

DEVELOPMENT AND USABILITY EVALUATION OF A COGNITIVE PROSTHESIS PROTOTYPE FOR PATIENTS WITH ALZHEIMER'S DISEASE AND THEIR CAREGIVERS

by

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A thesis submitted in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE
in
COMPUTER ENGINEERING

UNIVERSITY OF PUERTO RICO
MAYAGÜEZ CAMPUS
2012

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ABSTRACT

This work presents the development and usability evaluation of the prototype for a software cognitive prosthesis aimed at lessening some of the negative effects that Alzheimer's Disease (AD) has on both patients and their caregivers. The software application was design following the Participatory Design by Proxies approach, where health professionals and caregivers of individuals with AD were used as subject matter experts to inform the design decisions made. Once development was completed, the application was subjected to a heuristic evaluation by usability experts to uncover usability problems. The usability problems uncovered were corrected and the resulting application was evaluated by a group of caregivers of patients with AD. This usability evaluation consisted of an application walkthrough followed by a focus group, where both quantitative and qualitative measures were recorded. The participants of this study found the application useful and appropriate for them, however not for the individual with AD under their care. Findings also suggest that the use of multimedia content such as videos might not benefit individuals with AD if used as a guide while they complete tasks. In addition, caregivers highlighted the need their user group has for assistance while using computer applications like the one developed for this project. Future work will focus on directing the use of multimedia in the implementation of Reminiscence and Music Therapy, on changing the application to a mobile platform, and on doing more experimentation to answer remaining research questions about the application's usability from the perspective of individuals with AD.

RESUMEN

Este trabajo presenta el desarrollo y evaluación de usabilidad del prototipo de una prótesis cognitiva destinada a reducir algunos de los efectos negativos que la Enfermedad de Alzheimer (EA) tiene sobre los pacientes y sus cuidadores. Esta aplicación fue diseñada siguiendo el Diseño Participatorio Representativo, donde profesionales de salud y cuidadores de personas con EA fueron utilizados como expertos en la materia para informar las decisiones de diseño. Una vez completado el desarrollo, la aplicación fue sometida a una evaluación heurística por expertos en usabilidad para descubrir problemas de usabilidad. Los problemas descubiertos fueron corregidos y la aplicación resultante fue evaluada por un grupo de cuidadores de pacientes con EA. Esta evaluación de usabilidad consistió en un recorrido de la aplicación seguido de un grupo focal, del cuál se recopilaban medidas tanto cuantitativas como cualitativas. Los participantes de este estudio encontraron que la aplicación es útil y apropiada para ellos, mas no para las personas con EA bajo su cuidado. Los resultados también sugieren que el uso de contenido multimedia, como vídeos, no es beneficioso para personas con EA como guía para realizar tareas. Además, los cuidadores destacaron la necesidad que su grupo de usuarios tiene de recibir ayuda durante el uso de aplicaciones informáticas como la desarrollada para este proyecto. El trabajo futuro se centrará en dirigir el uso de multimedia hacia la implementación terapia de Reminiscencia y Musicoterapia, en cambiar la aplicación a una plataforma móvil, y en hacer más experimentos para responder a preguntas de investigación sobre la usabilidad de la aplicación desde la perspectiva de las personas con EA.

To all the families struggling with Alzheimer's Disease,
especially Aurea Frank's.

ACKNOWLEDGEMENTS

This work would not have been possible without the continuous support of my wife, my family, and my advisor and committee. First, to God, who put this dream in my heart and gave me the perseverance and everything else I needed to see it come to fruition. Second to my wife, Glorianne Vázquez, who endured this long journey side by side with me, proof-read every single word I wrote, and provided guidance and unconditional support on a daily basis. I also thank the rest of my family, whose support and words of encouragement were deeply appreciated. Thank you also to Dr. José Borges, graduate committee president, who provided much support and encouragement throughout this journey and always believed in me. Also thank you to my graduate committee members, Dr. Nestor Rodríguez and Dr. José F. Vega, for sharing their perceptions and wisdom, which pushed me to do better. Many thanks to Dr. Walter Rodríguez for providing a neuropsychology perspective in the definition of the application's modules. Thank you also to Dr. José Lopes DaSilva and the Aguada Caregiver's Support Group for lending their time and help in conducting this study. Lastly, this work would not have been possible without the help of Toby and the gang. They continuously brought happiness throughout this process.

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CHAPTER 1: INTRODUCTION

1.1 Justification

Alzheimer's disease (AD) is a progressive and fatal brain disorder that destroys brain cells, causing problems with cognitive functions such as: (1) Memory, (2) Orientation, (3) Language, (4) Judgment, (5) Perception, and (6) Attention (Alzheimer's Association, 2005). People with AD have difficulties performing complex sequential tasks and over time, their symptoms get severe enough to affect work, lifelong hobbies, social life, and interpersonal relationships, often leading to the death of the patient. According to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Diseases (DSM-IV TR), the early onset for AD is at the age of 65 years or below, and the late onset occurs after 65 years of age (American Psychiatric Association, 2000). The Puerto Rico's Census Bureau (2008) reports that this group represents approximately 12.8% of Puerto Rico's population and is expected to increase throughout the next decade. The prevalence of AD in the United States is reaching nearly 10% of individuals over the age of 65 and 50% of individuals over the age of 85. In Puerto Rico, AD has been moving up in the list of the top 10 reasons of death during the past decade, reaching a high at the fifth place in the year 2004 (Puerto Rico Census Bureau, 2008). With a fast-growing elder population and the high prevalence of AD among them, this disorder's diagnosis rate is expected to triple by the year 2050 (Alzheimer's Association, 2005). All these facts accrue to the increasing importance of developing interventions aimed at providing social support for the people who are affected by the symptoms of this disorder.

People with AD may have difficulty functioning without supervision, thus negatively impacting their quality of life. Current interventions for individuals with AD may involve memory training, memory support, or assisting daily life activities which are impaired by the condition. These interventions, as well as the day-to-day care giving, are usually handled by family members

of the patient with AD. Currently almost 90% of the people with AD receive home care by a family member (Alzheimer's Association, 2005). The cognitive and behavioral decline on individuals with AD has a toll on the wellbeing of their caregivers and often causes them to isolate and overload themselves. This has a devastating effect on their life, usually damaging their interpersonal relationships and work performance (Bellodi, 2011).

1.2 Objectives

This thesis work looked into assessing the viability and usability of a cognitive prosthesis aimed at lessening the negative effects that AD has on both patients and caregivers. This cognitive prosthesis had the main purpose of assisting individuals with AD in carrying out their day to day living tasks. Traditional intervention programs for caregivers are based on a service model that provides information, instrumental support, and psychosocial support in the form of telephone, videophones, newsletters, and static web content (Chiu, et. al, 2009). While this service model is of great advantage to caregivers, the author of this thesis believes part of the burden family members and other caregivers carry while looking after a patient with AD can be transferred to a software cognitive prosthesis that outlines steps to perform tasks of daily living for the patient to achieve, thus increasing their ability to carry out everyday tasks and improving their independence. An objective of this project was evaluate if the use of multimedia to guide users would be beneficial in helping them carry out day to day tasks. This was done by incorporating multimedia content into the outlining of the task's steps in order to use familiar voices and images as cues and guides of what to do in certain situations. The use of multimedia content allows for incorporating verbal instructions to guide patients while completing the tasks. In recent studies, this has been found to improve performance and patient's mood while completing the tasks (Lancioni, et al., 2011). Reality Orientation (RO) is a cognition-oriented technique for dementia patients with memory loss and time-place disorientation (Zanetti, et al., 2002). There is increasing evidence to support the

efficacy of this technique in the cognitive deficits of individuals with AD (Zanetti, et al., 2002). The application was built so that this RO technique is applied to individuals with AD through multimedia content which will be visible at all times during their interaction. Another objective of the application was to incorporate a digital version of Reminiscence Therapy (RT), which provides social support by inviting the patient to reflect on a variety of aspects relating to their lives. RT is used to target communication and language skills deterioration in individuals with AD by evoking memories about past events. This kind of therapy takes advantage of the fact that even when the working memory of an AD patient is impaired; their long-term memory often still functions at a greater capacity (Alm, et. al, 2007). The main objective with RT was to incorporate it in the application using multimedia sources such as audio and video. This will help in triangulating stimuli through different sensorial channels, thus maximizing its effect.

Usability design principles are vital to the success of the application's objectives since the needs of older users are often excluded from the objectives of mainstream computerized applications. Furthermore, this project aimed at taking a Universal Usability approach towards the design of the application. Universal Usability looks to enable all citizens to succeed using communication and information technology in their tasks (Shneiderman, 2000). Given that there are other conditions that can result in impaired cognitive functions, people other than individuals with AD might benefit from the development of the cognitive prosthesis following a Universal Usability approach. It is important to note that usability heuristics such as Jakob Nielsen's (1993) might need to be adapted in order to accommodate the particular needs of the older users group (O'Connell, 2007). Participatory design is an approach which actively involves the end users in the design process. The nature of the target population's cognitive impairment hindered carrying out this design approach. For this reason, the participatory design approach was modified to be what is described by Boyd et al. (2006) as participatory design with proxies. This design includes proxies

to assume the roles normally filled by users (Boyd et al., 2006). These proxies were health care professionals who are experts in the fields of geriatric medicine, psychiatry, and neuropsychology, as well as primary caregivers for individuals with AD.

In order to verify that the needs of the target population were met, a heuristic usability evaluation was done to the application. This evaluation focused on assessing the applications usability in terms of heuristics that have been adapted to the older users populations such as: (1) Visibility of System Status, (2) Match between System and the Real World, (3) User Control and Freedom, (4) Consistency and Standards, (5) Recognition Rather Than Recall, and (6) Aesthetic and Minimalist Design (O'Connell, 2007).

1.3 Research Methodology

This section describes the sequence of research methods that were applied in order to achieve the thesis objectives. This information will be divided in three phases: analysis and design, implementation, and usability evaluation/testing.

1.3.1 Analysis and Design

During the analysis phase, a review of the most recent literature relevant to this study was made in order to define the system's requirements taking into consideration the contribution of research projects that have successfully addressed issues in common with the current thesis work. In order to align the thesis' objectives and system's requirements with needs of the research population, semi-structured interviews were held with healthcare professionals with the purpose of gaining insight into AD's impact on the life of patients suffering from it and assess the current situation of technological interventions in this area.

The prototype design was done within a participatory design approach in which the healthcare professionals represented the interest of the individuals with AD. They assisted in the design process by evaluating the prototype's appropriateness in terms of the user's cognitive and

physical capabilities and their needs. This process was iterative and the design underwent many changes in order to adjust it to the users' interaction abilities. At the end of this process, a horizontal prototype incorporating input from the participatory group designers was submitted to a heuristic evaluation. Results from this evaluation were used in the implementation of a fully functional prototype.

1.3.2 Implementation

The cognitive prosthesis was implemented using the horizontal prototype from the analysis and design phase and results from its usability evaluation. The implementation was done using the Java Standard Edition Development Kit version 6 and the NetBeans 6.5 development environment.

1.3.3 Usability Evaluation/Testing

Upon completion of the implementation phase, a group of caregivers of individuals with AD was recruited with the purpose of conducting a usability test. The methods used for the usability test were chosen based on the amount of users needed to employ them successfully. The test included: (1) an application walkthrough, (2) a focus group, and (3) a post group questionnaire,

CHAPTER 2: PREVIOUS WORK

2.1 Introduction

Nowadays, computers and computerized services are an integrand part of how people operate in society. They are used in the business sector, health care facilities, educational institutions, and many public services among other places. Integrating technological breakthroughs into the health care sector brings many benefits to both providers and beneficiaries of health services. It is the intent of this chapter to highlight this integration of health care and technology, giving emphasis on the most current and relevant literature regarding senior-focused design, the most common cognitive disabilities for this population, and evidence based approaches for this integration such as assistive technology, participatory design with proxies, and computerized reality orientation. Also, an overview of AD and its effects on human-computer interaction will be discussed.

2.2 Alzheimer's Disease and Human-Computer Interaction

People experience a myriad of age-related changes through the course of their lives that affect their functional abilities in the realms of sensory processes, motor skills, and cognitive abilities (Jacko & Sears, 2002). This is particularly noticeable in individuals with AD, due to the disease's degenerative effects on cognition. Attention must be given to the diminished abilities people show in these three realms while designing software in order to create interfaces that are technologically inclusive for these people. Age-related changes in cognition are of extreme importance to the performance of individuals with AD in computer-based tasks. Computer tasks generally demand cognitive abilities such as psychomotor speed, attention, memory, and reasoning. In individuals with AD, these abilities are usually impaired (Jacko & Sears, 2002). Therefore, care should be taken when designing interfaces so excessive load is not put on impaired cognitive

abilities. This can be achieved by applying new design methodologies and principles that are specifically tailored for the AD patient's population. Some examples are: (1) appealing to a range of different cognitive processes and modalities, (2) supporting tasks at lower levels, and (3) adapting traditional methods such as participatory design, in order to fit targeted population's needs (Jacko & Sears, 2002).

2.3 Assistive Technology

Computer technology may be beneficial for family caregivers who are providing care for an older person with a chronic condition or illness such as AD's dementia. Generally, the prevalence of chronic conditions such as dementia increases with age and consequently older adults are more likely to need some sort of care or assistance. Studies have consistently shown that utilizing support service and activities that engage the brain in continued activity are beneficial in slowing down the progression of AD, thus improving patients' and caregivers' quality of life (De Leo, Brivio & Sautter, 2011). The proposed thesis work looks to implement such support services and activities through the use of technological interventions which fall into the domain of assistive technology. The assistive technology (AT) field deals with the study and development of devices used to assist, adapt, or rehabilitate people with disabilities (United States Congress, 1998). AT has increased functional abilities, independence, and access to mainstream society, creating a method of equalization between persons with and without disabilities (Brodwin, Star, & Cardoso, 2004). LoPresti, Mihailidis, and Kirsch (2004) indicate that any assistive technology for people with cognitive disabilities must accommodate the individual user's skills and deficits. AT is of great relevance to this thesis work since the literature reviewed indicates that such interventions can increase the efficiency of traditional rehabilitation practices by enhancing a person's ability to engage in therapeutic tasks independently, which constitutes one of the thesis' secondary objectives (LoPresti et al., 2004). There are other areas which are closely related to assistive technology which

are pertinent to the proposed thesis work. These areas will be discussed in the following sections.

2.3.1 Universal Design

It is often the case people with disabilities have to wait for an adaptation of an existing product in order to meet their needs. This happens in part because computer devices manufacturers often design products for the average user in order to maximize their profits. However, “adaptations are frequently inadequate in accommodating for the motor limitations exhibited by certain individuals” (Capilouto, Higginbotham, McClenaghan, Williams, & Dickerson, 2005). That being said, it is the aim of the author to address the needs of individuals with AD in a proactive manner, which is the purpose of the design for all or universal design methodology.

The design for all motto is to design for all potential users so that they can enjoy equal participation society. The author believes design for all benefits everyone, not just the individuals with disabilities. For instance, designing to minimize the AD patient’s memory load can benefit non AD patient since memory deficits is an age-related change common in people as they grow older (Czaja & Lee, 2002). Another example is the design of a GPS display in a vehicle. The designer should apply the design for all concepts used in a computer terminal for blind people. By adding voice representation of the GPS data, the designer would benefit the driver of the vehicle, since he/she is virtually blind in terms of the GPS screen. This virtual blindness takes place since it is not possible (or at least recommendable) to pay attention to the screen while driving (Emiliani, 2006).

Design for all is a proactive methodology in contrast with adaptation which is reactive. Among the biggest problems with reactive approaches is the viability in sectors of the industry in which technology changes rapidly. The proposed thesis work looks to address this by creating a flexible application that can be easily tailored to the needs of a specific person within the population of individuals with AD.

2.3.2 Senior Focused Design

It has become evident that population all across the world is aging and that people over the age of 65 are becoming a fast-growing computer user group. Currently, computers are deeply embedded into society. Thus, there is an increasing need of technology in order for people to attain full social participation and solve problems which could not be easily addressed in the past (Emiliani, 2006). Senior-focused design is aimed at addressing the needs of the aging population by accommodating their expectations and work styles by applying the most current technologies (O'Connell, 2007).

Aging is characterized by a diversity of ongoing and incremental functional declines such as vision or hearing loss, or cognitive deterioration (Jacko & Sears, 2002). Approximately 72% of people 65 and over suffer some degree of disability. This makes senior-focused design and universal design overlap. Therefore, as was seen in the previous section, groups different from seniors can benefit from senior-focused design. Senior-focused design entails several principles adapted from mainstream usability engineering and software development in order to meet the needs of the senior population. Of these principles the ones with more relevance to this thesis work are (1) involving seniors during usability testing, (2) engaging seniors, (3) place seniors in control, (4) emphasize discernibility, (5) accommodate seniors' work styles.

A software development cycle following the senior-focused design approach should involve seniors in its usability testing so that the application appropriateness is assessed during and not at the end of the process when changes are more difficult to incorporate (O'Connell, 2007). This will be seen more in depth later on in another section about participatory design. It is important to create an environment in which seniors feel comfortable working with technology. This environment is the outcome of engaging seniors in the use of computers. Applications must encourage seniors to the transition of watching someone else use a computer to actually giving computing a try for

themselves (O'Connell, 2007). Their experience must be worthwhile from the beginning which can be done by giving them personalized welcome messages including multimedia content. Seniors culture should be taken into consideration from the beginning of the design process. This can help in giving encouragement to their participation in computer-based tasks (O'Connell, 2007). An example of this is adding content that showcases the value of computer applications to seniors.

One of the most important considerations to make when designing applications for individuals with AD is to relieve their cognitive load. This principle is part of a bigger category which deals with placing seniors in control. There are several ways of relieving cognitive load in seniors' interaction with computers and all of them revolve around letting the computer do the remembering for the seniors (O'Connell, 2007). This remembering by the computer can be seen in static selection lists where seniors can just select an item rather than remember and type it. In addition, seniors should be put in control of the navigation by providing them with obvious pathway to content, helping them return from pop-up messages or error windows to the starting point, and by not forcing them to explore the complete application in order to find the content they are interested in (O'Connell, 2007). This issue can be addressed by empowering successful searches in applications.

A successful search is one that brings the senior all and only the information sought (O'Connell, 2007). There are several ways of implementing successful searches for seniors. One of the most popular is to lead seniors through the searching process with clearly marked fields to enter their terms. During the search process and all through the application, seniors should be given feedback of what the system is currently doing. This has the purpose of keeping them confidently in control by communicating about the state of the system as seniors perceive it (O'Connell, 2007). Information on the purpose, time to completion, and current status of lengthy process can help seniors to stay focused on the application.

It has been seen that individuals with AD and seniors in general face visual and auditory impairments. These impairments create many obstacles in their interaction with computers. This stresses the importance of helping seniors discern both visual and auditory stimulus from computer applications. O'Connell (2007) suggests that emphasizing discernibility in applications entails helping seniors discern graphics, promoting legibility, drawing contrast among screen elements and applying color as supporting signals.

It is also important to accommodate seniors' work styles in order for them to have a smooth transition between a non-computing to a computing-assisted functioning. There are several ways of accommodating seniors' work styles of which O'Connell recommends making software configurable, providing large clickable areas, offering alternative access to information, and giving seniors enough time to complete tasks.

Finally, it is crucial taking into account the anxiety some senior users feel while interacting with computer system and incorporating ways to cope with this anxiety into the design of user interfaces targeted to seniors. Computer anxiety sometimes prevents seniors from taking full advantage of computers and in some cases causes computer use avoidance (Hogan, 2009). This phenomenon can manifest itself in computer users of all ages, but according to Hogan (2009), computer anxiety increases with age, thus older adults show higher levels. One of the most prominent causes for computer anxiety is the senior users' lack of previous exposure to computers, which often makes them overestimate the degree of expertise they need to use them appropriately. (Holzinger, et. Al, 2011).

2.3.3 Cognitive Prostheses

Specially designed computer systems can offer more specific support for people suffering from a variety of cognitive ailments. These systems called cognitive prostheses (CP) are developed to support and augment the cognitive abilities of its users (Arnott, Alm, & Waller, 1999). Cognitive

prostheses are characterized by using computer technology, being designed specifically for rehabilitation purposes, assisting individuals in performing some of their everyday activities, and being highly customizable to the needs of the individual (Cole, 1999). Since people with cognitive disabilities will often have physical and sensory limitations, the design of CP must consider how well the technology matches the individual's physical and sensory abilities. Such abilities may include: (1) vision, (2) hearing, (3) tactile sense, (4) coordination, and (5) ability to speak (LoPresti et al., 2004). It is of particular importance to support high customization in CP design in order for it to be effective through changes in the person's needs due to the progress of the condition creating the cognitive disability (LoPresti et al., 2004).

It has been stated that people with AD show a decline in their executive functions as the disease progresses. Healthcare professionals divide this progression into mild, moderate, and severe stages depending on the symptoms observed (Alzheimer's Association, 2005). These impairments can be compensated by the assistance of CP in everyday living. However, care should be taken in selecting a CP for individuals with AD, since according to Buettner, et. Al (2010), many of these are most effective for patients on the mild to moderate stages.

Planning, prioritization, tasks switching, problem solving, and adaptability are some of the cognitive skills associated with executive functioning. In addition, there are memory skills such as prospective memory that allow the user to remember tasks that need to be performed (Jacko & Sears, 2002). Prospective memory aids are an example of CP used to give support this kind of memory. These memory aids have shown to be most effective if tailored to a specific user's needs and work styles. This problem was addressed by Chute and Bliss (1994) through the use of object-oriented programming, a programming approach which simplifies modification and adaptation of the properties of software objects or entities (LoPresti et al., 2004).

Nowadays, systems such as personal organizers and schedulers are being use to try to

improve the performance in practical and daily living tasks of users with various cognitive disabilities (Arnott et al., 1999). PDA's have also shown promise in providing automatic cues to people with dementia to perform hand-washing tasks with more independence (Arnott, Alm, & Waller, 1999). Allen, McGrenere, and Purves (2007) designed and evaluated a palmtop device for image communication for people with cognitive impairment called aphasia. Patients with aphasia often have difficulty communicating written or verbal language and they generally retain their ability to recognize images (Allen, McGrenere, & Purves, 2007). Allen et al. (2007) used participatory design (PD) with two healthcare professionals to complete the design phase. Then they conducted an informal usability study with 5 patients with aphasia to identify usability problems and provide preliminary feedback on the usefulness of the application. Later, they ran a 1 month field study with 2 patients to explore how they could integrate the system into their lives. From their study, Allen et al. (2007) concluded that customizability is an integrant part of the success of technological interventions with patients suffering from cognitive impairments.

Reminiscence is an important type of therapy used to help elderly people who have dementia thanks to the fact that although their short-term memory may be impaired their long-term memory often remains intact (Alm, Arnott, Dobinson, Masssie, & Hewines, 2001). Reminiscence therapy for individuals with AD involves exposing them to music, picture, video, and other types of multimedia content related to their past. It is believed that these activities triggers memories from their past that provides them with structure for meaningful interactions, causing calming effects and reducing disrupting behavior in these individuals (Cohene, Baecker, Marziali, & Mindy, 2007). Also, these activities do not require patients to keep a conversation topic active, which is something that depends of short-term memory. Computer-based reminiscence can act as an aid to conversation with their families and caregivers and is advantageous over classical reminiscence because of the flexibility that software can provide to changes needed due to the condition's progression or to

having different users.

Computer-based prompting systems are becoming extremely popular in the area of cognitive stimulation. Currently there are several projects implementing 24-hour prompting systems in the home of people with dementia that can give them appropriate prompts for completion of daily living activities (Alm et al., 2001). Other effort for cognitive stimulation with individuals with AD was reviewed where an interactive multimedia internet-based system (IMIS) was used. The IMIS consists of 19 tasks or stimulations exercises across the domains of attention, calculation, gnosis, language, memory, and orientation (Tárraga, et al., 2006). This study was a randomized control trial to assess the efficacy of using IMIS versus psychopharmacological treatment both in conjunction with each other and by themselves. The study showed that both classic cognitive stimulation treatment and computer-based treatment improved cognition in patients who were treated with a stable dose of cognitive enhancing medicine compared with those who were treated only with cognitive enhancing medicine. These results show that it is possible to augment the effects of medications using cognitive stimulation procedures, with the result that patients have improved outcomes (Tárraga, et al., 2006).

Communications technology is also being used to assist people with cognitive deficits and their families. Poon et al. (2005) designed and implanted cognitive interventions for seniors with memory problems. Telemedicine applications allow direct communication between healthcare providers and patients through the use of communication technology such as telephones, emails, and internet-based instant messaging (Czaja & Lee, 2002). In their study, Poon et al. (2005) examined and compared the feasibility, acceptability, and clinical outcome of a cognitive intervention program for older patients with mild cognitive impairment and mild dementia using telemedicine versus a conventional face-to-face method. They concluded that telemedicine was a feasible and acceptable means in providing cognitive assessments and intervention to older persons

with mild cognitive deficit (Poon, Hui, Dai, Kwok, & Woo, 2005). In another study, Czaja and Rubert (2002) designed an intervention using a computer-integrated telephone system (CTIS) to augment the home-based family therapy by facilitating the caregivers' ability to access formal and informal support services. The CTIS is a custom-built application that uses a computer to operate three specialized telephony boards to send and received both voice and text information regarding patient or caregivers' health services requirements. The study also included a 31-item usability questionnaire to be completed by the users in order to assess their perceptions of the system. This study concluded that computer-based communication technology can provide support for both caregivers and care recipients to reduce isolation and access information about caregiving resources in the community and local or national support organizations (Czaja & Rubert, 2002).

2.4 Participatory Design

Participatory design is an “approach towards computer systems design in which the people destined to use the system play a critical role in designing it” (Schuler & Namioka, 1993). In any computer system design process, knowing the user is critical so the designers can create a system that meets the needs and expectations of the users. Nielsen (1993) recommends that instead of guessing, the designers should have access to a pool of representative users after the start of the design phase. Involving user early in the design process helps designers avoid taking paths that diverge from the project's scope by giving them a deeper insight of the design problem through the eyes of the users. It has also been reported that “obtaining user feedback at each phase of the process also changes the nature of the final evaluation, which is used to fine tune the interface rather than discover major usability problems” (Beaudouin-Lafon & Mackay, 2002). Although users play a vital role in participatory design, this does not implicate that the design should be deferred to them. In participatory design, users and designers must work together in clarifying the design problem as well as in exploring design solutions (Beaudouin-Lafon & Mackay, 2002). One

of the many advantages of following a participatory design approach is that users are usually best at understanding the subtleties of the problem domain that the designer cannot abstract from other methods of analysis. Care must be taken when using participatory design since there are several pitfalls that can make it yield undesirable results. First, designers should understand the extent to which users can contribute to the design. Since users are not designers, as Nielsen (1993) states, it is no reasonable to take up the role as designers without the help. Another pitfall thinking that participatory design is just asking the users what they want. As is stated by Nielsen (1993), the user is not always right, meaning that they often do not know what they want, need, or what is good for them in terms of computer systems design. Thus, users' participation should include a two-way communication between the user and the designer, through which users can convey their view of the design problem. Then, the designers can act upon those views and users can evaluate the outcome and give feedback to the user, starting again the cycle of collaboration. Finally, it is recommended that the pool of users participating in the design be refreshed periodically since their exposure to the design process usually makes them less representative of average users who have little or no knowledge of computer systems design.

There are occasions where it is not feasible to use target users as part of a participatory design process. An example of this is involving patients with cognitive impairments in participatory design. Since this patients have difficulties with a wide range of cognitive abilities, it is not appropriate to expect them be able to fully participate and contribute to the design. Participatory design assures that the special needs population is not marginalized from software design considerations. Therefore, it is in the best interest of patients within this population to be included in the design process in some way. A variation of participatory design has been used involving people who can significantly represent the interests of the prospective users of the systems. This variation is called participatory design with proxies, because the people involved in the process act

as proxies of the target users (Boyd, et al., 2006). Boyd-Graber et al. (2006) used speech language pathologist to serve as proxies for the design and development of a PDA system to support people with aphasia. They reported that this approach allowed them to research the needs of people with aphasia at a distance, allowing them to gain a deeper understanding of the condition and to prepare for interacting directly with individuals at a later stage of the project (Boyd, et al., 2006). Cohene et al. (2007) applied participatory design with proxies using caregivers and family members on the design of memory books for individuals with AD. In the design of an orientation aid for amnesics, Wu, Baecker, and Richards (2005) applied participatory design with proxies using a neuropsychologist and a computer scientist. From these examples it can be observed that the composition of the proxies group depends on the domain of the design problem. Thus, care should be taken in selecting such group so that it can be a good representation of the patients.

2.5 Reality Orientation

Reality orientation (RO) is a psychosocial intervention technique widely used in the rehabilitation of patients with dementia (Metitieri, et al., 2001). Its objective is to reorient the patient by continuously stimulating him/her with information from the environment. There are two modalities of this type of intervention. Formal RO requires exposure to facts from the environment surrounding the patient (e.g. time, date, weather, and season) on an hourly basis while awake. Group RO is a class-like intervention where many patients requiring orientation are gathered together to receive it (Metitieri, et al., 2001). From a study with patients suffering from dementia, Metitieri et al. (2001) concluded that RO can slow down the decline in cognitive function by seven months with respect to their control group, which did not receive any orientation therapy. RO should be administered with care of not making it a demeaning, depersonalizing, and confrontational experience (Woods, 2002). The aim must be to address the “individual goals and needs of the person with dementia, using a variety of memory aids and simple (but intensive)

learning techniques” (Woods, 2002). Several randomized control trials have found RO to have positive effects in retarding the progress of dementia. In particular, Woods et al. (2003) concluded that the results from their study of cognitive-stimulation compared favorably with trials of drugs for dementia. Another study determined that RO has benefits in both cognition and behavior in people with AD type dementia (Zanetti, et al., 2002). Through the literature review of RO it has become clear that most RO implementations are of low fidelity, where whiteboards and paper calendars are used. To the knowledge of the author, currently there are no computer systems implementing RO, fact that stresses the contribution of this thesis work to the area of cognitive stimulation.

CHAPTER 3: SYSTEM DESCRIPTION

3.1 Introduction

The software cognitive prosthesis (Cogpros), object of this thesis, is focused on ameliorating the quality of life of individuals with AD by implementing traditional AD interventions in a digital manner. It consists of modules that incorporate RO and RT as well as modules for tasks management, medication management, and digital communications.

The system was implemented using the Java Standard Edition 6 and the NetBeans integrated development environment. It was designed to be a standalone desktop application and its design follows a desktop variant of the model MVC1 architecture where the view has both data processing and presentation logic, and the data access is done through java beans.

The following sections of this chapter present an overview of the system modules' graphical interfaces, giving special attention to considerations based on the AD interventions discussed in the literature review section.

3.2 System Graphical Interfaces

As shown in figure 3.1, the main window of the Cogpros application is comprised of a left navigational menu, a bottom navigational menu, and a main content panel. Clicking on any item from the navigational menus will open content into the main content panel. Regardless of the content that is being displayed in the main panel, the menu items in both navigational menus are always visible to the user.

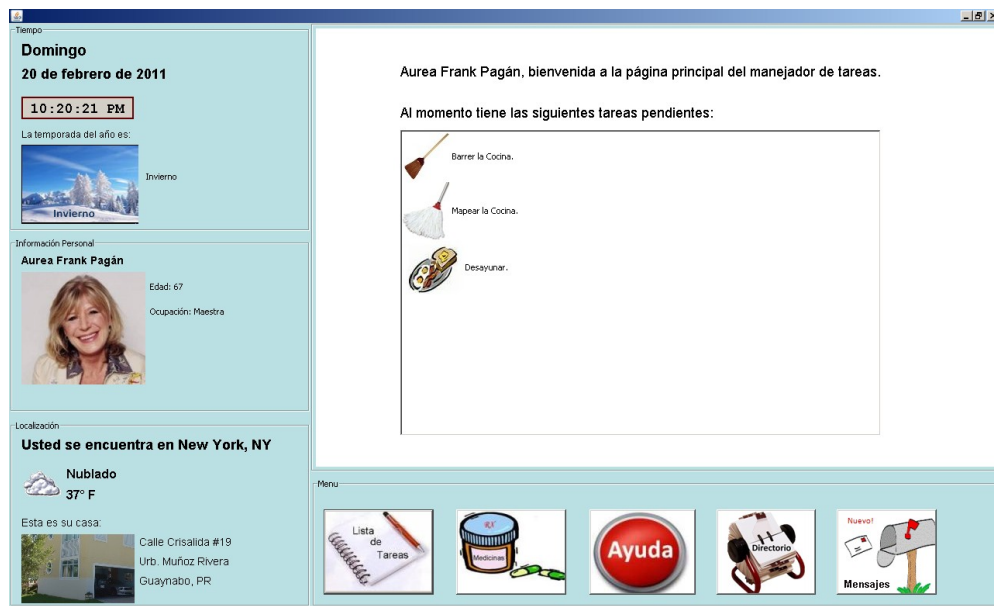


Figure 3.1 System's main window.

3.2.1 Reality Orientation Modules

As was previously stated, during an RO session, the person with AD is surrounded by familiar objects that can be used to stimulate their memory. In order to address RO, Cogpros contains three modules which will expose the users to facts from the time they are living in, their surrounding environment, and their lives. The users will have visibility of the RO modules at all times during their interaction with the system. These modules are described below.

3.2.1.1 Time Orientation Module

The time orientation module aims to provide the system's user with facts about the current time, which includes day of the week, day of the month, month of the year, year, time of the day, and season of the year. The time orientation module can be seen at the top left corner of figure 3.2. The area enclosing the time orientation module is a clickable panel which when clicked, opens the user's calendar in the main panel.

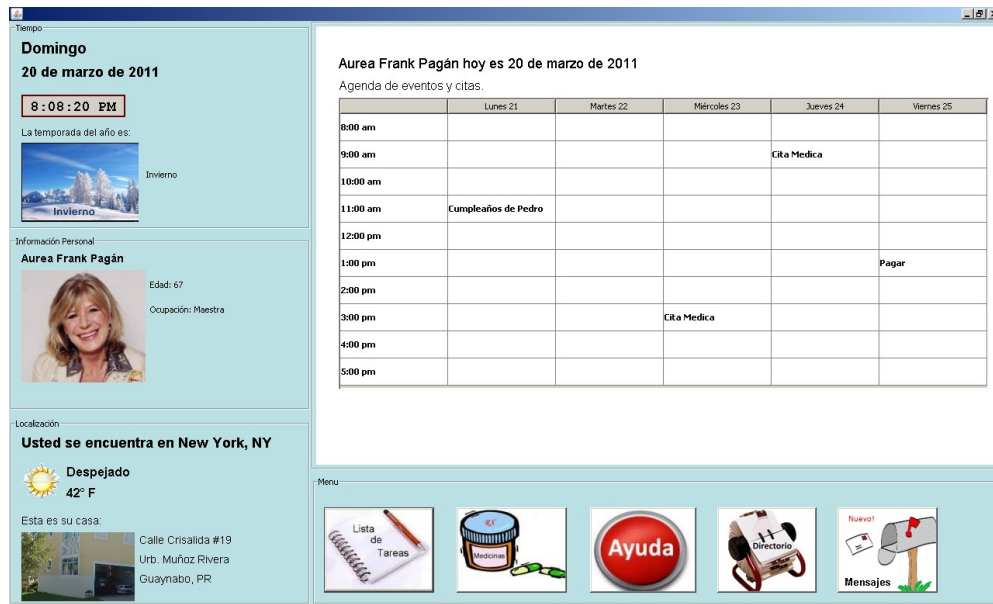


Figure 3.2 Time orientation module.

Each cell in the calendar represents an hour of a day during a day of the current week. If the user has an appointment or activity scheduled for the current week, it will be shown on the calendar. When an item in the calendar is clicked, a pop-up window with additional information is displayed. An example is shown in figure 3.3.

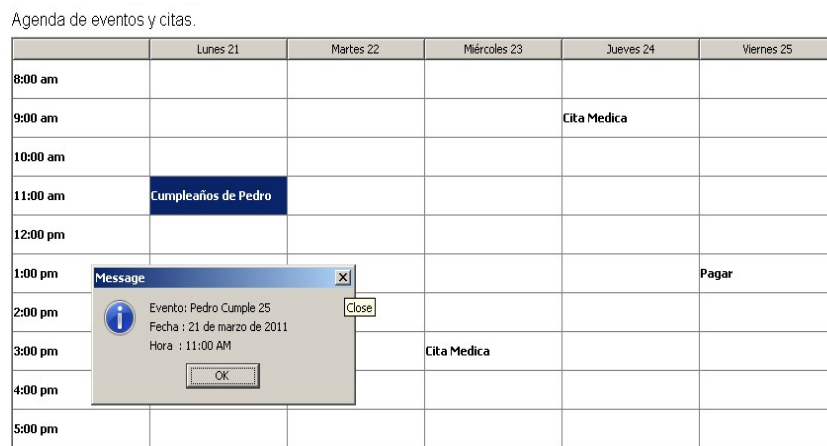


Figure 3.3 Calendar item detail pop-up window.

3.2.1.2 Personal Orientation Module

The purpose of personal orientation module is to keep the user aware of their personal circumstances. This includes a current picture of the user, his/her first name, last name, age, and occupation. When clicked, a page opens in the main content with additional personal information, as seen in figure 3.4.

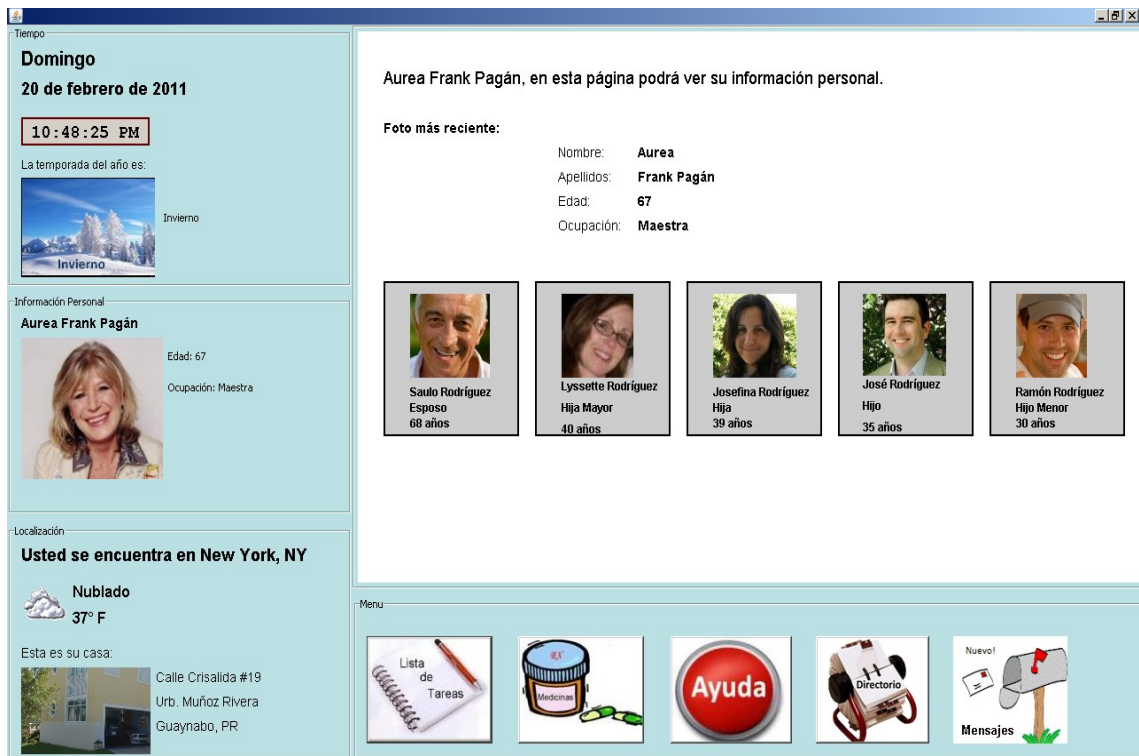


Figure 3.4 Personal orientation module

This page includes pictures of the user's family members with their personal information. If any of these pictures is clicked, then another page will open in the main content panel with additional pictures of this person at different stages of his/her life. The rationale behind this is to

use the images as an implementation of reminiscence therapy. An example of this additional page can be seen in figure 3.5.



Figure 3.5 Relative's pictures window

3.2.1.3 Space Orientation Module

The space orientation module is intended to serve as a way for the user to be aware of his/her surroundings. As shown in lower left part of figure 3.6, this module includes the city and state the user is currently in, the weather, the user's home address, and a current picture of the user's house. When this module's area is clicked, a page opens in the main content panel with more information about the user's location. This page, shown on the main content panel of figure 3.6, includes pictures of different rooms of the user's house, and a map of the user's neighborhood.



Figure 3.6 Space orientation module

This map highlights locations of interest to the user (e.g. supermarket or pharmacy). If any of these locations is clicked, then the system will display the route from the user's house to the selected location as shown in figure 3.7



Figure 3.7 User's Neighborhood

3.2.2 Tasks Management

The task management module of the application allows users to see which of their daily tasks are pending and provides detailed information on how to accomplish these tasks. The entry point for this module is the first button in the bottom navigational menu. When this button is clicked, the task management module is displayed in the main content panel as seen in figure 3.8 below.

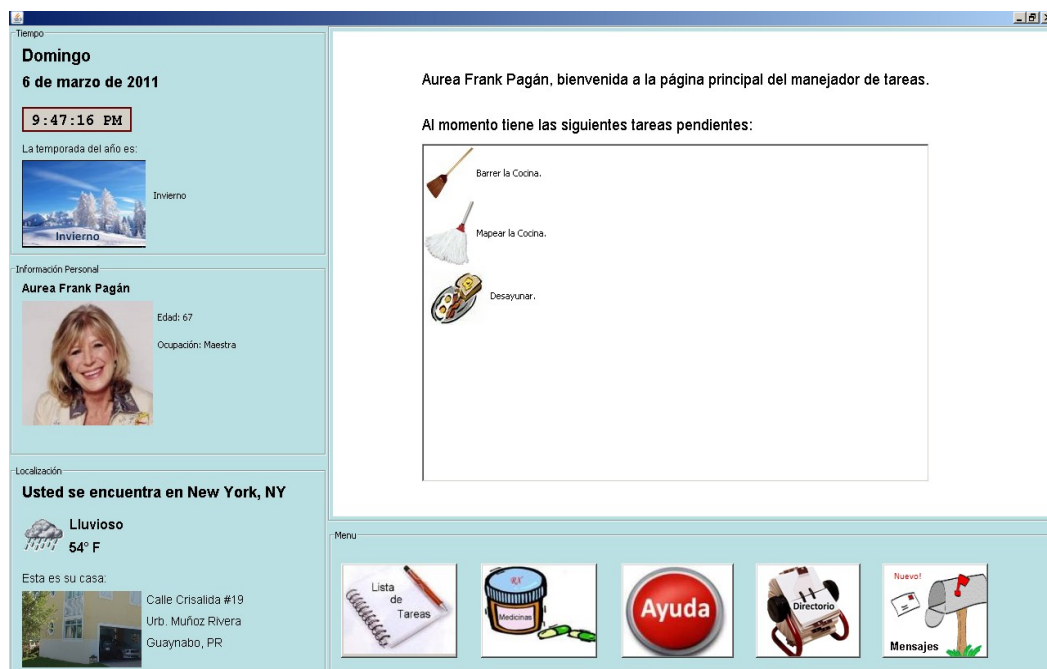


Figure 3.8 Task Management Module

Each task is presented in a list with an icon that is representative of the task. Clicking any of the items from the list will open the task's details in the main content panel as can be seen in figures 3.9 and 3.10. Figure 3.9 shows tasks instructions in video format. The user can press the play button to start playing the video and the stop button to stop. If the user presses on the play button after having pressed the stop button, the video will resume playing where the user left it off.

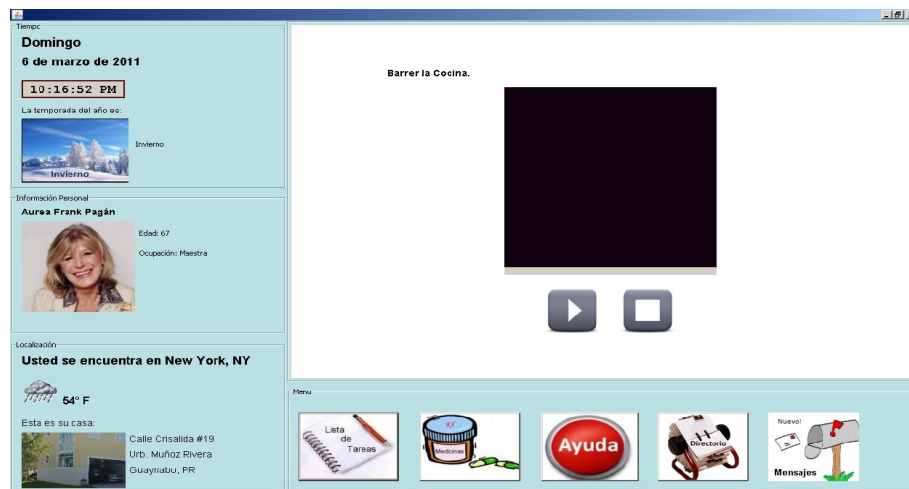


Figure 3.9 Task Video Instructions

Task instructions are also given to the users step by step through images. Each one of the images represent one step for completing the task. Images are presented one a at time and are accompanied by a caption describing the step. Figure 3.10 shows this task instructions format. The task instructions are displayed on the main content panel along with two buttons, one to go back to the previous step, and the other to go forward to the next step.



Figure 3.10 Task Step by Step Instructions

3.2.3 Medication Management

The medication management module is accessed using the second button from left to right of the bottom navigational menu. This module helps the user keep track of the medication the user has to take as well as the dosage and the frequency. As shown in figure 3.11, the medication management module also provides information indicating the purpose of the medication and an illustration of how does it look. When it is time to take the next dosage of the medication, the system will open a pop-up window instructing the user to do so. After the user does, he/she has to confirm this by clicking on the “Yes” button on this pop-up window. Based on the user’s input to the pop-up window and the time it was last opened, this module tells the user when to take the next dosage of the medication.

en esta página podrá ver información sobre sus medicamentos.

| Foto | Condición | Dosis | Frecuencia | Próxima Dosis |
|---|----------------|------------|----------------|--|
|  | Alzheimer | 2 Tabletas | 2 Veces al Día |  07:56 PM |
|  | Alta Presion | 1 Tableta | 1 Vez al Día |  07:56 PM |
|  | Alzheimer | 1 Tabletas | 2 Veces al Día |  07:56 PM |
|  | Anti-Depresivo | 1 Tabletas | 1 Vez al Día |  07:56 PM |



Figure 3.11 Medication Management Module

3.2.4 External Communication

The Cogpros application provides the user with several modules and features to facilitate

communication between the users and the external world. These modules are the telephone directory, the email messaging, and the emergency assistance button. These are described in more detail in the following sections.

3.2.4.1 Emergency Assistance

Figure 3.12 shows the emergency button, a red oval with the caption “Ayuda” which means Help in Spanish. When this button is pressed, the application opens a pop-up window that tells the user the emergency assistance telephone number (911) is being dialed. Provided that the computer where the system is running is plugged in to a telephone jack, the system will place the call to 911. The user can respond to this call using the computers’ built-in microphone and speakers and can cancel the call by pressing the “Cancelar Llamada” button on the pop-up window.

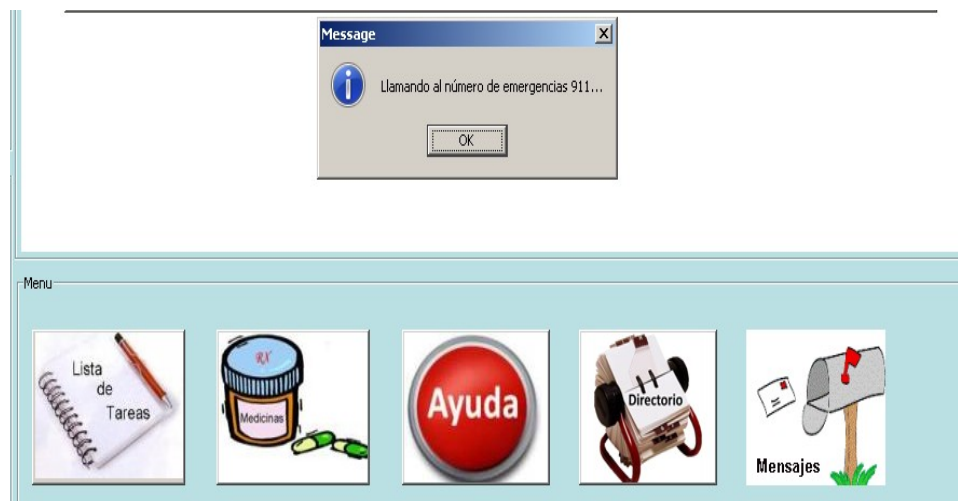


Figure 3.12 Emergency button.

3.2.4.2 Telephone Directory

The telephone directory module display opens in the main content panel when clicking on the rolodex button on the bottom navigational menu. This module, as shown in figure 3.13, has a tabbed panel containing both personal and emergency contacts.



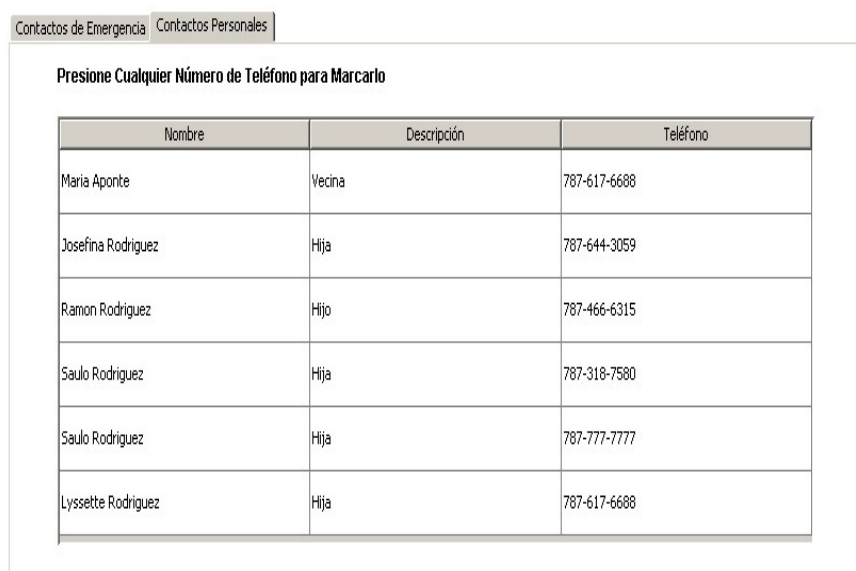
Figure 3.13 Telephone directory module.

The emergency contacts tab has the telephone numbers for the police department, the medical emergencies agency, the fire station, the electrical power company, and the water company. These contacts are shown along with their telephone numbers and the agency's logo as seen in figure 3.14. When the user clicks on any of the contacts, a pop-up window opens letting the user know that the number for that contact is being dialed by the application.



Figure 3.14 Emergency contacts tab.

The personal contacts tab has a table containing the telephone contact information for some of the user's personal acquaintances. This table, shown in figure 3.15, includes the name of the person, the relationship of the person with the user, and the telephone number. As with the emergency contacts tab, when clicking on any of the contacts in the personal contacts tab, a pop-up window is opened informing the user that the contact's number is being dialed.



The screenshot shows a web interface with two tabs: 'Contactos de Emergencia' and 'Contactos Personales'. The 'Contactos Personales' tab is active. Below the tabs is a button labeled 'Presione Cualquier Número de Teléfono para Marcarlo'. Below the button is a table with three columns: 'Nombre', 'Descripción', and 'Teléfono'. The table contains six rows of contact information.

| Nombre | Descripción | Teléfono |
|--------------------|-------------|--------------|
| Maria Aponte | Vecina | 787-617-6688 |
| Josefina Rodriguez | Hija | 787-644-3059 |
| Ramon Rodriguez | Hijo | 787-466-6315 |
| Saulo Rodriguez | Hija | 787-318-7580 |
| Saulo Rodriguez | Hija | 787-777-7777 |
| Lyssette Rodriguez | Hija | 787-617-6688 |

Figure 3.15 Personal contacts tab.

3.2.4.3 Email Messaging

The email messaging is intended to serve as a mail client that can be configured to be the front end for any email service provider (e.g. yahoo). The client is opened in the main content panel when clicking the messaging button on the bottom navigational menu. The email client is shown in figure 3.16 below.

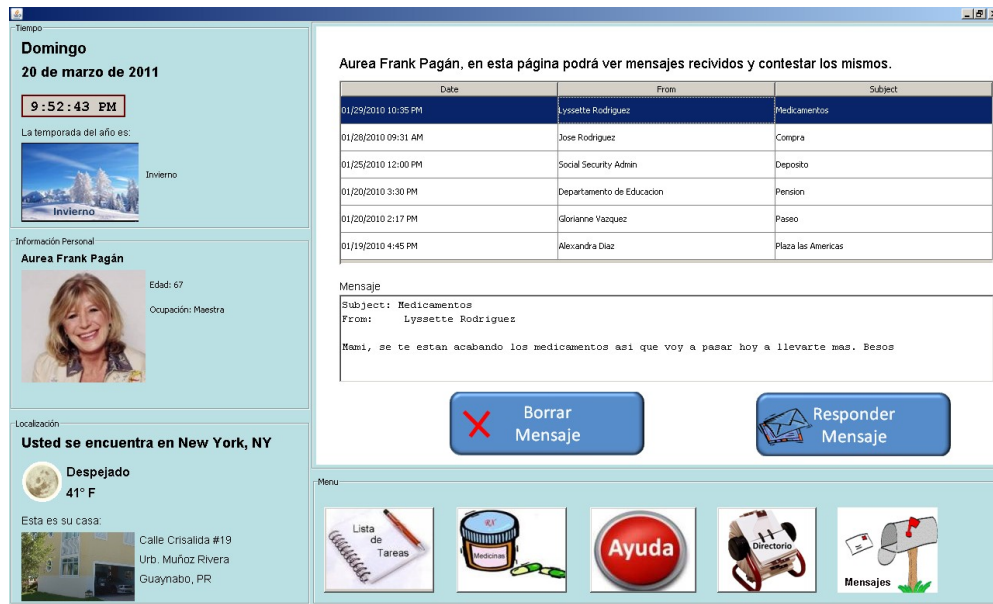


Figure 3.16 Email messaging client.

The client shows a list of the most recent unread emails ordered by date in descending order. Below the messages list, a message area is shown where content of the email selected from the list is displayed. The module also has a button for deleting messages and a button for replying to the selected message. Neither of these buttons is functional. Composing a new message from this module is not currently implemented on this prototype.

CHAPTER 4: HEURISTIC EVALUATION

4.1 Introduction

A determining factor in the success of a software user interface is its usability. Usability is a set of attributes that in general describe a user interface as being easy to use. Nielsen (1993), associates usability with the following five attributes: (1) learnability – which describes how easy to learn is the system, (2) efficiency – which describes the performance users' gain by using the system, (3) memorability – which describes the ease with which users remember how to use the system once they learn it, (4) error prevention – which describes how able a system is of preventing or reducing users' errors, and (5) satisfaction – which describes how pleased or satisfied users are when using the system .

There are a myriad of usability testing methodologies available. Some of these methodologies are too complex or expensive to be practical in many testing scenarios. According to Nielsen (1997), one method that is widely used due to its simplicity and relative affordability is the Heuristic Evaluation (HE). The goal of HE is to improve the usability of user interfaces by finding usability problems before its intended users are involved in the testing process. This is achieved by having a small set of usability experts examine the interface and determine if it complies with a set of recognized principles (Nielsen, 1993).

4.2 Heuristic Evaluation

A HE was done to the Cogpros application in order to identify usability problems in its design. In the following section, the process employed in performing an HE for Cogpros is outlined. The HE procedure will be presented along with the evaluations' results and their implications in terms of the application redesign and implementation.

4.2.1 Procedure

The Heuristic Evaluation was done by three evaluators. The only eligibility criterion for the evaluators was being versed in Usability Engineering, especially on conducting Heuristic evaluations. The evaluation started by giving the evaluators a document containing a detailed description of the Cogpros application and all their modules. This document also instructed the evaluators to focus on a list of heuristics or guidelines when evaluating the system. These heuristics were: (1) visibility of the system's status, (2) the use of language appropriate for the targeted users, (3) the use of good navigation paths, (4) the use of standards and good consistency, and (5) the minimization of the users' memory load. After reviewing this document and discussing it with the author, the evaluators proceeded with the HE. The expected outcome of this evaluation was usability problems found on the system, which on the evaluators' opinions pose a usability problem. These problems are accompanied by a rating indicating how severe they are. The evaluators were provided with a list of common tasks that can be done through the system in order to facilitate evaluation process. Along with the list of tasks, the evaluators were also provided with the list of heuristics to be used for this evaluation. The tasks and heuristics lists are included in Appendix A.

Once the evaluators inspected the system by completing the tasks given to them, they compiled the list of usability problems. Each item on the list includes a description of the usability problem, a rating (Table 4.1) of how severe the problem was, and in some cases suggestion as to how to solve the problem. The following section presents a summary of the results of these heuristic evaluations.

4.2.2 Evaluation Results

The end product of these evaluations was a list of usability problems found and their severity. This severity was determined using Nielsen's (1993) severity ratings, as seen on Table 4.1 below.

Table 4.1
Single Rating Scale for the Severity of Usability Problems (Nielsen, 1993)

| Description | Rating |
|--|--------|
| This is not a usability problem at all. | 0 |
| Cosmetic problem only – need not be fixed unless extra time is available on project. | 1 |
| Minor usability problem – fixing this should be given low priority. | 2 |
| Major usability problem – important to fix, should be given high priority. | 3 |
| Usability catastrophe – imperative to fix this before the product can be released. | 4 |

The first evaluator's findings are documented on Table 4.2. This evaluator found a total of 19 usability problems. The usability problems' severity distribution is 10 (55.6%) severity 4 problems, 4 (22.2%) severity 2 problems, and 4 (22.2%) severity 1 problems.

Table 4.2
First Evaluator's Usability Observations

| Observation | Severity |
|---|----------|
| The user has to remember a command in order to start the application. | 4 |
| It is not intuitive that the time, personal information, and location panels are clickable. | 4 |
| It is hard to associate the time panel with the agenda. | 4 |
| Missing picture under "Most recent picture" label. | 2 |
| There is no back button in any of the application windows/menus. | 4 |
| It is not intuitive that you can click a family member's picture to access more pictures of that person. | 2 |
| Getting the weather is confusing as there are two different locations for it. | 4 |
| The icon for the task manager reads "Lista de Tareas" while the page the user is taken when clicking the icon makes reference to "Tareas Pendientes". | 1 |
| There is no way to mark tasks as completed. | 4 |
| On the "Desayunar" task, there are too many elements on the page. | 2 |
| There is no way to mark a medication as taken already. | 4 |
| The medications table is editable and edits are not undoable. | 4 |
| The tabs' text on the phone directory is too small. | 1 |
| There is no cancel call button. | 1 |
| The logo for getting immediate assistance is confusing as "Ayuda" is often used to get help with the application. | 4 |
| There is no way to cancel the emergency call. | 4 |
| There is no way to tell apart read from unread messages. | 2 |
| Message headers are not consistent with applications written language (Spanish). | 1 |

The second evaluator's findings are documented on Table 4.3. This evaluator found also a total of 19 usability problems. The problems' severity distribution is 1 (5.6%) severity 3 problem, 8 (44.4%) severity 2 problems, and 9 (50%) severity 1 problems.

Table 4.3
Second Evaluator's Usability Observations

| Observation | Severity |
|---|----------|
| The label containing the name of the season on the time panel is too small. | 2 |
| Finding the medical appointments by clicking on the time panel was not intuitive. | 3 |
| Need to standardize the space between the information of Maria's children on the personal information page. | 1 |
| A back button should be included so the user could come back to the pictures of Maria's children instead of clicking on Maria's picture. | 2 |
| Written instructions could be included on the side of the map in case does not understand the map. | 1 |
| The font on the description of the tasks manager is too small. | 1 |
| On the breakfast task, the numbers from 11 through 13 do not follow the same pattern of the rest of the numbers. On the numbers from 1 through 10 the number that follows is directly below but the number 12 is at the side. | 2 |
| The title of the task says "Barrer la cocina" but in the video the instructions are for sweeping the living room. | 2 |
| Orthographic error on instruction number 2. The word "gavinete" should be "gabinete". | 1 |
| Orthographic error on instruction number 3. The word "heche" should be "eche". | 1 |
| Icon for medications is a little confusing. Could be changed to a different image or the font should be a little bigger. | 2 |
| The name of the medicines and the dose information should be centered on the table. | 1 |
| The dose for Zolof and Namenda should say "tableta" instead of "tabletas" since is just one tablet. | 1 |
| On the address book, the font for the information of the contact is too small and decentralized. | 1 |
| A call button should be included on another column or just beside the number so the user can know where to press to dial the number. | 2 |
| The icons for dialing emergency numbers, may be better to put them at the bottom of the table of contacts instead of on an additional tab. | 2 |
| Orthographic error on the title on top of the table with the messages. The word "recividos" should be "recibidos". | 1 |
| The label containing the name of the season on the time panel is too small. | 2 |

Table 4.4 shows the finding of the third evaluator. This evaluator found a total of 4 usability problems. These problems' severity distribution is 1 (25.0%) severity 3 problems, and 3 (75.0%) severity 1 problems.

Table 4.4
Third Evaluator's Usability Observations

| Observation | Severity |
|--|----------|
| Some of <u>the text on</u> is too small (E.g. Season of the year text). | 2 |
| On the mopping task, it would be good having a button to go back to the beginning. | 2 |
| The calendar only has appointments from 8am – 5pm. | 3 |
| There's no button to exit the application (e.g. Logout button). | 2 |

As part of the evaluation, all evaluators were asked an open ended question about the way steps are presented on each task manager's tasks. This question asked which presentation method is better, a wizard or a page that show all steps at the same time. All three evaluators concurred on the wizard method being more appropriate for the intended end user. The open ended question can be seen below:

“In the pending tasks windows, the user can select to complete any of three available tasks. The mopping and preparing breakfast tasks are outlined using pictures. The steps for these tasks are presented in different ways. For the mopping task, the steps are presented one at a time, and the user must press the forward arrow to see the next step. The preparing breakfast task has all the steps on the same page. Which presentation method do you find more appropriate?”

4.2.3 Redesign and Implementation Implications

The results from the three evaluators were considered in the redesign of the application. Evaluators reported a total of 40 usability problems of which 19 were resolved during the redesign. When selecting what problems to address, the author selected those with a high enough severity to prevent the showcase of the different system modules on a demo with actual users. These problems are listed in table 4.5 below, along with their severity and reporting evaluator.

Table 4.5
Usability Observations Addressed on Redesign

| Observation | Severity |
|--|----------|
| 1. It is not intuitive that the time, personal information, and location panels are clickable. | 4 |
| 2. Missing picture under “Most recent picture” label. | 2 |
| 3. It is not intuitive that you can click a family member's picture to access more pictures of that person. | 2 |
| 4. It is hard to associate the time panel with the agenda. | 4 |
| 5. There is no way to mark tasks as completed. | 4 |
| 6. There is no way to mark a medication as taken already. | 4 |
| 7. The medications table is editable and edits are not undoable. | 4 |
| 8. The tabs’ text on the phone directory is too small. | 1 |
| 9. There is no cancel call button. | 1 |
| 10. The logo for getting immediate assistance is confusing as “Ayuda” is often used to get help with the application. | 4 |
| 11. There is no way to cancel the emergency call. | 1 |
| 12. Message headers are not consistent with applications written language (Spanish). | 1 |
| 13. The label containing the name of the season on the time panel is too small. | 2 |
| 14. The title of the task says “Barrer la cocina” but in the video the instructions are for sweeping the living room. | 2 |
| 15. Orthographic error on instruction number 2. The word “gavinete” should be “gabinete”. | 1 |
| 16. Orthographic error on instruction number 3. The word “heche” should be “eche”. | 1 |
| 17. The dose for Zoloft and Namenda should say “tableta” instead of “tabletas” since is just one tablet. | 1 |
| 18. Orthographic error on the title on top of the table with the messages. The word “recividos” should be “recibidos”. | 1 |
| 19. Some of the text on is too small (E.g. Season of the year text). | 2 |

Before and after images of some of the fixed usability problems are shown below. A brief explanation of the usability problem and the approached followed towards its solution is as well included. This section will make reference to the fixed usability problems by their number as seen on Table 4.5. Figure 4.1 shows before and after views of usability problem 1.

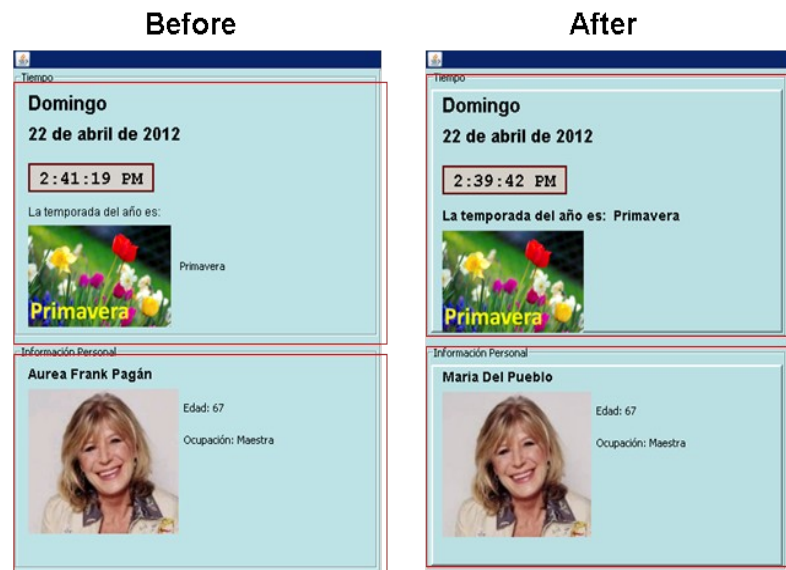


Figure 4.1 Problem 1's Before and After Images.

The root of problem 1 was that the fact that the panels were meant to be perceived as buttons was not intuitive enough. As seen on the after image, this was fixed by giving the panel's border an emboss effect so they more closely resemble a conventional user interface button. Figure 4.2 shows before and after images for problem 3.



Figure 4.2 Problem 3's Before and After Images.

Problem 3 is another case user interface elements that are clickable but do not appear to be. As can be seen on the after image for this problem, emboss effects were added to the family members' images as well as tooltips to inform the users they can click on the images for more information. Figure 4.3 shows before and after images for problem 5.

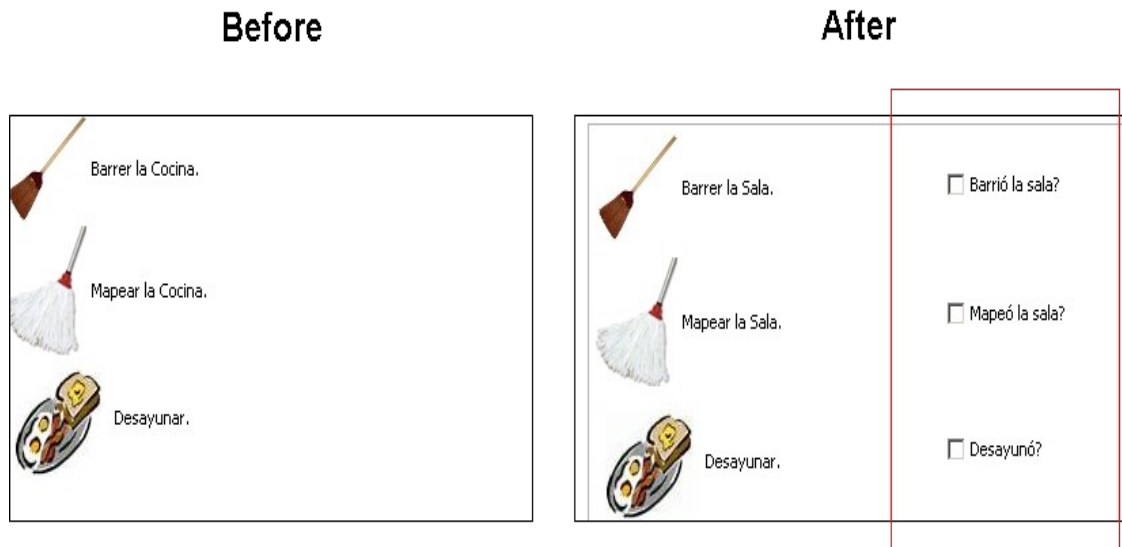


Figure 4.3 Problem 5's Before and After Images.

In problem 5, users had no way of marking tasks as completed on the task management module. This was redesigned so that they can check a box indicating the task is done. After a task's box is checked, the task is removed from the task management page. Finally, Figure 4.4 shows the before and after images for problems 10 and 11.

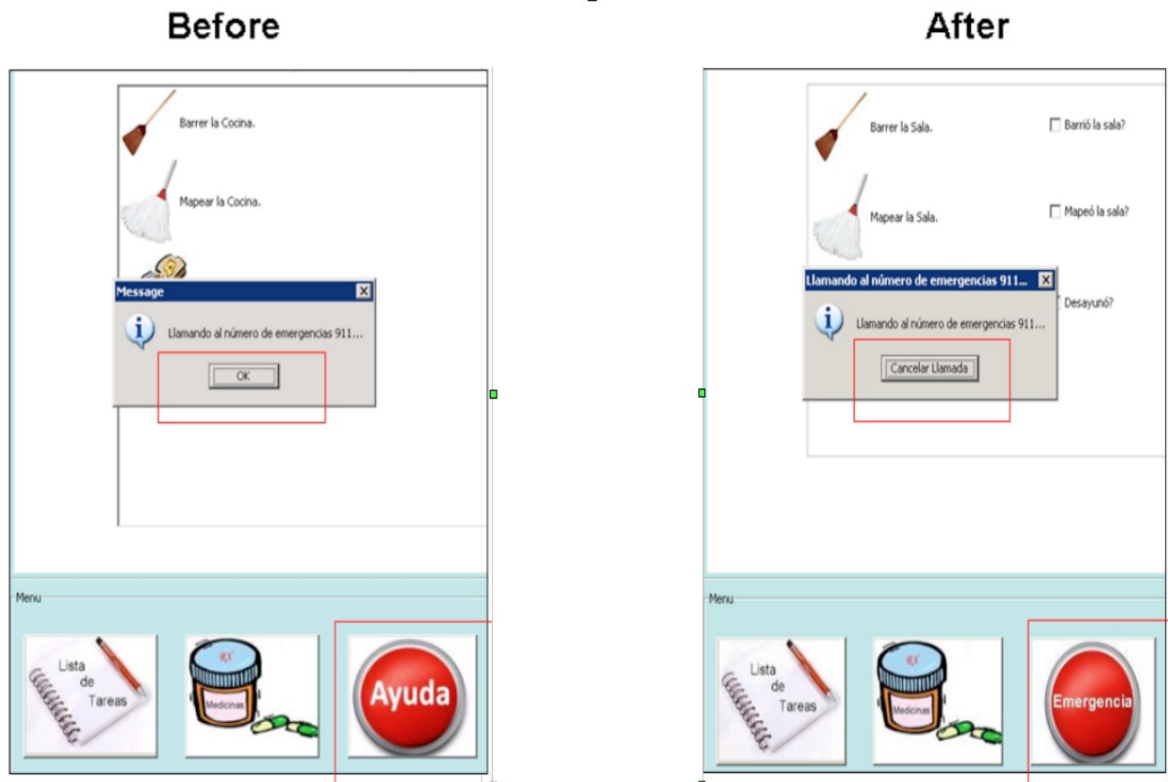


Figure 4.4 Problems 10's and 11's Before and After Images.

On problem 10, the label for the emergency call button was identified as a possible source of confusion for the users since the word used (“Ayuda”, the Spanish word for Help) could be interpreted as the system’s help and not as an emergency call button. This was resolved by changing the label to read “Emergencia”, the Spanish word for Emergency. The issue with problem 11, which can also be seen on Figure 4.4, was a missing cancel button on the the emergency call window, which posed a problem for accidental calls. This was resolved by adding such button as seen on the after image.

As was mentioned on this section’s introduction, the purpose of conducting the HE is identifying potential usability problems which would prevent the application from being used by users from the target population. Although fixing all severity 3 and 4 problems is typical during the redesign phase, the severity of some of the problems reported by the evaluators does not seem

appropriate within the context of the prototype's purpose. For this reason, some of the high severity usability problems found by the evaluators were not addressed during the redesign phase. These problems are numbered from 1 to 6 on figure 4.6 below.

Table 4.6
Severe Usability Problems not Addressed through Redesign

| Observation | Severity |
|--|----------|
| 1. The user has to remember a command in order to start the application. | 4 |
| 2. There is no back button in any of the application windows/menus. | 4 |
| 3. Getting the weather is confusing as there are two different locations for it. | 4 |
| 4. Finding the medical appointments by clicking on the time panel was not intuitive. | 3 |
| 5. The calendar only has appointments from 8am – 5pm. | 3 |

Problem 1 was not addressed because this system is intended to always be running on the system, under the supervision of an AD patient's caregiver, thus a senior user should never have to start the application. Problem 2 was not addressed because the application was designed to relieve the user complex navigation paths by having all possible navigation options visible at all times, which would be hindered by the presence of a back button. Problem 3 is not considered a usability problem because even though the weather is shown on two places of the application, these places are related to the same application module. The first one is on the location button, where a weather overview for the current location is shown, and the second one is on the main panel, after clicking the location button, where more detailed weather information is displayed. Problem 4 was not addressed because it was considered to be of lower severity than reported. Finally, problem 5 was not addressed because this is the time range commonly used for AD patient's medical appointments (Mayo Clinic, 2010). This is done to avoid symptoms of sundowning – a state of confusion at the end of the day and into the night common in individuals with AD - interfere with the medical

appointment (Smith, 2011).

In order to expose the system to the end users, it has to be stable enough so that their experience is not hindered. As was shown in this chapter, the heuristic evaluations done on the Cogpros application helped uncover many usability problems that were not caught during the design phases of the project. Although not all usability problems were fixed, the author believes the set of problems that were are representatives of the main issues that would render the system unfit for user exposure. In the next chapter, the methodology employed in presenting the system to its intended end users will be described and the data obtained from such interaction will be presented.

CHAPTER 5: METHODS AND RESULTS

5.1. Introduction

The user interface (UI) is the part of a computer application users will interact with the most. As such, it can weigh in for a big part of the application's overall usability, affecting the user's perception and satisfaction. Given the power the UI has over the success of an application, it is important to validate its design through Usability Testing. A usability test has the purpose of informing the design of an application by gathering data from which to identify and rectify usability deficiencies (Rubin & Chisnell, 2008). Conducting usability tests with real users is one the most fundamental usability methods (Nielsen, 1993). This kind of testing allows the designers to collect information about the application from the users it was designed for, giving them insight into how usable the application really is, and asserting any design assumptions made about the target user population and their computer usage.

This chapter will present the methodology employed in conducting a test with the intended users of the Cogpros application. This includes a description of the test goals, the design used, the participants of the test, the assessment instrument used, the statistical analysis applied to the data collected, and the procedure followed. Results of the statistical analysis will also be presented for both quantitative and qualitative measures.

5.2. Methodology

5.2.1. Test Goals

As stated on Chapter I, the objective of this thesis is to assess the viability and usability of the Cogpros application, which is aimed at lessening the negative effects that AD has on both patients and their caregivers. Given this objective, a test was designed in which real life users where

exposed to the application in order to accomplish the following goals: (1) Determine if the concept of a software cognitive prosthesis is perceived as useful by the users, (2) Identify usability problems in the user interface, (3) Validate assumptions made throughout the design process about what content and features would be more appropriate for the target population, and (4) Get a measure of the users overall satisfaction with various aspects of the application.

The next section will present the design chosen for Cogpros usability test along with the key features of this design and the rationale for its selection.

5.2.2. Design

Literature on Usability testing is filled with a myriad of testing designs, each with a different purpose (Rubin & Chisnell, 2008). A review of several of these designs was done in order to find one whose purpose lined up more closely to the testing goals. Based on this review, the exploratory study design was chosen. In an exploratory study, the main objective is to examine the effectiveness of preliminary design concepts (Rubin & Chisnell, 2008). According to Cozby (2004), this type of design has the advantage of being useful in providing researchers with background on a particular topic which can then be used to address research questions, generate formal hypothesis and develop more precise research problems, and this is well aligned with the testing goals outlined in the previous section of this chapter. However, due to the small sample sizes this type of design generally uses, it has the disadvantage of not yielding results that can be generalized to the population at large. Furthermore, its exploratory nature and flexible but unstructured research process might inhibit the ability to make definite conclusions about the findings, thus leading to only tentative results (Cozby, 2004).

In the next section, the profile of the test participants will be described as well as the strategy employed in selecting them for this study.

5.2.3. Participants

The sampling for this study's participants was done following a single-stage cluster sampling approach, where 16 caregiver support groups sponsored by the Alzheimer's Federation of Puerto Rico (FAPR) were treated as clusters. Cluster sampling involves dividing the population into groups called “clusters” and randomly selecting an amount of clusters to include in the sample. After the cluster(s) have been selected, the researchers can either use all elements within the selected clusters, which is called single-stage sampling, or randomly select a subset of each selected cluster, which is called two-stage sampling (Cozby, 2004). In order to select one random cluster from the 16 groups, each group was assigned a number from 1 through 16. Once each group had a number assigned to it, a random number generator software was used to generate a number between 1 and 16, where the generated number represented the selected cluster (Haahr, 1998). The group selected using this approach was the Aguada, PR Alzheimer's support group, led by Dr. José Lopes DaSilva.

The group selected for the study consisted of 13 people, 9 (69%) were females and 4 (31%) were male. The participants were all natives of Puerto Rico and residents of the Aguada township. Their ages ranged between 37 and 85 years old ($M = 65$, $SD = 12.4$). The exclusion criteria for participation in the study were: (1) being younger than 21 years old, (2) having been diagnosed with AD, (3) having severe cognitive deficits, (4) not having a caregiver relationship with a person with AD, or (5) having experience with an application similar to the one being studied.

5.2.4. Instruments

The usability testing component of this study consisted of a walkthrough of the application given to the participants, followed by a focus group and post group questionnaire to be completed by the participants.

During the focus group, the participants and the moderator talked about the application's

clinical implications, the participants' perceived usability of each module, and the impact the application could have on both their lives and on the lives of the individuals with AD under their care. In the focus group, the participants were also able to provide recommendations they believed would make the application better and more usable by individuals with AD and their caregivers.

The post focus group questionnaire, which can be seen in Appendix B, had the objective of collecting background data about the participants and the AD patient(s) they have under their care. It also was intended to assess how satisfied they were with the application. With a total of 16 questions, this questionnaire consisted of 4 multiple choice and 2 open ended questions where the participants were asked about their ages and those of the individuals with AD under their care, the relationship between them and their patient, the stage of their patient's AD, the gender of their patient, and the living arrangement of their AD patient. The remaining questions of the questionnaire were part of a set of 4-point likert scale questions designed to gather the participants' opinions about different aspects of the application and how useful it would be for both them and the individual with AD under their care.

The next section will present the statistical analysis strategies used to gain knowledge on the participants' feelings, reactions, and satisfaction about the role an application like the one being studied could play in their day-to-day as they take care of the individual with AD.

5.2.5. Statistical Analysis

For data analysis, descriptive statistical tests were used in order to obtain frequencies and distributions of the general characteristics of the test's target population. Furthermore, measures of central tendency such as means and standard deviations, were used to gain understanding of the participants' experience as caregivers of individuals with AD, in particular of the living arrangement of their patients, the relationship they have with them, and the AD stage they are at.

Frequencies and proportions were also used to identify patterns in the participants' responses

to preference and satisfaction likert scales. In order to create an index based on likert scale responses, internal reliability analysis using Cronbach's alpha (α) coefficient was performed on the scale responses. This analysis was used to identify which items of the likert scales could be aggregated to form a reliable index. Additionally, the non-parametric correlation coefficients of Kendall's tau (τ) and Spearman's rho (ρ) were calculated for several variables under study to identify possible relationships or dependencies between variables that could confound the results.

The analysis employed for the qualitative data collected from the focus group involved a process called coding, where themes and categories were developed and assigned to the data (Krueger, & Casey 2000). These themes and categories were used to uncover patterns and contrasts on the data, which were then analyzed in terms of their meaning and in the context of the test goals. Findings produced by this process were sent to the members of the AD support group so participants of the focus group could review and validate them.

The following section will outline the procedure followed to plan and carry out the focus group.

5.2.6. Procedure

This project's researcher contacted the leader of the Aguada, PR Alzheimer's support group over the phone to present him the research project. During this call, the support group's leader received an overview of the purpose of the project, the inclusion and exclusion criteria for the study, and the format and purpose of the focus group. After the presentation, the group's leader expressed his interest in having his group be part of the study, and a date was set for the focus group to take place.

As preparation for the study, a moderator's guide and an informed consent form for the group participants were created. The moderator's guide contains the introductory remarks the moderator used to begin the group and set of guide questions that the moderator used to focus the

conversations during the group. The moderator guide and the consent form can be seen in Appendixes C and D respectively. A moderator for the focus group was selected and coached by the project's researcher, giving her a presentation of the project and its objectives, the test goals, and the application. The guide questions were also provided to the moderator before hand so she could become familiar with them.

The study took place during the support group's regular meeting day. Present in the group were 13 participants, the group's leader, the moderator and the project's researcher. Before starting the study, the participants were handed the informed consent form, which was also read out loud by the moderator. After all participants read and signed the consent forms, they handed them in to the moderator, who started with the introduction of the study. During the introduction, the participants were presented with the study's purpose. They were also asked about previous focus group or market research experience, of which all participants had none. Subsequently, they were told about their rights to privacy, and how everything said during the group would be kept confidential. They were also reminded the focus group interview's audio was going to be recorded and transcribed later, and that they were not going to be identified by name on the transcript, as explained in the consent form.

The study started with a presentation of the application by the project's researcher, where participants were walked through all the modules in the application and given background on their motivation and expected implications. Participants were encouraged to comment at all times during this presentation. Following the presentation, the moderator started the focus group with a brief introduction, where group members were thanked for their participation, reminded about their rights to privacy and confidentiality, and talked about the format and structure to be followed throughout the focus group interview. Next, the moderator started the discussion using the guide questions. The researcher served as the note-taker for the focus group and answered occasional

questions about the application. After the discussion was over, the moderator summarized the main points of the discussion and the participants were given the opportunity to comment or ask questions about these. Once this was done, the participants were thanked for their participation and handed out the questionnaire. Both the moderator and the researcher went around the room answering questions about the questionnaire. After all questionnaires had been handed in, the researcher thanked the participants and the group leader once again, and the study concluded.

The next sections will present the results produced by the statistical analysis of the data collected on the study.

5.3. Results

5.3.1. Quantitative Data

5.3.1.1. Descriptive Statistics

Descriptive statistics were calculated for the 13 patient's questionnaire responses. These are summarized and presented in the tables to follow. Out of the 13 participants, 9 (69%) were females and 4 (31%) were male. The participant's ages ranged between 37 and 85 years old ($M = 65$, $SD = 12.4$), while the age of the individuals with AD they care for ranged between 64 and 94 years old ($M = 79$, $SD = 10.9$). All participants were residents of Aguada, PR.

Table 5.1 shows the frequency of the participant's responses when asked about the nature of their relationship with the AD patient under their care. Results were split evenly between the three categories with four participants (30.8%) reporting a parent-child relationship, four participants (30.8%) a spousal relationship, and five participants (38.4%) reporting other kind of relationship. Of the five participants that reported other kind of relationship, three disclosed that they have a working relationship with the AD patient.

Table 5.1

Participant's Relationship with the AD patient under their care

| Relationship | Frequency | Percent |
|--------------|-----------|---------|
| Parent-Child | 4 | 30.80% |
| Spouse | 4 | 30.80% |
| Other | 5 | 38.40% |

When asked about the stage of their patients' AD, the participants responded as seen on Table 5.2. Four (30.8%) participants reported the patient under their care is at the initial stage of the disease, two (15.40%) reported their patient is at an intermediate stage, and a majority of seven (53.8%) reported their patient being at an advanced stage of AD.

Table 5.2

Stage of AD for Patients under the Participants Care

| Stage | Frequency | Percent |
|--------------|-----------|---------|
| Initial | 4 | 30.80% |
| Intermediate | 2 | 15.40% |
| Advanced | 7 | 53.80% |

Participants were asked where do the patients they care for live. Their responses are summarized in Table 5.3. Two (15.4%) responded their patients live by themselves, five (38.40%) responded that their patients live with their spouse, three (23.1%) responded they live with a caregiver, 1 (7.7%) responded the individual he/she cares for lives in a home, and two (15.4%) responded the patient lives on other location.

Table 5.3

Living Arrangement of individuals with AD under the Participants Care

| Living Arrangement | Frequency | Percent |
|--------------------|-----------|---------|
| By Himself/Herself | 2 | 15.40% |
| With Spouse | 5 | 38.40% |
| With Caregiver | 3 | 23.10% |
| Home | 1 | 7.70% |
| Other | 2 | 15.40% |

Participants were presented with a series of Likert scales with questions about their impressions and satisfaction with the application's modules. Table 5.4 shows a summary of their responses a question stating they understood the application's purpose. A majority of the participants agreed with the statement, with four (33.33%) responding *agree* and seven (58.33%) responding *totally agree*. One (8.33%) participant reported not understanding the application's purpose with a response of *totally disagree* and another one did not answer this question.

Table 5.4
Frequency of Participants that Understood the Application's Purpose

| Response | Frequency | Valid Percent |
|------------------|-----------|---------------|
| Totally Disagree | 1 | 8.33% |
| Agree | 4 | 33.33% |
| Totally Agree | 7 | 58.33% |
| Missing | 1 | |

As can be seen on Table 5.5, a majority of the participants expressed interest in using the application, with five (41.7%) participants responding *agree* and six (50%) participants responding *totally agree*. One (8.3%) participant responded *totally disagree* and another one did not respond to this question.

Table 5.5
Frequency of Participants that Would Like to Use the Application

| Response | Frequency | Valid Percent |
|------------------|-----------|---------------|
| Totally Disagree | 1 | 8.30% |
| Agree | 5 | 41.70% |
| Totally Agree | 6 | 50.00% |
| Missing | 1 | |

Participants were asked if they perceived the application as easy to use. As seen in Table 5.6, most participants perceived the application as easy to use, with five (41.7%) responding *totally agree*, another five (41.7%) responding *agree*, one (8.3%) participant responding *disagree*, and one

(8.3%) participant responding *totally disagree*. One participant did not answer this question.

Table 5.6
Frequency of Participants that Perceived the Application as Easy to Use

| Response | Frequency | Valid Percent |
|------------------|-----------|---------------|
| Totally Disagree | 1 | 8.3% |
| Disagree | 1 | 8.3% |
| Agree | 5 | 41.7% |
| Totally Agree | 5 | 41.7% |
| Missing | 1 | |

When asked about the application's graphics, most participants agreed they are visually attractive. As can be seen in Table 5.7, six (50.7%) participants responded *totally agree*, and five (41.7%) participants responded *agree*. One (8.3%) participant responded *totally disagree*, and one participant did not respond to the question.

Table 5.7
Frequency of Participants that Perceived the Application's Graphics as Visually Attractive

| Response | Frequency | Valid Percent |
|------------------|-----------|---------------|
| Totally Disagree | 1 | 8.3% |
| Agree | 5 | 41.7% |
| Totally Agree | 6 | 50.7% |
| Missing | 1 | |

Participants were split evenly when asked about the complexity of the application's navigation. As can be observed on Table 5.8, half of the participants agreed that the navigation was too complex, with three (30%) participants responding *totally agree* and two (20%) participants responding *agree*. The other half of the participants disagreed about this, with three (30%) participants responding *totally disagree*, and two (20%) participants responding *disagree*. Three participants did not answer the question.

Table 5.8
*Frequency of Participants that Perceived the Application's Navigation as
 Complicated*

| Response | Frequency | Valid Percent |
|------------------|-----------|---------------|
| Totally Disagree | 3 | 30.0% |
| Disagree | 2 | 20.0% |
| Agree | 2 | 20.0% |
| Totally Agree | 3 | 30.0% |
| Missing | 3 | |

Table 5.9 shows what the participants responded when asked if the terminology used in the application was too complex for an AD patient. To this question, four (36.4%) participants reported *totally agree*, four (36.4%) participants responded *agree*, and three (27.2%) responded *disagree*. Two participants did not provide an answer for this question.

Table 5.9
*Frequency of Participants that Perceived the Terminology Used too Complex for an
 AD patient*

| Response | Frequency | Valid Percent |
|---------------|-----------|---------------|
| Disagree | 3 | 27.2% |
| Agree | 4 | 36.4% |
| Totally Agree | 4 | 36.4% |
| Missing | 2 | |

The participants were asked if they thought the patient under their care could use the application. As seen in Figure 5.10, the majority of the participants think the patients under their care would not be able to use the application with six (50%) participants responding *totally disagree* and three (25%) participants responding *disagree*. One (8.3%) participant responded *agree* and two (16.7%) participants responded *totally disagree*. One participant did not provide an answer for this question.

Table 5.10

Frequency of Participants that Think their Patient Could Use the Application

| Response | Frequency | Valid Percent |
|------------------|-----------|---------------|
| Totally Disagree | 6 | 50.0% |
| Disagree | 3 | 25.0% |
| Agree | 1 | 8.3 |
| Totally Agree | 2 | 16.7% |
| Missing | 1 | |

The participants were asked if they perceived the application as not useful for their patient. The frequency of the participant's responses are recorded in Table 5.11. A majority of the participants perceived the application as not useful for the patients they have under their care with six (60%) participants responding *totally agree*, one (10%) participant responding *agree*, two (20%) participants responding *disagree*, and one (10%) participant responding *totally disagree*. One participant did not answer this question.

Table 5.11

Frequency of Participants that Perceived the Application as Not Useful for their Patient

| Response | Frequency | Valid Percent |
|------------------|-----------|---------------|
| Totally Disagree | 1 | 10.0% |
| Disagree | 2 | 20.0% |
| Agree | 1 | 10.0% |
| Totally Agree | 6 | 60.0% |
| Missing | 3 | |

Participants were also asked if they perceived the application not useful to them. Their responses are summarized in Table 5.12. The majority of the participants did not perceive the application as not being useful with three (25%) participants responding *totally disagree* and five (41.7%) responding *disagree*. Of the participants that agreed that the application is not useful to them, one (8.3%) responded *agree* and three (25%) responded *totally agree*. One participant did not answer this question.

Table 5.12

Frequency of Participants that Perceived the Application as Not Useful for them

| Response | Frequency | Valid Percent |
|------------------|-----------|---------------|
| Totally Disagree | 3 | 25.0% |
| Disagree | 5 | 41.7% |
| Agree | 1 | 8.3% |
| Totally Agree | 3 | 25.0% |
| Missing | 1 | |

All of the participants agreed when asked if they would recommend the application to other caregivers. As can be seen in Table 5.13, eight (61.5%) participants responded *totally agree* and five (38.5%) participants responded *agree*.

Table 5.13

*Frequency of Participants that Would Recommend the application to other
Caregivers*

| Response | Frequency | Valid Percent |
|---------------|-----------|---------------|
| Agree | 5 | 38.5% |
| Totally Agree | 8 | 61.5% |

An internal reliability analysis using Cronbach's alpha (α) coefficient was performed to the likert scale question items to determine which of these could be combined to create an index that can reliably measure the participants' satisfaction with the application. For an index based on multiple items to be found reliable, it must have a coefficient of reliability greater than 0.7 (Villa, 2008). The alpha coefficient for an item based on all the likert scale question was of 0.508, which is not reliable. The item's total statistics yielded by the reliability analysis were used to select which questions to remove from the index in order to increase its reliability. A total of three questions were removed from the index and from the reliability analysis. These questions were questions 11, 15, and 16 from Appendix B. After removing these questions, the alpha coefficient increased to 0.704, which means that an index created by combining all but these three questions can be deemed

reliable. The index that was created is an integer that can assume values between -14 and 14 and is directly proportional to the participants' satisfaction. The computed indexes ranged between 1 and 8, with a mean of 3.58 and standard deviation of 2.429.

In order to identify possible spurious relationships between the variables under study, two non-parametric correlation coefficients were calculated. Table 5.14 and Table 5.15 show Kendall and Spearman correlation matrices respectively. In order to determine the strength of the relationship between variables at different levels of significance, critical values were determined for both correlation coefficients. For an alpha of .01 and a sample size of 13 a critical value of 0.703 was obtained and for an alpha of .05 and the same sample size, a critical value of 0.560 was obtained. As can be observed on both Table 5.14 and Table 5.15, a strong correlation could not be established between any of the variables under study at either level of significance.

Table 5.14
Kendall's Correlation Matrix

| | <i>Participant's Age</i> | <i>Patient's Age</i> | <i>AD Stage</i> | <i>Satisfaction Index</i> |
|--|--------------------------|----------------------|--|---------------------------|
| Participant's Age | - | | | |
| Patient's Age | 0.121 | - | | |
| AD Stage | 0.113 | 0.370 | - | |
| Satisfaction Index | -0.127 | 0.019 | 0.058 | - |
| $\alpha = 0.05$ (Critical Value = 0.560) | | | $\alpha = 0.01$ (Critical Value = 0.703) | |

Table 5.15
Spearman's Correlation Matrix

| | <i>Participant's Age</i> | <i>Patient's Age</i> | <i>AD Stage</i> | <i>Satisfaction Index</i> |
|--|--------------------------|----------------------|--|---------------------------|
| Participant's Age | - | | | |
| Patient's Age | 0.196 | - | | |
| AD Stage | 0.123 | 0.061 | - | |
| Satisfaction Index | -0.228 | 0.097 | 0.058 | - |
| $\alpha = 0.05$ (Critical Value = 0.560) | | | $\alpha = 0.01$ (Critical Value = 0.703) | |

5.3.2. Qualitative Data

After the participants were presented with the Cogpros application, the moderator of the focus group engaged them into several discussions about AD and the application. These discussions revolved around a set of questions developed based on the literature review and designed to elicit the participants' description of their caregiving experience and how technology, Cogpros in particular, can be used to enhance their quality of life and that of the individuals with AD under their care. The participants were asked open-ended questions in an effort to gain insight into their perceptions about the applications usability. When needed, probing questions were used to gain specific information or further details. A copy of the moderator's guide and a transcript of the focus group can be found in Appendixes C and E respectively.

Table 5.16 contains the themes identified for the questions asked during the focus group session. When talking about the application's utility, some participants reported concern on how the stage of their patients' disease might hinder the application's utility. This resonated across the whole group and some participants mentioned they felt the application would be useful even with a patient with advanced AD, since it has features targeted to the caregiver. Participants also reported they might lack the skills to operate the application, which might turn into a source of fear and frustration. Another theme identified was the lack of computer resources at their homes.

Table 5.16
Identified Themes

| Question Topic | Themes |
|-----------------------|--|
| Application's utility | <ul style="list-style-type: none">• Patients with advanced AD will not be able to use the application.• Useful for caregivers as well.• Not everyone has a computer.• Lack of skills, fear, frustration towards technology. |

Table 5.16 Continues

Table 5.16 Continued

Table 5.16
Identified Themes

| Question Topic | Themes |
|--|---|
| Reminiscence Therapy | <ul style="list-style-type: none"> Matches reality since patients do respond to reminiscence stimuli. |
| Cognitive prosthesis/ Assistive Technology | <ul style="list-style-type: none"> Needed aid. Would use with help. Generation of users is not tech-oriented |
| Time Management Module | <ul style="list-style-type: none"> Patients constantly ask about time/date. Extremely beneficial for caregivers. |
| Medication Management Module | <ul style="list-style-type: none"> Needs to be managed carefully. Need for reminders is paramount. Difficulty managing drug interactions. |
| Tasks Management Module | <ul style="list-style-type: none"> Patients with AD get easily confused and overwhelmed. Directions given to patients should be short and one at a time. Video is difficult for them. Difficult to find what they need on the video. |
| Communications Module | <ul style="list-style-type: none"> Physicians' contact info is important. |

On the topic of reminiscence therapy, participants mentioned that even though they had not heard of it before, it is familiar since they have experienced it when interacting with their patients. Participants identified the concepts of cognitive prosthesis as a much needed aid. The novelty and technological nature of it is an issue that causes anxiety to them, but they feel they would be able to get past it if they have help readily available when interacting with the application. This theme of anxiety and fear towards technology was present throughout several of the discussions during the focus group.

When discussing the different application modules, the participants were able to identify features that address needs their patients have in common. Participants reported individuals with AD constantly ask about the current date and time, which makes the Time Management module really useful for them. When looking at the Medications Management module, participants

recognized its usefulness, but as seen on Table 5.16, they identified key features that would improve this module's ability to address the main issues caregivers have when dealing with their patients' medications. All participants agreed that individuals with AD get easily confused and overwhelmed. Because of this, tasks given to them should be short, clear, and given one at a time. This is consonant with one of the three task manager approaches presented to the participants during the application's walkthrough. On this approach, tasks are shown one at a time and navigation arrows are available to move back or forward in the task step's progression. Participants found video tasks not suitable for individuals with AD, as they would have to rewind the video in order to review the task's steps, something that given their cognitive deficiencies would prove to be too difficult for them. When discussing the Communications module, participants mostly expressed interest in a clear distinction between the different types of contacts they can manage, with an emphasis on having their physicians' contacts highlighted by the application.

In the next chapter, both quantitative and qualitative results will be interpreted and discussed in the context of the objectives of this project and the current literature. Then, conclusions will be drawn, pointing out how the project objectives were addressed, the project's limitations and future work.

CHAPTER 6: CONCLUSIONS

6.1. Introduction

The main objective of this thesis work was to assess the viability of using technology as the means for implementing clinical interventions to help individuals with (AD) and their caregivers. More specifically, this research sought to develop and do usability testing on a working prototype of a software cognitive prosthesis using design principles tailored to individuals with AD. Caregivers of individuals with AD were used as the subjects of the usability test. This research also looked into evaluating the effectiveness of using multimedia content to guide users while carrying out tasks of daily living. One of the application's modules was built specifically for this and part of the usability test focused on it. In addition, this research set out to examine how feasible was implementing a digital version of Reminiscence and Reality Orientation Therapies, both of which were also built into the prototype and assessed during the usability test. This section is organized by research objective. For each objective, a summary of results will be presented along with interpretations contextualized on the current literature. Implications of the findings will be discussed. Finally, limitations and recommendations for future researchers will be presented in the context of the directions for future work.

6.2. Discussion

As was mentioned above, this thesis work has as its main objective assessing the viability and usability of a cognitive prosthesis aimed at lessening the negative effects that AD has on both individuals and caregivers. During the focus group, caregivers of individuals with AD reported that the individuals under their care would not be able to use the Cogpros application. This was expected given that a majority of the participants reported that the individual with AD under their care is on the last stage of the disease, and according to current research, many cognitive prostheses

(CP) are most effective for individuals in the mild to moderate stages of AD (Buettner, et. al, 2010). However, it cannot be stated with statistical certainty that the caregivers did not find the application appropriate for the individuals they take care of because of their AD stage. This could be explained by the fact that there were not enough individuals with mild or moderate AD in the sample, thus a comparison of caregiver's beliefs across stages of AD could not be done. This lack of predictive power of this finding points out a limitation of the research, which was not using a sample more representative of individuals with different stages of AD. Other limitations of this research are the small sample size used and the exploratory design nature, which prevented generalizing these results to the population at large, thus rendering them as tentative. This research was limited by the fact that the types of interactions appropriate for different levels of AD were not clear. It is recommended for future research projects to consider choosing a between-groups research design where the testing factor is the individuals' AD stage so definite conclusions can be made about what interventions are more appropriate for individuals on each stage of the disease.

When discussing if this application could help lessening the negative effects that AD has on them, caregivers reported they believe it could. Most of the caregivers felt they have the skills to use the application, although some felt they might require assistance in doing so. The results show a weak inverse relationship between the satisfaction index and the participants' ages. This relationship suggests that the older the participants, the less satisfied they are with the application. This was an expected outcome supported by the fact that one of the greatest barriers for computer use by seniors is computer anxiety, which correlates with previous investigations on this topic. Computer anxiety caused by a limited exposure to computers was a recurrent theme across the focus group's conversations, and according to the participants, this is due to a lack of computer resources in their homes and in their communities. This phenomenon is congruent with current research that states that one of the most prominent causes for computer anxiety is the senior users'

lack of previous exposure to computers, which often makes them overestimate the degree of expertise they need to use them appropriately. (Holzinger, et. al, 2011). A recommendation for future studies is to include a needs assessment component on the research project to identify what computer resources are available to the target population and tailor the application to make use of these resources. An example of this could be developing a similar application that can run in smart phones or tablets, so this technology's high accessibility can be leveraged in reaching users matching the demographics of the participants of this project's focus group.

As discussed above, the majority of the participants did not find the application appropriate for the individual with AD under their care. In addition, a sizable minority of the participants did not find the application useful for caregivers of individuals with AD. Given these findings, it was expected that only a small majority of the participants would recommend this application to other caregivers of individuals with AD. However, this was not the case as all the participants reported they would recommend the application to other caregivers. A possible explanation for this is that the participants might think this application would be more appropriate for a younger caregiver, because of the inverse relationship between age and the satisfaction. They might also be recommending it because they think other caregivers might have less computer anxiety and more computer resources available. Another explanation for the caregivers' decision to recommend the application to others is their social desirability bias. Social desirability bias describes the tendency that respondents have to answer questions in a manner that will be perceived as positive by others (Cozby, 2004). In this case, the participants of the focus group might have felt inclined to respond positively when asked if they would recommend the application because they thought not doing so would be seen in an unfavorable way. This bias was a limitation of this research and for future projects, it is recommended capturing a measure of social desirability in the study so this data can be correlated with the quantitative results.

Another objective of this project was to evaluate the benefits of exposing users to multimedia content. Specifically, assessing if the use of multimedia to guide users would be beneficial in helping them carry out tasks of daily living. This was addressed by the application's task management module, where users are presented with steps to complete tasks. Three different approaches of presenting the tasks to the users were presented. When asked which one they preferred, the participants of the focus group found more appropriate the approach where users are presented with a picture of each step at a time and they can navigate back and forth through these pictures. Participants were in agreement that a video demonstration of how to complete a task is not the most convenient way to present this information to an individual with AD. They believe individuals with AD would not be able to interact with the video while completing the task's steps. Nevertheless, this should not be interpreted as meaning that the usage of videos is not appropriate on interventions for individuals with AD. The Cogpros application was limited in this regard since it made use of video content in only one way. There are scenarios where the usage of video can be beneficial to individuals with AD, for instance in implementing a digital version of reminiscence therapy (RT), which provides social support by evoking memories about past events, thus helping patients maintain good mental health (Alm, et. al, 2007). Incorporating into the application a digital version of RT was another of the objectives of this project. This was done through the use of pictures of members of the family of the individual with AD. For each family member, the system stores pictures from different moments in their lives and these are presented to the individuals with AD along with information about the moment the picture was taken. Participants found this beneficial, given their experiences with traditional implementations of this intervention. It is recommended that future projects consider using videos on the implementation of different interventions where this type of multimedia content is more appropriate. Examples of these

interventions are RT and music therapy, which studies have shown support the well-being of people with dementia (Topo, et al., 2004).

Although conclusions and generalizations cannot be made about this application's use for individuals with AD, several implications for their caregivers can be made. First, the caregivers of individuals with AD are interested in exploring how technology can be leveraged to assist them on their care taking. Caregivers admitted to feelings of anxiety towards technology, however they see it as something that would alleviate many of the hardships they encounter while taking care of individuals with AD. Most caregivers found the application's navigation complex and stressed that receiving help in while these kinds of computer applications is essential for the success of any computerized intervention targeted to serve their user group.

While the objectives of this thesis work were met, several action items have been identified to expand on the work already done and improve the Cogpros application such that it can be used by individuals with AD and their caregivers in the future. These are presented in the following section.

6.3. Future Work

There are several considerations that need to be taken for the Cogpros application to move from the prototype stage into a full fledged software cognitive prosthesis. The nature of these considerations is twofold: of a features nature and of an experimental nature.

A full development iteration should be done, using as a starting point retrofitting the feedback from the focus group into the design. Individuals with AD would benefit from the implementation of a video version of RT, because the sensorial stimulation they can receive from video content is far greater than that of Cogpros current RT implementation, which uses only images. Another feature that could be implemented is a music therapy module, which has the

potential of supporting the wellbeing of people with dementia as described by Topo, et al. (2004). Additional features to target computer anxiety should be considered in order to increase the users confidence in using the application, thus allowing them to take full advantage of its features and capabilities. Another feature-related recommendation is to make Cogpros a mobile application that can be accessed through smartphones. Smartphones have the capability of supporting an application like Cogpros as well as added advantages innate to the mobile nature of the device. One of these advantages is its higher accessibility and availability to users in comparison to their desktop and laptop computers counterparts (Armstrong, et. al, 2010).

After addressing the addition of new features and improvements to existing ones, further experimentation should be done on the interface to gain understanding of how the caregiver's perspective is affected by variables like the patient's stage of the disease. In addition, there are questions left unanswered about the application's usability from the perspective of individuals with AD, since this research project only involved a focus group with a sample of their caregivers. In order to add more significance and conclusive power to the research's findings, an experimental design should be considered. Moreover, the sample size of the experiment should be chosen so that results are statistically significant.

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APPENDIX A:

Cogpros Prototype Heuristic Evaluation

Cogpros is a cognitive prosthetics software intended to lessen the negative effects that Alzheimer's Disease (AD) has on both patients and caregivers by assisting individuals with AD in carrying out their day to day living tasks and in the process exposing them to experimental cognitive therapies which the literature suggest are effective in slowing AD's progression. AD is a progressive and fatal brain disorder that destroys brain cells, causing problems with cognitive functions such as: Memory, Orientation, Language, Judgment, Perception, and Attention. People with this disease have difficulties performing complex sequential tasks and over time, their symptoms get severe enough to affect work, lifelong hobbies, social life, and interpersonal relationships, often leading to the death of the patient.

The software application is composed of several modules which address some of the cognitive deficits seen in individuals with AD. The time, place and person modules focus on helping the users keep track of their daily activities and commitments, making them aware of their surroundings, and reminding them of their personal and family details. The application also incorporates modules for tasks management, medication schedule, phone directory, messaging, and a panic button in case of emergencies.

A list of typical user tasks is included with this form to give you a better idea of what the users can do with the system. After completing the tasks provided in this list (*Tasks for Heuristic Evaluation*), examine the guidelines below and for each guideline write down any usability problem you discover along with its severity rating. For your convenience, a legend for heuristic severity ratings has been appended at the end of this document. After evaluating the system using the guidelines, please answer the question in the last page.

Evaluation Guidelines

1. Visibility of System Status

The system should keep seniors confidently in control by communicating about the state of the system as they interact with it. This includes, but is not limited to:

2. Match between System and the Real World

The system should speak the user's language, with words, phrases and concepts familiar to the user, rather than system-oriented terms. Follow real-world conventions, making information appear in a natural and logical order.

3. User Control and Freedom

Seniors should feel in control of navigation. The system should provide seniors with obvious navigation from one module to another.

4. Consistency and Standards

Screen design and functionality structure of the system should be consistent.

5. Recognition Rather Than Recall

Make objects, actions, and options visible. User memory load should be minimized by displaying dialogue elements and allowing the users to choose from them.

6. Aesthetic and Minimalist Design

Dialogues should not contain information which is irrelevant or rarely needed. Every extra unit of information in a dialogue competes with the relevant units of information and diminishes their relative visibility.

Open Question

In the *pending tasks windows*, the user can select to complete any of three available tasks. The *mopping* and *preparing breakfast* tasks are outlined using pictures. The steps for these tasks are presented in different ways. For the mopping task, the steps are presented one at a time, and the user must press the forward arrow to see the next step. The *preparing breakfast* task has all the steps on the same page. Which presentation method do you find more appropriate?

Severity Ratings Scale:

The following 1 to 4 rating scale can be used to rate the severity of usability problems:

- 1 = Cosmetic problem only: need not be fixed unless extra time is available on project
- 2 = Minor usability problem: fixing this should be given low priority
- 3 = Major usability problem: important to fix, so should be given high priority
- 4 = Usability catastrophe: imperative to fix this before product can be released

Tasks for Heuristic Evaluation

Task 1

1. Start up the system.
2. Determine the current date, time and season of the year.
3. Determine what medical specialist is Aurea meeting on Thursday.

Task 2

6. Find out the user's name, age, and occupation.
7. Determine how many children Aurea has.
8. View Maria's oldest daughter's pictures.

Task 3

1. Find out Maria's address.
2. Determine what the current weather is like.
3. Find out the route for going from Maria's house to supermarket.

Task 4

1. Find out what tasks Aurea has to complete today.
2. Determine what Aurea is going to have for breakfast today.
3. Look at the instructions for sweeping the floor.
4. View the steps Aurea has to follow to mop the floor.

Task 5

1. Determine how many medications Aurea takes for Alzheimer.
2. Determine which medication Aurea takes for high blood pressure.

Task 6

1. Dial Maria Aponte's number from the application.
2. Call the fire department from the application.
3. Get immediate emergency assistance.

Task 7

1. Check Maria's inbox for new messages.
2. Read Alexandra Diaz's message.

APPENDIX B:

POST FOCUS GROUP QUESTIONNAIRE



Universidad de Puerto Rico
Recinto Universitario de Mayagüez

Por: © José R. Arzuaga

Instrucciones: A continuación aparecen una serie de preguntas. Circule la alternativa que mejor describa su respuesta. Utilice el espacio que se provee para contestar aquellas preguntas que necesitan explicación. Para las preguntas 6-10, circule la alternativa que mejor describa cuán de acuerdo o en desacuerdo se siente con cada aseveración.

1. ¿Cuál es su edad? _____
2. ¿Qué relación tiene con la persona con Alzheimer que tiene a su cargo?
 1. Hijo(a)
 2. Hermano(a).
 3. Nieto(a).
 4. Sobrino(a).
 5. Padre/Madre
 6. Esposo(a).
 7. Otra _____
3. ¿Cuál es la edad de la persona con Alzheimer que tiene a su cargo? _____
4. ¿En qué etapa del Alzheimer se encuentra la persona de la que cuida?
 1. Inicial.
 2. Intermedia.
 3. Avanzada.
5. ¿Cuál es el género de la persona con Alzheimer que tiene a su cargo?
 1. Femenino.

2. Masculino.
6. ¿Cómo es el arreglo de vivienda de la persona con Alzheimer que tiene a su cargo?
1. Vive solo(a).
 2. Vive con su cónyuge.
 3. Vive con usted.
 4. Vive en una institución de cuidado.
 5. Otro: _____
- | | | | | |
|---|--------------------------|------------|---------|-----------------------|
| 7. Entendí cuál es el propósito del sistema demostrado hoy. | Totalmente Desacuerdo | Desacuerdo | Acuerdo | Totalmente Acuerdo |
| | 1 | 2 | 3 | 4 |
| 8. Me gustaría utilizar este sistema. | Totalmente Desacuerdo | Desacuerdo | Acuerdo | Totalmente Acuerdo |
| | 1 | 2 | 3 | 4 |
| 9. El sistema se ve fácil de usar. | Totalmente Desacuerdo | Desacuerdo | Acuerdo | Totalmente Acuerdo |
| | 1 | 2 | 3 | 4 |
| 10. Las gráficas del sistema lo hacen visualmente atractivo. | Totalmente Desacuerdo | Desacuerdo | Acuerdo | Totalmente Acuerdo |
| | 1 | 2 | 3 | 4 |
| 11. El acceder y moverse entre los distintos módulos del sistema es complicado. | Totalmente Desacuerdo | Desacuerdo | Acuerdo | Totalmente Acuerdo |
| | 1 | 2 | 3 | 4 |
| 12. El lenguaje utilizado en el sistema es muy complicado para un paciente con Alzheimer. | Totalmente Desacuerdo | Desacuerdo | Acuerdo | Totalmente Acuerdo |
| | 1 | 2 | 3 | 4 |
| 13. La persona con Alzheimer de quien cuido, podría utilizar el sistema. | Totalmente Desacuerdo | Desacuerdo | Acuerdo | Totalmente Acuerdo |
| | 1 | 2 | 3 | 4 |
| 14. No veo en qué el sistema podría beneficiar al paciente de Alzheimer de quien cuido. | Totalmente Desacuerdo | Desacuerdo | Acuerdo | Totalmente Acuerdo |
| | 1 | 2 | 3 | 4 |

| | | | | |
|--|------------|------------|---------|------------|
| 15. No veo en qué el sistema podría beneficiarme. | Totalmente | Desacuerdo | Acuerdo | Totalmente |
| | Desacuerdo | | | Acuerdo |
| | 1 | 2 | 3 | 4 |
| 16. Recomendaría este sistema a otras personas que cuidan de pacientes de Alzheimer. | Totalmente | Desacuerdo | Acuerdo | Totalmente |
| | Desacuerdo | | | Acuerdo |
| | 1 | 2 | 3 | 4 |

APPENDIX C:

FOCUS GROUP MODERATOR GUIDE

GRUPO FOCAL

Grupo focal para evaluar la usabilidad del prototipo de COGPROS, un sistema de computadoras que servirá como una prótesis cognitiva para pacientes de Alzheimer.

Guía de entrevista

Introducción. Bienvenidos y gracias por aceptar nuestra invitación para formar parte de este grupo. Cada uno de ustedes ha sido seleccionado porque sus puntos de vista son importantes para nosotros. Esta entrevista no es un examen, es decir, no existen contestaciones ciertas o falsas. **Luego de ver una presentación del prototipo, queremos que ustedes conversen sobre potenciales beneficios de este sistema. También queremos saber qué del sistema encontraron útil, que piensan que se puede mejorar, que se puede eliminar y que se puede añadir. Esta conversación será utilizada para determinar si las asunciones tomadas en el diseño del prototipo fueron correctas y para informar futuras fases de desarrollo del sistema.**

1. Es muy importante que mantengan la confidencialidad de toda la información que se comparta en este grupo.
2. No es necesario que hablen en ningún orden particular. Cuando tengan algo que decir, por favor compártanlo
3. Por favor, mantengan silencio cuando otra persona esté hablando.
4. Recuerden que es importante que conozcamos el punto de vista de cada una de las personas del grupo.
5. No es necesario que estén de acuerdo con las opiniones o experiencias de las otras personas del grupo; pero deben expresar sus puntos de vista sin hacer comentarios negativos sobre las opiniones de las otras.
6. Tenemos una hora y media para hacer esta entrevista; puede que algunos momentos yo tenga que interrumpirles para redirigir la entrevista. Al final de la entrevista tendremos 30 minutos para hablar sobre aquellos temas que nos gustaría compartir con el grupo y que no son parte de la entrevista.

Agrademos mucho la disponibilidad de ustedes para participar en este grupo.

Lo/as facilitadores se presentan. Se les explica el rol de la/os facilitadores y la/os observadores en el grupo

Preguntas Guía.

1. Ahora queremos que nos digan quiénes son y nos hablen un poco sobre la persona con Alzheimer por quien asisten a este grupo.

a) ¿En qué etapa de la enfermedad se encuentra?

2. Demostración del sistema.

3. ¿Han escuchado sobre los tipos de tratamientos mencionaron durante la demostración?

a) Prótesis cognitiva.

b) Terapia de reminiscencia.

c) Orientación a la realidad.

4. ¿Piensan que este sistema sería útil para ustedes o sus familiares?

5. Módulo de tareas

a) ¿Que les gusta?

b) ¿Que no les gusta?

c) ¿Que falta?

d) ¿Que es innecesario?

e) ¿Que cambiarían?

f) ¿Que harían diferente?

6. Módulo de manejo de medicamentos

a) ¿Que les gusta?

b) ¿Que no les gusta?

c) ¿Que falta?

d) ¿Que es innecesario?

e) ¿Que cambiarían?

f) ¿Que harían diferente?

7. Módulos de orientación en tiempo, espacio, y persona

- a) ¿Que les gusta?
- b) ¿Que no les gusta?
- c) ¿Que falta?
- d) ¿Que es innecesario?
- e) ¿Que cambiarían?
- f) ¿Que harían diferente?

8. Módulo6s de comunicación

- a) ¿Que les gusta?
- b) ¿Que no les gusta?
- c) ¿Que falta?
- d) ¿Que es innecesario?
- e) ¿Que cambiarían?
- f) ¿Que harían diferente?

9. ¿Qué otras funciones le gustaría ver en el sistema que piensan serían de utilidad para ustedes o sus familiares?

10. De acuerdo al nivel de la enfermedad de su paciente, ¿cuáles módulos podrían ser útiles

- a) ¿Cuáles no?
- b) ¿Qué cambios (si alguno) recomendaría?

11.¿Tienen alguna recomendación que nos ayude a mejorar esta entrevista?

Se reparte el cuestionario. (Ver cuestionario en documento aparte).

APPENDIX D:

FOCUS GROUP PARTICIPANT CONSENT FORM



Universidad de Puerto Rico
Programa de Maestría en Ingeniería de Computadoras

Hoja de Consentimiento Informado Para Participar en Investigación

El programa graduado de Ingeniería de Computadoras de la Universidad de Puerto Rico les solicita a sus estudiantes llevar a cabo una investigación como parte de los requisitos para obtener el grado de maestría. Es por esto, que solicito su asistencia para participar en este estudio. Sin embargo, antes de que decida si va a formar parte del estudio, quiero explicarle el propósito, los procedimientos del mismo y otros asuntos pertinentes a su participación.

Propósito

El propósito de este estudio es evaluar la usabilidad del prototipo de un sistema de computadoras diseñado para asistir a pacientes de Alzheimer y a sus cuidadores. La información que usted nos provea es muy importante porque ayudará a los investigadores a entender maneras en las cuales este sistema puede ser de utilidad, así como áreas de oportunidad para mejorar el mismo. De esta manera, el sistema podrá ser desarrollado de manera que atienda aquellas necesidades más salientes en el día a día de los pacientes de Alzheimer y de quienes los/as cuidan. En general, su participación es valiosa y nos ayudará a entender y mejorar la calidad del sistema de manera que sea de provecho para las personas afectadas por esta condición.

Participación

Su participación en este estudio es voluntaria. Antes de decidir si participará en la investigación debe entender el propósito y los procedimientos de la misma. Luego debe firmar esta hoja de consentimiento aceptando participar en el estudio. Se le proveerá una copia de esta hoja para que la tenga en su poder. Usted puede decidir no participar o abandonar el estudio en cualquier momento, y esto no afectará los servicios que obtiene en estas facilidades. Si decide participar esto no significa que tendrá más beneficios.

Procedimientos

Su participación consta de reunión junto con otros 12 participantes. Durante esta reunión a usted se le dará una demostración del sistema de computadoras. Luego de ésta, usted podrá dar: (1) su opinión sobre el impacto que un sistema como éste tendría en su vida, (2) su opinión sobre las funciones del sistema y (3) recomendaciones sobre como mejorar estas funciones o como añadir funciones que usted piensa sería de utilidad. La entrevista durará aproximadamente 90 minutos y será grabada en audio. Usted no será identificado(a) y no está obligado(a) a contestar todas las preguntas, pero esperamos su participación activa.

La audio grabación será transcrita para propósito de análisis y evaluación. La grabación será destruida una vez se haya transcrito.

Riesgos o Molestias

Los riesgos por participar en este estudio son mínimos, ya que no se conocen ni se anticipan riesgos por contestar preguntas. No obstante, ciertas preguntas podrían causarles molestia a algunas personas. Si esto le sucede, o se siente incomoda o preocupada puede dirigirse a los investigadores, ya que éstos están capacitados para manejar dicha situación.

Beneficios

Usted no obtendrá ningún beneficio directo o inmediato por su participación en esta investigación. Sin embargo, usted y otras personas puede que se beneficien en el futuro de los resultados obtenidos en este estudio.

Confidencialidad

Toda la información provista por usted será confidencial hasta donde está permitido por la ley. Su participación permanecerá en anonimato, ya que ninguna forma tendrá su nombre. En la transcripción de la audio grabación, a usted se le identificará con un código, y su información personal no será divulgada a menos que usted así lo autorice por escrito. Al momento de presentar o publicar los hallazgos del estudio, usted no será identificada personalmente.

Preguntas o Dudas

De surgir algunas preguntas o dudas adicionales relacionadas con este estudio, usted se puede comunicar con el investigador al teléfono (646) 248-2775.

Firmas

Al firmar este documento certifico que todas las preguntas sobre el estudio se me han sido contestadas satisfactoriamente. Entiendo que se me entregará una copia de esta hoja de consentimiento. Mi firma en esta hoja certifica que he leído este documento o el mismo se le fue leído y explicado. Yo entiendo la información y consiento a participar en el estudio voluntariamente.

Firma del Participante

Fecha

Firma del Investigador

Fecha

APPENDIX E:

FOCUS GROUP TRANSCRIPT

Transcript of Focus Group on Cogpros : A Cognitive Prosthesis Prototype for Alzheimer's Disease Patients May 26th, 2012 – Aguada, PR

Facilitators:

9. Dr. Glorianne Vázquez – Moderator

10. José Arzuaga - Note-taker

Transcript

| Person | Discussion |
|-------------|---|
| Dr. Vázquez | <p>Bienvenidos y gracias por aceptar nuestra invitación para participar en este estudio de investigación. El propósito de este grupo es explorar la utilidad de el prototipo de una prótesis cognitiva para facilitar el cuidado de pacientes de Alzheimer. Cada uno de ustedes ha sido seleccionado porque sus puntos de vista son importantes. Esta entrevista no es un examen. Tampoco existen contestaciones correctas o incorrectas. El propósito, es hacer una serie de preguntas para que todos conversen sobre como este programa de computadoras podría facilitar el cuidado de su familiar con Alzheimer. Esta conversación será grabada y utilizada para propósitos de investigación únicamente. Todos ustedes poseen las mismas características: familiares de un paciente de Alzheimer. Todos nosotros debemos mantener la confidencialidad y la privacidad de toda la información que se comparte en este grupo. Esto es bien importante tenerlo claro. Todos nosotros nos comprometemos a mantener el derecho a la privacidad de la información y de los seres humanos.</p> <p>Les recuerdo los siguientes puntos importantes:</p> <ul style="list-style-type: none">4. La entrevista durará aproximadamente 60 minutos.17. La facilitadora del grupo es responsable de dirigir la discusión y hacer las preguntas necesarias para el estudio de investigación.18. Entre nosotros se encuentra también José Arzuaga, quien presentará el programa de computadoras en un momento. Durante la conversación, el Sr. Arzuaga estará tomando notas y ofreciendo información adicional el proyecto de investigación.19. Para propósito de la entrevista y la transcripción de la misma, se le asignaran nombres ficticios, de manera que ninguno de ustedes pueda ser identificado por su nombre real.20. Antes de comenzar la entrevista, le pedimos que apague su celular y evite salir durante la duración de la misma. |

| Person | Discussion |
|---------------------------|--|
| Dr. Vázquez, Continued | <p>21. No es necesario hablar en ningún orden particular.</p> <p>22. Conteste a todas las preguntas posibles.</p> <p>23. Por favor mantenga silencio mientras otras personas hablan.</p> <p>24. Si siente alguna molestia durante la entrevista o se siente incómodo favor de notificarlo de inmediato a la facilitadora.</p> <p>25. No es necesario esté de acuerdo con las respuestas de las personas aquí presentes. Exprese su opinión libremente.</p> <p>26. No hagamos comentarios negativos sobre la opinión de las personas o sus respuestas.</p> <p>27. Al finalizar la entrevista, habrá una sección de 10 minutos para que pueda expresar libremente cualquier tema u ofrecer recomendaciones sobre la entrevista.</p> |
| Dr. Vázquez | Ahora vamos a comenzar, con la presentación del programa de computadoras por el Sr. José Arzuaga. |
| José Arzuaga | <p>Mi nombre es José Arzuaga y soy estudiante de maestría de la Universidad de Puerto Rico en Mayagüez. La idea que tuve para mi proyecto de maestría fue crear lo que llamamos una prótesis cognitiva que pueda ayudar tanto al cuidador como al paciente de Alzheimer a manejar sus actividades del diario vivir. Primero que todo, quiero agradecerles que hayan sacado el tiempo para estar aquí, al yo no ser paciente o cuidador de pacientes de Alzheimer, hice ciertas suposiciones de que podría ser útil para ustedes en este sistema pero estas cosas no son necesariamente ciertas y necesito entonces la opinión de ustedes para que me ayuden a decir, "mira, esto aquí funciona, esto otro no funciona, esto puede ser mejor..." y así yo puedo hacer un software de mejor calidad. Esto que les voy a enseñar hoy es solo un prototipo, con este mismo propósito, para poder enseñárselo a las personas y que me den su opinión para así mejorarlo.</p> <p>Básicamente, lo que yo traté de hacer fue incorporar diferentes terapias que se han estado usando para manejar el Alzheimer, como la orientación a la realidad y la terapia de reminiscencia, en esto, para que los pacientes lo puedan utilizar de manera que se puedan mantener orientados en tiempo, espacio, y persona, y también puedan tener un flujo de recuerdos que los puedan ayudar a mantenerse al tanto de estas cosas que son tan difíciles de agarrar. A veces uno tiene las cosas en la punta de la lengua y no las puede sacar del lugar donde lo tiene en la memoria. Yo hice una investigación bastante exhaustiva de artículos científicos sobre este tema y pues, extraje, cosas que se le podían añadir a este sistema.</p> |
| José Arzuaga | -Presentación de sistema- |
| Dr. Vázquez | Como dijo José, ya les presentó el sistema. Esto es un prototipo, verdad. Y entonces ahora queremos saber cuál es su opinión, porque ustedes son los expertos. Ustedes son los que están cuidando de lleno a estas personas y pues, nosotros tenemos cierta experiencia personal pero ustedes son los que ahora están haciendo esto y queremos saber que piensa. Él asumió ciertas cosas, leyó la teoría y en base a eso diseñó el programa pero esto está en la primera fase y este tipo de diálogo nos ayuda a informar |

| Person | Discussion |
|--------------|--|
| | las próximas fases. Queremos saber qué encontraron útil, qué les gustó, y ya veo que ustedes son un grupo bien formado así que no tenemos que comenzar con reglas de grupo, pues veo que ya saben de mantener todo en confidencialidad, de hablar uno a la vez, de respetar las opiniones, así que, lo mencioné brevemente pero de verlos ya veo que son así. Vamos comenzar el diálogo, díganme lo primero que les venga a la mente en cuanto a en qué puede ser útil. |
| Fabiola | Esto es para, lo puede manejar la misma persona cuando está en sus comienzos, cuando todavía están conscientes para usar esas cosas porque por ejemplo en mi caso yo conozco más de una persona que están caminando, que se pierden, o que se han perdido, pero un sistema así, no se, digo, a lo mejor, no lo pueden usar. |
| Dr. Vázquez | Eso es lo que se tiene pensado, verdad? Que el sistema sea tanto para personas que tengan la condición en las primeras etapas o sino, para los cuidadores cuando las personas ya están en etapas avanzadas. |
| Jose Arzuaga | Exacto. Según lo que dice la literatura y las investigaciones, aún en etapas bastante avanzadas, ciertas cosas, como ver fotos, música de tiempos pasados, recuerdos, estas cosas ayuda también a manejar el stress en pacientes de Alzheimer, y aunque uno no vea una mejoría, si ayuda a manejar otros síntomas como la ansiedad, la agresión y la depresión en el paciente de Alzheimer, y estas cosas serían beneficiosas. Cosas como el listado de tareas, el directorio de teléfonos, y la mensajería son cosas que necesitan una habilidad cognitiva mayor, en cambio estas cosas, así como el manejador de medicamentos, son cosas que el cuidador si podría usar para recordarse de recordarse de dar los medicamentos. |
| Pedro | Una preguntita. Lo que pasa es que mucha gente no tiene computadoras en las casas. Ese es el problema más grande que hay. Y si no tienen eso en la casa, es difícil llevarlos a otro lugar. Ese el problema más grande que hay. |
| Jose Arzuaga | Uno de los estudios que leí, hace algo parecido a esto pero en vez de usar una computadora, lo hace con una cartulina, entonces tiene en esa cartulina, o en una pizarra, todos los días con la fecha del día, la temporada, la temperatura, y entonces le pegan fotos de las personas, tienen una parte de la pizarra para manejar los medicamentos, y cosas así. Es un poquito más rústico en el sentido de que no está usando la computadora, pero se ha visto que es muy útil, tanto para el cuidador recordarse de las cosas que tienen que hacer y las tareas que tiene que hacer con el ser querido que está cuidando, como para el paciente, que puede ver y tener esa estimulación visual por ejemplo con las fotos de sus familiares y cosas por el estilo, y eso es una alternativa que se puede usar ante el no tener una computadora. |
| Luz | Mira, esto me recuerda a mami, que mami cuando ella se sentía así pues, así pues un poquito curiosa, muchas veces que lo empezaba a hablar de las cosas de antes y de las fotos, y le decía, "mami, enseñame las fotos de cuando tu eras joven" y ella como que cambiaba iba, y sacaba su álbum de fotos y empezaba, "esta era yo, mira que bien yo me veía" y entonces pues eso como que la hacia ponerse feliz. |
| Dr. Vázquez | Yo creo que esto está relacionado a los tipos de terapia que Jose mencionó, y también queríamos verificar si han escuchado estos términos. Lo de las prótesis cognitivas, no |

| Person | Discussion |
|--------------|--|
| | se si han escuchado este término. |
| José Arzuaga | Exacto, esto sería una prótesis cognitiva. Me imagino que han escuchado lo que es una prótesis, que si una persona pierde un brazo, o pierde una pierna, pues le ponen un sustituto. Una prótesis cognitiva es exactamente eso, un sustituto, pero de las funciones cognitivas de la persona. Por ejemplo, yo tengo problemas con la memoria, pues esta prótesis cognitiva me ayuda a recordarme de cosas que si tenerla no me recordaría. Me puedo recordar de eventos, los cumpleaños de mis hijos por ejemplo, de las tareas que tengo que hacer, de las citas a las que tengo que ir, y pues estos vendría siendo una prótesis cognitiva que es lo que estamos tratando de evaluar aquí. |
| Don José | Yo conozco de una aplicación para teléfonos que utiliza el GPS para localizar al paciente de Alzheimer en momentos de emergencia o de estar perdido y le dice al cuidador donde se encuentra el paciente. |
| José Arzuaga | Ese ejemplo es un tipo de prótesis cognitiva y básicamente parte de una rama que usa la tecnología para aplicarlo a la medicina y ciencias del comportamiento y a esta le llaman tecnología asistiva y todo esto está dentro de la rama de tecnología asistiva y eso es lo que vendría siendo este tipo de aplicación. |
| Dr. Vázquez | Y es verdad, el punto que usted estaba trayendo, que no todos tenemos computadoras, o el conocimiento de como usar una computadora pero yo creo que ahora las cosas en la computadoras, con los iPads, como que son más grandes. |
| Saul | Si, más cómodos. |
| Dr. Vázquez | Si, más cómodo para aquellos que se les hace difícil el “typing” en el “keyboard”, pero yo creo pensando a ver, y esto sería algo medio utópico, pero si en un futuro, el mismo gobierno pudiera patrocinar este tipo de proyecto y proveerle a los cuidadores. |
| María | Esto yo lo interpreto como que, no es que sea, es actual, verdad? Y es una necesidad. Lo que pasa es que una población como la nuestra no está entendida de esto, pues, nuestros enfermos, pues, no todos están en estos niveles, este, no son cibernéticos, y yo me cuento entre ellos, yo soy una jibara de Añasco, pero esto entonces, hay que tratar de ver cómo nos ayudamos. Siempre va a ver, que buscar las rutas, y ser valiente para utilizar estos sistema, así como los que los jóvenes. Y ver como se incorporan estos programas que de alguna manera nos hacen visualizar, porque estos es algo más palpable por que esta ahí a la vista y esto mucho ayudaría, y hay que valerse de estos recursos externos y hay que moverse hoy en día en muchos respectos porque habrán quienes no tendrán nietos, no tendrán hermanos, no tendrán parientes, pero de alguna manera buscan la ayuda de otros y hay que moverse entonces a pedir ayuda. |
| Dr. Vázquez: | Si, eso es un buen punto. Ahora queríamos enfocarnos en los módulos que José presentó. Tiene cuatro módulos, verdad? |
| José Arzuaga | Tiene el de orientación en tiempo, espacio y persona, que tiene tres componentes. Tienen el manejador de tareas, el módulo de medicamentos, y el directorio telefónico y de mensajes. |
| Dr. Vázquez | Exacto. Así que, enfocándonos en cada uno de esos módulos. Vamos a comenzar con el de manejo de tiempo. Qué les gusta? Qué no les gusta? Qué hace falta? Qué es |

| Person | Discussion |
|--------------|--|
| | innecesario? Cómo lo cambiarían? Qué piensan? |
| Todos | Si. |
| María | Siempre están preguntado. |
| Todos | [Risas]. |
| Luz | Sí, ellos siempre están preguntando "Qué día es hoy? Qué hora es?" |
| Todos | Ajá, ajá. |
| María | Si. y la hora, el tiempo. |
| Todos | [Risas en acuerdo]. |
| Dr. Vázquez | Y entonces, en cuanto al módulo de manejo de medicamentos. |
| Felix | Ese estuvo bueno. |
| Manuel | Eso me gustó. |
| Dr. Vázquez | Algo que le añadirían, que creen que le hace falta |
| Fabiola | Si, por que a veces a ellos se le pasan las horas y no se toman los medicamentos. Es muy útil. |
| Dr. Vázquez | Entonces el otro, el módulo de tareas que se presentó que enseña los pasos de como hacer una tarea. Qué piensan de ese módulo? |
| Zoraída | Me gusta como se ve visualmente cuando va cambiando y va presentando una a la vez porque a mi me confunde cuando los enseña todos, yo me pierdo. Pienso que sería mejor enseñarlas una por una con el nombre. |
| Dr. Vázquez | Y piensa que sería una por una mejor como en foto on en un video. |
| Zoraída | En foto. Que sea paso por paso. |
| Dr. Vázquez | Entiendo, si, que sea paso por paso. Entonces el otro módulo es el de comunicación. Qué piensan de este módulo, que tiene los teléfonos personales, de la persona, de la familia, de los médicos, también de recursos en la comunidad? Piensan que le hace falta algún otro número, alguna otra función? |
| Pedro | Eso está conectado al teléfono? |
| Dr. Vázquez | Si, esto estaría conectado al teléfono de su casa y usted hablaría a través de las bocinas y el micrófono de la computadora. |
| María | Me gusta que tienen los números de los familiares y los médicos. |
| Don José | Una cosa, en el directorio, los números están subdivididos? |
| José Arzuaga | No, no están subdivididos. |
| Don José | Podrían estar subdivididos por los familiares, y uno que es bien importante es los médicos, que si el urólogo, el ginecólogo, y los otros son los de emergencia. En el módulo de medicamentos, yo fui hace poco a una charla sobre farmacología, un tema que no se da mucho. Las medicinas se ven muchas iguales, pero con diferentes características, y algunas no se pueden machacar. Cuando uno machaca una medicina, |

| Person | Discussion |
|-------------|--|
| | uno tiene que saber cuál, algunas pierden efectividad, hasta un 10%, y si tu le das la medicina en una batida, si se la está tomando pero no le hace nada. Eso sería una sugerencia para el sistema, pero la información se la tenemos que dar nosotros. Sería interesante mostrar "warnings" sobre con que se puede tomar y con que no se puede tomar. Otra cosa es el efecto de varios medicamentos. Por ejemplo, yo soy cardiólogo y receto esto, "pero pérate, ese medicamento no se puede tomar con este otro que me recetó otro médico." |
| Dr. Vázquez | Entiendo. Se refiere a las contraindicaciones? |
| Don José | Claro, eso, y si queremos manejar bien los medicamentos tenemos que hacerlo así. Por ejemplo, si el médico pregunta cuáles son los medicamentos que está tomando el paciente? Pues están ahí, todo eso está ahí en la aplicación, pero falta más información de los medicamentos, para que sea más útil. |
| Dr. Vázquez | ¿Algo más que quisieran añadir, algún comentario acerca del grupo? Les agradezco la oportunidad, les agradezco la confianza que nos dieron y la apertura, y la forma en que fluyo el grupo. Así que de parte del equipo le damos muchas gracias. |
| Todos | No. |
| Dr. Vázquez | Les agradezco la oportunidad, les agradezco la confianza que nos dieron y la apertura, y la forma en que fluyo el grupo. Así que de parte del equipo le damos muchas gracias. |
| Todos | Gracias a ustedes (Comenzaron a aplaudir). |