**Faculdade de Engenharia da Universidade do Porto**

# STAlz: remotely supporting the diagnosis, tracking and rehabilitation of patients with Alzheimer's

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Mestrado Integrado em Engenharia Informática e Computação

Supervisor: Nuno Honório Rodrigues Flores (PhD)

July 27, 2013

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# Abstract

The ever increasing quality in health care led to an impressive improvement of the life expectancy rate in the last decades, which results in an increase in the number of elderly people. Of the diseases associated with aging, Alzheimer's Disease (AD) is one of the most prevalent, representing a rate of up to 80% of all the dementia cases. Due to its symptoms (memory loss, mood changes, disorientation to space, time and people, among others) the disease represents a heavy burden to the patient, the caregiver and the health care system. This comes to show that solutions addressing this topic and that try to improve the current way of tackling the disease are urgent and necessary.

The research on the state of the art regarding the current way of handling the disease showed that difficulties exist: in obtaining information from the patient periodically; in being able to support the rehabilitation of the patient in a remote environment; in establishing a more permanent contact with the caregiver regarding important events that happen to the patient and can change the disease's progress rate; and, lastly, in having an easy and intuitive way of analyzing the disease's progress.

This dissertation addresses these issues by proposing a system capable of: providing the health care professionals with data gathered periodically from the caregiver and the patient; increasing the proximity between the caregiver and the health care professionals; allowing the patient to perform cognitive stimulation exercises in a remote offline environment and by supporting the analysis of the disease's progress by the health care professionals.

For the system to be useful, it needed to be designed with its target group in mind. Thereby interfaces were designed according to the existing guidelines when developing for older adults and more specifically, older adults with dementia. These were tested and tuned according to the feedback of the actors relevant to the system (health care professionals, caregivers and patients).

The feedback received, regarding the system's usefulness and usability, from the health care professionals and caregivers is positive and the results obtained through the testing of the system are promising.

# Resumo

A cada vez mais crescente qualidade nos serviços e tratamentos na área da saúde levou a um crescimento enorme da esperança média de vida nas últimas décadas, o que resulta num aumento do número de pessoas idosas (com idade igual ou superior a 65 anos). Das doenças associadas ao envelhecimento, a Doença de Alzheimer (AD) é uma das mais prevalentes, representando uma taxa de até 80% de todos os casos de demência. Devido aos seus sintomas (perda de memória, mudanças de humor, desorientação no tempo, espaço e às pessoas, entre outros) a doença representa um pesado fardo para o paciente, o prestador de cuidados de saúde e o sistema de saúde. Isto mostra que soluções que abordem este tema e que tentem melhorar a forma como a doença é abordada atualmente são urgentes e necessárias.

A investigação feita relativamente ao estado da arte da forma de lidar com a doença demonstrou que existem dificuldades: em obter informação sobre o paciente periodicamente; em ser capaz de providenciar ao paciente uma forma de fazer reabilitação num ambiente remoto; em estabelecer um contacto mais permanente e constante com o prestador de cuidados de saúde relativamente a aspetos importantes que acontecem com o paciente e que podem mudar a taxa de progressão da doença; e, por último, em fornecer aos profissionais de saúde uma forma de analisar de forma fácil e intuitiva a progressão da doença.

Esta dissertação aborda estas questões propondo um sistema capaz de: providenciar os profissionais médicos com informação recolhida periodicamente do paciente e do cuidador; aumentar a proximidade entre o cuidador e os profissionais médicos; permitir ao paciente realizar exercícios de estimulação cognitiva num ambiente offline e remoto e de suportar a análise da progressão da doença por partes dos profissionais médicos.

Para o sistema ser útil, era necessário que fosse desenhado tendo em conta os seus utilizadores finais. Assim, as suas interfaces foram desenhadas tendo em conta as *guidelines* existentes no que toca a desenvolvimento para idosos, e mais especificamente para idosos com demência. Estas foram testadas e ajustadas de acordo com o *feedback* dos intervenientes finais do sistema (profissionais médicos, pacientes e cuidadores).

O *feedback* recebido por parte dos profissionais médicos e dos cuidadores é positivo e os resultados obtidos através do teste do sistema são promissores.

# Acknowledgements

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Last, but certainly not least, I would like to thank my parents and my sister, not only for their unconditional love and support but also for the sacrifices they made so that I could be where I am today.

Hélder Moreira

*“It all starts with a goal.’*

Michael Phelps

# Contents

# List of Figures

# List of Tables

# Abbreviations

| | |
|---|---|
| AD | Alzheimer's Disease |
| HCP | Health Care Professionals |
| GPS | Global Positioning System |
| PwD | Patient with dementia |
| FAQ | Frequently Asked Questions |
| UCD | User Centered Design |
| RoR | Ruby on Rails |
| MVC | Model-View-Controller |
| HTML | Hyper Text Markup Language |
| CSS | Cascading Style Sheets |

# Chapter 1

# Introduction

Life expectancy nowadays is substantially bigger than some decades ago. There are many factors contributing to that, but more important are the consequences of that fact. The incidence of diseases associated with aging is growing exponentially, creating a burden in the patient, the patient's primary caregiver and also the health care system.

Alzheimer's disease (AD) is one of those diseases, being the most common type of dementia [Ass12d]. It is a neurodegenerative disease, resulting in severe disability, caused by memory loss, difficulty in doing everyday tasks, lost of orientation regarding time, space and people and eventually leads to death.

The diagnosis of the disease is hard, not existing, as of today, a single test that can indicate whether a person has AD or not. Therefore the diagnosis procedure consists in a series of medical histories, an analysis of the symptoms and the ruling out of other diseases.

AD monitoring is done nowadays in the conventional way: the patient, most of the times accompanied by the caregiver, goes to an appointment every 4-6 months. In this appointment, the doctor tries to determine the disease's progress through caregiver feedback and a series of cognitive tests or exercises and establishes a line of treatment that will be re-evaluated in the next appointment.

As for rehabilitation [1] there are some studies that show results and indicate that memory functions can in fact be preserved and in some case improved [Á03] [BCA+02].

The current method of rehabilitation relies on the patient performing these exercises on the appointments with the physician, visiting a facility prepared for that effect or have the visit at home of an occupational therapist with whom he will perform the exercises.

This being said, it is possible to see that AD is in fact an "heavy" disease, having an immense burden on the people involved by its degenerative nature and symptoms. This

[1] while this is a gray area and a general consensus on the medical community has not yet been established on whether it is in fact possible to rehabilitate patients suffering from AD

comes to show that the need to seek solutions and ways to improve the tackling of the disease, thus reducing its burden (both money and psychological wise), is increasingly crescent.

## 1.1 Issues in tackling Alzheimer's disease

Nowadays, monitoring, diagnosing and rehabilitating AD in a patient is a delicate and long process. Since the patient is likely an older adult, and the disease may already have impaired some of his cognitive functions, the need for a caregiver to accompany the patient, and also provide important information, becomes indispensable.

We are facing, therefore, a situation where to monitor and rehabilitate the patient, we need to take into account three different actors: the patient, the caregiver and the doctor. And each of these actors brings additional difficulties into the process.

In most cases, the doctor is part of a public health care system, has on his care dozens of patients, having dementia only represent a small part on his workload [MCG+08]. As for caregivers, most of them are not full-time caregivers, meaning they have jobs and limited availability [Ass08]. All these factors contribute to the fact that a patient does not have a regular, with small intervals of time, appointment routine that would allow the physician to gather and interpret in a more precise and relevant way the patient's symptoms and behaviors and to perform rehabilitation in an interval that would be meaningful and could provide favorable results.

## 1.2 Bridging the gap

The use of technology in the home environment in order to enable the senior population to live as autonomously as possible is the focus of many nations' strategies to address the concerns related to aging and respective diseases.

Whether it would be by supporting people to be socially active, by assisting them in the management of chronic diseases, by monitoring for specific events like falls or wandering, or by any other action that could provide further independence, technology is seen as an enabler for a more autonomous living [For09].

This dissertation proposes a mobile-based system, STAlz[2], that supports the diagnosis, tracking and rehabilitation of the Alzheimer's disease. STAlz uses a mobile application for the caregivers and patients and a web application for the health care professionals. It aims at providing *1)* Frequent monitoring and evaluating metrics; *2)* remote offline rehabilitation; *3)* increased proximity and *4)* support to health care professionals.

[2] The name is derived from the concept of "stalling Alzheimer's" as well as the union of the words "support", "track" and "Alzheimer".

## 1.3 Report Structure

Besides this chapter, this dissertation has 6 more chapters. Chapter 2 makes an overview on Alzheimer's disease and on the current way of approaching it. In Chapter 3, a relation between AD and technological solutions is established, analyzing which technological solutions nowadays focus AD and also detailing the state of the art regarding technological approaches at applications for older adults and older adults with dementia.

The thesis statement is explained throughout Chapter 4, analyzing the approaches proposed for the open issues found. This goes on to be instantiated in a concrete solution, STAlz, in Chapter 5. In there it is described the specification, implementation details and decisions made on the system.

Chapter 6 details the validation methodology used and details the results obtained, discussing them, while Chapter 7 concludes this report by making an overview of the status of the system and proposing possible future work.

# Chapter 2

# Alzheimer’s disease on older adults

This chapter will detail the information gathered on the elderly population, and the incidence of dementia in this age group, more specifically Alzheimer’s disease.

## 2.1 Elderly population

As stated by the World Health Organization, the definition of an older or elderly person is still somewhat arbitrary. Attempts have been made to clearly state the border between mid and old age, such as the age where one can begin to receive pension benefits, or the age where one surpasses the average life span of humans. These however do not apply to all the civilizations (developed countries vs less-developed countries) and thus this is still a gray area. [Org12]

Despite these inconsistencies in terms of a clear age number where one becomes an elderly person, some symptoms are shared by every human entering this stage of life and can be used to determine when it starts occurring:

- Reduced circulatory system function;
- Reduced lung capacity;
- Reduced immune system function;
- Reduced mental and cognitive ability.

Understanding the older adult phase and its symptoms becomes indispensable in order to allow an adequate response when a person enters this phase, since there are everyday more people entering and living it. Due to the lowering of the fertility and birth rate in some countries, the improvements in the health care and social security systems and the aging of the working-age population, we face a shift in the age balance of the population [PMMM11], having the elderly population (65+ years old) reach and even surpass the younger one (aged 5 and younger) [KH09].

This can be witnessed in the population of the European Union (EU), who has the oldest population in the entire world. In 1960, 34 million people were aged 65 and over in the EU. That number has increased to 61 million in 2000, which represents approximately 16% of the total population. [PMMM11]

In figure 2.1, we can analyse the age pyramid in the EU where it is possible to see that the percentage of population aged 65 and over was of approximately 22.5% in 2005 and is projected to reach, according to Eurostat, more than 30% by 2050. [Com08]

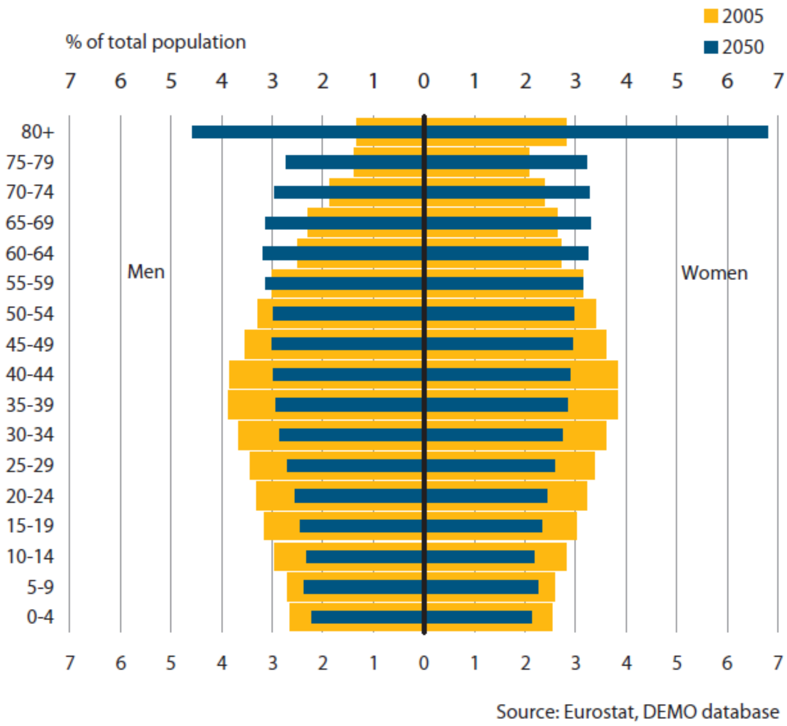



Figure 2.1: Age pyramid in the EU in 2005 and 2050.

Looking at a specific country, Portugal, the life expectancy at birth went from 67 years in 1970 to 80 years in 2010. At 65 years old, the life expectancy experienced a growth of 5 years, increasing from 14 in 1970 to 19 in 2011. According to data provided by the Portuguese's National Statistic Institute, the percentage of population with 80 or more years has grown 35% between 1990 and 2006. It is also possible to see that the number of population with 65 or more years *per* 100 people in an active age (15 to 65 years old) has increased from 20 to 26 in the same period. [Est07]

This increase in the elderly population raises new concerns on aging related diseases and symptoms, being dementia one of the most common and troubling [FDRAT99]. It can be characterized as a serious loss of global cognitive ability, happening at a higher rate than what would be expectable from normal aging, and affecting cognitive areas such as memory, attention, language and problem solving [Ass12a].

Among the most common forms of dementia are: Alzheimer's disease, vascular dementia, frontemporal dementia, semantic dementia and dementia with Lewy bodies [Ass12c].

The next section will detail the analysis made to the Alzheimer's disease current state of the art in terms of diagnosing, monitoring and rehabilitating.

## 2.2 Alzheimer's disease

Alzheimer's disease (AD) is a neurodegenerative disease, which is the most common type of dementia accounting for 50 to 80 percent of all dementia cases [Ass12d]. It was first described by German psychiatrist and neuropathologist Alois Alzheimer in 1906 and named after him. There is currently no cure for the disease and while the cause and progression rate are still not fully understood, the following are considered to be some early indicators of a possibility of AD [Ass12a]:

- Memory loss that disrupts daily life;
- Challenges in planning or solving problems;
- Difficulty completing familiar tasks at home, at work or at leisure;
- Time and spatial disorientation and confusion;
- Trouble understanding visual images and spatial relationships;
- New problems with words in speaking or writing;
- Misplacing things and losing the ability to retrace steps;
- Decreased or poor judgment;
- Withdrawal from work or social activities;
- Changes in mood and personality.

The disease is a major cause of disability in older people (eventually leading to death) and represents a substantial burden and decrease in the quality of life of not only the patient, but also of the designated caregiver and the public health system, since it has a huge impact physical, psychological, economical and social wise [MCG+08]. According to the Alzheimer's Association, it is estimated that the disease costs on average 172 billions dollars globally in annual costs. [ANMF10]

When tackling the disease, there are usually three different actors involved, as seen in figure 2.2. The interaction between these three members (health care professional, patient and caregiver) is vital to guarantee an environment where the AD patient can be supported and a proper course of diagnose/treatment established.

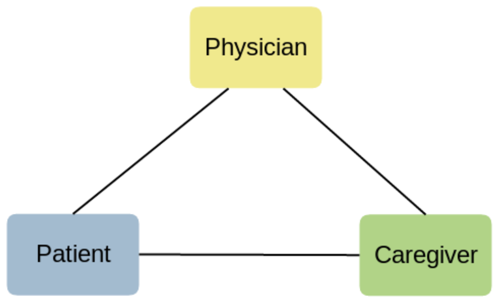



Figure 2.2: The relation between the actors in an AD environment.

### 2.2.1 Stages

A patient with AD is normally categorized in one of three different stages: early/mild, moderate/middle or severe/late, and symptoms and signs can be associated with each phase [Gui13] [Cli13]. For further detail on each phase and the symptoms associated with it, please see appendix A.

### 2.2.2 Caregivers

Caregivers can be classified as formal or informal. Formal caregivers are usually paid providers while informal caregivers are usually a related member who assists the patient at home with his needs. When care is being provided in the home it is usually seen a mixture between formal and informal caregiving [Gro13].

Caregiving takes a large personal toll on the dementia informal caregiver (from here on only referred as caregiver) and her/his family: 55% have less time for other family members; 49% give up vacations, hobbies or social activities; 30% get less exercise than before. Over 40% report high levels of emotional stress. One in five dementia caregivers is in fair or poor health and 18% say that caregiving has made their health worse [Ass08].

More than even general caregivers, AD caregivers experience harder circumstances and burdens. They spend more hours a week providing care than other caregivers (nearly 1 in 4 provide "constant care" – committing 40 hours a week or more) and they do it for a longer period of time (71% for more than a year and 32% for five years or more) [Ass08].

Like other caregivers, the majority of AD caregivers work full or part time. But, as stated, even more than other caregivers, their responsibilities at work are adversely affected by the demands of caregiving [Int09]. Two thirds of working Alzheimer caregivers reported that they missed work because of their caregiving responsibilities; 14% gave up work entirely or chose early retirement; 13% cut back on their work hours or took a less demanding job; 8% turned down a promotion; 7% lost job benefits. Besides this, economical difficulties also arise. Around half of the caregivers have made modifications to their loved one's home (52%) and obtained assistance devices to accommodate their needs (48%) [Ass08].

These indicators come to show how demanding and burdening caregiving for an Alzheimer's patient can be. To know more about this, what their main difficulties are and how they could be addressed, several informal caregivers were interviewed[1] as part of the research made.

They reported that it was common not knowing what to do and how to react to some situations. A closer relation between the caregiver and the medical professionals associated with the patient's treatment could be key to ensure that the caregiver is well informed and trained to deal with the situations that can emerge.

### 2.2.3 Diagnose

There is no test that can confirm a diagnosis of Alzheimer's disease. This makes it so the diagnosis needs to rely mainly in a medical evaluation that includes [Ass12b]:

- A thorough medical history;
- Mental status testing (see 2.2.4);
- A physical and neurological exam;
- Tests (such as blood tests and brain imaging) to improve diagnosis and rule out other symptom-similar diseases.

This kind of diagnosis (based on evaluation over time) is a slow, thorough process that can take long periods of time. Alzheimer's symptoms are similar to other dementias which can make the diagnosis difficult.

To better understand the state of the art and as part of the research made regarding diagnosis, monitoring and rehabilitating the Alzheimer's disease, medical specialists working at the Hospital S. João (Porto, Portugal) were interviewed. They stated that this is an even more tardy process since the moments of evaluation are usually very widely spaced (6 months usually). This is mainly due to two factors: *1)* constraints in the health care system. The doctor has time constraints while the health care system has both limited time and money to maintain a stricter schedule of appointments; *2)* for the metrics gathered to be meaningful, we need to space the data gatherings. The spacing required is however smaller than the current time interval of appointments.

Summarizing on this, while there is a minimum interval of time between data gatherings, the time between appointments greatly exceeds it, suggesting that even though the evaluations need to be spaced, they could be done in a smaller interval than what is done currently and this could potentiate a better and earlier diagnosis of the Alzheimer's disease.

[1] these caregivers were volunteers for the project and were part of one of the follwoing centers: Centro Social Paroquial de Rio Tinto, Associação Social e Cultural de S. Nicolau, Centro de Convívio para idosos do Bonfim and Hospital S. João.

### 2.2.4 Monitorization

The monitoring of AD patients is nowadays done almost completely at routine appointments, in a time interval of 4 to 6 months each. In each appointment, the doctor tries to establish the patient's and the caregiver's cognitive and pshycological state to better determine the course of treatment to follow.

As said, the physician examines not only the patient but also the caregiver. There are some reasons behind this: *1.* the caregiver is the person who typically spends more time in contact with the patient and by examining his/her state of mind, it is possible to gather information about the patient; *2.* since the patient's answers as to how he has been doing (*i.e* has he been doing well, is the patient agitated frequently, does the patient eat and sleep well) cannot be verified due to the cognitive impairment associated with the disease, the caregiver is a reliable source of information regarding these issues; *3.* the stress associated with being the caregiver of an AD patient affects the caregiver's health and that is something the physicians are looking to prevent.

There are cognitive assessment tests designed to help the physician in this evaluation. Some of them focus on the patient, assessing his cognitive state, while others focus on the caregiver, assessing his stress and burden as well as the patient's main cognitive functions through the caregiver.

The following sections present some of the most used cognitive assessment tests used for these evaluations.

#### Mini Mental State Examination (MMSE)

The MMSE [Soc12] (see example on section B.1) is a series of questions and tests designed to test a number of different mental abilities, including memory, attention and language. The test has a maximum score of 30 points and values above 27 are considered normal, however scoring below 27 does not mean the person has dementia. The mental abilities of the patient might be impaired for some reason (difficulty hearing, for instance) and that needs to be taken into account.

This test can be used as a diagnosis tool but is also used to measure changes in a patient who is already diagnosed with AD, providing information on how quickly the disease is progressing and the patient is deteriorating. These are important factors when considering the course of action and the medication suited for the patient.

On average, patients with AD who are not receiving treatment lose two to four points each year.

#### Montreal Cognitive Assessment Test (MOCA)

The MOCA [NPB+05] (see example on section B.2) is a cognitive assessment test developed to assist first-line physicians in detecting mild cognitive impairment. It is a one page 30 point test that can be administered in approximately 10 minutes. It assesses several areas of cognitive function, such as: memory, attention and concentration, executive functions, language, conceptual thinking, calculations and orientation.

Values above 26 are considered normal and it is also taken into account the literacy of the patient to adjust the score.

#### Frontal Assessment Battery (FAB)

The FAB [DSLP00] (see example on section B.3) is a short behavioral battery to assess frontal lobe functions. It can be performed in about 10 minutes and used in a bedside or clinic environment.

It explores six different areas with highly user-friendly tests: conceptualization, mental flexibility, motor programming, sensitivity to interference, inhibitory control and environmental autonomy. More than evaluating the cognitive deterioration's rate, the test is also useful to diagnosis AD patients as it can be used to differentiate between degenerative disorders involving subcortical structures [Cen12].

The test has a maximum score of 18, with higher scores indicating better performance.

#### Neuropsychiatric Inventory (NPI)

The NPI [Cum97] (see example on section B.4), developed in 1994, was designed to assess dementia-related behavioral symptoms which in the opinions of the creators, were not sufficiently addressed in other tests. It covers many sub-domains of behavioral functioning like: delusions, agitation/aggression, hallucinations, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability and aberrant motor activity, night-time behavioral disturbances and appetite and eating abnormalities.

It is a test administrated to the caregiver of the patient, and a screening question is asked about each sub-domain. If the responses indicate problems, the domain is further explored with additional questions to establish the frequency, severity and distress caused by that problem.

#### Zarit Burden Interview (ZBI)

The ZBI [ZRBP80] (see example on section B.5) presents itself as a measure for the caregiver stress. Each item is a statement, which the caregiver rates based on frequency on a scale of 0 (never) to 4 (nearly always). By analyzing the responses it is possible to obtain indicators on the patient's condition.

This measure was analysed [HBP00] and results showed that the measure had good internal consistency reliability and that it is unrelated to age, gender, locale, language, living situation, marital status, or employment status, indicating its suitability for use with a variety of populations.

#### Instrumental Activities of Daily Living (IADL)

The IADL, scale of Lawton and Brody [LB69] (see example on section B.6) is an instrument to assess independent living skills. It is useful for identifying how a person is functioning at the present time and for identifying improvement or deterioration over time.

The test should be done to the caregiver of the patient, and there are 8 domains of function measured with the Lawton and Brody IADL scale. Historically, women were scored on all 8 areas of function; men were not scored in the domains of food preparation, housekeeping and laundering. However, current recommendations are to assess all domains for both genders. Persons are scored according to their highest level of functioning in that category. A summary score ranges from 0 (low function, dependent) to 8 (high function, independent).

### 2.2.5 Rehabilitation

Cognitive stimulation, in general, and memory rehabilitation, in particular, is a wide area of research, and therefore the research made was focused on cognitive stimulation and memory rehabilitation related only to AD.

The evidence currently available suggests that cognitive rehabilitation produces significant improvements in targeted areas, at least for a part of treated patients, and that alternative and innovative ways of memory rehabilitation in the AD context can be effective and useful [CBT06] [VN01]. Studies have also shown [Á03] [BCA+02] that memory can in fact be preserved and in some cases improved.

Another aspect to note is that the constant and direct participation of a relative or carer as co-therapists enhance the efficiency of the cognitive stimulation process in AD patients. [VN01].

Rehabilitation is made in various areas, being the most common [Pen]:

- *Attention* - aimed at improving and maintain concentration and attention of the person in all its forms: focused attention, sustained, selective, alternating and divided; spatial orientation of attention, alertness and executive attention;

- *Executive functions* - aimed at training their own behavior, the ability to sequence and organize the information, removing irrelevant data, abstract language understanding and reasoning about visual information;

- *Language* - designed to improve the patient's ability to communicate, by expressing herself and by understanding others. These exercises train aspects like naming objects, sentence construction, word meaning, among others;

- *Memory* - activities to improve the recovery of verbal information, visual information, faces, stories, events, spatial locations, visual scenes, groups of words and objects, etc;

- *Perception* - Works the recognition of the most important features of visual stimulation: the shape, color, size, contour, position in space, isolated details, lines and edges.

These rehabilitation exercises are performed by patients almost exclusively in occupancy centers or in hospitals. This becomes a problem because according to the physicians consulted, for a useful cognitive stimulation the patient needs to practice the exercises a minimum of 3 times a week, and, as stated before, the appointments are made in a time interval that does not allow for this. The occupancy centers where patients could perform this stimulation are also often overcrowded, and even if they were not, mobility (both caregiver and patient) and availability (caregiver) issues would also create an obstacle for a proper rehabilitation schedule.

These factors contribute to the fact that only a small share of AD patients has access to rehabilitations methods that could provide cognitive stimulation and at least delay the progress of the disease.

## 2.3 Summary

AD is a major cause of disability in older people and creates an immense burden in the patient, the caregiver and the public health care system.

As of today, there is no test to determine whether a person has AD and therefore the diagnosis relies on medical histories, mental status testing, physical and neurological exam as well as medical exams to rule out other diseases. This is a long process, that becomes even longer when combined with the time (both of the health care professionals and the hospital) and money (hospital) constraints that lead to an overly space set of appointments.

The same situation applies to monitoring. While there is a need to keep the data gathering moments spaced through time, this interval is wider than necessary. This poses problems in the disease monitoring, compromising a quick intervention from the HCPs when an abnormal situation occurs or a change in the course of treatment is necessary.

Regarding rehabilitation, while there is no clear consensus in the medical community, there are studies suggesting that it can indeed be made with promising results. The areas where it is more common are: attention, executive functions, language, memory and perception.

# Chapter 3

# Technological approaches and related work

Nowadays, mobile technologies have evolved to a point where they are more accessible, more inexpensive and more easy to use. They gather an array of features such as motion sensing, video calls, wireless communication, GPS tracking, voice recognition among others, making them perfect targets for the development of technology products.

Mobile phones who offer such functionalities are commonly labeled as smartphones. By definition, smartphones are mobile phones that offer more advanced computing and connectivity abilities than a contemporary feature phone (lower-end mobile phones that feature basic functionalities and usually have proprietary operating systems (OS) with limited third-party software support). In other words, smartphones are devices which integrate typical mobile phone capabilities with common features of handheld computers [Mou11].

According to estimates, by the end of this current year, there will be 1.4 billion smartphones in use. Of these, 798 million will run Android, 294 million will run Apple's iOS, and 45 million will run Windows Phone. With the world population at 7 billion that will mean one phone for every five people in the world. The annual smartphone growth rate in 2013 is projected to be 44 percent. This is 3 points down from 2012's, when the growth rate was 45%, but is still a fast growing pace [Ins13].

Recent numbers show that in the EU5 (UK, France, Germany, Italy and Spain) users aged 55 or older represent 18.1% of the composition of the whole smartphone market, surpassing the 18-to-24 bracket with its 14.5% (Figure 3.1).

This comes to show that smartphones are indeed a platform to look for when developing applications for older adults. Their market penetration is already high, and will grow in the future. They are light, easy to carry, relatively inexpensive and provide many aspects that could be exploited, improving the quality of life of the elderly population.

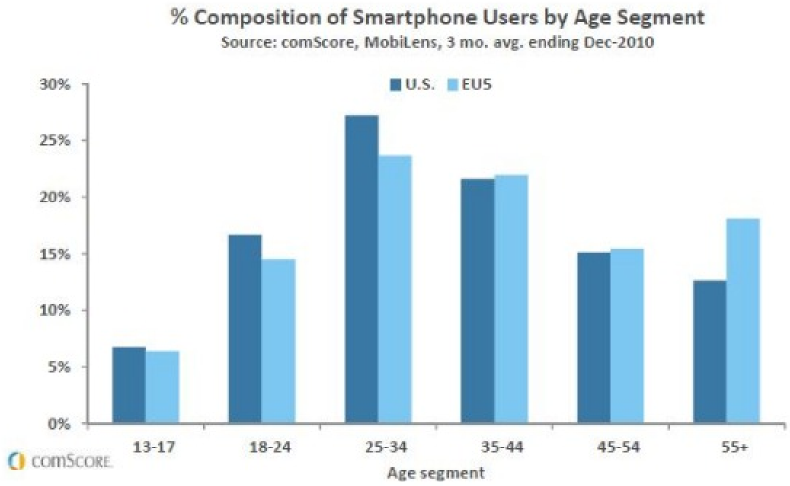



Figure 3.1: Smartphone penetration divided by age segments [Cha13].

To better understand the state of the art in technological solutions that focus on the problem described in this work, research favoured solutions aimed at monitoring and rehabilitating AD. While STAlz also aims at supporting the diagnosis (through monitoring) it does not provide a diagnosis for the disease and thus solutions which aim at that (for instance, the solutions mentioned in [LRG+09] and [SGGR+10]), were not considered as related work so as to not widen too much the research.

## 3.1 Monitorization

To date, the author is not aware of any tool or technological solutions focused on monitoring AD patients. Given that, the scope was widened to include solutions focused on monitoring elderly patients in general.

### 3.1.1 Vassilis Pigadas et al.

The system presented in this research product [PDPM11] utilizes a smartphone and wearable sensors to offer extra protection to patients that have been recently hospitalized or suffer from chronic diseases. It aims at providing constant monitoring of the patients with the use of an array of sensors, such as light, GPS, and accelerometer.

Since the work was still in progress at the time, there are no results on the usability, usefulness or functionalities present in the system, and also no information on its current development phase.

### 3.1.2 VALMA

The Voice, Activity and Location Monitoring System for Alzheimer's disease (VALMA) [TSW+11] is a system that tries to improve the patient's quality of life. It retrieves measures of physical, audio, sleep and GPS activity through the use of sensors. The system aims at being unobtrusive (i.e., maintain regular appearance), sensitive (i.e., high resolution), simple to use and control and considerate of private data.

The goal is that these measures of everyday activity will impact the diagnosis of the disease and provide better information on how to slow the disease's progress.

### 3.1.3 iWander

iWander [SDT10] is an application designed to try and evaluate whether the patient is wandering, by collecting data in the background from the device's Global Positioning System (GPS), the device's sensors and user feedback, and then evaluating it in a Bayesian network.

The system determines the probability of the person being wandering. Depending on the probability, iWander takes actions that could range from helping navigate a patient to a safe location (using Google's Navigation), to placing a call to 911 (or the caregiver) and providing the patient's coordinates.

### 3.1.4 Guide Me

Guide Me [LSK+04] presents itself as a system aimed at improving the patient's quality of life. It's a system that provides information over the patient's location, indicating whether he's wandering. This is done by comparing the patient's location to the location he was supposed to be going. It also provides a life-line for the patient, which can be activated by clicking the only button in the device, which will then place a call to the designated caregiver.

The feedback for the system was positive, with doctors saying the the system could allow for patients with AD to remain at home longer, without the need to go into a full-time care facility so soon in the disease progress.

### 3.1.5 AlzNav

AlzNav [Mou11] is a mobile application that provides older adults and persons with dementia, as well as their caregivers, with a greater sense of safety whenever they go outdoors.

It achieves this goal by monitoring their location and making sure that they remain within a safe perimeter. Whenever they stray from their safe zone, they are alerted to this circumstance and can choose to call for help or be navigated back to a safe place. Caregivers are also automatically alerted of the situation, and of their cared for's location, so that they can take action if necessary.

### Summary

While the solutions presented regarding monitorization present a valuable asset when monitoring general health indicators and when tracking dementia patients geographically (mainly in advanced stages of the disease), none focuses on monitoring AD patients specifically and none is able to measure relevant AD data even if not aiming at it specifically. Additionally, no solution found to date treats the caregiver as a source of information rather than just a receiver of the information gathered by the systems.

## 3.2 Rehabilitation

Studies have shown that the rehabilitation results are improved, particularly if it stimulates both information acquisition and information retrieval. On this line, computer training is a good way of stimulating these parts as it include exercises aimed at stimulating new information learning and exercises involving information retrieval from semantic memory [CBT06]. This results in improvements not only on the patient's performance in the computer tests but also at traditional cognitive assessment tests.

### 3.2.1 CogWeb

CogWeb [Cog12] is a web platform that provides the patient with cognitive stimulation programs in various areas, such as: attention, concentration, memory, language and executive functions. The system does not focus a particular disease and it provides ways of monitoring the patient's progress through performances reports. It also automatically adjusts the patient's exercises according to the results in the different exercises.

### 3.2.2 RehaCom

RehaCom [Reh12] is a computer program designed to provide the patient with brain exercise. It is a modular system, widely used in cognitive rehabilitation and with many types of different adaptive games to allow the patient to feel engaged and motivated. [RMR10].

It uses a special keyboard along with a joystick to provide the patient with a simple interface and covers areas such as: attention, memory, executive functions, field of view training and visuo-motor skills. Due to the fact that it requires special equipment, the system is used mainly clinics and hospitals.

Even though not directly aimed and used to treat AD, RehaCom has demonstrated to have sufficient flexibility, simplicity, accessibility, dynamics and objectivity to make a useful contribution to clinical practice [MBS+12]. Due to its interactive capabilities, it allows the treatment of a large number of patients and record their results, while reporting effectiveness in recovery of attention and memory with reliable progress and transfer effects to other functions.

The figures 3.2 and 3.3 represent two examples of games from this platform.

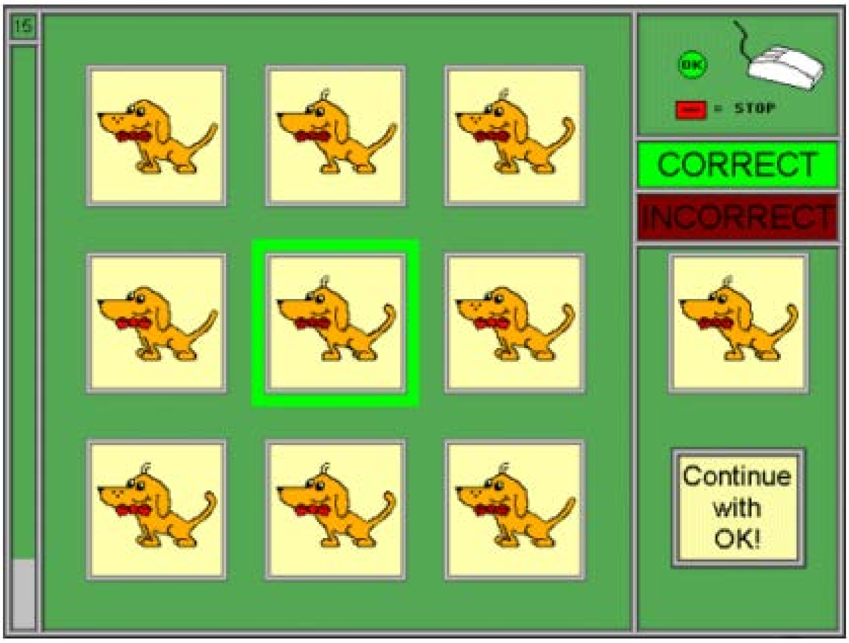



Figure 3.2: Example of an attention game from RehaCom [RMR10].


Figure 3.3: Example of a game, Plan a Day, from RehaCom [RMR10].

### 3.2.3 Lumosity

Lumosity [Lum12] is a web platform designed to provide an online brain training. It provides the patients with brain stimulating exercises in the areas of memory, attention, flexibility, speed of processing and problem solving. The Lumosity brain training focuses mainly in games, relying on the user experience and engaging games to keep the patient motivated. Each game targets a critical component of brain function, with them being adaptive, meaning that the difficulty is adapted automatically to the user's response [HS09].

A recent study has shown that patients using the Lumosity program along with brain boosting foods have showed significant effects in brain performance and learned significantly better than the patients in the counter groups. [Kpo12].

The figures 3.4 and 3.5 represent two examples of games from this platform.

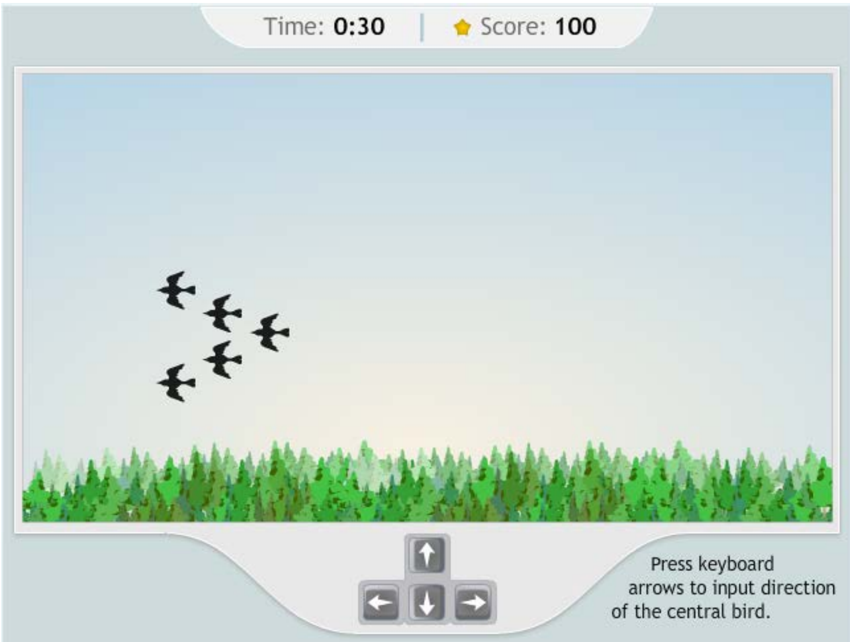



Figure 3.4: Example of an attention game from Lumosity [Lum12].

### Summary

The solutions presented in the past sections present a good base to work on in the area of rehabilitating exercises since they have showed good results and efficiency. The need for an active internet connection and in some cases specific equipment are however dependencies that limit their usage and availability to a larger group of users. These solutions combine a gaming experience with cognitive rehabilitation concepts, providing the user with a nice experience while at the same time stimulating key areas of the brain.

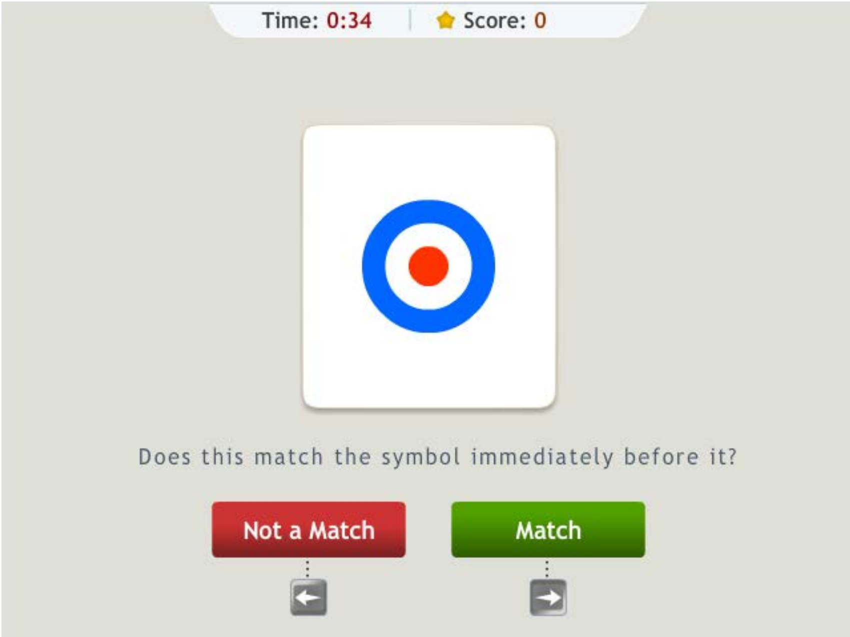



Figure 3.5: Example of a speed matching game from Lumosity [Lum12].

## 3.3 Design guidelines when developing for AD patients

Apart from technological solutions, a research was made on design guidelines and principles to follow when developing for older adults and more specifically persons with dementia. The results of this research can be seen in the following sections.

### 3.3.1 Principles of Universal Design

The Center for Universal Design at North Carolina State University has developed a set of seven Principles of Universal Design aimed at designing products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design [CJM+97] [Sto98].

These principles may be applied to evaluate existing designs, guide the new products' design process as well as teaching students and practitioners and are quoted in the following sections.

#### Principle 1: Equitable Use

The design is useful and marketable to people with diverse abilities.

- Provide the same means of use for all users: identical whenever possible; equivalent when not;
- Avoid segregating or stigmatizing any users;
- Provisions for privacy, security, and safety should be equally available to all users;

- Make the design appealing to all users.

**Principle 2: Flexibility in Use**

The design accommodates a wide range of individual preferences and abilities.

- The design accommodates a wide range of individual preferences and abilities;
- Accommodate right- or left-handed access and use;
- Facilitate the user's accuracy and precision;
- Provide adaptability to the user's pace.

**Principle 3: Simple and Intuitive Use**

Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.

- Eliminate unnecessary complexity;
- Be consistent with user expectations and intuition;
- Accommodate a wide range of literacy and language skills;
- Arrange information consistent with its importance;
- Provide effective prompting and feedback during and after task completion.

**Principle 4: Perceptible Information**

The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

- Use different modes (pictorial, verbal, tactile) for redundant presentation of essential information;
- Provide adequate contrast between essential information and its surroundings;
- Maximize "legibility" of essential information;
- Differentiate elements in ways that can be described (i.e., make it easy to give instructions or directions);
- Provide compatibility with a variety of techniques or devices used by people with sensory limitations.

**Principle 5: Tolerance for Error**

The design minimizes hazards and the adverse consequences of accidental or unintended actions.

- Arrange elements to minimize hazards and errors: most used elements, most accessible; hazardous elements eliminated, isolated, or shielded;
- Provide warnings of hazards and errors;
- Provide fail safe features;
- Discourage unconscious action in tasks that require vigilance.

**Principle 6: Low Physical Effort**

The design can be used efficiently and comfortably and with a minimum of fatigue.

- Allow user to maintain a neutral body position;
- Use reasonable operating forces;
- Minimize repetitive actions;
- Minimize sustained physical effort.

**Principle 7: Size and Space for Approach and Use**

Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

- Provide a clear line of sight to important elements for any seated or standing user;
- Make reach to all components comfortable for any seated or standing user;
- Accommodate variations in hand and grip size;
- Provide adequate space for the use of assistive devices or personal assistance.

### 3.3.2 ENABLE project

ENABLE is a three year longitudinal study, funded by the European Commission and involving five countries to examine the feasibility of devices, and to assess the socio economic costs of providing technology to enhance the quality of life of people with dementia and their caregivers [Jon04].

It was conducted as an exploratory and descriptive study, with the overall aim being to determine whether it is possible to facilitate independent living of people with dementia, and to promote their well being by facilitating access to enabling technological systems and devices. Between March 2001 and June 2004, the Enable methodology was guided by the ethical considerations and the needs of people with dementia in research from five European countries – England, Lithuania, Ireland, Finland, and Norway, with the overall objective for the study being to:

1. Define the feasibility of the devices;
2. To assess the effects of providing assistive devices to people with dementia;
3. Provide a comparative analysis of the devices tested by European countries.

### Guidelines designed by the ENABLE project

Since most patients with dementia (PwD) are people above 65 years old, not only we need to consider their special needs, we also need to take into account the changes related to elderly people. Some examples of these changes are [Jon04]:

*Reduced physical strength, mobility, and co-ordination*
Poor balance
Reduced ability to handle small controls and objects

*Visual changes*
From 55 to 75 years of age the field of vision is reduced by 50%
Ability to distinguish differences in contrast and light is generally reduced
Ability to focus is reduced
A person of 89 years needs many times more light than a younger person
Reduced ability to discriminate colours, especially between green and blue
The eye is more vulnerable to glare, because it takes longer for the pupil to contract

*Changes in hearing ability*
Reduced ability to hear high frequency sounds is quite common (cannot hear birds any more). But the largest consequences are when the ability to hear frequencies between 300 and 3000 Hz is reduced, because this is where the human voice lies.
It is more difficult to distinguish where the sound comes from.

*Slower reaction time*
Increased time to make decisions
Longer response time on signals
The combination of quick movements and dexterity increases reaction time

*Changes in memory and learning ability*

Learning and perceiving new information takes longer
It takes longer to recall memory
It takes longer to recall names on persons and things

With these and the needs of people with dementia in sight, the ENABLE project establishes that products and applications are appropriate for people with dementia if they have the following characteristics:

- They give a feeling of independence to the person;
- They support the person in making choices;
- They have a positive impact in her/his life;
- They support the skills maintained and do not emphasize lost skills;
- They do not treat the user as a person with disabilities, but supports the self image of being a person with abilities;
- They remind of solutions that existed before;
- The use of the products is possible by the information visible/available at all times.

These characteristics led the ENABLE project to establish a set of guidelines that should be followed when developing a product aimed at people with dementia. They are the result of close co-operation with and inputs from the partners in the project, focus groups with professionals, carers and people with dementia, and from the process of and discussions during the assessment study. These were experienced and defined by the Bath Institute of Medical Engineering [EBC] as follows:

- No learning should be needed on the part of the user. Devices that require even some limited learning were useful for people in the early stages of dementia and for carers, but could not be easily used by people in the later stages of dementia;
- Support equipment should seem familiar. For people with dementia a new device has to operate and feel just like similar equipment they have always been used to. The supportive features need to be incorporated in an invisible way;
- Control should not be taken away from the user. The product should not need a third party person to intervene so that the user can proceed with his experience;
- The user should be reassured by the device. Support technology should not be threatening or alarming. Examples of this are lights: they should not turn on or off rather than fade in and out;

- Devices that make judgments about user behaviour must deal with errors. Such judgments are by definition probabilistic and will inevitably on occasion be in error. Any errors should be false positives, *i.e.* something turns off when it doesn't need to, rather than stay/turn on when it should not;
- For devices that are providing backup and support to ensure safety it is preferable that the user should not have to interact directly with the device. In these cases the best support device is one that can detect when it has to support the user and do so automatically without their intervention;
- Safety critical devices must have a backup that can call for help.

**Complementing the principles of universal design**

Even though the principles of universal design (section 3.3.1) aim at making all products usable by all users, special needs apply in how technology can be of benefit to people with dementia, and these have been defined in ENABLE, who complemented the principles of universal design [EBC].

**Principle 1: Equitable Use (3.3.1)**

| Needs | Requirements |
|---|---|
| - Prevent stigmatisation<br>- Maintain social contact<br>- Safety<br>- Ethical considerations<br>- Age relevance and familiarity<br>- Enough time to carry out tasks<br>- Support empowering and reassurance<br>- Low cost or available financing | - High quality products for adults<br>- If using pictograms, make sure they are logical and self-explanatory to this age group<br>- Emphasise interactive aspects<br>- Intrinsic safety<br>- Consent procedures in case of monitoring<br>- Familiar and attractive design, the way they are used to. Adapting a product they are used to<br>- Aesthetically pleasing<br>- Avoid childishness, use familiar concepts, avoid "funny", special and decorative fonts for information |

Table 3.1: Principle 1: Equitable Use

**Principle 2: Flexibility in use (3.3.1)**

| Needs | Requirements |
|---|---|
| - Adaptability to individual needs and changing conditions | - Pre-programmable choices (invisible to PwD) |
| - "Happy helpers", do not annoy caregivers | - User friendliness for the caregivers: no extra work, integration of product in daily activities |
| - Right as well as left-handed mode of use | - Preferably not for one OR the other |
| - Adaptability to pace and coordination problems | - Ensure enough time to carry out an activity and enough time between activities.<br>- Individual settings if possible |

Table 3.2: Principle 2: Flexibility in use

**Principle 3: Simple and intuitive use (3.3.1)**

| Needs | Requirements |
|---|---|
| - Solve common problems easily, increase independence | - Link with long term memory<br>- Intrinsic logic |
| - Minimal need for learning | - Few functions, operations and choices in one product |
| - Experience of sucess | - Recognizable product / function |
| - Avoid stress, produce stimulation | - Avoid too much information at one time. |
| - Avoid confusion | - Remove irrelevant and confusing information and decoration |
| - Maintaining of familiar situations | - Restrict number of actions necessary |
| - Using long term memory | - If several steps: logical, visual and clear |
| - Pleasurable to use products, aesthetics, touch, dignity | - Product and control must be together |
| - Not to have to reaseon | - Preferably no remote control |
| - Feeling of enabling | - Switch should give traditional feedback, by feeling the turn or a click<br>- Easy to see it<br>- Pushbutton controls with click provides good tactile cues |
| - Feeling of familiarity and a natural solution to a problem | - Do not mix different types of operation, like turning, pushing, pulling<br>- Automatic functions must not be confusing |

| | |
|---|---|
| - Assistance in time orientation<br>- Respect for normal age related changes | Add aids to already existing and used technology, e.g. place an automatic calendar next to a clock or an aid that shows what time of the day |

Table 3.3: Principle 3: Simple and intuitive use

**Principle 4: Perceivable information (3.3.1)**

| Needs | Requirements |
|---|---|
| - Meet the needs associated with normal aging changes in vision | - No glare or reflexes, provide large letters and numbers and good contrast between text and background<br>- Sufficient lighting<br>- Consistent color coding<br>- Put the most important information in the middle of the visual field<br>- Make certain that text has the size and dimensions in relation to reading distance and light<br>- Good fonts are Helvetica, Arial and Verdana<br>- Information must be clearly visible, in simple, plain words, in understandable language<br>- Isolate individual messages<br>- Reduce speed of spoken messages<br>- More functions in one product can be confusing |
| - Meet the needs associated with common age related cognitive problems | - Form, colour and materials must support the recognizability and/or function of the product<br>- Put the product in a logical place<br>- Avoid unnecessary decoration (for example background decoration)<br>- Give analogue instead of digital numbers, for example for a clock<br>- Use letters rather than symbols /pictograms<br>- If using graphical illustration (pictograms) for information, make sure it is logical and familiar, and combine with text<br>- Use more signals to attract the attention to the same function, e.g. image, sound and color |

| | |
|---|---|
| - Meet the needs associated with normal age related hearing changes | - Do not rely on auditory cues or warnings only<br>- Make volume control logical and easy to operate<br>- Keep auditory messages in the range between 500 and 1500 Hz<br>- Reduce or remove confusing background noise<br>- If auditory message is given, use a sound first to get the attention<br>- Sound pitch. Choose intermittent or continuous |

Table 3.4: Principle 4: Perceivable information

**Principle 5: Tolerance for error (3.3.1)**

| Needs | Requirements |
|---|---|
| - Reliable products, these users have lower tolerance for errors | - The product must work immediately, no waiting time, because of short concentration span<br>- Prototypes must be fail safe to be tried with this user group |
| - Experience of failure is distressing to people with dementia, and lead to not wanting to use the product | - Fail safe backup<br>- No possibility to injure oneself |
| - Feeling of safety and security is depending on stable functionality | - Spoken messages of danger must be clearly distinguishable from background noise<br>- Emphasize good diction and pronunciation in spoken messages. Some consonants are difficult to distinguish from each others in auditory messages: s, f, sh<br>- Fireproof<br>- No loose parts<br>- Safe to put in the mouth, not contain hazardous materials or colors.<br>- As few plugs or electric flexes as possible<br>- Domestic appliances must switch off automatically if failure |

| | |
|---|---|
| - Supporting safe taking of medication | Give clear messages of what is wrong if errors<br>- Not expect reasoning in error corrections<br>- Not breakable, stable, solid, good quality products<br>- In signaling, red is danger, green is safe<br>- Alerting the person of dangers is not enough, it is often necessary to alert the carer also |

Table 3.5: Principle 5: Tolerance for error

**Principle 6: Low physical effort 3.3.1)**

| Needs | Requirements |
|---|---|
| - Meet the needs associated with lower physical strength, poorer fine co-ordination | - Large controls, suitable to the hand's optimal, functional position<br>- Avoid fine manipulation<br>- As few manual operations and little hand strength as possible<br>- Sometimes it is easier to control a product with both hands |

Table 3.6: Principle 6: Low physical effort

**Principle 7: Size and space for approach and use 3.3.1)**

| Needs | Requirements |
|---|---|
| - Relevant in relation to where product is positioned | - Not require unfamiliar movements or locations<br>- Place all controls within comfortable reach of where the user normally is for each activity<br>- Use mechanical principles to ease movements |

Table 3.7: Principle 7: Size and space for approach and use

Design concerns when developing for older adults and older adults with dementia has been the target of several studies and effort. This has produced several guidelines and principles that could be followed to maximize the usability of the solutions produced.

These guidelines have in consideration not only the special needs of older people, but always of people with dementia. Perceptible information, minimum physical effort, tolerance for errors, flexibility in use while being simple at the same time are some examples of these guidelines.

## 3.4 Summary

Throughout this chapter we have analyzed the approaches made at AD in terms of technological solutions. Solutions regarding the monitoring of dementia patients were analyzed, suggesting that while they present a valuable asset when monitoring general health indicators and when tracking dementia patients geographically (mainly in advanced stages of the disease), none is able to monitor AD patients specifically. Additionally, no solution found to date treats the caregiver as a source of information rather than just a receiver of the information gathered by the systems.

Regarding rehabilitation, the solutions presented are a good base to work on in the area of rehabilitating exercises. They have showed good results and efficiency, combining a gaming experience with cognitive rehabilitation concepts. They show however some limitations, such as, the need for an active internet connection and in some cases specific equipment. This limits the availability of these solutions to a larger group of users.

When developing for older adults, and more specifically older adults with dementia, special concerns are needed in terms of design and interface. With that in mind, research was made to establish the work done so far regarding this. This area has been the target of great effort in the last years, and was able to identify a great set of concerns„ producing guidelines and principles that can be used to maximize the usability of the solutions designed. Perceptible information, minimum physical effort, tolerance for errors, flexibility in use while being simple at the same time are some examples of those.

# Chapter 4

# Bridging the gap on Alzheimer's disease

After analyzing the current state of the art regarding diagnosis, monitoring and rehabilitation in Alzheimer's disease (see chapter 2), the author identified a list of issues in need of attention:

1. *Overly spaced data gathering moments* - The interval between appointments is usually bigger than what was desirable, making the information about the patient overly spaced and incomplete;

2. *Lack of remote rehabilitation* - The patient does not have an offline and mobile platform to perform cognitive stimulation exercises remotely, that could provide the doctor with results to analyze the disease's progress;

3. *Inadequate communication* - Unpredicted events that happen with the patient (hallucination, agitation, other diseases, etc.) are a major cause of stress and worrisome for the caregiver, who has no unobtrusive method of communicating with the doctor;

4. *Lack of health care professionals support* - The occupational therapist, for instance, has no technological solutions to support his work with the caregiver, allowing him to easily establish progress metrics on the patient's and the disease's progress.

These issues reflect the constraints that arise when we are dealing with availability and mobility concerns for three diferente actors, as seen in figure 4.1.

None of these issues is resolved by the technological state of the art in the area (see chapter 3). While the solutions presented in section 3.1 present a valuable help to monitor

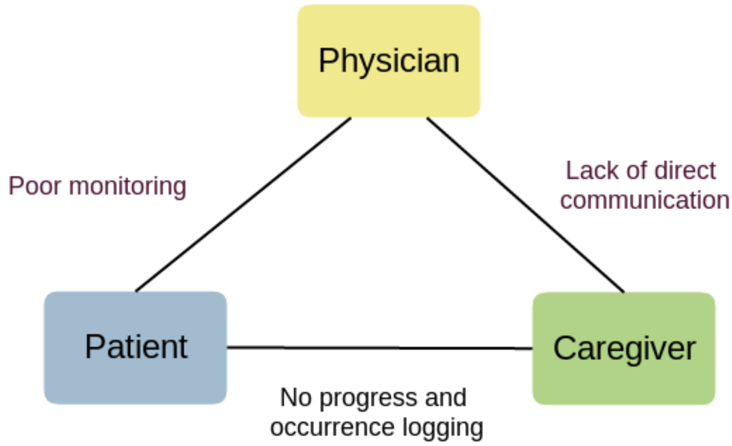



Figure 4.1: The relation between the actors in an AD environment and issues that come from it.

general health indicators and to help control the patient in a more advanced stage of a dementia disease, none focuses specifically on monitoring the disease progress of AD patients. Furthermore, no solution treats the caregiver as a source of information rather than just a recipient.

Regarding the rehabilitation solutions in section 3.2, they present a good base to work on in the area of rehabilitating exercises since they have showed good results and efficiency. The need for an active internet connection and in some cases specific equipment are however dependencies that STAlz eliminates. The fact that all the solutions found are developed for computer usage is also a difference to note, since the introduction of a new factor, touch screens, could lead to innovative methods and exercises.

## 4.1 Thesis statement

The presented work is based on the author's belief that:

*Introducing a mobile-based system, with remote communication capabilities, will improve monitoring and rehabilitation of Alzheimer's patients, by supporting both caregivers and health care professionals in their tasks.*

By providing the patient/caregiver with a mobile device and the health care professionals with a web platform, it could be possible to: *1)* enhance and narrow the data gathering moments; *2)* provide remote offline rehabilitation; *3)* improve the channels of communication between the caregiver and the health care professionals and *4)* support the health care professionals with metrics that could help establish the disease's progress.

## 4.2 Research methodology

The research methodology followed throughout the work detailed in this document was design research. Design research [CJB04] can be characterized as an iterative and cyclical process that relies in the following steps: plan, observe, design, prototype, test and then repeat (see figure 4.2).


Figure 4.2: Design research methodology steps, source: http://assets.uxbooth.com/uploads/2010/05/process.png

These steps aim at providing the maximum possible knowledge about the target audience. The design research techniques can be applied before, during, or after the design solution is established. If done before or during the design phase, it is known as user research; if after, it is known as user testing. User research attempts to answer questions like "who will use this design?" and "how does this concept work in the context of our target audience" whereas user testing seeks to answer: "how effective is this design?"

The research done throughout this dissertation incorporates both: indirect interviews to both caregivers and health care professionals before and during the design and development phase, and usability tests with caregivers and patients to test the effectiveness of the design produced. These usability tests will complement the feedback gathered from medical professionals in the empirical validation of the work proposed.

## 4.3 Approach to issues

In the following sections a detail of the approach follows, attempting to tackle with the issues mentioned before.

### 4.3.1 Overly spaced data gathering moments

The indicators gathered in section 2.2.4 (NPI, ZBI, IADL, MMSE, MOCA and FAB) were analyzed, taking in consideration two aspects: whether it would be possible to gather them in a remote mobile environment, and whether the data gathered would still be valid.

According to the doctors consulted, in the cases of the NPI, ZBI and IADL, the conclusion was that the data could be gathered by remotely interviewing the caregiver and it would still be viable.

As for the MMSE, FAB and MOCA, to guarantee that the results are valid, the tests need to be made by a medical professional. Furthermore, these also show some constraints regarding the periodicity and the environment in which they are made. Since the patient can learn the test and the answers, hence affecting the patient's score, it cannot be done in short periods of time. It needs also to be done in an environment handled by the physician, where no other distractions are available, otherwise that could also influence the results.

Regarding the NPI, the feedback gathered was that even though it was possible to perform the interview remotely in a mobile environment, the test was too big for the caregiver to maintain attention through the interview and the questions are not user-friendly, which could lead to having the results compromised. Given this, a shorter version of the test, NPI-Q [KCK+00], was chosen .

With this in mind, a mobile system could allow the caregiver to answer ZBI, IADL, and NPI-Q questionnaires remotely: the health care professional defines a periodicity or even a non recurrent occurrence and the caregiver answers the questionnaire in the mobile device application. The data can be later analyzed and the scores will help establish disease's progress. An aspect to note is that this can also be applied when a diagnosis is not yet defined since the patient's results can help achieve it.

As for the MMSE, FAB and MOCA, even though they cannot be done remotely, their results can also be analyzed to establish the disease's progress, the difference being the fact that the test needs to be made by a medical professional and he could insert the results manually in the system.

### 4.3.2 Lack of remote rehabilitation

Even though the current state of the art provides a good base to work on in terms of exercises, there are some limitations that can be addressed. The need for an active internet connection, for specific hardware or for the caregiver and patient to go to a hospital/occupancy center are some examples. With this in mind, it is believed that a system that could provide the patient with an offline and mobile application where he can realize cognitive stimulation exercises could solve these limitations.

A main difference to the work available is the fact that the patient uses a mobile application to perform the exercises, instead of a normal computer. This brings several advantages: *1.* portability (a mobile device is easier to transport than a normal computer); *2.* cost (a mobile device running Android, for instance, has a lower cost than a normal computer); *3.* the usability that the mobile environment allows, using touch devices for the user's input.

### 4.3.3 Inadequate communication

This issue is addressed by providing the caregiver a way to establish contact with the doctor using a mobile device application. While some of the health care professionals reported giving patients their personal contact, they also reported that many occurrences are not reported because the caregiver does not feel they are important enough to "bother" the physician. With the approach proposed, the caregiver is able to use the system to report abnormal situations that occur with the patient in a non unobtrusive way and ask questions to the doctor, who can manage his side of the communication in his web application in an asynchronous way.

Furthermore, an area where some frequently asked questions and answers are visible to the caregiver could allow for a quick reassurance when some unexpected situation happens, which according to the doctors consulted is a cause of great stress on the caregiver.

### 4.3.4 Lack of health care professionals support

By implementing the approaches mentioned in the above sections, specially regarding remote rehabilition 4.3.2, the health care professionals will have a solid basis regarding metrics to work with the patient, supporting the establishment of the disease's progress.

Adittionally, occupational therapists, for instance, will have a tool to support their work when visiting a patient at home, cognitive exercise wise. Also, having a way of interacting with the patient when the home visits are in a longer interval, detailing for instance exercises for the patient to perform, is also a gap appointed by the experts consulted and that could be fulfilled by the system. Also, by providing a web application where an analysis can be made on his patients' results, it becomes possible to see which areas are most affected, supporting the decision on the best course of intervention in each specific case.

## 4.4 Summary

As a result of an analysis of the state of the art regarding diagnosis, monitoring and rehabilitating AD, a list of open issues in need of attention was identified: *1)* Overly spaced data gathering moments; *2)* lack of remote rehabilitation; *3)* inadequate communication and *4)* lack of health care professionals support.

It is believed that with the introduction of a mobile-based system these issues could be tackled. A mobile device for the patient/caregiver and a web application for the health care professionals could: *1)* enhance and narrow the data gathering moments; *2)* provide remote offline rehabilitation; *3)* improve the channels of communication between the caregiver and the health care professionals and *4)* support the health care professionals with metrics that could help establish the disease's progress.

The next chapter will explore an instantiation to this concept, going in further detail into it's specification and implementation process.

# Chapter 5

# STAlz: remotely approaching Alzheimer's disease

This chapter will detail the methods, process and choices followed and made during the design and development of STAlz. STAlz is a mobile-based system that provides the aspects detailed in chapter 4: *1)* enhances and narrows the interval between the data gathering moments; *2)* provide remote offline rehabilitation; *3)* improve the channels of communication between the caregiver and the health care professionals and *4)* support the health care professionals with metrics that could help establish the disease's progress.

It is composed by a mobile application, to be used by the patient and caregiver, and by a web application, meant to be used by the health care professionals. These two components are connected and interact through a web server, which will contain a database where relevant data is stored, as seen in figure 5.1.

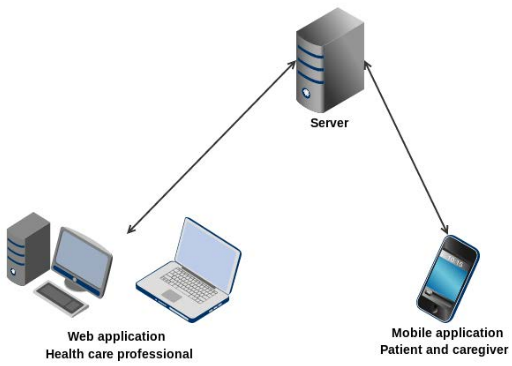



Figure 5.1: Interaction between the components of the system.

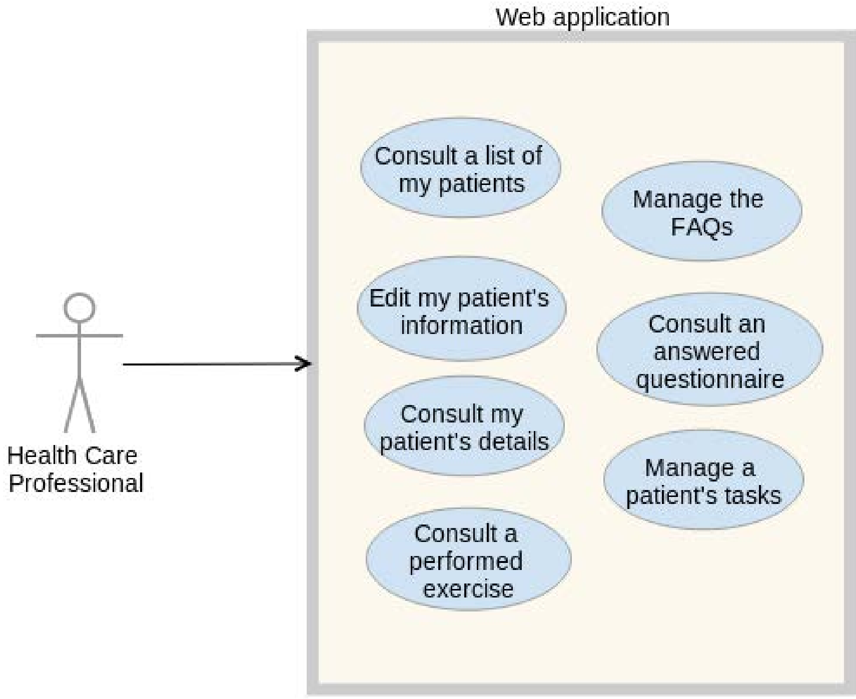



Figure 5.2: Use cases for the health care professional.

### 5.0.1 Use cases

Figures 5.2 and 5.3 represent the use case for both health care professionals and patient/-caregiver respectively.

### 5.0.2 Requirements specification

In the next sections both the functional and non-functional requirements of STAlz are detailed.

#### Functional requirements

*Caregiver*

Being a caregiver, the user needs to be able to:

- Consult frequently asked questions (FAQ);
- Report and send to the physicians an audio message regarding an occurrence;
- Report and send to the physicians a text message regarding an occurrence;
- Review an occurrence report before sending it to the physician;
- Consult a list of pending tasks requested by the physician;
- Answer a questionnaire previously prescribed by the physician;

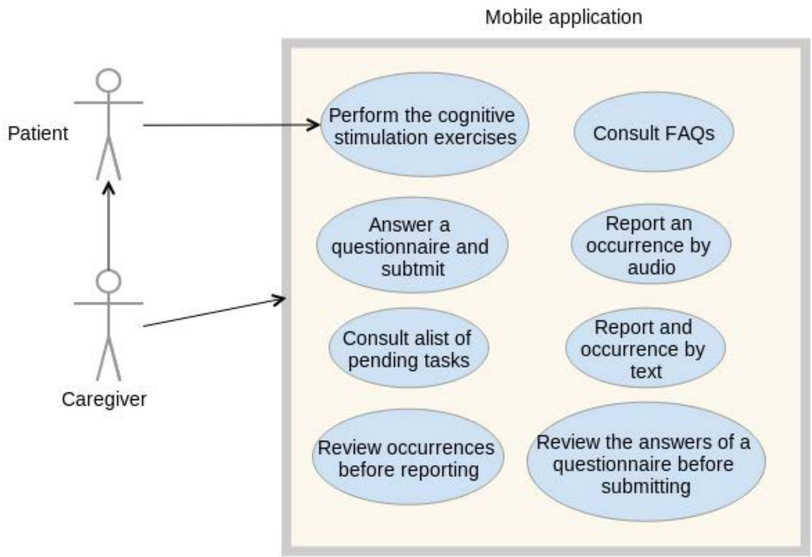



Figure 5.3: Use cases for both the patient and caregiver.

- Review the answers given to a questionnaire and eventually change some answers before sending it to the physician;
- Synchronize the application's data with the server.

*Health care professional*

Being a health care professional, the user needs to be able to:

- Consult a list of patients associated with him;
- Edit the details a patient;
- See the patient's progress and details (questionnaires' answers, exercises' scores, etc);
- Consult an answered questionnaire (specific answers and corresponding score);
- Consult the details of an exercise (how many times the user played, how many wrong clicks, how many right clicks, at what time in seconds did the user clicked on the screen, etc);
- Add, edit or delete items on the current list of FAQs;
- Add, edit or delete tasks for his patients;

*Patient*

Being a patient, the user needs to be able to:

- Peform the cognitive exercises present in the application.

**Non-functional requirements**

*Usability*

Usability is key in an application aimed at older people like STAlz. The users need to be able to use the application without any doubts, understanding the options available at any given time and without the need of a learning process.

*Fault prevention*

To try and prevent failure, STAlz follows an approach where it limits the options available to the users. This means that caregivers only have access to what they need to use, health care professionals have access to what they need to use and so on. By doing this, the chances of a user making a mistake by entering an area where he didn't even need to be, but is because he miss-clicked on a button, are minimized.

*Internet availability independence*

STAlz aims at being both an online and offline platform (mainly the mobile application), meaning that all functionalities need to work with or without an active internet connection. This is indispensable to assure that users can use it without having to worry about if there is internet at the time (which is still a somewhat confusing concept for most elderly people).

*Reliability*

Reliability stands for the ability of a system or component to perform its required functions under stated conditions for a specified amount of time. Applied to STAlz, this means that users need to be able to trust in the system, feeling confident that it won't fail and giving them the confidence needed to use it and rely on it.

*Robustness*

Even if errors are to avoided, the system needs to be able to cope with them and continue to operate despite abnormalities in input that can arise. Being a system aimed at elderly people, it is important that no detailed message be delivered (since the user wouldn't be able to understand it and this could confuse him), and instead provide the user with a reassuring message, or even no message at all, and deliver the complete and detailed message to the system administrator.

## 5.1 Implementation

In the following sections can be found detail on what methodology was followed in the development of STAlz, the architecture of both the mobile and web application, an overview of the technologies used and the detailing of the functionalities present in the system.

### 5.1.1 Methodologies

During the design and development of STAlz, a user-centered design (UCD) approach was followed. It is a process in which the needs, wants, and limitations of end users of a product are given extensive attention at each stage of the design and implementation process.

User-centered design can be characterized as a multi-stage problem solving process that not only requires the analysis and prediction of how users are likely to use a product, but also the test of the validity of the assumptions regarding user behaviour in real world tests with actual users.

In figure 5.4 we can see a scheme on how the UCD process works.

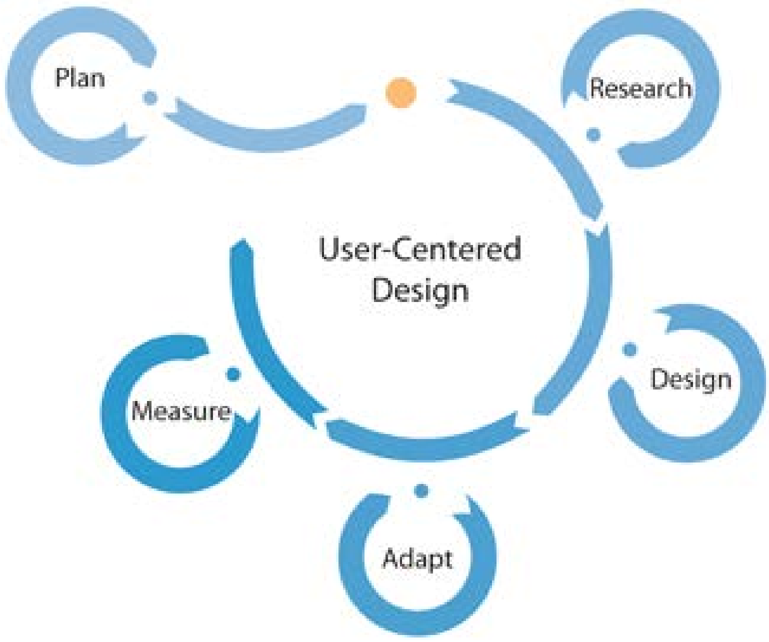



Figure 5.4: User-centered design methodology, source: `http://www.sapdesignguild.org/resources/ucd_process.asp`

This approach was followed due to the fact that we're dealing with a system aimed at elderly people and their needs and limitations are normally higher than users familiar with technology. Thus, it was imperative that we designed the system with as much usability as possible. By following this process we were able to understand how a first-time user reacts to the system, see how their learning curve looks like and adapt the design with that in mind.

### 5.1.2 Architecture

The next two sections detail the architecture for both parts of the system —server and mobile application.

### Server

The figure 5.5 represents the entity model diagram for the server of STAlz.

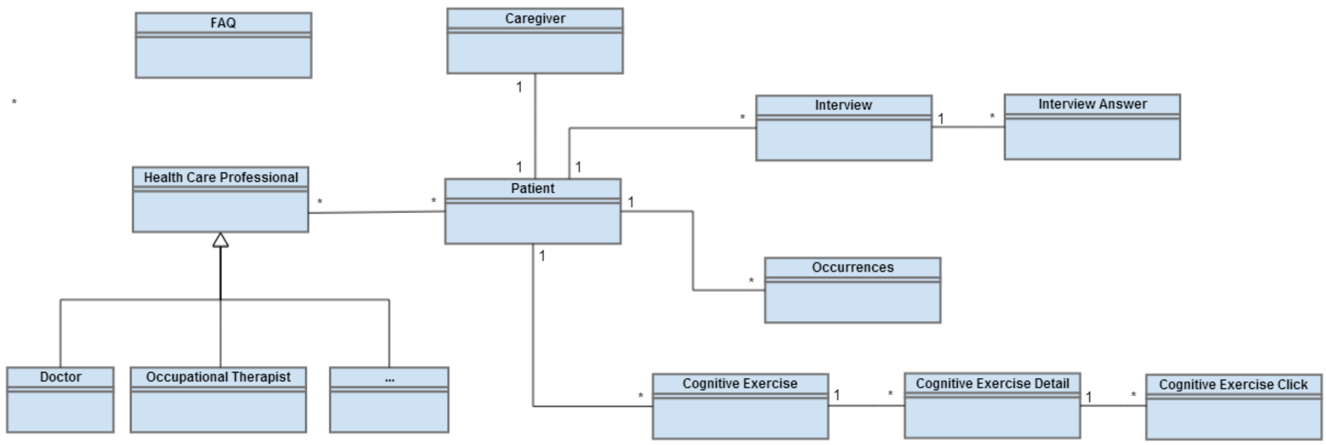



Figure 5.5: Entity model diagram for the server of STAlz.

### Mobile application

The mobile application's architecture can be described through the flow diagrams in figures 5.6, 5.7, 5.8 and 5.9, where we can see the possible flows of execution of the application.

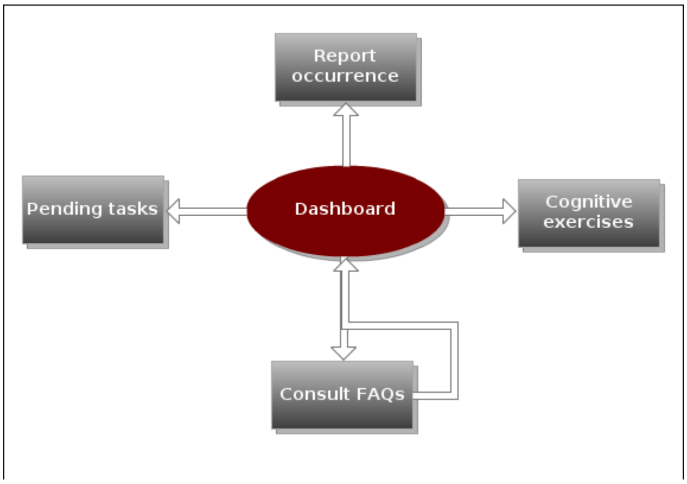



Figure 5.6: Flow diagram for the dashboard area in the mobile application.

## 5.1.3 Technologies

The following sections will describe the most relevant technologies used to implement a working version of STAlz, detailing on their advantages and why they were chosen.

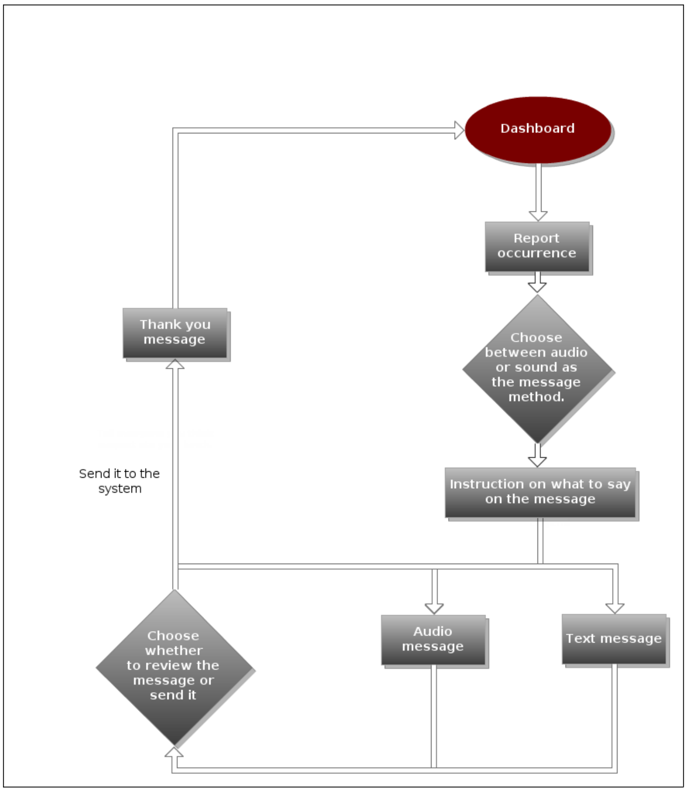



Figure 5.7: Flow diagram for the occurrence area in the mobile application.

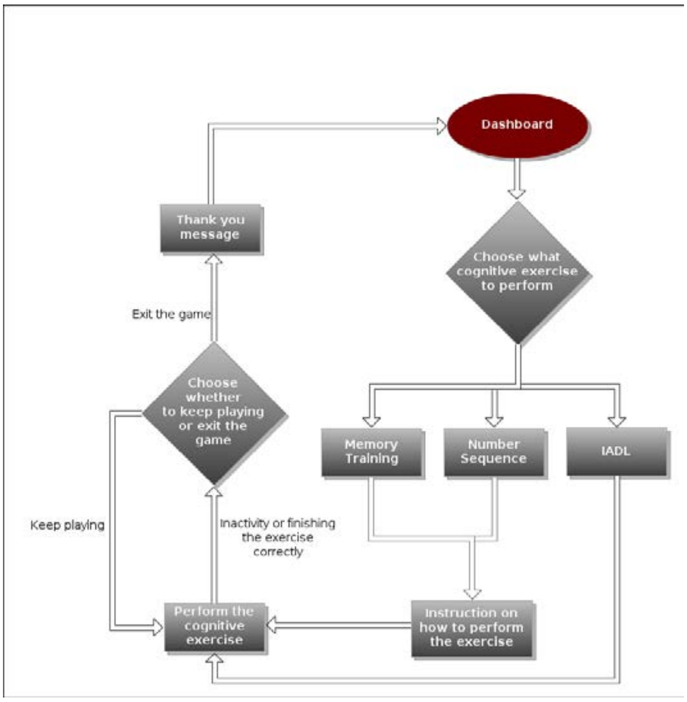



Figure 5.8: Flow diagram for the cognitive exercises area in the mobile application.

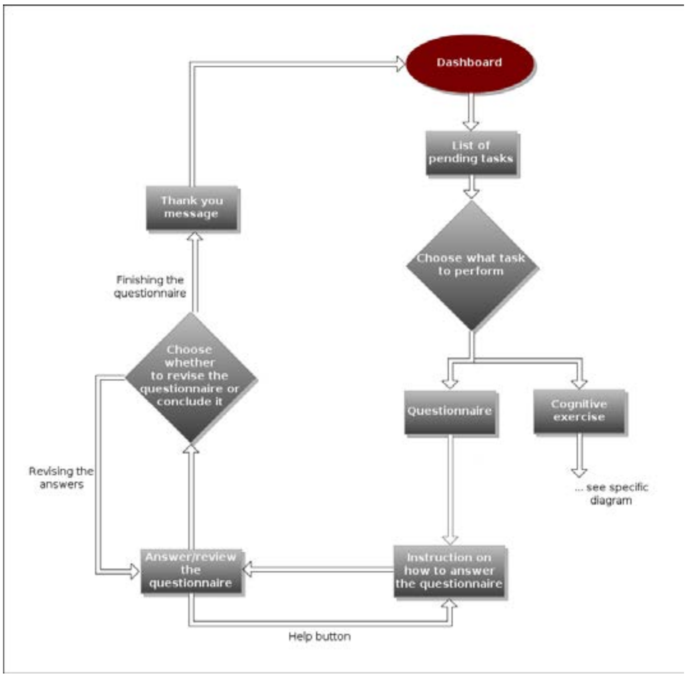



Figure 5.9: Flow diagram for the pending tasks and questionnaire area in the mobile application.

### Android

Android is a Linux-based operating system designed mostly for mobile devices. It is used mostly in smartphones and tablet computers and is developed by Open Handset Alliance, a consortium of 84 companies led by Google.

According to IDC, Android currently holds 75% of the smartphone market share, information from the third quarter of 2012 [Cor12], and this alone makes it an excellent platform to be used by STAlz.

Besides the highest market share, Android also provides some aspects that were key in the decision of choosing it as STAlz's mobile platform:

- Fully customizable application interfaces;
- Low price and high accessibility devices;
- Open source;

The first point gains extreme relevance when we're dealing with target users, elderly people, that require special attention on the design and layout of the interfaces as is the case of STAlz.

### Ruby on Rails

Ruby on Rails [oR13] (RoR) is a web application framework for the Ruby programming language. It uses the Model-View-Controller (MVC) architecture to organize application programming and enforces the use of well-known engineering patterns, such as Active record, Convention over Configuration and Don't Repeat Yourself.

Understanding the MVC pattern is key to understanding RoR. MVC divides the application into three layers, each with a specific responsibility.

The View layer is composed of "templates" that are responsible for providing appropriate representations of your application's resources. Templates can come in a variety of formats, but most view templates are HTML with embedded Ruby code (.erb files).

The Model layer represents your domain model (such as Account, Product, Person, Post) and encapsulates the business logic that is specific to the application. In Rails, database-backed model classes are derived from ActiveRecord::Base. Active Record allows you to present the data from database rows as objects and embellish these data objects with business logic methods. Although most Rails models are backed by a database, models can also be ordinary Ruby classes, or Ruby classes that implement a set of interfaces as provided by the ActiveModel module.

The Controller layer is responsible for handling incoming HTTP requests and providing a suitable response. Usually this means returning HTML, but Rails controllers can also generate XML, JSON, PDFs, mobile-specific views, and more. Controllers manipulate models and render view templates in order to generate the appropriate HTTP response.

RoR gives the web developer the ability to create applications that gather information from the web server, query the database and render templates out of the box, boosting the development's process.

The figure 5.10 goes into further detail about the RoR interaction with the system, by substituting the server component in figure 5.1 for a more detailed scheme of the RoR's components.

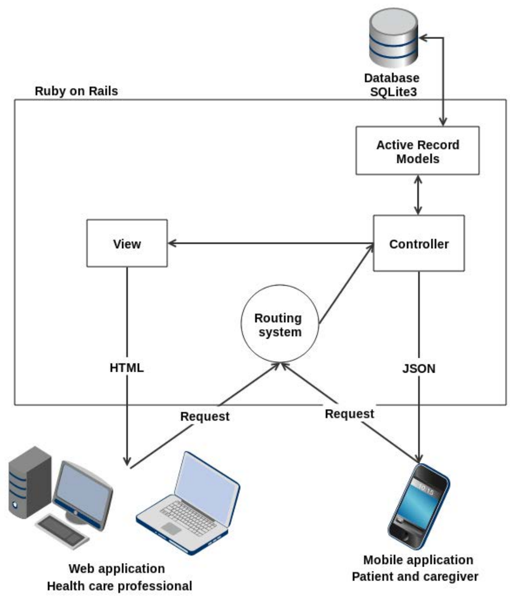



Figure 5.10: Interaction between the RoR components and the system.

### Front-end technologies

Hyper-Text Markup Language (HTML), Cascading Style Sheets (CSS) and jQuery were used as front-end technologies. These technologies are standards when it comes to web application rendering and user interface [Sur13]. The combination of the three provides the user with a powerful and intuitive user interface which is one of the goal of this system.

## 5.1.4 Mobile application

STAlz's mobile application is aimed at both caregivers and patients and contemplates four main areas: tasks, cognitive exercises, occurrence report and FAQ that are accessible from the application's dashboard (seen on figure 5.11).

It was developed for use in both smartphones and tablets. All the areas are available in both types of devices, with the only exception being the cognitive exercises. This is due to the fact that, given the results of tests made in an initial phase of the development process, the experience of performing the cognitive stimulation exercises in a smartphone environment was not optimal. Lack of screen space that would allow for bigger sizes in fonts and elements of the exercises was the reason most pointed out.


(a) Tablet (b) Smartphone.

Figure 5.11: STAlz's dashboard layout

For an easier understanding of each area, each of them will be detailed separately while presenting the layouts designed for the effect [1].

### Tasks

This area comprises all the tasks and requests sent from the health care professional to the caregiver/patient. The user can select from a list of pending tasks, figure 5.12, to select

[1]For space purposes, in this section only the layouts from the smartphone interfaces will be presented. The ones from the smartphone are similar and can be found in appendix D.

what tasks he wishes to perform. The physician can prescribe tasks such as a questionnaire or a cognitive exercise.

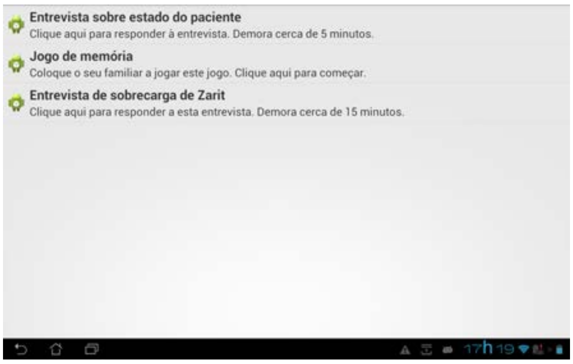
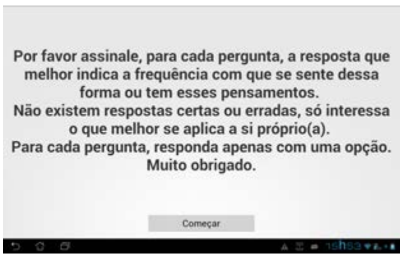


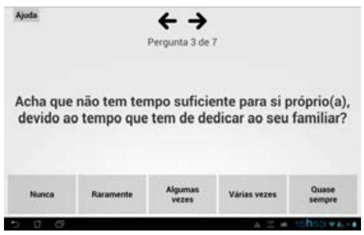

Figure 5.12: List of pending tasks in the tablet interface.

Having selected a task (for instance, a ZBI questionnaire 2.2.4), the user is presented with an initial instruction, explaining him the purpose of the questionnaire and how to proceed. This can be seen in figure 5.13a.

When the user proceeds to the questionnaire, a minimalistic interface was chosen to ensure the that the focus was on the task itself and not on design distractions (figure 5.13b). The question occupies the central area of the screen, ensuring it is the main focus of the user. The options available for answering are seen on the bottom area, having each button the same size, and therefore the same "weight" as an answer. On the top side of the screen, the user has 2 areas: *1)* help button —shows a help screen with an instruction similar to the one seen on figure 5.13a and *2.* navigation —arrows used for the user to navigate through questions and the indication of his current position.




(a) Instruction seen before starting a ZBI questionnaire.

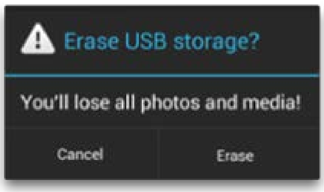



(b) Questionnaire example in the tablet interface.

Figure 5.13: ZBI questionnaire in the tablet version.

The interview has no value if not completed in one sitting, or if not completed at all, and therefore the user cannot finish (saving and sending it to the physician) without answering all the questions. It is still possible to use the back button to cancel the task.

A custom dialog was developed for when the user finishes the interview. This was necessary, because the default dialog provided by Android, see figure 5.14a, did not meet the requirements of the target users. Even though the font sizes could be increased, the distinction between message and buttons and between the two buttons was not clear enough. Additionally, it was gathered that without the normal border of a button, most users did not recognize the two buttons as something "clickable". The custom dialog designed can be seen in figure 5.14b.




(a) Default dialog layout in Android 4.


(b) Custom dialog in the tablet version.

Figure 5.14: Default Android dialog and custom dialog designed for STAlz.

### Cognitive Exercises

For the prototype version of STAlz three different cognitive exercises were chosen: IADL, Number Sequence and Memory Training.

The exercises implemented are mainly related to memory and attention, because according to the experts in the area that were consulted these are the most promising areas where cognitive rehabilitation could provide results.

They are based on the current state of the art and on exercises detailed in the book "Doença de Alzheimer - Exercicios de Estimulação" [NP] which is a reference in terms of cognitive stimulation exercises and focuses completely on AD.

#### *IADL*

In this exercise, figure 5.15, the goal is for the patient to identify the correct order in a series of images provided. The images form a task or action associated with the instrumental activities of everyday living which are normally easier for the patient to identify.

The amount of images varies according to the difficulty level.

#### *Memory Training*

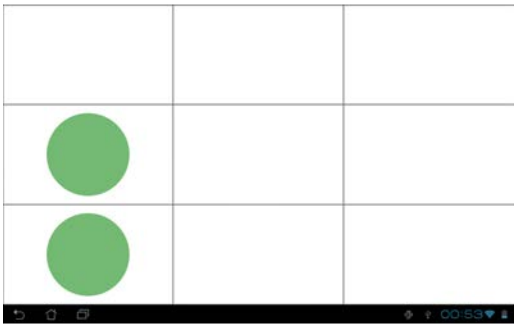
In this exercise, figure 5.16, the patient is presented with a grid, where some cells are filled. After a given time, all cells are cleared and the patient needs to recall which cells were filled.

Images can also be used as filling. The grid size, number of images and time before the images disappear varies according to the difficulty level.

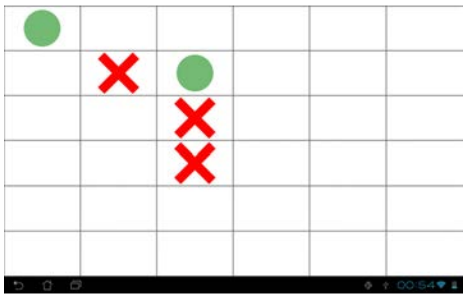

(a) Initial state.


(b) Overlay seen over the already selected images.

Figure 5.15: Layout of the IADL cognitive exercise.



(a) Initial state. The circles will disappear after some seconds.



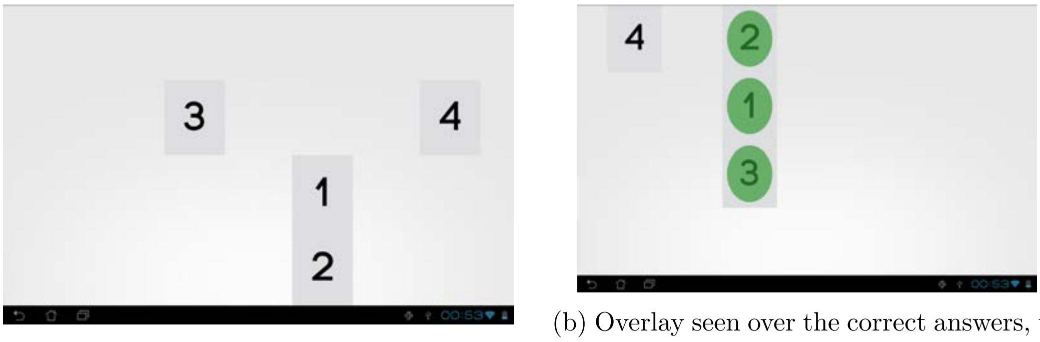
(b) Advanced state, where the user is trying to remember where the circles initially were.

Figure 5.16: Layout of the Memory Train cognitive exercise.

### *Number Sequence*

This exercise, figure 5.17, asks the patient to identify the correct order of a sequence of numbers. The patient is required to tap/select the numbers in the correct order.

The numbers are placed randomly across the entire screen, and the sequence length varies according to the difficulty level.




(a) Initial state.

(b) Overlay seen over the correct answers, to establish a sense of progress.

Figure 5.17: Layout of the Number Sequence cognitive exercise.

### *Settings*

An area of settings, as seen on figure 5.18, was designed so that several aspects of the cognitive exercises could be customized by the health care professionals. Aspects like the initial difficulty at which a game starts or the number of correct rounds the user has to play before moving on to the next difficulty are some examples.

There are however others that could be considered and weren't due to the timeframe available. This is discussed in further detail in section 7.2.


Figure 5.18: Settings availabe for the health professional to customize the exercise experience.

In order to try and prevent the user from losing attention, a decision was made to make the cognitive exercises as "fullscreen" as possible. While exercise IADL shows a single instruction in the top area of the screen (because that area couldn't be filled with more images), the two other use the entire screen area as part of the exercise in respect to this decision.

This presents however a problem when the user wants to leave the game, if he is not familiarized with the back button on the Android interface. Even though the usability tests, when performed with caregivers and patients, revealed that most of them are familiarised with the back button, a solution was still required for those who weren't.

With this in mind, the user is presented with a custom dialog (figure 5.19) after a given time of inactivity. There he can choose wether he can continue to play or leave the exercise. By doing this it is possible to use the entire screen for the exercises, increasing the user experience, and still accommodate both users who are and aren't familiar with the back button in Android interfaces.


Figure 5.19: Custom dialog designed to be presented to the user when he's inactive for a given time.

### Occurrences

The occurrences area is designed to give the user the ability to report out-of-ordinary situations to the health care professionals. There is the option to report the situation as a text message, for users who may be familiarized with the writing process in an Android device, and as a sound message, as seen on figure 5.20.


Figure 5.20: Screen where the user chooses by what means he pretends to report an occurrence.

If opting for a sound message, the user is presented with an initial instruction, asking him to be precise in the message and to include such as when it happened and how it happened. After this, a screen is shown indicating that the user has 90 seconds to record the message.

When recording, a countdown is shown at all times presenting the user with how much time he still has left on the recording. After he is done (or the time reaches an end), the user can review his message, record it again or send it to the system for further analysis by the doctor. This can be seen in figure 5.21.


Figure 5.21: Layouts of the report occurrence by audio message area.

A similar process occurs if we're dealing with a text message. After an initial instruction, the user is presented with an area where he can write his message and send it to the doctor, seen on figure 5.22b.

An aspect of note is that in Android, whenever the text area loses focus, the keyboard is hidden. To bring it to foreground, the user needs to press the text area, giving it focus. Since this may be a confusing concept, a button was added, whose function is to bring the keyboard to foreground in case the person for some reason manages to hide it. This can be seen on figure 5.22a.


(a) "Show keyboard" button.


(b) Text occurrence report screen.

Figure 5.22: Layouts of the report occurrence by text message area.

### FAQs

Users can consult a list of FAQs in order to obtain the answer to some doubts that can be quite frequent amongst Alzheimer's caregivers. Examples of this are: "how to deal with the patient's food regime", "how to deal with his WC habits", "he's extremely agitated, is this normal?", etc.

The answers to these questions can be found in STAlz, where the caregiver has access to a list of questions (see figure 5.23), whose answer can be seen by clicking on the question.

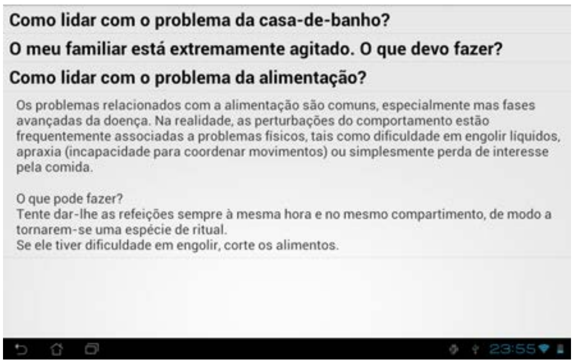



Figure 5.23: FAQs list in the tablet interface.

These FAQs can be added, edited or deleted by the health care professionals on the web application.

### 5.1.5 Web application

The web application (figure 5.24) is aimed at the health care professionals and provides a platform for them to both interact with the caregiver/patient and make an analysis on the results gathered through the system.

It accommodates various areas, directly related to the areas seen on the mobile application, and for each of these a detail will be given on what functionalities the user can make use of.

A thing to note is that the web application didn't receive as much development effort as the mobile application. Health care professionals are typically people used to use technology and even though their needs were taken in consideration, due to the timeframe available, some were not implemented in this prototype.

This is due to the fact that to validate the hypothesis detailed in chapter 4, a bigger effort and focus had to be given to the usability and overall design of the mobile part of the system. Even though a nice interface can provide the health care professionals with an easier way to visualize and analyze the data, to validate the hypothesis given, we had to make sure that both the caregiver and patient can create relevant data in the first place and that that data reaches the health professionals, being its format secondary for the hypothesis. This justifies the decision for the focus of development in the mobile application, and is discussed in further detail in section 7.2.

The health care professionals can consult in detail the answers given by the caregivers to the questionnaires (figure 5.26) as well as the patient's scores in his cognitive rehabilitation exercises (figure 5.25). Besides this, it is also possible to see the occurrences reported by the caregiver, whether they are audio or text occurrences (figure 5.26).

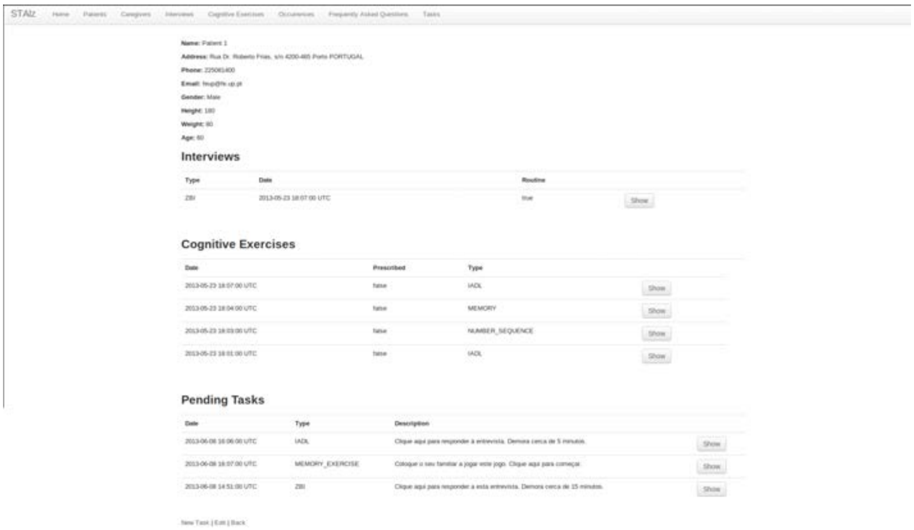



Figure 5.24: Overview of a patient in the web application.

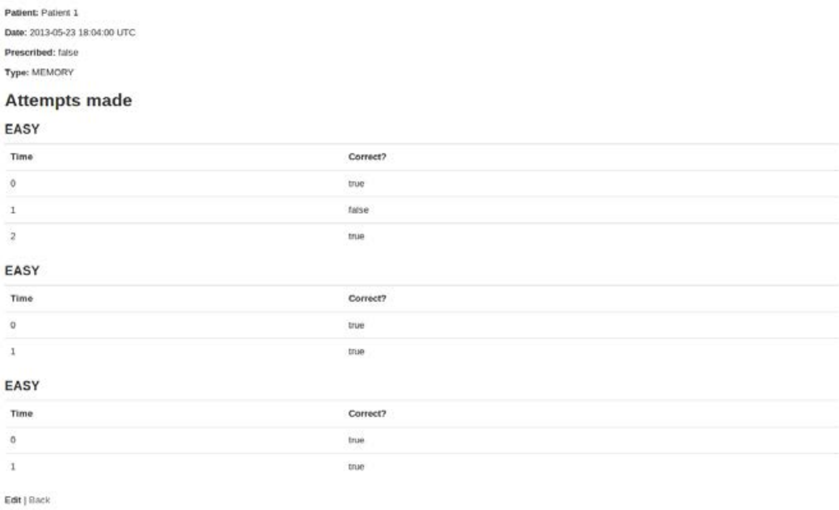



Figure 5.25: Cognitive exercise results of a test patient in the web application.


Figure 5.26: Interview results for a questionnaire seen on the web application.


Figure 5.27: List of occurrences for a test patient seen on the web application.

It is possible to access and edit information about the patient and their respective caregiver, as well as the frequently asked question that will be available in the mobile application. The physicians can also prescribe tasks for the patient or caregiver to perform directly from their respective detail page.

### 5.1.6 Interface concerns on the mobile application

According to the principles and guidelines detailed in section 3.3.2, several interface concerns were taken into account on STAlz. They can be found in the following sections, accompanied by an explanation of the decision made and why it was made.

#### Brightness

In order to improve the user's ability to see clearly the application, whenever the application is brought to foreground, the device's screen brightness is changed to the maximum, being reseted when the application is taken back into background.

This improves the user's overall experience and makes every aspect of the interface perfectly clear to users, who given their age, have tendency to have vision problems.

#### Text color

To maximize the user's experience and overall usability, black was chosen as the text color. This allows for a high contrast (black on white) which maximizes the clearness of the labels seen on screen.

This becomes even more important when we're aiming at users who have a tendency to have vision problems as STAlz does.

### Keep awake

Normally, to wake an Android device, the user needs to press a physical button and then slide an element on the screen. While this is intuitive for most Android users, elderly people may find the procedure confusing and troubling, as stated by the tests performed.

To prevent this the screen never turns off, when STAlz is on the foreground, having used the Android flag *FLAG_KEEP_SCREEN_ON* to achieve this.

### Buttons

The buttons present in the STAlz application aim at being not only clearly understandable but also perfectly clickable. Given the fact that elderly people may show some difficulties clicking accurately in small areas of the touch screen, a special concern was given towards the size of the buttons and the minimum margin between any two given buttons.

Besides this, the button states were also overridden in order to make them more understandable. This can be seen in figure 5.28, where the "report occurrence" button is pressed.


(a) Smartphone


(b) Tablet

Figure 5.28: Example of the button state when pressed.

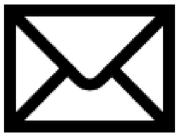
### Icons

STAlz's icons follow the same color pattern decided for the labels in the application: black. This was done as to not compromise and even enhance the contrast desired for the application.

They also try to represent in a clear and minimalist way the concept that they are being associated with. Some of these examples can be seen in figures 5.29a, 5.29b, 5.29c and 5.29d. [2]

[2]Credits Venkatesh Aiyulu, Jon Testa and Henry Rider from The Noun Project.

(a) Cognitive exercises icon.



(b) Occurrences icon.

#### Fullscreen

The concept of "pulling down" a status bar can be confusing for STAlz's target users. In order to prevent the user from accidentally opening the status menu by scrolling down the status bar, and to maximize the user's attention in the screen, fullscreen mode is used throughout the application.

There are only two exceptions to this: the dashboard and the cognitive exercises menu. In these, to allow the advanced users to access the settings, the status bar of the application is left visible.

#### Settings

To avoid confusing the user with unnecessary options, the settings were limited to the dashboard and the cognitive exercises menu, as detailed in section 5.1.6. These settings are meant only for an advanced user (either a physician or a caregiver familiar with technology), meaning that: *1.* they cannot be easily accessed by the user; *2.* the system needs to work even if these settings are never accessed.

To access the settings in newer versions of Android (after version 4.0), and with the disappearance of the physical buttons in Android devices, the user needs to press a button in the action bar. In older ones, they can be accessed by clicking the physical *menu* button.

#### Languages

STAlz currently supports both Portuguese and English languages. The default language is chosen according to the device's selected language at the moment. If the application is

(c) Tasks icon.



(d) FAQs icon.

Figure 5.29: Examples of icons used in STAlz

launched from a device using a language that it does not have a translation to, English is used by default.

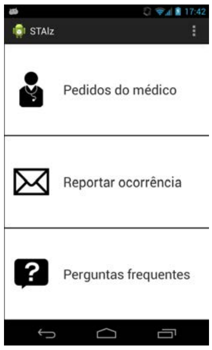
### Supported screens and orientations

A special attention was given to screen sizes and orientations, in order to maximize STAlz's compatibility and mobility. While cognitive exercises are more intuitive and easy to use in a tablet-sized interface, the portability associated with a smartphone is also something to take note of. With this in mind, STAlz supports both smartphone and tablet sizes.

In an early stage of development, experiments were made to evaluate the effectiveness of having the cognitive exercise be realized in a smartphone-sized interface. These experiments revealed that while possible, the results were not optimal and the interface didn't have enough space to accommodate the "exercise" area as well as instructions. Given this, it was decided that in smartphones the cognitive exercises section would be disabled, having this be a layout directed entirely towards the caregiver. These interfaces can be seen in figures 5.30.


(a) Landscape - tablet


(b) Portrait - tablet




(c) Portrait - smartphone.

Figure 5.30: STAlz's dashboard layout

Another aspect that was considered was the orientation of the device. While in smartphones, the portrait mode is the most intuitive one, in tablets that is not the case. To accommodate this, it was decided that on smartphones only portrait mode would be available while on tablets both portrait and landscape are possible. The exception to this are the cognitive exercises, which require an landscape mode to be performed.

Figure 5.30b shows STAlz's dashboard on a tablet in portrait mode.

## 5.1.7 Synchronization concerns

One of the main aspects of STAlz is the fact that it works without an active internet connection. To achieve this, a client-side database is used on the Android device.

This database contains data previously synched with the server that needs to be available for the user to see (tasks and FAQs) but also data not yet synched (cognitive exercise's results, occurrences, tasks' results, among others). When a synchronization occurs, the data is deleted on the device's database, resulting in the fact that at any given time, the only data present, related to cognitive exercises, tasks' results and occurrences (basically content the user has created), is data not yet present in the server.

A problem with this approach is that it requires that at a point in time the device be synchronized with the server. This can be quite challenging for older people, as the concepts of internet and synchronizing may reveal themselves confusing.

To try and prevent this, the option to sync the device was left as an advanced option, intended to be used by a caregiver familiarized with technology or an occupational therapist when visiting a patient's home, and the devices tries to communicate with the server, every time some content is created by the user. If it is able to do that, then not only that content is synchronized but all that is present in the device.

Another solution can rely on an Android service running in background, and synching the application whenever there is an active internet connection. This solution minimizes the time between synchronizations, since it is made as soon as possible (as soon as it is needed and there is an internet connection). This approach was not introduced in the current prototype of STAlz due to time constraints and is referenced as possible future work.

## 5.2 Summary

Throughout this chapter, we were able to see the specification and implementation process and decisions made on STAlz. It is a system composed by a mobile application, to be used by the patient and caregiver, and by a web application, meant to be used by the health care professionals. Through this, it provides the aspects detailed in chapter 4: *1)* enhance and narrow the data gathering moments; *2)* provide remote offline rehabilitation; *3)* improve the channels of communication between the caregiver and the health care professionals and *4)* support the health care professionals with metrics that could help establish the disease's progress.

On the next chapter it will be possible to see the results obtained when testing the system, as well as an analysis thereof.

# Chapter 6

# Validation and discussion

An ideal validation for a system like STAlz would be to analyze the results of real usage at people's home over a relevant interval of time, to validate whether the application was usable and whether patients and caregiver were indeed producing relevant data for the health care professionals.

A validation like this was however not possible, due to time constraints. Maintaining the empirical validation approach, usability tests were performed with both patients and caregivers to establish the system's usability. Besides this health care professional and caregivers were consulted, at first to establish the system's usefulness, and after this, to establish what features were useful and they would found fit to a system of this nature. This contact was constant throughout the design and development phase, which allowed STAlz to be improved and focused to the target user group.

The results of these measurements and their analysis is detailed throughout this chapter.

## 6.1 Usability tests with caregivers

Several caregivers were interviewed with the objective of establishing the system's usability, while at the same time gathering feedback over improvements that could be made to the application.

### Test description

The test consisted in asking the caregiver to simulate several situations and then use the mobile application to deal with them accordingly. To establish whether the application was clear without any previous formation and/or learning, it was decided to not make any introduction on the application itself, letting the user have the first contact when performing the tasks. If the caregiver showed difficulties some tips were given and those difficulties taken into consideration.

The tasks were the following:

1. The doctor has sent you an interview called Zarit Burden Interview for you to answer. From the application's main menu, answer the interview and send the answers to the doctor;

2. Following the previous question, after answering the interview, you want to change your answer to question number four and then send the answers to the doctor. Do this, starting from the point where you finished answering the interview;

3. Your relative is extremely agitated and you want to report that situation to the doctor. Do that, starting in the main screen menu;

4. Following the last task, imagine you don't know if you misspoke when recording the message. Check to see if that happened, record the message again and send it to the doctor. Do this, starting at the point where you finished recording the message for the first time;

5. You are unsure about how to deal with your relative's food habits. Use the application to try and clarify that, starting at the main screen.

At the end of the test, the subjects were questioned on their opinion on the usefulness of the system and any ideas for improvement or additional functionalities. A full version of the test can be seen in chapter C.1.

### Metrics

Throughout the test, the caregiver was monitored for performance. Besides monitoring whether the caregiver was able to perform the required tasks, every misclick, click in the wrong location and, in general, wrong action by the caregiver was counted as an error.

### Subjects

The caregivers were not chosen due to any specific characteristic. Some demographic aspects were however monitored: whether the caregiver wears glasses, has a cellphone and is familiar with a touch device. Considering these characteristics, a pool of 10 caregivers was scrutinized to try and represent the potential target users of STAlz.

As seen in table C.1, 50% of the subjects wear glasses, 80% of the subjects own a cellphone and 50% of them have never experienced a touch device. This allowed for us to cover various possibilities ranging from subjects with sight problems, to subjects with no previous experience with touch devices or with cellphones or technology at all.

### Setup

The devices used for the test were a LG Nexus 4 and an Asus Transformer TF101.

At the beginning of the test, the concept and purpose of the application were explained, as was the purpose of the test. It was clearly explained and stressed out that it was the prototype's performance that was being evaluated, not the patient's. Before actually starting, participants had the opportunity to touch and experiment a little with the device, and basic functionalities, like the use of the physical back button to return to the previous screen, were explained. For many, it was their first experience with a smartphone and therefore a little contact with touch devices was needed before hand as to not compromise the reliability of the test's results.

### Results

The results show that even people with no previous experience in smartphone/tablet devices were able to perform the core activities of the system, such as answering an interview, consulting a FAQ and reporting an occurrence to the attending physician. It is also possible to state that the number of errors progressively decreased throughout the tests, indicating that the design decisions taken improved the system's overall usability. These initial results suggest that with a clean and minimalist interface, even people with no experience whatsoever with touch devices can perform tasks associated with monitoring and tracking Alzheimer's disease.

A graphic comparing the average number of errors done by task can be seen on figure 6.1. It is possible to see that in all tasks the average is lower than 0,5. It also shows the task 1 as the one with the higher average of errors, which reflects the task that was the target of most effort in terms of interface tuning.

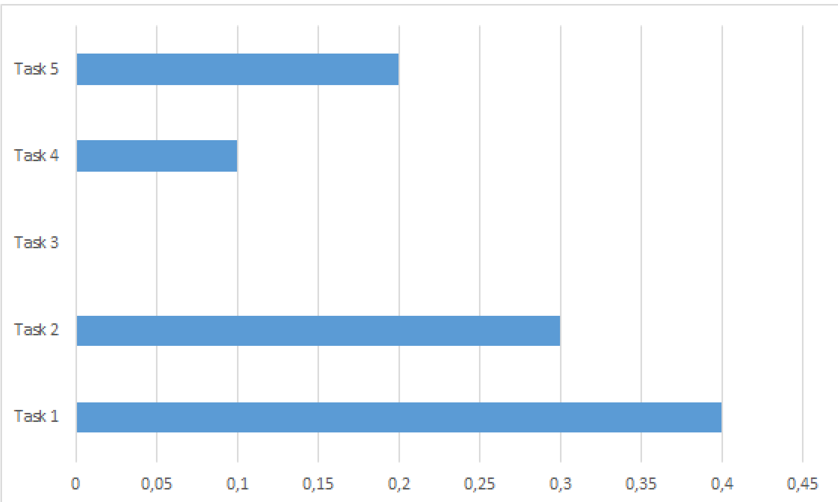



Figure 6.1: Average number of errors by task in the caregiver's usability test.

Regarding usefulness, when asked their opinion on the system, all the caregivers were unanimous to the fact that it would be a great help on their job and on keeping them in a more regular contact with the medical staff responsible for their patient's treatment. This way, the system would allow for a more close relation between the three parts involved in the patient's life: patient, caregiver, health care professionals. As for new functionalities, none was capable of suggesting a functionality not already in the system.

The complete results to the tests can be seen on appendix C.

## 6.2 Usability tests with patients

With the collaboration of the Hospital S. João and the Delegação Norte Alzheimer Portugal some AD patients were asked to experiment the cognitive exercises presents in the prototype. This allowed for a better understanding of whether the layouts were well designed, the difficulty modes were appropriate and so on.

### Test description

The test consisted in asking the patient to perform the cognitive exercises, while recording their performance. Depending on the patient's performance and even will, the difficulty could be adjusted. The objective was to experiment in all the implemented difficulties.

### Metrics

Throughout the test, the patient was monitored for performance. Every click on the screen was registered, as was the time (since the begin of the exercise) at what it happened. Every click was categorized as correct and incorrect. These results were organized by attempt, due to the different difficulties at which the patient could be playing.

### Subjects

There was no special criteria when choosing the patients for this test. Since they were made in collaboration with the Hospital S. João and Delegação Norte Alzheimer Portugal, the patients selected were the ones available to perform the test (because they came to an appointment on Hospital S. João or were being visited at home by the Delegação Norte Alzheimer Portugal).

As seen in table C.7, 80% of the subjects wear glasses, 80% of the subjects own a cellphone and neither of them have never experienced a touch device. As with the caregivers, this gave us some diversity, allowing various possibilities ranging from subjects with sight problems, to subjects with no previous experience with touch devices or with cellphones or technology at all.

### Setup

The device used for the test was an Asus Transformer TF101.

At the beginning of the test, the concept and purpose of the application were explained, as was the purpose of the test. It was clearly explained and stressed out that it was the prototype's performance that was being evaluated, not the patient's. If it was the patient's first contact with a touch device, they were given some insight on touch devices and some time to come in contact with the device before starting the test.

### Results

The results show that every patient was able to understand the concept behind the cognitive stimulation exercises implemented and was also able to perform them without any third part help.

The results also suggest that the exercise that patients found more troublesome was the Memory Training. It was the only one where some patients were not able to complete the exercise, apart from the number of errors given. It is also the exercise where the most number of errors (incorrect clicks) were given.

This can be witnessed in figure 6.2 where it is clear that the exercise where most errors were given is the Memory Training, while the Number Sequence and IADL are close to zero in terms of errors.

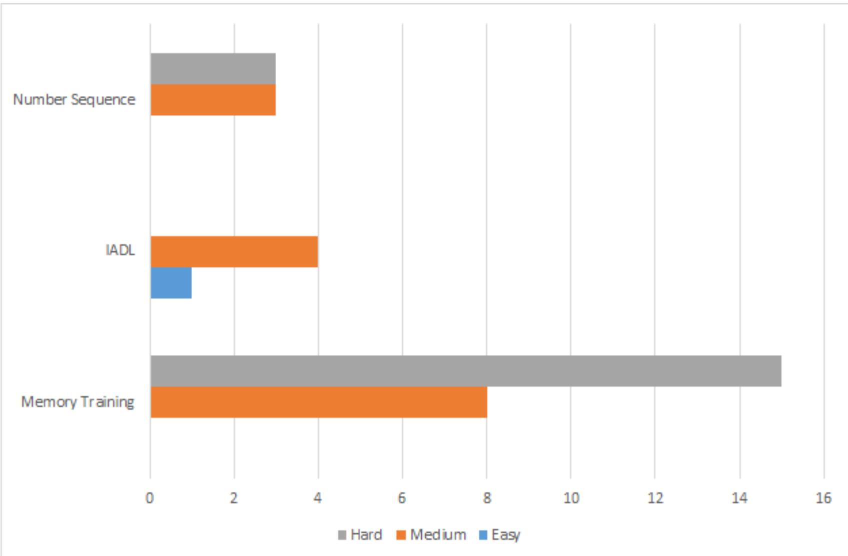



Figure 6.2: Average number of errors by exercise and difficulty in the patient's usability test.

These results are discussed in further detail in section 6.4 and can be found in full detail in appendix C.

One thing to note is that with patient 7, while being able to understand the concept and how to perform the exercise, it was not possible to count the number of incorrect clicks in the Memory Training and Number Sequence exercises. Since these are more sensitive exercises that require more accurate clicks, the patient, due to not being used to touch devices, had difficulty pressing only one area, activating more than one click every time there was a click.

Since this was an isolated incident and has not occurred with any other patient (even the ones without any touch experience as well) more tests are pending to decide on whether it is a situation in need of attention.

## 6.3 Feedback gathered from health care professionals

The health care professionals consulted were very open and receptive to the system and its concept and their input and ideas were used for the current prototype, according to the development methodology used. It was stated that the system could indeed provide a closer communication channel between the patient/caregiver and the physicians and also allow the periodical gathering of metrics useful for a diagnose/tracking/rehabilitation scenario.

Apart from the general insight on design, some ideas and improvements were given for the cognitive exercises on their current iteration:

1. Allow the health care professional to personalize the difficulties, creating specific difficulties for every patient;

2. Let the circles have different colors in the Memory Training exercise;

3. Increase the difficulties of the Number Sequence exercise;

4. Experiment with the use of photographs instead of drawings on the IADL exercise.

Apart from this, they also provided some ideas for other cognitive exercises that could work well in a touch environment:

1. Intruder - from a group of objects or words, let the patient click on the one who does not fit the same category;

2. Word Search - from a group of apparently random letters, let the patient find a group of words;

3. Object Picking - Select all the objects related to a certain category from a group of related and non-related objects and a category (food, school, etc).

## 6.4 Results analysis

The initial results gathered are quite promising and indicate that it is indeed possible to provide patients, caregivers and health care professionals with a mobile system that could improve the way that AD is tracked and treated nowadays. The approaches detailed in chapter 4 revealed themselves profitable, and can provide a good starting point in a system with the same goal as STAlz.

The caregivers, even those with no previous technological experience at all, were able to perform the tasks required by the system, answering interviews, reporting occurrences and sending that data to the health care professionals. The tests were performed throughout the development phase according to the User Centered Design and some aspects were improved due to this method. Among these are the spacing between buttons, the font size, the brightness of the screen and the keep awake aspect (for more detail, see section 5.1.6. It is suggested that the improvements solved these issues by the lowering seen in the number of errors made by the caregivers.

As for the patients, the results indicate that they were all able to understand the concept of the exercises as well as perform them. They also suggest that some tuning is needed on the difficulties of the exercises. In order to establish a line of progression on the patient's cognitive stimulation, it is necessary that they show some difficulties while performing the exercises. With the training, hopefully, these difficulties could be lowered indicating an improvement. If the patient is able to perform all the exercises without any problem, this will harden establishing his progress.

With this in mind, some adjustment is needed in the difficulties of both the IADl and Number Sequence exercises. Almost all the patients showed no trouble performing these, they rarely made errors thus indicating a need for an increase in the challenge provided by these exercises.

Overall, these results support the idea that this system could be used as a useful diagnosis, tracking or rehabilitation instrument for AD patients.

## 6.5 Summary

While an ideal validation was not possible due to time constraints, the system was validated through an empirical approach using usability tests and feedback. To this, several caregivers and patients were asked to perform usability tests, and both caregivers and health care professionals were consulted on their thoughts about the usability of the system and what functionalities would be useful.

The patients and caregivers selected for the usability tests were able to cover a wide range of possibilities, ranging from persons with sight problems to persons with little to no technological experience.

The results gathered are promising, revealing that the small adjustments made throughout the development phase were fruitful and suggesting that with some tuning on the cognitive rehabilitation exercises, mainly in their difficulties, STAlz could be used as a useful support instrument for the diagnosis, tracking and rehabilitation of AD patients.

# Chapter 7

# Conclusions

Being an incurable disease with symptoms that cause extreme burden in patients and caregivers, new ways of diagnosing, tracking and rehabilitating patients with AD are urgent. After a thorough reasearch on the current state of the art of diagnosis, tracking and rehabilitation of AD several issues were encountered (see chapter 4).

A mobile-based system, STAlz, was designed to approach and solve those issues, by providing *1)* frequent monitoring and evaluating metrics; *2)* remote offline rehabilitation; *3)* improved communication between the caregiver and the health care professionals and *4)* support to the health care professionals.

The system was validated with both caregivers and patients of AD, and the results were promising, suggesting that through the use of technology, and more specifically mobile technology, it is in fact possible to provide new ways of approaching AD.

## 7.1 Contributions

The presented work has the following contributions:

1. *Frequent monitoring and evaluating metrics* - A way to monitor the patient remotely through the caregiver, in smaller intervals than what is done currently;

2. *Remote offline rehabilitation* - A way for the patient to be able to do cognitive stimulation exercises remotely and offline, while allowing the health care professionals to personalize this training and analyze the patient's progress;

3. *Increased proximity* - A way of establishing a more permanent contact with the caregiver, in two ways: (1) relieving and reassuring him, by providing answers to frequently asked questions (FAQ) and situations associated with the AD and (2) allowing for the caregiver to report important situations that otherwise would wait until the next doctor's appointment;

4. *Support to health care professionals* - A way to support health care professionals in their work of analyzing the patient's progress and even diagnose it.

Besides these contributions, STALz can also provide some important guidelines when developing interfaces for older adults and older adults with dementia in both general applications and cognitive exercises wise. Its interfaces were tested with usability tests and showed consistency and usability, thus providing a good reference point for any future work in the area.

## 7.2 Future work

Besides work on future functionalities, there are still improvements that could be made on the current prototype and that reflect the feedback gathered from health care professionals as well as an analysis of the tests' results.

- Improve some of the instruction messages in the cognitive exercises to reduce the learning needed outside of the application;
- Let the circles have different colors in the Memory Training exercise;
- Increase the difficulty in the IADL and Number Sequence exercise;

As for future functionalities, there is quite a margin for progress. In the area of cognitive stimulation exercises there are many that could reveal themselves a nice addition to the system. The addition of new exercises would be extremely valuable because it would provide the patient with more variety and the health care professionals with a wider range of exercises when trying to aim at a specific cognitive area. The ability to personalize the exercises' difficulties and other even other aspects could also be a functionality considered.

The tasks that the health care professionals can prescribe could also be extended. Apart from the ones currently available, the physician would have the option to remind the caregiver of important events, for instance "don't forget the new medication", reminder for appointments, general questions on how patient is, etc. These would provide more flexibility to the system and after some validation with the health care professionals on what questions/aspects would be relevant this could be a nice addition to the system.

Regarding FAQs, allowing the physicians to establish questions and answers for each patient individually could be a nice addition to the system, since every pair of patient and caregiver has specific needs. This would however fall out of the FAQ concept and therefore an area could be created for the exchange of questions between the caregiver and the doctor. This can be done today with the report occurrence area, that while not ideal or designed for that effect can fill that gap, but a dedicated area to questions and answers would be valuable to the system.

The report occurrence area could also see some improvements by allowing the caregiver to see whether the doctor has seen his report or not. Given the fact that occurrences can be reported while offline (being synched when online), the caregiver can think that the doctor has already seen his report when that in fact hasn't happened. A way to provide the caregiver with that information and even some follow-up on the subject reported would be the next step for this area.

As for the synchronization method, as detailed before, it could be improved. The current method assures that every time the user produces some content, a synchronization attempt is made, and if successful it synchronizes all the data in the application. An improvement could be made by creating a service that would synchronize the application every time an active internet connection was established. This could mean more burden on the data transfer but on the other hand would assure that the application would be synched with the server every time that it was possible.

The web platform of the system also needs to be worked on since the effort dedicated to it was lower than to the mobile application. To validate the approaches detailed in chapter 4, it was only required a functional web platform and therefore the layout, usability and advanced functionalities are aspects to work on in the future.

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# Appendix A

# Alzheimer's disease phases and symptoms

**Early/Mild**

- *Memory loss for recent events* - Individuals may have an especially hard time remembering newly learned information and repeatedly ask the same question;

- *Difficulty with problem-solving, complex tasks and sound judgments* - Planning a family event or balancing a checkbook may become overwhelming. Many people experience lapses in judgment, such as when making financial decisions;

- *Changes in personality* - People may become subdued or withdrawn — especially in socially challenging situations — or show uncharacteristic irritability or anger;

- *Difficulty organizing and expressing thoughts* - Finding the right words to describe objects or clearly express ideas becomes increasingly challenging;

- *Getting lost or misplacing belongings* - Individuals have increasing trouble finding their way around, even in familiar places. It's also common to lose or misplace things, including valuable items.

**Moderate/Middle**

- *Show increasingly poor judgment and deepening confusion* - Individuals lose track of where they are, the day of the week or the season. They often lose the ability to recognize their own belongings and may inadvertently take things that don't belong to them;

- *Experience even greater memory loss* - People may forget details of their personal history, such as their address or phone number, or where they attended school. They repeat favorite stories or make up stories to fill gaps in memory;
- *Need help with some daily activities* - Assistance may be required with choosing proper clothing for the occasion or the weather and with bathing, grooming, using the bathroom and other self-care. Some individuals occasionally lose control of their urine or bowel movements;
- *Undergo significant changes in personality and behavior* - It's not unusual for people with moderate Alzheimer's to develop unfounded suspicions — for example, to become convinced that friends, family or professional caregivers are stealing from them or that a spouse is having an affair. Individuals often grow restless or agitated, especially late in the day. People may have outbursts of aggressive physical behavior.

**Severe/Late**

- *Lose the ability to communicate coherently* - An individual can no longer converse or speak coherently, although he or she may occasionally say words or phrases;
- *Require daily assistance with personal care* - This includes total assistance with eating, dressing, using the bathroom and all other daily self-care tasks;
- *Experience a decline in physical abilities* - A person may become unable to walk without assistance, then unable to sit or hold up his or her head without support. Muscles may become rigid and reflexes abnormal. Eventually, a person loses the ability to swallow and to control bladder and bowel functions.

# Appendix B

# Scales and tests in dementia

## B.1 Mini Mental State Examination

## Mini Mental State Examination (MMSE)

**1. Orientação** (1 ponto por cada resposta correcta)

Em que ano estamos? _____
Em que mês estamos? _____
Em que dia do mês estamos? _____
Em que dia da semana estamos? _____
Em que estação do ano estamos? _____

**Nota**:____

Em que país estamos? _____
Em que distrito vive? _____
Em que terra vive? _____
Em que casa estamos? _____
Em que andar estamos? _____

**Nota**:____

**2. Retenção** (contar 1 ponto por cada palavra correctamente repetida)

"Vou dizer três palavras; queria que as repetisse, mas só depois de eu as dizer todas; procure ficar a sabê-las de cor".
Pêra _____
Gato _____
Bola _____

**Nota**:____

**3. Atenção e Cálculo** (1 ponto por cada resposta correcta. Se der uma errada mas depois continuar a subtrair bem, consideram-se as seguintes como correctas. Parar ao fim de 5 respostas)

"Agora peco-lhe que me diga quantos são 30 menos 3 e depois ao número encontrado volta a tirar 3 e repete assim até eu lhe dizer para parar".
27_ 24_ 21 _ 18_ 15_

**Nota**:____

**4. Evocação** (1 ponto por cada resposta correcta.)

"Veja se consegue dizer as três palavras que pedi há pouco para decorar".
Pêra ______
Gato ______
Bola ______

**Nota**:____

**5. Linguagem** (1 ponto por cada resposta correcta)

a. "Como se chama isto? Mostrar os objectos:
Relógio ____
Lápis______

**Nota**:____

b. "Repita a frase que eu vou dizer: O RATO ROEU A ROLHA"

**Nota**:____

c. "Quando eu lhe der esta folha de papel, pegue nela com a mão direita, dobre-a ao meio e ponha sobre a mesa"; dar a folha segurando com as duas mãos.

Pega com a mão direita____

Dobra ao meio ____

Coloca onde deve____

**Nota**:____

d. "Leia o que está neste cartão e faça o que lá diz". Mostrar um cartão com a frase bem legível, "FECHE OS OLHOS"; sendo analfabeto lê-se a frase.

Fechou os olhos____

**Nota**:____

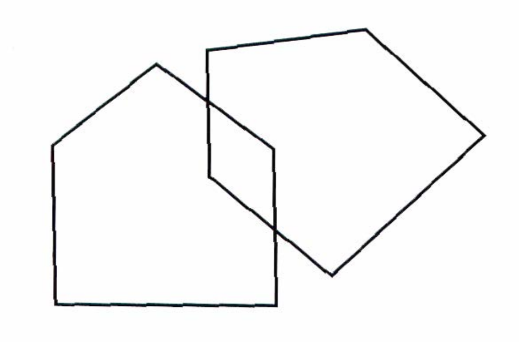
e. "Escreva uma frase inteira aqui". Deve ter sujeito e verbo e fazer sentido; os erros gramaticais não prejudicam a pontuação.

Frase:

**Nota**:____

**6. Habilidade Construtiva** (1 ponto pela cópia correcta.)

Deve copiar um desenho. Dois pentágonos parcialmente sobrepostos; cada um deve ficar com 5 lados, dois dos quais intersectados. Não valorizar tremor ou rotação.



Cópia:

**Nota**:____

**TOTAL**(Máximo 30 pontos):____

| | |
|---|---|
| **<u>Considera-se com defeito cognitivo</u>**: | • analfabetos ≤ 15 pontos<br>• 1 a 11 anos de escolaridade ≤ 22<br>• com escolaridade superior a 11 anos ≤ 27 |

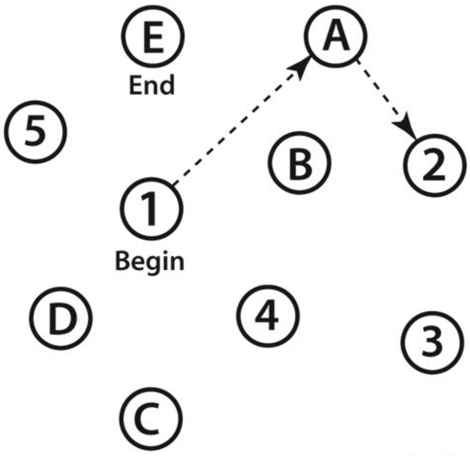
## B.2 Montreal Cognitive Assessment Test

NAME :
Education : Date of birth :
Sex : DATE :

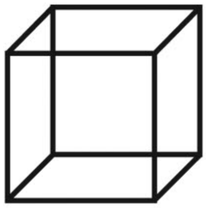
# MONTREAL COGNITIVE ASSESSMENT (MOCA)

Version 7.1 Original Version

## VISUOSPATIAL / EXECUTIVE




[ ]



Copy cube

[ ]

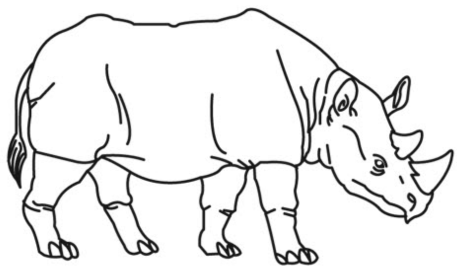
Draw CLOCK (Ten past eleven)
( 3 points )

[ ] Contour [ ] Numbers [ ] Hands

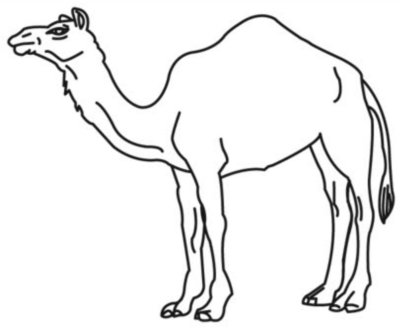
POINTS ___/5

## NAMING

[ ]



[ ]



[ ]

___/3

## MEMORY

Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

| | FACE | VELVET | CHURCH | DAISY | RED |
|---|---|---|---|---|---|
| 1st trial | | | | | |
| 2nd trial | | | | | |

No points

## ATTENTION

Read list of digits (1 digit/ sec.).
Subject has to repeat them in the forward order [ ] 2 1 8 5 4
Subject has to repeat them in the backward order [ ] 7 4 2
___/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B
___/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65
4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**
___/3

## LANGUAGE

Repeat : I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ]
___/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words)
___/1

## ABSTRACTION

Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler
___/2

## DELAYED RECALL

| Has to recall words **WITH NO CUE** | FACE [ ] | VELVET [ ] | CHURCH [ ] | DAISY [ ] | RED [ ] | Points for UNCUED recall only |
|---|---|---|---|---|---|---|
| **Optional** Category cue | | | | | | |
| Multiple choice cue | | | | | | |

___/5

## ORIENTATION

[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City
___/6

 www.mocatest.org Normal ≥ 26 / 30

TOTAL ___/30
Add 1 point if ≤ 12 yr edu

Administered by: ____________________

## B.3 Frontal Assessment Battery

# Frontal Assessment Battery

**Purpose**
The FAB is a brief tool that can be used at the bedside or in a clinic setting to assist in discriminating between dementias with a frontal dysexecutive phenotype and Dementia of Alzheimer's Type (DAT). The FAB has validity in distinguishing Fronto-temporal type dementia from DAT in mildly demented patients (MMSE > 24). Total score is from a maximum of 18, higher scores indicating better performance.

**1. Similarities (conceptualization)**
"In what way are they alike?"

- A banana and an orange

(In the event of total failure: "they are not alike" or partial failure: "both have peel," help the patient by saying: "both a banana and an orange are fruit"; but credit 0 for the item; do not help the patient for the two following items)

- A table and a chair
- A tulip, a rose and a daisy

**Score** (only category responses [fruits, furniture, flowers] are considered correct)

Three correct: 3 Two correct: 2 One correct: 1 None correct: 0

**2. Lexical fluency (mental flexibility)**
"Say as many words as you can beginning with the letter 'S,' any words except surnames or proper nouns."

If the patient gives no response during the first 5 seconds, say: "for instance, snake." If the patient pauses 10 seconds, stimulate him by saying: "any word beginning with the letter 'S.' The time allowed is 60 seconds.

**Score** (word repetitions or variations [shoe, shoemaker], surnames, or proper nouns are not counted as correct responses)

> 9 words: 3 6 -9 words: 2 3 -5 words: 1 < 3 words: 0

**3. Motor series "Luria" test (programming)**
"Look carefully at what I'm doing."

The examiner, seated in front of the patient, performs alone three times with his left hand the series of "fist–edge–palm."
"Now, with your right hand do the same series, first with me, then alone."
The examiner performs the series three times with the patient, then says to him/her:
"Now, do it on your own."

**Score**

Patient performs six correct consecutive series alone: 3
Patient performs at least three correct consecutive series alone: 2
Patient fails alone, but performs three correct consecutive series with the examiner: 1
Patient cannot perform three correct consecutive series even with the examiner: 0

**4. Conflicting instructions (sensitivity to interference)**
"Tap twice when I tap once."
To ensure that the patient has understood the instruction, a series of 3 trials is run: 1-1-1.

"Tap once when I tap twice."
To ensure that the patient has understood the instruction, a series of 3 trials is run: 2-2-2.

The examiner then performs the following series: 1-1-2-1-2-2-2-1-1-2.

**Score** No errors: 3 1 -2 errors: 2 > 2 errors: 1
Patient taps like the examiner at least four consecutive times: 0

**5. Go–No Go (inhibitory control)**
"Tap once when I tap once."
To ensure that the patient has understood the instruction, a series of 3 trials is run: 1-1-1.

"Do not tap when I tap twice."
To ensure that the patient has understood the instruction, a series of 3 trials is run: 2-2-2.

The examiner then performs the following series: 1-1-2-1-2-2-2-1-1-2.

**Score** No errors: 3 1 -2 errors: 2 > 2 errors: 1
Patient taps like the examiner at least four consecutive times: 0

**6. Prehension behaviour (environmental autonomy)**

"Do not take my hands."

The examiner is seated in front of the patient. Place the patient's hands palm up on his knees. Without saying anything or looking at the patient, the examiner brings his own hands close to the patient's hands and touches the palms of both the patient's hands, to see if he will spontaneously take them. If the patient takes the examiner's hands, try again after asking the patient: "Now, do not take my hands."

**Score**

Patient does not take the examiner's hands: 3
Patient hesitates and asks what he/she has to do: 2
Patient takes the hands without hesitation: 1
Patient takes the examiner's hand even after he/she has been told not to do so: 0

**Interpreting results**
A cut off score of 12 on the FAB has a sensitivity of 77% and specificity of 87% in differentiating between frontal dysexecutive type dementias and DAT

**ReferenceS**
Dubois, B. ; Litvan, I.; The FAB: A frontal assessment battery at bedside. Neurology. 55(11): 1621-1626, 2000.

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## B.4 Neuropsychiatric Inventory

phone: (206) 543-8637; fax: (206) 616-5927
e-mail: naccmail@u.washington.edu
website: www.alz.washington.edu

**NACC Uniform Data Set (UDS) – Initial Visit Packet**

# Form B5: Behavioral Assessment – Neuropsychiatric Inventory Questionnaire (NPI-Q[1])

Center: ______________ ADC Subject ID: __ __ __ __ __ __ __ __ __ __ Visit Date: __ __/__ __/__ __ __ __ ADC Visit #:__ __ __

**NOTE: This form is to be completed by the clinician per informant interview, as described by the training video. (This is not to be completed by the subject as a paper-and-pencil self-report.) For information regarding NPI-Q Interviewer Certification, see UDS Coding Guidebook page 34. Check only one box for each category of response.** Examiner's initials:__ __ __

Please ask the following questions based upon changes. Indicate "yes" only if the symptom has been present in the past month; otherwise, indicate "no".

For each item marked "yes", rate the SEVERITY of the symptom (how it affects the patient):
1 = Mild (noticeable, but not a significant change)
2 = Moderate (significant, but not a dramatic change)
3 = Severe (very marked or prominent; a dramatic change)

1. NPI informant: ☐ 1 Spouse ☐ 2 Child ☐ 3 Other (*specify*): ______________________

| | | Yes | No | | Severity | | |
|---|---|---|---|---|---|---|---|
| 2. DELUSIONS: Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way? | 2a. | ☐ 1 | ☐ 0 | 2b. | ☐ 1 | ☐ 2 | ☐ 3 |
| 3. HALLUCINATIONS: Does the patient act as if he or she hears voices? Does he or she talk to people who are not there? | 3a. | ☐ 1 | ☐ 0 | 3b. | ☐ 1 | ☐ 2 | ☐ 3 |
| 4. AGITATION OR AGGRESSION: Is the patient stubborn and resistive to help from others? | 4a. | ☐ 1 | ☐ 0 | 4b. | ☐ 1 | ☐ 2 | ☐ 3 |
| 5. DEPRESSION OR DYSPHORIA: Does the patient act as if he or she is sad or in low spirits? Does he or she cry? | 5a. | ☐ 1 | ☐ 0 | 5b. | ☐ 1 | ☐ 2 | ☐ 3 |
| 6. ANXIETY: Does the patient become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense? | 6a. | ☐ 1 | ☐ 0 | 6b. | ☐ 1 | ☐ 2 | ☐ 3 |

## B.5 Zarit Burden Interview

# ENTREVISTA DE ZARIT DE SOBRECARGA DO CUIDADOR

## ZARIT BURDEN INTERVIEW

*Zarit, Orr & Zarit, 1985*

**Instruções:**

Segue-se uma lista de perguntas em relação com sentimentos ou ideias que as pessoas têm, por vezes, quando cuidam de um familiar doente. Por favor assinale, para cada pergunta, a resposta que melhor indica a frequência com que se sente dessa forma ou tem esses pensamentos (“nunca”, “raramente”, “algumas vezes”, “bastantes vezes”, “quase sempre”, etc.).

Não existem respostas certas ou erradas, só interessa o que melhor se aplica a si próprio(a). Muito obrigado.

---

1. **Acha que o seu familiar pede mais ajuda do que ele(ela) realmente precisa?**

   ☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

2. **Acha que não tem tempo suficiente para si próprio(a), devido ao tempo que tem de dedicar ao seu familiar?**

   ☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

3. **Sente-se em "stress" por ter de se dividir entre o cuidar do seu familiar e as suas outras responsabilidades (trabalho/família)?**

   ☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

4. **Sente-se envergonhado(a) com o comportamento do seu familiar?**

   ☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

5. **Sente-se irritado(a) quando está com o seu familiar?**

   ☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

6. **Acha que o seu familiar está presentemente a afectar, de forma negativa, a sua relação com outros membros da família ou com os seus amigos?**

   ☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

7. **Tem medo do que o futuro pode reservar ao seu familiar?**

   ☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

8. **Acha que o seu familiar está dependente de si?**

   ☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

9. Sente-se em tensão quando está com o seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

10. Acha que a sua saúde se tem ressentido por causa do seu envolvimento com o seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

11. Acha que não tem tanta privacidade quanto desejaria, por ter de cuidar do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

12. Acha que a sua vida social se tem ressentido por estar a cuidar do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

13. Sente-se desconfortável quando recebe visitas dos amigos, por causa do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

14. Acha que o seu familiar espera que cuide dele como se fosse a única pessoa com quem ele pode contar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

15. Acha que não tem dinheiro suficiente para cuidar do seu familiar, tendo em conta todas as suas outras despesas?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

16. Acha que já não será capaz de continuar a cuidar do seu familiar por muito mais tempo?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

17. Sente que perdeu o controlo sobre a sua vida desde que a doença do seu familiar apareceu?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

18. Deseja que pudesse ser uma outra pessoa a cuidar do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

19. Sente-se indeciso(a) quanto ao que fazer com o seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

20. Acha que devia estar a fazer mais pelo seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

21. Acha que podia cuidar melhor do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

22. De uma maneira geral, de que forma se sente sobrecarregado(a) por estar a cuidar do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

23. Acha que o seu familiar pede mais ajuda do que ele(ela) realmente precisa?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

24. Acha que não tem tempo suficiente para si próprio(a), devido ao tempo que tem de dedicar ao seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

25. Sente-se em "stress" por ter de se dividir entre o cuidar do seu familiar e as suas outras responsabilidades (trabalho/família)?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

26. Sente-se envergonhado(a) com o comportamento do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

27. Sente-se irritado(a) quando está com o seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

28. Acha que o seu familiar está presentemente a afectar, de forma negativa, a sua relação com outros membros da família ou com os seus amigos?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

29. Tem medo do que o futuro pode reservar ao seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

30. Acha que o seu familiar está dependente de si?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

31. Sente-se em tensão quando está com o seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

32. Acha que a sua saúde se tem ressentido por causa do seu envolvimento com o seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

33. Acha que não tem tanta privacidade quanto desejaria, por ter de cuidar do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

34. Acha que a sua vida social se tem ressentido por estar a cuidar do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

35. Sente-se desconfortável quando recebe visitas dos amigos, por causa do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

36. Acha que o seu familiar espera que cuide dele como se fosse a única pessoa com quem ele pode contar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

37. Acha que não tem dinheiro suficiente para cuidar do seu familiar, tendo em conta todas as suas outras despesas?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

38. Acha que já não será capaz de continuar a cuidar do seu familiar por muito mais tempo?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

39. Sente que perdeu o controlo sobre a sua vida desde que a doença do seu familiar apareceu?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

40. Deseja que pudesse ser uma outra pessoa a cuidar do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

41. Sente-se indeciso(a) quanto ao que fazer com o seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

42. Acha que devia estar a fazer mais pelo seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

43. Acha que podia cuidar melhor do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

44. De uma maneira geral, de que forma se sente sobrecarregado(a) por estar a cuidar do seu familiar?

☐ nunca ☐ raramente ☐ algumas vezes ☐ bastantes vezes ☐ quase sempre

**Cotação dos itens:** nunca=1; raramente=2; algumas vezes=3; bastantes vezes=4; quase sempre=5

## B.6 Instrumental Activities of Daily Living

# ESCALA DE ACTIVIDADES INSTRUMENTAIS DE VIDA DIÁRIA (AIVD)

## Escala de Lawton e Brody

*SLawton M.P; Brody E.M. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist. 1969 Autumn;9(3):179-86*

A escala deve ser administrada a um acompanhante.

Não aplicável: cotar 9 (não aplicável) quando a tarefa nunca foi feita na vida. Nos casos em que a tarefa não é feita no presente por motivos aparentemente independentes da vontade ou capacidade do sujeito (ex: o sujeito não tem telefone em casa ou nunca usa os transportes públicos porque não precisa), o examinador deve formular a questão da seguinte maneira: "suponha que o doente tinha que fazer um telefonema, usar um transporte público, etc…., acha que seria capaz de o fazer?" e cotar de acordo com a resposta.

**Instrumental Activities of Daily Living Scale (I.A.D.L.)**
Tradução: LEL com alterações de acordo com o projecto LADIS

Nome: ______________________________________________

Data da Observação: ____/____ /____ Observador: ______________________________

### A. Capacidade para usar o telefone

| | |
|---|---|
| 1. Usa o telefone por sua iniciativa, marca os números, etc. | 1 |
| 2. Marca alguns números conhecidos | 1 |
| 3. Atende o telefone, mas não marca | 1 |
| 4. Não usa o telefone de todo | 0 |
| Não aplicável | 9 |

### B. Compras

| | |
|---|---|
| 1. Faz todas as compras independentemente | 1 |
| 2. Só faz, independentemente, pequenas compras | 0 |
| 3. Necessita ser apoiado para fazer pequenas compras | 0 |
| 4. Completamente incapaz de ir às compras | 0 |
| Não aplicável | 9 |

**C. Cozinhar**

| | |
|---|---|
| 1. Planeia, prepara e serve adequadamente as refeições, de modo independente | 1 |
| 2. Prepara as refeições adequadamente, se lhe forem dados os ingredientes | 0 |
| 3. Aquece e serve refeições já preparadas ou prepara refeições, mas não mantêm uma dieta adequada | 0 |
| 4. Necessita que lhe preparem e sirvam as refeições | 0 |
| Não aplicável | 9 |

**D. Lida da casa**

| | |
|---|---|
| 1. Cuida da casa sozinho ou com assistência ocasional (ex.: ajuda para trabalhos domésticos mais pesados) | 1 |
| 2. Faz trabalhos leves, como lavar a loiça e fazer as camas | 1 |
| 3. Faz tarefas diárias leves, mas não pode manter um nível aceitável de limpeza | 1 |
| 4. Necessita de ajuda em todas as tarefas domésticas | 0 |
| 5. Não participa em qualquer actividade doméstica | 0 |
| Não aplicável | 9 |

**E. Tratamento da Roupa**

| | |
|---|---|
| 1. Cuida completamente da lavagem da sua roupa | 1 |
| 2. Lava pequenas peças (meias, cuecas, etc..) | 0 |
| 3. Toda a lavagem de roupa é feita por outros | 0 |
| Não aplicável | 9 |

**F. Deslocações**

| | |
|---|---|
| 1. Viaja independentemente em transportes públicos ou conduz o seu próprio carro | 1 |
| 2. Desloca-se de táxi, mas não usa transportes públicos | 1 |
| 3. Viaja em transportes públicos quando acompanhado por outras pessoas | 1 |
| 4. Viaja, limitado a táxi ou automóvel particular com assistência de outros | 0 |
| 5. Não viaja de todo | 0 |
| Não aplicável | 9 |

**G. Responsabilidade com os seus próprios medicamentos**

| | |
|---|---|
| 1. É responsável em tomar a sua medicação em dosagens correctas e a horas certas | 1 |
| 2. É responsável, se a medicação é organizada previamente e separada em doses | 0 |
| 3. Não é capaz de tomar conta da sua própria medicação | 0 |
| Não aplicável | 9 |

**H. Capacidade para tratar das finanças**

| | |
|---|---|
| 1. Trata de assuntos financeiros independente (assina cheques, faz pagamentos, vai ao banco, etc.), mantendo organizado a sua escrita | 1 |
| 2. Trata dos assuntos diários, mas necessita de ajuda para ir ao banco, ou tratar de assuntos mais complicados | 0 |
| 3. Incapacidade para utilizar o dinheiro | 0 |
| Não aplicável | 9 |

# Appendix C

# Usability tests

## C.1 Caregivers

Table C.1: Demographic and general aspects about the caregivers who performed the usability tests.

| | Aspect | | | |
|---|---|---|---|---|
| Caregiver | Age? | Has glasses? | Has mobile phone? | First time touch device? |
| 1 | 27 | No | Yes | No |
| 2 | 49 | No | No | Yes |
| 3 | >50 | No | Yes | Yes |
| 4 | 26 | No | Yes | No |
| 5 | 21 | No | Yes | No |
| 6 | 50 | Yes | Yes | No |
| 7 | 45 | Yes | Yes | No |
| 8 | >50 | Yes | Yes | Yes |
| 9 | 61 | Yes | Yes | Yes |
| 10 | 56 | Yes | Yes | Yes |

Table C.2: Task 1's results of the caregiver's usability test.

| | Can identify the area of "Pending tasks" as the correct one? | Can identify the correct interview to answer? | Can understand the instruction given? | Can understand the answer buttons and their meaning? | Can send the answers to the HCP after finishing my interview? | Number of errors | Observations |
|---|---|---|---|---|---|---|---|
| 1 | Yes | Yes | Yes | Yes | Yes | 0 | |
| 2 | No | Yes | Yes | Yes | Yes | 1 | Rename the option "Pending tasks". Presses the icon in the pending tasks list instead of pressing the name. |
| 3 | No | No | Yes | Yes | Yes | 3 | Doesn't understand the concept "Pending tasks". Increase start button size in instructions. |
| 4 | No | Yes | Yes | Yes | Yes | 0 | "Pending tasks" is not appropriate. |
| 5 | Yes | Yes | Yes | Yes | Yes | 0 | "help" button may not be useful. At most, could explain the question. |
| 6 | Yes | Yes | Yes | Yes | Yes | 0 | |
| 7 | No | Yes | Yes | Yes | Yes | 0 | Change "pending tasks" to "to-do tasks" or "activities". |
| 8 | Yes | Yes | Yes | Yes | Yes | 0 | |
| 9 | Yes | Yes | Yes | Yes | Yes | 0 | |
| 10 | Yes | Yes | Yes | Yes | Yes | 0 | |

Table C.3: Task 2's results of the caregiver's usability test.

| | Can identify the correct button in the dialog? | Can identify the button which is pressed as the answer previously given? | Can understand the arrow buttons as navigation items? | Uses swipe? | Can change the answer? | Can send the answers to the HCP after finishing revising the answers? | Number of errors | Observations |
|---|---|---|---|---|---|---|---|---|
| 1 | Yes | Yes | Yes | No | Yes | Yes | 0 | |
| 2 | Yes | Yes | No | No | Yes | Yes | 0 | Change the arrow's icons. Increase current question font size. |
| 3 | Yes | Yes | No | No | Yes | Yes | 1 | Increase current question font size. |
| 4 | Yes | Yes | Yes | No | Yes | Yes | 0 | |
| 5 | Yes | Yes | Yes | Yes | Yes | Yes | 0 | |
| 6 | Yes | Yes | Yes | No | Yes | Yes | 1 | The help button should explain the layout or the question. |
| 7 | Yes | Yes | Yes | No | Yes | Yes | 0 | Should provide feedback when changing an answer. Help button should display the instruction. |
| 8 | Yes | Yes | Yes | No | Yes | Yes | 1 | |
| 9 | Yes | Yes | Yes | No | Yes | Yes | 0 | |
| 10 | Yes | Yes | Yes | Yes | Yes | Yes | 0 | |

Table C.4: Task 3's results of the caregiver's usability test.

| | Can identify the correct area? | Can understand the instruction given? | Can understand the time available? | Can record the message? | Can send the message to the HCP? | Number of errors | Observations |
|---|---|---|---|---|---|---|---|
| 1 | Yes | Yes | Yes | Yes | Yes | 0 | |
| 2 | Yes | Yes | Yes | Yes | Yes | 0 | Improve the instruction, change the "record a sound". |
| 3 | Yes | Yes | Yes | Yes | Yes | 0 | |
| 4 | Yes | Yes | Yes | Yes | Yes | 0 | Change the instruction to something more clear as to what the person should record. |
| 5 | Yes | Yes | Yes | Yes | Yes | 0 | |
| 6 | Yes | Yes | Yes | Yes | Yes | 0 | Record again button should only appear after listening what has been recorded is complete. |
| 7 | Yes | Yes | Yes | Yes | Yes | 0 | |
| 8 | Yes | Yes | Yes | Yes | Yes | 0 | |
| 9 | Yes | Yes | Yes | Yes | Yes | 0 | |
| 10 | Yes | Yes | Yes | Yes | Yes | 0 | |

Table C.5: Task 4's results of the caregiver's usability test.

| | Can understand the "Listen" button? | Can understand the concept of record again? | Can send the message to the HCP? | Number of errors | Observations |
|---|---|---|---|---|---|
| 1 | Yes | Yes | Yes | 0 | Remove the button "Listen" while recording for the second time |
| 2 | Yes | No | Yes | 1 | Increase the record again button. |
| 3 | Yes | Yes | Yes | 0 | Increase the record again button. |
| 4 | Yes | Yes | Yes | 0 | Increase the send to HCP button. |
| 5 | Yes | Yes | Yes | 0 | |
| 6 | Yes | Yes | Yes | 0 | Put the sound at maximum when listening. |
| 7 | Yes | Yes | Yes | 0 | |
| 8 | Yes | Yes | Yes | 0 | |
| 9 | Yes | Yes | Yes | 0 | |
| 10 | Yes | Yes | Yes | 0 | |

Table C.6: Task 5's results of the caregiver's usability test.

| | Can identigy the are for the FAQs? | Can read clearly the question? | Can understand how to access the answer to a certain question? | Number of errors | Observations |
|---|---|---|---|---|---|
| 1 | Yes | Yes | Yes | 0 | Change the arrow icons. Identified the back button. |
| 2 | Yes | Yes | Yes | 0 | Change the icons. Identified the back button. |
| 3 | Yes | Yes | Yes | 1 | Remove the icons. Identified the back button. |
| 4 | Yes | Yes | Yes | 0 | |
| 5 | Yes | Yes | Yes | 0 | Identified the back button. |
| 6 | Yes | Yes | Yes | 1 | Increase space between lines. Thought the home button was to go back to the dashboard. Identified the back button. |
| 7 | Yes | Yes | Yes | 0 | Identified the back button, arrows don't mean much. |
| 8 | Yes | Yes | Yes | 0 | |
| 9 | Yes | Yes | Yes | 0 | Identified the back button. |
| 10 | Yes | Yes | Yes | 0 | Identified the back button. |

# Usability testing protocol

## Introduction

Hi, my name is Hélder, I'm an engineer student and I'm working on a project help both the caregiver and the patient of Alzheimer's disease. In order to do that, and to make the project suitable to the needs of the people who deal with this daily, I need your help. I will ask you to perform simple tasks in this smartphone/tablet and this will take at maximum 20 minutes. I want to assure you before moving on that you are not the one being tested but our application. The goal is to develop this system as close to Alzheimer's patients and respective caregivers needs as possible and your help is extremely valuable.

The system's goal is to provide the patient and the caregiver with a tool that would allow them to be in contact to the doctor, without having to go to the doctor's office all the time. The doctor can send questions for the caregiver to answer and the caregiver can also send important things to the doctor. There are 4 main areas but today we will focus only 3 of them. Pending tasks, where you can see what tasks has the doctor asked you to do; frequently asked questions, where you can find answer to some questions that most of the persons going through these disease have and an area where you can tell the doctor when something out of the ordinary happens.

## Questions

What's your name?
How old are you?
Do you wear glasses?
Do you have a cellphone?
Is this your first contact with a touch device, such as, a tablet?

## C.2 Patients

Table C.7: Demographic and general aspects about the patients who performed the usability tests.

| | Aspect | | | |
|---|---|---|---|---|
| Patient | Age? | Has glasses? | Has mobile phone? | First time touch device? |
| 1 | 74 | Yes | Yes | Yes |
| 2 | 78 | Yes | Yes | Yes |
| 3 | 67 | Yes | Yes | Yes |
| 4 | 52 | No | No | Yes |
| 5 | >60 | No | No | Yes |
| 6 | 85 | Yes | Yes | Yes |
| 7 | 62 | Yes | Yes | Yes |
| 8 | 61 | Yes | Yes | Yes |

Table C.8: Patient 1 usability test's results.

| Exercise | Difficulty | Nr of wrong clicks | Completed the exercise? |
|---|---|---|---|
| Memory Training | Easy | 0 | Yes |
| | Medium | 1 | Yes |
| | Hard | 1 | Yes |
| IADL | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| Number Sequence | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| | Hard | 0 | Yes |

Table C.9: Patient 2 usability test's results.

| Exercise | Difficulty | Nr of wrong clicks | Completed the exercise? |
|---|---|---|---|
| Memory Training | Easy | 0 | Yes |
| | Medium | 1 | Yes |
| | Hard | 3 | No |
| IADL | Easy | 0 | Yes |
| | Medium | 2 | Yes |
| Number Sequence | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| | Hard | 1 | Yes |

Table C.10: Patient 3 usability test's results.

| Exercise | Difficulty | Nr of wrong clicks | Completed the exercise? |
|---|---|---|---|
| Memory Training | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| | Hard | 2 | Yes |
| IADL | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| Number Sequence | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| | Hard | 0 | Yes |

Table C.11: Patient 4 usability test's results.

| Exercise | Difficulty | Nr of wrong clicks | Completed the exercise? |
|---|---|---|---|
| Memory Training | Easy | 0 | Yes |
| | Medium | 1 | Yes |
| | Hard | 2 | Yes |
| IADL | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| Number Sequence | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| | Hard | 0 | Yes |

Table C.12: Patient 5 usability test's results.

| Exercise | Difficulty | Nr of wrong clicks | Completed the exercise? |
|---|---|---|---|
| Memory Training | Easy | 0 | Yes |
| | Medium | 2 | Yes |
| | Hard | 4 | No |
| IADL | Easy | 1 | Yes |
| | Medium | 1 | Yes |
| Number Sequence | Easy | 0 | Yes |
| | Medium | 1 | Yes |
| | Hard | 1 | Yes |

Table C.13: Patient 6 usability test's results.

| Exercise | Difficulty | Nr of wrong clicks | Completed the exercise? |
|---|---|---|---|
| Memory Training | Easy | 0 | Yes |
| | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| | Medium | 0 | Yes |
| | Hard | 0 | Yes |
| | Hard | 1 | Yes |
| IADL | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| Number Sequence | Easy | 0 | Yes |
| | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| | Medium | 0 | Yes |
| | Hard | 0 | Yes |
| | Hard | 0 | Yes |
| | Hard | 0 | Yes |
| | Hard | 0 | Yes |

Table C.14: Patient 7 usability test's results.

| Exercise | Difficulty | Nr of wrong clicks | Completed the exercise? |
|---|---|---|---|
| Memory Training | Easy | - | Yes |
| | Easy | - | Yes |
| | Medium | - | Yes |
| IADL | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| Number Sequence | Easy | - | Yes |
| | Easy | - | Yes |
| | Medium | - | Yes |
| | Medium | - | Yes |
| | Hard | - | Yes |
| | Hard | - | Yes |

Table C.15: Patient 8 usability test's results.

| Exercise | Difficulty | Nr of wrong clicks | Completed the exercise? |
|---|---|---|---|
| Memory Training | Easy | 0 | Yes |
| | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| | Medium | 1 | Yes |
| | Medium | 2 | Yes |
| | Hard | 0 | Yes |
| | Hard | 2 | Yes |
| IADL | Easy | 0 | Yes |
| | Medium | 1 | Yes |
| Number Sequence | Easy | 0 | Yes |
| | Easy | 0 | Yes |
| | Medium | 0 | Yes |
| | Medium | 0 | Yes |
| | Medium | 1 | Yes |
| | Hard | 0 | Yes |
| | Hard | 1 | Yes |
| | Hard | 0 | Yes |
| | Hard | 0 | Yes |

# Appendix D

# Smartphone interfaces

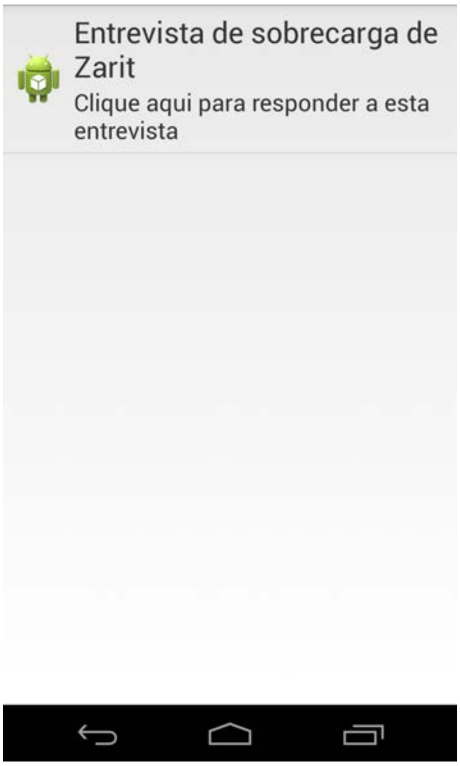
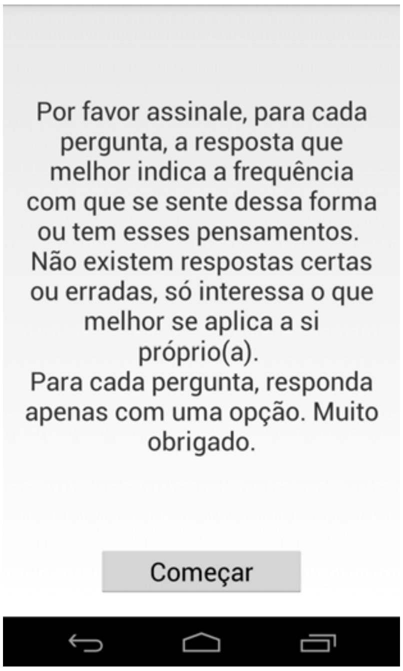
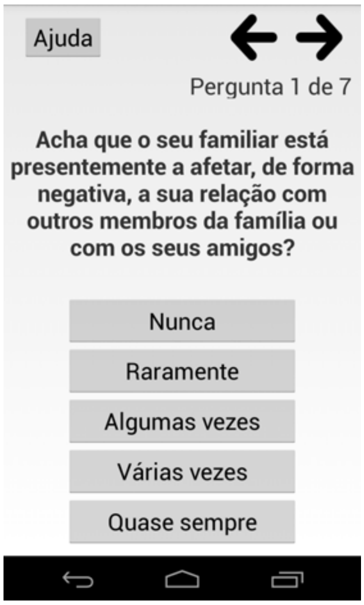



Figure D.1: List of pending tasks in the smartphone interface.




(a) Instruction seen before starting a ZBI questionnaire.




(b) Questionnaire example in the smartphone interface.

Figure D.2: ZBI questionnaire in the tablet version.

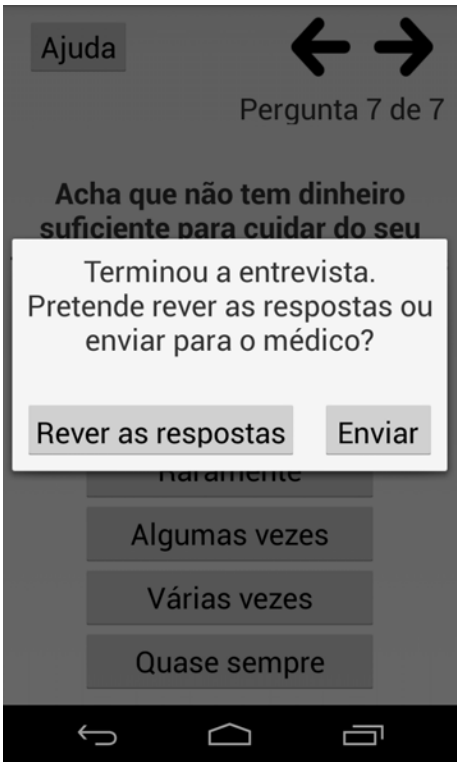



Figure D.3: Smartphone version of the custom dialog designed.


Figure D.4: Screen where the user chooses by what means he pretends to report an occurrence.

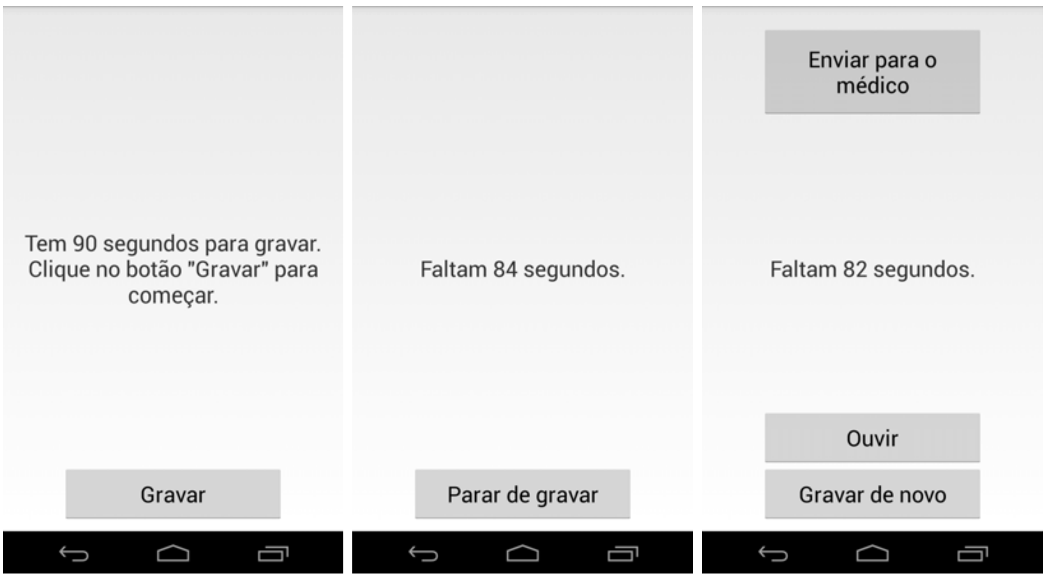
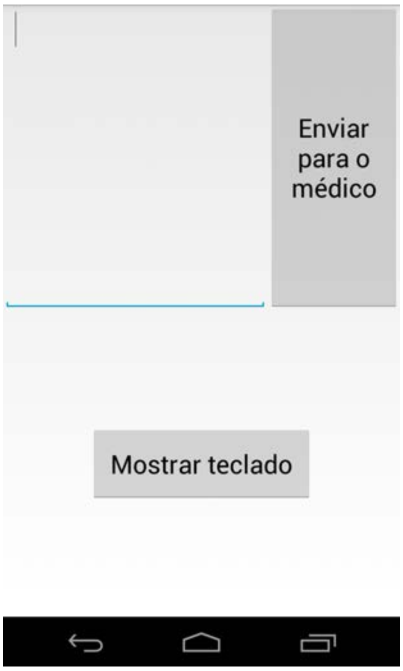
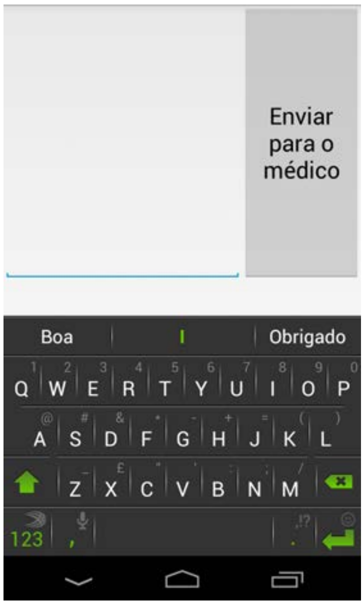



Figure D.5: Smartphone layouts of the report occurrence by audio message area.




(a) "Show keyboard" button.




(b) Text occurrence report screen.

Figure D.6: Smartphone layouts of the report occurrence by text message area.

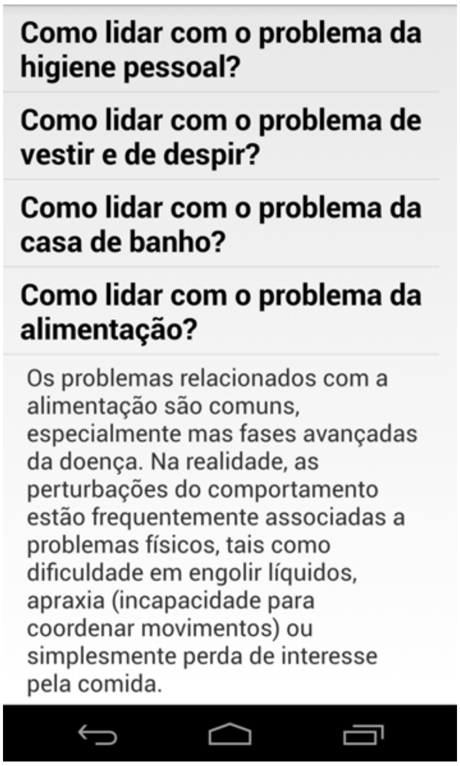



Figure D.7: FAQs list in the smartphone interface.