

THE UNIVERSITY OF HULL

Experiences with everyday technology and wellbeing in dementia

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by

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Overview

This portfolio thesis consists of three parts: a systematic literature review, an empirical paper and a set of appendices. The thesis as a whole explores the use of everyday technologies in dementia and how everyday technology is experienced by individuals living with dementia and their care partners.

Part one is a systematic literature review that explores how people living with dementia and their care partners experience and view using technologies to enhance wellbeing through social engagement, participation and leisure. The review additionally aimed to understand what views and experiences people with dementia and their care partners have in relation to the usability of everyday technology. Ten papers were reviewed, and the data were synthesised from a narrative approach. The findings indicate that everyday technology has the potential to have a positive impact of different areas of wellbeing for people living with dementia. The overall findings are discussed within the context of wider literature, with consideration of areas for further research and clinical implications.

Part two of the portfolio is an empirical study that aimed to understand how couples, where one person is living with dementia, experience co-creating a digital life story book together. The study aimed to understand whether co-creating a digital life book supports couples' wellbeing and, if so, how does it support their wellbeing. Four married couples ($n=8$) completed the 6 week study of creating their digital life story book and participated in an interview following the 6 weeks. The research used a qualitative method, gathering data using a Constructivist Grounded Theory approach. Because full data saturation was not met, the final data were analysed using Thematic Analysis. Four superordinate and eight subordinate themes emerged from the data. The

findings are discussed around the wider context of literature exploring life story work and couples' wellbeing in dementia, with the implications for clinical practice and further research discussed.

Part three consists of a set of appendices relating to both the systematic literature review and the empirical paper. Included in these appendices are a reflective statement and an epistemological statement which explores the researcher's journey throughout the research process, and the philosophical position including the underlying assumptions of the research.

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Part One: Systematic Literature Review

**The use of everyday technologies to enhance wellbeing and enjoyment for people
living with dementia: A systematic literature review and narrative synthesis**

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Please see Appendix A for the Guidelines for Authors.

Abstract

Background

Everyday technologies, such as laptops and tablets, are often used for enjoyment, pleasure, leisure and social participation. Despite this, whilst considerable research has investigated exploring people's experiences of using assistive technologies, it is not clear how everyday technologies are experienced by individuals living with dementia. The aims of this review were to explore the experiences and views of people living with dementia and carers about using everyday technology to enhance their wellbeing and enjoyment, social engagement, participation and leisure, as well as understand their views about the usability of everyday technology in dementia.

Methods

A systematic search of the literature was conducted using the electronic databases: PsycINFO, PsycARTICLES, CINAHL Complete and EThOS. Five qualitative studies and five mixed method studies were included and synthesised using a narrative approach. The methodological quality of the studies was assessed using the National Institute for Clinical Excellence Qualitative Quality Appraisal (2012), which uncovered key variation in the quality of the included, synthesised studies.

Findings

The review suggests that everyday technologies can help support wellbeing, particularly when technology is used in a group setting and when individuals received the right amount of support to help engage in the technology. Four major themes relating to experiences and views were derived from the findings of the 10 included studies: 'Technology use maintaining a sense of identity', 'Assumptions held by the self and

others', 'The importance of others' and 'The usability of technology influencing effective engagement'.

Conclusions

Overall, everyday technologies appear to have a positive impact on different aspects of the wellbeing of people living with dementia. Clinical implications of these findings include supporting opportunities for people living with dementia to use everyday technology for enjoyment and making these technologies more widely available and accessible.

Key words: *dementia, everyday technology, wellbeing, enjoyment, pleasure*

Introduction

Wellbeing is an important aspect of being human. Whilst definitions of wellbeing vary, it can be conceptualised by five elements: positive emotions, engagement and being absorbed in activities, positive relationships, meaning and a sense of achievement (Seligman, 2012). Since living with dementia increases the risk of experiencing depression and anxiety (Kraus et al., 2008), it is important to focus on how wellbeing can be maximised as part of enabling people with dementia to ‘live well’ (i.e. reach an optimal state of health and wellbeing despite health-related adversity; Harris & Wallace, 2012). Evidence indicates that psychological health, social engagement, functional ability and positive relationships are associated with living well with dementia (Clare et al., 2019). Finding ways to facilitate or enhance these factors for people with dementia remains a clinical and research priority.

We are living in a digital world and the use of Assistive Technology (AT), devices that either allow an individual to perform tasks that they would otherwise be unable to do or which increase the ease and safety with which tasks can be performed (Cowan & Turner-Smith, 1999), has been shown to promote independence and quality of life and support wellbeing in dementia (see Cahill, Macijauskiene, Nygård, Faulkner, & Hagen, 2007; Mulvenna et al. 2010). Examples of AT include automated prompts, locator devices and safer walking devices (Alzheimer’s Society, 2015). However, as suggested by Astell (2013), focusing solely on dementia-specific AT and assuming that this is the only technology suitable for promoting wellbeing in people with dementia can perpetuate stigmatisation around using technology. Assistive technologies for safety can lead to feelings of incapability (Brittain, Corner, Robinson & Bond, 2010), indicating the potential for AT to diminish wellbeing.

In contrast to AT, everyday technologies (ETs) - electronic, technical, digital devices such as app-enabled computers, tablets and smartphones - already exist in people's lives at home (Beasley & Conway, 2012) and are more readily accessible. Research into the use of ETs by people with dementia is growing, with studies indicating that such "off-the-shelf" technology can increase social benefits for people with dementia by increasing discussion around shared interests (Capstick, 2011) and increasing independent engagement with pleasurable activities (e.g. Lim, Wallace, Luszcz & Reynolds, 2013). Furthermore, ETs are often cheaper to acquire than many specialist dementia technologies (Bowes, Dawson & Greasley-Adams, 2013) suggesting they are more likely to be used.

Enjoyment has been cited as the main reason why people engage in technology (Lin & Yu, 2011) and this prompts the question of to what extent ETs have been researched in dementia in terms of enjoyment. ETs are likely to facilitate positive emotions, such as enjoyment and pleasure, supporting wellbeing and personhood in turn. ETs may promote 'positive person work' in dementia, such as maintaining personhood through play, creation, validation and collaboration (Kitwood, 1997) as everyday technology allows individuals to play a variety of games (Pedell, Beh, Mozuna & Duong, 2013).

A review conducted by Pinto-Bruno et al. (2017) found that people with dementia can benefit from ICT interventions in relation to maintaining, facilitating and creating social engagement and participation. Their review noted that the most "promising" evidence (p.16) that technology use supports social participation in dementia came from qualitative studies. Reviewing the qualitative evidence in this area could therefore help illuminate our understanding of people's experiences of using technology for enjoyment and pleasure as well as social engagement. Looking at the experiences of using technology from the perspective of people with dementia is important as the views of

these individuals can often be unheard (Span et al., 2013) and empowerment for people with dementia is a growing issue (The Dementia Engagement and Empowerment Project, 2013). Furthermore, the perspectives of caregivers are important to explore in order to fully understand how the social environment around the person might impact on experiences of using technology with respect to enjoyment, social participation and engagement.

Recent research has also drawn a distinction between engagement and ‘effective engagement’ which can be defined as a level of engagement to achieve intended outcomes that can only be established in the context of the specific intervention used (Yardley et al., 2016). It is important to understand what experiences of using technology facilitate or hinder ‘effective engagement’ in ETs from the perspective of people with dementia. For example, the usability of ET may influence effective engagement in dementia but this may vary (Lim et al., 2013). Yardley and colleagues concluded that qualitative research is needed to understand how technological interventions can meet the aims of users of technology.

In view of this, a qualitative systematic literature review incorporating the views of those living with dementia and their caregivers would provide a deeper understanding of the experiences of using everyday technology within their social world, and how technological interventions can help influence enjoyment, pleasure, effective social participation and engagement.

As such, the current review aimed to answer the following questions:

- 1. How do people with dementia and their care partners experience using everyday technologies to enhance their wellbeing through social engagement, participation and leisure?*

2. *What are the views of people with dementia and their care partners about using everyday technology to enhance wellbeing?*
3. *What experiences and views do people with dementia and their care partners have in relation to the usability of everyday technology in dementia?*
4. *What is the methodological quality of studies in this area?*

Method

Search Protocol

The lead researcher (LS) conducted a systematic literature search in December 2018 across three electronic databases: PsycINFO, CINAHL and PsycArticles in order to capture a broad range of disciplines likely to contribute to dementia research. To extend the inclusivity of this review, further searches were run on the EThOS database to explore grey literature. Furthermore, the reference and citation lists of included papers were scanned for relevant papers. Further data were sought through contact with relevant researchers considered to be influential in this area (see Appendix B).

A broad search strategy was designed, guided by previous literature reviews relating to dementia and technology use (Hitch, Swan, Pattison & Stefaniak, 2017; Joddrell & Astell, 2016). Further search terms were added based on the key words from retrieved papers. For a detailed description of how the search terms were generated, see Appendix C. The key search terms were as follows:

Terms relating to dementia - *dementia or Alzheimer* or mild cognitive impairment*

AND

Terms relating to everyday technology - *technolog* or digital* or electronic* or device* or computer* or tablet* or “mobile phone*” or smartphone* or internet or iPad**

AND

Terms relating to the purpose of the use of technology (with respect to wellbeing) - *Social or engagement or inclusion or involvement or participation or leisure or pleasure or enjoy**

In addition, the search terms *dementia* AND *technology* were used on the EThOS database to retrieve doctoral theses in this area.

The terms were searched for firstly within the title of the study, and then articles’ abstracts to help identify relevant papers.

Inclusion and Exclusion Criteria

Tables 1 and 2 show the inclusion and exclusion criteria for papers alongside the rationale for each criterion. Limiters were applied to retrieve papers written in English only.

Table 1. Inclusion criteria and rationale

Inclusion Criteria	Rationale
The study aimed to explore views and experiences of using ET in the form of computers, tablets, devices or phones to support wellbeing via social engagement, participation, enjoyment, pleasure and leisure in dementia.	To find papers which explored the lived experience, views and opinions, or to find papers that reflected on this in their results section.
The study had at least one discrete, overarching theme within the findings relating to views/experiences of using everyday technologies to support wellbeing via social engagement, participation,	To identify and include studies that may not have directly investigated links between ETs and wellbeing but did have important incidental findings relevant to the aims of this review. Search terms were generated from using

enjoyment, pleasure and leisure in dementia.	theoretical literature around positive psychology and wellbeing (Seligman, 2012; Diener, 1984; Cohen-Mansfield, Dakheel-Ali & Marx, 2009) as well as previous research emphasising the need to explore social engagement further in everyday technology (Astell, 2013).
Participants had to be people with dementia or mild cognitive impairment (MCI) or an informal/formal carer to those living with dementia or MCI	To find papers relevant to the clinical population and to incorporate multiple perspectives from key people in the social environment of individuals living with dementia. MCI was included as often research samples are mixed and to include people who are early in the dementia journey as MCI can be a precursor to dementia (Janoutová et al., 2015).
The study employed a qualitative or mixed-methods methodology.	To ensure subjective views and lived experiences were captured.
The study included original quotes in the write up	For rich data to capture depth of experiences and views.
Written in English	To find papers which were written in the known language of the researcher, as there was no access to translation.

Table 2. Exclusion criteria and rationale

Exclusion	Rationale
Studies that do not capture experiences or views. For example, studies that only present quantitative data.	To ensure that the data analysed directly answered the research question which aims to explore views and experiences.
Studies that explore assistive technology use in relation to activities of daily living (ADLs) or safety (e.g. technology to track individuals, to assist with practical difficulties and/or to rehabilitate memory) only	It is argued that there is a distinct difference between technologies that support safety and ADLs and those that facilitate positive emotions, leisure, participation and engagement (Alzheimer's Society, 2015).
Studies focusing on technology use for leisure, social participation and engagement in a population other than individuals living with dementia or mild cognitive impairment and respective caregiver views (e.g. Parkinson's).	To ensure that data being examined related solely to the experiences, views and opinions of people who are living with dementia and their caregivers.
Reviews, reflective or discussion papers and conference presentation summaries	To ensure studies that are included in the review capture lived experiences, opinions and views.

Quality Assessment

Methodological quality was assessed using the checklist for qualitative studies created by the UK National Institute for Health and Care Excellence (NICE, 2012). A subset of papers was rated by a peer researcher to increase the transparency of the quality appraisal process. Three papers were randomly selected and were checked by a peer researcher to ensure reliability in quality rating; no disagreement in ratings emerged.

The checklist (see Appendix D) was used to critique the quality of each research study with regards to design, method, reflexivity and trustworthiness. In studies where a mixed methodology was used, only the qualitative aspects of the study were evaluated using the quality checklist. Methodological quality was not assessed as part of the inclusion criteria, but rather to help contextualise the findings of the synthesis. The quality scoring checklist can be found in Table 3.

Table 3. The NICE (2012) checklist quality checklist scoring criteria

Description	Score
All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter.	++
Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.	+
Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.	-

Data Synthesis

Studies included in the review were qualitative in focus and varied in their design and the type of ET used / evaluated. Meta-analysis was therefore not appropriate. Narrative synthesis was employed to analyse and synthesise research findings relating to the aims

of the review. Narrative synthesis aims to understand and synthesise ideas and theories around how and why an intervention may be beneficial for a population (Tong, Flemming, McInnes, Oliver & Craig, 2012) as well as telling a story about the findings (Popay et al., 2006).

In line with the procedure outlined by Popay et al. (2006) for conducting a narrative synthesis, relevant information, such as participant quotes and themes, was extracted using a data extraction form (Appendix E), and a preliminary synthesis was created through grouping studies by modality of technology use (individual, one-to-one and group-based) and tabulation of frequency of findings (Appendix F). Relationships within and between studies were then explored (Appendix G). Finally, a narrative synthesis of the data was developed and refined in relation to emergent themes and sub-themes.

Results

Identification and Characteristics of Relevant Studies

10 papers from electronic searches met the inclusion criteria for the review. The process of selecting papers is outlined in Figure 1.

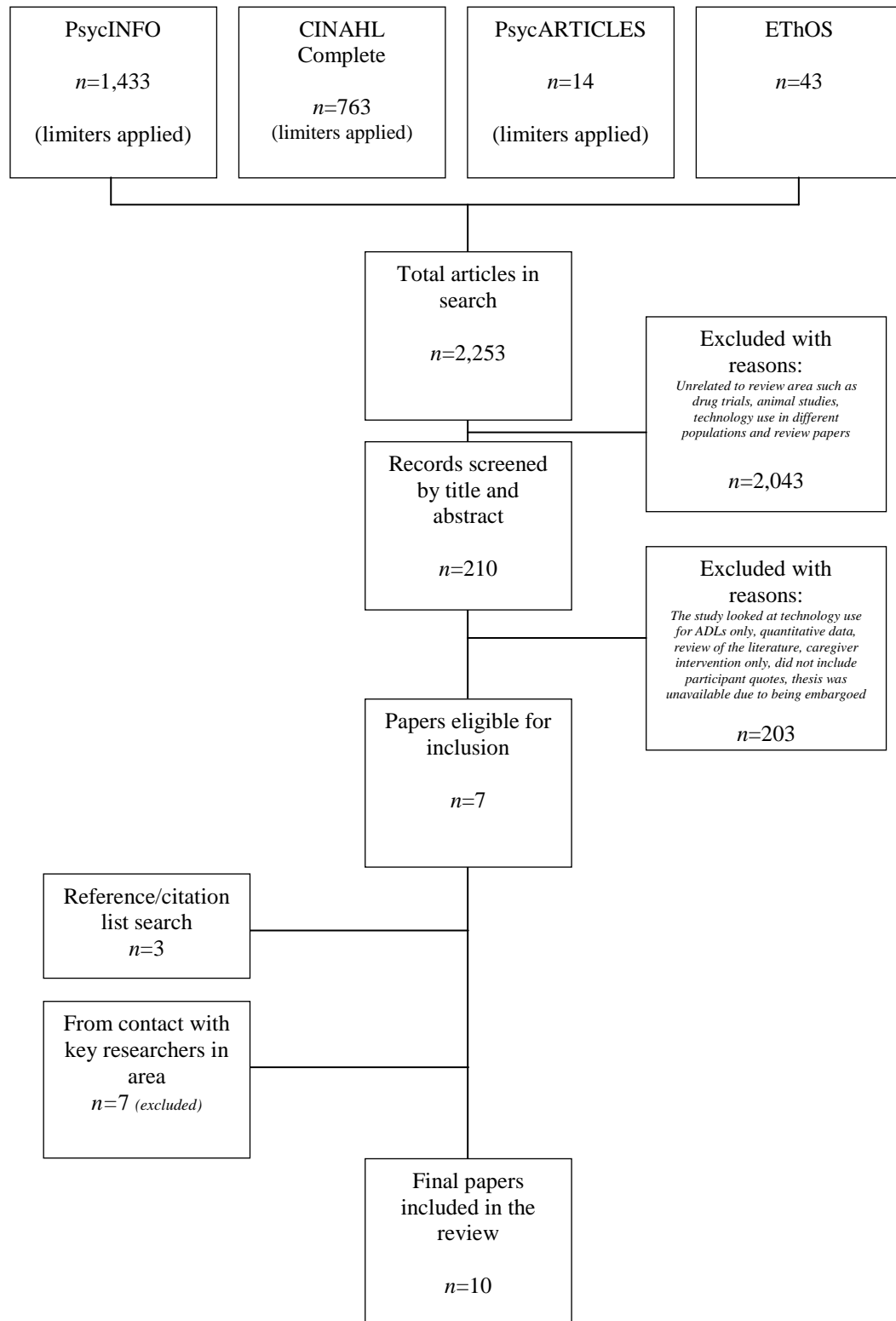


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses

(PRISMA) diagram detailing selection of papers

One of the published papers from the database search (Cutler, Hicks & Innes, 2016) matched a doctoral thesis paper from EThOS. In this case, both papers were read and compared and the published, peer-reviewed version was included. A published paper identified by a key researcher (see Appendix B) matched a doctoral paper from EThOS (Smith, 2015). The doctoral thesis was included as it had richer qualitative data.

Table 4 details the characteristics of the included studies along with the relevant findings extracted for analysis. Five studies employed a mixed methodology and five used only qualitative methods. Overall, 3 studies included the perspectives of people with dementia only, 1 study focused on the perspectives of caregivers either formally (e.g. staff) or informally only (e.g. family, volunteers) and 6 studies included perspectives from both individuals with dementia and those in a caring role.

Technology use was predominantly in a group or/and one-to-one ($n=9$) setting with the remaining studies exploring individual use ($n=1$) only. All studies included touchscreen technology (e.g. smartphones and tablets), some specially adapted for older people ($n=2$). One adaptation was picture-based touchscreen software for older people (Lazar et al., 2016), with another adaptation being a touch-screen movie player (Alm et al., 2009). A selection of studies evaluated other technologies alongside touchscreen technology (e.g. gaming consoles/systems; $n=2$). One study did not employ a specific intervention and instead explored naturalistic use of everyday technology (Hedman, Lindqvist & Nygård, 2016). Studies were conducted in community settings ($n=6$) and residential care facilities and inpatient units ($n=4$). All studies were completed in English-speaking countries.

Quality of Included Studies

The quality ratings of each study can be found in Table 4. Most studies lacked researcher reflexivity, with little or no attention paid to the relationship between the researcher and participant or consideration of the impact of the researchers' own biases and values on the research. Poor researcher reflexivity is often cited as a limitation of qualitative research (Newton, Rothlingova, Gutteridge, LeMarchand & Raphael, 2012). Four papers discussed issues of reflexivity explicitly (Astell et al., 2014; Hicks, 2016; Smith, 2015; Swan et al., 2018). This may be a result of limitations on word-counts in peer-reviewed papers.

The papers also varied in the richness of data presented, with the following papers including more participant quotes than others (see Astell et al., 2014; Smith, 2015; Hicks, 2016; Groenewoud et al., 2015; Lazar et al., 2016). Across studies, chosen qualitative methods appeared appropriate in relation to the aims of the studies but not all studies provided a clear rationale for including qualitative methods or clearly explain how data analysis occurred.

Table 4. Summary of characteristics of studies included in the literature review

Author and Year	Technology used	Aims	Qualitative Methods utilised	Participants	Modality	Setting	Duration of technology use	Quality Checklist Score
1. Alm et al. (2009) <i>UK</i>	Multimedia technology on touchscreen	Investigated ways in which an interactive entertainment system for people with dementia could engage and support them	<i>Mixed methods:</i> Qualitative methods - questionnaire (staff) and interviews (people with dementia)	13 professionals and 5 individuals with dementia	One-to-one	Care facility	Three sessions which were 10 minutes long over a number days	-
2. Astell, Malone, Williams (2014) <i>UK</i>	Laptop and iPhone™	To present the self-described journey of a person with dementia in his re-learning of old technologies and learning of new ones and the impact this had on his life	<i>Qualitative:</i> Case study using thematic analysis from online blog and diary entries.	1 individual with dementia	One-to-one	Community setting	On a daily basis (8 months in total)	++
3. Cutler, Hicks, Innes (2016) <i>UK</i>	Apple iPad™, Nintendo Wii™, Nintendo DS™	To capture experiences and views of using digital gaming from people with dementia.	<i>Mixed methods:</i> ethnographic field notes, self-completed questionnaire, focus group discussions. Qualitative data was analysed thematically.	29 individuals with dementia	Group led by facilitators “Tech Clubs” delivered by a local council at 4 accessible venues. The sessions were 2 hours and ran for 6-8 weeks.	Community dwelling	2 hour sessions over 6-8 weeks	+
4. Groenewoud et al. (2017) <i>Netherlands</i>	Apple iPad™	To explore experiences and views of independent tablet games	<i>Mixed methods:</i> Qualitative from post-game interviews and in researcher field notes.	54 people with dementia (24 men, 30 women).	Group	5 small-scale living facilities for people with dementia	3 sessions	++
5. Hedman, Lindqvist & Nygård (2016) <i>Sweden</i>	Everyday technologies (including tablet and smartphones)	This study explored how persons with MCI experience both technology in the present and their views of using technology in the future.	<i>Qualitative:</i> grounded theory analysis was used to analyse semi-structured interviews	6 people with MCI	Individual	Community dwelling	Continuous as this was not an intervention study	+
6. Hicks (2016) <i>UK</i>	Apple iPad™, Microsoft Kinect™, Nintendo Wii™, Nintendo Balance Board™	To explore ways to support older men living with dementia and to examine the impact of technology on older men with dementia in rural areas, particularly with regards to social inclusion.	<i>Qualitative:</i> Thematic analysis of interviews, focus groups and reflexive field notes.	22 men with dementia alongside 15 care partners and 5 community volunteers.	Group	Community dwelling in rural areas	9 sessions which lasted around 2 hours	++
7. Lazar, Demiris, Thompson (2016) <i>USA</i>	A commercially available computer system designed for	To evaluate a commercially available system designed to encourage the engagement of people with dementia in activities and social interactions	<i>Mixed methods:</i> semi-structured interviews with family members and staff analysed thematically.	5 individuals with dementia, 4 family members and 7 staff members	One-to-one	Memory Care Unit	Weekly hour sessions over 6 months	+

8.	Smith (2015) UK	older adults in community settings Touchscreen technology	<p><i>Study 1</i> – To explore how technology is received by members of a day care centre, explore if technology enables interaction through enjoyment and if familiarity with technology increases over time.</p> <p><i>Study 2</i> – To focus on enjoyable activities and what factors shape engagement and interaction with technology, if the devices present observable challenges/gains and what they are, and whether technology use involves new knowledge and retained learning.</p>	<p><i>Qualitative:</i> Used visual ethnography to analyse qualitative data and illustrated the findings thematically.</p>	<p>In Study 1, there were 9 women and 3 men living with dementia. 9 participants in a supporting role (including the researcher, paid staff, students, and volunteers) also consented to take part. In Study 2, 16 participants took part where 10 were living with dementia and 6 were in a supporting role.</p>	Groups and one-to-one setting	<p>Study 1 was based in a well-established charity organisation offering community groups for people with dementia.</p> <p>In Study 2, the focus was exploring touch-screen computers on a one-to-one basis with participants in their own homes.</p>	<p>Study 1 - Two, one hour sessions per week over a period of four weeks</p> <p>Study 2 – Four sessions every week</p>	++
			<p>Explore the experience of staff and residents, using iPads as a medium to engage meaningful occupation.</p>	<p><i>Mixed methods:</i> Combining descriptive quantitative and thematic analysis through interviews, focus groups and surveys</p>	<p>7 residents and 8 staff members participated in the qualitative component</p>	One-to-one	<p>Mental health service that included three acute in-patient units (Australia).</p>	<p>Each site had a different implementation strategy and developed their use of iPads organically</p>	++
			<p>To provide insight into the experience of the person with dementia with regard to using touchscreen technology and the impact that it has on individual staff working with the person they care for and to develop a better understanding of the perceptions of people engaged in dementia care as to the potential for the use of touch screen technology.</p>	<p><i>Qualitative:</i> Used thematic analysis to analyse interviews and focus groups.</p>	<p>In the interviews, 10 participants with dementia and one member of staff were included.</p> <p>In the focus groups, 10 care home staff and managers participated in the study.</p>	Group and one-to-one setting	<p>The study was carried out in 11 care homes</p>	<p>Differed across the settings, developed their own use of touchscreen technology</p>	+

Synthesis of Findings

The narrative synthesis resulted in 4 themes and 10 subthemes, as displayed in Table 5.

An example of the synthesis process is provided in Appendix G.

Table 5. Themes and subthemes derived from the synthesis of findings

Themes	Subthemes	Papers
Technology use maintaining a sense of identity	<i>Learning and achievement</i>	Astell et al., 2014; Cutler et al., 2016; Groenewoud et al., 2017; Hicks, 2016; Swan et al., 2018; Alm et al., 2009; Upton et al., 2011; Lazar et al., 2016
	<i>Past and future interests</i>	Swan et al., 2018; Groenewoud et al., 2017; Hedman et al., 2016; Lazar et al., 2016; Hicks, 2016
	<i>Reminiscence</i>	Swan et al., 2018; Upton et al., 2011; Lazar et al., 2016; Hicks, 2016
Assumptions held by the self and others	<i>Positively challenging assumptions about the self and others</i>	Hicks, 2016; Cutler et al., 2016; Groenewoud et al., 2017; Astell et al., 2014; Alm et al., 2009; Upton et al., 2011
	<i>Feeling negative assumptions of the self were actualised</i>	Swan et al., 2018; Groenewoud et al., 2017; Hedman et al., 2016; Lazar et al., 2016
The importance of others	<i>Others' role in scaffolding technology use</i>	Swan et al., 2018; Groenewoud et al., 2017; Astell et al., 2014; Smith, 2015; Cutler et al., 2016; Lazar et al., 2016
	<i>Technology as a shared experience</i>	Cutler et al., 2016; Hicks, 2016; Groenewoud et al., 2017; Upton et al., 2011; Smith, 2015
	<i>Enhancing relationships</i>	Upton et al., 2011; Swan et al., 2018; Lazar et al., 2016
The usability of technology influencing effective engagement	<i>Problems encountered</i>	Groenewoud et al., 2017; Hedman et al., 2016; Lazar et al., 2016; Upton et al., 2011
	<i>Solutions found</i>	Upton et al., 2011; Lazar et al., 2016

Technology use maintaining a sense of identity

Findings from several studies suggested that using everyday technology helped maintain a sense of identity through a sense of achievement. In turn, the synthesis

linked this to experiences of learning something new, using technology relating to past interests and growing interests and reminiscing about one's life.

Learning and achievement

Most of the studies showed that learning how to use different everyday technologies influenced a sense of mastery and achievement, which increased feelings of enjoyment. Individuals with dementia described how learning about using ET helped to foster hope around future learning (Astell et al., 2014; Cutler et al., 2016), as well as a sense of mastery, achievement and progress over learning something new (Cutler et al., 2016; Groenewoud et al., 2017; Hick, 2016). One study found that engaging in ETs helped them to relearn (Astell et al., 2014) how to use aspects of technology they found difficult previously. This finding was evident across studies of varying methodological quality:

“I’m hoping to learn more next week about the iPad” – *person living with dementia (PLwD)* – From the theme of “Promoting life-long learning” - Cutler et al. (2016) – page. 111

A sense of achievement was evident when the technology involved the use of ‘scoring games’ which provided a form of tangible achievement (Groenewoud et al., 2017). Further to this, a sense of achievement was enhanced through using technology in groups as it offered opportunities for others to comment on their successes at using technology (Groenewoud et al., 2017) but to also encourage learning through positive feedback (Cutler et al., 2016).

A sense of learning something new was conveyed through individuals describing how they felt they had ‘used their brains’ and felt as though the learning was stimulating (Cutler et al., 2016; Hicks, 2016) and compared using the technology to less stimulating activities (Groenewoud et al., 2017). Learning about the technology offered individuals

something to do which increased feelings of enjoyment (Hicks, 2016; Cutler et al., 2016; Groenewoud et al., 2017):

“It is nice to have something to do. And it is intelligent. It is a nice therapy” – *PLwD* – From the theme
“Having something to do” – Groenewoud et al. (2017) – page. 42

Caregivers shared this view, and spoke about how experiences of technology helped individuals with dementia to learn more, build on their knowledge and generate a sense of accomplishment and confidence (Swan et al., 2018; Alm et al., 2009; Upton et al., 2011). An increase in observed confidence was something only spoken about from the perspective of carers. Staff commented on how using technology was a ‘learning curve’ (Lazar et al., 2016):

“Able to kind of learn more and sort of build on their knowledge – a sense of accomplishment and confidence in themselves” – *Staff* – From the theme of “Belonging” - Swan et al. (2018) – page. 5

Past and future interests

Some included studies found that positive experiences of ETs offered a means to engage in past interests and hobbies that shape individuals’ lives and sense of identity. They also offered individuals a way of pursuing and broadening their interests. This finding was consistently evident across 5 studies of varying methodological quality.

Individuals with dementia described how they enjoyed the technology if it was linked to their own interests (Groenewoud et al., 2017; Hicks, 2016; Smith, 2015). Technology offered a way to continue to engage in physical interests, such as sport, which helped to maintain a sense of identity despite physical limitations (Hicks, 2016):

“I loved the golf game... I can’t play it in reality... I can’t go out and play on a course anymore. I don’t have the money or equipment and... I’m not physically able to now but I love it” – *PLwD* - From the theme “Meaningful activity” – Hicks (2016) – page. 148

Further to this, disengagement and indifference was expressed if the technology did not match individuals' interests (Smith, 2016; Groenewoud et al., 2017):

“I think there is nothing in it. I cannot do anything with it and it doesn't work like I want it to” – *PLwD* –

From the theme “Sense of insecurity” – Groenewoud et al. (2017) – page. 43

This was also evident from the perspective of caregivers. Using ET was a way of keeping up with interests people with dementia may not otherwise be able to easily engage with. Positive affect and enjoyment was observed by family members when individuals based their technology use on their past interests (Hicks, 2016):

“Yes he really enjoys it. He used to play golf and fly fishing. He misses his golf and was in his element the other day when you played golf”- *Carer* – From the theme “Meaningful activity” – Hicks (2016) –

page. 149

Caregivers mentioned that when they discovered the interests of the individuals with dementia, they decided to focus the use of technology around their interests when first introducing the technology, which increased their engagement (Cutler et al., 2016):

“...it was discovered that both participants were artistic...Following from this it was decided that the iPads would be used . . . to be creative . . .” – *Carer* – From the theme “Mental stimulation” - Cutler et al.

(2016) – page. 114

Reminiscence

Some studies found that technology was an effective way of engaging in reminiscence and story-telling and was an opportunity for an individual to share aspects of their past with others (Swan et al., 2018). This finding was pertinent to those who had used technology in a group setting.

Individuals living with dementia reflected on how they reminisced about their past through using technology (Swan et al., 2018) and how this increased enjoyment (Upton et al., 2011). The use of specific ET, such as the iPad, offered a way to capture their life story more easily than on paper (Upton et al., 2011):

“I think the iPads appeal to a lot of people here. They bring back memories from our younger days. It was most enjoyable” – *PLwD* – From the theme “Reminiscence and recall” - *Upton et al. (2011)*

Carers spoke about the process of reminiscence through using technology more often than individuals with dementia, with emphasis focusing on the “shared” process of reminiscence through using technology. However, it is unclear in one study (Swan et al., 2018) if this was because carers were asked more about this topic than individuals with dementia. Further information about interview schedules would help understand if/how the questions were different for carers and people with dementia and increase transparency over the process. Caregivers described how individuals were able to engage in reminiscence through the apps everyday technologies offer, such as YouTube (Swan et al., 2018; Lazar et al., 2016; Hicks, 2016). From one study, staff described how they created a group project on the iPads around past memories which helped bring about shared enjoyment (Swan et al., 2018):

“We did have a bit of a project where they’d put together a bit of story of something they enjoyed in their past and shared that with others, so yes promoting a shared experience” – *PLwD* – From the theme “Belonging” - Swan et al. (2018) – page. 6

Family members from another study spoke about how happy memories were brought back through the use of games on everyday technology (Lazar et al., 2016):

“[she] absolutely loves the casino one, and that’s because she used to meet her favourite sister in Las Vegas.” – *family member* – From the theme “Reminiscence” - Lazar et al. (2016) – page. 379

Assumptions held by the self and others

Positively challenging assumptions about the self and others

Across several studies, experiences of using technology challenged negative assumptions that individuals with dementia held about themselves in relation to technology use. This may have related to beliefs linked to dementia and / or longstanding beliefs that existed prior to living with dementia. Whilst the assumptions of individuals with dementia and those who care for them were discussed in the studies reviewed, only three of the studies (Astell et al., 2014; Hicks, 2016; Smith, 2015) discussed researchers' own assumptions about dementia, thus affecting the trustworthiness of findings within this theme, as little attention was paid to researcher reflexivity and the researchers' own influence on the research process (Finlay, 2002).

Individuals with dementia described surprise at how much they enjoyed using everyday technology (Hicks, 2016) and the positive feeling arising from realising that they could use and interact with the technology (Cutler et al., 2016; Groenewoud et al., 2017; Astell et al., 2014, Alm et al., 2009):

“It was great to see I could do it” – *PLwD* - From the theme “Optimising mental, physical and social stimulation” – Cutler et al. (2016) – page. 119

Further to this, one individual expressed gratitude towards his new ability in using technology, as it differed from previous negative experiences of using the same technology (Astell et al., 2014):

“I only have to think back six months and recall that I could barely use a Television Remote Control. The changes in me are incredible” – *PLwD* - From the theme “Identity” – Astell et al. (2014) – page. 10

One individual with dementia described that friends, relatives and carers had mentioned that a diagnosis of dementia would change their ability to use technology, and were

therefore “shocked” to see when he was able to successfully use ET for enjoyment (Astell et al., 2014):

“They were sure that a diagnosis of dementia would leave me without these skills forever. Some of them have been shocked to see me use me use an iPhone.” – *PLwD* – From the theme “Challenging negative perceptions” – Astell et al. (2014) – page. 16

Similarly, caregivers reflected on their surprise (Upton et al., 2011; Cutler et al., 2016) when individuals with dementia successfully navigated ETs. A volunteer described how in their technology group they could not discriminate between who was facilitating the group and who was the person living with dementia (Hicks, 2016). As a result, the volunteer felt they learnt more about dementia:

“I wasn’t sure who was the volunteer and who was the person with dementia...” – *Volunteer* – From the theme “Challenging others’ assumptions” – Hicks (2016) – page. 160

Feeling negative assumptions of the self were actualised

In contrast, some studies reported that the experiences of technology may have strengthened negative assumptions individuals with dementia held about themselves. One study found that individuals with dementia felt as though they were not able to use technology because of their age rather than their dementia (Swan et al., 2018):

“I’m too old for that” – *PLwD* – From the theme of “Doing” – Swan et al. (2018) – page. 5

Another study reported that an individual felt a sense of failure after difficulty using the technology and compared themselves to previous successful experiences of using technology, influencing low self-esteem (Groenewoud et al., 2017):

“I did not like the effort. I used to be able to do this” – *PLwD* - From the theme “Failure, low self-esteem”

– Groenewoud et al. (2017) – page. 42

Another study found that an individual living with MCI felt as though they would not be able to engage as well in technology if their memory difficulties progressed as the technology would not be simple to use (Hedman et al., 2016). This suggests that for some technology use can be a negative experience that activates future negative assumptions of the self:

“And like then you have to adapt these things, I’ll never manage this, with Spotify and all that. If...if I get a little more scatterbrained, eh? That won’t work.” – *Person with MCI* – From the theme “Downsizing” –

Hedman et al. (2016) – page. 6

Furthermore, negative assumptions about using technology in dementia were reflected upon in a study focusing on staff views. Because staff had difficult experiences of using the technology, they felt, with certainty, that it would be more problematic for individuals with dementia (Lazar et al., 2016), linking to negative assumptions, such as that individuals will not be able to use technology, that are held about people with dementia:

“If we’re having a hard time using it, it’s definitely gonna be hard for [residents]” – *Staff*–

from the theme “Challenges” – Lazar et al. (2016) – page. 381

The importance of others

All but one of the studies (Hedman et al., 2016) focused on experiences of using everyday technology in either a group or one-to-one setting. This finding was reported in studies of varying quality but those with a higher quality appraisal (Swan et al., 2012; Astell et al., 2014; Groenewoud et al., 2017; Hicks, 2016; Smith, 2015) gave further insight to the direct experience of the importance of sharing the experience of using

technology with others as more detailed quotes were used in these studies. It was less clear in lower quality studies what role other people played in technology use and its relationship with wellbeing (e.g. Alm et al., 2009).

The importance of having a caregiver helping to scaffold technology use appeared linked to increased engagement with technology. Shared experiences of technology with other people with dementia, particularly in a ‘club’ setting, helped increase laughter, conversation and enjoyment. ET use also helped increase social interactions and enhanced relationships between individuals with dementia and carers.

Others’ role in scaffolding technology use

From the perspective of people with dementia, having other people involved was important to help learn to use everyday technologies. An important aspect of this was ensuring the right support, such as explaining how to use apps on a device, was matched to individuals’ existing knowledge of using devices (Swan et al., 2018; Groenewoud et al., 2017; Astell et al., 2014; Smith, 2015; Cutler et al., 2016):

“Taught how to put it in, and then we are left to our own” – *PLwD* – From the theme “Doing” – Swan et al. (2018) – page. 5

When scaffolding was inappropriately matched to the person living with dementia, then disengagement from the technology was experienced (Smith, 2015; Groenewoud et al., 2017):

“I didn’t fully understand it. I would if someone told me to do such and such” - *PLwD* - From the theme “Sense of insecurity” – Groenewoud et al. (2017) – page. 43

Conversely, the importance of having others scaffolding learning around technology was only described by caregivers in one study (Lazar et al., 2016), despite many studies incorporating the views of both individuals living with dementia and those in a caring role. In the study conducted by Lazar and colleagues, a family carer described how their relatives would lose interest in the technology if there was not someone there:

“One time when I was using [the system], and [she] was playing blackjack, I had to leave, and I said ‘You know you can still keep playing’ and she’s like ‘No, I don’t want to’” – *Family member* – From the theme “Influencers” – Lazar et al. (2016) – page. 379

A professional carer reflected that it was important for the staff member helping others to learn about technology to have enthusiasm and knowledge around using the technology or else the process of learning would be seen as difficult:

“You have to have someone that’s knowledgeable” – *Staff member* – From the theme “Influencers” – Lazar et al. (2016) – page. 382

Technology as a shared experience

The importance of using technology with other people with dementia was described as a shared, positive experience across several studies. Technology use helped to influence social interaction and participation. Some of the studies explored experiences of using technology in a ‘club’ setting (Cutler et al., 2016; Hicks, 2016; Groenewoud et al., 2017) and found that individuals with dementia reflected on how being in a group and learning how to use technology with others increased enjoyment, laughter, conversations and subsequently overall wellbeing as it was a shared experience where many could join in (Hicks, 2016; Upton et al., 2011). One study reflected on how sharing the experiences in a group helped others to encourage and be encouraged when using technology (Cutler et al., 2016), which fostered a sense of motivation around

technology use. Participants in one study described how the social interaction of using technology in a group influenced self-esteem (Groenewoud et al., 2017) as others were able to comment on the successes of using the technology. Specifically, having technology groups in rural environments led to enhanced social interaction and confidence, as people with dementia reflected on how there are little opportunities for meeting people and the technology groups provided the means for socialising whilst engaging in the everyday technologies (Hicks, 2016):

“Well it helped to sort of meet other people. I don’t socialise that much.” – *PLwD* – From the theme

“Social Participation” – Hicks (2016) – page. 147

Caregivers also shared this view, with family members reflecting on how the social element of the technology clubs was most important, particularly as they lived in a rural area but also that they perceived the technology clubs to be interesting and enjoyable for individuals with dementia (Hicks, 2016). Furthermore, carers described how the novelty of using technology stimulated conversation and laughter among those using the technology (Cutler et al., 2016; Smith, 2015):

“I think the social benefits were brilliant” - *Family member* – From the theme “Life-long Learning” –

Hicks (2016) – page. 155

Enhancing relationships

Some studies also reflected on how relationships between carers and individuals living with dementia were enhanced through shared use of technology. Only those in a formal, paid caring role described this consequence of technology use. Care staff learned more about people through the use of technology (Upton et al., 2011) and technology provided a topic of conversation between staff and individuals with dementia (Swan et

al., 2018). In one study (Lazar et al., 2016) staff members reflected on how using technology helped bridge age gaps and generational differences:

“I think it influences as well the relationship between staff and the residents, a closer relationship” – *Staff member* – From the theme “Quality of Life” – Upton et al. (2011) – page. 16

The usability of technology influencing effective engagement

Problems encountered

Of the studies reviewed, some report problems encountered when using everyday technology, which hindered effective engagement. This finding was evident in studies deemed to have a higher methodological quality; the study receiving the lowest quality rating (Alm et al., 2009) was unclear in the reporting of views and experiences relating to the overall usability of technology.

Individuals with dementia described annoyance and frustration when technology did not work properly and when the applications available on the technology did not meet expectations of what would be enjoyable (Groenewoud et al., 2017):

“It did not run smoothly” – *PLwD* – From the theme “Annoyance” – Groenewoud et al. (2017) – page. 43

Furthermore, individuals reflected on the sophistication of some of the technologies, and would have preferred variations of popular apps, such as Spotify, that were simpler to navigate (Hedman et al., 2016). The cost of technology was also a concern: people with dementia explained that whilst they enjoyed using the technology, they felt reluctant to use it further due to its costs (Groenewoud et al., 2017).

Carers were also found to be concerned about using ETs. This included experiences of technology failing and causing frustration and disengagement from using it, as well as devices being physically unattractive and bulky (Lazar et al., 2016; Upton et al., 2011).

Solutions found

Solutions to problems were reflected on in two studies where staff adapted technology to help individuals use it more easily (Upton et al., 2011; Lazar et al., 2016).

“People have said oh it’s quite heavy...so I tend to think oh I can put it [the device] on a cushion or a pillow”– *Staff* – From the theme “Technology as a challenge” – Upton et al. (2011) – page. 17

Discussion

Overview of findings and implications

To our knowledge, this review is the first to collate and synthesise the experiences and views of people with dementia and caregivers about using everyday technology to enhance wellbeing and enjoyment through social engagement, participation and leisure as well as the usability of ET in dementia. Whilst findings were consistent amongst the higher and lower rated studies synthesised, better quality studies that explicitly acknowledged researcher reflexivity and provided a rich account of data made a stronger contribution to the synthesis. The findings of the review are similar to other reviews in the area in emphasising the role of technology to help social participation and enjoyment (Pinto-Bruno et al., 2017; Hitch et al., 2017) but also the importance of others both for sharing the experience but also for scaffolding support (Jodrell & Astell, 2016). However, other reviews have included assistive technologies alongside everyday technologies in their reviews. This review extends our understanding of ETs

by exemplifying what experiences of them are potentially important for wellbeing in dementia.

The review highlights that using everyday technology helped to challenge negative assumptions that individuals with dementia may hold about themselves, particularly internalised stigma (Corrigan et al., 2010) around being unable to learn new ideas when living with dementia. This emphasises the potential that ET may have to increase self-efficacy and mitigate feelings of low mood in the context of dementia, as low self-efficacy expectancy can contribute to increased levels of depression (Maddux & Meier, 1995).

The findings of included studies were unclear about whether the negative assumptions held about ones' ability of using technology were linked to a diagnosis of dementia, or other longstanding beliefs around technology, suggesting an area for future research. Overall, this links to the idea of 'scaffolding' in using technology, emphasising that learning about technology needs to be matched to the individual to buffer against those feelings of not being able learn new ideas. 'Effective engagement' (Yardley et al. 2016) in ETs in dementia might therefore be increased when other people are involved in scaffolding the use of technology; the presence of scaffolding appears connected with experiences of positive emotions in response to technology use (e.g. enjoyment) whereas the absence of scaffolding hinders engagement.

ETs offered a way to feel included and accepted by others, maintain a sense of continuity with the past and keep up with personal interests. This links to Kitwood's (1997) description of engaging in meaningful activity as a key aspect of wellbeing in dementia, as well as encompassing the 'global sentient states' of personal worth, and social confidence that Kitwood and Bredin (1992) describe as fundamental foundations

for wellbeing in dementia. The findings suggest that when there is a goodness of fit between preference, abilities and activities in using ETs, it can be linked to the positive experience of flow; positive engagement in a task that leads to a sense of satisfaction (Czikszenmihalyi, 1990). Experiencing flow motivates people to further engage with activities as they are rewarding for a sense of achievement and development or maintenance of skill, factors highly pertinent to wellbeing in dementia (see Clarke & Wolverson, 2016).

This review highlights that ET can support multi-sensory reminiscence with videos and music, helping people maintain their sense of identity through life story work. The use of ETs, when used in a group, facilitated enjoyment and self-expression through play and creation, which are key aspects of positive person work in dementia (Kitwood, 1997). Overall, it is plausible that using ET can help maintain personhood through multiple avenues, and this then potentially fosters a greater sense of wellbeing in dementia. Future research that investigates the specific uses of ET, such as exploring past interests and shared reminiscence through technology, would help illuminate further what specifically is enjoyable about using ETs, and the implications this has on a sense of identity.

Feeling included in a group has been suggested to be a key need in dementia to support wellbeing and reduce isolation (Kitwood, 1997), suggesting the use of ET in a group could support this. Cognitive Stimulation Therapy (CST) groups are an existing intervention for people with dementia to enjoy activities that are stimulating (Woods, Aguirre, Spector & Orrell, 2012). A main finding from a study exploring views about a CST group was that positive experiences were associated with being in a group (Spector, Gardner & Orrell, 2011). The findings from this review suggest that using ETs in existing groups, such as CST groups, may help to influence wellbeing further.

The review highlights the potential for everyday technology to promote interaction between caregivers and people living with dementia; including having fun together and feeling connected, linking to ideas that wellbeing in dementia should not be viewed only in the context of the individual but to consider social wellbeing, such as social acceptance and integration (Keyes, 1998). It is therefore important for research to investigate how technologies for wellbeing in dementia can be designed to have an element of 'co-use'. The extent to which using ETs together can help facilitate relationships between caregivers and those living with dementia, thus influencing relationship-centred care (Woods, Keady & Seddon, 2008) and wellbeing for both the individual living with dementia and their caregivers, is another avenue for future research.

This review also found that caregivers had their negative assumptions around dementia challenged meaning they were able to see the person beyond dementia instead of being seen as 'the disease' (Burstow, 2006). However, the negative assumption that technology is difficult for people with dementia may have the potential to prevent individuals with dementia from using technology, as many caregivers are often 'gatekeepers' of what is available. This reiterates the power of labelling people with dementia as incapable of using technology, how the reactions of others can potentially increase feelings of "otherness" (Green, Davis, Karshmer, Marsh, & Straight, 2005) thus influencing the person with dementia's experiences of their sense of self (Sabat, 2001). Generally, this suggests there is an assumption held that everyday technologies are not dementia friendly, which can prevent individuals from opportunities to use ETs.

Technical problems and the high perceived cost of technology found in this review contrasts to previous ideas by Bowes et al. (2013) about ET perhaps being a cheaper alternative to assistive technology. Existing leisure literature has established that money

is a barrier to accessing leisure activities generally in dementia (Innes, Page & Cutler, 2016), and that the cost of technology may inherently be a barrier to accessing enjoyable leisure activities. Future research could investigate affordable access to everyday technologies.

Limitations

A particular challenge for any qualitative review lies in navigating a triple hermeneutic (Suri, 2014), where the reviewer is interpreting the work of other researchers, who have interpreted the experiences of participants who have made sense of their own experiences. Because qualitative research does not aim to create objectivity or replicability, the researcher must aim to enhance trustworthiness to establish its rigor (Krefting, 1991). Some studies included in this review did not explicitly report evidence of reflexivity. Furthermore, some did not report steps taken to enhance the trustworthiness and one study did not specify how data analysis occurred. Because of this, it is difficult to interpret the findings of some of the studies included in this review as trustworthy (Lincoln & Guba, 1985), impacting on the trustworthiness of synthesis overall.

A further limitation is that leisure, enjoyment and pleasure are all subjectively defined within differing contexts. For example, what may be seen as enjoyable for one person may not be for another. Furthermore, the impact of culture will influence the way these constructs are also experienced (Diener & Suh, 2003). Whilst the first author attempted to operationalise the constructs by grounding definitions in theory (e.g. Seligman, 2012) and to constantly reflect on their own assumptions to mitigate the impact on the synthesis, it is important to consider that the researcher's own interpretations of these definitions would have influenced interpretation of results.

The review is limited by the heterogeneous samples included, which include differing diagnoses, intervention based versus naturalistic use of technology, and different settings in which technology was used. Factors such as previous experiences of using technology, gender, socio-cultural identity, current social support and age may all influence the degree to which individuals used and accessed technology. Demographic information in the studies was variable, making it difficult to interpret if any of the above factors influenced the experiences reviewed in any way, suggesting there needs to be better reporting of this information in studies. Nonetheless, this study has the strength of providing a preliminary overview of how ETs can be used to support wellbeing and enjoyment in dementia.

Conclusion

The findings of this review indicate that using everyday technology can be a helpful means to maintaining a sense of identity in dementia through engagement with meaningful and enjoyable activities in social contexts. The findings remind us that we should not assume that individuals with dementia cannot learn something new and are unable to use technology. We should ensure opportunities to use everyday technologies are there for those who wish it.

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Part Two: Empirical Paper

**Understanding the shared experiences of creating a digital life story with
individuals with dementia and their spouse**

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Please see Appendix A for the Guidelines for Authors.

Abstract

Introduction

Life story books in dementia are used as a part of person centred care. Whilst current literature demonstrates associations between completing life story books and increased wellbeing, little is known about the process and how it is experienced by individuals living with dementia. Life stories are often created with a loved one, such as a partner or spouse; however, research has yet to explore life story work as a shared endeavour. Furthermore, the use of technology to create life stories is growing, with little known about how digital elements are experienced. This study aimed to understand these gaps by exploring the shared experiences of individuals with dementia and their partner/spouse creating a digital life story book.

Design and Methods

Four couples participated in the six-week creation of their digital life story book. Following this, qualitative data relating to couples' experiences were collected via semi-structured interviews.

Findings

Thematic Analysis was used to interpret data and identified four superordinate themes relating to the shared experiences of creating their digital life story book: 'Creating a life story book is a huge undertaking', 'Looking back and looking forward: The emotional journey', 'Whose story is it and who does it belong to?' and 'Challenges of using technology to build the life story book'.

Conclusions

Overall, this study demonstrated that creating a digital life story was a positive experience that can support couples' wellbeing; but that we should not underestimate the time it will take and range of emotions experienced. The experience of using technology varied, emphasising that we must be mindful of individual preferences before considering a digital approach.

Key words: *dementia, life story, technology, wellbeing, couples*

Introduction

Reminiscence interventions in dementia focus on the process of thinking and telling others about one's past experiences (Cappeliez, O'Rourke & Chaudhury, 2005). For individuals with dementia, the connection between past and present life events can become fractured as cognitive impairment can challenge the ways in which a life story is structured and communicated (Kindell, Burrow, Wilkinson & Keady, 2014). Life story work is an autobiographical approach that allows people to reminisce and share their life experiences (McKeown, Clarke & Repper, 2006). The information may be recorded and displayed in a life story book complete with photographs, text and other relevant memorabilia (Pietrukowicz & Johnson, 1991). Life story work typically involves working alongside a person and also often their family and/or caregivers, to find out more about their past and use that information to inform their care (McKeown et al., 2006).

Autobiographical memory relates not only to the retrieval of past memories, but also to the concept of the self (Brewer, 1986) and has been viewed as fundamental for the experience of personhood (Conway & Pleydell-Pearce, 2000). The concept of personhood has been broadly defined as having agency, autonomy and identity (Higgs & Gilleard, 2015). Kitwood (1997) recognised that autobiographical knowledge is an essential part of identity and personhood meaning the cognitive impairments relating to autobiographical memory can therefore threaten personhood. Enabling people to sustain their personal narratives is a core part of maintaining personhood in dementia care.

Research demonstrates that life story work in dementia can be an enjoyable activity for those involved (Clarke, Hanson & Ross, 2003), can help carers improve understanding of an individual's life in the context of their past (Clarke et al., 2003; Murphy, 2000),

improves relationships between care staff, patients and their families (Hansebo & Kihlgren, 2000) and enables others able to see the person living with dementia as a person rather than solely the dementia (McKeown, Clarke, Ingleton, Ryan & Repper, 2010).

Current research suggests links between life story interventions and increased wellbeing in dementia (Haight, Gibson & Michel, 2006; Subramaniam, Woods & Whitaker, 2014; Subramaniam & Woods, 2016). However, to date, it has not been clear what specific experiences of creating a life story book might be linked to increases in wellbeing. Whilst measures of wellbeing are theoretically underpinned, they may not always capture individual experiences which are important for wellbeing (Clarke & Wolverson, 2016), emphasising that exploratory research of life story work may contribute to a more contextualised understanding of wellbeing in relation to life story interventions. Research by Gridley, Brooks, Birks, Baxter & Parker (2016) found in a care home setting for people with dementia that life story work appeared to be beneficial for identity as well as skills being reaffirmed; however, experiences of creating a life story book in the community and earlier in the dementia journey have yet to be explored.

As we are living in a digital world, recent attention has been paid to creating life stories using everyday technologies, such as laptops and tablet computers. It has been argued that digital technology, including music and sound recordings, offers the potential to trigger autobiographical memories in ways that differ from a traditional pen and paper static format (Subramaniam & Woods, 2016). Individuals living with dementia have also reflected that using a tablet may capture their life story more easily than on paper (Upton et al., 2011), and a recent review suggested that using everyday technology has the potential to facilitate reminiscence but that more research exploring the specific experiences of using technology for reminiscence and life story work is required

(Sweeney, 2019). In addition, commercial organisations now provide online platforms for digital life story creation. Whilst the evidence base relating to digital life story books in dementia is scarce, a recent exploratory study (O'Philbin, Woods & Holmes, 2018) found that individuals living with dementia expressed a desire to complete a digital life story book in a one-to-one setting, with a loved one, and with the aim of producing something that allowed them to share memories with others, reinforcing the importance of understanding the experiences of co-creating a life story book.

Indeed, most people will complete their life story book alongside another person usually a family member or paid carer. A study by Subramaniam et al., (2014) found that including a family member in the process of creating a life story book improved quality of life more when compared to those who had engaged in a life story intervention without a family member. As such considering couplehood is also essential to understand the individual in the context of their relationships, with an emphasis that care approaches should enrich both the experiences of those living with dementia and their partners (Hellström, Nolan & Lundh, 2005). Limited studies have explored the effects that life story work has on family members and care staff (McKeown et al., 2006; Subramaniam & Woods, 2012). Subramaniam & Woods (2012) report that the inclusion of family members in reminiscence groups with people living with dementia improved relationships between people with dementia and their family carers, illustrating the importance of life story creation as a shared process. Investigating shared perspectives of creating a life story book from individuals with dementia *and* their spouse or partner is important so not to ignore the social environment and relationships that an individual with dementia is part of (Woods, Keady & Seddon, 2008).

In summary, whilst previous research has suggested that creating a life story book can be associated with increases in wellbeing, further exploratory research is required to

understand and contextualise the psycho-social processes associated with wellbeing when co-creating a life story book with a loved one, in a dyadic context. This would help understand what specific aspects of life story work should be focused on and could help inform which approach is important for wellbeing. Further to this, recent growth in the use of digital life story books highlights the need to understand how digital life story books are experienced by people living with dementia and how they influence subjective wellbeing.

Based on these gaps in the literature, the current study aimed to explore and understand shared experiences of creating a digital life story book for individuals living with dementia in the community and their spouse/partner. The study aimed to answer the following questions:

1. *How do couples experience co-creating a digital life story book?*
2. *Does co-creating a digital life story book support couples' wellbeing, and if so, what experiences support couples' wellbeing?*

Method

Design

This study took a qualitative design, where data were collected from semi-structured interviews following participation in a 6-week intervention study requiring couples to create their digital life story book. Data were analysed using thematic analysis.

The study was guided by the principles of Constructivist Grounded Theory (Charmaz, 2006) in that it is assumed that there is no objective truth to discover (Guba & Lincoln, 1994), and that categories and themes are constructed by the researcher interacting with

the qualitative data, rather than emerging solely from the data (Charmaz, 2006). As a result, it is understood that the researchers' personal, philosophical and theoretical understandings will influence the research process, including data analysis (Willig, 2013). Therefore, researcher reflexivity is essential as it allows the researcher to consider their own influence on the research process through introspection and reflection (Finlay, 2002). Specifically, Charmaz (2017) suggested that it is important to develop methodological self-consciousness around the researcher's personal, philosophical and theoretical assumptions as this can help researcher reflexivity. As a result of this, the primary researcher kept a reflective journal throughout the research journey (see Appendix S & T for the researcher's reflective and epistemological statements) to reflect upon personal experiences and assumptions that influenced the appraisal of data, and the process as a whole.

The primary researcher (LS) held a constructivist approach, and assumed that each life story is constructed differently and as a result each understanding of what wellbeing means will be different to couples and also to the individuals within them. It was assumed that people are able to live well with dementia, and that individuals living with dementia are able to experience positive feelings, such as enjoyment. There was also an assumption that qualitative findings could help understand what processes and experiences of creating a digital life story in dementia influence a sense of wellbeing.

The primary researcher (LS) also reflected on their experiences of dementia and reminiscence, both at a personal and professional level, considering how they would influence the research. The researcher reflected on their own experiences of reminiscence, and had created their own life story book for themselves as part of a project unrelated to the current study, which influenced feelings of enjoyment. The researcher previously ran reminiscence groups within a care home for people living with

dementia, and thus held the assumption that reminiscence is a positive process for individuals living with dementia.

Sample

Participants were recruited from the NHS and community dementia support settings via posters, word of mouth through staff and other service users, and via the online Join Dementia Research (JDR) database from the North of England. The inclusion and exclusion criteria for the study are displayed in Table 6 and 7.

Five couples were recruited. An additional 5 couples initially showed interest in the life story book when approached through the JDR database, but did not consent to participate due to feeling too busy to engage fully with the intervention or feeling family stress was a barrier. A couple who declined an invitation to participate spoke about wishing to focus on pharmacological research in dementia (e.g. drug trials), and did not want to participate in psycho-social research.

Table 6. Inclusion criteria and rationale

Inclusion Criteria	Rationale
A self-reported diagnosis of dementia or a self-reported diagnosis of mild cognitive impairment (MCI). No participants recruited had a self-reported diagnosis of MCI.	It is important that the individuals were early in their dementia journey so they could participate in the making of their book as much as possible (McKinney, 2017). MCI can be a precursor some diagnoses of dementia, such as Alzheimer's Disease (Klekociuk, Saunders & Summers, 2016), and therefore those who are living with MCI may be early in their dementia journey. This is the rationale for including people with MCI.
Both participants live in the community together.	As life story work is less researched in a community setting and two thirds of individuals with dementia live at home (Social Care Institute for Excellence, 2013). Furthermore, couplehood can be affected by moving into residential care (Graneheim, Johansson & Lindgren, 2014).
Have a spouse or partner who was involved in their care. There were no limits or requirements for number of hours caring. The spouse did not have to identify as a	Some spouses/partners will not necessarily identify as a caregiver in the context of dementia (Hayes, Boylstein & Zimmerman,

carer or primary carer.	2009).
Self-report being comfortable in using technology, such as a laptop or tablet, to be able to use Book of You which is the digital life story website.	As the research was exploring experiences of digital life stories, it was important that participants reported they felt comfortable in using technology.
Internet access.	In order to access the online life story book resource.
Both the individual with MCI or dementia and their spouse/partner have capacity.	In order to give informed written consent to participate. Guidance on assessing capacity (British Psychological Society, 2008) was consulted when assessing capacity to consent to research.
Both individuals in the couple are aged 60 and above (to include people with early onset dementia who are older adults).	An age limit has been set as it is possible that the experience of completing life stories for younger couples with dementia may differ from older couples, as research has suggested the experience of dementia may differ in younger adults (Clemerson, Walsh & Isaac, 2014)

Table 7. Exclusion criteria and rationale

Exclusion Criteria	Rationale
Lack of fluency in English	To ensure participants are able to express their views and experiences in the interview process
Not wanting to participate/not being able to give consent. If one member of the couple does not consent, it will not be possible for both members to take part.	As the study is interested in exploring couples' experiences, both individuals will be required to give written informed consent to participate.
Both individuals in the couple having uncorrected impairments in vision and/or hearing or motor skills that may impair engagement with the website. If one person has an impairment and the other individual does not, it is possible to be still included in the study.	To ensure that individuals were able to engage with the website features.
The possibility of life story work bringing up upsetting memories was explained in the information sheet given to participants and communicated that this research may not be suitable for them.	To ensure individuals are able to give informed consent and consider the possible consequences of creating a life story book.

Five couples ($n=10$) were initially recruited to the study. Demographic information regarding the participants is outlined in Table 8. The ages ranged from 74-91 years

(mean=83 years). All couples were married, ranging from 24 – 66 years (mean=54 years).

Of the couples recruited, two couples requested additional support with technology to put their story together. The level of support was matched to the couples' requests and was coordinated by the primary researcher (LS). For example, one couple wanted a reminder of how to add a page and help adding their photos to their computer but then preferred to put their story together without further assistance, and one couple wanted the researcher to actively create their digital life story together with them. One couple felt comfortable in using the technology without help. The other two couples explained that their children would offer support with technology.

Three couples had access to technology (a laptop and a tablet) and two couples used tablets provided by the research team as they did not have access to these in their home and preferred to use a tablet over their desktop computer.

Table 8. Demographics of recruited participants

Pseudonym of person living with dementia (PLwD) and their spouse	Diagnosis (<i>if known</i>)	Time since diagnosis (<i>if known</i>)	Frequency of using technology	Main reasons for using technology generally	Experiences of reminiscence, life story or family tree activities previous to the study
Jimmy (Male, PLwD)	Alzheimer's Disease	>5 years	Weekly	Taking photos and videos, staying in contact with friends	None
Doreen (Female, Spouse)					
Bernard (Male, Spouse)	Alzheimer's Disease	<5 years	Daily	Staying in contact with friends, browsing the internet	None
Anne (Female, PLwD)					
Robert (Male, Spouse)	Dementia (unknown type)	<5 years	Monthly	Staying in contact with friends	None
Sandra (Female, PLwD)					
Bill (Male, PLwD)	Dementia (unknown type)	<5 years	Daily	Browsing on the internet (e.g. online shopping)	None
Poppy (Female, Spouse)					
Jeffrey (Male, PLwD)	Dementia with Lewy bodies	<5 years	Weekly	Browsing on the internet, staying in contact with friends	None
Catherine (Female, Spouse)					

Procedure

Ethical Approval

The study was reviewed and approved (see Appendix N) by the Yorkshire & Humber Leeds East Research Ethics Committee (REC reference: 18/YH/0141)

Materials

The digital life stories were completed using *Book of You*, a community interest company who provide a resource for creating a digital life story for individuals living with dementia (www.bookofyou.co.uk). The book can be accessed online via a laptop, tablet or smartphone. All the books are private and password protected. Individuals have the opportunity to put words, pictures, film and music in their book. There is no limit to the amount of content individuals are able to create. Users are also given a user guide, including a telephone support number to get into contact with Book of You directly. For the purpose of the research there was free access for research participants indefinitely.

Six-week study

Potential participants who received information about the study through NHS and community organisations contacted the primary researcher by email or telephone to discuss the research or if recruited through the JDR database the primary researcher contacted participants by email or telephone. If interested, the primary researcher met each couple at either a community centre or the participants' home to explain the research, assess capacity to consent and gain written informed consent. Once participants had consented to participate in the research, the primary researcher met them either at their home or a community venue to provide them with their login to the

digital story book tool (*Book of You*). At this meeting, the primary researcher showed them how to use the tool and answered any questions. Participants were asked to work on their digital life story book at least once a week together for six weeks. Six weeks was chosen as it has been used in previous life story work research (Subramaniam et al., 2014) and reflected the timescale in which *Book of You* typically work in the community. The couples were offered the opportunity to have the primary researcher help them put their book together over the six-week study. Whilst the study itself was six weeks, the individuals could keep their login to their digital life story book indefinitely, and could add to their story after the study had finished.

Interview

After six weeks, a semi-structured interview between the primary researcher and the couple took place exploring their experiences of creating their digital life story book together (see Appendix M for the interview schedule). Topics included what their life story means to them, what aspects they enjoyed/did not enjoy about creating the life story and their experiences of using technology. The semi-structured interviews were conducted in either the participants' home or a community centre, and lasted from 38 to 58 minutes.

Analysis

A fundamental aspect of developing a theory using Constructivist Grounded Theory is data saturation (Charmaz, 2006). The recruitment of five couples meant that the breadth of available data could not be adequately assessed to have reached saturation. Therefore, a thematic analysis was used to analyse data derived from semi-structured interviews to answer the research questions, and this led to the identification of superordinate and subordinate themes (Braun & Clarke, 2006). The process was guided by Constructivist

Grounded Theory (Charmaz, 2006), as a constant comparative method guided analysis. An inductive method was chosen, meaning themes emerged from interactions with the data rather than pre-existing codes derived from other theoretical constructs (Patton, 1990). The researcher transcribed and completed initial coding for each interview before completing the next interview to allow for constant comparison. This also allowed the primary researcher to adapt interview questions based on the initial coding of transcripts. Data analysis was an iterative process in which the researcher went back and forth to revisit codes, constantly comparing them to the overarching themes and refining them on this basis. The process of conducting a thematic analysis is depicted in Table 9.

Table 9. The process of conducting a thematic analysis (Braun & Clarke, 2006, p87)

Phase	Process
1. Familiarisation with the data	The data will need to be transcribed in order to conduct a thematic analysis. The audio recordings of the interview were transcribed immediately after the interview had taken place to allow for constant comparison.
2. Generating initial codes	This phase includes assigning initial codes to the data representing the most basic element of the raw data (see Appendix O). As in this study an inductive approach was taken, coding emerged from interactions with the data rather than being theory driven. As TA was informed by Constructivist Grounded Theory, analysis ran in parallel to data collection.
3. Searching for themes	This phase begins when initial codes have been identified and involves sorting the codes into potential themes and collating the relevant participant quotes within the identified themes. At this stage, relationships between codes and themes and different levels of themes (e.g. subthemes) are considered (see Appendix P) as well as using the emerging themes to guide interview schedules in future interviews. In this study, this was an iterative process in which the researcher revisited codes and compared them to the emerging themes.
4. Reviewing themes	This stage involves the refinement of initial themes. There are two processes to this stage, with the first being reviewing at the level of coded data extracts (e.g. "Do the data extracts for each theme form a coherent pattern?") and the second in relation to the entire data set (e.g. "Does the thematic map (see Appendix Q) reflect the meanings evident in the data set as a whole?")

5. Defining and naming themes

This process aims to capture the essence of what each theme is about, and determines what theme captures.

Results

Four couples ($n=8$) worked on their life story book for six weeks and participated in the subsequent interview. Jeffrey and Catherine withdrew from the study during the study after week 3 due to ill health. Therefore, no data were available from this couple in the final analysis.

Thematic analysis revealed four overarching themes in the data: '*Creating a life story book is a huge undertaking*', '*Looking back and looking forward: The emotional journey*', '*Whose story is it and who does it belong to?*' and '*Challenges of using technology to build the life story book*'. Table 10 displays the superordinate and subordinate themes.

Table 10. Summary of superordinate and subordinate themes emerging from thematic analysis

Superordinate theme	Subordinate theme
Creating a life story book is a huge undertaking	<i>Reminiscence is a part of everyday conversation versus finding the time for their life story book</i>
	<i>Life story books structure reminiscence</i>
Looking back and looking forward: the emotional journey	<i>Memories of the past affecting the present</i>
	<i>Emotions relating to the process of putting the story together</i>

Whose story is it and who does it belong to?

Our story together

Telling our story: others hearing and responding

Challenges of using technology to build the life story book

Challenge of technology viewed as positively and negatively

Engagement with digital media

Superordinate theme 1: Creating a life story together is a huge undertaking

Whilst it was seen as valuable, what was involved in the creation of a digital life story book was initially underestimated by participants, especially when participants compared it to reminiscence in conversations. As a result, participants found it hard to find time to create their life story book when leading an active life.

Reminiscence is a part of everyday conversation versus finding the time for their life story book

Couples explained that reminiscence is a natural part of their conversations together;

Bernard: "You might not be aware but you are doing it [reminiscing] all the time... Both Anne and I talk about our life over the years quite a lot...I remember bits about Anne and she remembers bits about me...Our conversations often start with "Do you remember this?"" -

spouse

Indeed, during the interviews couples demonstrated the ease with which they naturally reminisce and share memories together;

Poppy: "We've also been to [place] ...that was a highlight"- spouse

Bill: "I remember the big plateau...I can remember that...I remember we went in a bus" -

PLwD

When comparing conversations to the creation of the book, participants reflected on how it required a lot of time and planning, such as reviewing and selecting photographs and time to reflect on memories;

Jimmy: "It might have been thinking about it for a few days then going forward with it..." -

PLwD

Another couple spoke about how slowing down to reminisce took a lot of energy and time when leading a busy life and found reminiscence in conversations easier to engage in;

Interviewer: "Is that something you both found? Just the time and energy it took?"

Anne: "Yes it took a lot" - PLwD

Bernard: "Yes, I think that it was more time consuming. I mean just speaking to you now we've covered a lot of ground.....we can't do six weeks solidly...we've got other things" - spouse

The impact of dementia also influenced how long it took to build the book, and participants explained that the process cannot be rushed;

Anne: "Yes that's it...we didn't want to [rush]" - PLwD

Bernard: "I think also this is the Alzheimer's quite frankly...and the concentration...it does tire her..." - spouse

The life story intervention was described as being different to other interventions in dementia care that promote engagement in activities;

Bernard: "Anything she can do she is doing. I notice when she's doing something suddenly she's not she would like to do something else" - spouse

Therefore, when participants had active lives it was difficult to find the time to create their book. Poppy and Bill spoke about how they tried to create their book on a quiet day and found it enjoyable to stop and reminisce, but were unable to focus on it recently as they were busier than usual;

Poppy: "It was nice sitting...but unfortunately the last two Sundays we've been quite busy" - spouse

Doreen and Jimmy also explained that stopping to reminisce was a positive contrast to their busy lives;

Doreen: "We're always trying to keep busy...but for me it was really nice to do this... it was really nice for us to just sit back and reminisce" - spouse

Life story books structure reminiscence

Although effortful it appeared that creating a life story formalised reminiscence conversations by creating a structure. One couple explained that talking about memories and sharing them can be more important than writing them down as it can be easier and thus more enjoyable;

Bernard: "You do it unconsciously...you don't sit down together...it just happens... we could relate it...like the first time we met you...we'd talk about that and bring it up but when you've got to put it all down into there..." - spouse

Anne: "You don't realise no!" - PLwD

However, whilst the process required more effort than expected, creating a life story was seen as a valuable way to formalise reminiscence. Participants spoke how it brought a structure back to memories as well as the memories themselves becoming more vivid;

Jimmy: “and it’s brought time slots back into detail...there’s something there [laughs]” -

PLwD

Some couples valued having someone to help them to structure events, such as their spouse, researcher or family member;

Bernard: “It’s more successful to put your life structure together with someone else there...somebody like [our daughter] to help put things down” - spouse

Superordinate theme 2: Looking back and looking forward: The emotional journey

Participants described a range of emotions when reliving past memories. When couples reflected on their strength overcoming difficulties together; they felt grateful for life in the past and in the present. Couples reflected on the positive emotions they felt when working together to create their life story and how this motivated them to think about what they wanted to achieve in the future.

Memories of the past affecting the present

When memories were relived in the present moment, enjoyment and gratitude of a shared life together was often experienced;

Poppy: “It’s all been very pleasant...We’ve had a good life and lived a happy life...I wouldn’t have altered any of it...It’s been nice to look back on it” – spouse

Sandra: “It takes you back and how you enjoyed it” - PLwD

Participants explained their books had automatically focused on life achievements and spoke with amazement and surprise at all they have achieved, resulting in feelings of pride and accomplishment as well as feeling humbled;

Bernard: "Well we thought wow we've achieved a lot...especially from the background we came from...it's made us feel extremely humble" – spouse

Anne explained that she felt more confident about what she had achieved in her job, suggesting that thinking about achievements has potential to increase self-esteem in the present;

Interviewer: "So [your daughter] mentioned earlier that she noticed you look more confident when you were speaking about your memories"

Anne: "Yes...yes...it did thinking about my jobs" - PLwD

Overcoming difficulties and adversity was also an important focus of reminiscence with couples reflecting on a range of difficulties faced, such as poverty. When difficulties and challenges were spoken about in a narrative of overcoming together it emphasised shared strength and resilience;

Poppy: "We were lucky that we came through it all..." – spouse

Couples reported laughing together when creating their life story books and humour was also present throughout the interview process;

Doreen: "It was a laugh! Do you remember that?" - spouse

Jimmy "[laughing] Oh I recall that! [laughing]" - PLwD

However, some participants explained they felt sadness associated with losses in their life, highlighting how important it is to not underestimate the complexity of emotions during life story work. In the interview, their spouse helped to tell the story, suggesting the importance of supporting each other through the shared difficulties in life and in the retelling of those memories;

Robert: "A bit sad that it's all gone... I said I've done it for so many years...it's time for somebody younger to..." - spouse

Sandra: "To take over yes..." - PLwD

Another couple explained that difficult memories are an important part of who they are and they should not be forgotten when writing a life story book. When talking about a traumatic memory in her early years, Anne explained that "it was a big part" of her identity and that it was important to include in the story.

Emotions relating to the process of putting the story together

Participants explained during the interviews that they felt a sense of enjoyment and achievement relating not only to reliving past memories, but to the process of creating the book together;

Jimmy: "We have mission successfully accomplished" - PLwD

One couple spoke about how it highlighted to them both what the person with dementia could still do and challenged assumptions;

Doreen: "The thing is you're still quite capable...what it has done has highlighted to me the fact that he still has loads of memory left" - spouse

A general sense of enjoyment was derived from putting the story into a book, with couples reflecting on the value of making their story together;

Sandra: "It feels good yes...we've enjoyed it haven't we?" - PLwD

Whilst focusing on the past and the present was discussed as a key focus of the content of the book, it appeared that the life story was seen as important and encouraged

participants to consider the future and what couples would still like to achieve and accomplish;

Bernard: “Norway and that coast along there...Sweden and Norway. We’ve never been there”

– spouse

Jimmy: “I want to encourage others to write the story...developing from your project!” - PLwD

Superordinate theme 3: Whose story is it and who does it belong to?

The experience of creating a digital life story brought up questions about inclusion and ownership. Participants reflected that the story was theirs to tell as a couple but that it belonged to many people including their family and the wider community. Others hearing and responding to the story was as important as telling the story.

Our story together

Completing the process as a couple emphasised a sense of unity and identity for participants. Participants explained that it is a shared story belonging to both of them and that it would be difficult to write their stories separately;

Poppy: “Yes [it would be different] ...our lives have been together anyway...” - spouse

Jimmy explained their identity as a couple was a focus of their story;

Jimmy: “The introduction to my story is ‘Doreen the bedrock of my life’” - PLwD

The different roles within a couple were mirrored in the life story process, with each having a role in putting the story together, with one person leading on the digital aspects and the other bringing the memories together. They reflected that working together as a team was one of the enjoyable aspects of creating their life story;

Jimmy: "It's been a team job." - PLwD

Doreen: "That's been the good thing about it!" - spouse

Similarly, Poppy explained that often she would encourage Bill to talk about past events to cue his recall;

Bill: "Yeah...and I've got a terrible memory anyway [laughs]" - PLwD

Poppy: "I jeer him on with it...triggers memories to it" - spouse

The togetherness and shared identity was further evident throughout the interviews in the use of inclusive language, "we" and "us", in the interviews.

Telling our story: Others hearing and responding

The importance of stories being heard by others was important. Whilst stories needed to be written down they also needed to be shared with other people. Reactions from family members, when sharing stories, made couples view their story differently, suggesting how others hear the story can influence a re-appraisal of life events for the couple;

Poppy: "Oh yes because they're learning as well! They say oh we didn't know this and that and ask did you really do that? You forget too...we think oh yes of course that happened..." - spouse

A sense of legacy within the family was seen as an important consequence of creating their story;

Jimmy: "I am mindful of the fact...in the process...I've been writing this up for...we have one daughter Natalie...it's information for Natalie to read...and to receive" - PLwD

One couple spoke about the importance of sharing stories with care staff and others in community as a way to informing person-centred care;

Jimmy: “We might be able to use this in our dementia community to give staff an idea or concept so anyone can engage in it and would have information available for their care” -

PLwD

The same couple noticed positive change in their wellbeing and attributed this to feeling understood by others in the community when they read their book;

Jimmy: “We always looked at it [the life story] from a community perspective...as an example of how to encourage wellbeing” - PLwD

Being truly listened to is significant, with one couple expressing upset that their family members did not share their interest and enthusiasm for their life story, proposing that the life story process does not end when the book is completed;

Robert: “I think it should be important to them [family] ...the life we led...they don’t seem too bothered about the life we had” - spouse

The importance of feeling heard by others was evident during the interview as couples’ shared their stories. Responses from the interviewer encouraged further reminiscence and enjoyment;

Doreen: “...That was in one of the [place]”

Jimmy: “Yep”

Interviewer: “That sounds like such an adventurous holiday!”

Doreen: “[laughing] it was!” – spouse & PLwD

Superordinate theme 4: Challenges of using technology to build the life story book

All participants spoke about the consequences of using technology to build their life story. Participants reflected on the challenges faced when using technology but these

challenges were viewed differently across couples. Participants spoke about their reasons for using or not using digital aspects in the book, such as music and video, the overall importance of using family photographs and using the internet when photos were not available.

Challenge of using technology viewed as positively and negatively

Some participants viewed the idea of creating the book digitally as a positive challenge and were motivated to learn something new alongside making their story. Persisting with the technology when faced with difficulties led to a sense of achievement and accomplishment;

Jimmy: "It was a challenge...but I did pick it up and stuck at it" - PLwD

Jimmy and Doreen reflected on the benefits that technology provided, such as allowing the flexibility to build upon the story in the future and in connecting with distant family;

Doreen: "His younger sister lives away so we can share it with her" - spouse

It appeared the difficulties encountered in the usability of the technology affected the experience of creating the story, with one couple explaining that they enjoyed it until the technology stopped working and another explaining the process was dominated by frustration when technology failed;

Robert: "I enjoyed the writing when it's going smooth" – spouse

Bernard: "You can get very frustrated when it doesn't work" - spouse

Another couple explained that they attempted to use the technology but felt it was too difficult, so were supported by family members;

Poppy: "Well our daughter did most...I left that to her...when you get into your 80s and if you have a good family you let them take charge...and they're better with the technology than we are...To be honest we weren't really capable" - spouse

Bill: "Definitely not now" - PLwD

One spouse explained he felt the technology was "beyond [him]." As a result, some participants reflected that a traditional pen and paper life story may be easier to access when feeling less confident with technology;

Interviewer: "Do you think it would have been easier to do it on paper?"

Sandra: "Paper...yes...."

Interviewer: "Do you think you would have preferred it?"

Sandra: "Yeah..." - PLwD

Engagement with digital media

Participants wanted to use more digital media in the book, such as videos and music but uncertainty in how to access this stopped them from including it;

Jimmy: "I would like to include more music...it's something to work on I think" - PLwD

In contrast, one couple explained that they wouldn't have used music as they were not interested in it, indicating that digital aspects of life story need to be thought about in the context of the individual and couples' preferences;

Robert: "We weren't into that" - spouse

Photographs appeared to be a fundamental aspect of the story with all participants discussing how the photographs helped cue storytelling and that creating a life story book with the images was more enjoyable than just looking at a photograph;

Jimmy: “You can look an image and say fine but to actually produce something is brilliant” -

PLwD

Some couples described upset at the lack of photos and discussed how the digital aspect of the life story meant they were able to find lost images to put in their story;

Robert: “We’ve lost them! We had hundreds...We think they’re important. We saw photos we never knew existed” - spouse

Whilst having access to a website was viewed as useful, as it provided the tools to create a life a story, all participants reported they would still like to have a printed copy, indicating that a digital copy would not replace a hard copy.

Robert: “We’ll print it off” – spouse

Discussion

Summary of findings and implications for clinical practice

The current study emphasises how we must not underestimate the experience of creating a life story in terms of time and emotional energy required. Literature often conceptualises life story work as a time-limited and activity-focused intervention or tool (Subramaniam et al., 2014; McKeown et al., 2010; Thompson, 2011; Moos & Björn, 2006), Indeed, we viewed completion of the digital life story tool *Book of You* as a time- and activity-focused intervention in the initial stages of the research. However, this assumption was challenged when couples explained it was the experience of stopping, slowing down and having protected space to share and relive their story that was most enjoyable in the process of undertaking the life story. Life story work, although intensive, was seen as a different activity to other interventions couples had engaged in;

the opportunity to slow down and stop seemed particularly valued in the context of participants' active and busy lives. The clinical implication of this is that living well with dementia needs a goodness-of-fit between keeping active, which is frequently encouraged (Alzheimer's Society, 2016), and opportunities to slow down to engage in reminiscence and life story work, whilst acknowledging additional support may be needed because of the time and effort this requires.

The importance of a shared identity was demonstrated in this study, especially in how enjoyment, happiness and pride were derived by involving spouses in the process of building their life story book. Whilst previous research has focused on an *individual's* achievements, (McKeown et al., 2010; Gridley et al., 2016), this study suggests that enjoyment was specifically associated with achievement relating to building the book *together*, paralleling shared achievements in life as a couple, which was also focus of the content of the books. Doing things together as a couple is an important aspect of maintaining couple identity and wellbeing in dementia (Hellström et al., 2005).

Experiencing enjoyment and happiness has been described in 'broaden and build theory' as important for driving personal growth and flourishing, resulting in psychological resources, such as optimism and resilience, and social resources such as strengthening of existing bonds (Fredrickson, 2001). Overall the experiences of co-creating a life story book as a couple highlight the importance of 'doing with' rather than 'doing to' as an important hallmark of person-centred care (Kitwood, 1997) but also that experiencing enjoyment and happiness when engaging in life story work as a couple may possibly facilitate not only personal growth and flourishing, but a shared, collective growth and flourishing.

Another important consideration is how the story is shared with others as in this study the experience of wellbeing was attributed to with how others responded to the story,

including family members, the community and the interviewer. The importance of sharing the story has been viewed as a fundamental aspect of reminiscence generally (Cappeliez et al., 2005). Active listening (Rogers & Farson, 1987) includes listening for meaning and responding to feelings, and has been associated with positive change such as empowerment and shared understanding (Street, Makoul, Arora & Epstein, 2008). Families and care staff must actively listen to the story to increase wellbeing rather than just simply pay attention (Robertson, 2005) to the story as reactions from others alter how wellbeing is experienced. Clinically, this suggests that life story work does not finish when a book is 'complete', and that we need to ensure others, including care staff, keep the story alive by active listening. For example, sharing how listeners felt when hearing the story to validate feelings and facilitate shared understanding.

Previous research has suggested that describing upsetting memories is one of the biggest challenges of life story work (McKeown et al., 2015). Kaiser and Eley (2017) discuss the challenge of upsetting memories in life story work and suggest that acknowledging upset in life story work is crucial, linking back to the importance and role of active listening. Our findings highlight that an exploration of difficulties was a shared experience for couples and linked to their sense of identity as a couple, meaning it should not be shied away from or seen as a barrier to engaging someone in life story work. At the same time, it is important to consider the role of clinical supervision from a mental health professional to help those who are facilitating life story work feel comfortable and skilled in approaching the challenges that this work may bring.

This study highlighted that when difficult emotions were experienced and spoken about in a narrative of overcoming and resilience, positive emotions such as gratitude, which has been seen as a fundamental aspect of wellbeing (Emmons & Mishra, 2011), also ensued. Gratitude appeared to be a key part of how couples experienced wellbeing and

future research should therefore investigate the role of gratitude as a framework for life story approaches in dementia.

The above findings that relate to couples' wellbeing are similar to Seligman's (2012) model of approaches that cultivate a sense of wellbeing. These include a particular focus on sharing our wellbeing with others, engaging in an activity we truly enjoy, achievement in life but also in the here and now and positive emotions, such as happiness, pride, and gratitude. These factors were seen as important experiences of life story work that led to an overall sense of couples' wellbeing.

This study also expands on the survey conducted by O'Philbin et al., (2018) around preferences of using digital life story and offered insight to how digital life story books are experienced. The current study highlights that the use of technology needs to be approached with the individuals' preferences and needs in mind. Scaffolding and working within the person's 'Zone of Proximal Development' (Vygotsky, 1978) to create a life story book may ensure that individuals learn how to use the technology at the right level, meaning frustrations around the process are avoided. A recent review by Sweeney (2019) concluded that scaffolding was an important aspect of using everyday technology for effective engagement and enjoyment for individuals living with dementia. Overall, experiences of using technology varied, highlighting that when digital approaches are used they need to be considered on an individual basis and with the right amount of support and scaffolded learning.

Strengths and Limitations

Despite the richness in data gathered, a clear limitation of the study was the small sample size, meaning there was a lack of breadth of data. Thus, data saturation was

unable to be reached. However, thematic analysis has its merits as a flexible and accessible approach that can usefully summarise rich data as well as generating unanticipated insights (Braun & Clarke, 2006), meaning the study was able to provide new insights to what experiences are important for couple wellbeing in digital life story work despite data saturation not being achieved.

The social graces framework (Burnham, 2012) would suggest this study lacks diversity in areas such as sexuality, ethnicity, race and geography. All participants identified as White British and were from a small regional area in the North of England, meaning the experiences of couples from other ethnicities and locations were not represented.

However, the aim of this research was to explore experience rather than aiming to generalise findings across populations. Furthermore, all couples were in heterosexual relationships. Research has shown that the experience of dementia is different in same-sex couples (McParland & Camic, 2018); understanding the shared experiences of creating a life story in same sex-couples is an important avenue to consider for research in the future.

There was also a cross-over in roles as researcher and facilitator; the primary researcher helped two couples with the digital aspects of their book which could affect the way data analysis was approached, and thus the methodological quality. However, the primary researcher continued to reflect on their assumptions using a reflective diary to ensure methodological self-consciousness and reflexivity. Literature has highlighted that occupying the space of an ‘insider’ can help participants feel comfortable in the research process (Dwyer & Buckle, 2009), meaning that a cross-over in role can act as a potential strength and limitation of the study.

Conclusions

Overall, the present study highlights that that we should not underestimate the time and range of emotions experienced by couples when creating a digital life story book. It appears that the experience was positive not only for individuals living with dementia but also their spouses, emphasising the importance of couplehood in creating a life story. Experiences of using technology to create their story was variable, highlighting that an individual's preferences and comfort in using technology need to be considered before undertaking a digital life story book.

Author Contribution

LS designed the study, carried out the data collection and analysis and wrote the paper. EW and CC supervised the data collection and analysis and assisted in preparing the paper.

Declaration of conflicting interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Part Three: Appendices

Appendix A: Guidelines for authors for submission to *Dementia*

This Journal is a member of the Committee on Publication Ethics.

Please read the guidelines below then visit the Journal's submission site <http://mc.manuscriptcentral.com/dementia> to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of *Dementia* will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to *Dementia*, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 2,500-3,000 words. Innovative practice papers should include the words 'Innovative Practice' after the title of their article when submitting to the journal. For further information about innovative practice papers, please refer to the guidelines.

The journal also publishes book reviews.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: [How to Help Readers Find Your Article Online](#).

2. Editorial policies

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dementia in their article and avoid using pejorative terms such as ‘demented’ or ‘suffering from dementia’. We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information. Alternatively, Alzheimer’s Australia sets out guidelines for dementia-friendly language. Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

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Books for review should be sent to: Book Review Editor, Dementia, Caroline Swarbrick
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7. Further information

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dem.pra@sagepub.com

Appendix B: Contact with leading researchers

Dear Laura,

Gail mentioned in her reply to you that she had forwarded your email to me. I think the topic of your review is very interesting and the inclusion/exclusion criteria are appropriate. I wonder what your search terms were as there are quite a few recent and relevant papers that are not included in your list. I have listed some of them below for you. I like your research question but wonder if it needs narrowing slightly? I think the views and perspectives of technology from people living with dementia and those in supporting roles (could be friends, neighbours, informal/formal carers, spouse or other family members) is sufficient rather than describing multiple perspectives which sounds like you will be including GP's, memory services or stakeholders maybe. Of course, the subjective nature of the topic will mean that social engagement, inclusion, pleasure and leisure means different things to different people. For example an ADL like grocery shopping could be a task for some but an enjoyable activity for others. Researchers and authors will also have their view on this and will adapt their methodologies accordingly. It may be that you will need to cast your net a little more widely to capture the recent literature and to take into account different interpretations of what is leisure and pleasure etc. This is a very fast moving area as you will know and there is definitely literature on robotics and dementia that isn't in your list.

Good luck

Smith, S.K., Mountain, G.A. & Hawkins, R.J. (2018). Qualitatively exploring the suitability of contemporary technology in encouraging the social participation of people living with the moderate stages of dementia. *Dementia* doi.org/10.1177/1471301218802897

Smith, S. K. & Astell, A. (2017). Independent Living Functions for the Elderly (IN-LIFE), Supporting Communication in Dementia in 'Harnessing the Power of Technology to Improve Lives, Studies in Health Technology and Informatics', Volume 242 pp. 16-22 DOI 10.3233/978-1-61499-798-6-16

Gibson G, Dickinson C, Brittain K & Robinson L (2018) Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them (Forthcoming/Available Online). Ageing and society. <https://doi.org/10.1017/S0144686X18000661>.

Killin L, Russ TC, Surdhar S, Yoon Y, McKinsty B, Gibson G & MacIntyre D (2018) BMJ Open, 8 (4), Art. No.: e020281. <https://doi.org/10.1136/bmjopen-2017-020281>.

[Cognitive stimulation therapy in dementia care: exploring the views and experiences of service providers on the barriers and facilitators to implementation in practice using Normalization Process Theory](#) Dickinson C,

Gibson G, Gots Z, Stobbart L & Robinson L (2017) International Psychogeriatrics, 29 (11), pp. 1869-1878.

Smith, S.K. and Mountain, G.A. (2012) New forms of information and communication technology (ICT) and the potential to facilitate social and leisure activity for people living with dementia. *International Journal of Computers in Healthcare*, Vol. 1, No. 4, pp.332-345. file:///X:/icoss_smith1/User/fs1sks/Publications/IJCIH010404%20SMITH.pdf

Technologies to Support Community-Dwelling Persons With Dementia: A Position Paper on Issues Regarding Development, Usability, Effectiveness and Cost-Effectiveness, Deployment, and Ethics [Franka Meiland](#), PhD, corresponding author, [1 Anthea Innes](#), PhD, [2 Gail a-Casal](#), DClinPs, [6 Dianne Gole](#), PhD, [7 Jochen René Thyrian](#), PhD, [8 Shirley Evans](#), PhD, [9 Rose-Marie Dröes](#), PhD, [1 Fiona Kelly](#), PhD, [10 Alexander Kurz](#), MD, PhD, [11 Dymona Casey](#), PhD, [15,16 Marijke Span](#), PhD, [17 Heike Felzmann](#), PhD, [18 Jaada Tsolaki](#), MD, PhD, [19 and Manuel Franco-Martin](#), MD, PhD20

This paper was part of the thesis ([Smith, 2015](#)) identified and included in the review. This paper and the thesis were identical in content; however the doctoral thesis was included as it had richer qualitative data.

These papers focused on assistive technology **only**

Not relevant to research question (e.g. focusing on CST or post-diagnosis support)

Does not include the experiences or views of using everyday technology

Review article

Appendix C: Narrative of how search terms were generated

Search terms on databases: <i>PsycINFO</i> , <i>CINAHL</i> <i>and MEDLINE</i>	Primary researchers' commentary
Experience* or perception* or attitude* or view* or feeling* or reaction* or subjective*	These were the initial terms used to generate a first understanding of the research area, particularly technology as a broad area (including assistive technology). This preliminary search helped to understand what keywords were important for the scope of this review.
AND	
dementia or Alzheimer* or memory loss or cognitive impairment	
AND	Consultation with the University of Hull's library team suggested to ensure there is reference to 'wellbeing' or 'quality of life' in the search strategy.
"assistive technolog*" or technolog* or digital or electronic or device* or computer or tablet or mobile phone or smartphone or internet or social media	
AND	
qualitative or interview* or "focus group*" or "case stud*" or "grounded theory" or narrative or thematic or phenomenolog* or discourse*	
AND	
wellbeing or quality of life or meaningful activity or pleasure	

Experience* or perception* or attitude* or view* or feeling* or reaction* or subjective* AND dementia or Alzheimer* or memory loss or cognitive impairment AND “assistive technolog*” or technolog* or digital* or electronic* or device* or computer* or tablet* or “mobile phone*” or smartphone* or internet or <u>iPAD*</u> AND qualitative or interview* or “focus group*” or “case stud*” or “grounded theory” or narrative or thematic or phenomenolog* or discourse* AND “quality of life” or “wellbeing” or “well being” or “well-being” or wellness	<p>It was found that terms relating to experience were not keywords in papers, even if the paper did explore experiences. As a result, this was taken out to broaden the search.</p> <p>After looking at other papers, it was found that using commercial names for technology, such as iPad, were used as keywords in studies, therefore this was added into the search. Other commercial names, such as Android, were not used. As the focus of the study was looking at ‘everyday technology’ as opposed to ‘assistive technology’, ‘assistive’ was taken out of the search terms. Including ‘everyday’ in the search term was considered, but it was decided to keep the term ‘technology’ as some studies may not necessarily use the term ‘everyday technology’. This was decided to capture the breadth of everyday technologies that may exist.</p>
dementia or Alzheimer* or “memory loss” or “cognitive impairment” AND	<p>After using these search terms, it was discovered that “wellbeing” and “quality of life” were too broad, and many studies that were relevant were missed if they did not include these in their keywords.</p>

<p>technolog* or digital* or electronic* or device* or computer* or tablet* or “mobile phone*” or smartphone* or internet or <u>iPAD*</u></p> <p>AND</p> <p>“quality of life” or “wellbeing” or “well being” or “well-being” or wellness</p>	<p>At this point, other reviews were consulted to understand how to frame the search terms more specifically to incorporate the key aspects of wellbeing explored in the research question (e.g. Pinto-Bruno et al. 2016)</p>
<p>dementia or Alzheimer* or “memory loss” or “cognitive impairment”</p> <p>AND</p> <p>technolog* or digital* or electronic* or device* or computer* or tablet* or “mobile phone*” or smartphone* or internet or iPAD*</p> <p>AND</p> <p>Social or engagement or involvement or participation or leisure or pleasure or enjoy*</p>	<p>At this point, the focus became clearer as it was decided to look at social engagement, participation and leisure specifically, based on models of wellbeing and a scoping of the literature. Constructs relating to that focus were searched for here.</p>
<p>dementia or Alzheimer* or “mild cognitive impairment”</p> <p>AND</p> <p>technolog* or digital* or electronic* or device* or computer* or tablet* or “mobile phone*” or</p>	<p>Search terms relating to qualitative-specific papers were added again to check if this helped with the search strategy. Some qualitative papers were missed out by adding a section of search terms relating to experiences and perspectives. Furthermore, it was found that there were a few mixed methods studies would</p>

smartphone* or internet or iPad*	fit inclusion criteria but were excluded if this
	search term remained, therefore it was taken
AND	out to broaden the search.
Social or engagement or involvement or	
participation or leisure or pleasure or enjoy*	It was wondered at this point if a separate
	category specific to caregivers would help
AND	specifically search for caregiver views as well as
	individuals with dementia.
qualitative or preference* or perspective* or	
experience* or view* or attitude* or "lived	
experience" or opinion* "subjective experience"	
dementia or Alzheimer* or mild cognitive	When the above search terms were added to the
impairment	database along with “carer or caregiver* or
	informal carer or family carer or relative or
AND	staff*”, only 882 papers were found, missing
	some of the key papers from the review. The
technolog* or digital* or electronic* or device* or	final search terms are described below.
computer* or tablet* or “mobile phone*” or	
smartphone* or internet or iPad*	
AND	
Social or engagement or inclusion or involvement	
or participation or leisure or pleasure or enjoy*	
AND	
“carer or caregiver* or informal carer or family	

carer or relative or staff*”

dementia or Alzheimer* or mild cognitive
impairment

AND

technolog* or digital* or electronic* or device* or
computer* or tablet* or “mobile phone*” or
smartphone* or internet or iPad*

AND

Social or engagement or inclusion or involvement
or participation or leisure or pleasure or enjoy*

**These were the final search terms, linking to the
clinical area of dementia. Mild cognitive
impairment (MCI) remained in the search
terms as often dementia and MCI samples are
mixed, and it would be important to consider
experiences early in the dementia journey.**

Appendix D: Copy of NICE (2012) quality checklist

Study identification: Include author, title, reference, year of publication		
Guidance topic:	Key research question/aim:	
Checklist completed by:		
Theoretical approach		
1. Is a qualitative approach appropriate? For example: <ul style="list-style-type: none"> Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? Could a quantitative approach better have addressed the research question? 	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: <ul style="list-style-type: none"> Is the purpose of the study discussed – aims/objectives/research question/s? 	Clear Unclear Mixed	Comments:

<ul style="list-style-type: none"> • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed? 		
Study design		
3. How defensible/rigorous is the research design/methodology? For example: <ul style="list-style-type: none"> • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified? 	Defensible Indefensible Not sure	Comments:
Data collection		
4. How well was the data collection	Appropriately	Comments:

<p>carried out?</p> <p>For example:</p> <ul style="list-style-type: none"> • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic? 	<p>Inappropriately</p> <p>Not</p> <p>sure/inadequately reported</p>	
<p>Trustworthiness</p>		
<p>5. Is the role of the researcher clearly described?</p> <p>For example:</p> <ul style="list-style-type: none"> • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants? 	<p>Clearly described</p> <p>Unclear</p> <p>Not described</p>	<p>Comments:</p>
<p>6. Is the context clearly described?</p> <p>For example:</p>	<p>Clear</p> <p>Unclear</p>	<p>Comments:</p>

<ul style="list-style-type: none"> • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered 	Not sure	
<p>7. Were the methods reliable?</p> <p>For example:</p> <ul style="list-style-type: none"> • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to? 	<p>Reliable</p> <p>Unreliable</p> <p>Not sure</p>	Comments:
Analysis		
<p>8. Is the data analysis sufficiently rigorous?</p> <p>For example:</p> <ul style="list-style-type: none"> • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? 	<p>Rigorous</p> <p>Not rigorous</p> <p>Not sure/not reported</p>	Comments:

<ul style="list-style-type: none"> • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data? 		
<p>9. Is the data 'rich'?</p> <p>For example:</p> <ul style="list-style-type: none"> • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites? 	<p>Rich</p> <p>Poor</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p>10. Is the analysis reliable?</p> <p>For example:</p> <ul style="list-style-type: none"> • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? 	<p>Reliable</p> <p>Unreliable</p> <p>Not sure/not reported</p>	<p>Comments:</p>

<ul style="list-style-type: none"> • Did participants feed back on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored? 		
<p>11. Are the findings convincing?</p> <p>For example:</p> <ul style="list-style-type: none"> • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent? 	<p>Convincing</p> <p>Not convincing</p> <p>Not sure</p>	<p>Comments:</p>
<p>12. Are the findings relevant to the aims of the study?</p>	<p>Relevant</p> <p>Irrelevant</p> <p>Partially relevant</p>	<p>Comments:</p>
<p>13. Conclusions</p> <p>For example:</p> <ul style="list-style-type: none"> • How clear are the links between 	<p>Adequate</p> <p>Inadequate</p> <p>Not sure</p>	<p>Comments:</p>

<p>data, interpretation and conclusions?</p> <ul style="list-style-type: none"> • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? <p>Is there adequate discussion of any limitations encountered?</p>		
Ethics		

<p>14. How clear and coherent is the reporting of ethics?</p> <p>For example:</p> <ul style="list-style-type: none"> • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee? 	<p>Appropriate</p> <p>Inappropriate</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p>Overall assessment</p>		
<p>As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)</p>	<p>++</p> <p>+</p> <p>—</p>	

Appendix E: Data Extraction form

Data Extraction Form

Title, Author, Date, Location	
Relevant Aims	
Sample	
Design and Methodological Approach	
Summary of Relevant Findings	
Author Discussion of Relevant Themes	

Participant Quotes	
Reference - How many papers found by reference list	
Reference - How many papers found by citation list	

Appendix F: Initial tabulation of occurring themes

	Learning, (re-learning), mastery, growth, achievement, self-esteem, confidence	Social interaction	Assumptions of self, challenging assumptions of self, challenging assumptions from others	Reminiscence	Importance of others	Problems (practical, annoyance)	Linking to past interests, individualised environment <i>And</i> Growing interests	Failure, low self- esteem	Admiration for technology	Having something to do, purpose	Engagement, enjoyment, stimulating <i>OR</i> Disengaged, unsuccessful	Effort	Ability to simplify technology
Cutler, Hicks & Innes (2016) • Group • Perspectives of PLwD	✓	✓	✓		✓						✓		
Swan et al. (2018) • Perspectives of PLwD and staff	✓	✓	✓	✓	✓	✓			✓		✓		
Groenewoud et al. (2017) • Group • Perspectives of PLwD	✓					✓	✓	✓	✓	✓	✓		✓
Astell, Malone & Williams (2014) • One-to-one • Perspectives of PLwD	✓	✓	✓				✓			✓	✓		
Alm et al. (2009) • One-to-one • Perspective of PLwD and care staff	✓		✓								✓		
Lazar, Demitris & Thompson (2016) • One-to-one • Perspective of staff and family members	✓	✓		✓	✓	✓	✓						
Hicks (2016) • Group • Perspectives of PLwD, care partners, community volunteers	✓	✓	✓				✓				✓		
Smith (2015) • One-to-one and group • Perspectives of PLwD	✓	✓			✓		✓				✓		
Upton et al. (2012) • Group and one-to-one • PLwD and care staff		✓		✓		✓							
Hedman , Lindqvist & Nygard (2016) • Individuals • Individuals living with MCI							✓					✓	✓

Appendix G: Example of synthesis process

<i>Supporting studies: example findings</i>	<i>Commentary</i>	<i>Synthesis</i>
<i>Cutler, Hicks & Innes (2016)</i> <i>“Promoting life-long learning”</i> “I want to learn more on the iPad.” “ <u>I’m hoping to learn</u> more next week about the iPad” “It’s all new and I like learning new things, I would like to be shown how to use more of the iPad” “Well you felt you were learning something” “I learnt <u>things I could never master before</u> ”	The use of everyday technology allowed people to feel as though they were learning something. In some, they were able to achieve a sense of mastery over skills they found difficult previously. Further learning something new fostered hope around learning in the future.	<i>Subtheme: learning and achievement</i> The majority of these findings suggest that people with dementia felt they had learnt something new by engaging with the technology and this influenced a sense of achievement. In some cases, individuals were able to feel as though they mastered something they had never mastered before (Cutler et al. 2016) and the experience of learning something new fostered hope about future learning.
<i>Groenewoud et al. (2017)</i> <i>“Need for achievement”</i> “I like the score counting. <u>I want to reach higher scores</u> ”. “ <u>I like it to gain points</u> . That’s me, I want points”. “Oh yeah, that will be fine. If I have the time. <u>I am doing it to learn something new, to benefit from it.</u> ”	Learning something new is a need. Having scoring games on the technology helped with a sense of achievement (e.g. tangible measure of achievement). One of the main drivers for participating in this research was to learn something new, reflecting the importance of learning to people.	Furthermore experiences of using the technology influenced enjoyment over the relearning of technologies. Positive affect such as enjoyment, stimulation and accomplishment was influenced by technology use in these papers. More specifically a sense of achievement was strengthened

<p>“It is nice to have something to do. And it is intelligent. It is a nice therapy”</p>		<p>when scoring games were used (Groenewoud et al., 2017), perhaps as it provided a tangible</p>
<p><i>Astell, Malone & Williams (2014)</i></p> <p>“Re-learning”</p> <p>When I reflect on the last ten weeks <u>I am amazed at how much I have learned and re-learned.</u>”</p> <p>“I sometimes find it unbelievable that I <u>have been able to understand, sometimes complex instructions, and retain at least some of them.</u>”</p>	<p>Re-learning is as important as learning in dementia. It is important to have support to facilitate the re-learning of technology.</p>	<p>achievement that people could look and reflect on with others in a group setting.</p> <p>This theme was evident from multiple perspectives including those living with dementia, staff members and informal carers.</p> <p>The main difference was than increased confidence was spoken about more from the perspective of staff than individuals with dementia.</p>
<p><i>Alm et al. (2009)</i></p> <p>No theme</p> <p>“It <u>brings fun and a sense of achievement</u> – you can make things happen”</p> <p>“<u>Confidence building opportunities</u>”</p>	<p>A sense of achievement brought about using everyday technology was observed by staff members.</p> <p>Staff observed increasing levels of confidence after using the technology.</p>	
<p><i>Hicks (2016)</i></p> <p>“Life-long learning”</p> <p><u>But seriously it’s progress.</u></p> <p><u>Everybody wants to be involved in progress don’t you?</u> No matter what you do. It opens a new</p>	<p>The use of everyday technologies allowed individuals to feel a sense of progress. The word ‘everyone’ suggests that progress is viewed as an essential part of being a person.</p> <p>The importance of learning</p>	

chapter in your mind doesn't it?	something new and the
You would think it would never	achievement associated with it
work but it does...But what	was also discussed by carers,
you've proved is that things like	emphasising the relevance of
that machine have opened our	this theme from both
education.' (Phil, Done	perspectives.
Roaming, Focus group)	
'I think the social benefits were	
brilliant, and <u>I think he felt he</u>	
<u>had achieved something</u> , I	
noticed all the men were very	
competitive, they all wanted to	
win, and that's good, that's	
healthy coz you know, most	
people are, aren't they?'	
(Jean, Done Roaming, Interview)	
<hr/>	
<i>Swan et al. (2018)</i>	The importance of learning
"Belonging"	something new and build upon
"Able to kind of learn more and	existing knowledge was found in
sort of build on their knowledge	staff groups. What differed from
– a <u>sense of accomplishment and</u>	the perspective of those living
<u>confidence in themselves"</u>	with dementia was the perceived
	confidence, and how using the
	technology appeared to increase
	confidence in those living with
	dementia from the perspective of
	staff members.
<i>Lazar et al. (2016)</i>	Staff reflected on how learning
"Influencers"	something new was a 'learning

As S3 said, there was also a curve', depicting the natural
"learning curve," as might be processes of learning something
expected for any new new.
technology. (staff)

Appendix H: Confirmation of suitability for submission to *Dementia*

Anuj Khera [Anuj.Khera@sagepub.in]
To: LAURA SWEENEY
Inbox 24 January 2019 06:24
- You forwarded this message on 24/01/2019 09:27.

Dear

Thank you for the email.

The editors have confirmed the suitability of your paper for the journal subject to the peer review.

You may submit your paper on the journal's submission site.

Let me know if you need any assistance.

Sincerely,

Mr. Anuj Khera

Dementia: the international journal of social research and practice

Appendix I: Participant Information Sheet

Version Number 5

27th September 2018

IRAS Project ID: **242059**



Information Sheet

A study of couple's experiences of creating a digital life story book whilst living with dementia

We would like to invite you to take part in our research. The study will be looking at couple's experiences of making a digital life story book whilst living with dementia. We would first like to tell you:

- Why this research is being carried out
- What will happen if you take part

You may want to talk to other people before you decide to take part. Please read through this information sheet; if you have any questions please get in touch with the researcher whose contact details are at the bottom of this information sheet.

What is the purpose of the study?

A life story book is a collection of photos, text and other things important to your life. There are no rules about what must go in a life story book: it is completely unique to how that person wants to make it. Life story books can be helpful because making one can be a fun

pastime, can stimulate memory through reminiscing about the past and can be shared with other people involved in the care of that individual so that person can learn a little bit more about what that person's life has been like.

Because now we are living in a digital world, there is a lot of interest in digital life story books - creating a book on a tablet or laptop. It's easy to share and make copies and can be made more interactive with music and videos.

This research is interested in learning about couple's experiences of creating a digital life story book when one individual is living with memory difficulties, mild cognitive impairment or dementia and how these experiences are related to wellbeing. We also hope that it will help us to work together to learn more about how best to support individuals with memory difficulties, mild cognitive impairment or dementia and their spouses/partners.

Why have I been asked to take part?

We have sent you this information if you gave us your contact details after seeing a poster or being told about our study. This may have been at places like a memory clinic, at local groups for people with dementia, or on a website.

Do I have to take part?

You do not have to take part if you do not want to. Both individuals in the couple must agree to take part in the study. You are free to withdraw from the study up to the point where the study results are analysed and written up. You do not have to give a reason for this and your decision will not affect your health care or legal rights.

What will happen if I want to take part?

If you decide to take part in the study, you will speak to the researcher over the phone to check you are eligible to take part. Following that, you will both meet the researcher together at a time and place that is convenient for you to sign consent forms and to be introduced how to use the digital life story software provided by a Community Interest Company called “Book of You”. You will be given a username and password to login to your book. You will also be given a user-guide to keep and a support phone number for Book of You if you have any technical difficulties. If you feel that you would like some help to complete the book we have a student volunteer who can come and help you in using the digital life story software, but this is optional. You will be asked spent time together filling in the book at least once a week together for a 6-week period. You will be able to add photos, videos and text to your digital life story book. The book is stored on a secure website, meaning only you and the people you share your login with will be able to see your book. Nevertheless, it is strongly recommended that you should make sure no sensitive/personal details (e.g. bank details) are included in anything you upload. It is recommended that you fill it in at least once a week so you have enough opportunity to use the book. The researcher will ask you how often you logged in to create your book. After six weeks, the story doesn’t need to be finished; we are interested in the experiences of making the life story book together. After three weeks, the researcher will contact you via telephone to check how things are going and to see whether you may need any extra support from a student volunteer. After 6 weeks, the researcher will arrange to meet you at a time and place convenient for you to ask you about your experiences of creating a digital life story book together. There are no right or wrong answers to any of the questions, we are interested in hearing about your stories. These sessions will be audio-recorded and will approximately last one hour. The audio tapes are to allow the researcher to go back and look through everything that was said and to make a record.

What will happen if I don’t want to carry on with the study/can’t carry on with the study?

If you don’t want to carry on the study or cannot carry on due to unforeseen circumstances, please let the researcher know as soon as possible. You do not have to give a reason, but please let me know if you would like to. If you wish to withdraw from the study, the researcher will check which parts of the study you would like to be withdrawn from and if applicable which aspects of the study you would like to remain a part of. For example, you may wish to stop filling in the life story book but would still like to be interviewed about your experiences or vice-versa.

If you have said something in the interview which you do not want to be used in the analysis of the study, please tell the researcher at the time of interview which parts you don't want to be used.

There are some occasions that we will not be able to take your data out of the study if more than 1 week has passed since your interview. This is because your data may have already been used to produce the study's results.

What are the possible benefits of taking part?

Many people find making a life story book enjoyable, and we hope that you may enjoy creating your own life story book too. You will be able to keep your digital life story book after you finish the study. We hope that the information we get from the study may increase our understanding of the experiences important to living with dementia, such as knowing about the experiences of sharing life story work with a loved one and experiences relating to digital parts of life story work. This may help us understand what specific parts of life story work are important to help support individuals and families living with dementia.

What are the possible disadvantages and risks of taking part?

Meeting with the researcher will involve sitting and talking for around 1 hour. This may be tiring for some individuals. We can take breaks and do this over a couple of sessions if this would suit you more.

People may have experienced difficulties in their life. It is possible that the process of making a life story book may upset people, especially if it reminds them of difficult aspects of their life. If you think that you have memories or events in the past you would rather not discuss then it may be this research isn't for you. If at any point you feel uncomfortable in either making the life story book or the interview, please inform the researcher and you will be able to stop participation in the research and access further support as needed. There is a list of support options which the researcher will give you.

When does the research stop?

The research stops when you have completed the final interview.

Will my taking part in this study be kept confidential?

We will follow ethical and legal practice and all information about you will be kept confidential. The data will be collected by the researcher and will be stored securely by the researcher at the University of Hull. A number rather than your name will be used on the data so information will never be identifiable.

Once the audio recordings have been written down, they will be destroyed. The written copy of what was said in the interview will be kept in a locked facility at the University of Hull, and will be destroyed after 10 years. The only people who will be able to access this will be the main researcher and research supervisors (contact information at the bottom of the sheet).

The only time we may need to share information is if we become concerned during the process. This would be if you tell the researcher something that suggests you or someone else may be at risk of serious harm. If this happens, the researcher would need to contact the appropriate organisations to make sure that people are kept safe. If such circumstances did arise, the researcher would talk to you about this before contacting anyone.

What happens to the results of the research study?

The lead researcher Laura is a trainee clinical psychologist and the results will be written into a report for a thesis, and submitted to an academic journal as part of her training. They may be published. Some direct quotes from your interview may be used in the report, but they will be under a false name. No information which could identify you will be included.

What if there is problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by sending your complaint to:

Research Team

Humber Teaching NHS Foundation Trust

Trust Headquarters

Willerby Hill, Beverley Road

Willerby

HU10 6ED

The research team can be contacted on 01482 301726 and/or you can send an email to ResearchTeam.hnf-tr@nhs.net

Who is organising and funding the research?

Humber Teaching NHS Foundation Trust and the University of Hull are funding the research. The research is part of the requirement for a Doctorate in Clinical Psychology qualification.

Who has reviewed the study?

A Research Ethics Committee is an independent group of people who review research studies. They want to make sure that researchers protect the rights and well-being of people who take part in their study.

More information about life story work

There are sources of information on the following websites:

- www.dementiauk.org
- www.alzheimers.org.uk

For more information about Book of You specifically and digital life story, you can access their website at:

- www.bookofyou.co.uk

What happens now?

If you are interested in taking part in the study, please contact the researcher **Laura Sweeney** via telephone to discuss further questions, comments or queries (details at the bottom of this form). Thank you for taking the time to read this information.

Yours Sincerely,

Laura Sweeney

Trainee Clinical Psychologist

Contact details

Laura Sweeney

Department of Psychological Health and Wellbeing

Aire Building

Cottingham Road

Hull

HU6 8RX

Telephone: 07398134920

Email: L.Sweeney@2016.hull.ac.uk

Supervised by:

Dr Emma Wolverson & Dr Chris Clarke

Department of Psychological Health and Wellbeing

Aire Building

University of Hull

Cottingham Road

Hull

HU6 8RX

Telephone:

01482 464170 (Emma)

01482 464106 (Chris)

Email: E.Wolverson@hull.ac.uk (Emma)

C.Clarke@hull.ac.uk (Chris)

Appendix J: Participant Consent Form



IRAS ID: 242059
Participant Identification Number for this trial:
Date: 15th June 2018
Version Number: 4

CONSENT FORM

Title of Project: A study of couple's experiences of creating a digital life story book whilst living with dementia

Name of Researcher: Laura Sweeney

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw. I understand that if one week has passed since my interview that my data may have already been analysed, therefore I won't be able to withdraw that data but will be able to withdraw future involvement in study.
3. I confirm that direct quotes from the interview may be used in future publications and understand that they will be anonymised.
4. I give consent for Book of You (Community Interest Company) to make a login so I can access software to create a digital life story book
5. I agree to take part in the 6-week intervention of the study where I will create a digital life story book with my partner/spouse
6. I agree to take part in the interview following the 6-week intervention and understand the interview will be audio taped
7. I agree to have further interviews in the future if the researcher wants to clarify any further information
8. I wish to receive a summary of the results once the research is complete

☐☐☐☐☐☐☐☐

Name of Participant Date Signature

Name of person taking consent Date Signature

When completed: 1 for participant; 1 for researcher file

Appendix K: Demographic Form

Demographic Data Form

Please could you tell us some information about you both? This information will be anonymised and will be kept confidential.

Person living with dementia's age in years:

.....

Spouse/partner age in years:

.....

Person living with dementia's gender:

.....

Spouse/partner gender:

.....

What is the ethnic background of the person living with dementia?

- White British
- Other White Background (Please Specify)
- Multiple Ethnic Background (Please Specify)
.....
- Asian
- Asian British
- African/Caribbean
- African British/Caribbean British
- Other Ethnic Group (Please Specify)
.....
- I'd rather not say

What is the ethnic background of the spouse/partner?

- White British
- Other White Background (Please Specify)
- Multiple Ethnic Background (Please Specify)
.....
- Asian
- Asian British

- African/Caribbean
- African British/Caribbean British
- Other Ethnic Group (Please Specify)
.....
- I'd rather not say

How many years have you and your spouse/partner been married/in a relationship? (Please delete as appropriate)

.....

Do you both live together? (Please circle answer)

Yes No

If you know, what diagnosis of dementia has been given and when was the diagnosis given?

.....

Do you receive any additional help relevant to dementia care? (If yes, please specify)

.....

Have you ever done any reminiscence, life story or family tree activities in the past? (If yes, please specify)

.....

On average, how often do you use technology?

- Hourly
- Daily
- Weekly
- Monthly
- Yearly
- Never

What do you use technology for? (Circle all that apply)

- Games
- Staying in contact with friends
- Browsing the internet
- Taking photos & videos
- Watching videos
- Listening to music

- Other (please specify)

.....

Appendix L: Recruitment Flyer

[removed for digital archivng]

Appendix M: Semi-Structured Interview Schedule

Draft Interview Schedule (Semi-Structured)

Version Number: 1

This interview is interested in finding out about your experiences of making your digital life story book together and what you noticed about your wellbeing when making the book. I'd like to hear about **both** of your experiences, so will ask both of you to share your thoughts on each question.

- First, could you tell me how often you sat down together to make your life story book?
- How long did you spend making your digital life story book?

Meaning of life story

- What does your own life story mean to you? How do you feel when thinking about your life?

Process of putting together a digital life story

- Could you tell me a little bit about the process of putting the story together?
 - **Prompt:** What did you enjoy the most? Is there anything you didn't like about putting your story together?
- Can you tell me what it was like adding chapters of your life to the book? What chapters did you include?
- What were your experiences of using *a)* photos *b)* videos *c)* music?
- How easy/difficult was it to put together your story?

Wellbeing and life story

- When making your digital life story book, how did it make you feel?
 - **Prompt:** Ask about which aspects of the digital life story link to specific feelings

- Could you tell me about your experiences of making the digital life story book together? Do you think your experiences would have been different if you made it on your own?
- Has your experience of living with dementia changed since starting making your life story book?

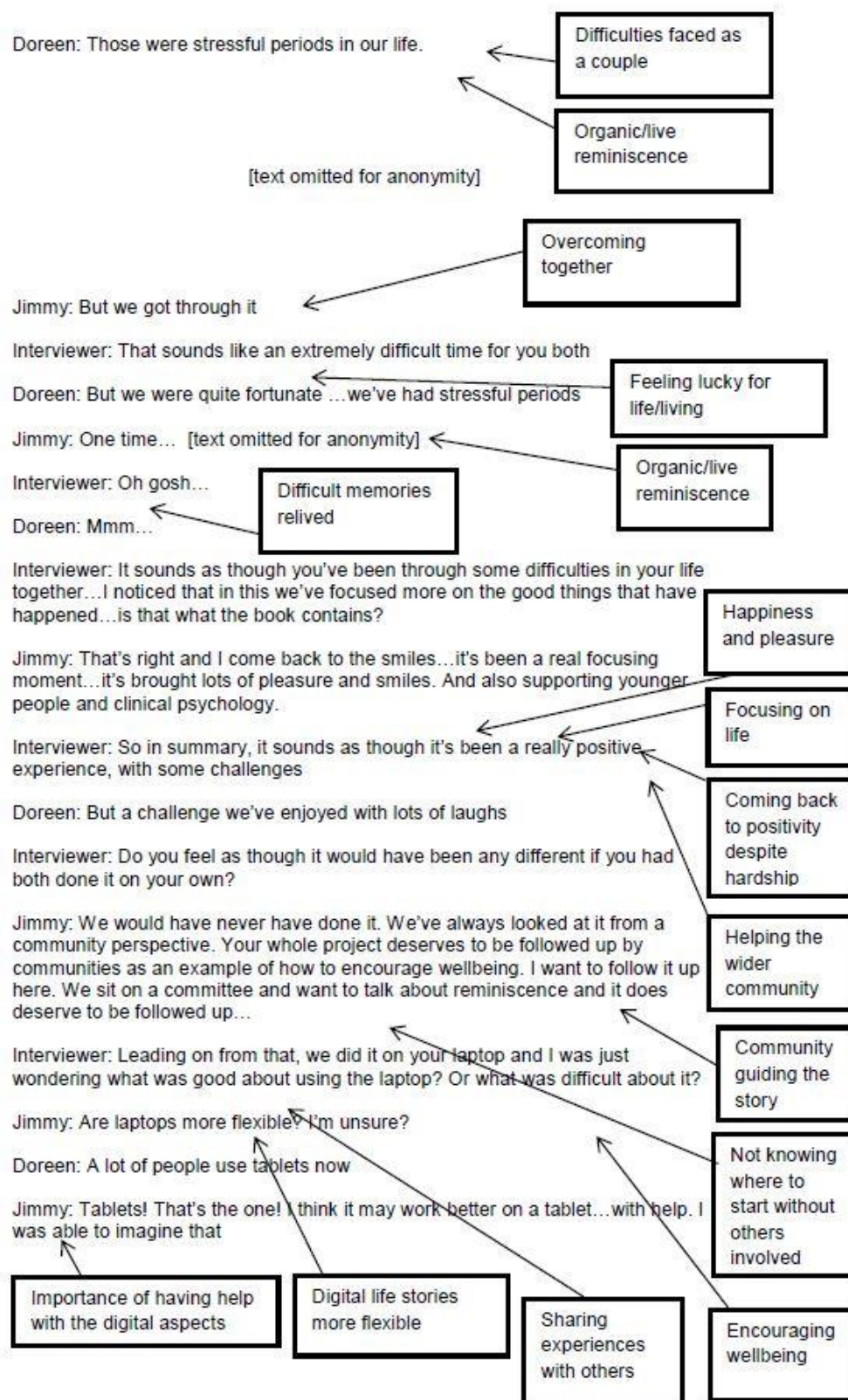
In the future

- Do you think you will continue to use your digital life story book in the future?
 - Yes - What will you use it for & why?
 - No – Why do you think you won't use it?

Appendix: N: Confirmation of Ethical Approval

[removed for digital archiving]

Appendix O: Worked analysis of transcript



Appendix P: Worked example of theme generation

Quotes	Initial Coding	Focused Coding	Searching for themes	Superordinate theme?
<i>"...but I did pick it up and stuck at it"</i>	Difficulties using technology	The process of learning, wanting to stick at it and feeling motivated to continue despite the difficulties faced. Sense of achievement.	Achievement a result of persisting with difficulties of using technology Positively challenged?	Challenges of using technology to build the life story book
<i>"It was a challenge and here and now as we speak we erm have mission successfully accomplished..."</i>	The challenges faced when using technology – feeling successful overcoming them	Reflecting back on his experiences of using the technology to put his story together. He saw it as a mission and something difficult but feels as though he has achieved his goal.	Achievement and success despite difficulties. Positively challenged?	
<i>"Something for our family to read...they have access to it."</i> <i>"Also his younger sister lives away so we can share it with her" -</i>	Ease of sharing story digitally	Sharing the life story with loved ones is important and can be easier to share digitally when they live away.	Sharing with others a benefit of stories been made digitally. The positives despite challenges?	
<i>"I would log in and then without realising log out"</i>	Laughter	Using humour to cope when faced with difficulties when using the technology	Laughter helped to overcome challenges	

<i>[laughing]"</i>				
<i>"I started to feel as though it was beyond me at all. I couldn't keep up with it"</i>	Difficulties using technology	Feeling out of depth when using technology, affecting sense of self.	Technology use influencing a sense of self that is unable to use technology. Feeling out of depth. Negatively challenged?	
<i>"You can get very frustrated when it doesn't work...trying to get different things and that together..."</i>	Annoyance with technology	Frustration at the technical difficulties encountered. Need for the process to be smooth/to work how people would like it to.	Feeling the challenges outweighed enjoyment. Negatively challenged?	
<i>"Well our daughter did most...I left that to her...when you get into your 80s and if you have a good family you let them take charge...and they're better with the technology than we are...To be</i>	Feeling the technology was too difficult to use	Found it difficult to use the technology. The need for other people to help scaffold the process?	Feeling negatively challenged but overcoming it through help from family members.	

<p><i>honest we weren't really capable"</i></p> <p><i>"Definitely not now"</i></p>				
<p><i>"I enjoyed the writing when it's going smooth"</i></p>	<p>Enjoyment when technology was working</p>	<p>The process of writing a fundamental part of enjoyment. When the technology inhibited writing the story, enjoyment was lost.</p>	<p>Problems with technology outweighing the enjoyment from writing the story. Negatively challenged?</p>	
<p><i>"We weren't into that"</i></p>	<p>Preferences of technology</p>	<p>Music and videos are not part of the couples' interests and thus was not an important part of their digital story</p>	<p>Identity affecting what digital aspects were used</p>	
<p><i>"I would like to include more music...it's something to work on I think"</i></p>	<p>Future thoughts about what to include</p>	<p>Wanting to use digital aspects but not knowing how to use them exactly.</p>	<p>Feeling out of comfort zone when using digital aspects</p>	
<p><i>"We've lost them! We had hundreds... We think they're important. We saw photos we never knew existed"</i></p>	<p>Finding photos on the internet when photos were lost</p>	<p>The importance of photos in life story process led to feelings of potential grief when they were lost. Looking at photos on the internet helped when family photos were lost.</p>	<p>Using photos from the internet is an important part of building the digital life story</p>	
<p><i>"No there</i></p>	<p>Not having a lot of photos to use</p>	<p>Photographs were not always common place.</p>	<p>Photos are important to</p>	

<i>weren't a lot of photos [at that time]...no there isn't any photos [in the book]"</i>		Having photos is important to have in the book.	include in the book but not always possible	
<i>"You can look an image and say fine but to actually produce something is brilliant"</i>	The differences between viewing images and creating/making something with it	Creating and building something with a photo enhances enjoyment when looking	Putting photos into a story can enhance enjoyment	
<i>"We've printed it off yesterday for the first time...the complete"-</i>	Importance of having a printed version	Having a complete life story book in a printed format is important. Waiting to print it out/sense of accomplishment	Having a complete printed version important to couples	
<i>"We'll print it out"</i>	Importance of having a printed version	Wanting a traditional book documenting their life story	When the story is finished important to print	

Appendix Q: Thematic Maps (Version 1 and 2)



Appendix R: Supporting quotes for themes

Theme	Subtheme	Supporting Quotes
CREATING A LIFE STORY TOGETHER IS A HUGE UNDERTAKING	Reminiscence is a part of everyday conversation versus finding the time for their life story book	<p><i>"We got the box down and started sifting away...putting relevant stuff...working on the headline stuff...y'know...erm...careers and stuff...through the decades...and errm getting material to fit into that...and then in the process..."</i></p> <p><i>"It might have been thinking about it for a few days then going forward with it..."</i></p> <p><i>"We've also been to [place name]"</i> <i>"I remember the big plateau...I can remember that"</i> <i>"We landed and we went down the valley..."</i> <i>"I remember we went in a bus"</i></p> <p><i>"Yes that's it...we didn't want to [rush]"</i> <i>"I think also this is the Alzheimer's quite frankly...and the concentration...it does tire her..."</i></p> <p><i>"All we had then was a domestic oven...but anyway we did four rings on top. One fellow used to bring a camping stove."</i> <i>"We used to take stuff. We've still got stuff up there [laughs]"</i></p> <p><i>"It was nice sitting...but unfortunately the last two Sundays we've been quite busy"</i></p> <p><i>"Anything she can do she is doing"</i></p> <p><i>"We're always trying to keep busy...but for me it was really nice to do this... it was really nice for us to just sit back and reminisce"</i></p> <p><i>"Is that something you both found? Just the time and energy it took?"</i> <i>"Yes it took a lot"</i> <i>"Yes I think that it was more time consuming. I mean just speaking to you now we've covered a lot of ground....we can't do 6 weeks solidly...we've got other things"</i></p>
	Life story books structure reminiscence	<i>"and its brought time slots back into detail...there's something there"</i>

[laughs]

"It's worthwhile and valuable to record it and I suppose some people aren't able to relate life story and the beauty and that sometimes illness can permit you from doing it. It was quite good. I can see where people are coming from."

"I just thought it was the ideal way...start at the beginning and go. We're nearly at the end now"

"Just bringing things together and I couldn't have done it without Doreen bits and pieces bringing it together and in the process it brings your life structure back again"

"We feel comfortable and relaxed in your company...we felt reassured if you like..."

"Oh yes...it's more successful to put your life structure together with someone else there"

"That format...helped to get me into it...but to focus...the idea and concept"

"You do it unconsciously...you don't sit down together...it just happens"

"You don't realise no!"

"Absolutely...it was the putting it in..."

"Yes..."

"...that was difficult?"

"Absolutely yes...we could relate it...like the first time we met you...we'd talk about that and bring it up but when you've got to put it all down into there..."

"Both Anne and I talk about our life over the years quite a lot...I remember bits about Anne and she remembers bits about me...Our conversations often start with "Do you remember this?""

"You might not be aware but you are doing it [reminiscing] all the time"

**LOOKING BACK AND
LOOKING FORWARD:
THE EMOTIONAL
JOURNEY**

Memories of the past
affecting the present

"Oh yes and our lives are very good now...and basically we've had a good life haven't we?"

"It takes you back and how you

enjoyed it”

“It’s been a real focusing moment...it’s brought a lot of pleasure and smiles”

“We’ve lived a good life”

“The smile...and both of us...it’s been really...a brilliant experience!”

“It’s all been very pleasant...We’ve had a good life and lived a happy life...I wouldn’t have altered any of it...It’s been nice to look back on it”

“Well we thought wow we’ve achieved a lot...especially from the background we came from...it’s made us feel extremely humble”

“Well...a sense of...we’ve achieved something”

“It makes me feel good...I’ve done a lot... a lot of things”

“I feel sort of satisfied with our decent life...and brought the kids up...that’s been our achievement really”

“We’ve achieved our ambition. We’re content”

“We’ve had our ups and downs and things but we’ve come through it alright...”

“So we’ve progressed through that...we’re in our 62nd year of marriage...and it’s just wow...looking at what we’ve achieved”

“We were lucky that we came through it all...”

“It was a laugh! Do you remember that?”

“[laughing] Oh I recall that! [laughing]”

*“You’ll ask for lemonade [laughs]”
“[laughs] We’re laughing because I’ve never drunk much...”*

“Some weren’t so good...I was safe there because my place was next to the supervisor [laughs]”

		<p><i>"A bit sad that it's all gone... I said I've done it for so many years...it's time for somebody younger to..."</i></p> <p><i>"To take over yes..."</i></p> <p><i>"Is that something you spoke about when doing the book?"</i></p> <p><i>Yes...it's a big part of me...if I didn't I should have done"</i></p> <p><i>"That's right and I come back to the smiles..."</i></p> <p><i>"So [your daughter] mentioned earlier that she noticed you look more confident when you were speaking about your memories?"</i></p> <p><i>"Yes...yes...it did thinking about my jobs"</i></p>
	Emotions relating to the process of putting the story together	<p><i>"The thing is you're still quite capable...what it has done has highlighted to me the fact that he still has loads of memory left...some bits get mixed up with other bits...and crossover sometimes...but the story is so..."</i></p> <p><i>"We have mission successfully accomplished"</i></p> <p><i>"It feels good yes...we've enjoyed it haven't we?"</i></p> <p><i>"It's been a really happy point in our lives [to complete the book]"</i></p> <p><i>"Oh yes! We will probably carry it on and finish it"</i></p> <p><i>"Norway and that coast along there...Sweden and Norway. We've never been there"</i></p> <p><i>"Yes...I don't think we've got many years to add and we're not get any younger [laughs]"</i></p>
WHOSE STORY IS IT AND WHO DOES IT BELONG TO?	Our story together	<p><i>"The introduction to my story is 'Doreen the bedrock of my life'"</i></p> <p><i>"I don't see how we could have done really. We're both the same"</i></p> <p><i>"Yes [it would be different] ...our lives have been together anyway..."</i></p> <p><i>"Jimmy and I and sometimes we have our differences in opinion but over</i></p>

this we haven't because we've both been working on the same thing so we haven't had any differences in opinion [all laugh]"

"We're more a couple in some ways because we do most things together."

"Yes it's a nice thing to do...having done it ourselves"

"It's been a team job."

"That's been the good thing about it!"

"He's done all the stuff on the computer himself but I've been the memory in the background"

"Yeah...and I've got a terrible memory anyway [laughs]"

"I jeer him on with it...triggers memories to it"

Telling our story: others
hearing and reacting

"I am mindful of the fact...in the process...I've been writing this up for...we have one daughter Natalie...it's information for Natalie to read...and to receive"

"Oh yes because they're learning as well! They say oh we didn't know this and that and ask did you really do that? You forget too...we think oh yes of course that happened..."

"We always looked at it [the life story] from a community perspective...as an example of how to encourage wellbeing"

"We might be able to use this in our dementia community to give staff an idea or concept so anyone can engage in it and would have information available for their care"

"I think yes because some of the reactions from others [daughter] makes you think oh golly I didn't realise"

"I think it should be important to them [family]...the life we led...they don't seem too bothered about the life we had"

"That sounds like such an adventurous holiday!"

<hr/>		
<i>"[laughing] it was"</i>		
CHALLENGES OF USING TECHNOLOGY TO BUILD THE LIFE STORY BOOK	Challenge of using technology viewed as positively and negatively	<i>"...but I did pick it up and stuck at it"</i>
		<i>"It was a challenge and here and now as we speak we erm have mission successfully accomplished..."</i>
		<i>"Something for our family to read...they have access to it"</i>
		<i>"Also his younger sister lives away so we can share it with her"</i>
		<i>"I would log in and then without realising log out [laughing]"</i>
		<i>"I started to feel as though it was beyond me at all. I couldn't keep up with it"</i>
		<i>"I enjoyed the writing when it's going smooth"</i>
		<i>"You can get very frustrated when it doesn't work...trying to get different things and that together..."</i>
		<i>"Well our daughter did most...I left that to her...when you get into your 80s and if you have a good family you let them take charge...and they're better with the technology than we are...To be honest we weren't really capable...you couldn't do it Bill"</i>
		<i>"Definitely not now"</i>
<hr/>		
	Engagement with digital media	<i>"We weren't into that"</i> <i>"I would like to include more music...it's something to work on I think"</i>
		<i>"We've lost them! We had hundreds...We think they're important. We saw photos we never knew existed"</i>
		<i>"No there weren't a lot of photos [at that time] ...no there isn't any photos [in the book]"</i>
		<i>"You can look an image and say fine but to actually produce something is brilliant"</i>
		<i>"Well it was getting the photographs out and looking at the photographs. We probably wouldn't have got them out just to...I think that's it...We</i>
<hr/>		

probably wouldn't have bothered"

*"Paper...yes..."- when discussing the
preference over digital and
traditional life story books*

*"We've printed it off yesterday for
the first time...the complete"*

"We'll print it out"

Appendix S: Epistemological Statement

Epistemological Statement

Ontology can be defined as the study of being or '*what is there to know?*' with epistemology being defined as how knowledge can be acquired or '*how can we know?*' (Willig, 2013; Ritchie, Lewis, Nicholls & Ormston, 2013). The research paradigm includes that of ontology, epistemology and methodology, with the ontological and epistemological stance influencing the methods that a researcher will pursue (Guba, 1990). In all research, but particularly qualitative research, the researcher must acknowledge that they will influence and be implicated in the research process. A researcher's approach will be always based on the underlying assumptions about what reality is (*ontology*), what can be known about reality (*epistemology*) and how we can understand reality (*methodology*). This statement is an account of the researcher's assumptions of the empirical research outlined in this portfolio, and seeks to make transparent the approach the researcher has taken.

Positivist epistemology implies that it is possible to describe the truth and that the truth can be measured and known. This stance is often associated with quantitative methodologies as positivism is concerned with quantifiable observations (Collins, 2018). Aligned with this view, it is assumed that researchers can be viewed independent of their research, that there is minimum interaction with research participants (Wilson, 2014) and researcher bias does not influence the research process (Ponterotto, 2005). With regards to the current study, this paradigm would assume that there is a 'true' joint experience of making a life story book that is associated with wellbeing in a sample of

older people living with dementia and their spouses/partners; however this stance is problematic for the following reasons.

The notion that dementia was solely a result of neurological influences was challenged by Kitwood (1990), who explained that the experience of dementia was likely to be influenced indeed by neurological aspects, but also the psychological and social factors. Because of this, it appears contradictory to assume that there is one 'true' experience of wellbeing in creating a life story book within a couple living with dementia. In addition, everyone's life stories, and relationships, are inherently different and it is not possible to control for different life experiences and relationships, emphasising that a positivist approach would be unsuitable for a study of this nature.

Whilst there are many existing theoretical understandings of wellbeing in dementia that have been developed into a range of assessment measures, it has been suggested that the aspects that we, as researchers, might expect to be important for quality of life when living with dementia are actually experienced quite differently by people living with dementia (Clarke & Wolverson, 2016). Further to this, it is important to think about how wellbeing in dementia is likely to be complex, multi-dimensional and not easily broken down into measurement scales (Clarke & Wolverson, 2016) and very little has been done to understand the multidimensional aspects or components of wellbeing in the context of living with dementia (Venturato, 2010). This also poses the question of whether wellbeing is subjective, objective or both, with literature often separating inner experiences of wellbeing and external perceptions of wellbeing (Alatartseva & Barysheva, 2015). The primary research question was concerned with the couples' own indicators of wellbeing, highlighting the subjectivity of wellbeing across individuals and couples. Therefore, it appears as though the existing assessment tools would be unlikely

to capture the experiences of couples' wellbeing and how this is constructed when creating their own life story, suggesting the 'truth' of wellbeing may not be easily discovered.

After reflecting on the above, a positivist approach was deemed inappropriate based on the grounds that it was too reductionist to search for a 'truth' regarding couples' wellbeing, when one individual is living with dementia, in the context of creating their life story. Furthermore, a positivist approach would be reductionist in that each couple living with dementia is likely to have different life experiences both individually and as a couple. The subjectivity of experience and how this experience is constructed was considered to be an important aspect, meaning attempting to capture the 'truth' would be at odds with the variation of experiences within the population. A social constructivist epistemology was considered to be more appropriate, as this holds the assumption that realities are constructed through interactions and we invent the properties of the world rather than discover them (Kukla, 2013). Constructivist approaches are less concerned about the 'truth' regarding knowledge, but are more interested in how 'knowledge' is constructed through the use of dialogue (Willig, 2013) and that experience and meanings are wholly subjective, leading to multiple realities coexisting (Berger & Luckmann, 1966). A constructivist stance would assume that the researcher acts as a detective, building an understanding through induction from the subjective experiences (Gergen, 1999), and that the realities will be co-created between the researcher and participant (Guba & Lincoln, 1994), emphasising the active role the researcher will play in the research process.

As aforementioned, the epistemological stance of the researcher will influence the chosen methodology (Guba, 1990). Based on the research aims and question, a

qualitative methodology was chosen as this could give voice to those living with dementia about their shared experiences of creating a life story book. It could also acknowledge interactions between the researcher and participant. This was deemed as particularly important as the lead researcher (LS) was often involved in actively helping individuals put their life story together meaning the lead researcher was a part of the constructed reality taking place. For example, the lead researcher helped one couple put the photos into their digital life story book and actively engaged in conversations and discussions about the couples' life as a result. A detailed account of reflections about the process of being the volunteer and the researcher is available in the Reflective Statement (see Appendix T).

Due to the aforementioned complexities in objectively defining the experiences of living with dementia and wellbeing as well as considering the importance of researcher reflexivity, the following research methods were considered:

Interpretative Phenomenological Analysis (IPA)

IPA methodology is concerned with understanding detailed meanings of personal lived experience and is deemed as particularly useful for topics which are 'complex and ambiguous' (Smith & Osborn, 2015, p. 41). The present study was looking at *joint* experiences of couples making their life story book, and IPA has a focus on concentrating on an *individual* participant and how they make sense of their own individual experiences (Willig, 2013), suggesting it may be inappropriate to pursue this methodology based on the assumption that joint experiences will be co-constructed by the couple. Due to the present study aiming to explore shared experiences rather than solely individual experiences, IPA was rejected.

Constructivist Grounded Theory

In the initial stages of the study, Constructivist Grounded Theory was deemed the most appropriate method to answer the research questions as it aims to develop an inductive, theoretical and reflexive perspective, emphasising the social conditions in which research occurs (Charmaz, 2006). This methodology emphasises that the data being collected is constructed by the researcher, including their perspectives, privileges and values. Constructivist grounded theory suggests that the theory that is emergent from the data is just one interpretation that may be and that “data do not provide a window on reality” (Charmaz, 2000, p.524) and that the interaction between the researcher and participant therefore produces the data. This was an important consideration due to the lead researcher’s active involvement in the digital life story intervention with some of the couples who participated. The method of constructivist grounded theory starts with open coding of qualitative data (e.g. transcripts) (Strauss & Corbin, 1998). Running notes are kept where the researcher lists their observations and insights based on the codes, which is known as ‘memo-writing’ (Glaser, 1998). Initial coding is often done line by line, whereas ‘focused coding’ occurs when the most frequent codes are put into categories. Finally, ‘theoretical coding’ occurs where the categories are compared in order to see how these are similar and different to one and another and how these can be integrated theoretically (Charmaz, 2006). Constant comparative analysis forms a large part of grounded theory and the constructivist version, as it guides where to go next to clarify emerging theoretical concepts (Glaser & Strauss, 1967). The process of data collection and analysis is continued until no new categories can be identified, also known as ‘theoretical saturation’ (Willig, 2013).

The final analysis

Constructivist Grounded Theory was pursued but had to be discredited due to being unable to meet data saturation due to difficulties in the recruitment process, meaning that whilst the data had depth, it lacked breadth. Data saturation is crucial part of grounded theory methodology as it refers to the stage in data collection where no new categories emerge, thus an emergent theory explaining these categories can be developed. Whilst there is not a concrete answer to '*how many participants are needed*' for a grounded theory study (Francis et al., 2010), it was felt that the sample may have not reached saturation point in terms of eliciting experiences and views from a range of couples, and thus the development of an emergent theory would not be possible.

The research team explored a reflexive approach, and discussed using a Thematic Analysis of the data informed by the assumptions underpinning Constructivist Grounded Theory. Grounded theory is a thematic approach and in its early stages mirrors thematic analysis in its process. For example, grounded theory and inductive thematic analysis both begin by initial coding of transcripts line by line. Following this, grounded theory suggests the next step is 'focused coding' where the most frequent initial codes are interpreted into categories and these categories are compared for similarities and differences and explored how they can be integrated into a theory. Grounded theory is an iterative process, highlighting the concurrent use of sampling, coding, constant comparison and memo-taking to influence theory generation (Glaser & Strauss, 1967). Thematic analysis in the early stage is not dissimilar, in that following initial coding the researcher will search for themes and the researcher's thought process will influence the sorting of codes and the relationships with and between them (Braun & Clarke, 2006). Grounded theory approaches have been applied to the data-analysis stage of thematic analysis previously to determine appropriate coding and the

development of themes from the quotes (Heydarian, 2016). Because of the similarities of the two approaches, and the general neutrality of thematic analysis, meaning it can be informed by other approaches, the present study utilised a thematic analysis guided by the principles of constructivist grounded theory.

Inductive thematic analysis was utilised to analyse the data, meaning coding and themes are directed by the content of the data ('bottom-up') which is in comparison to deductive thematic analysis whereby the coding and themes are directed by existing concepts or ideas ('top-down') (Braun & Clarke, 2006). It was felt that an inductive approach of thematic analysis aligned with the research questions of looking at shared experiences and meanings of couple wellbeing when creating their digital life story. The thematic analysis adopted a constructivist paradigm (see Burr, 1995) emphasising that meaning and experience are influenced socially rather than solely being inherent in individuals. A thematic analysis from this perspective does not seek to focus on the individual experience only but attempts to explore the sociocultural contexts that enable and influence the individual accounts that are given in the research (Braun & Clarke, 2006).

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Appendix T: Reflective Statement

Reflective Statement

Before: where the study came from

Ever since I was little, one of my fondest memories is looking through photographs with my grandmother which she kept organised in old Quality Street tins. Every time I saw her I would insist that I wanted to look through photographs of her and her life with our family. I loved to sit and listen to the stories she would tell, especially as our lives were so different. I learnt a lot from sitting, listening and reminiscing with her. Our tradition of sifting through photographs and talking about our lives continued every visit until she passed away when I was 16 years old. I still look at the photos in the Quality Street tins, but it never feels the same.

Reminiscing has always resonated with me, probably because I have had such fond memories of thinking and talking about family life stories. I remember at school I was given the project of making my own life story, and ensured that my gran was on hand to help put the photos together. I always felt happy looking at photographs, and I always felt happy sharing the joy with loved ones around me. When I started university, I got involved with a group which organised activities for individuals living with dementia in a residential setting and helped facilitate a reminiscence group for individuals. We played games, listened to music and chatted about our lives. Often society focuses on what people with dementia *cannot* do, but here I truly saw what people with dementia *still can do* and *continue to do*. Care staff explained they were surprised at how much individuals could speak about in the reminiscence sessions and how much they enjoyed

it. I realised that the care staff so desperately wanted to sit and reminisce with every person, but were pulled into so many different responsibilities that made it difficult to create time and space for it. I had the luxury of time as a student with only five hours of lectures and seminars in my final year. After participating in the reminiscence sessions, I started to think a lot more about reminiscence in general and how it can potentially be therapeutic not just when living with dementia but for everybody!

When attending the research fair in the first term of the clinical doctorate, it only felt right that my empirical research would take the direction of exploring wellbeing in dementia. I am so grateful that I was able to share my ideas to Emma and Chris, who were always very welcoming in their approach. The world of academia can be a scary place, especially when you're a newbie. I was worried about getting it right and felt very out of place for a long time. Emma and Chris gave me the confidence to share my ideas and to not be scared.

I have always been interested in qualitative research methods, but never felt equipped to use them previously. During my undergraduate dissertation, I was aiming to understand links between smartphone use, depression and anxiety in a sample of students. The results were non-significant and on their own didn't mean much. I remember really struggling to write the results and discussion! What brought the study to life were anecdotal accounts of how students *felt* when they had to give up their smartphone for a few hours. Whilst by no means it was formal qualitative evidence, as we did not attempt to interview participants, I remember that these quotes actually became the foundation for the discussion, and from that point I realised that understanding *experiences* of a phenomenon is just as important. Deciding to break out of my comfort zone of using

purely quantitative methods and be true to my epistemological stance of social constructivism was a big part of formulating an initial research question.

In the initial phases of developing a research question looking at life story work in dementia, I was surprised at the scarcity of research out there, especially when reminiscence therapy seems to be so widely used in health settings. I was also surprised at how little was known about how life story work is experienced by the individuals engaging in that work, meaning a qualitative/exploratory study seemed to fit with the research gap. I reflected on my own experiences of reminiscence with a loved one, and how my experiences of reminiscence changed when I did it in isolation, and wondered what research was out there about joint reminiscence. I realised there are many different types life story work, with a growth of interest in digital life story work. I remember actively searching the internet for examples of digital life story work and came across *Book of You*. I approached them to find out more about their work and to talk through some of my research ideas. Kathy, the Director of *Book of You*, welcomed my ideas with open arms and this helped give me the confidence to move forward with exploring experiences of creating a digital life story book with a loved one. Kathy suggested that instead of interviewing couples in Wales, to run the 6 week intervention myself in Yorkshire. After assessing the feasibility of this with the research team, we agreed this would be possible within the scope of the doctoral thesis. I had to continuously remind myself that I did not have all the time in the world to do this. Kathy explained that volunteers, often students, help the individuals put their book together, so agreed this could be part of our study too. Two volunteers were recruited from 10 people who showed interest and they both attended *Book of You* training, however the couples who took part did not want any extra help, or the volunteers were

not able to reach their location. This aspect of the study was difficult for me, as I felt I had let the volunteers down. They were both admirable people who were very committed to my research project. I only wish I could have helped them more, especially when a few years ago I was in the same position of looking for lots of different clinical and research experiences.

I was initially very excited to do an intervention study but had moments of doubt when I was warned by other trainees to stay far away from interventions and to make it easy for myself. However, making my thesis as easy as possible wasn't part of my values and pursuing this piece of research only felt right.

During: experiencing the research

My overall experiences of the research were positive, but not free from stress, upset and frustration. I am very grateful to all the couples I have spoken to on my research journey and feel very privileged that they welcomed me into their life stories, something which is personal and intimate. It was touching to share moments of emotion with the couples. For some, I was very much a part of putting the story together, meeting every week and going through the photographs, putting their photographs on a tablet and putting it into the digital life story book. Of course this cannot be a robotic process, and we spent hours just chatting about the meaning behind the story. As a result, I got to know some of the couples well and there indeed was a crossover between researcher and volunteer which should not be ignored in qualitative research, especially as the digital life story was sometimes actively co-constructed between myself and the couple. The crossover meant that I witnessed my own interpretation of happiness and joy when couples spoke about their life story and their experiences of creating a digital life story book.

However, the interaction and crossover between researcher and volunteer meant there

was something human about our interaction and participants reflected that this helped them feel at ease with the interview. I remember seeing on Twitter a researcher stating that you should not just recruit participants and forget about them as soon as you have your data, especially when in this research; they have shared the most intimate parts of their life and story. This is something that stuck with me, and I am grateful my research gave me the opportunity to meet others and learn from them and build relationships with the wider community.

I remember my supervisors asking me if I had the time to be meeting couples each week for a few hours to put their story together. I reassured them that I had the time when in reality, I probably didn't. This paralleled with the lack of time experienced by care staff to facilitate reminiscence that I mentioned earlier; as my responsibilities grew, my time diminished. Even though time wasn't on my side, I continued to meet with couples regularly for them to update me on where they were up to and to chat about the next chapter that they had put in their book. I never saw it as work and listening to the stories that the couples shared with me was always the most enjoyable part of my day.

One of the biggest difficulties that I encountered was recruitment. I tried to pre-empt the difficulties with recruitment by starting early and communicating ideas about my study to services in the NHS and community sector. In August 2018 of my reflective diary I wrote:

"I am feeling hopeless. My expectations of where I thought I would be versus where I actually am are very different. How will I get this hope back?"

This hopelessness was in relation to recruitment. I was told by someone who I approached for the research that I was wasting my time and that older people cannot use technology. This links back to a finding from the systematic literature review,

emphasising the negative assumptions held by others can influence how the individual living with dementia perceives their own abilities and may have the potential to prevent people from engaging in something they want to use. I often felt deflated when the gatekeepers to research participants would not share the same enthusiasm that I had about digital life story work. The theme of time emerges again; the gatekeepers did not have the time to think about research projects amongst their never ending list of clinical responsibilities and that is understandable. The difficulties of recruitment dominated research supervision, and we all spoke about wider issues, like the impact of austerity, and how this has potential to influence the relationships, or lack of, with services, affecting the recruitment process. Whilst recruitment slowed, it gave me a chance to channel my energy into my systematic literature review and this helped me feel hopeful again.

Often the empirical paper is at the forefront of trainees' minds for the most part of the journey. For a long time, I only had my literature review to focus on! The question around experiencing the use of everyday technology for pleasure rather than purely assistive seemed appropriate to investigate, particularly as Emma had recently been to a conference where they spoke extensively about technology in dementia. Also, it seemed appropriate considering my reflections on how others perceived the use of everyday technology in the recruitment process for the empirical. The process of data extraction and quality assessment was arduous and it gave me an appreciation of the overall process of writing a systematic literature review especially when I tend to look at reviews firstly when researching a topic! The analogy of the literature review question being a compass rather than an anchor was very helpful as it allowed me to be much more flexible in my thinking around the process.

Choosing a journal that fit with the aims of the review and empirical study but also my values was an important part of the process. When completing initial searches for the systematic literature review, the word “demented” often appeared in titles and keywords of papers that were published recently. My initial reaction was shock around the language used in research, especially when there is research emphasising how this language has the potential to disempower and depersonalise people living with dementia. *Dementia* seemed the most appropriate journal to submit to not only because of the wide readership across multi-disciplinary professionals but mainly that they emphasise that all research should avoid using pejorative language (e.g. “demented” or “suffering with dementia”) and encourage all authors to read the Dementia Engagement and Empowerment Project (DEEP) guidance that is written by people living with dementia about respectful language.

After: Looking back and looking forwards

At the beginning of this research, I feel as though my outlook on what life story work entails was quite reductionist in that I held the assumption that talking about your life story must always be enjoyable. However, as I started to begin the interviews, I soon began to realise that the process is very complex, and at times, is not always happy and that difficulties are a large part of individual and couple identity. I had underestimated everything in terms of the emotional and practical journey of piecing together a life story. In my mind I held the assumption that a positive memory equals a positive outcome on wellbeing, when in reality I began to realise that difficult memories and overcoming them can also have an influential role on how a person, and couple, feels in the present moment. As a result of listening to people’s stories and experiences, I feel my initial assumptions have changed since the beginning.

The theme of time has permeated the whole journey from my initial experiences of running reminiscence groups, from trying to manage my time between the research, clinical and academic aspects of the doctorate, and couples' reflections that time is precious and it can be hard to carve out time to stop, sit back and reminisce amongst an active life. The findings from the empirical paper have made me realise that taking time, stopping and reminiscing is an important thing to consider in a hectic life dominated by so much activity.

I'm looking forward to continue thinking about my research (after a little break!) and plan to feedback to Book of You in August about how couples experienced making their digital life story book. Working with them has taught me a lot about community approaches to dementia care and I really do hope that this research in any way can help inform the valuable work they do for the community.

I still don't feel equipped in using qualitative methods, but I'm not sure I ever will. I think the hurdles in the data analysis have given me a greater appreciation of the diversity of approaches out there. It's made me realise that even if you've chosen a specific type of analysis to start with, you don't always have to stick to it. I've learnt to accept that a flexible approach to research is absolutely okay and that has been a huge learning curve for me.

I have really appreciated everything I have learnt and continue to learn on my research journey. I have in particular found this experience helpful in shaping and informing my practice on a specialist dementia inpatient unit where I am currently on placement, particularly as life story work informs parts of formulation and intervention.

Understanding that you cannot "just do a *little* bit of reminiscence" to support wellbeing, like we all may think from time to time in our busy working day, will help

me consider that the emotional and practical undertaking of life story work should never be underestimated and that there needs to be protected space for this approach.

I will continue to remember in all areas of life, including research, that there is never a complete story, just like the stories shared in this research, and continuing to look towards the future is as important as reflecting on the past.