Design of Mobile Application Prototype for the care and monitoring of patients with Multiple Sclerosis

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Abstract

Multiple sclerosis is a degenerative neurological disorder that represents the leading cause of disability in young adults. Their diagnosis has a tremendous emotional impact and a significant effect on the lives of those affected and their families. The advancement of communication networks, the rapid growth of mobile technologies, and the development of Artificial Intelligence have sparked interest in developing digital health advisors and conversational agents as virtual therapists. Some studies show that there are more than 100,000 health applications. However, while some of them have been popular for certain features they offer, they do not meet the individual needs of patients with Multiple Sclerosis. In this article, User-Centered Design is considered an essential factor for the design of any product. The stages proposed by the ISO 9241-210: 2019 are implemented to design a conversational agent, as Digital Health Advisor, aimed at patients with Multiple Sclerosis and caregivers. It will also serve as a source of information for all users, present in the social environment of patients.

Keywords

Mobile application prototype, User-Centered Design, Digital Health Advisor, Conversational Agents, Multiple Sclerosis

1. Introduction

Multiple Sclerosis (MS) is a degenerative, chronic, autoimmune, and inflammatory disease that affects the central nervous system. Although the causes of its origin are still unknown, several theories have been formulated regarding its multifactorial nature, involving the interaction of environmental situations and the genetic and immunological susceptibility of each individual as factors that induce an autoimmune response and promote neural degeneration [1].

In the world, it affects more than 2 million people and represents the first cause of disability in young adults, since its maximum peak occurs around the age of 25, although cases can be found in children and older adults [2].

In Mexico, according to a 2014 study, between 11 and 20 people per 100,000 inhabitants suffer from the disease; which represents approximately 20,000 patients throughout the country. These numbers vary according to latitude, being higher in the north of the country: in Chihuahua, 12 per 100,000 inhabitants; in Nuevo León, 30 per 100,000, and in the Federal District, 10 per 100,000 [3].

In recent years, the prevalence of Multiple Sclerosis has been increasing and it occurs more frequently in women than in men, in the case of white people, it affects 1 per 1000, maintaining the ratio 2: 1 associated with sex [1, 3].

The symptoms of MS can vary depending on the areas of the central nervous system affected. The most frequent clinical manifestations include: *paralysis, ataxia, tremors, weakness, tingling, visual*

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problems, loss of strength or sensitivity, short-term memory problems, and urological alterations, among others [3].

Although to the date there is no cure, significant progress has been made in treatments to reduce symptoms, managing to contain the evolution of the disease with early interventions through the use of certain drugs, however, the sequelae of the disease are irreversible [4].

Coinciding with the most productive stage of a person, the diagnosis of multiple sclerosis has a great emotional impact and a significant impact on the lives of affected patients and their families, since it implies a strong investment of resources (such as financial, time, efforts, among others). Additionally, the unequal incidence and prevalence between the different sexes and the loss of functionality caused by the progression of the disease force family members to rethink gender roles, causing a clash with traditional gender stereotypes, which are not always accepted by society and produce dissociation and discomfort in the people affected [4, 5].

Due to the non-lethal nature of the disease and its appearance in the early stages of adulthood, patients with multiple sclerosis require support and care from their environment, the socio-health system, and society in general [4].

New technologies have had a direct impact on all areas of life. In the field of health, we find concepts such as *connected health*, *eHealth*, *telehealth*, *telemedicine*, and *mHealth*, which refer to the use of health technology to provide medical care to patients remotely. In this sense, and due to people's interest in monitoring their physical condition, there is a trend toward the development of devices for monitoring blood pressure and heart rate, diabetes control, thermometers, weights, and, to a greater extent, fitness, diet and activity trackers [6].

The advancement of communication networks, together with the growing production of devices and the development of Artificial Intelligence, have laid the foundations for the use of *Digital Health Advisors* (DHA) that allow the collection and interpretation of patient data as well as monitoring their health status, personalize treatment plans, share information with the care team, and provide reminders and alerts about medication and appointments with medical staff. However, there are still barriers to its development [7].

Another current trend in the field of medicine has been the use of *conversational agents*, also called *chatbots* or *voicebots*. The use of chatbots as virtual therapists constitutes a source of support for professionals in the detection, diagnosis, and treatment of various depressive disorders. Conversational interfaces help improve and expand access to mental health services where demand exceeds supply and there are difficulties in some rural communities to access these services [8, 9, 10].

Carried out studies have shown that there are more than 100,000 applications for health. However, there is a great fragmentation between them regarding the cost barrier that affects the access by users, and the limited clinical functionality by not considering the specific needs of patients with different levels of the disease, among others [7, 11]

In the last ten years, specific applications for patients with MS have been developed, such as *Cleo MS health & wellbeing app, Emilyn, Lumosity*, and *Be Focused*. However, while they have had some popularity, they suffer from the same access and functionality limitations as similar apps designed for other chronic conditions.

The present work takes the User-Centered Design, defined in the ISO9241-210: 2019 standard [12], as the basis for designing a digital health assistant oriented to patients with MS and caregivers. The assistant will benefit from the potential of voice assistants and use Machine Learning techniques to analyze user needs and act accordingly. It will also serve as a source of information for all users, present in the social environment of the patients.

2. Materials and Methods

The design of user interfaces has gone through a long evolutionary period, from Command-Line Interfaces, Graphical User Interfaces present in all products, 3D User Interfaces present in video games, to Augmented and Virtual Reality interfaces that combine uniquely our physical and digital worlds. Although in the past humans had to learn the language of computers to interact through a console, today, and thanks to Natural Language Interfaces, it is the computers that have learned to speak the user's language [7].

The constant innovation in interface design, together with the growing interest in increasing usability by improving the interaction between man and machine, has triggered the emergence of a design discipline known as User Experience (UX). Currently, UX designers face multiple challenges leading to a change in design approaches. Which have been transformed from *focused on technology* to *focused on the experience of the interaction with the technology*.

These new approaches that place the human at the center of design have become the basis for how new interfaces and user experiences are conceived and developed.

2.1. User-Centered Design

User-centered design (UCD), according to the ISO9241-210:2019 standard [12], is a process that involves users in the different stages through which the design and development of a given product go. The term was keyed in the 1980s by Donald Norman [13], who proposed guidelines to follow, to achieve good usability results when designing user interfaces.

The primary goal of UCD is to increase the ease of use of a product to create maximum user satisfaction and increase performance [6]. Figure 1 shows the user-centered design process defined in ISO 9241-210:2019 standard.



Figure 1: Stages of User-Centered Design defined in ISO 9241-210:2019 standard.

2.1.1. Identification of the context of use

Understanding users, their desires, motivations, principles, and intentions is essential to good design. In these stages are identified: system's users, conditions, and application context as well as user requirements.

Access to users in the field of health is complex, even more, when it comes to patients with Multiple Sclerosis, as it is a rare disease. In this scenario, it is convenient to use user representations through the *Persona* technique.

In this case, the Persona technique allows us to represent the needs of groups of real users from profiles of fictitious characters that must include details such as *name*, *age*, *marital status*, *location*, *occupation*, *tastes*, *hobbies*, *motivations*, *needs*, and *frustrations*[14, 15].

To determine the profiles, an extensive documentary review was carried out: *publications on social networks, interviews*, and *life stories* of patients with MS, available on the websites of foundations and charitable institutions. A total of 110 samples² were analyzed and processed using the text analysis technique: *Tagging*, which made it possible to obtain ethnographic data from patients with MS around the world and to identify their main needs, motivations and frustrations.

The needs of patients with MS were characterized by their intersection with the dimensions, defined by [7], which considers *functional*, *emotional*, *medical*, and *personal* needs.

² Taken from Multiple Sclerosis Foundation website and correspond to interviews with patients who have managed to cope with the disease.

2.1.2. Specification of requirements

At this stage, the user requirements are determined. The needs, objectives, and the organizational and use requirements of the product are identified taking into account the context of use [12].

A review of the most widely used existing applications in the context of MS was carried out in order to select a sample for analysis. The selection was made taking into account the following parameters:

- **Functionality:** it refers to the main function for which it was designed: *digital advisor*, *reference app, training, social, utilitarian,* or/and *appointment scheduler*.
- **Purpose:** whether the app was created specifically for MS or general purposes.
- Audience: refers to the types of users it is aimed at: *patients*, *caregivers*, or *health professionals*.
- Availability: refers to the availability to be downloaded by users on the most used mobile platforms (Android and IOS), multi-language support, and its monetary cost.
- **Rating:** evaluation metric based on three indicators: *number of downloads, rating,* and *number of reviews.*

For the diagnosis, the Survey technique was used. Using Google Forms, an online questionnaire was generated consisting of 12 questions addressed to identify which of the medical applications found are being used in the context of MS, knowing the opinion of patients regarding the support provided by the use of these apps, the perception regarding the need for new apps and the identification of those functionalities that they consider necessary to cope with the disease.

For the preparation of the questionnaire, were taken into account the characteristics of DHA for patients with chronic diseases, defined by [7], which are directly related to the main needs of patients with MS: *to provide information and to facilitate communication*.

To identify the information about MS that users consider most important, three indicators were defined: *information about the disease, information about treatments*, and *information about diets and lifestyles*. Similarly, the functionality facilitating the communication was evaluated based on the indicators: *communication with specialists, communication with patients*, and *communication with people who share tastes and affinities*.

Open-ended questions were used to identify other functionalities of the DHA that are considered necessary by users.

The questionnaire was made available to people suffering from MS through the group "Esclerosis Múltiple sin distinción" and the page "Esclerosis Múltiple México" on Facebook. Data corresponding to a sample of 19 users was processed.

2.1.3. Production of the design solution

To produce design solutions, the tasks that the user will perform, and their interaction with the system and the interface, must be planned taking into account the entire experience and the meet of user requirements. The design must be concrete and modified based on the feedback obtained from the user evaluation. Designing user interactions involves making decisions about how the users will complete system tasks rather than describing what the interface will look like [12].

In this sense, low fidelity prototypes are a very useful tool as they focus on showing a vision of the design aligned with the needs and objectives of the user instead of producing interactive screens [16].

In this stage, the different User Interface (UI) patterns present in the most used applications for MS that were analyzed. Additionally, were analyzed the interaction patterns in DHA and chatbots implemented in the most used platforms for communication and socialization such as: *Whatsapp*, *Telegram*, *Instagram*, and *Facebook*.

The prototypes were designed using the free tools: draw.io and Invision Studio.

The digital prototype was made available to the members of the group "Esclerosis múltiple sin distinción" to carry out the first evaluation to check if the design met the user's requirements.

2.1.4. Design evaluation

Evaluation is one of the most important stages in any process. Despite the existence of ergonomic design guides that provide useful support to designers, the evaluation of a product from a usability point of view is an essential element to obtain designs that meet user requirements. User-centered evaluation allows design improvement by providing feedback on the strengths and weaknesses of the design solution from the user's perspective [12].

Due to the clinical manifestations of the disease present in patients that make it impossible for them to move and the restrictions associated with the pandemic, it has not been possible to carry out usability tests to evaluate the designs and obtain feedback based on the experience of use by patients.

3. Results

With the implementation of the User-Centered Design process, were identified the main user's needs, also, a prototype of the mobile application to support and follow up with patients with MS was designed. This section shows the results obtained with the implementation of each stage.

3.1. Identification of the context of use

In this first stage, the needs of the patients were identified: *knowing about existing treatments, diets, and lifestyles, communication with other people, emotional support,* and *communication with specialists,* among others (See Figure 2). These needs were organized around four axes that represent the dimensions associated with needs: *functional, emotional, medical,* and *personal* (See Figure 3).



Figure 2: General user needs observed in the analysis.

There were identified two main types of users: *Patients* and *Caregivers*. Also, was added a third group: *Others*, which includes those users who are part of the patient environment and society in general: *friends*, *family*, and *co-workers*, among others. Figure 4 shows the general description of People belonging to the different groups.



Figure 3: User needs grouped around the dimensions: functional needs, emotional needs, medical needs and personal needs.



Figure 4: General description of User Persona profiles.

3.2. Specification of requirements

The results obtained from the processing of the 19 samples revealed that 58% of the respondents have not used the medical applications on the market, and 41.18% have used *Emilyn*, *Doctoralia*, *Luminosity*, and *Cleo* is the most used (See Figure 5).



Figure 5: Information about the users surveyed and the use of medical applications by them.

Patients who have used mobile applications evaluated, on a scale of 1-5, their perception of the level of support provided by the app used and, although they consider that the apps have been of little help, 95% show a positive opinion in respect to the need for apps that provide support for living with MS (See Figure 6).



Figure 6: Criteria on the perception of the utility of the applications used and the need for new medical apps for MS.

Through a Liker Scale, it was possible to know the level of importance attributed by the patients to the functionalities of a DHA for MS. Considering the scale from 1 to 5, with 4 and 5 being the values that represent the highest levels of importance, it was obtained the following results.

Regarding the functionality of the DHAs as a source of information about MS, 84% consider that it is very important to provide information on the disease, 84.2% grants importance to information related to existing treatments, while 89% think that it is very important to be informed about diets and lifestyles, among others (See Figure 7).



Figure 7: Information that an app must provide in the context of the MS.

About the functionality of facilitating communication that characterizes a DHA, 84% of users think that, to serve as support for patients with MS, a DHA must facilitate communication with other patients, the 73.7% sustain that it is very important to favor communication with people who share tastes and affinities, and only 57.9% attribute importance to communication with specialized personnel (See Figure 8).



Figure 8: Communication options that an MS app should provide.

As a result of the diagnosis, it was possible to verify the needs of the patients found in the context specification stage. Additionally, there were identified other functionalities of the DHA that constitute medical-functional needs of patients, such as the ease of *managing reminders for the consumption of medications*.

3.3. Production of the design solution

Based on the characterization of the users, the identification of their main needs, and the analysis of the interface and interaction patterns of the applications they use most frequently, the main characteristics of a DHA for patients with MS were defined (See Textbox 1) and, a first low-fidelity prototype was designed (See Figure 9).

Textbox 1 Essential features of a DHA for patients with MS and their caregivers.

Information and monitoring:

- The application detects moods through the analysis of voice and/or text commands.
- Advice on health-related issues through integration with a digital assistant.
- Recommendations to patients based on their mood.

User overview:

- A patient profile that provides a brief picture of the patient, their history, and a set of goals and milestones they want to achieve.

Coordination and personal management:

- A shared calendar with medical appointments, and recommended activities, among others.

- A personal calendar with medication schedule reminders.

The prototype features a main screen and a notification panel. For the design of the interface, several criteria were taken into account: minimalist design, functionality easy to identify, and easy to remember by users.



Figure 9: Main sections of the low fidelity prototype created using the tool: draw.io.

Figure 10 shows the interaction sequence with the chatbot on the main screen. The menu sections: *Mis Recordarios* and *Mis Consultas* were not implemented in this first version.



Figure 10: Basic interaction sequence

By using the tool *Invision Studio*, the prototype was provided with some basic functionality to evaluate its design. Figure 11 shows the sequence of screens of the functional prototype.



Figure 11: Working prototype implemented using the tool: *Invision Studio*. Available at https://bit.ly/36mCU2K.

The functional prototype was made available to patients with MS through the group "Esclerosis múltiple sin distinción", and a first exchange was carried out to obtain feedback regarding if it met the user's requirements.

In general, the users agreed that the interface of the digital prototype was very intuitive and easy to use. Observations and comments mainly focused on changes around:

- The colors used: the dark background and also the notification icon and the toggle writing/audio icon are almost invisible.
- Improve the interaction of the Record button as not all users speak at the same speed and the recording ends automatically after 10s.
- The possibility of having a history of conversations with the chatbot.

Finally, based on the suggestions made, a second prototype was designed (see Figure 12) where the main screen was modified to show the conversation history to the user, and the recording button was replaced by two controls: text input and a record button to let the user decide the interaction method with the chatbot. Regarding the colors, since it is a very subjective topic, once the app has been implemented, the interface will assume the colors of the theme used by the user on their mobile device.



Figure 12: Prototype main screens with improvements included.

4. Conclusions

Digital health advisors, together with the potential of conversational agents as virtual therapists, constitute a necessary tool for supporting patients with MS. However, the available solutions do not meet the individual needs of users.

With the implementation of the User-Centered Design, a mobile application prototype was designed that constitutes an alternative for the care and support of patients with multiple sclerosis. Through the first interaction with users of the prototype, it was possible to verify that the prototype meets the main requirements of users: obtain information about the disease and have communication channels with other patients, and people having similar tastes or opinions, among others.

The comments provided by the users allowed us to detect deficiencies in the interaction with the chatbot. Also, were identified new patient needs such as: *keeping the conversation history* and *medication management*.

Once the conditions associated with the pandemic have been normalized, it is intended to carry out a final evaluation of the prototype from the point of view of usability tests.

Regarding the final product, it is desired to incorporate machine learning algorithms that allow the analysis and processing of information collected by the conversational agent to detect patient needs and suggest emotional, personal, or functional support and/or monitoring actions by health specialists. Additionally, the product will constitute a source of information for other users to guarantee a greater understanding of the disease by society.

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