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Helping to stay aware! - MEM+ a computerised application for Alzheimer's patients

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Abstract

Dementia is, unfortunately, a well-known problem of nowadays, product of a set of generational transformations and a result of better life conditions. Memory is the key factor in this type of illness and it is nuclear to understand how it is constructed to hypothesise and try to determine how it degenerates. In this paper, memory structures are presented as a starting point of the research and then based on what type of memories are more affected on Alzheimer's patients an application has been devised: MEM+. This application aims at tracking the illness evolution and at the same time provide cognitive stimulus with a set of serious games. To devise a small prototype of the application a participatory design has been conducted.

1. Introduction

The Alzheimer disease is a type of dementia which causes a global, progressive and irreversible deterioration of the several cognitive functions (memory, attention, concentration, language, and reasoning, among others). This deterioration has some consequences such as changes in behaviour, character, and functional capability of the patient,

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making it difficult to complete its daily routine [1]. Currently Alzheimer already affects 7.3 million people only in Europe, by this century's midpoint, global demographic changes will double or even triple the number of people over age 65 in many countries, also increasing the numbers of the disease, causing therefore a major social and medical problem. The initial symptoms of the disease include loss of memory, spatial and time disorientation, confusion, reasoning and thinking problems. These symptoms become increasingly worse as the brain cells continue to die and their inter-connections alters.

To date, no cure was found to Alzheimer disease. However, there are some medicines that allow the symptomatic treatment of most of the cognitive and behavioural changes. Although, they cannot avoid the progressive neurological loss, the existent medicines can help to stabilize and minimize some symptoms. Nevertheless, Alzheimer disease curing should gather the pharmacological and non-pharmacological interventions.
The non-pharmacological ones, belongs to a group of interventions that strive to maximize the cognitive function and person well-being, as well as helping her/him in the process of the disease adaption. The activities developed try to stimulate people's capabilities, preserving, most of the time, their autonomy, comfort and dignity.

Taking these findings into consideration, the work here presented aims at maximizing the patient cognitive functioning, by exercising his/her memory. The application, called MEM+ - for MEMory+-, presupposes that the patient lays on an initial or intermediate stage of the disease, where he/she can still walk, recognise people and can associate words to objects and colours. MEM+ is being developed with the aid of specialised technicians and professionals, mainly from the Portuguese Alzheimer Association[†]. In this paper, we discuss the importance of memory formation and the need for a participatory design during the specification and development of the project, and simultaneously a small prototype is presented as well as the requirements and rationale behind its conception. Finally some future research directions are identified and some conclusions are drawn.

2. Related Work

Memory is the vehicle that allow us – humans – to construct our story over the years. Singer [2] concluded that identity formation was based on the generation of narratives from lived experience. Singer *et al.* [3] proposed a model of narrative identity which identifies a dual memory system that generates autobiographical memories and self-defining memories (see Fig. 1).
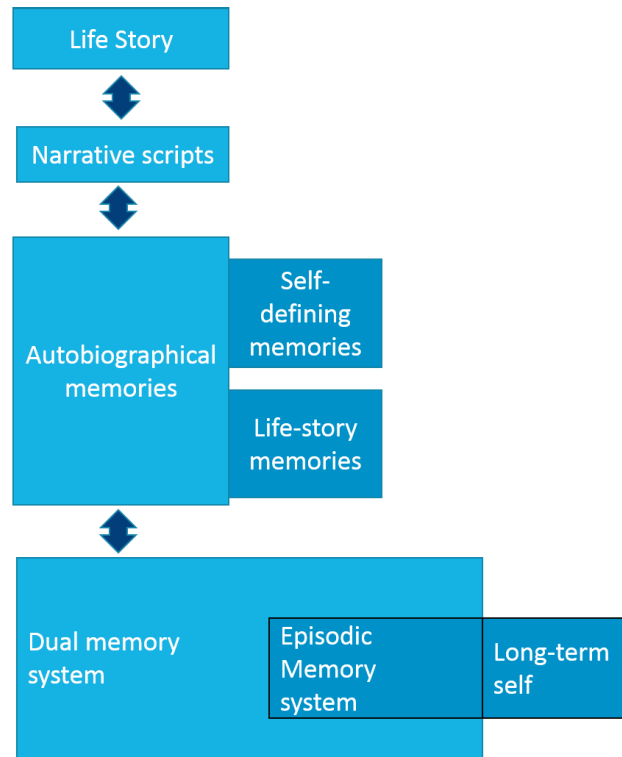
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Fig. 1 - Narrative Identity's Model‡

From this model, it is possible to understand that the dual memory system generates autobiographical and self-defining memories. The episodic memory system works with the actual memories and evaluates them in order to understand if they are valuable enough to belong the long-term self-memories. The life-story memories reveal memories that are important to the self during a particular life-period (following [4]), being linked to long-term goal pursuits, and are more affectively intense, important and detailed than other less important autobiographical memories. One could ask if these life-story memories will be constituents and central to the narrative identity. In our research context, one could also ask if these memories are the ones that keep being remembered or if these are the ones that disappear?

Following Singer and colleagues [3], similar to life-story memories, self-defining memories are vivid, affectively intense and well-rehearsed. They build on life-story memories by connecting to other significant memories across lifetime periods that share their themes and narrative sequences. They reflect individuals' most enduring concerns (e.g. achievements, etc.) and/or unresolved conflicts (sibling rivalry, addictive tendencies, etc.). Are these self-defining memories persistent in our memories our do they tend to go away?

Narrative intelligence has been defined as the human ability to organise experience into a narrative form [5], and again is a process that can be re-constructed in order to help Alzheimer's patients.
This evidence was the major drive for the development of this project, and in particular of the application MEM+, because if someone has lost the ability to remember some important moments of his/her life, there is the chance that by being presented with a story that tells presents such events, the memories may came back or at least help the remaining memories to stay *alive*. But how relevant is this for Alzheimer's patients?

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‡ Adapted from [3].

Alzheimer's disease is the most frequent form of dementia in elderly people [6] and for the time being no cure was found. Based on this, we centred our research on a non-pharmacological approach, which has already given some indications of being potentially beneficial for patients [7], [8]. In [9], a randomized pilot study was con-ducted to assess the efficacy of an interactive, multimedia tool of cognitive stimulation in Alzheimer's disease. The multimedia tool allowed the patients to exercise their memory, attention focus and recognition of activities and emotions [8]. In this pilot study, the patients that underwent the multimedia tool also received a pharmacological treatment. The results showed some improvements in their cognitive achievements but because of the multitude of variables involved in the study, the authors could not tell explicitly if they would come only from the use of the multimedia application.

Another pilot randomised controlled trial was conducted in order to compare the effects of a formal computer-based, cognitive training program [10] with more passive computer-based activities in older adults with mild cognitive impairment (MCI). The goal was to determine whether intensive computer-based cognitive training is feasible in subjects with MCI and to estimate the size of its effect on cognition [11]. The results obtained found that intensive computer-based mental activity training is feasible in elders with MCI, and that it is possible to enhance cognitive function in subjects with MCI, who are a vulnerable group with a high risk of developing dementia. However, the limitations included the small sample size, which restricted the authors' ability to determine whether their findings were due to chance or lack of power.

Other approach was taken by the Everyday Technologies for Alzheimer's Care (ETAC) initiative, which was launched by the Alzheimer's Association and Intel Corporation in 2003 - to identify and fund promising research in the use of technology, especially information and communication technologies (ICTs) for monitoring, diagnosing, and treating Alzheimer's disease (AD [12]. This initiative searched ways to improve quality of life and care while reducing healthcare costs, using interdisciplinary teams and information and communication services. This study proposes ways to use information technologies for caring and diagnosis of Alzheimer's disease, such as tools for tracking and monitoring of patients, for providing help to caregivers. The PocketPC (PocketBuddy) technology provided portable, non-invasive support for gathering data about the Alzheimer's patient and the caregiver during daily care giving activities, by recording behavioural and emotional changes observed by the caregiver. By using web technology, data can be made accessible to a virtual network of family, friends, and healthcare professionals.

The first definition of serious games was given by Clark Abt [13]: "Games may be played seriously or casually. We are concerned with serious games in the sense that these games have an explicit and carefully thought-out educational purpose and are not intended to be played primarily for amusement. This does not mean that serious games are not, or should not be, entertaining (…)". To face new challenges caused by society aging, several researchers started to develop serious games as a re-education platform to help slowing down the decline of people suffering from Alzheimer[14].

According to the authors, in the last few years, there have been some academic works and some commercial software (Nintendo's Brain Age, Big Brain Academy, etc.) trying to use serious games, however they are not appropriate for Alzheimer patients as they do not provide any form of in-game assistance able to recognize cognitive errors and to support the user accordingly. This support would provide dynamic difficulty adjustment for matching the user's particular skills and cognitive profile. A multidisciplinary team set specific guidelines for designing and implementing effective serious games targeting Alzheimer's patients. They cover the following aspects:

- Choosing right in-game challenges by tracing the patient's cognitive abilities, determining the appropriate number of steps for each challenge, keep the player focused and enjoying himself (a familiar context and a smooth learning curve are important for this).
- Designing appropriate interaction mechanisms for cognitively impaired people. It is known that physical activities can have positive effects on brain, so Nintendo Wii like games are a good choice, minimizing the learning curve. It is also mentioned the importance of being possible to use the games at home, once it reduces mobility costs.
- Producing effective visual and auditory assets to maximize cognitive training. Bright warm colours such as red, orange and yellow are best seen by the elderly, simple textures should be used for all objects in the game and colours of important visual information should be brighter, contrasts should be clearly defined. Unnecessary information in the screen should be avoided, as it can be difficult for patients to find objects in complex scenes.
- Implementing artificial intelligence for providing adequate assistive prompting and dynamic difficulty adjustments: Recent discoveries showed that it is more beneficial for Alzheimer's patients to be helped through completion of a challenge, than restarting the challenge. The use of Dynamic difficulty adjustment (DDA), which

consists of calculating the level of the player in order to match the game to his abilities, is a helpful technique to set the right level of challenge so that the player can be fully concentrated and avoid discouragement, maximizing the level of cognitive stimulation.

These findings are quite relevant for our research since they define the essentials about memory, memory's creation and applications on the non-pharmacological approaches to the illness. It is quite important to pinpoint that in our research we aim to benefit not only the patients but also their families and caregivers. Narrative is fundamental in our approach since it will help to re-tell the patients' own story, and to interconnect the simulation games to provide/enhance cognition training. To date, we did not find in the literature any application in this particular context, Alzheimer Disease, but it has already proven to be highly relevant in domains such as Autism Spectrum Disorders and Down's syndrome [15].

3. Participatory Design

During the development of the MEM+ it has been applied a participatory design approach - following the principles of ([16]) - by involving specialized professionals and technicians with different backgrounds. To date, it has been difficult to include patients because end-users of MEM+ mainly because they do not like to have their weaknesses exposed. The participatory design has been conducted through informal meetings between developers and specialized professionals. In these meetings, which usually lasted for about one hour, the professionals explain what they do in their daily routines with the patients, and developers try to: (a) understand how such daily routines can be portrayed in a computerized environment and the benefits of its computerisation for the patients; (b) understand how such routines can be extended through the use of a computer.

4. Application: MEM+

MEM+ is being developed with several different goals:
- to collect information about the patient's life-story, and generate a set of questionnaires that allow to track the evolution of the disease;
- to construct little narratives that with the info portrayed in each questionnaire;
- to develop personalised cognitive stimulus games.

Being narrative intelligence interdisciplinary and defined as the capability of humans organize their life experiences as narratives, the story/narrative of the application is created through a set of questions asked to the patient regarding his/her history of life. The application poses several questions to the patient and provides a set of answers for each question. Each group of answers is generated regarding information previously supplied by someone close to the patient, a relative. For each question showed, the patient should select the correct answer, proceeding to the next question and respective answers. At the end of the interaction, the application provides a small story for the patient giving emphasis on the issues that were wrongly answered by the patient. The story is enhanced by the usage of any multimedia file that may help improving the recalling process. The next sections explain the format of the questions and their relationships among each other.

4.1. Questions

As initially referred, the application presents a set of questions and answers to the patient, according to the data initially inserted in the application, by someone close to the patient. The following questions are always presented, regardless of the scenario – Table 1:

Table 1. Group1: Questions about the patient

Nr.	Question
1	What's your name?
2	Date of birth?
3	Marital status?

These questions are exclusively directed to the patient. From this point several scenarios will be possible, according to patient's life. The scenarios differ because of the questions initially responded by the patient. General questions can be posed to the patient, as shown in Table 2.

Table 2. Group1: Questions about the patient's parents.

Nº	Question
1	What's your Father's name?
2	Where was your Father born?
3	When did your Father died?
4	What's your Mother's name?
5	Where was your Mother born?
6	When did your Mother died?

4.2. Categories, Priorities and Rules

The questions are grouped according to the following categories: patient, relative and event. Questions about the category patient are all related with the patient (for instance, name, age, etc.). Questions about the category relatives are all family related. Relatives are divided in two types: the ones that influenced the patient on childhood and adolescence, like their parents and siblings, among others; and the ones that later influenced the patient's life, like husband/spouse, children, grandchildren, etc.

So we defined two subcategories of relatives: level 1 and 2, respectively. There's a huge tendency for the patients, as the disease develops, to remember more relatives level 1. Questions about the category event are all connected to important moments in patient's life such as wedding, child's birth, associated to the respective event's date.
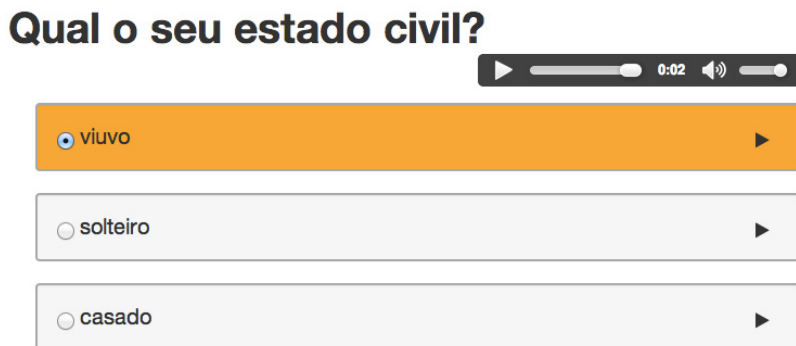
The questionnaires have the following category order: first questions about the patient him/herself, secondly, relative (level 1 and 2) questions. At last, questions about category event are associated with patient's relatives, so they will be organized along with the relative's questions, for both levels. Then, inside each category and subcategory, there will be some group of questions. For example: in relative level 1, the sequence will be: Parents, Siblings and In-Laws. In Relative Level 2, sequence will be as follows: Nephew/Niece, Husband/Spouse, Children, Son/Daughter In-law and Grandchildren. Each question of each group will be numbered by ascending order, being questions of each group done according to that numbering. Table 3 shows the order of the questions in the questionnaire.

Table 3. Order of Questions

Order	Category	Subcategory	Group
1	Patient	N/A	Group1: Patients
2	Relative	Level 1	Group2: Parents
3	Relative	Level 1	Group3: Siblings
4	Relative	Level 1	Group4: In-laws
5	Relative	Level 2	Group5: Nephew/Niece
6	Relative	Level 2	Group6: Husband/Spouse
7	Relative	Level 2	Group7: Children
8	Relative	Level 2	Group8: Son/daughter in-law
9	Relative	Level 2	Group9: Grandchildren

4.3. Questionnaires

A questionnaire consists of a set of questions directed to a particular patient, as well as the set of answers generated for each question at runtime. Each questionnaire has 5 questions maximum per group. Each question has as maximum 4 answers, only one of them is correct (see Fig. 2).

Qual o seu estado civil?

▶ ━━━━●━━━ 0:02 ◀)) ━━●━━

- ⊙ viuvo   ▶
- ○ solteiro   ▶
- ○ casado   ▶

Fig. 2. Question and correspondent set of answers.

Therefore, the experience will be different each time the patient runs the application. Each time the patient interacts with the application, a record is maintained with all the questions made, as well as the answers given for each of those questions. Therefore, in the next interaction, a history analysis is done, defining the suitability of the questions for further utilisations. If the patient happens to answer consecutively wrong to more than 80% of the questions from a given group of questions (consecutively means more than 5 times in a row), the application will treat this set of questions as being forgotten, and will exclude such set from the questionnaire.

It is important to pinpoint that this history record can only be accessed by the administrator profile that is responsible of keeping the track of the evolution of the disease. After the questionnaire, and regardless of how many questions the patient got right, the system provides the patient with a small excerpt of his/her life's story, emphasising the details that were mainly "forgotten" by the patient. By now, this story is presented in the application in text format. To produce, each story a set of templates were defined for the different case scenarios. This way, it is quite simple to generate the stories based on a memory loss pattern (for example, the patient has forgotten all memories about relatives level 2).

The story model is specified with the use of eXtensible Mark-up Language (XML). Hence, for the story definition a Document Type Definition – DTD - file was developed specifying which are the elements that have to be read from the database, which ones are optional, what their attributes are, and how they can be structured with relation to each other. The use of XML was mainly chosen in order to guarantee the portability of the data in a categorized manner to other functionalities of the application, for example the memory exercising games. The story is presented in text and audio format, providing a small story narration for the patient (see for example Fig. 3).

Fig. 3 - An example of post-questionnaire story narration

5. Usability Principles

Usability is one of the issues that has been tackled during the participatory design approach, mainly because of the age of the end-users and not directly because of their illness. There are some guidelines that should be followed to reduce the possibility of errors or faults (taken from [17]):

- There should exist enough white space to keep an uncluttered look. The font used should be *a sans serif font, like Arial with a 12-14 point size*. Words in all caps letters or italic are harder to distinguish and should not be used and there should be an easy way to change font size.
- Older people's colour perception changes, and they lose contrast sensitivity, so it is a good choice to use high-contrast colour combinations, such as black type against a white background. Avoid layering shades of the same colour, such as dark blue type on a light blue background. Avoid colours that clash. For example, dark blue on red is very difficult on the eye. Yellow and blue and green in close proximity, are difficult for many older people to see. Colours should be used to group information visually.
- Since many older people's hearing or vision declines, they often need transcripts, captions, and low background sound.
- The use of patterned backgrounds should be avoided and a dark text colour or graphics against a light background improves readability.
- There should be a standard page design and a consistent use of icons. Design should be minimalist and avoid any distractions.
- Icons and buttons should be large and stand out from the surrounding text. Links should have descriptive and easy to read text, and should contain verbs when they refer to an action.

Based on this set of guidelines MEM+ was developed with a page design based on orange and red colours, thick borders were introduced with the goal of augmenting the contrast (see Fig. 4).

Fig. 4 – MEM+ Interface with usability issues

6. Conclusions

In this paper, it was presented an approach to minimise the problems associated with patients with Alzheimer's disease. The goal of the approach is to track the evolution of the disease and at the same time to devise a set of serious games that aim to exercise and maximise the cognitive and functional competences of the patients. By the time being, it is not possible to devise major conclusions. Nevertheless, it is possible to establish a set of next goals: continue improving the prototype already developed, conduct an evaluation study with a set of patients in a medical context during a long period of time (at least 3 months).

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