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Reminiscence and digital life story work for dementia care

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Summary

The overall objective of this thesis is to make an original contribution to literature and practice on the topic of reminiscence and life story work for people living with dementia and their caregivers. These approaches are popular in practice and considered important by experts, but there is still an uncertain evidence base.

Chapter 2 is a systematic review and meta-analysis of reminiscence therapy for dementia, in which some positive but inconsistent effects of reminiscence on quality of life, communication, cognition, and depressed mood have been identified. These effects vary across intervention modality and setting.

Chapter 3 presents a qualitative exploration of user experiences of three different implementations of a digital life story work intervention. Qualitative interviews were carried out with people with dementia, family caregivers, and care staff. A thematic analysis was used to analyse interview data. All participants reported that they enjoyed the intervention, found it useful, and valued using multimedia. Limited IT skills were a significant barrier for most.

Chapter 4 is an investigation into a self-guided, app-based, digital life story work intervention using a Citizen Science approach. Data on usage, experience of individual sessions, and quality of life were collected through the app, and follow-up interviews were also carried out. Engagement with the app was very low, though it appeared to provide some enjoyment to those who used it.

In Chapter 5, the preferences of people with dementia and caregivers in relation to digital life story work were explored. Caregivers completed an online discrete choice experiment survey, and people with dementia completed a simplified online survey. A private one-to-one intervention setting (rather than a community group setting) appeared to be the most important attribute to both participant groups. User IT skills emerged as an essential consideration when designing the intervention.

Chapter 6 is an evaluation of life story work touchscreen apps that are available to people with dementia and their caregivers on app repositories. Ten apps were included, and the accessibility of each app was evaluated. User reviews were carried out by people with dementia, or caregivers of people with dementia.

Chapter 7 concludes this thesis. It brings together the findings from all of the chapters, as well as identifying the implications and limitations of those findings. Directions for future research are also discussed.

The results of this thesis provide support for the use of facilitated reminiscence and digital life story work in both community and care home settings. Results contribute to learning and understanding around how ICT and different ICT systems influence the experience of life story work for people with dementia and their caregivers, in both positive and negative ways. Reminiscence and digital LSW were found to be enjoyable and meaningful for people with dementia and their caregivers, both professional and family.

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Chapter 1. Introduction

Introduction

They say knowledge is power, so what better way to have the knowledge to be able to communicate with a person with dementia than to find out what was important to them in terms of their memories, experiences, life events, values, and beliefs? (Dunne & Dunne, 2017, p. 8).

Prevalence and impact of dementia

Globally, 46.8 million people are living with dementia, representing 5.2% of people over the age of 60 (Prince et al., 2015). In the UK alone, over 850,000 people are living with dementia, and this number is projected to double over the next 25 years, reaching 2 million by 2050 (Lewis, Karlsberg-Schaffer, Sussex, O' Neill & Cockcroft, 2014). In addition, there are 700,000 informal caregivers of people with dementia in the UK, 39% of whom spend more than 100 hours per week caregiving. Currently, dementia costs the UK economy 26 billion pounds per year, eclipsing the costs of cancer, heart disease, and stroke combined (Lewis et al., 2014; Luengo-Fernandez, Leal, & Gray, 2015).

Dementia is an umbrella term for a range of progressive neurological disorders, the four most common of which are Alzheimer's disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies. In the Diagnostic and Statistical Manual of Mental Disorders (DSM V), the American Psychiatric Association (APA; 2013) categorise dementia as a major neurocognitive disorder, causing a significant decline in memory and cognition that hinders independence in day-to-day life. Dementia affects a range of faculties, including short-term memory, mood, behaviour, language, learning capacity, orientation, comprehension, judgement and communication (APA, 2013; World Health Organisation, 1993). The stages of dementia are usually categorised as mild, moderate, or advanced, depending on the severity of symptoms. The rate at which dementia progresses varies across individuals, meaning the experience for each person can be very different. Dementia has a profound effect on memory, though early memories for past experiences and events from one's personal life remain relatively intact (Addis & Tippett, 2004; Kopelman, 1989; Schroots, Van Dijkum, & Assink, 2004). In the following sections, the relationship between dementia, autobiographical memory and identity will be explored, before turning to approaches that can improve life for people affected by dementia, with a specific focus on reminiscence and digital life story work (LSW).

Autobiographical memory function and impairment in people with dementia

Greenberg and Rubin (2003, p. 688) define autobiographical memory as the 'memory of a personally experienced event that comes with a sense of recollection or reliving". There is disagreement among neuropsychologists about what autobiographical memory specifically is, but it is thought to comprise two relatively independent memory systems: personal incident memory (i.e. episodic memory) and personal semantic memory (Baddeley, 1992; Dritschel, Williams, Baddeley, & Nimmo-Smith, 1992; Greenberg & Rubin, 2003). Personal Incident Memory is memory for specific events in one's life, including contextual information such as the time and place. Semantic memory is memory for personal information that is not centred around specific events, such as names of preferred sporting teams, and details about where one lived (Addis & Tippett, 2004). There is a good deal of evidence that people with dementia have impaired episodic and semantic memory (Addis & Tippett, 2004; Greene, Hodges, & Baddeley, 1995). However, it is also well documented that impairment in different aspects of autobiographical memory in dementia is disproportionate, and that there are temporal gradients, whereby recent memories are more impaired than older memories (Addis & Tippett, 2004; Kopelman, 1989). Bluck, Alea, Haberman, and Rubin (2005) proposed three general functions of autobiographical memory: directive, social, and self. The 'directive' function involves using the past to guide present and future actions, in addition to attitudes, behaviour, and thoughts. The 'social' function revolves around sharing memories to nurture existing relationships, and to a lesser extent, develop new ones. Finally, the 'self' function relates to the contribution of autobiographical memory to the maintenance of personal biographical identity and a sense of continuity. Autobiographical memory is closely related to life stories (Habermas & Bluck, 2000; McAdams, 2001), and according to Rosenwald and Ochberg (1992, p.1), life stories 'are the means by which identities may be fashioned'.

Autobiographical memory, identity, and dementia

Some psychological and philosophical theories suggest that there is a relationship between autobiographical memory and identity (e.g. Parfit 1986; Schechtman, 1996), but research results have been inconclusive. Addis and Tippett (2004) observed that 20 people in mild to moderate stages of Alzheimer's disease had a weaker sense of identity than 20 age-matched healthy controls, due to autobiographical memory impairment. However, Naylor and Clare (2008) did not identify a significant correlation between scores on measures of

autobiographical memory and self-concept, and suggested that there is no straightforward connection between autobiographical memory impairment and identity in people with dementia. In a later review, Caddell and Clare (2011) concluded that some parts of identity are well preserved in people with dementia, even at more advanced stages. This was later supported by empirical work, in which Eustache and colleagues (2013) observed that people with mild to moderate Alzheimer's disease (AD) and healthy controls had similarly preserved self-identity and that this remained relatively stable over the two-week testing period. However, participants reported that they were 14 years (on average) younger than they were, and appeared to be living a 'pre-AD identity' suggesting that people with AD may not be able to update their self-knowledge due to episodic memory impairments. Eustache and colleagues (2013) suggested that this supports the concept that identity has two sides. One side is broad and stable throughout life and can persist despite cognitive impairment. The other side varies across time and experiences, is more fragile, and can be disturbed by cognitive impairment (Eustache et al., 2013). This corroborates previous work by Ricoeur (1990) among others, who proposed that identity consists of two sides, 'sameness' and 'selfhood'. 'Sameness' is representations of oneself as the same being. It is forged over time, and therefore deeply integrated, for example, 'I am outgoing'. 'Selfhood' on the other hand, is a more transient representation of oneself, with different characteristics over time, for example, 'I am a PhD student'. Ricoeur's (1990) theory challenged Locke's (1689/2001) concept of the Tabula Rasa, in which every mind is a blank slate at birth, and filled with memories and experiences that shape identity. Ricoeur (1990) argued that individuals have a different sense of identity over time, rather than a 'permanent self', as proposed by Locke. Following their study, Eustache and colleagues (2013) suggested that the two approaches are complementary, and that autobiographical memory impairment can impair the updating of self-representations related to the present, but not enduring personality traits.

Continuity Theory

Atchley (1999, p.1) describes continuity theory as 'a theory of continuous adult development, including adaptation to changing situations'. It suggests that middle-aged and older adults have relatively stable internal and external structures as they age. Internal structures include experiences, preferences, dispositions, temperament and skills, while external structures relate to physical and social environments, such as relationships, social roles, and activities (Atchley, 1989). Atchley (1989) suggests that continuity can be

viewed as an adaptive strategy, in which individuals try to understand and interpret change by recalling their past (Atchley, 1989). Given these ties to recall, Parker (1995) advocates that reminiscence (discussed later in detail, beginning p. 17) is a valuable tool to facilitate a sense of continuity for older adults, and that life stories are a product of reminiscence processes which help individuals to adapt to change. As self-identity can become fragmented over the course of dementia, life stories may be instrumental in facilitating a sense of continuity as people with dementia transition through later life, and adapt to change, while maintaining a sense of self (Whitbourne, 1985; as cited in Parker, 1995),

> Individuals build lifestories as they age, and these stories incorporate past events into an organized sequence, giving them a personal meaning and a sense of continuity….Lifestories are altered throughout the lifespan; they change as details are forgotten and as certain scenes are high- lighted. These biases may be selective mechanisms designed to preserve identity (p. 521)

Kitwood's Theory of Person Centred Care

Person-centred care is a concept that was introduced to dementia care by the late Tom Kitwood, though the term originated in the work of Carl Rogers (1961) in relation to psychotherapy. Kitwood (1988) distinguished person-centred care from approaches that focus solely on the medical and behavioural management of dementia. He advocated that the clinical presentation of dementia is not only a result of health and neurological impairment but also the person's personality, their biography and social psychology between them and those around them (Kitwood, 1993):

> Dementia Presentation (D) = Personality (P) + Biography (B) + Health (H) + Neuropathological Impairment (NI) + Social Psychology (SP)

In 1997, Kitwood's pivotal book, *Dementia Reconsidered*, triggered a major shift in the dementia care community. For the first time, the PERSON with dementia was placed at the centre of care, rather than the person with DEMENTIA. Previously, the person's dementia had been the main focus of care, rather the person themselves. Kitwood (1997, p.8) also introduced the concept of personhood, "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being". He claimed that to

achieve personhood, people with dementia must have the following psychological needs fulfilled: comfort, attachment, inclusion, occupation, and identity. This, in turn, contributed to the central need for love (Kitwood, 1997). Since the introduction of the term 'person-centred care', understanding and expertise in dementia care have evolved, though Brooker (2004) cautions that it's meaning may have become lost. Due to Kitwood's untimely death in 1998, he could not develop or clarify the concept of person-centred care further. Using his work as a foundation, Brooker (2004) later went on to clarify what person-centred care constitutes in relation to dementia. She proposed that person-centred care (PCC) encompasses four key elements:

1. Valuing people with dementia and those who care for them (V)
2. Treating people as individuals (I)
3. Looking at the world from the perspective of the person with dementia (P)
4. A positive social environment in which the person living with dementia can experience relative well-being (S)

Therefore, PCC = V + I + P + S (Brooker, 2004, p. 216).

Person-centred care is viewed as the fundamental value in caring for somebody with dementia. It is much more than individualised care, but rather a movement that reaches much further (Brooker, 2004). It requires that care providers recognise each person as a unique individual, with a unique biography and identity. Bruce and Schweitzer (2008) list several ways in which awareness of a person's life story contributes to person-centred care, including the of understanding meaning and behaviour, facilitating communication, supporting identity and providing ideas for meaningful occupation. Knowledge of people's life stories is therefore considered essential to provide true person-centred care. Bell and Troxel (2001), argue that a person's biography is as important to person-centred care, as a medical history is to medical care.

Moving from pharmacological to psychosocial interventions
Despite ongoing efforts, a disease-modifying treatment for dementia has yet to be developed, and people with dementia are not living as well as they can be (Dowrick & Southern, 2014). The most prevalent unmet needs among people with dementia are psychological distress, daytime activities, and companionship (Bakker et al., 2014; Kerpershoek et al., 2017; Miranda-Castillo, Woods, & Orrell, 2013; Orrell et al., 2008; van

der Roest et al., 2009). Approximately 90% of people with dementia are affected by distress that leads to behavioural, psychological, and social challenges at some point over the course of the disease (Ballard, Corbett, Chitramohan & Aarsland, 2009). This is also distressing and concerning for caregivers and can present challenges for treatment and care (Hurt, 2008; Rosdinom, Zarina, Zanariah, Marhani & Suzaily, 2013). In the past, pharmacological interventions were the first port of call to relieve these challenges. Now, there is now a growing consensus that psychosocial interventions should be used in the first instance, as evidence shows that the risks of antipsychotic prescribing outweigh the benefits (Corbett, Burns, & Ballard, 2014; Orgeta, Qazi, Spector, & Orrell, 2014; Testad et al., 2014). The aim of psychosocial interventions is to improve quality of life and to maximise capacity and capability despite cognitive decline (Rabins, 2007). There are promising research results that psychosocial interventions can significantly benefit people with dementia, caregivers, and relatives, though the evidence base is still being developed, and more high-quality research is needed (Lawrence, Fossey, Ballard, Moniz-Cook, & Murray, 2012; Olazarán et al., 2010; Orgeta et al., 2014; Testad et al., 2014).

Reminiscence Therapy

Reminiscence Therapy is one of the most popular psychosocial interventions for people with dementia. Simply put, it is 'the discussion of past activities, events and experiences, usually with the aid of tangible prompts' (Woods, Spector, Jones, Orrell, & Davies, 2005, p. 2). 'Prompts' might include photographs, letters, music, certificates, or videos. The development of reminiscence as a therapeutic intervention is often traced back to the work of Robert Butler (1963). Previously, reminiscing was viewed as being 'stuck in the past'. However, Butler introduced the concept of Life Review, a natural reflection on life's experiences, both positive and negative. This challenged negative perspectives of reminiscence and helped it to be viewed as a necessary and positive evaluative process. Reminiscence also became associated with Erikson's (1950) psychoanalytic theory of psychosocial development, the first theory of personality to include older adults. According to this theory, a person's final stage of development (Ego Integrity versus Despair), involves looking back to resolve one's accomplishments and losses, attain 'wisdom', and avoid despair. Later, in the 1970s, a pivotal study of reminiscence took place (Langer, 2009). Two groups of older men were asked to imagine themselves at 55 years of age. One group was placed in an environment mirroring that era, with 1950s radio, décor, TV, food, and media, while the other was placed in a 1970s environment. After five days,

men in both groups showed physical and cognitive improvements, but these were more significant in those who were assigned to the 1950s environment (Langer, 2009). This study was instrumental in accelerating the popularity of reminiscence therapy.

The first identified study of reminiscence therapy for dementia was carried out by Kiernat (1979). In the following years, its use in dementia care in the UK was popularised by Norris (1986) among others and implemented widely. Since its introduction, reminiscence has encompassed various definitions, conceptualisations, theoretical foundations, and goals. This has created some barriers in assembling a high-quality evidence base of its effects on people with dementia, as interventions are not often reported in detail, creating difficulty in understanding what aspects or approaches of interventions were most successful. Following a concept analysis of reminiscence in relation to dementia, three reoccurring attributes were identified:

1. Reminiscence is a process of recall, which occurs in stages.
2. Reminiscence is an interaction, which involves recalling or telling of early events or a memorable early experience which may occur with or without specific purposes.
3. Reminiscence is an interaction between the person and one or more individuals. (Dempsey et al., 2014, p. 179)

Classifications of Reminiscence Therapy

There have been four main taxonomies of the types and functions of reminiscence therapy since the 1990s. Wong and Watt (1991) described seven types of reminiscence comprising integrative reminiscence, instrumental reminiscence, transmissive reminiscence, escapist reminiscence, defensive reminiscence, obsessive reminiscence, and narrative reminiscence. Later, Webster (1993) developed the Reminiscence Function Scale, which encompassed eight primary functions of reminiscence: boredom reduction, death preparation, identity, problem-solving, conversation, intimacy maintenance, bitterness revival, and teach/inform. Gibson (1994) presented just two types of reminiscence: general reminiscence that uses broad and loosely relevant triggers to prompt conversation; and specific reminiscence, that uses highly relevant personal stimuli related to a person's life history. More recently, Westerhof, Bohlmeijer, and Webster (2010) distinguished between three categories of 'therapeutic' reminiscence therapy: simple reminiscence, life review, and life review therapy. Simple reminiscence involves giving

general prompts to a person concerning their past, to stimulate the recall and discussion of pleasant memories (Haight & Dias, 1992; Westerhof et al., 2010). Life Review can be considered 'integrative reminiscence' which is a more structured, systematic, evaluative process in which the objective is to achieve a sense of self-worth, and reconcile with one's past (Westerhof et al., 2010; Wong & Watt, 1991). Finally, Life Review Therapy is essentially Life Review, with some additional therapeutic features such as elements of problem-solving therapy or narrative therapy (Westerhof et al., 2010).

Life Story Work

LSW is one of the many facets of reminiscence therapy. The terms are often used interchangeably, but LSW is usually more personal and individual, with an emphasis on capturing memories (Eley & Kaiser, 2017; Woods & Subramaniam, 2017). It is a biographical approach and considered particularly useful at times of change and transition (Woods & Subramaniam, 2017). Although life storybooks are often an outcome of life review, LSW itself should be considered a 'therapeutic activity' as it may provide enjoyment and improve wellbeing for the person rather than a 'therapy' (McKeown et al., 2017). Drawing upon previous work (e.g. Murphy 1994; Murphy & Moyles, 1997), the following definition of LSW was proposed,

> ...LSW is a form of intervention carried out in health or social care practice, and is an umbrella term, encompassing a range of terms/interventions, for example, biography, life history, life stories. It is usually undertaken to elicit an account of some aspect of a person's life or personal history that goes beyond a routine health assessment undertaken to plan care and treatment and aims to have an impact on the care the person receives. LSW implies collaboration with another/others to gather and record information, and it usually results in a 'product', for example, a storybook, collage, notice board, life history/biography summary, or tape recording. It is an ongoing, dynamic process rather than a task to be completed and is usually planned and purposeful, although it does not need to be carried out systematically (McKeown, Clarke, and Repper, 2006, p. 238).

Given that LSW draws upon aspects of autobiographical memory that are generally less affected by dementia (i.e. early memory for specific events), it can be a good fit for people with dementia as it provides an opportunity to concentrate on those memories that are

more intact, and focus on what the person *can* remember, rather than memory that is more impaired (Addis & Tippett, 2004; Kopelman, 1989).

Although LSW is a more specific term than reminiscence, it embodies a range of approaches (Woods & Subramaniam, 2017). For example, some studies that refer to LSW carry out an individualised integrative process of life review with participants, while others document less intensive, and less structured approaches with the simple recording of anecdotes (Woods & Subramaniam, 2017). LSW is associated with outcomes such as improved quality of life, personhood, self-identity, understanding, communication and relationships (Bruce & Schweitzer, 2008; Gridley, 2017). In care settings, LSW can improve care, facilitate the understanding of behaviour, communication, and provide a common ground, in addition to contributing to improved staff satisfaction and motivation (Bruce & Schweitzer, 2008; Gridley, 2017). However, outcomes can vary considerably depending on the specific type of LSW. Following a review of LSW resources, Kindell, Burrow, Wilkinson, and Keady (2014) have emphasised the need to clarify the focus and goals of LSW for people with dementia. They proposed that LSW creates various points of connection, which are each associated with different outcomes,

1. Emotional connections: LSW as a psychological process to help the person connect positively with their own identity, and with others to promote emotions and coping on a psychological level.
2. Interactional connections: LSW as a means of creating a life storybook or other resource, to support communication, memories, and conversation on an ongoing basis.
3. Building new connections: LSW as a process to build and develop supportive relationships between people with dementia, their relatives, and care staff to challenge depersonalised care.
4. Practical care connections: LSW as a way to inform the creation of a suitable care plan, built around the person's uniqueness.

While LSW is associated with several benefits, there are also limitations and challenges to be considered. McKeown, Ryan, Ingleton, and Clarke (2015) conducted an in-depth case study analysis, to explore the experiences of people with dementia, relatives, and care staff in relation to LSW in health and social care settings. They identified challenges relating to

personal disclosures, variable quality of life storybooks, enabling people to tell their own life story rather than their relative or staff members. McKeown, Gridley, and Savitch (2017) warn that life storybooks can be underused, or even overused. Often life storybooks can be put away 'for safe keeping' or caregivers may not even know of their existence. Overuse may occur when others become so interested in the life storybook that they do not realise the person with dementia is overwhelmed or in need of a break during the activity. Perhaps the happy medium is to see life storybooks being used, but the other person or people remain vigilant of the experience of the person with dementia while using them. Other challenges revolve around consent, privacy, the recall of upsetting memories, ownership of the life story, and relaying sensitive information about others (Batson, Thorne & Peak, 2002; Grøndahl, Persenius, Baath, & Helgesen, 2017; McKeown et al., 2017; Murphy, 2000). Providing training and supervision to LSW facilitators to handle any personal disclosures or distressing memories sensitively is essential, as people with dementia need to be supported in LSW. Gibson (2005) advises that personal disclosures should be omitted from any records, but not be excluded from discussions. It is also important to acknowledge that not everyone will enjoy, or be comfortable, with discussing the past and that other psychosocial interventions might be more to their liking (McKeown et al., 2017).

Previous reviews of reminiscence therapy and life story work

In an early Cochrane review, reminiscence was associated with some improvements in cognition, mood, general behaviour, carer strain, and staff knowledge (Woods et al., 2005). However, the meta-analysis comprised just four small and relatively low-quality randomised controlled trials (RCTs), that were a mixture of group and individual intervention modalities. The authors emphasised the need to follow clear and detailed protocols, and to conduct rigorous research, so that key elements of reminiscence can be defined and evaluated (Woods et al., 2005). In a later review of seven studies, reminiscence therapy was associated with improved mood and aspects of cognitive function (Cotelli, Manenti, & Zanetti, 2012). Again however, studies were small, employed various methodologies, and were of relatively low quality. Kwon, Cho and Lee (2013) reviewed 10 studies of reminiscence therapy for dementia and reported improvements in cognition, communication, and quality of life. However, the included studies were not referenced or described, and the review methods were not reported in detail. In a review of psychosocial interventions to address distress in people with dementia in care home

settings, Testad and colleagues (2014) observed that reminiscence was consistently associated with improved mood, though the six included RCTs were quite varied in terms of intervention length and frequency. Most recently, Huang and colleagues (2015) identified a small effect of reminiscence therapy on cognition, and a moderate effect on depression in a review of 12 studies. The review authors also carried out sub-group analyses to compare the effects in community and care home settings and found that reminiscence had a more significant effect on depressive symptoms in people in care homes. However, studies were of poor quality, and two-thirds did not report clear descriptions of the treatments. Furthermore, intervention modalities and differing control conditions could not be explored.

More specific reviews of reminiscence therapy for dementia have also been carried out. In a review of six studies, Kim and colleagues (2006) highlighted early evidence of group reminiscence being associated with improvements in communication and cognition, and recommended it as a cognitive-linguistic intervention for people with dementia. Later, Blake (2013), conducted a 'mini-review', exploring the effects of group reminiscence on depressive symptoms in people with dementia, including papers from four databases published after 2002. Four trials were identified, all showing significant benefit for depressive symptoms, though again, the quality of studies was poor. Subramaniam and Woods (2012) focused on individual reminiscence interventions for people with dementia. The review included five RCTs, all of which happened to take place in care homes. The most positive results concerning mood, wellbeing, and aspects of cognitive function were in the three studies that involved the creation of a life storybook (Subramaniam & Woods, 2012).

Although studies of LSW interventions are typically included in broader reminiscence reviews, there appear to be two published reviews specific to LSW for dementia. In a review of LSW intervention methodologies in care home settings, Moos and Bjorn (2006) found that LSW was associated with positive self-identity, enhanced quality of life, and improved social interactions. In the five interventions that used life storybooks, the quality and quantity of interactions between participants with dementia and care staff improved. It was concluded that more qualitative work is needed. In a recent review of both qualitative and quantitative studies, Grøndahl and colleagues (2017) explored the use of life stories with people with dementia, their relatives, and care staff. Following an

integrative analysis of five studies, the authors concluded that the use of life stories in care homes might contribute to the 'maintenance of the person with dementia as a whole person' (p. 4). They identified how using life stories enabled the person with dementia to be heard, relatives to see the whole person, and care staff to understand the person with dementia and their relatives. However, it was also emphasised that very few studies have focused on how to actually use life stories, and more rigorous research was called for.

While the above reviews document promising evidence in favour of reminiscence work, the evidence is limited by small sample sizes, different intervention approaches, heterogeneous groups, and relatively low-quality studies. There has been a resounding call for more high-quality research of reminiscence therapy for dementia, with detailed reminiscence methods and comparable groups. In recent years, large, high-quality RCTs of reminiscence therapy for people with dementia have been published (e.g. Charlesworth et al., 2016; O' Shea et al., 2014; Woods et al., 2012). Accordingly, this thesis includes a review of reminiscence therapy for people with dementia, including subgroup analyses of different reminiscence modalities and settings in Chapter 2.

Digital reminiscence and life story work

There is increasing interest in how information and communication technology (ICT) can be used to assist people with dementia (SCIE, 2012). One application has been using ICT based interventions in reminiscence and LSW. ICT provides access to a range of stimulating multimedia materials such as archived TV and radio broadcasts, videos, and photographs. The combination of video, music, and audio narration with photographs and text can then create a compelling multisensory experience for the person with dementia. As interest in using digital technologies for reminiscence purposes developed, Subramaniam and Woods (2010), set out to explore the feasibility of ICT-based reminiscence interventions for people with dementia, in a review of 11 studies. Although most included trials were small pilot studies, it was concluded that the approach is feasible. The authors highlighted the need for more research, to understand how these systems can best be used therapeutically with people with dementia as well as their caregivers (Subramaniam & Woods, 2010).

Several studies have found that people with dementia and caregivers prefer digital reminiscence approaches to conventional ones (Astell et al. 2004; Astell et al., 2005; Astell, Ellis, Alm, Dye & Gowans, 2010; Sarne-Fleischmann & Tratinsky, 2008). In Scotland, a

touchscreen multimedia device called CIRCA was developed for the purposes of reminiscence with people with dementia. When digital reminiscence using CIRCA was compared to conventional reminiscence, it emerged that digital reminiscence was less hard work for family caregivers and care workers, and more enjoyable for all involved. (Astell et al., 2005; Astell et al., 2010; Astell et al. 2004). Furthermore, when participants with dementia used CIRCA, they were found to play a more active role in conversations than when traditional reminiscence was used (Alm et al., 2004). Similar multimedia devices incorporating generic or personalised reminiscence stimuli have also been found to have positive effects on users both at home and in care facilities (Kerssens et al., 2015; Olsen, Hutchings & Ehrenkrantz, 2000).

The creation and use of a digital life story 'book', in which the person can combine various multimedia stimuli, is a growing trend in digital reminiscence (Woods & Subramaniam, 2017). Following their review of ICT based reminiscence, Subramaniam and Woods (2010) suggested that these biography-type systems are one of the best ways of maintaining the identity of the person with dementia, a key objective of reminiscence work. There is some early, promising work supporting this trend (Critten & Kucirkova, 2017; Damianakis, Crete-Nishihata, Smith, Baecker, & Marziali, 2010; Ludwin & Capstick, 2015; Lynch, Reilly, Lowe, Rhoda, & McCarron, 2016; Stenhouse, Tait, Hardy, & Sumner, 2013). For example, Critten and Kucirkova (2017) supported three people with dementia to create personalised digital life stories on an iPad app. They found that the digital life story book helped participants to access their personal memories, and were excited to create and share their digital life stories. An Irish study found that digital life stories were a powerful tool in facilitating communication and supporting person-centred care in a disability support service with people with an intellectual disability who had a diagnosis of dementia (or were at an increased risk of it). The digital life story book included photos, audio narration, music and video clips and was created for the person with dementia with the support of their relatives and close caregivers (Lynch et al., 2016). In a community setting, Stenhouse and colleagues (2013) led a four-day digital story-making workshop, in which they supported participants to create their digital life stories with photographs, audio narration and music through person-centred relationships. Using participant reports and facilitator reflections, they found that the participants became more confident and more engaged throughout the workshops, and had improved communication and increased confidence. It was suggested that the social interaction and expression of

themselves through their digital life stories had a therapeutic value to participants.

Overall study design

The work presented in this thesis was undertaken as a Knowledge Economy Skills Studentship, supported by European Structural Funds. These studentships are based on a collaboration with a company partner, in this case a North Wales social enterprise 'Book of You'. The collaboration involves the student spending time with the company and designing and implementing research studies in consultation with them to address issues of interest and concern to the company.

Accordingly, the core of this thesis is an evaluation of the services offered by Book of You. This was done with a view to understanding more about the effects of the service in addition to the experiences of those receiving it, and to make recommendations regarding further development of the service. Chapters 3 and 4 present this evaluation, first of local face-to-face services and then of an attempt to offer the service through a self-guided touchscreen app using a Citizen Science approach. These chapters are summarised in the following section 'Structure of the thesis'. Developing optimal pathways for service delivery is a key theme that runs alongside this throughout this thesis, and is discussed in more detail in Chapter 7 (p. 174).

The remaining chapters support this development through a variety of methods. In Chapter 2, existing literature on the effectiveness of reminiscence work is reviewed, with the intention of providing Book of You with the best available, high quality evidence in making their case to service commissioners. Chapter 5 explores preferences of people with dementia and carers relating to specific options being considered by Book of You for their service development. Finally, Chapter 6 explores the market context for life storybook apps, to inform Book of You in relation to potential next steps following the difficulties experienced with the self-guided touchscreen app in Chapter 4.

Thus, whilst each chapter has a specific and distinct research design, the overall theme is a multiple mixed methods evaluation to inform service development, applying research to real-world application.

The Medical Research Council Framework (MRC, 2008) for Complex Interventions identified four key components for the evaluation of complex interventions: 'development', 'feasibility/piloting', 'evaluation' and 'implementation' (see Figure 1.1). According to the

MRC, each stage is equally important and neglect of development and piloting work may not be conducive to the production of strong interventions for evaluation and
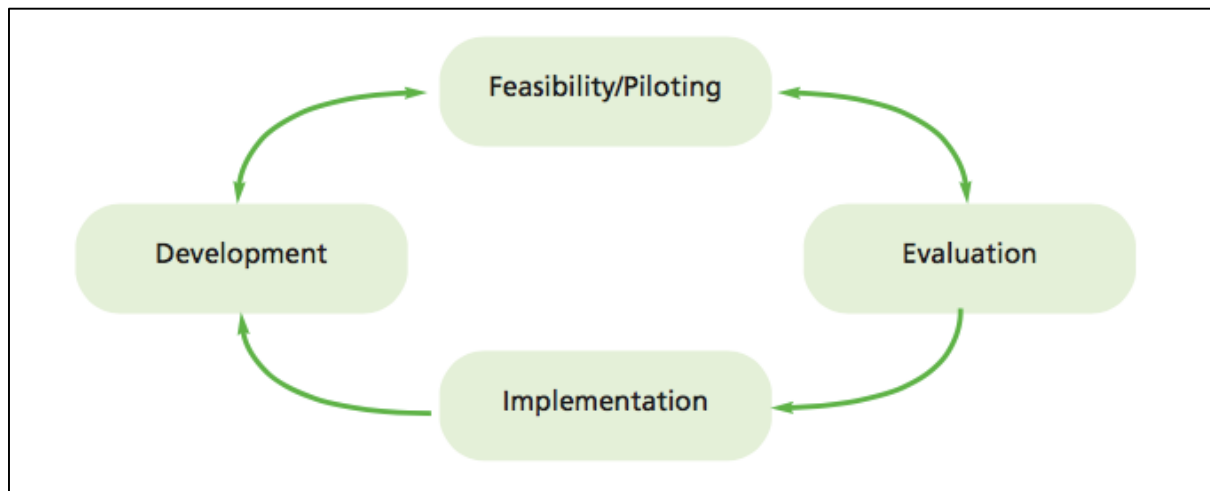
Figure 1.1. MRC Framework for the evaluation of complex interventions (adapted from MRC 2008). From 'Randomisation and chance-based designs in social care research' by B. Woods & I. Russell, 2014.

implementation. The work presented in this thesis falls within the 'development' and 'feasibility / piloting' phases of the model, with consideration at an early stage of real-world implementation, but effectively taking forward ground work towards larger, controlled studies of effectiveness. Within the 'development' phase, the importance of systematically reviewing the evidence (Chapter 2) and considering the possibilities and avenues of implementation are highlighted (Chapters 3-5). In the 'feasibility/piloting' phase, there is an emphasis on small scale work to assess feasibility and potential future evaluation methods, using participant interviews or focus groups (Chapter 3). Given the nature of the funding of this work, it is possible to begin considering elements of the 'Implementation' phase as the service is currently functioning in North Wales.

Theoretical underpinnings

The work in this thesis is underpinned by Kitwood's Theory of Person-Centred Care described earlier in this chapter (p. 15-16). Biography is the essence of reminiscence and life story work, and according to Kitwood (1997), is key to person centred care. Therefore, biography is a central component of this thesis, with each chapter aiming to contribute to greater understanding of the optimal way to facilitate the sharing and understanding of a person's life story, so as to facilitate and improve person centeredness. Kitwood (1993, 1997) and later Brooker (2004) also assert that a person centred approach must include

and value the perspective of the person with dementia. The voice of the person with dementia features significantly in this thesis and underpins both the methodology and the objectives of the chapters. For example, in Chapter 3, people with dementia shared their personal experiences and perspective of a local LSW service through semi-structured interviews as part of an evaluation of the service. Later, in Chapter 6, people with dementia were asked to provide their reviews of digital LSW apps in an attempt to evaluate and document those that are most accessible for this group. In both these chapters, the outlook of the person with dementia was paramount to the evaluation (which is crucial as they are the target population). The core values of this theory are again emphasised through a Citizen Science approach in Chapter 4 whereby people with dementia and those who care for them were empowered to become more than study participants and contribute to the research study on a greater level.

Objective of the thesis

The overall aim of this thesis is to make an original contribution to literature and practice on the topic of reminiscence and digital LSW for people living with dementia and their caregivers. The specific objectives of each research chapter are as follows:

Chapter 2: To systematically review the evidence for the effectiveness of reminiscence therapy and life story work with people with dementia.

Chapter 3: To explore and understand more fully the experiences of those using the Book of You services, including perspectives of people with dementia, family carers and care staff in care homes.

Chapter 4: To explore the potential of Book of You as a self-guided digital life story work app, and the experiences of people with dementia and caregivers who use it.

Chapter 5: To understand more fully the aspects of digital life story work services that are important to people with dementia and caregivers.

Chapter 6: To explore and evaluate existing digital life story work apps that are available for people with dementia and caregivers.

Structure of the thesis

This thesis consists of seven individual chapters. Five are based on journal articles which have been submitted for publication (Chapter 2, 3, and 4), or will be submitted for publication shortly (Chapter 5 and 6).

Chapter 1, the current chapter, provides an overview of reminiscence and digital LSW including a brief overview and theoretical background.

Chapter 2 is a systematic review exploring reminiscence therapy for dementia. It 'sets the scene' of the current research landscape following the recent publications of some new high-quality RCTs. This is a summary review, following my role in producing the most recent Cochrane review of reminiscence therapy for dementia (submitted January 2018), and is focused on the domains of well-being, cognition, mood, and communication. The review included 22 randomised controlled trials, with 16 included in the meta-analysis. Sub-group analyses of intervention modality and setting were also carried out. The review highlights that reminiscence has some positive, but inconsistent effects in all four outcome domains, which vary across intervention modality and setting.

Chapter 3 presents a qualitative exploration of user experiences of three different implementations of a digital LSW service. The objective of this study was to gain insight into participant experiences of the intervention, the advantages and limitations of using a technological interface for LSW, and how context impacted participants' experiences. All participants reported that they enjoyed the intervention, found it useful, and valued the ability to add multimedia materials to the digital life storybook. Limited ICT skills were a significant barrier for many participants, and some participants with dementia felt upset or frustrated at times during the LSW sessions. This chapter provides evidence for the feasibility, and the positive impact of a supported digital LSW intervention and digital life storybook.

Chapter 4 is a study of a self-guided, app-based, digital LSW intervention, using a Citizen Science approach. The aims of this study were to investigate the feasibility of a digital life storybook app and the overall intervention approach, and explore the effects of the intervention in relation to quality of life, and users' experiences with the app. To do this, we assessed momentary session feedback, usage data, quantitative measures of well-being, and carried out follow-up phone interviews. No significant effects or correlations

were found on any outcome measure. Engagement with the app was low, though it appeared to provide some enjoyment to those who used it. Qualitative feedback was varied, with respondents citing several different reasons for not, or no longer engaging with the app. The approach shows some potential, but more motivators and fewer barriers are required to improve engagement in future research and practice.

Chapter 5 is an exploration of the preferences of people with dementia and their caregivers, concerning digital LSW services. Caregivers completed an online discrete choice experiment, while participants with dementia completed a simplified, online survey. A private one-to-one intervention setting (rather than a community group setting) appeared to be the most important attribute to both participant groups, while user ICT skills affected the preferences of both groups.

Chapter 6 is a review of touchscreen apps that facilitate digital LSW for people with dementia and their caregivers. The aim of the review was to document currently available apps and evaluate their accessibility for people with dementia, through user reviews and evaluations. This was done with the view to providing practical advice and recommendations to prospective users while highlighting potential improvements that can be made by developers to improve app accessibility. Nine apps were evaluated and reviewed by people with dementia, or caregivers of people with dementia.

Chapter 7 concludes this thesis. It brings together the findings from all of the previous chapters, as well as identifying the implications and limitations of those findings. The possible directions for future research are also discussed in this concluding chapter.

Contribution of others to the thesis

As well as contributions from my supervisor, others have contributed towards some chapters in the thesis. Chapter 2 is based on a Cochrane Review, in which Ms Emma Farrell was a co-author, and assisted with screening and data extraction. Dr Gill Windle provided helpful feedback on early drafts of Chapter 3. Ms Alli Suddaby assisted with recruitment in Chapter 4. Dr Emily Holmes and Dr Siobhan Bourke offered advice regarding the design of the discrete choice experiment in Chapter 5. In Chapter 6 Ms Maria Caulfield carried out an independent search for apps, and Dr Phil Joddrell provided an independent evaluation of the included apps. Members of the Irish Dementia Working Group, and others who preferr to remain anonymous provided user reviews in Chapter 6.

Chapter 2. Reminiscence therapy for dementia: A systematic review of the evidence from randomised controlled trials

Summary

Reminiscence therapy is a popular psychosocial intervention that is widely used in dementia care. It involves the discussion of past events and experiences with others, using tangible prompts to evoke memories or stimulate conversation. This review evaluates the effectiveness of reminiscence therapy for people living with dementia. It includes studies from the specialised register of the Cochrane Dementia and Cognitive Improvement Group (ALOIS). Searches yielded 185 records of which 22 studies (n = 1,972) were eligible for inclusion. The meta-analysis is comprised of data from 16 studies (n =1,749). The review included four large multi-centre high-quality studies and several smaller studies of reasonable quality. Outcomes of interest were quality of life, communication, depressed mood, and cognition. Reminiscence therapy has the potential to improve these outcomes at post-treatment and follow-up, but effects were inconsistent across intervention modalities (group/individual) and settings (care home/setting). Individual approaches were associated with improved cognition and mood, while group approaches were linked to improved communication. The impact on quality of life appeared most promising in care home settings. There remains much diversity in reminiscence approaches, making it difficult to compare them. Development of more detailed manuals and training is needed so that that common approaches can be established and shared.

Introduction

Reminiscence therapy is one of the most popular psychosocial interventions for people living with dementia. Although there are many conceptualisations of reminiscence, it is typically described as the discussion of past activities, events, and experiences, usually with the aid of tangible prompts from the past such as photographs, music, or familiar objects (Woods et al., 2005). Digital reminiscence therapy has also become popular in recent years, taking advantage of multimedia resources, archives, and apps (Subramaniam & Woods, 2010).

The development of reminiscence therapy is often traced back to the work of Robert Butler (1963), who introduced the concept of life review – the reflection on one's life experiences, and thereby promoting adjustment and integrity. Previously, reminiscence had been perceived as harmful and pathological, but Butler's work helped it to be viewed in a new light, as a way of helping people to make sense and meaning of life, and of promoting adjustment and integrity. This interpretation of reminiscence also fitted well with Erikson's (1950) late life stage of development (Integrity V Despair), in which the person reflects on life seeking meaning and satisfaction.

Reminiscence therapy has long been associated with a wide range of definitions, aims, and conceptualisations. Westerhof and colleagues (2010) proposed three main classifications of reminiscence: simple reminiscence, life review, and life review therapy. 'Simple reminiscence' is the recollection and sharing of selected personal and shared memories, typically in a group setting. 'Life review' is a structured and chronological process, with the aim of navigating and evaluating positive and negative memories. It is generally carried out on a one-to-one basis. 'Life review therapy' was classified as an extension of life review, and includes additional therapeutic elements with the aim of helping people re-evaluate negative life events in a more positive way. Another term, 'life story work', is frequently associated with life review and other aspects of reminiscence. Here, the emphasis is usually on creating a narrative biography, or another tangible outcome such as a memory box or scrapbook, which can be used to benefit the person after the completion of the intervention (McKeown et al., 2006; Murphy, 2000).

The first identified study of reminiscence therapy for people with dementia was almost 40 years ago (Kiernat, 1979). Soon after, it was introduced into dementia care by Norris (1986) and implemented widely. Reminiscence therapy became popular in practice, though research did not progress with the same momentum. However, reminiscence has consistently been found to have positive effects on older people with depressed mood (Pinquart, Duberstein & Lyness, 2007; Bohlmeijer, Smit & Cuijpers, 2003) including those living in long-term care environments (Zhang, Hwu, Wu & Chang, 2015). Similarly, life review has been found to be helpful in preventing depression and improving quality of life in older adults (Bohlmeijer, Roemer, Cuijpers & Smit, 2007; Pot et al., 2010). From a cognitive standpoint, reminiscence may be valuable for people with dementia as there is an emphasis on long-term memories, which people with dementia (like all older adults) recall more often than recent memories (Morris, 1994). Similarly, earlier memories often represent well-rehearsed anecdotes, meaning that reminiscence therapy may be a useful tool for communication because the person with dementia can speak confidently about these memories.

Previous reviews of reminiscence therapy for people with dementia have yielded some positive results, though the quality of included studies has been an ongoing issue. In the first Cochrane Review of this topic, Woods and colleagues (2005) identified a positive effect of reminiscence therapy on cognition scores at later follow-up time points, but not at post-treatment. Just 5 studies were included, and the authors stressed the need for large, high-quality studies, and the use of detailed intervention protocols to ensure that interventions reflect true reminiscence therapy (Woods et al., 2005). Two reviews of 7 and 12 studies respectively, found that reminiscence was associated with improved cognitive function and depressed mood, though review authors highlighted the low quality of studies and absence of intervention protocols (Cotelli et al., 2012; Huang et al., 2015). Testad and colleagues (2014) also found that reminiscence was consistently associated with improved mood, but highlighted the variation in intervention length and frequency among the six included studies. In a review of 10 studies, Kwon and colleagues (2013) found that reminiscence was associated with improved cognitive function and quality of life, though the included studies were not referenced. A review of individual reminiscence therapy found that structured life review resulting in the production of a life storybook had positive psychosocial outcomes for people with dementia, while less structured simple reminiscence interventions were not as effective (Subramaniam and Woods, 2012). Kim

and colleagues (2006) focused on group reminiscence therapy and identified a significant benefit to communication and cognition (Kim et al., 2006). Blake (2013) also investigated the effects of group reminiscence work in a 'mini-review'. There was a significant benefit on depressive symptoms though again, the quality of the four included studies was poor.

Both the volume and quality of reminiscence research has advanced significantly in recent years, particularly with the recent completion of new large, multicentre RCTs (e.g. Amieva et al., 2016; Charlesworth et al., 2016). Therefore, a further review of reminiscence therapy for dementia is timely. This review was carried out with the Cochrane Collaboration Cognitive Impairment and Dementia Group (Woods, O' Philbin, Farrell, Spector, & Orrell, 2017). The aim of this review is to review the quality and nature of evidence from studies of reminiscence therapy for dementia, and evaluate its effectiveness in the domains of quality of life, communication, depressed mood, and cognitive function.

Methods

Search Method

A systematic search for RCTs evaluating the effects of reminiscence therapy for people with dementia was carried out. The search term 'reminiscence' was used to search the ALOIS database four times between October 2015 and April 2017. Studies were identified from the following sources:

1. Major healthcare databases: Medline, Embase, Cinahl, PsycINFO, and Lilacs
2. Trial registers: ISRCTN; UMIN (Japan's Trial Register); the WHO portal (which covers ClinicalTrials.gov; ISRCTN; the Chinese Clinical Trials Register; the German Clinical Trials Register; the Iranian Registry of Clinical Trials and the Netherlands National Trials Register, plus others)
3. *The Cochrane Library*'s Central Register of Controlled Trials (CENTRAL)
4. Grey literature sources: ISI Web of Knowledge Conference Proceedings; Index to Theses; Australasian Digital Theses
5. Additional resources: The Alzheimer's Society library, published letters in the BPS (British Psychological Society) magazine, personal contact with various specialists in the field.

Inclusion criteria

Types of studies. RCTs (including randomised cluster trials and crossover trials) with a passive control group that investigated the effects of reminiscence therapy as an intervention for dementia were considered for this review. Studies needed to be published in a peer-reviewed journal, and be available in English. There were no specific criteria relating to study settings.

Interventions. Interventions needed to meet the definition of reminiscence therapy described in the introduction above (Woods et al., 2005) and be aimed at people with dementia. The minimum intervention duration was 4 weeks or 6 reminiscence sessions. Studies were included if a comparison was made to 'no treatment', 'treatment-as-usual' or passive control conditions. Comparisons with other types of activities or therapies were not considered for this review.

Participants. Participants with a diagnosis of dementia (of any type or severity) were included. Those with mild cognitive impairment (MCI) were not included. Family or professional caregivers were included where studies recruited dyads.

Outcome measures. Studies that assessed the effects of a reminiscence therapy intervention on people with dementia were included, provided that standardised assessments, rating scales, or questionnaires were used. Outcome measures could be self-reported, proxy-reported, or observational. Outcomes that were measured at post-treatment (typically immediately after, or within a month of the intervention) and follow-up (usually 1 month to 6 months post-intervention) were considered. Outcomes of interest were:

- Quality of life
- Communication
- Depressed mood
- Cognition

Adverse outcomes were also considered. Reminiscence may bring up some sad or upsetting memories, which should be anticipated and managed sensitively by facilitators. Potential adverse outcomes were identified through negative responses in the quality of life or mood of participants.

Data extraction and management

Two reviewers worked independently to extract descriptive study characteristics, quality information, and results of analyses from published reports. Where necessary, additional information was requested from study authors. This review is concerned with change scores (improvements/decrements) between baseline and later assessments. The mean, standard deviation, and the number of participants for each treatment group at each time point were extracted. The required summary statistics from baseline were then calculated by hand. In this case, a zero correlation between baseline and later assessments was assumed. This is a conservative method which overestimates the standard deviation of the change from baseline but is considered to be preferable in a meta-analysis. Reviewers

compared and reached consensus on the extracted data and calculated summary statistics. The information was recorded and entered into Review Manager (RevMan) 5.3 software (2014).

The review authors sought to obtain data from intention to treat analyses. Where this was not available, they extracted the data reported on those who completed the trials. In cross-over trials, only data from the first intervention phase were included. Where studies used cluster randomisation, this was adjusted for if the study was of sufficient size.

Two review authors independently assessed the quality of each study and rated it using the methods and guidelines in the Cochrane Handbook of Systematic Reviews of Interventions (Higgins & Green, 2011). Cluster trials were also assessed for additional biases.

Data analysis

RevMan 5.3 software (2014) was used. The meta-analyses presented overall estimates of the treatment difference from a fixed-effects model. Heterogeneity was assessed using a standard Chi-square statistic and an i^2 statistic. To interpret heterogeneity, Cochrane guidance (Higgins & Greene, 2011) was followed (i.e. 0% to 40% might not be important; 30% to 60% may represent moderate heterogeneity, 50% to 90% may represent substantial heterogeneity; 75% to 100% is considerable heterogeneity). Where there were high levels of heterogeneity of the treatment effect between studies, a random-effects model was used. This produces wider confidence intervals than a fixed-effects model. Where pooled trials used the same measure to assess an outcome, the mean difference (MD) was used. Where pooled trials used different measures to assess the same outcome, the standardised mean difference (SMD) was used. Where studies used more than one instrument to measure the same outcome, the analysis was conducted using the most common or extensive measure.

<div align="center">**Results**</div>

Trials

From the initial set of references identified by the updated systematic searches since the previous review (Woods et al., 2005), 185 additional records were identified across four searches. Records were independently assessed screened by two study authors (EF & LO'P) who then reached a consensus on inclusion/exclusion. The original review (Woods et al., 2005) included five studies (Baines, Saxby & Ehlert, 1987; Goldwasser, Auerbach & Harkins, 1987; Lai, Chi & Kayser-Jones, 2004; Morgan, 2000; Thorgrimsen, Schweitzer & Orrell, 2002). However, the Morgan (2000) study is now a published journal article (Morgan & Woods, 2012) rather than a doctoral thesis. Sixteen new studies met the review inclusion criteria (Akanuma et al., 2011, Amieva et al., 2016, Azcurra, 2012; Charlesworth et al., 2016; Gonzalez, Mayordomo, Torres, Sales & Melendez 2015; Haight, Gibson & Michel, 2006; Hsieh et al., 2010; Ito, Meguro, Akanuma, Ishii & Mori, 2007; Melendez, Torres, Redondo, Mayordomo & Sales, 2015; O'Shea et al., 2014; Sarkämo et al., 2013; Subramaniam et al., 2013; Tadaka & Kanagawa, 2007; Van Bogaert et al., 2016; Woods et al., 2012b; Yamagami, Takayama, Maki & Yamaguchi, 2012). One study recruited participants with Alzheimer's disease (AD) and Vascular Dementia (VD) but analysed the two participant groups separately with a different control group for each disease type (Tadaka & Kanagawa, 2007). For this review, the review authors considered the report to be two separate studies: Tadaka & Kanagawa (2007a) including participants with AD, and Tadaka and Kanagawa (2007b) including participants with VD. Therefore, a total of 22 studies were included in the review. Characteristics of included studies are presented in Table 2.1. Six were excluded from the meta-analyses as they were rated as having an unclear risk of selection bias for randomisation (Akanuma et al., 2011; Baines et al., 1987; Goldwasser et al., 1987; Gonzalez et al., 2015; Hsieh et al., 2010; Yamagami et al., 2012). The review authors attempted to contact the authors of the more recent excluded studies for clarification on randomisation methods but did not receive a response.

Participants, settings, dementia type and severity

Data from 1,972 participants (or dyads) are included in this review. The average participant was over 75 years of age. Fourteen studies recruited participants from residential/hospital care settings, while eight recruited community-dwelling participants

(See Table 2.1). Interventions took place in the care homes where participants resided, or community locations such as day centres.

All studies recruited participants with a diagnosis of dementia. Although most did not specify a diagnosis type in recruitment, three specifically recruited people with a diagnosis of AD (Azcurra, 2012; Gonzalez et al., 2015; Melendez et al., 2015) and one specified a diagnosis of VD (Ito et al., 2007). Most studies sought to recruit participants in the mild to/or moderate stages of dementia, typically using the CDR, GDS, or MMSE to screen potential participants.

Reminiscence Interventions

Most studies implemented simple reminiscence interventions whereby participants took part in discussions about specific themes of the past in small groups (e.g. Akanuma et al., 2011, Amieva et al., 2016, Baines et al., 1987; Charlesworth et al., 2016; Gonzalez et al., 2015; Goldwasser et al., 1987; Hsieh et al., 2010; Ito et al., 2007; Melendez et al., 2015; O'Shea et al., 2014; Sarkämo et al., 2013; Tadaka & Kanagawa, 2007a; Tadaka & Kanagawa, 2007b; Thorgrimsen et al., 2002; Woods et al, 2012b; Yamagami et al., 2012). In one study, care staff were trained to deliver simple reminiscence in small groups following a structured education programme (O'Shea et al., 2014). Five studies implemented the more structured approach of life review (Azcurra, 2012; Haight et al., 2006; Lai et al., 2004; Morgan & Woods, 2012; Subramaniam et al., 2013). One trial (Van Bogaert et al., 2016) used a standardised reminiscence intervention based on the SolCos model (Soltys & Coats, 1994), while another implemented a music reminiscence intervention (Sarkämo et al., 2013). Three studies (Charlesworth et al., 2016; Thorgrimsen et al., 2002; Woods et al., 2012b) implemented joint reminiscence interventions, following the Remembering Yesterday Caring Today (RYCT) program. This was developed by Schweitzer and Bruce (2008) and is a large group-based approach, bringing together people with dementia and family caregivers with a focus on active reminiscence.

The length of the reminiscence interventions ranged from 4 weeks (the minimum number for inclusion in the review) to 24 months. Three studies held monthly or 6 weekly maintenance sessions after the initial interview (Amieva et al., 2016; Charlesworth et al., 2016; Woods et al., 2012b). The total median possible reminiscence exposure time was 11.5 hours (3-39 hours), while the median individual session length was approximately 53

minutes (30 minutes-2 hours). In two studies the session length was unclear (O' Shea et al., 2014; Thorgrimsen et al., 2002).

Quality of Studies

Studies were rated as having a low risk (+), unclear risk (?), or high risk (-) of bias in each quality domain. Ratings are reported in Table 2.1.

Randomisation (selection bias). All studies randomised participants to treatment or control groups. This was a criterion for inclusion in the review. Several used computerised randomisation, though some used more basic methods, such as sealed envelopes. Three studies used cluster randomisation (Gonzalez et al., 2015; Melendez et al., 2015; O' Shea et al., 2014), and three used an accredited trials unit (Charlesworth et al., 2016; Woods et al., 2012b; Subramaniam et al., 2013). As mentioned previously, six studies did not detail the method of randomisation and were excluded from the meta-analyses.

Allocation concealment (selection bias). Allocation concealment details were rarely reported in detail, even when further information was requested. Replies generally stated that there had been adequate allocation concealment, and in these cases, good practice has been assumed. Low-risk methods included the use of independent researchers, remote services, and sealed envelopes.

Blindness. As with most psychosocial interventions, participants cannot be blinded to the experience of taking part in an intervention (or not taking part in the case of control groups) making performance bias difficult to evaluate.

The majority of studies used independent researchers who were blinded to group allocation to complete the outcome assessments. Proxy-rated measures were typically completed by a person who knew the participant and could reliably comment.

Contamination was a risk in care home studies in which control and intervention participants resided and socialised together. Two studies seemed to have at least one person who worked in the care home implement the intervention, meaning that aspects of reminiscence could have been carried over into daily care and contaminate control

conditions (Goldwasser et al., 1987; Haight et al., 2006). However, close adherence to the study protocol would have minimised this risk.

Incomplete outcome data (attrition bias). Five small studies reported zero attrition (Akunuma et al., 2011; Baines et al., 1987; Haight et al., 2006; Morgan & Woods, 2012; Thorgrimsen et al., 2002). The highest attrition rate was 28% (23% from the intervention group and 34% from the control group) which was reported by one of the largest community-based studies (Woods et al., 2012b).

Data extracted from several studies were from intention to treat analyses (Amieva et al., 2016; Azcurra, 2012; Charlesworth et al., 2016; Lai et al., 2004; Melendez et al., 2015; O'Shea et al., 2014; Woods et al., 2012b). Other studies carried out the analyses without data from dropouts (Hsieh et al., 2010; Särkämö et al., 2013; Subramaniam et al., 2013; Tadaka & Kanagawa, 2007a; Tadaka & Kanagawa, 2007b; Van Bogaert et al., 2016 and Yamagami et al., 2012). One study reported results from both a per protocol and ITT analysis, but only data from the per-protocol analysis could be extracted (Ito et al., 2007). In an older study, one participant dropped out, and the authors randomly excluded one participant from each of the two other groups (Goldwasser and colleagues, 1987). The most common reported reasons for attrition were the health of the person with dementia, death, the health of the caregiver, and the person with dementia moving into residential care. One trial did not report attrition rates (Gonzalez et al., 2015).

Selective reporting. There was no evidence of selective reporting in any of the included studies. Studies that had a protocol (i.e. Charlesworth et al., 2016; O'Shea et al., 2014; Van Bogaert et al., 2016; Woods et al., 2012b) detailed the same outcome measures in the protocol as the published papers, while other studies reported results on all outcome measures detailed in the methods section.

Other bias. Cluster trials were assessed for additional biases associated with clustering such as recruitment bias, baseline imbalance, loss of clusters, and comparability with individually randomised trials.

Facilitator training and supervision. O' Shea and colleagues (2014) provided the most training to reminiscence facilitators. They ran a structured education-based reminiscence

program in which care home staff received three days of training. Telephone support and site visits augmented this. Five studies did not report details on facilitator training or reminiscence experience (Akanuma 2011; Goldwasser 1987; Gonzalez 2015; Hsieh 2010; Ito 2007). Others did not specify the number of training hours but reported that the intervention was delivered by appropriate facilitators, such as psychologists or gerontologists (Melendez et al., 2015; Morgan, 2012; Särkämö et al., 2013; Subramaniam et al., 2013; Tadaka 2007a; Tadaka 2007b). In the remainder of studies, between 4 hours and 1 day of training was provided to facilitators.

Treatment Protocol. The use of a protocol or structure in reminiscence therapy interventions is important to ensure that the intervention is delivered as intended, and reflects true reminiscence therapy. All studies reported using a protocol or structure, though the level of detail varied considerably. Some studies outlined session structures while others used standardized reminiscence interventions, the most popular of which were Haight's Life Review Model and Life Review Experiencing Form (Haight, 1992; Haight et al., 2006; Morgan & Woods, 2012; Subramaniam et al., 2013) and the RYCT program (Schweitzer & Bruce, 2008; Charlesworth et al., 2016; Thorgrimsen et al., 2002; Woods et al, 2012b)

Table 2.1 Description of included studies and bias ratings

Study ID	Participants	Intervention	Duration/Frequency	Randomisation	Allocation concealment	Blinding	Attrition bias	Selective reporting	Other bias	Training & supervision	Intervention protocol
Akanuma et al. 2011	24 care home residents with VD	Group RT	1hr/week for 12weeks	?	?	+	+	+	n/a	?	+
Amieva et al. 2016	326 community residents with AD*	Joint Group RT	90min/week for 12weeks + maintenance 90min/6 weeks for 21 months.	+	+	+	?	+	n/a	+	+
Azcurra 2012	90 care home residents with AD*	Individual life review	60mins twice/week for 12weeks	+	+	+	+	+	n/a	+	+
Baines et al. 1987	10 care home residents with mod-severe cognitive impairment*	Group RT	30 mins, 5 times/week for 4weeks	?	?	+	+	+	n/a	+	+
Charlesworth et al. 2016	144 community residents with a dementia diagnosis*	Joint Group RT (RYCT program)	2hrs/week for 12weeks + maintenance 2hrs/month for 7 months.	+	+	+	+	+	n/a	+	+
Goldwasser et al. 1987	20 care home residents with a dementia diagnosis*	Group RT	30 mins, twice/week for 5weeks.	?	?	?	?	+	n/a	?	+
Gonzalez et al. 2015	42 care home residents with AD	Integrative Group RT	60 mins/week for 10weeks.	?	?	?	+	+	?	?	+

Study ID	Participants	Intervention	Duration/Frequency	Randomisation	Allocation concealment	Blinding	Attrition bias	Selective reporting	Other bias	Training & supervision	Intervention protocol
Haight et al. 2006	30 care home residents with a dementia diagnosis	Individual life review with production of a life storybook	60mins/week for 6weeks	+	?	?	+	+	n/a	+	+
Hsieh et al. 2010	61 care home residents with a dementia diagnosis	Group RT	40-50mins once/week for 12 weeks	?	?	?	?	+	n/a	?	+
Ito et al. 2007	40 care home residents with VD*	Group RT	60mins/week for 12 weeks.	+	+	+	+	+	n/a	?	+
Lai et al. 2004	66 care home residents with a dementia diagnosis*	Individual life review with the production of a life story book	30 mins/week for 6weeks	+	?	+	+	+	n/a	+	+
Melendez et al. 2015	30 community residents with AD	Group RT	30 mins, twice/week for 10weeks	+	+	+	+	+	?	+	+
Morgan & Woods 2012	17 care home residents with a dementia diagnosis	Individual life review (Haight's life review Model).	30-60mins/week for 12weeks	+	?	?	+	+	n/a	+	+
O' Shea et al. 2014	304 care home residents with a dementia diagnosis	Group RT	Duration unspecified. 3-4times/week for 14weeks (range 12 – 17 weeks)	+	+	+	+	+	+	+	+
Subramaniam et al. 2013	24 care home residents with a dementia diagnosis	Individual life review with production of Life Storybook	1hour/week for average of 12weeks.	+	+	+	+	+	n/a	+	+

Study ID	Participants	Intervention	Duration/Frequency	Randomisation	Allocation concealment	Blinding	Attrition bias	Selective reporting	Other bias	Training & supervision	Intervention protocol
Särkamo et al. 2013	59 community residents with a dementia diagnosis (and a caregiver)	Music listening group reminiscence	90min/week for 10weeks	+	+	+	?	+	n/a	+	+
Tadaka & Kanagawa 2007a	24 community residents with AD	Group RT	90min/week for 8weeks	+	+	?	+	+	n/a	+	+
Tadaka & Kanagawa 2007b	36 community residents with VD	Group RT	90min/week for 8weeks	+	+	?	+	+	n/a	+	+
Thorgrimsen et al. 2002	11 community residents with a dementia diagnosis (and a caregiver)	Group RT (RYCT)	Duration unspecified. Once/week for 18weeks	+	+	+	+	+	n/a	+	+
Van Bogaert et al. 2016	72 care home residents with a dementia diagnosis	Individual RT (SolCos model)	45mins, twice/week for 8weeks.	+	+	+	+	+	n/a	+	+
Woods et al. 2012b	488 community residents with a dementia diagnosis (and their caregivers)	Joint Group RT (RYCT)	2hrs/week for 12 weeks + maintenance 2hrs/month for 7months	+	+	+	+	+	n/a	+	+
Yamagami et al. 2012	54 care home residents with a dementia diagnosis.	Group RT	60mins, twice/week for 12weeks	?	?	?	+	+	n/a	+	+

* The number of participants in groups relevant to the current review, rather than the total number of participants in the study.

Meta-analysis

Acronyms for each measure are detailed in Appendix B.

Self-reported quality of life – overall. (See Figure 2.1*). For the overall evaluation of the effects of reminiscence on quality of life post-treatment, eight studies (1,060 participants) were included in the meta-analysis. No significant differences between reminiscence and control groups were observed at post-treatment (random effects, SMD 0.11, 95% CI -0.12 to 0.33; Z = 0.95, P = 0.34).

Five studies, with 874 participants, also measured quality of life at follow-up (Amieva et al., 2016; Azcurra, 2012; Charlesworth et al., 2016; Särkämö et al., 2013; Woods et al., 2012b). All five implemented group reminiscence interventions. Again, the SMD was not statistically significant (random effects, SMD 0.35, 95% CI -0.11 to 0.80; Z = 1.50, P = 0.13).

Self-reported quality of life – modality. One small study of 23 participants measured self-reported quality of life at post-treatment following an individual life review intervention (Subramaniam et al., 2013). Results indicated that the intervention had a significant positive effect on self-reported quality of life (MD 7.0 points, 95% CI -0.14 to 14.13, Z = 1.92, P = 0.05.

Seven studies implemented group interventions, of which six used the QoL-AD (Amieva et al., 2016; Azcurra, 2012; Charlesworth et al., 2016; O' Shea et al., 2014; Särkämö et al., 2013; Thorgrimsen et al., 2002; Woods et al., 2012b). The analysis included 1,037 participants in total, and no significant effect was identified (SMD 0.06, 95% CI -0.15 to 0.28, Z = 0.59, P = 0.55). The findings for group reminiscence at follow-up time points have been detailed above (Section 3.5.2).

Self-reported quality of life - setting. Three care home studies were included in the meta-analysis (See Figure 2.1). A fixed effects analysis of data from 193 participants showed a statistically significant SMD of 0.46 (95% CI 0.18 to 0.75, Z = 3.17, P= 0.002) in favour of reminiscence interventions. At follow-up, one care-home study with 88 participants

(Azcurra, 2012) reported significant effect on the SRQOL (MD 9.8 points, 95% CI 7.05 to 12.55, Z = 6.98, P < 0.00001).

Five studies were community-based and included a total of 867 participants (See Figure 2.1). All five used the QoL-AD scale, and the mean difference between reminiscence and control groups was not statistically significant (fixed effects, MD = -0.57 points, 95% CI -1.37 to 0.22; Z = 1.41, P = 0.16). In contrast, the mean difference across the two care home studies (O' Shea et al., 2014; Subramaniam et al., 2013) that used the QoL-AD was significant, and much larger at 3.58 points (n = 105; 95% CI 0.66 to 6.51, Z = 2.40, P = 0.02). Four studies (Amieva et al., 2016; Charlesworth et al., 2016; Särkämö et al., 2013; Woods et al., 2012b) measured the effects of reminiscence on the quality of life of 786 community-dwelling participants at follow up. The mean difference (QoL-AD, fixed effects) was 0.17 points (95% CI -0.79 to 1.13), which was not statistically significant (Z = 0.35, P = 0.73).

Proxy rated quality of life. Five studies with 763 participants used the proxy version of the QoL-AD, in which a family carer or care staff member rated the person's quality of life (Charlesworth et al., 2016; O'Shea et al., 2014; Särkämö et al., 2013; Thorgrimsen et al., 2002; Woods et al., 2012b). All five implemented group reminiscence interventions. A random-effects model revealed a MD of 0.35 points (95% CI -1.23 to 1.94) which was not statistically significant (Z = 0.44, P = 0.66). Three also measured at follow-up time points (Charlesworth et al., 2016; Särkämö et al., 2013; Woods et al., 2012b) and again, no significant difference was identified (MD -0.15 points; 95% CI -1.14 to 0.83, Z = 0.30, P= 0.76).

Observed quality of life. Two studies used the WIB, which is an observational measure of quality of life (Azcurra, 2012; Lai et al., 2004). It is completed during six hours (minimum) of observation of the person undertaking their usual activities. There was no indication of an effect on WIB scores at post-treatment across 154 care home residents (MD 0.00 points, 95% CI -0.17 to 0.18, Z = 0.06, P = 0.95) or at follow-up (random effects, MD -0.40 points, 95% CI -1.34 to 0.54, Z= 0.83, P = 0.41).
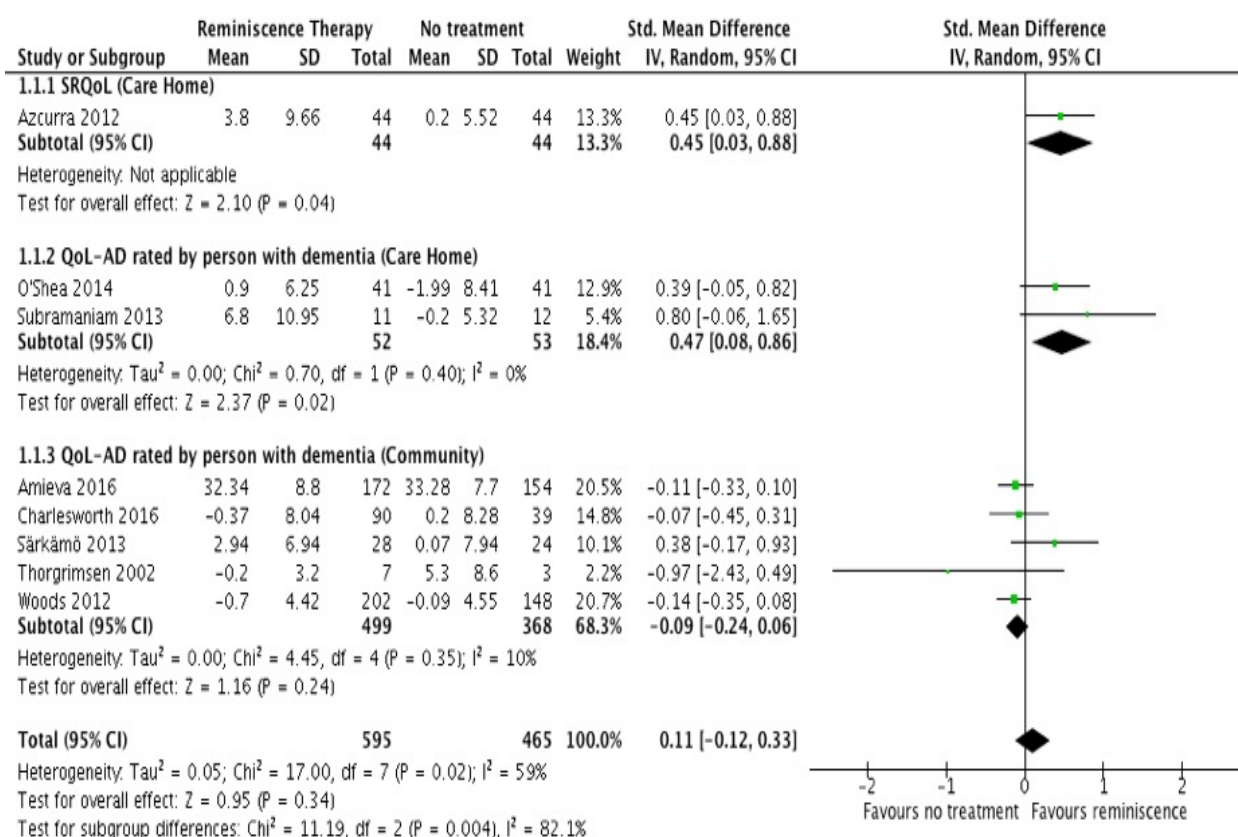
Figure 2.1. Meta-analysis Self-Reported Quality of Life

Communication and interaction – overall. (See Figure 2.2). Six studies using an assortment of communication measures were included in the post-treatment analysis (in this analysis, negative scores indicate *improved* communication). Data from 249 participants were included. A statistically significant difference favouring reminiscence was identified at post-treatment (SMD = -0.51, 95% CI -0.97 to -0.05; Z = 2.18, P = 0.03). At follow up, four studies including 204 participants reported communication outcome data (Azcurra, 2012; Lai et al., 2004; Tadaka & Kanagawa, 2007a; Tadaka & Kanagawa, 2007b). Again, a significant effect favouring reminiscence was identified (SMD = -0.49, 95% CI -0.77 to -0.21; Z = 3.40, P = 0.0007).

Communication and interaction – modality. Two studies of individual reminiscence, including 96 participants, reported post-treatment data from measures of communication (Haight et al., 2006; Lai et al., 2004). The overall effect size (SMD, random effects) was -0.74 (95% CI -2.38 to 0.89) which was not statistically significant (Z=0.89, P = 0.37). In contrast, the post-treatment analysis of four studies of group reminiscence, including 153

participants (Azcurra, 2012; Tadaka & Kanagawa, 2007a; Tadaka & Kanagawa, 2007b; Thorgrimsen et al., 2002), did indicate a statistically significant benefit of reminiscence in relation to communication (SMD = -0.39, 95% CI -0.71 to -0.06; Z = 2.34, P = 0.02).

Longer-term follow-up data were available from one study of individual reminiscence, with no evidence of an effect (Lai et al., 2004). Data from three studies (N = 138) of group reminiscence were available (Azcurra, 2012; Tadaka & Kanagawa, 2007a; Tadaka & Kanagawa, 2007b). Similar to post-treatment, a significant benefit was identified (SMD -0.63 points, 95% CI -0.97 to -0.29; Z=3.60, p= 0.0003).

Communication and interaction – setting. Three studies were community-based and involved 65 participants. A significant effect on communication and interaction was identified (SMD -0.57, 95% CI -1.08 to -0.06; Z = 2.21, P = 0.03). Two studies, including 50 participants, also reported communication and interaction outcomes at follow up (Tadaka & Kanagawa, 2007a; Tadaka & Kanagawa, 2007b). Both used the withdrawal subscale of the MOSES. The mean difference was -3.64 points (95% CI -7.21 to -0.06), which was statistically significant (Z = 2.00, P = 0.05).

Three studies, involving 184 participants, took place in care homes (See Figure 2.2). Here, no significant effect was identified (random effects, SMD -0.52, 95% CI -1.29 to 0.24; Z = 1.34, P = 0.18). Two care home studies (Azcurra, 2012; Lai et al., 2004), both using the SES, also reported data from 154 participants at follow up and found a statistically significant MD of -0.93 points (random effects, 95% CI -1.77 to -0.09; Z = 2.16, P = 0.03).

Depressed mood – overall. (See Figure 2.3)**.** In mood analyses, negative scores were indicative of improvements in mood. Ten studies, including 973 participants, included a measure of depressed mood in post-treatment evaluation. A non-significant SMD favouring reminiscence interventions was identified (SMD -0.03, 95% CI -0.15 to 0.10; Z = 0.40, P = 0.69). At follow-up, data from 747 participants across six studies were included. Again, the SMD was not statistically significant (random effects, SMD -0.16, 95% CI -0.43 to 0.11; Z = 1.15, P = 0.25).

Depressed mood – modality. Four studies, involving 131 participants, used an individual reminiscence approach (Haight et al., 2006; Morgan & Woods, 2012; Subramaniam et al., 2013; Van Bogaert et al., 2014). The effect on depressed mood was statistically significant

Study or Subgroup	Reminiscence Therapy Mean	SD	Total	No treatment Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
1.7.1 Social Engagement Scale (Care home)								
Azcurra 2012	-0.6	2.09	44	-0.1	1.7	44	23.5%	-0.26 [-0.68, 0.16]
Lai 2004	-0.42	2.43	36	-0.55	2.26	30	22.1%	0.05 [-0.43, 0.54]
Subtotal (95% CI)			80			74	45.6%	-0.13 [-0.44, 0.19]
Heterogeneity: Tau² = 0.00; Chi² = 0.93, df = 1 (P = 0.34); I² = 0%								
Test for overall effect: Z = 0.77 (P = 0.44)								
1.7.2 Communication Observation Scale for Cognitively Impaired (Care Home)								
Haight 2006	-4.33	5.73	15	5.26	5.81	15	14.8%	-1.62 [-2.46, -0.78]
Subtotal (95% CI)			15			15	14.8%	-1.62 [-2.46, -0.78]
Heterogeneity: Not applicable								
Test for overall effect: Z = 3.77 (P = 0.0002)								
1.7.3 Holden Communication Scale (Community)								
Thorgrimsen 2002	-4.2	7.9	7	-3	2.7	3	8.2%	-0.16 [-1.51, 1.20]
Subtotal (95% CI)			7			3	8.2%	-0.16 [-1.51, 1.20]
Heterogeneity: Not applicable								
Test for overall effect: Z = 0.22 (P = 0.82)								
1.7.4 MOSES Withdrawal Subscale (Community)								
Tadaka 2007 (AD)	-5	5.35	11	0.2	5.81	10	13.6%	-0.90 [-1.80, 0.01]
Tadaka 2007 (VD)	-3.8	6.75	17	-0.2	7.53	17	17.7%	-0.49 [-1.18, 0.19]
Subtotal (95% CI)			28			27	31.4%	-0.64 [-1.18, -0.09]
Heterogeneity: Tau² = 0.00; Chi² = 0.49, df = 1 (P = 0.49); I² = 0%								
Test for overall effect: Z = 2.29 (P = 0.02)								
Total (95% CI)			130			119	100.0%	-0.51 [-0.97, -0.05]
Heterogeneity: Tau² = 0.19; Chi² = 13.19, df = 5 (P = 0.02); I² = 62%								
Test for overall effect: Z = 2.18 (P = 0.03)								
Test for subgroup differences: Chi² = 11.78, df = 3 (P = 0.008), I² = 74.5%								

Favours reminiscence   Favours no treatment

Figure 2.2. Meta-analysis communication

in favour of reminiscence (SMD -0.41, 95% CI -0.76 to -0.06, Z = 2.32, P = 0.02). On the other hand, a significant difference was not identified in the analysis of the six studies(N=842) of group reminiscence (SMD 0.03, 95% CI -0.10 to 0.17, Z = 0.49, P = 0.63).

One small study of individual reminiscence measured depression at follow-up using the GDS-SF (Morgan & Woods, 2012), and reported a significant benefit of reminiscence (MD = -3.70, 95% CI -5.74 to -1.66, Z = 3.56, P = 0.0004). Five studies of group reminiscence reported measures of depressed mood at follow-up, though all were community-based meaning that the results were confounded with the intervention setting. The SMD was -0.04 (95% CI -0.19 to 0.11) which was not statistically significant (Z = 0.52, P= 0.60).

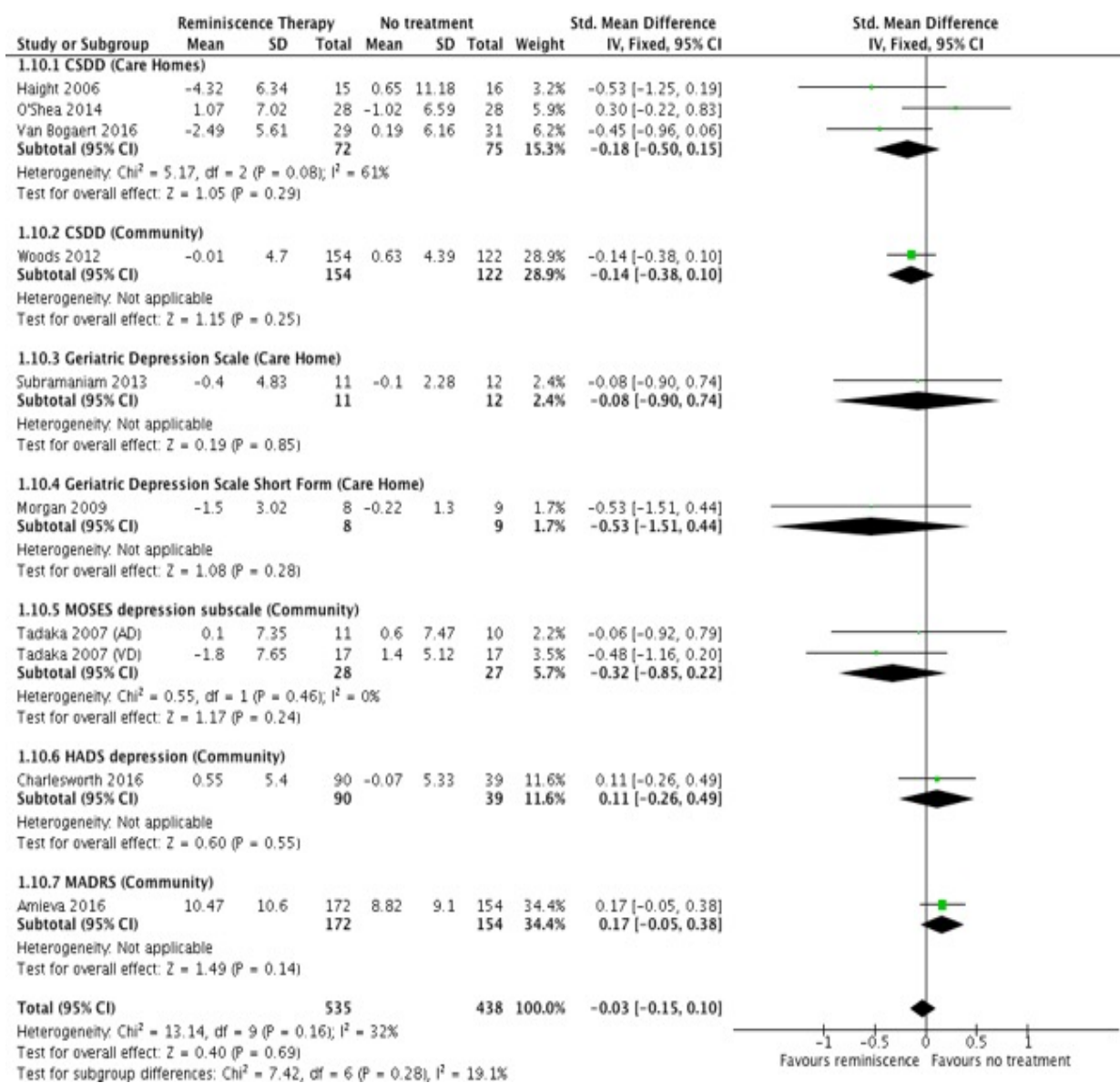| | Reminiscence Therapy | | | No treatment | | | | Std. Mean Difference | Std. Mean Difference |
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Fixed, 95% CI	IV, Fixed, 95% CI
1.10.1 CSDD (Care Homes)									
Haight 2006	-4.32	6.34	15	0.65	11.18	16	3.2%	-0.53 [-1.25, 0.19]	
O'Shea 2014	1.07	7.02	28	-1.02	6.59	28	5.9%	0.30 [-0.22, 0.83]	
Van Bogaert 2016	-2.49	5.61	29	0.19	6.16	31	6.2%	-0.45 [-0.96, 0.06]	
Subtotal (95% CI)			72			75	15.3%	-0.18 [-0.50, 0.15]	
Heterogeneity: Chi² = 5.17, df = 2 (P = 0.08); I² = 61%									
Test for overall effect: Z = 1.05 (P = 0.29)									
1.10.2 CSDD (Community)									
Woods 2012	-0.01	4.7	154	0.63	4.39	122	28.9%	-0.14 [-0.38, 0.10]	
Subtotal (95% CI)			154			122	28.9%	-0.14 [-0.38, 0.10]	
Heterogeneity: Not applicable									
Test for overall effect: Z = 1.15 (P = 0.25)									
1.10.3 Geriatric Depression Scale (Care Home)									
Subramaniam 2013	-0.4	4.83	11	-0.1	2.28	12	2.4%	-0.08 [-0.90, 0.74]	
Subtotal (95% CI)			11			12	2.4%	-0.08 [-0.90, 0.74]	
Heterogeneity: Not applicable									
Test for overall effect: Z = 0.19 (P = 0.85)									
1.10.4 Geriatric Depression Scale Short Form (Care Home)									
Morgan 2009	-1.5	3.02	8	-0.22	1.3	9	1.7%	-0.53 [-1.51, 0.44]	
Subtotal (95% CI)			8			9	1.7%	-0.53 [-1.51, 0.44]	
Heterogeneity: Not applicable									
Test for overall effect: Z = 1.08 (P = 0.28)									
1.10.5 MOSES depression subscale (Community)									
Tadaka 2007 (AD)	0.1	7.35	11	0.6	7.47	10	2.2%	-0.06 [-0.92, 0.79]	
Tadaka 2007 (VD)	-1.8	7.65	17	1.4	5.12	17	3.5%	-0.48 [-1.16, 0.20]	
Subtotal (95% CI)			28			27	5.7%	-0.32 [-0.85, 0.22]	
Heterogeneity: Chi² = 0.55, df = 1 (P = 0.46); I² = 0%									
Test for overall effect: Z = 1.17 (P = 0.24)									
1.10.6 HADS depression (Community)									
Charlesworth 2016	0.55	5.4	90	-0.07	5.33	39	11.6%	0.11 [-0.26, 0.49]	
Subtotal (95% CI)			90			39	11.6%	0.11 [-0.26, 0.49]	
Heterogeneity: Not applicable									
Test for overall effect: Z = 0.60 (P = 0.55)									
1.10.7 MADRS (Community)									
Amieva 2016	10.47	10.6	172	8.82	9.1	154	34.4%	0.17 [-0.05, 0.38]	
Subtotal (95% CI)			172			154	34.4%	0.17 [-0.05, 0.38]	
Heterogeneity: Not applicable									
Test for overall effect: Z = 1.49 (P = 0.14)									
Total (95% CI)			535			438	100.0%	-0.03 [-0.15, 0.10]	
Heterogeneity: Chi² = 13.14, df = 9 (P = 0.16); I² = 32%									
Test for overall effect: Z = 0.40 (P = 0.69)									
Test for subgroup differences: Chi² = 7.42, df = 6 (P = 0.28), I² = 19.1%									

Figure 2.3. Meta-analysis depressed mood

Depressed mood – setting. In the five care home studies (Figure 2.3, N = 187) no effect of reminiscence therapy was identified at post-treatment (SMD -0.19, 95% CI -0.48 to 0.10; Z = 1.32, P = 0.19). The five community-based studies (N=786) all involved group interventions and also showed no effect on depressed mood (SMD 0.01, 95% CI -0.13 to 0.16, Z = 0.20, P= 0.84). The results at longer-term follow-up are outlined above *(Depressed mood – modality)* as all group studies were community-based. A single care home study (Morgan, 2000) also provided follow-up data from 17 participants and identified a significant benefit of reminiscence to depressed mood (MD = -3.70, 95% CI -5.74 to -1.66, Z = 3.56, P = 0.0004)

Cognition – overall. (See Figure 2.4). Where studies used more than one measure of cognition, the analysis was conducted with the most common or extensive assessment. For the AMI and AMI (E) this was the PSS sub-scale. Data from 14 studies involving 1,219 participants were analysed. A statistically significant difference favouring reminiscence was identified (SMD = 0.11, 95% CI 0.00 to 0.23; Z = 1.97; P = 0.05).

The MMSE was the most widely used cognitive measure, employed in nine studies (n = 437). A fixed effects analysis of data taken from this measure yielded a statistically significant MD of 1.87 points (95% CI 0.54 to 3.20; Z = 2.76, P = 0.006). On the other hand, a significant effect of reminiscence was not identified on either sub-scale of the AMI and extended AMI (E), which were used by four studies (n = 456).

Nine studies reported follow-up data from a total of 983 participants. Neither the overall effect size (SMD = 0.04, 95% CI -0.09 to 0.17; Z = 0.61, P = 0.54) nor the differences on individual measures were significant when assessed individually. The MD on the MMSE at follow-up was 1.8 points (95% CI -0.06 to 3.65) and not significant (Z = 1.90, P = 0.06).

Cognition – modality. Individual reminiscence interventions were implemented by five studies (Haight et al., 2006; Lai et al., 2004; Morgan & Woods, 2012; Subramaniam et al., 2013; Van Bogaert et al., 2016). Data from 196 participants revealed a significant effect size in favour of reminiscence (SMD = 0.32, 95% CI 0.04 to 0.61; Z = 2.22, P= 0.03).

In contrast, a significant effect was not identified across the nine studies of group reminiscence, involving 1023 participants (SMD 0.07, 95% CI -0.05 to 0.20; Z = 1.17, P = 0.24). However, MMSE data for 281 participants was reported by six studies of group reminiscence at post-treatment. When data from this measure was considered independently, a statistically significant effect in favour of group reminiscence was identified (MD 1.81 points, 95% CI 0.17 to 3.46; Z = 2.16, P = 0.03).

At follow-up, a significant effect was not found in analyses of either modality.

Cognition – setting. Six studies, involving 230 participants, were based in care homes (See Figure 2.4). A significant effect in favour of reminiscence was identified (SMD 0.29, 95% CI 0.03 to 0.56; Z = 2.19, P = 0.03). Eight studies (n = 989) were carried out in
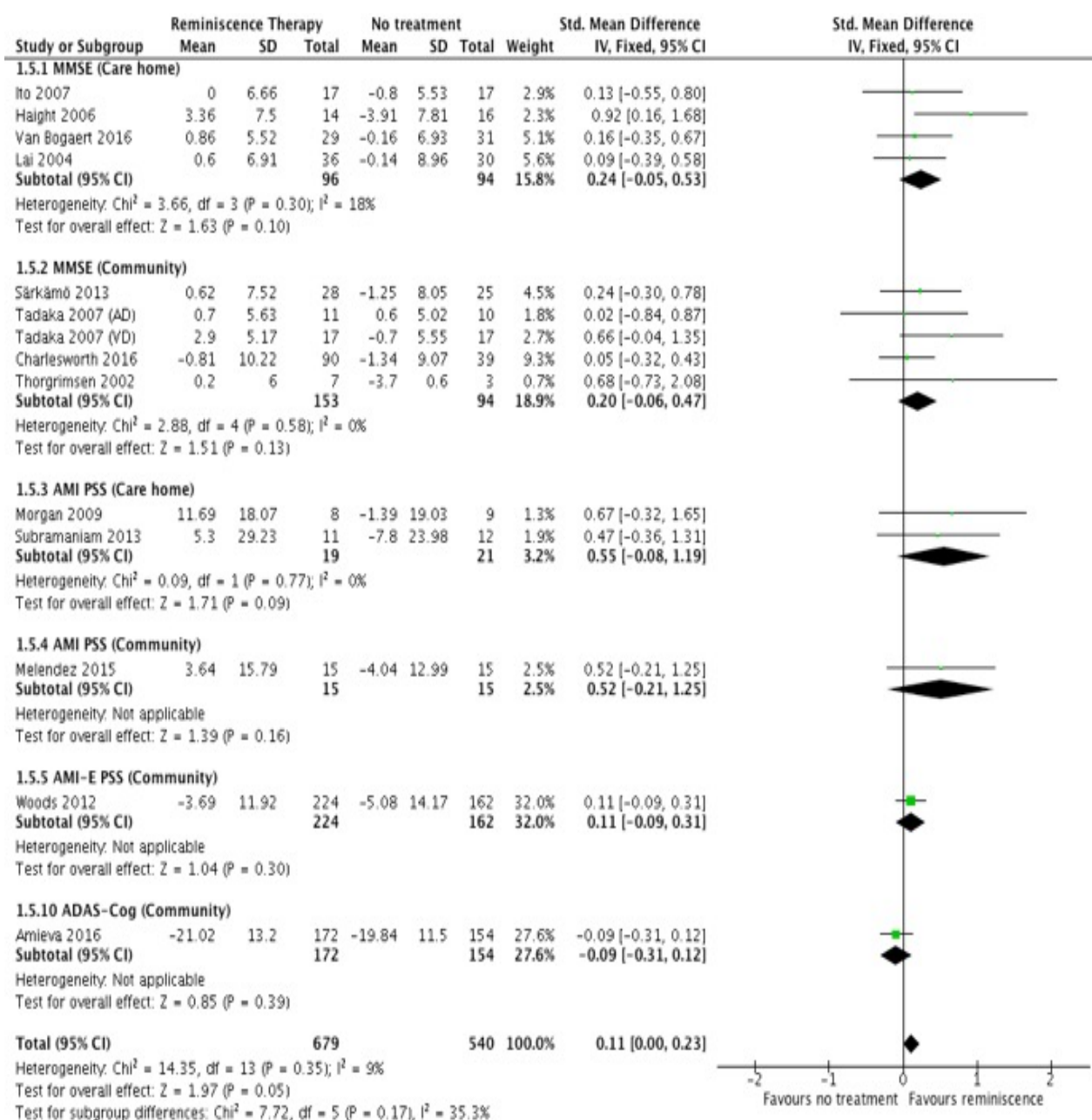
Figure 2.4. Meta-analysis cognition

community settings. The benefit to cognitive function in this context was not statistically significant (SMD 0.07, 95% CI -0.05 to 0.20, Z = 1.13, P = 0.26). At follow-up, no significant effects were identified in care home (2 studies, 83 participants) or community settings (7 studies, 900 participants).

Adverse outcomes. While no adverse events were observed on the outcome measures of interest, two studies reported incidences of adverse outcomes. Charlesworth and

colleagues (2016) reported three 'serious adverse events' that were attributable to the RYCT intervention. Specific details were not given, though it was reported that these events did not lead to withdrawal from the trial. Woods and colleagues (2012) reported one adverse event, in which a participant became upset in one of the intervention sessions relating to marriage. There was a detailed protocol in place for dealing with distressing events, which was implemented. While adverse events are regrettable, it is important to view them in context of the total number of participants and intervention sessions.

Discussion

This is the largest review of reminiscence therapy for people with dementia to date. It includes 22 RCTs and data from more than 1,900 participants. The results of the meta-analyses, which included 16 studies and data from 1,749 participants, provide the strongest evidence thus far that reminiscence therapy can benefit people with dementia in the domains of quality of life, communication, mood, and cognition. However, these effects are relatively small and inconsistent across reminiscence modalities (group/individual) and settings (care home/community).

Included studies cover various reminiscence activities including simple reminiscence, life review, joint reminiscence work, and music listening reminiscence. Intervention intensities and durations varied widely across included studies. In addition to treatment-as-usual groups, some studies also compared reminiscence to alternative activities or measured additional outcomes, but these were beyond the scope of the current review. Despite growing interest in digital reminiscence, no studies of this met the inclusion criteria.

The quality and volume of studies have improved since earlier reviews of reminiscence therapy for dementia. Several included studies are very large and of high quality, while some smaller studies of reasonable quality are also included. The volume of data made it possible to exclude studies that were rated as having an unclear risk of randomisation bias from the meta-analyses, without undermining them. Furthermore, there were sufficient data to carry out subgroup analyses of intervention modalities and settings for the first time. Although most included studies reported using an intervention protocol or structure, several did not report these in sufficient detail. In numerous cases, additional study information had to be requested as published reports did not include enough detail, particularly in relation to randomisation and allocation concealment.

Reminiscence therapy had a significant benefit on self-reported quality of life at both post-treatment and follow-up, but only in care home settings. One study of individual reminiscence measured self-reported quality of life at post-treatment, and found that reminiscence had a significant benefit (Subramaniam et al., 2013). No significant effect was

identified in studies of group reminiscence, or community-based studies. Similarly, a significant effect was not identified on measures of observed or proxy rated quality of life.

There was a significant improvement in communication scores of reminiscence groups compared to control groups at both post-treatment and follow-up. However, in sub-group analyses of intervention modality, a benefit was only observed in group reminiscence approaches. In the subgroup analysis of setting, there was a significant benefit to communication in community settings at post-treatment, and in both community and care home settings at follow-up.

There was no benefit of reminiscence to depressed mood overall. However, in subgroup analyses, individual reminiscence was associated with improvements in depressed mood at both post-treatment and follow-up. Though it should be noted that just one small study measured depressed mood at follow-up (Morgan & Woods, 2012). No significant effects were observed in subgroup analyses of group reminiscence, community-based reminiscence, or care home based reminiscence.

In relation to cognitive outcomes, those who received reminiscence therapy exhibited greater improvements than controls at post-treatment. However, in subgroup analyses, a significant effect was identified only when the intervention was individual or based in a care home. At follow-up, no significant effects were identified in any subgroup analysis. When MMSE scores were considered independently, results of this review (nine studies, N = 437, MD = 1.87; 95% CI 0.54 to 3.20) bear similarity to the Cochrane Review of Cognitive Stimulation for dementia (Woods et al., 2012a; N = 600, MD = 1.74 points; 95% CI 1.13 to 2.36). However, when the overall effect is considered, results of cognitive stimulation (14 studies, N= 658, SMD =0.41, 95% CI 0.25 to 0.57) appear more positive than those in the current review (14 studies, N = 1229, SMD = 0.11, 95% CI 0.00 to 0.23).

Results of the current review are in line with previous reviews of reminiscence therapy for dementia. Improvements in cognition and mood reflected have often been cited (Blake, 2013; Cotelli et al., 2012; Huang et al., 2015; Kwon et al., 2013; Subramaniam & Woods, 2012, Testad et al., 2014; Woods et al., 2005). Huang and colleagues (2015) also delineated between care home and community settings, and similar to the current study, the effects of reminiscence on mood were stronger in care home settings. Similarly,

individual reminiscence and reminiscence in care homes have previously been associated with improved quality of life (Subramaniam & Woods, 2012). Communication has been measured less often in previous reviews, but a significant benefit of group reminiscence to communication seen in the current review has been identified previously (Kim et al., 2006). The results of the current review suggest that communication is now an important outcome of reminiscence therapy to consider, particularly in group-based reminiscence therapy.

Limitations

The range of reminiscence interventions across included studies makes it difficult to compare and contrast results. Studies that implemented individual reminiscence interventions were typically small and took place in care homes, while group interventions were generally much larger and mostly took place in community settings. Therefore, it is difficult to be certain of what underpins any differences in outcomes between individual and group interventions. Similarly, it was not possible to distinguish between simple and integrative approaches or between varying lengths of intervention exposure in the analyses. While the results of this review indicate the potential for reminiscence to improve psychosocial outcomes for people with dementia, it is difficult to translate what these significant differences actually mean in terms of real-life benefit to people with dementia. For most measures, there are currently no international agreed-upon benchmarks to apply in this situation.

Conclusion

Reminiscence therapy can now be viewed as an eco-psychosocial intervention, with a credible evidence base. There is promising evidence that it can improve quality of life, communication, depressed mood, and cognition for people with dementia, but effects vary considerably across intervention modalities and settings. Furthermore, the effects are mostly small in size. Individual reminiscence may benefit cognition and mood, while group reminiscence may have positive outcomes in relation to communication. Benefits to quality of life seem most promising in care home settings. In future research, a large-scale RCT of individual reminiscence work would be helpful to ascertain if the promising results in the current review can be replicated on a larger scale. Efforts should be made to learn more about the characteristics of participants that are associated with better outcomes and levels of engagement so that interventions can be tailored and targeted effectively and

efficiently. Finally, the development or use of more detailed standardised manuals would be helpful so that common approaches can be shared and developed.

Chapter 3: Implementing digital life story work for people with dementia: The relevance of context to user experience.

Summary

Digital Life Story Work (LSW) is fast becoming a major trend in reminiscence work for people with dementia. Multimedia materials (i.e. music, video, audio narration) can be combined with conventional resources (i.e. photographs and text) and added to digital life storybooks to create a multisensory experience. The purpose of this study was to explore user experiences of three different implementations of digital LSW. Sixteen participants including people with dementia (n = 6), family caregivers (n = 6), and care staff working in a dementia care home (n = 4) took part. Participants were interviewed about their experience of learning to use a digital life storybook in one of three contexts: a community group; one-to-one sessions at home; or in a care home. People with dementia and family caregivers took part in weekly workshops for 6 weeks, while care staff received 6 weeks of training and were then encouraged to use digital life storybooks with residents. Thematic analyses were carried out on each dataset separately so that experiences could be compared and contrasted. Participants enjoyed the intervention, found it useful, and valued the ability to use multimedia stimuli in the digital life storybooks. Limited information and communication technology (ICT) skills was the most frequently cited barrier, and the digital life storybooks were used for some additional unanticipated, but useful purposes. Themes and subthemes from each participant group in each context are presented in this chapter. The results of this chapter provide evidence for the feasibility and positive impact of a supported digital LSW intervention, and the use of digital life storybooks in three contexts. Results also provide useful insight and feedback for the future development and implementation of this approach in research and practice.

Introduction

Life Story Work (LSW) is a popular psychosocial intervention for dementia, in which people are given the opportunity to talk about and have important parts of their life recorded in some way. This makes up a life story, which can then be used to benefit the person in the present (McKeown, et al., 2006; Murphy, 2000;). LSW falls under the 'umbrella' of reminiscence work or reminiscence therapy.

In a review of 11 conventional life story resources (e.g. downloadable forms, booklets, books and boxed multimedia resources) for people with dementia and their caregivers, Kindell and colleagues (2014) found that 'making connections' was a recurrent theme across the objectives of the resources. They proposed that LSW can foster connections in four distinct ways: emotional connections, interactional connections, practical care connections, and building new connections. Emotional connections seek to provide psychological support to people with dementia and their relatives, with the objective of promoting positive self-identity. In interactional connections, a tangible life story 'resource' is produced to enable continued enjoyment through shared knowledge. Practical care connections aim to provide appropriate care and activities for the person with dementia using autobiographical information learned through LSW. Finally, building new connections refers to the formation of positive relationships between people with dementia, relatives, and care staff through collaborative work.

With growing accessibility to information and communication technology (ICT), LSW interventions involving the creation of a digital multimedia type 'book' have become more popular (Woods & Subramaniam, 2017). An evolving approach to this is through a series of workshops or sessions, in which people with dementia are assisted to play an active role in creating their life storybook. Although research into this approach is still developing, and settings and implementations vary greatly, results have been mostly positive (Damianakis, Crete-Nishihata, Smith, Baecker, & Marziali, 2009; Ludwin & Capstick, 2015; Lynch, Reilly, Lowe, Rhoda, & McCarron, 2016; Massimi et al., 2008; Stenhouse, Tait, Hardy, & Sumner, 2013; Subramaniam & Woods, 2016).

Ludwin and Capstick (2015) worked one-to-one with ten people with dementia who were living in a care home to create personal life story videos based on their early life.

The films consisted of personal and generic photographs, with participants' narration or singing providing the soundtrack. Using a mixed methods approach, the authors identified a significant effect of the intervention on participants' well-being and social participation over the six-week intervention. It was reported that the intervention helped participants to leave the dementia 'label' behind as they discussed their diverse interests and life experiences with facilitators. Similarly, Massimi and colleagues (2008) worked with a single person with dementia to develop his life story over one month. The participant enjoyed the experience and showed improvements on measures of self-identity and apathy. Qualitative evidence also revealed that it helped his relatives to 're-interpret' his condition. More recently, Subramaniam and Woods (2016) worked one-on-one with people with dementia in care homes to convert conventional life storybooks into life story movies. Five out of six participants showed improvements on quality of life and autobiographical measures after receiving the digital life storybook. A thematic analysis also revealed that participants, relatives, and care staff considered the digital life stories a useful tool to help trigger memories, and that participants (mostly) responded positively to viewing them. Mulvenna and colleagues (2017) took a slightly different approach and provided five weeks of training to 28 people with dementia and their caregivers in reminiscence, using a reminiscence app called InspireD. Following the training, participants were encouraged to use the app over 12 weeks, and usage data was collected through the app. They found that participants used the app approximately once per week and that for the most part, people with dementia used the app for reminiscence, while caregivers used it for both reminiscing and compiling stimuli.

Digital life stories have also been created in group settings, though there is less research on this. Stenhouse and colleagues (2013) evaluated a four-day digital story-making workshop for people with early-stage dementia. In the workshops, participants were supported by facilitators to create their digital life stories using photographs, audio narration, and music. A thematic analysis of the facilitators' reflections suggested that participants became more confident and engaged with the activity and others, and were observed to have a greater sense of purpose and improved speech.

Other research has explored training professional care staff to implement LSW interventions with people in their care. A study of digital life storybooks for people with intellectual disabilities and dementia (or who were at risk of developing it), found that

participants, relatives, and staff approved of the digital life storybooks, and considered them a powerful means of supporting person-centred care and meaningful conversation (Lynch et al., 2016). In a study involving ten care homes, it was found that supporting and training staff to deliver a conventional reminiscence intervention had several significant benefits. Staff had better attitudes towards individual contact with residents, a greater sense of personal accomplishment, reduced emotional exhaustion, reduced depersonalisation, a better sense of their professional role and development, and better self-rated mental health scores. Most rated the intervention as a helpful tool for communicating with residents. Staff in half of the care homes mentioned that they felt the use of reminiscence led to greater contact with residents and more positive experiences. However, the results showed weak evidence for an effect of the intervention on care home residents (Gudex, Horsted, Jensen, Kjer, & Soerensen, 2010). Clarke, Hanson and Ross (2003) found that the implementation can be an issue due to time constraints or a lack of support from management. Despite initial enthusiasm, staff on a unit in an NHS hospital were unable to implement a LSW intervention with people in their care because they were too busy. However, when the research team employed a support worker who could prioritise the intervention, it was more successful. The resulting life stories encouraged practitioners to see the person behind the 'patient' and to build and strengthen relationships with them and their relatives.

There is some concern that recalling certain memories or topics may cause distress to participants, and there is a risk that the person might fixate on the past (Bruce & Schweitzer, 2008; McKeown, Gridley, & Savitch, 2017; Ryan et al., 2017). However, studies comparing participant responses to reminiscence have generally found that negative responses are relatively rare compared to positive responses (Damianakis et al., 2010; Sarne- Fleischmann & Tractinsky, 2008; Subramaniam, Woods, & Whitaker, 2013). It should also be noted that reminiscence and LSW may not appeal to everyone (Coleman, 1986). For example, Clarke and colleagues (2003) found that more reserved individuals did not want to share information while others had painful memories they did not want to revisit.

Following a review of digital reminiscences resources for people with dementia and their caregivers, Subramaniam and Woods (2010) concluded that the approach is feasible but more research is needed to understand how to best use ICT-based reminiscence

resources therapeutically with people living with dementia and their caregivers. Digital LSW research has become more popular in recent years, but there is still a need to explore the experiences of stakeholders across different settings and implementations. Research into digital LSW in professional care settings remains scarce, but it is important to explore what supports implementation, and its impact on stakeholders.

Aim

The aim of this study is to explore user experiences of a digital LSW intervention involving the creation of a digital life storybook, from the perspectives of community-dwelling people with dementia and their family caregivers, and care staff working in care homes. We aim to address the following research questions:

1. What are participants' experiences of digital LSW service delivered through weekly workshops?
2. What are the advantages and disadvantages of using a technological interface for LSW?
3. How does the context (e.g. the setting) affect user experiences of a digital LSW intervention?

<center>**Methods**</center>

Background to the Intervention

Book of You[1] is a Welsh social enterprise that organises and delivers LSW workshops in community, individual, and care home contexts. It has created a digital life storybook app that enables users to combine photo, text, video, music, and audio narration to construct a digital life storybook on a computer, tablet computer, or mobile phone (See Figure 3.1). Workshops take place individually in the person's home or in a group setting in community locations such as libraries or community centres. A facilitator works with participants each week for 6 consecutive weeks to teach them how to use the digital life storybook and support them to begin creating their own. In care home contexts, Book of You provide 4 weeks of training to care staff (2 hours per week) who can then create digital life storybooks for residents. In all contexts, the workshop facilitators are volunteers, who have received one day of training in reminiscence, digital LSW, and the digital life storybook app. Book of You receives external funding and grants, meaning that there was no financial cost to any participant or care home in the current study. This research was secondary to the Book of You workshops, meaning that they were not explicitly organised for the purposes of this research.

Participants

Participants were drawn from those who were signed up to begin Book of You workshops but had not started them yet. Care staff were recruited from care homes that had just completed the workshops or were nearing completion. Overall, 12 dyads (consisting of a person with dementia and their caregiver) and 12 staff members (across 2 care homes) were approached.

People with dementia-caregiver dyads. To be eligible to participate in the study, participants needed to meet the DSM-IV (APA, 2013) criteria for dementia of any type, and be in the mild to moderate stages. Dementia severity was assessed using the Clinical Dementia Rating scale (CDR; Hughes et al., 1982). Participants needed to be able to communicate and understand communication. This was assessed using relevant items on the Clifton Assessment Procedures for the Elderly (CAPE; Pattie & Gilleard, 1979).
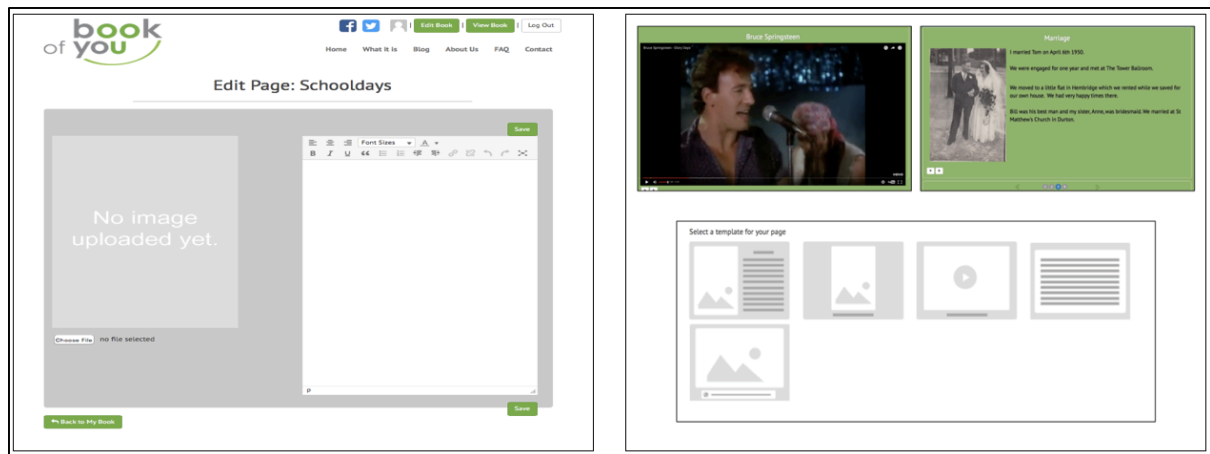
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[1] http://www.bookofyou.co.uk

Figure 3.1. Examples of the Book of You user interface

Participants were only included if judged to have the mental capacity to give consent and if they had a relative willing and able to participate. The Mental Capacity Act 2005 (Department of Health, 2005) and British Psychological Society guidelines were used to judge this. Exclusion criteria included the presence of active major psychiatric disorders, uncorrected sensory impairment, and a high level of agitation.

On the first day of group workshops (before they commenced), the researcher explained the research study, distributed information sheets, and invited attendees to take part. They were assured that they could take part in the intervention without participating in the research, and that this would have no effect on how the intervention was delivered. Potential participants from the individual context were initially informed about the research and given an information sheet by the Book of You facilitator, though it was stressed that taking part was not required to participate in the intervention. Those who expressed interest were contacted by the researcher, who phoned them to arrange a time to meet them to explain the research and invite them to take part. In both contexts, the researcher explained the information sheet to potential participants, answered any questions, and checked if they were eligible to participate. Those who met the inclusion criteria were asked to sign a consent form. Introductory interviews were carried out directly before the first workshop. Information sheets and consent forms are presented in Appendix C.

Professional care staff. To be eligible to participate, care staff needed to be employed in a dementia care home and have participated in the LSW workshops. The

researcher approached participating care homes and asked permission to approach staff members to take part in the research. The care home activities coordinator informed the researcher of who had taken part in the workshops. The researcher distributed information sheets and explained the study to potential participants. If they wished to participate, the researcher distributed consent forms and arranged a time to come back and meet for the first interview, after the workshops were complete. Information sheets and consent forms are presented in Appendix C.

Ethical Approval

Ethical approval was given by the Bangor University Healthcare and Medical Sciences Academic Ethics Committee.

Intervention – Person with dementia-caregiver dyads

Person with dementia-caregiver dyads took part in a group context or an individual context. For Book of You, teaching participants how to use the app was a priority, but often, reminiscence naturally occurred as a result of working with items and materials from the past. Group context participants attended weekly hour-long workshops in their locality for six weeks. Workshops were held in a local day centre but were attended by people with dementia and their caregivers who were living in their own homes. Participants were contacted by the Book of You facilitator before the first workshop and encouraged to bring photographs or items that they wanted to add to their digital life storybook. Individual context participants were visited in their homes by a facilitator once a week for six weeks. Therefore, there were fewer time constraints and workshops were generally between one and two hours long. The facilitator contacted participants the week before the first workshop and encouraged them to prepare some materials to include in their digital life storybook. Where possible, workshops were run in consecutive weeks. Each dyad was given a password and username so they could access their book between workshops if they wished. Participants were shown how to use and add different materials to their books each week (Appendix D). The facilitator demonstrated how to use the digital life storybook while helping participants to create their own.

Intervention - Care staff participants

Workshops were two hours per week over four consecutive weeks. The care homes had Wi-Fi access, and all staff members carried tablet computers (provided by the care home)

while on their shift to record care notes. The care home managers invited staff members to participate in the workshops, but it was not mandatory. Not all staff members could attend every week due to shift work. Workshops were flexible and worked around what participants wanted to learn rather than a set plan, though the facilitator ensured that every template was covered (Appendix D). Each staff member selected one resident with whom to learn the process of creating a life storybook. During workshops, the facilitator demonstrated how to work with a particular template and participants tried it for themselves using materials relevant to the resident they had chosen (with permission). Staff members were able to access the digital life storybooks between workshops if they wished to consolidate their knowledge. After the four-week period ended, a follow-up workshop was arranged four weeks later in case any extra assistance or training was needed.

Data collection

People with dementia and family caregivers. Participants were interviewed three times over the course of the intervention: before the first workshop, after the third workshop, and after the final workshop. This was to get a sense of participants' experiences over the course of the intervention. Interviews were semi-structured and followed a general topic guide, which was partly informed by the research questions (Appendix E). Interviews were recorded using an encrypted digital recorder. The first interview was brief and introductory, with the aim of establishing a relationship between the interviewer and participants. The person with dementia and their caregiver in the group context were interviewed together for the first interview, and individually for the second and third. They took place during the workshops in a quiet adjoining room. Participants from the individual contexts were interviewed together in their home, as they indicated that they would prefer this.

Care staff participants. Care staff participants were interviewed twice, 4 weeks after the final training workshop, and then 4 weeks after the first interview. Interviews were semi-structured, and a general topic guide was used (Appendix E). With the permission of management, interviews took place during work hours, in a quiet area of the care home.

Data Analysis

Data were analysed using deductive thematic analyses whereby the research questions informed the topic guide (Braun & Clarke, 2006). The analysis was conducted using methodology set forth by Braun and Clarke (2006), in which there are six individual steps. The first step, familiarisation, was achieved by transcribing the semi-structured interviews verbatim and then carefully reading through the transcripts twice. Transcripts were then checked against the interview recordings for accuracy and missing data. In the second step, transcripts were carefully reread, and initial basic codes were extracted. This was done by manually noting patterns in the margins of the transcripts. The basic codes were then organised into possible themes and subthemes in the third step using a thematic map. The fourth step involved reviewing and refining these themes and subthemes in two phases. While re-reading the original dataset, any data that may have been missed in the original coding was checked. The thematic map was refined as some themes merged while others were discarded. After establishing that the themes and subthemes 'worked' with the dataset, they were named and defined in the fifth step. These themes were then discussed with the second author (BW). Relevant extracts from the dataset were placed into the corresponding themes and subthemes in a table. This table was used to refine and check each theme against the corresponding data extracts to ascertain if they were coherent and relevant. In the sixth and final step, the report was produced. Data from each context were analysed separately so that experiences in each context could be explored and compared to the others.

Participant Characteristics

Despite relatively high interest in the LSW workshops, just half of those approached were eligible or wished to participate in the research (Table 3.1). In general, people were concerned about time or were already taking part in other research studies.

Table 3.1. Recruitment of participants

Action	N
People with dementia	
Invited to take part	12
Agreed to take part	6
Family caregivers	
Invited to take part	12
Agreed to take part	6
Care staff	
Invited to take part	12
Agreed to take part	4

People with dementia. Six people with dementia took part in the research (3 from each context). Participant characteristics are summarised in Table 3.2. One participant from the group context dropped out after the initial introductory interview, as she did not want to be interviewed. She continued to attend the workshops with her caregiver until her health declined four weeks later. Group participants that took part were from the same workshop group.

Family Caregivers. Each person with dementia participated with a family caregiver. Characteristics of family caregivers are summarised in Table 3.2. The caregiver of the participant with dementia who dropped out withdrew from the workshops and the research following the second interview, due to his wife's poor health.

Professional caregivers. Four professional caregivers working in two private care homes in North Wales opted to take part in the research. One was a team leader, and the others were general care staff. The team leader was the only male participant in this group. Three of the four care staff participants had basic to average ICT skills (self-reported) while one reported having little to no experience with ICT.

Person with dementia data

There were two themes in the data from participants with dementia, each with two subthemes. These were 'Memories' including the subthemes 'evoking memories' and 'sharing memories', and 'Intervention Limitations', including the subthemes '"it's not for everyone"' and 'ICT as a barrier'.

Memories

Evoking memories. For all participants, doing digital LSW (at home and during workshops) evoked memories and was (mostly) an enjoyable experience. Although Mr D struggled to participate in the interviews, he spoke to the researcher at length about his earlier memories with evident enjoyment and pride.

"The only way to get moving is if you tell him, alright I can't remember anything sometimes but often just a little thing jumps in, and I know what I've done, and I feel chuffed" (Mr K, individual context).

"It jogs your memory. You think about things you haven't thought about for years" (Mr J, group context).

"Well, I think this is a big thing to help my memories which is something I need actually it's so annoying not having the memories so the help is going to be ideal" (Mr M, individual context).

Sharing memories. The opportunity to share memories with family and future generations was particularly important to Mr M and Mr J.

"I'm really pleased now it's all being done it means we've got my life story which is wonderful. I mean the Grandchildren will enjoy it I think they'll look back in years and think Grandad did this and Grandad did that you know" (Mr M, individual context).

"It would be good for them to know about their relatives...I wish I had...I know nothing about my Dad" (Mr J, group context).

Intervention Limitations

'It's not for everyone'. Mrs B felt that LSW wasn't for her and spent the following workshops focusing on music she liked, while Mr J acknowledged that LSW isn't something everyone would enjoy.

"...I mean what's bad about bringing back memories and things like that. I mean it ain't everybody's cup of tea, but it depends on your own attitude" (Mr J, group context).

"Em well, I don't want my life story" (Mrs. B, group context).

During the interviews, Mr K frequently spoke about his frustration at not being able to remember names, faces, and places. In the first workshop, Mr D became upset as he recalled a family tragedy when discussing his childhood.

"Yeah because the thing that upsets me is I forget the names of people and it's hard and how can I put it, I'm not upset, but I think why don't I remember and it yeah..." (Mr K, group context).

ICT as a barrier. The 'digital' nature of the life storybook was a significant barrier. Although participants participated in the workshops and enjoyed reminiscing, none interacted with their life storybook independently.

"I have sort of given up on a lot of things with the computer because I couldn't work it properly" (Mr R, group context).

Table 3.2. Descriptive characteristics of participants with dementia and family caregivers

Participant Type	Person with dementia	Age Bracket (years)	Gender	Self-reported ICT skills	Dementia severity (CDR)	Family caregiver	Relationship	Self-reported ICT skills
Community group participants	Mr J	70-85	Male	None	Mild	Mrs J	Wife	Average
	Mr R	70-85	Male	None	Moderate	Ms E	Sister	None
	Mrs B	70-85	Female	None	Mild	Mr B	Husband	Basic
Individual context participants	Mr D	70-85	Male	None	Moderate	Mrs D	Wife	Average
	Mr K	70-85	Male	None	Moderate	Ms K	Partner	Good
	Mr M	70-85	Male	None	Mild	Mrs M	Wife	Basic

"I don't like to play on that one (tablet computer) in case I do something wrong..." (Mr M, individual context).

Caregiver data

Three themes were identified, and are outlined in Table 3.3.

Expectations and usage.

Expectations and apprehension. In the initial interview, caregivers were asked about their expectations of the intervention. Some were apprehensive about how their relative would find the experience, while others had positive expectations.

"I'm interested to see what will happen really [laughter]" (Ms E, group context).

"I'm apprehensive for Mr K really, not for me. I'm a bit concerned about him because he does tend to get quite upset sometimes if memories come along and he thinks about things. He doesn't get madly upset he just gets a bit upset, and I don't want him to be upset I want him to have pleasure out of it, do you know what I mean?" (Ms. K, individual context).

Using the digital life storybook. Caregivers were asked about using the digital life storybooks between workshops. Group context caregivers reported low usage, though Mr R and Ms E had discussions about the past with their relative, which may have been prompted by the workshops.

"We did discuss what he could remember and where he'd been you see. This is his problem you see. He can't remember. We went back all the way to when he was in the army, and that is when he remembered...so he doesn't remember things over the years after that. That's the problem" (Ms E, group context).

On the other hand, caregivers from the individual context reported using the digital life storybook more often between workshops, particularly as the weeks progressed and they became more confident with using it.

Table 3.3. Findings from the perspective of family caregivers

Theme	Subtheme
Expectations and usage	Expectations and apprehension
	Using the digital life storybook
	Different plans
Intervention context: individual versus group	Group context
	Individual Context
ICT considerations	Multimedia access and capacity
	Limitations or learning?

"Yeah all week I've been at it, well he's been telling me, and I've been doing it" (Ms K, individual context).

"Usually on a Saturday afternoon the family all arrive and sort of when we're waiting for them to come 'oh we'll get it out and have a little look at it" (Mrs. D, individual context).

Different plans. Group context participants viewed the digital life storybook as something to use in the future as a memory aid when the person with dementia's condition worsened, rather than a meaningful activity to engage with now.

"…It's going to probably help her, probably not immediately, but probably a bit later on when things…well you know they're not going to get better are they? So it will probably help when things get a bit further along the line" (Mr R, group context).

"It is something to hold onto in the future. We may not need it. It may not get as bad as we think it might get but em... It's always wise to have it there" (Mrs. J, group context).

On the other hand, participants from the individual context felt that it was something they should use now, and continue adding to.

"Oh, I think we'll carry on using it yeah because we'll be writing about the new holiday and then every holiday we go on and things that crop up" (Mrs. M, individual context).

"There's so much you can add into it. Our lives are continuing, Mr K's life is continuing, so you know you've got to write all these extra things in" (Ms K, individual context).

Intervention context.

Group context. When asked about the benefits of the LSW service and digital life storybook, caregivers from the group context spoke primarily about the social benefits of attending the workshops, both for themselves and the person with dementia.

"I think it's very helpful it's nice to meet other people" (Ms E, group context).

"There's no real impact beyond meeting other people and getting him out of his chair which is quite important because otherwise he would sit and watch war films on TV [laughter]…it's socialising" (Mrs. J, group context).

Individual context. Conversely, caregivers from the individual context felt that the intervention would be better in a one-to-one setting than in a group setting. Ms K also emphasised how the facilitator has made it an enjoyable experience for her and Mr K.

"It's the one to one I think; it's better from Mr K's point of view because you tend to be overwhelmed by everybody else and there will always be somebody that's piping up and saying things, and you don't get a say" (Ms K, individual context).

"I think we had the option to go into a group one or individual and I thought it's better to talk one to one because in a group you can get side-tracked or it was nice [the facilitator] was here concentrating on us and what we wanted to put in it" (Mrs. M, individual context).

"He's enjoyed it, and she's (the facilitator) made it nice. It's not been heavy do you know what I mean? It's been light, and it's been nice" (Ms K, individual context).

Technology.

Multimedia access and capacity. All family caregivers valued the ability to use and combine multimedia stimuli in the digital life storybook.

"I don't know how people managed before. They would look through heaps/sheets of photographs and somebody, one or two people, would have to be there saying this is what happened you know what you did, and all that sort of thing or maybe they wrote everything down in longhand or in a notepad or something like that so this is sort of everything all rolled into one is em Book of You. It's there for everybody to contribute a little bit" (Mrs. J, group context).

"And when she [the facilitator] first came she said 'and where did you go to school and she said and who was your teacher and she just brings this picture up and showed us and to see his face! Just light up! Because you can't always remember people's names can you? But if you saw…that footballer last week when she brought the picture up the look on your face was fab! That was worth the whole of the six weeks that was. And that's so so clever that you can do that isn't it?" (Ms. K, individual context).

Limitations or learning? Although family caregivers valued the digital nature of the life storybook, it was a significant barrier for those in the group context.

"I say I'm not a technological person so if it doesn't come up quickly, then I tend to go away from it" (Mrs. J, group context).

Family caregivers from the individual context felt that the digital aspect of the intervention was a learning experience and became more confident as the sessions continued. Although, the nature and longer session length of the individual context meant that they received more one-to-one attention from the facilitator to learn how to use the digital life storybook. All three mentioned using a 'how to' guide they received from the facilitator.

"On Saturday, I started it and went through it and thought oh I haven't put a title in what do I do help. And the Book Of You had sent me a lot of notes, so I went to the bit, found what to do, managed to get back in and did and felt so proud of myself. I made a mistake, but I managed

to correct it. It gave me the confidence you know if I do make a mistake again I can just not worry about it and just go back in and do it now" (Mrs. M, individual context).

Care Staff Findings

Themes and subthemes from the care staff data are outlined in Table 3.4.

Table 3.4. Findings from the perspective of care staff

Theme	Subtheme
Connecting and sharing	Collaboration and communication
	Meaningful interaction & conversation
	"it's too personal"
ICT: creating opportunities	Accessing relevant materials
	A new skill
The Influence of the Work Environment	Time and priorities
	Convenience
	The impact of management

Connecting and sharing

Collaboration and communication. The digital life storybooks presented an opportunity for staff, residents, and relatives to have a shared goal. Care staff spoke about working with families, with each other, and with residents to create the life storybooks.

"It helps the family, the client, and ourselves I think to become one effort for that one person I feel" (Ms V, CH2).

"We learn so much just talking to somebody, communicating with the families and even talking to some of the residents who still talk to us" (Mr M, CH1).

Staff in both care homes also used the digital life storybook as a tool to communicate with residents' family members. In the second care home, this was it's primary use. The digital life storybook was used to share moments that occurred in the care home that family members might have not otherwise seen. Photos and videos of recent activities and events

in the care home were also recorded and added to residents' digital life storybooks so that family members could view them through a shared password. This takes the digital life storybook beyond its original LSW use and towards a vehicle for communication with relatives.

> *"...we have one gentleman whose eating's very poor, and we've had him eating at the table, and it's a moment, isn't it? You know, and we took that picture and showed the family and she's [intake of breath] you know, and it's a thank you. And it's nice to have a thank you at the end of the day" (Ms V, CH2).*

> *"I've actually took one this morning, a video of one of them drying up the dishes and putting the dishes away. Em...drawing, having walks outside, took photos of people sat in the car. Whatever activity they're doing, we will try to take a couple of pictures we've taken some of some of them singing and dancing so..." (Ms. P, CH2).*

Meaningful interaction and conversation. Care staff felt that the digital life storybook helped them to have meaningful interactions with the residents they cared for. They viewed it as a tool to learn more about residents and to stimulate conversation.

> *"I think it's just setting the resident with us, and just...little sparks come back, and somethings that were part of their life can come back and yeah... it's hard to explain really but the whole thing together when they see all these little pictures and em the little memories cos the memories are still there, it's just short-term things that's not there" (Mr M, CH1).*

> *"We've got one gentleman who loves rugby so we went back to rugby years ago where he'd remember so I could communicate with him with it, and he could feed back to me as well, so it was like communicating about something that he liked...I found that I could actually have a conversation with him with which surprised me really because he actually answered some of the questions, so it was a nice communication that we had" (Ms V, CH2).*

Some also felt that the digital life storybook was a useful tool to help calm residents if they felt distressed.

"It does work I think it's a good thing. Like I said we had a gentleman who was clearly agitated and the girls put it on and straight away there was a mood change and he started singing...So it does I think it reflects on them something that they recognise because they're lonely aren't they...in their own minds... it helps us to communicate with them better and to sort of just settle them a little bit" (Ms P, CH2).

'It's too personal'. Staff members in both care homes endeavoured to set up a digital life storybook for every resident. However, in the first care home (CH1), some family members did not want one set up for their relative as they were concerned about privacy. In the first care home, the intervention was introduced as a new scheme, while in the second (CH2) it was implemented from when it first opened.

"Some [relatives] are very good they want to...they're all for it, and others are just...they're not keen at all.... There's some that don't want to do it they feel as though it's just, it's too personal do you know what I mean? And they think their loved one would not want them to...I dunno...expose that much" (Mr M, CH1).

ICT: creating opportunities.

Accessing relevant materials. Care staff valued the ability to find and add multimedia materials that are personal and meaningful to residents. One chose to make digital life storybooks for residents that were from areas that were familiar to her so she could have in-depth conversations about them.

"I think it's getting the residents and families involved and em putting the life stories and what things are meaningful to them on to a book... on to a video, download a piece of music that you know they love...It's amazing just go on YouTube, and things come up which is related to the residents" (Mr M, CH1).

A new skill. Although some staff members experienced a little difficulty using the digital life storybook, they were able to navigate it with relative ease for the most part. They felt that using the digital life storybook and attending the workshops had been a learning experience.

"I'm getting better... I mean I'm in my 50s I wasn't brought up with computers, to be honest with you. I think it's more of a struggle for the older carers but we're getting into it. The younger carers they just know everything you know they know where it is it's fantastic for them. It's a learning process for us as well" (Mr M, CH1).

"Nil [computer skills to start with] really but I've got the hang of doing them. But it's helped me with computers at home as well" (Ms V, CH2).

The influence of the work environment.

Time and priorities. As expected, time was a crucial factor in care staff using the digital life storybook. Reported time constraints were consistent with reported usage (i.e. less time was associated with less use and vice versa). Despite this, care staff had a positive attitude towards the digital life storybook and wanted to use it more.

"It's just... getting the time. If we do have a bit of time, we can sit down, but it just depends what kind of day we're having here. If we're having a good day yes we'd have time, but it doesn't happen quite often (laughter)..." (Ms G, CH1).

"When we're busy you know we can't use it as much as we'd like to" (Ms V, CH2).

Convenience. Both care homes had Wi-Fi, and staff members carried a tablet computer with them on their shift to record care notes. The digital life storybook was accessible on these tablets which provided convenient and instant access to any resident's digital life storybook.

"Well, I think it's quite handy because we've got it on us and we can go...when we're sitting down with the residents we can go straight on it we don't have to go and look for something... to look for photos or get something from their room we've got them with us.... And you know by the time we've gone to get a photo from the room they wouldn't be interested then cos you've got to do it when they're sitting, and the person is interested. Because do you know another minute and they've changed again haven't they? That's dementia yeah" (Ms G, CH1).

The impact of management. Management in both care homes were supportive of the intervention and keen to have the digital life storybooks integrated into the daily care routine. They appointed LSW 'champions' to encourage integration, and held occasional meetings with staff who had attended the training workshops. Staff members who had good ICT skills were assigned to be 'tutors' and assist other staff if needed.

"[The manager] is very keen to get this going and em like I said we want to get it going as well" (Mr M, CH1).

"Yeah and we've got good tutors if we need to know something or maybe not sure of something we can just go to certain people who are involved in computers..." (Mr M, CH1)

Discussion

This study aimed to explore user experiences of a digital life storybook from the perspectives of people with dementia, family caregivers, and care staff across three different implementations of LSW. It provides insight into these experiences and adds to evidence supporting the feasibility of digital LSW for people living with dementia and their caregivers. This research also highlights examples of digital life storybooks being used for additional, but valid, purposes.

Making connections is a common theme that was identified in the data from all three participant groups. For participants with dementia, the intervention helped them to reconnect with their past by evoking distant and forgotten memories. This supports findings from previous studies using ICT based approaches to reminiscence work (Damianakis et al., 2010; Lynch et al., 2016; Massimi et al., 2008; Sarne-Fleischmann & Tractinsky, 2008; Subramaniam & Woods, 2016). For family caregivers, making connections referred to LSW evoking memories for the person with dementia (individual and group contexts), and the social aspect of attending workshops (group context). According to the formulation proposed by Kindell and colleagues (2014, p. 159), the connections made by care staff through the intervention were examples of 'interactional connections' and 'building new connections', in which the primary outcomes are enjoyment and promoting person-centred care. Care staff felt that the digital life storybooks improved the quality of communication between themselves and residents. This reflects previous findings of both conventional (Clarke et al., 2003; Gudex et al., 2010; Kellett, Moyle, McAllister, King, & Gallagher, 2010; Subramaniam et al., 2013) and digital (Lynch et al., 2016; Sarne- Fleischmann & Tractinsky, 2008, Subramaniam & Woods, 2016) LSW interventions. In addition to improved communication with residents, care staff also discussed how they communicated more with relatives. This reinforces previous findings that both traditional and digital LSW can build and strengthen relationships between care home staff, the person with dementia and their relatives (Clarke et al., 2003; Kellett et al., 2010; Sarne- Fleischmann & Tractinsky, 2008; Subramaniam & Woods, 2016).

The digital nature of the intervention presented both opportunities and challenges for participants. In addition to their own pictures and items, participants had access to powerful multimedia stimuli that were personal to them through the use of the internet,

which they enjoyed and appreciated. For example, Mr K had no photographs from his past and relied on resources from the internet for materials for his digital life storybook. Music seemed to be particularly meaningful, which has also been identified in previous work (Mulvenna et al., 2017; Subramaniam & Woods, 2016). On the other hand, ICT was a significant barrier for all participants with dementia and some caregivers. Participants with dementia did not interact with the reminiscence device and depended on their caregivers to do so. Conversely, although Mulvenna and colleagues (2017) identified a significant correlation between the person with dementia's and caregiver's use of a reminiscence app, they also observed that people with dementia sometimes used the app without their caregiver, and were able to interact with it independently. In that study, participants also had mild to moderate dementia but received training at the onset of the 12-week trial.

Conflicting aims has long been an issue in reminiscence work (Kindell et al. 2014; McKeown et al., 2006; Subramaniam & Woods, 2010; Woods & Subramaniam, 2017). According to Kindell and colleagues (2014), LSW 'has the potential to be a diverse activity, carried out in a variety of settings, in different ways, using different materials, by a variety of people, with potentially different objectives' (p. 153). In the present study, different participant groups prioritised different goals, and these goals varied across contexts. 'Mission creep' was present in the ways that care staff used the digital life storybooks, i.e. they were used in additional (but positive) ways that went beyond the initial aims of the developers. Care staff in the second care home primarily viewed the digital life storybooks as a means of sharing moments and activities from the care home with relatives of residents. They felt this improved their relationships with relatives and made their work more appreciated. This was a useful added function, though over-focusing on this use of the digital life storybook may risk excluding the resident. Meanwhile, family caregivers from the group context felt that LSW was something to do in the future when their relatives' condition worsened. This differs from caregivers from the individual context, who were keen to continue using and adding to their relative's life storybook.

All three participant groups had a favourable view of the intervention and the digital life storybook. They enjoyed it and felt that it was a good thing to do which resembles previous findings (Damianakis et al., 2010; Massimi et al., 2008; Sarne-Fleischmann & Tractinsky, 2008; Subramaniam & Woods, 2016). However, we also saw how reminiscence evoked negative emotions for some participants with dementia as well

as positive ones. Mr K and Mr D from the individual context had tearful moments, and Mr K often felt frustrated when he could not remember people or places. Despite these sad or frustrating moments, they felt their overall experience was positive which is reflected in previous work (Damianakis et al., 2010; Sarne-Fleischmann & Tractinsky, 2008). For example, Damianakis and colleagues (2010) observed 291 positive reactions to reminiscence stimuli among participants with dementia and MCI, compared to just 6 negative, and 16 mixed reactions. In other research, negative responses were considered natural expressions of loss and in one case, viewed in a positive light (Sarne-Fleischmann & Tractinsky, 2008; Subramaniam et al., 2013). However, it is crucial to equip facilitators and care staff to manage natural expressions of loss carefully and sensitively (McKeown et al., 2017). An advantage of digital LSW is that the user can easily remove materials that evoke negative reactions if needed. Subramaniam and colleagues (2013) found that all participants in their study opted to exclude traumatic and distressing memories from their life storybooks.

Results of this research suggest that different intervention contexts have different implications for implementation. Usage of the digital life storybook was higher among participants in the individual context then the group context. Family caregivers from the individual context also reported that they became comfortable using the digital life storybook (likely due to more one-on-one time with a facilitator) and had plans to continue adding to it, which was not salient in the group context data. The Book of You service does not have current or planned systems to check and encourage implementation with previous users. Six-monthly maintenance sessions could be a potential way to achieve this.

For care staff participants, implementation is somewhat different because carrying out digital LSW was viewed as part of daily care, both by staff and management. Following a digital LSW intervention, Lynch and colleagues (2016) highlighted the importance of organisational support for success and sustainability. Gudex and colleagues (2010) speculate that their hospital-based LSW intervention was not fully implemented despite enthusiasm from staff members, due to a lack of interest, time and support from management. In the present study, care staff were positive about the intervention and received a good deal of support from management, though time remained an issue. Management held meetings and appointed staff tutors to encourage the use of the digital

life storybooks. This is something that participants from the Gudex study reported that they would have wanted. Care staff in the present study viewed the digital life storybook training as learning a new skill. Similarly, Gudex and colleagues (2010) found that staff members who received reminiscence training scored significantly better on measures of personal accomplishment than staff who received no training.

Strengths and limitations

A small convenience sample was used meaning that it is likely not representative of people with mild to moderate dementia, their caregivers, or care staff. The facilitator was involved in initially distributing information sheets to potential participants in the individual context. Even though it was stressed that this was optional, it may have created bias. Time constraints with participants in the group context reduced the depth of the interviews conducted, while the caregiver's presence in the individual context may have led to less input from the person with dementia, as the caregiver mostly spoke. On the other hand, the semi-structured topic guide facilitated the emergence of individual experiences, and these experiences were considered and analysed separately, meaning that distinct perspectives could emerge.

Rigour/Credibility of findings

Long and Johnson (2000) suggest that the credibility of qualitative studies is enhanced greatly by seeking the respondents' views on the emerging themes and checking that they do indeed resonate with their experiences. In this study it was not possible to attain respondent validation, largely due to several months passing between data collection interviews and data analysis (as recruitment was constrained to those interacting with LSW service). However, other steps were taken in an effort to address the rigour and credibility of findings. During the interviews, clarification was sought on what participants were saying throughout the interviews, by summing up what they had said and asking if this was correct. I was very aware of my position as a researcher both personally and in relation to the life story work service and took the time to explain this to all participants. I kept field notes which I referred back to throughout the data collection and analysis process. The transcripts and potential themes arising from these were discussed with my supervisor (who had not been involved with interviewing). Later, when a list of themes and subthemes was established, these were again discussed with my supervisor. The

results of this chapter provide several extracts of participant interviews to support the findings.

Implications for practice and research

This multiple perspective study shows that a digital life storybook is feasible in care homes, and in individual and group contexts for people with dementia and their caregivers if upsetting memories can be managed sensitively. The data highlights some strengths of the service but also some issues in clarifying the objectives of its use.

Among people with dementia and family caregivers, enjoyment of the intervention appeared to be similar, though participants from the individual context put more weight on reminiscence, while those from the group context felt strongly about the socialisation aspect. Conducting the intervention in a private individual context was more conducive to learning how to use and create a digital life storybook. However, it is crucially important to have facilitators who will deliver the intervention in a positive, enjoyable way and ensure they are prepared to deal with potential negative emotions that may result from reminiscing. In care homes, the intervention was relatively successful, with benefits reportedly reaching the residents and their relatives, in addition to the care staff. Future research should address the limitations of the current study, and explore the views of care home residents and their relatives.

Conclusion

This study provides evidence for the feasibility and positive impact of digital LSW delivered through a service. The intervention appears to be feasible and valuable in all three contexts, though different contexts are associated with slightly different outcomes.

Chapter 4. Exploring the feasibility of a self-guided, digital life story work app for people living with dementia and their caregivers: A Citizen Science approach

Summary

Digital Life Story Work (LSW) has become a popular approach to reminiscence work for people with dementia. The aim of this study was to investigate the feasibility of a self-guided digital LSW research app for people living with dementia and their caregivers, and to explore user experiences of it. A Citizen Science approach was used, and 101 participants consented to participate in this three-month intervention. Participants were given access to a digital life storybook app, that also included research elements (e.g. information sheet, consent forms, quantitative measures). Participant experiences were explored using momentary session feedback, usage data insights, quantitative measures of well-being, and follow-up qualitative phone interviews. Engagement with the app was low, though momentary assessment data indicated that it appeared to provide some enjoyment to those who used it. No effects were identified on measures of quality of life. This is the first study into a self-guided digital LSW app for people with dementia and their caregivers. This chapter will draw on user experiences and usage insight data, to make recommendations regarding the development of digital LSW and Citizen Science approaches for people with dementia and their caregivers.

The research presented in this chapter has been submitted to *The International Journal of Computers in Healthcare* for consideration for publication.

Introduction

Dementia is now seen as one of the biggest health and social care challenges globally, surpassing cancer, heart disease, HIV, and AIDS. In the UK alone, dementia costs an estimated 26 billion pounds per year, and this cost is set to rise rapidly (Lewis et al., 2014). In 2012, the British Prime Minister launched a national challenge to fight dementia, with increased and improved research at the forefront (Department of Health, 2015). This initiative led to the establishment of the World Dementia Council (WDC), in which 'fostering a culture of open science and collaborative global research, including the use of global big data approaches' was one of five key global priorities (WDC, 2017). To address the Prime Minister's challenge, the UK government has committed to investing over 60 million pounds to support both conventional dementia research (to find a cure by 2025) and other streams of research, including the potential for a 'Citizen Science' approach (WHO, 2017).

Over the last decade, Citizen Science has become an increasingly popular research approach, assisted by innovations in technology (Rothstein, Wilbanks, & Brothers, 2015; Socientize Consortium, 2013). There are several definitions and conceptualisations of Citizen Science, but simply put, it is 'a series of activities that link the general public with scientific research' (Socientize Consortium, 2013, p21). It encompasses a wide range of activities that take place at various levels and intensities. Haklay (2012) proposed that there are four main levels of Citizen Science which are assigned depending upon the extent of volunteer engagement. These range from 'Extreme Citizen Science' (Level 4) to 'Crowdsourcing' (Level 1). In 'Extreme Citizen Science' (Level 4), the research is collaborative, and members of the public are involved in all aspects including problem definition, data collection, and analysis. For example, the Arctic Hunters Project aims to develop mobile technology that can assist indigenous subsistence hunters with forecasting the weather in the face of climate change. Participants record their experiences and contribute their knowledge which is then combined with scientific knowledge to collectively address these issues (Jennett, Cox, Mastracci & Regalado, 2014). In 'crowdsourcing' (level 1) on the other hand, participants only contribute to data collection or provide computing power. For example, in the North Carolina King Tides project, the public is asked to submit photos of flooding in their area so that scientists can learn more about the causes and impact of high coastal water levels (North Carolina King Tides

Project, 2017). Other taxonomies classify Citizen Science by the number and spread of participants, and the time or resource investment required (Roy et al., 2012), or by the general aims of the project (Wiggins & Crownston, 2011). Recently, Den Broeder, Devilee, Van Oers, Schuit, and Wagemakers (2016) proposed a single framework to classify Citizen Science projects combining the three above taxonomies. This framework is made up of three characteristics: the aim of citizen engagement, the level of participation, and geographical size (Table 4.1).

The advantages of Citizen Science can be grouped into three main categories: increased research capacity, better knowledge, and benefits for citizens (Den Broeder et al., 2016; Socientize Consortium, 2013). One of the main drivers behind the development of Citizen Science is that it enables researchers to collect and analyse data that might not have been manageable any other way. It also facilitates collecting data across large areas or lengthy timescales. The idea behind Citizen Science is that combining public and scientific knowledge may produce improved knowledge and the development of new research methods. Benefits for citizens mainly revolve around gaining more knowledge and understanding about the subject and research methods, in addition to new skills and abilities (Den Broeder et al., 2016). Additional potential benefits include empowerment, attitude changes, and community development (Den Broeder et al., 2016; Haywood, 2013; King et al., 2016; Socientize Consortium, 2013). It is also important to consider what attracts, motivates, and retains participants in Citizen Science research. Although motivation depends upon the project type and level of involvement, common motivators include interest in the research topic, enjoying the research task, helping others, feeling part of a team, financial incentives, and receiving recognition and feedback (Jennet, Furniss et al., 2014).

Initially, the Citizen Science approach was used almost exclusively in the biological and physical sciences which has constrained research into the approach itself (Follett & Strezov, 2015). However, it is now gaining traction in other fields including health and social sciences. Jennet, Furniss, and colleagues (2014) suggest that using Citizen Science in health or social sciences brings about a shift from participants reporting in the third person (observations about their environment) to the first-person (information about themselves) which may affect participation and motivation. In recent years, information and communication technology (ICT) has brought about a new wave of Citizen Science

Table 4.1. Citizen Science descriptive characteristics

Aims	1.	Investigation: aimed at answering scientific questions
	2.	Education: aimed at educational goals
	3.	Collective goods: public health, management of infectious diseases, protect and manage natural resources
	4.	Action: citizens and scientists collaborate to address local concerns
Approaches	A.	Extreme citizen science: Citizens in charge from problem definition, data collection and analysis, to interpretation and knowledge development
	B.	Participatory science: Participation of citizens in problem definition and data collection
	C.	Distributed intelligence
		a. Citizens as basic interpreters
		b. Volunteered thinking
	D.	Crowdsourcing
		a. Citizens as sensors
		b. Volunteered computing
Size	i.	Local
	ii.	Mass

From "Citizen Science for public health" by L. Den Broeder, J. Devilee, H Van Oers, A. J. Schuit, & A. Wagemakers, 2016, Health Promotion, 1, 1-10.

approaches whereby the public and research scientists collaborate online through apps, wearable technology, sensors, games, etc. (Jennet, Furniss, et al., 2014; Rothstein et al., 2015). In March 2015, the first major smartphone-based health research study, 'mPower' was launched (Sage Bionetworks, 2015). 'mPower' is a clinical observational study conducted exclusively through an iPhone app to monitor key indicators of Parkinson's Disease progression and diagnoses. The study used a remote approach whereby participants downloaded the app and self-guided through the sign-up and consent process. Within the app, participants are asked to input demographic information, complete two questionnaires (repeated), and carry out four 'tasks' to measure voice, posture, stability reaction time etc. A total of 9,520 participants consented to participate (though 86% were

healthy controls), with 8,320 completing at least one survey or task (Bot et al., 2016). Soon after the launch of 'mPower', a similar app, 'Share the Journey: Mind, Body & Wellness' was released, this time aimed at breast cancer survivors (Sage Bionetworks, 2015). Again, participants used the app to fill out surveys and share novel sensor data. Data from these studies are being used in ongoing research which has not yet been published, meaning there is currently little information available about participants' experiences with these research apps.

In line with the 2013 G8 Dementia Declaration Open Science and Data Commitments (Department of Health, 2013), the UK Government procured an online dementia Citizen Science platform[2] involving two app-based psychosocial interventions. Digital life story work (LSW) was selected as one of these interventions, due to its popularity and early promising research findings. LSW is a biographical approach that gives people the opportunity to talk about past events and experiences with another person or group of people, and have these recorded in some way, typically in a life storybook. This is then used to benefit the person in the present (McKeown et al. 2006, Murphy, 2000). LSW can help the person to make sense of their identity and connect the past to the present. It can be important for others, as it facilitates communication and understanding of the person with dementia (Coleman, Ivani-Chalian & Robinson,1998; Kellet et al., 2010; Russell & Timmons, 2009; Woods & Subramaniam, 2017). In recent years, innovations in ICT have prompted a shift from conventional LSW using scrapbooks and photo albums, to digital LSW using apps, digital presentations, and digital archives (Subramaniam & Woods, 2016). Digital LSW introduces a range of relevant and stimulating multimedia content that users can compile to create a digital type of 'book' (Subramaniam & Woods, 2010).

Despite limited research, there is promising evidence that digital LSW is feasible and beneficial for people with dementia (Damianakis et al., 2009; Lynch & colleagues, 2016; Subramaniam & Woods, 2010; Subramaniam & Woods, 2016). For example, Subramaniam and Woods (2016) found that a digital life storybook that played as a movie was associated with improved quality of life and aspects of autobiographical memory for five out of six people with dementia living in care homes. A thematic analysis also revealed

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[2] www.dementiacitizens.org

that participants, relatives and care staff considered the digital life stories a useful tool to help trigger memories, while participants elicited (mostly) positive reactions in response to viewing them. Similarly, using observational methods and interviews, Damianakis and colleagues (2010) found that six people with dementia enjoyed having their life stories in a digital DVD format and that most memories triggered were positive. Lynch and colleagues (2016) used a touchscreen app to create a digital life storybook (LSB) for people with intellectual disabilities who had dementia or were at risk of developing it. They found that the LSB was a powerful tool to facilitate meaningful conversation and that it supported person-centred care. The participants, their families, and caregivers approved of the intervention.

However, personalised psychosocial approaches, such as LSW, can be challenging to implement as they may be demanding on time and often require additional resources (Lawrence et al., 2012; Subramaniam & Woods 2012). These challenges can also be paralleled in research. For example, in one of the above studies, the mean researcher production time for one digital life storybook DVD was 135 hours (Damianakis et al., 2010; Smith, Crete-Nishihata, Damianakis, Baecker & Marziali, 2009). Similarly, in the work by Subramaniam and Woods (2016) described above, converting a conventional life storybook to a video on DVD was a lengthy process, that could stretch over 7 to 10 weeks in total. Incorporating digital LSW into a Citizen Science platform may have the potential to reduce the time and resource burden of this intervention, as participants create their own life storybook and respond to research questionnaires electronically. However, Gibson and colleagues (2016) found that implementing standard protocols to test the usability of ICT systems (e.g. audio and video recording, voicing thoughts during use) may not be appropriate for use with people with dementia, and there is need to explore new ways to collect this kind of data.

Aims

The aims of this study are twofold. The first is to deliver and investigate the effects of, a LSW intervention for people with dementia conducted purely through an iOS app interface, using a Citizen Science approach. The second is to explore how Citizen Science may best be applied in the context of dementia. The following research questions will be addressed:

1. What are participants' general experiences with the app?
2. What are participants' daily experiences of LSW 'sessions' using the app?
3. Is a remote app-based LSW intervention feasible for people living with dementia and their caregivers/supporters?
4. Does the use of a LSW app affect the quality of life of people with dementia, and where applicable, their caregivers/supporters?
5. How might Citizen Science best be applied in the context of dementia?

Methods

Intervention Overview

The Dementia Citizens Book of You (DCBY) app is a LSW app for iOS devices that enables users to create a personalised digital life storybook made up of chapters and pages. It was adapted and simplified from an existing web-based system to function as an iOS touchscreen app, and include research components. The developers carried out three phases of research, in which they interviewed a small number of people living with dementia, and their caregivers. In phase 1 they explored user perspectives (n=14) of the idea of the initiative and key features. Phase 2 was carried out to gather reactions to an early prototype of the app and establish improvements to be made (n = 16). Following adjustments based on previous feedback, phase 3 and 4 were carried out over a 2-week period. In these phases, reactions and opinions of people with dementia and caregivers to the app were sought (n = 8) so that final improvements could be made before the launch.

The app includes six chapter suggestions (e.g. Childhood) each containing three suggestions of page titles (e.g. School, Toys, Pets). There were also options to add new chapters and pages, with free text titles. Users could add photographs from their device, take new photographs, or search for images using an inbuilt Google Image Search. The app also had an audio recorder that enabled users to record music or audio narration to accompany their photos. There was also an option to add text captions to photographs or videos. All of the media features were local meaning that users did not have to navigate away from the app to engage with the features. The app also included guidance and instructions on how to create a life storybook and use the app. In addition to the digital life storybook platform, the app contained several research elements. Screenshots of the DCBY user interface are presented in Figure 4.1.

Design

This study was designed as a 3-month single group (repeated-measures) study in which participants use the DCBY app and fill out the quantitative measures over a 3-month period. In a second phase, follow-up feedback was sought from those who had registered interest in the study.
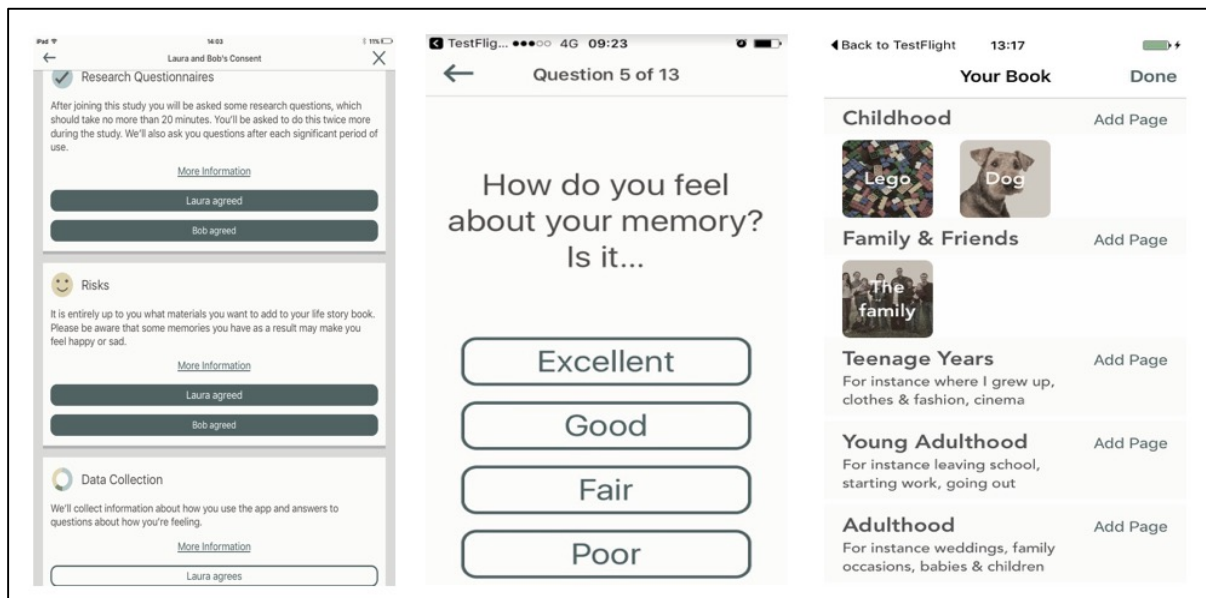
Figure 4.1. Screenshots of Dementia Citizens Book of You app user interface

Participants

Participants were people with a diagnosis of dementia, and their caregivers living in the UK. In this context, the term caregiver refers to a relative, friend, or professional caregiver who sees the person with dementia on a regular basis. People with dementia could also take part independently.

Potential participants were identified and contacted through various pathways. Join Dementia Research (JDR) was the primary recruitment tool. JDR is a nationwide database, operated by the National Institute of Health Research, of people with dementia, carers and others who are interested in participating in dementia research. It matches potential participants with appropriate research projects. Researchers also distributed flyers and information sheets at dementia-related events. To contact 'harder to reach' people, organisations such as the Alzheimer's Society and Age Cymru already in contact with the target population were used to share information about the study with potentially interested parties.

The inclusion criteria for the study required that participants be a person living with dementia with the mental capacity (Department of Health, 2005) to consent to participate in the research. Both those living in care homes and those who were community-dwelling could take part. Where caregivers were involved, the inclusion criteria required that they take part with a person with dementia who is participating in

the study, and see this person at least once a week. Participants needed to own, or have access to, an iOS device (iPhone, iPad, or iPod Touch), and internet connection.

A total of 3,070 people (1,209 people with dementia and 1,861 caregivers) 'matched' with the study on JDR. The researcher contacted all matches who provided their e-mail address and indicated that they (or their representative) wanted to be contacted via e-mail. Therefore, 371 people with dementia and 1,628 caregivers were approached through JDR. Unfortunately, it was not possible to distinguish which recruitment pathways participants came from when they signed up for the study. However, it appeared that JDR recruitment contributed a significant proportion, as there was a clear association between the number of JDR e-mails sent each day and the subsequent number of study sign-ups on that day.

At the end of the intervention period, an additional evaluation phase was carried out. Those who had registered their interest (n= 388) on the Dementia Citizens website, were invited by e-mail (excluding 27 people who unsubscribed from e-mail alerts) to relay their thoughts or experiences of the DCBY app and the initiative overall. Potential participants were offered a £5 voucher as an incentive to take part. The same inclusion/exclusion criteria applied.

Procedure

This study obtained ethical approval from Bangor University School of Healthcare Sciences. Data collection began just before the formal launch of the app in July 2016 and ended in December 2016.

The researcher contacted 'matches' on JDR via e-mail with information about the study and directed them to the Dementia Citizens website (Appendix F). Here, potential participants were presented with the information sheet and inclusion criteria (Appendix G). Those who wished to take part entered their e-mail address and were automatically sent instructions on how to download the app. At this point, the research team had no more direct contact with potential participants unless it was requested.

In addition to the digital life storybook platform, the DCBY app includes information sheets, consent forms, guidance, and outcome assessments relating to the

research. Upon downloading the app, users were again presented with the key study information (accompanied by illustrations) in a series of swipe-through screens. Here, potential participants were asked screening questions to ensure that they met the inclusion criteria (e.g. dementia diagnosis, capacity to consent).

Consent forms were presented on the swipe-through screens after the study information was presented. A series of consent statements were presented, and participants were asked to indicate their agreement or disagreement by ticking a box. An example of this is presented in Figure 4.1. If participants agreed with all consent statements, they entered the study and the app started collecting and storing data. If participants with dementia were taking part with a caregiver, consent was required from both parties. If participants did not consent to take part, they were still able to use the app, but it did not contain research components or collect any data.

If consent was given, participants were presented with baseline assessments. Upon completion of these assessments, guidance and instructions for creating a digital life storybook were displayed through another series of swipe-through screens. Here, participants were encouraged to use the app at least twice a week for approximately 30 minutes each time. In addition to the information provided within the app, guidance videos were available on the Dementia Citizens website.

In a second phase, follow-up feedback was sought from those who were involved in the study. However, the researcher could not distinguish between those who had gone on to download and use the app, and those who took no action after registering interest. Therefore, an information leaflet (Appendix G) and an invitation to participate in this additional phase of research was distributed to all those who had registered interest in the app in addition to subscribing to e-mail updates (n = 361). Those who wished to take part were asked to contact the researcher, who then organised a convenient time to telephone participants. Participants with dementia were also given the option of communicating via e-mail (two people chose this option). The researcher explained the details of the study, what would happen, and obtained verbal consent (or written consent from those responding via e-mail). Interviews were semi-structured, and a topic guide was used (Appendix H). The data was not subject to analysis, After the interview was complete, the researcher arranged to send the £5 store voucher to the participant.

Measures

Within the app, there were three main research components. These were passive data, momentary assessments, and occasional assessments.

      App usage data. The app automatically collected the following data:

- Usage frequency

- Usage duration

- First and last time accessed

- Chapter title suggestions selected

- Page title suggestions selected

- Number of pages created

      Momentary Assessments. Momentary assessments were presented each time participants completed a LSW session (maximum once per day). These were used to assess the person's experience of that LSW session. In this study, a 'session' is defined as a series of events with less than ten minutes separating each event. The assessments were made up of short statements about the session. Participants responded on a five-point smiley-face Likert scale. A higher rating was indicative of a more positive experience. Those who were participating independently were presented with four statements. If participating with a caregiver, both the person with dementia and their caregiver were presented with five statements. Statements are presented later in Table 4.4.

      Occasional Assessments. These were presented to participants at baseline (after giving consent), six weeks post-baseline (halfway through the intervention), and 12 weeks post-baseline (at the end of the intervention).

      Quality of Life- Alzheimer's Disease (QOL-AD; Logsdon et al., 2002). The QOL-AD is a 13-item questionnaire designed to measure quality of life. It includes both a self-report scale and a caregiver proxy report of the quality of life of the person with dementia. Participants are asked to respond to brief, simply worded questions about their current quality of life by selecting one of four response choices: *poor, fair, good or excellent.* All items are rated according to the person's current quality of life (Appendix I). The total possible score on each scale ranges from 13 to 52 with a higher score signifying a better

quality of life. The QOL-AD is typically administered in an interview format, but for the current study, it had to be adapted so that it could be presented on a screen without having an interviewer present. For the self-report scale, text from the interview guide that is supplied with the QOL-AD was displayed on the screen for each question. The proxy-report scale was presented only where the person with dementia participated with a caregiver. The app automatically inserted the first name of the person with dementia that was entered during the sign-up process, so that a cohesive and understandable question was formed. For both scales, it was necessary to present the responses vertically rather than horizontally (as they appear in the paper version), due to the layout and size of the screen. Examples are presented in Appendix K.

Short Warwick Edinburgh Mental Well-Being Scale (SWEMWBS; Stewart-Brown et al., 2009). Caregiver well-being was measured using the SWEMWBS. This scale has seven items and asks participants to respond to statements about their experience over the last two weeks, on a five-point Likert Scale ranging from *none of the time* to *all of the time* (Appendix J). Possible scores range from 7 to 35, and a higher score is indicative of better well-being. Again, responses were presented vertically on the screen rather than horizontally. No other adaptions were made. Examples are presented in Appendix K.

Statistical Analysis

SPSS 24.0 (IBM Statistics Inc., Chicago, IL, USA) was used in all data analyses.

Occasional Assessments. Where there were responses at all three time points, a non-parametric Friedman test was used to explore if there was a significant change in scores over the course of the intervention. Where there were responses to just two time-points, a paired samples *t*-test was carried out to assess differences. Pearson Product-Moment correlations were carried out on usage data and improvements in quality of life scores.

Momentary Assessments. Response frequencies, medians, and inter-quartile ranges were calculated.

Results

Table 4.2 summarises the flow of recruitment, while participant characteristics are summarised in Table 4.3. In total, 388 people registered interest in the study, 134 of these downloaded the DCBY app, and 101 consented to participate in the intervention and research. Twenty-one people accepted the invitation to take part in follow-up phone interviews, though two did not respond after their initial acceptance. Therefore 19 people (4 people with dementia and 15 caregivers) participated in this follow-up research and were interviewed about their experiences with the DCBY app.

Table 4.2. Participant flow through the study

Action	N
DCBY Citizen Science study	
Registered Interest	388
Downloaded DCBY app	134
Consented to take part in Phase 1 (total)	185
• Persons with dementia participating with caregiver (i.e. in dyads)	84
• Caregivers participating with a person with dementia (i.e. in dyads)	84
• Persons with dementia participating independently	17
Follow-up phone interviews	
Registered for Dementia Citizens e-mail communications	361
Invited to take part in follow-up phone interviews	361
Expressed interest in participating	21
Consented to take part in Phase 2 (total)	19
• Participants with dementia	4
• Caregivers	15

Table 4.3. Characteristics of study participants at baseline.

Characteristics	N(%) or Mean (SD)
Participants with dementia	
N	101
Age	74.93 (11.14)
Gender	
• Male	39 (38.6)
• Female	61 (60.4)
Living situation	
• Care home	16 (15.8)
• Community-dwelling	85 (84.2)
Caregivers	
N	84
Age	56.35 (11.81)
Gender	
• Male	15 (17.9)
• Female	69 (82.1)

Usage data

Pages. Of those who consented to participating, 55 did not create a single page. Across the other 46 participants, 435 pages were created in total (*Mean* = 9.46 pages, *Median* = 5 pages, *Range* = 1-62 pages). 52% of these 46 participants created at least five pages. The most popular chapter titles were 'family' (33%), 'leisure' (21%), and 'childhood' (20%). The most popular page titles were 'Family', 'School', 'Hobbies', 'Trips', 'Where I Grew Up', and 'Weddings'. Further details are presented in Figure 4.2.

Sessions. The information and consent process was considered a 'session' meaning that all 101 consenting participants had at least one session. 70% of participants had 5 or fewer sessions, while 21% had 10 or more (*Mean*= 5.9 sessions, *Median* = 3 sessions). Just 3% of participants completed the requested 24 sessions over the 3-month intervention.
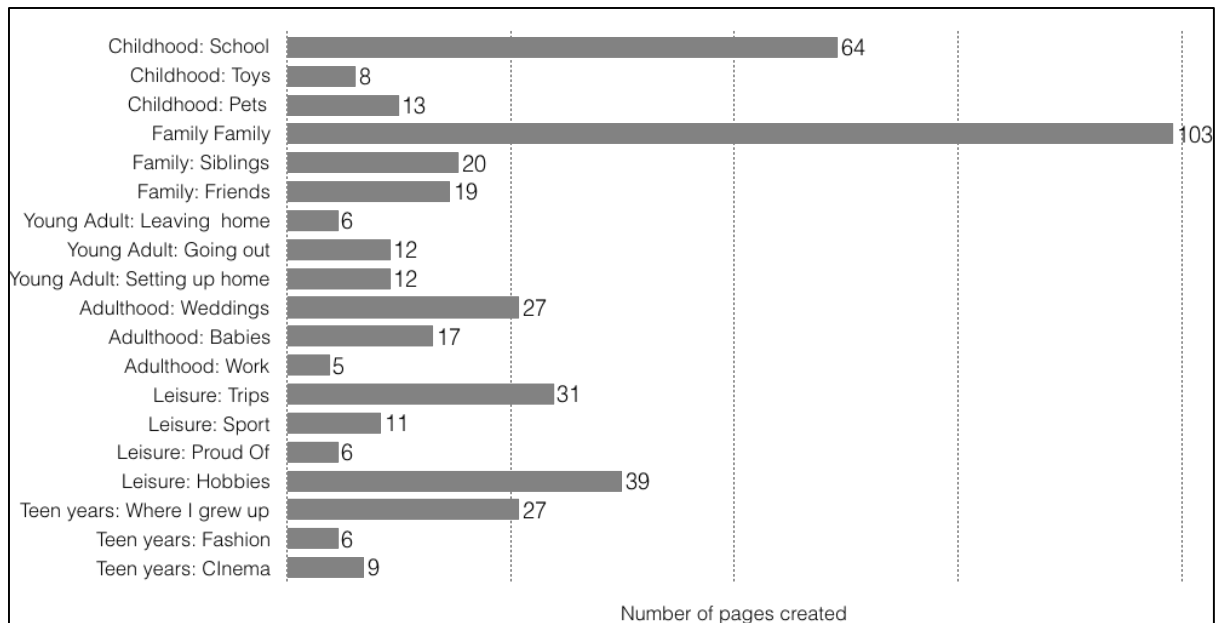
Figure 4.2. Page titles selected by participants

Time. Time spent using the app varied dramatically and ranged from 1.38 minutes to 5.94 hours (*Median* =11.28mins, *IQR* =28.5mins). 'First seen' and 'last seen' dates were available for each participant. These were the dates that participants first accessed and last accessed the app. 35% had the same first, and last seen dates. Overall, there was a median of 15 days (*IQR* = 52.5 days) between first seen and last seen dates.

Momentary Assessments

Forty participants completed a momentary assessment at least once. 19 completed them 2 or more times, while 5 completed them 5 or more times. Median scores are presented in Table 4.4. On each of the items, the median score was 4 (on a 5-point scale), suggesting relatively high levels of interest, enjoyment and involvement.

Occasional Assessments

Due to high attrition and inconsistency in questionnaire completion, only baseline and 6-week data from the QOL-AD (caregiver report) and SWEMWBS could be included in the analysis. At 12-weeks post-treatment, there were just 6 responses to the QOL-AD (caregiver report) and SWEMWBS.

Table 4.4. Momentary Assessment Scores

Question	n	Minimum	Maximum	Median (IQR)
Person with dementia				
Q1. I was interested	96	2	5	4(1)
Q2. I enjoyed it	96	2	5	4(2)
Q3. I felt involved	96	2	5	4(2)
Q4. I feel cheerful right now	96	2	5	4(1)
Q5. It was good to share memories (if carer present)	53	3	5	4(2)
Caregiver (if present)				
Q1. I was interested	53	3	5	4(1)
Q2. I enjoyed it	52	3	5	4(1)
Q3. I felt involved	53	3	5	4(1)
Q4. I feel cheerful right now	53	2	5	4(1)
Q5. Compared to the start of the session I feel	53	3	5	4(1)

QOL-AD (self-report). Scores on the QOL-AD (self-report) decreased over the course of the intervention between baseline (M = 33.59, SD = 7.21), 6 weeks post-baseline (M = 28.88, SD = 6.46), and 12 weeks post-baseline (M = 28.46, SD = 5.84). However, a non-parametric Friedman test on the QOL-AD showed that these changes were not statistically significant, χ^2 (2, N=11) = 1.25, p > 0.05.

QOL-AD (caregiver report). Scores on the caregiver version of the QOL-AD (n=11) decreased between baseline (M=30.27, SD= 6.25) and 6-weeks post-baseline (M=28.46, SD=5.99). Again, this difference in scores was not statistically significant (t (12) =1.95, p = 0.075).

SWEMWBS. On the SWEMWBS (n=11), there was little difference between scores at baseline (M = 23.46, SD = 4.16) and 6-weeks post baseline (M = 23.25, SD = 4.72). This change was not statistically significant (t(12)= -0.297, p = 0.772).

Correlations. Pearson Product-Moment correlations were carried out to explore if there was a relationship between the number of pages created, and improvements on measures of quality of life (in cases where at least two time-points completed). There was no significant correlation between the number of pages created and improved performance on self-report quality of life measures for participants with dementia (QOL-AD; r (18) = -0.115, p = 0.77), or caregivers (SWEMWBS; r (10) = 0.015, p = 0.96). Correlations were also not significant between the number of sessions completed and improvements in performance on quality of life measures for participants with dementia on the QOL-AD (r (20) = -0.12, p = 0.61) or caregivers on the SWEMWBS (r (12) = -0.34, p = 0.24). Finally, there was also no significant correlation between time spent using the app and improved performance on quality of life measures for participants with dementia on the QOL-AD, (r (20) = -0.12, p = 0.61) or caregivers on the SWEMWBS (r (12) = -0.43, p < 0.126).

Follow-up Feedback

Participants with Dementia

Four people with dementia provided their opinions on the intervention and the app. Two preferred to communicate via e-mail, rather than by phone. The three participants who used the app (Robert, Peter, Patricia), did so independently.

Robert. Robert was interviewed over the phone. He was a frequent user of the app but felt angry and frustrated at the number of automated e-mails he received and the number of app updates that were required. The app was hosted on a platform that sent automated e-mails to the user when it needed to be updated. Robert was signed up to both of the apps in the Dementia Citizens initiative. Therefore, he received double the number of e-mails. He found the updates *"extremely complicated"*. Robert was originally enthusiastic about the app and the idea but felt the app was poorly designed (he is a retired designer himself). He was visited by a volunteer from the Alzheimer's Society on a weekly basis, and the volunteer also struggled to understand the app updates. The researcher assisted Robert with updating the app, and he planned to continue using it.

Sarah. Sarah preferred to communicate via e-mail. She is very keen to participate in treatment trials and felt that the DCBY app intervention would not be of help to her.

"To be quite frank the reason why I did not pursue this project was that I thought it looked a bit like "do somethingism," i.e. "we have to do something. This is something, so we will do it." I was completely unable to see that the programme would benefit me, and on the contrary, expected it to prove irritating".

"...those are my feelings, and they are unlikely to change unless science comes up with something solid and successful, which, in my view, the Book of You (the DCBY app) was not."

Paul. Paul preferred to communicate via e-mail. He liked the idea of the app but felt the functionality was limited.

"Downloading the app was fine. The research questions could have been a bit less vague but were fine to answer. As for the app, I found it a tad basic compared to ones of a similar nature. You couldn't do much with it. I still think it would have made it more valuable if it allowed you to type under photos as well as speak as you're restricting the number of people who can use it just to allow voice recording. The theory was good, but it just didn't do it for me in practice".

"I use it each time you release a new version (updates) *to try and work out what's changed. I'm not sure I found out so it would always be useful for you to say".*

Patricia. Patricia has vascular dementia and some problems with her eyesight, though she could see the screen and the colours quite clearly. She did not have any problems downloading the app but when she tried to use it she found it too complicated. She felt there was too much information to digest and the information (swipe-through) screens *"went on and on"*. This prevented her from being able to think clearly and made her mind feel *"hazy".* Every time she tried to use the app she felt *"unable to think about anything".* Patricia told us that she would have liked to use the app but the information overload prevented her from doing so.

Caregivers

Follow-up feedback was provided by 15 caregivers. Further information is outlined in Table 4.5. All interviews were carried out over the phone.

The Idea. There were mixed reactions about the idea of doing life story work.

"When you set it (a life story book*) up it kind of hits you. It's a good positive thing but also scary because you remember the person they should have been. You try to avoid that subconsciously but it brings it back"* (Sophie)

"I liked the idea (of life story work) *but I couldn't face it"* (Peter)

"I thought it was a great idea and I wanted to do it for Mum. However, when I sat down to look at it properly it sounded very time intensive" (Catherine)

"Even if I did use it I didn't see how it was going to be helpful and it looked time consuming" (Dawn)

"I loved that you could load photos onto it because you can carry it everywhere. That's what I really liked. It's so much easier than having to sit down and put photos into albums" (Aileen)

DCBY app usability. Most of the caregivers interviewed did not have problems downloading the app, though some did not reach that point as they had the wrong device or weren't interested after they learned more about it.

"Downloading it was quite easy to follow" (Fionnuala)

"The installation was fine, but when I realised what it was I gave up on trying to be involved with it" (Peter)

"No problems with installing, downloading and looked as though very easy to operate... Easy to use and easy to follow" (Aileen)

Most caregivers who used the app felt that it was straightforward (despite some having limited ICT skills), though one person struggled to add audio and music recordings.

> *"I managed to upload photos, and I managed to get music. I did it on my iPad and found it easy to do. The technology didn't worry me"* (Noleen)

> *"It was easy to use and easy to follow"* (Aileen)

> *"I liked everything about it, and all the categories are good, but I personally find them overwhelming"* (Sophie)

> *"I found it easy to use and intuitive though I didn't really get into the 'nuts and bolts' of it"* (Jane)

One caregiver was disappointed when she bought a new iPad and realised that she could not transfer the app and book she had been building up across from her old one

> *"I got a new iPad and presumed I would be able to use the same app but I couldn't"* (Ruth)

Experiences with the DCBY app. Privacy and security concerns affected two of the participants interviewed. In one case, a caregiver was very keen to participate and use the app with her husband, but he was put off by the ethical and consent declarations. Another caregiver did not agree to the terms and conditions of the app as she uses her mobile phone for online banking.

> *"He decided he didn't want anything to do with it because the ethics form made him anxious...I was dying to do it, but he felt strongly about it"* (Aileen)

> *"I didn't go very far because I didn't agree to the terms and conditions. I'm very particular about what I put on my phone. I use it for online banking"* (Fionnuala)

Table 4.5. Caregiver characteristics in follow-up interview

Pseudonym	Type	Point dropped out	Reason
Ellen	Professional	After two months of use	Health of person with dementia
Mary	Family	Before registering interest	Idea did not appeal to them
Peter	Family	Between downloading and consent	LSW too difficult
Dawn	Family	Between downloading and consent	Did not think app would be helpful
Fionnuala	Family	Consent	Privacy/security
Aileen	Family	Consent	Privacy/security
Jennifer	Family	Registered interest	Lack of time
Sophie	Family	After one LSW session	Lack of time
Sheila	Family	After two weeks	Health of person with dementia
Noreen	Professional	After one month	Lack of time
Jane	Professional	Between downloading and consent	Couldn't create multiple profiles
Rhonda	Family	After registering interest	Wrong device
Ruth	Friend	After 8-10 weeks	IT problems (could not add more pages)
Caroline	Family	After registering interest	Device
Catherine	Family	Onboarding	Lack of time

In general, experiences using the app were positive among the caregivers interviewed, though none had used it for the full 3-months.

"It was good for me because I learned stuff, but I don't think he was really understanding what we were doing and what we were trying to...I would certainly say to other people that they should download and use it. It's excellent" (Sheila)

"The app was helpful because it was a talking point and my Mum feels encouraged when she remembers things. I will start using it again... It was very useful to be able to talk through things" (Noreen)

"She was enjoying using it but became very confused and had short attention span" (Ellen)

The research elements. Caregivers had mixed reactions regarding the research elements in the app.

"The questionnaires were very relevant" (Ellen)

"When I was doing it with the lady I look after, when I was doing the questions I felt they were too long-winded. It depends what stage you're at. By the time I got to the third option, she would ask what I said the first time" (Ruth)

"The questions were reasonable they were fine. I liked smiley faces" (Sheila)

"She [the person with dementia] would always just point to happy smiley. I didn't think she enjoyed it sometimes, but she just picked the last choice. I don't know if it was really accurate of her experience" (Ellen)

In some cases, caregivers reported that they had responded to the questionnaires, or parts of the questionnaires, on behalf of the person with dementia as they could not do it themselves.

"...on a few of the questions I answered for her because I knew she wouldn't be able to answer some...I interpreted what she thought and answered for her (the person with dementia)" (Noleen)

"I had to answer on [the person with dementia's] behalf because they were too hard for him" (Sheila)

One caregiver found the smiley face momentary assessment scales slightly confusing, as sometimes they came up and didn't relate to what she had been doing. This caregiver added materials to the app in preparation for going to visit her relative and would then be asked about her experience of the LSW session which did not make sense to her. Notifications to complete feedback were automated, meaning it's possible this happened to other participants too.

"When the questions came up, it was a little bit confusing for me because it wouldn't necessarily relate to what I had been doing" (Noleen).

Discussion

This study is one of the first to use a self-guided digital Citizen Science approach with people living with dementia and their caregivers. It is also the first study to implement a self-guided, app-based LSW intervention with this population to date. This research aimed to investigate participants' general experiences using this app in relation to day-to-day use and quality of life, and explore the feasibility of the app, and how a Citizen Science approach may be best applied in the context of dementia.

Given engagement and retention levels in the current study, it would appear that this particular implementation of this intervention is not feasible for people living with dementia and their caregivers. Despite initial interest in the app, 65% of potential participants were lost between receiving download instructions and downloading the app. This suggests that the download process may have been a sizeable barrier. Of those who downloaded the app, 25% did not consent to participate in the study meaning that, in total, almost 75% of potential participants were lost before the study began. Engagement was low among consenting participants, with approximately half not adding a single page to their digital life storybook. One-fifth of participants had at least 10 LSW sessions, though this was still significantly lower than the requested minimum of 24 sessions over the course of the intervention, which 3% of participants completed. The correlation between improved SWEMWBS performance and time spent using the app is relatively high (even though it is not significant), potentially suggesting that caregivers with more positive well-being persisted more with the app. When retention and response rates of consenting participants are compared to other apps, the results are not too dissimilar. Average retention in general apps (across all industries) is 25% in month 2 and 20% in month 3 (Perro, 2017). In the current study, retention was slightly higher with 33.7% of participants retained in month 2, and 22.8% in month 3. Perro (2017) defined 'retention' as a person returning to the app at least once in 30 days. When we explore further, 77.2% of consenting DCBY participants last accessed the app before day 60 and 82% before day 90. However, this is not necessarily indicative of engagement, but rather the number of days between the first and last time participants accessed the app. While the DCBY app performed slightly better than general apps in terms of retention, it also required more engagement and commitment than a standard app, and retention alone is not enough to be an indicator of 'success'.

In the 'mPower' study, 87.4% of participants completed at least one study 'task' which was greater than the 77.2% of participants who completed at least one quality of life questionnaire. Throughout the 6-month study, 9.4% of 'mPower' participants contributed data on at least five separate occasions (Bot et al., 2016). In the current study, just 5% of participants filled out post-session feedback five or more times across the 3-month intervention period. However, it should be noted that the 'mPower' study involved almost 10,000 participants and was purely observational, unlike the current study which comprised 101 participants and required engagement with the intervention before having the option to complete post-session feedback. Mulvenna and colleagues (2017) carried out a behavioural usage analysis of how 28 people with dementia and their caregivers used a reminiscence app. This method of data collection is similar to the usage data that was automatically collected by the DCBY app in the current study. Across the 12-week study, the app was used approximately once per week, which is significantly more than the current study. However, reminiscence and app training was provided to participants before the intervention began, unlike the current study in which participants received guidance solely through the app.

Responses to post-session feedback indicated that both participants with dementia and caregivers had positive experiences with the app on a number of factors including enjoyment, involvement and interest. This is similar to previous studies of digital LSW interventions, in which both participants and caregivers found LSW enjoyable and interesting, though these were supported interventions (Damianakis et al., 2009; Massimi et al., 2008; Subramaniam & Woods, 2016). However, post-session feedback response rates were low, with just five participants responding on five or more occasions. On quality of life measures, no significant differences were observed between baseline and later time points, so there is no evidence from this study that the DCBY app had an impact on participants' quality of life. Furthermore, there was no correlation between usage and improved quality of life, though the sample sizes in the analyses were small.

Qualitative feedback was varied, with respondents citing several different reasons for not, or no longer, engaging with the DCBY app. Among caregivers, reasons related to ICT were cited most often, though those who used the app felt it was relatively straightforward to navigate. Other reasons included participant health, the idea of LSW,

and a lack of time. Participants with dementia also had mixed responses, with no one specific reason standing out. One person did not use the app as they felt it would not be helpful, two had ICT related problems, and another felt the app was too basic compared to other apps. Overall, experiences with the app were mixed but positive in most cases. None of the participants who gave follow-up feedback engaged with the app for the full 3-month intervention. Participants had generally positive attitudes towards the research elements within the app, but there is a need for further development to ensure they are presented at the right moments.

Citizen Science occurs at several levels and intensities, which in turn affects the experiences and motivations of participants (Den Broeder et al., 2016; Socientize Consortium, 2013). Applying Den Broeder and colleagues' (2016) descriptive framework (Table 4.1), the aims of the current study fit best with 'collective goods' while the size can be described as 'mass'. However, locating the approach of the current study within the framework is more difficult. Although there was a small amount of participatory design in the development of the app, it was not enough to be considered 'participatory science'. On the other hand, the approach consisted of more than 'crowdsourcing', as participants were not simply 'sensors'. As the current approach was relatively low-level Citizen Science, some important external participant motivators were not facilitated, such as learning new information, feeling part of a team, financial incentive (excluding follow-up qualitative interview participants), and receiving recognition and feedback (Jennett, Furniss et al., 2014; Socientize Consortium, 2013). Perhaps with more support and validation, in addition to participants playing a greater role in the development of the intervention, engagement and retention levels could be improved. Another potential factor affecting motivation may be that the intervention requires time and effort to create a LSB before it can be used primarily for viewing. Similarly, some of the main benefits of Citizen Science for participants listed by Den Broeder and colleagues (2016) such as enhanced scientific literacy and new skills and abilities, were not present in the current approach. However, the issue remains that the majority of research into Citizen Science has been conducted in the physical sciences, in which participants are contributing information about their surroundings rather than themselves. Using this approach to explore people's personal experiences may have implications for motivation, that are yet to be discovered (Follett & Strezov, 2015; Jennett, Furniss, et al., 2014).

Limitations

A clear limitation of this study was the sample size, which declined over the three-month intervention period, meaning that the quantitative analyses are likely not representative. Furthermore, the app was only compatible with iOS devices meaning that the pool of potential participants was relatively small, making the analyses more vulnerable to declining retention rates. Although it was possible to look at overall engagement with the app through the number of sessions and pages created, it was difficult to explore engagement over time, with the exception of examining responses to quantitative measures and first/last access dates. Aside from those who participated in the qualitative feedback portion of the research, the app did not provide the facility of obtaining additional participant feedback.

Implications and future research

As an approach, Citizen Science has the potential to be feasible with this population. There was high interest in this intervention, but more motivators and fewer barriers are required to keep participants engaged. Furthermore, there is a large movement towards participatory dementia research, with people living with dementia advocating to be more involved in research meaning there is scope for digital Citizen Science type approaches (Bryden, 2016; Scottish Dementia Working Group Research Sub-Group, 2014). Although this work did not meet some of the intended research aims, it provides insights on both the successes and shortcomings of a digital Citizen Science approach and an app-based LSW intervention for people with dementia and their caregivers. It also highlights the potential for the local post-session research elements to collect data regarding usability and feasibility.

Future research should address the limitations of the current study. Study tasks should be more manageable, have a simplified download process, provide more feedback to users, and have simplified ICT functionality. People living with dementia and caregivers should be involved in the development of the intervention and research to a greater extent. Pilot testing lasting at least half of the length of the projected intervention would be helpful, to explore potential attrition. Larger numbers of participants should be recruited at the outset, so that research analyses are still possible despite the seemingly inevitable decline in retention rates across all apps, both health research related, and in general.

Conclusion

The self-guided digital life storybook app delivered through a Citizen Science approach was not a successful intervention for people with dementia and their caregivers. Engagement was low, and no significant effects on any measures were identified. However, there does appear to be potential for using digital Citizen Science approaches with people with dementia and their caregivers as there is interest among this group in this type of approach.

Chapter 5. The preferences of people living dementia and caregivers in relation to digital life story work: A survey and discrete choice experiment.

Summary

Little is understood about the optimal way to implement digital life story work (LSW) with people with dementia and their caregivers. The aim of this chapter was to explore the preferences of these people with dementia and their caregivers in relation to digital LSW, to improve future engagement. There were 67 caregiver respondents on an online discrete choice experiment (DCE) survey containing 16 pairwise choices. Attributes included setting, usability and accessibility, price, session focus, and follow-up assistance. The DCE was analysed using a random effects logit model. Willingness to pay and odds ratios were also calculated. An abridged online survey was completed by 17 people with dementia, in which they also made choices about different aspects of digital LSW services. Caregivers valued 4 out of 5 attributes in the DCE [setting ($p = 0.000$), price ($p = 0.000$), advanced usability and accessibility ($p = 0.001$), and follow-up assistance ($p=0.034$)]. Data from participants with dementia showed that the most preferred setting was an individual one-to-one setting (70.6%), and the most preferred use of digital life storybooks was to share memories with others (64.7%). Marginally more participants with dementia said they would pay for the service (53%) rather than only use it free of charge (47%). Those with advanced information and communication technology (ICT) skills preferred to learn how to use the digital life storybook (64.7%), while those with elementary/intermediate skills, preferred to have it created for them (35.3%).This exploratory study provides an insight into preferences of people with dementia and caregivers, of how digital LSW services are implemented. Results suggest that ICT can play a significant role in how people with dementia and caregivers want digital LSW to be implemented. The work presented in this chapter can contribute to future planning and tailoring of these services.

Introduction

In the absence of disease-modifying treatments, the most effective interventions for people with dementia and their caregivers are the development and provision of services to support them (Nolan, Ryan, Enderby, & Reid, 2002). Life Story Work (LSW) is a popular psychosocial intervention for people with dementia and their caregivers. It involves talking about life experiences and memories with others and using this information to create some kind of life story record that can benefit the person on an ongoing basis (McKeown, Clarke & Repper, 2006; Murphy, 2000). It is viewed as a person-centred approach, with getting to know the person at its heart (McKeown et al., 2010; McKinney, 2017). LSW values the person with dementia and can foster understanding of biography, behaviour, and discourse, in addition to promoting communication, reinforcing identity, and providing ideas for meaningful occupation (Brooker, 2004; Bruce & Schweitzer, 2008; Gridley, 2017; McKeown et al., 2010).

Advancements in information and communication technology (ICT) have introduced new possibilities for LSW. Multimedia stimuli such as video, audio narration and music, can now be placed alongside traditional text and photographs to create a digital life storybook. Some small studies have found promising evidence that digital LSW can benefit people with dementia in the areas of communication, self-identity, quality of life, mood, and enjoyment (Damianakis et al., 2010; Ludwin & Capstick, 2015; Massimi et al, 2008; Stenhouse et al., 2013; Subramaniam & Woods, 2010; Subramaniam & Woods, 2016).

Although LSW appears to be valuable and enjoyable for people living with dementia and caregivers (McKeown et al., 2010; Subramaniam & Woods, 2010), engagement and uptake remain an issue. For example, in 3- and 6-month follow-ups, Damianakis and colleagues (2009) reported that some participants viewed their digital life storybooks rarely (once per month), despite being asked to view it at least once per week. In the current thesis, there has been mixed engagement with digital life storybooks. In Chapter 4, 134 people downloaded a digital LSW app, but 82% did not reach the half-way point of the 3-month intervention, and 91% did not complete it. In follow-up qualitative feedback, even those who found digital life storybooks enjoyable and useful did not remain engaged over time. Following a facilitated digital LSW intervention in Chapter 3, family caregivers of

people with dementia in LSW groups stated that they would only continue to use their digital life storybook if their relative's condition deteriorated dramatically, despite valuing and enjoying it. On the other hand, Subramaniam and Woods (2016) reported that all six participants in their study viewed their digital life storybooks several times per week, with some assistance from care staff to do so. In this study, a completed 'movie' was prepared for participants, with their input relating to content and format. As previous research interventions have varied greatly in relation to setting, session focus, types of digital life storybook, and modality (i.e. group and individual), it is not entirely clear which factors of digital LSW interventions or digital life storybooks are most appealing to people living with dementia and their caregivers. As there are so many potential implementations of digital LSW, it is important to understand user preferences so that we can begin to piece together the optimal method of delivery, to improve future engagement.

One way of eliciting preferences of how services are delivered is through a discrete choice experiment (DCE). In DCEs, participants make choices between different 'packages' of a good or service. This method draws upon Lancaster's (1966) Economic Theory of Value. It assumes that people obtain value/benefit from the different attributes that make up goods or services, rather than the goods or services as a whole. Therefore, changes to the attributes of a good or service may cause individuals to switch to another good or service that will provide a more beneficial combination of attributes. Essentially, DCEs draws out the characteristics of a particular good or service that are important to individuals by considering their choices between different goods or services that have varying levels of the same attributes.

The aim of this study was to explore choices made by people living with dementia and their caregivers concerning digital LSW services. To elicit preferences, an online DCE for caregivers and a simple online survey for people living with dementia were used. This study aims to address the following research questions:

1. What features of a digital LSW service intervention are preferred by people with dementia?
2. What features of a digital LSW service intervention are most important to caregivers or supporters of people with dementia?

Methods

This study had two arms. In Study 1, participants with dementia completed an online survey regarding their preferences of digital LSW services. In Study 2, caregivers' preferences were explored using an online DCE. In both arms, a hypothetical LSW service was presented to participants, including a digital life storybook operated through an app.

Study 1

Participants

Participants were a convenience sample of people with dementia living in the UK. The inclusion criteria for the study required that participants have the mental capacity (Department of Health, 2005) to consent to participate. As the survey was online, participants needed to own, or have access to a computer, tablet computer, or smartphone, in addition to an internet connection. Recruitment took place between the May 17th and July 11th, 2017. Participants were offered a £5 store voucher for taking part in the survey.

Potential participants were primarily identified and contacted through Join Dementia Research (JDR). JDR is a nationwide database of people with dementia, caregivers, and others who are interested in participating in research on dementia. It is operated by the National Institute of Health Research, and matches potential participants with appropriate research studies. Social media and the North Wales Dementia Network were also used to circulate information about the study.

Survey Design

The survey in Study 1 was modelled on the DCE in Study 2, though it was greatly simplified to avoid the cognitive load of a DCE. Previous qualitative research (Chapter 3) exploring the experiences of people with dementia and their caregivers of a digital LSW service was used to inform the survey design. Discussions with a LSW service and a clinical psychologist experienced in LSW also contributed to the survey design. The survey comprised 10 questions, and participants could save their progress and return to the study at a later point if they wished to take a break. A progress bar kept participants informed of their progression throughout the survey.

Procedure

Interested participants were provided with a link to the survey via e-mail. When they clicked the link, they were first presented with the information sheet and a digital consent form (Appendix M). If consent was given, the survey opened. Participants were asked to supply their age and gender, in addition to their self-reported ICT skills and any previous experience with digital LSW. A brief background of LSW and a video describing a LSW service were provided. Respondents were then asked to select their preferred choice of setting, app usability and accessibility, price, follow-up assistance, and session focus.

Analysis

Results were analysed in SPSS version 24. Descriptive statistics were used to describe the sample while frequency data were used to illustrate preferences.

Study 2

Participants

Participants were caregivers of people with dementia, living in the UK. In this context, 'caregiver' refers to a family member, friend, or professional caregiver who sees the person with dementia regularly. Again, access to the internet and a computer, tablet computer, or smartphone were required. A £5 store voucher was offered to participants for taking part in the study. Similar to Study 1, JDR was the primary recruitment pathway, and study information was also circulated using social media and the North Wales Dementia Network. Recruitment took place between May 17th and July 11th, 2017.

Study Design

The purpose of DCEs is to elicit preferences. They are often used in health economics to explore preferences concerning healthcare products and packages. In a DCE respondents are asked to make choices between pairs of hypothetical scenarios that describe a good or service. Participants are presented with a pair of scenarios, each with the same attributes but varying levels of these attributes. For example, the attribute 'price' could have levels of 'no cost', '£25', and '£50'. One pair of scenarios is one choice set. The attributes, levels, and definitions pertaining to the current study are presented in Table 5.1, and an example of a choice set is shown in Figure 5.1. Again previous research (Chapter 3), and discussions with an experienced clinical psychologist and LSW service informed the survey design.

The DCE had 3 attributes with 2 levels, and 2 attributes with 3 levels, resulting in 72 potential choice sets (3^2 x 2^3). An orthogonal main effects plan (52a) from a published design catalogue (Hahn & Shapiro, 1966) was used to reduce this to a manageable number. This 'plan' informs the construction of the choice sets. According to the plan, 16 choice sets were required to ensure orthogonality (showing pairs of levels proportionately often). To determine the necessary sample size, a 'rule of thumb', that each main effect level of interest should be represented across the design at least 500 times, was applied (Orme, 2010). Therefore it was estimated that a two-alternative, forced choice format with 16 choice sets, would require a minimum of 47 participants.

It was not possible to select dominant choice sets (those in which one service contains all preferred attribute levels and the other contains the least preferable levels) for removal, as the intervention was psychosocial and the 'preferred option' was not apparent in most attributes. The DCE did not contain any additional tests for transitivity. This was to avoid increasing the cognitive load by adding more choice sets. Here, transitivity implies that if a person chooses one package in a choice set, they should transitively choose that same package in another choice set where it has at least one additional preferred level of an attribute, and has no inferior levels of the other attributes (McIntosh & Ryan, 2002). The survey also contained demographic questions and comprised 23 items in total. Again, participants could save their progress and return to the survey if they wanted a break. A progress bar kept participants informed of their progression throughout.

Procedure

Similar to Study 1, potential participants were directed to the survey through a link sent via e-mail. They were firstly presented with an information sheet and consent form. If consent was given, the survey began. Participants were asked to provide their age, gender, current caring situation, and self-reported ICT skills. Again, participants were given general information about LSW and a brief video about a LSW service was played. The definitions of attributes and levels were presented (Table 5.1), in addition to instructions and an example of how to complete the DCE. The definition table could be kept open to refer back to if desired.

Aspect of Service	Service A	Service B
Setting	Community group	One to one at home
Price	£25	£50
Accessibility & Usability	Advanced	Basic
Follow Up Assistance	Manual only	Manual and workshop
Session Focus	Book built for you	Learning how to use the app and receive help building a book

Which service would you prefer?

Service A   Service B

Figure 5.1. Example of a DCE choice set

Analysis

Data were managed in Microsoft Excel (cleaning and organising), SPSS version 24 (descriptive data) and STATA version 10 (DCE data). A random effects logit model was used to analyse the data, and service choice was the dependent variable.

$$U = \beta_0 + \beta_1 setting + \beta_2 price + \beta_3\ usability + \beta_4\ followup + \beta_5 focus + \varepsilon$$

U = utility derived by individual

β_0 = constant term

β_i = estimated coefficient for each attribute

ε = error term

It was hypothesised that respondents would prefer an individual setting, a low price, a follow-up LSW session and written guidance manual, basic accessibility and usability, and the session focus to involve learning how to use the app. Effects coding was used to input

qualitative attributes (i.e. setting, accessibility and usability, follow-up assistance, and session focus). As 'app accessibility and usability' had three levels, one level was selected as a 'base case' and omitted from the model. The coefficient of the omitted level was calculated by multiplying -1 by the sum of the estimated coefficients of the other two levels. As price is a value attribute, it was coded using the value of each level (i.e. 0, 25, 50). Level coding is presented in Table 5.1. Confidence intervals for coefficients were estimated using non-parametric bootstrapping methods (Phillips, Maddala & Johnson, 2002). A simulation of 1000 non-parametric bootstrapping iterations was run to create 95% confidence intervals around the β-coefficient. The β-coefficient values were used to estimate the relative importance of each attribute. The p-value and magnitude of the coefficient were used to represent the degree of preference for each of the attributes. The sign of the coefficient was used to determine which level of the attribute was preferred (only where attributes had two levels and were non-value). The marginal rates of substitution (MRS) between price and other (statistically significant) attributes were then analysed. This represents the amount of money the respondent was willing to pay for one level of an attribute over another. The same non-parametric bootstrapping method was used to create 95% confidence intervals around the MRS estimates (Phillips et al., 2002). Subgroup analyses of caregiving situation and self-reported ICT skills were attempted, but not possible due to the distribution of sample sizes in the subgroups. Each coefficient was exponentiated and reported as an odds ratio. Odds ratios greater than 1 represent positive utilities, whereby respondents have given more importance to the attribute level. Negative odds ratios between 0 and 1, represent a lower probability of a respondent choosing an alternative when this attribute level is shown.

Table 5.1. Attributes, levels, definitions and coding

Attributes	Levels	Level description and effect coding ( )
Setting	Group	The workshop is in a small group of 6-8 people with dementia and caregivers. It takes place in a community setting such as a room in a community centre or library. A volunteer from the service facilitates the workshop (1)
	One to one	The workshop is with one person with dementia and their caregiver (if they wish). It takes place in the home of the person with dementia/caregiver. A volunteer from the service facilitates the workshop (0)
Price	Free	You do not pay for the service (0)
	£25	You pay £25 in total for the service, lasting six weeks for 2 hours per week (25)
	£50	You pay £50 in total for the service, lasting six weeks for 2 hours per week (50)
App accessibility and usability	Elementary	The app is simple to use. The skill level needed is similar to that of using Facebook and viewing news articles online (base case)
	Intermediate	The app usability is intermediate. The skill level needed is similar to that of online shopping, playing games and using e-mail.
	Advanced	The app usability is advanced. The skill level needed is similar to that of downloading apps, setting up programmes such as Dropbox or iCloud, and configuring settings.
Follow Up	Manual only	When you finish the workshops, you are given a written detailed guide on how to use the digital life storybook (1)
	Manual and follow up	When you finish the workshops, you are given a detailed written guide on how to use the digital life storybook, and you have a one hour follow up workshop with the same volunteer (0)
Session Focus	Book only	The volunteer makes a digital life storybook for you during the workshops while you dictate the content (1)
	Book & learn how to use app	A volunteer works with you to teach you how to use the app and help you to build your digital life storybook (0)

Results

Study 1
Participants with dementia

All questionnaires were completed fully, except one which had one question unanswered. The survey was completed by 17 people with dementia. Characteristics of participants with dementia are outlined in Table 5.2.

Survey responses

Most participants with dementia (71%) responded that they would prefer the intervention setting to be one-to-one in their home, rather than in a community group (29%). Almost two-thirds (65%) wanted to focus on learning how to use the app while being supported to create their own digital life storybook during the sessions. However, only participants with self-reported advanced ICT skills chose this option. Just over one third (35%) chose the alternative option of having the service build their life storybook for them, under their instruction. Of these participants, three had elementary, and two had intermediate, self-rated ICT skills. Nearly two-thirds (65%) of participants indicated that they would mainly use their digital life storybook 'to look at with family and friends, and enjoy shared memories'. The remaining responses were split evenly between 'to look at on my own and enjoy memories and music' (17.5%) and 'to show to new people to help them to understand my life experiences and interests' (17.5%). When five attributes were presented together (see Table 5.3), 'being taught how to use the digital life storybook and being helped to create my digital life storybook' was the most popular choice (41%), followed by 'doing life story work individually in my home' (23.5%), and 'having the service build my life storybook for me while I tell them what to put in it' (17.6%). The two least popular attributes were 'being given a written guidance manual on how to use the book after the workshops are finished' (11.8%) and 'doing life story work in a group in a community centre or library' (5.9%). When presented with three price options for a 6-week digital LSW service, marginally more participants said they would pay for the service (53%), than only use it free of charge (47%). Of those who responded that they would pay for the service, most (78%) indicated that they would consider a small amount such as £25, while 22% would consider a more significant sum such as £50.

Table 5.2. Characteristics of participants with dementia

Characteristics	N(%) or Mean (SD)
N	17
Age	61.65 (12.33)
Gender	
Male	8 (47.1)
Female	9 (52.9)
Self-reported ICT skills	
Elementary	3 (18.8)
Intermediate	2 (12.5)
Advanced	11 (68.8)
Have you ever used a LSW service before?	
Yes, a digital service	2 (11.8)
Yes, a non-digital service	1 (5.9)
Both a digital and non-digital service	0 (0)
No	14 (82.4)
Other	0 (0)

Table 5.3. Survey responses of participants with dementia

Characteristics	N(%) or Mean (SD)
Setting preference	
Private one-to-one at home	12 (70.6)
Community Group	5 (29.4)
Session focus preference	
Service builds a life storybook for me with my instruction	6 (35.3)
Learn how to use the app and be supported to build my own life storybook	11 (64.7)
I would mostly use my digital life storybook	
To look at on my own and enjoy memories and music	3 (17.6)
To look at with family and friends and enjoy shared memories	11 (64.7)
To show to new people to help them understand my life experiences and interests	3 (17.6)
Most important thing when doing life story work	
Doing Life Story Work in a group in a community centre or library	1 (5.9)
Doing Life Story Work individually in my home	4 (23.5)
Having the service build my life storybook for me while I tell them what to put in it	3 (17.6)
Being taught how to use the digital life storybook and helped to make my own one	7 (41.2)
Being given a written instruction guide on how to use the book after the workshops are finished	2 (11.8)
Paying for the service (6 sessions, 2 hours each)	
I would only use it free of charge	8 (47.1)
£25	7 (41.2)
£50	2 (11.8)

Study 2

Caregiver participants

There were 67 caregiver respondents in Study 2. The analysis included all completed online surveys. A completed survey was defined as at least 50% of the choice sets being completed. Two participants did not respond to all 16 choice sets but completed 15 and 8 questions respectively. Characteristics of caregiver participants are presented in Table 5.4. The sample was predominantly female, and most participants had advanced self-reported ICT skills. One participant responded 'other' to the question about their caregiving situation but did not elaborate further. Two participants had previous experience with LSW. One had seen a presentation about it, while the other had encountered traditional LSW through a supported living association.

Preferences for digital LSW services, magnitude and statistical significance of results Table 5.5 shows the results of the estimated regression model. All attributes were in the direction of the a-priori hypotheses. Participants had strong and statistically significant preferences for the intervention setting, preferring it to take place one-to-one at home rather than in a community group (β = -0.802; p= 0.000). Price was the only quantitative attribute. Participants preferred to pay a lower price for the service, evidenced by the negative direction of the coefficient (β= -0.019; p= 0.000). Regarding app accessibility and usability, participants wanted to avoid an app that was of advanced usability and accessibility (β= 0.180; p= 0.001). The intermediate level of the accessibility and usability attribute was statistically significant (β= 0.000; p= 0.998). As the basic level of this attribute was the base case in the effects coding, it was not possible to generate a p-value. However, as the confidence interval passed 0 in one of the other levels, it is likely that the basic level was not significant. Follow-up assistance was a statistically significant driver of preferences, with an additional follow-up life story session and a guidance manual being preferred to a manual alone (β= -0.150; p= 0.034). The coefficient for session focus was small and not significant (β= -0.032; p= 0.651). The constant term was positive and significant, suggesting that respondents were considering other attributes not included in the current DCE (β= 0.164; p= 0.023). MRS values of willingness to pay are also presented in Table 5.5. These are the values that respondents place on each attribute, relative to price. Setting was the most important attribute relative to price, with caregivers

Table 5.4. Characteristics of caregiver respondents

Characteristics	N(%) or Mean (SD)
N	67
Age	54.12 (16.34)
Gender	
Male	11 (16.4)
Female	56 (83.6)
Caregiving Situation	
The person I care for lives in residential care	22 (32.8)
The person I care for lives with me	20 (29.9)
The person I care for lives at home but not with me	24 (35.8)
Other	
Self-reported ICT skills	
Elementary	2 (3.0)
Intermediate	27 (40.9)
Advanced	37 (56.1)
Have you ever used a LSW service before?	
Yes, a digital service	1 (1.5)
Yes, a non-digital service	2 (3.0)
Both a digital and non-digital service	1 (1.5)
No	61 (91)
Other	2 (3.0)

willing to pay an additional £41.45 for a service in an individual setting rather than a community group. The MRS on the advanced level of the accessibility and usability attribute indicates that participants would pay £9.31 less for the service if this was the case. Participants were willing to pay an additional £7.75 to have a follow-up session in addition to a guidance manual, rather than a manual alone.

When the odds ratios are interpreted (Table 5.5), a service in an individual setting was preferred twice as much as a service in a group setting, all else being equal (OR = 0.45). Price had an odds ratio of 0.98, with participants showing a marginal preference for

less expensive interventions. When app usability and accessibility was advanced, the alternative (i.e. basic accessibility and usability) was preferred (OR = 1.20), while intermediate usability and accessibility had equal odds (OR = 1) to the basic alternative. In follow-up support, the odds of preferring one service over another increased by 0.14, when a follow-up manual and an additional LSW session were provided. For session focus, the odds of choosing a service that trains people to use the app, and supports them to create their own digital life storybook were marginally higher than the alternative of having their book built for them (OR =0.97).

Table 5.5. Results of the random-effects logit regression model

Attribute	β-coefficient	95% Confidence Interval		P Value*	Odds Ratio	MRS (£)	95% Confidence Interval	
Setting	-.802	-.960	-.644	.000	0.449	41.45	31.720	54.716
Price	-.019	-.024	-.015	.000	0.981	-		
Usability-Basic	-.180					-		
Usability-Inter	.000	-.129	.129	.998	1.000	-		
Usability-Adv	.180	.065	.296	.001	1.198	-9.317	-15.517	-3.557
Follow-Up Assistance	-.150	-.297	-.003	.034	0.861	7.75	0.851	15.620
Session Focus	-.032	-.184	.120	.651	0.969	-		
Constant	.164	.017	.310	.023	1.178	-		

No. observations = 1062; No. individuals = 67; Wald chi2(6) = 181.56; Log likelihood = -609.96778

*Statistically significant at p < 0.05

95% confidence intervals generated using non-parametric bootstrapping

Usability & accessibility base case (basic) calculated by assuming estimate for effects coded omitted variable = -1(sum of estimated levels)

Marginal rate of substitution values = β-coefficient for significant attribute/β-coefficient for price

Discussion

This is one of the first studies to explore the preferences of people living with dementia and caregivers in relation to digital LSW. Through a discrete choice experiment, four attributes that significantly shaped family caregiver preferences were identified. When ranked, the intervention setting had the most influence on caregiver preferences, followed by advanced app usability and accessibility, follow-up assistance, and the price of the intervention. Using an online survey of people with dementia, preferred features of digital LSW services in relation to setting, session focus, price, and planned future use of digital life storybooks were identified.

The intervention setting had the most significant influence on caregiver preferences, to the extent that they were willing to pay an additional £41.45 to have the intervention take place one-to-one in their homes, rather than in a group setting. Furthermore, they were twice as likely to pick a service in an individual setting than the alternative group setting. Similarly, among participants with dementia, the individual setting was more popular than the community group setting. However, it is important not to disregard group-based LSW, as almost one-third of participants with dementia indicated that they would prefer this over the individual option. In previous research, positive outcomes of digital LSW have been identified in both individual and group settings among community (Massimi et al., 2008; Stenhouse et al., 2013), and care home residents (Damianakis et al., 2010; Ludwin & Capstick, 2015; Subramaniam & Woods, 2016). Similarly, qualitative work presented in Chapter 3 highlights the positive effects of both group and individual reminiscence, both for participants with dementia and caregivers.

Learning how to use the app while being supported to create their own digital life storybook was the most popular choice of session focus among participants with dementia. However, only those who reported having advanced ICT skills selected this option. Those with elementary or intermediate skills chose the alternative option; to dictate the content of their digital life storybook and have the service create it for them. This is similar to a previous study of a supported digital LSW intervention with people with dementia (Stenhouse et al, 2013). They observed that participants did not want to interact with ICT to create their digital life storybook, and instead, dictated the content to

the researcher who created the digital life story book for them. Similarly, in a behavioural usage analysis of a reminiscence app, Mulvenna and colleagues (2017) observed that caregivers acted as 'admins' and added reminiscence stimuli to the app, while participants with dementia mostly used the app to reminisce. In Chapter 3, ICT was a significant barrier for all participants with dementia, and they depended on their caregiver to operate their digital life story books. Although session focus was not a significant attribute in the caregiver sample, advanced accessibility and usability (relative to basic) of the digital life storybook app was a significant driver in caregiver preferences. The analysis showed that caregivers were willing to pay an additional £9.32 to avoid a digital life story book that was advanced to use. Similarly, in Chapter 3, all caregivers (both family and care staff) struggled with the more advanced aspects of the digital life storybook app such as video and music, despite some having good self-reported ICT skills.

The majority of participants with dementia selected the 'free' price option, but when the two 'paying' options (i.e. £25 and £50) were combined, it emerged that marginally more indicated that they would contribute to the costs of the LSW service. Although price was a significant driver of caregiver preferences with a lower price being preferred, the odds ratio showed that this was marginal. To our knowledge, the attitudes of people with dementia and caregivers towards paying or contributing to LSW services are not explored elsewhere in the literature.

The level of follow-up support provided by the LSW service was a significant driver in caregiver preferences, with a follow-up session and guidance manual being preferred to a manual only. Results suggest that the follow-up session was valued at an additional £7.75 by caregivers. In some previous research, engagement with digital life story books waned over time despite participants seeing value in it (Damianakis et al., 2010; Chapter 3; Chapter 4). Although caregivers in the current study don't appear to value additional follow-up sessions particularly highly, they may be helpful to iron out ICT or other issues with the digital life storybook, and perhaps have the potential to prolong engagement with it.

When participants with dementia were asked how they would use their digital life storybook, the most popular response was 'to look at with family and friends and enjoy shared memories'. Indeed, LSW tends to be a shared activity in which sharing memories is

associated with improved communication, identity, and understanding of the person with dementia (Bruce & Schweitzer, 2008; Gridley, 2017). For example, Massimi and colleagues (2008) found that their case study participant enjoyed using his digital life storybook with family and had invited friends to his home to view it. His relatives discussed how it helped them to see him as a person, separate from his diagnosis. Similarly, McKeown and colleagues (2010), observed that people with dementia (and caregivers) took great enjoyment and pride from people taking an interest in their life story. The other responses were split evenly between the other two options; to show new people so they can learn about the person; and to use alone to enjoy memories. Even in such a small sample, this demonstrates that people with dementia can have very different preferences of how they would want to use digital life storybook, which should be considered.

Limitations

A clear limitation of this study is the lack of comparability between responses in the online survey for participants with dementia, and the DCE for caregivers. DCEs are associated with a high cognitive load, so the survey for people with dementia was simplified to prevent this. The sample of participants with dementia is small, and the recruitment process means that it is probably not representative of the wider population of people living with mild to moderate dementia and caregivers. Although the caregiver sample is a reasonable size and exceeds the minimum required number of participants, sub-group analyses were not possible due to the distribution of participants across sub-groups. Only a limited number of attributes could be included, which is a general drawback of DCEs due to limitations in the amount of information people can process.

Implications and Future Research

The results of this exploratory work can serve as a practical tool for digital LSW organisations to use in combination with other research and user consultation to plan services. Results offer insight into preferences of people living with dementia and caregivers in relation to digital LSW, and provide some groundwork for more in-depth and thorough investigation. The importance of considering user ICT skills, and tailoring the intervention to these skills from the outset is clear.

More research with larger sample sizes is needed to explore aspects of digital LSW services that are important to people with dementia and caregivers. Relatively few DCEs

have been conducted with people with dementia and caregivers of people with dementia, and more work is needed to validate this method with this group. In future research, ideally, both people with dementia and caregivers would complete a DCE survey, so that results can be compared. Carrying out a shorter DCE in a supported setting with a researcher could help to alleviate the cognitive load associated with this method. As there is evidence to show that digital LSW can be valuable in care home settings (e.g. Damianakis et al., 2010; Subramaniam & Woods, 2016), preferences among care home residents, staff, and relatives should also be explored.

Conclusion:

This exploratory study provides initial insights into preferences of digital LSW services among people with dementia and caregivers. Results suggest that most (but not all) participants with dementia prefer an individual intervention setting, and would use their digital life storybooks to share memories with family and friends. Marginally more participants would pay for the service than use it free of charge, while self-reported ICT skills dictated their preference for the focus of the LSW sessions. For caregivers, the results of the DCE show that an individual intervention setting, a low price, a digital life story book that is not advanced to use, and an additional follow-up session is the most preferred.

Chapter 6. An evaluation and review of touchscreen life story work apps for people with

dementia

Summary

The aim of this study was to review and evaluate touchscreen life story work apps that are available for people with dementia and their caregivers. Following a systematic approach to identification and inclusion, nine apps were included in the review. Apps are described with reference to the target market, compatibility, cost, multimedia capacity, and the sign-up/sign-in process. A study author and an independent evaluator used the App Evaluation Tool (AET) to rate the accessibility of each app for people with dementia. AET evaluation scores ranged from 44% (MemLife Journal) to 75% (Stories etc). Performance was poorest on items relating to text size, colour customisability, gesture instructions, accessible hints, and feedback after adding items (e.g. photographs, video, text). Three people with dementia and four caregivers provided brief reviews of their experiences using the apps. The most common concerns related to the display (e.g. colour, text size) or a lack of clear instructions. The results of this research highlight the existence of good-quality apps that can be used for the purposes of LSW with people with dementia privately, in research, or in practice. In addition, results can help to inform app developers on how their apps could be made more accessible and more appealing to this population.

The work presented in this chapter will be submitted to *Dementia* for consideration for publication in the coming week.

Introduction

Touchscreen apps are becoming increasingly available, affordable, and accessible. Stimulating daytime activities are one of the most frequently reported unmet needs among people with dementia, potentially adding to the difficulties faced by caregivers as they try to combat this with limited time and resources (Black et al., 2013; Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015; NICE-SCIE 2007). Although the majority of research into using touchscreens with people with dementia has revolved around assessment or cognitive rehabilitation, there is now growing interest in how touchscreens might be used for leisure or enjoyment (Joddrell & Astell, 2016).

The benefits of using touchscreens with people with dementia were identified initially in 1986 by Carr, Woods and Moore. However, there remained a pervasive assumption that people with dementia, and older people in general, could not learn how to use touchscreen devices but this has since been invalidated by more research (French 2016; Lim, Wallace, Luszcz, & Reynolds, 2013; Wandke, Sengpiel, & Sönksen, 2012). In fact, touchscreens have made computing more accessible for people with dementia as they remove the level of hand-eye coordination needed to operate a mouse and monitor is not required (French, 2016; Wandke et al., 2012). There is now evidence that some people with dementia can operate touchscreens independently (Astell et al., 2016; French, 2016; Kerkhof, Bergsma, Graff, & Dröes, 2017; Lim et al., 2013). For example, Kerkhof and colleagues (2017) observed that some participants with dementia could operate touchscreen apps independently after they had become familiar with them. In some research of touchscreen games, it has been found that people with dementia can interact with tablets and games, even if they had not used one before. However, there were also several people with dementia who needed support to operate touchscreens, and the required level of support varied considerably from person to person (Astell et al., 2016; French, 2016; Kerkhof et al., 2017; Lim et al., 2013).

Tyack and Camic (2017) reviewed touchscreen intervention studies for people with dementia and concluded that touchscreen apps could be considered as a feasible way of supporting wellbeing for this group. Similarly, French (2016) highlighted the success of a three-year NHS-funded digital inclusion programme, in which people at all stages of dementia interacted in a mostly positive way with touchscreen devices and apps. This

project and other recent research has also highlighted that touchscreen apps can serve as an enjoyable activity for people with dementia, even if they have not been necessarily developed with people with dementia in mind (e.g. Astell et al., 2016; Groenewoud et al., 2017; Kerkhof et al., 2017). For example, Astell and colleagues (2016) found that participants with dementia enjoyed playing 'Solitaire' and 'Bubble Explode', both of which had been developed for the general public rather than people with dementia specifically.

There is growing interest in using touchscreen apps for the purposes of life story work (LSW) with people with dementia. In August 2016, the UK Government procured the Dementia Citizens initiative[3], in which a digital LSW app was one of two touchscreen apps launched UK-wide for people living with dementia and their caregivers. This was a costly initiative in which two apps were purpose-built specifically for people with dementia and their caregivers. More information about this initiative and accompanying digital LSW app is presented in Chapter 4. LSW is considered a meaningful psychosocial intervention for people living with dementia, in which they discuss important parts of their life with another person and have these recorded in some way (Kitwood, 1997; McKinney, 2017; McKeown et al., 2006; Murphy, 2000). Digital LSW usually involves the production of a digital 'book' using various multimedia stimuli such as photo, video, and audio. The evidence base for digital LSW is still being established, but there is some promising evidence relating to enjoyment, well-being, and communication (e.g. Subramaniam & Woods, 2016; Damianakis et al., 2009; Ludwin & Capstick, 2015). In a recent case study of a touchscreen app and life stories for people with dementia, Critten and Kucirkova (2017) found that all three participants (and their caregivers) enjoyed the intervention and experienced feelings of confidence, empowerment, and increased self-esteem. This is one of the only published studies of touchscreen-based digital LSW for people with dementia to date. In Chapter 4 however, no significant benefit of using the purpose-built LSW touchscreen app was identified, and while some participants enjoyed using it, most did not engage with it.

In one study, Kerkhof and colleagues (2017) found that two caregivers felt that the level of support needed by their relative with dementia to operate the touchscreen device actually added to the demands of caregiving. Similarly, Groenewoud and colleagues (2017)

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[3] www.dementiacitizens.org

found that in addition to providing enjoyment and improved self-confidence, using apps could also cause annoyance and a sense of insecurity to users with dementia who struggled to operate them. These findings highlighted the importance of providing apps that are accessible to people with dementia, and of choosing the right apps for the right person. This then prompted the establishment of the AcTo Dementia project[4], which aims to identify accessible touchscreen apps for people living with dementia and provide evidence-based recommendations of them (Joddrell et al., 2016). This project included the development of the App Evaluation Tool (AET, Joddrell et al., 2016), which is used to evaluate the accessibility of touchscreen apps for people living with dementia. In this context, accessibility refers to the design of apps for people who experience cognitive or physical difficulties, such as people living with dementia.

In tandem with growing interest and increased touchscreen accessibility, more LSW apps are populating online app stores and repositories. Several are marketed to caregivers of people with dementia or people with dementia themselves. These are welcome developments, but it is crucial to identify apps that are of good quality and accessible to people with dementia and their caregivers, to avoid frustration and wasted time. Furthermore, it would be helpful to capitalise on pre-existing touchscreen apps for research or practice. Therefore, the aims of this study are:

1) To document and describe touchscreen life story work apps that are currently available to people with dementia and their caregivers
2) To evaluate the accessibility of these apps for people with dementia
3) To provide user reviews of the apps, written by people with dementia and their caregivers.

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[4] www.actodementia.com

Methods

Search Methods & Procedure

Our characterisation of LSW was based on those of Murphy (2000) and McKeown and colleagues (2006), who suggest that it involves thinking about or discussing important parts of one's life, and recording these in some way. This record is then used to benefit the person in the present. To identify potential apps, two researchers worked independently to carry out searches of the Apple App Store, iTunes, and the Google Play Store using combinations of the keywords: dementia; Alzheimer's; reminiscence; life story; life history; life storybook; biography. A web-based search of apps using the Google Advanced Search engine was also performed. Searches were carried out between 20/1/2017 and 20/2/2017.

The following inclusion and exclusion criteria applied:

1) It had to be possible to download the app on a touchscreen device, such as a tablet computer or smartphone
2) Creating a life storybook or life story record had to be the primary purpose, or one of the primary purposes, of the app
3) Apps had to be targeted towards adults, and not have a juvenile or childish theme
4) Apps must have been available to the general consumer, and not solely for the use of care organisations
5) Apps must have been available to download in the UK and Ireland

Each search within each app store produces hundreds of thousands of suggestions that change from day to day as more apps are added to the repositories. Therefore, apps were considered until there were over 20 apps in a row that bared no relevance to dementia, reminiscence or LSW. To determine if the apps met the above criteria, the app names, images, and descriptions were screened. Where necessary, apps were downloaded and explored further to determine if the criteria were met. Following independent evaluation, the two search authors had a follow-up meeting to compare their results and finalise a list of apps for inclusion in the review.

App descriptions and ratings

Each included app was downloaded onto a tablet computer. The researcher used each app for approximately 20-30 minutes and recorded basic information about each one. Apps were then rated using a modified version of the AET (Joddrell et al., 2016). The AET is a 42-item tool designed to evaluate and assess the suitability and accessibility of touchscreen apps for people living with dementia. It covers seven categories including interaction, feedback, aesthetic design, app design, customisation, obstacles, age appropriateness. There is also an additional category for evaluations specific to touchscreen games. Items that were not relevant to LSW apps (n = 18) were removed before the evaluation. As not all items were relevant to each app, percentage scores were calculated (for example, items relating to volume control would not be applicable if the app did not have sound). Apps were rated by the researcher and a developer of the AET. There was fair inter-rater agreement on the AET evaluations, according to Landis and Koch's (1977) rule of thumb (Kappa = 0.33, P < 0.05). The average ratings were presented, though in three cases the second rater (AET developer) could not carry out the rating, so the available rating was presented (i.e. MemBook, Stories etc, GreyMatters).

App reviews

People with dementia and caregivers of people with dementia were recruited as 'app reviewers'. To be eligible to take part, app reviewers needed to have the mental capacity to consent to take part in the research and be living with dementia, or caring for somebody with dementia. This was judged following guidance from the Mental Capacity Act (Department of Health, 2005).

The researcher contacted the Irish Dementia Working Group (IDWG) and distributed information sheets (Appendix N) to members with dementia at one of their bi-monthly meetings. The IDWG is a national dementia advocacy group based in Ireland, made up of people with dementia and their caregivers. Those who agreed to take part attended a group meeting with the researcher. The group meeting took place in a large room in the same location that the IDWG meeting took place, and reviewers could carry out the reviews in a quiet corner or with another person. After signing the consent form, the four reviewers were randomly assigned an app to review. This was done by using an online random number generator. Only apps that had an AET evaluation of 60% or more

were assigned to reviewers with dementia. Reviewers were asked to use the app for between 15 and 20 minutes, and then write or dictate a brief review of the app. If they wished, they could then review a second app. The researcher was present in case any reviewer required some assistance.

The research was also publicised on social media. Information sheets (Appendix N) were sent to those who expressed interest in taking part by e-mail. The researcher then phoned those who responded to the e-mail to explain the study, and to give potential reviewers the opportunity to ask questions. An information sheet and consent form were also posted to the participants with a stamped addressed envelope to return the consent form. Following confirmation of consent, reviewers were 'assigned' an app to review. This was done using a random number generator, though if an app had previously been reviewed, it was not included. The researcher explained how to download the apps, and if the app had to be paid for, gave them a code to download it for free. Reviewers were asked to use the apps for between 15 and 20 minutes, and write a review of their experiences. All reviewers were also given the option of sending the review via e-mail, post, or dictating it over the phone. All reviewers opted to send their reviews via e-mail.

 All reviewers were provided with a list of prompts to assist with the review, but it was stressed that these were optional (Appendix O). Reviewers were each posted a £10 store voucher for taking part.

Results

App repositories were searched, and the titles, thumbnails, and/or descriptions of 56 apps were reviewed for inclusion. Ten apps met the inclusion criteria and are described in Table 6.1. Some excluded apps and reasons for exclusion are presented in Appendix Q.

Target market. Apps were mostly targeted towards general consumers (Stories etc, weGather, MemLife Journal), older people and their caregivers (MindMate, LifeBio Studio, Tangible Memories, Storii), and people with dementia and their caregivers (MemBook, My Life Story). One app was targeted specifically at caregivers of people with dementia ('Greymatters').

Compatibility: Five of the included apps were only compatible with Apple IoS devices, with three being available for iPad only. Four were compatible with both Apple and Android devices, while one was available for Android devices only.

Cost: All apps were free to download except for 'My Life Story' which cost £6.99 for the first two albums, and a further £39.99 for unlimited albums thereafter. The 'GreyMatters' app offered in-app purchases, mostly relating to additional reminiscence packages that were not relevant to the digital life storybook function. However, there was also an option to purchase additional profiles ($19.99). None of the other included apps contained in-app purchases. 'MemLife Journal' provides users with the option of converting their digital life storybook to a PDF and paying to it printed and bound with an affiliate partner.

Multimedia components: Multimedia components included photo, text, audio narration, video, and music. Almost all apps facilitated photographs and text, and five also facilitated audio narration. 'GreyMatters' and 'Storii' facilitated the inclusion of all five multimedia components.

Sign-up process: Several included apps had some kind of sign up process whereby the user entered their name, e-mail address, and created a password. In most apps, these details were saved so that users did not have to repeat the sign-in process each time they used the app. However, the 'Storii' and weGather apps required a username and password each time they were opened, with no option of having the sign in credentials saved. The

Table 6.1. Description of included apps

App Name	Compatibility	Price	Description	Photo	Text	Narration	Video	Music	Average AET %
Stories etc	iOS	Free	Users can record their record their story by video, voice, or text. There are also prompting questions if desired. Individual stories can be grouped into themes, and users can e-mail the story to friends or family. It is aimed at general consumers.	✔	✔	✔	✔		75%
MindMate	iOS/Android	Free	LSW is one of 4 main functionalities of the app. Users can build a life storybook. The app is aimed at older people in general, though it does mention dementia on the website and in the app store description.	✔	✔				70%
LifeBio Studio	iOS	Free	This app contains several prompts and questions. Users can video record themselves responding to these questions. No typing is required after the initial login. This app is aimed at older people in general and those who care for older people.	✔		✔	✔		64%
weGather	iOS/Android	Free	Users can add life memories and connect with family members who can comment and collaborate on photographs and text. It is aimed at general consumers.	✔	✔				63%
GreyMatters	iPad only	Free	Users can build a life storybook and have the option of recording 'reminder' videos. The app contains games and reminiscence tools, but it is predominantly a digital life storybook. It is aimed at caregivers of people with dementia.	✔	✔	✔	✔	✔	61%

App Name	Compatibility	Price	Description	Photo	Text	Narration	Video	Music	Average AET %
MemBook	Android only	Free	Users can create several digital 'scrapbooks' of their life story on a book-like template. However, this app does not appear to be maintained, and authors could not get in touch with developers. It is designed for people living with dementia and their caregivers.	✔	✔				59%
Storii	IoS/Android	Free	Users can create their life story, and use the app to connect with others who also have Storii. They can then share their content with their connections. It is not specifically aimed at people with dementia or caregivers but mentions dementia on the website and in the app store description.	✔	✔	✔	✔	✔	56%
Tangible Memories: Story Creator	iPad Only	Free	Users can record their digital life story which can be viewed as a slideshow or printed out. Printouts can be scanned by the app which will then play any sound recordings associated with that page. It has been designed 'particularly for older people and their carers'	✔	✔	✔		✔	54%
My Life Story	iPad Only	£7.99	Allows users to create slideshows of their life story, using different albums. This app is specifically designed for people living with dementia and their caregivers. It also contains in-app purchases.	✔	✔	✔		✔	50%
MemLife Journal	iOS/Android	Free	Users can build a timeline of memories using prompts if desired. There is an option to collaborate with others while maintaining control of sharing and editing. It appears to be targeted at general consumers, though it mentions Alzheimer's Disease in the description.	✔	✔				44%

apps that were developed with people with dementia in mind (e.g. MemBook, My Life Story), had no sign-up or sign-in process, so users could begin using the apps immediately after downloading them. The 'GreyMatters' app required that an e-mail account is linked to the users' iPad, and users had to sign up to the GreyMatters mailing list. Following the initial sign up, users did not have to sign in again

AET Evaluations. AET evaluations also are presented in Table 6.1. Average AET scores range from 44% to 75%. Stories etc (75%), 'MindMate' (70%), and Life Bio Studio (64%) were awarded the highest ratings. Across apps, there was relatively poor performance on items related to text size, colour customisability, gesture instructions (such as swiping, zooming), accessible hints, and feedback when items were added.

App reviews

Information regarding recruitment is presented in Table 6.2. Nine people with dementia (members of the IDWG) were informed about the research, and four agreed to take part. Seven family caregivers responded to the study information on social media and distributed through the North Wales Dementia Network. Of these, four family caregivers agreed to be an app reviewer and consented to take part in the study.

Table 6.2. App reviewer recruitment table

Action	N
People with dementia	
Approached to be an app reviewer	9
Participated as an app reviewer	4
Family caregivers	
Expressed interest in being an app reviewer	7
Participated as an app reviewer	4

App. My Life Story

Reviewers. Kathy and Anne (Members of the IDWG)

"The app seems straightforward to use at the beginning, but some parts are not clear. It always needs to be clear what the next step or next button to press is to avoid getting frustrated. It's brilliant that you can speak about your photos. I have been looking for something like this for a long time. We feel very strongly that there should be a free trial. It's very good, but I would not buy this without trying it out first. Unlimited albums seem very expensive since there are so many free apps available".

App. Stories etc

Reviewers. Dolores (Member of the IDWG)

"It's clear what to do in the app, and it's easy to use, but it doesn't tell you how to save pages. Everything is easy to read, and the colours are very clear. The text is big. I would try it with somebody but not on my own. I'm not very good with computers, I never have been, so I wouldn't feel confident doing it on my own. I found that the app froze quite a lot. There were too many options to save things. I would recommend this to a friend".

Author note: The app did not crash during other testing periods so it may have been due to the device that was being used at the time.

App. weGather

Reviewer. Dolores (Member of the IDWG)

"It is clear what you have to do on the app, and it's easy to use. I like that you can ask your family to be part of it with you and share memories, but the writing is small and not very clear. It would be good if the pictures were larger. I would like more options on it like speaking".

App. MindMate

Reviewers. Kathy and Anne (Members of the IDWG)

"This is an app I would pay for. It is very clear, you have all the buttons on the screen,

and it tells you the date and time on the top. It makes you feel like you're in control. The prompts are excellent, and it's clear what the next step is. The only part that isn't completely clear is adding a photo. We weren't sure how to confirm that we picked photos or that we had to go into the album first. We loved the app but it's a pity you can't put voice on it too, we would really love that. We would recommend this to friends".

App. weGather

Reviewer. Suzy (with the help of her Mum, who is living with dementia)

"weGather is really easy to use, and the instructions are straightforward. We had a few difficulties signing in, but this was resolved after resetting the password twice. One frustration was that we needed to sign in with an email and password every time we opened the app, there didn't seem to be a way to save these details and ultimately save time! We found the App a little boring; the featured photographs could have been more varied with some photos of the present day. We wondered if there was an assumption that older people/ people living with dementia just like looking at old photos, not recent memories? We also wondered if some animations or brighter colours would appeal to the intergenerational market. We liked the option of sharing photos/memories and asking family/friends to contribute - this was a lovely idea however you would need to rely on family/friends to have an iPhone and commitment to download the App. We would not recommend this App to friends".

App. LifeBio Studio

Reviewer. Penny (with the help of her Mum, who is living with dementia)

"It dives straight in with recording. It would have been nice to have a page of explanation first, to understand what we were about to do, maybe show an example of someone else doing it. In retrospect, we should have positioned the camera better, so the finished result looks good, rather than a wobbly, handheld, selfie style recording. Clearer instructions at the start would have helped. My mum is in the early/mid stages of dementia and has never really used a computer. She would have had no idea how to use it without help. Someone used to technology may have managed but considering it may well be used by people with cognitive issues, it would have been

better to have more information (and simplified) on how to get started. The colours are a bit dull and do not draw you in. It would have been good to incorporate clear, strong colours that stand out. It was a good activity to do together. My mum is a great talker and of course, loves talking about her past a great deal, so she really enjoyed doing it. There was no time limit on the recording which meant she could talk for as long as she wanted. It was good to have the questions to prompt a response. It was helpful to see those on the screen as you record to help mum remember. It is not a very attractive app, the layout is not very inviting, and it's not clear what all the menu options were for. I think the colour scheme needs to be improved, and the developers should add a clearer explanation of what you are about to do at the start. It is quite time-consuming, so to know that you can come back to it another time before you begin and not lose your recordings would be helpful. From my experience, it could only be used by someone with dementia with help. I would possibly recommend this to a friend, but I am not sure it is any different from recording it yourself on your iPhone".

App. Tangible Memories: Story Creator
Reviewer. Penny (with the help of her Mum, who is living with dementia)

"Resources' tells you what to do, but perhaps it should be renamed 'How to create your story', which is a bit more obvious. Otherwise, you find yourself wondering how it works and going to FAQs. FAQs are helpful but very detailed and perhaps a bit overwhelming! I like the idea of combining audio with text and a photo. Also for some older people, it might be easier to capture audio than film them. It is easy to use if you are good at using an iPad, but it is fairly straightforward to work out once you get to the 'create project' stage, even if you're not very good at technology. The homepage is simple and inviting. The other pages, e.g. about, faqs, resources, look a bit clinical. I'm sure they could be laid out better, which would mean you'd be more likely to read them. It was a good activity to do together, fairly easy to use. I like that you can stop and start your project, so it does not need to be created all at once, and that you can create more than one project at a time. It is an easy way to access photos, memories, and audio in one place. It can be used in many ways, for example as a distraction, to prompt conversation or to connect with visitors/carers. It takes a bit more planning as you need to have photos in mind and stories you think would be good to tell.

Perhaps a list of prompt questions might help. If I had to change something, it would be the layout of menu pages. I would use this app with somebody with dementia".

App. Storii

Reviewer. Colleen, a caregiver for a person living with dementia

"The summary sounds very promising – particularly the idea of sharing the contents with other parties who can add and edit. In actuality, I found the app so unfathomable and user-unfriendly that I gave up! As did my partner, who is very tech savvy. There was no introduction or explanation, and I can't imagine the majority of carers (never mind people with dementia themselves) having the first idea where to start. I'm not a great fan, personally, of deliberately misspelt words either (e.g. kidz, storii) and much preferred the simplicity and self-explanatory titles of Memlife and MemBook. They do what they say on the tin, which 'Storii' most certainly does not".

App. Memlife Journal

Reviewer. Colleen, a caregiver for a person living with dementia

"This is a smaller app, thereby using up less storage on one's phone and – hurrah – it links to one's computer, so all the info is there as well where it is, of course, much easier to see and to use. A major plus. I know not all patients or carers are elderly but a great many are and small, fiddly things are a challenge and frustrating for them to use. I see the app is funded, thereby losing some screen space to advertising, but that is an observation rather than a criticism. I didn't spend very long in the app as I was keen to try the next one, but it seemed comprehensive and easy to use. I liked it. One criticism: you can't close down the app from within it on a phone – even after logging out I still had to go to Close All Apps to escape. Finally, it was nice to get a "welcome" email from Memlife. Touches like that have a positive psychological effect, I think. The I.T world can seem a cold and impersonal one, particularly to the older generation; anything friendly and supportive is helpful".

App. Membook

Reviewer. Colleen, a caregiver for a person living with dementia

"This was quite appealing, simple and straightforward. It is very limited (particularly in comparison with Memlife), but I liked the idea and could imagine sitting with my mum and her being quite engaged for a short while (she has very limited concentration), particularly as the album covers are bright and colourful".

App. *GreyMatters*

Reviewer*.* Mick, a caregiver for a person living with dementia

"A little difficult to download. There is also some work to be done like adding email address (user and carer) before you can really start and this may cause confusion. Once it is up and running, it is fairly easy to use. To benefit from it, you really need to do some work in adding pictures, music etc. To avail of more profiles, you need to purchase various items from the app store which of course is more expense and work. The layout colours are nice, and the interface is clear and user-friendly. The help section is quite good and has some positive, simple advice on how to engage with the user. Once set up, the app is quite good and may be of some benefit in a family setting.

Discussion

The aim of this research was to review and evaluate touchscreen LSW apps that are available to people with dementia and their caregivers. This was done with the view to providing practical advice and recommendations to prospective users, and highlighting possible improvements that could make the apps more accessible to people with dementia. Brief reviews of each app were carried out by people with dementia or caregivers of people with dementia, while a researcher and independent reviewer evaluated the accessibility of each app using the AET.

When apps were ranked according to their average AET evaluation score 'Stories etc', 'MindMate', 'LifeBio Studio', and 'weGather' were rated as the most accessible for people with dementia. 'MindMate' and 'LifeBio Studio' are marketed to older people, while 'Stories etc' was developed for the general consumer. In addition, having high AET scores, reviews of these apps were predominantly positive. In particular, the 'MindMate' reviewer stated that it was an app she would pay for (it is currently free to download). In previous research of touchscreen apps and dementia, it has been found that apps can be a source of pleasure and enjoyment, even if they are not specifically marketed to, or developed for, people with dementia or even older people in general (Astell et al., 2016; French, 2016; Kerkhof et al., 2017). Although 'LifeBio Studio' was ranked as the third most accessible app using the AET, the reviewer felt that it lacked basic instructions, and needed brighter and bolder colours. In fact, an absence of clear instructions, and issues related to colour, layout, and text size were common concerns among reviewers. This bears similarity to findings from a recent study, in which focus group data revealed that people with dementia and their caregivers had issues with the small size of app elements, the lack of a clear 'home' button, and unrecognisable symbols on buttons. It was found that participants desired more customisability in relation to the interface, less scrolling, fewer screens, and fewer required clicks (Kerkhof et al., 2017). In the current study, AET ratings relating to the customisability of text size and colours, feedback when an element was added, and assumption of prior knowledge of gesture controls such as swiping and zooming, were the poorest.

Some of the above design issues may have relatively simple resolutions through added or simplified instructions, improved colour schemes, and more choice about

interface appearance (e.g. changing text size). In a study of apps for people with dementia, Astell and colleagues (2016) identified some design issues in two touchscreen games. Later, Joddrell and Astell (2017) demonstrated how one of these apps ('Solitaire'), was made more accessible through collaboration between researchers, app users (i.e. people with dementia) and app developers. Participants who used the amended app made fewer errors and progressed further through the game compared to those who used the original version. However, performance on the amended version of other game ('Bubble Explode') was similar to the original version, suggesting that there may be a ceiling effect.

In the current evaluation, reviewers with dementia had mixed feelings about using the apps independently during testing. Dolores mentioned that she would only use the app with another person, while several caregiver reviewers felt it was unlikely that their relative with dementia would be able to use the apps independently. On the other hand, this was not a concern for Kathy and Anne, both of whom are living with dementia. These observations are similar to previous studies of touchscreen apps for people with dementia, in which some participants could operate them independently while others required varying levels of support (Astell et al., 2016; French, 2016; Kerkhof et al., 2017; Lim et al., 2013). Critten and Kucirkova (2017) found that all three participants in their study needed some support to use a touchscreen LSW app. The app in question was designed for children and is therefore not included in the current study. In Chapter 4, qualitative feedback indicated that a touchscreen LSW app was manageable for some participants with dementia on their own, but others felt that there was an information overload and found it too difficult to use.

Limitations

New apps are constantly being added to app repositories meaning that new eligible apps may be available that are not included in the current review. Similarly, as apps are frequently updated, it is possible that slightly different versions were subject to reviews and evaluations. Although the AET was designed to be used with all types of apps, so far, it has only been used with gaming apps. Consequently, the evolution of the tool to date has been based on discoveries within gaming apps. This is the first time the AET has been used with non-gaming apps, and it may require modifications or additions for the evaluation of LSW apps. For example, items relating to the sign-up and sign-in process may be useful.

Implications and Future Research

The results of this review offer a basis to provide practical guidance and recommendations to people with dementia or caregivers who may be interesting in using a touchscreen app for LSW. Results will be converted to plain language and published as a blog post on the AcTo Dementia website. Results will also be communicated to developers of the included apps, in the hope that they can make the apps more accessible and user-friendly where needed. For research, results highlight the existence of freely available, good-quality apps that can be used for the purposes of LSW with people with dementia and their caregivers. Future research should involve longer testing periods and have several reviews of each app by reviewers with varied ICT experience and skills. Ideally, a person with dementia should always be involved in the review process. Where possible, researchers should work with app developers and app users to address design issues and explore the relative benefits of doing so.

Conclusion

There exists some freely available, good quality, touchscreen LSW apps that can be considered for use in practice and research with people with dementia and caregivers. There are areas in which accessibility can be improved (e.g. text size, customisability, instructions) through collaboration and communication with app developers, people with dementia, and researchers.

Chapter 7. Discussion

Discussion

The objective of this thesis was to contribute to knowledge and practice concerning reminiscence and digital life story work (LSW) for people with dementia and their caregivers. Reminiscence is a popular approach with this group but it still has an uncertain evidence base. In recent years, more studies examining its effects have been published, warranting an updated review of this topic. Therefore, the first study in this thesis is a review of reminiscence therapy for dementia (Chapter 2). The focus of the thesis then moves to digital LSW, one of the many facets of reminiscence therapy. Growing availability and accessibility of information and communication technology (ICT) has led to increased interest in digital LSW, particularly in using ICT to create a digital life storybook that incorporates a range of multimedia stimuli (Woods & Subramaniam, 2017). Following a review of ICT-based reminiscence work, Subramaniam and Woods (2010) concluded that the approach is feasible, but that more work is needed to explore how it can be best implemented with people with dementia (Subramaniam & Woods, 2010). As there are several possible approaches to LSW, both digital and conventional, three supported implementations of digital LSW were explored in Chapter 3. The perspectives and experiences of people with dementia, family caregivers, and care staff were sought. In Chapter 4, the 'digital' aspect of digital LSW was taken a step further. The feasibility and impact of a remote, self-guided life storybook app and digital Citizen Science approach was explored. The wide range of possible implementations of digital LSW, and varied engagement with it prompted an exploration of the preferences of people with dementia and caregivers of digital LSW in Chapter 5. The digital life storybook apps presented in Chapters 3 and 4 of this thesis were costly and time-consuming to develop. Therefore, Chapter 6 is a review and evaluation of available touchscreen apps that can be used in LSW with, or by, people with dementia.

Summary of findings, how they fit within the existing literature, and the contribution of findings to practice and research.

Chapter 2. Reminiscence therapy for dementia: A systematic review of the evidence from randomised controlled trials.
The aim of Chapter 2 was to review and evaluate the effectiveness of reminiscence therapy for people with dementia in the areas of wellbeing, cognition, communication, and mood.

The review included 22 randomised controlled trials (RCTs) comprising a total of 1,972 participants. Six trials were excluded from the meta-analysis as they were rated as having a high risk of selection bias for randomisation. Therefore, the meta-analysis included data from 1,749 participants. Subgroup analyses of intervention modalities (i.e. individual/group) and settings (i.e. care home/community) were carried out, and the nature and quality of the evidence was evaluated. Results suggest that reminiscence therapy had some positive but small effects on all four outcomes of interest, though these effects varied considerably across different settings and modalities. Individual approaches were associated with improved cognition and mood, while group-based approaches had a positive impact on communication. The effect on quality of life and cognition appeared most promising in care home settings. The evidence was of reasonable quality, but intervention structures and protocols were rarely reported in sufficient detail. Reminiscence approaches and durations varied widely, and additional information often had to be requested from study authors.

Results support findings from existing reviews, in which improvements in mood (Blake et al., 2002; Cotelli et al, 2012; Huang et al., 2015; Subramaniam & Woods, 2012; Testad et al., 2014; Woods et al., 2005) and aspects of cognition (Cotelli et al, 2012; Huang et al., 2015; Kim et al., 2006; Kwon et al., 2013; Subramaniam & Woods, 2012; Woods et al., 2005) have been identified. Similarly, results parallel the previous findings that group reminiscence (Kim et al., 2006), and reminiscence in general (Kwon et al., 2013) can significantly benefit communication. In earlier work, improved performance on quality of life measures was identified in individual reminiscence interventions or care home interventions (Subramaniam and Woods, 2012), which corresponds with the results of Chapter 2. However, unlike the review by Kwon and colleagues (2013), an overall effect of reminiscence on quality of life was not identified, though studies in that review were not described or referenced. Huang and colleagues (2015) compared the effects of reminiscence between care home and community settings. They identified a more significant impact of reminiscence on participants in long-term care settings, compared to community-dwelling participants. Similarly, in Chapter 2 the effect of reminiscence therapy on depressed mood in people with dementia was found to be greater in care homes than community settings.

It appears that the last review of reminiscence therapy for dementia was published three years ago (Huang et al., 2015), making this review a timely addition to the evidence base. It is the most extensive review of the subject to date and represents a significant contribution to the research literature. The meta-analyses were of a sufficient size to compare different reminiscence modalities and settings and therefore provide helpful insight into the aspects of reminiscence that contribute to different outcomes for future research and practice. Although results are promising, there remains a need for more high-quality work in this area, especially comparing the effects of simple and integrative reminiscence.

Chapter 3. Implementing digital life story work for people with dementia: The relevance of context to user experience.

The aim of this study was to explore user experiences and perspectives of three different implementations of a supported digital LSW intervention. Participants learned how to use and create a digital life storybook in either (a) a community group for people with dementia and family caregivers facilitated by a volunteer, (b) private one-to-one sessions also with a volunteer for people with dementia and family caregivers, and (c) a dementia care home for care staff. Two themes, each with two subthemes were identified in interview data from people with dementia. These were (a) '*Memories*' – 'evoking memories', 'sharing memories', and (b) '*Intervention limitations*' – "it's not for everyone", 'ICT as a barrier'. Themes and subthemes in family caregiver data related to (a)'*Expectations and usage*' – 'expectation and apprehension', 'using the digital life storybook', 'different plans', (b) '*Intervention context: individual versus group*' – 'group context', 'individual context', and (c) '*ICT considerations*' –'multimedia access and capacity', 'limitations or learning?'. Finally, themes identified in care staff data were (a) '*Connecting and sharing*'- 'collaboration and communication', 'meaningful interaction and conversation', 'it's too personal', (b) '*ICT: creating opportunities*' – 'accessing relevant materials', 'a new skill', and (c) '*the influence of the work environment*' – 'time and priorities', 'convenience', 'the impact of management'. Making connections was a common theme across the datasets. All participants enjoyed using the app and felt that the intervention was a positive experience. However, two participants with dementia from the individual context became upset in two instances during the LSW workshops. One was frustrated because he could not remember names, and the other recalled a sad memory.

Results suggest that an individual context is best for creating a digital life storybook and learning how to use it, while the group context may have more social value.

Results support previous research in which similar themes and findings have been identified. Similar themes or outcomes of LSW have been reported in previous work. These include enhanced meaningful communication between care staff and residents (e.g. Clarke et al., 2003; Gudex et al., 2010; Kellett et al., 2010; Sarne- Fleischmann & Tractinsky, 2008), enhanced communication between care staff and relatives (e.g. Clarke et al., 2003; Gudex et al., 2010; Kellett et al., 2010; Sarne- Fleischmann & Tractinsky, 2008; Subramaniam & Woods, 2016), positive experiences for people with dementia, despite sad or frustrating moments (Damianakis et al., 2010; Sarne-Fleischmann & Tractinsky, 2008; Subramaniam et al., 2013), evoking memories and reconnecting with the past for participants with dementia (e.g. Damianakis et al., 2010; Sarne-Fleischmann & Tractinsky, 2008; Subramaniam & Woods, 2016), difficulties using ICT (Stenhouse et al. 2013), appreciation of multimedia resources (Sarne-Fleischmann & Tractinsky, 2008), and implementation being influenced by the work environment (Gudex et al., 2010). The common theme 'making connections' was an overarching theme in a previous review of life story resources by Kindell and colleagues (2010).

This work demonstrates the feasibility of a supported digital LSW intervention delivered through a volunteer-based service in community group settings, individual one-to-one settings, and care home settings. Results can help shape the development of digital LSW approaches and provide some insight into what outcomes may be associated with different contexts. For example, the individual setting was more conducive to creating and learning how to use the digital life storybook, while socialising was viewed as the primary benefit of the group setting. Results of this research have directly influenced changes in the LSW service that was involved in the evaluation. The sensitive management of poignant or distressing moments is now at the forefront of volunteer training, and the service has simplified the more complicated aspects of the LSW app (e.g. adding video and audio). Other significant implications for practice are the findings that multi-level management support was essential for implementation in care homes, and that the digital life storybook can also be used for other positive purposes. As digital LSW research is still a relatively new addition to the dementia care literature, the results of this exploratory work can contribute to the groundwork for more extensive studies in the future.

Chapter 4. Exploring the feasibility of a self-guided, digital life story work app for people living with dementia and their caregivers: A Citizen Science approach.

The objective of Chapter 4 was to investigate the feasibility and impact of a self-guided digital LSW research app for people with dementia and their caregivers using a Citizen Science approach. The study took place over a three-month period, and included 101 participants. The app was a purpose-built digital life storybook, containing built-in research questionnaires relating to quality of life (QoL-AD, SWEMWBS) and day-to-day experiences of each LSW session. Engagement with the app declined considerably across the intervention period. Response rates on the quality of life questionnaires were low and no significant effects were identified. Similarly, no significant correlations between app use and quality of life were identified. Post-session feedback on the experience of each session was mostly positive, though response rates were also low. Follow-up phone interviews with 19 participants revealed various reasons for no longer engaging with the app and the study. They included difficulties with ICT, not valuing LSW as an intervention, and not having enough time to participate. Overall, the intervention was not successful due to the high attrition rates and no evidence of any impact on quality of life. However, the post-session feedback and some usage data indicate that those who engaged with the digital life storybook enjoyed it. The high level of initial interest in the research study suggests that Citizen Science has potential.

The study presented in Chapter 4 represents a novel intervention and research approach with people with dementia and their caregivers. In an existing self-guided app-based study for people with Parkinson's Disease, engagement with the intervention was higher than in Chapter 4, but it required less commitment as it was purely observational and involved fewer research tasks (Bot et al., 2016). The positive responses to post-session feedback support previous work that has found interacting with digital life storybooks to be enjoyable, interesting, and engaging for people with dementia and caregivers (Critten & Kurcikova, 2017; Damianakis et al., 2009; Massimi et al., 2008). However, these interventions were carried out with the support of a facilitator unlike the intervention in Chapter 3. The decline in participant engagement with the app is relatively in line with retention rates in general apps across all industries (Perro, 2017).

Although the intervention as a whole was not considered successful due to poor engagement and no identified positive effects on users, this study provides some tentative

support for the feasibility of a Citizen Science approach. People with dementia and caregivers are calling for greater inclusion in dementia research (e.g. Bryden, 2016; Scottish Dementia Working Group Research Sub-Group 2015), and Citizen Science is a viable research approach that can support this movement. The Citizen Science approach in Chapter 4 was a low level and did not truly embody the spirit of Citizen Science, but results provide some 'lessons learned' that will be helpful in using this approach with people with dementia in future. In particular, that future approaches should be more participatory, with greater inclusion of potential users at all stages of development, and ensure that motivators such as validation, incentives, and feedback are present. Findings suggest that digital LSW is not a suitable intervention to pair with Citizen Science, possibly because it involves significant time and effort to create a LSB before it can be used primarily for viewing.

Chapter 5. Investigating the preferences of people with dementia and caregivers in relation to digital life story work: A discrete choice experiment and online survey.

The aim of Chapter 5 was to explore the preferences of people with dementia and their caregivers of approaches to supported digital LSW interventions. An online survey was completed by 16 people with dementia, and 67 caregivers completed an online discrete choice experiment (DCE). Four attributes significantly impacted caregiver preferences. These attributes and (favoured levels) were an individual setting, lower price, avoiding advanced app usability, and an additional LSW session. Preferences of participants with dementia varied, but results suggest that an individual setting was more popular than a group setting and that most participants would use their digital life storybook to share memories with friends and family. Marginally more participants with dementia said they would pay for the service rather than only use it free of charge. ICT skills were identified as an essential consideration in the design of a service, as they affected how the person with dementia would interact with the app. Those with elementary to intermediate skills would want to dictate the content of their life storybook but have somebody else create it, while those with advanced skills would prefer to learn how to use it so they can create their own. Similarly, avoiding an advanced app was a significant driver in caregiver preferences. Even though there were just 16 respondents with dementia, all possible options on each survey item were selected at least once.

This is one of the first studies to explore preferences of people with dementia and caregivers of digital LSW. Although digital LSW has been found to be enjoyable for people with dementia in both group and individual settings (e.g. Massimi et al., 2008; Stenhouse et al., 2013), caregivers in the current study showed strong preferences for it to be in individual settings. In Chapter 3, there were varied preferences of the intervention setting. Caregivers in the group setting appreciating the social aspect of groups while those in individual settings participants could not see how it could work in a group. Results support previous findings by Stenhouse and colleagues (2013) who observed that when participants in their study were uncomfortable with technology, they preferred to have a researcher create their digital life storybook for them. Similarly, Mulvenna and colleagues (2017) observed that caregivers acted as 'administrators' and added the reminiscence stimuli to the app, while participants with dementia primarily used it to view the reminiscence stimuli.

A 'director and producer' model in which the person with dementia or their family 'directs' the content of their digital life storybook to a facilitator who creates it has often been used in previous digital LSW interventions for people with dementia (e.g. Damianakis et al., 2009; Ludwin & Capstick, 2015; Massimi et al., 2008; Stenhouse et al., 2013;). However, an important finding of Chapter 5 is that participants with dementia who were comfortable with ICT would prefer to learn how to use a LSW app and create their own digital life storybook. Results from the DCE provide insight into which aspects of LSW services are important to caregivers, and the trade-offs they make between attributes of services, which can help with the future provision and design of digital LSW interventions. Results from the survey for participants with dementia highlighted which aspects of LSW were generally preferred, but also highlight the importance of tailoring facilitated LSW interventions on a case by case basis.

Chapter 6. An evaluation and review of available apps for life story work with people with dementia.

The aim of Chapter 6 was to review touchscreen apps that are available to people with dementia and caregivers to use to create a digital life storybook. Ten apps were included. The App Evaluation Tool (Joddrell et al., 2016) was used to rate the accessibility of each app for people with dementia. Ratings ranged from 44% to 75%, with the average rating being approximately 60%. Reviewer responses to the apps varied, and the most common

concerns related to an absence of clear instructions, or the size and colour of different elements within the app. Two reviewers with dementia were comfortable with using the apps and did not require additional assistance or guidance, while the other had little or no experience and did not want to use it on her own.

This is one of the first reviews of digital LSW apps for use with or by people with dementia to date. Many of the common issues identified in the included apps, such as the presentation of elements and lack of customisability have been highlighted in previous work (Kerkhof and colleagues, 2017). Attitudes of reviewers with dementia towards using apps independently bears similarity to earlier findings in which some people with dementia were able to operate them independently, while others required varying levels of support (Astell et al., 2016; French, 2016; Kerkhof et al., 2017; Lim et al., 2013). However, this contrasts with one of the only published studies of a touchscreen LSW apps for people with dementia to date, in which all three participants needed support to operate it (Critten & Kucirkova, 2017).

This review highlights the existence of good quality and freely available touchscreen LSW apps that are available to people with dementia and their caregivers including some that are not targeted to, or developed for, this group. Future initiatives or research studies may be able to harness these apps, rather than go through the time consuming and costly process of developing a new one. Results of the review will be converted to plain language and communicated to people with dementia and caregivers through the AcTo Dementia[5] website, which provides independent, evidence-based touchscreen app recommendations to people with dementia and their caregivers. In addition, these results will be communicated to developers of the included apps, in the hope that any accessibility issues can be improved.

Discussion of findings

Theoretical considerations.
Life storybooks are often associated with being an output of life review, but Morgan and Woods (2010) argue that LSW should be an intervention in its own right. In fact,

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[5] www.actodementia.com

Subramaniam and colleagues (2013) suggest that the process of life review may not be as important as the presence of a life storybook itself. In their study, one group of people with dementia took part in a life review intervention which included the production of a (conventional) life storybook. The other group received a gift of a structured and chronological life storybook that been created for them by their relatives and the research team. Directly after the life review intervention, the life review group showed significant improvements on measures of quality of life and autobiographical memory compared to the gift group. However, after the gift group received their life storybook, they showed similar improvements in quality of life and autobiographical memory to the life review group and the difference between the two groups was no longer evident.

The concept of LSW is not exactly 'pinned down', but it seems to fall somewhere between life review and simple reminiscence. Conventional LSW is often associated with life review, but Haight and Dias (1992) studied different characteristics of reminiscence with 240 participants and proposed that there are three essential criteria for life review. They suggest that it should (a) be conducted one-to-one so that participants have the privacy to revisit sad or distressing life events, (b) be evaluative (this is the therapeutic element), whereby participants can discuss how they feel about their life events with a trained practitioner, and (c) be structured and chronological so that the entire lifespan is covered and there is 'wholeness'. They define simple reminiscence as a 'random recall of past events' (p. 289). When we revisit McKeown and colleagues' (2006) definition of LSW presented in Chapter 1, they write that LSW 'is usually undertaken to elicit an account of some aspect of a person's life or personal history' (p. 238) which implies some sort of narrative. Even the term 'Life Story Work' implies a story of one's life. This infers that LSW is closer to life review, than it is to simple reminiscence (i.e. presence of criterion c), even more so when carried out on a one-to-one basis (i.e. presence of criterion a and c).

Digital LSW on the other hand, appears to veer closer to simple reminiscence. The digital LSW interventions detailed in this thesis place more emphasis on collecting an assortment of memories or 'snapshots' from a person's life, rather than placing them along a trajectory, or looking at the entirety of life events. For example, in Chapter 3, participants with dementia enjoyed recalling memories and discussing the past, but their digital life storybooks did not necessarily cover the story of their lives. One participant's digital life storybook consisted solely of music by Elvis Presley. In Chapter 4, most participants did

not seem to work through phases of their lives, and mostly focused on chapters relating to leisure and family instead (see Fig. 4.2). Using apps to gather and view memories from one's life story appears less structured than conventional LSW, particularly where they are used without any guidance or involvement of a facilitator. This raises the questions of whether digital LSW is in fact LSW at all, or if it should perhaps be viewed in a different light, as a way of highlighting important, but unconnected, experiences or events from a person's life. A conventional life storybook imposes a kind of sequence that is usually not present in digital apps. Of course, books don't have to be read or viewed from start to finish, but digital formats encourage 'dipping' in and out of different parts more than conventional ones. For example, in Chapters 3 and 4, participants could view a full list of chapters and pages, and jump between them with one click (or tap!). In Chapter 4, no significant improvements or correlations relating to quality of life were associated with using a digital LSW app. As multimedia stimuli may have the capacity to make life storybooks more powerful (Subramaniam and Woods, 2010), perhaps digital LSW could be better implemented in a more structured way to create a cohesive life narrative with benefits that could stretch beyond enjoyment.

Contribution to theory

In Chapter 1, Continuity Theory and Kitwood's Theory of Person-centred care were discussed in relation to reminiscence and life story work for people with dementia (p. 15-16). Continuity theory suggests that life-stories are essential tools to help individuals adapt to change and maintain a sense of identity. In the above section (*Theoretical Considerations*, p.167), theoretical considerations of reminiscence and digital LSW are discussed. If maintaining identity and adapting to change are the main goals of a LSW intervention, perhaps this is best served using a more chronological approach, closer to Life Review than simple reminiscence, that helps to preserve a timeline. Results of the review in Chapter 2 suggest that cognitive performance is most consistently improved on cognitive tests such as the MMSE rather than those focused on autobiographical memory. However, it was not possible to delineate between different types of interventions in the analyses (e.g. life review versus simple reminiscence). In Chapter 3, the digital LSW intervention evoked memories for participants with dementia and helped them to reconnect with their past. One family caregiver in Chapter 3 spoke of how her relative with dementia was remembering more as the sessions continued. However, as identity was not

directly measured in this work, it is difficult to understand fully how the results contribute to this particular theory.

Kitwood's Theory of Person-Centred Care is the theoretical underpinning of this thesis, but the results also support Kitwood's suggestion that life stories are the key to person-centred care. When Brooker's (2004, p. 216) interpretation of Kitwood's Theory is considered (i.e. valuing people with dementia and those who care for them (V), treating people as individuals (I), looking at the world from the perspective of the person with dementia (P), and providing a positive social environment in which the person can experience relative well-being (S)), results point to the presence of life storybooks in care homes in Chapter 3 contributing to all four elements. The person with dementia was valued as they were able to tell their story, and were given time to have meaningful discussion and conversation based around this (V). The focus on the person's personal life history and understanding more about that person contributes to them being treated and viewed as an individual with their own set of experiences (I). Knowledge of the person's life story helped care staff to look beyond the disease and see the person. By focusing on their life story, the perspective of the person with dementia was accounted for, and care staff were able to gain insight into how to best communicate with and understand that person (P). In addition, the presence of the life storybooks in the care home contributed to creating a positive social environment as they provided a meaningful activity for the residents, a tool for conversation, and a way to promote understanding amongst staff (S).

It has been suggested that the relationship between the person with dementia and those who care for them is vital to achieve successful person-centred care, and that 'relationship-centred care' might in fact be a more appropriate term (McCormack, 2004; Nolan, Davies, Brown, Keady, & Nolan, 2004). The term 'relationship centred care' was originally proposed by an American Task Force who suggested that the interactions between people are the foundation to any therapeutic or healing interventions or activities (Tresolini et al., 1994). Reminiscence and LSW may potentially be key contributors to relationship-centred care as they are social activities that foster meaningful communication and interaction between the person with dementia, caregiver, and facilitator or health professional. The results of Chapter 3 support this idea. Care staff felt that they were better equipped to communicate with residents as a result of the

intervention, and also used the life storybooks to help calm residents if they became distressed.

Relationship-centred care has similar themes to the 'Triangle of Care for Dementia' (Hannan, Thompson, Worthington, & Rooney, 2016). According to the Triangle of Care, meaningful involvement, open communication, and inclusion of caregivers of people with dementia in care settings can lead to better care for that person. Previous research has found that involving family caregivers is beneficial for care, and very important for people with dementia, family caregivers, and professionals (Royal College of Nursing, 2011). In Chapter 3, the digital life storybooks fostered communication and collaboration between residents with dementia, care staff, and relatives. Care staff used the life storybooks to have meaningful communication and conversation with resients, in addition to using it to share photographs and videos of moments in the care home with relatives that they would have otherwise missed. Channels of communication were also opened up through care staff asking questions to inform the life storybooks. They valued the opportunity to do this, and felt better able to communicate with relatives, and made their work more appreciated. In community settings, some family caregivers commented on how they were learning more about their relative, and how enjoyable the sessions were for them as well as the person with dementia. Participants with dementia (mostly) enjoyed discussing their life history with others and were evidently proud of their accomplishments.

Nolan and colleagues (2004; 2006) built upon the work of Tresolini et al (1994(developed the Senses Framework which is based on the subjective perceptions of care experiences for both care providers and care recipients. According to Nolan, Davies, and Brown (2006, p. 9-10),

> *"...the Senses Framework captures the important dimensions of interdependent relationships necessary to create and sustain an enriched environment of care in which the needs of all participants are acknowledged and addressed"*

The basis for this framework is that caregivers and care recipients should feel a sense of security, belonging, continuity, purpose, achievement, and significance. Results of the current thesis point to reminiscence and life story work being useful methods to contribute to, and foster, relationship-centred care. Now, the extent to which the interventions contribute to each of the 'senses' are considered.

Security: Reminiscence and LSW can foster a sense of security as the person can discuss their life stories and experiences their personal perspective where there are no right or wrong answers. In Chapter 3, participants with dementia enjoyed creating their life story and felt it was a predominantly positive experience. On the other hand, one participant felt frustrated at not being able to remember names and places, but enjoyed and looked forward to the sessions. Although there was some initial apprehension, family and staff caregivers felt that the intervention was good for their relative with dementia, and enjoyed it themselves. In addition, participants in the individual modality felt comfortable with the facilitator and felt that she made the sessions 'light' and 'fun'. However, the ICT aspect introduces new challenges as it involves a new dimension of understanding and learning whereby there is certainly potential to get things wrong. In Chapter 5, participants with weaker ICT skills indicated that they would prefer a facilitator to create their digital life storybook for them (avoid failure), while dictating the content (experience success). In Chapter 6, some reviewers with dementia felt they wouldn't be comfortable using apps along as they were concerned about their lack of ICT experience. This is perhaps exacerbated when coupled with challenges they faced as a result of their dementia.

Continuity: As discussed earlier, continuity is facilitated by LSW, potentially enhancing autobiographical memory and maintaining a time-line through the lifespan, especially when conducted chronologically, as in life review work. However, results of Chapter 2 suggest that is still unclear whether this contributes to significant improvements in autobiographical memory. Cognitive change is most evident on other cognitive tests such as the MMSE which focuses more on recall.

Belonging: Group reminiscence can foster a sense of belonging through group membership, sharing, and communication. Family caregivers in the reminiscence groups in Chapter 3 felt that the social aspect of the groups was the most important aspect of the intervention, for both themselves and the person with dementia as they could enjoy their time together and meet others in similar situations. In Chapter 2, group reminiscence was associated with significantly improved communication for people with dementia which may indicate growing confidence and ease with other group members as they become more familiar with each other. Even though the Citizen Science approach in Chapter 4 was centred around individual LSW, it had the potential to foster a sense of belonging for both the person with dementia and their caregiver through creating a community of users.

Although the intervention fell short of this, there is certainly scope for Citizen Science approaches to foster a sense of belonging when implemented at a high level.

Purpose: As LSW focused on a person's life, it can considered a meaningful activity with the person at the heart of it (McKeown et al., 2010). The purpose of life story work is to create a tangible outcome in the form of a digital life storybook. Care staff and family caregivers in Chapter 3 felt that developing the digital life storybooks was a positive thing to do. Participants with dementia were pleased about creating them (with the exception of one person who dropped out) and some were excited about sharing the finished product with others. Some caregivers mentioned how creating the life storybook was something that they and their relative with dementia would sit down to do together. Ms K spoke of how her and her partner were a 'team'; she searched for resources online and 'built' the life storybook, while Mr K gave her the information. They both looked forward to the visits from the Book of You facilitator each week. Interestingly, in Chapter 4, this 'purpose' of creating a digital life storybook that could have lasting benefits was not great enough to motivate most participants to continue to use the app and create their life story record, though perhaps this was due to the unsupported digital nature of the intervention creating a barrier.

Achievement: In creating a digital life storybook, and having meaningful communication and conversation as a result, a sense of achievement was present for participants in Chapter 3. Participants with dementia felt proud to share their life story and their achievements with others, even if they could not necessarily use the app independently. Some also looked forward to sharing it with others. Both family caregivers and care staff felt that they were participating in a meaningful activity for the person that they could continue to benefit from, even after the sessions were complete. There was an additional sense of achievement for family and care staff as they felt that they were learning a new skill (ICT) and felt proud of themselves for doing so. In Chapter 5, both family caregivers and participants with dementia showed clear preferences for a digital LSW intervention to take place in an individual setting rather than a group setting. Tying into a sense of security above, perhaps this is due to participants valuing ICT support, in order to avoid a situation whereby they couldn't 'work' the digital life storybook. Similarly, participants with dementia who had strong ICT skills preferred to learn how to create their own digital

life storybook, while those with weaker skills wanted to control the content but have the facilitator actually create it.

Significance: In reminiscence and digital life story work, a person's experiences and perspective is validated through the creation and use of a life storybook, in addition to the discussions during the creation and during the use. In Chapter 3, some participants with dementia had sad moments but felt that the overall experience was positive and enjoyable. Family caregivers in the group intervention valued socialising with people in similar to situations to themselves. However, in Chapter 4, caregivers had mixed responses to the idea of life story work. Some felt that it would be 'pointless' or emotionally challenging to think about what their relative was like before their diagnosis, while others felt very positive about it.

Implementation and practice considerations of digital life story work

According to Russian playwright Anton Chekhov**,** 'knowledge is of no value unless you put it into practice'. Research is valuable when findings can be translated into practice to benefit people with dementia and their caregivers. For the most part, the results of this thesis provide further support for the use of reminiscence and digital LSW in both community and care home settings, while highlighting implementation and practice considerations.

Care home settings

Findings from Chapter 2 suggest that reminiscence has a more significant effect on quality of life, mood, and cognition in care home settings than in community settings. This was also identified in a review by Huang and colleagues (2015) in relation to mood (but not cognition). Continuity theory (discussed in Chapter 1) suggests that reminiscence and LSW can be particularly helpful for older people who are going through changing situations (Atchley 1989/1999; Whitbourne, 1985; as cited in Parker, 1995). Perhaps, care home environments are more receptive to positive effects of reminiscence because the person has moved from their home, relinquished many of their possessions and transitioned to a care home and communal living, making the maintenance of identity a particular issue.

Improved person-centred care in residential settings is often associated with LSW. It has been found to contribute positively to person-centred care through enhancing the

knowledge and understanding of staff members about residents' individuality and life stories (Eritz et al., 2016; McKeown et al., 2006; McKeown et al., 2010). Following a systematic review of the literature on LSW, McKeown and colleagues (2006) concluded that care staff considered life stories as a means of getting to know and understand the person with dementia, which in turn led to improved care practices. The results of Chapter 3 point to improved and more personal communication between care staff and residents, as they were able to use the digital life storybook as a conversation aid and learn more about the residents. Unfortunately however, the experiences of residents were now sought directly. In a RCT of 73 people with dementia and 99 care staff, Eritz and colleagues (2016) compared the effects of supplying staff with residents' life histories or medical histories. Staff who received the life histories had a significantly better perception of residents' personhood, and had improved conversations with residents compared to the control group. Benefits reportedly reached the residents too, as they had significantly better scores on quality of life measures compared to those in the control group. However, an earlier study involving 348 care home residents across ten Danish nursing homes found that a reminiscence intervention improved the way staff viewed the residents, but there was little long-term effect of the intervention on the residents themselves (Gudex et al., 2010). Care staff also experienced benefits including improved feelings of personal accomplishment, less emotional exhaustion, less depersonalisation, improved mental health and improved emotional exhaustion. For residents, no significant differences between reminiscence and control groups were identified except for a quality of life subscale 'response to surroundings'. The authors suggested that one possible reason for this may have been poor implementation of the intervention due to staff having a lack of time, lack of resources, and inadequate support from management to implement it effectively. Staff reported that they would have wanted more discussion about the reminiscence activities at meetings, more involvement from management in the reminiscence training, and more recognition for those who actively used it. In Chapter 3, care staff discussed and appreciated the support that they had received from management in relation to the digital LSW intervention. Management provided support at multiple levels by hosting meetings with staff who participated in the initiative, and appointing staff tutors to assist with ICT queries. Following the digital LSW training sessions, management displayed certificates of completion on the wall, and discussed their work with relatives and at conferences. Staff who took part in the digital LSW training were referred to as "Book of You Champions'.

Reminiscence and digital LSW modalities

Haight and Dias (1992) have suggested that for an enjoyable activity and meeting others, group-based reminiscence approaches are preferable while individual approaches are best if the purpose is to be therapeutic. Findings from the review presented in Chapter 2 suggest that group-based reminiscence is associated with improved communication while individual reminiscence was found to be associated with improved mood and aspects of cognition. In Chapter 3, caregivers in the group setting felt that the social aspect of the intervention was the most beneficial part, both for themselves and their relative with dementia. Group-based LSW has merit, but there is less focus on one's individual memories as others contribute to the discussions and conversation. As reminiscence and LSW involve the use of prompts (e.g. photographs, music, etc.), they help to provide structure and focus in conversation for people with dementia, in addition to evoking memories (Milton, 2017). Furthermore, the focus on long-term memories means it can be a particularly helpful conversation aid as these are more accessible for people with dementia, enabling them to contribute in both group and individual contexts. In reminiscence groups, people can find common ground, share memories and interests, and compare experiences. Reminiscence can be particularly helpful conversation aid, as the focus of reminiscence and LSW is typically on longer-term memories, which are more accessible for people living with dementia (Alm et al., 2004).

Results suggest that for the purposes of LSW, a supported individual setting appears to be the most effective for actually reminiscing and creating a digital life storybook, while a group setting lends itself more to socialising and meeting new people. In Chapter 3, the individual intervention setting was most conducive to creating a life storybook. Furthermore, in Chapter 5 it emerged that caregivers and people with dementia (for the most part) showed preferences for LSW to be delivered in an individual setting rather than a group setting. Creating a life storybook can be a time-consuming process, and the digital aspect adds a new dimension of understanding and learning which may be better supported in an individual setting with a facilitator. When participants were presented with a self-guided digital life storybook app, engagement was very low suggesting that the presence of a facilitator to support the intervention might be important (Chapter 4).

Sad or distressing memories

As the essence of reminiscence and LSW involves recalling and reflecting on life events, it will not be appropriate for some, as this may be a sad or distressing experience. In particular, the nature of individual reminiscence means it is likely to have more intensity, as there is more focus on the person and their life story, especially if the intervention is intended to be evaluative. Even in the less structured digital LSW intervention presented in Chapter 3, two out of three participants in the individual context had sad or distressing moments. On the other hand, in individual reminiscence, specific topics can be avoided, which may not be possible in group work as others contribute to the discussion. In Chapter 4, some caregivers felt that they couldn't face LSW, as it was too painful for them. Trained and experienced facilitators and care staff are not only helpful to guide the intervention, but also to support the person should any distressing memories arise. Therefore, simple reminiscence may be a more suitable approach in approaches in which a person uses a LSW app alone, as a facilitator or caregiver may not be present to support them should a distressing memory arise.

ICT-related considerations

The work presented in this thesis provides some insight into how ICT impacts LSW for people living with dementia and their caregivers. ICT has been a double-edged sword throughout the chapters of this thesis. For example, in Chapter 3, participants could not operate the digital life storybooks independently, which likely would not have been an issue had they been using a conventional life storybook. On the other hand, Mr K in that same chapter did not have photographs or items from his past, but the facilitator and his caregiver were able to source photographs of his schoolteachers, local area, and videos of his favourite football teams online. In Chapters 4 and 6, some participants with dementia and caregivers could use the digital life storybooks independently, while for others it was a significant barrier. Perhaps life story movies may be a better option for those who struggle to interact with tablet computers as no ICT skills are required to use them, with the exception of turning them on. Subramaniam and Woods (2016) found that chronological life story movies (adapted from life storybooks) were associated with significantly improved scores on measures of memory for personal events, but not the type of memory that is closest to storytelling. They suggested that this part of autobiographical memory may be aided best with the process of storytelling and that a life story movie does not facilitate this, but instead enhances memory for factual information. Therefore, for some

people with dementia, a conventional life storybook may be a more suitable option, even though there is an opportunity cost of having less access to multimedia resources.

An interesting consideration is the use of pre-existing, freely available LSW apps in practice and research with people with dementia, even if they have not been explicitly designed with this population in mind. In Chapter 3, the digital life storybook was developed for people who use the LSW service, or pay to access it. The Dementia Citizens Book Of You (DCBY) app in Chapter 4 was designed and developed specifically for the research study, which was very costly and time-consuming. It was available for three months and is now obsolete. Using pre-existing apps that are available to the general consumer is slowly becoming more customary in dementia research (e.g. Critten & Kurcikova; Grøndahl et al., 2017), and has been common in other areas of dementia research such as touchscreen games (Astell et al., 2016). In Chapter 6, some good quality, accessible, and freely available LSW apps were identified on various app repositories. Reviewers with dementia and caregiver reviewers had favourable impressions of these apps. Some of the apps had similar capabilities as those discussed in Chapter 3 and 4, but represent a more cost-effective and efficient way to carry out digital LSW in future research and practice. Now, there is guidance on how apps can become more 'dementia friendly' through the AcTo Dementia Project (Joddrell et al., 2016) and will hopefully improve the quality of freely available LSW apps for people with dementia and their caregivers.

Nowadays, each new generation has more experience with ICT than the previous, and the number of people with dementia and caregivers who have limited ICT skills and experience will decline in the coming years. ICT is becoming more and more pervasive in everyday life and can replace real-life social interaction and communication. Alm and colleagues (2004) previously characterised a digital reminiscence programme as a cognitive 'prosthesis' for people with dementia. Perhaps it is best considered in this way, as an 'aid' to communication and conversation with others, rather than an intervention in itself so that ICT will not overtake social interactions and stimulating 'real-life' contact with others.

Strengths, Limitations, and personal experiences

An overall strength of this thesis is the inclusion of first-hand perspectives of people with dementia and caregivers in each of the study chapters. The direct experiences of participants with dementia and caregivers were sought in Chapter 3 through in-person semi-structured interviews, while participants in Chapter 4 responded directly to questionnaires and could voice their opinions in follow-up phone interviews. In Chapter 5, an online survey and DCE were used to get a sense of the preferences of people with dementia and caregivers in relation to LSW. People with dementia and caregivers acted as 'reviewers' in Chapter 6 so that their personal opinions of the apps could be included. The voice of the person with dementia has been a significant consideration throughout this thesis, though it would have been preferable to have had a higher number of participants with dementia in each of the study chapters, and more depth in the interviews in Chapters 3 and 4.

Each study had individual limitations, but the sample size, particularly of people with dementia, is an enduring limitation throughout this thesis. Furthermore, only people with mild-moderate dementia who had the capacity to consent to participate in research were included in this thesis. In Chapter 3, 16 participants took part, but the study would have benefitted from a higher number as the interview environment, time constraints, and the presence of caregivers reduced the depth of the interviews. Although 101 participants consented to take part in Chapter 4, engagement declined rapidly with just 3% completing the requested 24 sessions. Therefore the quantitative analyses were limited, and some could not be carried out as intended. Furthermore, only 19 participants took part in the follow-up phone interviews, of which just 4 were people with dementia. Considering that the intervention was not particularly successful, it would have been helpful to learn more from both participants groups about their personal experiences with it. In Chapter 5, 17 participants with dementia filled out the online survey, far less than the 67 caregivers who completed the DCE. Although the number of caregiver participants exceeded the required minimum, distribution across groups meant that subgroup analyses were not possible. A convenience sample was used in each of the above chapters, meaning that results are likely not representative of the broader population of people living with mild to moderate dementia.

A particular strength of Chapter 2 is that it is an abridged version of a Cochrane Collaboration Review. Cochrane Reviews represent the 'gold standard' for high quality, trusted information and hold all reviews to a high standard. The review methodology is therefore very rigorous which translates to the abridged version presented in Chapter 2. However, the strict inclusion and exclusion criteria stipulated by the Cochrane Collaboration means that some work of potential interest was excluded, for example, studies that may not have strictly been RCTs or may have had unclear randomisation methods.

In Chapter 3, the data from each participant group was analysed separately, meaning that experiences of each group in each implementation could be explored. Recruitment was constrained to people who were interacting with the LSW service, limiting the potential pool of participants. This also meant that the data collection process was particularly long, as it had to coincide with LSW workshops. However, the managers of the LSW service and the volunteer facilitators were very accommodating throughout the study, and keen to improve their service. Interviewing in the care homes was challenging at times, as residents or other staff members would often interrupt and disrupt the flow of the interview. In hindsight, the topic guide was limited, and the study would have benefitted from it being more developed. Although the sample size of the study is small, it is one of the larger multi-perspective qualitative studies of digital LSW to date.

Chapter 4 was particularly challenging. The initiative and research study were procured by the UK government and involved a range of stakeholders. The app design and parameters were predominantly influenced by other groups, who had slightly different aims concerning the end product. Initially, this piece of research was projected to take place in the first year of this PhD, but there were several external delays that were out my control, and the government backing became less than initially anticipated. The app development process was far more time-consuming than expected, despite me having limited input into the design. In the beginning, the intended design of the project included a website that would serve as an online community in which participants could respond to questionnaires or communicate with others, in addition to two simple apps. It was envisaged that participants would use the apps as the 'intervention', and the website would be the research and Citizen Science element. Later in the process, this was changed to the design that is presented in Chapter 4, whereby the entire study takes place within

one app. A particular disadvantage of this is that there is no tangible output of this costly initiative as the app is now obsolete and the website has no purpose. The approach lacked the community aspect that was originally envisaged, which would have better represented a Citizen Science approach.

Chapter 5 was not originally planned, but as the Dementia Citizens initiative (Chapter 4) did not generate particularly rich data, I became concerned that this thesis would lack enough of a quantitative element. Following varied engagement with digital LSW in Chapter 3, I became interested in exploring what people with dementia and caregivers preferences are in relation to digital LSW services and interventions. It was fortunate that I could partly model the DCE and survey on the qualitative work in Chapter 3, meaning that I had sufficient time to carry out the study. However, it was necessary to collect data online which likely contributed to the difficulty in recruiting participants with dementia. Given the cognitive load of DCEs, it was not feasible to create one for people with dementia, meaning the results of the two surveys are not directly comparable. The study would have benefitted from a more extended planning period, in which the survey for participants with dementia could have been developed further.

The key strength of Chapter 6 was that people with dementia and caregivers reviewed the included apps and shared their personal perspectives on them. I was fortunate to have the support of AcTo Dementia, who kindly supplied me with their App Evaluation Tool (AET) which is not yet officially in circulation. One of the developers ran tests of inter-rater reliability which improved the reliability of the AET ratings. However three apps were not evaluated by a second person, which is a limitation. The most challenging part of this study was the search for the apps, as the search functions on the various app repositories are not intended for these purposes, and not particularly advanced. A general limitation of this review is that new apps are launched every day meaning that the list of included apps may no longer be comprehensive.

Recommendations for policy and future research

Regarding policy, further support should be given to initiatives that explore the potential of Citizen Science approaches with people with dementia through touchscreen apps. Although participants did not engage with the Citizen Science intervention in the current thesis, the high level of initial interest and the general movement towards participatory

research (Scottish Dementia Working Group Research Sub-Group 2015; Bryden, 2016) suggests promise for this approach. The literature on Citizen Science points to the importance of high-level involvement of 'citizens' and the presence of motivators such as validation, feedback, monetary incentive, and a sense of community (Jennett et al., 2014b; Socientize Consortium, 2013). The intervention in the current thesis was a relatively low level of Citizen Science, lacked motivators, and did not involve people with dementia and caregivers to a large enough extent in the design and development phases. Perhaps research into higher level Citizen Science for people with dementia coupled with an intervention that is more readily stimulating such as a game or cognitive exercise app may gain more traction.

The most recent draft of the National Institute for Health and Care Excellence guidelines (NICE, 2018) suggests that group-based reminiscence combined with other interventions such as cognitive stimulation should be offered to people with mild to moderate dementia. Although results from this thesis suggest that group reminiscence is enjoyable and may have communicative benefits not seen in individual reminiscence, they also indicate that individual reminiscence is just as, if not more valuable, and generally preferred by people with dementia and their caregivers (Chapter 2, Chapter 3, Chapter 5). However, recalling memories or reflecting on one's life is not an appropriate or helpful intervention for everyone, in fact, some may find it distressing. Group reminiscence may have less 'intensity' than individual reminiscence due to the nature of group chat rather than one-to-one work, which may suit some participants better. Therefore both individual and group reminiscence should be offered as an intervention to people with dementia, but as one of a range of interventions.

Future research should look to exploring more structured digital LSW for people with dementia that focuses on memories across the life trajectory, to understand if this is more beneficial than the simple LSW interventions implemented in this thesis. In fact, a recently published protocol outlines a planned RCT of a structured individual LSW intervention, involving digital life storybooks for community-dwelling people with dementia and their caregivers, which should provide a helpful contribution to the literature (Elfrink, Zuidema, Kunz & Westerhof, 2017). Outcomes of interest include the reduction of neuropsychiatric symptoms, quality of life, and health of both the person with dementia and their caregiver. It is unclear as to whether the digital life storybook tool will

be one that is pre-existing, or will be purpose-built for the intervention. The use of existing touchscreen apps for digital LSW would be a helpful avenue to explore, particularly if partnerships with app developers can be established so that apps can be continually modified and improved according to user recommendations. Furthermore, it would be interesting to compare the effects of conventional structured LSW with digital structured LSW, as multimedia may have the potential to make the experience more powerful. Finally, the experience of people with dementia <u>during</u> reminiscence or LSW sessions should be considered, rather than relying solely on post-session measures. Brooker and Duce (2000) previously used an observational method called Dementia Care Mapping for these purposes, which perhaps could be built upon.

Reminiscence and digital LSW in other long-term neurological conditions
Although reminiscence has often been used with older people, LSW has been applied extensively to other groups (Woods & Subramaniam, 2017). These groups include people with intellectual disabilities (Hussain and Raczka, 1997; Middleton and Hewitt 1999), depression (Hallford & Mellor, 2013), physical illnesses such as cancer (Leung, 2010), and children and young people (particularly those who are looked after or in care; Willis & Holland, 2009). There is a good deal of research on the use of LSW with people with intellectual disabilities suggesting that it can contribute to beneficial outcomes such as improvements in interest, pleasure, and connection to the community (Van Puyenbroeck & Maes, 2008). LSW is viewed as being particularly useful at times of change and transition, which is a significant and sometimes frequent factor in the lives of people in these groups.

A more recent development is the application of life story work with people with long term neurological conditions such as those arising from stroke (e.g. aphasia), or an acquired brain injury (e.g. memory loss). In some ways, these groups are analogous to people with dementia, as there is a disconnect between previous and current capabilities. Similar to people with dementia, these new challenges can often impair a person's sense of self and self-efficacy. In this thesis, it was found that digital LSW and reminiscence were considered enjoyable and meaningful activities that promoted communication and interaction in different settings and modalities, with varying levels of facilitator support. Therefore, perhaps there is potential for these approaches to be used with people with other long-term neurological conditions such as those mentioned above. Research into the use of reminiscence and LSW with these groups is limited, but biographical work has been

associated with improved wellbeing and identity renegotiation for people who have aphasia (Corsten, Schimpf, Konradi, Keilmann, & Hardering, 2015) and acquired brain injury (Fish & Richeson, 2005; Jenkins & Stranaghan, 2010). For people with stroke-induced aphasia, reminiscence and digital LSW may serve as a 'prosthetic' to augment the storytelling process (past or present), while those with memory loss can benefit from the use of prompts and the focus on memories which may be more deeply engrained, providing possibilities for 'successful' recall to improve self-efficacy.

Conclusion

In conclusion, this thesis has reported on some of the most recent empirical evidence of reminiscence therapy, and explored various approaches to digital LSW for people with dementia and their caregivers. There is promising evidence to support the use of facilitated reminiscence and digital LSW in both community and care home settings. Digital LSW has a greater emphasis on different 'snapshots' of a person's life compared to conventional LSW, which emphasises the wholeness of the life story. Results contribute to learning and understanding around how ICT and different ICT systems influence the experience of LSW for people with dementia and their caregivers, in both positive and negative ways. Results add to the weight of recommendations for group reminiscence and LSW to be used widely in dementia care, and provide evidence that individual approaches should be valued equally, if not more. Results are generally consistent with existing research. Reminiscence and digital LSW were found to be enjoyable and meaningful for people with dementia and their caregivers, both professional and family.

Dissemination of findings

The author aims to publish all of the chapters in peer-reviewed academic journals. The research presented in Chapters 2, 3, 4, and 5 have been submitted for consideration for publication in *The International Journal of Reminiscence and Life Review, Ageing Research Reviews, The International Journal of Computing in Healthcare*, and *Alzheimer's and Dementia* respectively. The work presented in Chapter 6 will be submitted to *Dementia* as an innovative practice paper. Findings from Chapters 3, 4, and 6 have been presented at national and international conferences, in addition to smaller local events.

The following presentations at national and international conferences based on this thesis have been made to date:

September 2017, IGS 65th Annual & Scientific Conference, Wexford, Ireland.
Oral presentation: Implementing Digital Life Story Work for People with Dementia, the Relevance of Context to User Experience.

May 2017, Sonas 9th International Dementia Conference, Dublin, Ireland.
Poster presentation: Life Story Apps for People Living with Dementia: A Review.
Oral presentation: A novel digital life story work application for people with dementia and their caregivers.

October 2016, Centre for Ageing and Dementia Research Conference: Raising Awareness - Raising Standards, City Hall, Cardiff, UK.
Poster presentation: A Digital Life Story Work App for People with Dementia and their Caregivers.

November 2016, 26th Alzheimer Europe Conference, Copenhagen, Denmark.
Oral presentation: A Digital Life Story Work App for People with Dementia and their Caregivers.

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Appendix

Appendix A: Ethical approval letters

Approval letter following application to do the work carried out in Chapter 2.

COLEG IECHYD A GWYDDORAU YMDDYGIADOL
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL GWYDDORAU GOFAL IECHYD
SCHOOL OF HEALTHCARE SCIENCES

PRIFYSGOL
BANGOR
UNIVERSITY

Healthcare and Medical Sciences Academic Ethics Committee

Our ref: SW/SM

29 January 2015

Laura O'Philbin
25 Friars Road
Bangor
Gwynedd

Dear Laura

Re: Proposal 2014-12-04 An evaluation of the effects of using an ICT based reminiscence app for people who have dementia and their caregivers.

Thank you for your application to the AEC which was subject to an expedited review as requested. All of the necessary documentation was provided and appropriately completed.

I am therefore able to give approval for your study on behalf of the AEC, and this letter constitutes evidence of that approval should it be necessary for any applications to other RECs. Attached are recommended areas for attention as part of preparation for external approval.

Please note that approval from this AEC does not convey automatic authority to proceed with your study. You are formally advised that it is essential to confirm with the relevant authorities whether you are required to submit your proposal to any other Ethics Committee(s), such as Local NHS Research Ethics Committee, and NHS Research Governance Departments, prior to commencing your study.

Should you need to make any substantial amendments to your study protocol during the lifetime of the research, you are required to submit notice of these to the AEC for further approval, including major amendments requested by an external REC or R&D Commit

If you have any queries, please do not hesitate to contact me for clarification.

Yours sincerely

Dr Sion Williams
Chair, HCMS AEC

c.c. Bob Woods, Supervisor

PRIFYSGOL BANGOR   BANGOR UNIVERSITY
FRON HEULOG   FRON HEULOG
FFORDD FFRIDDOEDD   FRIDDOEDD ROAD
BANGOR, GWYNEDD   BANGOR, GWYNEDD
LL57 2EF, UK   LL57 2EF, UK

FFÔN: 01248 383150   TEL: 01248 383150
FFACS: 01248 383175   FAX: 01248 383175

WWW.BANGOR.AC.UK

Healthcare and Medical Sciences Academic Ethics Committee

- The debrief form could also include contact details for support should psychological distress occur as a result of the research for both participants and relatives and could be addressed more fully in Part 2 Q12.

- The proposal does not comment on the availability of Welsh language materials (forms, PIS, consent forms, study instruments). As the proposed study is to be conducted in the Conwy area, please clarify if potential participants and their relatives are offered language choice if they choose to participate in the study.

PRIFYSGOL BANGOR   BANGOR UNIVERSITY
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Registered charity number 1141565

HCMS AEC approval letter V2 July 2013

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Approval letter following application for substantial amendment to include qualitative interviewing in people's homes (Chapter 3), and the work detailed in Chapter 4.

COLEG IECHYD A GWYDDORAU YMDDYGIADOL
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL GWYDDORAU GOFAL IECHYD
SCHOOL OF HEALTHCARE SCIENCES

Healthcare and Medical Sciences Academic Ethics Committee

PRIFYSGOL
BANGOR
UNIVERSITY

Our ref: SW/SM

10th February 2016

Laura O'Philbin
25 Friars Road
Bangor
Gwynedd

Dear Laura

Re: Proposal 2014-12-04 An evaluation of the effects of using an ICT based reminiscence app for people who have dementia and their caregivers.

Thank you for your application for approval for a substantial amendment to the above study.

I am happy to grant approval for this substantial amendment on behalf of the AEC, and this letter constitutes evidence of that approval should it be necessary for any applications to other RECs.

Please note that approval from this AEC does not convey automatic authority to proceed with your study. You are formally advised that it is essential to confirm with the relevant authorities whether you are required to submit your proposal to any other Ethics Committee(s), such as Local NHS Research Ethics Committee, and NHS Research Governance Departments, prior to commencing your study.

Should you need to make any further substantial amendments to your study protocol during the lifetime of the research, you are required to submit notice of these to the AEC for further approval, including major amendments requested by an external REC or R&D Commit

If you have any queries, please do not hesitate to contact me for clarification.

Yours sincerely

Dr Sion Williams
Chair, HCMS AEC

HCMS AEC approval letter V2 July 2013

Approval letter following application for substantial amendment to include follow-up interviews with participants in Chapter 4, and the work detailed in Chapters 5 and 6.

COLEG IECHYD A GWYDDORAU YMDDYGIADOL
COLLEGE OF HEALTH AND BEHAVIOURAL SCIENCES

YSGOL GWYDDORAU GOFAL IECHYD
SCHOOL OF HEALTHCARE SCIENCES

Healthcare and Medical Sciences Academic Ethics

PRIFYSGOL
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UNIVERSITY

Our ref: SW/SM

1 February 2017

Laura O'Philbin
25 Friars Road
Bangor
Gwynedd

Dear Laura

Re: Healthcare and Medical Sciences Academic Ethics Committee (HCMS AEC) Review:
Proposal number: 2014-12-04
Project title An Evaluatino of the Effects of using an ICT Based

Thank you for your application to the AEC which was subject to an expedited review as requested. All of the necessary documentation was provided and appropriately completed.

I am therefore able to give approval for your study on behalf of the AEC and this letter constitutes evidence of that approval should it be necessary for any applications to other RECs.

Should you need to make any substantial amendments to your study protocol during the lifetime of the research, you are required to submit notice of these to the AEC for further approval, prior to making any changes to the conduct of the study.

Please note that approval from this AEC does not convey automatic authority to proceed with your study. You are formally advised that it is essential to confirm with the relevant administrators whether you are required to submit your proposal to any other Ethics Committee(s) such as Local NHS Research Ethics Committee and NHS Research Governance Departments — <u>prior</u> to commencing your study.

You are required to notify this AEC of any amendments to your proposal that you are required to make by any external body.

Once you have received approval from an external REC, you must provide a copy of your letter of approval for this AEC.

If you have any queries, please do not hesitate to contact myself or Dr Joyce Wilkinson, Vice Chair, for clarification.

I wish you well with your research.

Yours sincerely

Dr Sion Williams
Chair HCMS AEC

Appendix B. Acronyms for included measures in Chapter 2

ADAS-Cog: Alzheimer's Disease Assessment Scale for Cognition;

AES-C: Apathy Evaluation Scale - Clinician;

AMI: Autobiographical Memory Interview;

AMI-E: Autobiographical Memory Interview Extended Version;

AMS: Alzheimer's Mood Scale;

CAPE: Clifton Assessment Procedures for the Elderly;

CASI: Cognitive Abilities Screening Instrument;

CDR-SB: Clinical Dementia Rating - Sum of Boxes;

CES-D: Center for Epidemiological Studies - Depression;

COS: Communication Observation Scale;

CSDD: Cornell Scale for Depression in Dementia;

DEMQOL: a self-reported outcome measure designed to enable the assessment health-related quality of life of people with dementia;

GDS: Geriatric Depression Scale;

GDS-SF: Geriatric Depression Scale - Short Form;

GHQ-12: 12-item General Health Questionnaire;

HADS: Hospital Anxiety and Depression Scale;

MADRS: Montgomery-Åsberg Depression Rating Scale;

MOSES: Multidimensional Observation Scale for Elderly Subjects;

PANAS: Positive and Negative Affect Schedule;

QoL-AD: Quality of Life in Alzheimer's Disease;

SES: Social Engagement Scale;

SR-QoL: Self-Report Quality of Life

WIB: Well-being/Ill-being Scale;

Appendix C. Information Sheets and Consent forms pertaining to Chapter 3

PARTICIPANT INFORMATION SHEET

What are the benefits of Digital Life Story Books?

You are being invited to take part in a research study.
Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
In recent years, many people with memory problems have enjoyed the opportunity to narrate, compose and produce their own life story book. With new technology, the life story book can be created on a computer, with words, pictures and music. This project aims to explore the experiences of people in creating and using this digital life story book.

What happens in a digital life story book?
In preparing a digital life story book, you can talk about past memories with their relative and/or supporter. This can include looking at photographs, watching videoclips, listening to music or simply just talking. It is entirely up to you what they want to talk about. You can choose which memories, photos or videos to include in your life storybook. You will be able to look at it with relatives and friends. The idea is to encourage conversation about memories in a pleasurable, sociable way.

Why have I been chosen?
You have been invited to take part because you are interacting with Book of You and you have reported difficulties with memory.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason.

What will happen to me if I take part?
If you decide to take part, you will participate in the Book of You life story work sessions as intended. We will ask you to have an informal discussion with us about your thoughts and experiences of the life story work sessions three times. This discussion will be audio recorded. If there is anything that you do not want to do or answer, you do not have to.

All participants will be asked to

1) Meet with a researcher for about 10 minutes for an informal introduction interview. The time stated to complete the interviews and questionnaires is an estimate; you may take as many breaks as you want or feel necessary.

2) Meet with the same researcher for about 30 minutes two weeks later for an informal interview about your experiences with Book of You.

3) Meet with the same researcher four weeks later, to repeat this interview for the final time.

The researcher will be happy to come and meet with you and your relative in a convenient place for you.

What do I have to do?
Taking part in the study does not involve any lifestyle restrictions or changes. You can carry on your everyday activities as normal while participating in the study. All we ask is that you keep your appointments with us during the time that you are taking part.

What are the possible disadvantages and risks of taking part?
None have been identified.

What are the possible benefits of taking part?
If you decide to take part, we hope that this may be of some help to you, and previous research has indeed suggested that using the digital life story book is an enjoyable experience. For all participants, the information we get from this study may help us to better treat people with memory difficulties in the future.

Will my taking part in the study be kept confidential?
Yes. All information collected about you and your relative during the course of the study will be kept strictly confidential. All data will be stored under secure conditions and will be stored separately from identifying details. Only the researchers involved in the study will have access to this data. Your life story book will be password protected so that only you and your relative have access to it.

What will happen if I don't want to carry on with the study?
You will be free to withdraw from the study at any time, without giving a reason. We will need to use in the study any data collected up to the point of withdrawal.

What if something goes wrong?
If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a

solution. Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be fully addressed. Please address your complaint to the Manager of the School of Healthcare Sciences:

Dr Huw Roberts, Fron Heulog, Bangor University, Bangor LL57 2EF
Tel: 01248 383136 E-mail: huw.roberts@bangor.ac.uk

Who is organising and funding the research?
This research is funded as a Knowledge Economy Skills (KESS) Scholarship. This scheme is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys. This funding covers the running costs of the research project which is being led by Laura O' Philbin (PhD student) and supervised by Professor Bob Woods, a clinical psychologist at Bangor University.

What will happen to the results of the research?
The results of the research will be published in journals, presented at conferences and form part of a doctoral thesis. No participants will be identified in any publication arising from the study, without their written consent. We will make arrangements for participants to be informed of the findings of the study where desired.

Who has reviewed the study?
All research in Bangor University is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the Healthcare and Medical Sciences Academic Ethics Committee.

Who can I contact for further information?
For more information about this research, please contact:

Ms Laura O' Philbin   or   Professor Bob Woods
Tel: 01248 383188   Tel: 01248 383719
Email: hsp456@bangor.ac.uk   b.woods@bangor.ac.uk

Dementia Services Development Centre
Bangor University, Ardudwy, Holyhead Road, Bangor LL57 2PX

Thank you for considering taking part in this research study!

What are the benefits of Digital Life Story books?

Invitation to participate in a research study

We invite you as a relative of_____ to take part in a research study. relative has agreed to take part in this research and has signed the consent form.

Before you decide to take part, it is important that you understand why the research is being conducted and what will be required of you should you agree to be involved. Please take time to read the following information and discuss it with others if you wish. Ask us if there is anything that is not clear or if you require further information about the study. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

In recent years, many people with memory problems have enjoyed the opportunity to narrate, compose and produce their own life story book. With new technology, the life story book can be created on a computer, with words, pictures and music. This project aims to explore the experiences of people in creating and using this digital life story book.

What happens in a Life Review/Life Storybook group and other group?

In preparing a digital life story book, participants will talk about past memories with their relative and/or supporter. This can include looking at photographs, watching videoclips, listening to music they like or simply just talking. It is entirely up to the participant on what they want to talk about. The participant will decide what memories, photos or videos will be included in their life story book and they will be able to look at it and go through it with relatives and friends. The idea is to encourage participants to talk about their memories in a pleasurable, sociable way.

Why have I been chosen?

You have been invited to take part because your relative has difficulties with memory and is living with dementia. Also, your relative suggested you to develop life storybook for him/her. We are looking for 6 people who have memory difficulties and their caregivers to take part.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason.

What will happen in this research?

We will ask you to use the 'Book of You' digital story book with your relative for four weeks and then we will have an informal discussion about it. This will be audio recorded. We will ask you

to complete some questionnaires with us about your quality of life, mood and relationships. If there is anything that you do not want to do or to answer, you do not have to.

Following discussion of any questions you may have with a researcher, and signing the consent form, **all participants** will be asked to:

1) Meet with a researcher for between an hour and an hour and a half for an informal interview and to complete with you some questionnaires covering your quality of life and relationship with your relative. The time stated to complete the interviews and questionnaires is an estimate; you may take as many breaks as you want or feel necessary, and even complete the process over two sessions if preferred.

2) Meet with the same researcher two weeks later to repeat this interview and some of the questionnaires.

3) Meet with the same researcher four weeks later, to repeat this interview and these questionnaires with the researcher for the final time.

The researcher will be happy to come and meet with you and your relative in a convenient place for you.

What do I have to do?

Taking part in the study does not involve any lifestyle restrictions or changes. You can carry on your everyday activities as normal while participating in the study. All we ask is that you keep your appointments with us during the time that you are taking part.

What are the possible disadvantages and risks of taking part?

None have been identified.

What are the possible benefits of taking part?

If you decide to take part, we hope that this may be of some help to you, and previous research has indeed suggested that using the digital life story book is an enjoyable experience. For all participants, the information we get from this study may help us to better treat people with memory difficulties in the future.

Will my taking part in the study be kept confidential?

Yes. All information collected about you and your relative during the course of the study will be kept strictly confidential. All data will be stored under secure conditions and will be stored separately from identifying details. Only the researchers involved in the study will have access to this data. Your life storybook will be password protected so that only you and your relative have access to it.

What will happen if I don't want to carry on with the study?

You will be free to withdraw from the study at any time, without giving a reason. We will need to use in the study any data collected up to the point of withdrawal.

What if something goes wrong?

If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be fully addressed. Please address your complaint to the Manager of the School of Healthcare Sciences: *Dr Huw Roberts, Fron Heulog, Bangor University, Bangor LL57 2EF*
Tel: 01248 383136 E-mail: huw.roberts@bangor.ac.uk

Who is organising and funding the research?

This research is funded as a Knowledge Economy Skills (KESS) Scholarship. This scheme is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys. This funding covers the running costs of the research project which is being led by Laura O' Philbin (Masters student) and supervised by Professor Bob Woods, a clinical psychologist at Bangor University.

What will happen to the results of the research?

The results of the research will be published in journals, presented at conferences and form part of a Masters thesis. No participants will be identified in any publication arising from the study, without their written consent. We will make arrangements for participants to be informed of the findings of the study where desired.

Who has reviewed the study?

All research in Bangor University is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the Healthcare and Medical Sciences Academic Ethics Committee.

Who can I contact for further information?

For more information about this research, please contact:

Ms Laura O' Philbin	or	Professor Bob Woods
Tel: 01248 383188		Tel: 01248 383719
Email: hsp456@bangor.ac.uk		b.woods@bangor.ac.uk

Dementia Services Development Centre
Bangor University, Ardudwy, Holyhead Road, Bangor LL57 2PX

Thank you for considering taking part in this research study

What are the benefits of Digital Life Story books?

Invitation to participate in a research study

We invite you as a staff member of a dementia care home to take part in a research investigation as you have completed training sessions with Book Of You. Before you decide to take part, it is important that you understand why the research is being conducted and what will be required of you should you agree to be involved. Please take time to read the following information and discuss it with others if you wish. Ask us if there is anything that is not clear or if you require further information about the study. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

In recent years, many people with memory problems have enjoyed the opportunity to narrate, compose and produce their own life storybook. With new technology, the life storybook can be created on a computer/tablet computer, with words, pictures, video and music. This project aims to evaluate the effects of creating and using this digital life storybook and will look at quality of life and relationships between participants and their caregivers.

What happens in life story work?

In preparing a digital life storybook, participants will talk about past memories with their relative and/or professional caregiver. This can include looking at photographs, watching videoclips, listening to music they like or simply just talking. It is entirely up to the participant on what they want to talk about. The participant will decide what memories, photos or videos will be included in their life storybook and they will be able to look at it and go through it with relatives and friends. The idea is to encourage participants to talk about their memories in a pleasurable, sociable way.

Why have I been chosen?

You have been invited to take part because you are a staff member at Glyn Menai and care for residents living with dementia.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason.

What will happen in this research?

We will have an informal discussion about your thoughts of Book Of You and then again three to four weeks later. This will be audio recorded. If there is anything that you do not want to do or to answer, you do not have to.

Following discussion of any questions you may have with a researcher, and signing the consent form, participants will be asked to:

1) Meet with a researcher for between 10 minutes and 20 minutes for an informal interview regarding your thoughts and experiences of Book Of You. The time stated to complete the interviews and questionnaires is an estimate; you may take as many breaks as you want or feel necessary, and even complete the process over two sessions if preferred.

2) Meet with the same researcher three to four weeks later to repeat this interview.

The researcher will be happy to come and meet with you at your place of work or a convenient place at a time that suits you.

What do I have to do?

Taking part in the study does not involve any lifestyle restrictions or changes. You can carry on your everyday activities as normal while participating in the study. All we ask is that you keep your appointments with us during the time that you are taking part and use Book Of You as often as you would have normally.

What are the possible disadvantages and risks of taking part?

None have been identified.

What are the possible benefits of taking part?

If you decide to take part, we hope that this may be of some help to you, and previous research has indeed suggested that using the digital life storybook is an enjoyable experience. For all participants, the information we get from this study may help us to better treat people with dementia in the future.

Will my taking part in the study be kept confidential?

Yes. All information collected about you and the person you care for during the course of the study will be kept strictly confidential. All data will be stored under secure conditions and will be stored separately from identifying details. Only the researchers involved in the study will have access to this data.

What will happen if I don't want to carry on with the study?

You will be free to withdraw from the study at any time, without giving a reason. We will need to use in the study any data collected up to the point of withdrawal.

What if something goes wrong?

If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be fully addressed. Please address your complaint to the Manager of the School of Healthcare Sciences: *Dr Huw Roberts, Fron Heulog, Bangor University, Bangor LL57 2EF*

Tel: 01248 383136 E-mail: huw.roberts@bangor.ac.uk

Who is organising and funding the research?

This research is funded as a Knowledge Economy Skills (KESS) Scholarship. This scheme is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys. This funding covers the running costs of the research project which is being led by Laura O' Philbin (Masters student) and supervised by Professor Bob Woods, a clinical psychologist at Bangor University.

What will happen to the results of the research?

The results of the research will be published in journals, presented at conferences and form part of a Masters thesis. No participants will be identified in any publication arising from the study, without their written consent. We will make arrangements for participants to be informed of the findings of the study where desired.

Who has reviewed the study?

All research in Bangor University is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the Healthcare and Medical Sciences Academic Ethics Committee.

Who can I contact for further information?

For more information about this research, please contact:

<div align="center">

Ms Laura O' Philbin   or   Professor Bob Woods

Tel: 01248 383188   Tel: 01248 383719

Email: hsp456@bangor.ac.uk   b.woods@bangor.ac.uk

Dementia Services Development Centre

Bangor University, Ardudwy, Holyhead Road, Bangor LL57 2PX

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Thank you for considering taking part in this research study!

Consent Form

Participant Identification Number/Pseudonym for this trial:..

Digital Life Storybook Project

Name of researcher: .... **Please initial boxes**

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that all information given by me or about me will be treated as confidential by the researcher

4. Give permission for my interviews with the researcher to be audio recorded for the purposes of collecting data

5. I agree to take part in the above study.

Name of Participant   Date   Signature

_____   _____   _____

Researcher   Date   Signature

_____   _____   _____

Relative consent form Group 1, English, Version 1. 21/11/14
IT based reminiscence app
Contact: Ms L. O' Philbin Tel: 01248383188 Email: hsp456@bangor.ac.uk

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Appendix D: Life Story Work Workshop Content for people with dementia and their caregivers

1. General information about Book of You and life story work. Learning how to add photographs, learning how to add text, creating the front cover, and choosing a title for the digital life storybook.

2. Focus on video templates, i.e. how to upload videos from YouTube

3. Learning how to record audio narration to play over photographs and adding mp3 music files.

4. Learning how to move pages around the digital life storybook. Learning how to edit and delete pages.

5. Cover anything that has been missed or unclear. Learning how to source materials online.

6. Group participants: Celebration lunch
   One to one participants: Revise anything that is unclear

Appendix E: Semi-structured topic guides for interviews in Chapter 3

Semi-structured topic guide for people with dementia and family caregivers

Introductory interview

1. What are your expectations of doing life story work?
2. How are you with computers?

Follow up interviews

1. How have you been getting on with the digital life storybook?
2. How about in between the workshops?
3. What do you think about doing Book Of You in a group (for group context participants)/one-to-one at home (for individual context participants
4. What are your general thoughts/feelings about Book Of You
5. Do you think there are benefits of Book Of You?
6. Do you think there are any disadvantages of Book Of You?
7. What are your plans for the digital life storybook after the workshops finish?
8. Is there anything you liked about Book Of You?
9. Is there anything you didn't like about Book Of You?

Semi-structured topic guide for care staff

1. What are your expectations of doing life story work with residents?
2. How are you with computers?
3. How have you been getting on with the digital life storybook?
4. Have you been using Book Of You?
5. Do you think there are benefits of Book Of You?
6. Do you think there are any disadvantages of Book Of You?
7. How does Book Of You fit in with your work schedule?
8. Would anything make it easier for you to use Book Of You?
9. Does anything hinder you using Book Of You?

Appendix F. Initial e-mail contact with people who are signed up to Join Dementia Research

Hi there,

Thank you for signing up with 'Join Dementia Research' and volunteering for research. We're looking for people for a new research study into dementia care, and we'd love you to take part.

What is the Book of You research study?
Book Of You is an app for smartphones and tablets which you can use to take part in a 12-week research study into dementia care. You can use the Book of You app on your smartphone or tablet to enjoy making and viewing a life story book and to take part in a research study. This is a collection of photos, words and other things that reflect important aspects of your life. You'll also be asked some questions about your wellbeing. The research study is being carried out by researchers from the Dementia Services Development Centre at Bangor University, and will help us understand how to provide better life story book apps to people with dementia and their carers in the future.

Who is the study for?
To join this study, we're looking for people who

1. Have a diagnosis of dementia, or, are involved in caring for someone with dementia
2. Be able to consent, this means you understand what the study involves and can agree to take part
3. Have access to an iPad, iPad mini, iPhone or iPod touch

SIgn up to join the study
If you'd like to use the pilot app and take part in the study, please go to **www.dementiacitizens.org/book-of-you** and sign up to take part in the study. You'll also find full details of the research study on the webpage. If you sign up we'll email you some instructions for installing and using the Book Of You app. We'll be on hand to guide you through the process if you need any help.

If you're not eligible or decide that you don't want to take part in this study, please let us know and we won't contact you again.

If you have any questions you can get in touch with me by replying to this e-mail or by phoning me on 01 248 383 188.

Best wishes and thank you for your time,

Laura O' Philbin

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Laura O' Philbin
Book of You Research Lead (PhD student)
Dementia Services Development Centre,
Bangor University,
Ardudwy, Normal Site, Bangor, Gwynedd, LL57 2PZ

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Appendix G. Information Sheet pertaining to Chapter 4 (Phase 1: DCBY App)

PARTICIPANT INFORMATION SHEET

What is the purpose of the study?

In recent years, many people with memory problems have enjoyed the opportunity to narrate, compose and produce their own life storybook. With new technology, the life storybook can be created on a computer, tablet computer or mobile, with words, pictures and music. This project aims to evaluate the effects of creating and using this digital life storybook and will look at enjoyment and quality of life of participants with memory problems and their relatives.

What happens in a digital life storybook?

Participants will be prompted by in-app notifications to upload reminiscence materials such as old photographs, videos or music onto the Book of You app on their device. There will be suggestions of possible items to upload but you will have complete control over what you want to add to it. You can add as much material as you like to the app and you can view it as often as you wish.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be taken through the consent process on the app. If you decide to take part you are still free to withdraw at any time without giving a reason.

What will happen to me if I take part?

You will be given access to the Book Of You app on your smartphone or tablet. Before starting, you will be asked to fill out one to two brief questionnaires about your quality of life. You will be asked to fill out the same questionnaires twice more. You will be prompted with infrequent notifications to use the 'Book of You' digital storybook. After each use, some questions about how you are feeling and how much you enjoyed the session will appear on the screen. All questions are answered on a scale so there is no need to write any responses. If there is anything that you do not want to do or to answer, you do not have to.

What do I have to do?

Taking part in the study does not involve any lifestyle restrictions or changes. You can carry on your everyday activities as normal while participating in the study. All we ask is that you use Book of You a couple of times a week during the time that you are taking part.

What are the possible disadvantages and risks of taking part?

Some memories may make you feel happy or sad. However, it is entirely up to you what materials you want to add to Book of You.

What are the possible benefits of taking part?

If you decide to take part, we hope that this may be of some help to you, and previous research has indeed suggested that using the digital life storybook is an enjoyable experience and may have a positive effect on well-being. For all participants, the information we get from this study may help us to better treat people with memory difficulties in the future.

Will my taking part in the study be kept confidential?

Yes. All information collected about you and your relative during the course of the study will be kept strictly confidential. Your life storybook will only be available on your personal device. We will not have access to the content of your life story book and we will not store any identifying information about you.

What will happen if I don't want to carry on with the study?

You will be free to withdraw from the study at any time, without giving a reason. We will need to use in the study any data collected up to the point of withdrawal.

What if something goes wrong?

If you need assistance or have a query about any aspect of your participation, there is a contact form in the app that you can use to contact the researcher. If you wish, you can provide your phone number so the researcher can telephone.

If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be fully addressed. Please address your complaint to the Manager of the School of Healthcare Sciences:

 Dr Huw Roberts, Fron Heulog, Bangor University, Bangor LL57 2EF
Tel: 01248 383136 E-mail: huw.roberts@bangor.ac.uk

What will happen to the results of the research?

The results of the research will be published in journals, presented at conferences and form part of a PhD thesis. No participants will be identified in any publication arising from the study, without their written consent. We will make arrangements for participants to be informed of the findings of the study where desired.

Who has reviewed the study?

All research in Bangor University is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the Healthcare and Medical Sciences Academic Ethics Committee.

PARTICIPANT INFORMATION SHEET

Invitation to participate in a research study

You are invited to take part in this research because you signed up for the Dementia Citizens Book Of You app research but have either

- Not used it at all
- Started to use it but then stopped.

Before you decide to take part, it is important that you understand why this research is being conducted and what will be asked of you should you agree to be involved. Please take time to read the following information and discuss it with others if you wish. If anything is unclear or if you want more information, please ask us.

What is the purpose of this research?

The purpose of this research is to find out why people did not use/stopped using the Dementia Citizens App. The drop out rate is quite high so we are interested in finding out when participants stopped using it and why.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part please let us know and we can arrange a time to chat.

What do I have to do?

Taking part in this research does not involve any lifestyle restrictions or changes. If you decide to take part you and your relative will be contacted by a research (Laura O' Philbin) at a pre arranged date and time. She will run through a verbal consent process on the phone with you and then ask you some questions about when you stopped using the app and why. If there is anything you don't want to answer you don't have to. The researcher will take notes on what you say.

What are the possible disadvantages and risks of taking part?

None have been identified.

What are the possible benefits of taking part?

We hope that the information we learn in this research will help us to create better and more engaging apps for people with dementia and their carers in the future. If you complete the phone interview with us you will be given a £5 Tesco Voucher as a small token of thanks. This will be posted to you.

Will my taking part in the study be kept confidential?

Yes. All information collected about you and your relative during the course of this research will be kept strictly confidential. Once the phone interview is completed and the voucher has been sent, your details will be deleted from our records.

What will happen if I don't want to carry on with the study?
You will be free to withdraw or stop the interview at any time, without giving a reason. We will need to use any data collected up to the point of withdrawal.

What if something goes wrong?
If you need assistance or have a query about any aspect of your participation, you can contact the lead researcher Laura O' Philbin by phone, post or e-mail. Her contact details are listed at the end of this page.

If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be fully addressed. Please address your complaint to the Manager of the School of Healthcare Sciences:
 Dr Huw Roberts, Fron Heulog, Bangor University, Bangor LL57 2EF
Tel: 01248 383136 E-mail: huw.roberts@bangor.ac.uk

What will happen to the results of the research?
The results of the research will be published in journals, presented at conferences, and form part of a PhD thesis. No participants will be identified in any publication arising from the study without their written consent. We will make arrangements for participants to be informed of the findings of the study where desired.

Who has reviewed the study?
All research in Bangor University is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the Healthcare and Medical Sciences Academic Ethics Committee.

Who can I contact for further information?

Ms Laura O' Philbin   Professor Bob Woods   Dementia
Services Development Centre
Tel: 01248 383188   Tel: 01248 383719   Bangor
University, Ardudwy,
E-mail: l.o-philbin@bangor.ac.uk   E-mail: b.woods@bangor.ac.uk   Holyhead Road,
Bangor LL57 2PX

Appendix H: Semi structured topic guide for follow-up phone interviews in Chapter 4

1. Introduction (explaining the reason for the study, what will happen and be discussed on the phone call)
2. Verbal consent
3. Are you a person with dementia/memory problems, or are you supporting a person with dementia/memory problems?
4. What stage did you stop using the app at / When did you stop using the app?
5. Why did you stop using the app?
6. What did you think of
   a. Signing up to use the app
   b. Information and consent aspect
   c. The research elements
   d. The digital life storybook itself
7. How do you think your experience could have been improved?
8. How do you think the app could have been improved?
9. How could things have been done differently (e.g. research elements, signing up)

    Incentive information and arranging for delivery

Quality of Life in Alzheimer's Disease

QOL-AD

Instructions for Interviewers

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below. The interview is carried out with the subject and/or an informant. The subject should be interviewed alone.

Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type):

I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.

Point to each word (poor, fair, good, and excellent) on the form as you say it.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area.

If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four.

If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

1. **First of all, how do you feel about your physical health? Would you say it's poor, fair, good, or excellent? Circle whichever word you think best describes your physical health right now.**

2. **How do you feel about your energy level? Do you think it is poor, fair, good, or excellent?** If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.

3. **How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?**

4. **How about your living situation? How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?**

5. **How about your memory? Would you say it is poor, fair, good, or excellent?**

6. **How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent?** If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.

7. **How do you feel about your marriage? How is your relationship with (spouse's name). Do you feel it's poor, fair, good, or excellent?** Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it's a family member or friend. If there is a family caregiver, ask about their relationship with this person. It there is no one appropriate, or the participant is unsure, score the item as missing.

8. **How would you describe your current relationship with your friends? Would you say it's poor, fair, good, or excellent?** If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?**

9. **How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it's poor, fair, good, or excellent?**

10. **How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?**

11. **How about your ability to do things for fun, that you enjoy? Would you say it's poor, fair, good, or excellent?**

12. **How do you feel about your current situation with money, your financial situation? Do you feel it's poor, fair, good, or excellent?** If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.

13. **How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Would you say it's poor, fair, good, or excellent?**

Scoring instructions for QOL-AD:

Points are assigned to each item as follows: poor = 1, fair = 2, good = 3, excellent = 4.
The total score is the sum of all 13 items.

The Short Warwick-Edinburgh
# Mental Well-being Scale
(SWEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5

Appendix K. Qol-AD and SWEMWBS as they appear in the Dementia Citizens Book of You app
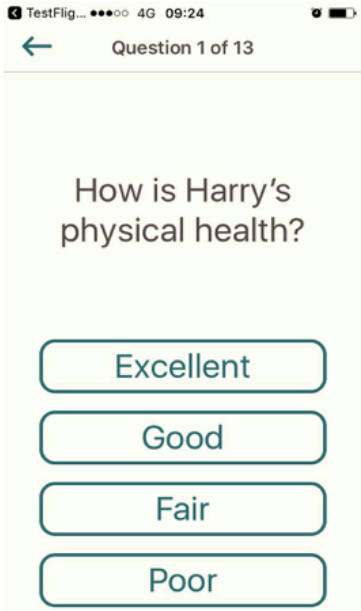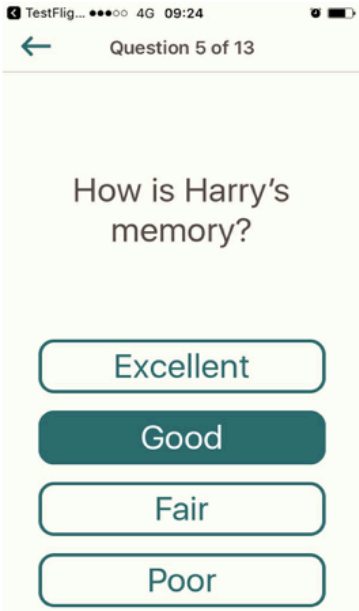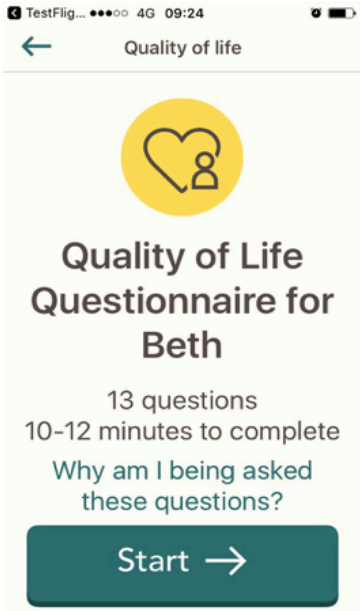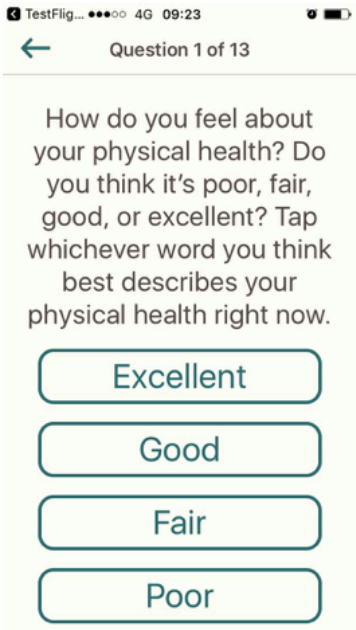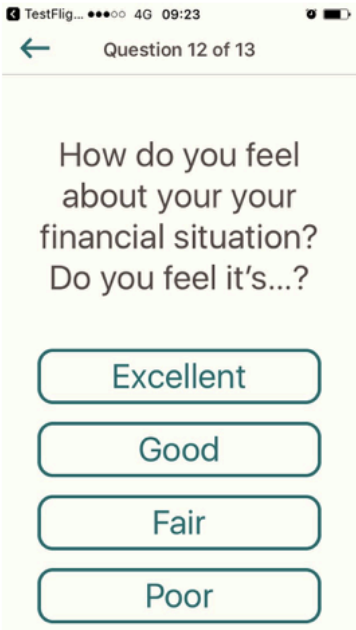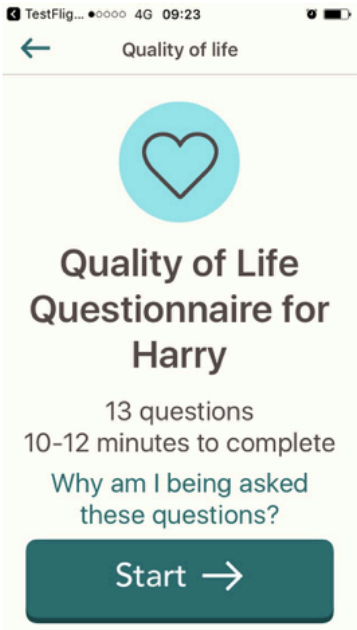
PARTICIPANT INFORMATION SHEET (presented through BOS Survey Software with Bangor, DSDC and KESS logos)

What is the purpose of the study?
In recent years, many people with memory problems have enjoyed the opportunity to narrate, compose and produce their own life storybook. With new technology, the life storybook can be created on a computer, tablet computer or mobile using words, video, pictures and music. This project aims to look at what aspects of delivering this kind of service are important to people so that services can be improved in the future.

Why have I been chosen?
You have been asked to take part because you experience some memory problems.

Do I have to take part?
No. It is up to you to decide whether or not to take part.

What will happen if I take part?
If you choose to take part you will complete an online survey. You will be asked about your preferences about life story work. You will also be asked some basic questions about yourself.

What do I have to do?
Taking part in the study does not involve any lifestyle restrictions or changes. You will be asked to complete a survey that will take between 15 and 20 minutes to complete. There are no right or wrong answers – we are simply seeking your views.

What are the possible risks of taking part?
Some people may find filling out surveys a little tiring. There is a 'finish later' option on every page so you don't have to do it all at once. There will also be a bar at the top of the page that will measure your progress so you will know how much is left to do.

What are the possible benefits of taking part?
You will be contributing to research that will help provide life story work better services to people with memory problems and their caregivers. As a small token of our appreciation we will offer you a £5 Tesco voucher at the end of the survey.

Will my taking part in the study be kept confidential?

Yes. All information collected about you during the course of the study will be kept strictly confidential. All survey responses will be anonymised, so you will not be identified in any reports or publications.

What will happen if I don't want to carry on with the study?
You will be free to withdraw from the study at any time, without giving a reason. We will need to use in the study any data collected up to the point of withdrawal. To withdraw you can just close the survey page.

What if something goes wrong?
If you need assistance or have a query about any aspect of your participation, you can contact the researcher, Laura O' Philbin. Her details are at the bottom of this page.

If you are unhappy about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns. Any complaint about your participation or possible you might have suffered will be fully addressed. Please address your complaint to the Manager of the School of Healthcare Sciences: *Dr Huw Roberts, Fron Heulog, Bangor University, Bangor LL57 2EF*
Tel: 01248 383136 E-mail: huw.roberts@bangor.ac.uk

Who is organising and funding the research?
This research is funded as a Knowledge Economy Skills (KESS) Scholarship. This funding covers the running costs of the research project which is being led by Laura O' Philbin (PhD Student) and supervised by Professor Bob Woods, a clinical psychologist at Bangor University.

What will happen to the results of the research?
The results of the research will be published in journals, presented at conferences and form part of a PhD thesis. No participants will be identified.

Who has reviewed the study?
All research in Bangor University is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and approved by the Healthcare and Medical Sciences Academic Ethics Committee.

If you would like any more information about this study please contact

Ms Laura O' Philbin

Dementia Services Development Centre
Bangor University
Ardudwy
Holyhead Road,
Bangor,
LL57 2PX

E-mail: l.o-philbin@bangor.ac.uk
Tel: 01248383188

Consent

If you are happy with the above information and wish to take part please respond to the following statements

I confirm that I have read and understand the project information provided	Yes	No
I understand my participation in voluntary and that I am free to withdraw at any time without giving a reason	Yes	No
I understand that all information given by me or about me will be treated as confidential by the researcher	Yes	No
I agree to take part in the above research project	Yes	No

Again, if you have any questions about the study or giving your consent to be in the study, you can contact the lead researcher Laura O' Philbin.
You can send her an e-mail on l.o-philbin@bangor.ac.uk or phone her on 01 248 383 188

PARTICIPANT INFORMATION SHEET (Presented on BOS Survey Software with Bangor, DSDC and KESS logos)

What is the purpose of the study?
In recent years, many people with memory problems have enjoyed the opportunity to narrate, compose and produce their own life storybook. With new technology, the life storybook can be created on a computer, tablet computer or mobile, with words, pictures and music. This project aims to look at what aspects of delivering this kind of service are important to people so they can be improved in the future.

Why have I been chosen?
You have been asked to take part because you involved in caring for a person living with dementia. We are looking for at between 70 and 90 people to take part.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to tick some boxes indicating that you give your consent to taking part. If you don't want to take part you can click 'no' or simply close this page.

What will happen if I take part?
If you choose to take part you will complete an online survey. The survey will involve looking at hypothetical ways in which a company can do life story work with people with dementia and their caregivers and choosing which you prefer. There are no right or wrong answers. You will also be asked some questions about yourself.

What do I have to do?
Taking part in the study does not involve any lifestyle restrictions or changes. You will be asked to complete a survey that will take between 20 and 30 minutes to complete. There are no right or wrong answers – we are simply seeking your views.

What are the possible disadvantages and risks of taking part?
Some people may find filling out surveys a little tiring. However, there is a 'finish later' option and progress bar on every page.

What are the possible benefits of taking part?
You will be contributing to research that will help life story work services provide better services to people living with dementia and their caregivers. As a small token of appreciation you will be offered a £5 Tesco voucher at the end of the survey. We will post this to you at the end of the study.

Will my taking part in the study be kept confidential?
Yes. All information collected about you during the course of the study will be kept strictly confidential. All survey responses will be anonymised so you will not be identified in any reports or publications.

What will happen if I don't want to carry on with the study?
You will be free to withdraw from the study at any time, without giving a reason. We will need to use in the study any data collected up to the point of withdrawal. To withdraw you can just close the survey page.

What if something goes wrong?
If you need assistance or have a query about any aspect of your participation, you can contact the researcher, Laura O' Philbin. Her details are at the bottom of this page.

If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be fully addressed. Please address your complaint to the Manager of the School of Healthcare Sciences:
 Dr Huw Roberts, Fron Heulog, Bangor University, Bangor LL57 2EF
Tel: 01248 383136 E-mail: [*huw.roberts@bangor.ac.uk*](mailto:huw.roberts@bangor.ac.uk)

Who is organising and funding the research?
This research is funded as a Knowledge Economy Skills (KESS) Scholarship. This scheme is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys. This funding covers the running costs of the research project which is being led by Laura O' Philbin (PhD Student) and supervised by Professor Bob Woods, a clinical psychologist at Bangor University.

What will happen to the results of the research?
The results of the research will be published in journals, presented at conferences and form part of a PhD thesis. No participants will be identified in any publication arising from the study. We will make arrangements for participants to be informed of the findings of the study where desired.

Who has reviewed the study?
All research in Bangor University is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the Healthcare and Medical Sciences Academic Ethics Committee.

Consent:

If you are happy with the above information and wish to take part please respond to the following statements

I confirm that I have read and understand the project information provided	Yes	No
I understand my participation in voluntary and that I am free to withdraw at any time without giving a reason	Yes	No
I understand that all information given by me or about me will be treated as confidential by the researcher	Yes	No
I agree to take part in the above research project	Yes	No

If you would like any more information about this study please contact
Ms Laura O' Philbin
l.o-philbin@bangor.ac.uk

Dementia Services Development Centre
Bangor University
Ardudwy
Holyhead Road,
Bangor,
LL57 2PX

PARTICIPANT INFORMATION SHEET

What is the purpose of the study?

In recent years, many people with dementia have enjoyed the opportunity to narrate, compose and produce their own life storybook. With new technology, the life storybook can be created on a computer, tablet computer or mobile, with words, pictures and music. This project aims to look at what kind of resources there are to do this and review these resources.

Why have I been chosen?

You have been asked to take part because you are living with dementia.

Do I have to take part?

No. It is up to you to decide whether or not to take part.

What will happen if I take part?

You will be asked to try out a Life Story Work programme on a laptop, tablet computer or mobile phone. You can choose which device you want to use.

What do I have to do?

Taking part in the study does not involve any lifestyle restrictions or changes. You will be asked to try out a Life Story Work programme. You can choose how long you want to try it out for but we ask that you use it for a minimum of 20 minutes. You will be asked to write a brief review about what you think about the programme.

If you wish you can write the review by yourself or over the phone with the researcher. Otherwise you can come to the **Ashling hotel on Wednesday 22nd March at 10am**. The researcher will sit with you and assist you with reviewing the app. There are no right or wrong answers – we are simply seeking your views. Refreshments will be provided at the Ashling Hotel.

What are the possible disadvantages and risks of taking part?

Some people may find it a little tiring. The review does not need to be long and you can withdraw at any time without giving a reason.

What are the possible benefits of taking part?

You will be contributing to research that will help life story work services provide better services to people with memory problems and their caregivers. As a small token of appreciation we will send you a €10 Tesco or Marks and Spencer voucher if you complete the research. If you wish, you can be named as an author on the paper.

Will my taking part in the study be kept confidential?

You can keep your name and information private if you wish. If you don't want your information to be kept private we can add you as an author on the paper.

What will happen if I don't want to carry on with the study?

You will be free to withdraw from the study at any time, without giving a reason.

What if something goes wrong?

If you need assistance or have a query about any aspect of your participation, you can contact the researcher, Laura O' Philbin. Her details are at the bottom of this page. If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. Any complaint will be fully addressed. Please address your complaint to the Manager of the School of Healthcare Sciences: Dr Huw Roberts, Fron Heulog, Bangor University, Bangor LL57 2EF. Tel: 01248 383136 E-mail: huw.roberts@bangor.ac.uk

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Who has reviewed the study?

All research in Bangor University is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the Healthcare and Medical Sciences Academic Ethics Committee.

If you have any questions you can contact the researcher, Laura, by e-mailing l.o-philbin@bangor.ac.uk or phoning 01 700 5748. Thank you for your time.

Life Story App Reviewers: Information Sheet

In recent years, many people with dementia have enjoyed the opportunity to narrate, compose and produce their own life storybook. With new technology, the life storybook can be created on a computer, tablet computer or mobile, with words, pictures and music. This project aims to look at what kind of resources there are to do this and to review these resources.

Why have I been asked?

You have been asked to take part because you care for/support somebody with dementia.

Do I have to take part?

No. It is up to you to decide whether or not to take part.

What will happen if I take part?

You will be asked to try out a Life Story Work app on your tablet computer or mobile phone.

What do I have to do?

Taking part in the study does not involve any lifestyle restrictions or changes. You will be asked to try out a Life Story Work app. You can choose how long you want to try it out for but we ask that you use it for a minimum of 20 minutes. You will be asked to write a brief review of what you think about the app. If you don't want to type/write a review, the researcher can meet with you or phone you to assist with writing it. We will provide ideas on how to write the review. There are no right or wrong answers – we are simply seeking your views. This review will then be included in an overall review.

What are the possible disadvantages and risks of taking part?

Some people may find writing a review a little tiring. We can help you with it.

What are the possible benefits of taking part?

You will be contributing to research that will help new and existing life story work apps provide better services to people with memory problems and their caregivers. As a small token of appreciation we will send you a £10 Tesco/Marks&Spencer voucher if you complete the review. You can choose which one you prefer. If you wish, you can be added as an author on the research paper we write at the end. Alternatively, you can choose to keep your details private.

Will my taking part in the study be kept confidential?

You can keep your name and information private if you wish.

What will happen if I don't want to carry on with the study?

You will be free to withdraw from the study at any time, without giving a reason.

What if something goes wrong?

If you need assistance or have a query about any aspect of your participation, you can contact the researcher, Laura O' Philbin (her details are at the bottom of this page). If you are unhappy about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to find a solution. Any complaint will be fully addressed. Please address your complaint to the Manager of the School of Healthcare Sciences: Dr Huw Roberts, Fron Heulog, Bangor University, Bangor LL57 2EF. Tel: 01248 383136 E-mail: huw.roberts@bangor.ac.uk.

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Who has reviewed the study?

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For more information please contact

Laura O' Philbin - DSDC Wales, Bangor University
Phone: 01248383188
E-mail: hsp456@bangor.ac.uk

Appendix O. Guidance provided to app reviewers in Chapter 7

- Is it clear what you have to do on the app?

- How is it to use?

- How clear are the colours/text size?

- Is there anything you like about the app?

- Is there anything you don't like about app?

- Is there anything you would change about the app?

- Would you recommend this app to a friend?

- If a caregiver: Would you use this app with somebody with dementia?

Appendix P. Excluded apps and reasons for exclusion (Chapter 7)

App Name	Reason for exclusion
Book Of You	A web app that cannot be downloaded onto a device.
My Life Software	Not available for general consumers, and appears to have closed down.
Mind Mate Pro	Not available for general consumers.
Remind Me Care	This is a web app and cannot be downloaded onto a device.
Replay Sporting Memories	Reminiscence tool, and creating a life story book is not the primary focus.
Our Big Box	Appears to have been a reminiscence app, and has closed down due to a lack of funding.
Storii Care	Not available for general consumers.
ireminiscence	No longer exists even though the website does
Alzium Supporter/ Alzium Caregiver	Main functionality related to care planning.
See what I Mean (Personal)	Still in development. It translates words into pictures so users can build collections of meaningful images.
See what I Mean Care	Not available for general consumers.
House of Memories	Reminiscence tool, and creating a life story book is not the primary focus.
Dementie en herinneringen	Not available in English
Demenz	Not available in English
The Daily Sparkle	Not a life story work app. This is a digital reminiscence magazine subscription service.

Appendix Q. App Evaluation Tool used in Chapter 7.

App Evaluation Tool

Interaction

1. Is more than one type of gesture control required for essential functions? [No = +1]

2. ↳ If **Yes**, is there an option to select which type of gesture control is used? [Yes = +1]

3. Are interactive elements easy to operate (e.g. responsive)?
[No = 0, Moderately = +1, Yes +2]

4. Is prior knowledge of gesture controls required, without direction or labels (e.g. scrolling, pinch to zoom)? [No = +1]

Feedback

5. Is there audio feedback following correct user input? [Yes = +1]

6. Is there *different* audio feedback following incorrect user input?
[Yes = +1 UNLESS critical]

7. Is there text feedback following correct user input? [Yes = +1]

8. Is there *different* text feedback following incorrect user input?
[Yes = +1 UNLESS critical]

9. Is there animated feedback following correct user input? [Yes = +1]

10. Is there *different* animated feedback following incorrect user input?
[Yes = +1 UNLESS critical]

11. Is there audio, text and/or animated feedback upon completion of a task/activity?
[Yes = +1]

Aesthetic Design

12. What is the size of the smallest *necessary* text? [Small = 0, Medium = +1 or Large = +2]

13. Are the fonts used for *necessary* text easy to read? [Yes = +1]

14. What is the size of the smallest *necessary* interactive elements?
[Small = 0, Medium = +1 or Large = +2]

15. Are the colours of interactive elements well contrasted with other elements/the background? [Yes = +1]

16. Is the background clear and undistracting? [Yes = +1]

App Design

17. Are there automatic prompts/hints if the user is inactive? [Yes = +1 UNLESS critical]

18. Are there automatic hints if the user is incorrect? [Yes = +1 UNLESS critical]

19. Are there hints available for the user to access manually, if required? [Yes = +1]

20. Are all required elements visible on-screen at the same time? [Yes = +2]

21. ↳ If **No**, are there clear labels/instructions informing the user how to access the off-screen elements? [Yes = +1]

22	Does the app feature any themes of explicit or violent materials? [No = +1]
23	↳ If **Yes**, is there an option to turn these off? [**Yes** = +1]

Customisation

24	Does the app feature a simplified option e.g. change the difficulty level? [**Yes** = +1]
25	Is there an option to control the volume/presence of music/sound effects *within* the app? [**Yes** = +1]
26	Is there an option to increase the size of the text? [**Yes** = +1]
27	Can you customise the colour scheme/backgrounds? [**Yes** = +1]
28	Can you change the speed of any automatic animations or processes? [**Yes** = +1]

Obstacles

29	Does the app feature adverts? [**No adverts** = +3, **Yes but not intrusive** = +1, **Yes and intrusive** = 0]
30	Was the app free to download? [**Yes** = +1]
31	Are there any In-App Purchases available? [**No** = +1]
32	Are there interactive elements in easily accessible locations onscreen that could disrupt the user's experience if unintentionally touched? [**No** = +1]
33	Are there recurring pop-ups, e.g. Game Centre, Facebook, Twitter etc.? [**No** = +1]
34	Did the app crash during testing? [**No** = +2, **Yes once** = +1, **Yes repeatedly** = 0]

Age Appropriateness

35	Is the overall theme childish/juvenile? [**No** = +1]
36	Are any animations childish/juvenile? [**No** = +1]
37	Are any sound effects/vocal effects childish/juvenile? [**No** = +1]
38	Is the app recommended for users under the age of 16? [**No** = +1]

Game Apps (only complete if applicable)

39	Is there a multiplayer option using the same device, i.e. pass & play? [**Yes** = +1]
40	Does the game require prior knowledge of the rules (i.e. could not be played intuitively)? [**No** = +1]
41	Does the game require rules additional to traditional/classic version of the game? [**No** = +1]
42	Can you customise game specific options? [**Yes: 1 to 2 options** = +1, **3 to 4 options** = +2, **5 or more options** = +3]

Total Score /48