

The potential of digital storytelling technology for home-based dementia care in Brazil

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Abstract

Background: Dementia has become a major public health issue due to its high prevalence and serious consequences. In this context, the use of Information and Communication Technologies (ICT) could provide support for communication between people living with dementia and their formal and informal caregivers, both locally and remotely. More specifically, multimedia communication in the form of digital story narratives might improve communication in such care networks through richer forms of expression of life experiences and care activities.

Objective: To explore caregiver perspectives on the communication issues and requirements involved in caring for people with dementia at home, and their reactions to digital storytelling technology as a possible intervention.

Method: Semi-structured interviews were carried out with ten community caregivers in a countryside town of Sao Paulo state, Brazil. Each involved discussion of communication issues, and feedback on a mobile digital storytelling app and associated stories.

Results: Formal and informal caregivers were both concerned about how to understand and to be understood by the people they were caring for, and saw value in digital storytelling as a new kind of assistive communication tool for more visual communication. Caregivers also wanted better ways of capturing or stimulating memories and conversation in people with dementia and saw digital stories as an extension of current social media systems for sharing life experiences.

Conclusion: One of the greatest challenges in caring for people with dementia is communication, especially to understand their feelings, frustrations, and language. Another major challenge is finding time to go beyond caring for their basic activities of daily living (ADL) to enhance their quality of life through more meaningful conversations and experiences. Requirements for new digital storytelling technology were suggested for each of these challenges.

Keywords: Alzheimer, caregiver, multimedia communication, older adults

INTRODUCTION

In 2018, Data from the Continuous National Household Sample Survey (PNAD – Continuous - Characteristics of Residents and Households) showed that Brazil was on its way to becoming a country with a predominantly older population. The same survey points out that the Brazilian population has maintained the ageing trend of recent years and has gained 4.8 million older adults since 2012, surpassing the 30.2 million mark in 2017. The 4.8 million new older adults in five years correspond to a growth of 18% of this age group, which has become increasingly representative in Brazil (IBGE, 2018).

This demographic shift is resulting in higher numbers of people with dementia in the country and a growing problem of care. There is a cultural expectation of caring for older adult relatives in extended households in Brazil, and a corresponding lack of care home provision.

This means that the majority of people with dementia live with family and are supported by a combination of family members and home care services. This situation may be shared with other low or middle-income countries where the proportion of all people with dementia is expected to increase. In 2015 dementia affected about 5% of the older population in the world (47 million people worldwide) (WHO, 2017b). The number of people with dementia tends to triple from 50 million to 152 million by 2050 (WHO, 2017a).

There is no medical cure for dementia and very few technologies directed at improving the well-being and quality of life of people with dementia. An exception to this is reminiscence technology, comprising physical or digital artifacts and media for triggering memories, conversation, and emotions (e.g. Astell et al 2018, Woods et al 2018). Contemporary approaches in this area configure personal profiles of media taken from the past

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life of the person with dementia and share these with formal and informal caregivers, usually in institutional settings such as care homes (e.g. Interactive Me, Remind Me Care). However, little attention has been given to how this would work in domestic settings where the person with dementia is living at home and receiving home care from family, friends, or professional care visitors. Furthermore, these systems are complex and would benefit from simplification to make them accessible directly to people with dementia, as well as to their caregivers.

In our prior work, we have been exploring the potential of mobile digital storytelling technology for supporting photo narrative communication in communities with low levels of literacy (Frohlich et al 2012). Digital stories are characterized by short personal films consisting of a series of still images with voice, music, and text files (Lambert, 2013). Usually, these are assembled in community workshops using video editing software, but we have been creating simple apps for assembling media elements in smaller groups on a smartphone or tablet. These have the potential to facilitate communication between people with dementia and their formal and informal caregivers, not only for reminiscence but also for more practical communication of information and emotions. In a previous study, we tested the value of a digital storytelling app called Com-Phone in a Brazilian care home, with one resident with dementia and her formal and informal caregivers (Abrahão et al., 2018). Although we thought the use of digital storytelling might support the act of reminiscing about the past life of the resident, in fact, it was valued most for capturing her current life and that of her remote relatives outside the home.

In this paper, we developed this work further by exploring the communication issues and requirements reported by caregivers of people with dementia living in their own homes or the homes of their relatives. This is particularly relevant to the Brazilian context where care homes are less common. We also assess their reactions to the same digital storytelling app that we translated into Portuguese and employed in our care home trial (Com-Phone: <http://digitaleconomytoolkit.org/com-phone/>) We interviewed both formal and informal caregivers as informants on these issues while recognizing that future work should assess the perspectives of people living with dementia themselves. We considered caregivers as informants on the lives of people with dementia and experts on their own experiences as caregivers.

We begin by giving some background to the known challenges of caring for people with dementia, before going on to report our methods

and findings on this topic, based on home visits to 10 formal and informal caregivers.

BACKGROUND TO DEMENTIA CARE

Dementia syndrome can be conceptualized as a set of symptoms associated with a decline in memory or other reasoning skills, such as language, orientation, executive function, attention, and calculation. The decline of these skills has great potential to reduce an individual's ability to perform everyday activities (WHO, 2017c).

The fundamental steps for performing basic activities of daily living (ADLs), such as dressing, bathing, and eating will be affected by dementia. The instrumental activities of daily living (IADLs) linked to household chores, medication administration, and paying bills, for example, will also be affected. Studies point to the hierarchy of functional decline in the older population, starting with the IADL, while the ADL remains preserved for a longer period of time (Fagundes; 2017). In view of disease progression, there is an increase and demand for constant care and supervision, being dementia one of the leading causes of disability and dependency among older people worldwide (Abreu et al 2020; WHO, 2017c).

Gerontological literature defines and classifies caregivers into two types. The formal caregiver is composed of qualified and salaried caregivers to perform the caregiving function. There is also the informal caregiver, who is usually represented by the household resident without qualification, usually a family member or sometimes a friend or neighbour who performs support and voluntary care tasks (Lyons & Zarit, 1999).

An important context of care is in the home of the person with dementia or family and friends. Keeping people at home longer as they age alleviates the pressure on public or private institutions such as care homes (Luker et al, 2019). However, staying at home increases the impact of support on informal caregivers (Belger et al, 2019).

When a family member takes on the role of caring for the older person, this caregiver experiences a cascade of changes in their social, financial, emotional, and family routine. Informal caregivers devote more time to care activities, abandoning various productive, leisure, and personal care activities after taking care (Abreu et al 2020). Formal home care services fill this gap but create new challenges for the communication of individuals with dementia and their informal caregivers (Macinko, Harris & Phil, 2015; Brazil et al, 2017).

The person with dementia often loses the ability to communicate thoughts and needs as the disease progresses. This makes it increasingly difficult to

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Table 1. Participants demographic characteristics

		Formal caregivers	Informal Caregivers	Total
Age (years)	Mean (\pm std)	34.6 (\pm 16.17)	43.2 (\pm 9.26)	38.9 (\pm 21.92)
	Min	22	22	22
	Max	46	74	74
Gender	Female	6	3	9
	Male	0	1	1
School	High school	3	1	4
	Bachelor	2	3	5
	Post-grad	1	0	1
How long has been providing care (years)	Mean	7.5	3.7	5.6

*std = Standard deviation

interact socially and maintain personal relationships with caregivers, family, and friends, plan daily activities, express basic needs and thoughts to those around them (Woodward, 2013). At an advanced stage, communication problems become even more important and are aggravated by memory loss and intellectual deficits (Weiner et al., 2008; Delfino & Cachioni, 2016).

Caregivers of people with dementia mention that the main communication barriers are the difficulty of communicating due to repetitive solicitations, marked vocabulary decrease, unfinished sentences, naming difficulties, and often lack of dialogue (Oliveira et al., 2016; Delfino & Cachioni, 2016; Österholm, & Hydén, 2016). In this respect, ICT interventions have the potential to stimulate more and better communication and social contact (Wang, 2007; Cotelli, Manenti & Zanetti, 2012; Gil et al, 2017).

Previous studies show that digital storytelling in the context of dementia has enabled professionals to facilitate and stimulate the ability of people with dementia to communicate and improve their sense of well-being and support self-expression. This type of technology brings the opportunity to introduce the person with dementia into more social environments, reminding the person and caregivers of the importance of the present and construction of legacy (Astell, et al; 2018). Also, digital storytelling is used as a communication and social connection tool with family, friends, and community, for health education, legacy, memory support, and reminiscence (Rincon, 2021). In our study, we found that mobile digital storytelling was used to create a diversity of stories on behalf of the person with dementia to capture past memories and current activities, but also by remote family members wanting to share their current activities, and by researchers or health professionals in documenting and sharing therapy sessions (Abrahão et al 2018). Reviewing other work, we found confirmation of these values and a recurrent contrast between product and process (Ferraz et al 2022). Story recordings become permanent life history products counteracting memory loss in people

with dementia, and helping family and other caregivers to understand and celebrate their lives. However, the process of creating these recordings is itself collaborative and social, helping the person with dementia to reminisce and interact with both professional and lay caregivers creatively and enjoyably. In this context, we wondered whether caregivers themselves would see value in the technology for providing

care to people with dementia in the home.

METHODS

This exploratory qualitative study had a total sample of 10 caregivers (professionals who provide home care services and informal caregivers (family/friends) of older people with a diagnosis of dementia in the interior of the state of São Paulo, Brazil.

Caregivers from the São Carlos area of São Paulo state were invited by phone to participate in an interview. The participants were later divided into Formal Caregivers and Informal Caregivers according to the following inclusion criteria: being caregivers of dependent persons with dementia (formal or informal), being older than 18 years old, and having preserved cognitive and communication skills. Table 1 shows the demographic characteristics of the caregiver sample. A total of 4 informal and 6 formal caregivers took part in the study.

All participants signed a Consent Form and Copyright Declaration and were given a Participant Information Sheet explaining the aims and methods of the study. Participation was voluntary and the participants' full anonymity was assured. This project was approved by the Research Ethics Committee of the Federal University of São Carlos (3,105,608). Table 1 contains the demographic characteristics of the participants.

Data collection took place through interviews previously scheduled at the home or place suggested by the participants with a semi-structured questionnaire and performed by two field researchers in each interview (Researchers: Paula da Silva and Larissa Ferraz). All interviews were recorded, transcribed, and translated into English. The validity of these translations was checked by back-translating them to Portuguese for comparison with the original transcripts.

First, the researchers presented the project aims as well as its methodology and answered any questions participants had. Participants were

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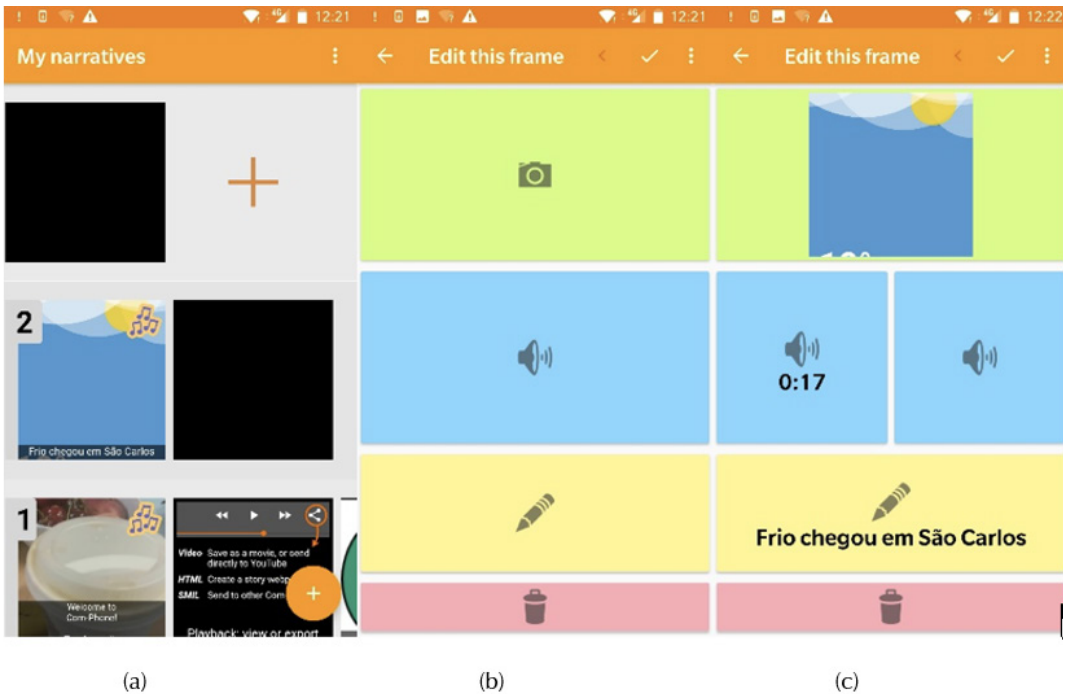


Figure 1. The Com-Phone App interface shows the home screen with a vertical stack of stories (a), an empty frame screen prompting image, sound and text input (b), and example content populating a full frame (c)

given a participant information sheet about the study and signed a consent form to take part. The interview was divided into two parts. The first part contained issues related to care and challenges in communicating with persons with dementia:

- 1) What are your roles and responsibilities in the care of the person with dementia?
- 2) How do you work together with other people/professionals to provide this care?
- 3) Can you describe a typical day in your life with the cared person?
- 4) What are the main challenges and barriers in communication between caregivers?
- 5) What types of communication problems do you have with the cared person?
- 6) How do you record and share life experiences and memories with the person?
- 7) When you think of technology, how do you think it could help with these communication problems?

In a second part of the interview, participants were shown a live demonstration of a mobile digital storytelling app called Com-Phone running on an android tablet. It has a simple interface that allows the creation of multimedia narratives, combining photos, audio, and text (Frohlich et al, 2012). This was used in our previous study in a care home setting (Abrahão et al., 2018) and is available in both English and Portuguese versions on the Google Play store: <https://play.google.com/store/apps/details?id=ac.robinson.mediaphone&gl=GB>

Figure 1 shows the basic interface to Com-Phone. This can be used to create digital stories comprising an unlimited number of frames containing any combination of image, sound, and text. Up to three channels of sound can be added so that users can mix voice, music, and ambient sound on each frame. A home screen (1a) shows the existing set of stories in reverse chronological order, and a 'plus' button to add a new story. This cues the first frame screen (1b) for users to add images, sound, or text from resident media on the phone or by recording them live (1c). Frames are saved and added until the whole story is saved. This can then be exported in a number of formats including video to other devices or social media sites (e.g. YouTube).

After seeing how Com-Phone worked, participants were shown example stories on the tablet created in the previous study (Abrahão et al., 2018), as well as a printed collection in the form of a 'talking photo album' with printed pictures and voiceover. For example, Figure 2 shows a playback of printed digital stories of a visit by the researchers to a care home resident with dementia. The pictures and sound were recorded on the Com-Phone app but printed out and recorded into a commercial Talking Photo Album from Talking Products. This allows 30 seconds of sound to be recorded and played back from each page of the album.

After these demonstrations, another round of questions was asked to get initial reactions and

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Figure 2. A talking photo album from the Abrahão et al (2018) study

critical feedback:

- (1) What were your overall impressions of the Com-Phone application to make stories?
- (2) Would you use that? Would that be useful? Why?
- (3) What devices do you think would be best for using this technology?
- (4) What should be the social network for sharing these stories? Who should be part of it?
- (5) What communication problems did you report in the first part of the interview? And which ones were not addressed?
- (6) For problems that have not been addressed, can you think of other technologies that could solve them or how our technology can be expanded and improved?

DATA ANALYSIS

The data were analysed through the thematic analysis of content by two impartial judges, which consists of a set of communication analysis techniques. These use systematic procedures and objectives to describe the content of messages (Bardin, 1977). A set of communication analysis techniques was performed aiming to obtain, by systematic and objective procedures for describing the content of messages, indicators that allow inference of knowledge regarding production/reception conditions (inferred variables) of these interview/sentence points. This analysis was divided into (1) pre-analysis; (2) exploration of the material; (3) data processing and interpretation.

Pre-analysis: All interviews were recorded, transcribed, and translated into English by an international research team from Brazil and the UK. The Brazilian researchers (da Silva, Ferraz, & Castro) worked from the original Portuguese transcripts while the UK researchers (Frohlich & Chrysanthaki) worked from the English translations. Initially, spreadsheets with a categorization of the data were generated by both Brazilian interviewers independently (da Silva & Ferraz) and later checked and extended by two other researchers (Frohlich & Castro).

Exploration of the material: After consistent ordering in the pre-analysis, the next aspect was the systemic administration of the data, coding operations, enumeration.

Data processing and interpretation: The interpretation used thematic analysis as a tool, counting one or several themes/items of significance, creating comparisons. The categories and themes from the transcription were analysed by two of the authors (da Silva & Ferraz). Categories emerged after the researchers read and interpreted the data (inductive method) for communication, technology, and feedback with sub-categories as follows:

- (1) *Communication:* in this category were included all data in which caregivers describe communications challenges faced in care activities. They usually used some examples or described

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situations that fitted in ADL; feelings; sensations; aggressiveness; consent; autonomy; Social participation and legacy.

(2) *Technology*: This category includes all information involving devices for communication, social media, and any different ways to register memories and share information for care coordination. The main reports involved coordination of care; sharing coordination; past memories; current memories; networks and social media - Whatsapp / Facebook / Instagram; photography - participation/attention and connectivity.

(3) *Feedback*: This category refers to the participant's view of the subjects of what was discussed in the intervention, exploring what is the perspective they have on this type of multimedia communication related to the potential of connectivity; positive aspects; negative aspects, and why?; adoption - would not use; utility - yes or no and why? devices - tablet, cellular, album, and suggestions; social network - family, friends, caregivers, and others.

RESULTS

Communication issues involving the care recipient

Our participants face communication challenges every day when caring for persons with dementia. When delivering care, both types of caregivers mentioned difficulties for coordinating personal hygiene (bathing), resistance to ingesting the medicine, and difficulty understanding what the person is feeling or needs. The biggest fear is not realizing if the person cared for is in pain:

"Ah ... it's a difficult thing, not knowing... sometimes she gets very restless, so we do not know what she wants, at the same time she says that it is one thing, she changes to another, I have doubts about what she really wants, then we ... The bigger difficulty is this ... if it's pain." (Formal Caregiver).

"It's when you think they're feeling something and they do not know how to communicate, they cannot anymore, right? So there you have to see what it is they're feeling, the pain where it is, what place, then you have to find out as if they were a child." (Informal Caregiver).

In our study, both formal and informal caregivers mention the difficulty of understanding what the cared person is feeling, difficulties with speech, as well as lack of communication, and symptoms of aggression were commonly mentioned. Boundaries to communication in later stages of dementia when the person does not understand and cannot express themselves may be relevant in this case. Further communication distresses them and knowing when to persist and when to stop may be an important strategy. Management of conflict with the person with dementia when they get angry and sometimes resist suggestions or instructions was considered an important challenge to overcome:

"...Speech, the speech is coiled, complicated, sometimes we do not understand and have to ask to repeat, it is the main ... the main communication problem." (Formal Caregiver).

"This problem of communication is because she arrives at the stage where she no longer communicates with us, we try to explain to her but she does not understand ... If you start to talk a lot she ends up getting aggressive." (Informal Caregiver).

"He sometimes does not understand what we're talking about, he's dispersed and he ends up being too stubborn and he does not take the things that we say seriously." (Informal Caregiver).

Care coordination and daily routine activities

All staff desires for technology were about the daily routine, including shift work and staff handovers for staff-staff communication. That feeling was reflected by the answers about delivering care and responsibilities.

Even considering the involvement of care professional friends of the family, the focus seems to be on health care and there is a gap in wellbeing outcomes. Considering the roles and responsibilities in caring; in the majority, the group of formal caregivers indicated that the main care is focused on personal hygiene, food, and medicine administration. Similar to the other group, informal caregivers also mentioned the same care and responsibilities: *"Most care is for the daily routine with the difficulties that they have ... for example, having breakfast and the typical care that they have difficulty due to age."* (Informal caregiver).

In addition to the aforementioned care, the responsibility for contact with family members receiving the care was mentioned: *"So in some cases, I review the routine and the events between the care team and the older person."* (Formal caregiver).

Considering a typical day with the person with dementia, the participants in both groups, formal and informal caregivers describe difficulties in the Activities of daily living (ADL), which are basic tasks of self-care, such as eating, bathing, dressing, toileting (being able to get on and off the toilet and perform personal hygiene functions and transferring). Here a Formal Caregiver describes her experiences caring for people with dementia as a group: *"On a typical day they get up early, take a shower, then we serve breakfast. Those who cannot feed themselves, those who are in an advanced phase of dementia, we help feed them. Many people do not want to have coffee, so we change the menu, for porridge or other things that they can swallow because they have a hard time swallowing."* (Formal Caregiver)

Both groups of caregivers agreed that there were no communication problems regarding the co-

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ordination of care within the family. Informal caregivers verbalized the need for them to liaise with formal caregivers for some aspects of care such as nutrition needs, for example. Formal caregivers highlighted the importance of teamwork between different professionals: *"We work as a team, do we not? Everyone helps to take care, when one can be doing another task, the other goes and does it too, so it's a team, it does not have a specific function, everyone helps a little."* (Formal Caregiver).

This fact was also clear in the group of informal caregivers and the word GROUP was mentioned in the different interviews: *"Listen ... The work of the group makes a whole. I, as husband, are also responsible for her, my role is to give, let's say, every possible tool to the formal caregivers."* (Informal Caregiver).

Social media and digital content

When questioned about how they recorded and shared life experiences and memories with the care performed, both formal and informal caregivers stressed the use of digital social networks to share and make communication simpler and faster. The use of WhatsApp was mentioned by several people, (mentioned six times) as well as Instagram (mentioned three times) and Facebook (mentioned two times):

"Surely to be clear about the information, to leave the communication less formal, you know? Although family members who seek the information are very receptive to the pass-through." (Formal caregiver).

"There are always photos that are posted on social networks as Face and Insta (in reference to Facebook and Instagram)." (Formal Caregiver).

Usually, the person with dementia is outside this process of sharing using social media. The sharing of social media is usually a form of communication and memory for professionals and family/friends:

"We make videos using the phone, also audios, photos, we use Facebook, 'Whats' and Instagram for posting these videos, only my grandfather does not use any, who really uses it is my cousin who post, who plays with him but he does not pay much attention, pay attention for a few minutes." (Informal Caregiver).

"Perhaps if the activity that uses technology was gradually inserted into his routine, he would get used to the idea and follow the activity" (Informal Caregiver).

However, attempts were made by informal caregivers to share photos with the person being cared for, as a way of sharing memories and promoting well-being with positive responses to visual stimuli such as smiles, for example:

"Ah you start talking about family, you talk about the kids, you show photos that they like, aaah ... things that you think they are going to like, my father lived a long time on the farm, so he likes to see horses, cows ... you know? Then we show him these things and he's very happy." (Informal Caregiver).

"We work with her with photos from the past, our marriage, the birth of the children, the grandchildren, we show her, she looks, she does not have an answer, but you realize she is watching, so she's seeing, it's got ... I cannot explain to you what it would be, but I realize that there is an interest ...and so we communicate with her this way." (Informal Caregiver).

Photos were also mentioned as evidence of the quality of care, for positive or negative experiences: *"... for example, he is not eating, then yesterday he did not eat well, look today he ate, today he is fine, today he is doing the nails, we take the picture and send it to the family and other people via WhatsApp and then a relative ends up monitoring by that instrument."* (Formal Caregiver).

When talking about new technology for addressing communication issues, the caregivers demonstrated openness towards innovative solutions: *"I think it (technology product) could aid them understand things more easily, as well as preserve some of the memories. Communication would be easier, at least for purposes of their day-to-day routine."* (Formal Caregiver).

The main conclusions of the first part of the interview were that most caregivers are active in ADL care, but mention difficulties in understanding what people with dementia are feeling, difficulties with speech, as well as lack of communication and symptoms of aggression. Formal caregivers reported not having difficulties in the contact with family members in relation to the care provided. Informal caregivers concurred with this and emphasized the importance of teamwork with professional caregivers.

Digital storytelling technology feedback

After the demonstration of the digital album with stories from a previous study (Abrahão et al. 2018) formal and informal caregivers believed the application Com-Phone had the potential to bring family, formal caregivers, and persons with dementia together:

"And I think ... it is a very cool initiative and mainly makes a bridge... ... I think it ends up comforting the family members..." (Formal Caregiver).

"I think it's very interesting in the part of interacting with the family with the caregivers, it's a story that is going to be kept." (Formal Caregiver).

"I think it is very useful, it serves as the basis even to prepare people for tomorrow, families, caregivers and all this comes to help, so I think we

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have to work and always think about tomorrow trying to bring news and things which can be absorbed by the family, by the caregivers and bring much more comfort to the patients and the people in the states that the mind really is deteriorating in the day to day." (Informal Caregiver).

The different caregivers also pointed out that they would use the application and that it would be useful for reminiscing, social participation, and collecting mementos for the future. They believe that technology could help in communication problems, to share life experiences and memory, as well as to coordinate health care. For example, one informal caregiver suggested using family photos to see how much is remembered by the person with dementia: *"Oh I would use it because ... it would be useful because you take the family picture and show it to them so they can see if they are remembering these things and for them to see that they are ... seeing something different, like things they will save in the mind, try to save, right?"* (Informal Caregiver).

Another felt that digital storytelling could be a way for them to remember and communicate an experience of their own: *"It would be useful because even for us, it would be a different way of remembering a moment and an experience that we lived with some people."* (Informal Caregiver).

Similarly, a formal caregiver saw digital storytelling as a tool for them to use in their work with the person with dementia and their relatives: *"I would use it, of course. Most of the old people I deal with have remote memories about their children and relatives. With the possibility of showing a photo with sound or writing, somehow they would recover their memory, at least at that moment."* (Formal Caregiver).

As for the best device to use this technology, Tablets, cell phones, and even laptops were mentioned:

"The easiest would be to use the smartphone which is what we have and the most used, but I think that laptop would also be a good one." (Informal Caregiver).

"Tablets ... as they have difficulties always need to have help in using, in cases that the routine is a little busy maybe that would be a con, but has the pro that is an intermediary (an interaction)." (Formal Caregiver).

"I believe it would be the computer or laptop because of the size of the image..." (Formal Caregiver).

Both kinds of caregivers suggested features that would be useful, and integration with existing social media systems: *"I think ... just thinking about involving family directly, I think of WhatsApp and videos and share it with a relative."* (Formal Caregiver).

There were a diverse set of responses to the question about who should be included in a story-sharing network. However, some participants suggested that the network be kept small and limited to the family and friends of the person with dementia: *"The family, the friends, right? That sometimes friends do not have a chance of being together and in the album they would be, he would be watching, remembering, it is very interesting."* (Formal Caregiver).

Others felt that the formal care team should be incorporated in the network, keep them informed of family stories: *"The family, the caregivers ... and the older person, I think they would be ideal scenarios."* (Formal Caregiver).

Some participants felt that the digital stories could be of benefit to other families or caregivers of people with dementia, creating a kind of care community across which to share information in story form:

"I think more family members and institutions responsible for care and legal rights of older people." (Formal Caregiver).

"Starting with who should be part, I think the community in general, but having a focus on the families who live with them.. to share experiences and exchange tips on how it works with them, how it did not work, and so on..." (Informal Caregiver).

Ethical issues were also pointed out, such as authorization of the persons with dementia oversharing these stories: *"So I think it's kind of complicated, I think I should have the person's permission, but she does not ... sometimes she cannot have that insight, now it could be otherwise shared by the family, by the person in charge."* (Formal Caregiver).

DISCUSSION

Previous studies have found that poor communication between a person with dementia and their caregivers, contributes to the caregiver's tension and markedly increases the impact of support. Difficulties in interpersonal relationships and communication with the health care team are considered fundamental challenges that cause a high level of frustration and emotional load (Gentry, Fisher 2007; Woodward, 2013). Poor communication has also been found to have a particularly profound effect on the lives of people with dementia, as it affects their ability to interact socially, maintain relationships, plan daily activities and express basic needs and thoughts to those around them. The person with dementia loses the ability to communicate thoughts and needs as the disease progresses, making it increasingly difficult to interact socially and maintain personal relationships with caregivers, family, and friends (Woodward, 2013; Delfino, &

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Cachioni, 2016). In this sense, information and communication technologies have the potential to improve the quality of the provided care, often perceived as pressures on caregivers (D'Onofrio et al, 2017; Lucero et al, 2019).

In this study, we have tried to understand some of the obstacles to communication in these contexts, from formal and informal caregivers' perspectives. Returning to the aims of the study, we discuss these obstacles first before considering the role of ICTs and their possible re-design.

Communication obstacles

Dementia produces a noticeable decline in cognitive function and usually interferes with independence in performing basic daily activities (ADL) such as dressing, eating, personal hygiene, and physiological activities (Classification of Mental Disorders and Behavior - 10, 2011; Fernandes, 2018).

Although the formal caregivers participating in the research report that most care is for the activities of daily living, the coordination of this care is always linked to a team with many caregivers providing this care to the same person. As far as communication is concerned, the main difficulties are related to the understanding of the feelings and sensations due to the absence or poor expression of people with dementia that they care for. Communication problems with the family were not reported, but important issues related to the autonomy of the individual are mentioned in the caregivers' reports, considering psychosocial factors such as family, education, health care, initiative, and motivation of the older person, as cited by Argimon & Stein (2005). In turn, all informal caregivers reported their involvement in ADL care. Similar to formal caregivers, the main reported obstacles in communication are also concerned with demonstrations of feelings and expressions such as pain by people with dementia. Symptoms of aggression were also mentioned by caregivers.

The communication barriers most commonly mentioned by caregivers of persons with dementia in the literature are difficulty in communicating due to repetitive requests, marked diminution of vocabulary, unfinished phrases, anomic aphasia, and often lack of dialogue (Oliveira et al., 2016; Österholm & Hydén, 2016). Some of these factors were mentioned by our participants as well as the use of non-verbal communication to compensate. Our caregivers were also curious about the effect of physical and environmental factors on communication such as grooming, music, soundscapes, or outdoor experiences.

These findings are aligned with literature showing that ADL care is central to high-quality

residential and home-based care, but further research is needed on the association between ADL care, communication, and wellbeing (Giebel & Sutcliffe, 2018).

Role of digital storytelling technology

During the study, both caregiver groups mentioned using social media to coordinate care and share memories, especially Whatsapp, Instagram, and Facebook. It is important to emphasize that these social media were not used by the persons with dementia who they care for. Typically the technology was used by others, with selected content shown to people being cared for. This suggests a challenge and requirement for existing social media systems to be made more accessible to people with dementia themselves as a specific class of disabled users. This will mean improving interfaces to both web and native Apps, across a range of mobile and fixed devices (e.g. Kort, 2011; Petrie, Savva & Power, 2015).

In addition, both formal and informal caregivers thought that mobile digital storytelling technology of the kind represented by Com-Phone had the potential for improving communication with people with dementia. In fact, eight out of the ten caregivers interviewed said they would use this technology to make multimedia stories with the people they cared for, as a recreational activity. They saw this primarily as a recording tool for activities and memories that might also stimulate a different kind of conversation and interaction with the person with dementia. However, the high educational level and generational difference of caregivers in relation to those cared for can affect the view of the older adults in the use of multimedia communication. The platform used was not dementia-friendly or universal design. Experimental group activities with people with dementia that empower the engagement and social participation of older adults towards a universal design might bring a new perspective and re-evaluation of caregivers regarding the perception and engagement of people with dementia in the use of this kind of technology (Sterns et al 2008).

In this connection, there were concerns over the privacy of resulting digital stories and who they should be shared with. Possible recipients were small groups of family, friends, and caregivers, as well as larger dementia support groups or even health and government institutions. These equated broadly with the different approaches of existing social networks participants were familiar with, such as WhatsApps for more closed and private sharing, or Instagram and Facebook for wider sharing.

Technology recommendations

The findings suggest a number of recommendations for what might be called 'assistive media' technolo-

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gies having therapeutic benefits for health and well-being in dementia care (Frohlich et al 2019).

First, there is clear difficulty in both understanding and communicating with people with dementia because of their own language impairment. This implies value in using aspects of existing assistive communication systems, normally applied in a speech therapy setting, to the dementia context. For example, simple ways of indicating emotions or communicating through pictures may be helpful for people with dementia and their caregivers (Phillipson & Hammond 2018, Stans et al 2019). Digital storytelling technology might also be employed herein creating audio-visual materials for communication such as talking flashcards, and these might even be printed using augmented paper technology to allow sounds to playback from physical cards (e.g. Frohlich et al 2004).

Second, although social media systems are used by formal and informal caregivers to keep in touch with each other and even share media with the people they are caring for, none seem to be accessible directly by people with dementia. This is unfortunate because messages and media could at least be received by such people in the absence of their caregivers to establish a remote connection. Dedicated photo displays might be designed in this context, or special ambient modes for tablets kept on a stand so that people with dementia can see picture-based messages arrive as easily as glancing at a traditional photo frame. Beyond this, caregivers seemed to request integration of digital storytelling tools into existing social media systems such as WhatsApp and Instagram, so they can enrich the communications they already send to each other over these channels. Indeed, this seems to be happening spontaneously to some extent, as seen by the introduction of Instagram stories for summarizing trips and activities.

Third, caregivers were impressed with the Com-Phone app itself and its ability to capture memories and stories in audiovisual form. They saw value in this for capturing stories from the people they were caring for, as well as from themselves, and using those stories later as reminders and triggers for further talk. This is a traditional use of digital storytelling in capturing personal histories for sharing and might be applied to good effect in this context where memory loss is slow and degenerative and might be counteracted by recording and rehearsal. The use of stories and media in a home context for this purpose is likely to involve very different interactional dynamics than those in a care home setting, leading to a new form of domestic reminiscence (Campbell et al, 2019).

Limitations and future research

In this study, there was no participation of people with dementia, which leaves us with incomplete results. Although we have some considerations that serve as a comparison in our previous case study (Abrahão et al, 2018) which involved a participant with dementia, future studies with this target user are essential for us to reflect on a friendly dementia design in digital storytelling products. In addition, we did not have authorization from the ethics committee to characterize the care recipients of the interviewed caregivers, nor the degree of severity of dementia, and, despite all caregivers being responsible for people with dependence, the lack of more information about the peculiarities of each case can have a great impact on the data about the communication issues presented in the current study.

In general, we did not find any marked differences in the reported communication problems in the home care setting, compared with those reported for institutional settings, in our ongoing study, not published yet. The interpersonal dynamics between both formal and informal caregivers and people with dementia appear to be similar across settings, and there is a perceived lack of time by both types of caregivers to focus on emotional as well as physical needs, but further studies are necessary to compare both settings. It is likely that the unavailability of 24/7 professional care in the home will be felt keenly by informal caregivers at crisis moments and over long periods of time. But these were no complaints made by participants in our study when talking about communication issues. In fact, communication between informal and formal caregivers themselves was reported by both groups to be very good.

Another important point was the application and therefore, the platform used, whose design was not dementia-friendly or universal design. But after considering both the interviews and the case study mentioned above, a hybrid between digital; for family, friends, and formal caregivers, with a paper album; for people with dementia and digitally disengaged informal caregivers, it seems to us a more inclusive means and we will continue with future research in an attempt to adapt this interface using augmented paper (Frohlich et al, 2020).

This study is just exploratory to raise demands and feasibility, but more robust studies such as randomized clinical trials using digital storytelling in dementia care communication could expand this intervention and answer questions about its effectiveness.

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Finally, concerns over the privacy of stories and whom they should be shared with led to discussions about the size of the sharing network. Opinion differed between participants whether this should be family or community centred, with benefits being seen for wider circulation as an educational tool for others. This suggests that strong attention should be paid to ethical and privacy issues in any application of storytelling techniques in this area so that the wishes of caregivers and people with dementia themselves are taken into account.

CONCLUSIONS

Caring for people with dementia in the home is a challenging task for both formal (professional) and informal (family & friend) caregivers. Through in-depth interviews with a small number of these caregivers, we found that one of the greatest challenges is communication with people with dementia, especially in understanding

their feelings, frustrations, and language. Another major challenge is finding time to go beyond caring for their basic activities of daily living (ADL) to enhance their quality of life through more meaningful conversations and experiences. Requirements for new communication and digital storytelling technology were suggested for each of these challenges. First, new assistive communication technology could help with the expression of ideas through predictive speech or text options and visual stimuli. Second, new assistive media technology such as digital storytelling tools could help caregivers facilitate storytelling and remembering in people with dementia, or capture joint activities in richer forms. In both cases, designers should strive to allow people with dementia themselves to operate the technology and at least consume digital content themselves, rather than always being the recipients of technology experiences mediated by others.

Ethics

This study was approved by the Research Ethics Committee of the Federal University of São Carlos (3,105,608).

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