



PRIFYSGOL
BANGOR
UNIVERSITY

Implementing Digital Life Story Work for People with Dementia: Relevance of Context to User Experience

O Philbin, Laura; Woods, Bob; Windle, Gill

International Journal of Reminiscence and Life Review

Published: 10/03/2020

Publisher's PDF, also known as Version of record

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

O Philbin, L., Woods, B., & Windle, G. (2020). Implementing Digital Life Story Work for People with Dementia: Relevance of Context to User Experience. *International Journal of Reminiscence and Life Review*, 7(1), 22-32. <https://journals.radford.edu/index.php/IJRLR/article/view/209/148>

Hawliau Cyffredinol / General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Implementing Digital Life Story Work for People with Dementia: Relevance of Context to User Experience

Laura O' Philbin, Bob Woods, & Gill Windle

Bangor University

The purpose of this study was to explore user experiences of three different implementations of digital LSW. Sixteen individuals, including people with dementia (n = 6), family caregivers (n = 6), and care staff (n = 4) working in a dementia care home 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-on-one sessions at home; or in a care home. People with dementia and family caregivers took part in weekly workshops for six weeks. Care staff received six weeks of training and were then encouraged to use digital life storybooks with residents. Thematic analyses of each dataset were carried out. 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. Results of this work 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.

Key Words: Digital Life Story Work; ICT; Dementia; Reminiscence

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, Clarke, & Repper, 2006; Murphy, 2000). 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 digital LSW 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. Research into this approach is still developing with settings and implementations varying greatly. However, results have been generally positive. For example, Ludwin and Capstick (2015) worked one-on-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 mixed methods, a significant benefit to participants' well-being and social participation was identified 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 et al. (2008) worked with a single person with dementia to develop his life story over one month. He enjoyed the experience and showed improvements on measures of self-identity and apathy while qualitative evidence 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. Digital life stories have also been created in group settings, though there is less research on this. Stenhouse, Tait, Hardy, and Sumner (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 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 with other people, and they were observed to have a greater sense of purpose and improved speech.

Other research has explored training 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

Laura O' Philbin, Bob Woods, and Gill Windle, Dementia Services Development Centre, Bangor University, Bangor, Wales

Correspondence concerning this article may be addressed to Laura O' Philbin, Dementia Services Development Centre, Wales, Bangor University, Holyhead Road, Bangor, Wales, LL57 2PZ. Email: lauraophilbin@gmail.com

developing it) found that participants, relatives, and staff approved of the digital life storybooks and considered them to be a powerful means of supporting person-centred care and meaningful conversation (Lynch, Reilly, Lowe, Rhoda, & McCarron, 2016). Another study involving ten care homes found that supporting and training staff to deliver a conventional reminiscence intervention had several significant benefits for staff and their attitudes towards residents (Gudex, Horsted, Jensen, Kjer, & Soerense, 2010). Most rated the intervention as a helpful tool for communicating with residents, and half felt it led to more positive experiences and contact with residents. However, the results showed weak evidence for an effect of the intervention on care home residents themselves. 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 a National Health Service hospital were unable to implement a LSW intervention with people in their care because they were too busy. The program was more successful when the research team employed a support worker who could prioritise the intervention. The resulting life stories encouraged practitioners to see the person behind the ‘patient’ and to build and strengthen their relationships with 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 responses of participants with dementia 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 et al. (2003) found that more reserved individuals did not want to share information while others had painful memories they did not want to revisit.

In 2010, Subramaniam and Woods highlighted that while ICT-based reminiscence approaches are feasible, more research is needed to understand how to best use digital reminiscence resources therapeutically with people living with dementia and their caregivers. Ten years on, this continues to be a key gap within the literature. Therefore, this study brings together the views of three stakeholder groups (i.e. people with dementia, family caregivers, care staff) to draw comparison between three intervention contexts so that we can understand what approaches work best and for whom. It will also enable exploration of how implementation across different contexts can be supported to inform practice.

Aim of the Current Study

The aim of this study was to explore user experiences of a digital LSW intervention involving the creation of a digital life storybook, from the perspectives of people with dementia and family caregivers living in the community and care staff working in care homes. Specific aims were to explore (a) participants’ experiences of a digital LSW service delivered through weekly workshops (b) the advantages and disadvantages of using a technological interface for LSW, and (c) how the context (e.g. the setting) affects user experiences of a digital LSW intervention

Method

Background to the Intervention

Book of You¹ is a Welsh social enterprise that organises and delivers LSW workshops in community, individual, and care home contexts. A social enterprise is a commercial organization that has specific social objectives that serve its primary purpose. Book of You 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 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 for four to six 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 four 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 a small group. The training involved learning about reminiscence, LSW, and how to use the digital LSB. Volunteers had personal experience of dementia, and were confident using ICT. Volunteers also received ongoing support from Book of You. To work with Book of You, volunteers applied using an application form and undertook a phone or face to face interview with the manager of the service. All volunteers were required to have police clearance to work with vulnerable people. Book of You received 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, and they were not explicitly organised for the purposes of this research.

¹ <http://www.bookofyou.co.uk>

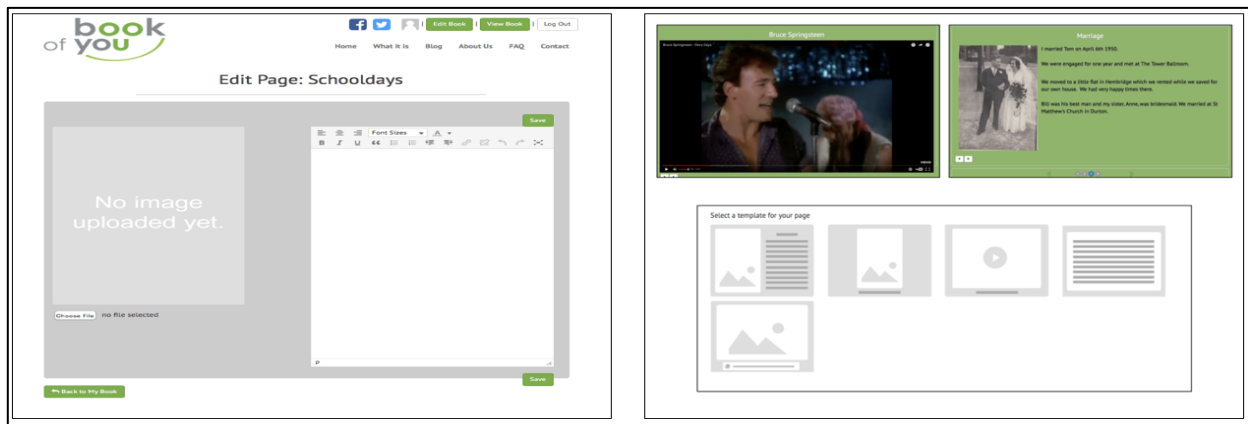


Figure 1. Digital life storybook interface.

Participants

Participants were drawn from those who were signed up to begin the 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 (i.e. person with dementia and their caregiver) and 12 staff members (across two care homes) were approached to take part.

Person with Dementia-Caregiver Dyads. To be eligible to participate in the study, participants needed to meet the DSM-IV (APA, 2000) 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, Berg, Danziger, Coben, & Martin, 1982). Participants needed to be able to produce and understand oral communication. This was assessed using relevant items from the Clifton Assessment Procedures for the Elderly (CAPE; Pattie & Gilleard, 1979). Participants were only included if they were 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.

Dyads of people with dementia and carers were recruited through the intervention. The researcher invited those who were signed up to take part in the workshops (group or individual) to participate in the study. 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 LSW facilitator, though it was stressed that taking part in the research was not a requirement 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.

Care staff. To be eligible to participate, care staff needed to be employed in a dementia care home and to 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.

Participant Characteristics

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

People with Dementia. Twelve people with dementia were invited to take part in the research (as part of a dyad), and six agreed to participate. Participant characteristics are summarised in Table 1. One participant from the group context (Mrs B) dropped out after the initial introductory interview, as she did not want to take part in further interviews. She continued to attend the workshops with her caregiver until her health declined four weeks later. The other participants attended all six workshops.

Family Caregivers. Each person with dementia participated with a family caregiver. Therefore, six family caregivers took part in the study. Characteristics of family caregivers are summarised in Table 1. Due to his wife's

Table 1. *Characteristics of People with Dementia and Caregivers*

Participant Type	Person with dementia	Age Bracket (years)	Gender	Self-reported ICT skills	Dementia severity (CDR)	Family caregiver	Relationship	Self-reported ICT skills
Group-context 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

poor health, Mr B withdrew from the workshops and the research following the second interview.

Care Staff. 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.

Ethical Approval

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

Intervention - Person with Dementia-Caregiver Dyads

People with dementia and caregivers took part in the intervention in a group context or an individual context. For the LSW service, teaching participants how to use the app was a priority, but often, reminiscence naturally occurred as a result of working materials from the past. Group context participants attended weekly hour-long workshops in their locality for six weeks. The setting was an activity room in a day centre. Group cohesion was facilitated through the provision of tea, coffee, and biscuits just before each session. 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 in both contexts 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. Participants were shown how to use

and add different materials to their books each week following different workshop content topics. These topics are outlined in Table 2. The facilitator demonstrated how to use the digital life storybook while helping participants to create their own. All person with dementia-caregiver dyads attended all sessions with the exception of Mr and Mrs B.

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 a tablet computer (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 topic was covered. 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 aspect of the digital LSB and participants tried it for themselves using materials relevant to the resident they had chosen (with permission). Topics are outlined in Table 2. After the training 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

Table 2. *Life Story Work workshop content*

Topic Number	Topic Content
Topic 1	General information about Book of You and Life Story Work. How to add text Creating the front cover and choosing a title
Topic 2	Moving pages around the digital life storybook Editing and deleting pages. Sourcing materials online (e.g. through digital archives, Google Image search).
Topic 3	Adding and uploading photographs and adjusting photograph size
Topic 4	Adding and uploading videos from the internet Searching YouTube
Topic 5	Recording audio narration to play over photographs Adding mp3 music files.
Topic 6	Open for questions or revising topics that users struggled with.

the intervention. Interviews were semi-structured and followed a semi-structured topic guide. The topic guide explored items including life storybook usage, benefits, disadvantages, barriers, facilitators, expectations, etc. Interviews were audio 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. Interviews took place just after the first, third, and sixth workshops on the same day 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: four weeks after the final training workshop and then four weeks after the first interview. Again, a semi-structured guide with the same topics was used (with the exception of a question exploring how it fits with staff members' work schedule). 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 a deductive thematic analysis whereby the research questions informed the topic guide, and coding was carried out in the context of the research questions and topics (Braun & Clarke, 2006). Thematic analyses involve "identifying, analyzing, and reporting patterns (themes) within data" (Braun & Clarke, 2006, p79). Data from each context were analysed

separately, so that participant experiences in each context could be explored and then compared.

Interviews were transcribed verbatim by LO'P and any potentially identifying information was removed during this process. Transcripts were carefully read and re-read before the process of coding began. Coding was carried out by hand using hardcopies of the transcripts, highlighter pens and note columns. Segments of data were labelled so that initial codes could be created and applied to the other transcripts. These labels mirrored the broad questions in the topic guide. There were several iterations of coding. New codes were created and existing codes were refined as understanding of the data developed. Codes were then extracted and organised into possible themes and subthemes using a thematic map. Tables in Microsoft Word were used to gather the data (excerpts from the transcripts) relevant to each theme and subtheme. Then, these were checked against coded excerpts and against the dataset as a whole. The themes and subthemes were discussed, reviewed, and refined between two authors (LO'P and BW), before being named and defined. If there were disagreements in the analysis, these would be referred to the third author (GW) for discussion and clarification. LO'P and BW then selected compelling extracts that were representative of each theme and subtheme. As expected, several themes mirror the topic guide, though some do not and were entirely data driven.

Results

Person with Dementia Findings

There were two themes in the data from participants with dementia, each with two subthemes.

Memories

Evoking memories. For all participants, doing digital LSW (at home and during workshops) evoked memories and was an enjoyable experience except in a small number of cases where negative memories came up. 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.

"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 [pleased]" (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 were engaged 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).

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

Caregiver Findings

Three themes emerged from caregiver data, each with two to three subthemes: *Expectations and usage*, *Intervention context*, and *Technology*.

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" (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..." (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.

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

Different plans. Group context participants viewed the digital life storybook as something to use in the future as a memory aid when their relative's dementia progresses, 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).

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 was better in a one-on-one setting than in a group setting. Ms K also emphasised how the facilitator had made it an enjoyable experience for her and Mr K.

"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).

Technology.

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

"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 [Mrs K's] 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'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 they became more confident as the sessions continued. Although the nature and longer session length of the individual context meant that they received more one-on-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..." (Mrs. M, individual context).

Care Staff Findings

Three themes were identified in data from care staff participants, each with two to three subthemes. These were *Connecting and Sharing*; *ICT Creating Opportunities*; and *The Influence of the Work Environment*.

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 the primary use of it. The digital life storybook was used to share

moments that occurred in the care home that family members might have not otherwise seen. Activities and events in the care home were recorded and added to residents' digital life storybooks for relatives to view through a shared password.

"...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).

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

"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 just, 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 fifties. 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).

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.

"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.... " (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 and contexts 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.

Experiences of a Digital LSW Service Delivered Through Weekly Workshops

All three participant groups had a favourable view of the intervention and the digital life storybook. Similar to previous findings, participants enjoyed the intervention, and felt that LSW was a worthwhile thing to do (Damianakis et al., 2010; Massimi et al., 2008; Sarne-Fleischmann & Tractinsky, 2008; Subramaniam & Woods, 2016). The intervention helped participants with dementia reconnect with their past by evoking distant and forgotten memories (Damianakis et al., 2010; Lynch et al., 2016; Massimi et al., 2008; Sarne-Fleischmann & Tractinsky, 2008; Subramaniam & Woods, 2016). Similarly, family caregivers felt that the intervention was valuable for their relative and spoke positively about it. In care homes, the intervention was relatively successful, with benefits reportedly reaching the residents and their relatives, in addition to the care staff. Care staff felt that the digital life storybooks developed and strengthened their relationships with residents and their relatives, supporting previous findings (Clarke et al., 2003; Sarne-Fleischmann & Tractinsky, 2008; Subramaniam & Woods, 2016). They also used the digital life story books for additional, but positive, purposes that went beyond the initial aims of the intervention (i.e. 'mission creep'). In one care home, the digital life storybooks were primarily viewed as a means

of sharing events and moments with relatives through a shared password. This is a valid added function, but over-focusing on this may risk excluding the person with dementia.

LSW also evoked negative emotions for some participants with dementia. 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 that their overall experience was positive, which is reflected in previous work. For example, Damianakis et al. (2010) observed 291 positive reactions to reminiscence stimuli among participants with dementia and MCI, compared to 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).

The Advantages and Disadvantages of Using a Technological Interface for LSW

The digital nature of the intervention presented both opportunities and challenges for participants. In relation to negative emotions, an advantage of digital LSW is that the user can easily remove materials that evoke those reactions if desired. Subramaniam et al. (2013) found that all participants in their study opted to exclude traumatic and distressing memories from their life storybooks. The digital aspect of the intervention also meant that participants had access to powerful relevant multimedia stimuli through the internet, which they enjoyed and appreciated. For example, Mr. K had no photographs from his past and relied solely on internet resources to create 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 posed a significant barrier to all participants with dementia (and some caregivers), who depended on their caregivers to use the digital life storybook. Perhaps this may not have been the case with a traditional life storybook, though to our knowledge, this question has not been specifically addressed in the literature. However, Mulvenna et al. (2017) observed that people with dementia sometimes used a reminiscence app without their caregiver and were able to interact with it independently. In that study, participants had received training at the onset of the 12-week trial, meaning they may have had more time to spend learning how to use the app, without the added task of creating and using a digital life storybook.

The Effects of the Intervention Context on the User Experience

Conflicting aims has long been an issue in reminiscence work (McKeown et al., 2006; Subramaniam & Woods, 2010; Woods & Subramaniam, 2017). According to Kindell et al. (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). Results of this research suggest that different intervention contexts have different implications for implementation.

Enjoyment of the intervention appeared to be similar across group and individual contexts, although 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. Family caregivers from the individual context 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. Meanwhile those in the group context struggled to operate it and viewed it as something to use in the future if their relatives’ dementia progresses.

In care settings digital LSW was considered part of daily care, both by staff and management. The importance of organisational support for success and sustainability has been highlighted previously (Lynch et al., 2016). Gudex et al. (2010) speculate that their hospital-based LSW intervention was not fully implemented (despite enthusiasm of staff) due to a lack of interest, time, and support from management. In the present study, care staff received strong support from management, though personal time remained an issue. Management held meetings and appointed staff tutors to encourage the use of the digital life storybooks which participants in the Gudex et al. study reported that they would have wanted. Care staff in the present study viewed the digital life storybook training as learning a new skill. This supports findings from Gudex et al. (2010) who observed that staff members who received reminiscence training scored significantly better on measures of personal accomplishment than staff who received no training.

Each context had a different intervention exposure. Group context participants received six hours training, individual context participants received between six and twelve hours training, and care staff received up to eight hours depending on how many workshops they had time to attend. These differences will have likely impacted how comfortable participants became with the digital LSB interface and, in turn, how they used it. In the current study, the time participants spent using the digital LSB outside of sessions was not specifically recorded. Rather, we relied on general self-report. Due to the responsive nature of the workshops, the content was possibly quite varied depending on the specific participant or group.

Strengths, Limitations, and Practice Considerations

A small convenience sample was used; consequently, the results are likely not representative of the populations. However, although the sample size is small, the core themes identified in this manuscript cover a wide range of topics across several perspectives and contexts, and achieve a high level of saturation. The facilitator was involved in initially distributing information sheets to potential participants in the individual context, which may have created bias despite stressing that the study was optional. 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. The first-hand voices of care home residents were not included in this study which limits the balance of data collected. On the other hand, the semi-structured topic guide facilitated the gathering of individual experiences. Data from each participant group were analysed separately meaning that experiences of each group in each implementation could be explored.

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. Other 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 additional 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.

Conclusion

This multiple perspective exploratory study provides evidence for the feasibility and value of digital LSW delivered through a face-to-face service in care homes and community-based contexts for people with dementia and their caregivers, provided that upsetting memories can be managed sensitively. Different contexts are associated with slightly different outcomes. The individual context appears optimal for creating a digital life storybook and learning how to use it, while the group context may have more social value. In care homes, the digital life storybook was also used for additional but positive purposes that sometimes seemed to overtake the primary LSW function (e.g. a photo sharing tool with family). Future research should address the limitations of the current study and explore the views of care home residents first-hand.

References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev. ed.). Washington, DC: American Psychiatric Assoc.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Bruce, E., & Schweitzer, P. (2008). Working with life history. In M. Downs, & B. J. Bowers (Eds.), *Excellence in dementia care: Research into practice* (pp. 168-186). Maidenhead: Open University Press.
- Clarke, A., Hanson, E. J., & Ross, H. (2003). Seeing the person behind the patient: Enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*, 12(5), 697-706.
- Coleman, P. (1986). *Aging and reminiscence processes*. New York, USA: John Wiley & Sons.
- Damianakis, T., Crete-Nishihata, M., Smith, K. L., Baecker, R. M., & Marziali, E. (2010). The psychosocial impacts of multimedia biographies on persons with cognitive impairments. *The Gerontologist*, 50(1), 23-35.
- Department of Health. (2005). *Mental capacity act*. London: HMSO.
- Gudex, C., Horsted, C., Jensen, A. M., Kjer, M., & Soerensen, J. (2010). Consequences from use of reminiscence - A randomised intervention study in ten Danish nursing homes. *BMC Geriatrics*, 10(1), 33.
- Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. *The British Journal of Psychiatry*, 140(6), 566-572.
- Kellett, U., Moyle, W., McAllister, M., King, C., & Gallagher, F. (2010). Life stories and biography: A means of connecting family and staff to people with dementia. *Journal of Clinical Nursing*, 19(11-12), 1707-1715.
- Kindell, J., Burrow, S., Wilkinson, R., & Keady, J. D. (2014). Life story resources in dementia care: A review. *Quality in Ageing and Older Adults*, 15(3), 151-161. //doi.org/10.1108/QAOA-02-2014-0003
- Ludwin, K., & Capstick, A. (2015). Using participatory video to understand diversity among people with dementia in long-term care. *Journal of Psychological Issues in Organizational Culture*, 5(4), 30-38.
- Lynch, S., Reilly, E., Lowe, F., Rhoda, J., & McCarron, M. (2016). Creating life stories through digital technology as a means of supporting person-centred, relationship based care across the continuum of dementia. *Age and Ageing*, 45(suppl 2), ii12.
- Massimi, M., Berry, E., Browne, G., Smyth, G., Watson, P., & Baecker, R. M. (2008). An exploratory case study of the impact of ambient biographical displays on identity in a patient with Alzheimer's disease. *Neuropsychological Rehabilitation*, 18(5), 742-765.
- McKeown, J., Gridley, K., & Savitch, N. (2017). Identifying and overcoming challenges in life story work. In P. Kaiser, & R. Eley (Eds.), *Life story work for people with dementia: Ordinary lives, extraordinary people* (pp. 200-211). Philadelphia: Jessica Kingsley Publishers.
- McKeown, J., Clarke, A., & Repper, J. (2006). Life story work in health and social care: Systematic literature review. *Journal of Advanced Nursing*, 55(2), 237-247.
- Mulvenna, M., Gibson, A., McCauley, C., Ryan, A., Bond, R., Laird, L., et al. (Sep 19, 2017). Behavioural usage analysis of a reminiscing app for people living with dementia and their carers. Paper presented at the *European Conference on Cognitive Ergonomics 2017*, Umea, Sweden. 35-38.
- Murphy, C. (2000). *Crackin' lives: An evaluation of a life story-book project to assist patients from a long stay psychiatric hospital in their move to community care situations*. Dementia Services Development Centre, Stirling.
- Pattie, A. H., & Gilleard, C. J. (1979). *Manual of the Clifton Assessment Procedures for the Elderly (CAPE)*. Sevenoaks: Hodder & Stoughton Educational.
- Retrieved from <http://data.theeuropeanlibrary.org/BibliograpResource/3000086623369>.
- Ryan, A., Bunting, B., Mulvenna, M., Curran, K., Laird, L., McCauley, C., et al. (2017). A strengths based approach in a study of facilitated reminiscence. Paper presented at the *18th Nursing Ethic Conference & 3rd International Ethics in Care Conference*, pp. 68-69.
- Sarne-Fleischmann, V., & Tractinsky, N. (2008). Development and evaluation of a personalised multimedia system for reminiscence therapy in Alzheimer's patients. *International Journal of Social Humanistic Computing*, 1(1), 81-96.
- Stenhouse, R., Tait, J., Hardy, P., & Sumner, T. (2013). Dangling conversations: Reflections on the process of creating digital stories during a workshop with people with early-stage dementia. *Journal of Psychiatric and Mental Health Nursing*, 20(2), 134-141.
- Subramaniam, P., & Woods, B. (2010). Towards the therapeutic use of information and communication technology in reminiscence work for people with dementia: A systematic review. *International Journal of Computers in Healthcare*, 1(2), 106-125.
- Subramaniam, P., & Woods, B. (2016). Digital life storybooks for people with dementia living in care homes: An evaluation. *Clinical Interventions in Aging*, 11, 1263-1276.
- Subramaniam, P., Woods, B., & Whitaker, C. (2013). Life review and life story books for people with mild to moderate dementia: A randomised controlled trial. *Ageing & Mental Health*, 18(3), 363-375.