

## ***Mobile digital storytelling in a Brazilian care home***

Abrahao, A.R.R.<sup>1</sup>, da Silva, P.F.C.<sup>1</sup>, Frohlich, D.M.<sup>2</sup>, Chrysanthaki, T.<sup>2</sup>, Gratão, A.<sup>1</sup>  
& Castro, P.C.<sup>1</sup>

<sup>1</sup> Federal University of Sao Carlos/UFSCar, Gerontology Department.

<sup>2</sup> University of Surrey, Digital World Research Centre.

### **Abstract.**

Digital stories are short personal films made up of a series of still images with voiceover, music and text. The technical barriers to creating such stories are falling with the use of mobile apps which make it easy to assemble story elements as audiophoto narratives on a smartphone or tablet. In this case study, we explored the potential of mobile digital storytelling in a care home context. It was used for four weeks as form of multimedia communication between formal and informal carers inside and outside the home, and a care home resident suffering from dementia. The home was located in São Carlos, Brazil as part of a larger international project called Time Matters (UK and Brazil), in which Time stands for 'This is me'. Fifteen digital stories were made by participants in the trial, which is about one for every visit of the researchers to the care home. Stories focused mainly on the resident; capturing aspects of everyday life discussed in **Visit conversations** (4), documenting **Social events** (3) inside or outside the home, recording **Therapy sessions** (3) with the resident or **Health reports** (3) by professional carers, and forming **Media albums** (2) of the residents' art or life. In general, the technology was most useful for facilitating richer conversations with the resident and other participants, and stimulating greater expressivity and creativity in the resident herself. The desire to document the resident's *current* life and interests in the home for later reminiscence by their family, stands in contrast to conventional reminiscence therapy and related digital systems. These use media artefacts to stimulate reminiscence of residents' *past* life outside the home.

### **Keywords:**

Digital storytelling, mobile, multimedia narratives, photo sharing, dementia, care home, family and friends, informal carers, formal carers, reminiscing, memory, communication.

## 1 Introduction

Despite extensive scientific funding and research, dementia remains one of the biggest challenges of national and international health care (25). In the year 2010, the cost of dementia in the world totalled \$604 billion: equivalent to 1% of gross domestic product (GDP) (26).

As the disease progresses, several factors may result in relocation to a care home, especially when their informal caregivers struggle to cope with the increasing burden of care, and their own aging process (2). Moving to a care home is a difficult period, being a stressful time for both the person with dementia and their families and friends (21). Residents of these institutions during their first four weeks of admission often feel anxiety, depression and loneliness (13). Relatives who used to be informal caregivers also experience grief and ambiguous loss when they are separated from their loved ones. As a result, these caregivers usually require a significant role and remote involvement with resident care (8).

With the advance of the disease, the need for meaningful remote and co-present interaction and enjoyable activities with the resident becomes even more important. Caregiver inability to understand and be understood by the person they are caring for is one of the most commonly mentioned communication barriers for both formal (professional team) and informal (family/friends) caregivers (22). Surprisingly little attention or communication technology has been applied to this problem. In a review of 66 technology studies to meet the needs of people with dementia and their caregivers, (27) concluded that: *“The findings show that research on the role of technology in dementia care is still in its infancy.”*

One exception is the use of reminiscence therapy with residents at which family and friends may (or may not) be present (30). This usually involves life review and the handling of physical media artefacts in ‘memory boxes’ to stimulate the residents’ memory and conversation about the distant past (4,28). Other occupational therapies involving art, craft, music and drama are also used, but these are difficult to fit into busy care schedules and seldom involve the use of new technology. Email and text-based channels of communication may supplement phone contact between remote family and friends and modern care homes, but residents themselves are unlikely to be able to use these effectively as their disease progresses.

One technology which has not been fully considered in this context is that relating to ‘digital storytelling’. Digital stories are short personal films made up of a series of still images with voiceover, music and text (17). These can now be made quite simply on smartphones and tablets, using apps to assemble these media elements into ‘audio photo narratives’ (9). A number of popular photo sharing systems are now including such facilities for making video stories out of photographs (e.g. Instagram Stories, Snapchat Stories, iPhoto Memories, etc). The possibility of using digital stories as a form of multimedia communication between dementia sufferers in a care home and their formal and informal carers, could provide a richer channel of both co-present and remote interaction between them. It might also extend earlier attempts to use multimedia content in reminiscing activities (see below), by offering it to formal and

informal carers as well as dementia sufferers. We test these predictions in a small-scale field trial in Brazil, after reviewing related work in the area.

## 2 Related work

Reminiscence is a mental process that involves the recovery of significant autobiographical memories (6). Therefore, as an intervention strategy, it is a psychological process of recovering personal experiences, lived in the past that are used for therapeutic purposes (19). Although the clinical value of reminiscence has not yet been demonstrated, reminiscing may offer opportunities for mental stimulation, amelioration of the behavioural and psychological symptoms of dementia (3,30). The sense of personal identity, continuity, self-esteem and efficacy are restored as the individual manages to self-orientate with the past and maintain social connectivity with the present, despite her/his dementia (16).

The production of collages, gift boxes and albums of life story are popular recollection support activities. Despite its many benefits, the reminiscence interventions using old photo albums are often perceived as intensive activities for dementia patients (12). Nevertheless, narrative is one of the best non-pharmacological interventions for patients with dementia (5).

Moreover, digitizing family photo albums can help with individual care planning for the care home resident. The use of innovations for creative expression through digital narratives can help in memory, communication, and influencing sensory aspects, participation and quality of life (23). Case studies (15) show that drama therapy using life history improves communication between older institutionalized patients and caregivers.

In the early stages of dementia, bright colours, interesting sounds and flashing objects can attract attention more than other activities. A multi-sensory approach to interaction and care is particularly important when a person has advanced dementia. Several authors have begun to design and test multimedia systems which stimulate dementia sufferers with digital media of various kinds. This includes both university and industry initiatives to digitize memory cues for reminiscing and communication.

In the university category, researchers from the Universities of Dundee and St Andrews in Scotland developed a system called *CIRCA* for presenting multimedia stimulation to dementia sufferers to stimulate conversation (11). This was found to support reminiscence and put them on an equal conversational footing with caregivers (1). Researchers at Pace University in the USA challenged their computer science students to design services for dementia and Alzheimer patients. These included mobile apps for families to share photos, video clips and music with loved ones remotely (31). Although not targeted at people with dementia, Waycott and colleagues from the University of Melbourne, Australia, developed and tested digital story sharing with older housebound adults. In one study they examined the sharing of video stories over the internet or via a community display (7). In another study, they developed a photo display system called *Enmesh* which allowed older adults living at home to share photo-and-text stories with each other and their remote carers (29). Both studies showed

participants were willing to create story content and benefitted from deepening relationships with carers and peers.

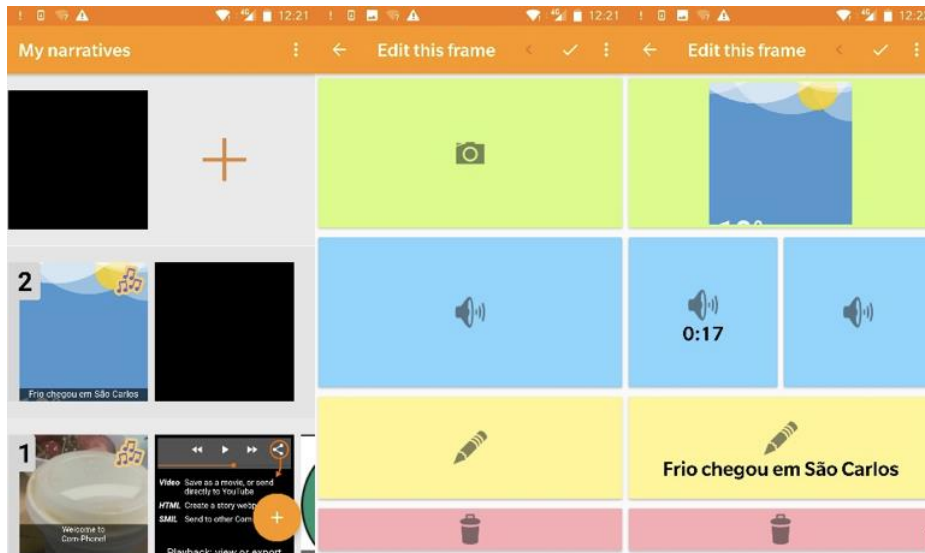
Finally, a number of commercial systems for reminiscing have come onto the market in recent years. For example, *MyLife*, *InteractiveMe* and *RemindMeCare* are all touch-screen systems designed for care home use in profiling residents with personal and internet media relating to their interests and past. Care home staff, family and friends are expected to input data in collaboration with residents, who can then access the materials alone or with others. No formal evaluations have yet been published, although the market success of these systems provides some indication of value to users.

### 3 Methods

Given that mobile digital storytelling has never been carried out before in a care home setting, we set about testing the approach with an existing system of our own, with a single resident and their formal and informal caregivers. A simple field trial was conducted using the *Com-Phone Story Maker* app as a ‘technology probe’ (14) to uncover the benefits and requirements for future systems, customised for this context. *Com-Phone* is part of the Community Media (*Com-Me*) toolkit designed to support multimedia communication in communities with low levels of literacy (<http://digitaleconomytoolkit.org>). It is an open source Android app available free on the Google Play store. It allows users to assemble photo narratives on a smartphone or tablet and annotate each photograph with voiceover and/or text in a multimedia slide show (10). Three screen shots of the interface are shown in Figure 1. The narratives can be saved as movies and uploaded to social media sharing systems such as YouTube. Full details of its capabilities are given in the user manual for Com-Phone from the website above. For our study, we created a Portuguese language version of the app and made it available within a single care home, acting as a case study.

The case study was conducted in a private care home, having about 24 residents and 26 care staff, in São Carlos, in the countryside of São Paulo state in Brazil, in 2017. All the residents of this care home have neurocognitive impairment and present dependency for daily living activities of levels 2 or 3 (in a 0-3 Katz scale, being 3 totally dependent) (18).

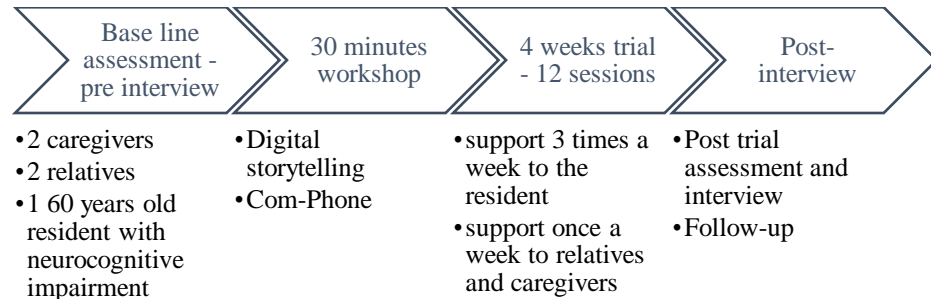
One female resident aged 60 with dementia was invited to participate following the inclusion criteria of presenting important neurocognitive impairment but still having communication skills remaining, with score of ten (10) on the Mini Mental State Exam (MMSE) (20). After that, we invited the resident relatives and carers to participate. Final participants were: two family members, one sister and the brother-in-law; and two caregivers, one manager and the nutritionist. Four Brazilian researchers (Abrahão, da Silva, Castro and Gratão) also participated in the fieldwork. The study protocol (875.356/2014 and 2.069.671/2017) received ethics approval from the Federal University of São Carlos Ethics Committee and all volunteers signed a consent form.



**Fig. 1.** The *Com-Phone* interface, showing the home screen (left), the options for an individual frame (middle) and a frame populated with image, sound and textual content (right).

The procedure used in the trial is illustrated at Figure 2. After a baseline interview, the participants attended a half-hour workshop about digital storytelling and the *Com-Phone* app, and then used tablets and smartphones to create their stories over the next four weeks. A Portuguese version of the app was installed on an Android tablet kept in the care home for the duration of the trial, and also on the Android smartphones of the researchers and the resident's sister. A principle researcher and author (Abrahão) led the fieldwork in the trial and attended all care home visits. She was occasionally accompanied by another field researcher on a subset of visits (da Silva, Castro or Grato). In fact, these researchers became important participants in the study itself because the technology proved difficult to hand over to other participants for unassisted use. During the trial period, the researchers met the resident for twelve one-hour sessions (usually scheduled every 2 days). They also met family members and care home staff four times to support story creation and upload onto YouTube. Every week the researcher uploaded the narratives at YouTube for sharing them.

After the four-week trial period, participants answered questions in two post-trial interviews (soon after and follow-up) about their experiences with the software, as well as about the values of the system in supporting communication. Because of the significance of the field researchers in the trial and their involvement in both therapy and story creation sessions, they were also interviewed as additional 'participants' by UK author four (Chrysanthaki) who did not attend any of the sessions in Brazil.



**Fig. 2.** Trial procedure

## 4 Results

The data were analysed with frequency and thematic analysis in the following way. First, we collected 15 digital stories made by participants in the study, over one month from 24<sup>th</sup> May to 26<sup>th</sup> June 2017. These stories comprise multimedia narratives in sound, image and text. Stories were assembled into a ‘story-book’ transcript with English translation in the form of a PowerPoint slide show with associated sound. This was eventually printed (without translation) as a photobook which was given back to the care home resident as a memento of the study. The storybook was also used to code the technical characteristics of stories as described in Section 4.1 below. Unfortunately, the content of the 15<sup>th</sup> story was lost due to a failure of the authors’ phone, which had to be reset. We include it in the analysis so far as we can, without knowing the exact characteristics or including it in the storybook transcript.

Second, we recorded all pre and post-trial interviews with participants and field researchers, and created both Portuguese and English transcripts. These were subject to separate content analyses for each type of participant; generating four different perspectives on the technology intervention from the care home resident, care home staff, family and friends, and researchers themselves. The results of these analyses are given in Sections 4.2-4.5 below, summarising answers to similar questions asked and themes which emerged in each type of interview as salient to participants themselves.

### 4.1 Story characteristics

The best way of introducing the characteristics of stories made in the trial is to describe a typical story, such as that shown in Figure 1. This comprises five frames containing one image each, in which some of the frames have additional text, voiceover or music. The total duration of the story was one minute, 45 seconds (1:45) and was authored by one of the field researchers with help from the resident and her sister. Creation was done on the sister’s phone. The features of this story approximate to an average story of 6.53 frames and images, with 2.2 voiceovers and text messages and 0.4 music clips, all with an average duration of 1:25. Most stories were authored by the researchers in collaboration with other participants on either a phone or tablet. The distribution of

these characteristics across the story corpus is shown in Table 1, together with a description and classification of their content and authorship.

This particular story is not very story-like, which is also typical of the corpus. It was recorded during a visit to the resident of her sister and brother-in-law, by a researcher who was also present. The researcher begins the story by recording a short conversation with the resident about what she is wearing for the visit, perhaps prompted by the fact she is wearing a warm woollen hat, scarf and cardigan indoors with her legs covered by a blanket. The first three frames show this in pictures and sound before showing the exchange of a prescription between the resident and her sister, and a group shot of all visitors around the resident's chair (researchers in white). In effect, the 'story' is a **visit conversation** illustrated with photographs, text and music in no particular order, and serves as a reminder for all parties of the time they had together. Four other story types could be observed in the corpus. These were **social events** beyond a regular visit, **therapy sessions** documenting progress in some ongoing cognitive or sensori-motor training programme, **health reports** by formal carers, and **media albums** containing collections of artwork or media of various kinds. These appeared to have different functions and appeal depending on who they were made by and made for. Therefore, we illustrate them below in relation to the perspectives of different trial participants.



**Fig. 3.** A typical story (number 11)

**Table 1.** Characteristics of recorded stories (key to authors: RS=Researcher, HR=Home resident, FF=Family or Friend, FC=Formal Carer).

Story number	Primary author	Co-authors	Platform	Story type	Story content	No. Frames	No. Images	No. Voice overs	No. Music clips	No. Texts	Duration (Min:Sec)
1	FF	HR	Phone	Media album	Family makes a photo album for resident						
2	RS	HR, FF	Tablet	Visit conversation	Resident made her first story and had 3 visitors	6	6	2	0	5	00:31
3	RS	FC	Tablet	Health report	Resident was not feeling well	2	2	2	0	2	01:13
4	RS	HR, FF	Phone	Visit conversation	Discussing forthcoming birthday party	7	7	7	0	0	02:17
5	RS	HR	Tablet	Media album	Resident exhibits her art work	20	20	0	1	7	02:57
6	FF	RS	Phone	Social event	Resident goes to a dentist appointment	2	2	2	0	2	00:29
7	FF	RS	Phone	Social event	Sister-in-law's birthday party	5	5	1	0	5	00:39
8	FF	RS	Phone	Social event	Resident's birthday party	8	8	1	1	2	01:02
9	RS	HR, FF	Phone	Therapy session	Cognitive training session	7	7	6	0	0	03:52
10	RS	FF	Tablet	Health report	How the resident felt the past week	1	1	1	0	0	00:30
11	RS	HR, FF	Phone	Visit conversation	Talking on a family visit	5	5	2	2	2	01:45
12	RS	HR	Phone	Therapy session	Cognitive stimulation through craft	9	9	2	1	0	01:17
13	RS	FC, FC	Phone	Health report	Resident care history and diet	2	2	2	0	1	01:19
14	RS	HR	Tablet	Therapy session	Learning to use whatsapp voice calling	5	5	2	0	2	00:39
15	RS	HR, FF	Phone	Visit conversation	Saying goodbye with photos	10	10	3	0	0	01:29
Mean						6.53	6.53	2.2	0.4	2.2	01:25

## 4.2 Resident perspective

The formal post-trial interview with the resident was difficult because the resident found it tiring and wasn't able to answer many of the questions. However, she was much more talkative in the story creation sessions. So findings in this section are brief and taken mainly from these sessions and the content of stories themselves.

The resident's favourite stories were the social events, specifically her dentist appointment (story 6) with her brother-in-law and sister. The two frames of story 6 are in Figure 4. She may have felt a sense of freedom because of the trip outside the care home to the dentist office, excitement due to being with her family and she got a gift (toothbrush) from the dentist. She told us that she would like to share this story with her extended family, in the post interview.

Story 5 was also noteworthy for the resident. In this one, a story was created as a kind of media album to showcase the resident's artwork with music clips. It is worth mentioning that she has hypergraphia and repeatedly draws simple nature pictures such as apples and flowers, making them almost without interruption every day. She also colours different pictures made by others as a gift, for example, the painting of a cake drawing, because her birthday was due soon.

In this sense, simple everyday actions are special to her, and most of the stories are about these routine activities. She likes to win little gifts and mementos, shoes or even school supplies, such as paper clips described on story 4.

In addition, the resident therapy sessions were also theme for many stories, as for example the cognitive stimulation activities with smells and colours on story 9 and tactile therapy in story 12.





**Fig. 4.** Going to the dentists (story 6)

The resident was unable to perform the activities alone using the Com-Phone application and required help for commands and direct aid for using the features of the app, as described in the second story. She had co-participation in carrying out the stories and tried to interact with another app (*WhatsApp*) (story no. 14). However, she had positive interaction with researchers, was responsive and communicative during the meetings, as portrayed in the story 4. In effect, the main benefit of the technology to the resident was in the process of story creation which was done collaboratively with either the researchers, her family or both.

She greatly enjoyed the family and researcher visits in their own right, and welcomed the opportunity to create multimedia artefacts about her life with their help. In fact some of the stories are about the resident's relationship with the researchers, such as the last Story 15 in which she says goodbye and says to them: *"Don't forget me"*.

### 4.3 Family and friend perspective

The family participants showed great interest in trying new ways of communication with the resident. They made about half of the 15 stories and were very engaged with the process and possibilities of the trial. The extended family visited the resident on festive dates, while the close family members such as the sister responsible for the resident, visited on average three times a week for four weeks.

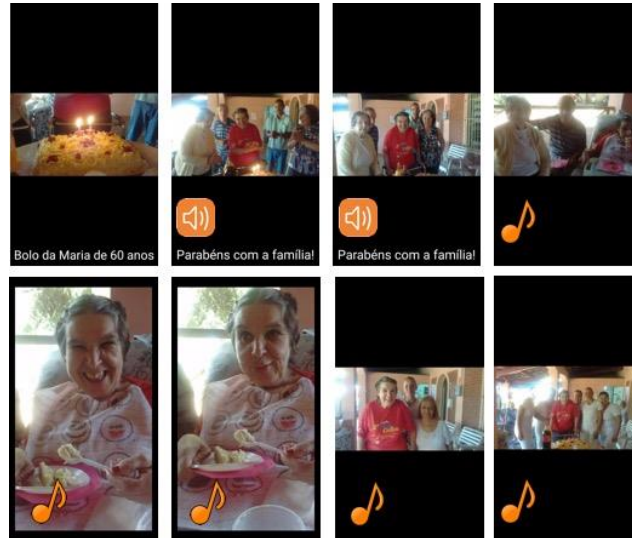
The resident's sister and brother-in-law needed aid to interact with the application in the beginning of the project, but gradually became more independent in making stories themselves. At the end of the study, they needed help only to upload the stories to the study YouTube channel.

The sister did not choose just one favourite story, but pointed out all the stories with family reunions. She said that every story has its own meaning. These were stories of social events, such as story 8 describing the resident's birthday when the largest number of family members and friends were gathered. The sister is the primary author of this story, which contains eight frames, seen in Figure 5, with photos taken by her own family. Family, friends and caregivers reunion was what made the story so important and meaningful for her, according to her post interview comments: "*The most beautiful is when we are all gathered... was her (resident) birthday here at the care home, with all the carers, the care home owner, a party that symbolizes happiness, friendship, joy, because every year of life is a new opportunity.*"

On the first voice recording, the resident and her sister are naming and saying the relation of each of the people in the photos, which the resident does not meet often, the other siblings and mother. She is happy because all these people had gone to visit her. The song on the following frames is Roberto Carlos' musical track "Happy birthday to you", whom is one of the resident's favourite singers since childhood.

The family appreciated the possibility of sharing day-to-day activities with the resident and her artwork, by means of digital narratives, according to a statement from the post-trial interview: "*We took more pictures of her, didn't we? We took more of her daily routine in the clinic, like the little flowers that she likes to draw... Bringing her the pictures, the colours, because she cannot walk and she does not go out of the clinic. So we are bringing some of the beauty, a little joy, the positive energy also that I think this is to live: it's sharing.*" The sister reports that regular conversation on her visits is repetitive, covering topics such as food, paintings the resident has done, people she has seen. But there was a sense with the storytelling technology that a wider range of topics are introduced through photographs and the things different people say about them.

When asked what she would like to do with the stories after they are made, the sister mentions their historical value for her and the rest of the family, and sharing with younger generations such as her daughter (the resident's niece). The family have an awareness that the stories will be even more precious in the future when the personality or the person of their loved one is lost: "*It is history. It means that it was what we lived; moments, souvenirs and memories. So we have to keep it in the heart...*" These memories are not just those of the resident herself in happier times before the care home, but of the times spent with her in the care home, good and bad, and the care given to her by the family itself. "*I have as recorded, I have as photos, very important to remember also that I was here with my sister for the best steps (crying)*".



**Fig. 5.** HR birthday party (story 8)

In this connection, it is also worth mentioning that the family liked to watch the stories related to formal caregivers, to see the care that is being provided to the resident and thus establishing a better communication with the formal caregivers.

#### 4.4 Formal carer perspective

The formal caregivers who work in the institution failed to participate in most story-making sessions and didn't create stories pro-actively. Probably the task of making the stories brought more demands, increasing the burden of care. Another issue observed by the researchers was the lack of support and guidance of the care home management. For these reasons the care home staff did not keep track of all the stories being made in the trial and did not have a favourite as such.

However, they did make three stories collaboratively with the lead field researcher (Abrahão). The researcher interviewed them about the resident and recorded their talk on *Com-Phone*. She later added image files to the frames. In these conversations, the formal caregivers made comments about the resident, how she arrived at the institution to live, her health condition, her diet (story no. 13) and about what happened in her day-to-day care (stories 3 and 10).

For example, story 13 depicts the story of the resident with the institution when she arrived at the care home, including the rehabilitation after a surgery due to a hip fracture (see Figure 6). At first, she could not walk and had limited locomotion, but after a while with physiotherapy and adequate diet, the patient was able to walk with the aid of a walker. In the first frame of story 13 the care home manager discusses the state of the resident when she joined the home. *"The resident arrived in a very difficult condition in order to have a quick recovery. She had surgery to put on a prosthesis*

*after a trochanter fracture, but she suffered rejection... the prosthesis was removed, and later the movements rehabilitation was very difficult because without articulation it is almost impossible to walk. But today she still presents difficulty to walk, even on account of coping with her weight. But she walks normally today, like any other person with the disability that she has, without the trochanter.*” In the second frame of the story, the nutritionist discusses her diet. This is important due to the resident’s tendency to gain weight caused by knee joint problem, reduced mobility and low physical activity level. *“Her diet is normal, except that she is using skim milk, non-fat yogurt, we are not giving dessert candy, she is eating more fruit and we have reduced the calories of all her meals a little, that’s all.”* Together the resulting story summarises the early care of the resident in a way which may be useful to other staff or to the resident’s family and friends.

When asked about the value of the system in the post-trial interviews, the manager was sceptical that the resident would be able to use it, and didn’t see the need to record health reports herself since she speaks to the family almost every day. The nutritionist felt that the system might be evolved into a game which could help the resident communicate better, but did not see a professional value in it for herself or her colleagues.



**Fig. 6.** Health report story (story 13)

#### **4.5 Researcher perspective**

There were four Brazilian researchers in total involved in the study recruitment and data collection (Abrahão, da Silva, Castro and Grato). They usually visited the care home in pairs. Their roles varied and evolved over time depending on story theme, participant and project requirements. During the first session, after meeting and consenting all participants involved (resident, family/relatives/staff), researchers acted as facilitators in the digital technology training workshop. Using content from their story of arrival to the care home and weather example, the purpose of this workshop was to teach both the resident and the family members what digital story telling was

and how they could use the app using the tablet and/or the smartphone to make their own stories. It was soon realised by the researchers that the tablet was the most appropriate technology platform for the resident whilst family members decided to use their personal mobile devices for the duration of the study. After the training session, using pictures from her phone and in collaboration with the resident, the resident's sister decided to make their own first story. *"They were doing it together. The main practice person was the sister who was putting everything in but she was showing the resident, the brother in law. They seemed to be doing it together. The resident actually chose one of the pictures". (Researcher)*

The researchers' role in this instance was just to observe the resident with the family interacting with the new technology and assist them when in need. For example, the resident's sister requested some help for uploading the media from her phone and for posting the finished story on YouTube channel. Uploading did not seem to work directly from the sister's phone. Furthermore, since the resident did not use the internet, she couldn't view any stories on YouTube. These technology issues acted as a barrier to the development of a culture of digital story sharing on the project. Stories tended to be made locally in the care home or at the sister's house, and then shared face-to-face on a tablet or phone during a family or researcher visit. Further technology use and access problems prevented the resident from privately reviewing stories on the tablet.

During the second visit, and whilst family members were also present, the resident started using the tablet for the first time. With a step by step guidance by the researcher, the resident took photos of the researcher, selfies with herself holding the tablet, created an audio and created a whole story by herself. Researchers felt that the resident was really efficient and intuitive in using the touchscreen whilst family members felt really pleased that the resident could create the content on her own and learn how to use the tablet. Family members would even take the opportunity to change the task (story making) and use the *Com-Phone* technology for other cognitive task performance (colour identification task, reminiscence). The main difficulty identified by researchers for a resident with dementia in the use of *Com-Phone* technology was the 'click and hold' function: *"If you click it, just touch one click you open the frame to watch the video, if you click and hold you are going to add the story. On the day this was the main difficulty and the access to the whole story. She did not overcome this difficulty. She was not able to click when she wanted to watch it and click and hold when she wanted to add it."* After the end of each session, the tablet was returned to the researcher as the care home did not want to leave the technology with the resident or care home staff. Lack of access to the tablet in between visits was an indication of the lack of care home staff engagement with the study in the absence of research staff. It also compromised the ability of care home staff and resident to develop a sense of ownership and familiarity with technology and the growing repository of stories.

Researchers spent most of their time with the resident and helped her with the story making process as a joint act. During this time, they developed a close relationship with the resident and learned via this task who she was and what made her happy and motivated: *"When she usually draws it is flowers and apples. When it is something different, someone else has drawn for her to colour inside. She considers them as*

*presents. She does not like books for colouring. She likes people to draw for her... We talked about what she draws, what she likes and she asked us to put some music with the drawings and then she watched all the photos. She watched the presentation and she enjoyed it very much. She laughed throughout. She asked us if she could have it and we said yes, she could have it all in an album at the end”.*

Stories became a means of communicating the resident’s likes and dislikes (e.g. photo frame layout) and her daily routines and activities within the care home. For example, towards the end of the 9<sup>th</sup> session the resident talked to the researchers about how she liked to eat in the kitchen as eating on the porch or dining room was too isolating. Walking to kitchen though was challenging so she asked them to take a picture of her favourite object ‘the walker’. This eventually appeared within story 8.

The use of the storytelling technology helped researchers to facilitate rich conversations with the resident and their relatives, and stimulated greater expressivity and creativity in the resident herself. On the last day of the visits, the sister brought in a picture of the resident as a child. Although the resident liked seeing herself as a child what she loved mostly was a frame that she asked the researcher to create which captured both herself now and her picture as a child.

Creating digital stories not only gave the residence a sense of purpose but also for family members it was a mean of connecting their loved one with the world and her relatives/friends outside the care home environment. During the 7<sup>th</sup> session the researcher was asked to help the family put a story together about a birthday party they attended so they could share it with the resident. They brought photos, texts to put on the smartphone and asked the researcher to post it directly on the You Tube channel:

*“resident was watching as the story was being made. The sister also provided some narratives and was explaining to resident ‘who is who’ and how the people were after some time that she has not seen them, what they are doing and how the party went”.*

In other instances (on visit days of cognitive training) and usually in the absence of relatives, the researchers’ role in the digital story making process was different. Researchers became the core authors of stories usually to document in real time or narrate an incident that involved resident’s engagement (bonfire, 2<sup>nd</sup> birthday party with interns) or non-engagement with a task (Visit 3, resident’s refusal to do the cognitive training). Similarly, the researchers created stories about their interviews with care home staff.

For the researchers using digital story telling technology in this context was a new and exciting learning experience. When asked about what they liked the most in the study they argued that they enjoyed the interaction with the resident, the family and the opportunity they both had via the study to access and learn how to use the technology:

*“What I liked the most was the interaction. I feel that I was able to enter the life of the resident. The family’s life as well but mainly the resident’s life because I went inside the care home. I also liked the technology part because it was new and the resident did not know it and she learned how to use it. Sometimes she would not even look and she would continue to draw but she was listening and then she was asking us to put it again, and again and again. She enjoyed more listening than watching. She*

*started to talk with the stories as if someone was asking a question. She answered again as if the person was there but she realised it was a story, She still talked to it anyway.”*

One researcher focused more on the benefits of the technology in bridging the gap between the relatives and the resident in the care home: *“Talking to the sister was my favourite one as she was the only one who verbalised the communication problem because the resident feels it and if she had access to the phone she would talk a lot to her family.” The researcher felt the technology provided another way for the sisters to talk.*

## 5 Discussion

At the outset of the study we noted the distressing nature of admitting a family member with dementia into a care home, and the need for **remote** involvement of family and friends in their care. We also cited research showing problems in communication with dementia sufferers and the need for meaningful and enjoyable **co-present** activities with them, particularly as the disease progresses. In the context of a relative lack of technology support for these problems, we cited multimedia systems for the support of co-present **reminiscing** conversations. We wondered if digital storytelling could extend this approach as a more general form of multimedia communication between care home residents with dementia and their formal and informal carers.

The short answer to this question is that we have found a strong value in the co-present creation and sharing of digital stories for a resident and her close family who visit regularly to spend time with her in the care home. Surprisingly, and in contrast with computer-supported reminiscing therapy, the most common and valuable stories were those relating to the resident’s current rather than past life. These served to elicit richer conversations with the resident in the process of creating the stories, and acted as mementos for the family themselves to look back on in the future. Other values were evident in the findings, together with additional discoveries about the design, integration and management of storytelling technology in this context. These will now be discussed under the headings of Technology and Values, before outlining their implications for Future Research.

### 5.1 Technology

Surprisingly few usability problems were discovered with the *Com-Phone* app, even when used by the resident herself. It quickly became evident with her that a tablet was more suitable for interaction than a smartphone, because of the larger size of the fonts and display. But only a click-and-hold action was singled out for criticism, since this could be invoked accidentally with different consequences for story creation than a single click. With help from the researchers, the resident learned to contribute to the media design of stories, and enjoyed sharing them with others as they played full-screen.

Of far greater significance were problems of integration of the storytelling app with other software on the tablet and social media services on the web. Being able to

select a photo or sound clip from the tablet relied upon knowledge of the repository structure for media on the device, and a means of navigating it. Even more difficult was uploading a completed story to the YouTube channel created for the trial. This had to be configured on the device to point to the right account, and simply never worked from the sister's smartphone. Unfortunately, this was where the sister made all her independent story content relating to her own activities that she wanted to share with the resident. Even if this had worked, the resident has no independent access to the YouTube channel anyway and wouldn't have been able to see such stories without assistance. This compromised the remote sharing of stories in the trial and meant that we didn't really test this value.

A final lack of integration of the technology was with the care home management. For busy staff, new technology is a burden to master and maintain. This is even more true in a small-scale field trial where the technology will be removed at the end of the trial. Consequently, in this case, the staff chose not to engage with it and even refused to keep the tablet in the care home between researcher visits. This meant that the staff did not really test its value for themselves or allow the resident access to stories independently. If the first author (Abrahão) had not taken over the role of maintaining and using the tablet with the resident, the trial would have collapsed. In effect, she took over some aspect of care for the resident in this decision, and even became facilitator for the care home staff to record stories about the health of the resident. We will return to this point in Section 5.3 below because it has consequences for how care homes might accommodate such technology in their day-to-day care of residents. For now, it is sufficient to note that the cooperation of care home staff is as important as the technology itself to its long-term success.

## 5.2 Values

The range of values experienced by participants in the trial can be illustrated in connection with the five different types of stories they created. By far the greatest values were associated with the **visit conversation** and **social event** stories which made up nearly half the stories. Together these began to form a multimedia journal or diary of the resident's life in and out of the home, with special trips to the dentist and birthday celebrations making up the highlights. While these were fun for the resident to make and share, they had deeper meaning for the family. The resident's sister was aware that they were documenting her own care of her sister in the home, and the happy moments that she planned to look back on in the future. Given the progression of dementia over time and the gradual loss of memory and personality of the sufferer, this is not a surprising observation. However, it does reinforce the value of these stories for future reminiscing by family and friends.

The documentation of **therapy sessions** and **health reports** by the researchers, sometimes on behalf of care home staff, formed another set of stories. These were valued by the resident's family as a record of professional care given, and also as a testimony of character through adversity. The latter was illustrated most dramatically in health story 13 featured in Figure 6, which contained two bland photographs but a powerful narrative about how the resident had overcome mobility



problems on admittance to become mobile with the use of a walker (now her favourite object).

The final category of **media album** stories was also valued by the resident as a record of her many drawing and art works, and by family and friends who saw these as reflecting her personality. The use of digital media technology to essentially digitise and collate art works for archiving and broader review is a latent value which might be developed further in the future. It begins to connect with other forms of occupational therapy performed in care homes involving arts and crafts, and might be seen either as a method of capturing the outputs of those, or as a form of digital media art in its own right.

Moving away from a focus on the story **outcomes** in the study, there is much that can be said about the **process** of story creation and sharing that took place. Perhaps the strongest value of the technology discovered in the whole trial was its ability to draw the resident and her visitors into richer and more creative conversations about her life than usual. This was true for the researchers as much as for family members, who expressed delight in getting to know the resident on a deeper level through the kinds of conversations involved in story making. One reason for this may be that stories were essentially photo narratives with an average of 6 photos per story. This meant that participants were always looking to illustrate activities and ideas visually, as scaffolding for voice or text annotation. Another reason is that the images and stories themselves became points of conversation, and could be recycled with other visitors in different ways. The fact that they were always created and shared collaboratively, points to the highly social nature of the technology and some new possibilities for enhancing this in the future, as described below.

### 5.3 Future research

A number of implications for the design of digital storytelling technology follow from these observations, and we begin with these here. An **end-to-end solution** is needed for care homes, which allows stories to be remotely shared as easily as they can be made. This should either attend to integration with existing ICT systems in the care home, or alternatively provide a self-contained solution that operates without dependence on existing infrastructure. The former route is likely to be less expensive, but more challenging across the diversity of systems currently in place. Once achieved however, this solution should begin to address the requirement of remote communication between the care home and the family and friends of residents. This may unlock new values such as the sharing of social events outside the home that residents are not able to attend, and the reception of health reports by family and friends reassuring them of resident care in their absence.

Given that story creation was collaborative and involved interesting conversations with the resident, much more could be done to support this. **Larger displays** might be used in tabletop orientation or via projection on a wall, to facilitate better media browsing and larger group review. Indeed, a latent possibility exists to share or even make stories locally with other residents. This was not tested in our trial

but would reinforce the capture and sharing of *current* care home life by the whole population of residents.

The assembly of individual stories into a larger ‘book’ was used as a mechanism for analysis in the trial. This was surprisingly effective in educating the remote UK researchers about the life of the resident, and something that the family appreciated as a memento in both digital and printed form. Future developments might pay greater attention to the packaging of story collections as **digital or physical mementos**, and explore augmented paper technologies that allow media assets to be linked and played back from printed photos and photobooks (24).

Other implications for care home management and research follow from our findings. We recommend the establishment of a **new staff role** in care homes focussed on the mental health and wellbeing of residents, rather than their physical health. A large part of this role should involve liaison with family and friends, addressing *their* need to feel involved in the life of the resident as well as the resident’s need for an active social network. This was essentially the role played by Abrahão in our study. We think digital storytelling technology has a role to play in this process, but only if it can be embraced and managed by ‘wellbeing staff’ who see it as an integral part of their professional work.

Finally, our findings imply that research on reminiscing in dementia care should take a new direction. This should focus on documenting the current life of dementia sufferers, and support for future reminiscing by family and friends. More attention should be paid to the kinds of conversations involved in creating multimedia stories of the everyday lives and activities of people with dementia. These appear to have the potential to increase social engagement and creativity in dementia sufferers, and to deepen the topics of conversation that can be had with them by family, friends, care staff and strangers. The current case study did not record such conversations but reports their benefit anecdotally from the comments of participants. Future studies should examine this systematically with a larger population.

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