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MEMENTOS
**Friendsourcing the unmet needs of people with
dementia**

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To everyone who lost their loved one to the disease.

Resumo

A doença de Alzheimer, a forma mais frequente de demência, afeta cerca de 1% da população portuguesa e prevê-se que tal duplique durante as próximas três décadas. Sendo uma doença crónica, sem cura, o tratamento farmacológico resume-se a desacelerar a evolução da patologia, tratamento esse que pode ser complementado com atividades de estimulação não-farmacológicas.

A estimulação cognitiva e a terapia de reminiscência são duas das técnicas mais utilizadas para estimular os doentes. Ao evitar que estes se isolem do mundo que os envolve, promovendo a comunicação e a orientação para a realidade, diminui-se a perda de noção espaço-temporal e o seu declínio social. No entanto, todos estes processos são ainda bastante manuais, analógicos, com pouco material de suporte dinâmico ou personalizado para cada doente.

Com uma tendência cada vez maior para os cuidados centrados na pessoa, é necessário conhecer os seus gostos e a sua experiência de vida para se poder direcionar o tratamento de encontro ao que mais gosta, motivando-a mais facilmente e atingindo melhores resultados. A recolha dessa informação acaba por recair na rede de cuidadores, um processo moroso e por vezes demasiado exigente especialmente quando já há uma fraca disponibilidade quer física quer emocional por parte de quem lida com a doença.

Depois de se obter uma caracterização dos cuidadores e profissionais de saúde, assim como das suas necessidades, identicou-se uma falta de ferramentas de suporte à estimulação cognitiva, especificamente à terapia de reminiscência. Desenvolveu-se uma plataforma integradora que fornece o material necessário - eventos, fotos e música - para a reminiscência. Tal tem utilidade para os cuidadores que estão em casa com a pessoa com demência, passando pelos profissionais que podem conduzir melhor as suas consultas, indo até aos funcionários dos centros-de-dia que sabem agora mais sobre aqueles de quem tratam. Ao utilizar mecanismos de friendsourcing, essa recolha é partilhada por toda a família, fomentando-se a interação e interajuda, ao mesmo tempo que se alivia o esforço e se obtém material mais diverso. Com mais material promove-se a estimulação dos doentes, ao mesmo tempo que os fazemos comunicar mais com o mundo exterior, atrasando a evolução da doença.

Palavras-chave: Friendsourcing, redes sociais, demência, estimulação cognitiva, terapia de reminiscência

Abstract

Alzheimer's disease, the most common form of dementia, affects about 1% of the Portuguese population and it's predictable to double in the next three decades. Being a chronic disease, without cure, the main objective is to slow down its evolution. That can be achieved by combining both pharmacological and non-pharmacological treatments, like brain stimulation activities.

Cognitive stimulation and reminiscence therapy are two of the most used techniques used for stimulating the patient and avoid their isolation from the world they live in. By boosting their communication and exercising their reality orientation, we will improve their mental state, avoiding the loss of spatial-temporal reasoning and their social decline. However, all those processes are still mainly manual, analogic-based and with few dynamic materials to work with or even personalized to each patient.

Thanks to the increasing trend on person-centred therapy, there's a need to know the interests and life experience of each patient. Their treatment plan can then be designed to meet their likes, motivating them more easily and leading to better outcomes. The collection of that information is delegated to the network of caregivers and can result in a time-demanding and tough task, even more when they are already overburden with the disease.

After reaching a characterization of caregivers and professionals and their unmet needs, we identified a lack of tools to support cognitive stimulation, specially reminiscence therapy. An app was then developed to deliver an integrated platform that can provide all the needed material - events, photos and music - to perform that therapy. That has added value to caregivers who live with the person with dementia, healthcare professionals who can direct their appointments better and daycare centre's staff who can now know their patient's interests. By using friendsourcing techniques that collection is shared between the family, promoting the interaction and mutual help, as well as relieving the burden and collecting more diverse material. With more material the stimulation is more motivating, making the person with dementia communicate more frequently and therefore delaying the disease's evolution.

Keywords: Friendsourcing, social networks, dementia, cognitive stimulation, reminiscence therapy

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Chapter 1

Introduction

As the world's life-expectancy is getting bigger, people tend to live longer and therefore are more likely to suffer from neurodegenerative diseases, like Alzheimer's disease (AD), the most common dementia type. It's estimated that 35 million people have dementia and that number will double by 2030 and is likely to reach 115 million by 2050 [1]. Since this disease leads to memory loss, disorientation, anxiety and depression, it has major impacts not only on the patient itself but also on their caregivers.

In the early stages of Alzheimer's, the stimulation of the patient's memory will likely induce to a slower evolution of the disease [2]. That can be done through cognitive exercises, specifically via reminiscence therapy, the main focus of this thesis. Reminiscence therapy works on reviewing personal positive memories, which can be done mainly using photos and music. Without enough support material the reminiscence therapy will turn into an unmotivated and unpleasant activity, leading to its exclusion from daily habits.

In order to try to make it less painful to live with the disease, this project will focus on coordinating the patient's past memories with the network that is still their main anchor to a socially active life. This will range from creating meaningful archives of their past to the acknowledgement of their actual significant activities, allowing both to be populated by trustworthy members of that network.

There was a permanent focus throughout this project in creating a more effective involvement of the carers network in those patient's supportive applications. The developed app can be enriched with relevant information collected from the network via friendsourcing mechanisms, bringing people together. This aims to maximize the impact of those apps in all the involved stakeholders, from the people with dementia to their families, caregivers and healthcare professionals.

1.1 Motivation

Reminiscence therapy encourages patients to review past experiences of a pleasant nature, stimulation their long term memory. However, the existing support systems require too much time from the caregivers are often too complex, making their filled and stressful days even more overloaded. Making digital biographies of the elderly isn't an easy task, especially when the person isn't capable of being the main contributor of their own past anymore. When taking care of someone with Alzheimer's, the caregiver is forced to add up to his normal daily workload a huge amount of mental strength to give them all the medical, hygiene and emotional assistance.

As we can easily see, there isn't much free time available and if there is any they surely don't want to waste it doing repetitive and time consuming tasks like filling a large digital photo album. Using the tools available nowadays, this is a process that demands hundreds of hours just to fill in the needed information to operate.

These AD support tools should be concise enough to not requiring too much time from the carers network and, to avoid those risks of putting the patients into stressful situations, designed to be used by the caregivers and the healthcare staff. That extra human layer will intrinsically filter what to and not to show and also to analyse the patient reactions to the different triggers.

It should always be considered that those systems are better and easily used the less they demand from all the participants. In order to make them really usable and useful they should be kept simple, with just the necessary information. This will also help to diminish the potential privacy issues that could be raised with the use of this kind of tools who log your personal life.

1.2 Context

This master's thesis is part of a greater project on HCIM@LASIGE about technological appliances for people with dementia. Under this major umbrella the team developed independent apps, each with a specific target audience and purpose.

Although the apps are developed by different members, the team act as a whole, increasing the productivity and effectiveness of interviews and surveys. This way, on a single session, we asked questions regarding the project as a whole and also about both apps in particular. This win-win situation allowed to give more context to the interviewees about our work and also made us save time, asking all the needed information just once.

Currently there are two different apps: Remember-Me 2, related with reminiscence therapy, which will be described in detail on chapter 4, and Day2Day, related with daily life records and data visualization. In a nutshell, the healthcare professionals can set up questions to be done to the main caregiver every day, like if there was any incident or how was their humour. That collected data is then displayed to both caregivers and professionals and thanks to statistical information and variable correlation we can improve the pattern discovery and the quality of the medical appointments. This app is not the subject of this thesis and its details will not be further discussed. However, when analysing interviews and surveys, as well on the evaluation phase, it will be mentioned when it's relevant to the project and the reminiscence app.

From now on in this document, the pronoun 'we' will refer to the work done as a team, where 'I' means the main work of this thesis: the reminiscence branch of the MEMENTOS project.

1.3 Research goals

The main purpose of this project is to develop an integrated platform that can potentiate the communication between caregivers, family and people with dementia in order to increase patients cognitive stimulation, communication and social interaction. This was achieved by:

- Improve personal data collection through social media and crowdsourcing;
- Facilitate as far as possible some of that information collection by finding patterns common to most of the patients;
- Diminish the caregivers' burden while using tools to help people with dementia having a better quality of life;
- Deliver a synthesized and useful platform, simple and easily accessible, that can resume the patient's life, interests and daily routines;
- Make use of friendsourcing mechanisms to enrich the developed apps;
- Not being girded to static media, like photos, but open the reminiscence therapy to a more dynamic approach, which may include the use of media;
- Provide new mechanisms and tools to support regular healthcare appointments

1.4 Approach

Since there's a lot of different stakeholders potentially interested in this project's outcomes we shall address their specific needs, bringing them together under a same platform as much as desirable.

The wellness of the person with dementia is always the main concern when developing those apps and there are two major groups of stakeholders that are continuously working towards that goal: healthcare professionals and caregivers. To reach those two groups we started a partnership with Alzheimer Portugal association, making use of their network and giving them back our results and achievements.

In terms of healthcare professionals we conducted a series of individual interviews where we could analyse the different perspectives regarding each ones work field, as well as realize which needs are transversal, how do they interact between themselves and what information they should share. However, those professionals also need to interact and communicate with the caregivers.

The caregivers group is more homogeneous when compared to healthcare professionals. Although they could be very distinct between them, all share an identical burden and therefore have identical needs. Their availability to do individual interviews is also much smaller so we ended up collecting the data we need via online survey, who gave us a large number of detailed answers.

With all those various unmet needs, we started to develop two major prototypes: one towards the contributive gathering of biographic material to reminiscence therapy and another towards the record of daily life routines, like a digital diary to keep track of the disease evolution. Those two apps try to cover the main and most common aspects revealed on the interviews and the survey. Certainly there is more to be done but the main core is settled in those two main needs: a better way to collect biographic data from various providers and a faster and more efficient mean of communication between the caregivers and the professionals.

Those developed apps can only be considered useful after validated by those who are going to use it. We got back to the interviews, now in a more specific and restricted way, to talk about the developed systems. The approach regarding healthcare professionals was the same used to collect the requisites, however, we adopted a totally different one to reach the caregivers. Thanks to Alzheimer Portugal's sponsored activity *Café Memória*, a social gathering of people interested in Alzheimer's disease, we were invited to participate and lead five different sessions. There we could talk directly to different kinds of caregivers, converging their opinions with the ones given by the professionals. This allowed us to do some fine tuning

of the apps and to know where to go next. Both groups made suggestions about additional features that we could add and how can we improve the current ones.

Only with this close and iterative contact with all the stakeholders we can walk towards completion, delivering a functional and complete system that actually improves their life and work quality, as well the patients well-being.

1.5 Contributions

- **Requirements gathering** next to 9 healthcare professionals, each one with a different background, job and work environment. By interviewing people who have to interact with people with Alzheimer's but have different jobs, we can collect distinct opinions, perspectives and needs.
- **A characterization of the common Portuguese caregiver**, knowing their habits, needs and concerns. 536 caregivers answered a comprehensive online survey that allowed to characterize the common profile of the Portuguese caregiver. The questions covered their daily routines, habits towards cognitive stimulation exercises and also their feelings about social networks.
- **A collaborative and friendsourced web application** that allows the whole family to work together around the person with dementia, tightening the emotional links between them. This shared creation and population of life events allows caregivers and professionals to access personal material that otherwise would be hard to achieve. The platform enriches the reminiscence therapy sessions with different types of media, improving their quality and diversity, which consequently increases the well-being of the person with dementia.
- **The validation and first-person speech opinions** of those who have to deal with the disease daily, each one with their personal and singular perspective. After presenting the application to 50 current or former caregivers, we could collect meaningful feedback about the developed solution, as well as new ideas for further improvements. This feedback was also supported by the professional's perspective, with elicitation interviews to 2 neuropsychologists.

Chapter 2

Related work

One of the most devastating effects of Alzheimer's is the loss of identity. There is a correlation between changes in the identity and the decay of autobiographical information, which leads us to the need to preserve the identity of people with Alzheimer's disease. Although it's still unclear if identity should be considered as a static thing that belongs to the past or an ongoing process, its sense should definitely be stimulated.

However, we must have in mind that reminding someone with dementia that once was a successful entrepreneur and a family man can either be good - improving the referred sense of identity - or depressive since it may highlight current inabilities.

Lifelogging and reminiscence tools address two of the perspectives we have to considerate in this project. While stimulating a person's memory, we don't want to focus only on the past - the regular focus of reminiscence therapy - but also on the present or at least on the recent past. Events that happened a week ago should also be considered when reviewing old memories and therefore lifelog mechanisms are essential to this approach.

Besides those two temporal lines, the lack of personal material can be solved if we expand the network of contributors. By having a friendsourced approach, each element of a network of trustworthy friends and family can contribute with their own significant material towards a common goal. Nevertheless, this raises privacy concerns since there's personal information being exchanged throughout the network.

2.1 Lifelogging

Our daily life is full of information and the most part of it is never stored. Lifelogging is all about gathering as much information as possible such as geographical coordinates, events or people we've talked to. By creating a digital record of our lives, it will be rich enough to then be used in future memory. Features like knowing every one we ever met and every event we've attended to is useful to everyone and not just for someone with Alzheimer's [3].

That information can be gathered through wearable devices that have always collecting information like SenseCam, which takes photos from the patient's chest every thirty seconds, allowing the person to review what he actually saw during his day [4]. However this is not mandatory, with other approaches collecting information only on specific places or during some activities.

Therefore, there are some details transversal to all lifelogging tools that should be looked into when developing solutions for helping people with dementia. For reminiscence therapy sessions, it could be useful if the data coming from those lifelogs would be instantaneously aggregated as life events [5]. Those events aren't isolated from each other, they belong to a certain time frame and have interactions with people, places and also other events.

Memory supporting tools should save not only information about a certain event but also about other events which are somehow related with the first. Those tools should be able to give a context to the given information, making memory stimulation easier and more successful. However, that context should be concise and minimal, without overwhelming the user with the amount of data [6].

Another interesting aspect about lifelogs is the difference between reviving memories in the third or the first person: family photos are often portraits where everybody can see themselves. For memory purposes, it would be also useful to have photos taken by the person itself, which can appeal to memories taken from a first person viewpoint. Even if we don't record photos each half minute - the patient has the right to find it harmful in terms of privacy - it would be interesting to take a snapshot each time their location changes significantly.

To take advantage of that device and build a consistent identity of the patient, therapists could articulate the SenseCam photos with the past life of the person with dementia, so they can correlate their old interests with their actual life and habits. The family, caregivers and healthcare professionals could know better who that person is nowadays and what are their usual behaviours.

2.2 Reminiscence tools

The reminiscence therapy is a key procedure when dealing with this form of dementia. Through the use of life events, photos, music and other supports, the personal past of each one is used to maintain a better mental health. By remembering their daily routines or their past histories, the patients can stimulate their memories and promote the dialogue between themselves and the rest of world. This prevents the inevitable social isolation and respective declination [7]. There are two main approaches on reminiscence applications for people with Alzheimer's: the apps can either be developed for being used by the person with dementia or the caregiver.

2.2.1 Multimedia biographies

Multimedia biographies [8], although filled with information by the patient's family and friends, belongs to the first approach. The information collected by the caregivers is then available on a permanent basis through an always-on device that is placed at patient's home. In those biographies is advised to split the identity of the patient into chapters, making the process easier for the caregivers. With this approach they can remember more information that belongs to an identical time frame and the person with AD can remember more memories because they are contextualized temporally [9]. Those chapters could be, for example, childhood, marriage, children and other major life events.

It's not easy to choose what are the highlights of someone's life: only each one can decide what the most important moments were [10]. Even the family has different - sometimes opposite - ideas and memories that drives to a different sense of highlight. The past is not a clear and still thing, events interact with each other and sometimes people create a distinct, even erroneous, memory regarding their feelings about it at the time they occurred.

Nevertheless, after gathering useful photos and music about each chapter, that information is displayed on the Biography Theatre: an always-on computer disguised as a picture frame, placed in the patient's kitchen. The results of this experience were positive as the psychometric test revealed an increase in self-identity and a decrease in apathy. But, since there was only one person participating in this study, the results have no statistical meaning. Populating the Biography Theatre with personal information was time-consuming to the caregivers and even the patient sometimes felt fatigued by the reminiscing process [8].

Every time we speak in personal and biographical approach to the reminiscence therapy we must mind the overburdening of caregivers. It's not only the gathering of

photos and stories but also the discussions with the research team and the follow-up interviews, which may take months, that makes families think a lot before agreeing to being part of this research. In this particular approach [9] the creation of the biographies lasted for eight months in some cases, leading to 100 to 200 hours of work which can be too demanding for the carers. Also, the biographies were DVD-based which may add a barrier to both caregivers and patients: the DVD itself can get damaged and the remote controls of DVD players are not as intuitive as they could be.

About the presence of the device at patient's home, it improved his social life, with the whole family gathering around and even inviting his friends to come by and see the display. There was significant improvement in remembering family members' names and the patients often feel joy and happiness when watching their biographies. Besides, caregivers may remember how the person was before having Alzheimer's. However, as the patient's disease stage evolves, they find it harder to focus on the same activity during much time.

Although it doesn't bring back lost memories, the family notices an increase in the interest of the AD patient in his past and even discuss it with the caregivers, remembering some details that were almost lost forever, making him proud of who he was and what he has done.

2.2.2 Friendcrafting Memories

Friendcrafting is another web application, in this case more dedicated to the end-user, that is the caregivers. Its interface is more user-friendly, making use of a bookshelf where the user can choose from different books: Photos, People, Interests and Places. [11][12]



Figure 2.1: Friendcrafting Memories' landing page

Each of the books represents a different style of displaying the information acquired via Facebook through Remember-Me, another in-house developed service that is described further on this chapter. The user can review their events and who attended each but can also recall who are their friends and when and where they were together. There's also the option to open the interests books, where the platform collects information from Wikipedia about each Facebook page that the user likes.

Since we're going to re-design this interface we must first collect requisites from the stakeholders in order to direct our work towards their unmet needs. We intend to develop a concise system that could conjugate the best from tools like Portrait and this one. Therefore, we first must be sure how the information should be displayed to the caregivers. For this reason, interviews must be done to several healthcare and nursing home's staff to get information about their daily tasks, what they would like to know and what are the most interesting features of those already present in Friendcrafting Memories.

2.2.3 Portrait

A different approach, more dedicated to the staff of nursing homes and day care centres, is made by Portrait [13]. It's hard to establish patterns when each person with dementia is a different case and will react differently to an equal stimulus. Nevertheless, they all end on a common path: the deterioration of the AD patient's communication skills. Professional caregivers are mainly responsible for clinical acts or for keeping patient's hygiene and it's often difficult to create a personal connection with the patient. Also, there's an increasing need of knowing their likes and dislikes, as well as their past life, so the staff can see them as the person they were.

Therefore, Portrait is designed to be used by the professional caregiver and not by people with dementia. Its main goal is to help staff making conversation with the person with dementia through a system where the caregiver can access synthesized information about the patients and his interests. This will eventually stop the usual silence that drives all interaction between the staff and their patients, making it easier to find common subjects to start a conversation [14]. If those emotions and memories are not exercised, which is easier thanks to the lack of communication, they will get more and more isolated from the rest of the world, leading to depression, anxiety and to a quicker decline of their social and communication skills. Unfortunately, when dealing with Alzheimer's that decline is most of the times irreversible [15].

Nowadays, in order to fight against those bad habits, the approach is getting

more person-centred, where each patient has a different treatment plan and is taken care of as an individual, distinct from every other. As in the multimedia biographies tools, the past life of the patient is divided in several categories, having a structured summary of their background and interests. This way caregivers can see the person with dementia as the person who had lived a long life and not only the patient who needs healthcare support [16]. From the patients' point-of-view, this could help seeing the professionals as someone who is not too young to share interests or to have a decent conversation [7].

However, filling Portrait's needed information relies on the family ability to provide that material. That can turn out difficult when families are not as present as they could be or even when there's no sense of unity through the family, leading to opposite wills towards giving or not that personal info. In stress and depressive situations, like taking care of someone with dementia, people often have strong reactions on adding more work related to someone that personifies that stress. This may even end in the refusal of collecting personal information [14].

In order to minimize that extra work, the researchers could specify precisely their needs, for example "We need three, and only three, pictures of her wedding day". Like in multimedia biographies, it would be really useful if people in early stages of dementia could populate their portraits themselves with the help of caregivers or other professionals. Also, the system should be implemented in a manner that doesn't require a change in the actual workflows, so the integration could be more natural and not resulting in extra work for the professionals [7].

2.2.4 Computer-assisted reminiscence therapy

In the Computer-assisted reminiscence therapy (CART) project [17] there's a mix between personal and general memories. For each patient, the system has personal photographs, general photographs from public places that they should recognize and also a playlist of songs which they can, or at least should, relate to. That information is then synthesized on a tablet that should be used by the staff, like in Portrait.

When comparing with traditional approaches of reminiscence therapy, like using books, the staff noticed that the elderly can stay focused a longer time - in some cases that time duplicated - while interacting with a tablet. This could happen thanks to the larger stimulation created by multimedia or to a bigger curiosity while interacting with a technological device. Even more, while using a tablet the staff could zoom-in photos, focusing just on people's faces, which lead to a better recognition of the patient's pals and even allowed them to remember some of their names [17].

2.2.5 YouTube in group therapy sessions

Still with the approach focused on the caregivers' job, we can also extend the reminiscence therapy from photos to videos. YouTube and general video playlists can be set by the caregivers and then be the reminiscing trigger in facilitated discussions within a group of people with dementia [18]. Like Portrait, this process demands a dedicated occupational therapist, or another member of the staff, to stimulate the communication between the patients. The therapist can analyse the patients' verbal and non-verbal contributions and also their behaviour while experimenting this kind of reminiscence therapy.

Nowadays YouTube has plenty of 1980-2000, and even older, videos from music to historical or sporting events that could trigger old memories, promoting the patients' communication. Moreover, research has shown that music can be an effective method for relaxation and restoring memory and it is believed, particularly in AD patients, that music can reach parts of the brain that other communication tools cannot [19].

In this reminiscence therapy study, the results were positive since all the six participants requested to re-attend this activity and they all were pleased while watching those videos. These sessions were assumed to be more effective as the professionals know the patients likes and dislikes better, as well as their interests. But, like in the other studies about the tools mentioned before, the sample size is too small to draw statistical information from the real benefits in the delay of the evolution of dementia.

Nevertheless, all the people involved found this internet-based reminiscence therapy sessions more enjoyable than the traditional ones. Perhaps this sessions should be arranged in groups of people interests - like sports or documentaries - and make specific playlists to each group.

2.2.6 Virtual reality

Immersing people with dementia into virtual reality (VR) systems is another approach to stimulate their past memories. This is an easier way to put them in familiar environments, where simple photographs can be used to recreate an interactive significant place.

Engagement and motivation are one of the most challenging factors when dealing with people with cognitive issues. IVIRAGE [20] is an example of how this realism can improve that motivation and excitement about reminiscence therapy. Those VR places can be costumized to the patient's needs and interests, improving the benefits of those sessions. They can interact with objects that don't exist anymore

or even visit places that have suffered too many changes to be still remembered as somewhere familiar [21]. This can be particularly useful in countries who were at war and saw their old buildings and places destroyed.

It's argued that those physical objects related to daily life have as much value in storing memories as photographs [21], helping the refreshment of procedural memories and remembering old significant activities. Their manipulation via VR may not be as easy and natural as it should be, leaving an open window to a more groundbreaking approach. Nowadays with the proliferation of 3D printers those virtual objects might turn into tangible things, even independent of any digital platform, that could be used with people on later stages of the disease when comparing to fully-digital solutions.

The time travelling to the past has been also stated as a relevant form to help in the recovery of self [21]. Even if a certain place is still the same, it could be too far to make it worth the trip: as the disease evolves the ability to travel for long distances is quite diminished. Moreover, the immersion of the patients into actual places, like their own garden, also promoted the stimulation and dialogue about related past memories [21] and not only about the garden itself.

Nevertheless, the interaction - like navigation or manipulation - with those systems is stated as difficult to carry out by people with cognitive disabilities [21], which may suggest that we should focus more on static VR environments. The attention-span should also be taken into account: people with dementia have attention impairments, making it difficult to catch their attention for long periods [21]. Finally, caregivers must have an active approach when using this kind of tools, promoting the communication and stimulating the storytelling.

2.3 Friendsourcing and social microvolunteering

Friendsourcing is a specification of crowdsourcing, being a powerful mechanism to obtain direct input from those who are, at least on a primary analysis, considered trustworthy. The data is collected from sources that belong to a closed group, having previous social ties between them [22].

It can eventually then be enriched with social microvolunteering, a distributed work force that can solve requests than don't require much time to be done and that can be done online [23]. By using a social network like Facebook, this microvolunteering gets a personal facet, asking for help to those who know and care about the person with dementia. Since that request can be accomplished online, regardless the distance from the caregiver or that person, the whole network is more motivated to

participate, showing empathy and more commitment to the cause. This will increase the chances of having positive answers to the various requests [23], improving the effectiveness of that certain platform.

This kind of appeals in social networks to help people with dementia was already tried in a textual way [12]. In our context, we pretend to adapt it to collecting of personal information, like photos or life events, making the task faster and distributing the effort through the whole family and friends.

2.3.1 Remember-Me

Remember-Me was a full-semester assignment of Aplicações na Web (Web Applications, freely translated), a course of MSc in Computer Science by Faculdade de Ciências da Universidade de Lisboa. Under the title "Life logging for Alzheimer patients" [24], they developed an web application to help people with dementia by collecting data from the internet, specially from the patient's Facebook account. It is assumed that if the patient hasn't one - which is quite predictable - their caregivers must create a fresh new account and populate it with some photos and interests.

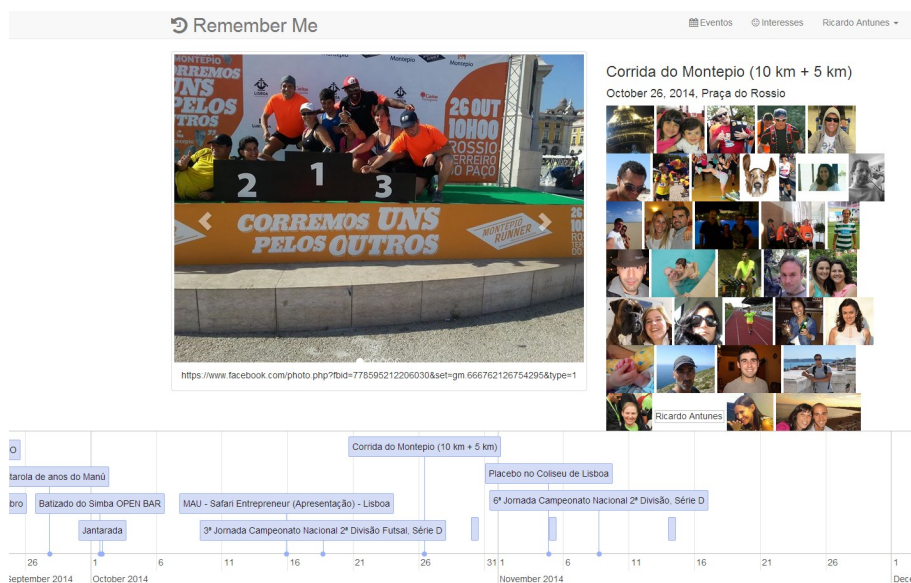


Figure 2.2: Details of an event, showing photos and people who attended it

Events, photos, places, videos and music can be collected automatically and then managed by a caregiver, which may add, edit or remove information. All the patient's events will be displayed in a time frame, allowing a more immediate perception of their order and succession.

When the user clicks on an event, additional data like who attended that event as well as some related photos are displayed. This interface isn't our main focus since

the great advantage here is the use of the webservices provided by this application. This allows a better abstraction because there's no need to directly communicate with Facebook.

The main purpose of Remember-Me is to provide the data needed to populate a future application that will allow caregivers and healthcare professionals or nursing homes staff to quickly access information about someone with dementia. Since that information is available to any application through Remember-Me's REST webservices, the core of our work can be set on the interface, accessibility and functionalities of that future application.

2.3.2 Social microvolunteering

People tend to embrace requests for help quite well [23] since posts containing questions stand out in the middle of the Facebook's news feed. In this particular case, blind people posted photos of unknown objects, asking the network for information about what was 'that'. This kind of volunteer work will eventually increase awareness in the rest of their social network as well as contribute to tighten the ties between those who help a common cause.

Facebook networking system is based on people that already had a previous offline connection or relationship [25], which means friendsourcing on Facebook has the 'friend' part guaranteed at start. Therefore, requesting help to noble causes, like collecting photos of someone with dementia or an event both attended, will probably have a positive answer.

However, that network should be large enough to take advantage from concentrating that request in just one place: the news feed. An application whose data is fed from a smaller or less active network will have a worse user experience, leading to a weaker motivation to use it. With that lack of motivation the end user will not gain enough experience to master its use, making it harder to take profit from it, leading to a snowball effect [26].

2.4 Information management regarding the stakeholders

While at nursing houses, people with dementia communicate mainly with their family and the health care staff or occupational caregivers. Since their professional caregivers are often occupied mainly with their body's condition, leaving the psychological status to a second layer, there's space for improvement thanks to the

potential communication channel that could link both family and the staff [27]. In fact, those healthcare professionals play a unique role in the communication process: there isn't anyone who has more information about their own patients than themselves. Therefore, they have the means to correctly inform the family about the daily life of the person with dementia. Besides that, they are the group who could also benefit more from having more biographical information about those patients, knowing them beyond the person who needs health care [7].

Since the patients themselves aren't able anymore to provide useful information about their lives, the family can give some input to the ones who take care of their elders during the most of the day. While some enjoy talking about past successes, others may not want to discuss it. It's common to the staff to adapt the conversations to what the patient wants to hear, even if that involves some white lies to avoid stressing them.

Therefore, the family can be helpful by picking the - hopefully - best memories of the patient: the appropriate topics for making conversation must be found by trial-and-error since there's no way to predict what they want to talk about that certain day. We should keep in mind that this kind of communication should be done directly to the staff and not via the person with dementia. Opening new communication channels between someone with dementia and their family must be a well-thought decision since they can't recall to whom have they spoke already a certain day. This may end up with family and friends receiving numerous calls during the same day, increasing their stress and overburdening them even more.

On another perspective, if the patient interacts directly with the system, their communication should be as natural as possible. If the patient was at the garden with her friend Amy and the system automatically detected Amy and took a picture of the event, it should be captioned as "You were at the garden with Amy.", so the gap between human and computer is more narrow [28].

Finally, the communication flow isn't strict to the professionals-caregivers pair: the professionals also need to talk between them and to share medical and other personal information about their patients. Nursing homes, even small institutions, work by shifts so there is always information that is lost. Those little, yet important, details like the person's humour or what they've eaten isn't recorded anywhere so that information is lost forever [7] and could be useful to make those staff transitions look seamless to the patients.

2.5 Ethical issues

Regarding the two approaches of reminiscence tools there are some ethical aspects that must be taken in consideration. In order to analyse the impacts of multimedia biographies on AD patients, a study was developed to explore their emotional and memory responses to the use of those tools. An interesting aspect regarding photos is that they are mostly only representative of happy moments but, as we all know, everyday life is made of happy and non-so-happy moments. While looking at their deceased husband or wife, sadness and happiness could be observed simultaneously which was the best result they could get given the circumstances [29].

Another positive point was the importance of just one photo for remembering the whole era when the photo was taken, linking their past life with present time in a better way. On one hand, caregivers find it hard to look at old photos and remember how pro-active their family member was, but on the other they also enjoy seeing that they probably had a good and plenty life [29]. Once again there are limitations on the statistical data we can retrieve from this study since there were only 12 patients tested. Even more, it's difficult to guarantee that every patient watches their biographies the same amount of times so we can truly compare each other. Also, there could be more specific psychological tests to assess if the patient's ego is, at least, not worse than when they started participating in this research.

Besides photos, reminiscence therapy can and should use other medium like sound clips collected during holidays so the revival could be more close to the reality. In fact, for reminiscing purposes, audio has a major benefit when comparing to other static media [30]. However, it's harder to review and analyse since there's always background noise and in some smartphones the quality of the microphone isn't good enough.

Applications designed to be used directly by the person with dementia may also create sadness because they remember them the need to be helped and to have a memory aid to know their own past. This could contribute to stigmatize even more a group that already suffers from social problems. Yet, we should always consider the will of who is going to use a certain app, provided that he's healthy enough to take that decision responsibly. For instance, if they don't mind to be controlled by a GPS tracking device, the ethical problem is vanished [31].

Still on emotions triggering, most of the computer-based reminiscence systems assume that the patient wants to reminisce and that the results will be positive but there is no way to assure that. A certain photo may trigger different reactions depending on how the person is feeling that day and different patients will react

differently to a photo of an identical subject. Each one has its own memories and had an easier or harder life which, associated to a different stage of dementia, can lead to unpredicted results while reviewing their biography through photos [32]. However, it would be useful to know the best and worst moments in a person's life: if one was bullied during school the tools should avoid displaying photos from that era. Nevertheless, the patients and their families enjoyed this experience, proving that watching their multimedia biographies triggers positive emotions and feelings in both parts and also improves the quality and quantity of patient's communication with their caregivers.

Finally, there is also a common concern if friendsourcing applications are potentially dangerous to face-to-face contact [31], promoting themselves that undesired isolation. However, since the natural path of the disease leads the person with dementia and their main caregivers to end up isolated at their own homes, that should not be a main issue.

Chapter 3

Understanding the actual dilemmas of the stakeholders

In order to retrieve not only the unmet needs of the stakeholders but also clarify some pre-concept ideas, we conducted semi-structured interviews to professionals, who work with people with dementia. To fetch the complementary perspective, we published an online survey directed to caregivers who live with the person with dementia and families of already institutionalized people.

Working together with the Alzheimer Portugal association allowed us to reach their network of professionals, receiving positive feedback from the ones who wanted to collaborate with our work. Besides the given interviews, they were also co-responsible for broadcasting the survey through their institutional pages, reaching a large number of caregivers.

3.1 Interview study

3.1.1 Goals

The needs and expectations of professionals vary accordingly to their work environment, experience and of course their specialization. The questions focused on their current practices and where do those practices fall short, specially regarding reminiscence therapy and the needed materials to perform it. Those shortcomings create personal expectations about how digital tools could help their current approaches, making their work easier or more stimulating and effective to the patients. This allows to understand how can we help on their daily activities and what type of materials would they like to work more often. Finally, those expectations also bring attached concerns, from the difficulty of using new technologies to privacy issues, that should be taken in consideration when designing the tools.

3.1.2 Participants

To get a wider range of distinct opinions, we conducted nine interviews with professionals from distinct areas: 4 neuropsychologists, 3 psychologists, 1 nurse and 1 occupational therapist, all connected to the Alzheimer Portugal association. Out of those nine professionals, seven work in Lisbon, one in Madeira island and another in Porto. They work in different contexts, from nursing homes specialized in Alzheimer's to day care centres or even in their own office. Apart from the nurse, everyone has experience with people with Alzheimer from 2 to 10 years.

From now on, for privacy reasons, the neuropsychologists will be referred as NP1 to NP4, psychologists as P1 to P3, the nurse as N and, finally, OT refers to the occupation therapist.

3.1.3 Methodology

We privileged face-to-face interviews to avoid losing emotions and corporal language when answering the questions. Eight of those interviews were done in person in the Great Lisbon area from November to February. The remainder was done via e-mail because of the geographical distance between the professional and our team.

Regarding its semi-structured planning, the questions asked were as homogeneous as they could be. We considered the background of each professional, leaving some space so they could talk about the aspects that are more meaningful to each one. Nevertheless, there was a transversal focus on the routines during the appoint-

ments, what kind of tools - digital or not - do they use and how do they exchange information between the different stakeholders.

The interviews were recorded in audio which was then transcribed to plain text. All those transcriptions were codified and analysed as the following section describe.

3.1.4 Design and analysis

We followed an iterative coding process where three researchers independently created codebooks. Each researcher coded the same three interviews, after which the codebooks were refined and merged. Using the merged codebook, two researchers proceeded to analyze three other interviews which lead to further refinement of the codebook and finally a Cohen's kappa agreement of $k=.95$ was achieved. This lead us to define four major aspects addressed by the professionals throughout the interviews: current practices, shortcomings, expectations and concerns.

Everything that's related to their proceedings, approaches, tools and techniques is identified to see how can new technologies help to improve their daily work. This also involves their relations with the remaining stakeholders, from the person with dementia, family, caregivers to other professionals. Those unmet needs are emphasized by the actual shortcomings of those current practices.

Looking towards the future, this new digital approach leads to expectations about how could those new tools improve their results and the person with dementia's well being. Needs regarding information and knowledge transfer are common to the professionals, as well as a wider availability of materials and exercises. However with new methodologies comes new concerns, particularly about privacy issues but also to avoid increasing the caregivers' overburden.

3.1.5 Results

Current practices

Before any approach to control or ease the disease, a **multidisciplinary evaluation** was referred by all professionals, being essential to understand the current stage of the disease and how bad has it affected their patients. **Cognitive** and **occupational evaluations** are complementary of each other, being both needed when addressing which functions does the person still preserves. It's also important to know if they are still capable of doing their own hygiene, deal with money or dress by themselves: the **daily living activities** that provides autonomy and self-awareness.

After the evaluation, professionals work to stop or at least slow the disease evolution by doing **stimulation exercises** regarding the patient's **reasoning, memory and social skills**. All those exercises should focus on the **person's strengths**, avoiding to focus on their lost abilities, which means it's fundamental to know their **past story**. Professionals have to deal with the present too: while **spatial and temporal orientation exercises** helps the patient to keep track of the current world, the **occupational profile** is also preponderant to maintain their life quality, bringing together their likes, habits and hobbies.

This **collection of information** can't always be done on the first person since it's quite common for people with Alzheimer's to have **major difficulties about expressing themselves**. Therefore, **family** and **caregivers** are often asked to deliver that info regarding their past and also their present life. It's a considerable aid to have a network of related people that could contribute to the person's well being in several ways, from daily feedback to reminiscence material or biographic details.

This helps not only the person with dementia but also the caregivers themselves, **committing them to the cause**. Also, by requesting tasks that are considered nice and easy, the network is more likely to give a positive answer. However, caregivers and family also need emotional support and the professionals are always concerned about their **overburden**. This exaggerated workload may lead them to exhaustion and consequently makes them less likely to give proper care to those who need help. Nevertheless, it's also stated that many caregivers need to have a **proper formation** about how to deal with people with dementia and knowing how to react in daily situations.

This leads us to one of the main subjects shared by all interviewees: **person-centred care**. This approach for cognitive stimulation puts the person on the spotlight and can be done either individually or in group: although individual sessions are more common, group ones are also useful to work their social cognition. This **familiarity** with the patients permits a more natural approach, knowing them by **who they were** before the disease, what they did for living, their major life events or meaningful places. A good knowledge of those aspects of each of their patients will allow professionals to develop and guide their activities, exercises and evaluation tests towards their **patient's singularities and interests**. The main focus will always remain in the person with dementia, working to ease their day:

"Someone who likes flowers, even if she can't already say that she likes flowers, will have pleasure when solving a flower-related activity." [NP1]

Furthermore, their likes may be combined with the stimulation exercises through

personal - who was collected via family and caregivers - or **generic material**, coming from other available sources.

The most referred working material was, by far, **photos**. Photos are mainly associated to **reminiscence**: they're what makes each of those sessions as personal as they could be, allowing both person with dementia and their family to remember their own past. Neuropsychologists and psychologists mentioned that direct questions aren't the most adequate way to use photos: instead of asking the patient 'Who is this?' it's better to say 'So, talk a little about this photo. Does it mean anything to you?' This way we are decreasing the chances of creating anxiety or even depressive feelings in both patient and family, which can get uncomfortable with the memory loss of the patient. Those **emotions** are the main concern on the outcomes of stimulation session, where the professionals take responsibility of dealing with it, controlling them and avoiding negative reactions.

Photos are also present in **other stimulation materials**, like Powerpoint slides used by several professionals, and also serve to reminisce about objects: when they're not available psychically they're shown on a photo. In fact, the **content recognition** in photos is a common process by neuropsychologists, which often use photos to make their patients identify and talk about relatives, places or significative objects. More than a moment, the photo captures people, situations or habits which belong to a specific time frame on the person's life. That can trigger many memories beyond the photo, making the person having remembrances of that era. Moreover, this content analysis should **start from a macro perspective**: the approach should start on recognizing things globally and then going step by step through details as far as we can make the person remember.

There were some discordant opinions about the most relevant time frame of the photos used in reminiscence therapy. NP1 referred that **past photos** are much more useful to patients since the recent memory is the first to fade away, making actual photos useless.

"It's like a traditional photo album where the most recent photos are on the last page. As the disease evolves the album vanishes from back to front, until there's only the front page left." [NP1]

However, besides agreeing with that **time-travel** approach, NP2 stated that the **current life** is still useful and photos of that era should also be shown to the patient. This way NP2 emphasizes the importance of stimulating both **short** and **long term memory**. It's also said that there isn't any problem if the person doesn't recall taking that photo: that's a situation where the psychologist has the right knowledge to deal with.

Besides photos, **music** is also used to do cognitive stimulation, having a special relevance since it can stimulate different parts of the brain that can't be reached through other materials. **Objects** are also an effective support to work with, triggering memories of their past work or hobbies. P1 mentioned

"Last week we did an activity [at their nursing home] with a sewing machine and tried to make her use it. It was a meaningful task because the lady was a seamstress and she ended up being capable of sew"

which is interesting because the procedural memory was still there despite the fact she's not able to orally express it anymore.

There are **other tools** used by a minority of professionals: videos for reminiscence therapy; calendars, diaries and newspapers for orientation; and games for general and reasoning stimulation. Although not always possible thanks to the shortness of material, **diversity** on the stimulation materials is seen as positive.

For specific exercises regarding stimulation, although expressing it with some sadness - many professionals used the word *unfortunately* - **paper and pencil** is still the most common support. **Digital tools** like Cogweb¹ are also referred by professionals but they reveal functional limitations and aren't widely adopted thanks to financial and other reasons. However, professionals say they use **laptops** and **tablet** devices to present reminiscence material to their patients.

Regarding the context where the stimulation sessions happen, the major part are done during appointments. Some professionals send **homework** to more differentiated patients but that didn't seem to be a common practice. They often stated that caregivers are not persuasive enough to make the person with dementia do things that they don't want to do. This often leads to demonstrations of anger towards the caregiver, frustration and a consequent bigger workload.

Finally, during the appointments professionals like to have some time to be **alone with the person with dementia**, creating a place where they can feel safe and **dump their problems** without **privacy** issues. Yet, the **caregivers' feedback** shouldn't be neglected, being useful specially when the person can't express by their own anymore. They're also needed to review their daily life, giving the information needed to assess the disease evolution.

Shortcomings

Those current practices don't fulfil all the desires of professionals, with tools and approaches often falling short or not being fully adequated to their current needs.

¹<https://www.cogweb.pt/>

Alike when talking about paper and pencil exercises, professionals say that, *unfortunately*, they don't use **new technologies** as often as they would like. This happens either because their always **limited time** or the **tools are themselves limited**. Those limitations are functional, since most of them don't provide any personalization features, and also on user experience, by demanding the use of a mouse which is too difficult to handle by people with cognitive impairments. Apart from customization aspects, the professionals also complained about the lack of **reality orientation material**.

About the relationships among those who deal with the disease, there's always more than one stakeholder to take in consideration. From the carer to the neurologist, from the family to the occupational therapist, there's different people involved, with different needs and interests but also with common ones. However, they don't **exchange information** as much as they could do. NP2 states that

"From a certain day, the caregiver is trapped inside their own home and barely has time to go to the appointments or leisure activities. There should be more information channels and tools so caregivers could communicate without leaving their houses."

They have a strong need to talk with others about the disease, especially others who share that hard situation they're into, but that communication is not as easy as it could be. It's not uncommon to see main caregivers being left alone by the rest of the family since they **drift apart**, avoiding to deal with the person with dementia.

They stated they have already tried some approaches to data registration but there wasn't any success. On their perspective, the failure was related to the use of **time-consuming tools**, like diaries or other traditional methods. Not only the increase of the caregiver's burden isn't negligible as they're not being able to tell the carer what they really need. This makes the caregiver ignore some details that they thought irrelevant but were actually meaningful. Even more, there are **caregivers** that are **too old** to learn how to interact with digital tools, or are **inapt** to profit from them because they're not used to deal with new technologies.

Biographic information collection is as problematic as data registration. Despite *"Photos are a very useful tool"* [NP1] their collection next to the caregivers or family is the main problem. In fact, the **communication with caregivers** is frequently described as difficult and inefficient, specially with distant families. When the patient is still capable of providing himself photos and biographic material everything works better. After that, when their mental skills are deteriorated enough, that task is delegated to those who take care of him and everything turns out to be a complicated process. *"People have fear that I can lose their photos"*, as NP2 says,

shows a fear of losing some last physical memory of who that person was before the disease, probably the last object that reminds the family of a past and happier life. Besides that sense of possession, **overburden** is also something that should be taken in consideration, as stated by P2:

"If we are requesting many things that means overload: one more thing to search for, one more thing they must do, one more worry."

Lastly, another raised flaw was the **staff's lack of knowledge** of their own patients. Sometimes, as we were told, staff on nursing homes don't know much more than their name. However, we noticed two antagonistic perspectives. On one hand we have the most common perspective:

"From my experience in day care centres and nursing homes, there's a big problem because assistants don't know a thing about the people they have there." [NP1]

On the other, nursing homes specialized in Alzheimer's give their staff archives about the patients. This contains personal information, their genealogy, where did they work or what are their interests. Nevertheless, they also stated that this archives are difficult to maintain, requiring too much time to keep them updated.

Expectations

Although considered that the **utility** of using **new technologies** depends on each case, regarding the disease stage, all the interviewees were open and interested in having more tools to work with, recognising them as **useful** to their daily work.

With a lot of actual shortcomings regarding communication and information, many expectations are also related with it. The **availability** and **persistence** of daily records and biographic information would allow professionals to **adapt their exercises** according to the person current status, giving them a more personalized approach. This is a major key to improve the quality of healthcare, relying on the data that should be shared between the stakeholders but is not.

To reach that, tools that **promote the contact** between them should be created, avoiding the isolation of the patients and their caregivers. This confinement will inevitably end in the deterioration of their mental and physical skills, being harmful to the health of both. By providing tools that can be **used at home** while promoting social interaction, we ease the sense of isolation, **bringing people together**. For those who have the person with dementia already institucionalized, NP2 alerted to

the potential interest of having the **nursing homes communicating** by their own initiative with the patients' family. This could approximate the family, making it harder to forget that they have someone they love in that institution, someone who needs and deserves attention.

On another perspective, systems that could serve as **digital diaries**, where the caregiver could synthesize the disease evolution, are also wanted by professionals. This kind of records would help them to do a **better assessment** of the disease, which was another found expectation.

Still on the information flow from caregivers to professionals, a bigger amount of **personal materials** would be useful to reminiscence therapy and reality orientation. For instance, NP2 talked about people who lived abroad and, even if they're able to travel there now, they wouldn't recognize any of the places because everything has changed. However, if there was any digital tool that could gather **old photos and information** about those places, they could make the patient **time-travel** back then, reviving all those old known places. **Tools based on the biography** of the patient would allow a more effective stimulation and therefore better outcomes.

Those materials can be gathered as easily as large is the network that can provide them. It would definitely help to **involve** the whole family to contribute and to relieve the burden of the main caregiver: professionals reinforced that by requesting **nice tasks** to the family they're more likely to participate than if they had to have a more psychical contact with the person. Apart from the personal material, tools who could display information about **actuality** - with news and current events - were also desired by some professionals.

Finally, the **contextualization** and **cohesion** of the memories emerged as an important feature regarding the display of that material: identity loss is almost inevitable after some time but can, once again, be delayed with some approaches. P2 referred to it as

"A map of Portugal's districts, they're all together in the beginning but then each district will start to drift apart and we will not be able to say that's Portugal anymore."

. This lack of cohesion is mentioned by a couple of professionals, commenting the importance to present everything with a related context. By integrating different subjects - people, places, events and so - under a common related ambient, all that information is more easily linked together. If all the useful information about the reality and personal orientation comes under some sort of umbrella, there will be a

natural harmony, promoting stronger and more easily seen connections between the different materials.

"It's like doing patchwork, sewing small pieces towards a whole objective: reinforce the person's identity" [P2]

Concerns

The new expectations raise new concerns, specially related with the stakeholders comfort and privacy. These are subjects that must be taken in consideration when developing our future tools, serving as guidance of what should be avoided.

Caregivers with **low literacy**, dysfunctional families or people who are **not familiar with technology** will have difficulties accessing and using these new digital tools. Also, their friends and family could be completely disconnected from the internet, destroying any collaborative approach.

"There are two completely different worlds: one is made of people who are 60-65 years old, with high school education or graduated. The other is composed by 80 year old's that just went to elementary school and never touched a computer." [NP2]

This **generation shift** is a problem that can't be solved by our means, being a structural issue that can only be eased as the time goes by. This means that the developed tools will be available to all who are interested in using them but they aren't for everyone. Someone will always have to act as a **proxy** between the tools and the person with dementia to soften those difficulties.

By using a proxy those tools requires a caregiver to operate and, once again, avoiding their **overburden** is something that must be always present. More than that, tools must also promote a better life quality for those people, contributing to their **well-being**. On a same key, when presenting information to the person with dementia, they might get **confronted with their own disease**, which may lead to depressive feelings that should be dodged as much as possible.

Last but not least, **privacy** was by far the most controversial subject in those interviews. Firstly, the Portuguese legislation is quite unclear and technically there's a legal vacuum about people with dementia. This way nobody knows for sure, for legal purposes, if someone with dementia should have a legal tutor or can take full responsibility for their choices, namely about their own privacy. Most professionals shield their work with an informed consent form, which should avoid any legal issues. We found very distinct opinions and noticed some exaltation on the interviewees:

while some handle this issue easily, mainly because the person with dementia doesn't seem to raise many questions, others defend that we should assume by default that no one wants to have their **life exposed to others**.

P3 told a couple of stories that exemplified how the **caregivers protect themselves** even under anonymity. Throughout their appointments, professionals often hear stories that are relevant to other caregivers and their share would benefit everyone who has to deal with the disease. However, when they ask for permission to share the stories, the most common answer is no. In a nutshell, we will always have **two types of privacy**: the patient's and the family's. When the family is asked to contribute with photos or even just information about the patient, they always have some fear to get overexposed to people that you don't know that well. Dealing with the disease and its consequences is hard enough so people can tend to make irrational decisions: everything that sounds a little bit shady will look more unpleasant and unnecessary than it really is.

Nevertheless, there are several examples of nursing homes with Facebook pages where they share photos of their activities and patients. The same occurs to caregivers, participating in some Facebook groups about the disease, where they can communicate and exchange experiences.

3.2 Online study

3.2.1 Goals

In order to reach the maximum number of caregivers we conducted an online survey about their actual habits when dealing with the person with Alzheimer's. After characterizing themselves, their support network and also the person who suffers from dementia, we focused on knowing their daily life and habits, which type of stimulation activities do they practice and also how are the information exchanges between the different stakeholders. With a greater focus on reminiscence therapy, we also asked about the used supports, subjects and what approaches produce better outcomes and reactions on the person with Alzheimer's.

3.2.2 Methodology

The survey, written in Portuguese and therefore directed to our country and society, was available online on the Google Forms platform for two weeks. It was publicized twice by Alzheimer Portugal and once by Café Memória Facebook pages, from where we got the majority of the answers. It was also shared in our personal

contact network and through the professionals interviewed before.

There were two main branches inside the questionnaire: caregivers who have the person with dementia institutionalized were asked about their relation with the institution, while the others were inquired about their daily habits with that person. The estimated time for completing the survey was 10 minutes and at the end of each section there was a text-field for comments, where people could add information that might be useful to understand them better, do suggestions or contact us for any other reason.

3.2.3 Analysis of the participants

In the 536 participants who answered the questionnaire, all responding as caregivers, 86.7% were female and 13.3% male. This might reveal a slightly misogynistic society where the women is always seen as more adequate to stay at home taking care of somebody. 80.8% have an high school education or higher, which may be explained by being an online survey, shared mainly by social networks.

53.6% of the caregivers are taking care of their progenitors, being their spouses the second most common case, with 13.6%. Most of them are employed (54.8%), share their home with the person they take care of (50.8%) and are helped daily by 1 to 3 people (86.4%). This percentage is pretty expressive towards the size of the helpers' network, showing that caregivers really end up alone and without much support from others around them. The contact between the main caregiver and the rest of the network is done either face-to-face or via telephone.

3.2.4 Results

Who are the centre of attention

The person with dementia is generally a female (71.4%), who is between 71 and 90 years old (80%) and still lives at home (75%). From those who aren't yet full-time institutionalized, the level of independence is quite low. 73.9% need help to do their personal hygiene and 89.3% aren't able to cook autonomously. Moreover, almost none can leave their homes unaccompanied (82.8%) neither deal with their own money (87.7%).

Daily routines and activities

Regarding the activities that caregivers still do with the person with dementia, the analysis will be done from the most to the less relevant, regarding the answers

got (Fig. 3.1).

Taking a stroll is done by the majority of the respondents, with 56.4% doing it at least once a week. The second most common activity is going out and meeting friends, with 40.6% for the same frequency. With less yet comparatively high relevance comes the review of old photos and visiting significant places. About the photos, 31.9% do it less than once a week and 33.7% more than that. The percentages regarding visiting places are quite similar, with 30.4% doing it less than once a week and 29.6% more often.

On a second level of importance to caregivers comes listening to music: although 20.5% do it everyday, only 25% do it weekly at least. With a smaller percentage of everyday frequency but with a higher overall we have reading magazines or books, with 36.2% doing it weekly or more.

The typical Portuguese costume of going out for a coffee opens the third tier, where the almost majority of the caregivers don't perform that action: 48.4% never take the person with dementia to the cafe. Going shopping is also quite uncommon, raising the percentage of never doing it to 51.5%. Finally, although it could be explained by the higher education of the caregivers who answered the survey, 70.8% don't go to church anytime.

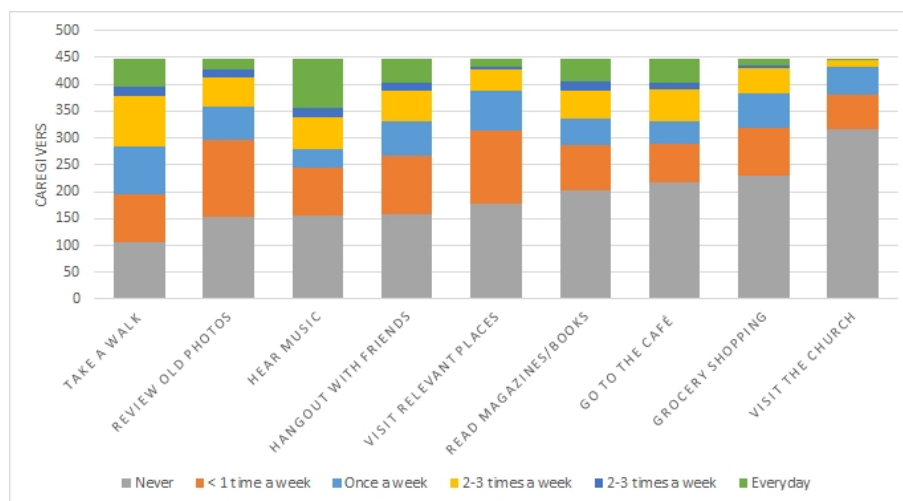


Figure 3.1: Statistical resume of the caregivers' habits with the person they take care of (n=448)

Nevertheless, the amount of caregivers that doesn't do any activity outside their homes isn't negligible. Even on the first tier which had the best results, the percentages for 'never' were 23.9%, 35.5% and 40% for going for a walk, hanging out with friends and visiting relevant places, respectively. These results were more significant than what we were expecting but can be explained by the disease's influences in the person's mobility capabilities. This feeling of isolation, as well as being left alone,

is explicitly expressed by some comments throughout the survey:

"We caregivers don't have anything to help us taking care of the person with this awful disease."

Cognitive stimulation habits

When enquired about doing cognitive stimulation exercises at home, the respondents were split at almost half, with 54.7% answering affirmatively. In most cases - 60% - caregivers use pencil and paper to do those activities, where 28.2% also make use of exercise books like Sudoku or cross-words. About digital tools, only 17.1% stated their use. This activity is commonly done daily (38.4%) or at least twice or three times a week (30.6%).

From those who answered negatively, 56.2% say the reason for not doing this kind of tasks is the patient's lack of interest:

"My mom is always restless and making her focus is an impossible task".

Not enough time, 23.2%, and nonexistence of support material, 22.2%, are some of the other reasons pointed. Sometimes the caregiver is also too old to do this cognitive training or even don't knowing how to deal with the person with dementia:

"How can I make her have interest in anything if she can't read or write?"

Going into the details of cognitive stimulation, 75.9% review memories in form of photos and music among others. The percentage even increases to 89.7% when asked if that review focuses on life events, like their marriage, birthdays or the born of a son. Caregivers state *"They only talk about the past"*, showing the distance that separates the one with dementia from the recent days. Personal photographs are the most common material to reminisce, with 87.1%, followed by significant objects and music, with 31.2% and 30.9% correspondingly. Some caregivers stated that are currently making memory boxes, filled with photos and objects. We also had some opposite thoughts, with people stating that

"There aren't any photos or videos to remember the past since she has lost everything during the decolonization."

. Other materials, like generic photos or videos are used in a less expressive way. The least popular option was online videos, for instance via YouTube, with only 21 positive answers, equivalent to 6.2%.

More than knowing what kind of materials do people use, we also wanted to know what, in the perspective of the carer, produces better results on the patient. Keeping the consistency, photos are the most successful option: 61.8%. Still, what makes those good results isn't only the type of reminiscence but also how we stimulate the person with dementia. Regarding this, 73.5% of the caregivers say that the better reactions happen when we talk about people. Like with the photos, the results here also have agreement: when talking about the past, 87.6% of the carers focus their speech on people instead of places or events.

Finally, when inquired about the retrieval of that material, most of the times everything is collected only by the caregiver. To the question 'Have you ever asked for third-party help to collect relevant material?', 71.8% answered negatively.

Ties between caregivers, healthcare professionals and institutions

As stated before, this survey had two main branches: those who have the person institutionalized didn't answered to the questions about daily habits and cognitive stimulation at home. Instead, they were asked about their relationship with that certain institution.

Under a scale from 1 to 5, where 5 is highly satisfied, 33.3% rated 3 in their satisfaction with the amount of information they get from the institution. The overall idea is positive since only 19.5% answered under 3. However, most of the times - 74.4% - that information is only received after being explicitly requested by the caregivers. We also got a lot of people complaining on the commentary box about the staff's lack of ability to deal with the disease:

"(...) those who have formation isn't much committed. Those who are often lack formation. It's sad but that's how I feel".

"Besides being satisfied with the institution, there's a lack of sensibility to deal with people with dementia. The institution itself isn't adapted or adequated to those people."

In line, when asked if the healthcare staff has enough knowledge about the person with dementia, for instance their life history or their interests, the opinion gets split: 50.6% think they don't.

Regarding the direct contact with the healthcare professionals, only the neurologist has a relevant frequency, with 47.5% stating that visits their office twice a year. Apart from that, the most common answer is 'Never': neuropsychologists (80.7%), psychologists (77.2%) and occupational therapists (76.4%) seem all pretty

far away from the caregivers. A distinct case appears regarding nurses: although 42.8% answered 'Never', 20.9% say that visits them every week. This result under the frequency 'Every week' is only followed, at a distance, by occupational therapists, with 12.5%. Those contacts are done face-to-face, with an expressive 91.2%, without any kind of explicit diaries or paper notes.

The disease on social networks

The final section of the survey was about the use of social networks, regarding our initial idea of making use of their functionalities to improve the caregivers' life quality. 69.5% use some social network and 49.2% takes part of some group, page or message board about the disease. On the other hand, actually only 21.9% uses a social network to share photos of the person with Alzheimer's with the rest of the family. The rate raises to 35.5% when asked about using social networks to display reminiscence material - like photos from the family - to the patient.

Finally, when inquired about how could social networks contribute to bring caregivers, family and professionals together, 32.7% of the respondents answered the maximum, 5. Again, in a scale of 1 to 5, the combining rate of answer 3, 4 and 5 was 79.7%, leaving a good hope to the effectiveness of the solutions developed further.

3.3 Discussion

Conciliating the perspective of caregivers and professionals isn't a difficult task since they share the most part of the current problems and expectations. However, there are some subjects that revealed divergent viewpoints of each one's problems and how they see the people around them.

On actual habits, both parts give much importance to the review of photos, music and magazines, being the most common activities. Beyond this information consumption, social interactions are also valued by both, with professionals expressing it by social stimulation and caregivers by going out with other friends. Yet, there's a significant number of caregivers that don't do any kind of activity outdoors and there's also a smaller group that don't do anything at all. As expressed on the interviews, from a certain day people just end up isolated at their homes and stop going outside.

On cognitive stimulation habits, specifically reminiscence therapy, the caregivers who do it are aligned with the professionals' general approach. Both groups prioritize the use of photos and music and the results about reminiscing through life events

were also very significant. Caregivers, as well as the most part of the professionals, prefer to focus on old memories than on recent ones. We have to keep in mind that this can be explained because the existent photo albums are populated with photos from the past and not necessarily because people don't like to reminisce supported by recent material. Again, talking about people is considered by the two groups one of most effective ways to do these therapy sessions. Regarding the chosen supports, all agree that personal physical photos are the most practical to use and therefore the most common.

The material needed for reminiscence therapy is considered scarce by caregivers and professionals, with the great majority of caregivers saying that they don't use any third-party material. This concern is shared by professionals but in another perspective: for that group the caregivers are that third-person, not offering them as much material as desired. This shows a though information transfer, supported by a deficient sharing inside the families and also from families and caregivers to professionals. However, not everything is misaligned about information exchange: caregivers also corroborated the professionals' expressed concern about the lack of knowledge of nursing home's staff on the person with dementia.

Besides that different, yet common, perspective about the small amount of available reminiscence material, relationships with healthcare professionals were the most controversial topic. After the interviews we got the idea that a reasonable part of caregivers go regularly to appointments with neuropsychologists, having an effective follow-up through the evolution of the disease. Surprisingly, the survey showed caregivers' only contact with healthcare professionals are with the neurologist, happening just once or twice a year. In fact, 80.7% stated they don't have any contact with a neuropsychologist, showing that most of the carers probably don't have any kind of guidance regarding cognitive stimulation exercises.

Finally, the answers about privacy and social networks seemed more negative by the professionals' viewpoint than the caregivers' one. The first group was very cautious about the subject, giving all the responsibility to the caregiver, keeping in mind there are some legal issues about who has the right to take decisions. In turn, the most part of the carers see social networks as positive and useful to bring people together and eventually help their daily living. Privacy questions were not specifically asked in the survey but they might be an issue: only a third are currently using social networks to present photos to the person with dementia, although half use it to participate in groups or pages related with the disease.

3.4 Implications for design

Since the majority of the caregivers ends up on being isolated at home, our tool should be available to use indoors. This way we increase the range of potential users, delivering a useful solution to those who are still able to leave their homes and also to those who don't.

3.4.1 Content personalization

In order to obtain better results on cognitive stimulation, especially reminiscence therapy, there must exist a previous customization of the contents used to reminisce about. Those contents must be directed specifically to each patient by getting to know their likes and interests and also using personal material. In truth, it's essential to see the person with dementia as a person, knowing how to motivate them to do these kind of exercises.

To use this personal content it's necessary to collect it beforehand, being this one of the main identified problems. This compilation must be quicker and more efficient, distributing the burden through several people. We should avoid the pitfall of having just one responsible for that gathering, making the process less time-consuming and more motivating to everyone.

Photos, music and objects are the most common support materials and therefore this optimization should focus on them. Since we're developing a digital solution, it's hard to work with the third dimension so the objects will, for now, be left out of the solution.

3.4.2 Enhancing cognitive stimulation

Conjugating what would be best for patient's health and more stimulating for the caregiver, the reminiscence material should be displayed in form of life events. Those events permit a temporal and spatial contextualization, as well as the identification of the participants on each event, both important actions referred by the professionals. This approach is reinforced by the caregivers, which report that the better results are achieved when the reminiscence session is about making the person talk about significative people. This can be encouraged by showing the names and photos of those who were present on each event.

A solution of this kind also permits to maintain the actual approach of the most of the caregivers, based on reviewing those events isolated from each other. This makes the transition from analogue to digital support a more natural process.

3.4.3 New ways of communication

Lastly, it's also necessary to deal with those who have the person with dementia on healthcare institutions. Meeting the needs of caregivers and professionals, we should guarantee that the staff has access to biographic information: something that allows them to know their patients better.

This information exchange may also be useful on the opposite way, improving the institution-family communication. This could allow the family to follow up the institution activities and updates more easily, eventually on a daily basis. By turning those activities into life events like the ones said before, a bi-directional life album of the person with dementia could be created, tightening the links between all the family members and the person, stimulating their communication and interaction.

Chapter 4

Friendsourcing the unmet needs

The interviews and survey depicted in the chapter before allowed us to identify the requirements for future tools that support people with dementia and their caregivers, formal and informal, in reminiscence therapy contexts. Remember-Me 2, the system developed by me, is a tool to facilitate personalized reminiscence therapy, either at home or at nursing homes.

On technical terms, it tries to ease the communication problems between the stakeholders, creating a common platform where they can share personal information about the person with Alzheimer. Moreover, friendsourcing features allow to share the task of collecting that data, decreasing the overburden of the main caregiver.

This chapter will address the process after gathering the unmet needs of both professionals and caregivers, in an software engineering perspective and its implementation, until the delivering of the actual version of Remember-Me 2.

4.1 Use scenarios

Since this application is designed to be used in different scenarios, contexts and stakeholders, those differences were turned into distinct use scenarios, each one showing a possible usage for Remember-Me 2.

These scenarios were done thanks to the information received from the interviews with the professionals, being then crosschecked with the one coming from the surveys. They serve as an indicator about what Remember-Me 2 should offer, at least, to the end user, leaving space for eventual new or improved functionalities.

All the following scenarios depict distinct situations where reminiscence therapy can be done by different stakeholders in different places. In the future, as we add new functionalities to the application, more scenarios can arise, showing new forms and approaches for doing this kind of therapy.

Reminiscence therapy at home

Maria is the oldest daughter of Brian, who was diagnosed with Alzheimer's a year ago. She wants to be sure that Brian doesn't isolate from the rest of the world, avoiding a faster evolution of the disease. Nevertheless, Brian's ability to move is getting worse and they spend progressively more time at home, without talking to anyone. To avoid that isolation Maria is collecting biographic material about her father which might be useful to stimulate his memory.

Being a basic user of Facebook, with some friends and photos on her own account, she creates a new account to represent Brian, inviting trustful friends and family to his network. With that network settled, she creates Facebook events that represent actual life events of her father, like his wedding or trips he made, inviting the friends that were present. Inspired by the idea and invitations of Maria, Mark - an old friend of Brian - remembers the trips he did with Brian and creates himself an event for each one, inviting other friends that were present with them. Without leaving her home, Maria receives the invitations to Mark's events via Facebook and promptly accepts them.

Now Maria has enough information to do reminiscence therapy with Brian. She grabs her tablet and logs in on Remember-Me 2, where she can access all those life events in a friendly and simple interface. She can ask his dad if he remembers that day, how did it go or who was there with him, even showing the photos of the participants. Maria lets Brian talking freely about whatever memories that certain material stimulate, promoting a rich dialogue between them.

Reminiscence therapy during an appointment

Sophia, neuropsychologist, sees her patients from month to month, where she does cognitive stimulation exercises during the appointments. Being always concerned on producing the best possible results, she would like to improve her reminiscence therapy exercises by using personal photos of significant people, places, events or objects. Unfortunately, she can't get any from most part of the families: caregivers don't have to time to collect that material by themselves. So, Sophia asked some of her patients' caregivers if they were available to help her collecting those photos through Remember-Me 2, where they could share the task between the rest of the family. With their acceptance, Sophia can now use the app to get more material to work with during the appointment, developing a dialogue about them with the patient. Moreover, Sophia can enrich those personal photos with other old photos of significant places, for instance the city where the patient lived his childhood.

She can also entry the session results and feedback in our system, thanks to the app Day2Day, not described on this thesis. This way she'll now by the next appointment which were the materials or part of the patient's life that gave her better results, improving the knowledge of good triggers session after session.

Reminiscence therapy done by daycare centre staff

Patricia, healthcare assistant on a daycare centre, has always a lot to do on her busy day. However, when performing healthcare tasks with her patients, she doesn't know much more than their name because there are no easily accessible biographic records. Patricia would like to know that person a little better, learning their interests and meaningful conversation subjects that could stimulate their social and mental skills. With the institution's adoption of Remember-Me 2, she can now look into the tablet - which is shared with all the staff - where the app is running and select that certain person. There, the app shows a summary of the person's interests and an outline of their life story.

Now, for instance when feeding that person, she can naturally stimulate him to talk, asking about the time he spent on France when he was younger or about his son born in 1979. Eventually Patricia even found common places or interests shared by both, strengthening the ties between herself and the patient. More than stimulating the patient, this also allows to turn intrusive tasks - like hygiene care - into something more natural to both patient and staff, improving the patient's well-being.

Reminiscence therapy with full-time institutionalized people

Oliver's mother has been recently institutionalized and the distance from his home to the nursing home conjugated with his two jobs doesn't allow to visit her everyday. Oliver's mom is still an active person and he likes to be updated about her activities at the nursing home. However, until now he had to call the institution from time to time to ask for his mom, which wasn't pleasing him much because the staff never has enough time to speak with him calmly. With the adoption of Remember-Me 2, he can now check for new events everyday, usually on the way back from work to home. He easily checks on his smartphone if there was something new happening today and even sees some photos that the nursing home added to that certain event.

By the weekend, when he can finally go to the institution to see her, both talk about the activities that occurred that week, doing reminiscence about the recent past. More than talking, Oliver brings his tablet and shows the photos to his mom, letting her see herself performing recent activities.

This scenario might also apply to those who are still at home but doesn't have a daily contact with their family.

4.2 Concept map

This concept map depicts the functionalities of the system composed by Remember-Me 2 and Day2Day, showing the information and knowledge exchanges, as well as the functionalities available to each role. Day2Day has a different target - more dedicated to healthcare professionals - and therefore is being described here just for completeness reasons.

4.2.1 Stakeholders' characterization

The system we developed has its main concern on the person with Alzheimer's so they stand on the centre of our triangle (Fig. 4.1). In each vertex we can see the ones who may improve their quality of life, working together towards a common goal and aiming not only to improve that life quality but also to ease the caregivers' daily routines. All of this can only be reached with effective communication channels between the parts involved, solving common problems and sharing data that's useful to everybody.

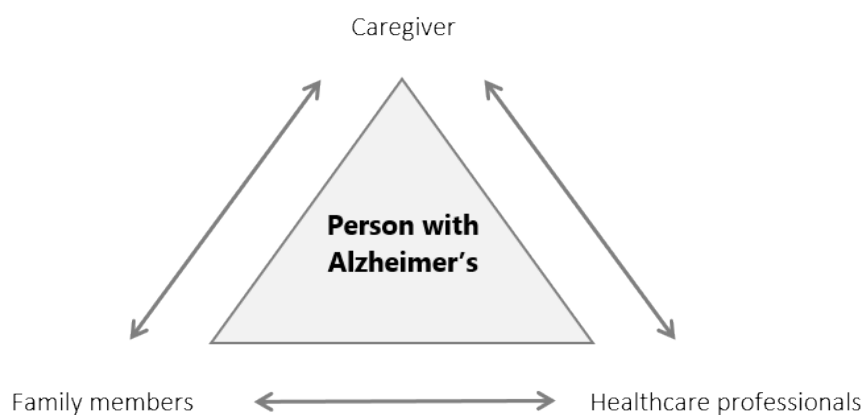


Figure 4.1: Stakeholders' interactions

Healthcare professionals is everyone who has to deal clinically with the person with dementia, from neurologists to nursing homes' assistants. *Caregivers* also contain different specific cases, from professional and paid caregivers to the family member that lives with the person. Finally, *Family members* are those who haven't a daily contact with the person.

Finally, the arrows around the triangle represent the information exchanges and communication channels between them.

4.2.2 Interactions between stakeholders

Caregiver → Healthcare Professionals

- They may
 - Input data about the daily life, routines, mood, incidents and medication;
 - Report extraordinary events and the person's reaction;
- In order to
 - Allow the professional to prepare their appointments better, with more and detailed information about the recent times, correlating the daily activities to the patient's cognitive performance;
 - Improve the detection of behavioural patterns;
 - Promote a better oriental-spatial stimulation and reminiscence therapy during the appointments, supplying more materials to work with;
 - Allow nursing home's staff to know better their patient, what are their likes and dislikes as well as their life story

Caregiver → Family members

- They may
 - Give updates about the daily activities and the disease evolution;
 - Input photos and details about recent events;
- In order to
 - Allow the whole family to stick together, tightening the ties between them and the person with dementia;
 - Make the rest of the family remember that the main caregiver also needs help and support in this hard time of their life;

Healthcare professionals → Caregiver

- They may
 - Input data about the performance on the cognitive tests;
 - Provide information about the disease evolution;
- In order to
 - Help caregivers adjusting their habits and routines to improve the mental state of the patient;

Healthcare professionals → Family members

- They may
 - Provide information about the disease evolution;
- In order to
 - Allow the caregivers to have a systemic vision of their pals and how could they improve their mental state;
 - Give more clinical details to support the decision of institutionalizing the person with dementia;

Family members → Caregiver

- They may
 - Provide content, like photos, events or interests, that can help the main caregiver to perform reminiscence therapy with the person with dementia
- In order to
 - Avoid overburdening the caregiver with the collection of biographical information

Family members → Healthcare Professionals

- They may
 - Provide content, like photos, events or interests
- In order to
 - Promote a better oriental-spatial stimulation and reminiscence therapy during the appointments, supplying more materials to work with;
 - Allow nursing home's staff to know better their patient, what are their likes and dislikes as well as their life story

4.2.3 Type of data exchanged on the system

- Remember-Me 2
 - Actual photographs
 - Past photographs
 - Life events
 - Friends' network
 - Music videos
 - Personal interests
 - Significant places
- Day2Day
 - Moods
 - Medication
 - Incidents
 - Caregiver's feedback
 - Neurological tests
 - Cognitive performance
 - Appointment's information

When using Day2Day, healthcare professionals might also correlate all those health related records with the recent events from Remember-Me 2. This may allow the discovery of patterns related with everyday life and events.

4.3 Remember-Me 2

The web application, named Remember-Me 2 after the first version [24], acts like an umbrella, aggregating different available approaches to do reminiscence therapy in different contexts, from homes to medical appointments. It runs as a Java Web Application under an Apache Tomcat server, using a MySQL database.

To address the found needs of caregivers and professionals we developed a friend-sourced based app, being Facebook the social anchor, promoting Facebook's functionalities towards more contextualized and interactive reminiscence therapy sessions. In a macro perspective, caregivers need to split and share their burden between the rest of the family, bringing people together around the person with dementia. On the other hand, professionals could benefit from an umbrella platform that could gather all the essential biographical information about their patient and both their recent and past life.

Facebook's events will act as life events: marks in the lifeline of the person with dementia like the born of a son or their wedding. Those events have participants, places and photos associated, serving as material for the reminiscence therapy. That personal material is also upgraded with the profile's interests, using them to know which artists are more meaningful to the person with dementia and therefore what songs should be presented to the user.

This tool is a part of the system composed by itself and Day2Day, with information exchanges that are not characterized here by being out of the subject of the current thesis and also because of the hiatus of Day2Day's development team.

4.3.1 Software architecture

Information gathering

The interviews and the survey showed the need to collect more material to reminiscence therapy, from biographic information to photos - personal and generic - and music. To reach that, Remember-Me 2 uses three different sources for gathering information. While Facebook is used to retrieve personal and biographic information, Flickr and YouTube are our gateway to access public material, specifically photos and music videos.

In order to promote a better understanding, the parent of this app - Remember-Me [24] - will be referred from now on as RM. Initially we were supposed to use RM as a black box, a closed module to our system, but due to Facebook's API changes and the lack of flexibility of the original application I had to do small and punctual

tweaks to fit our interests and needs. The access to the Facebook API is done by proxy via RM, making use of the code developed in-house. RM is written in Java and JSP so it uses Facebook4j², a Java wrapper for Facebook's API, to retrieve information from the referred social network.

Each time the user logs on Remember-Me 2 with their Facebook's credentials, the RM module will be activated and starts collecting events and interests associated to that profile. The collected data and its correspondent media is then stored in the MySQL database, described in the next section.

By contrast with Facebook's integration, Flickr and YouTube connections are done on-the-fly, without any data being stored on the database. The access to Flickr's³ and YouTube's⁴ API is done directly in Remember-Me 2, using plain Javascript, AJAX and REST services.

Information storage

Remember-Me 2 never interacts directly with the MySQL database: only RM uses it to store the information that is collected from the Facebook's profile of the user. The stored data will then be available via RM's webservice.

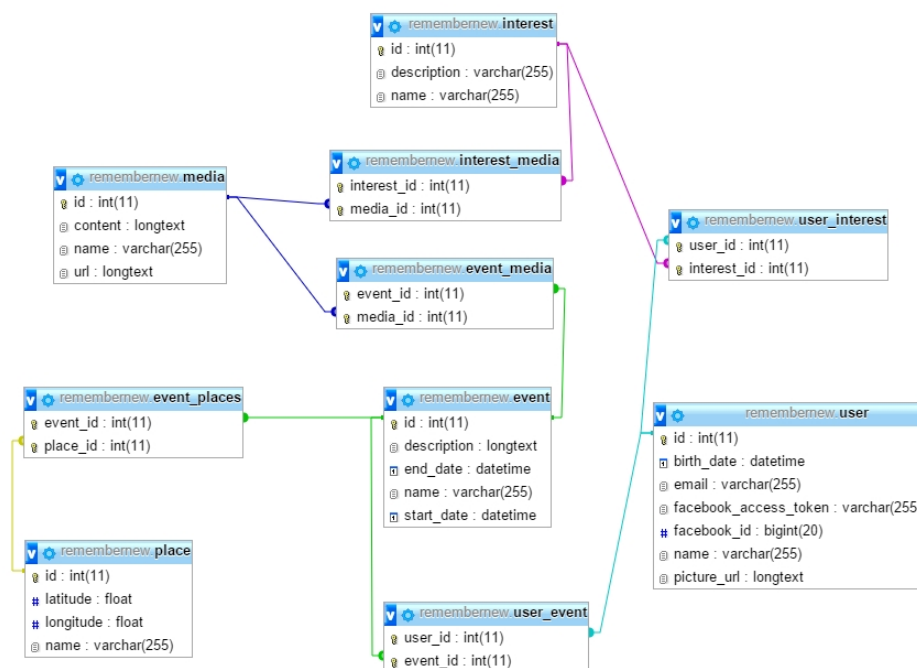


Figure 4.2: RM's database schema

²<http://facebook4j.org/>

³<https://www.flickr.com/services/api/>

⁴<https://developers.google.com/youtube/v3/>

In order to collect the biographical data needed, we want to be able to characterize and contextualize as much as possible each of the life events collected from Facebook. Therefore, the event itself - with its name, description, time and date - must be the focus of the database. Each event has users associated with it, as well as a place where it happened and media that are uploaded by the participants to the event's wall. Each user is associated with certain events, either their owns or accepted invitations by friends.

Apart from the events, RM also collects the interests of the profile, which means the likes they have. Regarding this specific approach, only the music-related likes are collected but other categories are easily added, like sports, books or movies. Since was not the main purpose of the thesis and RM's original approach is efficient enough to our actual needs, I didn't improve the relational database.

Information availability

In order to comply with good software development practices, the interface never interacts directly with the data layer. All the data exchanges are done through RM's webservices, populating the interface via AJAX requests.

Besides all the information regarding the events, those webservices' responses will allow to query Flickr's and YouTube's API to obtain the generic material related with each event and profile, further analysed in the Implementation details.

Remember-Me 2 Modules

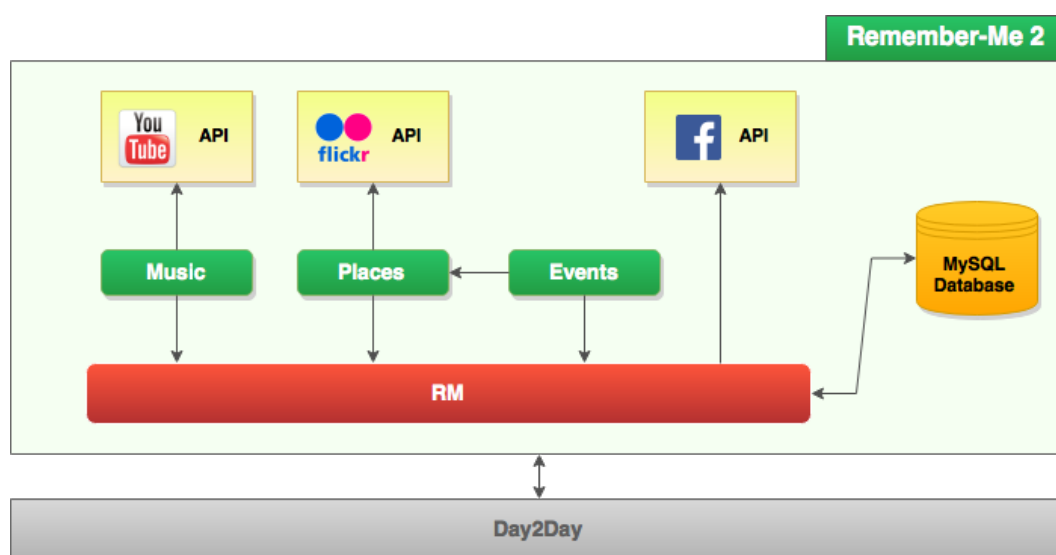


Figure 4.3: Software architecture diagram

The diagram above represents the different modules of Remember-Me 2, as well as the data exchanges between them, with the arrow representing a request. The newly developed modules, coloured green, use the webservice provided by RM to inquire outside sources. This occurs directly on Music and Places, and by proxy (via RM) on Events. Those three modules will be described in full detail on the next section.

4.3.2 The interaction with Facebook

Nowadays whenever we're connected to the internet we're connected to the social networks, being one of the greatest and easiest forms of communication and knowledge transfer. These social networks can be used beyond leisure, with direct and effective results on people's quality of life and on those who are around. By putting people with dementia - although through proxy - into that world, we're linking them to the rest of their family, friends and professionals in an almost seamless way. People on their network will remember them more often and probably are more willing to help those who are in charge daily for his well-being.

The user experience with Remember-Me 2 is divided in two different aspects: one regarding the collection of information and another about using the application itself, detailed on the next section. With the increasing use of different social networks, the use of friendsourcing techniques to enrich web apps is getting more common each day. By using the Facebook to gather the needed biographic material to populate Remember-Me 2, we want to distribute the burden through the friends' network and also mitigate the problems of making the user adapt to a new interface.

The first step, even before accessing the app, is to create a brand new Facebook profile to the person with dementia. For demonstration purposes a fake network was created, with Joaquim Torres, friend of Amélia Torres, representing the person with dementia. This doesn't necessarily represent the person itself: it's an account for using Remember-Me 2, which may or may not be shared with healthcare professionals. Each account must have an administrator and it should be someone who has, at least, basic knowledge of using Facebook. If the person with dementia already has a Facebook account there's no need to create a new one, skipping this step. The admin should also add a profile picture and invite known and trustworthy friends to the network.

The second step is about creating the life events as normal Facebook events. Each should have a name, description, date and also the place where it occurred. The admin may also add a cover photo, representing the event's main photo, if they have any. Now, the friends who are on Facebook and who took part of that event

should be invited to join it. After accepting the invitation, they can contribute with their own material only by uploading their photos to the event's wall.

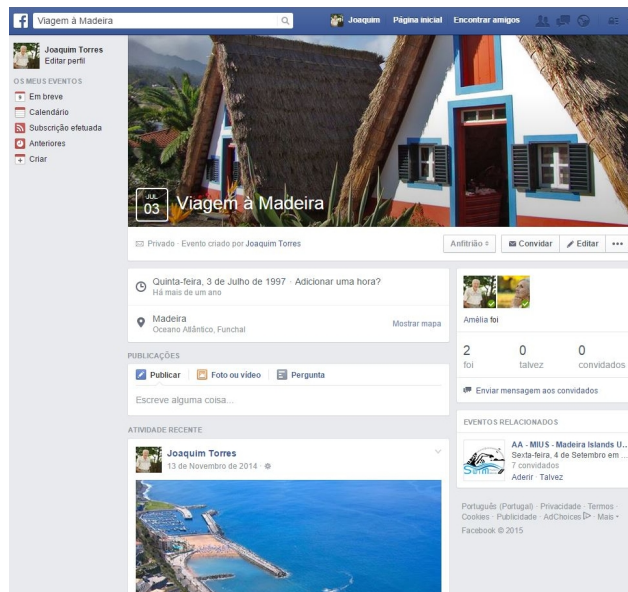


Figure 4.4: Example of a life event on Facebook

By doing this to as many events as desired, the admin is creating a contributive photo album of the person with dementia's life. This is an incremental and ongoing process, taking in consideration the administrator's spare time to do it. Each time the user enters on Remember-Me 2 the system will search for new events so that creation doesn't have to be an one-time operation.



Figure 4.5: The life events timeline as displayed on Facebook

Remember-Me 2 not only retrieves the events created by the profile but also the ones who were attended to. This increases the friendsourcing capabilities since friends on the network may create new events - or even invite the person to already existing ones - and contribute autonomously to the life album. The decision of accepting that third-party event on the life album is made by the account administrator: a certain event will only be displayed on the application if the invitation was accepted by the admin. Also, the application enriches the information got from Facebook with external sources, giving a better context to the end-user, for instance with old photos of the event's place. This way, beyond offering a simpler and clearer interface, it provides more related material, making the reminiscence therapy more useful and practical than using Facebook directly without Remember-Me 2.

This may be also useful to institutionalized people since those life events can also be recent events that occurred in the nursing home or daycare centre. Assuming that the institution has a Facebook account, it can create its own events and upload some photos to its wall. They can then invite the Remember-Me 2 associated account of the patient to those events. After accepting the invites, those events will appear on the app, allowing to follow the different daily activities, for instance a birthday or a trip. Now, those who have access to the application can be up-to-date to what is happening there with the person with dementia, strengthening the ties between them.

Finally, apart from the events collection, the system also takes into account the interests of the profile. The administrator should like pages that are relevant to the interests of the person with dementia, from music to books or movies. On the current approach only the likes related to music are analysed and then used to the Music related view. By knowing what kind of artists does that person loves, the application is able to present several playlists of meaningful songs, ready to improve the reminiscence therapy. Nevertheless, this can be easily extended to other categories so the given likes should be as comprehensive as possible.

4.3.3 Implementation details

Remember-Me 2 is developed in HTML5, CSS3 and JQuery⁵. In order to integrate it with RM services, JSP is also used to authentication purposes. Each of the following modules have a specific JSP file containing all the HTML5 and Javascript code, and a respective stylesheet for dealing with CSS.

When the user lands on the system for the first time, they're asked to login with the recently created Facebook account credentials, referring to the profile that they

⁵<https://jquery.com/>

want to reminisce about. After logging in the user can select which perspective do they want to use: Events, Places or Music.

All the modules make use of a common HTML5 file responsible for dealing with the navigation menu and the actual user context, showing them in which module they are currently. If we want to add a new module this is the only place where we have to add it, linking the new navigation option to the referring page. The only code written in JSP is common to every module and just serves to the platform know which user is currently logged in.

Events

The Events view is the most comprehensive and important perspective of the app. The application starts to query RM about all the events of the users and all its details: id, name, description, date and cover photo.

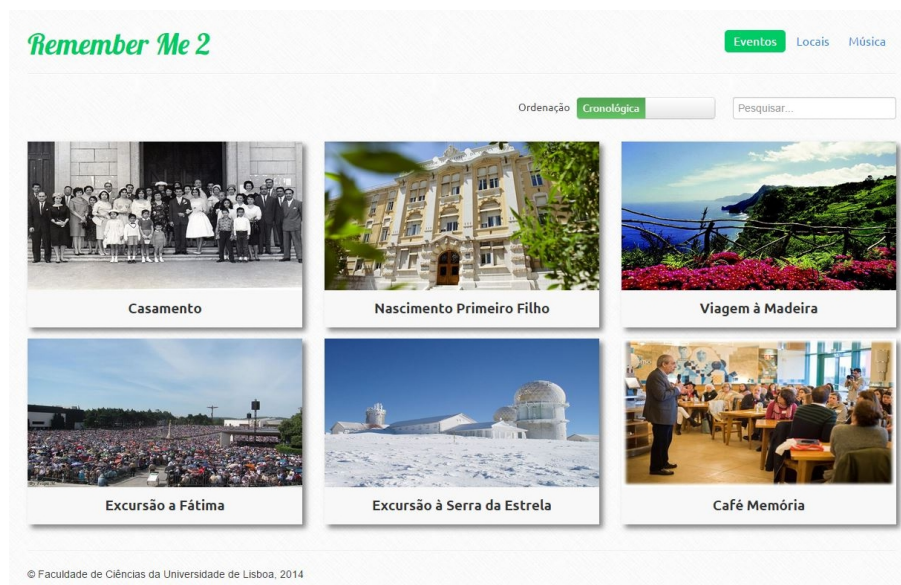


Figure 4.6: Landing page, showing all the available events

When a user selects a certain event, this module will ask RM for more information about that event. RM will retrieve where did that event happen, as well as who took part of it, collecting the friends who attended the event. Moreover, all the media posted on the events' wall will be gathered by RM and then displayed by Remember-Me 2 on an automatic slideshow. This is one major part of the friendsourcing functionalities, since all participants of a certain event may contribute with their own photos.

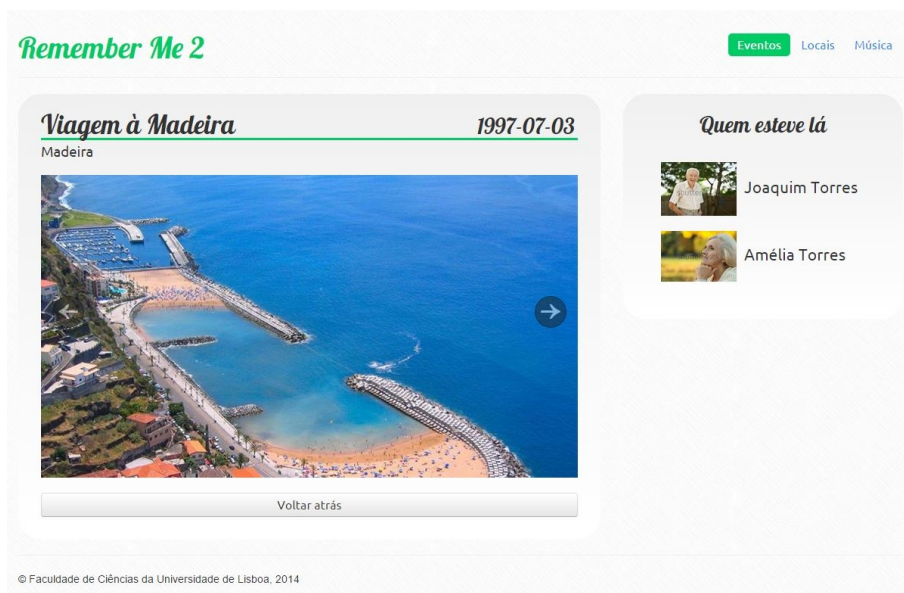


Figure 4.7: Event detail page

This event detail view also interacts with the Places: if the user clicks on the event's place they'll be directed to the page of that place, showing more photos of it regarding the date as will be explained next.

Places

The approach for the Places is exactly the same as for Events. After having all the events the algorithm will iterate through each one and get the Place via RM. All the places, one for each event, will then be displayed to the user, allowing them to pick one.

After choosing one, the system will search on Flickr for photos of that place, taken on that era. For instance, if the event happened in 1995, the search will target photos taken from 1990 until 2000, 5 years before and 5 years after the event's year. The most relevant retrieved photos will be then displayed in the same way they were on the event's page. If there aren't any photos available a message appears, warning the user for the unavailability of the generic photos.

To avoid the systematic display of pictures related with public transportation, there's a big archive about it on Flickr, a simple heuristic was added to the search. The search query is then composed by the place name and the terms - trams; bus; tram; carris; cp; buses; autocarro; electrico; - each one preceded by a '-' in order to exclude them from the search.

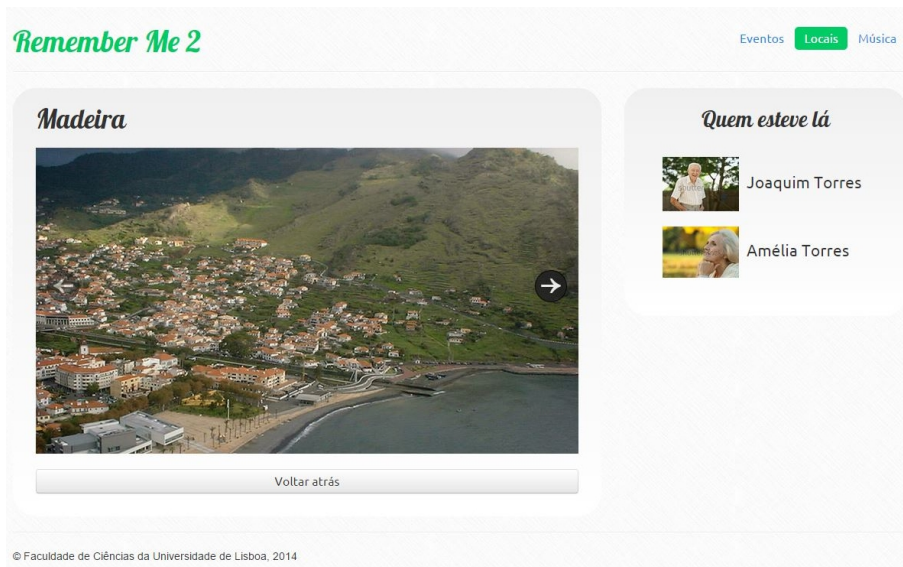


Figure 4.8: Places page

Music

This functionality is more isolated from the other two and doesn't make any direct use of friendsourcing. Remember-Me 2 starts by using RM services to obtain the music interests of the user logged on. When they select the Music option the application will present an artist list made by the Facebook's profile likes. After picking one, the app enquires YouTube about videos from that artist and returns a clickable list of options.

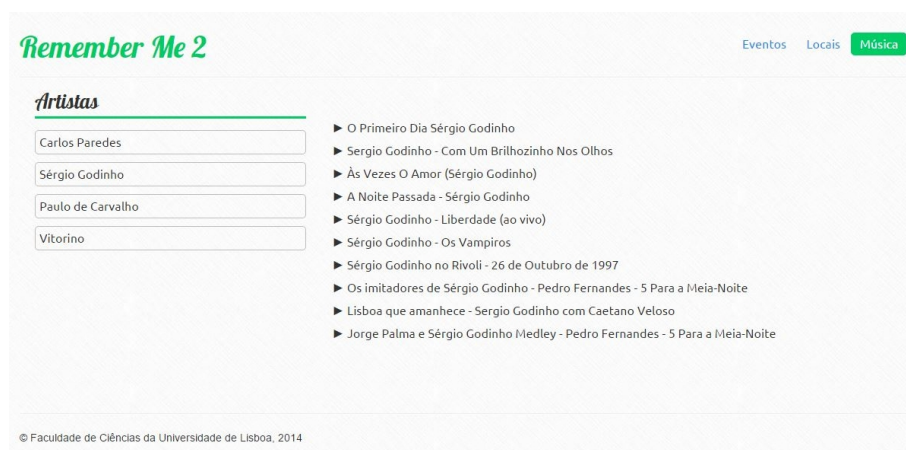


Figure 4.9: Music page

Just by selecting one of the available options, an *iframe* will show up and immediately starts playing the video. To select another artist the user just have to pick it from the list on the left of the screen.

4.3.4 Interface concerns

Since its ubiquitous disposition, we wanted Remember-Me 2 to be a device-agnostic application, using Twitter Bootstrap⁶ to reach that goal. Thanks to responsive web design, the app can be used in devices regardless their screen sizes, browsers or operative systems. All HTML5 elements are inside a fluid grid that automatically calculates the size of each element regarding percentages instead of absolute values. This allows to display the information in a user-friendly size, without any horizontal scroll.

This facilitates the use by those who are only familiar with browsing the internet on a computer, but also permits the more practical approach of presenting reminiscence material via tablet. Although possible, using a smartphone to present information to someone with dementia isn't a good option because of its small display, making it harder to see and to keep their attention. The best device for a more natural interaction is, undoubtedly, the tablet. Besides not having to deal with a mouse, it also allows a more immediate zoom into the photos, focusing people's faces or other relevant details.

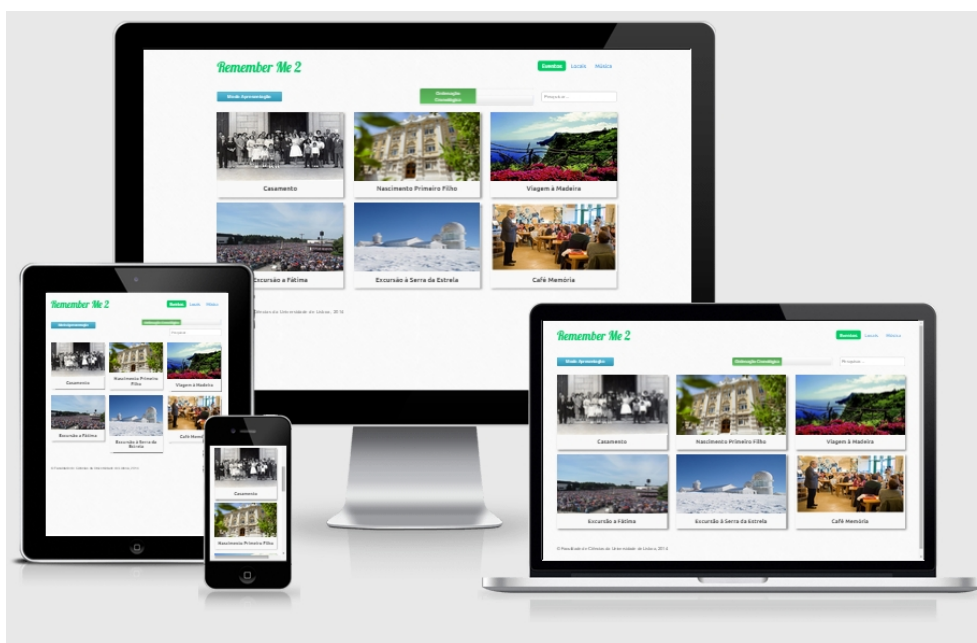


Figure 4.10: Remember-Me 2 on different screen sizes, pictured by Am I Responsive⁷

On a global perspective the interface was kept simple and clear, with a bright background letting the photos jut since they're the core of the app. The selectors and headers are in shades of green, an emotionally positive colour. The pages for

⁶<http://getbootstrap.com/2.3.2/>

⁷<http://ami.responsivedesign.is/>

Events and Places were also kept identical so the learning curve is softer, showing a different kind of information but with a similar presentation.

When presenting large amounts of info, like the Events or Places page, the user can filter the material to avoid being overwhelmed. This is available either by searching and by ordering the events and places chronologically or alphabetically.

To improve the user experience, the detail page of an event is connected to the page of its place. This avoids losing context when the user is reminiscing about a certain event and wants to switch to that respective place. For doing that, the user only have to touch on the place to be taken to its page, with more photos available. The context is also maintained by the friends list that is common to both views.

Finally, regarding the different slideshows of photos, they're all interactive, allowing the user to click on the navigation arrows or to swipe through the photos. Yet, if the user does nothing the photos scroll automatically. This automation also happens on the Music page when selecting a music video, which starts just by selecting it. This makes the application more intuitive to use, with fewer interactions, but doesn't scarifies functionalities to more advanced users.

4.3.5 Spin-offs

Presentation Mode

Thanks to distinct opinions regarding who should use the app, and also taking into account the different stages of the disease, a new kind of view was added to Remember-Me 2: Presentation Mode.

By clicking on this button, available on the Events page, the user turns Remember-Me 2 into a fully automatic application without any needed interaction. The app will start to present random photos from all events in a fullscreen slideshow, making the tool easier to use, similar to watch a TV programme.

Nevertheless this should not be the main usage of the application since the context of each photo is lost and the person should be accompanied to have someone to talk to and to stimulate their communication.

Portrait-like solution

This spin-off of Remember-Me 2 isn't the main focus of our app, which are the caregivers who still live with the person with dementia, but it shows a different way to collect biographical information for a system like Portrait [13].

Portrait, as described on the related work section, is a tool for healthcare staff of nursing homes, allowing them to get to know their patients better, being one of the related work closest to this project. Besides making caregivers adapt to a new platform, the task of collecting and adding data can't be shared and has to relapse on a single carer, being a problem on their approach. This turned out to be a time-consuming activity, increasing the burden of the caregiver and leading to a lack of motivation.

However, if we could use this friendsourced approach to fill that album of life events, the burden would be distributed through a wider network of contributors. With this new approach, the data displayed to the nursing-homes professionals is barely the same but it's collected via Facebook's profile of that certain person. Assuming it has life events associated to that profile, an illustrative picture and description of each will appear in the History tab. The level of detail of each event should be taken in consideration because of privacy issues, which probably would left the photos and who attended the event outside this data collection. The burden of collecting info is now split between all the trusted secondary caregivers, who take advantage of using a well-known platform to add their personal contribute to the life log of the person with dementia.

Besides events, interests and relevant places are also automatically collected from the profile and presented under the respective area. With special focus on the interests, they could be used to find common talking subjects to stimulate the patients communication while taking care of their health or hygiene condition.

Chapter 5

Prospective evaluation

To guarantee that the developed solution is effectively addressing real problems, we presented it to both groups of stakeholders - professionals and caregivers. We wanted to determine how can Remember-Me 2 improve the activities related to reminiscence that are already done, if they find it useful to their daily life and which new functionalities could be added.

Regarding healthcare professionals, the approach was similar to what was done pre-system, now with elicitation interviews being done to neuropsychologists. About caregivers, this time there was social and physical contact thanks to the participation in support group sessions for people with dementia and caregivers. The team conducted several focus groups where we could get in touch with both caregivers and people with dementia.

5.1 Elicitation interviews

5.1.1 Participants

We've contacted three of the four neuropsychologists interviewed before, now to criticize the developed tool. The selected neurologists have a different background and work environment, with one doing their work in Madeira and the others in Lisbon. They had the less coincident opinions on the first round of interviews and therefore represent two distinct perspectives: by analysing and combining the reviews we can reach a more conclusive review.

5.1.2 Methodology

The interviews aimed to validate the current features, retrieve suggestions of improvements and also concerns that could be raised. Both were recorded in audio to be further analysed, as the next section states, referring to the interviewees as NP1 to NP3.

Thanks to distance reasons, the interview with the neuropsychologist from Madeira island was done via Skype. The application was shown during the interview by streaming the display, explaining each functionalities as long as we were describing them. The remainders were done on person, letting the neuropsychologist to freely interact with the app as we talked and discussed related ideas.

5.1.3 Findings

Benefits for current practices

The person-centred approach present intrinsically along the app met the expectations of the professionals, helping the personalization of their appointments by introducing more personal material, allowing a better stimulation of their patients' memories.

The automatic retrieving of photos from the past was received with enthusiasm by both neuropsychologists, showing that this is specially useful to do reminiscence therapy during their appointments. Like in the first interviews, NP1 prefers photos about the past, stating that those are far more important than recent ones. On the contrary, NP2 values both recent and past photos, pointing that even if the person can't remember the event itself, they may remember the people who are in those photos.

NP2 also considered the music option as an *"extraordinary added value"* to their appointments because music is attached to the emotional memory, which is the last one to be forgotten. Even when the person can't express by words anymore we can make her react to musical stimulus, acting almost as a rebirth, showing facial expressions that were lost a long time ago.

The same neuropsychologist also pointed out the potential improvement during their medical appointments. On one hand, Remember-Me 2 could prevent the carer's burden of finding and carrying heavy photo albums to the appointments. On the other, it could also permit the professional to take the lead. By introducing the tool to the caregiver, the professional may ask if he or she is interested in contributing with information, filling some events already created. Moreover, it could allow a better previous preparation of the appointments:

"For instance, if someone on the family had his birthday the past week, I could easily have some photos which I could work with the patient immediately on our next appointment." [NP2]

The versatility of events, places and music was appreciated by both professionals, improving the diversity of the reminiscence therapy. Both stated that they often struggle with having enough materials to keep their stimulation sessions unique and dynamic. They reinforced that doing the same exercises on the same material over and over is extenuating and doesn't motivate the patient to collaborate.

On a social perspective, NP2 also praised the interaction promoted by the tool, of both caregivers and people with dementia, affirming that social interaction is as important as cognitive stimulation. If that social stimulation isn't boosted people will end up isolating from the surrounding environment and that's where this app may act, calling family and friends around the person with dementia. This kind of micro volunteering, asking small favours that can be done at a distance, improves the chance of getting positive answers. Moreover, NP2 adds that most people are afraid with the physical confrontation with the person with dementia, having more will to collaborate virtually.

It's also easier and subtle for the caregiver to ask for help than when they need aid with tasks that have a negative charge. NP2 guarantees that's a good pretext for talking with the remainder family and friends, fighting their own isolation and improving their mental well-being. The same neuropsychologist is very assertive by saying this kind of tools don't promote isolation:

"How I wish there were more tools that could allow, without leaving their homes, people to have significative days with social interaction."

People with dementia often have mobility issues that makes it difficult to leave their homes, and so they and their caregivers are already isolated. Now it's time to turn those hours they spend at home into something meaningful and significative for both.

New expectations

NP1 stated that all photos with people should have tags, helping the caregiver or the healthcare professional to identify who's on it, making the person with dementia talk about those people. Talking about people is one of the most effective reminiscence subjects so photos could be a powerful new source of knowing who was meaningful to the ones with dementia.

Still on events, they could be enriched with historical moments that are relevant to everyone. From inventions to influential celebrities, people could reminisce about things that changed their lives forever. Applying this idea to Portugal, everything that's related with the 25th April revolution is very remarkable on the over-60s population.

Another related perspective was the life-line notion that was brought by NP2. A current practice asks the elders to draw a line starting on their birth and ending on the present day, where they can themselves identify their life events, giving a positive or negative charge to each one. This could easily integrate with the current events approach, specially on patients who are still on a early stage of Alzheimer's and can provide information about their lives.

The music perspective opened more ambitious expectations, with NP2 enjoying the creation of a Pandora-like radio. By knowing the patient's likes through Facebook we could auto-suggest new artists that are somehow related with the current likes, creating customized radios that match the interests of each person.

Feedback mechanisms were also requested, with NP2 saying that cognitive stimulation should be always rewarding but sometimes things go wrong. A certain photo may trigger a deep emotional outcome hard to manage and therefore we wouldn't want to show that photo again in the future. This feedback could also be useful during appointments: by adding the notion of session - in which each appointment is a different session - we could record what was the person's reaction to what is currently being displayed, identifying which subjects produce better outcomes.

All the interviewees found the Portait-like spin-off very relevant, with NP3 suggesting new subjects like the person's habits - for instance what time do they like to wake up - and also their food tastes. This tightens the ties between the staff and their patients, being important to maintain their life quality and well-being.

Finally, the presentation mode also retrieved positive feedback, with NP2 complaining about the useless amount of time that people spend starring at innocuous TV shows when they could be reminiscing about old photos and events. By having a tablet on their hands that doesn't require any type of interaction, people with dementia could just appreciate those meaningful photos on something that requires less effort than go and find some old photo album.

Remaining constraints

The current major concerns of the professionals are the digital illiteracy of caregivers, not allowing them to profit from these tools. The utility of the tool depends on their self-awareness with new technologies, being hard to motivate someone who's not familiar with them to learn just to use these tools.

Facebook and other social networks can also retract potential users, sometimes driven by the lack of knowledge about how to keep their personal space and material safe from the others. The mistrust on social media, and also the internet itself, by the elders is something to be concerned with. A pedagogic approach may help to clarify some ideas but we should value and respect the personal beliefs of each one.

At last, these collaborative tools can only be beneficial and applicable in structured and committed families. Without a proper network of family members and friends that are motivated and interested in contributing for the well-being of the person with dementia, we won't be able to help them neither to promote their cognitive stimulation.

5.2 Focus groups

5.2.1 The Café Memória project

Café Memória⁸, Memory café in Portuguese, are meetings for people with memory impairments or dementia and their families and caregivers, where all can share experiences and find mutual support. Their main objectives consist in contribute to a better life quality and reduce the social isolation, besides making the society more alert and aware of this healthcare problem.

The sessions are free and supported by volunteers, being based on a person-centred approach, always including the heterogeneous participants as much as possible. Considering the caregiver role as preponderant, they can find in Café Memória a safe and sound environment to share their problems and preoccupations. This also

⁸<http://www.cafememoria.pt/>

serves as a platform to exchange information and scientific proved knowledge and somewhere where they can see the cognition of the person with dementia stimulated.

They happen in various places in Portugal, from Lisbon to Porto, Viana do Castelo or Campo Maior. The sessions occur always on Saturdays, on a monthly basis, and last for about 2 hours. This project started in April 2013 with sessions on Colombo's and CascaiShopping's Portugália, being then expanded in 2014 to Museu S. Roque and Campo Santa Clara, all in Lisbon Metropolitan Area, allowing a session on every Saturday for those who live in the Portuguese capital. After March 2014 the project also expanded to the rest of the country, with 4 more places. The expansion plan has 2 more places to open in a near future and 10 other potential partners.

From April 2013 to April 2015, 99 sessions took place, reaching a total of 684 different participants and 1823 entries. Regarding those participants, most of them (60%, N=597) are caregivers or family, with an average age of 56.6 years old (N=417). Last but not least, these sessions could only happen thanks to the 164 volunteers [33].

5.2.2 Sessions and participants

We took part of 5 different sessions during the month of May and June. 3 of those sessions took place in Lisbon, 1 in Cascais and another in Algés. We've reached 50 actual or former caregivers and 17 persons with Alzheimer's, as well as 11 other participants and, at least, 28 volunteers. The sessions' names were omitted for privacy reasons.

Session	Caregivers	PwD ⁹	Volunteers
Session 1	13	5	5
Session 2	10	3	6
Session 3	7	4	6
Session 4	15	3	7
Session 5	5	2	4
Total	50	17	28

The participants were heterogeneous, allowing us to see different realities and perspectives. Regarding the caregivers, we could establish contact with elders on

⁹Person with dementia or mild cognitive impairment

their 70s who were left alone by the rest of the family to complete families that participated together in the sessions. We also dealt with different stages of the disease, from people who can't communicate anymore to cases where we could maintain a healthy and productive conversation.

5.2.3 Procedure

Our team in each session were different because schedule and availability reasons. Although there was a core, where I belonged, common to all the sessions, several volunteers were recruited from the HCIM@LASIGE research group to fulfil a team of at least five elements. The sessions themselves were also different between them: the dimension and age of the participants was varied, as was the ratio between the number of caregivers and people with dementia.

Each session lasts for about 2 hours, happening in an informal environment where the main focus is to talk about the disease, sharing experiences and concerns. People are divided into several tables, composed by at least one volunteer from Café Memória's team, a member of our team and a random number of participants. The focus group is conducted by our member at the table, having to adjust it to the number of caregivers present in each one.



Figure 5.1: General view of two different sessions¹⁰

Every session is started by the host, where everyone, including our team, introduces themselves by playing a little social challenge. Then there's a short presentation, around 15 minutes, about our team and project, where the participants can get a broad view of the work done and how did we get here. After this, coffee and cake is served and each table starts their focus group, showing Remember-Me 2 and Day2Day operating on a tablet. This allows the discussing of ideas, suggestions and preoccupations and retrieving first-person feedback from those who these apps are aimed for. People were encouraged to be sincere and not afraid to tell if the apps are meaningless to them, if that's the case.

Figure 5.2: Focus groups¹⁰

After the focus group we handed out a short questionnaire to caregivers in order to retrieve explicit feedback from the tools and the session itself since it's not recorded in any way. The session ends with a global farewell moment lead by the host.

There are some constraints that should be taken in consideration regarding Café Memória. The first and most important is that the participants are mostly people who are more dedicated to the disease than usual, often with a higher education and knowledge about how can they help the person with dementia to have a better life. Second, thanks to the proximity of the places, there were some repeated participants between the sessions, which didn't turn out to be a problem since people always had something more to say. Finally, some of the participants were neither someone with Alzheimer's nor a caregiver, being there just for curiosity or because they're afraid of the disease. The contributions of those persons were poor but didn't affect the feedback collected from the main interested party: the caregivers.

5.2.4 Findings

General feedback

People generally reacted with enthusiasm and excitement after seeing both apps, identifying clearly their benefits and usefulness to their daily life. The enthusiasm on each caregiver is as big as they're more used with new technologies. We had several cases of people who are not familiar with digital devices and even them showed interest and found the apps useful for those who are able to deal with them. Finally, the requirement of a proxy, caregiver or familiar, to use the application is seen as positive and the only way to making this tools effective. Some state they've tried to let the person with dementia use the tablet to see photos but they ended up touching where they weren't suppose to.

¹⁰Photos taken from Café Memória Facebook page

Those who use technology daily show more interest in the tools and, consequently, contribute with more feedback and new ideas. Many quickly asked where are the tools available, how can they use them or how can they add more photos and music. We also found people that regardless not using digital tools to reminisce, review photo albums frequently, stating that emotions run high when doing that sort of activity.

Privacy issues varies a lot from person to person, with caregivers feeling completely fine about it and others just hating everything related with social media. It depended a lot on the personal perspective and how familiar they're with digital technologies. The afraid of the unknown was common, justified or not, and should be respected.

On a higher perspective, people think those apps should help to aggregate the people around the person with dementia, promoting the interaction between them and also looking to the problems with a more socially aware view. We could prove this problem by speaking with caregivers whose family just drifted apart, complaining about uninterested sons with no time to help them dealing with the person with dementia. Some caregivers see these new communication forms as a solution to those who have their folks institucionalized since they're not able to visit them as often as they would like.

Real-life utility

Some caregivers already do what Remember-Me 2 offers in a more primitive and non-collaborative way. For instance, one caregiver does reminiscence therapy with his wife using his cell-phone. By having his photo gallery ordered by events, he can display several photos of each one. The use of old photos is also familiar to that caregiver, stating that often uses Google and the Lisbon's city council website to collect past photos of meaningful places, stimulating his wife's communication. Besides this case there are more examples of caregivers who take photos with their mobile phones and then stimulate the person with dementia to reminisce about them, as well as photos of old places and people they found on the internet.

Still on photos from the past, more caregivers found it interesting even to themselves, helping them to remember places how they were and this way having more subjects to make conversation. We had a large family which attended to one of the sessions where the person with dementia lived abroad and still talks a lot about his homeland. They were interested a lot in this back-in-time feature, as well as dividing the life into chapters, a bigger version of events. Things like *Childhood in S. Tome*, *Moving to Lisbon* or *First job* made a lot of sense to that family. They also

approved the use of a social network since they think their friends may contribute with a lot of material, spreading this *"epidemically to family members that I don't even know"*.

The lack of reminiscence material was pointed out by caregivers too, with some regretting having access only to a few photos, ending up repeating them over and over, leading to non-motivating exercises. On the other hand, we've met a caretaker that receives a lot a photos from his family via e-mail but can't manage them very effectively. Although being pretty open to the use of Facebook, he thinks it's difficult to use it to present reminiscence material to his wife.

In fact, more knowledge and subjects to make conversation are a major point on the caregivers desires. The same happens with the availability of reminiscence material, with a lot of caregivers being motivated by getting more photos and also with the idea of accessing general objects. Also, reminiscing about the people we can see in the photos is considered very useful. Besides photos, talking about interests - like stated in Portrait spin-off - could also improve the communication. As we can see, this approach with many components is something that people found useful, promoting diversity and avoiding boredom.

About the music, many caregivers already have their radios always on, tuned on stations that are dedicated to non-recent music, affirming that they always get happier when listening to music and often sing along. Others also approve its use when the person with dementia is more agitated, serving to calm them down. A few carers also use YouTube to see excerpts of videos, mainly regarding TV shows and personalities. Furthermore, when presenting the application on the focus groups, this music perspective really got the attention of several persons with dementia, recognizing the artists that were playing.

Improvement suggestions and new ideas

A common desire to several carers are aids for daily living activities. Tools that could improve the autonomy of the person with dementia, helping them in their daily tasks. Things like remembering that they already put salt on the food they're cooking or check if the glasses aren't already on their face when they can't find them were some examples for this kind of tool.

Focusing more on people is another suggestion that were broadly referred, with some caregivers using genealogy trees in their reminiscence sessions. The focusing on those who surround the person with dementia seemed to be very appreciated by the caregivers, showing they have good outcomes when they talk about them. Once again, this matches with the results got from the online survey. Specifically

to Remember-Me 2, some caregivers suggested to present a new module, where the user could see all the members of the family, pick one, and then see which events they attended to.

We've collected a need disguised as complaint, regarding the "*useless time*" elders spend looking at their TVs, without getting any kind of stimulation from it. The caregiver suggested that we could make that large amount of time more useful and meaningful. This could be done either turning that reminiscence therapy into a TV channel or making the device itself as a new way for communication with the family, for instance. This opinion matches with the one got from NP2 back on the elicitation interview.

A caregiver also brought the gamification term to the table, saying that's an effective way to motivate the younger ones to contribute with more information. By promoting this healthy competition inside the family, which could include a leaderboard with each member, the whole network could get more committed to the cause and help more.

With a less personal approach, caretakers advised the inclusion of general material. This can go from newspapers, to historic or sport events or even 'iconic elements' of significative places, things that are familiar to everyone who lived there. Once again this is in line with some of the opinions got from the neuropsychologists.

Finally, one of the carers who isn't fond of Facebook suggested to import photos automatically to the platform just by inserting a SD card into the device. Another mentioned that those photos may be also presented in a chronological timeline, regardless the events they belong to.

Raised concerns

Social networks still cause stir on older people, showing disbelief and fear of being too exposed to unknown people. Facebook's privacy settings are hard to use and don't get people's trust, with caregivers stating that if it's on the web then we have just lost control of its privacy forever, no matter what. In fact, 'Facebook' is a word that triggered feelings of hate on some caregivers. However we also had people that were perfectly fine with the Facebook integration, although mentioned that this friendsourcing techniques are only useful if the network is wide enough.

Outside social networks some people also inquired the team about the privacy inside the application: who can see the photos and events, how can we access it and how safe it is. The idea of having an administrator of the account seemed to tranquilize them, giving the caregivers and family the power to decide what's available and what's not. This conservative approach allows to do a better assessment of the

pros and the cons, making a compromise between the privacy issues and the benefits of using a collaborative tool.

We also had caregivers that didn't find the apps useful. Some would prefer a game-based approach, something more similar to Cogweb. Someone else said that she never uses photos because, from her experience, photos don't stimulate the person with dementia, which goes against all the collected data from different sources. Another caregiver said she doesn't like tablet devices because they display the photos too small, making her eyes tired. We also identified a case where the person with dementia is afraid of the tablet, provoking stress. Another example of not approving Remember-Me 2 was this caregiver who doesn't like to talk about the past and, by her words, would feel offended if someone asked about her past because of being mentally ill.

Regarding the healthcare condition of people with dementia, caregivers alerted to the difficulty of catching their attention for large periods of time and also to the lack of motivation to do this kind of exercises. In the same vein comes the risk of presenting too much information at once, overwhelming the users.

5.2.5 Survey results

This 10-question survey aims to retrieve a declarative feedback about reminiscence therapy and how they see the apps functionalities' utility in their daily life. At the end of each session we handed out a printed survey to actual or former caregivers with the following distribution:

Session	No. of Answers
Session 1	13
Session 2	10
Session 3	7
Session 4	15
Session 5	5
Total	50

The results revealed that only 27.7% does or already did reminiscence therapy. When asked if they feel any difficulties on the collection of content, specially photos, 55% answered positively. Regarding the provenience of that material, 61.9% rarely uses third-party content and 9.5% state they never do. About the type of material

they currently use to reminisce, 95.2% use photos, 76.1% music and 52.4% objects. This supports the results from both online survey and professionals interviews.

About how they view the concepts demonstrated by our apps, 60% say that it's *very attractive*, and 38% *attractive*, to have a digital tool that gathers all this reminiscence material in only one place. We got an even more expressive result when inquired about if the family's contribution with information, photos or life events is relevant: 100% answered *attractive* or *very attractive*. By having this unanimity, the friendsourcing approach gains a bigger importance by allowing that desired contributive network.

Finally, on privacy issues, 67.3% stated they feel *comfortable* with the share of this kind of material and 20.4% even *very comfortable*. Only 2 participants said they're *not comfortable* with this sharing. This result is better than expected, showing that professionals are more concerned when dealing with privacy issues than the caregivers themselves.

The remaining 3 questions focus on Day2Day app and therefore are not relevant to the context of this thesis.

5.3 Discussion

Positive feedback

By starting this project almost from scratch, capturing the requirements of the various stakeholders, we were able to direct better the developed tools, increasing the chances of being effectively useful for those who will use them.

This could be proved by the positive feedback got from the elicitation interviews and the focus groups, showing that there's a lack on reminiscence material, leading to less frequent and motivating sessions. Remember-Me 2 allows a more contextualized approach, centred on the person and connecting the different memories more explicitly. This allows to stimulate different areas of the brain via distinct supports - photos and music - and promotes the communication of the person with dementia.

The reminiscence therapy can be costumized to the specific needs of the person, accordingly to the stage of the disease. In early stages, where the recent memory is still preserved, the life events can act as a diary where the caregiver can record their routines and recent trips or episodes. After that recent memory is lost, the same app can be used to create a life story of significative and remarkable events, like a wedding, the born of a child, major trips and so on. The gathering of generic material that is relevant to each one, like past photos of significative places, boosts

the long-term memory, allowing people to go back in time and revive those times. The remembrance doesn't have to be only about the place itself but also about habits or people who belong to that era.

By enabling friendsourcing techniques in the retrieval of that personal material, we are relieving the caregiver's burden and also promoting the interaction inside the family. In physically disperse families, this gathering of photos and interests can also be profitable to the whole network, sharing photos and information that is new to some elements. Working with Facebook events also allows to participate on third-party events, which finally permits to share the responsibility of the data collection for this kind of life-logging tools.

Negative feedback

However, Remember-Me 2 isn't flawless: the trade-off between friendsourcing and the use of Facebook frightened some caregivers. The mistrust on social networks is very present in older people, some explained by unawareness, fearing for their own privacy and also because they often have to decide for the person with dementia. Nevertheless, one of the main advantages of the tool is to permit this collaborative collection, which can only be achieved using a social network, Facebook or not.

Finally, digital illiteracy also takes away some potential users. By fear, ignorance or even because they feel too old to learn new techniques, they're not interested in moving this stimulation exercises to the digital world. A sensibilization for the benefits of these new tools could be profitable to both parts but this evangelization is not worthy if the caregivers aren't predisposed and motivated to learn new things.

Nonetheless, as often stated by caregivers in focus groups, we shall make the tool available to those who are interested and willing to use it. As the time goes by, more and more people are familiar in technology, reaching larger networks of users who could profit with this approach. If we help just one family then our work wasn't in vain.

Chapter 6

Conclusions

The research goals pointed on the introduction chapter settled the targets of this project and their completion should here be analysed. Still before the developed system, the interview study and the caregiver's survey permitted to obtain a good **characterization of the stakeholders**, assessing what are their daily routines and struggles. Moreover, the focus groups and their review of the current solution, as well as the elicitation interviews, opened new paths for further tools as well as the validation of the developed work.

By developing a **friendsourced application**, the **personal data collection** is assured as long as the network is large enough and contributes with material. With this collaborative approach, the **caregivers' burden** is diminished and shared between the network, improving their and the person with dementia quality of life. This personal material is also **enriched with public sources**, collecting third-party photos and music that are significant in some way to the person with dementia.

With that being said, **support materials** were also improved, allowing users to review personal and generic photos, places and music videos. This type of tools are important not only at **home** - although that was our main focus - but also at **regular healthcare appointments**, where professionals can use the gathered material to develop more personalized approaches, having more material to work with and increasing the diversity of their sessions.

6.1 Benefits

Speaking on applications to help people with dementia and other kinds of cognitive impairments, the focus should always stay on that person. The person-centred approach was the most heard notion during the project and if the apps are designed with that in mind they'll probably improve the quality of the actual processes. This approach demands having a good knowledge of the person as a person, and not only as someone who needs healthcare, and that requires some effort. To reach that we have to facilitate the access to significant biographical information to the interested parts.

The struggle of collecting personal material can be eased if it doesn't relapse only on the main caregiver. Reminding the dangers of overburdening the carers, applications that promote collaboration and volunteering are essential to help them in different ways. First, they can obtain material from other trustworthy sources without much effort, distributing the task of collecting throughout the network. Second, it avoids their isolation, promoting the social interaction and making the requests for help more subtle and discrete and therefore they can be more frequent.

Bringing people together can be reached in many ways with other approaches, not being exclusive to friendsourced communities. Caregivers need to talk and, more specifically, they need someone to hear them, someone who tells them that they're not alone. That group of people have a constant need of expressing worries and dump their daily frustrations and incidents with someone they can relate to. That listener doesn't have to be a family member or a friend, it can also be another caregiver on a common situation.

Concretely regarding reminiscence-based tools, extending the amount of available material is a key to success. The diversity is fundamental, from different kinds of materials - personal and general - to different supports - photos, music or videos. The attention of the person with dementia is hard to get and dynamic sessions can increase their interest and motivation to perform cognitive stimulation exercises via reminiscence.

If correctly used, more information means more chances of success: if the person with dementia doesn't remember anything from this era let's try another. This cannot happen if there isn't material from different times and environments. In line, if a person isn't reacting to photos let's try music or videos and see if they produce better results. As with caregivers, the communication of the person with dementia is a major objective, not letting them isolating in their own world and begin their social and mental recessive spiral.

6.2 Limitations

Approaches based on new technologies, even if simple and easy to use, always require some knowledge on how to interact with the devices. Even more, friend-sourcing applications also require familiarity with the internet and social networks. It's not plausible to ask a caregiver who never had a computer to start learning how to use it just to use this kind of tools - their lives are already too overwhelming to be asking for an effort like that.

The devices themselves and the required internet subscription could also be a limitation since they demand a financial effort. The actual economic situation of the Southern Europe isn't known as stable and every day more and more people struggle to have enough money for medication, nursing homes' monthly fees and other inherent expenses.

Still on the internet subject, friendsourced applications are always based on social networks. If people don't trust those networks they will get deprived of all the benefits of the collaborative platform. Everything has a trade-off and people should measure the pros and cons of giving away a little of their privacy to receive more help from trustworthy people. All the decisions should be done rationally, making the stakeholders realize if the benefits supplant the negative issues or not. However, the mistrust and mostly the fear of the unknown often drives people away from those new social environments.

We are also aware of isolated families, as well as socially or economically vulnerable cases. In Portugal, unfortunately, there are still elders that never saw the sea and don't have any kind of memories, for instance photos, from their past. The approach on those cases has to remain just on non-personal material, trying to find meaningful memories through conversation. Without significant materials to insert in this kind of apps, their utility is largely diminished.

Besides that, some families are less suitable to use tools that requires some effort and commitment. Dysfunctional families are often absent from the life of the person with dementia, not caring about their well-being or interested in keeping their mental and physical condition. In those cases, that lack of interest in digital tools is probably their minor problem. By various reasons, those people aren't motivated to use them and, in their perspective, the less they have to deal with the disease the better.

6.3 Future work

Thanks to both elicitation interviews and Café Memória sessions we could be inspired to develop new ideas about improving the current system or even create new modules to integrate it in the future. Also, some current issues still require more work.

- **Reminiscence through objects** would be improved if they could be printed at home on 3D printers, creating a repository of models of common objects or even creating them through photos. This idea amazed some professionals and caregivers also stated that they use objects to reminisce but, once again, they lack on variety;
- **Tagging people on photos** is also a top priority. Since the current Facebook's API doesn't allow to retrieve the tags easily, a workaround should be develop to associate people with photos;
- **Historical facts, news, inventions and famous personalities** could also be added as reminiscence material, generic information that is common to all the people of a certain age who lived in a certain country. It also could be saw as a country's timeline, with the milestones that changed our lives forever;
- **Activities of daily living** also need support, providing tools that could extend the self-sufficiency of the person with dementia, helping them in their daily chores and struggles. By promoting their autonomy we could delay the need of getting institucionalized and decrease the burden of caregivers;
- **Privacy issues** aren't fully solved, they deserve and demand a more detailed work to find ways and means to make the users more comfortable, educated and clarified about how can they keep their personal information confidential. Eventually a non-friendsourced version could be developed if there are enough caregivers interested in it;
- **Emotions detection** can improve the knowledge about people with dementia, specially when they can't express themselves anymore. By identifying their facial expression and the emotion associated with it we can provide better orientated stimulation sessions. Even more, by relating emotions with the displayed material we can detect patterns and learn to which materials do they react better;

- **Feedback mechanisms** should be available to those who use the app, simple positive/negative buttons that would record if the reaction to a certain stimulus was good or not. This would allow the system to learn with itself, knowing which materials, people or part of the patient's life should display more often. This is also useful on the Portrait-like approach, since each patient receives healthcare from various professionals that don't have the time to communicate which subjects result in better outcomes;
- **Digital diaries** could help both caregivers and people with dementia to keep track of their day, not in a clinical perspective as in Day2Day but in a future memory perspective. These records could be done while the disease is still on an early stage, being then used by the binomial caregiver-person for remembering the recent past;
- **New human-computer interfaces** are emerging everyday and should lead to the future, with smartwatches and other intelligent wearables opening new windows to a more natural approach to interact with this and other tools.

Appendix A

Interview guides

A.1 Pre-system

Objectivos

- Identificar e caracterizar quais as práticas de estimulação cognitiva?
- Caracterizar o sucesso das práticas de estimulação cognitiva.
- Caracterizar os envolvidos na estimulação cognitiva.
- Caracterizar o momento da estimulação cognitiva.
- Quando, quem, onde e porquê?
- Tipos de conteúdos (tipos de media, pessoas vs genéricos)
- Forma de apresentação

Regras de Ouro

- Não influenciar as respostas do entrevistado
- Respeitar os tempos de silêncio; dá tempo ao entrevistado para elaborar

Apresentação

Olá! Somos investigadores da Faculdade de Ciências, departamento de Engenharia Informática, e a nossa investigação actual foca em perceber as necessidades e oferta actual a nível de rastreio, acompanhamento e estimulação da pessoa com demência. Para podermos contribuir com inovação tecnológica nesta área é essencial percebermos quais as necessidades e procedimentos em uso actualmente para

podermos criar mecanismos que cumpram com os requisitos dos utilizadores finais, pacientes, cuidadores e corpo clínico. Vamos fazer uma pequena entrevista, de aproximadamente 30 minutos, em que faremos algumas questões de base mas que se pretende que possa explorar a sua área de interesse.

Caracterização geral

1. Há quanto tempo trabalha com pessoas com demência?
2. Pode falar-nos um pouco sobre a sua actividade actual, no que respeita a pessoas com demência? O que faz?

Rastreio/identificação da demência

1. Na sua actividade, que papel tem no diagnóstico da demência?
2. Como é feito esse diagnóstico? Que tipo de testes são usados? Ou é baseado em informação dada por terceiros?
3. Coloca em prática algum procedimento standard para rastreio da demência? Se não, onde e como é feito esse rastreio?
4. De que forma o diagnóstico precoce – e até a prevenção – poderão influenciar o o quadro clínico de uma pessoa?
5. Qual o papel das famílias/cuidadores no processo de diagnóstico?
6. Quais os intervenientes no processo de diagnóstico? (centros de saúde, familiares, outros médicos?)

Acompanhamento e intervenção

1. Quem são os envolvidos no processo de acompanhamento de uma pessoa com demência?
2. Quais as intervenções mais frequentes?
3. Na sua actividade, em que consiste o acompanhamento e intervenção?
4. Que procedimentos são usados na consulta, quais as suas frequências?
5. Que procedimentos são feitos fora da consulta e em que consistem?
6. Qual o papel das famílias/cuidadores no tratamento?
7. Com que tipo de dados trabalha?

8. Na consulta? questionários, testes, medições
9. Fora da consulta? diários? sensores?
10. O tipo de informação que recebe é suficiente para a adaptação das intervenções? Se não, em que medida poderia ser melhor?
11. Há transmissão de dados entre profissionais? psicólogo->neurologista

Estimulação cognitiva

1. Que tipo de conteúdos usa na estimulação cognitiva? (pode já estar respondido)
2. Esses conteúdos devem ser pessoais (auto-biográficos) ou não?
3. Acha que a utilização de material não-pessoal (p.e. fotografias genéricas de locais) pode ser igualmente benéfico num ambiente de reminiscência?
4. Acha que há maior benefício em apresentar conteúdos abstractos ou relacionados com pessoas, eventos ou locais? (E dentro destes últimos?)
5. É relevante estimular os interesses dos doentes ou é mais importante recordar as pessoas que pertencem à sua rede?
6. Actualmente, usa conteúdos pessoais/privados para a estimulação?
7. Como é que as pessoas envolvidas costumam lidar com questões de privacidade?
8. Como é avaliado o resultado da estimulação? Como é medido? É suficiente?
9. O resultado das sessões ou intervenções influencia as sessões seguintes?
10. São usadas ferramentas digitais ou é tudo com papel e lápis?

A.2 Elicitation

Boa tarde, no seguimento das nossas primeiras entrevistas criámos alguns protótipos com base nas ideias recolhidas que estamos agora a demonstrar para recolher um segundo feedback acerca da usabilidade e utilidade do que foi criado.

Antes da demonstração

1. Sente necessidade de ferramentas que suportem a recolha e partilha de informação biográfica dos pacientes?
2. O que acha da predisposição das famílias em colaborar com os cuidadores em pequenas coisas, com conotação positiva, que não ocupem muito do seu tempo?
3. Acha que as novas tecnologias poderiam motivar de forma mais eficaz as auxiliares a conhecer mais sobre os seus pacientes de forma mais interativa?
4. Acha que os cuidadores ficariam mais interessados em fazer estimulação cognitiva em casa se tivessem mais ferramentas de apoio?

Demonstração

1. Mostrar o Facebook do Joaquim Torres, falando sobre os interesses (likes) e os eventos
2. Aplicação Música, que funciona com base nos interesses do perfil do Facebook
3. Aplicação Locais, com base nos checkins do Facebook (GPS?)
4. Aplicação Fotos antigas, especialmente em contexto consulta
5. Aplicação Eventos, para demonstrar as capacidades colaborativas e friend-sourcing, exemplificando como acrescentar um novo evento
6. Aplicação Portrait
7. Aplicação Day2Day (duas perspectivas)
8. Mostrar estatísticas

Depois da demonstração

1. Acha que esta aplicação poderia ser útil para preencher esta lacuna?
2. Quais as vertentes que seriam mais úteis para o seu trabalho?

3. De forma imediata consegue identificar alguma funcionalidade que seria útil acrescentar, dentro destes temas?
4. Pensando nos seus pacientes, consegue ver vantagens óbvias desta aplicação sobre o modelo actual?
5. E consegue prever problemas que pudessem existir?
6. Exemplos: rede de suporte não contribuir, privacidade

Appendix B

Surveys

B.1 Online survey to the caregivers

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Questionário a Cuidadores de Pessoas com Demência

A Faculdade de Ciências da Universidade de Lisboa (Departamento de Informática) está a colaborar com a Alzheimer Portugal na concepção e desenvolvimento de tecnologias que melhorem a qualidade de vida de pessoas com demência e seus cuidadores. Para tal, é fulcral contactar com todos os intervenientes e recolher dados acerca dos seus hábitos e necessidades, de forma a que estes sejam tidos em conta nos sistemas futuros.

Este questionário tem como objectivo recolher informação acerca das atividades diárias da pessoa com Alzheimer e do papel da sua rede de cuidadores. Estamos interessados em perceber as atividades que fazem juntos, como é o dia-a-dia quer do cuidador quer da pessoa com demência, e também como comunicam com todos os envolvidos em torno da doença.

Será um questionário breve que não lhe demorará mais de dez minutos a responder, agradecemos desde já pela sua disponibilidade e interesse.

*Obrigatório

Caracterização do cuidador

Informação biográfica sobre si mesmo.

1. **Sexo ***

Marcar apenas uma oval.

- Feminino
 Masculino

2. **Habilitações Literárias ***

Marcar apenas uma oval.

- 4ª classe ou menos
 6ª classe
 9ª classe
 Ensino secundário
 Ensino superior

3. **Idade ***

Marcar apenas uma oval.

- Menos de 30
 30-40
 41-50
 51-60
 61-70
 71-80
 Mais de 81

4. A pessoa de quem cuida é sua / seu *

Marcar apenas uma oval.

- Cônjuge
- Mãe / Pai
- Irmã / Irmão
- Tia / Tio
- Avó / Avô
- Prima / Primo
- Sogra / Sogro
- Outro grau de parentesco
- Não pertence à minha família

5. Situação profissional *

Marcar apenas uma oval.

- A trabalhar
- Aposentado
- Desempregado
- Outra:

6. Vive na mesma casa que a pessoa de quem cuida? *

Marcar apenas uma oval.

- Sim
- Não

Caracterização da rede de suporte

Quem ajuda de forma activa a lidar com a pessoa de quem cuida.

7. Quantas pessoas o auxiliam diretamente no dia-a-dia? *

Marcar apenas uma oval.

- 1-3
- 4-6
- 6-9
- 10 ou mais

8. Como mantêm contacto? *

Marcar tudo o que for aplicável.

- Telefone
- Email
- Redes Sociais
- Pessoalmente
- Outra:

9. Quantas pessoas partilham a casa com a pessoa com demência *

Marcar apenas uma oval.

- Vive sozinha
- 1
- 2
- 3
- 4
- 5 ou mais

Caracterização da pessoa de quem cuida

Informação biográfica sobre a pessoa com demência

10. Idade *

Marcar apenas uma oval.

- 40-50
- 51-60
- 61-70
- 71-80
- 81-90
- Mais de 91

11. Sexo *

Marcar apenas uma oval.

- Feminino
- Masculino

12. Situação atual *

Marcar apenas uma oval.

- Em casa *Passe para a pergunta 13.*
- Em centro-de-dia *Passe para a pergunta 13.*
- Institucionalizada *Passe para a pergunta 46.*

Nível de independência da pessoa de quem cuida

Que capacidades funcionais a pessoa mantém até ao dia de hoje

13. Precisa de ajuda nas actividades da vida diária (tomar banho, vestir-se, usar a casa-de-banho, etc)? *

Marcar apenas uma oval.

- Sim
- Não

14. **Cozinha autonomamente? ****Marcar apenas uma oval.*

- Sim
 Não

15. **Sai de casa sozinho? ****Marcar apenas uma oval.*

- Sim
 Não

16. **É responsável pelo seu dinheiro e documentos? ****Marcar apenas uma oval.*

- Sim
 Não

Actividades do dia-a-dia

Como é o seu dia-a-dia ao lidar com a pessoa com demência e os seus hábitos

17. **Que actividades faz juntamente com a pessoa com demência? ****Marcar apenas uma oval por linha.*

	Nunca	Menos de 1 vez por semana	1 vez por semana	2-3 vezes por semana	5 vezes por semana	Todos os dias
Passear	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ir às compras	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ir ao café	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ler revistas ou livros	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ver fotografias antigas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ouvir música	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Conviver com colegas ou amigos	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ir à igreja	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visitar locais relevantes para a pessoa	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Actividades do dia-a-dia

Como é o seu dia-a-dia ao lidar com a pessoa com demência e os seus hábitos

18. **Faz estimulação cognitiva (exercícios de treino mental, raciocínio numérico, etc.) em casa? ****Marcar apenas uma oval.*

- Sim
 Não *Passe para a pergunta 22.*

Estimulação cognitiva

Exercícios de treino mental para a pessoa com demência

19. Que materiais utiliza **Marcar tudo o que for aplicável.*

- Papel e lápis
- Suporte digital
- Livros de exercícios
- Enigmas e passatempos (ex: sudoku, palavras cruzadas,...)
- Outra:

20. Com que frequência fazem estes exercícios? **Marcar apenas uma oval.*

- Diariamente
- 2-3 vezes por semana
- Semanalmente
- Uma vez a cada duas semanas
- Mensalmente

21. Se desejar acrescentar mais alguma informação sobre o tema por favor diga-nos aqui

.....

.....

.....

.....

*Passe para a pergunta 24.***Estimulação cognitiva**

Exercícios de treino mental para a pessoa com demência

22. Quais os motivos que a levam a não fazer estimulação cognitiva? **Marcar tudo o que for aplicável.*

- Falta de tempo
- Falta de material de suporte
- Pouco útil para a pessoa com demência
- Desinteresse por parte da pessoa com demência
- Outra:

23. **Se desejar acrescentar mais alguma informação sobre o tema por favor diga-nos aqui**

.....
.....
.....
.....
.....

Revisitar memórias passadas

Rever materiais que lhe permitam recordar o passado

24. **Costuma rever memórias, momentos, fotografias, músicas entre outros com a pessoa com demência? ***

Marcar apenas uma oval.

- Sim
 Não *Passe para a pergunta 32.*

Revisitar memórias passadas

Rever materiais que lhe permitam recordar o passado

25. **Costuma rever eventos (aniversários, casamento, nascimento de um filho, etc) da vida passada da pessoa com demência? ***

Marcar apenas uma oval.

- Sim
 Não

26. **Que suportes usa para rever a vida passada? ***

Marcar tudo o que for aplicável.

- Fotografias pessoais
 Fotografias genéricas (locais, eventos...)
 Músicas
 Objetos (ex: utilizados pela pessoa na sua antiga profissão)
 Vídeos
 Vídeos online (YouTube)
 Outra:

27. **Quais dos suportes leva a uma melhor reacção da pessoa com demência? ***

Marcar apenas uma oval.

- Fotografias
 Músicas
 Objetos
 Vídeos

28. Quando fala sobre o passado, costuma focar-se mais em... *

Marcar tudo o que for aplicável.

- Pessoas
- Locais
- Eventos (casamento, aniversários...)
- Outra:

29. Em qual dos casos a pessoa com demência tem uma reacção mais positiva? *

Marcar apenas uma oval.

- Pessoas
- Locais
- Eventos

30. Já pediu a ajuda de terceiros para recolher material relevante para estas sessões? *

Marcar apenas uma oval.

- Sim
- Não

31. Se desejar acrescentar mais alguma informação sobre o tema por favor diga-nos aqui

.....

.....

.....

.....

.....

Passe para a pergunta 34.

Revisitar memórias passadas

Rever materiais que lhe permitam recordar o passado

32. Quais os motivos que o levam a não rever momentos da vida passada? *

Marcar tudo o que for aplicável.

- Falta de tempo
- Falta de material de suporte
- Pouco útil para a pessoa com demência
- Desinteresse por parte da pessoa com demência
- Acho doloroso para mim mesmo
- Acho doloroso para a pessoa com demência
- Outra:

33. **Se desejar acrescentar mais alguma informação sobre o tema por favor diga-nos aqui**

.....

Intervenções partilhadas

Prolongar o trabalho feito durante as consultas durante o tempo que está em casa

34. **A pessoa com demência frequenta consultas ou tem algum tipo de acompanhamento para estimulação cognitiva? ***

Marcar apenas uma oval.

- Sim *Passe para a pergunta 36.*
 Não *Passe para a pergunta 40.*

Intervenções partilhadas

Prolongar o trabalho feito durante as consultas durante o tempo que está em casa

35. **Faz algum trabalho de continuação em casa depois das consultas? Por exemplo, exercícios de estimulação que o profissional prescreva. ***

Marcar apenas uma oval.

- Sim *Passe para a pergunta 36.*
 Não *Passe para a pergunta 40.*

Intervenções partilhadas

Prolongar o trabalho feito durante as consultas durante o tempo que está em casa

36. **Como é a reacção da pessoa com demência a esses trabalhos? ***

Marcar apenas uma oval.

	1	2	3	4	5	
Negativa	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Positiva

37. **Como é que transmite de volta ao profissional de saúde os resultados desses exercícios? ***

Marcar tudo o que for aplicável.

- Diário
 Registos em papel
 Por voz, em conversa
 Outra:

38. **Recebe informação vinda do profissional de saúde sobre como melhorar os resultados dos exercícios feitos em casa? ***

Marcar apenas uma oval.

- Sim
 Não

39. **Se desejar acrescentar mais alguma informação sobre o tema por favor diga-nos aqui**

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Registo de eventos

Como guarda a informação do dia-a-dia para memória futura ou para discutir com o profissional de saúde

40. **Guarda algum tipo de registos do dia-a-dia da pessoa de quem cuida? Por exemplo incidentes, alimentação, estados de humor, etc. ***

Marcar apenas uma oval.

- Sim
 Não *Passe para a pergunta 44.*

Registo de eventos

Como guarda a informação do dia-a-dia para memória futura ou para discutir com o profissional de saúde

41. **Em que formato faz esse registo? ***

Marcar tudo o que for aplicável.

- Agenda
 Calendário
 Papel ou caderno
 Formato digital
 Outra:

42. **O que regista? ***

Marcar tudo o que for aplicável.

- Como se alimentou
- Como dormiu
- Estado de humor
- Se teve de trocar a roupa da cama
- Episódios violentos
- Episódios apáticos
- Se estava ou não comunicativo
- Outra:

43. **Se desejar acrescentar mais alguma informação sobre o tema por favor diga-nos aqui**

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Passe para a pergunta 50.

Registo de eventos

Como guarda a informação do dia-a-dia para memória futura ou para discutir com o profissional de saúde

44. **O que o leva a não fazer qualquer registo ***

Marcar tudo o que for aplicável.

- Falta de tempo
- Falta de ferramentas
- Não vê utilidade nestes registos
- Nada deste género é pedido pelo profissional de saúde
- Outra:

45. **Se desejar acrescentar mais alguma informação sobre o tema por favor diga-nos aqui**

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Passe para a pergunta 50.

51. **Por norma, como é feito esse contacto? ***

Marcar tudo o que for aplicável.

- Telefone
 Email
 Pessoalmente
 Outra:

52. **De que forma transmite ao profissional de saúde os dados que este lhe pede? ***

Marcar tudo o que for aplicável.

- Diário ou equivalente
 Registos em papel
 Por voz, como se de uma conversa de tratasse
 Outra:

53. **Quão fácil é reportar os acontecimentos recentes aos profissionais? ***

Marcar apenas uma oval.

- 1 2 3 4 5

Difícil Fácil

54. **Quão satisfeito está com os meios de comunicação com os profissionais de saúde? ***

Marcar apenas uma oval.

- 1 2 3 4 5

Pouco satisfeito Muito satisfeito

55. **Sente que tem alguém que lhe esclareça todas as dúvidas? ***

Marcar apenas uma oval.

- Sim
 Não

56. **Acha que há informação que se perde frequentemente nesses contactos? ***

Marcar apenas uma oval.

- Sim
 Não

57. **Se desejar acrescentar mais alguma informação sobre o tema por favor diga-nos aqui**

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Redes sociais e a doença

De que forma já usa redes sociais para discutir a doença ou para se manter em contacto com a restante rede

58. **Utiliza alguma rede social? ***

Marcar apenas uma oval.

- Sim
 Não

59. **Participa nalgum grupo, página ou fórum relacionado com a doença de Alzheimer? ***

Marcar apenas uma oval.

- Sim
 Não

60. **Usa alguma rede social para partilhar fotos da pessoa com Alzheimer com a restante família? ***

Marcar apenas uma oval.

- Sim
 Não

61. **Já usou as redes sociais para apresentar material (ex: fotografias de familiares que estão longe) à pessoa com demência? ***

Marcar apenas uma oval.

- Sim
 Não

62. **Em que medida acha que as redes sociais podem contribuir para uma aproximação de toda a rede (cuidadores, família e profissionais)? ***

Marcar apenas uma oval.

	1	2	3	4	5	
Irrelevante	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Bastante útil

63. **Se desejar acrescentar mais alguma informação sobre o tema por favor diga-nos aqui**

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Com tecnologia
 Google Forms

B.2 Focus group survey

Questionário Pós-Demonstração – Café Memória

1. **Atualmente faz ou já fez terapia de reminiscência?**
Se não, por favor salte para a pergunta 5.
 Sim Não
2. **Sente ou já sentiu dificuldade na recolha de conteúdo, nomeadamente fotografias?**
 Sim Não
3. **Com que frequência costuma utilizar material proveniente de terceiros?**
 Nunca Raramente Frequentemente Sempre
4. **Que tipo de materiais costuma utilizar para a reminiscência?**
 Fotografias Músicas Objectos
5. **Como vê o uso de uma aplicação digital que reúna toda esta informação num só local?**
 Sem interesse Pouco interessante Interessante Muito interessante
6. **De que forma acha útil a contribuição dos restantes familiares com informação como fotos ou eventos para a terapia de reminiscência?**
 Sem interesse Pouco interessante Interessante Muito interessante
7. **A nível de privacidade, até que ponto se sente confortável com essa partilha?**
 Nada confortável Pouco confortável Confortável Plenamente confortável
8. **Regista diariamente informação sobre a evolução da doença?**
 Sim Não
9. **Até que ponto se vê a utilizar todos os dias uma aplicação para fazer esses registos acerca da pessoa com demência?**
 Dificilmente usaria Gostaria de tentar Usaria com bastante interesse
10. **Qual o grau de utilidade que vê numa aplicação deste tipo para todos os interessados?**
 Nada útil Pouco útil Útil Muito útil

Caso tenha questões que queira ver respondidas ou caso esteja interessado numa colaboração mais ativa por favor deixe aqui o seu contacto.

Appendix C

Codebook

Theme	Subject	Code
Current Practices	Status	status.strenghts
		status.nolost
		status.ocupational
		status.cognitive.low
		status.cognitive.mid
		status.express.low
		status.adl.low
		status.wellbeing
		status.memory.stm
		status.memory.ltm
	Biography	bio
		bio.likes
		bio.likes.music
		bio.work
		bio.hobbies
		bio.events
		bio.places
		bio.habits
		bio.people

Theme	Subject	Code
Current Practices	Approach	approach.solo
		approach.group
		approach.pcc
		approach.familiarity.yes
		approach.emotions
		approach.diversity
		approach.backInTime
		approach.caregiver.with
		approach.caregiver.without
		approach.caregiver.only
		approach.caregiver.feedback
		approach.pwd.feedback
		approach.caregiver.burden
		approach.caregiver.niceTask
		approach.globaltoparticular
		approach.formation
		approach.photo.contentrecognition
		approach.pwd.dump
		approach.pwd.private
		approach.homework
		approach.evolution
		approach.review
		approach.caregiver.compromise
		approach.generic
		approach.personal
		approach.recent
		approach.past

Theme	Subject	Code
Current Practices	Frequencies	frequency.weekly
		frequency.biweekly
		frequency.semestral
		frequency.anual
		frequency.daily
	Technics	tech.cognitive
		tech.ocupational
		tech.stimulation
		tech.stimulation.reasoning
		tech.stimulation.social
		tech.stimulation.reminiscence
		tech.orientation
	People	people.family.information
		people.family.photos
		people.family.videos
		people.family.musics
		people.family.objects
		people.family.others
		people.caregiver.information
		people.caregiver.information.likes
		people.caregiver.photos
		people.neurologist
		people.psychiatrist
		people.physician
		people.psychologist
		people.staff

Theme	Subject	Code
Current Practices	Tools	tools.photos
		tools.calendar
		tools.slides
		tools.music
		tools.diary
		tools.videos
		tools.videos.no
		tools.games
		tools.digital
		tools.support.tablet
		tools.support.pc
		tools.paperpencil
		tools.objects
		tools.newspapers
	Outcomes	outcomes.emotional
		outcomes.emotional.low
	Places	places.home
		places.daycare

Theme	Subject	Code
Shortcomings	Tech	tech.frequency.low
		tech.tools.limited
	Time	time.limited
	Knowledge	knowledge.staff.limited
		knowledge.pwd.limited
		knowledge.caregiver.limited
	Information	information.available.no
		information.available.reduced
		information.available.repeated
	Communication	communication.caregivers.low
	People	people.caregiver.isolation
		people.family.driftApart
		people.inapt

Theme	Subject	Code
Expectations	Tech	tech.usage
		tech.useful
		tech.depends
	Information	information.accessible
		information.permanent
		information.evolution
		information.contents
	People	people.approximate
	Tools	tools.available
		tools.communication
		tools.atHome
		tools.backInTime
		tools.bio
		tools.diary
		tools.actual
	Assessment	assessment

Theme	Subject	Code
Concerns	Caregivers	caregivers.burden
		caregivers.wellbeing
	PwD	pwd.confrontation
	People	people.nonTech
		people.illiterate
		people.proxy
	Privacy	privacy.professionals
		privacy.staff
		privacy.family
		privacy.caregiver.professionals
		privacy.benefits

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