Mnemosine: Improving Life Conditions of Alzheimer Patients and Caregivers

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Abstract - It is estimated that by 2050 over 100 million people will be affected by the Alzheimer’s disease. It not only affects the patient but also the whole family and specially the caregiver, who is continuously under great stress conditions. We propose a software environment, called Mnemosine, designed to improve the quality of life of both Alzheimer patients and caregivers, trying to reduce progression of disease as much as possible. Mnemosine provides the neuropsychologist and the caregiver with resources that ease monitoring the disease evolution and controlling the patient’s daily activity. Some other characteristics of Mnemosine are portability for the patient, alarms system and agenda for the patient’s daily routine, GPS route guidance and location, and predefined reports to evaluate disease progression.

Keywords: Alzheimer, Software, Caregivers.

1 Introduction

Alzheimer’s disease (AD) is a progressive neurological illness of the brain that leads to the irreversible loss of neurons and dementia. Currently, AD is the most common cause of dementia and the third cause of mortality, just behind cardiovascular diseases and cancer. According to Alzheimer’s Disease International[1] there are currently 30 million people with dementia in the world, with 4.6 million new cases annually. The number of people affected will be over 100 million by 2050[2]. Studies have shown that only in the United States AD prevalence is estimated to be 1.6% in the 65-76 age group, 19% in the 75-84 group and 42% in the greater than 84 group[3]. Although AD is largely a disease of older people, 2% of those affected are under 65 years of age.

Clinical studies have shown that the mean life expectancy after diagnosis is approximately seven years[4], and although there is no cure to AD, with appropriate treatment the mean life expectancy can be much longer[5][6]. Treatment is usually a combination of pharmacological and non pharmacological therapies. Pharmacologic treatment is based on the administration of some medications that mitigate the cognitive manifestations of AD. On the other side, several techniques such as musicotherapy, psychomotricity, physical stimulation, behavioral and cognitive interventions are widely used in the non-pharmacological treatments. Memory interventions are included in the cognitive therapies, as it may be possible, especially in the early stages of AD, to improve patient’s memory with treatment. The goal is to act over all the memory stages (immediate, short-term and long-term) and over the various processes it is composed of, such as codification, storing and retrieval of information[7].

AD may be among the most costly diseases for society in Europe and United States, with costs as high as $160 billion all over the world[8]. For that reason, any therapy that slows cognitive decline, thus delaying institutionalization of the patients and reducing caregivers’ efforts will have economic benefits[9].

Additionally, it is important to realize that AD not only affects the patient but also the whole family and specially the caregiver. The physical and emotional stress they have to bear is enormous[10]. Over 65% of the relatives who take care of Alzheimer patients will suffer a significant change in their lives and an important leak in their physical or psychological health, resulting about the 20% of them in a clinical profile known as “burn-out caregiver”[11]. As AD pushes a great burden on caregivers who must take care of patients continuously, sometimes even leaving their jobs in order to take care of the patient, it is also important to improve caregivers life conditions[12][13][14].

The main parts involved in the daily care of an Alzheimer patient are the patient itself, the caregivers (may be more than one) and the neuropsychologist. In this context, we propose a technological solution aimed at ease their tasks by enforcing the communication flow between them, thus enabling all of them to be informed at any moment about the state and evolution of the patient’s disease.

There are currently several commercial products, such as SmartBrain or Gradior, specially designed to stimulate the cognitive aspect of the disease through the use of various logic puzzles and memory reinforcement. SmartBrain is a multimedia interactive computer program created to stimulate and develop the main cognitive capabilities of adults, with two possible uses: treatment through cognitive stimulation, and prevention with mental training. Gradior is a quite easy-to-use computer tool geared to help specialists the brain training and computer assisted rehabilitation of some cognitive functions, such as attention, memory, perception or calculus. It is useful for people with cognitive impairment, including Alzheimer patients. Some other products, such as Keruve, are mainly useful for locating patients in case of any emergency. Other initiatives, currently being developed,
propose to encourage the patient’s personal autonomy (in controlled environments) through the use of some kind of physical devices to control his activity[15].

2 Our Proposal: Mnemosine

Our proposal is a software development, called Mnemosine, designed to improve the quality of life of both Alzheimer patients and caregivers, trying to reduce progression of disease as much as possible. It is essentially focused on Alzheimer patients in the two initial stages of disease, because they still keep most of their independence [16]. It is known that the patient is able to perform his daily tasks in the initial stages of the disease, although he may forget some details about how the task must be performed. Additionally, in the first stage the patient still recognizes his relatives, but he may forget some of their names, so it is convenient to make some cognitive exercises to refresh the memory. The software will require that both the patient and caregiver have enough technological background to use a personal computer and a mobile device at a user level.

Mnemosine can help people with AD and their caregivers with techniques based on improving the strengths and abilities of patients. This allows that people with AD can keep their self-esteem and self-confidence through their illness[17]. This framework can help caregivers and neuropsychologists to develop plans that address activities of daily living that maximize independence, improve function and minimize need for support. One of the main characteristics of Mnemosine is its adaptation to every individual patient, as it has been shown that treatment techniques that take into account the personal history, character and individuality of the person with AD have a positive impact on the progress of the disease.

Mnemosine helps to enhance the flow of information and knowledge between all the persons implied in the caregiving process, making easier to access to the physical and mental health status and current level of functioning. This allows a better coordination and integration of all the actions comprising the patient’s daily care.

Moreover, Mnemosine not only give support for promoting independence and maintaining function of AD patients. It is known that caregivers of AD patients are under stress conditions whose effect depend not only on the patients deficits but also on the caregivers own characteristics[18]. No matter the reasons that cause the caregiver burden, with Mnemosine the caregiver is partially freed of been continuously paying attention to the patient with his common tasks. It provides the patient with some autonomy while preserving the quality of the control exerted over him. Besides, it also eases the scheduling of the patient’s daily activities and the elaboration of diverse personalized materials that can be used in the patient’s cognitive exercises.

From the neuropsychologist point of view, this framework eases the communication flow with the patient and his environment. It also allows him to enhance the diagnostic tools for the disease evolution, as he can access the daily log of the patient activity. All this flexibility can be further exploited by reusing positive experiences carried out on similar patients.

2.1 Capabilities

The All the previously depicted characteristics of Mnemosine are possible by the smooth integration of the following capabilities:

- Personal Memory. This tool allows the edition of text and/or several multimedia resources (video, pictures, audio, or even a graphical representation of relative’s relations), depicting past lived experiences (a child’s

Figure 1. (a) Mnemosine-Home: Patient’s life book showing some social relations. (b) Mnemosine-Mobile. Basic browsing of patient’s life book.
Figure 2. (a) Mnemosine-Home: Exercise management directory. (b) Mnemosine-Mobile: Numeric cross reference exercise.

born, wedding, studies, etc.), or the social circle of the patient (relatives, friend, colleagues, etc.).

- **Cognitive exercises.** It allows the neuropsychologist to manage cognitive exercises, including creation and edition. On the patient’s side it allows the resolution of exercises to stimulate the cognitive capabilities and reduce progression of the disease.

- **Planning and monitoring the daily activity of the patient.** If we assume that daily routine is a key factor in Alzheimer’s patients, this tool make possible to schedule a limited set of activities for a certain period of time, including multimedia demonstrations of how he could perform them, and register to what extent the patient has been able to fulfill them.

- **Patient’s positioning system.** Mnemosine allows the definition of a geographic route, such as a walk around the neighborhood, or just going out to the grocer’s for milk, including the definition of a set of alerts in case the patient walks outside a secure area, or doesn’t come back inside the scheduled time. Among the types of alarms that Mnemosine can trigger there are phone calls autonomously made by the patient’s PDA device to relatives, or caregivers; or SMS sent to caregivers showing the GPS coordinates and the event that caused the warning.

- **Analysis of the progression of the disease.** Logs with the everyday activity of the patient are recorded on the mobile device and, thus can be easily uploaded to the neuropsychologist’s computer. All this information can be later presented to him through predefined reports which represent a very useful tool to analyze the evolution of the disease.

2.2 Implementation

**Type** We have implemented a fully operational prototype of Mnemosine which will be soon on a testing stage on an elderly residence with some AD patients. We have distributed the capabilities described in the previous section into two platforms which will be used by the patient, the caregivers and the neuropsychologist.

- **Mnemosine-Mobile:** It is integrated into a mobile device incorporating a GPS, such as a PDA-cell phone or Smartphone. It will be used by the patient during his everyday activities (demos, walks, exercises), to remember relevant past experiences, or just to recall some information about relatives or his social circle. At the same time it works as a positioning device useful to locate the patient in case of any emergency.

- **Mnemosine-Home:** This module runs on a personal computer and it can be used both by the caregiver and the neuropsychologist for creating demos, schedule activities, design controlled walk, describe past lived experiences, or input data into the patient’s life book. The neuropsychologist will use it in order to design and manage cognitive exercises, import user’s activity logs, and generate several reports with the patient’s activity.

The actual appearance of Mnemosine-Home and Mnemosine-Mobile is depicted in the following figures. They show some of the functionalities previously described.

Figure 1a shows a piece of the patient’s life book with a graphical representation of the social network of the patient. It is also possible to add new events describing past relevant experiences, and group them by social affinity (relatives, friends, works, and studies) using any combination of text and multimedia resources. It is also possible to browse the life book using the mobile device as shown Figure 1b.
The management of the cognitive exercises made through the Mnemosine-Home interface is depicted in Figure 2a. The neuropsychologist can create, edit or assign exercises to any of his patients (assuming no personal information is re-used between patients). This module can import information and resources from the patient’s life book when designing new cognitive exercises. The use of personal (private) elements from the patient life can act as a motivational element for solving those exercises. The interface for one of the implemented types of exercises on Mnemosine-Mobile is shown in Figure 2b.

The scheduling of the activities that the patient will have to perform during the day can be organized by the caregiver with the interface developed for Mnemosine-Home (Figure 3a). The user can browse the scheduled activities in the mobile device (Figure 3b). An alarm policy has been implemented so the caregiver will be warned in case the patient forgets, or doesn’t complete, any of the scheduled activities.

Routes can be easily defined by the caregiver using the interface shown in Figure 4a. The patient will have the GPS activated and the mobile device will send SMS, or even make a phone call to the predefined phone-numbers, in case the patient walks out a defined secure path or the time elapsed exceeds the prescribed period made by the caregiver.

3 Fitting all together: a case study

In a normal day the caregiver would prepare the next day agenda using Mnemosine-Home for each of the patients in the initial stages of the AD he is responsible for. He will synchronize the mobile devices so the patients can access their scheduled activities. In the morning, the patient will wake up and consult his agenda or just wait until his PDA notify him about an upcoming event. For example, if one of his granddaughters is going to visit him at noon, Mnemosine-Mobile will suggest him viewing a video showing the child playing in the park or some recent pictures of her.

Later, he could activate one of the predefined walks, for example to buy the newspaper, using Mnemosine-Mobile. The GPS will be activated during the walk to facilitate positioning the patient. In this example, our patient meets a friend who detains him longer than scheduled. When the estimated duration of the walk is exceeded Mnemosine-Mobile will send an SMS to the caregiver with the event description and position of the patient. The caregiver could then contact the patient and, if the answer is positive, discard the message.

After the walk, a new task is activated. In this case, the mobile device suggests the patient to make some exercises to keep tuned his cognitive skills. All the user activity is logged in the PDA for its further analysis. A visit to the neuropsychologist is scheduled in the afternoon. The doctor will synchronize the mobile uploading the user log upon arrival. The information includes walks, exercises and their marks and accesses to the life book. Mnemosine-Home adds all this information, so the doctor can visualize and analyze the information through the selection of any of the several reports available.

The neuropsychologist will then use Mnemosine-Home to design and schedule cognitive exercises in the patient’s agent. These exercises can be transferred from a data-base of existing ones, created by the modification of a previous one, or created from scratch. In this case, the doctor could use personal information from the patient’s life book, such as relative’s pictures, known places or personal-use utensils (i.e. breakfast mug, toothbrush, etc). Finally, the doctor downloads the new agenda and any relevant information that might be of interest for the caregiver to the patient’s PDA.
4 Conclusions

Alzheimer’s disease is the most common cause of dementia nowadays. It mainly affects older people, and it is estimated that by 2050 over 100 million people will be affected. AD not only affects the patient but also the whole family and specially the caregiver, who is continuously under great stress conditions. Although there is no cure to AD, some treatments, including memory interventions, are recommended in order to slow cognitive decline of the patient, thus delaying institutionalization and reducing caregivers’ efforts. Moreover, caregiving of Alzheimer patients has significant cost implications.

We propose a software development, called Mnemosine, designed to improve the quality of life of both Alzheimer patients and caregivers, trying to reduce progression of disease as much as possible. We stimulate the brain and cognitive capabilities of the patient as well as we provide the neuropsychologist and the caregiver with resources that ease monitoring the disease evolution and controlling the patient’s daily activity. This allows a better coordination and integration of all the actions comprising the patient’s daily care.

Mnemosine capabilities include functions to manage the life book of the patient, where different relevant experiences of the patient are stored in any multimedia format. It also includes all the management functions for adding, modifying and carrying out cognitive exercises. With Mnemosine the caregiver can schedule and monitor the daily activities of the patient, including the physical monitoring of the patient’s situation with the GPS positioning system. It also allows making reports about disease evolution that can help the neuropsychologist to schedule new therapies.

Our proposal has the advantage that it is portable for the patient, which can improve its self-confidence, individuality and reduces the need for support, as he can be assessed in his activities everywhere. Other advantages include the alarms system and the agenda for the patient’s daily routine. Moreover, this tool can help patients that cannot attend Alzheimer associations or the neuropsychologist because of a lack of mobility, center distance, shame (which is quite common in famous people affected), or initial states of the disease.

We strongly believe that this initial architecture is the base for including more functionalities, thus extending it to other types of dementia, or including characteristics as the integration of set-of-box devices (i.e. TDT) or domotics, or even the addition of social profiles coming from the internet.

5 References


