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FACULDADE DE CIÊNCIAS

DEPARTAMENTO DE INFORMÁTICA

Scrapbooks: Biographical Digital Scrapbooks For People With Dementia

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Mestrado em Informática

Dissertação orientada pelo Prof. Doutor Tiago João Vieira Guerreiro e co-orientada
pelo Prof. Doutor Luís Manuel Pinto da Rocha Afonso Carriço

2017

Acknowledgements

Achieving this thesis would not be possible without the brilliant incentive, support and guidance from Professor Tiago Guerreiro and Professor Luís Carriço, who were always available to listen and advise me. Apart from their great dedication to their profession, they show a huge willingness to help the neediest.

I would also like to thank Filipa Brito for always being available to help me in this cause that is so familiar to her.

A special thanks to Inês Machado for her support and for the brilliant images she made.

Finally, I would like to thank everyone who provided some of their time to collaborate in the studies carried out, especially to the psychologist who allowed me to test my work.

To everyone who suffer with the disease.

Resumo

Demência é o termo utilizado para descrever uma ampla variedade de sintomas, que envolvem um declínio ao nível da memória, linguagem, raciocínio e outras funções cognitivas, e que afetam gravemente a capacidade da pessoa para realizar atividades cotidianas.

Os números mais recentes [1] indicam que existem em todo o mundo 47 milhões de pessoas que vivem com demência. Com o envelhecimento natural da população, este número irá praticamente duplicar a cada 20 anos, atingindo mais de 131 milhões em 2050. A estimativa para o custo total mundial com a demência é superior a 733 biliões de euros.

A forma mais comum de demência, 60% a 80% dos casos, é a doença de Alzheimer [2]. A doença de Alzheimer geralmente progride lentamente e pode ser dividida em três fases: fase inicial, fase intermédia e fase avançada. Uma vez que esta doença afeta as pessoas de diferentes maneiras, é importante realçar que nem todas as pessoas têm os mesmos sintomas ou passam por todas as fases.

Na fase inicial, a pessoa torna-se mais esquecida de detalhes de eventos recentes, apresenta um mau julgamento e toma más decisões. Consciente disso, em geral, a pessoa encobre os seus lapsos de memória e os membros da família não os associam a uma doença. A próxima fase (fase intermédia) geralmente é a mais longa e pode durar anos. Naturalmente, com o progresso da doença, a pessoa exigirá um maior nível de cuidado. Nesta fase a pessoa começa a enfrentar sérios problemas, como esquecer-se de eventos da vida pessoal ou não conseguir lembrar-se da própria morada. Na fase mais avançada, a pessoa, eventualmente, torna-se incapaz de comunicar verbalmente ou cuidar de si mesma, e é necessário um acompanhamento pessoal 24 horas por dia a fim de garantir a maior qualidade de vida possível.

Uma vez que não existe cura conhecida, o objetivo dos especialistas é retardar a sua evolução. As intervenções farmacológicas têm benefícios limitados, e os especialistas reconhecem que, na melhor prática, as opções não-farmacológicas devem ser testadas primeiro e os tratamentos farmacológicos devem ser utilizados como uma segunda abordagem [3].

Existem muitos tratamentos não-farmacológicos [4], mas, uma vez que existem várias áreas de sobreposição entre eles, estes tratamentos raramente são realizados isoladamente. A terapia comportamental (que visa encontrar a origem de comportamentos desafiadores das pessoas com demência e elimina-los), a terapia de orientação para a realidade (lembrando as pessoas com demência de factos sobre si e sobre o meio envolvente), a terapia de validação (onde os psicólogos tentam encontrar os sentimentos

por detrás do discurso da pessoa com demência), a musicoterapia (onde a pessoa com demência dança, canta ou simplesmente ouve música), a aromaterapia (onde são utilizados óleos vegetais aromáticos para estimulação cognitiva), a terapia de estimulação cognitiva [5] (onde são realizadas atividades, como jogos, para estimular o pensamento, concentração ou memória da pessoa) e a terapia de reminiscência são apenas alguns exemplos.

A terapia de reminiscência geralmente envolve a discussão de atividades, eventos e experiências passadas com outra pessoa, ou grupo de pessoas, com a ajuda de imagens, vídeos, lembranças, gravações de música ou de sons para motivar a discussão. O objetivo é elicitar memórias que a pessoa com demência possa ter acerca do seu passado, sendo este um processo em grande parte conversacional. O foco desta tese é a terapia de reminiscência, que tem a vantagem de poder ser adaptada a pessoas com diferentes níveis de demência (mesmo as que não consigam verbalizar podem ouvir música).

Esta terapia pode ser executada de duas maneiras diferentes: em grupo, onde os participantes se reúnem para conversar sobre eventos passados; ou em sessões individuais, onde é feita uma revisão de vida na qual a pessoa é guiada cronologicamente através de experiências de vida e pode até produzir um livro de história da sua vida. Os cuidadores, geralmente os familiares mais próximos, também podem estar envolvidos no processo.

Vários estudos comprovam alguns dos benefícios importantes da terapia de reminiscência [6] [7], como melhorias ao nível do humor, do bem-estar e do sentido de identidade pessoal; o aumento da socialização e comunicação; e a redução do stress existente nos cuidadores.

Os cuidadores, já sobrecarregados com outras atividades diárias das suas vidas, acabam por sacrificar o seu próprio bem-estar em favor da pessoa com demência, ficando eles próprios reféns da doença. Além disso, quando estas atividades de estimulação de memória são realizadas por um psicólogo, estes acabam por não ter o conhecimento necessário sobre a pessoa, levando a uma falta de tópicos de discussão e a que não seja retirado o máximo proveito possível da terapia.

Ao longo dos anos têm sido criadas diversas tecnologias para auxiliar psicólogos, cuidadores e pessoas com demência no combate a esta doença, no entanto a maioria dos psicólogos continua a trabalhar com os métodos tradicionais, maioritariamente com papel e caneta, e com escassez de elementos autobiográficos da pessoa com demência. Após uma análise detalhada do trabalho relacionado, é possível chegar a algumas conclusões. As soluções como os DVDs têm um custo demasiado elevado, demoram demasiado tempo a criar e a sua produção resultará em um filme que exibirá sempre os mesmos conteúdos para a pessoa com demência, levando à existência de memórias que nunca

serão exploradas. Alternativamente, as ferramentas de imersão, como ferramentas de realidade virtual, geralmente não utilizam conteúdos autobiográficos, e as que o fazem requerem um grande esforço para criar ambientes virtuais.

O uso de ferramentas interativas parece ser o mais aconselhável, no entanto, atualmente, estas ferramentas não exploram todo o seu potencial. A capacidade de recolher e utilizar conteúdos de qualquer tipo de media, aliada à facilidade de recuperar grandes quantidades de dados acerca do passado da pessoa com demência não tem sido explorada.

Tendo em conta estes aspetos, o trabalho existente no grupo de investigação onde me inseri, e duas entrevistas preliminares realizadas com dois psicólogos diferentes, foi criado o Scrapbook. O Scrapbook é uma aplicação web destinada a ser utilizada por psicólogos durante sessões de terapia de reminiscência, e que tem como objetivo mitigar alguns dos problemas associados à terapia de reminiscência, nomeadamente a falta de informação biográfica acerca das pessoas com demência. A plataforma faz uso do crescimento constante das redes sociais, mais precisamente do Facebook, para extrair informações e conteúdos pessoais sobre as pessoas com demência, como gostos, locais visitados, fotografias, vídeos, eventos ou familiares, e interagir com os amigos para recolher novos conteúdos. Claro que nem todas as pessoas com demência têm uma conta no Facebook, e como tal o psicólogo tem também a opção de inserir estes dados manualmente. Para além das fotografias e vídeos recolhidos através do Facebook, o sistema é capaz de recolher outros conteúdos, vindos de outras Web APIs, baseados nos interesses das pessoas com demência e que podem também ser utilizados em jogos de estimulação cognitiva.

Um estudo de duas semanas realizado em ambiente real de consulta, com uma psicóloga e três pessoas com demência, deixou indicadores que o Scrapbook pode ser útil para os psicólogos e que pode trazer benefícios ao nível da apatia e da deambulação.

Palavras-chave: Demência, doença de Alzheimer, livro de histórias de vida, terapia de reminiscência, livro de histórias da vida social

Abstract

Dementia is a general term that describes a wide range of symptoms. These symptoms involve decline of memory, language, reasoning and other cognitive skills that affects a person's ability to perform everyday activities. The most common form of dementia is Alzheimer's disease.

There are worldwide nearby 47 million people living with dementia and this number will almost double every 20 years reaching more than 131 million in 2050. The total estimated worldwide cost with dementia is more than 733 billion euros.

Once there is no known cure, the goal of experts is to slow down its evolution by pharmacological (has limited benefits) or by non-pharmacological (best practice) interventions. One of these non-pharmacological treatments is reminiscence therapy. The main goal of this therapy is to elicit memories that people with dementia have from their past, which can bring improvements in the level of well-being and mood, or delay the evolution of the disease. It involves a caregiver sitting next to the person with dementia showing pictures, keepsakes or music to motivate the discussion.

Caregivers, usually already overburdened with other daily activities of their lives, end up sacrificing their own well-being in favour of the person with dementia, being themselves hostages of the disease. Furthermore, when the memory stimulation activities are carried out by a psychologist, they end up not having the necessary knowledge about the person, provoking a lack of discussion topics and, ultimately, ending up not taking full advantage of the therapy.

Thus, the goal of this project was to create a web platform that supports the work of psychologists, streamlining the collection of relevant information about people with dementia and using this information as a starting point to perform reminiscence therapy, which involves watching slideshows with images, videos or music.

A study, carried out in a real clinical environment, showed that the system was well accepted by psychologists, people with dementia and caregivers, and left indicators that Scrapbook can be truly useful for psychologists and can bring benefits in the level of apathy and ambulation.

Keywords: Dementia, Alzheimer's disease, life storybook, reminiscence therapy, social life storybook

Contents

List of Figures

List of Tables

Chapter 1

Introduction

Worldwide, the average life expectancy is increasing, leading to a substantial growth of the elderly population. The median age in Europe has increased from 35.7 years old in 1992 to 41.5 in 2012 and could reach 52.3 by 2050 [8]. The population aged 65 plus is expected to double in Europe from 1990 to 2050, and for the first time in human history, before 2020, people aged 65 and over will outnumber children under the age of 5 [9].

As life expectancy increase, the number of age related impairments and risk of chronic disease within the older population are also expected to rise. Dementia is not one specific disease, but a general term that describes a collection of symptoms caused by disorders affecting the brain. These symptoms involve decline of memory, language, reasoning and other cognitive skills that affects a person’s ability to perform everyday activities. This decline occurs because nerve cells (neurons), in parts of the brain involved in cognitive functions, have been damaged and no longer function normally [10]. Dementia symptoms appear more frequently after the age of 65.

The most common form of dementia (60 to 80 percent of cases) is Alzheimer’s disease [2]. In Alzheimer’s disease (AD), neuronal damage eventually affects parts of the brain that enable a person to carry out basic bodily functions, such as walking and swallowing. People in the final stages of the disease have a very limited mobility and require around-the-clock care. AD typically progresses slowly and can be divided into three general stages: early-stage, middle-stage, and advanced-stage. Once AD affects people in different ways, it is important to note that some people do not have all the symptoms or go through all the stages.

In the early-stage the person becomes more forgetful of details about recent events, presents a poor judgment and makes bad decisions. Aware of this, generally, the person covers up gaps or lapses in memory and the family members do not associate it with a disease. The next stage (middle-stage) is typically the longest and can last for years. Naturally, with the progress of the disease, the person will require a greater level of care. At this stage, the person begins to face serious problems, such as forgetting personal life events or being unable to remember his own address. At the late stage (advanced-stage) of AD, the person eventually becomes incapable of communicate verbally or look after herself. A personal care is required 24 hours a day in order to ensure the highest quality of life possible.

Once there is no known cure, the goal of experts is to slow down its evolution. Pharmacological interventions have limited benefits, and it is recognized by experts that, in the best practice, non-pharmacological options should be pursued first and pharmacological treatments should be used as a second approach [3].

There are many non-pharmacological treatments [4], but, once that there are several areas of overlap between them, these treatments are rarely used in isolation. Behaviour therapy (which aims to find the origin of people's challenging behaviours and eliminate them), reality orientation therapy (reminding people with dementia of facts about themselves and their environment), validation therapy (where psychologists try to find the feelings behind the speech of the person with dementia), music therapy (where the person with dementia dances, song or simply listens to music), aromatherapy (where aromatic plant oils are used to perform cognitive stimulation), cognitive stimulation therapy [5] (where activities, such as games, are carried out to stimulate thinking, concentration or memory) and reminiscence therapy are just some examples.

Reminiscence therapy generally involves the discussion of past activities, events and experiences with another person, or group of people, with the aid of pictures, videos, keepsakes, music or sound recordings to motivate the discussion. The goal is to elicit memories that the person with dementia has from his past. It is largely a conversational process. The focus of this thesis was reminiscence therapy, and the fact that it can be adapted to people with different levels of dementia (even those who cannot verbalize can listen to music), can be seen as an advantage.

This therapy can be done in two different ways: in group, where participants meet to talk about past events; or in individual sessions, where is made a life review in which the person is guided chronologically through life experiences, and may produce a life story book. Caregivers (usually the family members) can also be involved in the process.

Several studies have proven the benefits of this non-pharmacological treatment. Tadaka et al. [6] studied the effects of a reminiscence group program on 24 people with Alzheimer’s disease and 36 with vascular dementia. The subjects were randomly assigned to an intervention group, who followed a reminiscence group program for 8 weeks, and to a control group, who followed a routine day-care centre program. The results of the study showed that participants with AD from the intervention group exhibited significant improvement of withdrawal, when compared with participants from the control group. Regarding participants with vascular dementia, beyond significant improvement of withdrawal, the intervention group also showed improvements in cognitive function when compared with the control group. Wang et al. [7] conducted a study to test if reminiscence therapy can prevent the progression of cognitive impairment and upgrade affective function in elderly people with cognitive impairment. The subjects, 51 in the experimental group and 51 in the control group, participated in eight group sessions, one session per week. The results indicated that the cognitive function of the experimental subjects increased and that their depressive symptoms diminished following intervention.

As result, reminiscence therapy leads to some important benefits, like improving mood, well-being and sense of personal identity; allowing a greater socialization and communication; stimulating memories and reducing caregivers strain.

As referred, these therapies are rarely used in isolation. In this thesis, I focused in reminiscence therapy, but, with the knowledge obtained from the person with dementia, it is also possible to perform cognitive stimulation therapy.

From now on in this document, I will start to refer to a person with dementia as a patient.

1.1 Motivation

According to the World Alzheimer Report (2016) [1], there are worldwide 47 million people living with dementia. With the population aging, this number will almost double every 20 years reaching more than 131 million in 2050. The total estimated worldwide cost of dementia is more than 733 billion euros (which represents 1.09% of global GDP), and it will become a trillion-dollar disease by 2018. Despite all this, the concern and the support provided to these people are not increasing, leading to a lack of necessary treatments and to an overburden of informal caregivers (usually the closest family members).

Once AD is a chronic neurodegenerative disease, there is no known cure. The only option is to slow down its evolution by non-pharmacological treatments like reminiscence therapy. However, there are two major problems [11], identified by the psychologists, with traditional therapies: the lack of knowledge of psychologists about the people they care for; the difficulty in collecting personal material needed for reminiscence therapy. The lack of support material, will turn the therapy into an unmotivated and unpleasant activity, leading to therapy sessions in which, most of the time, they talk about the weather or the lunch.

Despite it was been proven that patients prefer a digital therapy rather than traditional reminiscence therapy methods [12], existing digital tools are not sufficiently useful, and there is a great expectation from psychologists about tools that may emerge.

1.2 Context

This master's thesis was developed at LaSIGE[1] (Large-Scale Informatics Systems Laboratory), which has already an extensive experience in projects around accessibility, namely for blind people [13], children with autism [14], and around support for people with dementia [11] [15] . These works have allowed the members of the laboratory to acquire a wealth of knowledge about dementia, namely its major implications in people's lives and the major limitations that psychologists face in the treatment of diseases such as Alzheimer.

Over the last few years several projects have been created around dementia, some totally independent and others representing an evolution of previous works. In 2014, some members of LaSIGE began to explore the possibility of using friendsourcing to help people with dementia [16] by collecting information about nearby places and people present there. This knowledge was used to create Remember-Me 2 [11], presented in Chapter 2, which uses social media and crowdsourcing to build the identity of a person with dementia and collect contents for reminiscence therapy.

Currently, and independently, new tools are being developed, namely Maty, a robotic partner to foster routines and communication, and another project that intends to perform cognitive stimulation through the exploration of 360º environments.

All these years of work in the area of dementia have led to a greater demand around new tools, mainly due to the greater knowledge we get about the needs of the end users. It also allowed us to create some contacts, especially with psychologists and day-care centres, which broke down some barriers, and allowed me to have more direct contact with professionals in this area.

1.3 Goals

The main goal of this thesis was to create a web platform that supports the work of psychologists, helping them to perform reminiscence therapy and slowing down the evolution of early and middle stage dementia. This way, the platform must be sufficiently agile to generate and collect meaningful contents and information about the patient and allow the psychologists to use/show those contents in a therapy session. Based on this, and on the needs of final users (psychologists, informal caregivers and patients), this main goal can be divided into three sub-goals: collect, display and evaluate.

The quality and quantity of information and contents that the person performing the therapy has about the patient, can be a deciding factor for the quality of reminiscence

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[1] http://www.lasige.di.fc.ul.pt/

therapy. Without meaningful contents (pictures, videos, music, keepsakes) it is more difficult to have a discussion theme, leading to a boring and uninteresting therapy from the patient's point of view. Therefore, collect meaningful information and contents about the patient is my first goal.

The second goal is to display the content and information collected about the patient. Contrary to what one might think, this is not just display in a random way all the stored contents. It is important to know how to display all the contents, that are so different from each other, and how to manage all the types of media in an enjoyable way from the patient's point of view.

It is also fundamental to know what contents or themes the patient enjoys to watch i.e., what type of contents allows him a remembrance, or he did not enjoy to watch, either by not being relevant or by bringing bad memories. This is my third goal: evaluate. With the visualization and evaluation of the contents and previous performance, it will be possible to improve the quality of the future contents, showing the ones that the patient enjoys to watch, and avoiding the presentation of bad contents which may cause anxiety and frustration in the patient.

My goal, is that the utilization of this platform lead to:

- An increase of the quality of life of psychologists, caregivers, and patients;
- An increase in proximity and knowledge between psychologists and patients;
- An increase in the confidence of caregivers in day-care centres;
- Avoid that friends and relatives forget of the person with dementia;
- A better and faster evaluation of therapy success;
- A slowdown in the evolution of the disease.

1.4 Approach

As previously mentioned, the team already had done a few projects around dementia. Antunes et al. [11] conducted a study that involves nine interviews to formal caregivers and 536 online questionnaires to informal caregivers of patients with dementia. The results of the study not only were important to their work, but were also an important source of knowledge for me. In addition, to better understand the current situation of the stakeholders and their needs, two preliminary interviews were conducted with two different psychologists. Having in mind this, the existing work of the research group where I am inserted, the analysis of related work and the goals previously defined I started to develop a new web platform: Scrapbook.

Scrapbook is a web application intended to be used by psychologists during reminiscence therapy sessions, that aims to mitigate some of the problems associated with reminiscence therapy, namely the lack of biographical information about the patients. The platform makes use of the constant grow of the social networks, namely Facebook[2], to extract information about the patients, such as likes, visited places, photographs, videos, events or relatives, and to interact with patients' friends in order to retrieve new contents based in the therapy results. Alternatively, once not all the patients have a Facebook account, the system is also prepared to work without this social mechanism, in which case psychologists can insert the data manually. The collected data, that already contains photographs and videos from patients, are used to recover even more photographs and videos from other web APIs (based on patients' interests), which can be used by the psychologists to perform reminiscence therapy. Additionally, although it is not the main focus of this thesis, the psychologist can make use of the two cognitive stimulation games provided by the platform.

As I adopted an iterative and user-centred design methodology, there was a close relationship between me and the end users, the psychologists. With this model the system grew incrementally and the feedback from the psychologists was constant. Beyond this feedback throughout the development phase, there were made two final studies which demonstrated the benefits and limitations of Scrapbook and that allowed to realize that the system can be further explored to support the stakeholders.

1.5 Contributions

Nowadays, professionals around dementia, namely the psychologists, have a big lack of tools to support their work. Most of assistive technological systems focus on improving accessibility in patients' lives tasks. The concern with psychologists' work, and to give them good conditions to do their work as best as possible, is lower than the desired.

Based on these, my main contributions are the design, based on an extended analysis of related work, that along with two interviews to psychologists allow me to identify the lacks of existing systems, and development of a web platform which is capable of:

- Collect and provide relevant contents about a patient;
- Provide the means to allow psychologists to perform reminiscence therapy and cognitive stimulation therapy;
- Record the evolution of the disease and the respective treatments.

Along with the design and development of the platform, I provide also the evaluation and validation of the platform by those who deal with it.

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[2] https://www.facebook.com/

Chapter 2

Related work

Works around memory loss or dementia come from far away. The concern with helping patients to maintain an acceptable quality of life, stay integrated in the society, and be able to perform their daily activities leads to the creation and exploration of a large number of technological approaches. People with dementia, more specifically people with Alzheimer's disease, saw their lives completely affected by the disease. Difficulties to remember life events (even the most recent), forgetting about places or known people, deterioration of social skills, inability to have a fluid conversation, disorientation (easily getting lost), mood swings, not managing self-care and behavioural issues are some of patients' challenges. Beyond this, it is important not to forget the psychologists, who cannot apply all their skills due to lack of knowledge and resources about patients' lives, and the caregivers, who are constantly overloaded. To address these needs, over time, several studies were made. The experts ended up exploring different technologies as they were appearing, starting with building simple things like DVDs and most recently exploring virtual reality tools.

The term assistive technology can be described as "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities." (Assistive Technology Act, 1998). Assistive technologies, like reminders or tracking tools, can help patients on their daily lives but are not a truly tool to help fight and prevent the evolution of the disease. The deceleration of the disease's evolution can be made by reminiscence therapy. Some tools act only as complementary tools, not performing the therapy but helping the psychologists to communicate and to obtain knowledge about the patient. Reminiscence therapy tools deserve a special attention in this chapter, once it is important to understand why, despite all the offer and studies made, the psychologists are eager for an efficient reminiscence therapy tool.

This chapter is divided as follows: first, I will present some existing tools to support patients' daily activities, which includes tools that give to the patient a sense of security or help him remember daily routines. Then, and most relevant, I will produce a deep report about existing reminiscence therapy tools. Finally, there are some tools that deserve a special attention, that, despite do not perform reminiscence therapy, are fundamental to assist psychologists in the therapy.

2.1 Tools to support patients' daily activities

As the disease progresses patients' ability to accomplish everyday tasks decreases. It is precisely in facilitating and providing the necessary security for carrying out those tasks that researchers have invested a lot of time. Throughout this section I will introduce some of these works and technologies, but, once the focus of this project is not to develop this kind of tools, please note that I will only give some examples of existing tools.

Some of these works focus on mitigate the consequences of loss of sense of orientation of patients. One of these works is KITE [17], an armband, for people with dementia, which monitors user's location and allows him to send automatically a message to a caregiver with his location when he get lost. Another interesting work around this area was performed by Sposaro et al. [18]. The iWander is an android application that monitors patient's location with the GPS and detects when the patient is wandering. When a wandering behaviour is detected, some actions are taken by the application, such as issuing audible prompts to the patient, offering directions to navigate him home, sending notifications to the caregiver containing the patient's location, establishing a line of communication between the patient and the caregiver and performing a party call between the caregiver and the local police. One lack of these works is the fact that the authors did not perform any evaluation test. Despite the existence of this type of works, patients with dementia (in more advanced stages) do not wander so much, and once these tools are not helpful to stimulate cognitive functions, their utility is low.

Another explored topic is reminders. Pollack et al. [19] presented the Autominder, a cognitive orthotic system, (embedded on a mobile robot) that aims to mitigate the effects of cognitive decline in elderly people, allowing them a satisfactory performance of routine activities and potentially enabling them to remain in their own homes longer. Autominder provides adaptive personalized reminders of daily activities, using a range of AI techniques to model patients' daily plans, observe and reason about the execution of those plans, and making decisions about whether and when it is most appropriate to issue reminders. Despite all this, the system was only tested in laboratory.

2.2 Reminiscence therapy tools

As previously mentioned, one of the possible non-pharmacological treatments for people with dementia is reminiscence therapy. Looking at the features and materials used in this therapy, such as images, videos or music, it is possible to note that new technologies can play an important role in helping both, psychologists and patients. Particularly, studies have focused on two main benefits of reminiscence therapy: improve cognitive function and quality of life of patients.

Due to the development of a large number of tools to promote this therapy, many of them end up being similar. It is important to realize that these studies began some time ago, when the technology was not as developed as it is now, and some of the used gadgets are now discontinued. However, the concepts applied and the results of the studies are relevant for my work and worth mentioning.

Over time, different studies have been exploring the devices that patients have at their homes. Passive interaction tools (tools that practically do not require interaction), like DVDs, have explored the fact that, at the time, much of the houses had a DVD player, plus a television, and the ease of use of the television remote control. However, today, DVDs and the DVD players gave place to streaming movies and computers, that are now present, not only in people's homes, but also in hospital clinics and care homes. Additionally, the number of elderly people using computers has grown. Interactive tools, such as web platforms take advantage of this growing. Lastly, immersive tools, like virtual reality tools, are growing and already begun to be explored.

In this section, I have chosen to divide the different works and systems by the way patients interact with them, namely passive interaction tools, interactive tools and immersive tools After this, a summary table will compare the features of my work with the features of existing works.

2.2.1 Passive interaction tools

Passive interaction tools are, fundamentally, DVD tools, which only require two types of interactions: select the content and play it. Its simplicity of use is what makes it attractive for researchers, however, its creation can be quite time-consuming. The creation process is relatively simple: the DVD creators ask to relatives of patients for old photos and videos, and create a single DVD that the patients must watch for a few weeks.

Baecker et al. [20] performed a study with 12 participants, where, for each one, during a period of 2 to 9 months the authors created a DVD (15 to 60 min) containing photos, videos, music and narration by family members. After this, the DVD was delivered to the caregivers, who were assigned to show the DVD to the respective patient twice a week for a period of 3 months. The results of the study were positive, and suggest that regular viewings of a visual biography provide memory stimulation and brings joy to the patient. The biographies also provided benefits to family members, such as better remembering how the loved one once was and being able to better accept the disease. Additionally, they also seemed to stimulate conversations between the AD individual and the family members, and to enable formal caregivers to better understand who is in their care and thereby approaching caregiving with greater knowledge and empathy.

Another very similar study was done by Damianakis et al. [21]. The authors, using digital video technology, constructed a DVD-based multimedia biographies (MBs) of people with AD or mild cognitive impairment (MCI). A team worked for one year with 12 families to produce the MBs. The initial task involved the collection and selection of pictures, videos, and stories about the patient. For each biography, the participants made decisions whether to structure their storyline chronologically (childhood, adolescence, adulthood) or by significant life events (marriage, children, travel, etc.). In most cases, family members and the patients were filmed as they provided narration that located images and other assets of the MBs into the context of a story. Initial versions of the MBs were viewed by participants or caregivers and revised according to their feedback. The final version of the MB was copied to a DVD, so that it could be played on a DVD player connected to the participants' home television. The results showed that patients' long-term memories were positive stimulated, and the family members really enjoyed to help construct the DVD.

One of the most referenced works when it comes to reminiscence therapy tools is the Multimedia Biographies [22]. The Multimedia Biographies consists in a DVD that contains pictures, videos, audio narration and music. These DVDs were produced by the authors with the help of caregivers and patients themselves, and required averaged 131.7 hours of work to produce 39.1 minutes of video. The authors chose to use this DVD format due the familiarity of patients and caregivers with a DVD player, the easy control of the DVD through the DVD's remote control and the possibility to watch the video at home. MBs were structured in two ways: temporally (childhood, youth, etc.) or thematically (family, hobbies, travel, career, etc.). The twelve participants and family members enjoyed participating in the production process, and reported that MBs helped them in the reminisce process by stimulating conversations about patients' past.

A more recent study, with the purpose of compare the benefits of digital scrapbooks with traditional ones, were made by Subramaniam et al. [23]. The authors "took" six patients who had already created their traditional scrapbooks, and converted them to the digital format (on DVD). The production process was carried out with the help of patients and their relatives, and, in addition to the pictures, the DVD contained music, videos, and audio narration (accompanied by subtitles) performed by the patient or family members. The results are encouraging, most of the participants mentioned that they prefer their scrapbook in digital form. Additionally, five participants showed improvement in measures of quality of life and autobiographical memory. All participants showed improvement or stability in depression scores. To note that the results, in some points, could still be better, and they were not because the patients had already reached the maximum score with traditional scrapbooks.

Despite the benefits of multimedia biographies, it is evident that this cannot be the best solution for patients and their relatives. The costs of creating DVDs are high and some teams spend weeks constructing an efficient DVD. This solution consumes a lot of time and money from patients' caregivers. Additionally, DVDs are static, i.e. the patient will watch the same content again and again.

Thinking about those problems, Kuwahara et al. [24] introduced a new concept: The Networked Interaction Therapy. The purpose of this system is to relieve the stress of people with dementia and their family members. The system consists in the use of a television and a set-top box that controls the connection to the Internet along with a camera and microphone for monitoring the user's status. Use cases involve online help through support groups or, for example, a scenario where the camera detects that the patient is not sleeping and shows to him an image of his mother to calm him down. Then, the same authors presented the reminiscence video, an audio-visual stimulus to be presented to people with dementia in order to hold their attention for enough time to allow the caregivers to rest. The authors provided for their experiment four types of videos. The first one was a reminiscence video, semi-automatically generated from the old photos provided by the family members, and the other videos are related to patients' hobbies and news clips. The images were annotated to allow, in a semi-automatic way (with a software built by the authors), the creation of several different videos. This way, the patient is not always seeing the same video. In order to evaluate the effects of narration, they added narrations only to the first half of each reminiscence video. The system evaluation results, with three users, showed that the reminiscence video made patients more concentrated and amused than other types of video clips used in the experiments. The results also indicated that the narration attached to the video may be important. Unfortunately, the authors did not evaluate the effects of the system on the disease evolution.

2.2.2 Interactive tools

Making use of technology development and its growth in people's lives, researchers have begun to explore alternatives to DVDs and its static characteristics. The resources provided by internet and the capabilities of computers or smartphones allowed the utilization of new types of contents. Currently the information used in the therapy can be obtained in different ways, leading to the existence of three types of contents: generic content, retrieved in real time from large databases, such as historic world events or famous people; personalized content, based on the interests and past of the patient; and autobiographical content, automatically recalled from past data posted by the patient on internet such as Facebook data or manually provided by caregivers or relatives.

One of first the multimedia tools to make use of the larges information databases to support reminiscence therapy was CIRCA [25]. The goal of CIRCA is to stimulate long-term memory of people with dementia. This computer program presents to patients, photos, videos and music focused on some themes, such as public events, media/film news, local life, travel/holidays, occupations, fashions, hobbies & recreation, sport and house & home, that are summarized in recreation, entertainment and local life. Each session is supervised by the caregiver but the patient is encouraged to interact with the system. The evaluation process, with patients and caregivers, showed that the system prompted memories from several patients, that none of the caregivers had heard before, provided a more naturalistic conversation experience, by removing pressure from the caregivers, and made the patients, who normally reacted poorly to traditional reminiscence intervention, more involved and alert. Furthermore, patients enjoyed physically interacting with the system themselves. The system has also another functionality, which consists in the presentation of 360° interactive environments where patients can walk through gardens and museums.

One of the systems with most concepts related to this thesis is Photostroller [26]. The Photostroller is a portable wheeled device, which contains a screen that shows a slideshow of images that fade from one to the other every 6 seconds. Images are collected from the Flickr API[3], accessed via a limited set of keywords, and a tuner, such as on a radio, is used to select image categories. A smaller display, set under the main screen, indicates the current search category, the title of the current image and gives feedback when the tuner has been adjusted. The system was tested in a care home and was well accepted, helping patients to remember past memories and to spend their time. Despite all this, the system only uses generic images and would probably improve the results if it presents personalized or autobiographical images for each patient.

Thinking of the idea of providing autobiographical content for the reminiscence therapy, Massimi et al. [27] created the Biography Theatre, an in-home ambient display, with the goal of avoid patients' loss of identity, that cycles through music, photographs, movies, and narratives drawn from the patients' lives. The authors conducted an exploratory case study with an 84-year-old male in a middle-stage of Alzheimer's disease. The system consists in a Sahara slate PC, always present on patient's kitchen table, which plays digital life histories structured in a custom database. Biography Theatre front-end sums up in a menu which allows patient or patient's caregivers to select a particular chapter of his life to review. If no chapter is selected within 5 minutes, the entire biography plays from the beginning until the end. At the end of the biography, the system returns to the main menu and repeats the biography after another 5 minutes. The user can pause the chapter, skip to the previous or to the next chapter, or return to a main menu by pressing simple buttons on the touch screen. The system is never turned off, and is

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[3] https://www.flickr.com/services/api/

connected to a pair of external speakers that can be used to turn off the volume if desired. As a result of this study, the patient demonstrated improvement on standardised tests of apathy and positive self-identity.

Employing this idea of using autobiographical content, Hashim et al. [28] presented a digital memory book for people with dementia, which can be used to assist users in managing their daily activities, to improve their reminiscence and to stimulate their cognitive function. The android application, which was tested and evaluated by a patient, is divided into a reminder for patients' daily activities, a gallery that contains photographs of family members (organized as a family tree) and past life events to perform reminiscence therapy, and two games (jigsaw puzzle and flash cards) to stimulate their cognitive function. The main problem of this system, is that all the information presented to the patient had to be provided by the caregiver and there is still no way to automate the collection of information nor scale the application.

Based on a study's result, that involves nine interviews to formal caregivers and 536 online questionnaires to informal caregivers of patients with dementia, Antunes et al. [11] implemented a web application: Remember-Me 2. This application takes advantage of the fact that Facebook is a platform already known by the users, to collect and understand which materials are relevant to the patients. These materials are contextualized and then made available for use by the caregiver as a material for reminiscence sessions. It has two applications of use: personalization of clinical care (psychologists know the patients) and support home reminiscence therapy. Unfortunately, the authors did not undertake any study to test the effectiveness of the system.

Another approach was performed by West et al. [29], who presented MEMENTO. MEMENTO is a system for reminiscence and memory sharing activities, that supports the creation of scrapbooks that are both digital and physical in form. It allows the user to create a scrapbook website, by interacting with a traditional scrapbook printed on Anoto paper[4]. In addition to adding regular photographs and written annotations, the user can add multimedia items, such as audio, digital photographs and videos. As the user interacts with the physical scrapbook, his changes are automatically synchronized with the website and can be viewed immediately. The scrapbook website appears as a sequence of navigable pages with embedded pictures, written annotations and hyperlinks to audio and video clips. An exploratory study was performed with seven users, young and with considerable computing experience, which proved the ease of use of the system, but it would be interesting if the authors had tested the system with real dementia patients and proved the influence of the system in their lives.

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[4] http://www.anoto.com/creative/ecosystem/paper/

Sarne-Fleischmann et al. [30] created an internet-based system, developed specifically for use by patients and their caregivers in the treatment of mild to moderate Alzheimer's disease. The system uses generic and personalized contents (manually inserted), according to patients' background and preferences, to perform reminiscence therapy. This web application enables independent use and administration for both, patients and caregivers, by including two main components. The front-end component, that supports patients' interactions with the system during the therapeutic sessions, and the back-end component, designed for the use of caregivers and family members, which facilitates the addition, update, and management of contents. Personal and generic objects were placed in separate albums to help users find their preferred contents more easily. The hierarchy of the system, to provide simple and intuitive flow, includes only three levels: login - entering the system by identifying the patient; select album - selecting the required album from up to six albums presented; and album view - watching the contents associated with the selected album. A pilot study, performed with five Alzheimer's patients, indicated high user satisfaction levels with the system, and a strong tendency towards repeated use. The system was found effective in prompting conversations and in evoking personal memories. The results also showed a clear preference of personal over generic material when both were available.

Despite this large number of studies, none of them explored the use of generic, personalized and autobiographical content at the same time.

2.2.3 Immersive tools

Immersive technology can be defined as the technology that blurs the line between the physical and digital world, thereby creating a sense of immersion. Immersion into virtual reality (VR) is the perception of being physically present in a non-physical world. With the emergence of VR world, also appears an infinite number of applications for this technology. The capability to create virtual worlds and "transport" patients to these worlds, makes this technology very interesting to explore in reminiscence therapy.

Chapoulie et al. [31] introduced IVIRAGE (Image-based VIrtual ReAlity with GEstures), an immersive VR system designed for reminiscence therapy which allows the presentation of familiar environments. Particularly, the system provides easy capture and display of familiar and personalized environments, by using image-based rendering, and supports gesture-based navigation in the environment through finger tracking. To enrich the sensation of immersion in the VR environments, the authors added ambient spatialized 3D sound rendering. The system typically plays sounds, such as street, car, ambient noise, crowds walking and talking etc. An experiment with 13 elderly adults were made, showed that the system adapts well to people with low mobility and can help generate conscious autobiographical memories.

Another approach was tested by Siriaraya at al. [32]. The authors created a 3D virtual world with the goal of stimulating patients' memories. This virtual world allows the patient to visualize and interact with objects that in the real world would be difficult to obtain (such as an old car). Its operation is quite simple: the world is presented in a projector and the movements, captured by a Kinect[5], allow the patient to move inside the virtual world. Initially the Kinect captured the whole body but the users became too tired, so in the final version are captured only the movements of the arms. In this virtual world patients are challenged to plant their virtual garden with the help of a caregiver. The results were positive, patients were able to immerse themselves in the virtual world, revealing details about their past (particularly their gardens) and discussing about the visual garden. As a negative aspect, it is necessary to highlight the fatigue provoked by the system and the irrelevant places and objects presented in the virtual world.

These are undoubtedly very interesting approaches with a lot of potential. However, like any other approach, has its own problems: the poor mobility of patients can make them incapacitated to use the system, or cause much fatigue, and the difficulty in creating new environments, or personalized environments for each patient, makes these virtual reality systems difficult to scale.

2.2.4 Summary

The reminiscence tools are now summarized in the table below. Please note that reminiscence therapy is not one of the columns in the table, since all works present perform it.

Table 1: Summary of existent reminiscence therapy tools

Work	**Content**	**Media Types**	**Cognitive stimulation (games)**	**Therapeutic and home treatment**	**Display device**	**Automatic gathering of content**
Baecker et al. [20]	Autobiographical	Image, video and audio	No	No	TV	No
Damianakis et al. [21]	Autobiographical	Image, video and audio	No	No	TV	No
Smith et al. [22]	Autobiographical	Image, video and audio	No	No	TV	No

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[5] https://developer.microsoft.com/pt-pt/windows/kinect

Subramaniam et al. [23]	Autobiographical	Image, video and audio	No	No	TV	No
Kuwahara et al. [24]	Generic, personalized and autobiographical	Image and video	No	No	TV	No
Gowans et al. [25]	Generic	Image, video and audio	No	Yes	Touch-screen monitor	Yes
Gaver et al. [26]	Generic	Image	No	No	Computer	Yes
Massimi et al. [27]	Autobiographical	Image, video and audio	No	No	Computer	No
Hashim et al. [28]	Autobiographical	Image	Yes	No	Android device	No
Antunes et al. [11]	Autobiographical and personalized	Image and audio	No	No	Tablet	Yes
West et al. [29]	Autobiographical	Image, video and audio	No	Yes	Computer	No
Sarne-Fleischmann et al. [30]	Generic and personalized	Image	No	Yes	Android device	No
Chapoulie et al. [31]	Generic and personalized	3D Image	No	No	BARCO iSpace	No
Siriaraya et al. [32]	Generic	3D image	Yes	No	Projector	No
Scrapbook	Personalized and autobiographical	Image, video, audio and text	Yes	Yes	Computer and tablet	Yes

Analysing table 1 and, again, dividing the tools by the way patients interact with them, there are some conclusions that can be taken. First, passive interaction tools focus mainly on autobiographical contents, that need to be manually recovered and inserted by the authors and cannot be used to perform cognitive stimulation games. Additionally, the authors of these tools just thought of using them as a treatment at home, where patients turn on the television and watch the video. The advantage of this type of tools is the combination of images, videos and audio in the final video. Curiously the only exception, reminiscence video [24], that uses generic, personalized and autobiographical contents, and that can generate random movies (always different) from stored contents, does not include music in movies.

Interactive tools, like web or android applications, have more potential than the previous ones once they can make use of internet connection to collect their contents, which can be presented in a non-static way. Despite this, most of the tools are only focused in one type of content (mostly autobiographical). The exception is the android application created by Sarne-Fleischmann et al. [30], which is capable of present generic and personalized content, but only uses images.

The immersive tools, or use personalized content, that is laborious to obtain [31], or use very generic content, which reduces the therapy efficiency [32]. Additionally, the devices used in these works, such as projectors or Kinects, are not frequently present at patients' homes or at day-care centres.

Finally, there are two columns that stand out due to the lack of exploration by the presented works. The first one is the cognitive stimulation column. Of course, the table is a summary of existing reminiscence therapy tools, that do not have necessarily to provide cognitive stimulation therapy, but once the contents are collected and stored, they can be used to play some games, like puzzles or flashcards. The only ones to explore this opportunity are Hashim et al. [28], whose system performed jigsaw puzzles and flashcards games based on autobiographical images, and Siriaraya et al. [32], who asked patients to plant their virtual garden. The second column to stand out is the automatic gathering of content. Despite the growing of large public databases, only three tools make use of them. The CIRCA [25], which only uses generic content, such as historical news events, the Photostroller [26], which also only uses generic content, and the Remember Me [11], that collects autobiographical images from Facebook Graph API.

Analysing this, we can see a lack that nobody has explored: the automatic gathering of autobiographical, personalized and generic images, videos and audio from large APIs, to perform reminiscence and cognitive stimulation therapy at home or at a day-care centre.

2.3 Supplementary tools to support reminiscence therapy

As previously demonstrated, there are a large number of systems that perform reminiscence therapy. However, there are also other systems that, although they do not have the necessary mechanisms to perform the therapy, are important aids to the psychologists.

One of the most relevant tools for my project is Portrait [33]. The Portrait is not a reminiscence therapy tool but rather a complement to existing reminiscence therapy systems, such as CIRCA [25] or Multimedia Biographies [22]. The goal is to provide, to formal caregivers, personal and social information about patients, within a three to four minutes time frame. The interaction with the screen is performed on a touch screen. The screen is divided into six topics: “Time Line”, “Family Tree”, “Things to Know”, “Hobbies & Interests”, “Family Stories” and “Photo Album”. The authors, in a study with three participants, could conclude that it is much easier for psychologists to have conversation topics (usually they talked about the weather or the lunch). Additionally, informal caregivers indicated that the Portrait system allows care staff to view the person with dementia as a person who had lived a varied and interesting life and not simply an entity who need look after.

Kuwahara et al. [34] think about patients who have difficulties leaving their own homes, and presented a networked reminiscence therapy system, that allows patients who cannot leave their homes to receive reminiscence therapy. This tool uses IP videophones and a web photo and video-sharing system. Its operation is simple: the psychologist may at any time perform a call to the patient (who has the option of reject) to start the therapy (the patient can also call to the psychologist). After this, the psychologist, through the data stored in the database, can present items (such as an image or video) on the patient’s screen. This way, they can both discuss about an image, making use of features that can improve the exchange of information between the two, such as zooming, panning, or selection of objects (visible on both sides). An evaluation performed by six volunteers allowed to conclude that there are no substantial differences between face-to-face therapy and the network therapy.

Important works to stimulate cognitive functions of patients, and that can be used in a reminiscence therapy session, are personal lifelogs tools. Chen et al. [35] provided a guideline for developing a lifelog application. According to the authors a lifelog application must provide: memory cues, rather than external copies of episodic memory; and information or items themselves (semantic memory support, when one needs to exact details about previous encountered information, or when one needs the original digital item, e.g. a document). This guideline focuses majoritarian in presenting, capture and retrieval data. Based on this guideline the authors presented iCLIPS, a prototype of personal life log search system. The goal of this prototype is to efficiently retrieve information from the massive collections of data. The system uses images of users’ daily activities automatically captured by Microsoft SenseCam[6] for twenty months. Along with the image, is saved the patient’s location (GPS), people nearby (Bluetooth), and time.

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[6] https://www.microsoft.com/en-us/research/project/sensecam/

People may be able to recall about the episodes or items, such as location, people present, weather conditions and date/time. Piasek et al. [36] studied the hypothesis of using lifelogging to help construct the identity of people with dementia. The authors reported details of three case studies, where recorded images. captured by Microsoft SenseCam, are reviewed by the patient at the therapy, wherein the authors conclude that this system helps psychologists to develop a more holistic version of the identity of people with dementia. Kikhia et al. [37] presented an external memory aid, which supports a person with mild dementia by using context-aware lifelogging techniques. They record information like images, locations or audio that can be later reviewed by the patient with the caregivers' help. Generally, the lifelogging approach raises three major problems: the large space needed to store all the data, the difficulty to retrieval relevant data, and the privacy of patients (what if the user forgets to turn of the camera?).

A different approach was presented by Martins et al. [16]. The authors created an application that can collect information from people with dementia's smartphones, for example their location. The system is based on crowdsourcing, where information about patients is collected from Facebook with the help of friends. The first step is to monitor, through GPS, when the patient is a long time away from home and stopped in the same place. After this, the system asks Facebook friends for information about that place or event, such as is location, photos, weather or people. The information obtained from patients' friends may be useful to perform reminiscence therapy.

My main concerns with this system are its efficiency and privacy problems. It becomes very difficult to understand when a patient exit is relevant or not. What if the patient just went to the doctor? And if he went to some place and did not want it to be public?

Another interesting work is KiMentia [38], an application destined to people with dementia. It is designed to be used at home and in appointments with psychologists. The main goal is to improve mental performance while doing exercises. The operation is simple: exercises are presented on a screen, such as complete words or find items in the supermarket (like shopping), and the patient answers through the movement of the hands (captured by a Kinect). The feedback received from tree psychologists and two physiotherapists who are taking part in the project was not great, the system received 93 points out of 140 possible.

Tárraga et al. [39] studied the usefulness of an interactive multimedia internet-based system (IMIS), the Smartbrain. The system was tested during of 24 weeks, with 46 patients suspected of having AD. The Smartbrain is an interactive multimedia tool that allows patients to carry out a variety of different stimulation programs, at different levels of difficulty and at various times during the day. The IMIS program consists of 19 separate tasks or stimulation exercises across the domains of attention, calculation, gnosis, language, memory and orientation. All participants began at the lowest level of difficulty (first of 15 levels), and the program monitored activity at each level. The difficulty is increased automatically after three consecutive performances within a single task without error, or when a patient was 80% correct over six consecutive sessions. A patient's level of difficulty decreased when his or her performance fell below 15% correct for three consecutive sessions or 20% correct for six consecutive sessions. For this study, the patients were randomly assigned to three experimental groups. The results showed that both the IPP (a daily program in the day-care centre that includes cognitive stimulation task) and IMIS improved cognition in patients with AD, but the IMIS program provided an improvement above and beyond that seen with IPP alone.

2.4 Outlook

As we can see throughout this chapter, several approaches have been tested to help people with dementia and those who relate to them. Possible consequences of dementia are the decline of memory, language, reasoning and other cognitive skills that affects a person's ability to perform everyday activities.

The first section of this chapter presents some examples of tools that can be used to help people with dementia in their everyday activities. However, from a certain point of time people with dementia, whether derived from this or other diseases, no longer have the mobility required to perform these activities, so these tools end up losing much of their usefulness.

At this advanced stage, and despite the low mobility of patients, they can continue to perform mental work, so reminiscence therapy, which tries to elicit past memories, presents itself as a good solution. All the presented reminiscence therapy tools have their advantages and limitations.

The passive interaction tools, despite the enormous cost and time required to produce them, have proven that they can positively stimulate the patients' memory or enhance their quality of life. In addition, the process of creating DVDs, in which patients and caregivers enjoyed to participate, allowed family members to remember how the patient once was and to accept the disease, and allowed formal caregivers to better understand who is in their care.

Also the immersive tools were able to help people with dementia. Although, generally, they do not use autobiographical contents, and the ones that use require a great deal of effort to create the virtual environments, the results showed that patients were able to immerse themselves in the virtual worlds, revealing details about their past, and generating conscious autobiographical memories.

From my point of view, and considering the existing technologies, the use of interactive tools is the most advisable. Previous works showed that these tools can help to provide a more naturalistic conversation between participants, to prompt patients' memories and to improve their levels of apathy and self-identity. However, currently, they do not explore all their potential. The capability of show contents of any type of media, allied to the ease of recover large amount of data related to patient's past, and the possibility of use patients' favourites contents to perform cognitive stimulation games is not explored.

Chapter 3

Supporting psychologists working with people with dementia

Although my biggest concern is with people with dementia, I considered that the best way to help them is helping those who are closest to them and who are technically able to work with people with dementia: the psychologists. Of course, many people with dementia do not have the computer skills, and caregivers may not have the necessary knowledge about the reminiscence therapy and the disease to perform the therapy. As such, the end users of Scrapbook, at least at this stage, will be the psychologists.

Having chosen to use an iterative and user-centred design methodology, there was a close relationship between me and the psychologists. In this model, the system grows incrementally, and the feedback from the psychologists of an iteration leads to a refining and adjustment of the requirements and design of the next iteration. This constant feedback lowered the risk of the project being delayed.

Since I am part of a team that already had some knowledge around dementia, the phases of requirements analysis and design were much more objectives than the expected. This initial knowledge was deepened after a detailed analysis of existing reminiscence therapy tools, which has proven some of the benefits these tools can bring.

However, these tools also have their limitations, and the final version of Scrapbook, which emerged from these initial ideas and from the successive feedbacks provided by psychologists, aimed to address these limitations.

This chapter describes the design process of the system, namely the requirements analysis and use case scenarios and, finally, based in the first two sections of the chapter, is presented an overview of the system.

3.1 System requirements

When it comes to define the system requirements it is necessary to consider the shortcomings of existing tools, but, above all, I must have a great concern with the well-being of end users.

To define the needs of end users two steps were made. First an extended analysis of the related work, and most precisely of the work of Antunes et al. [11], who conducted a study that involved nine interviews to formal caregivers and 536 online questionnaires to informal caregivers of people with dementia, and, second, two interviews, performed in the context of this thesis, with two different psychologists. Through these interviews, it was possible to draw some conclusions:

- New technologies are not used as often as psychologists would like partly because they are time-consuming;
- Psychologists use, to perform the therapies, platforms like Google Maps[7] (street view), Google Images[8] or YouTube[9];
- Psychologists have the expectation to have records and statistical graphs, to help them to do a better assessment of the disease;
- Music can stimulate parts of the brain that cannot be reached through other materials;
- The contents used in a session should always be carefully chosen by the psychologist;
- Patient's data must be protected so that only his psychologist can access it.

Having account these conclusions, as functional requirements Scrapbook should:

- Allow the recovery of pertinent information about the patients, in an easy way, and saving stakeholders time;
- Guarantee that the collected information about a patient is enough to ensure that the psychologist will know him;
- Involve caregivers in the process;
- Besides photographs, also use music, videos and texts as a therapy material;
- Use recent photographs but also past photographs once the recent memory is the first to fade away;
- Make sure that all the contents used in a therapy are pre-validated by a psychologist and its use is authorized by a caregiver;
- Provide an account for each psychologist, ensuring that patient's data are only accessible by the person responsible for him;
- Provide mechanisms to navigate through patients' favourite places;
- Allow a simple and fast process of session creation;

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[7] https://www.google.com/maps

[8] https://images.google.com/

[9] https://www.youtube.com/

- Allow the psychologist to synthesize the disease evolution, giving him the possibility of take notes and record patients' reactions. This process can not distract the patient from the normal course of the session;
- Provide to psychologist statistics about the sessions;
- Allow the edition of patient's profile at any time.

Relatively to non-functional requirements, the main concerns are:

- Usability – Since end users may not be familiar with new technologies, the system design must be minimalist and the use of the system must be intuitive;
- Performance – Once internet conditions may vary from place to place the system must have a short response and data transmission time;
- Availability – The system must always be available, so as not to interfere with the psychologist sessions calendar;
- Privacy – User data must be protected;
- Maintainability and Extensibility – Since this is only the first version of the system, it must be ready to meet new requirements or correct existing problems;
- Portability – The system must run in perfect conditions independently of the operative system, browser or device type;
- Documentation – Provide user guides, on-line help or quick-reference guides.

3.2 Use case scenarios

Scrapbook can have up to four stakeholders: patients, psychologists, caregivers and patients' friends. All these stakeholders may use the application in different scenarios and contexts, so for a better understanding of the requirements and advantages of the system, a list of potential use case scenarios is presented in this section.

To demonstrate the current difficult situation of stakeholders, the first use case scenario represents what happens, now, in real life, where there is no application that supports reminiscence therapy. Although all these use cases represent reminiscence therapy scenarios, the way in which the stakeholders interact with the application varies.

Reminiscence therapy without Scrapbook

> *Daniel is an 80-year-old former airline pilot, living in Lisbon, and diagnosed with Alzheimer's disease three years ago. Daniel's wife passed away five years ago, and now his only living relative is his daughter, Lara, aged 60. Unfortunately, Lara, who lives in Dublin, was forced to put her*

father in a nursing home. Lara, asked by Maria, the service psychologist, provided, along with a registration form, three photographs of Daniel so they could be used to perform reminiscence therapy. As the nursing home has quite a few seniors, only is performed one reminiscence therapy session every two weeks with each patient, which last for about 40 minutes.

As part of their appointments, Maria and Daniel meet. Maria does not have much information about Daniel and his past, and as it is the first time they meet, they start by talking about the photographs provided by Lara. In these photographs, although with some difficulty, Daniel was able to recognize his deceased wife and his daughter. From a certain moment, there was a lack of topic of conversation, reason why they ended up talking about the weather.

In the following meetings, Maria, knowing that Daniel was an airline pilot, searched on Google for images of his profession to stimulate the conversation. In addition to this, and to the photos provided by Lara, Maria also used Google Maps to navigate through the city of Lisbon, looking for places that would stimulate Daniel's memory. Maria is not apologist of this type of solution, but in the absence of a better alternative, and greater knowledge about Daniel, browse on Google turns out to be the best solution.

Reminiscence therapy with Scrapbook - content feeding by psychologist

Sai, aged 78, born in India but early moved to Portugal, was recently admitted to a nursing home due to his suffering with Alzheimer's disease. His only son began to feel overloaded and made the decision to hand him over to professional care. The nursing home, following the request of an adventurous psychologist, adopted a new web platform, Scrapbook, that aims to help psychologists in the fight against dementia.

After the admission of Sai to the nursing home, the psychologist, Alice, invited his son to a meeting in order to start the process of collection of information about Sai. At the meeting, Alice registered Sai on the platform, with the help his son, who provided four photographs, a list of interests, relevant places, and even two photographs of him, and one of each of Sai's grandchildren.

Now with these data, Alice can initiate the sessions with Sai, as usually every two weeks. Usually, five minutes before every meeting, Alice logs in into Scrapbook and creates a new session in the system. To do that, Alice selects the patient she will meet (Sai) and, after that, selects the contents to *be used in the reminiscence therapy session. These contents are provided by the system, which, for each interest or place, recovers three images and videos from Web APIs. After this step, Alice is ready to start the therapy with Sai. To perform the therapy, she uses two devices: a tablet, where she can swipe from one content to another, take notes and inset the patient's reaction about that content; and a monitor, connected with the tablet, responsible for showing to the patient the content to be seen at the time. At the end of the session Alice always inserts a note with her opinion about that session, mainly in case she wants to repeat it again. The contents available for each meeting will grow according to Sai's reactions, so Alice is happy to have always new contents to work with.*

Reminiscence therapy with Scrapbook – content feeding by social network

The nursing home recently accepted a new patient, Juliana, suffering from dementia. This new patient, aged 72, has a characteristic that catches the attention of Alice: Juliana used to be an active user on Facebook. Fortunately, Juliana, since her retirement, spends a lot of time on Facebook, where she creates photo albums of the family trips, and adds, every Christmas, a family photo where she identifies all her grandchildren. Furthermore, she likes to follow all television celebrities she appreciates. This is a big help for Alice's work once the Scrapbook allows, during the registration of a new patient, the log in with patients' Facebook account. The login process is only possible because Juliana's husband knows her Facebook password. Before Alice and Juliana start the reminiscence therapy process, Alice and Juliana's husband meet. At the meeting, her husband allows the Scrapbook to access important information Juliana has on Facebook, and automatically fulfils the registration form with her interests, favourite places, events she went, photographs, videos, and relatives' information. As some of the recovered interests are not relevant for Alice, she opts for remove them before finishes the registration. For a perfect operation of the system, Alice indicates Juliana's sons as her online caregivers.

Now Scrapbook works as a system of online content collection. It will, a few times a day (with time interval defined by the caregivers), create posts on Juliana's Facebook asking to friends for new contents, namely histories or images, or for validation of existing contents. Juliana's sons have the responsibility of validate the contents inserted by her friends, so that only authorized contents will be presented to Alice on the session creation.

Alice's work is the same, but now she knows if a content is approved by the caregivers, which will mean that it will probably be a good content to use in the therapy. In general, the system leaves Alice more focused in her work, facilitates the patients' registration and allows Juliana's friends and relatives to stay connected.

Reminiscence therapy with Scrapbook at home

The nursing home, which also works as a day-care centre, received a new patient, Wilson. Wilson, diagnosed with Alzheimer's disease two years ago, goes every morning during the week to the centre and leave after the afternoon snack. The nights and the weekends are always spent with his son, Peter, at his home. Alicia kept the normal registration procedures, but to improve the therapy benefits she suggests to Peter performing home therapy with his father.

Unfortunately, Wilson does not have a Facebook account, so all the contents and information are manually inserted on Scrapbook by Alice with Peter's help. The therapy performed at the nursing home, works as usually (one session every two weeks), but this time, at the end of each session, Alice creates one session to be performed at the weekend by Peter.

As part of Alicia's work, before every session, she goes check in the system the homework results.

3.3 Overview

The knowledge obtained from the previous works of the team, the analysis of failures and successes of related works, and the preliminary interviews with two psychologists make me feel confident that Scrapbook may be the right step. Scrapbook can be described as a tool that provides to psychologists the necessary mechanisms to perform non-pharmacological treatments, namely reminiscence therapy and cognitive stimulation therapy, with people with dementia. In addition, it works as a social life storybook of the person with dementia, where all the friends of the person can contribute with contents to be used during the sessions with the psychologist.

What makes the Scrapbook innovator is the range and quality of contents that it provides to the psychologist so he can do his job. The contents, images or videos, or are autobiographical, which automatically guarantees their quality, or are online collected based on patients' preferences, which does not guarantee their quality but that, at least, increases the probability of being.

Once the platform will be used during the meetings, and psychologists reported that they do not use new technologies as often as they would like partly because existing technologies are time-consuming, the goal was to create a quite simple and intuitive workflow which does not takes much time to register a patient and start a therapy session.


1. Psychologist meets with the caregiver to register the patient.

2. Psychologist creates a session with the collected contents.

3. Reminiscence therapy session with the patient.

4. At home, the caregiver provides new contents for therapy.

5. Psycologist creates a new session with contents provided by caregiver.

6. Reminiscence therapy session with the patient.

Figure 1: System overview

Figure 1 represents an overview of the system, and the way the different stakeholders interact with it. In an ideal workflow of the system, where all stakeholders collaborate, a meeting is held between the psychologist and one of the patient's caregivers to collect information about the patient and to register him in the platform. This process can be optimized if the patient has a Facebook account. From here, the psychologist can begin the sessions with the patient. Before each session, she chooses the contents to be used, avoiding negative contents, and during the session she registers patient's reactions in the system. Knowing to what contents the patient reacts, the system asks to patient’s friends on Facebook to provide similar contents. The responsibility of the caregiver, from the comfort of his home, is to validate the contents that will be collected for the psychologist. In the next session with the patient, the psychologist will have access to these new contents, initiating this way a cycle that always guarantees updated contents to her.

Chapter 4

Implementation

Scrapbook is a web application, developed within the context of this thesis, which makes use of a set of programming languages, such as PHP, HTML5, CSS3 or JavaScript, to provide the greatest possible user experience to its stakeholders. The system was developed after a meticulous elaboration of system requirements and with a close presence of a psychologist, making all design decisions well justified.

This chapter, the most technical of all, describes in detail how Scrapbook works. First, I provide a detailed description of the system design, namely is architecture and data model, followed by a presentation of the application interfaces, and finally an explanation about some details of my implementation.

4.1 System design

4.1.1 Software architecture

One of the advantages of Scrapbook, is that it provides to psychologists a wide variety of contents and always according to the preferences of the patient. The system makes use of four types of contents, divided into three types of media. Each one of these contents is recovered from different APIs.

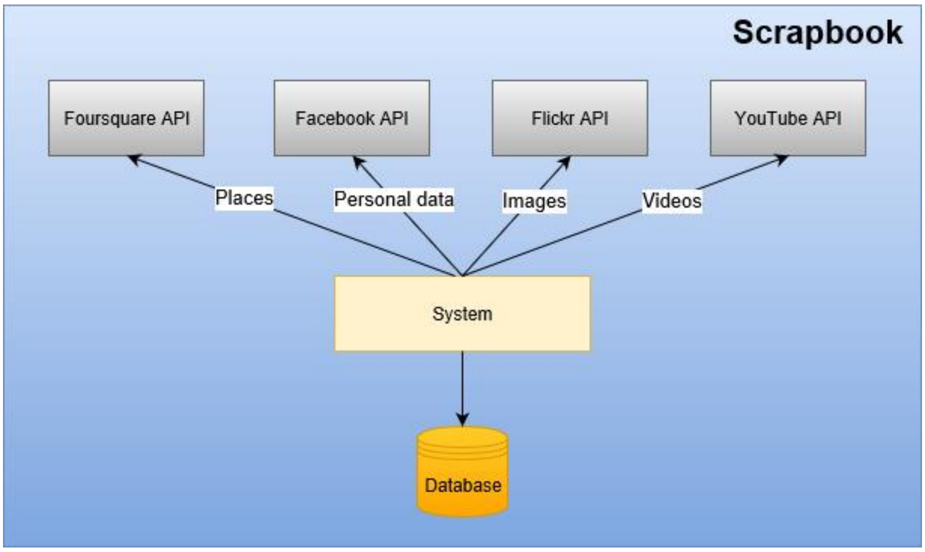

Figure 2: Scrapbook architecture

Flickr API is used to collect images, YouTube API[10] to collect videos and music, and Facebook Graph API[11] is responsible for providing personal patient data, which includes images, videos and texts. By contrast with these APIs, which collected data are stored into the database, Foursquare API[12] is used on-the-fly to collect relevant monuments near a place.

An example of interaction between the system and these APIs, which demonstrates the registration process of a patient, can be seen in figure 3. To meet good software development practices, the presentation layer never interacts directly with the database, so the system is divided into three layers: model, view and controller. The user interacts only with the view, the model interacts with the database and the controller is the intermediary.

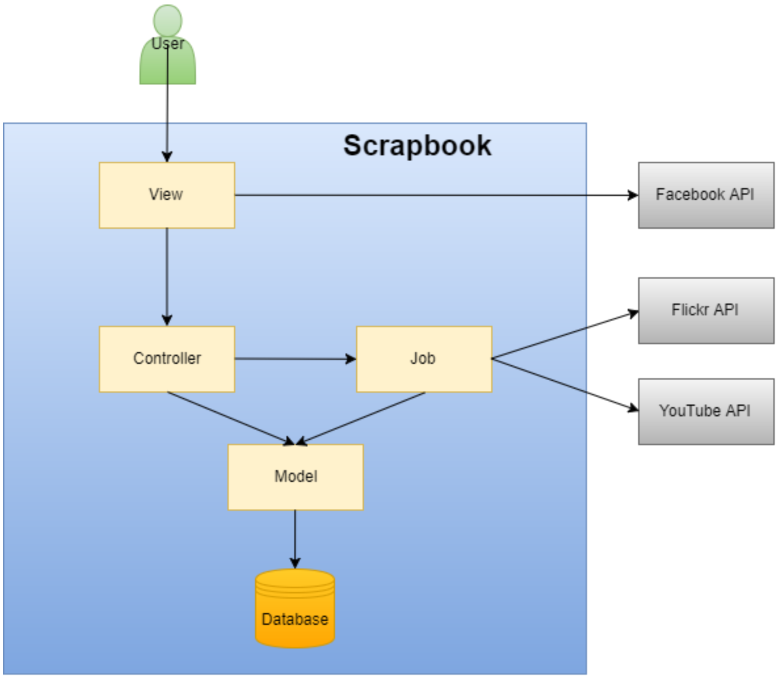

Figure 3: User registration diagram

The first connection to an external API is made after the page load when the psychologist clicks to login with Facebook. After the login, on the patient's account, the system makes a series of connections to automatically complete the entire patient registration form. Once I do not want to reload the page to complete the form after the login, all the connections are made through the Facebook SDK for JavaScript.

When the psychologist who is registering the patient completes the process, the controller starts its work. First contacts the model to insert the patient's personal

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[10] https://developers.google.com/youtube/

[11] https://developers.facebook.com/docs/graph-api

[12] https://developer.foursquare.com/

information, such as his name and birthday, into the database and then deliveries the hard work to a job, which runs in background so as not to force users to wait for the most time-consuming actions.

The job is Responsible for establishing connections with Flickr API and YouTube API. The connections are made in PHP, respectively, through the method `file_get_contents` and through Goole API Client Library for PHP[13]. As it gets the responses from the APIs, it contacts the model, which inserts the obtained data into the database. The existence of this job allows psychologists to perform other activities while waiting, or even perform a therapy with the contents that are becoming available over time.

4.1.2 Data model

For familiarity with the concepts and language, I adopted a relational database (DB), MySql. Furthermore, the features provided by this database management system are enough for the actual needs of Scrapbook.

When it comes to define the database structure, Facebook has a great influence, once it already has a defined structure, namely the separation of user information between likes, events, places, images or videos, and the separation of likes between music, books, movies, athletes, etc.

Due the characteristics of my database schema, more precisely because of the high number of existing relationships, it would be confusing to expose the whole database at once, so this section describes only the most important relationships, one by one, and the whole database schema can be seen in appendix A.

Patients, psychologists and caregivers

Figure 4 represents the connection between all Scrapbook direct participants. Each patient, is connected to a psychologist and to one or more caregivers. Although in the scope of this study each patient has only one psychologist responsible for him, the database is already prepared for cases where there is more than one psychologist working with a patient. It is important to note that, although the patient's friends on Facebook are also part of the stakeholders group, it is not necessary to keep any information about them, unless they are part of the group of caregivers or relatives, which contains a table of their own.

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[13] https://developers.google.com/api-client-library/php/

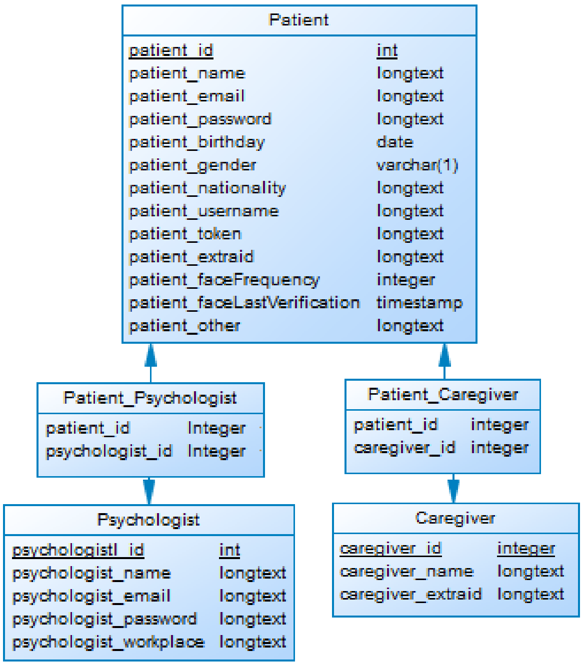


Figure 4: DB tables Psychologist, Patient and Caregiver

Since my intention is not to save data about psychologists and caregivers, their tables are quite simple. From the patients, I try to collect as much information as possible, namely the name, date of birth, gender, nationality and username. Additionally, there is a special attribute, `patient_other`, that allows the psychologist to insert any other information he considers relevant. These are the attributes shared by patients with or without Facebook account. The others are exclusive to patients with Facebook, namely the e-mail, the Facebook user access token and id, the `patient_FaceFrequency` (frequency of Facebook posts) and the `patient_FaceLastVerification` (represents the last time the system has read the replies of Facebook posts).

Images, videos and reactions

As the system works with three media types, and each one of them is collected from different APIs, I chose to split them into three tables. For images and videos, I store the URL, the name, the label (an additional description that later can be part of a tag system), the date, the type (to better recognize if it is a content manually inserted or online recovered) and an extra id (the id of the content in the API where it came from). The table of images has an additional field, `image_sizes`, which stores the available sizes of a Flickr image.

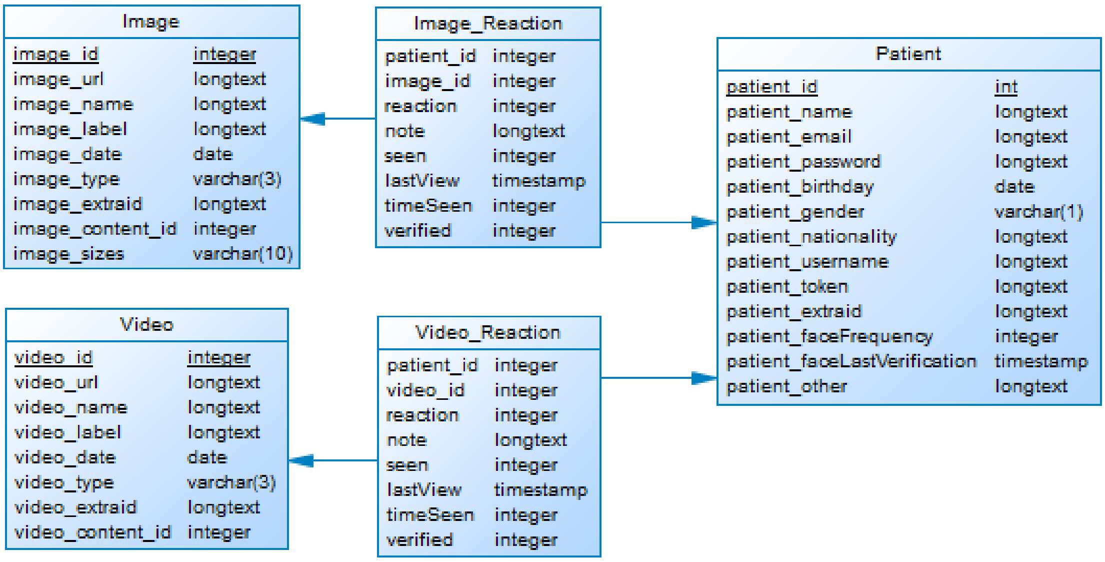


Image	
image_id	integer
image_url	longtext
image_name	longtext
image_label	longtext
image_date	date
image_type	varchar(3)
image_extraid	longtext
image_content_id	integer
image_sizes	varchar(10)

Image_Reaction	
patient_id	integer
image_id	integer
reaction	integer
note	longtext
seen	integer
lastView	timestamp
timeSeen	integer
verified	integer

Patient	
patient_id	int
patient_name	longtext
patient_email	longtext
patient_password	longtext
patient_birthday	date
patient_gender	varchar(1)
patient_nationality	longtext
patient_username	longtext
patient_token	longtext
patient_extraid	longtext
patient_faceFrequency	integer
patient_faceLastVerification	timestamp
patient_other	longtext

Video	
video_id	integer
video_url	longtext
video_name	longtext
video_label	longtext
video_date	date
video_type	varchar(3)
video_extraid	longtext
video_content_id	integer

Video_Reaction	
patient_id	integer
video_id	integer
reaction	integer
note	longtext
seen	integer
lastView	timestamp
timeSeen	integer
verified	integer

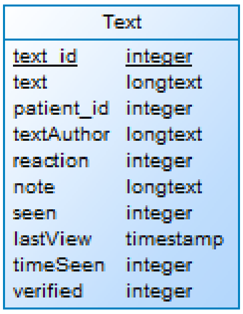
Figure 5: DB tables Image, Video, Image_Reaction, Video_Reaction and Patient

Along with the images and the videos, it is important to keep patients' reactions to those contents, so two intermediary tables were created. `Image_Reaction` and `Video_Reaction` store the patients' reactions (positive, negative or neither), the note taken by the psychologist about that content, the number of times that the patient saw the content, the last time he saw it, the total time lost to see it and a special field, verified, used if the patient has a Facebook account to indicate if the content was validated by a caregiver or not.

Texts

The structure of the table `Text` is slightly different from the previous. Since a text is unique for each patient, there is no need to have the reaction to text separated from the text itself.

Relatively to the table attributes, these are almost the same as for the other contents, the only addition is the attribute `textAuthor`, that stores the name of the author of the text.



Text	
text_id	integer
text	longtext
patient_id	integer
textAuthor	longtext
reaction	integer
note	longtext
seen	integer
lastView	timestamp
timeSeen	integer
verified	integer

Figure 6: DB table Text

Events, places, interests and family members

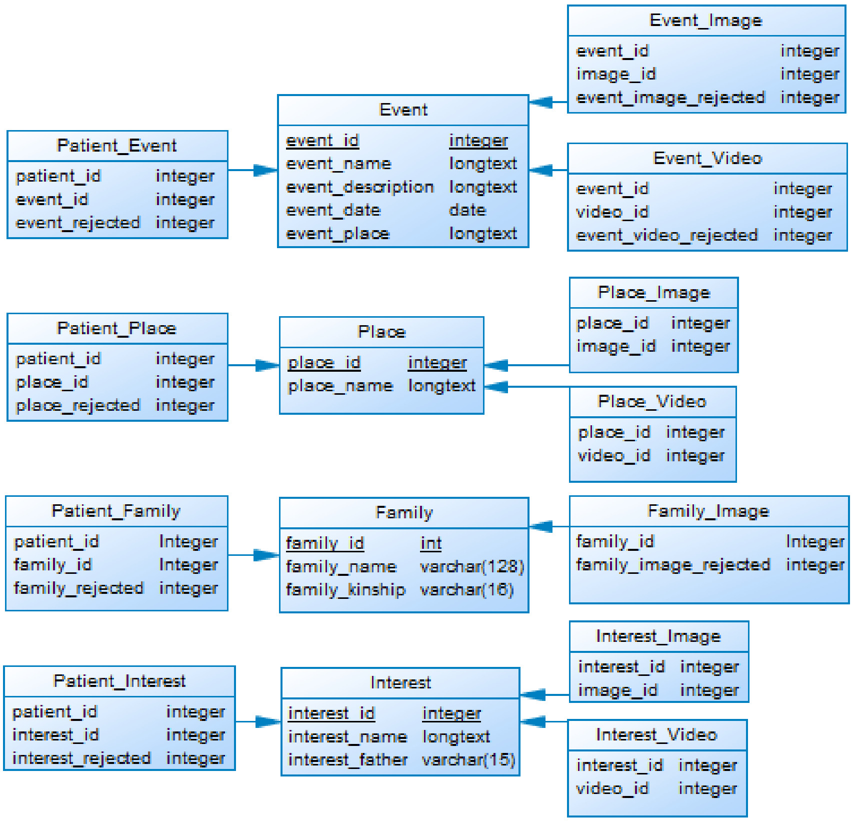


Figure 7: DB tables Events, Places, Family and Interests, and its relations

Figure 7 shows how the relation between patients, patients' data (events, places, interests and family members), images and videos is made. The structure is the same for all types of patient’s data, but let’s consider the places as an example. An intermediary table, `Patient_Place` makes the connection between each patient and each place. This table, beyond the patient id and the place id, has another attribute, `place_rejected`, only used when a place came from Facebook, which indicates whether that place was rejected by the psychologist or not. The tables `Place_Image` and `Place_Video` connect places and images, and places and videos, respectively. It should be noted that a family member can only be associated with images, not videos.

Relatively to the main tables, about an event I store the necessary information that helps the psychologist to contextualize it in time and space, namely name, description, data and place. For a place, only its name is stored, despite in the future it may be interesting to create a relation between the location of an event and a place. In the case of an interest, beyond the name, is stored the father of the interest (music, movie, etc.). Finally, about the family members, I store the name and the degree of kinship.

Also note that even if an event or family member is accepted by the psychologist, he may reject its images or videos.

Sessions

A session can be described as a selection of contents (images, videos and texts) to be presented to the patient in an order defined by the psychologist, and that can be performed more than once and at any time.

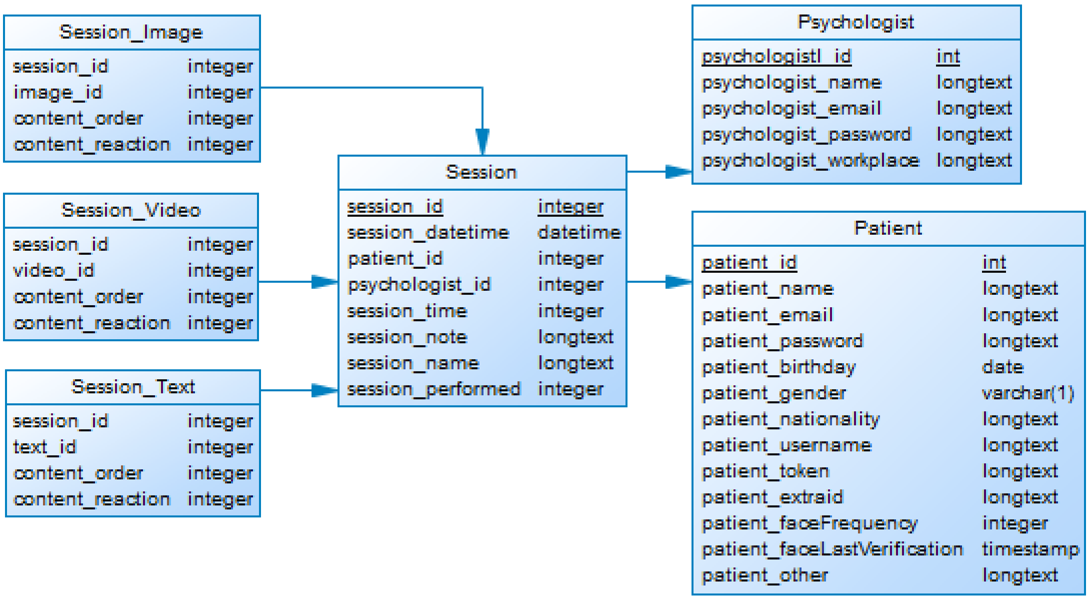


Figure 8: DB table Session and its relations

A session is characterized by its name (works as an identifier for the psychologist), and by the day and time at which the session is held for the first time. Additionally, some data are stored for statistical purposes, such as the total time spent on the session, the note taken by the psychologist about that session, and the number of times it was performed.

The table `Session` is connected with the tables `Session_Image`, `Session_Video` and `Session_Text`. These tables contain the id of the content to be presented, the order in which it must be presented and the patient's reaction.

Post

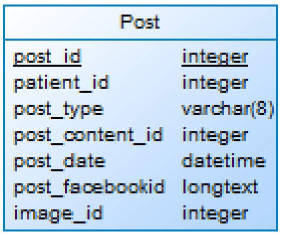


Figure 9: DB table Post

To record and manage the interactions with Facebook it was necessary to create a table. The table `Post` records all posts made on Facebook by Scrapbook. This record ensures that no duplicate posts are created in Facebook and that only replies to posts created by Scrapbook are read. The stored information about a post is the id of the patient, the type of the post (there are different types of posts), the id of the content (the subject), the date on which the post was made, the Facebook id of the post and the id of the image (if the post is about a specific image).

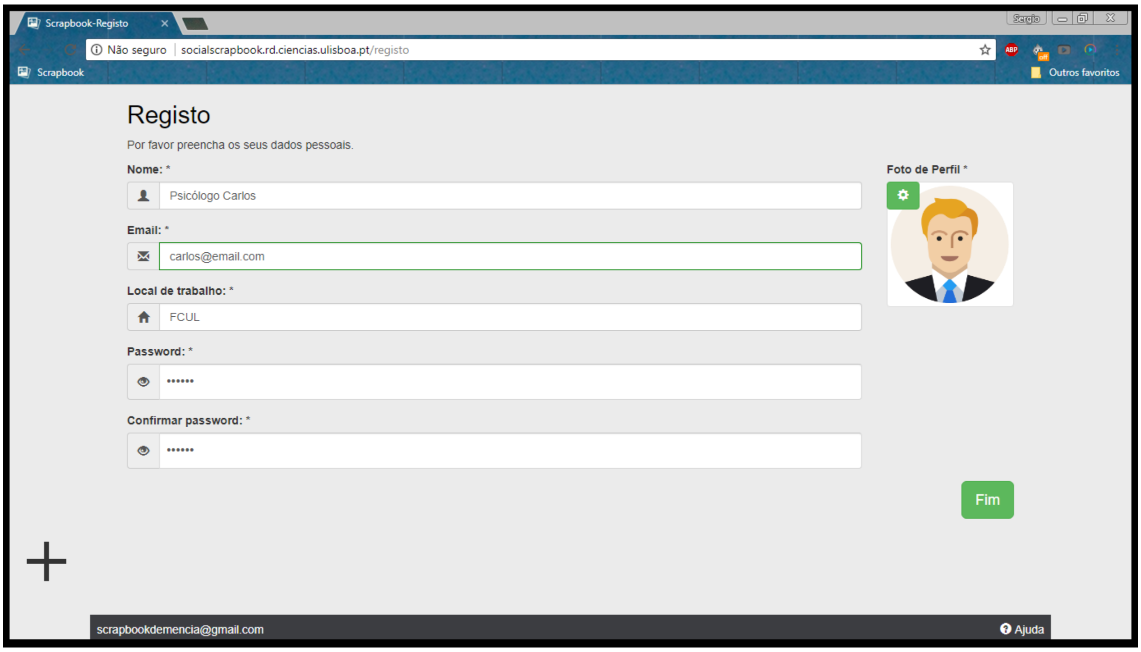
4.2 User interface and workflow

Scrapbook, being a web application, was designed to work correctly on any operating system or browser. In addition, to facilitate the task of psychologists, the responsive design of the system allows it to work perfectly on computers and tablets.

In this section, I will present the main interfaces of the platform, in an order that represents the normal interaction workflow of a psychologist with the system. In this case, the screenshots were taken on a computer running the Windows operating system and with the Google Chrome web browser.

Registration of a psychologist

The first step that a psychologist who intends to use the system has to perform is his registration. The registration screen is accessible through the homepage, and once completed this process the user is redirected again to the main page. Since at this stage I do not intend to gather much information about psychologists, this task is quite simple.



Registo

Por favor preencha os seus dados pessoais.

Nome: * Psicólogo Carlos

Email: * carlos@email.com

Local de trabalho: * FCUL

Password: * ••••••

Confirmar password: * ••••••

Foto de Perfil *

Figure 10: Psychologist registration page

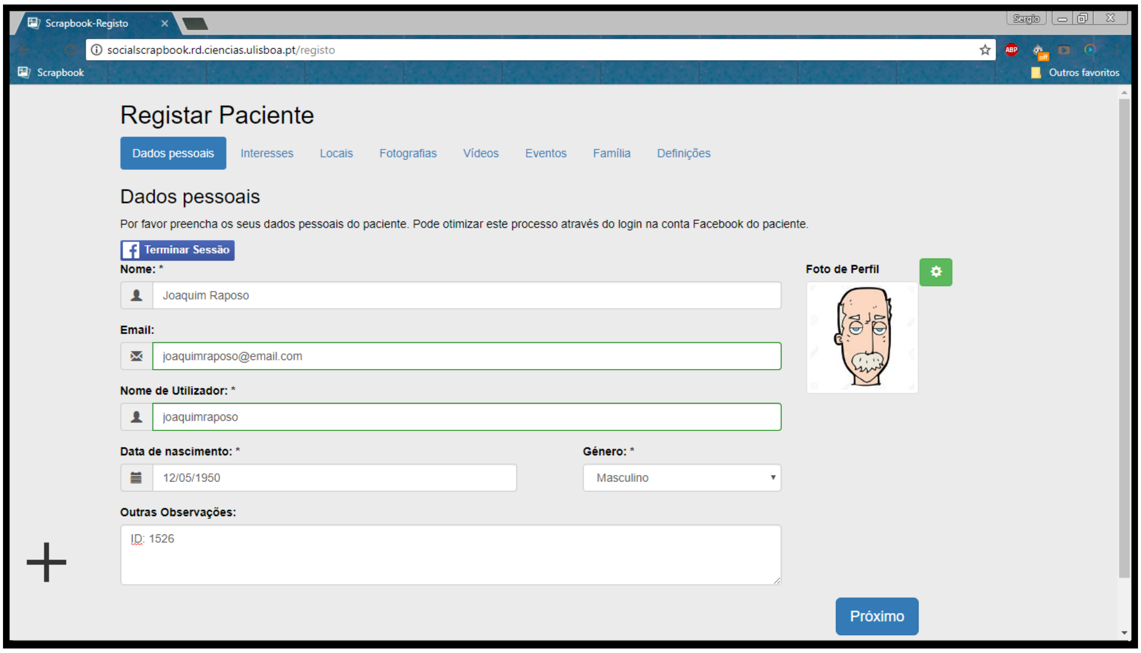
In addition to collecting psychologist’s data, the system is able to dynamically, without reloading the page, check if the entire form is well filled, if the email of the psychologist is already associated with another account and if the passwords match. In case of error a descriptive message is displayed.

Registration of a patient

Despite my intention to be able to have Scrapbook accounts for caregivers, in the context of this thesis this functionality was not implemented (we prefer to focus on more decisive details), and the only person who can register a patient is the psychologist.

The registration of a patient is probably the most important and time-consuming task for the psychologist. The complexity of this process will depend of the patient background. If the patient has no Facebook account, all the personal information must be extracted (from the patient or his caregivers) and inserted into the system by the psychologist. Otherwise, if the patient used to be an active user on Facebook and has a rich account, the psychologist role is to filter all the obtained information from Facebook, to ensure that just the relevant data for him are saved in the system. Lastly, there is the possibility to create purposely a Facebook account for Scrapbook and, this way, the work of the psychologist will be reduced.

When the psychologist clicks to login with Facebook a pop-up window will open, where the patient (or someone responsible for him) logs into his account and provides the necessary permissions for Scrapbook to be able to read all the data in his account. This will automatically fill out all the registration form of Scrapbook. When the registration process ends, for security reasons Scrapbook logs out of the patient's Facebook account in that browser.



Registar Paciente

Dados pessoais

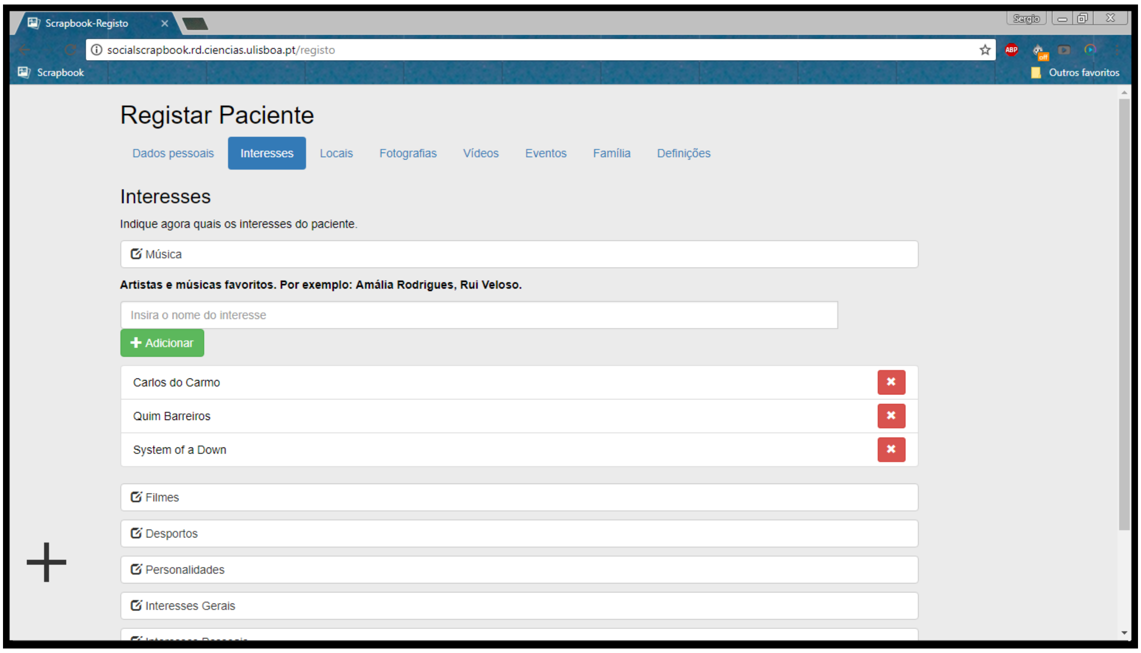
Por favor preencha os seus dados pessoais do paciente. Pode otimizar este processo através do login na conta Facebook do paciente.

Nome: * Joaquim Raposo
Email: joaquimraposo@email.com
Nome de Utilizador: * joaquimraposo
Data de nascimento: * 12/05/1950
Género: * Masculino
Outras Observações: ID: 1526

Figure 11: Patient registration page

To facilitate the task of the psychologist, the registration page is divided into several tabs. The first tab is intended for personal patient’s information, where are present the account details (such as username) and personal characteristics (such as name and date of birth).

The second tab, interests, is where most of the Facebook likes are recorded. As we can see in figure 12, the tab of interests is divided into sections. There are three reasons for this separation: make the collection of interests by the psychologist easier, thus providing a list of topics to address with the patient and caregivers; take advantage of the structure already defined by Facebook (which is similar to mine); and perform a more effective search of images and videos in the Web APIs (knowing the context of an interest is easier to filter the results).



Registar Paciente

Interesses

Indique agora quais os interesses do paciente.

Música

Artistas e músicas favoritos. Por exemplo: Amália Rodrigues, Rui Veloso.

Carlos do Carmo

Quim Barreiros

System of a Down

Filmes

Desportos

Personalidades

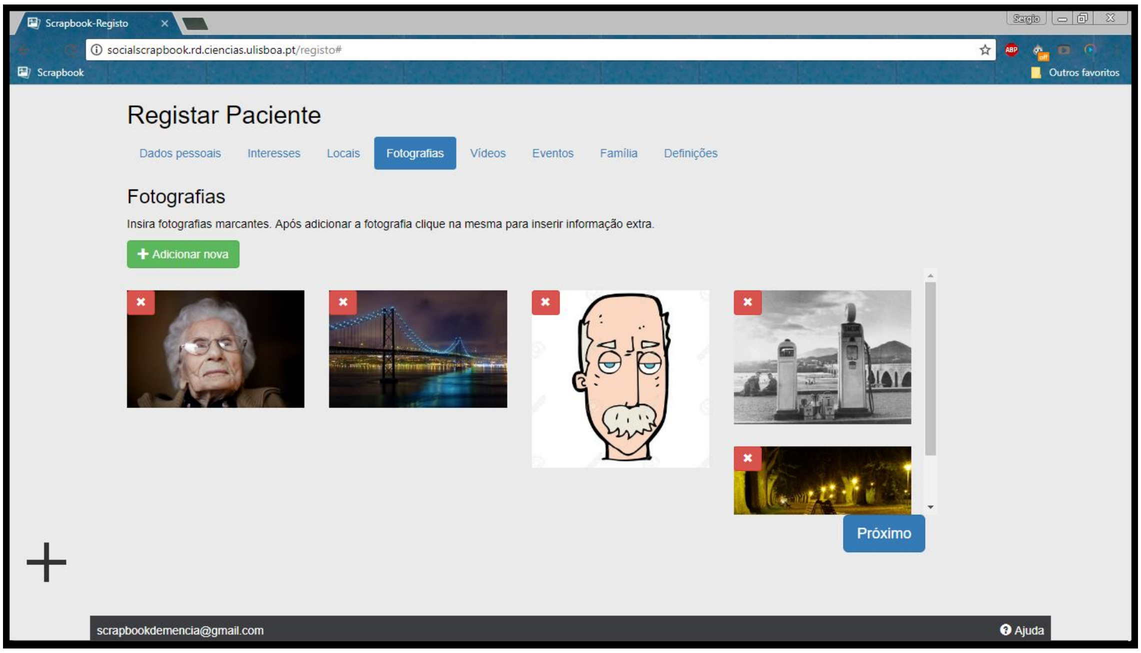
Interesses Gerais

Figure 12: Registering patient's interests

In the third tab, the psychologist inserts patient's favourite places. To facilitate the task and avoid errors, as the user interacts with the place insertion form, the system uses the Google Maps API to provide a list with more precise names, which works as a form autocomplete. Through Facebook the system automatically collects the visited places and the places where the patient lived.

The fourth (see figure 13) and fifth tabs, images and videos respectively, are quite similar. The psychologist chooses an image or video from his computer to upload to the system, and, then, he has the option of add more details about it, such as its name, location, description or date.

If the patient joined with Facebook, all his images and videos will already be in the system together with its description and date, but always with the possibility of being edited or removed. In addition, if the psychologist is using a tablet, the images can be taken and inserted automatically into the system, which facilitates the scanning process.



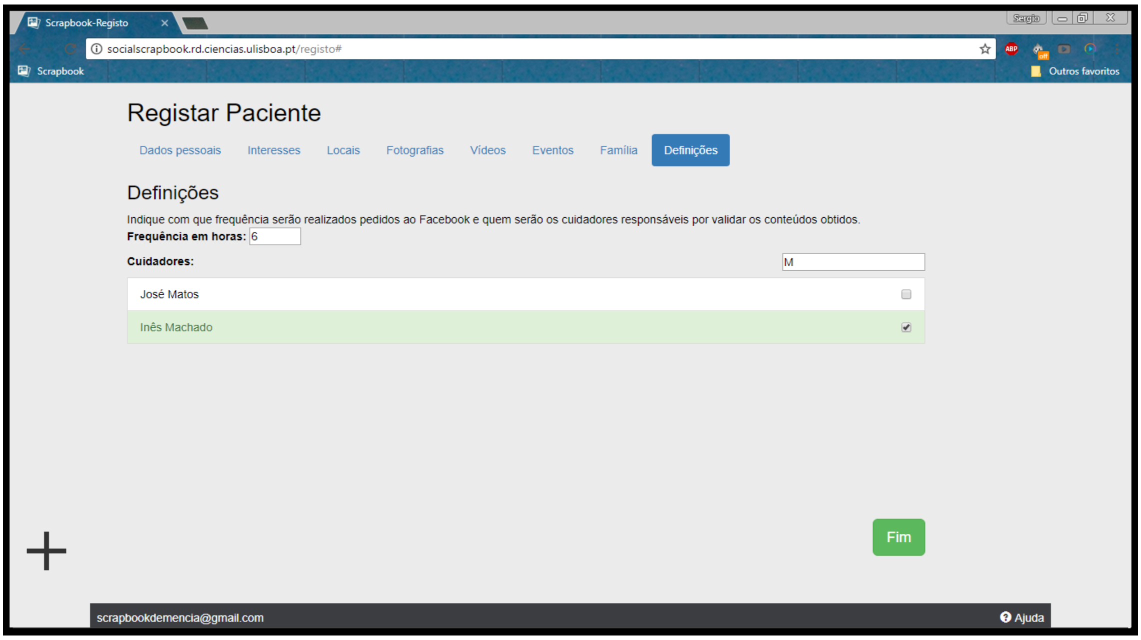
Registar Paciente

Fotografias

Insira fotografias marcantes. Após adicionar a fotografia clique na mesma para inserir informação extra.

Figure 13: Registering patient's photographs

The next tabs are events and family. The events tab is intended to Facebook events to which the patient has gone, or to events of his life, as marriage or birth of his children. Each event can have a name, description, place and date. Beyond this it can have images and videos. In the family tab, family members are registered, along with their name, and degree of kinship. If the information comes from Facebook, due to the limitations of the API, the system can only collect the relatives' profile photo, competing to psychologists decide whether to collect more images or not.



Registar Paciente

Definições

Indique com que frequência serão realizados pedidos ao Facebook e quem serão os cuidadores responsáveis por validar os conteúdos obtidos.

Frequência em horas: 6

Cuidadores: M

José Matos ☐

Inês Machado ☑

Figure 14: Defining patient's online caregivers during the registration process

Finally, there is a configuration tab (see figure 14) where the psychologist can set some things up, namely the interval between posts on Facebook or the name of patient's online caregivers.

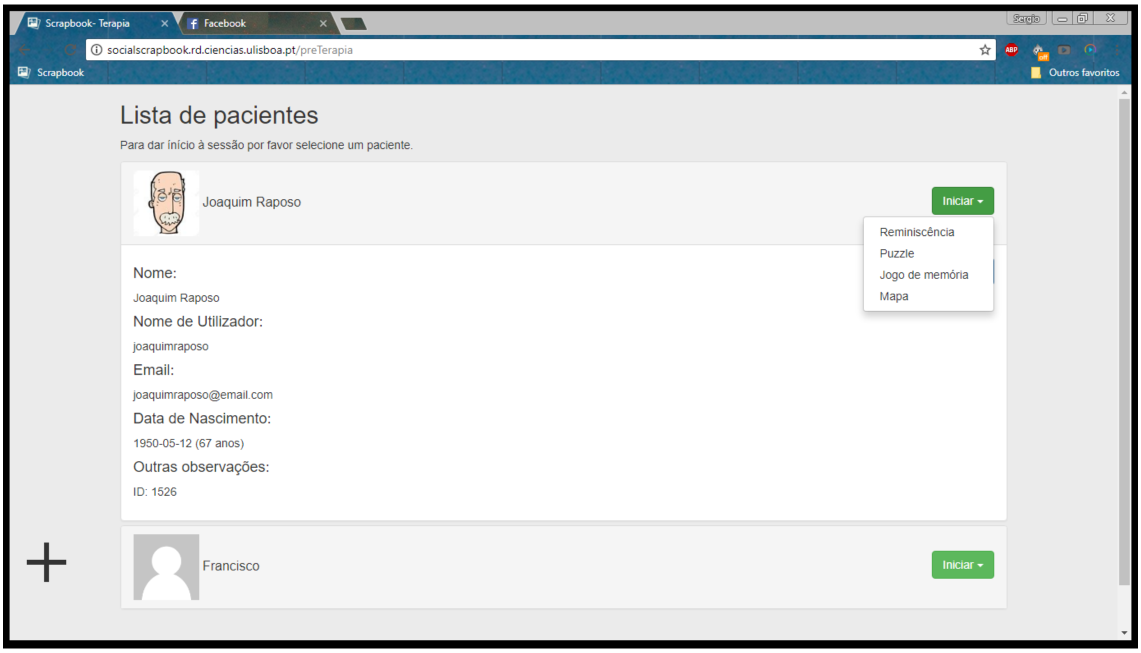
As in the psychologist registration page, the system dynamically checks if the entire form is well filled, and if the username or e-mail of the patient are already associated with another account. In case of error a descriptive message is displayed.

Preparing a session

After a psychologist registers a patient, he will be immediately associated with his account, becoming the only person who can access the information of that patient.

To perform a reminiscence therapy session, it is necessary to create a new session, which can be done in two steps. First, the psychologist selects the patient to perform the session and then the contents to use. If previous sessions have been performed the psychologist may choose to repeat it.

The screen of selection of patients can be seen in figure 15. The system presents a list (with name and image) of all patients that the psychologist has, and each item (patient) of the list can be expanded for more details.



Lista de pacientes

Para dar início à sessão por favor selecione um paciente.

Joaquim Raposo

Nome:
Joaquim Raposo
Nome de Utilizador:
joaquimraposo
Email:
joaquimraposo@email.com
Data de Nascimento:
1950-05-12 (67 anos)
Outras observações:
ID: 1526

Figure 15: Screen for selecting a patient to create a session

After selecting the patient, it is time to create the session. To create a session, the system presents to the psychologist three lists of contents (images, videos and texts) to use. Since I wanted to guarantee that this process was as simple and fast as possible, there are some features to help the psychologist in his task.

This way, as you can see in figure 16, there is a filter in the upper left corner (expanded in the figure) that allows the user to filter the contents by category (interests, places, etc.), remove contents that caused a negative reaction in the patient, and remove previously viewed contents. Besides this filter, there is still the option to group all the contents about the same theme, or to obtain more contents from the API about that theme.

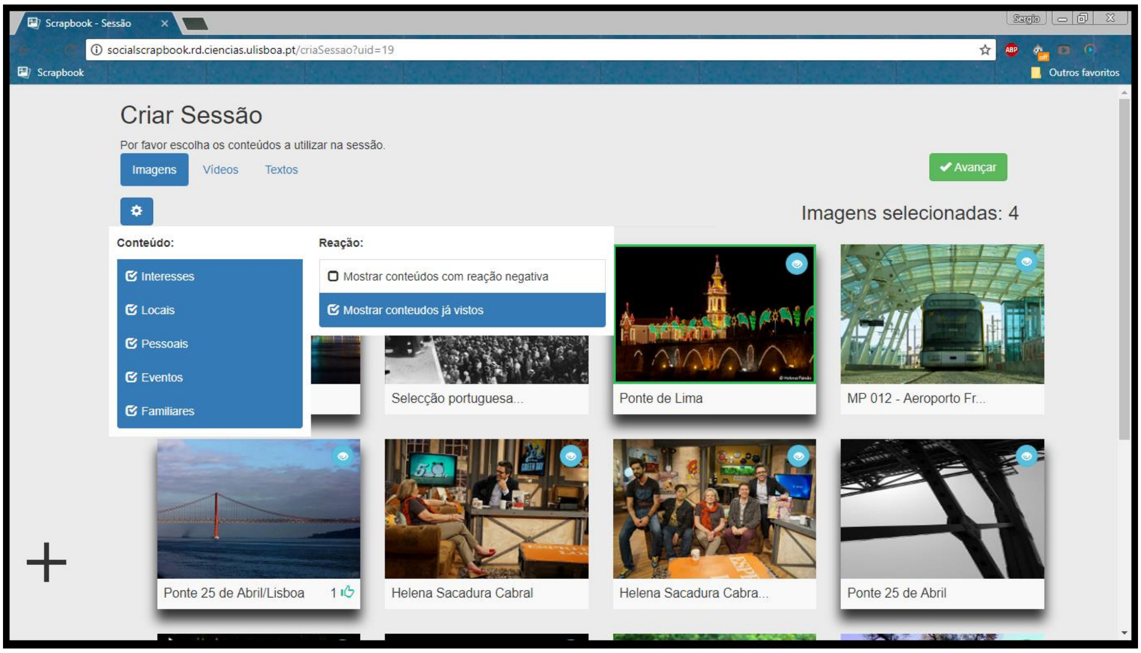
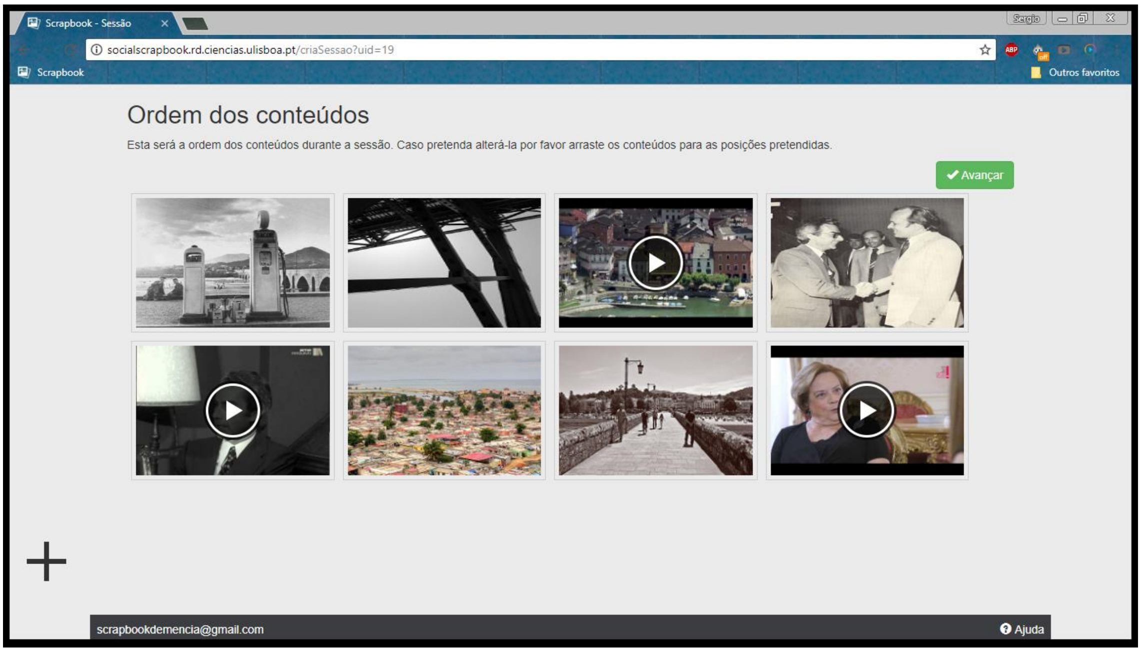


Figure 16: Screen for selecting contents to use in a session

Additionally, the psychologist can review the feedback he gives during the sessions, such as patients’ reactions (green or red box around the content) and notes (through a button present in contents with notes). If a content has been validated on Facebook, there is a special icon that indicates if the content was approved and by how many people.

Finally, when the psychologist selects a content, a shadow appears around the box of the content indicating that it was selected.

After selecting the contents for the session, the psychologist just need to set the order in which the contents will be displayed, as seen in figure 17.



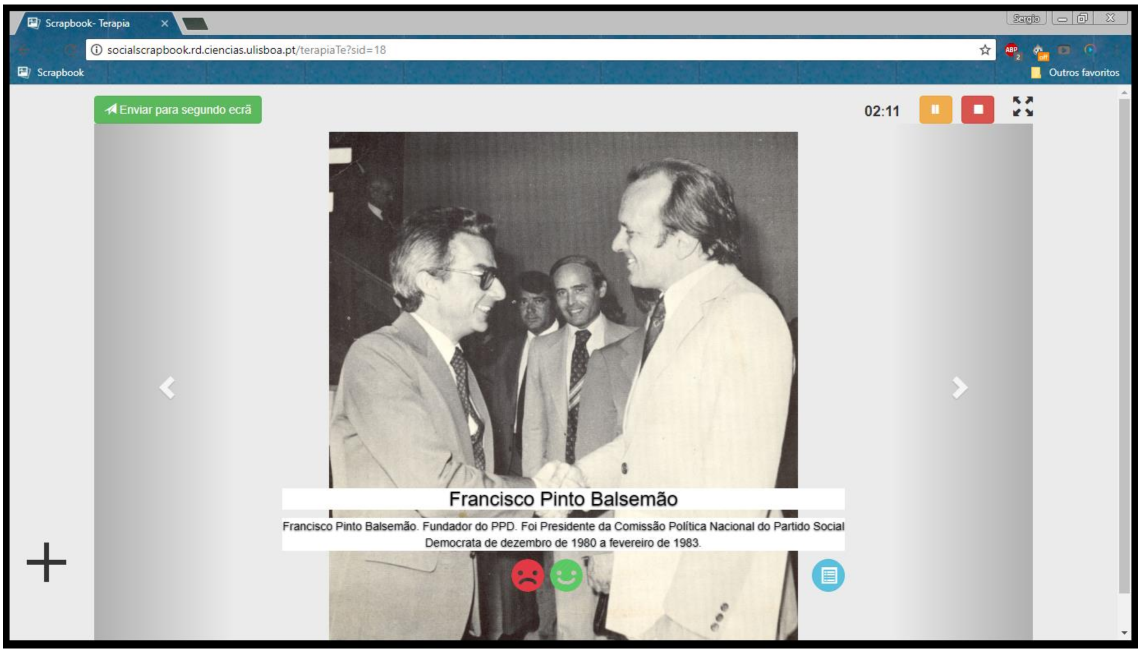
Ordem dos conteúdos

Esta será a ordem dos conteúdos durante a sessão. Caso pretenda alterá-la por favor arraste os conteúdos para as posições pretendidas.

Figure 17: Screen for defining the order of presentation of contents during the session

Performing reminiscence therapy

When everything is ready, the psychologist can start the session. Scrapbook design advises the use of two monitors to perform a session, in which each monitor presents a different page.



Francisco Pinto Balsemão

Francisco Pinto Balsemão. Fundador do PPD. Foi Presidente da Comissão Política Nacional do Partido Social Democrata de dezembro de 1980 a fevereiro de 1983.

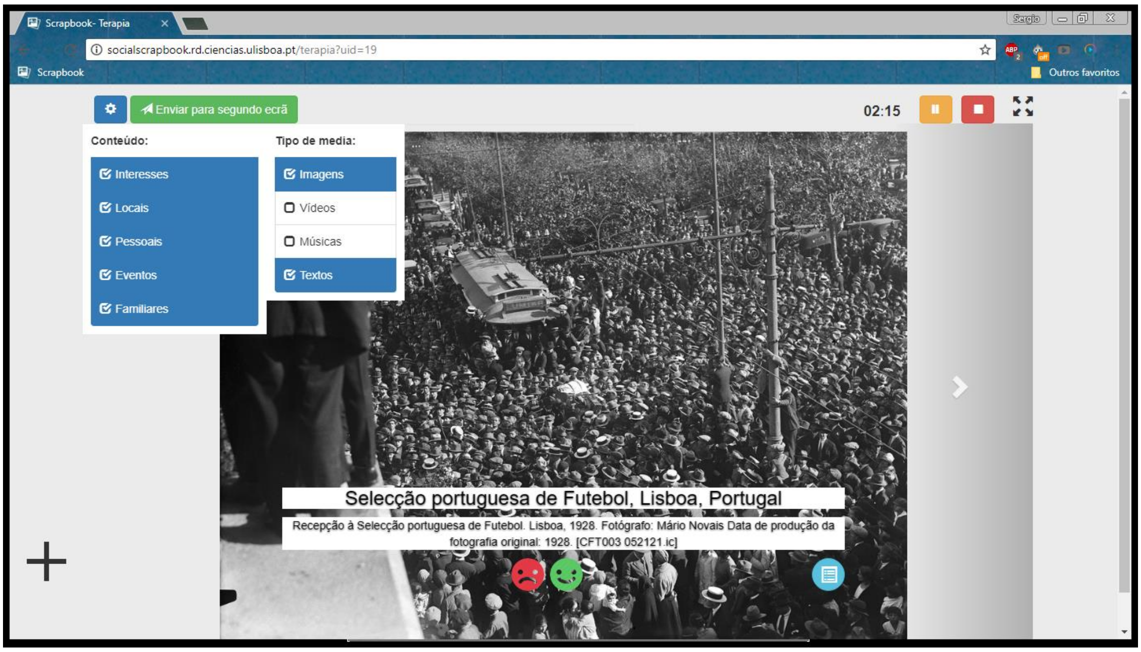
Figure 18: Psychologist screen during a reminiscence therapy session

The first page, presented in figure 18, is destined to the psychologist and allows the control of the session. It shows the elapsed time of the session and the respective pause/play and stop buttons, as well as the option to switch the content that is being presented. It also displays the name and description of the content being presented, and allows the psychologist to record the patient's reaction, either through the reaction buttons or through the note.

To open the second page/screen, the psychologist should click the "open second screen" button. A new tab of browser is opened and the psychologist must drag it to the second monitor. This second page, that should be used in full-screen mode, is connected and synchronized with the first one, and its only function is to present the content to the patient. This simplicity prevents the patient from being distracted during the course of the session.

Figure 19: Patient screen during a reminiscence therapy session

Alternatively, the psychologist may choose to skip the session creation process, in which case a session will be performed with all the available contents for that patient. The psychologist has always some control over the presented contents, since there is a filter (expanded in figure 20), similar to session creation filter, that allows filtering the type of presented contents.



Selecção portuguesa de Futebol, Lisboa, Portugal

Recepção à Selecção portuguesa de Futebol. Lisboa, 1928. Fotógrafo: Mário Novais Data de produção da fotografia original: 1928. [CFT003 052121.ic]

Figure 20: Screen of a reminiscence therapy session without a prior session creation

Map

Besides reminiscence therapy, the psychologist has the option to perform other activities with a patient. One of that alternatives is the map page. In this page, the psychologist can navigate through various relevant monuments (collected through the Foursquare API), for each one of patients' favourite places. Additionally, the psychologist can search for a specific location to navigate.

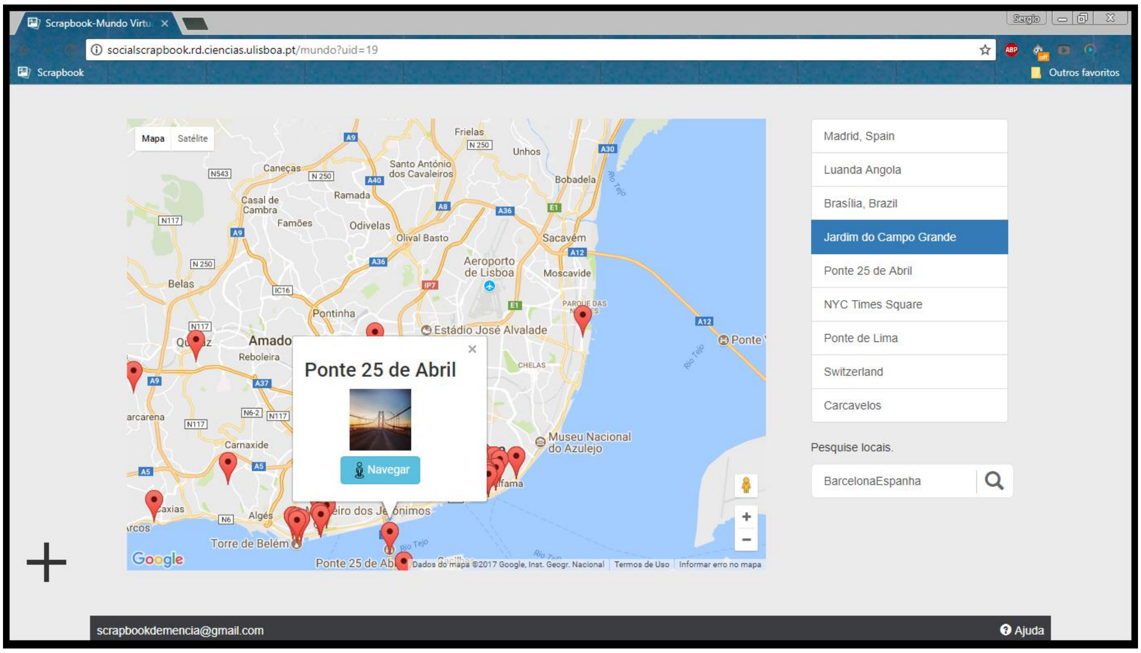


Figure 21: Map screen where it is possible to navigate through relevant monuments

Cognitive stimulation games

Another contribution from my work are the cognitive stimulation games with autobiographical and personalized contents. The system provides two types of games: jigsaw puzzle and memory flashcards.

The workflow to create a game session is similar to the creation of a reminiscence therapy session. First, the psychologist selects the patient and then the contents to use in the game. In the case of the jigsaw puzzle, an image is divided into several pieces and the patient has to drag and drop the pieces to the correct positions. Although not yet in practice, the implementation of the puzzle is prepared to have different levels of difficulty according to patient's ability.

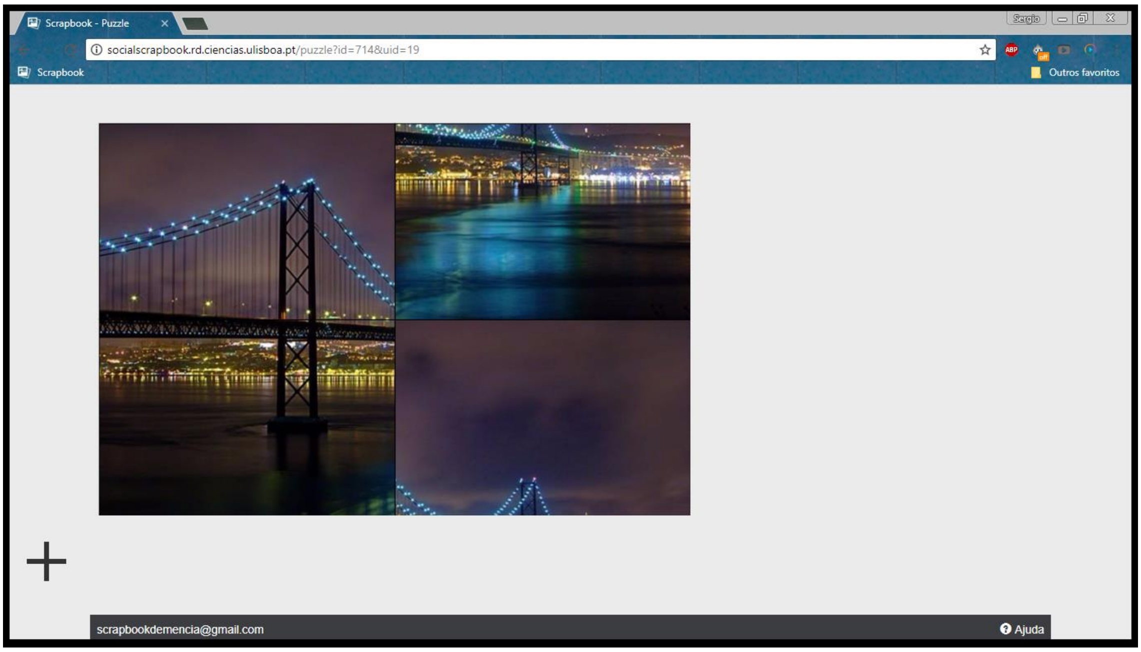


Figure 22: Screen of jigsaw puzzle game

In memory flashcard game, the psychologist can select the number of images that he understands appropriate for the patient. The more images, the more difficult the game becomes. In this game images are hidden (turned upside down) and the goal is to flip the images one by one until the patient finds all the pairs of images.

Tente encontrar todos os pares de imagens existentes.

Figure 23: Screen of memory flashcard game

Reminiscence therapy statistics

One of the expectations of psychologists, is to have something that allows them to evaluate the evolution of the disease and the results of the sessions. Thinking about these needs, the statistics page appeared.

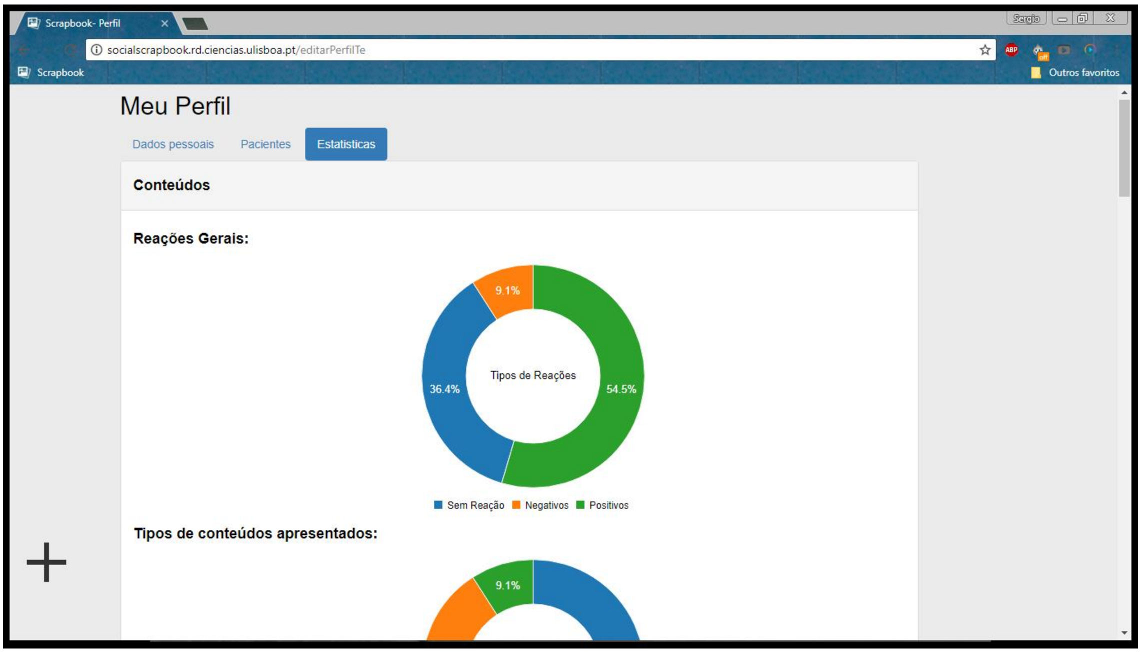


Figure 24: Psychologist statistics about patients' reactions

The statistics are present in two pages: the patient profile and the psychologist profile. The statistics can be about the contents used in the session, or about the session itself. In the first case, the system analyses the patient's reactions in function of the types of media and types of contents. In the second case, the system shows the evolution of the sessions, such as the evolution of the session duration or the patients' reactions over time.

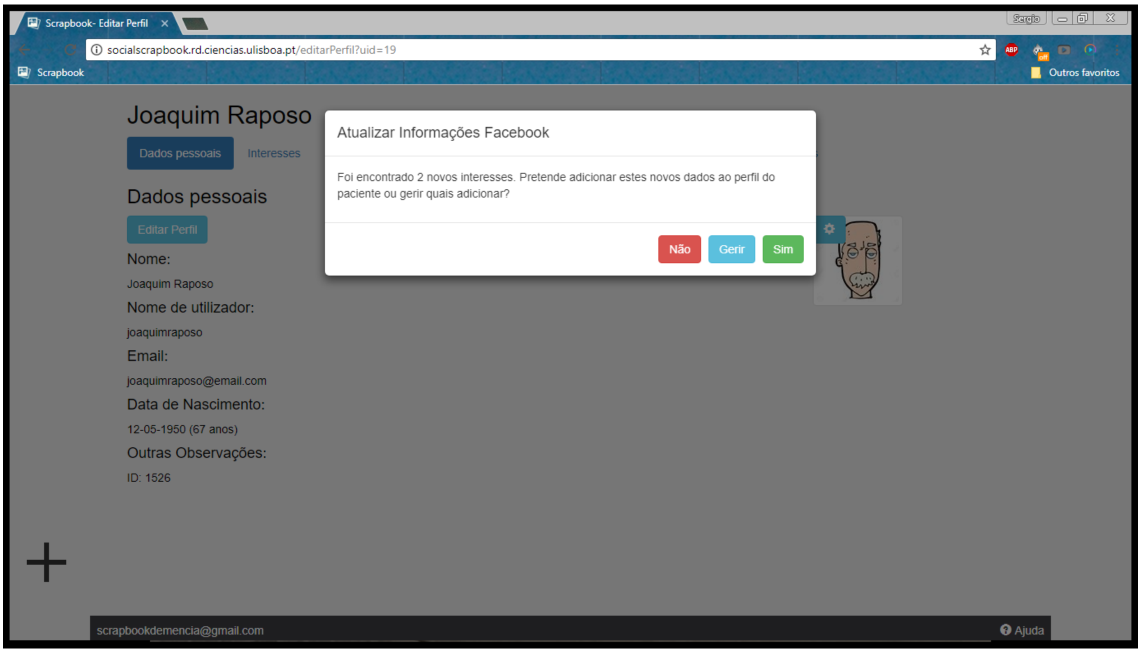
Statistics can be viewed through pie charts, line charts or tables.

Profile settings

The system has all the usual features of a profile edition page, which are available for both, the psychologist and the patient, but in addition the patient's profile edition page provides important features to the psychologist.

Here, the psychologist can manage all the contents and information, initially collected about the patient. This means that whenever the psychologist finds a new interest or place can add it, or if realizes that one of the interests inserted before is not interesting enough can remove it from patient's profile. This way, the psychologist will never be limited in his work by the patient's information inserted initially.

As you can see in figure 25, another important functionality, is the Facebook information update. As soon as the psychologist enters the patient profile page, the system checks for changes in patient's Facebook profile, such as new likes or photographs, and gives to the psychologist the option of choose which new contents to add or reject. Regardless of the option, the psychologist can at any time review the rejected information and add it.



Joaquim Raposo

Dados pessoais

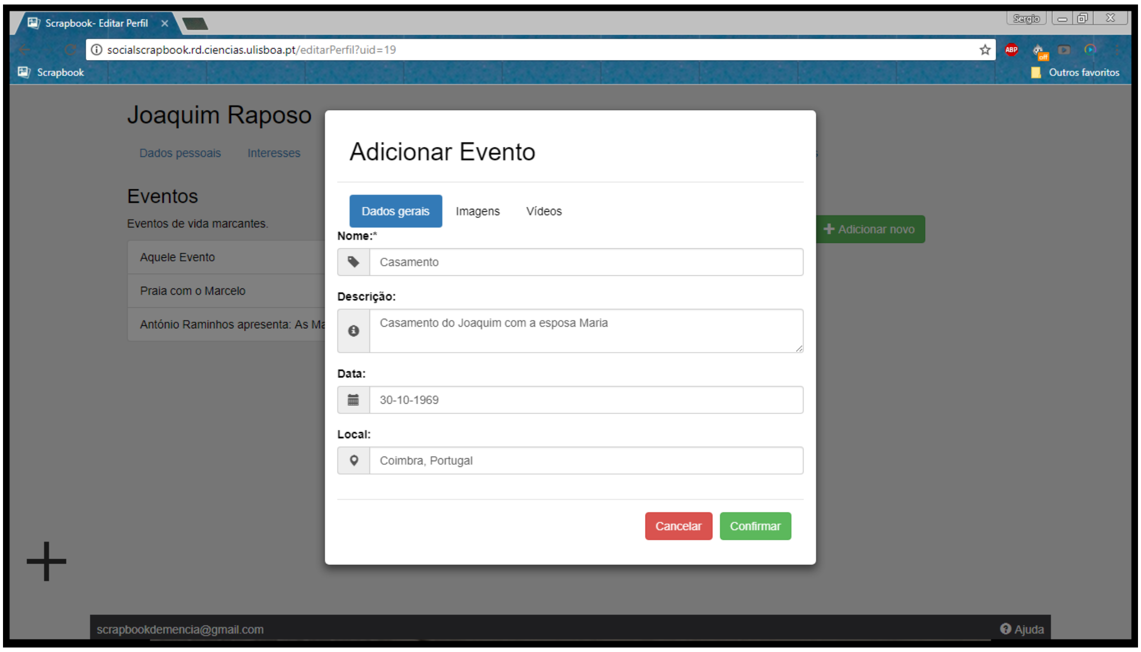
Nome:
Joaquim Raposo
Nome de utilizador:
joaquimraposo
Email:
joaquimraposo@email.com
Data de Nascimento:
12-05-1950 (67 anos)
Outras Observações:
ID: 1526

Atualizar Informações Facebook

Foi encontrado 2 novos interesses. Pretende adicionar estes novos dados ao perfil do paciente ou gerir quais adicionar?

Figure 25: Pop-up window alerting psychologist about new Facebook activity

It is also possible to add and edit events (see figure 26), relatives and Facebook settings.



Adicionar Evento

Nome:* Casamento

Descrição: Casamento do Joaquim com a esposa Maria

Data: 30-10-1969

Local: Coimbra, Portugal

Figure 26: Psychologist adding a new event to patient's profile

4.3 Implementation details

Behind what user sees, and the shown in the previous section, there is also a lot of work. Choice of technologies to use, concerns about the interface, background jobs, and data security are also part of my project and will be discussed in this section.

4.3.1 Used technologies

Once there was no budget available for this thesis, my goal was to keep the cost with necessary hardware and software as low as possible. Therefore, paid third-party services, despite some of them may increase the quality of my work, were not considered. This means that all used technologies are open source and free, which includes the tools used in the development process, programming languages and third-party services.

Beyond cost, it was necessary to consider other factors, namely my degree of knowledge about the technologies, the learning curve of them, the available documentation and the hardware limitations.

Back-End technologies

Regarding the back-end, used technologies are PHP and MySQL. These technologies are used along with the framework Laravel[14]. Laravel is a free, open-source, PHP web framework for the development of web applications, which was chosen mostly because

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[14] https://laravel.com/

it follows the architectural pattern model–view–controller (MVC), and ensures some important security features. Unfortunately, due the limitations of the shared host, I used an old version: 5.2.

Beyond programming languages, external APIs play a key role in Scrapbook. They are largely responsible for collecting the contents that are presented to users. The used APIs are:

- Facebook Graph API, to get personal information about a patient;
- Flickr API, to collect images;
- YouTube API, to collect videos;
- Google Maps API, to fill out forms that require location and to perform navigation in street view mode;
- Foursquare API, to get important monuments of a city.

Front-End technologies

The front-end is richer when it comes to used technologies. HTML5 is used for structuring and presenting the page content, CSS3 to define the page layout and JavaScript to provide the necessary dynamism to the webpages. To help me with the website design, I used a front-end framework: Bootstrap[15].

As fundamental part of my project I also used some JavaScript libraries, namely D3.js[16] and C3.js[17] (to generate charts), intro.js[18] (to perform the step-by-step guide of website) and jQuery[19] (to manipulate HTML elements and to make Ajax requests).

4.3.2 Interface concerns

Like any other quality web platform, it was necessary to take great care with the design of the interfaces, the organization of pages and the navigation menus. To provide the best user experience possible, my goal was to ensure that the Scrapbook had four key features, namely usability (is it easy to use?), value (is it useful?), adoptability (is it easy to start using?) and desirability (is it fun and engaging?).

As Scrapbook has a well-defined set of users and use case scenarios, I found it important to explain some of my decisions.

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[15] http://getbootstrap.com/

[16] https://d3js.org/

[17] http://c3js.org/

[18] http://introjs.com/

[19] https://jquery.com/

Responsive design

One of the requirements initially defined, even before interviewing the psychologists, was to produce a platform with a responsive design. The goal, is for the Scrapbook to be used by the psychologist on a tablet connected to an external monitor. The use of a tablet allows:

- An increase of the psychologist's privacy and a decrease of the possible distractions of the patient, once the psychologist can take his notes discreetly on his tablet, or consult the description of the content that is being presented without the patient seeing it;
- An approximation between psychologist and patient, since the physical barrier caused using a computer connected to another monitor disappears;
- A greater mobility of the psychologist, who can thus move to meet the patients, often with reduced mobility, to perform the session (in this case only the tablet will be used);
- Upload photos to patients' profile taken at the time with the tablet camera.

This means that the platform should be fully optimized to run in a tablet. Furthermore, not all institutions or psychologists have a tablet available, and the platform should also work properly on a computer screen, regardless of screen size.

Consequently, all the pages are optimized to run on any screen. Figure 27 shows the behaviour of the patient registration page, relative to the different devices and screen sizes.

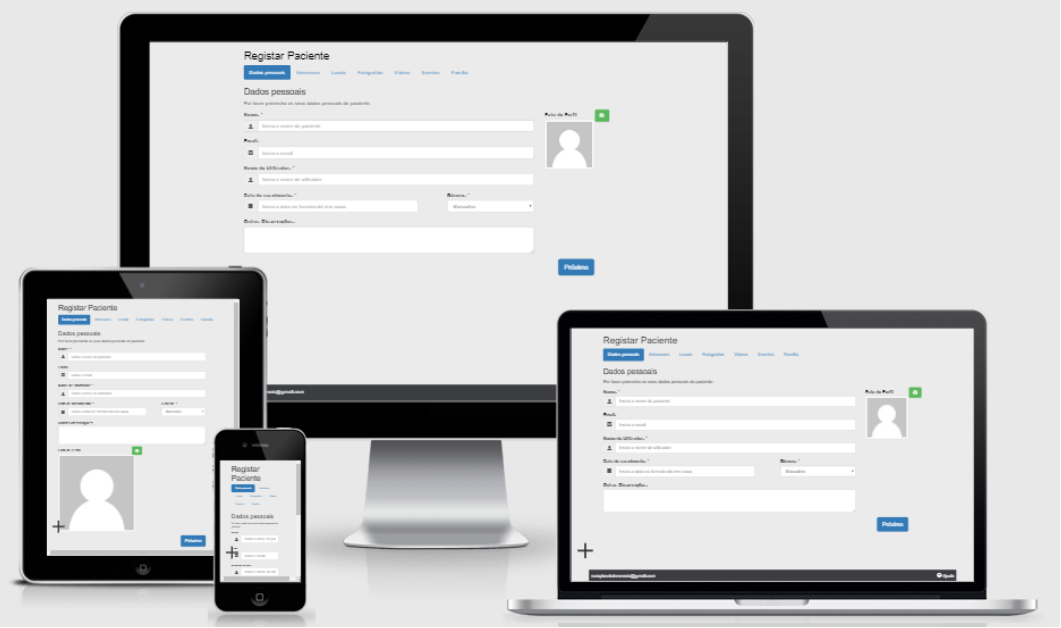


Figure 27: Responsive design of Scrapbook (provided by http://ami.responsivedesign.is/)

Usability concerns

In addition to the concerns with the responsive design, that by itself already guarantees a greater usability (avoiding for example that it is necessary to do horizontal scroll to see all the content of a page), there are other characteristics of the platform that intend to increase the usability.

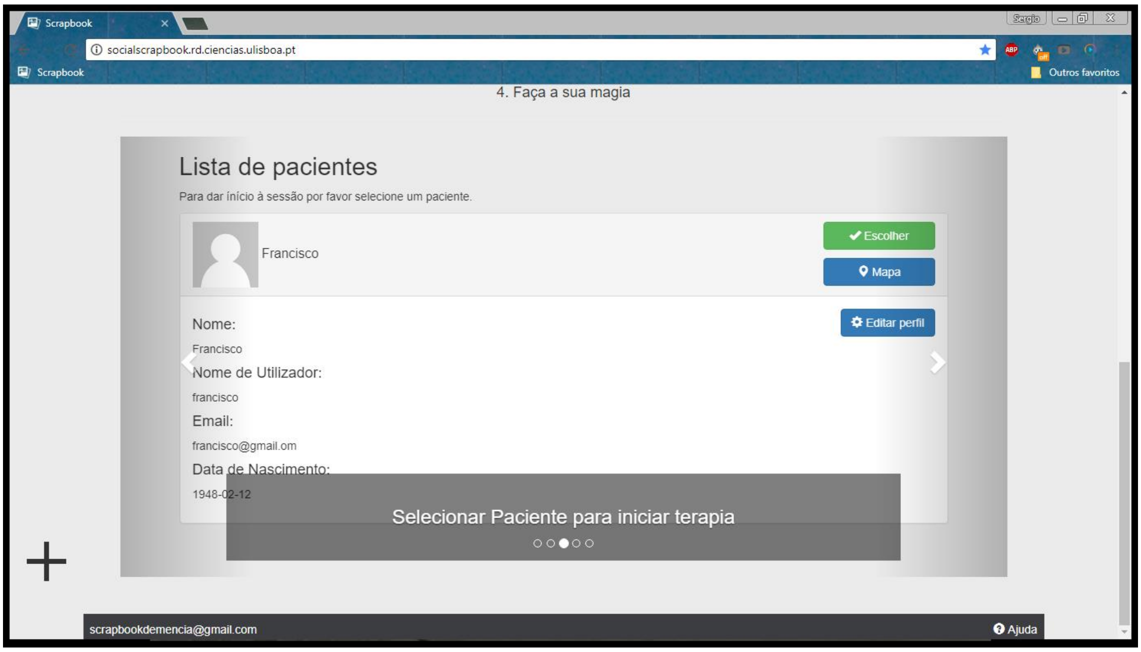
In general, the goal was to keep the interface as simple and intuitive as possible, avoiding unnecessary elements and texts. The background is light grey, the text is black and the text boxes are white. The colour of the buttons varies according to the action provided by it. For example, a button that leads to a cancel or remove action is red and one that represents an add action is green.

To make it more intuitive and easy for the psychologist to perform the intended action on the page, these are often divided into tabs, each one with its theme and, generally, containing elements that can be expanded for more details. This visualization of the details can be done through an accordion (see figure 15) or a modal (dialog box/pop-up window).

When creating a session or defining the contents for a game, the psychologist is dealing with a lot of images, videos and texts. To avoid chaos on the page and increase the loading time of it, only twelve contents of each type of media are displayed. If he wants to see more, must click on the "Load more” button at the bottom of the page to load eight more contents. In addition, there is the possibility of filtering the contents by its category.

The session creation page, has another important detail. Since twelve videos are initially embedded, the page load time was enormous. To drastically reduce the loading time, and prevent the user from waiting too long, I just embed on the page a thumbnail image of each YouTube video, and the actual video is loaded only when the user manually clicks the thumbnail to play the video.

Also fundamental is to guarantee that users know all the features of Scrapbook and never get lost. To do that on the homepage is presented a slideshow with the mode of operation of the platform. In addition, the "help" option is always present in the footer of all pages, and provides a step-by-step guide from that page. Part of the homepage can be seen in figure 28.



4. Faça a sua magia

Lista de pacientes

Para dar início à sessão por favor selecione um paciente.

Francisco

Nome:
Francisco
Nome de Utilizador:
francisco
Email:
francisco@gmail.om
Data de Nascimento:
1948-02-12

Selecionar Paciente para iniciar terapia

scrapbookdemencia@gmail.com

Figure 28: Part of Scrapbook homepage

Finally, I always tried to keep the menu simple, intuitive and without taking up too much space. To open the menu the user just need to click on the button “+” visible in figure 28. The menu itself (see figure 29) does not contain text and is all made up of icons. However, on mouse hover the item name is displayed (option only available on a computer) or, alternatively, the user can see a description of the menu through the "help" option.

Bem-vindo ao Scrapbook!!!

Uma plataforma de excelência no apoio ao combate à demência

Como Funciona?

1. Registe-se

2. Adicione os seus pacientes

Figure 29: Scrapbook menu

4.3.3 Background jobs

An important part of Scrapbook work is done in background, even if the user is not using the platform. Either because the job characteristics so require, or to avoid the waiting time of user, background jobs are essential for the smooth operation of the platform.

The creation and management of jobs is greatly facilitated by the use of Laravel. Jobs are stored in a database table, which acts as a queue, where jobs are being read and performed by a queue listener, running in background, as they are added. When jobs are done, they are immediately taken from the jobs table. If an error occurs during the realization of a job, it is recorded in the `failed_jobs` table.

Registration job

Registering a patient is a rather complex task. In addition to registering the personal data (name, date of birth, etc.), the system must store all interests, favourite places, events, family, images and videos of patients. For each interest and favourite place of the patient, the system collects three videos and three images, so that the more information gathered about the patient, the longer the operation will take.

To prevent users from waiting for the entire registration operation end, the registration process has been divided into two steps. First, the system stores the user's personal data and, then, with the user id that is returned after the first operation, a job to store the remaining patient information is added to the jobs queue. Meanwhile, the user leaves the patient registration page, and the queue listener detects the existence of a new job in the queue and executes it.

In addition to inserting patient photos, videos, events, and relatives, the job must connect with Flickr API and YouTube API to collect images and videos of places and interests. If that interest or location is already stored in the database, also the respective images and videos are, and there is no need to go get more images and videos about that theme. Otherwise, three images and three videos are collected for each theme.

If at first sight the process of video collection is simple, and the results obtained are satisfactory, the same could not be said about the images. Due to lack of monetary funds, the choice of the image collection API turned out to be the Flickr API. The search query is composed by the name of the interest or place, and to improve the results the search parameters had to be carefully defined. First, it is requested that the results are sorted by relevance, and then is applied a filter by the image tags. Images with the tags pintura, design, drawing, best friend, love or amor, are immediately excluded from the search query.

After performing the search and obtained the results, images are filtered again, this time by a filter created by me. The first criterion I consider is the number of tags. If an image has no tags or if it has too many tags, there is a great risk of not being an appropriate image for Scrapbook, and it is immediately excluded.

Next, there is an array of tags for each type of interest that is compared to the tags of the image. For an image to be accepted, at least one of the tags of the array must be present in the tags of the image. For example, if the system is looking for a music interest, it will check if tags like show, artist, festival, music, musician or singer are among the image tags.

This, despite making the process more time consuming and limiting the number of results, increases their quality.

It is important to note that the system stores only the URLs of the images or videos that come from Flickr, YouTube or Facebook, and that only contents inserted manually by the users are stored on the Scrapbook server.

More contents job

Another similar job is created when the patient reacts positively to a content. In this case, the system, in background, will get another image and video about the same theme of that content. The only difference from the previous search is that it must be checked whether the returned content already exists in the system.

Facebook job

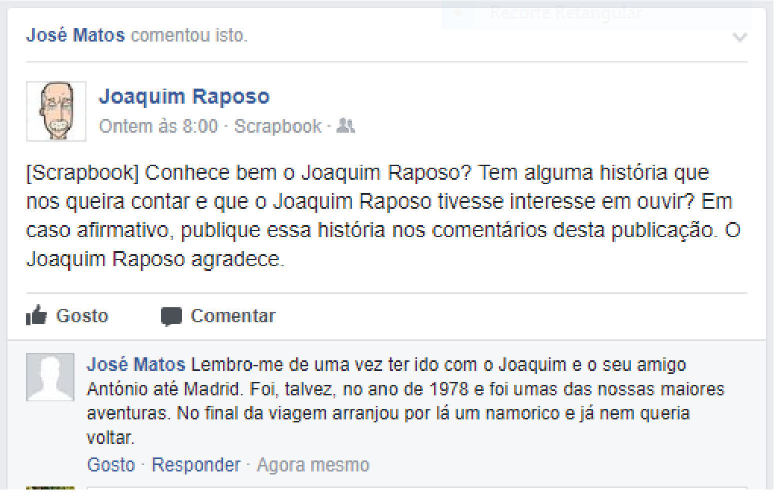
The most complex and innovative part of the system is probably the interaction with Facebook. The link with Facebook goes much further than the initial collection of data for registration.

During the patient's registration, is saved the id and access token of the patient’s Facebook account, the name of home online caregiver (or caregivers), and the interval between Facebook posts. With this information, Scrapbook will carry out posts on patient’s Facebook in search of more data about the patient.

To create posts and collect the replies the system:

1. Goes to the database collects all patients with Facebook and checks if it is time to make a new post (according to the interval defined in the patient registration). If yes, it proceeds to step 2;
2. Chooses what type of post it will do and performs it;
3. Stores the type of the post, the id and the creation date into the database;
4. Checks, during one week, if there are new replies to the inserted post.

The purpose of these posts is to validate with the caregivers the contents used in the sessions, and to allow the collection of more autobiographical and personalized contents. These goals lead to three types of posts. The first one aims to collect patient’s life histories. To do this, is asked to patient’s friends if they have histories about the patient that they want to tell. This is the only way that the system has to collect texts to use in reminiscence therapy. Along with the text is also stored into the database the text author.



José Matos comentou isto.

Joaquim Raposo
Ontem às 8:00 · Scrapbook ·

[Scrapbook] Conhece bem o Joaquim Raposo? Tem alguma história que nos queira contar e que o Joaquim Raposo tivesse interesse em ouvir? Em caso afirmativo, publique essa história nos comentários desta publicação. O Joaquim Raposo agradece.

José Matos Lembro-me de uma vez ter ido com o Joaquim e o seu amigo António até Madrid. Foi, talvez, no ano de 1978 e foi umas das nossas maiores aventuras. No final da viagem arranjou por lá um namorico e já nem queria voltar.
Gosto · Responder · Agora mesmo

Figure 30: Facebook post to collect life histories

Another type of post, is the one that collects images of interests or places. Initially, friends are asked to provide images about the interests or places for which the Scrapbook image collection engine did not found any results. This way, the goal was to ensure that all interests and locations have at least one image available. When all interests and places have at least one image, the Scrapbook tries to validate the images it already has (collected from Flickr) with the caregivers and to obtain new images, preferably autobiographical (such as a patient's image in a given place).

José Matos comentou isto.

Joaquim Raposo
15/7 às 2:00 · Scrapbook ·

[Scrapbook] Reparamos que o Joaquim Raposo pode ter interesse em imagens sobre "O Pátio das Cantigas". Tem alguma imagem sobre este interesse que o possa ajudar? Em caso afirmativo, insira essa imagem nos comentários desta publicação. O Joaquim Raposo agradece.

José Matos https://cdn-images.rtp.pt/.../ima.../15064_36535_6873.jpg...

Figure 31: Facebook post to collect new images

Finally, the Scrapbook also tries to collect more images about themes to which the patient has reacted positively. For this, the image to which the patient reacted is presented in the post and the friends are asked to comment with similar images.

Choosing the post to do is a matter of probabilities. Once it does not make sense to be asking every day for new histories, a post in search of histories has a very low probability of being made (that is why it is performed immediately at the beginning). With respect to posts to request images, the probability of being about a random interest, or place, or about one to which the patient has reacted positively is the same. Initially, it was debated whether it would not be best to give priority to obtaining images about themes to which the patient reacted well, however, in my opinion, the fact that the patient did not react to an image of a particular theme could mean that the images for that theme are of poor quality, or that there is simply no image for that theme, so I think it is a good option to ask to patient’s friends for help in searching for these images.

Whenever this process of interacting with Facebook is carried out (hourly) and, according to the psychologist's definitions, it is time to create a new post, the system also reads the replies of friends to previous posts. This collection of replies to old posts is only carried out for a week, so from that time the replies are no longer checked. To prevent inappropriate histories and images from reaching the psychologist's hands, only replies given by one of the caregivers, or that one of them liked, are considered. So that the psychologist can perceive the relevance of a content, it is presented during the creation of a session the number of likes that a given content had.

There are three types of replies to posts. A text, when the request is a history, and an image (inserted as an attachment) or a link to an image, when the request is an image. When the responses are different from the expected, Scrapbook replies to the comment telling the person the correct way to do it, as can be seen in figure 32.

[Scrapbook] Reparamos que o Joaquim Raposo pode ter interesse em imagens sobre "Bacalhau com natas". Acha que esta imagem pode ser útil? Em caso afirmativo, dê um gosto nesta publicação. Caso tenha outra imagem sobre este interesse que o possa ajudar pode insira-la nos comentários desta publicação. O Joaquim Raposo agradece.

José Matos Adoro um bom bacalhau com natas!

Joaquim Raposo Pedimos desculpa mas o Scrapbook não conseguiu detetar nenhuma imagem neste comentário. Se pretende adicionar uma imagem por favor clique em "Anexar uma foto ou vídeo" ou faça um comententário que contenha apenas o endereço da imagem. Obrigado.

Figure 32: Facebook comment response

The biggest advantage of this interaction with friends on Facebook, besides the increase in the amount of contents about a patient, is the fact that the contents that reach the hands of the psychologist have already been validated by humans and their quality is probably high. Apart from these practical aspects, I also wanted to bring the patient's friends closer to the patient himself, ensuring that they do not forget him.

In addition to these posts, is also performed a post at the time of patient registration, which explains to friends the operation of Scrapbook and stresses the importance of their replies to the posts.

4.3.4 Privacy issues

The security of Scrapbook is one of my concerns. This aspect assumes a special relevance once I am dealing with sensitive medical records. The private and clinic information of the patients, their interests, life events and personal images or videos need to be completely secure against eavesdropping attempts. To guarantee the data privacy, confidentiality and integrity two steps were taken.

First, I protect the data stored in the database by encrypting all the sensitive data. Values are encrypted using OpenSSL and the AES-256-CBC cipher. Furthermore, all encrypted values are signed with a message authentication code (MAC) to detect any modifications in the encrypted string. Additionally, the passwords are never saved, but rather a hash of it. These functionalities are in part provided by Laravel framework.

Second, I got to keep the uploaded files of the users, namely images and videos, protected from unauthorized access. To do that, all the files saved on Scrapbook server are encrypted. This means that every time a user uploads a file it is encrypted and saved, and every time the file is used it is decrypted and presented. The encrypt/decrypt process is made in PHP using OpenSSL, as a PHP extension, and the used algorithm is the symmetric AES-128-CBC.

Beyond this, I take into consideration other security aspects during the design of the system. Every input that comes from the user is validated (even coming from Facebook), in order to avoid attacks such as Cross-site scripting (XSS) or SQL injection.

Chapter 5

Evaluation

The evaluation of Scrapbook is a fundamental part of this thesis. In this chapter I will present the characteristics of the studies carried out, as well as their results. These results will demonstrate if Scrapbook is really useful to help psychologists in the fight against dementia and if our goals were achieved.

First, I will present the results of two preliminary interviews with two different psychologists, and, after, two studies which were carried out separately, that intend to validate the platform. Finally, there is a discussion section where the results of the studies are commented.

5.1 Preliminary assessments

During the requirements analysis phase, two informal interviews were performed, with two different psychologists, with the main goal of validate the concept of the platform with its main users.

The first interview was performed at Faculdade de Ciências da Universidade de Lisboa with a psychologist, paused of her professional activity, but with experience in dealing with people with dementia and in performing reminiscence therapy. This was the first time we tried to validate the concepts of the platform and, although the analysis of the related works made us confident about them, everything had to be very well considered.

In the first part of the interview we wanted to understand how reminiscence therapy was actually performed, and to obtain confirmation that certain functionalities would be truly useful for psychologists. In this first part, we realized that in fact no tool was used by the psychologists, and that features such as having notes and statistics about the contents, or have a schedule of session with the patient would be useful.

The second part of the interview consisted in presenting, although we are still at an early stage of the project, a functional prototype of Scrapbook. The first impression was good, and the psychologist seemed to marvel with the idea, however during the demo some natural concerns appeared.

Our initial idea for the platform would be to present all the contents available to the patient in an infinite slideshow carousel, and the only possible control of the presentation by the psychologist would be to filter the type of the contents to be presented (as seen in figure 20). This idea was immediately disapproved by the psychologist, who indicated that all contents should be previously validated by the psychologist before being used in the session in order to avoid any negative reaction of the patient. She also mentioned that a home session could be performed by a caregiver, but that all the contents used in that session should be chosen by the psychologist. Due to this requirement, we decided that the best solution would be to have a pre-selection of contents to be used in the session by the psychologist, which also attenuates the fact that some images collected from the Flickr API do not have the ideal quality.

In addition to this design problem, the psychologist was also very concerned about the confidentiality of patient data, so we decided to encrypt all the data stored in the server.

The second interview, conducted with a psychologist currently working in a residential home for the elderly, was carried out with the goal of presenting the platform to another psychologist, obtaining another opinion, and initiating contacts to carry out a more in-depth study, when the first version of the platform is completed.

The institution in question does not use any kind of digital tool to support psychologist's work, so when, during a session, there is a lack of contents about a patient, the psychologist ends up for example showing videos from YouTube or navigate in Google Maps through known places of the patient.

Once the platform had already been presented to another psychologist the problems founded in the platform were naturally minor. The only question that worried the psychologist was that, in a session, the reaction buttons, the time counter and the option to add notes, would distract the patient from what was important and would take away the psychologist's privacy. Therefore, a session is currently performed with two monitors. Apart from that, the psychologist was very enthusiastic about the concept of the platform, and it proved to be available to contribute to a more in-depth study.

5.2 Validation of Scrapbook with a psychologist

The initial idea of this thesis was to carry out a study of a few months, that would be able to test the efficiency of the platform with the patients, and to confirm if there would be a deceleration of the progression of the disease and an increase in the well-being of psychologists, patients and caregivers.

As time progressed, it was clear that a study of this magnitude would not be completed in time to be present in this thesis, so it was considered more appropriate to carry out another type of study.

5.2.1 Goals

We recruited a psychologist, contacted in the preliminary interviews, to conduct a two-week study with the purpose of validating the platform among psychologists. Once there is not enough time to evaluate the effects of the use of Scrapbook in the disease progression, the primary goal of this study was to evaluate the acceptance, usefulness and perceived effectiveness of Scrapbook by psychologists and patients. Particularly, we wanted to address the following research questions:

1. How do patients respond to a digitally-supported cognitive stimulation apparatus? How do psychologists cope and benefit from a digital tool to support therapy (Acceptance of technologic solution)?
2. Can a digital tool augment current biographical cognitive stimulation practices, namely in: a. Enabling the collection of broader knowledge about the person and her current interests (Usefulness); b. Enabling the preparation and maintaining a record of therapy sessions (Usefulness).
3. Does the digital tool aid in eliciting communication during the therapy session (Perceived Effectiveness)?

In addition, we wanted to test the user experience provided by the platform, namely usability (is it easy to use?), value (is it useful?), adoptability (is it easy to start using?) and desirability (is it fun and engaging?).

5.2.2 Ethical issues

Once the initial idea of this research study was to prospectively assign human participants to one health intervention and evaluate the effects on health outcome, to protect participants and guarantee the credibility of the study we asked for an Ethics Committee approval and a signed informed consent (appendix B) for each participant.

The study protocol was approved by the Ethics Committee of the Campus Neurológico Sénior.

The informed consent was signed by psychologist and patients, or a legal representative, prior to performing any study procedures. To ensure that they were fully informed about the nature and goals of the clinical study, the potential risks and benefits of study participation and their rights as research subjects it was delivered to them an information leaflet (appendix C). The date and time subject, or the subject’s legal representative, signed the informed consent form and a narrative of the issues discussed, were documented in the subject’s case report form (appendix D). The investigator retained the original signed informed consent form, and a copy was provided to the subject, or to the subject’s legal representative.

5.2.3 Methodology

Study design and duration

A prospective 2-week non-controlled study.

Participant selection

A psychologist who recruited a total of 3 patients diagnosed with dementia.

Patient inclusion criteria:

- Patients diagnosed with dementia;
- Aged 65 or older;
- MoCA [40] below or equal to 22;
- Being interested in participating in the study;
- Signing an informed consent form (patient or responsible caregiver).

Patient exclusion criteria:

- Inability to participate, as assessed by the psychologist, in the weekly sessions, i.e., likelihood of being able to participate in a minimum of one-hour weekly sessions for 2 weeks;
- Visual deficits that disable seeing images in a computer screen.

Procedure

Once the duration of the study was only two weeks, and would be performed only with one psychologist, the procedure was quite simple.

At week 0, days before the start of the study, we met with the psychologist to perform a briefing session which goal was twofold: 1) perform a semi-structured interview about the cognitive stimulation practices, needs, concerns, and expected outcomes; 2) present and explain the usage of Scrapbook through the creation of a fake user profile and of creating/performing sessions.

During week 1 and 2, each patient participated in at least one cognitive stimulation session weekly with the psychologist. The schedule of the sessions and its organization was responsibility of the psychologist. There was no time nor usage obligatory requirements for Scrapbook and as its usage was treated as an applicability indicator.

At the end of the study, at week 2, a semi structured interview was performed with the psychologist involved. This interview focused on understanding some aspects of the psychologist's interaction with Scrapbook, namely concerns acceptance, usefulness, effectiveness, efficiency and limitations. The interviews scripts can be seen in appendix E.

Along with the interviews, the platform usage statistics, such as number of sessions, duration of each session or the percentage of positive reactions of the patient, were also recorded in a log file for analysis.

5.2.4 Content analysis

Initial and final interviews were subjected to a thematic analysis, following a mixed inductive-deductive coding approach. Two researchers, who conducted the interview, independently created two codebooks, which have been refined and merged. After the merge, both researchers coded the two interviews with the same codebook. Finally, a Cohen's kappa agreement of k = 0.79 was calculated.

Once the purpose of these interviews was to understand psychologist's current practices and the effects of introducing a tool like Scrapbook in her work, the final codebook (appendix F) is divided into four themes: current practices, limitations, benefits, and concerns.

Extracted codes and themes allowed a formative understanding of the benefits and flaws of Scrapbook. Throughout the next sections I will present the themes identified and the main findings for each.

5.2.5 Current practices

The institution where the psychologist works is divided into several areas, such as the area of children, the area of young people and the area of the elderly. The area of the elderly is divided into three types of support: day care, home support and hospitalization.

Although there are other technicians and therapists, such as a speech therapist, there is only one psychologist responsible for performing reminiscence therapy and cognitive stimulation with the patients.

This psychologist works in two of these areas. In the day-care centre, where she does more informal group sessions and, once there is no evaluation of patients' disease, she adapts exercises to the patients as she gets to know them. This is a more informal approach, which herself considers cognitive stimulation, and works more as an occupation task. The second area is in the hospitalization, where she carries out the evaluation and rehabilitation of the patients. Here, she uses anamnesis[20] techniques to collect data about the patient and to construct intervention plans, which allows her to arrive at a definition of a therapeutic proposal for that patient. This proposal is then presented not only to the patient but also to the relatives, who cooperate with the staff of the institution.

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[20] Collection of relevant information about the patient to formulate a diagnosis

Group sessions

Being used to work in groups, the psychologist has acquired several mechanisms to optimize the results of the sessions, which, naturally, will always be different from the results of an individual session. In a group, the psychologist must be able to control the various personalities and reactions, as such, the same task is not given to everyone equally.

"We always have to give different activities [to patients], so it's always to have a plan B, C, D, E, F, always. That's why I carry my backpack, I have several types of various exercises."

These group sessions may involve mathematical exercises or drawing exercises, where patients are invited to draw something they like to then be discussed with the psychologist. Once the clear majority of the residents of the institution are local people, also old photographs of the city are projected, which patients love because they often remind them about places that no longer exist.

Individual sessions

In the hospitalization area is where reminiscence therapy and cognitive stimulation are performed individually with a patient. Here, the psychologist also likes to apply her creativity in the activities performed, however, since the knowledge about the patient and his limitations are greater, the approach is different. An evaluation of the disease and an anamnesis session with patient's caregiver, allow her to know patient's life history before the pathology, and to define an intervention plan.

"In the anamnesis, I ask what kind of music that person likes, how was the feeding, what is the favourite dish, that kind of things."

The activities performed with the patient depend of the area of memory that the psychologist intends to stimulate. These activities may involve the recognition of sounds, music or images (some of them provided by family members upon request of the psychologist) with the patient. The images that are not provided by family members are, generally, about patient's interests and are taken from the internet, and printed by the psychologist to be presented to the patient during the sessions. Additionally, Google Maps is also used to travel around the world, for example with people who have worked in different countries, and YouTube is used to play music, old movies or to show famous people linked to cinema.

Sometimes is also performed sensory stimulation, where the psychologist brings smells, such as food smells or vegetables to people who were cooks, or puts together a series of photographs of ingredients and tries to make a recipe with these photographs.

Since there is only one psychologist, the frequency of the sessions is not ideal, and it is usually only possible to have sessions with the same patient every two weeks. Due to this, psychologist also assigns different priorities to people, for example, people with a case of reversible vascular dementia have priority over an irreversible one.

Collection of material

The collection of autobiographical material is fundamental to increase the quality of the intervention. This collection of material/content is done with family members, but not always is easy to talk and meet family members to perform this step.

"Most of the time I do not have relatives interested or present. In the continuing care area, I already have a population that is not so local, they are hospitalized, they are here for three months (...) and people come from Porto [a distant city] and it is much more difficult because it will influence the whole rehabilitation, the patient will not have the presence of family members regularly, nor of friends."

This situation is clearly influenced by the area where the patient is placed, once in the day-care centre area, the presence of family members is daily. The psychologist reported that whenever she sees or meets patients' family members she asks them to bring everything they think that would be meaningful to him, be it objects or photographs.

Regarding the type of photographs, she usually asks for photographs about life events that have been remarkable to the person, such as the marriage, or about the profession itself, at the workplace, or even about children and grandchildren of patients.

"Whatever they are [photographs], they are always welcome."

The materials collected are mostly photographs, and the psychologist has even confessed that she has never received any video.

Patients' reactions and treatment effects

Patients' reactions vary greatly from patient to patient and from content to content. Sometimes several sessions are performed, where several photographs are presented, and no relevant stimulus occurs, and suddenly a photograph can significantly change the state of the patient and he begin to cry.

In normal situations, the psychologist collects the reaction of a patient to a content through his facial expression and emotional indicators. When the proximity between psychologist and patient increases, the patient feels more comfortable, becomes more open about his emotions, and the collection of the reaction to the stimulus and new information turns out to be easier.

In the best cases, the treatments bring improvements at an emotional level, at the level of the consciousness of the disease itself, and at levels of consciousness about self and other people.

In addition, to observe and evaluate the evolution of the disease, the MoCA [40] test is applied initially and close to patient discharge, and in which improvements are sometimes visible.

Information record

As part of her work the psychologist always keeps a record of each session. Although this psychologist is not apologetic to do these records during the sessions, since they can break the rhythm, the records are taken at the end of each session.

Typically, what is recorded is the date, time, patient name and information that is relevant to prepare the next sessions. It is, for example, recorded the reaction to a particular photograph, so that in the next session, if the psychologist wants to reawaken that reaction, she knows which photographs to use. To facilitate the registration of reactions to a photograph, all of them are numbered, so that the registration is associated with that number.

All records of the sessions are kept on paper for protection of patient data, and are solely for the use of the psychologist.

"I am very apologetic of the ethics and data protection of the person, in fact we have a platform of the network of continuing care in which I write there, but I only write the essential data, a very brief thing."

Eventually, information can be shared within the team to be used in other interventions.

"To not always walk with the computer, I have a folder in which I have the various files of the patients, it is this cover that I take later to the meetings (...) I still do not work much with computer."

Limitations

Besides the lack of psychologists, which makes the time available for each patient not ideal and prevents treatment effectiveness to reach its full potential, there are other limitations to the work of the psychologist.

One of these limitations is the lack of a wireless internet network. Although she has tried to use some cognitive stimulation applications, the fact is that she can only perform the therapy in her office, and even if she had access to a tablet she would not be able to move to meet a patient.

Another of the problems pointed out, is the complexity that keeping the materials requires. The psychologist says that she has bags full of materials, some books where she looks for activities, and several dossiers with images.

"If I could have a program that was intuitive and as I was putting some data I would be appearing several things related to those data (...) would be excellent, it would make my life much easier."

Above all, the psychologist feels the lack of a program that can help her keep her data, and provide materials and themes to work with patients.

5.2.6 Dealing with Scrapbook

After two weeks of interaction of the psychologist with the platform, we return to conduct a new interview to try to understand how was the experience of dealing with Scrapbook.

It should be noted that the version used in this study did not include all the features that the final version has. Logging in with Facebook, and cognitive stimulation games were not part of this version, keeping psychologist focused on reminiscence therapy sessions. These other features were presented to psychologist at the end of the interview.

As mentioned, the psychologist does not usually use the computer during sessions, only in cases that she need to carry out evaluation tests there, and despite having technological knowledge within the average, there are still some natural limitations regarding the use of computers.

From now on, to ensure the privacy of the patients who participated in the study I will start to refer to these as P1, P2 and P3. All patients were diagnosed with dementia, being patient P1 female with 77 years old, patient P2 male with 67 years old, and patient P3 also female with 80 years old.

Requisites week 0

At the end of week 0 interview, a demo was held, where the psychologist was invited to create her account, register a fake patient and start a session. In addition to the demo, a guide was also given to the psychologist explaining all the screens and how the platform works.

The purpose of the demo was not only to present the tool, but also so that she could check if everything was to her liking for the beginning of the study. Thus, the psychologist suggested two new functionalities to be implemented before the beginning of the study.

First, it was suggested to create an address search box on the map page. At the time, it was only possible to see relevant monuments of places that the patient had interest, but the psychologist suggested to create a search box where it was possible to search for specific addresses, without having to add this address to patient's profile. This suggestion seemed positive to us, so it was quickly implemented, and it is now possible to search for an address that the relevant monuments nearby are immediately presented.

In addition, the psychologist also suggested that it should not be mandatory for patients to have a profile photograph. Once the psychologist found this to be an unnecessary step and delayed the registration process, the mandatory profile photograph was removed and the patients have now a default avatar.

Usage time

The psychologist started the interview by noting that she did not have as much time as she would like to explore the platform, and that she would like to have had at least two more weeks to get to know the platform better and realize what it can offer to her.

Analysing the numbers, through log files and the database, and not knowing to which patients or contents they refer, it is possible to verify that in total three patients were submitted to reminiscence therapy sessions. A fourth patient was registered, but did not perform any session.

It is noticeable that for two of the patients only one session was performed. In one of these cases, the session lasted approximately 28 minutes and a total of 12 contents were seen. On average the presentation of a content lasted 2.3 minutes. More important than time, it is the patient's reaction to the contents, once he reacted positively to 10 of the 12 contents. The other two contents did not get any kind of reaction from the patient.

To the other patient who also performed only one session, it lasted approximately 25 minutes and, in total, 16 contents were presented. The percentage of positive reactions in that session was lower, only 8 (50%). For the remaining contents, 2 caused negative reactions and 6 did not cause any kind of reaction.

For another patient, two sessions were performed, with a six-day interval between each. In the first session 30 contents were seen, which represents more than 36 minutes of session. In total, 19 contents led to a positive reaction from the patient, 2 to a negative reaction and 9 did not cause any kind of reaction. In the next session, 12 contents were presented during 38 minutes. Relative to the reactions, were registered 6 positive, 3 negative and 3 without reaction.

Interacting with Scrapbook

The fact that the psychologist has only performed a session with two of the patients, is mainly due to the model of work adopted by her.

Before moving on to a reminiscence therapy session, the patient had to be registered on the platform which consumed the usual time of a session. In every first meeting with a patient was performed an anamnesis session, where the psychologist collected information about the patient to be inserted in Scrapbook.

This anamnesis session was, in two cases, carried out with the patient's relatives, and in the other case, due to the unavailability of the relatives, with the patient himself, who was not yet in an advanced stage of Alzheimer's disease and had some capacity to provide verifiable information about his past. This second case, with patient P1, is rather curious, since the psychologist reported that she sat with the patient and asked to her about her past information, such as songs she likes to hear or important places in her life. As the patient responded, the psychologist filled out the form.

Due to a problem on the shared server, the job responsible for registering the patients was removed, and some data from the first patient was lost. This problem was solved in the meantime, but in the conversation with the psychologist I advised her to insert less information during the registration and later to insert the remaining information in the profile edition, if she wanted to make sure that nothing was lost. During the interview, she revealed that after this suggestion she started to register a patient with less interests, only those needed to perform the first session, and as she discovered new interests, she added them to patient's profile.

Regarding session creation, the psychologist confessed that the first time she created a session, it did not go very well, but that the second time she felt quite comfortable and was already able to select the contents and change their presentation order.

Due to the short time she had available, she admitted that did not have the opportunity to use the map page during sessions, but used it to see where some of the places indicated by relatives, that she did not know, were.

When asked about the general quality of the contents, and if there used to appear contents not related to the intended theme, she does not seem to have a clear opinion. According to her, she can find a very good image and, then, another not so good, but confesses that was able to find at least one quality image for each one of patients' interests.

“I am reminded that I put the word Switzerland and it really appeared to me a very good [image], that it was identified very well, that it was with snow behind, a very green field and with those wooden houses, but then also can appear an image that looks like Alentejo [Portuguese region].”

Finally, although in the previous interview she revealed that only takes notes at the end of the session, here she chose to take notes about the presented contents (during the session), and inserted the reactions according to the facial expression of the patient.

Patients’ reaction

Although we are not evaluating the evolution of patients’ disease, it is relevant understand how do patients react to the treatment and to the fact that a new instrument is being used in their sessions. Before proceeding, it should be noted that both, patient P1 and P3, have no experience with computers.

In general, the participation and acceptance by the patients of the introduction of the platform in their sessions was good. But let's go for parts. Patient P1, being accustomed to having most of the sessions done in group, found fantastic to be able to be individually with the psychologist in her office. This patient, being a person who likes to learn, considered the use of Scrapbook as an apprenticeship. The psychologist said that she explained to the patient the purpose of the study, and that the patient "even understood it more or less" and saw this paradigm shift, and the introduction of the platform, as something very natural.

“She found it all very interesting, she liked it very much and she says she wants to continue because it is also a way to come learn and remember some things, and talk about subjects that usually with an image (...) they go to other subjects a lot and end up talking about other things.”

The other two patients who participated in this study represent much more advanced cases of dementia, and although physically they are in perfect condition they are often found to wander, completely disorganized and with a discourse that is not coherent.

P2’s anamnesis was performed with his wife, who in turn also asked to his daughters to provide photographs for therapy. This patient was the one that showed more signs of improvement.

"I've seen fantastic things, like I've never thought he [the patient] could do."

The psychologist says that she already has tried to work more often with P2, such as group tasks, but that she suddenly rises from the chair and walks away, completely disoriented. One of the great problems of this patient is that he cannot stand in the same place, much less be sitting in a chair for 20 minutes.

"Here I keep him seated and at least he tries to observe what I am showing to him and talk about it."

Despite this great step, which is to keep the patient seated and attentive, the most interesting matter in this treatment is the patient's reaction to the presented contents. Although the reactions to images are not extraordinary, the same cannot be said relatively to videos and especially songs.

"It was very interesting because his reaction to videos is spectacular, it's fantastic. Videos mostly with Beatles songs or ABBA songs, I see reactions there as I had never seen. He put his hands to his head and says 'my old days'. I get silly."

The psychologist also points out that, many times, P2 is not even able to answer the questions, or that answers disorganized, but that with the individual sessions of Scrapbook things started to be different, and the patient seems much more active and less apathetic.

At the level of the speech, the improvements were so notorious that the patient went from not being able to formulate a phrase to sing the refrain of some songs.

"Here I put the music he likes, that he really likes and he did something that I was amazed at, that is he can sing a refrain. For him, have a fluency of speech is very difficult, and here I can get at him rhythm (knocks on the table) and I get him to remember part of the refrain. He sang with me almost the whole refrain, which I had never seen."

P3's reactions were not as satisfactory as in the previous case. The anamnesis was performed with patient's daughter, and, here, the great improvement was in the psychologist's knowledge about the patient. The psychologist reports that she saw a completely different person in front of her after the anamnesis, and that discovered a lot of new information about the person.

The reactions of P3 to the contents are much more typical of Alzheimer's disease in an advanced stage, she sees the image, the psychologist feels that the patient recognizes something, but what she identifies in the image does not correspond to what is in the image.

"An image was of a frog, and she told me that it was a very bad dog she had known for some time."

This advanced stage of the disease, naturally, led to that the stimulation provoked by the images was not so great. However, there were contents related to her own personality and music, that managed to arouse her interest, although in this case the reaction was not as complex as it was with P2.

The disease is so advanced that the patient cannot even say her children's names or how many children she has, nor is she aware that the Scrapbook was introduced in her sessions.

Caregivers involvement

Something quite positive that can be drawn from this study is the involvement of caregivers. Although only three people with dementia participated in this study, the psychologist was able to collect information from four patients and, of these four, it was possible to speak personally with caregivers of three of them to collect photographs and personal information.

The psychologist's method involves performing an anamnesis session with one of the caregivers, to collect the contents and information needed to initiate the reminiscence therapy. With P2, the anamnesis was performed with patient’s wife, to whom she delivered the study informed consents, that later were delivered to P2’s daughters. The daughters liked the project so much that emailed to the psychologist photographs of the patient P2, paintings that the patient had made during his life, and family photographs. Overall, they found the project very interesting.

P3’s anamnesis was performed with her daughter, and in addition to all the information obtained, the patient's daughter was still responsible for delivering photographs of the patient to the psychologist so that the psychologist could digitize and insert them on the platform.

Regarding to the fourth patient, the psychologist says that she has already had the opportunity to be with the daughter, who has already provided the necessary data to proceed with the therapy.

Overall, the effect of this study on family members was positive, since they only want the best for their loved ones, and allowed an increased sharing of information between psychologist and family members, which the psychologist believes would hardly exist without Scrapbook.

Problems found

Scrapbook, like any other software being tested, was not immune from problems. Some of these problems have arisen from the psychologist's lack of experience, whether dealing with the platform or dealing with her own computer, but which are always important to perceive and correct, as they may represent cases of poor usability provided by the platform. Other cases were more serious and compromised the normal operation of the session.

The main problem pointed out by the psychologist was that she had never been able to correctly expand the screen and use the two monitors. Although the operation has been explained several times, and there is no software error, the psychologist says that this was always her greatest difficulty. This problem, although not impeding the session, is an obstacle, since the patient sometimes read the descriptions of the images and the effect was not the same. This problem was used by the psychologist to work the area of language with the patient. Other consequences of this problem were the privacy of the notes taken.

"A lot of times I had to take off the session from the second screen to write my note. I take it off from the second screen, the note it and put it back on the second screen."

Also related to the images presented, the psychologist complained that some of the images collected from the Flickr API contained text and the patient could read the text or, in other cases, that images were blurred, but understood that it was something that could not be controlled by the platform.

Another problem was uploading photos to Scrapbook. According to the psychologist, some of the photographs provided by family members when inserted were presented horizontally, and during the session patients had to turn their heads to see the photograph. This is a problem that remains unresolved, since after several tests, with different types of photographs, it was not possible to replicate the problem.

Also related to family photographs, has arisen another problem. The psychologist intended to add a new family member by entering only her name and degree of kinship, and leaving the insertion of the photographs of the family member for later. This was a situation for which the Scrapbook was not prepared, but was timely solved.

One of the most serious errors occurred during the session and forced the psychologist to start the session again. The error is not clear and could not be replicated by me, but according to the psychologist was a DNS error, which may have occurred due to the weak speed of the internet network of the institution.

The most serious problem occurred during the registration of P1. For some reason, the service that was responsible for running the background jobs on the shared host, such as the patient's registration job, stopped overnight, and was only restarted in the morning after the psychologist's warning. This problem only happened once, but the data entered about the patient were lost and had to be added again.

In addition to these problems, the psychologist also suggested that the contents could be presented differently during the session creation. Instead of the current theme filtering, it was suggested that the presentation of the images and videos should be already organized by themes on the page itself, for example, a first line with images about music, a second with general interests, a third with favourite places, and so on.

Concerns

The only concern of the psychologist regarding the use of the platform is the occurrence of errors.

In addition, she has a natural concern of her work, which is the content selection for therapy. Although it never happened to her, she heard reports of patients who feel such frustration about an image that they end up crying intensely. This is the biggest concern of the psychologist: the selection of content to use in the session.

Benefits and expectations

The benefits of the platform described by the psychologist in the interview are many. In a way, this is also why when asked if she would continue to use the platform, she readily responds that *"yes, of course"*, and sees only advantages in using the platform.

In the opinion of the psychologist, and knowing that she is a rather creative person, the platform can provide much more than just memory stimulation and reminiscence therapy.

"If I can get an image that has two numbers or has the months or seasons, I can work the spatial and temporal orientation. I'm working memory, but I'm also working orientation."

Besides the work of memory and orientation, the psychologist believes that, with Scrapbook, manages to work all the cognitive functions. She gives the example of attention, where for example she asked the patients to count the number of animals in an image, the language, where she asked the patients to read a text in an image, and the perception, asking for example about the colour of a dress.

She can also find ways to help the patient at motor level, where, for example, during a song she asks to the patient to raise his arms and keep up with the rhythm.

When asked if the possible use of the platform in the tablet would be advantageous, the psychologist says yes, and that she had already thought about buying a tablet exclusively for professional use.

"I find it very advantageous [use a tablet] because with the computer we always have a barrier."

New features

At the end of the interview was presented to the psychologist the final version of Scrapbook, which in addition to the login with Facebook also has two games of cognitive stimulation.

Regarding Facebook, the psychologist was a bit surprised by the situation and immediately raised doubts about privacy, and about who would be the person responsible for creating and managing the Facebook page. First, she was worried if it would be well accepted by the family that all the friends of the person could see what was happening, and suggested that the creation of a Facebook exclusively for the therapy purpose, where only she and the caregivers would have access.

Then she asked if it would be her or a caregiver to create and manage the account. People often do not know how to use social networks, and the psychologist would have to teach some family members or caregivers to interact with Facebook, but says that they would probably even get motivated and accept Facebook usage.

Despite these issues, it seems clear to her that this functionality could bring patient and family closer, especially those living abroad. In addition, the fact that the relatives know that the patient reacted to some image during the session, is pacific for the psychologist, and after clarifying her doubts, she sees as an advantage the use of Facebook, although with some reluctance, regarding to the capacity of relatives to use Facebook.

Regarding the games, she confessed to being an advantage to her work, and that they represent a lot of what she already does.

The importance of autobiographical content in games depends very much on the patient's Alzheimer's stage, since patients in a more advanced stage will not recognize the image, but patients in less advanced stages could react positively, as already happens with one of the puzzles that the psychologist performs, and which contains an image of the members of the institution.

The level of difficulty of the puzzle must be adjusted according to patient's ability. The psychologist suggests the realization of puzzles from 2 up to 15 pieces, once there are patients in the institution capable of making puzzles with difficulty above 500 pieces. For the rest, she does not find problems in this functionality and thinks the patients would be able to drag the piece of the puzzle in the tablet without difficulties.

Regarding the possible creation of an account for caregivers, where the psychologist could create a session for, later, the caregiver performs it at home with the patient, the psychologist has no doubts and advises to go ahead with the creation of the functionality.

One of the reasons for not implementing this functionality in this project, is because some psychologists mentioned in previous studies that caregivers are often not able to motivate patients to the session, which leads to even more frustration. However, the psychologist says that she only sends homework when she feels that caregivers and patients are ready for it.

5.3 Testing the social mechanism

Nowadays, almost everyone has a social network account. Of course, the percentage of early adults that currently have an account are low, but, with the aging of the previous generation soon this number will increase.

None of the patients who participated in the previous study had a Facebook account, and only one patient had a close caregiver with technological skills. This way, we knew from the beginning that no test would be performed to the social mechanism, so we felt it necessary to test it independently and in parallel with the previous study. This study was not performed in a clinical environment and its participants were not people with dementia.

5.3.1 Goals

Since we were not dealing with people with dementia and that the sessions were not conducted by a psychologist, the goals could not be to test acceptance, utility or perceived effectiveness. The goals of this study were:

- Test the receptivity of friends and family of participants;
- Check the quality of contents collected through the social mechanism;
- Test the mechanism of collection of content based on positive reactions;
- Test the platform behaviour on a tablet;

5.3.2 Methodology

Study design and duration

A 2-week non-controlled study.

Participant selection

Four participants who meet the following inclusion criteria:

- Active person in social networks, namely Facebook, with at least 3 photos or videos and a list of likes and places visited rich enough to allow a good characterization of the person;
- Have at least one friend available to collaborate;
- Availability to perform at least two sessions per week.

Procedure

To avoid creating posts in each participant's Facebook account and the unnecessary exposure of the study, Facebook accounts were created for each of the participants. This way, only the friends of the participant who were part of the study are aware of it.

In week 0, during a first meeting with the participant, the new Facebook profile was filled with real data, namely photos, videos, personal information, likes and visited places. At that time, the friends or relatives of the participant, previously advised of the existence of the study, were also added as friends to simulate the role of caregivers.

Two 20-minute sessions per week were performed during two weeks. In these sessions, held as a coffee talk, the participant sat next to the researcher, who played the role of psychologist.

After the last session, the participants were invited to respond to a small questionnaire (appendix G) where they evaluate the quality of the contents of each session and where they could tell how the experience was, how the Facebook friends reacted and give possible suggestions for Scrapbook.

5.3.3 Findings

Scrapbook behaviour

Overall, this study did not raise major problems. The first problem encountered was in the games. Since it had not yet been tested with the social mechanism, both the puzzle and the flashcard were not prepared to be performed with contents collected from Facebook, so at the end of the first session the participant was asked to perform a puzzle and it was not possible.

Regarding the quality of the contents, something that we wanted to evaluate in this study, the feedback from the participants was very positive. Since the system is dealing with younger people and their interests are more current, the quantity and quality of collected contents from the Flickr API is very good, and, in most cases, all three images collected about a theme were good. However, there was a problem with the music videos, which is the fact that artists’ most recent songs are those returned by the YouTube API. This way, although the participants knew the artists, they did not know the songs. This problem only occurs with current and active artists, and can be resolved by changing, when making the call to the API, the order of results from relevancy to number of views.

The collection of contents was so positive that one of the participants was from a different culture, and had interests completely unknown to the researcher, but despite this, and the session being created "blindly" (not knowing whether the contents referred to the desired interests), the participant could recognize quality of the contents. However, this same participant reported in the questionnaire that although the contents were not repetitive, the themes themselves were.

By analysing, through the questionnaires, the participants' opinion about their satisfaction with the quality of the contents of each session, we can observe that, from 0 to 10, the average satisfaction with the contents of the first session of each of the participants is 8, in the second session 8.25, and in the third and fourth sessions is 9. This increase in satisfaction may be related to the increase of autobiographical content collected from Facebook, but also to the fact that the researcher begins to know better the interests of the participants.

It is also important to refer that the algorithm of creation and collection of posts worked as expected, so its robustness is guaranteed for when it is used in a therapy environment. For this study, an initial frequency of posts of 3 hours was defined, to allow immediate collection of various contents to be used in the second session, and after that the frequency decreased. One conclusion that can be drawn from this study, is that it would be good if it were possible for the psychologist to define the post to be carried out on Facebook, that is, to choose what content he wants to get from patients' friends.

Analysing also some of the numbers, and the probabilities of each type of posts, it is possible to verify that among the 82 posts made throughout the study, 42 are posts that intend to obtain new contents regardless of the participant's reaction, 24 intend to obtain more content about themes to which the participant reacted positively, and 16 intend to obtain histories. Part of the difference in the number of posts between the first and second case, can be justified by the fact that the distance between the first and second sessions of one of the participants was one week, and from a certain point in time, the system had already requested contents about all the themes to which the participant had reacted positively, reason why the system began to request contents about themes that the participant had not yet seen.

Friends collaboration

One of the purposes of this study was to observe the behaviour of Facebook friends. At the interview (of the first study) the psychologist said that it was most likely to have to talk to the caregivers in person and explain to them the functioning of the system and the importance of its responses to the posts. And that is exactly what happened in this preliminary prospective study. In two of the cases, the initial post on Facebook, when registering the participant, and an initial explanation of the study, were not enough to entice friends to respond to posts, so only after a conversation, where it was all better explained, they began to collaborate.

In addition, it was interesting to observe some patterns of behaviour in friends. During the day, several posts were created, depending on the frequency, but the answers to these posts were given later. All friends, without exception, preferred to take five minutes out of their day and respond to all posts at once, then respond as they were posted.

Other of the patterns found, is the fact that friends, when inserting an image in the comments, also liked to insert text to describe that image. Currently, Scrapbook only stores the image but taking advantage of this behaviour, it would be a good idea to also save the text associated with the image. Also related with this situation, is the fact that some friends did not initially perceive the posts requesting images, and commented them with histories about that image instead of just insert a similar image, which may be an indication that a new way of requesting histories could be adopted, using images as a reminder to caregivers of themes for possible histories.

Analysing the numbers, we can see that of the 82 posts, 42 were answered by the friends, whether through likes, images or histories. Curiously, the posts asking for histories were the least commented (only 3 histories were collected), since friends found this a more time-consuming task (as reported in one of the questionnaires).

Limitations

The major limitation of this study is that it was not performed with people with dementia, and therefore caregivers of people with dementia. As such, no great conclusions can be drawn regarding the numbers of the caregivers' collaboration, since it is difficult to ask participants' friends to simulate the dementia of participants. In case the study was performed with people with dementia, I believe that friends collaboration would naturally be greater, as well as the quantity of relevant results.

5.4 Discussion

Now that the two studies have been presented, and their results are known, it is time to discuss them. I presented a first study, where a psychologist was in charge of using the platform in individual reminiscence therapy sessions with her patients, and a second study where, with people without dementia, the social mechanism of the Scrapbook was tested.

Looking for the goals of the first study, namely the evaluation of the acceptance, usefulness and perceived effectiveness of Scrapbook, and for the interviews, we can conclude that the results are quite satisfactory, even though the psychologist did not have as much time as she would like to explore the platform, in which, for example, the map was not actually used.

Regarding the acceptance of the platform by psychologists and patients, there is no doubt that it was positive. The psychologist was very motivated by the use of Scrapbook, in such a way that immediately sought to make sessions of anamnesis with caregivers to collect the necessary information to perform the sessions. In addition, the major indicator of this acceptance was that the psychologist intends to continue to use the platform in the future.

It was also very positive to see how psychologist has changed her ideology. In the first interview, she reported that she performed all the records of sessions in paper, and that she was reluctant to keep her records in the digital format, much due to the possible data exposure, however with Scrapbook, we can verify that she made use of, and found it useful, to be able to take notes and insert reactions about the contents during the session.

Patient acceptance was also good. Patient P1 found it fantastic to be able to be with the psychologist individually and saw the introduction of the platform as something very natural. On the other hand, patient P3 was in such an advanced stage of the disease that she was not even aware of this paradigm shift of her sessions.

Speaking of the advantages in the psychologists' work, we can see that Scrapbook made possible to approach patients and psychologist. With the use of the platform and the increase of the amount of autobiographical and personalized contents, there was more material to work individually. In addition, anamnesis sessions with family members, which without Scrapbook would not happened so early, led the psychologist to better know her patients, namely patient P3.

Looking at one of the limitations that the psychologist identifies in her current practices, which is the complexity of having the materials, and the dossiers of photographs she holds, we can also see that Scrapbook has solved this problem. With Scrapbook, some of the contents were directly sent by email or scanned by the psychologist and returned to the family, thus avoiding the physical storage of these.

From the point of view of the patients, and analysing another of the goals of the study (perceived effectiveness), the reports are quite positive, and even surprising considering the low number of sessions performed with the patients.

Patient P1, still in an early stage of Alzheimer's disease, loved to participate in the study, loved the closeness that it created between herself and the psychologist and found it fantastic to talk about subjects that she would normally not talk about. The psychologist reported that these sessions with the Scrapbook allowed them to talk about subjects they did not normally talk about.

Patient P3, is in a very advanced stage of Alzheimer's disease, nevertheless it was notorious the positive reaction to contents related to her own personality and music. From the point of view of patient P3, the great advantage was the knowledge that the psychologist acquired about her. Certainly motivated by the use of Scrapbook, the psychologist says that when she did the anamnesis session she began to see a completely different person, which meets one of the goals of this thesis: increase the proximity and knowledge between psychologists and patients.

The most positive case was the case of patient P2, where were reported benefits that were not expected in just two weeks. The fact that before this intervention he is not able to formulate a phrase, and during the session began to sing the refrain of several songs is a big step. Here is also visible the influence of Scrapbook, since the psychologist says that the patient already liked to listen to music, but that the reactions provoked by the music provided by the platform were greater because he was listening to the songs that he truly enjoyed.

In addition to the effects at cognition level, the effects on patient P2 attention and concentration were also visible. Before using the Scrapbook, the psychologist could not motivate the patient to be seated long enough to perform the sessions, and with the Scrapbook, the patient P2 sits down and observes the contents carefully. In addition, also reported an improvement in the level of apathy and ambulation.

I believe that this success history is also influenced by the dementia phase the patient is in. Being patient P1 at an initial stage, the reaction to the stimulus may not have been as high as the patient is still able to recall data from her past. On the contrary, patient P3 is at a very advanced stage of the disease, and it is natural that it is much more difficult to stimulate her memory.

Of course, this study may have been influenced by the fact that some patients generally did not have access to individual sessions, but in any case, the goal was not to compare the efficiency of Scrapbook use with the efficiency of current practices. At the very least this adherence provoked by the Scrapbook also demonstrates that the tool can work as a motivator or a guide to the work of the psychologist, and in this way, perform, for example, anamnesis sessions immediately when patients enter the institution.

We know that we could not evaluate the evolution of the disease over two weeks, nor was this the goal, but it was visible the increase of the adhesion, the decrease of the apathy and ambulation, and the increase of topic of conversation during the sessions.

It was also interesting to note the acceptance of family members of the use of the platform, as well as the increased collaboration and sharing of information between psychologist and patient, which can be seen as another advantage of Scrapbook.

Regarding the technical aspects of the use of the platform, the results are also promising. Starting with the interface, on which the psychologist was very pleased with the design, the only problem to register is the fact that the psychologist has found difficulties in expanding the screen, something that is due to the little technological ability of the psychologist, and that can be an indicator that it should be better explained, or even exemplified, how this task should be performed. Regarding navigation between the different menus, and most importantly, registration and preparation/execution of the session, no usability issues were reported.

Another of our concerns was the quality of the contents, but the psychologist assured that she could have at least a content with quality for each theme.

During this testing period, other problems naturally arose due to the precocious phase of the project we were in, but which were duly corrected.

Analysing also the opinion of the psychologist about the integration of Facebook and cognitive stimulation games, and joining that with some conclusions of the second study realized, there are still some concerns.

Although the mechanism is completely functional and it has been proven that content quality improves from session to session by collecting data through Facebook posts, there is always the question of motivating and teaching caregivers how to work with Facebook. However, it was already visible in the first study, the sharing of information between psychologists and familiars through e-mail, which can be a good indicator.

From the second study, no great conclusions can be drawn regarding the numbers of the collaboration of the caregivers, however, as a result of the study, it is assured that the social mechanism is fully functional and ready to be used in a real clinic environment.

Chapter 6

Conclusion

"Keep working hard on this, take it to the end, do not give up because I think this is really essential to the therapeutic community." [Psychologist]

Throughout this thesis, I described a series of steps, such as the deepening of knowledge about dementia, the analysis of related work and the elaboration of the platform requirements that resulted in the creation of Scrapbook. These steps leave me confident that Scrapbook could indeed be useful in supporting psychologists during their sessions with patients, and, consequently, improve the overall wellbeing of people with dementia.

Analysing the existing tools, we can see that none of them is as complete as Scrapbook. Within the interactive tools, which are those that currently I consider to be more effective, some of them make use of APIs such as Flickr or YouTube to obtain contents, but only two use Facebook to that purpose. Most tools either use autobiographical contents that have to be provided by caregivers, or use very generic contents. In addition, Scrapbook can be seen as a social life memory book, to which all friends of patients on Facebook can contribute, something that had just been done by Martins et al. [16], but in a different context.

We can then observe a lack that the Scrapbook aims to fill: the automatic gathering of autobiographical and personalized contents, being them images, videos or music, from large APIs to perform reminiscence and cognitive stimulation therapy.

The result of this thesis is a platform validated and tested by its end users, and with the guarantee that it can now be used in large scale by psychologists, since the probability of errors is low, the benefits are clear, and the few limitations turn out to be a lesser problem considering the limitations of current practices.

Analysing the goals and the expectations initially defined, the work done and the conclusions drawn from the studies, it is possible to define a list of benefits and limitations of this thesis, as well as leave some suggestions for future work.

6.1 Benefits

As accomplishment signal, the benefits and contributions of this thesis, meet our initial goals and expectations.

A study, carried out in a real clinical environment, left indicators that Scrapbook can bring several benefits to the different stakeholders.

For the psychologist, Scrapbook can increase:

- The knowledge about the patient, which increases the list of possible topics of conversation and brings patient and psychologist closer;
- The ease of collecting contents as well as increasing the number of personalized contents available to each patient;
- The possibility of working several cognitive functions with the patient, namely attention, memory, language and perception;
- The cooperation of relatives, providing contents, namely photographs, and as such increased number of autobiographical contents;
- The ease of keeping all the contents of the patients, thus avoiding the confusion of the dossiers.

Although no evaluation tests were done about the progression of the disease and the patients' quality of life, some improvements were reported, namely:

- Decreased apathy and ambulation;
- Improving the quality of sessions, especially due to increased focus on the patient and their interests;
- Greater receptivity to the sessions, especially at the level of adherence and attention;
- Ability to recall subjects that were not normally addressed.

In addition, it was implied in the result of the first study that there may be an increase in the quality of life of psychologists and patients.

6.2 Limitations

Unfortunately, it was not possible to prove some of the possible benefits of Scrapbook. I would like to have evaluated the possible influence of the platform on the evolution of the disease and of the levels of apathy and the quality of life in patients and psychologists, but two weeks are insufficient to draw strong conclusions about these aspects.

Furthermore, although a test to the social mechanism was performed, it was not possible to perform this study with people with dementia. This way, and although Scrapbook, in the first study, increased the collaboration of family members with new contents, it was not possible to test the possible influence of Scrapbook in avoiding, for example, that family and friends forget about the person with dementia.

Regarding Scrapbook, the biggest limitation I see is the collection of old photographs, be it about interests or places. Since Flickr is an image-sharing application, and these images are usually recent, there is a greater difficulty in collecting images from the patients' time. The system could have performed an image search based on the patients' date of birth, but due to this, it was not possible. However, this can be partially solved through the social mechanism or through the scanning of photographs by the psychologist who can insert them in the system.

6.3 Future work

Despite the complexity of Scrapbook, it presents only the essentials for psychologists to do their work with quality, and there are many more features that can make Scrapbook grow. Are they:

- Creation of a caregiver's account, where it becomes possible for the psychologist to send homework to the patient, thus allowing a greater regularity in the sessions, which could lead to an improvement from the point of view of the disease;
- Possibility of performing group sessions, where the system would be able to find common interests among all patients participating in the session, and thus psychologists who have group sessions or who have little time to work with patients individually, can try to stimulate everyone's memory at the same time;
- Creation of a tag system, where each content is associated with several tags, which can then be used, for example, to associate images of a family member or event with a place, or to infer new interests from the patient. For example, if a patient is Portuguese and responds well to contents about sports the system can suggest contents of Portuguese athletes;
- Improve the quality of collected images, either through the use of another API, or through the use of tools capable of identifying the subjects or elements present in an image, thus avoiding for example collecting images with embedded texts;
- Allow the edition of names and descriptions of images and videos that come from Flickr API and YouTube API;

- Integration of new cognitive stimulation activities or games, such as word games, quizzes, or games where life events are organized in chronological order;
- Allow the psychologist to choose what contents to request for on Facebook. Indicating only the theme of the content he desires, the system should be able to perform the post and collect the answers;
- Collect, associated with an image, the description of the image that friends may insert into Facebook;
- Provide the option of posting to a private Facebook group, where only those authorized by the caregiver have access to the posts, thus avoiding possible privacy issues;
- Evaluate the social mechanism of Scrapbook in clinical environment, and longitudinally compare the effectiveness of the reminiscence therapy provided by Scrapbook with the traditional reminiscence therapy.

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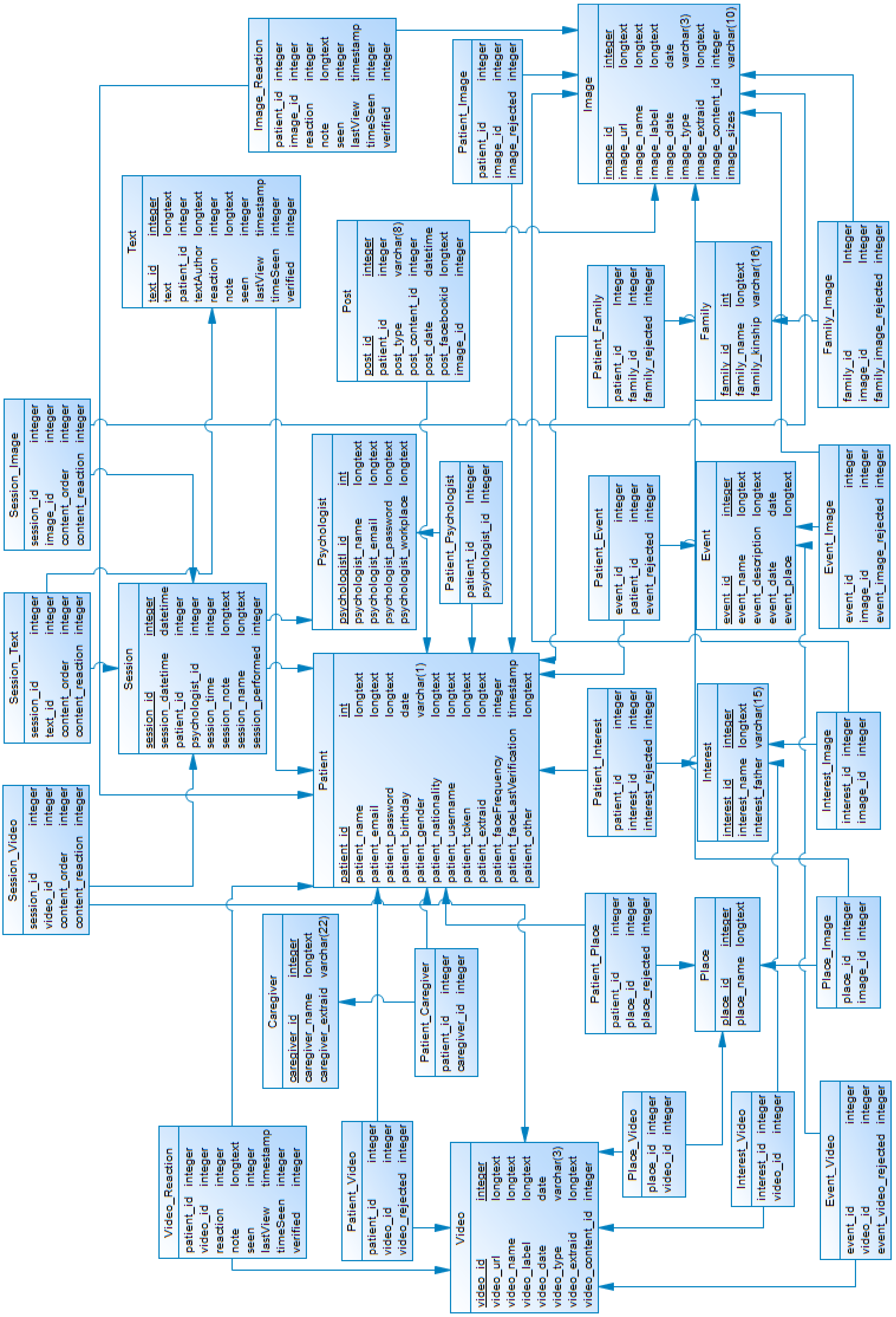
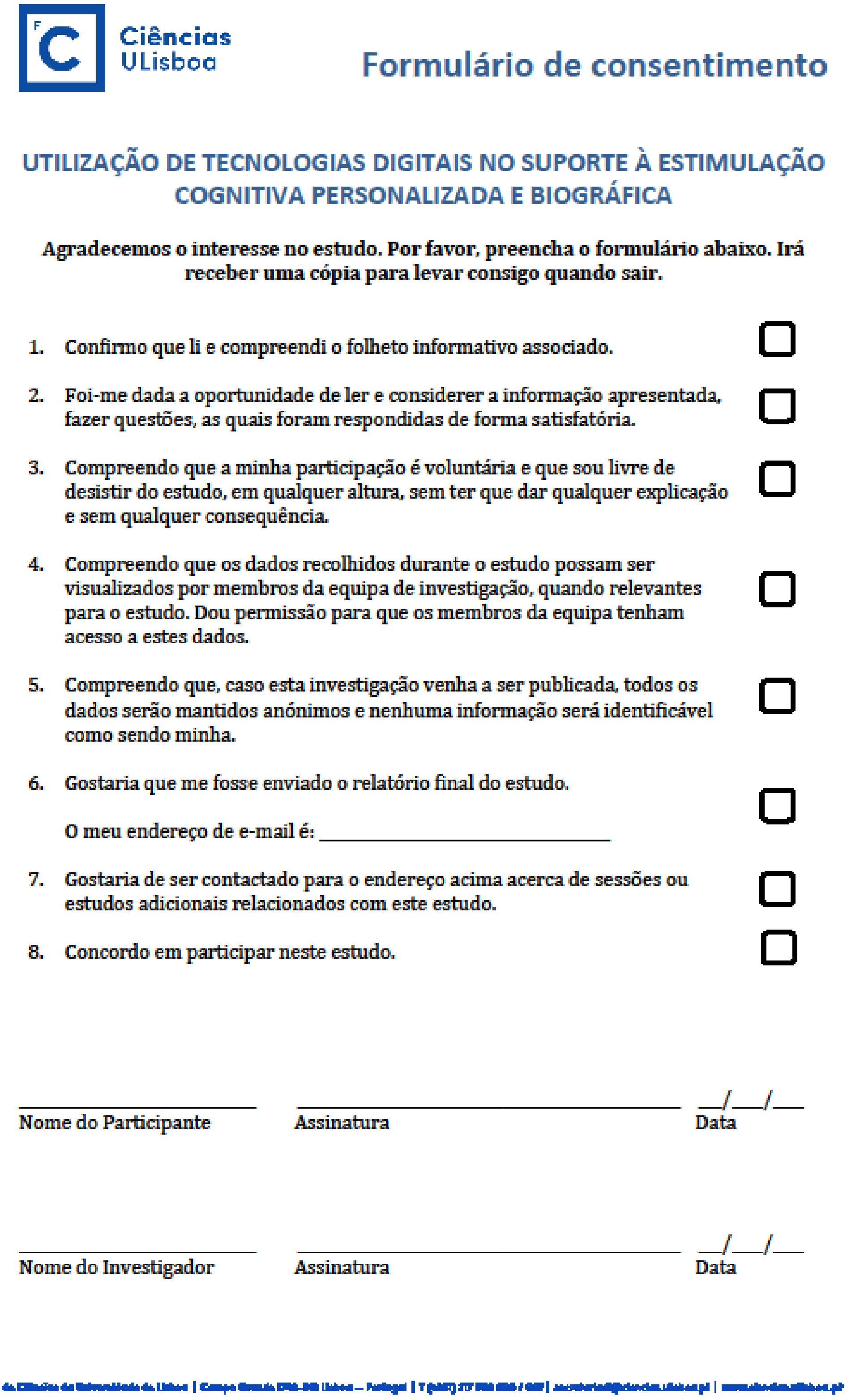
Appendix A Database model



Appendix B Informed consent



Ciências ULisboa

Formulário de consentimento

UTILIZAÇÃO DE TECNOLOGIAS DIGITAIS NO SUPORTE À ESTIMULAÇÃO COGNITIVA PERSONALIZADA E BIOGRÁFICA

Agradecemos o interesse no estudo. Por favor, preencha o formulário abaixo. Irá receber uma cópia para levar consigo quando sair.

1. Confirmo que li e compreendi o folheto informativo associado. ☐
2. Foi-me dada a oportunidade de ler e considerer a informação apresentada, fazer questões, as quais foram respondidas de forma satisfatória. ☐
3. Compreendo que a minha participação é voluntária e que sou livre de desistir do estudo, em qualquer altura, sem ter que dar qualquer explicação e sem qualquer consequência. ☐
4. Compreendo que os dados recolhidos durante o estudo possam ser visualizados por membros da equipa de investigação, quando relevantes para o estudo. Dou permissão para que os membros da equipa tenham acesso a estes dados. ☐
5. Compreendo que, caso esta investigação venha a ser publicada, todos os dados serão mantidos anónimos e nenhuma informação será identificável como sendo minha. ☐
6. Gostaria que me fosse enviado o relatório final do estudo. ☐

   O meu endereço de e-mail é: ______________________________
7. Gostaria de ser contactado para o endereço acima acerca de sessões ou estudos adicionais relacionados com este estudo. ☐
8. Concordo em participar neste estudo. ☐

______________________	______________________________________	__/__/__
Nome do Participante	Assinatura	Data
______________________	______________________________________	__/__/__
Nome do Investigador	Assinatura	Data

Appendix C Information leaflet

Vimos desta forma convidá-la/o a participar no nosso estudo de investigação focado no uso de tecnologias para melhorar sessões de estimulação cognitiva. Antes de decidir, gostaríamos de lhe apresentar os detalhes desta investigação, o porquê de estar a ser realizada, e as implicações da sua participação. Um membro da equipa da investigação irá ler consigo toda a informação detalhada neste folheto e responderá a quaisquer questões que possa ter.

Em que consiste o estudo “Utilização De Tecnologias Digitais No Suporte À Estimulação Cognitiva Personalizada E Biográfica”?

Este estudo insere-se num projeto de investigação em curso que tem como objetivo melhorar práticas de estimulação cognitiva, não-farmacológicas, para pessoas com demência, em ambiente de consulta de neuropsicologia, com suporte a tecnologias digitais. A equipa de investigação é composta por investigadores da Faculdade de Ciências da Universidade de Lisboa, da Faculdade de Medicina da Universidade de Lisboa, do ______________, e da ________________.

Em estudos passados, analisámos as práticas correntes de estimulação cognitiva, onde se verificou que a quantidade e qualidade de informação biográfica disponível é muito limitada. Em paralelo, verificou-se que os psicólogos e terapeutas tentam manter e enriquecer registos biográficos dos pacientes, de forma a melhorar as suas intervenções, seguindo uma perspetiva centrada na pessoa.

O objetivo do presente trabalho é desenvolver tecnologias que suportem a prática centrada na pessoa, permitindo recolher e gerir conteúdos autobiográficos, durante as sessões de estimulação, manter registos de respostas emocionais positivas e negativas a estes conteúdos, e assim potenciar uma intervenção mais eficaz. Em particular, desenvolvemos uma aplicação que permite que a neuropsicóloga introduza termos relevantes sobre o paciente (ex: cidades onde viveu, interesses, músicos preferidos, ...), e que procura automaticamente na Internet conteúdos (fotografias, vídeos, músicas) relacionados com estes termos. Ao apresentar os conteúdos ao paciente, a neuropsicóloga pode registar que a pessoa reagiu a um certo conteúdo e que este serviu para despoletar uma conversa; ao fazer isto, o sistema vai automaticamente enriquecer-se com mais conteúdos relacionados (por exemplo, fotos da mesma cidade ou outras músicas desse cantor) e permitir que estes sejam apresentados numa sessão futura.

Este estudo vem avaliar a usabilidade e aplicabilidade desta aplicação, observando qual o impacto ao nível da qualidade da consulta, para pacientes e neuropsicólogos.

Tenho de participar neste estudo?

A participação no estudo é voluntária. Vamos descrever o estudo e apresentar toda este folheto informativo, incluindo os detalhes da sua participação. Se concordar em participar, irá assinar um formulário de consentimento. Ser-lhe-ão fornecidas cópias deste documento e do formulário de consentimento informado.

E se eu desejar desistir do estudo?

É livre de desistir, em qualquer altura, sem ter que fornecer qualquer razão ou explicação.

O que terei de fazer no âmbito do estudo?

No âmbito do estudo, irá participar em sessões de estimulação cognitiva com uma neuropsicóloga da instituição que frequenta, em que este lhe irá apresentar, num computador, fotografias e músicas sobre as quais será convidado a conversar. O funcionamento da sessão será semelhante às sessões de neuropsicologia que já ocorrem atualmente, mas desta feita com o suporte desta aplicação digital.

Cada sessão demorará um tempo máximo de 1 hora mas não tem um tempo mínimo obrigatório. A utilização da aplicação também é facultativa: a neuropsicóloga poderá optar por não a usar ou interromper o seu uso, e você pode também pedir que a mesma não seja utilizada, momentaneamente, ou em definitivo.

O objetivo da investigação é avaliar como a tecnologia pode suportar a terapia. Não tem como objetivo avaliá-la/o a si. Todas as recomendações e melhorias sugeridas permitirão melhor esta tecnologia de apoio, e são bem-vindas.

Quais as desvantagens e riscos de participar?

Não estão previstos quaisquer riscos associados e a expectativa da equipa de investigação é de que as sessões de estudo sejam uma experiência agradável para os participantes.

O horário das sessões será marcado em articulação entre você e a neuropsicóloga que o segue.

Quais os possíveis benefícios de participar?

De acordo com a nossa experiência, as pessoas gostam de participar em estudos que promovem a comunicação com o corpo clínico. O seu envolvimento irá ajudar ao desenvolvimento de novas tecnologias para a intervenção não-farmacológica para pessoas com demência.

O que acontece quando o estudo terminar?

A análise dos dados terminará em setembro de 2017. Os resultados do estudo serão publicados em conferências e revistas académicas. Se desejar saber detalhes sobre os resultados e implicações do estudo, podemos fazer-lhe chegar uma cópia do relatório do estudo em outubro de 2017.

E se ocorrer algum problema?

Se tiver alguma preocupação sobre qualquer aspeto deste estudo, deve falar com o investigador responsável, Prof. Tiago Guerreiro, que fará o seu melhor para endereçar as suas questões [telefone: ________ ou e-mail: ________]. Pode também falar com o/a diretor/a da instituição que frequenta. Caso se mantenha descontente ou queira apresentar uma queixa formal, pode fazê-lo contactando o Prof. José Artur Martinho Simões, Diretor da Faculdade de Ciências da Universidade de Lisboa [e-mail: __________].

A minha informação será mantida confidencial?

Sim. Seguiremos todas as práticas éticas e legais e toda a informação sobre si será tratada em confidência. Para garantir anonimidade, registos pessoais estarão apenas disponíveis para a equipa de investigação. Se os dados forem usados para publicações ou apresentações, serão totalmente anonimizados, sem qualquer referência à sua identidade. Se forem tiradas fotos, e for nossa intenção usá-las em alguma apresentação, ser-lhe-á pedida autorização prévia. Se estiver disponível para que usemos fotografias ou vídeos para esse propósito, pedir-lhe-emos que assine autorizações específicas para o efeito.

O estudo passou por um processo de revisão?

Este estudo foi revisto pela Comissão de Ética do CNS - Campus Neurológico Sénior. Esta comissão analisou a proposta de estudo, bem como todos os seus materiais (questionários, formulários) e não levantou objeções do ponto de vista ético.

Quem posso contactar relacionado com este estudo?

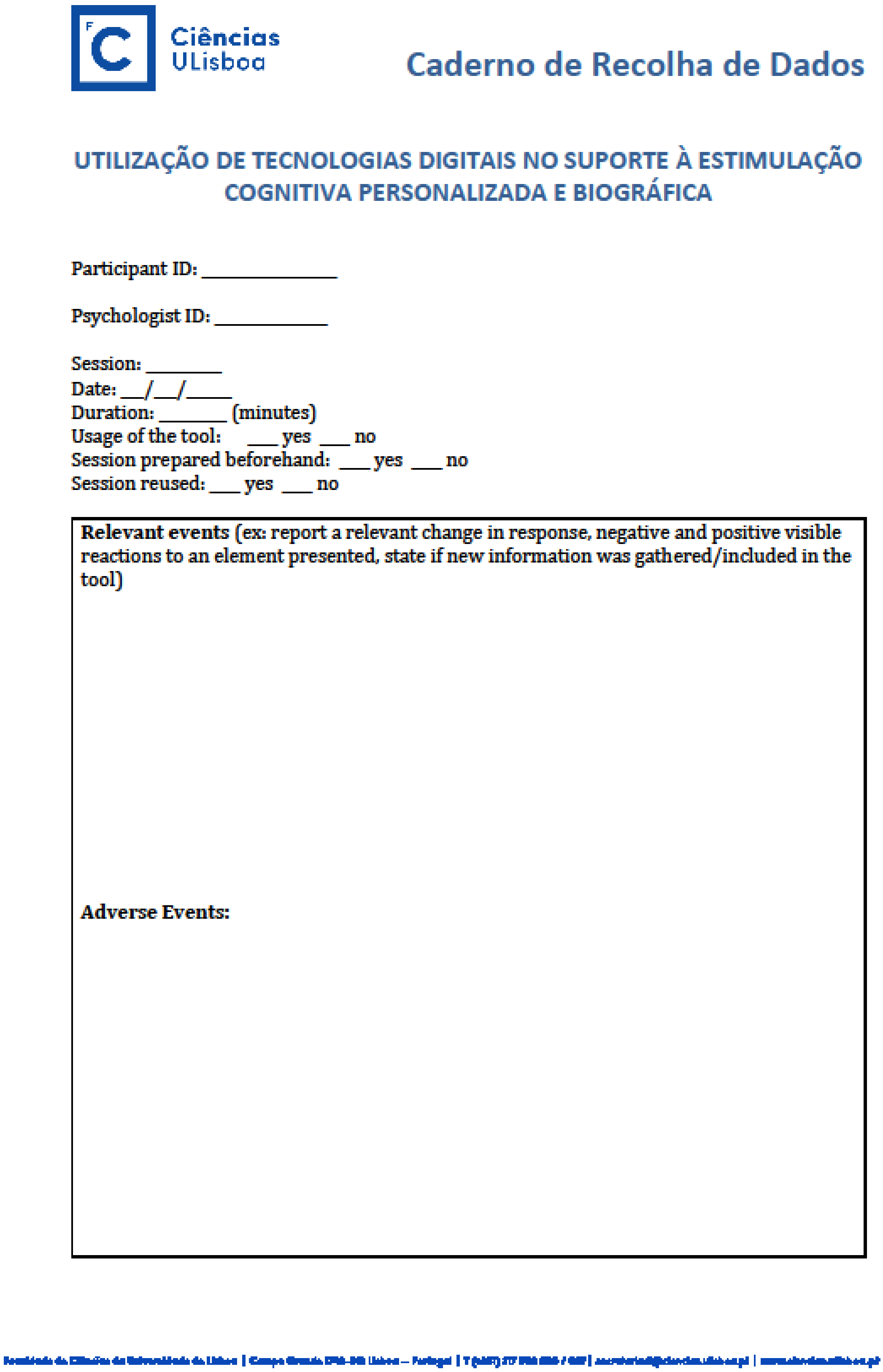
Prof. Tiago Guerreiro Faculdade de Ciências da Universidade de Lisboa		

Sinta-se à vontade para os contactar acerca deste estudo.

Obrigado

Obrigado por ter dedicado tempo a ler este folheto informativo e por considerar participar neste estudo.

Appendix D Data collection sheet



Caderno de Recolha de Dados

UTILIZAÇÃO DE TECNOLOGIAS DIGITAIS NO SUPORTE À ESTIMULAÇÃO COGNITIVA PERSONALIZADA E BIOGRÁFICA

Participant ID: ____________

Psychologist ID: __________

Session: _______
Date: __/__/____
Duration: ______ (minutes)
Usage of the tool: ___ yes ___ no
Session prepared beforehand: ___ yes ___ no
Session reused: ___ yes ___ no

Relevant events (ex: report a relevant change in response, negative and positive visible reactions to an element presented, state if new information was gathered/included in the tool)

Adverse Events:

Appendix E Interviews scripts

Appendix E1 Week 0 interview

Interview Script & Recommendations

1. Start by thanking the neuropsychologist for participating in the study.

a. "Boa tarde. Obrigado mais uma vez por participar neste estudo. Para além da sua participação na investigação, vamos-lhe pedir que utilize a ferramenta desenvolvida, o Scrapbook, em sessões de estimulação com recurso a conteúdos biográficos. Apesar de haver um interesse natural seu em ver a tecnologia a ser explorada e utilizada neste domínio, pedimos-lhe que hoje, nesta entrevista, e em todas as fases do estudo tente ser imparcial, recolhendo os benefícios e limitações e problemas da abordagem, de forma a podermos melhorar. Hoje, temos dois objetivos: o primeiro consiste em fazer uma pré-entrevista sobre práticas atuais para termos uma caracterização inicial; o segundo objetivo é familiarizar-se com o Scrapbook e ficar pronta a criar os seus registos de pacientes, preparar, executar e visualizar sessões."

2. Collect a signed informed consent (similar to the one presented to the patients).

3. Perform a 30-minute (max) interview about current practices and limitations

a. See seed questions below;

b. Use them to start a topic but delve deeper when the participants have something more to say;

c. Don't make questions that have already been answered by the participants;

d. When the answers are not satisfactory in detail, find alternative questions, to find information;

e. Make the participant talk, not you.

f. Don't be afraid of silences. Silences are good; they make the participant think and delve deeper. Don't rush.

Interview Seed Questions

- Nowadays, do you perform cognitive stimulation activities with the patients?
  - What type of activities?
  - If not, why not?
  - How regular are they?

    - Individually or in groups?
- Do you perform any type of reminiscence therapy or biographical cognitive stimulation?
- What type of biographical data is currently used about the patients in a therapy session? In what format (physical, digital)?
    - Is technology used in therapy sessions (ex: YouTube videos, or pictures of locations)?
    - What type of new knowledge is gathered in a session? How is it saved for future sessions?
    - How is knowledge about a person collected today? And stored? And shared with other members of the clinical team?

Scrapbook Presentation

1. If the participant read the tutorial, go straight to their questions, showing interactively how they should do;

2. If not, ask them to do the tutorial with you and explain things as needed;

3. Last, build a dummy profile, create a session, run the session (with likes and dislikes), show the results, prepare a second session (and show that they could use the previous one).

About the Study

Finish by instructing the participant to:

1. Collect informed consents after explaining the study to patients (using the information sheet);

2. Prepare beforehand the first session by:

a. Registering the patients;

b. Filling what they know about them (and want to use in the sessions) in their individual profiles;

c. Prepare the first session;

3. Use the “Caderno de Recolha de Dados” to register data about the study (dates and times, relevant and adverse events), for each patient (one sheet for each session and patient);

4. In each session, use the tool at their own convenience:

a. For example, if the person is disliking, cease using it and report that;

b. If that happens, continue the session normally talking with the person;

c. Ultimately, if they feel it is not useful, perform the session without the tool.

5. If something goes wrong with the tool (malfunctions), continue the session with the person as they would do without the tool, and report to us ASAP.

6. Try to schedule at least one session per week with each patient. If they and the patients can and want to do more, there is no upper limit.

Thank the participant!

Appendix E2 Week 2 interview

Interview Script & Recommendations

1. Start by thanking (again) the neuropsychologist for participating in the study.
    a) "Boa tarde. Obrigado mais uma vez por participar neste estudo. Esperamos que tenha sido uma boa experiência. O objetivo de hoje é falarmos um pouco sobre essa experiência e identificar não só os benefícios e limitações, mas como podemos continuar a melhorar a aplicação. Portanto, pedimos que seja o mais "exigente" possível connosco, porque todo o feedback que tivermos será bom para melhorar. Nós já fizémos uma análise às estatísticas de uso e pelo que percebemos conseguiu usar a plataforma com 3 pessoas, em sessões que duraram algum tempo substancial. Este uso já vai permitir que dê uma opinião bastante informada sobre a plataforma. Podemos começar?"

2. Perform a 30-minute (max) interview about current practices and limitations
    a) See seed questions below;
    b) Use them to start a topic but delve deeper when the participants have something more to say;
    c) Don't make questions that have already been answered by the participants;
    d) When the answers are not satisfactory in detail, find alternative questions, to find information;
    e) Make the participant talk, not you.
    f) Don't be afraid of silences. Silences are good; they make the participant think and delve deeper. Don't rush.

Interview Seed Questions

- Como foi a utilização desta plataforma?

- Foi custosa a sua adaptação a um sistema tecnológico para uso em consulta?
- E os pacientes como reagiram? E como estão a reagir?
- Quais as maiores dificuldades que teve no uso da plataforma?
- Teve problemas?
- Quais os maiores benefícios que observou?
- Quais as funcionalidades que acha mais importante?
- Qual a sua opinião sobre a preparação de sessões?
    - Benefícios e problemas/preocupações?
- Qual a sua opinião sobre a recolha de dados "manual", ex: pedir a familiares?
    - Benefícios e problemas/preocupações?
- Qual a sua opinião sobre a recolha de dados automática?
    - Os conteúdos automáticos tinham qualidade?
    - Benefícios e problemas/preocupações?
- Qual a sua opinião sobre o mecanismo de feedback (like/dislike)?
    - Benefícios e problemas/preocupações?
- Qual a sua opinião sobre a visualização de dados a posteriori?
    - Benefícios e problemas/preocupações?
- Vimos que as pessoas deram feedback positivo/negativo em vários conteúdos?
    - Como aferiu isso? Pode dar exemplos?
    - E notou resultado na geração de novos conteúdos?
- Houve envolvimento de outras pessoas (família, amigos, etc...)? Como? E o que achou disso?
- Que sugestões de melhoria tem?
- Surgiram-lhe algumas preocupações no uso desta plataforma?
- Continuaria a usar a plataforma? Como?

Present Scrapbook Social

- Que vantagens vê nesta adição social?
- Que problemas vê ou prevê?
- Teria sido útil nestas duas semanas que passaram?

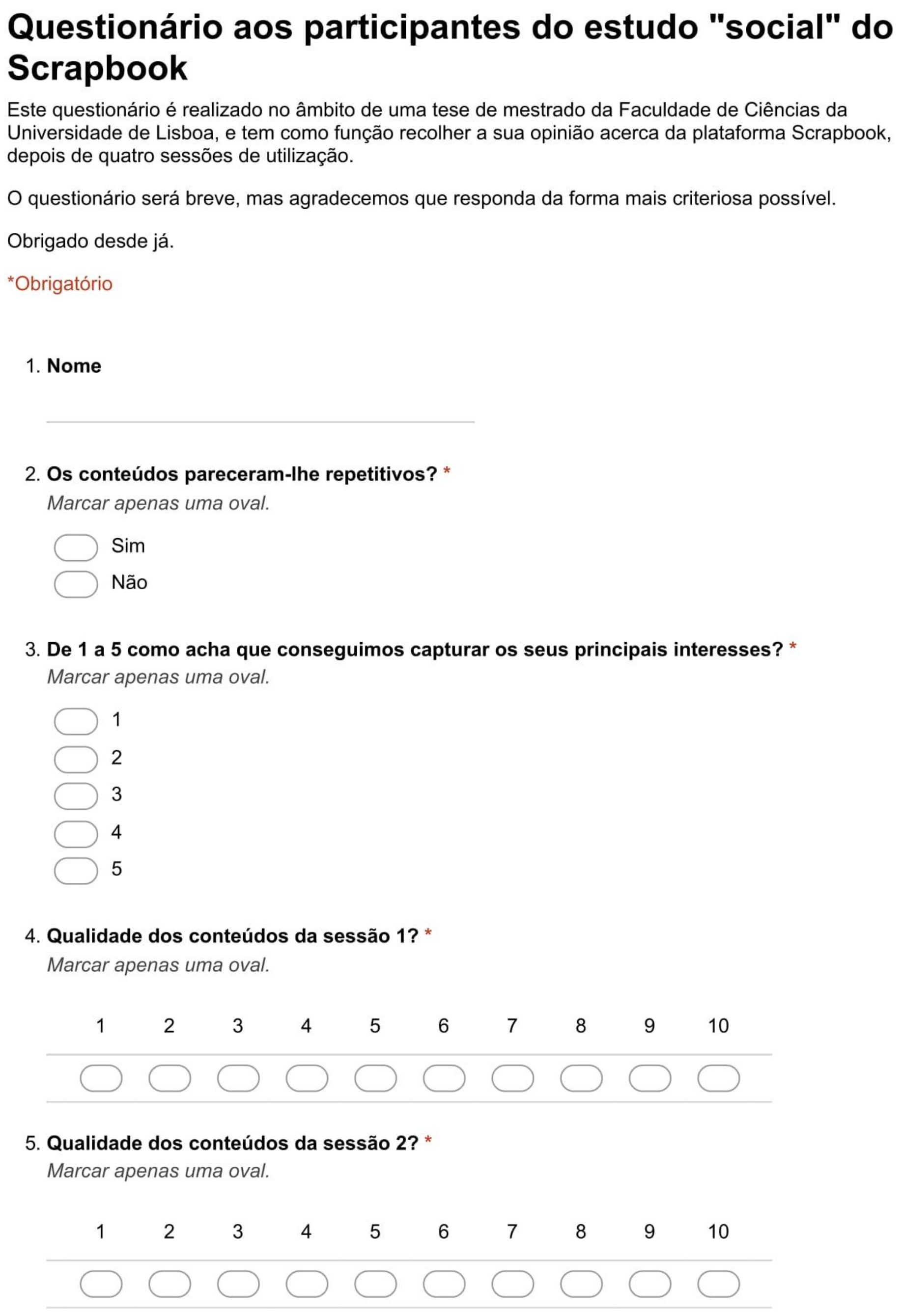
Appendix F Codebook

Theme	***Category***	***Code***
Current practices	Service	serv.daycentre
		serv.hospitalization
		serv.ambulatory
	Session	session.individual
		session.group
		session.personalization
	Techniques	tec.anamnesis
		tec.evaluation
		tec.rehabilitation
		tec.stimulation.cog
		tec.stimulation.sen.smell
		tec.stimulation.sen.drawing
		tec.stimulation.sen.dance
		tec.reminiscence
		tec.orientation
	Cognition	cognition.reaction
		cognition.atention
		cognition.memory
		cognition.language
		cognition.motor
	Intervener	intervener.caregiver
		intervener.otherprofessional
	Tool	tool.image
		tool.video
		tool.music

		tool.map
		tool.paper
		tool.book
		tool.object
	Documentation	doc.physical
		doc.digital
Limitations	Patient	patient.atention.low
	Structure	struc.psychologist.low
		struc.displacement.low
	Content	cont.quality.relevance
		cont.quality.sharpness
		cont.quantity.low
	Visualization	vis.horizontal
		vis.expansion
		vis.description
	Technology	tec.ability.low
		tec.error.critical
		tec.error.noncritical
		tec.lackequipment
	Time	time.limited
	Involvement	Involvement.caregiver.low
Benefits	Patient	patient.reaction
		patient.participation
		patient.progress.cog
		patient.progress.emot
		patient.progress.mot
		patient.adhesion
	Optimization	optimization.caregiverinvolvement
		optimization.collection

		optimization.contents
	Psychologist	psychologist.evaluation
		psychologist.patient.knowledge
Expectations	Application	application.cog.sti
		application.group
		application.cva
		application.tbi
		application.otherpathologies
	Functionality	func.session.themes
Concerns	Reaction	reaction.negative

Appendix G   Second study questionnaire



Questionário aos participantes do estudo "social" do Scrapbook

Este questionário é realizado no âmbito de uma tese de mestrado da Faculdade de Ciências da Universidade de Lisboa, e tem como função recolher a sua opinião acerca da plataforma Scrapbook, depois de quatro sessões de utilização.

O questionário será breve, mas agradecemos que responda da forma mais criteriosa possível.

Obrigado desde já.

*Obrigatório

1. **Nome**

____

2. **Os conteúdos pareceram-lhe repetitivos?** *

Marcar apenas uma oval.

○ Sim
○ Não

3. **De 1 a 5 como acha que conseguimos capturar os seus principais interesses?** *

Marcar apenas uma oval.

○ 1
○ 2
○ 3
○ 4
○ 5

4. **Qualidade dos conteúdos da sessão 1?** *

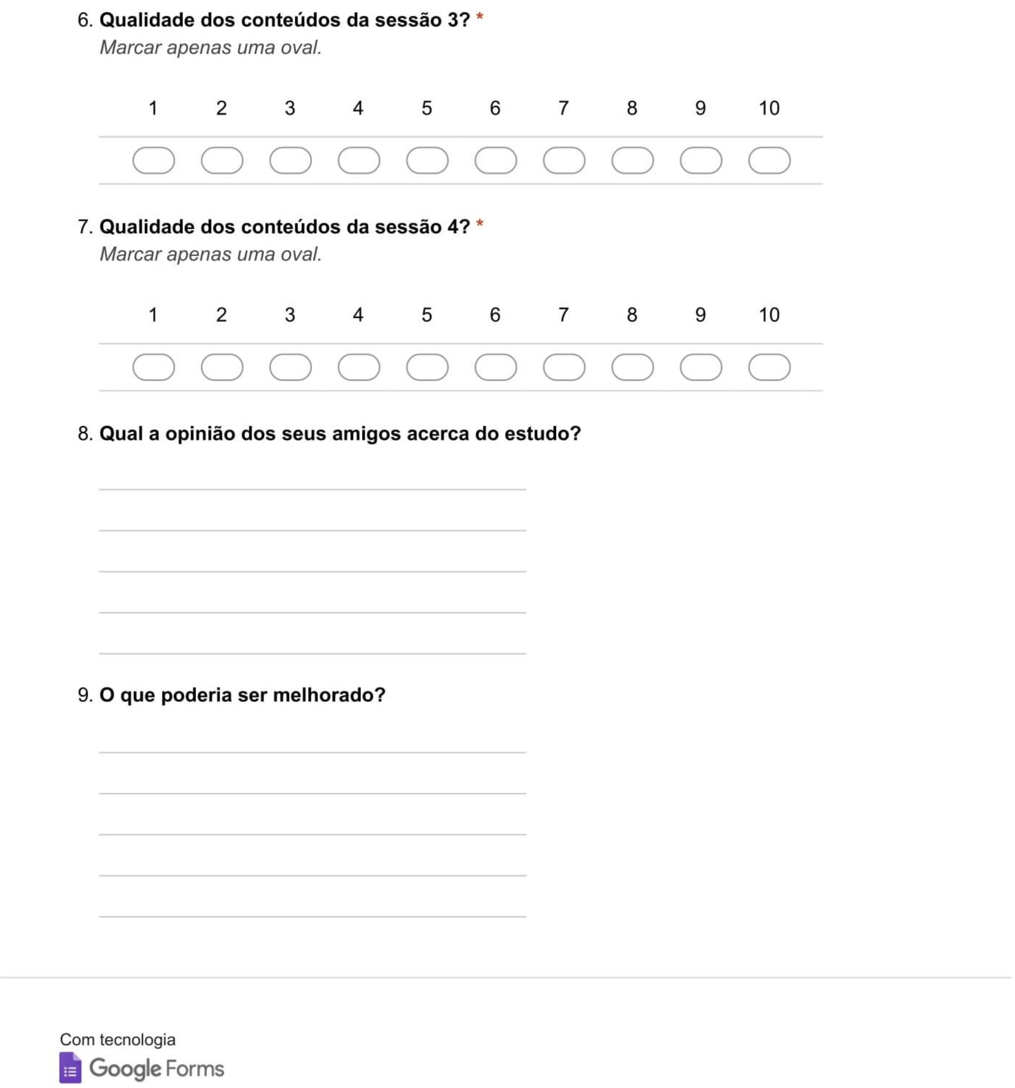
Marcar apenas uma oval.

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○

5. **Qualidade dos conteúdos da sessão 2?** *

Marcar apenas uma oval.

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○



6. **Qualidade dos conteúdos da sessão 3?** *

Marcar apenas uma oval.

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○

7. **Qualidade dos conteúdos da sessão 4?** *

Marcar apenas uma oval.

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○

8. **Qual a opinião dos seus amigos acerca do estudo?**

9. **O que poderia ser melhorado?**

Com tecnologia