‘It brings it all back, all those good times; it makes me go close to tears.’ Creating digital personalised stories with people who have dementia

Abstract

The purpose of these three case studies was to analyse and theoretically explain the contribution of digital multimedia personalisation to stimulate and share long-term memories of people who live with mild to moderate dementia. We investigated how the use of a freely available iPad app can, in a supporting context, facilitate the creation of personalised multimedia stories, including the participants’ audio recordings, texts and photos of items, places or people important to them. Three people who were recruited from a club for people living with dementia created personalised multimedia stories using their own photographs and/or pictures downloaded from the internet, with written captions and audio-recorded voiceovers. Our analysis focuses on the themes and symbols across the three final stories of the participants and the process of creating stories with the Our Story iPad app. The discussion concerns the theoretical value of multimedia and the practical value of story-making apps for people with dementia. We conclude that the multimedia features available with the Our Story app offer a unique opportunity for people living with dementia to store, access and generate memories, capture them in writing and audio; and the ability to continue adding to the original stories.

Key words: Dementia, multimedia, memories, touchscreens, personalised stories

In August 2016, the UK's Department of Health, and leading dementia charities- Alzheimer's Research UK and Alzheimer's Society- launched a new platform "Dementia Citizens", which aims to 'help people with dementia and those who care for them, using apps on smartphones and tablets'. This objective builds on reminiscence therapy research and the activity of compiling personal pictures to capture and elicit memories in people with dementia, both of which have been part of sensitive dementia care services for many years. The upsurge of interest in the potential of apps to facilitate the creation of "books of life" or "personal stories", has led us to formally evaluate the role of the story- and book-making app *Our Story* for people living with dementia. In this article, we report a summary of three case studies of people living with dementia, who created or co-created their own digital personal books using the freely available iPad app called Our Story. We were interested in how the use of current, widely available and affordable digital technologies might facilitate the elicitation and sharing of special memories and the role of personalisation and multimedia in this process.

Delimitation of terms

Several terms are used in the literature to refer to the artefacts that contain personal stories and are created by, or with, people living with dementia, including books of life, personal stories or life history books. We use the word 'story' when referring to the digital version of participants' stories and 'book' when referring to the printed version of their oral or digital stories. The stories reported in our study are all personal or personalised, and multimedia.

Personalisation

Personalisation can refer to a number of resources and practices but in this case, it refers to the personal nature of the photographs and the book-making activity with people

living with dementia. In the medical discourse and rehabilitation programmes related to dementia, personalisation is typically used to describe an individualised response or individualised programmes (e.g., Franco, Jones, Woods & Gomez, 2009). In our case, personalisation refers to the process during which books created for or with people living with dementia are personally relevant to them, and to the fact that such personalised books contain their personal photographs, other images personal to their memories, and record their own words. Such a personalisation is possible without the use of technologies, with a number of documented and anecdotally reported positive effects of creating "life history books" (e.g., Thompson, 2011), with the use of printed photographs, newspaper clippings or any other documents eliciting memories. The creation of life history books is suggested to be carried out together with professional carers or family members and to be always a 'pleasurable, sharing and empowering process' (Alzheimer's Society, n.d.).

Digital personalisation is a relatively new technique enabled by touchscreen devices (such as smartphones and tablets). These devices are multimedia, which is an important new capability in the context of eliciting, accessing and storing personal memories.

Multimedia

Multimedia means the combination of several media into one device. We used an iPad2 in this study but other touchscreen devices might be employed. Touchscreen devices are multimedia because they have a camera (for both video and picture-taking), an audio-recorder and text-input functions. In the context of use with people living with dementia, the front-facing camera is useful because it means that new pictures can be easily taken and stored in the device. Text can be easily added by using the embedded touch keyboard and sounds recorded with the inbuilt microphone. With access to the Internet, relevant pictures can be searched online and stored on the device. In addition, there are a number of

applications (so-called "apps") to arrange the pictures in a sequence or in a visually appealing format. One such application is Our Story, which was developed in 2011 and has been used with a wide variety of users across the world since (see http://www.open.ac.uk/creet/main/projects/our-story).

The Our Story app and personalised multimedia stories

There are many tablet/smartphone apps that can be used to create a digital personalised story, including My Story™, Book Creator™, StoryMaker™ or Book of You™. We chose to use Our Story for this study because of our familiarity with the app through previous projects (see e.g., Kucirkova, Messer, Critten and Harwood, 2014; Critten and Kucirkova, 2015), and practical reasons such as access to the app developers in case of problems with its technical design and the app's free availability on the Apple and Google Play stores. The key features of Our Story relevant for this study are its open-ended design (users can create any digital stories with no restriction on the number of pictures, length of audio- or video-recordings); possibility to share the final story in multiple ways (in the current version of Our Story, finished stories can be printed out in three formats or shared with others via dropbox or email by selecting the 'share' feature and inserting the recipient's details). The app's main screen is based on a gallery of pictures and a timeline. Users can drag pictures from the gallery on the timeline in any order they wish, crossing any periods, events or moments, corresponding to the spontaneous nature of reminiscing. Our aim was not to evaluate the value of the app per se but rather the overall approach of using personalised multimedia stories for people living with dementia. Our familiarity with the app led to its use in this study but other apps may be used for this purpose.

Thus far, the value of multimedia personalised stories has not been explored empirically. Past research provides some indication of the potential benefit of multimedia and

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personalisation for people living with dementia. Following their study with hypermedia, Alm, Gowans, Ellis, Dye, Campbell & Vaughan (2007) argue that the combination of various links (links to videos or photos for example) provides multiple prompts, which is aligned with the premise of the multiple trace theory of how memories are stored. However, Alm et al. (2007) also caution that too many stimuli might overwhelm the participants and therefore a judicious balance between engagement and overstimulation needs to be sought. In another study, Gowans, Campbell, Alm, Dye, Astell, & Ellis (2004) have developed a series of interactive entertainment system prototypes, and documented many successes of the system enabling people living with dementia to create their own music, bond with caregivers (CIRCA project) and experience "flow" when playing a digital game (The Living in the Moment project). Some technologies were co-produced with their caregivers (see The CIRCA project).

Our study does not focus on technology specifically designed for people with dementia, aka assistive technology (or AT for short) and does not use an experimental research approach (cf e.g,. Nauha, Keranen, Kangas, Jamsa and Raponen, 2016). However, previous experimental research on assistive technology provides some relevant insights. For example, Gibson, Dickinson, Brittain, & Robinson (2015) used semi-structured interviews with 13 people living with dementia, 18 current family carers and 8 former carers. They identified three main types of assistive technology used by people living with dementia: AT accessed through professional services, AT obtained privately and AT used or customised by the family members. If we were to assign Our Story to one of these categories, then it would fit best the third category of AT.

As for the epistemological orientation adopted for our study, the notion of social inclusion with technology strongly resonated with us. Our approach to dementia is nested within psycho-social models (e.g., Taft, Fazio, Seman, & Stansell, 1997; Pratt & Wilkinson,

2003; Buijssen, 2005), which ‘encourage a strong focus on the remaining skills that the individual has, as opposed to what skills or experiences that have been lost’ (Kalsy-Lilico, 2014, p.97) and the importance of interactions between carers and people living with dementia and the socio-technological environment they operate in. This orientation is compatible with the use of novel, community-oriented research methods. Capstick (2011) and Ludwin & Capstick (2015) used participatory visual methods, as part of service user initiatives at the School of Health Studies, University of Bradford, UK. The method of film-making used in these studies is similar to our approach in its objective of encouraging people living with dementia to create their own stories about an aspect of their lives and thus empowering them in communicating their memories in an attractive digital format. Capstick (2011) described the adaptations needed for the filmmaking activity of two women with early onset dementia who used a simple flip camera. Interestingly, the design of a flip camera is similar to the design of an iPad in terms of its simplicity: it is a light, portable device with only one button for the main navigation (the play/stop button on flip cameras and the ‘home button’ on an iPad).

We aimed to build on this body of work and respond to the recent interest in the value of tablet and smartphone apps for people living with dementia, with a focus on multimedia personalised stories and printed books created with the Our Story app. We aimed to contribute to the literature on both a theoretical and practical level. This dual aim was pursued as two research questions:

How can an iPad app facilitate the creation of multimedia personalised stories by people living with mild to moderate dementia?

What is the role of multimedia and personalisation in the stimulation, preservation and sharing of special memories in people living with mild to moderate dementia?

We hypothesised that families and carers can often help people living with dementia to remember important events in their lives by reminiscing, typically with the use of photographs, which can help them retain a sense of self-identity (Alm et al, 2007). What is less known is how digital photographs accessed and arranged with a multimedia personalised app might benefit people living with dementia. It is not known how the creation, retrieval and storage of personal memories in a digital multimedia format together with a printed book might impact on this process. The current study attempts to go some way in addressing these areas.

Methods

Study Context

Data were collected in a club for people living with mild to moderate dementia, run by a housing association and funded by the county council and the Health and Wellbeing Partnership (UK's health and wellbeing social enterprise). There were eleven club members aged between 63 and 94 at the time of the study. Some club members were brought to the club by their family members; others took the free club-provided transport. There were two paid members of staff working in the club, together with two regular volunteers. The club was run for one day per week (10:00am-3pm) and offered a range of activities, interspersed with rest periods.

Study procedure

After an initial visit to the club, the first author of this study explained the research aims and objectives to all club members and gave out leaflets with more information about the research, inviting the club members and their families to join. All the club members were shown the features of an iPad and everyone took photos of chosen objects and of each other.

Overall, three club members agreed to take part, with one member joining together with her husband. They were introduced to the Our Story app in detail. Later on, they were encouraged to 1, continue to use the iPad camera; 2, select and order photographs in order of importance to the participant; 3, describe who or what was important to them in each photograph (typed as a caption or audio-recorded); 4, use the finished printed version of the story as a prompt for later reminiscing and discussion with family.

In line with the current efforts to empower people living with dementia to use technologies independently (see e.g., Jones, 2004), the club members participating in the study were encouraged to create their stories on their own but offered help from the first author as and when needed. The first author visited the participants in the club (overall, seven weekly visits) and in the participants' home if they chose to create their stories together with their family (which was the case for one participant – Audrey and her husband). There was a follow-up interview visit one week after the final stories had been compiled by all the participants and given to them in a booklet form.

Study Participants

Table 1 details some key characteristics of the three study participants. These descriptions were provided by the staff at the club or by Audrey's spouse or by the participants themselves. No memory or other formal tests were used.

Table 1: Descriptions of the three participants

Name (pseudonym)	Age (in years)	Qualitative description
Audrey	72	Audrey ran a multi-million pound turnover business, and was

		married with children. She lived with her husband who is her main carer. Her memory loss was quite significant, e.g., she couldn't remember the names of members of her family.
George	84	George lived by himself in sheltered housing. He appeared slightly absent-minded and quiet at first. His long-term memory was good, and he liked to take part in activities in the club.
Robert	94	Robert also lived in sheltered housing. His short-term memory lasted about five minutes. He often forgot why he was at the club or how he could get home. He loved doing quizzes and had good long-term memory.

Ethics

The study was approved by the Human Research Ethics Committee at The Open University and ethical standards and guidelines for investigations of vulnerable groups were followed throughout. The first author's personal experience of having a family member with dementia further ensured that a sensitive and respectful procedure was followed throughout the study. All participants in the study were deemed capable of giving informed consent (as defined by the Mental Capacity Act, 2005) and their ongoing consent to participate in the study was checked at each session. We invited all club members to participate in the study and chose the final participants based on their expressed voluntary agreement and wish to take part in the study and the researcher's discussion with the participants' caregiver(s) and/or the club staff. We used pseudonyms for the participants as well as characters appearing in their stories. We partially anonymised the locations they mentioned in their stories to preserve the original character of the stories. The participants were fully in charge of choosing the pictures and other content for their stories and deciding how the final stories

will be used and stored. The presence of family members (where possible) further ensured that the participants' choices were fully respected and acted upon.

Study analysis

We adopt the definition of a case study as outlined by Gerring (2004, p.341): 'an in-depth study of a single unit (a relatively bounded phenomenon) where the scholar's aim is to elucidate features of a larger class of similar phenomena'. The case study approach enabled us to see the value of the multimedia personalised stories with rich contextual detail and an authentic way of assessing the value of these stories for people living with dementia. The data were collected by the first author who had one-to-one interviews with the participants over several occasions, either at home (with Audrey and her husband) or at the club during relaxation times. The interviews with the participants, field notes and observations, were analysed qualitatively, using basic content analysis, with the focus on key themes in participants' accounts and in the final stories they had created. To analyse the stories created by the three participants, we adapted the analysis procedure of Borkan, Shvartzman, Reis and Morris (1993). Borkan et al. (1993) examined the themes in the interviews of patients and staff at the primary care clinic in Israel during the Gulf war, and like us, were interested in understanding the unique nature of personal stories because 'by looking at their stories, one can see how individuals organised and made sense out of their experiences' (p.189). The relating of personal experiences was not necessarily in sequence and the participants were given opportunities to add to their stories at a later time. Utilising Borkan et al.'s (1993) approach, we focused on, and categorised, the participants' stories according to their main themes and sub-themes. Critical reflection was used to establish key themes and determine which features of the Our Story app, and of the approach adopted, facilitated or inhibited the process. The first author's field notes, and reports from visits were discussed with the second

author via emails and face-to-face as part of the critical reflection process. This helped us identify the researcher's own perspective and response to the study protocol and study process throughout the project. To ensure reliability and validity, we followed the criteria put forward by Golafshani (2003, p.604) which state that 'reliability and validity are conceptualized as trustworthiness, rigor and quality in qualitative paradigm'. We triangulated the interview data with the field notes and observations and collectively decided on the key themes. To ensure reliability, we asked an independent researcher, a professor emeritus at The Open University, who has experience working with Our Story and vulnerable groups, to review our analysis and final themes and establish the face validity of our analysis method.

Findings

The story-making process was different for each study participant given the stage of their dementia, family circumstances and ability to handle the iPad independently. This section captures the process for each participant, followed by a brief description of the digital story they created.

Table 2: Learning to use the iPad camera and the app

	Audrey	George	Robert
1. Using the camera on the iPad	Audrey found it difficult to hold the iPad and tap on the camera icon as one of her hands was slightly uncoordinated. She	George managed to hold and focus the camera, but could not hold it steady to take the photo. With encouragement, he was able to take	Robert had good coordination but was concerned he might drop the iPad. He was able to take photos when somebody held the

	managed to focus the camera herself, then had help to hold it.	photos by himself.	iPad for him.
2. Select and order the photos on the app	Audrey loved looking through the photos and was very careful in her selection. She had over twenty photos to choose from and utilised 12 for her story.	George only had one tattered piece of paper with a photo so all his photos came from the Internet. He used 12 out of 15 pictures found online.	Robert had no photos but picked out pictures from leaflets at the club. His other photos were found on the Internet. Overall, he had 20 photos and used 14 for his story.
3. Describe who or what was important in the photos, using captions and audio-recording	Audrey was unable to use the keyboard so she dictated her captions. She started doing an audio-recording but found it difficult to remember names and events when shown her story.	George was unable to use the iPad keyboard and dictated his story. At a later date he was audio-recorded and spoke for over half an hour, adding details and new memories to his story.	Robert dictated his story. He had used a keyboard before but his fingers were stiff. He decided not to be audio-recorded, but was happy to talk about his memories.
4. Use the finished	Audrey showed her	George showed his	Robert showed his

printed version as a prompt for discussion	story to three of her colleagues at the club. She explained who the people were but could not remember names unless she read the captions.	story to club members and to his family. People were very interested in his story, and his family kept one of the booklets.	story to other club members who were sitting at his table. One of the men had been in the RAF, and they discussed the pictures in detail.

Participants' individual stories

The starting point for Audrey's story was a discussion of favourite foods at the club. Audrey's photographs consisted of her mother and father, husband and grandchildren who were photographed with the iPad at her home. Her husband also took her to visit members of the family and photos were taken of her grandchildren with the iPad. She described her feelings for her mother and her father, and her mother-in-law with whom she was very close. From the Internet, she had two photos of places: a famous shop where she used to go with her mother; and a town hall where she had her wedding reception. The captions Audrey wrote for these photographs are summarised in Table 3.

Table3: Transcript of Audrey's story

Story title: Audrey's Happy Memories

1. *These are my parents. We lived on the edge of London.*

2. *This is my mother. I loved her so much. She was very caring and had a lovely*

smile. She went out to work. I used to help by tidying up at home and my sisters did the cooking. They were good cooks too. I used to tell my sisters off because they were so untidy.

3. *This is my father. He was a manager for a large firm. He was very strict and used to tell me that I couldn't go out until I had helped my mother. I remember him wearing a uniform during the war. He used to drive a jeep. If I saw him in the street I wasn't allowed to go and talk to him. I could only talk to him at home.*

4. *We used to go to Oxford Street sometimes to do shopping. This is John Lewis which was very posh.*

5. *This picture shows the Town Hall which reminds me of getting married to Tom. I knew Tom as he lived locally. He used to play football at the football stadium. I used to tell my mum that I would take my brother out for a walk in his pushchair but I would take him to the stadium although I was not allowed to.*

6. *Here is the receipt for our wedding reception in London. It was a wonderful reception. Tom and I lived in a small cottage after we got married.*

7. *This is my mother-in-law. She was such a nice person and I loved her very much. She used to help me with the children.*

8. *This is Steve and my mother-in-law having fun.*

9. *This is a model of my dog. He looks like Lassie. We loved him so much that we had this model made of him.*

10. *Here is my baby grandchild. Such a beautiful picture.*

11. *Here are my grandchildren growing up. Emily is the eldest and the twins are Harry and Sophie. The twins love to jump all over the furniture! Actually they all did! They were very boisterous when they were little.*

12. *This is a picture of Tom and me. I look very smart don't I?*

The starting point for George's story was an image in a newspaper cutting of his grandfather who was a famous engine driver.

Figure 1 to be inserted about here

George chose photos of places where he was brought up in North London, and steam trains and images of the Kings Cross Station. He also included images of his various employments, as captured in Figure 2.

Figure 2 to be inserted about here

George's full story is included in Table 4.

Table 4: Transcript of George's story

Story title: Story of a North London Family

1. *This is Edward my grandfather. We called him GrandfatherTed. This picture is from a cigarette card as he was a famous engine driver.*

2. *All the children in North London knew him. He used to carry a bag of*

peppermints in his pocket and hand them out.

3. *My grandfather had 23 children. We all lived in a court near Pentonville Prison. Seven of our families lived there. My grandfather was very clean. He used to go out in the road and sweep it clean. He used to clean the coal lorries off too.*

4. *I remember these trams; they used to go down the shafts under the Thames.*

5. *This is near Kings Cross. I remember a big shop called Gamages. We couldn't afford any of the things but we liked to look at the toys.*

6. *My grandfather and I both worked on the locos* (locomotives) *at Kings Cross. I started there after the war, on the steam trains. My grandfather had retired by then.*

7. *My grandfather drove this train The Aberdonian. He was the licensed driver so no-one else was allowed to drive it.*

8. *I used to move The Flying Scotsman around the tracks to fill it up with water and coal. The big flaps on the front are to stop the wind going into the cab.*

9. *I used to stand on the roofs to sweep the chimneys, but I used a brick and a cord. You had to drop it in the chimney and swing it around a few times and it dislodged the soot.*

10. *This is the driver's cab with the driver and the fireman. I used to stoke the fire and I trained to become a part-time driver.*

11. *I used to shunt the coaches to make a train. Sometimes you would put a whole train together and an engineer would come along and say a wheel was a bit bent on a coach. You had to take all the coaches off so that coach could go to be repaired, then you had to put the whole train back together again in the right order.*

12. *I became a coal man and I loved it especially meeting people. I used to carry big sacks of coal on my back even up flights of stairs in blocks of flats. I worked as a brickie for a while, and then I became a window cleaner for ten years. I loved it and would still be doing it today except that I had a fall and had to give it up.*

The starting point for Robert's story was an activity in the club involving looking at replicas of advertising leaflets from the 1950s.

Figure 3 to be inserted about here

The pictures in Robert's story consisted of scientific instruments, RAF badges, wartime aeroplanes and items from the 1950s. The textual transcript of Robert's story is below.

Table 5: Transcript of Robert's story

1. *I started work when I was about 14. I didn't have a suit so I wore a jacket like this one with trousers. I couldn't afford jeans, they were very expensive.*

2. *I started off the industrial area in London at Smith's Instruments*

Factory.

3. *The factory made instruments such as this pyrometer. It was used to measure the temperature in boilers and furnaces.*

4. *This is one type of pyrometer but the factory made different kinds of scientific instruments.*

5. *In 1942 I was eighteen and I joined the RAF. I trained to become a wireless operator and a navigator.*

6. *This is the navigator badge with the N on the wing. My badge also had a W for wireless operator.*

7. *I was taught to fly in a tiger moth like this. I did my first solo flight in one.*

8. *This is a picture of a typical aircrew during the war. I wore a similar uniform.*

9. *This is a Lancaster. I sometimes flew in these over Germany.*

10. *These are Lancasters flying above the clouds to keep hidden.*

11. *After the war I went back to London and back to work. This is a television from the early fifties. I remember watching the Coronation on a television like this.*

12. *My first car was a Morris Minor but it wasn't as smart as this one. I think it was originally blue but I painted it a dark green with a pot of*

paint and a brush. You did that in those days!

13. *I used to love all kinds of sport, and I joined London Football Club, and played for them too.*

We classified the participants' stories into broad semantic categories of family and work. Despite the fact that all stories were open-ended, prompted by a different stimulus and told independently, family and work were the key themes in all three stories. In addition, there were some shared topics (or sub-themes) across all three stories: 1, Diligence in keeping the environment and his/her own appearance clean and 2, Poverty. For the former, Audrey mentioned that she used to *'tell [her] sisters off because they were untidy'*; Robert mentioned that: '*I didn't have a suit so I wore a jacket like this one with trousers*' and George said: '*My grandfather was very clean. He used to go out in the road and sweep it clean. He used to clean the coal lorries off too.*' For poverty and external markers of wealth Robert mentioned that: '*I couldn't afford jeans, they were very expensive*.' George and Audrey reminisced about expensive department stores in which they could not afford to do shopping: *'I remember a big shop called Gamages. We couldn't afford any of the things but we liked to look at the toys*.'(George). *'We used to go to Oxford Street sometimes to do shopping. This is John Lewis which was very posh'*. (Audrey).

By sharing details of how things were before has highlighted the unique socio-technological developments in the war/post-war years (e.g., Audrey not talking to her father in the street; George filling up the locomotive with water and coal and Robert's descriptions of war-related jobs and occupations). The stories also showed aspects of 'making do and mend' such as George using a brick on a rope to sweep the chimney, and Robert painting his

own car using a pot of paint and a brush. As such, the participants offered us shorter stories within their individual stories.

The participants' precise memory of the names of certain key locations, their reminiscing about positive personal characteristics of family members (or other people close to them) and their shared experience of war, contrasted with happy times after the war, constituted some common threads across all three stories. In all three cases, the strongest memories were from the participants in their teens and early twenties (Audrey at home with her sisters; George remembering his grandfather; Robert as a young man at work) and, while there were memories of later times, they appeared of less importance.

In the Discussion, we move away from the details of the participants' stories to a consideration of the procedure through which their memories were elicited and shared, and draw on the interview data to establish the relevance of our approach to future research concerned with personalised multimedia stories and people living with dementia.

Discussion

This study extends current research in two important ways: first, it builds on the body of literature concerned with reminiscence therapy (e.g., Woods, Spector, Jones, Orrell, & Davies, 2005), by documenting an approach where tangible prompts were made part of the participants' multimedia stories and where their memories became part of shareable digital and printed "life books". Keeping people with dementia calm and responsive is sometimes perceived as more important than supporting their social communication, which may lead to their social isolation (Kellett et al, 2010). Studies show that by engaging and empowering people living with dementia with the reminiscences of families and carers, supports their identity and self-esteem and enables them to access long-term memories (Alm et al, 2007;

Kellet, Moyle, Mcallister, King and Gallagher, 2010). Our study adds to this work by documenting and explaining how an iPad app might facilitate the creation of stories and books by people with mild to moderate dementia and the role of multimedia and personalisation in this process. We found that for three people with different stages of dementia, a supportive use of a touchscreen story-making app can facilitate the elicitation, storage and sharing, of special memories. The process was enjoyable for all three participants (and their carers) and meant that the club members experienced positive feelings of confidence, empowerment and increased self-esteem.

Second, our study adds to the literature examining the use of technology with people living with dementia and their carers. Digital technologies, when combined with personally relevant content can be a powerful tool in reminiscence therapy for people living with dementia (Astell et al., 2009). In a recent study in Denmark (Ward, 2016), ten people with dementia aged between 67 and 83 years, took their own photos using digital cameras on a group trip to a church, and photos around the community buildings where they met. The resulting photos were displayed to all the participants, which stimulated group discussions. The participants made up storyboards from the photos and added captions, which were made up into poems. When the study was completed, the participants were given a photobook of the photos and the poems generated during the sessions. The photobooks were very much appreciated by all of them (Ward, 2016). Our study is the first to examine the value of digital photos used in a multimedia format, together with audio recordings and textual captions and the possibility to print the stories out as booklets. In the absence of other data on the use of this kind of approach with people living with dementia and in light of our previous work with digital personalised stories with other vulnerable groups (children and adolescents with

severe learning difficulties), we offer some thinking points and practical considerations for future research in this area.

The value of multimedia for people living with dementia

According to Mayer's (2003) theory of multimedia, multimedia learning is effective because of four key effects: the coherence effect, the multimedia effect, the spatial congruity effect and the personalisation effect. According to the multimedia theory, people learn more deeply when information is presented in words together with pictures rather than in words alone ("the multimedia effect"); they learn more when distracting material is excluded ("the coherence effect"); when words and pictures are placed close to each other ("the spatial contiguity effect") and when words are presented in a conversational style ("the personalisation effect", see Mayer, 2003 for details). With the Our Story app, the final stories created by the club members contained pictures together with words and audio-recordings, thus fulfilling the multimedia criterion. The pictures and written captions appeared next to each other both on the screen and in the printed version of the book, with no distracting or extraneous material, thus corresponding to the coherence and spatial contiguity effect. The stories were personally meaningful to each participant and were captured in a conversational style (the personalisation effect).

In comparison to a printed personalised book, the use of an iPad facilitated the integration of pictures stored on the device and pictures accessed from the device on the internet. The possibility to access external images was very important for all three participants as they did not have many or any personal photographs reminding them of the past. Many people of the typical age group for people with dementia, particularly those over the age of eighty, have few or no photos of themselves growing up. The participants in the case studies all had homes in London during the war, and two of them, Audrey and George,

had their houses bombed. The use of photos from the internet was crucial to aid in accessing memories, especially in the case of George, who had no photos of his family from his childhood.

In addition, given the embedded camera in the iPad, new pictures could be easily taken and added to the story. Audrey and her husband had photographed her grandchildren and her daughter-in-law on a visit to them specifically for Audrey's story. However, she did not use these newer photos, and when she created her story on the iPad she could not remember their names. She preferred the photos of them when they were babies or young children when she had memories of them. In her case, the camera of the iPad assisted in taking pictures from her lounge and combining reminiscing with an experience of the present moment. As such, the possibility to store, access and seamlessly change digital pictures was an important asset in the story-making procedure. In addition, when reflecting on the process of story-making, the field notes show that the possibility to easily edit, reposition, enlarge, swap, delete and reinsert pictures largely facilitated the story-making process. Moreover, the iPad did not act only as a picture repository, camera, and keyboard, but also as an audio-recorder, which facilitated a convenient audio-recording of participants' reminiscing (notably in George's case).

In addition to these multimedia effects, personalisation played a role in the story-making process.

The value of personalisation for people living with dementia

All three participants were personally involved and instrumental in creating their own digital stories. They enjoyed the process of reminiscing together with the first author and commented that the activity has brought back some "happy times" that the participants were

keen to share with the researcher at later interviews. For example, Robert commented: '*It has been so nice talking about things that happened in the past. Sometimes I feel very down and things seem bleak, but I really enjoyed putting together my story*.' George revealed: '*All those places and things have gone now. Places like Gamages went a long time ago, and the trams aren't running now. It brings it all back, all those good times; it makes me go close to tears'*. In this sense, the use of the app fulfilled the aim of engaging the participants in what the Alzheimer's Society described as important for the "Remembering together: Making a life history book": a 'very enjoyable and rewarding' process, leading to a 'valuable resource which will help you to interact with the person with dementia as well as remembering what makes them unique' (www.alzheimers.org).

The unique personal attributes and quality of the stories the three participants shared with us were further enhanced through the possibility of sharing the stories with others. All three participants were delighted to see their digital stories printed out and enjoyed sharing it with their families. George, for example told us: '*Yes, I showed it to my son and my grandchildren. They took it and I haven't seen it since! My son said, you never told me about this, but he never talks to me! He comes in to see me, asks how I am and then sits down and watches the telly. My grandchildren loved it especially learning about my grandad and the steam trains. I won't see that again now they've got it* (smile).' George was given another copy of the story for him to keep. The possibility to see the story in a printed and digital form thus represented a significant moment for the participants, validated their memories and afforded them a permanent format they can keep and share with others. Based on previous work with the Our Story app (e.g., Kucirkova, Sheehy & Messer, 2015) we argue that the use of the app balanced and reinforced the multimedia and personalisation effects we observed here.

The role of Our Story for people with dementia

Our Story brought personalisation and multimedia assets within one, easy-to-use programme and made the story-making process enjoyable, as illustrated by these comments from the post-interviews:

> Robert: 'I love technology. It is wonderful to use this small computer and use the internet.'
>
> Audrey: 'It is really easy to take the photos as long as someone holds this [the iPad]. I liked choosing the photos and thinking up what to write underneath.'
>
> George: 'Yes, I liked pulling out the pictures and putting them down there [story line]. It was very easy to put together the story.'

From a practical point of view, it was helpful that Our Story was available as a free app for all tablets, which, in comparison to assistive technology, are widely available, accessible and affordable.

Study caveats and limitations

We did not collect interview data from the carers and family members. This was mostly because of the unstructured nature of their participation and because only one carer (Audrey's husband) had formally agreed to take part in the study. We acknowledge the paramount role family carers play in the lives of people living with dementia and suggest that future research designs studies extend our findings by the focus on the *dyad* of carer/person living with dementia.

This study was a qualitative study of three cases with detailed observations, interviews with the participants and analysis of the final stories they created. Our

methodology is aligned with the participatory methods that are relevant for particular participants and their local contexts. Our findings are not generalizable to the wider population but they are valuable in suggesting some practical recommendations and theoretical considerations for future large-scale studies interested in using a digital personalised iPad app to elicit and support reminiscing in people living with dementia.

Lastly, although we did not notice any limitations of using Our Story in this particular research, we can anticipate some potential difficulties for future studies. First, it should be borne in mind that the club members who chose to participate in our study all enjoyed reminiscing about their histories during club activities and to the first author when she visited. However, other people living with dementia and indeed other club members might not find this an easy or enjoyable process because of possible sad memories or physical constraints in using the iPad (e.g., poor eyesight or poor hand coordination inhibiting iPad use). Second, the researcher-participant dynamics and in the case of Audrey, the carer-participant dynamics, have positively influenced the outcomes in this study. This may not be the case in all future research and we recommend working with sensitive carers and caregivers where possible. The third caveat concerns the ease of the Our Story use. The researcher previously used the app in studies and was therefore very familiar with occasional glitches or protocol adjustments resulting from technological constraints. Future research might need to include additional time for familiarisation and training purposes with the software used for the study- as elaborated next.

Practical Recommendations

Our practical recommendations directly address the study caveats and concern three main aspects: the participants' digital competence, the importance of a supporting context in using personalised multimedia stories and the use of an open-ended iPad app.

Despite the ubiquity of digital personal technologies among the UK population (see Ofcom, 2016), we found that none of the participants had a computer, and only one (Robert) had used one at all. This meant that it was crucial that the researcher spends time with the participants and explains the use of the app as well as of the iPad (i.e. how the camera feature works, how the final stories can be shared with others via email etc.). We recommend that future research considers participants' digital competence for the study design and allows sufficient time to ensure the participants are comfortable with the technology use.

Our Story was originally developed for pre-school children and is marked by simple navigation, presence of big colourful buttons and iconic guidance. The simple design facilitated the participants' independent use of the app when needed and desired. Other factors that facilitated the reminiscing process were the clues or starting points for their reminiscences. Robert's memories of the RAF started during a quiz, for George it was a newspaper article and Audrey's memories of her family were triggered by talking about favourite foods. There was a need for a separate or quiet space at the club so that the participants could spend time thinking about their personal histories without being interrupted. It was also found to be helpful that the reminiscing process happened over a number of sessions, to discuss what had already been written and pictured in the stories. The app provided a necessary structure and scaffolding for these discussions. Often, digital pictures elucidated further memories, which could be enriched with more pictures and recordings. In this regard, we recommend that researchers interested in personalised multimedia stories choose apps that are easy-to-use and have no templates or other content-constraining features.

Researchers employing participative methods will be familiar with the need for a sensitive, competent, attentive and responsive support of the researcher throughout the study.

We found that spending time with the participants during the visits to the club, as well as the personal interviews, made them more likely to be happy to talk through their reminiscences. The first author joined in many of the activities with the club members and got to know them personally before starting the study. It was very important to ensure that each of the participants was the narrator of their own stories, and that the researcher was a sympathetic listener who did not add to, or interrupt their story-telling (see Crichton and Koch, 2007). Because it was difficult for one of the participants (Audrey) to remember the thread of her reminiscing, any interruptions by the researcher could have destroyed Audrey's ability to recall her story. The time and skills such an approach necessitates are an important consideration for future research.

In conclusion, we do not know whether our approach has actually supported the long-term memory of people living with dementia, but we can deduce that the supportive use of the app served as an effective tool for participants to access their long-term memories. Overall, the approach reported here acknowledges the unique personal emotional needs of each individual with dementia and adds to the emerging literature on the value of touchscreens for people living with dementia.

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Figures

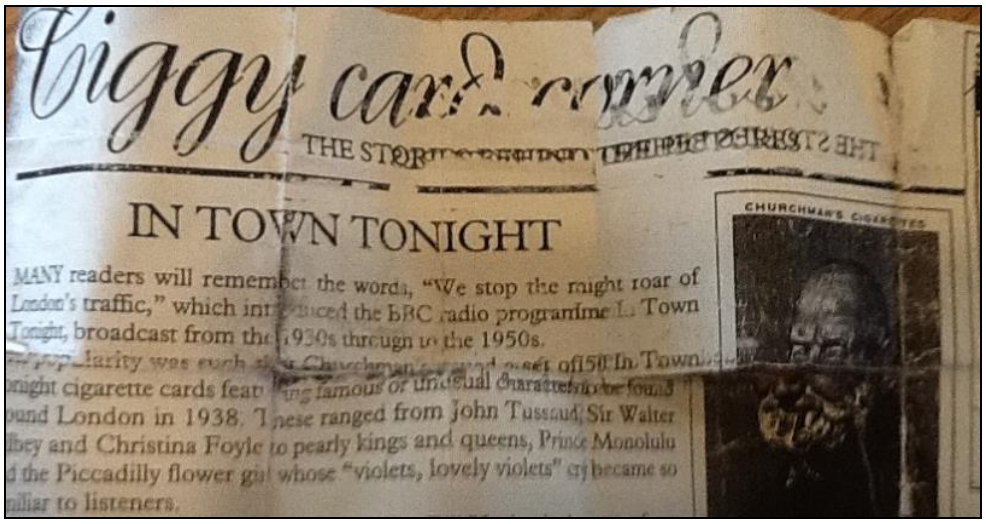

Figure 1: Photocopy of a part of the newspaper article chosen by George

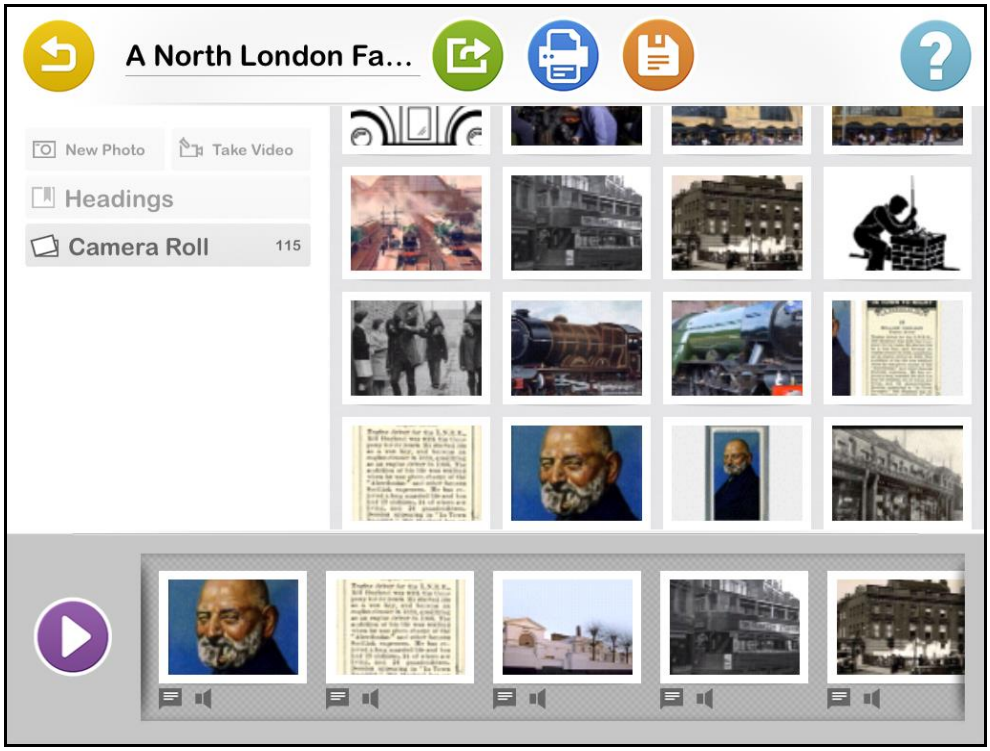

Figure 2: Screenshot from the Our Story app showing George's selection of photos and storyline

Figure 3: Facsimiles of adverts and leaflets from the fifties used for eliciting stories