M. J. M., Thijssen, M., Dekker, J., Hoefnagels, W. H. L. and Olderikkert, M. G. M., 2007. Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial. *The Journals Of Gerontology. Series A, Biological Sciences And Medical Sciences*, 62 (9), 1002-1009.

Groenewoud, H., de Lange, J., Schikhof, Y., Astell, A., Joddrell, P. and Goumans, M., 2017, People with dementia playing casual games on a tablet, *Gerontechnology*, 16, (1), 37-47.

Gubrium, J.F. and Lynott, R.J., 1987. Measurement and the interpretation of burden in the Alzheimer's disease experience. *Journal of Aging Studies*, 1 (3), 265-285.

Guttmacher, S., Kelly, P.J. and Ruiz-Janecko, Y., 2010. *Community-based health interventions*. John Wiley & Sons.

Hall, C.B., Lipton, R.B., Sliwinski, M., Katz, M.J., Derby, C.A. and Verghese, J., 2009. Cognitive activities delay onset of memory decline in persons who develop dementia. *Neurology*, 73 (5), 356-361.

Hammersley, M., and P. Atkinson., 1983. *Ethnography: Principles in Practice*. London: Tavistock.

Hancock, G.A., Woods, B., Challis, D. and Orrell, M., 2006. The needs of older people with dementia in residential care. *International journal of geriatric psychiatry*, 21 (1), 43-49.

Hanson, E., Magnusson, L., Arvidsson, H., Claesson, A., Keady, J. and Nolan, M., 2007. Working together with persons with early stage dementia and their family members to design a user friendly technology based support service. *Dementia*. 6 (3), 411-434.

Harding, N. and Palfrey, C., 1997. *The social construction of dementia: Confused professionals?*. Macmillan.

Harley, D., Fitzpatrick, G., Axelrod, L., White, G. and McAllister, G., 2010. Making the Wii at home: game play by older people in sheltered housing. *HCI in Work and Learning, Life and Leisure*, pp.156-176.

- Havighurst, R.J., 1963. Successful aging. *Processes of aging: Social and psychological perspectives*, 1, pp.299-320.
- Hayter, J., 1974. Patients who have Alzheimer's disease. *The American journal of nursing*, 5, 1460-1463.
- Heath, C., Hindmarsh, J. and Luff, P., 2010. *Video in qualitative research. Analysing social interaction in everyday life*. Sage publications. London.
- Hellström, I., Nolan, M., Nordenfelt, L. and Lundh, U., 2007. Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14 (5), 608-619.
- Herskovits, E., 1995. Struggling over subjectivity: Debates about the "self" and Alzheimer's disease. *Medical anthropology quarterly*, 9 (2), 146-164.
- Higgins, H.C., Horton, J.K., Hodgkinson, B.C. and Muggleton, S.B., 2010. Lessons learned: Staff perceptions of the Nintendo Wii as a health promotion tool within an aged-care and disability service. *Health promotion journal of Australia*, 21 (3), 189-195.
- Hill, N.L. and Kürüm, E., 2010. Agreeableness and activity engagement in nursing home residents with dementia. *Journal of gerontological nursing*, 36 (9), 45-52.
- Hislop, J., Arber, S., Meadows, R. and Venn, S., 2005. Narratives of the night: The use of audio diaries in researching sleep. *Sociological Research Online*, 10 (4).
- Hochgraeber, I., Riesner, C. and Schoppmann, S., 2013. The experience of people with dementia in a social care group: Case study. *Dementia*, 12 (6), 751-768.
- Hodgson, N., Gitlin, L.N. and Huang, J., 2014. The influence of sleep disruption and pain perception on indicators of quality of life in individuals living with dementia at home. *Geriatric Nursing*, 35 (5), 394-398.
- Hoe, J., Hancock, G., Livingston, G. and Orrell, M., 2006. Quality of life of people with dementia in residential care homes. *The British Journal of Psychiatry*, 188 (5), 460-464.
- Hoe, J., Katona, C., Roch, B. and Livingston, G., 2005. Use of the QOL-AD for measuring quality of life in people with severe dementia—the LASER-AD study. *Age and ageing*, 34 (2), 130-135.
- Hogg, M. A. and Dominic, A., 1988. *Social Identifications: A Social Psychology of Intergroup Relations and Group Processes*. London: Routledge.
- Hoelter, J.W., 1986. The relationship between specific and global evaluations of self: A comparison of several models. *Social Psychology Quarterly*, 129-141.
- Holloway, I. and Galvin, K., 2010. *Qualitative Research in Nursing and Healthcare*. Chichester : Wiley-Blackwell, 2010. 3rd ed.

Holstein, M., 1997. Alzheimer's disease and senile dementia, 1885–1920: An interpretive history of disease negotiation. *Journal of Aging Studies*, 11 (1), 1-13.

Hubbard, G., Downs, M.G. and Tester, S., 2003. Including older people with dementia in research: challenges and strategies. *Aging & mental health*, 7 (5), 351-362.

Hurt, C., Bhattacharyya, S., Burns, A., Camus, V., Liperoti, R., Marriott, A., Nobili, F., Robert, P., Tsolaki, M., Vellas, B. and Verhey, F., 2008. Patient and caregiver perspectives of quality of life in dementia. *Dementia and geriatric cognitive disorders*, 26 (2), 138-146.

Ignatieff, M., 1989. Citizenship and moral narcissism. *The political quarterly*, 60 (1), 63-74.

Ijsselsteijn, W. A., Nap, H. H., de Kort, Y. A. W. and Poels, K., 2007. Game design for elderly users. Presented at Future Play 2007, Toronto, Canada.

Innes, A. and Manthorpe, J., 2013. Developing theoretical understandings of dementia and their application to dementia care policy in the UK. *Dementia*. 12 (6), 682-696.

Innes, A., Kelly, F. and Dincarslan, O., 2011. Care home design for people with dementia: What do people with dementia and their family carers value?. *Aging & Mental Health*, 15 (5), 548-556.

Innes, A., 2009. *Dementia studies: A social science perspective*. Sage publications.

Innes, A. and Sherlock, K. Rural communities. In: Innes, A., Archibald, C. and Murphy, C. eds., 2004. *Dementia and social inclusion: Marginalised groups and marginalised areas of dementia research, care and practice*. Jessica Kingsley publishers.

Innes, A., 2003. Developing ethnically sensitive and appropriate dementia care practice. In: Adams, T. and Manthorpe, J., 2003. *Dementia Care: An Evidence based Textbook*. London: Hodder Arnold.

INVOLVE., 2007. *Good practice in Active Public Involvement in Research*.

Israel, B.A., Schulz, A.J., Parker, E.A., Becker, A.B., Allen, A. and Guzman, J.R., 2008., Critical issues in developing and following CBPR Principles. In: Minkler, M. and Wallerstein, N. *Community-based participatory research for health: From process to outcomes*. San Francisco: Jossey-Bass. 2nd ed. 47-66.

James, W., 1948. *Essays in pragmatism* (No. 7). Simon and Schuster.

Jamieson, A., 2012. Learning in later adulthood: Transitions and engagement in formal study. *Educational Gerontology*, 38 (3), 201-211.

- Jamieson, A., 2007. Education and the quality of life in later years. *Quality in Ageing and Older Adults*, 8 (3), 15-23.
- Jenkins, A. and Mostafa, T., 2015. The effects of learning on wellbeing for older adults in England. *Ageing and Society*, 35 (10), 2053.
- Jewitt, C., 2012. An introduction to using video for research. National Centre for Research Methods Working Paper 03/12.
- Joddrell, P. and Astell, A., 2016. Studies Involving People with Dementia and Touchscreen Technology: A Literature Review. *JMIR Rehabilitation and Assistive Technologies*, 3, (2), 10.
- Joddrell, P., Hernandez, A. and Astell, A.J., 2016. Identifying existing, accessible touchscreen games for people living with dementia. In *International Conference on Computers Helping People with Special Needs*. Springer International Publishing.
- Kahlbaugh, P., Sperandio, A., Carlson, A. and Hauselt, J., 2011. Effects of Playing Wii on Well-Being in the Elderly: Physical Activity, Loneliness, and Mood. *Activities, Adaptation & Aging*, 35 (4), 331-344.
- Kamar, O., 1997. Light and death: Art therapy with a patient with Alzheimer's disease. *American Journal of Art Therapy*, 35 (4), 118.
- Kamegaya, T., Maki, Y., Yamagami, T., Yamaguchi, T., Murai, T. and Yamaguchi, H., 2012. Pleasant physical exercise program for prevention of cognitive decline in community-dwelling elderly with subjective memory complaints. *Geriatrics & gerontology international*, 12 (4), 673-679.
- Kayali, F., Luckner, N., Hödl, O., Fitzpatrick, G., Purgathofer, P., Stamm, T., Schlager-Jaschky, D. and Mosor, E., 2013. Elements of play for cognitive, physical and social health in older adults. In *Human Factors in Computing and Informatics*. Springer, Berlin, Heidelberg.
- Kayama, H., Okamoto, K., Nishiguchi, S., Yamada, M., Kuroda, T. and Aoyama, T., 2014. Effect of a Kinect-based exercise game on improving executive cognitive performance in community-dwelling elderly: case control study. *Journal of medical Internet research*, 16 (2), 61.
- Keese, M., 2006. *Live longer, work longer*. OECD. Paris
- Keleher, H.M. and Verrinder, G.K., 2003. Health diaries in a rural Australian study. *Qualitative Health Research*, 13 (3), 435-443.
- Kelly, F. and Innes, A., 2013. Human rights, citizenship and dementia care nursing. *International Journal of Older People Nursing*, 8 (1), 61-70.

- Kelly, F., 2010. Recognising and supporting self in dementia: a new way to facilitate a person-centred approach to dementia care. *Ageing and Society*, 30 (01), 103-124.
- Kessels, R.P. and Hensken, L.M., 2009. Effects of errorless skill learning in people with mild-to-moderate or severe dementia: a randomized controlled pilot study. *NeuroRehabilitation*, 25 (4), 307-312.
- Kirkby, S. and McKenna, K., 1989. Experience, research, social change: Methods from the margin. Toronto: Garamond. 49, 317
- Kitwood, T., 1997. *Dementia Reconsidered: the person comes first*. Buckingham: Open University Press.
- Kitwood, T., 1993. Person and process in dementia. *International journal of geriatric psychiatry*, 8 (7), 541-545.
- Kitwood, T. and Bredin, K., 1992. Towards a theory of dementia care: personhood and well-being. *Ageing and society*, 12 (3), 269-287.
- Kitwood, T., 1990. The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing and Society*, 10 (2), 177-196.
- Kitzinger, J., 1995. Qualitative research. Introducing focus groups. *BMJ: British Medical Journal*, 311 (7000), 299-302.
- Kong, A.P., 2017. The use of free non-dementia-specific Apps on iPad to conduct group communication exercises for individuals with Alzheimer's disease (Innovative Practice), *Dementia*.
- Kong, A.P., 2015. Conducting cognitive exercises for early dementia with the use of apps on iPads. *Communication Disorders Quarterly*, 36, (2)102-106.
- König, A., Amieva, H., Andrieu, S., Bremond, F., Bullock, R., Ceccaldi, M., Dubois, B., Gauthier, S., Kenigsberg, P.A., Nave, S. and Orgogozo, J.M., 2014. Recommendations for the use of Serious Games in people with Alzheimer's Disease, related disorders and frailty. *Frontiers in aging neuroscience*, 6, 54.
- Kontos, P.C., 2004. Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and society*, 24, 829.
- Konstantinidis, E.I., Billis, A.S., Mouzakidis, C.A., Zilidou, V.I., Antoniou, P.E. and Bamidis, P.D., 2016. Design, implementation, and wide pilot deployment of FitForAll: an easy to use exergaming platform improving physical fitness and life quality of senior citizens. *IEEE journal of biomedical and health informatics*, 20 (1), 189-200.
- Krause, N., 2006. Social relationships in late life. *Handbook of aging and the social sciences*, 6, 181-200.

Kurz, A., Clare, L. and Lautenschlager, N.T., 2013. Add life to years: psychosocial interventions for people with cognitive disorders. *International psychogeriatrics*, 25 (09), 1389-1391.

Kydd, P., 2001. Using music therapy to help a client with Alzheimer's disease adapt to long-term care. *American Journal of Alzheimer's Disease & Other Dementias*, 16 (2), 103-108.

Landesman, S., 1986. Quality of life and personal life satisfaction: Definition and measurement issues. *Mental retardation*, 24, 141-143.

Langlois, A. and Anderson, D.E., 2002. Resolving the quality of life/wellbeing puzzle: Toward a new model. *Canadian Journal of Regional Science*, 25 (3), 501-512.

Lauriks, S., Reinersmann, A., Van der Roest, H.G., Meiland, F.J.M., Davies, R.J., Moelaert, F., Mulvenna, M.D., Nugent, C.D. and Dröes, R.M., 2007. Review of ICT-based services for identified unmet needs in people with dementia. *Ageing research reviews*, 6 (3), 223-246.

Lawrence, E., Sax, C., Navarro, K.F. and Qiao, M., 2010, February. Interactive games to improve quality of life for the elderly: Towards integration into a wsn monitoring system. In: *eHealth, Telemedicine, and Social Medicine, 2010. ETELEMED'10. Second International Conference*.106-112. IEEE.

Lawton, M.P., Winter, L., Kleban, M.H. and Ruckdeschel, K., 1999. Affect and Quality of Life Objective and Subjective. *Journal of Aging and Health*, 11 (2), 169-198.

Lawton, M.P., 1997. Assessing quality of life in Alzheimer disease research. *Alzheimer disease and associated disorders*.

Lawton, M.P., 1996. Quality of life and affect in later life. *Handbook of emotion, adult development and aging*, 327-348.

Lawton, M.P., 1994. Quality of life in Alzheimer disease. *Alzheimer Disease & Associated Disorders*, 8, 138-150.

Leach, M. J., Francis, A. and Ziaian, T., 2014. Improving the Health and Well-Being of Community-Dwelling Caregivers of Dementia Sufferers: Study Protocol of a Randomized Controlled Trial of Structured Meditation Training. *Journal of Alternative & Complementary Medicine*. 20 (2), 136-141.

Leahey, A. and Singleton, J.F., 2011. Utilizing therapeutic recreation to empower persons with Alzheimer's in a day center: a case report. *Therapeutic Recreation Journal*, 45 (2), 135.

Lee, G.H., 2016. Effects of Virtual Reality Exercise Program on Balance, Emotion and Quality of Life in Patients with Cognitive Decline. *The Journal of Korean Physical Therapy*, 28 (6), 355-363.

Legouverneur, G., Pino, M., Boulay, M. and Rigaud, A.S., 2011. Wii sports, a usability study with MCI and Alzheimer's patients. *Alzheimer's & Dementia*, 7 (4), 500-501.

Lemert, E.M., 1972. Human Deviance, Social Problems, and Social Control (2TM ed). *Englewood Cliffs, NJ*.

Leng, F.Y., Yeo, D., George, S. and Barr, C., 2014. Comparison of iPad applications with traditional activities using person-centred care approach: Impact on well-being for persons with dementia. *Dementia*, 13 (2), 265-273.

León-Salas, B., Olazarán, J., Cruz-Orduña, I., Agüera-Ortiz, L., Dobato, J.L., Valentí-Soler, M., Muñiz, R., González-Salvador, M.T. and Martínez-Martín, P., 2013. Quality of life (QoL) in community-dwelling and institutionalized Alzheimer's disease (AD) patients. *Archives of gerontology and geriatrics*, 57 (3), 257-262.

León-Salas, B., Logsdon, R.G., Olazarán, J., Martínez-Martín, P. and The MSU-ADRU., 2011. Psychometric properties of the Spanish QoL-AD with institutionalized dementia patients and their family caregivers in Spain. *Aging & mental health*, 15 (6), 775-783.

Leung, P., Orrell, M. and Orgeta, V., 2015. Social support group interventions in people with dementia and mild cognitive impairment: a systematic review of the literature. *International journal of geriatric psychiatry*, 30 (1), 1-9.

Levine, M. and Perkins, D., 2004. Self-help groups. In: Levine, M., Perkins, D.D. and Perkins, V. eds., 2004. *Principle of community psychology: perspective and applications*. Oxford University Press. 300-337.

Liang, J., Krause, N.M. and Bennett, J.M., 2001. Social exchange and well-being: is giving better than receiving?. *Psychology and aging*, 16 (3), 511.

Lieberman, D.A., Chamberlin, B., Medina, E., Franklin, B.A., Sanner, B.M. and Vafiadis, D.K., 2011. The power of play: innovations in getting active summit 2011. *Circulation*, 123 (21), 2507-2516.

Lloyd, V., Gatherer, A. and Kalsy, S., 2006. Conducting qualitative interview research with people with expressive language difficulties. *Qualitative health research*, 16 (10), 1386-1404.

Lloyd-Yeates, T., 2014. iPads for older people: Changing how we care. *Sign Post. Journal of dementia and mental health care for older people*, 20 (1).

Lloyd-Yeates, T., 2013a. Alive to new possibilities. *Journal of Dementia Care*, 21 (1).

Lloyd-Yeates, T., 2013b. Working one-to-one with iPads. *Journal of Dementia Care*, 21 (2).

- Logsdon, R.G., Gibbons, L.E., McCurry, S.M. and Teri, L., 1999. Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging*, 5, 21-32.
- Logsdon, R.G., Gibbons, L.E., McCurry, S.M. and Teri, L., 2002. Assessing quality of life in older adults with cognitive impairment. *Psychosomatic medicine*, 64 (3), 510-519.
- Luzny, J., 2013. Quality of Life in Patients with Dementia. *Ceska a slovenska neurologie a neurochirurgie*, 76 (1), 90-95.
- Lyman, K.A., 1989. Bringing the social back in: A critique of the biomedicalization of dementia. *The Gerontologist*, 29 (5), 597-605.
- Lynott, R.J., 1983. Alzheimer's disease and institutionalization: The ongoing construction of a decision. *Journal of Family Issues*, 4 (4), 559-574.
- Madhok, S., A. Phillips, and K. Wilson., 2013. Introduction. In: Madhok, S., 2013. Action, agency, coercion: reformatting agency for oppressive contexts. In *Gender, agency, and coercion* (pp. 102-121). Palgrave Macmillan UK.
- Maiden, N., D'Souza, S., Jones, S., Müller, L., Pannese, L., Pitts, K., Prilla, M., Pudney, K., Rose, M., Turner, I. and Zachos, K., 2013. Computing technologies for reflective, creative care of people with dementia. *Communications of the ACM*, 56 (11), 60-67.
- Maillot, P., Perrot, A. and Hartley, A., 2012. Effects of interactive physical-activity video-game training on physical and cognitive function in older adults. *Psychology and aging*, 27 (3), 589.
- Maki, Y., Ura, C., Yamaguchi, T., Murai, T., Isahai, M., Kaiho, A., Yamagami, T., Tanaka, S., Miyamae, F., Sugiyama, M., Awata, S., Takahashi, R. and Yamaguchi, H., 2012. Effects of intervention using a community-based walking program for prevention of mental decline: a randomized controlled trial. *Journal of the American Geriatrics Society*, 60 (3), 505-510.
- Manera, V., Petit, P.D., Derreumaux, A., Orvieto, I., Romagnoli, M., Lyttle, G., David, R. and Robert, P.H., 2015. 'Kitchen and cooking,' a serious game for mild cognitive impairment and Alzheimer's disease: a pilot study. *Frontiers in aging neuroscience*, 7.
- Marceglia, S., Bonacina, S., Zaccaria, V., Pagliari, C. and Pinciroli, F., 2012. How might the iPad change healthcare? *Journal of the Royal Society of Medicine*, 105 (6) 233-241.
- Marshall, M.J. and Hutchinson, S.A., 2001. A critique of research on the use of activities with persons with Alzheimer's disease: A systematic literature review. *Journal of advanced nursing*, 35 (4), 488-496.
- Marshall, T.H., 1950. *Citizenship and social class*. Cambridge.

Mason, E., Clare, L. and Pistrang, N., 2005. Processes and experiences of mutual support in professionally-led support groups for people with early-stage dementia. *Dementia*, 4 (1), 87-112.

Matsui, T., Nakaaki, S., Murata, Y., Sato, J., Shinagawa, Y., Tatsumi, H. and Furukawa, T.A., 2006. Determinants of the quality of life in Alzheimer's disease patients as assessed by the Japanese version of the Quality of Life–Alzheimer's Disease Scale. *Dementia and geriatric cognitive disorders*, 21 (3), 182-191.

Matthews., A. and Mackenzie, M. eds., 2000. *SMART Technology thinking about the person. Opening doors for older people project*. West Lothian Council.

McCallum, S. and Boletsis, C., 2013. Dementia games: A literature review of dementia-related serious games. In *International Conference on Serious Games Development and Application*. Springer, Berlin, Heidelberg.

McCallum, S., 2012. Gamification and serious games for personalized health. *Studies Health Technology and Informatics*, 17, 85-96.

McCormack, B., 2004. Person-centredness in gerontological nursing: an overview of the literature. *Journal of clinical nursing*, 13 (s1), 31-38.

McKeown, J., Clarke, A., Ingleton, C. and Repper, J., 2010. Actively involving people with dementia in qualitative research. *Journal of clinical nursing*, 19 (13-14), 1935-1943.

McLaughlin, E., Parker, G., Porter, S., Bernard, S. and Boyle, G., 1997. The Determinants of Residential and Nursing Home Care among Older People in Northern Ireland. *Report to the Department of Health and Social Services (DHSS)*, Belfast, Northern Ireland.

McLaren, A. N., Lamantia, M. A. and Callahan, C. M., 2013. Systematic review of non-pharmacologic interventions to delay functional decline in community-dwelling patients with dementia. *Aging & Mental Health*, 17 (6), 655-666.

McLeod, S., 2008. Social identity theory. *Simply Psychology*.

McParland, P., Kelly, F. and Innes, A., 2017. Dichotomising dementia: is there another way?. *Sociology of health & illness*, 39 (2), 258-269.

McParland, P., Cutler, C. and Innes, A., 2016. The challenges of implementing and evaluating a pilot music and movement intervention for people with dementia (innovative practice). *Dementia*.

Meiland, F., Reinersmann, A., Bergvall-Kareborn, B., Craig, D., Moelaert, F., Mulvenna, M., Nugent, C.D., Scully, T., Bengtsson, J. and Dröes, R.M., 2007. COGKNOW: Development and evaluation of an ICT-device for people with mild dementia. *Studies in Health Technology and Informatics*, 127, 166-177.

Melunsky, N., Crellin, N., Dudzinski, E., Orrell, M., Wenborn, J., Poland, F., Woods, B. and Charlesworth, G., 2015. The experience of family carers attending a joint reminiscence group with people with dementia: A thematic analysis. *Dementia*, 14 (6), 842-859.

Mental Capacity Act. 2005. Department of Constitutional Affairs. Legislation.Gov.UK.

Merchant, C. and Hope, K.W., 2004. The Quality of Life in Alzheimer's Disease Scale: direct assessment of people with cognitive impairment. *Journal of clinical nursing*, 13 (2), 105-110.

Milne, A., 2010. The 'D' word: reflections on the relationship between stigma, discrimination and dementia. *Journal of Mental Health*, 19 (3), 227-233.

Miranda-Castillo, C., Woods, B., Galboda, K., Oomman, S., Olojugba, C. and Orrell, M., 2010. Unmet needs, quality of life and support networks of people with dementia living at home. *Health and quality of life outcomes*, 8 (1), 132.

Missotten, P., Ylief, M., Di Notte, D., Paquay, L., De Lepeleire, J., Buntinx, F. and Fontaine, O., 2007. Quality of life in dementia: a 2-year follow-up study. *International Journal of Geriatric Psychiatry*, 22 (12), 1201-1207.

Mittelman, M.S., Haley, W.E., Clay, O.J. and Roth, D.L., 2006. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *neurology*, 67 (9), 1592-1599.

Moniz-Cook, E., Vernooij-Dassen, M., Woods, B., Orrell, M. and Network, I., 2011. Psychosocial interventions in dementia care research: the INTERDEM manifesto. *Aging and Mental Health*, 15 (3), 283-290.

Moniz-Cook, E., Vernooij-Dassen, M., Woods, R., Verhey, F., Chattat, R., Vugt, M.D., Mountain, G., O'connell, M., Harrison, J., Vasse, E. and Dröes, R.M., 2008. A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging and Mental Health*, 12 (1), 14-29.

Moody, H.R., 2004. Structure and agency in late-life learning. *Old age and agency*, 29-43.

Morgan, J., 2016. Gaming for dementia research: a quest to save the brain. *The Lancet Neurology*, 15 (13), 1313.

Morgan, D.L., 2007. Paradigms lost and pragmatism regained methodological implications of combining qualitative and quantitative methods. *Journal of mixed methods research*, 1 (1), 48-76.

Morgan, D.L., 1996. *Focus groups as qualitative research*, (16). Sage publications.

Mukherjee, M (PI)., 2017. Wii-Fit for Improving Activity, Gait and Balance in Alzheimer's Dementia 2017, ClinicalTrials.gov

Mulvenna, M.D., Nugent, C.D., Moelaert, F., Craig, D., Dröes, R.M. and Bengtsson, J.E., 2010. Supporting people with dementia using pervasive healthcare technologies. In *Supporting people with dementia using pervasive health technologies* (3-14). Springer London.

Murphy, C., User involvement in evaluations. In: Innes, A. and McCabe, L. eds., 2007. *Evaluation in Dementia Care*. Jessica Kingsley publishers. London. 214–229.

Murphy, K., Jordan, F., Hunter, A., Cooney, A. and Casey, D., 2015. Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia*, 14 (6), 800-824.

Murphy, K., Jordan, F., Hunter, A., Cooney, A. and Casey, D., 2015. Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia*, 14 (6), 800-824.

Murphy, J.P., 1990. Pragmatism from Pierce to Davidson Boulder. Boulder, co: Westview 1 – 6.

Muscio, C., Tiraboschi, P., Guerra, U.P., Defanti, C.A. and Frisoni, G.B., 2015. Clinical trial design of serious gaming in mild cognitive impairment. *Frontiers in aging neuroscience*, 7.

Musselwhite, C., Marston, H.R. and Freeman, S., 2016. From Needy and Dependent to Independent Homo Ludens: Exploring Digital Gaming and Older People.

Narushima, M., 2008. More than nickels and dimes: the health benefits of a community-based lifelong learning programme for older adults. *International Journal of lifelong education*, 27 (6), 673-692.

Näsi, M., Räsänen, P. and Sarpila, O., 2012. ICT activity in later life: Internet use and leisure activities amongst senior citizens in Finland. *European Journal of Ageing*, 9 (2), 169-176.

Nelson, C., Treichler, P.A. and Grossberg, L., 1992. Cultural studies: An introduction. *Cultural studies*, 1, 5.

National Institute for Health and Clinical Excellence (Great Britain), 2006. *Dementia: Supporting people with dementia and their carers in health and social care*. London, England: National Institute for Health and Clinical Excellence.

Nimrod, G., 2010. The fun culture in seniors' online communities. *The Gerontologist*, 51 (2), 226-237.

Nimrod, G., 2009. Seniors' online communities: A quantitative content analysis. *The Gerontologist*, 50 (3), 382-392.

Novella, J.L., Jochum, C., Jolly, D., Morrone, I., Ankri, J., Bureau, F. and Blanchard, F., 2001. Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. *Quality of life research*, 10 (5), 443-452.

Novelli, M.M., Nitrini, R. and Caramelli, P., 2010. Validation of the Brazilian version of the quality of life scale for patients with Alzheimer's disease and their caregivers (QOL-AD). *Aging & mental health*, 14 (5), 624-631.

Nygård, L., 2006. How can we get access to the experiences of people with dementia? Suggestions and reflections. *Scandinavian Journal of Occupational Therapy*, 13 (2), 101-112.

O'Donovan, C. and Hussey, J., 2012. Active video games as a form of exercise and the effect of gaming experience: a preliminary study in healthy young adults. *Physiotherapy*, 98 (3), 205-210.

Olazarán, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., Del Ser, T., Woods, B., Beck, C., Auer, S., Lai, C. and Spector, A., 2010. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dementia and geriatric cognitive disorders*, 30 (2), 161-178.

Olsson, A., Engström, M., Skovdahl, K. and Lampic, C., 2012. My, your and our needs for safety and security: relatives' reflections on using information and communication technology in dementia care. *Scandinavian journal of caring sciences*, 26 (1), 104-112.

Onoda, K. and Yamaguchi, S., 2014. *Revision of the Cognitive Assessment for Dementia, iPad Version (CADi2)*.

Orgeta, V., Orrell, M., Hounscome, B. and Woods, B., 2015. Self and carer perspectives of quality of life in dementia using the QoL-AD. *International journal of geriatric psychiatry*, 30 (1), 97-104.

Orpwood, R., Gibbs, C., Adlam, T., Faulkner, R. and Meegahawatte, D., 2005. The design of smart homes for people with dementia—user-interface aspects. *Universal Access in the information society*, 4 (2), 156-164.

Orrell, M., 2012. The new generation of psychosocial interventions for dementia care. *The British Journal of Psychiatry*, 201 (5), 342-343.

Pachana, N.A., Liddle, J., Peel, N.M., Beattie, E., Juang, C. and Knight, B.G., 2015. an we do better? Researchers' experiences with ethical review boards on projects with later life as a focus. *Journal of Alzheimer's Disease*, 43 (3), 701-707.

Padala, K.P., Padala, P.R., Lensing, S.Y., Dennis, R.A., Bopp, M.M., Roberson, P.K. and Sullivan, D.H., 2017. Home-Based Exercise Program Improves Balance and Fear of Falling in Community-Dwelling Older Adults with Mild Alzheimer's Disease: A Pilot Study. *Journal of Alzheimer's disease*, 59 (2), 565-574.

Padala, K.P., Padala, P.R., Malloy, T.R., Geske, J.A., Dubbert, P.M., Dennis, R.A., Garner, K.K., Bopp, M.M., Burke, W.J. and Sullivan, D.H., 2012. Wii-fit for improving gait and balance in an assisted living facility: a pilot study. *Journal of aging research*, 2012.

Pang, G.K.H. and Kwong, E., 2015. Considerations and design on apps for elderly with mild-to-moderate dementia. In: *Information Networking (ICOIN), International Conference on* (348-353).

Parker, D., Mills, S. and Abbey, J., 2008. Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *International Journal of Evidence-Based Healthcare*, 6 (2), 137-172.

Park, M., Butcher, H.K. and Maas, M.L., 2004. A thematic analysis of Korean family caregivers' experiences in making the decision to place a family member with dementia in a long-term care facility. *Research in nursing & health*, 27 (5), 345-356.

Peirce, C.S., 1905. What pragmatism is. *The Monist*, 161-181.

Philippe, R (PI)., 2013. Health Related Quality of Life Effects of Off-the-shelf Computer Gaming in Alzheimer Disease and Related Disorders Populations 2013, ClinicalTrials.gov

Phillipson, C. and Scharf, T., 2004. *The impact of government policy on social exclusion among older people*. London: Office of the Deputy Prime Minister.

Phinney, A. and Moody, E.M., 2011. Leisure connections: benefits and challenges of participating in a social recreation group for people with early dementia. *Activities, Adaptation & Aging*, 35 (2), 111-130.

Phinney, A., Chaudhury, H. and O'Connor, D.L., 2007. Doing as much as I can do: The meaning of activity for people with dementia. *Aging and Mental Health*, 11 (4), 384-393.

Phinney, A., 1998. Living with dementia from the patient's perspective. *Journal of gerontological nursing*, 24 (6), 8-9.

Pillai, J.A. and Verghese, J., 2009. Social networks and their role in preventing dementia. *Indian journal of psychiatry*, 51 (5), 22.

Polistico, K., Ross, J. and Leibick, M., 2016. A serious gaming alternative to pen-and-paper cognitive scoring: A pilot study of BrightScreener (TM). *Journal of Pain Management*, 9 (3), 255.

Ponterotto, J.G., 2006. Brief note on the origins, evolution, and meaning of the qualitative research concept thick description. *The Qualitative Report*, 11 (3), 538-549.

- Powell, J., Gunn, L., Lowe, P., Sheehan, B., Griffiths, F. and Clarke, A., 2010. New networked technologies and carers of people with dementia: An interview study. *Ageing and Society*, 30 (6), 1073-1088.
- Procci, K., Bowers, C., Wong, C. and Andrews, A., 2013. Minigames for mental health: improving warfighters' coping skills and awareness of mental health resources. *Games For Health: Research, Development, and Clinical Applications*, 2 (4), 240-246.
- Purdie, N. and Boulton-Lewis, G., 2003. The learning needs of older adults. *Educational Gerontology*, 29 (2), 129-149.
- Rabins, P.V., 2000. Measuring quality of life in persons with dementia. *International Psychogeriatrics*, 12 (1), 47-49.
- Rahmani, E. and Boren, S.A., 2012. Videogames and health improvement: a literature review of randomized controlled trials. *Games For Health: Research, Development, and Clinical Applications*, 1 (5), 331-341.
- Rattray, J. and Jones, M.C., 2007. Essential elements of questionnaire design and development. *Journal of clinical nursing*, 16 (2), 234-243.
- Ready, R.E., Ott, B.R. and Grace, J., 2004. Patient versus informant perspectives of Quality of Life in Mild Cognitive Impairment and Alzheimer's disease. *International journal of geriatric psychiatry*, 19 (3), 256-265.
- Ready, R.E. and Ott, B.R., 2003. Quality of life measures for dementia. *Health and Quality of Life Outcomes*, 1 (1), 11.
- Ready, R.E., Ott, B.R., Grace, J. and Fernandez, I., 2002. The Cornell-Brown scale for quality of life in dementia. *Alzheimer Disease & Associated Disorders*, 16 (2), 109-115.
- Reason, P. and Bradbury, H. eds., 2008. *The Sage Handbook of action research: Participatory Inquiry and Practice* (2nd Edition): Sage. London
- Reuben, D.B., Roth, C.P., Frank, J.C., Hirsch, S.H., Katz, D., McCreath, H., Younger, J., Murawski, M., Edgerly, E., Maher, J. and Maslow, K., 2010. Assessing care of vulnerable elders—Alzheimer's disease: A pilot study of a practice redesign intervention to improve the quality of dementia care. *Journal of the American Geriatrics Society*, 58 (2), 324-329.
- Rescher, N., 2005. *Studies in pragmatism*. Transaction publications.
- Riley, P., Alm, N. and Newell, A., 2009. An interactive tool to promote musical creativity in people with dementia. *Computers in Human Behavior*, 25 (3), 599-608.
- Robertson, J.M., 2014. Finding meaning in everyday life with dementia: A case study. *Dementia*, 13 (4), 525-543.

Robinson, L., Brittain, K., Lindsay, S., Jackson, D. and Olivier, P., 2009. Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence. *International Psychogeriatrics*, 21 (3), 494-502.

Robson, C., 2002. Real world research. 2nd. Edition. Blackwell Publishing. Malden.

Rodriguez, J., 2013. Narrating dementia: Self and community in an online forum. *Qualitative Health Research*, 23 (9), 1215-1227.

Rorty, R., 1990. Pragmatism as anti-representationalism. In: Murphy, J.P. and Rorty, R., 1990. *Pragmatism: From Peirce to Davidson*. Boulder, CO:: Westview Press.

Rosenhan, D.L., 1973. On being sane in insane places. *Science*, 179 (4070), 250-258.

Rösler, A., Seifritz, E., Kräuchi, K., Spoerl, D., Brokuslaus, I., Proserpi, S.M., Gendre, A., Savaskan, E. and Hofmann, M., 2002. Skill learning in patients with moderate Alzheimer's disease: a prospective pilot-study of waltz-lessons. *International journal of geriatric psychiatry*, 17 (12), 1155-1156.

Routasalo, P. and Pitkala, K.H., 2003. Loneliness among older people. *Reviews in Clinical Gerontology*, 13 (4), 303-311.

Russell, C.W., 2016. People with dementia, contributing to learning and teaching in higher education: Innovative practice. *Dementia*.

Rusted, J., Sheppard, L. and Waller, D., 2006. A multi-centre randomized control group trial on the use of art therapy for older people with dementia. *Group Analysis*, 39 (4), 517-536.

Ryder-Jones, C, Bullock, A, and Anderson, L., 2012, Wii can make a difference, *Journal of Dementia Care*, 20, (1) 16-17

Sabat, S. R., 2010. Maintaining the self in dementia. In: Hughes, J., Lloyd-Williams, M. and Sachs, G. eds., 2009. *Supportive care for the person with dementia*. Oxford University Press.

Sabat, S.R., 2002. Surviving Manifestations of Selfhood in Alzheimer's Disease: A case study. *Dementia*, 1 (1), 25-36.

Sabat, S.R., 2001. *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*. Wiley. Oxford.

Sabat, S.R. and Collins, M., 1999. Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease*, 14 (1), 11-19.

- Sabat, S.R., Fath, H., Moghaddam, F.M. and Harré, R., 1999. The maintenance of self esteem: lessons from the culture of Alzheimer's sufferers. *Culture & Psychology*, 5 (1), 5-31.
- Sabat, S.R. and Harré, R., 1992. The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, 12 (4), 443-461.
- Salek, M., Walker, M. and Bayer, A., 1999. The community dementia quality of life profile (CDQLP): A factor analysis. *Quality of life research*. 8, 660.
- Sanders, S. and Morano, C., 2008. Chapter 8; Alzheimer's Disease and Related Dementias. *Journal of gerontological social work*, 50 (1), 191-214.
- Saposnik, G., Mamdani, M., Bayley, M., Thorpe, K.E., Hall, J., Cohen, L.G. and Teasell, R., 2010. Effectiveness of Virtual Reality Exercises in STroke Rehabilitation (EVREST): rationale, design, and protocol of a pilot randomized clinical trial assessing the Wii gaming system. *International Journal of Stroke*, 5 (1), 47-51.
- Sarantakos, S., 2012. *Social research*, 4th edition: Palgrave Macmillan, Basingstoke.
- Sarantakos, S., 2005. *Social research*, 3rd edition: Palgrave Macmillan, Basingstoke.
- Štatiénė, S., 2015. Learning in Later Life: The Perspective of Successful Ageing. *Applied Research In Health And Social Sciences: Interface And Interaction*, 12 (1) 11-23.
- Scherer, M.J., 2002. The change in emphasis from people to person: introduction to the special issue on Assistive Technology. *Disability and rehabilitation*, 24 (1-3), 1-4.
- Schikhof, Y., Goumans, M., Joddrell, P. and Astell, A., 2017. Comparing Recent Reviews about Touchscreens for Dementia with Lessons Learnt from the Field. *Studies In: Health Technology And Informatics*, 242, 1-4.
- Schikhof, Y., Groenewoud, J.H., Cordia, A.L. and Lange, J.D., 2014. Designing happy games (apps) for people with dementia. *Gerontechnology*, 13 (2), 160-161.
- Schwartz, S.J., 2002. Comparing psychological and sociological approaches to identity: Identity status, identity capital, and the individualization process. *Journal of adolescence*, 25 (6), 571-586.
- Selai, C., Vaughan, A., Harvey, R.J. and Logsdon, R., 2001. Using the QOL-AD in the UK. *International journal of geriatric psychiatry*, 16 (5), 537-538.
- Selai, C.E., Trimble, M.R., Rossor, M.N. and Harvey, R.J., 2000. *The Quality of Life Assessment Schedule (QOLAS): a new method for assessing quality of life (QOL) in dementia*. Springer Publishing Company.
- Selwood, A., Thorgrimsen, L. and Orrell, M., 2005. Quality of life in dementia—a one-year follow-up study. *International journal of geriatric psychiatry*, 20 (3), 232-237.

- Shaw, S.M. (2006). "Resistance". In: Rojek, C., Shaw, S. and Veal, A. *Handbook of leisure studies*. 533–545. New York: Palgrave Macmillan.
- Sheehan, B.D., Lall, R., Stinton, C., Mitchell, K., Gage, H., Holland, C. and Katz, J., 2012. Patient and proxy measurement of quality of life among general hospital in-patients with dementia. *Aging & mental health*, 16 (5), 603-607.
- Sherratt, K., Thornton, A. and Hatton, C., 2004. Music interventions for people with dementia: a review of the literature. *Aging & mental health*, 8 (1), 3-12.
- Shin, H.Y., 2006. A preliminary study on the Korean version of quality of life-Alzheimer's disease (QOL-AD) scale in community-dwelling elderly with dementia. *J Prev Med Public Health*, 39 (3), 243-248.
- Shulman, D. Labelling theory. In: Ritzer, G. eds., 2005. *Encyclopedia of Social Theory*. Thousand Oaks. Sage publishers. 427–28.
- SNIPHR. The Swedish National Institute of Public Health Research., 2006. *Healthy Ageing project: a challenge for Europe*. Stockholm.
- Silverman, D., 1985. *Qualitative methodology and sociology. Describing the social world*. Gower publishing. UK.
- Singh-Manoux, A., Richards, M. and Marmot, M., 2003. Leisure activities and cognitive function in middle age: evidence from the Whitehall II study. *Journal of Epidemiology & Community Health*, 57 (11), 907-913.
- Siriiraya, P. and Ang, C.S., 2014. Recreating living experiences from past memories through virtual worlds for people with dementia. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems*. ACM.
- Sixsmith, A., 2006. New technologies to support independent living and quality of life for people with dementia. *Alzheimer's Care Today*, 7 (3), 194-202.
- Smebye, K.L., Kirkevold, M. and Engedal, K., 2012. How do persons with dementia participate in decision making related to health and daily care? A multi-case study. *BMC health services research*, 12 (1), 241.
- Smith, J.A. ed., 2015. *Qualitative psychology: A practical guide to research methods*. Sage publications.
- Smith, D.M., 1973. *The Geography of Social Well-being in the United States: An Introduction to Territorial Social Indicators*. New York : McGraw-Hill.
- Span, M., Hettinga, M., Vernooij-Dassen, M., Eefsting, J. and Smits, C., 2013. Involving people with dementia in the development of supportive IT applications: A systematic review. *Ageing research reviews*, 12 (2), 535-551.

- Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R. and Verhey, F., 2008. Effectiveness of Nonpharmacological Interventions in Delaying the Institutionalization of Patients with Dementia: A Meta-Analysis. *Journal of the American Geriatrics Society*, 56 (6), 1116-1128.
- Splithof, R. and de Vries, J.R., 2016. The Effects of Exergaming on Elderly with Dementia in a Dutch Nursing Home: a Pilot Study.
- Spradley, J. P., 1980. *Participant observation*. Wadsworth Publishing Co Inc. New York.
- Steeman, E., Godderis, J., Grypdonck, M., De Bal, N. and De Casterlé, B.D., 2007. Living with dementia from the perspective of older people: Is it a positive story?. *Aging & mental health*, 11 (2), 119-130.
- Stern, C. and Munn, Z., 2010. Cognitive leisure activities and their role in preventing dementia: a systematic review. *International Journal of Evidence-Based Healthcare*, 8 (1), 2-17.
- Stets, J.E. and Burke, P.J., 2000. Identity theory and social identity theory. *Social psychology quarterly*, 224-237.
- Stryker, S. and Burke, P.J., 2000. The past, present, and future of an identity theory. *Social psychology quarterly*, 284-297.
- Stryker, S., 1980. *Symbolic interactionism: A social structural version*. Benjamin-Cummings Publishing Company.
- Swann, J.I., 2012. From pottery to plays: arts activities in the home. *Nursing & Residential Care*, 14 (4), 195-198.
- Sweeting, H. and Gilhooly, M., 1997. Dementia and the phenomenon of social death. *Sociology of Health & Illness*, 19 (1), 93-117.
- Taillon-Hobson, A., 2014. Two-week virtual reality training for dementia: Single-case feasibility study. *Journal of rehabilitation research and development*, 51 (7), 1069.
- Tan, W., 2014. Android app for elderly dementia patients.
- Tarnanas, I., Schlee, W., Tsolaki, M., Müri, R., Mosimann, U. and Nef, T., 2013. Ecological validity of virtual reality daily living activities screening for early dementia: longitudinal study. *JMIR Serious Games*, 1 (1).
- Tashakkori, A. and Teddlie, C., 1998. *Mixed methodology: Combining qualitative and quantitative approaches* (46). Sage publications.
- Tatsumi, H., Nakaaki, S., Torii, K., Shinagawa, Y., Watanabe, N., Murata, Y., Sato, J., Mimura, M. and Furukawa, T.A., 2009. Neuropsychiatric symptoms predict change in

quality of life of Alzheimer disease patients: A two-year follow-up study. *Psychiatry and clinical neurosciences*, 63 (3), 374-384.

Tay, L., Chua, K.C., Chan, M., Lim, W.S., Ang, Y.Y., Koh, E. and Chong, M.S., 2014. Differential perceptions of quality of life (QoL) in community-dwelling persons with mild-to-moderate dementia. *International Psychogeriatrics*, 26 (8), 1273-1282.

Taylor, M.J. and Griffin, M., 2015. The use of gaming technology for rehabilitation in people with multiple sclerosis. *Multiple Sclerosis Journal*, 21 (4), 355-371.

Teddlie, C. and Tashakkori, A., 2009. *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*. Sage publications.

Theng, Y.L., Dahlan, A.B., Akmal, M.L. and Myint, T.Z., 2009, April. An exploratory study on senior citizens' perceptions of the Nintendo Wii: the case of Singapore. In *Proceedings of the 3rd international convention on rehabilitation engineering & assistive technology* (10). ACM.

Thomas, D.R., 2003. A general inductive approach for qualitative data analysis: School of Population Health. *University of Auckland, New Zealand*.

Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga Lopez, M., Woods, R.T. and Orrell, M., 2003. Whose quality of life is it anyway?: The validity and reliability of the Quality of Life-Alzheimer's Disease (QoL-AD) scale. *Alzheimer Disease & Associated Disorders*, 17 (4), 201-208.

Tobiasson, H., Sundblad, Y., Walldius, Å. and Hedman, A., 2015. Designing for active life: Moving and being moved together with dementia patients. *International Journal of Design*, 9 (3), 47-62.

Tobiasson, H., 2010. Game over or play it again and again: participatory design approach within Special Housing.

Tobiasson, H., 2009. Physical action gaming and fun as a tool within elderly care: Game over or play it again and again. In: *The 17th Congress of the IEA, Beijing 2009*.

Tomori, K., Nagayama, H., Saito, Y., Ohno, K., Nagatani, R. and Higashi, T., 2015. Examination of a cut-off score to express the meaningful activity of people with dementia using iPad application (ADOC), *Disability & Rehabilitation: Assistive Technology*, 10, (2), 126-131.

Topping, K. and Ehly, S. eds., 1998. *Peer-assisted learning*. Lawrence Erlbaum Associates, Inc publishers.

Turner, B.S., 2001. The erosion of citizenship. *The British journal of sociology*, 52 (2), 189-209.

- Tyack, C. and Camic, P., 2017. Touchscreen interventions and the well-being of people with dementia and caregivers: a systematic review. *International Psychogeriatrics*, 29, (8), 1261-1280.
- Tyack, C., Camic, P., Heron, M. and Hulbert, S., 2015. Viewing Art on a Tablet Computer, *Journal Of Applied Gerontology: The Official Journal Of The Southern Gerontological Society*.
- Ulbrecht, G., Wagner, D. and Gräßel, E., 2012. Exergames and their acceptance among nursing home residents. *Activities, Adaptation & Aging*, 36 (2), 93-106.
- Upton, D., Bray, J., Tim, J. and Upton, P. 2013., Touchscreen technology - the evidence, *Journal of Dementia Care*, 21, (3), 16-17.
- Upton, D., Upton, P., Jones, T., Jutla, K., Brooker, D. and Grove, H., 2011. Evaluation of the impact of touch screen technology on people with dementia and their carers within care home settings. *UK: University of Worcester*.
- Välimäki, T., Vehviläinen-Julkunen, K. and Pietilä, A.M., 2007. Diaries as research data in a study on family caregivers of people with Alzheimer's disease: methodological issues. *Journal of Advanced Nursing*, 59 (1), 68-76.
- Van Ort, S. and Phillips, L., 1992. Feeding nursing home residents with Alzheimer's disease. *Geriatric Nursing*, 13 (5), 249-253.
- Van Tilborg, I.A., Kessels, R.P. and Hulstijn, W., 2011. Learning by observation and guidance in patients with Alzheimer's dementia. *NeuroRehabilitation*, 29 (3), 295-304.
- Volicer, L. and Bloom-Charette, L. eds., 2013. *Enhancing the quality of life in advanced dementia*. Routledge.
- Waite, J., Harwood, R., Morton, I. and Connelly, D., 2008. *Dementia care: a practical manual*. Oxford University Press.
- Walker, M.D., Salek, S.S. and Bayer, A.J., 1998. A review of quality of life in Alzheimer's disease. Part 1: Issues in Accessing Disease Impact. *Pharmacoeconomics*, 14 (5), 499 - 530
- Wang, L.Q., Chien, W.T. and Lee, I.Y., 2012a. An experimental study on the effectiveness of a mutual support group for family caregivers of a relative with dementia in mainland China. *Contemporary nurse*, 40 (2), 210-224.
- Wang, H.X., Xu, W. and Pei, J.J., 2012b. Leisure activities, cognition and dementia. *Biochimica et Biophysica Acta (BBA)-Molecular Basis of Disease*, 1822 (3), 482-491.
- Wang, Z. and Mu, J., 2010. Community nursing intervention on quality of life in patients with senile dementia. *Modern Preventive Medicine*, 37 (5), 840-844.
- Weiner, M.F., Martin-Cook, K., Svetlik, D.A., Saine, K., Foster, B. and Fontaine C.S., 2000. *Alzheimer Disease Association Disord*, 1 (3), 114-6.

Whitehouse, P.J. and Whitehouse, C.C., 2005. The Intergenerational School: Integrating intergenerational approaches in the care of those with age-related cognitive challenges. *Australasian Journal on Ageing*, 24 (1).

Whitman, N.A. and Fife, J.D., 1988. *Peer Teaching: To Teach Is To Learn Twice*. ASHE-ERIC Higher Education Report No. 4, 1988. ASHE-ERIC Higher Education Reports, The George Washington University, One Dupont Circle, Suite 630, Dept. RC, Washington, DC 20036-1183.

Willcocks, D., Peace, S. and Kellaheer, L., 2005. *Private Lives in Public Places: Research-based Critique of Residential Life in Local Authority Old People's Homes*. Routledge.

Wilkinson, H. Including people with dementia in research: methods and motivations. In: Wilkinson, H. ed., 2002. *The perspectives of people with dementia: Research methods and motivations*. Jessica Kingsley publishers.

Wimo, A., Jönsson, L., Bond, J., Prince, M., Winblad, B. and International, A.D., 2013. The worldwide economic impact of dementia 2010. *Alzheimer's & Dementia*, 9 (1), 1-11.

Wiseman, V., Conteh, L. and Matovu, F., 2005. Using diaries to collect data in resource-poor settings: questions on design and implementation. *Health Policy and Planning*, 20 (6), 394-404.

Withnall, A., 2009. *Improving learning in later life*. Routledge. London.

Wolak-Thierry, A., Novella, J.L., Barbe, C., Morrone, I., Mahmoudi, R. and Jolly, D., 2015. Comparison of QoL-AD and DQoL in elderly with Alzheimer's disease. *Aging & mental health*, 19 (3), 274-278.

Wolak, A., Novella, J.L., Drame, M., Guillemin, F., Di Pollina, L., Ankri, J., Aquino, J.P., Morrone, I., Blanchard, F. and Jolly, D., 2009. Transcultural adaptation and psychometric validation of a French-language version of the QoL-AD. *Aging & mental health*, 13 (4), 593-600.

Wong, G.H., Ng, C.K., Lai, C.K., Lee, M.N., Lum, T.Y., Jiang, N., Shie, H.W., Wu, J.Y. and Dai, D.L., 2015. Development of six arts, a culturally appropriate multimodal nonpharmacological intervention in dementia. *The Gerontologist*, 55 (5), 865-874.

Woods, B., Spector, A.E., Jones, C.A., Orrell, M. and Davies, S.P., 2005. Reminiscence therapy for dementia. *The Cochrane Library*.

Woods, R.T., 2001. Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects. *Aging & Mental Health*, 5 (1), 7-16.

World Health Organization., 2012. *Dementia: a public health priority*. World Health Organisation.

World Health Organisation., 2002. *Active Ageing: A policy framework*. World Health Organisation. Geneva.

World Health Organisation., 1997. *Measuring Quality of Life*. Division of mental health and prevention of substance abuse. World Health Organisation.

Yamaguchi, H., Maki, Y. and Takahashi, K., 2011. Rehabilitation for dementia using enjoyable video-sports games. *International psychogeriatrics*, 23 (4), 674-676.

Yoon, J.E., Lee, S.M., Lim, H.S., Kim, T.H., Jeon, J.K. and Mun, M.H., 2013. The effects of cognitive activity combined with active extremity exercise on balance, walking activity, memory level and quality of life of an older adult sample with dementia. *Journal of physical therapy science*, 25 (12), 1601-1604.

Zarit, S.H., Femia, E.E., Watson, J., Rice-Oeschger, L. and Kakos, B., 2004. Memory club: A group intervention for people with early-stage dementia and their care partners. *The Gerontologist*, 44 (2), 262-269.

Zhou, W., JiangBing, M. and Rui, L., 2010. Community nursing intervention on quality of life in patients with senile dementia. *Modern Preventive Medicine*, 37 (5), 840-844.

APPENDICIES

Appendix 1: Technology and Dementia Literature Review Search Criteria

Search terms and Boolean Phrasing	Limiters	Databases
("Nintendo Wii*" OR Wii*) OR (Xbox OR "Xbox Kinect*") OR exergaming OR "motion based technolog*" OR "motion technolog*") AND (dementia OR Alzheimer*)	English language / all article types excluding news reports / open search fields / unlimited to 2017 / only dementia related not cognitive impairment / excludes behaviour control and carer education / no prevention / no clinical focus	Bournemouth University Search Engine (MySearch) / Psycinfo / Web of Science / Scopus / CINAHL / Metline Complete
Wii* OR Kinect* OR exergam* OR motion based technolog* AND (dementia OR Alzheimer*)		
(Nintendo Wii* OR Xbox Kinect* OR exergaming OR motion based technolog*) AND (dementia OR Alzheimer*)		
((DE "Dementia") OR (DE "Alzheimer's Disease")) AND (Wii* OR Xbox OR exergaming OR "motion based technolog*" OR "motion technolog*")		
((MH "Alzheimer Disease") OR (MH "Dementia")) AND (Wii* OR Xbox OR exergaming OR "motion based technolog*" OR "motion technolog*")		
("Apple iPad*" OR iPad*) OR touchscreen* AND (dementia OR Alzheimer*)		
iPad* OR touchscreen* AND (dementia OR Alzheimer*)		
(Apple iPad* OR touchscreen*) AND (dementia OR Alzheimer)		
PlayStation OR (Sony PlayStat*) And dement* OR Alzheimer*		

Appendix 2: QoL-AD Questionnaire

People with dementia version

Interviewer administer according to **standard instructions**. Circle responses.

Domain	Scale			
1 Physical health	Poor	Fair	Good	Excellent
2 Energy	Poor	Fair	Good	Excellent
3 Mood	Poor	Fair	Good	Excellent
4 Living situation	Poor	Fair	Good	Excellent
5 Memory	Poor	Fair	Good	Excellent
6 Family	Poor	Fair	Good	Excellent
7 Marriage	Poor	Fair	Good	Excellent
8 Friends	Poor	Fair	Good	Excellent
9 Self as a whole	Poor	Fair	Good	Excellent
10 Ability to do chores around the house	Poor	Fair	Good	Excellent
11 Ability to do things for fun	Poor	Fair	Good	Excellent
12 Money	Poor	Fair	Good	Excellent
13 Life as a whole	Poor	Fair	Good	Excellent

Comments

Quality of Life-AD - Standard instructions for Interviewers

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below. Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type): **I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.** Point to each word (poor, fair, good, and excellent) on the form as you say it.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area. If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four. If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments. As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you

may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

1. First of all, how do you feel about your physical health? Would you say it's poor, fair, good, or excellent? Circle whichever word you think best describes your physical health right now.

2. How do you feel about your energy level? Do you think it is poor, fair, good, or excellent? If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.

3. How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?

4. How about your living situation? How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?

5. How about your memory? Would you say it is poor, fair, good, or excellent?

6. How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent? If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.

7. How do you feel about your marriage? How is your relationship with (spouse's name). Do you feel it's poor, fair, good, or excellent? Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it's a family member or friend. If there is a family caregiver, ask about their relationship with this person. If there is no one appropriate, or the participant is unsure, score the item as missing. If the participant's rating is of their relationship with someone other than their spouse, note this and record the relationship in the comments section.

8. How would you describe your current relationship with your friends? Would you say it's poor, fair, good, or excellent? If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?**

9. How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it's poor, fair, good, or excellent?

10. How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?

11. How about your ability to do things for fun that you enjoy? Would you say it's poor, fair, good, or excellent?

12. How do you feel about your current situation with money, your financial situation?

Do you feel it's poor, fair, good, or excellent? If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.

13. How would you describe your life as a whole? When you think about your life as a whole, everything together, how do you feel about your life? Would you say it's poor, fair, good, or excellent?

SCORING INSTRUCTIONS FOR THE QOL:

Points are assigned to each item as follows: poor=1, fair=2, good=3, excellent=4.

The total score is the sum of all 13 items.

QoL-AD Caregiver Questionnaire version

The following questions are about your relative's quality of life. When you think about your relative's life, there are different aspects, some of which are listed below. Please think about each item, and rate your relatives current QoL in each area using one of the four words. Please rate these items based on your relatives life at present (e.g. within the past few weeks). If you have questions about any item, please ask the person who gave you this form for assistance. Circle responses

Domain	Scale			
1 Physical health	Poor	Fair	Good	Excellent
2 Energy	Poor	Fair	Good	Excellent
3 Mood	Poor	Fair	Good	Excellent
4 Living situation	Poor	Fair	Good	Excellent
5 Memory	Poor	Fair	Good	Excellent
6 Family	Poor	Fair	Good	Excellent
7 Marriage	Poor	Fair	Good	Excellent
8 Friends	Poor	Fair	Good	Excellent
9 Self as a whole	Poor	Fair	Good	Excellent
10 Ability to do chores around teh house	Poor	Fair	Good	Excellent
11 Ability to do things for fun	Poor	Fair	Good	Excellent
12 Money	Poor	Fair	Good	Excellent
13 Life as a whole	Poor	Fair	Good	Excellent
Comments				

Appendix 3: Ethics Checklist and acceptance letters



Initial Research Ethics Checklist

Note: All researchers must complete this brief checklist to identify any ethical issues associated with their research. Before completing, please refer to the BU *Research Ethics Code of Practice* which can be found at www.bournemouth.ac.uk/researchethics. Project Supervisors or School Research Ethics Representatives can advise on appropriate professional judgement in this review. A list of Representatives can be found at the aforementioned webpage. **Sections 1-5 must be completed by the researcher and Section 6 by the Project Supervisor or School Ethics Representative prior to the commencement of any research.** Approved ethics checklists should be submitted in accordance with the school-specific ethics process and will be stored for audit purposes. Students should also retain a copy for inclusion in their dissertation, which will be checked to ensure that it complies with any ethical constraints identified on the ethics checklist. Please refer to erss.bournemouth.ac.uk/researchsupport/bids/writing/processes.html for school-specific processes.

1 RESEARCHER DETAILS						
Name	Clare Cutler					
Email	ccutler@bournemouth.ac.uk					
Status	<input type="checkbox"/> Undergraduate	<input type="checkbox"/> Postgraduate	<input type="checkbox"/> Staff			
School	<input type="checkbox"/> BS	<input type="checkbox"/> AS	<input type="checkbox"/> DEC	<input type="checkbox"/> HSC	<input type="checkbox"/> MS	<input type="checkbox"/> ST
Degree Framework & Programme						
2 PROJECT DETAILS						
Project Title	An evaluation of the 'Tech Club'					
Project Summary	Below					

Project Summary

Sufficient detail is needed; include methodology, sample, outcomes etc. This is an evaluation of a local authority commissioned project. This project aims to support and encourage people with dementia to keep healthy and active, to maintain active memory functions, to remain independent and to function in the community for as long as possible through the delivery of the Tech Club. The project also aims to answer; what are the benefits of a technology group on the quality of life for people with dementia living within the community?

Objectives of the Technology Club

- Support older people through mental stimulation;
 - Support older people to maintain dignity;
 - Encourage older people to be socially active;
 - Maintain a healthy life style;
 - Provide opportunities for older people to improve their physical and mental health through leisure and learning;
 - Support carers/family members by providing activities that they can participate in with the people with dementia when at home.
-
- To understand the importance of engaging with leisure activities as a community intervention
 - To provide support to carers/professional carers to enable continuation of technology engagement at home or within the community day centre setting through demonstrating methods and techniques to engage and communicate with people with dementia to use the identified technologies.
 - To collect first hand experiences, comments, feelings and opinions of using the technology from people with dementia
 - To challenge assumptions around the capabilities of what people with dementia can do
 - To use gaming technology (Apple iPad, Nintendo Wii and Xbox Kinect) to determine QOL benefits for people with dementia

Evaluation design and methodological approach

The Tech Club sessions will be delivered in February, March and April 2014. Two individual programmes will be delivered and will last for six weeks each. Each session (one per week) will last for approximately two hours and will be delivered at two different venues. Both venues were selected by the service commissioner and have been risk assessed. Required practical equipment, venue hire and refreshments will be purchased and provided by the service commissioner. The groups will run with an initial group size of 10 participants minimum. Each of the weekly sessions will be facilitated by two BUDI facilitators (the first will lead the sessions and the second will be a BUDI staff member who is the PhD student who will be an observatory participant only). The weekly sessions will enable participants to experience use of the Nintendo Wii, Xbox Kinect and the Apple I Pad. Each participant will be given the choice at the beginning of the session which technology they would like to use, following a semi structured programme as per project proposal. The sessions will be evaluated using the following data collection methods:

- Quality of Life measures (QOL) (pre and post intervention and a follow up at the six month point).
- This study aims to address the four main components of QOL (social, physical, psychological and emotional). QOL measures will be taken using QoL-AD. A number of social life questions will also be asked at this stage, independent of the QoL measure. Such questions will ask the participant to explain what their daily activities consist of, if they go out for fun, where they go and how often (for example).
- The participants will be asked to indicate their mood / feelings upon arrive at the Tech Club. This will require the participant to pick a rating on a 10 point scale. This will then be replicated at the end of the session to provide an indicator as to the impact of the Tech Club.
- Ethnographic style field notes will be taken throughout the sessions. There will be a particular focus on observing participants' reactions, emotions, perceptions and responses throughout the duration of the sessions, whilst they are both using the technologies and watching others (this technique has been successfully used in previous studies (Theng et al. 2009; Tobiasson 2009).
- The participants will be asked to complete an evaluation sheet at the end of each session. This will be a simple user friendly tick box sheet and will ask questions such as, How did you enjoy the session today? What was good about the session? What was bad about the session? This will provide a broad sense of how the participants found each technology directly after they have used them.
- An informal discussion will be conducted at the end of the session. This will give the participants an opportunity to comment on or discuss each session as and when it happens in more detail. The participants will have the freedom to express their likes and dislikes, what they found fun or what they found difficult to understand / take part in. It will also allow the facilitator to explore any differences indicated in the 10 point scale.
- Photographs and video recordings will be taken throughout each session with the consent of participants. The sessions may be recorded (with consent) to assist in observing the sessions to ensure nothing was missed.
- Carers will also be provided with a 'diary' where they will be asked to note down any changes in the participants or comments made by the participants before, after and between the sessions. This will capture additional data outside of the sessions.
- All of the above will then be analysed to form a written report by the research team for the service provider as part of the Tech Club project. The above data will also be used as the main data for the PhD study looking into QOL benefits. This will also be analysed, reported on and written up (for publication or conference presentations).

Participants will be accessed via voluntary sector colleagues²⁸⁴ and the service commissioner who will be assisting with the recruitment of participants identified through their existing use of services/support. All participants will have the ability to consent and established process consent procedures used in dementia research (Dewing 2008) will be adhered to.

Proposed Start & End Dates	ASAP (Once received ethical approval) - The contract with the service commissioner specifies a start date for the clubs in August. The project report is due 3 months after the completion of the groups.		
Project Supervisor	Professor Anthea Innes		
Framework Project Co-ordinator			
3 ETHICS REVIEW CHECKLIST – PART A			
I	Is approval from an external Research Ethics Committee (e.g. Local Research Ethics Committee (REC), NHS REC) required/sought?	Yes	<u>No</u>
II	Is the research solely literature-based?	Yes	<u>No</u>
III	Does the research involve the use of any dangerous substances, including radioactive materials?	Yes	<u>No</u>
IV	Does the research involve the use of any potentially dangerous equipment?	Yes	<u>No</u>
V	Could conflicts of interest arise between the source of funding and the potential outcomes of the research? (see section 8 of BU Research Ethics Code of Practice).	Yes	<u>No</u>
VI	Is it likely that the research will put any of the following at risk: Stakeholders? Researchers? Participants? The environment? The economy?	Yes Yes Yes Yes Yes	<u>No</u> <u>No</u> <u>No</u> <u>No</u> <u>No</u>
VII	Does the research involve experimentation on any of the following: Animal tissues? Human tissues (including blood, fluid, skin, cell lines)? Genetically modified organisms?	Yes Yes Yes Yes	<u>No</u> <u>No</u> <u>No</u> <u>No</u>
VIII	Will the research involve prolonged or repetitive testing?	Yes	<u>No</u>
IX	Will the research involve the collection of audio, photographic or video materials?	<u>Yes</u>	No
X	Could the research induce psychological stress or anxiety, cause harm or have negative consequences for the participants or researcher (beyond the risks encountered in normal life)?	Yes	<u>No</u>
XI	Will the study involve discussion of sensitive topics (e.g. sexual activity, drug use, criminal activity)?	Yes	<u>No</u>
XII	Will financial inducements be offered (other than reasonable expenses/ compensation for time)?	Yes	<u>No</u>

XIII	Will it be necessary for the participants to take part in the study without their knowledge / consent at the time?	Yes	<u>No</u>
XIV	Are there problems with the participant's right to remain anonymous?	Yes	<u>No</u>
XV	Does the research <i>specifically</i> involve participants who may be vulnerable?	<u>Yes</u>	<input type="checkbox"/> No
XVI	Might the research involve participants who may lack the capacity to decide or to give informed consent to their involvement?	Yes	<u>No</u>
4 ETHICS REVIEW CHECKLIST – PART B			
<p>This research will be conducted through the participation of individuals who are considered to be vulnerable. In order to adhere to BU, service commissioner and Social Care and Research Committee ethical guidelines, the researcher has had enhanced CRB check carried out and has experience of working with people with dementia. This research project will be submitted to both HSC and BBC ethics committee.</p> <p>An information sheet will be provided to all participants to inform them of the purpose of the research, why they have been chosen, what they have to do, any benefits or disadvantages of taking part, confidentially procedures, what will happen to the information once given and further information such as complaints procedures and contact details to BU ethic committee. The information sheet will be explained and explored with each participant ensuring that there is an opportunity to ask questions or to discuss the process. No personally identifiable data will be collected and it will not be possible to link any individual to any one example, providing confidentiality and anonymity to every participant.</p>			
Ethical Issue:		Action:	
5 RESEARCHER STATEMENT			
I believe the information I have given is correct. I have read and understood the BU Research Ethics Code of Practice, discussed relevant insurance issues, performed a health & safety evaluation/ risk assessment and discussed any issues/ concerns with the Project Supervisor / School Ethics Representative. I understand that if any substantial changes are made to the research (including methodology, sample etc), then I must notify the Project Supervisor / School Research Ethics Representative and may need to submit a revised Initial Research Ethics Checklist. By submitting this form electronically I am confirming the information is accurate to my best knowledge.			
Signed	C.Cutler	Date	2014

Appendix 3: Ethics Approval Letters

**School of Health and Social Care
Research Governance Review Group
Review Report (staff study)**

Evaluator(s): Professor Anthea Innes; Clare Cutler

Title: An evaluation of the 'Tech Club'

Reviewers: Dr Jane Hunt; Dr Martin Hind

Report prepared by: Martin Hind.

Date: 06.02.14.

Dear Anthea

Thank you for submitting your evaluation study to the Research Governance Review Group (RG2) for ethical approval. This evaluation study has been reviewed in tandem with Clare Cutlers PhD Research Degree, of the same title, that also exists within this work; that approval has been dealt with in a separate RG2 approval letter.

All the responses to the interim RG2 report (28.01.14.) have been fully addressed and this evaluation study is approved to commence immediately.

Thank you for taking the time to submit your evaluation study to the research governance review group.

Please do not hesitate to contact Martin Hind if you have any queries, or need further clarification in relation to any aspect of your studies progression through RG2.

Yours sincerely



Professor Vanora Hundley
Deputy Dean for Research and Enterprise

**School of Health and Social Care
Research Governance Review Group
Review Report (staff study)**

Student: Clare Cutler

Title: An evaluation of the 'Tech Club'

Level: PhD.

Supervisors: Professor Jonathan Parker;
Professor Anthea Innes

Reviewers: Dr Jane Hunt; Dr Martin Hind

Report prepared by: Martin Hind.

Date: 06.02.14.

Dear Clare

Thank you for submitting your PhD research study to the Research Governance Review Group (RG2) for ethical approval. This research study has been reviewed in tandem with the service evaluation, of the same title, that also exists within this work; that approval has been dealt with in a separate RG2 approval letter.

All the responses to the interim RG2 report (28.01.14.) have been fully addressed and this research study is approved to commence immediately.

Thank you for taking the time to submit your research study to the research governance review group.

Please do not hesitate to contact Martin Hind if you have any queries, or need further clarification in relation to any aspect of your studies progression through RG2.

Yours sincerely



Professor Vanora Hundley
Deputy Dean for Research and Enterprise

Appendix 4: Participant Information Sheet



**Dementia Institute
(BUDI)**

Tech Club: Information sheet for participants and their families

Bournemouth University would like to invite you to take part in a set of technology sessions, called the Tech Club. This is following the success of the Technology Club in 2013. The purpose of the Tech Club is to provide an informal, fun and social environment where you can meet new people, learn about technologies and most importantly have fun!



Clare Cutler (Facilitator and PhD student)

The Tech Club will take place at the [Venue], for six weeks, one session a week and will last for 2 hours. During the sessions we will use the Nintendo Wii, Nintendo DS, Apple I Pad and Xbox Kinect. Two facilitators will be present at the Tech Club, one to lead the sessions and support the use of the equipment. The second, Clare Cutler, will observe the sessions and collect data as part of her PhD research study to evaluate the benefit of the Tech Club.

At the end of each session you will be invited to share any thoughts or comments you may have on the session and the technologies you used on that day. With your permission we would like to record the sessions and take photos to capture the activities you are doing and to help the facilitators to evaluate the Tech Club. You have the right to request that any photos or recordings which have been taken are not to be used should you change your mind.

A slight change from last year's programme is that apart from participating in the sessions you will be asked to complete a short questionnaire about your life before the start of the six sessions and at the end of the six sessions. You will also be contacted three months after the Tech Club to again complete the same short questionnaire. These questionnaires will help inform the researcher as to the quality of life benefits of the use of technology for people living with dementia. The questionnaires will not ask for any private or confidential medical information.

The evaluation of this Tech Club may be used to inform future clubs locally, regionally and nationally. The findings from the Tech Club and the PhD may be published in journal papers and presentations to allow us to share what we found from the evaluation and the PhD study. When we have finished the Tech Club and written up our evaluation we will give the [name of service provider] some feedback to help them consider how to provide services like the Tech Club in the future.

All the information we collect will be seen only by the evaluation team and will be stored according to data protection regulations at the University. All information will be kept confidential and we will remove all names and identifying features when writing up the report, PhD or publications, so that no one can be identified.

Participation at each session is voluntary. If you decide that you are no longer enjoying the sessions you do not have to attend and can leave at any point. If you would like to take part in this study, we will ask you to sign a consent form. If you have any questions or concerns, please call Clare Cutler, Project Manager, ccutler@bournemouth.ac.uk (contact number). If you have any questions about the conduct of this research or wish to make a complaint, contact Anthea Innes, BUDI director and PhD supervisor (contact number).

The Tech Club has received ethical approval from Bournemouth University Ethics Committee. Thank you for reading this and we hope to see you soon.

Appendix 5: Consent Form



Tech Club Consent Form

(Venue Participants)

Please tick or initial each box

I confirm that I have read and understood the information sheet for the above study and have been able to ask questions	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason	
I understand that all information will be kept confidential	
I agree that photos/video recordings can be taken	
I agree that the data can be used on condition that they are kept confidential and anonymised	
I understand that all data will stored safely and will be seen only by the evaluation team	
I agree to take part in the Tech Club project	

Participant Name:

Signature:

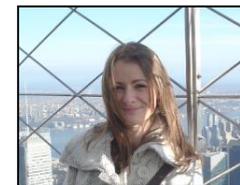
Date:

Interviewer Name:

Signature:

Date:

Appendix 6: Recruitment poster



Clare Cutler (Facilitator and PhD student)

Tech Club!!!

The Tech Club is a six week programme being run by Bournemouth University Dementia Institute specifically for people living with dementia.

The Tech Club is an opportunity to have fun in an informal and social environment whilst exploring the world of technology. No experience is required, just an open mind to have fun.

Venue

**Six sessions once a week for two hours
during April and May 2014**

We invite you to come along and join in the fun (limited spaces available). If you would like to take part please contact Clare Cutler (Project Manager [contact number] / ccutler@bournemouth.ac.uk) who will provide you with further detail.

Appendix 7: Evaluation Form: People with dementia

Tech Club session 4: Evaluation Form

Really did not enjoy	Did not enjoy	Neither enjoyed or not enjoyed	Enjoyed	Really enjoyed
				
1	2	3	4	5

How did you enjoy the session today?

Yes	No	Don't Know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Did you enjoy using the iPad?

Did you enjoy the guide useful?

Did you feel that you are learning?

What did you enjoy about the session?

What did you not enjoy about the session?



Appendix 8: Evaluation Form: Carer

TECHNOLOGY SESSIONS: Staff Evaluation Form

To what extent do you agree or disagree with the following statements:	Strongly Disagree	Disagree	Neither Agree/Disagree	Agree	Strongly Agree
1. The participant has enjoyed the Tech Club	<input type="checkbox"/>				
2. The participant has benefited from these sessions	<input type="checkbox"/>				
3. The sessions have made a positive impact on the participant	<input type="checkbox"/>				
4. The sessions have been successful in engaging the participant in activities which he/she would not normally do	<input type="checkbox"/>				
5. Activity sessions like these should be carried out regularly	<input type="checkbox"/>				

Have you noticed any positive impact or change that you think the sessions have influenced on the participant? **Yes** **No**
Please explain...

Have you noticed any negative impact or change that you think the sessions have influenced on the participant?
Please explain...

Have these sessions influenced your views about activities for people with dementia can do?
Please explain...

Do you think that the Tech Club has made a positive impact on any of the below quality of life aspects for the participant?
 Social Psychological Physical Emotional Please add any further comments.....

Do you think that the Tech Club has made a negative impact on any of the below quality of life aspects for the participant?

Social Psychological Physical Emotional Please add any further comments.....

Appendix 9: End of session discussion script

1. Did you enjoy today's session?
2. What did you enjoy the most / which equipment?
3. Was there anything you did not like about the session?
4. If you could change the sessions, what would you change (to make them better)?
5. Is there anything different that you would like to do in the next session?

Appendix 10: 10 point activity guide

Session Six (DC)

1. Turn iPad on and off.
2. Find apps and scroll across pages.
3. Rotate the screen.
4. Find the camera App.
5. Take four photos.
6. Make a video recording of the room.
7. Use the Photo App to view the photos.
8. Use the Photo App to view the video.
9. Go back to the main page.
10. Go over the above and teach others.

APPS

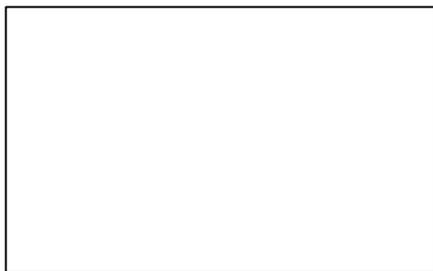
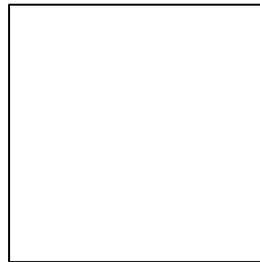
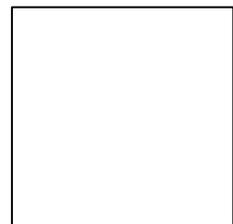


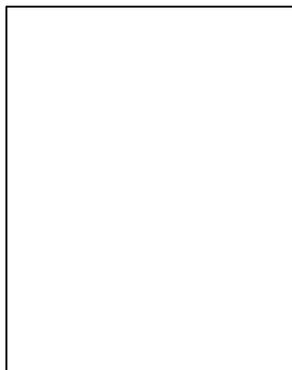
Photo APP



Camera APP



Home Page



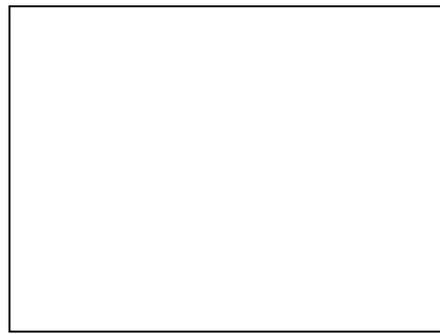
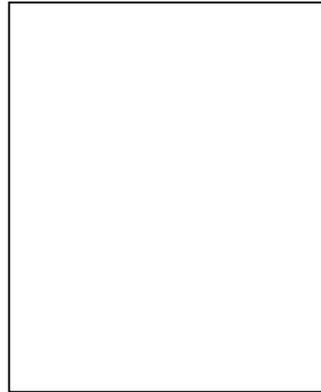
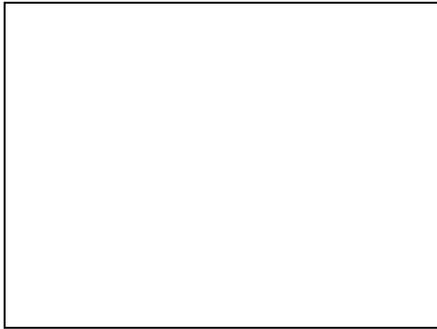
Appendix 11: Three point activity choices

iPad Activity Choices

Choice 1: Use the iPad to explore hobbies (using the internet).

Purpose of this? Opportunity to take part in your hobbies and interests using the iPad.

Benefit to you? A chance for you to look at your hobbies and interests, to keep up to date on the latest news on your hobbies/interest, learn more about hobbies/interests.

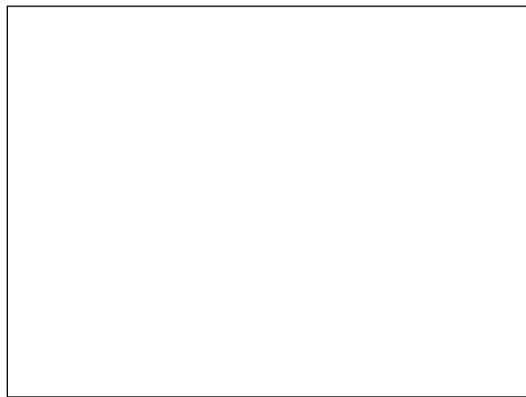


iPad Activity Choices

Choice 2: Using Game, Art and Music Apps

Purpose of this? Time to explore different apps using the iPad to see what the iPad can offer.

Benefit to you? A chance for you to be creative and have fun.



iPad Activity Choices

Choice 3: Use Instruction Guide

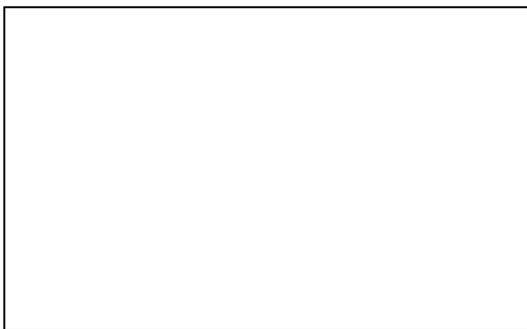
Purpose of this? Introduction to learning how to use the iPad.

Benefit to you? A chance for you to learn how to use the iPad to enable you to be able to do choice 1 and 2 alone.

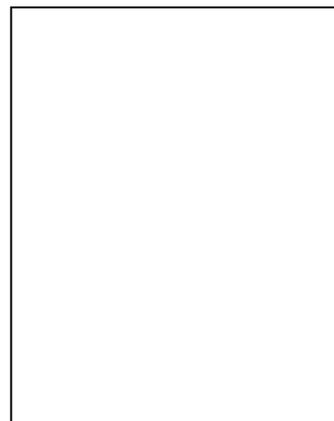
Guide

1. Turn iPad on and off
2. Find apps and scroll across pages
3. Rotate the screen
4. Find Google Earth app
5. Enlarge and decrease the size of the page using your fingers
6. Get back to the main home page
7. Find the BBC news app
8. Select a story and higher and lower the volume
9. Go back to the main page
10. Go over the above and teach others

APPS



Home Page



Appendix 12: Coding process

Phase 5, stage 1: Coding process

Phase 5: stage 1- Defining themes in NVivo			
Overarching theme 1	Me, Myself and I - A Battle for Self, Independence and what's meaningful		
	Taking part in Meaningful Activity	Sources	Refs
	<i>Access to Hobbies and Interests OR Activity</i>	19	38
	Enjoyment of session as a whole	28	68
	General Interest OR preference to use iPad	37	96
	Playing games and competition	28	53
	Something to look forward to	9	18
	Something different OR something to do	21	41
	Rejuvenate skills OR hobbies	4	7
	Improved mood	6	10
	Remembering the session OR facilitator	28	68
	<i>Barriers to Activity OR Hobbies and Interests</i>	6	7
	Equipment Limitations	16	22
	General dislike of equipment	10	13
	Equipment undermining skills and ability	7	13
	Pace of Instruction	7	16
	<i>Suitability of Activity</i>	14	39
	Fluidity of session OR having to wait for turn or support	16	30
	Not doing what wanted OR No challenge	12	23
	Waste of time OR Frustration	10	17
	It's too much	6	11
	No purpose OR need for equipment OR sessions	16	33
	<i>Ability to Address Physical Health</i>		
	Additional health issues OR lack of energy	9	18
	I'm in good health	10	16
	Physical challenge	15	27
	Mobility OR Physical restrictions	15	25
	Ability to Express Self and Life Experience	Sources	Refs
	<i>Talking about self-OR previous experience</i>	28	72
	Centre of attention OR affirming skills OR talents	10	19
	<i>Self-expectation and wanting to succeed</i>	16	22
	Disappointment in performance OR frustration in self	11	16
	Sense of achievement OR happy with self	16	54
	Acknowledgement of ability OR success	10	15
	<i>Self and dementia</i>		
	Aware of ailment OR poor ability	26	60
	Dementia not bad OR good memory	14	14
	Activities not done anymore	18	41
	<i>Self as a whole and everyday life</i>		
Life and self-linked to age	15	30	
Positive outlook on self-OR life as a whole	25	59	
I'm lucky	8	18	
<i>Low self esteem OR confidence</i>	14	34	

Apprehension OR Nervous	13	27
Reassurance OR confirmation	13	17
Fear of being judged	7	10
Just Luck OR embarrassment of success	5	9
Exercising Independence, Choice and Control	Sources	Refs
<i>Having a voice</i>	26	58
Doing what wanted to or could do	12	20
Differences in answers OR opinions	7	16
Growing confidence	17	35
Questioning rationale OR justification for session OR equipment	16	28
<i>Affirming Independence - I can do it for myself</i>	13	19
Being left alone	12	34
Ownership	13	24
Not physically restricted	8	17
<i>Wanting more information</i>		
More information required about tech OR activity	9	20
More information required about session	13	40
<i>Choosing how to engage</i>		
Wanting to watch	21	30
Wanting to take part OR joining in	16	20
Not wanting to take part	15	37

Inclusion, Education and People			
Overarching theme 2	Togetherness - The importance of People, Company and Conversation	Sources	Refs
	<i>Company and Companionship</i>	11	27
	Importance of people and meeting people	20	44
	Familiarity	9	16
	Socialising	14	25
	<i>Friends and Family</i>		
	Talking about family	26	69
	Don't have or don't see family	22	36
	I have friends	15	18
	Don't have or don't see friends	14	23
	Family get on well	20	30
	<i>Conversation</i>		
	Equipment catalyst for conversation	19	59
	Conversation about interests	9	13
	Entitled To Be Educated - Life Long Learning and Teaching	Sources	Refs
	<i>Difference in learning styles and levels of learning</i>	14	29
	Not learning anything	7	8
	Variation in levels of support	18	42
	Continuing progression	5	10
<i>Teaching OR providing advice and suggestions</i>	29	74	
<i>Ability to learn and evidence of learning</i>	21	40	
Encourage cognitive activity and concentration	16	31	
Kinaesthetic learning	18	43	

Recognition of difficulty	8	19
<i>Wanting to learn OR understand</i>	29	79
Learning agendas	16	28
Home use OR plan for continued learning	20	34
A Struggle For Inclusivity - The Right To Be Included	Sources	Refs
<i>Challenged perception and recognition of success</i>	17	37
<i>What I can do</i>		
Ability to undertake everyday activity OR have fun	24	40
Activities currently engaged in	15	35
<i>Barriers to inclusion - Deprecation of PWD</i>	18	59
Negative impact on group	11	26
Taking over PWD OR session	17	56
Others doing it for them	14	25
Answering for or influencing PWD	12	21
Pressuring PWD to take part, get it right OR adding pressure	20	41
<i>Enablers to inclusion - Atmosphere, support, praise and encouragement</i>		
<i>Support</i>		
Recognition of ability Or no support required	14	25
Success through support	18	44
In the same boat - peer to peer support	9	27
PWD working together OR Peer to peer support	27	93
PWD and Carer working together	8	32
<i>Atmosphere</i>	5	15
Laughter, Jovialness and Friendly	25	92
No pressure	8	10
<i>Praise and Encouragement</i>		
Encouragement OR praise from carers	8	32
Encouragement OR praise given by PWD	17	116
Encouragement OR praise given by facilitator	8	17

Appendix 13: Data reduction process

Phase 5, stage 2

Theme: Togetherness: The importance of people, company and conversation

The process which was followed to come to the conclusion that the data from this theme was not being used is:

1. Answer - what are the findings of this section?

Friends and family: QoL scale findings suggest that participants consider these relations as fair and above. That there are good relationships but that some participants don't see their family or friends. That there was lots of talking about family. That there is a potential parallel between the idea of friends and family and physically seeing friends and family. Suggesting the question on the scale could be notional but this is not able to be evidenced.

2. Answer – what research questions does this section answer?

RQ1 – The Tech Club provides the opportunity for conversation and socialisation.

3. Answer – what is the unique contribution from this data?

Method – Using technology to stimulate conversation. However, this has been reported in other papers I have co-authored.

4. Is any of the data better suited elsewhere?

No

On the answers provided for the above, this data are not being included in the overall thesis findings on the basis that:

- RQ - Data from this section answers RQ1 as it provides an opportunity for the participants to engage in conversation and to socialise.
- Unique contribution – Using technology to stimulate conversation. However, this has been reported in our papers that I have co-authored so is not a contribution. There is nothing particularly significant or novel in these findings.
- **Remove whole section and do not use findings**

Theme: Independence, Choice and Control

The process which was followed to come to the conclusion that the data from this theme was not being used is:

1. Read through of whole section and all quotes

After reviewing this section, it was determined that there was a repeat of some data, which had the same name at subtheme and next level (affirming data and having a voice) after these findings were merged six findings were left (affirming independence, being left alone, ownership, having a voice, choosing how to engage and choice and control). Affirming independence, being left alone, ownership were merged under the name Affirming Independence. Choosing how to engage and choice and control were merged under the name Choice and Control. This left three subthemes – Affirming independence, Choice and control and Having a voice.

2. Answer - what are the findings of this section?

- Affirming independence – participants vocally wanting to do activities their self as appose to having it done for them.
- Being left alone - participants vocally wanting to do activities alone as appose to doing this with someone.
- Ownership – participants physically holding the equipment showing they wanted to do the activity as appose having this done for them.
- The above three were merged at this point as the data supports the same findings.
- Choice and control – Shows participants preference in activity and doing what they wanted to do.
- Choosing how to engage - Shows a different in preference on how to engage.
- The above two were merged at this point as the data supports the same findings. Some of this data actually showed that the participants had a voice so some of this was merged.
- Having a voice - shows people with dementia have a voice and are capable of more than carers expect.

3. Answer – what research questions does this section answer?

- Affirming independence (after merge) – Answers RQ1. The Tech Club gives the opportunity to do things alone and by themselves, that this shows a retaining of skills and a development of new skills. Independence in activity.
- Having a voice – Answers RQ1. The Tech Club gives the opportunity for the participants to express their thoughts and opinions. The tech Club encourages feedback and seeks the voice of the participants.

4. Answer – what is the unique contribution from this data?

As a section, nothing.

5. Is any of the data better suited elsewhere?

- Affirming independence and Having a voice moved to regaining Self theme. Moved here because it shows participants using their voice to communicate their thoughts and feelings – this element can be lost.
- Choice and control will not be used as elements of this is not relevant or useful (does not answer any research questions) and also duplicates data and points made in the ‘Self Enhancement’ section – participants switching to an activity they could do.
- **Affirming independence and having a voice moved to self-theme / Choice and control not being used**
- RQ - Data from this section answers RQ1 as it provides an opportunity for the participants to engage in conversation and to socialise.
- Unique contribution – Using technology to stimulate conversation. However, this has been reported in our papers that I have co-authored so is not a unqiue contribution. There is nothing particularly significant or novel in these findings.
- **Remove whole section and do not use findings (except those described above)**

Theme: Meaningful Activity

The process which was followed to come to the conclusion that the data from this theme was not being used is:

1. Answer - what are the findings of this section?

- Access to hobbies – Participants enjoyed the Tech Club, there was a slight change in mood (decrease and increase), the participants felt that the session was something to look forward to and was different. There was also a preference to use the iPad.
- Barriers to hobbies (within the session) – Equipment, facilitation and that not all activities were suitable?
- Meaningfulness – two participants identified that they felt that they had no purpose or need for the equipment, that some felt that the Club was a waste of time. Yet that despite this, the Tech Club was meaningful in the sense of what it enabled the participants to do – access to their hobbies. This data was not used on the basis that it was representative of only two participants within one session when there were was frustration surrounding the use of the equipment.

2. Answer – what research questions does this section answer?

- RQ1. Ability to access hobbies
- RQ3. Opinions on technology

3. Answer – what is the unique contribution from this data?

- Method: Access to hobbies through Tech (already known)
- A potential difference between meaningful to and meaningful for (this is largely notional and based on not much significant data).
- As a section, nothing.

4. Is any of the data better suited elsewhere?

- Something different / new; Rejuvenation of hobbies and skills; preference to use the iPad – can go into the access to learning theme. These were moved to learning on the basis that rejuvenation of hobbies and skills is an element of relearning. Preference to use iPad is a learning agenda and something new can be linked to wanting a challenge or cognitive activity.
- Fluidity of session; not doing what wanted; suitability of activity – can be moved to reflections. Equipment limitations (sensors – moved to reflections; internet connections – moved to reflections). All of these are more reflections of process than firm solid findings.
- **Three sections moved to learning / Four sections moved to reflections. Enjoyment of session / improved mood / mobility restrictions – data not being used as this is not relevant to the thesis and alone do not answer any RQ's.**

Theme: The struggle for inclusivity

The process which was followed to come to the conclusion that the data from this theme was not being used is:

1. Answer - what are the findings of this section?

- Barriers to inclusion – That stigma, labelling and pressure can act as a barrier to inclusivity and due to this that carers tend to do things for the participants which in some cases the participants say they can do for themselves.
- Enablers to activity – That a good atmosphere, support and encouragement enables activity and therefore inclusion. That there is a strong element of peer to peer support and encouragement which are

also enablers for activity / inclusion. That with support there was success and levels of independence.

- Challenge perception - That the Tech Club challenged perception around ability of the participants.

2. Answer – what research questions does this section answer?

RQ1 – enables inclusivity

3. Answer – what is the unique contribution from this data?

- Method – enables inclusivity using a different method (technology)
- Method – challenges perception using a different method (technology)
- As a section nothing

4. Is any of the data better suited elsewhere?

Barriers to inclusion:

- Deprecation of participants – Some data went to access to learning theme as it was quotes from carers saying that pwd cant think and take in new information – this is contradicted by the participants ability to learn. Other data went to regaining self theme – this as it is about the role of the people with dementia and the carer. Could be used to support loss of self for the participants.
- What I can do – moved to regaining self theme as this is about ability and skill, where people talk about wanting to do but not being able to. Not sure how this will fit at this moment but sure it fits here.
- Pressurising participants and negative impact on group moved to reflection section as these are reflections of process than firm solid findings.
- Taking over participants and answering for participants were moved to the regaining self theme.

2 sections moved to reflections / 2 section moved to self / 1 section moved to learning / 1 section? / 2 sections taken out

Enablers to inclusion:

- Atmosphere and praise and encouragement taken out on the basis that they don't add anything new to the research, they don't answer any RQ's and they do not tell us very much.
- Support – some has gone to access to learning theme – talks about peer to peer support, I think this sits in learning as its learning from peers and highlights the importance of learning from others in similar situations. Some data taken out. Data looking at participants and careers working together and support not required not needed as this does not add anything, the data are not very strong and it does not answer any questions.

2 sections taken out / 1 section moved to learning

Challenged perception

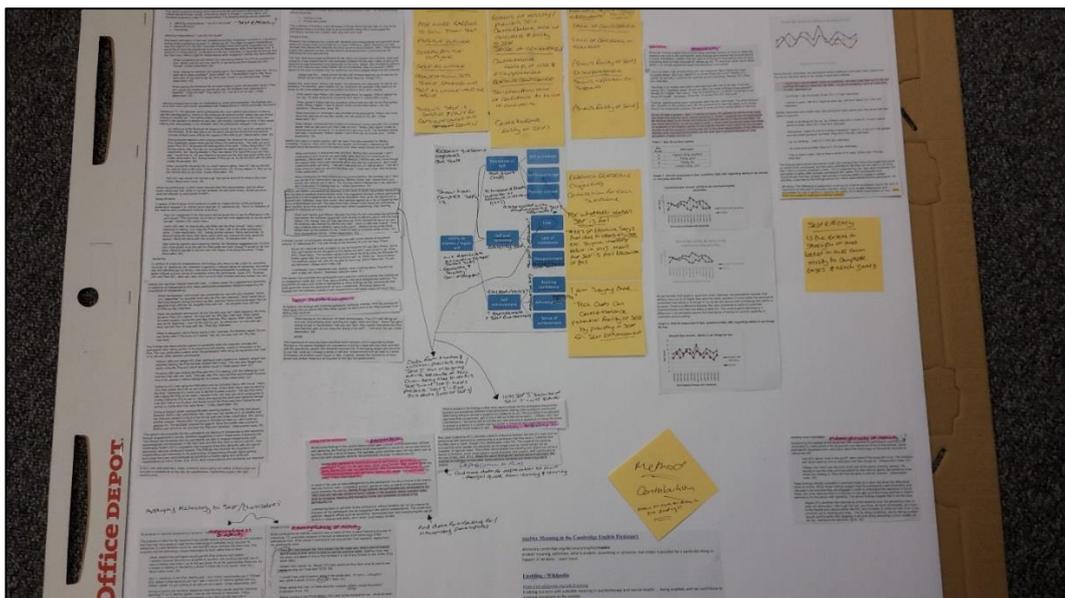
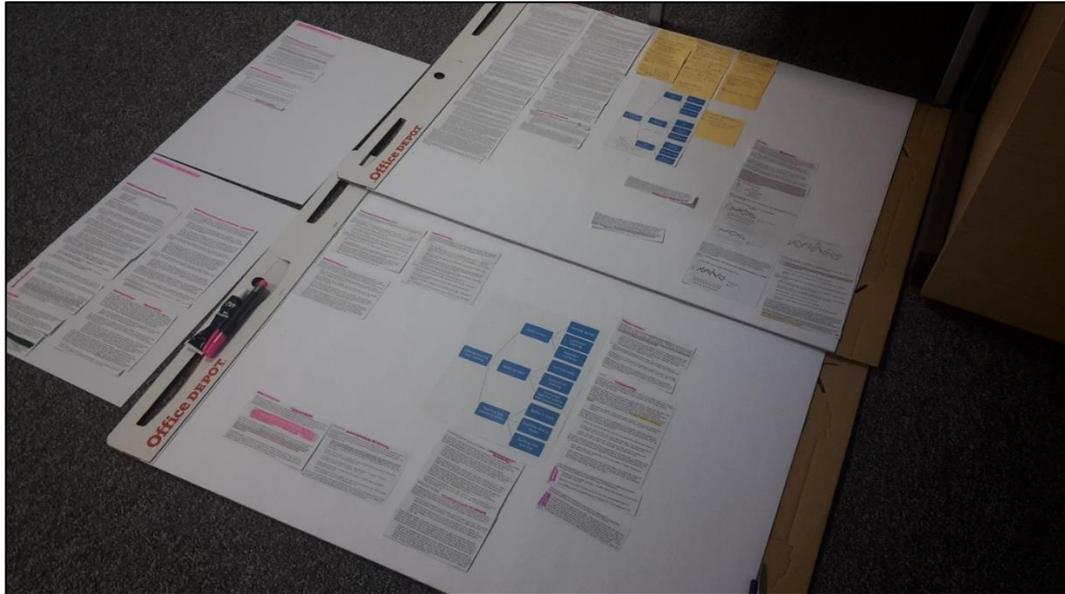
- This data has not been used on the basis that it focuses on carers and this is not the focus of my research, challenging perception was also not the focus of my research. The data from this subtheme was weak, only used when in relation to learning.

In total for Inclusivity section – 5 sections taken out / 2 sections moved to reflections / 1 section to self / 2 sections to learning. In total for all findings:

- 1 whole subtheme removed / 9 sections taken out and not used (across three remaining subthemes) / 6 sections moved to reflections / 3 sections to self 5 sections to learning

Appendix 14: Pen, paper and data movement

Phase 5, stage 3: Approach to data reduction



Overview of data movement and theme refinement

Me, Myself and I - a battle for self, independence and what's meaningful	
Ability to Express Self	
Perception of self	
Self as a whole	
Positive Outlook	
Self and dementia	
Loss	
Lack of confidence	
Disappointment	

Self enhancement	
Sense of achievement	
Affirming skills OR talents	
Growing confidence	
Exercising Independence, Choice and Control	
Affirming Independence: I can do it for myself	Merged and moved to self
Being left alone	
Ownership	
Having a voice	Moved to self
Choice and control	Removed
Choosing how to engage	
Wanting to watch	
Wanting to take part OR joining in	
Not wanting to take part	
Taking part in Meaningful Activity	
Access to Hobbies and Interests	
Enjoyment of session as a whole	Removed
Improved mood	
Something different OR something to look forward to	Moved to learning
Rejuvenate skills OR hobbies	Moved to learning
Preference to use iPad	Moved to learning
Barriers to Activity OR Hobbies and Interests	
Equipment Limitations	Moved to reflections
Fluidity of the session	Moved to reflections
Suitability of activity	Moved to reflections
Mobility OR Physical restrictions	Removed
Meaningfulness of activity	
No purpose OR need for equipment OR sessions	Unsure placement
Wanting more information	Unsure placement
Not doing what wanted	Moved to reflections
Waste of time OR Frustration	Unsure placement

Inclusion, Education and People	
The struggle for inclusivity: the right to be included	
Barriers to inclusion: Deprecation of PWD	
Doing it for the participants	?
What I can do	Moved to self
Pressurising PWD to take part, get it right OR adding pressure	Moved to reflections
Taking over the session	Removed
Answering for or influencing participants	
Negative impact on group	Moved to reflections
Enablers to inclusion: Atmosphere, Support, Praise and Encouragement	
<i>Atmosphere</i>	Removed
Laughter, Jovialness and Friendly	
No pressure	
Support	
Success through support	Moved to learning
In the same boat - peer to peer support	Moved to learning
PWD and Carer working together	Removed
<i>Praise and Encouragement</i>	Removed

Encouragement OR praise given by PWD	
Encouragement OR praise from carers	
Encouragement OR praise given by facilitator	
Challenged perception	
Learning and teaching	
Desire to learn	
Learning agenda	
Continued learning	
Wanting a challenge	
Ability to learn	
Learning styles	
Evidence of learning	
Encourage cognitive activity	
Teaching and providing advice	
Ability to teach	
Teaching what is known	
Teaching new learning	
Togetherness: the importance of people, company and conversation	
Friends and Family	Removed
Family and friends, we get one well	
Don't have or don't see family	
Don't have or don't see friends	
Talking about family	
Company and Companionship	
Importance of people and meeting people	
Familiarity	
Socialising	
Conversation	
Equipment catalyst for conversation	
Conversation about interests	

Appendix 15: Theme refinement

Phase 6, stage 1

Access to Learning and Teaching		
	Sources	Refs
Teaching and providing advice	72	205
Teaching what is known	15	33
Teaching new learning	21	46
In the same boat - peer to peer support	29	118
Not learning anything	7	8
Ability to learn	151	337
Motor skills and cognitive activity	16	31
Something different OR something to look forward to	25	58
Evidence of learning	22	49
Rejuvenate skills OR hobbies	4	7
Learning styles	28	72
Variation in levels of support	18	42
Success through support	18	44
Continued learning	20	34
Desire to learn	78	219
Learning agendas	33	104
Wanting a challenge	8	19
Preference to use iPad	37	96

Ability to regain self		
	Sources	Refs
Self enhancement	142	367
Sense of achievement	22	69
Growing confidence	28	57
Having a voice	26	58
Affirming skills OR talents	10	19
Affirming Independence	28	90
What I can do	28	74
Self and dementia	116	292
Loss of self attributes	39	114
Perceived loss of self attributes	18	59
Disappointment in performance OR frustration in self	11	16
Lack of confidence	14	34
Doing it for the participants	14	25
Apprehension OR Nervous	15	35
Just Luck OR embarrassment of success	5	9
Perception of self	41	105
Self as a whole	15	30
Positive outlook	26	75

Appendix 16: Final themes

Phase 6, stage 2

Access to Learning and Teaching		
	Sources	Refs
Desire to learn	90	234
Learning agendas	70	200
Continued learning	20	34
Ability to learn	139	322
Cognitive activity	49	108
Evidence of learning	26	56
Learning styles	64	158
Teaching	65	197
Peer to peer teaching	44	151
Teaching new learning	21	46

Ability to regain self		
	Sources	Refs
Perception of self	41	105
Self as a whole	15	30
Positive outlook	26	75
Fragility of self	131	357
Loss of self attributes	39	114
Perceived loss of self attributes	60	158
Self esteem	32	85
Supporting self	106	292
Increased self esteem	54	115
Self efficacy	52	177