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Usability Engineering for Medical Apps using the Example of an App for Epilepsy Self-Management with a Neurosensing System

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ABSTRACT

Improving epilepsy management by addressing the gap in seizure documentation of people with epilepsy may help to increase seizure control and reduce risks related to epilepsy and recurrent seizures. To facilitate usage of and commitment to seizure documentation, the MOND project (Mobile Smart Neurosensing System for the Detection and Documentation of Epileptic Seizures in Daily Life) applied a user-centered design approach to develop an app for epilepsy self-management. The app concept and design were evaluated using semistructured interviews among a small sample of patients. Feedback includes acceptance and willingness to use the app, focus on customizability concerning nomenclature of symptoms and seizure types and suitable input formats for different functionalities (dialogue-like interaction vs. texts; checklists vs. text boxes).

Keywords: Epilepsy, Seizure diary, Health Apps, Human-machine interaction, User-centered design

INTRODUCTION

The main symptom of epilepsy is the recurrent occurrence of epileptic seizures, which bear a great risk for patients (Ramgopal et al., 2014). These seizures can result in accidents, injuries and premature deaths, but also limit autonomy, mobility and quality of life of affected individuals. Therefore, the main target of epilepsy treatment is to reduce seizure frequency and reach seizure freedom, if possible. Accordingly, physicians heavily rely on information regarding seizure type(s), intensity and frequency to choose and adapt therapy, mostly in form of anti-seizure medicine (Bidwell, 2015). The best way to capture this information is by video-electroencephalography (VEEG) monitoring performed by trained clinical staff. However, this requires people with epilepsy to be hospitalized with no guarantee that seizures will occur during this period (Baumgarter et al., 2001; De Cooman et al., 2014). Instead, patients are usually asked to maintain a seizure diary. However, different studies have shown that seizure documentation by means of a diary is not reliable (Hoppe et al., 2007; Blum et al., 1996; Kerling et al., 2006). People with epilepsy only document about 50-70% of their seizures during the day and less than 20% of the seizures that occur at night (Bidwell et al., 2015). Reminder functions do not improve this, since seizures can be associated with impaired consciousness (Hoppe et al., 2007; Blum et al., 1996; Kerling et al., 2006). It is also not always possible to have seizures documented by others, e.g. relatives, because not all seizures can be observed or because another person is not always present, especially at night (Ramgopal et al., 2014; Bidwell et al., 2015).

To address this gap, the MOND project is developing a wearable neurosensing system for automated seizure detection. As part of this project, an app connected to the sensor is being developed to assist users with epilepsy management.

This research aims at developing and evaluating an epilepsy self-management app, including a digital epilepsy diary, medication management and display of data collected via a connected sensor system. Also, the tool can be used to facilitate physician-patient communication. It has already been shown that for health apps just as for digital applications in general, usability is of importance for usage and success, especially the aspects of satisfaction, learnability and efficiency (Liew et al., 2019). Within the development of eHealth applications, there is a lack of published usability evaluations, especially using qualitative methods that can lead to more specific insights on problems or necessary changes rather than show an overall measure of usability (Maramba et al., 2019). The main objective pursued in this paper is to describe the user-centered design process with focus on long-term usage support. An established method to promote user experience, motivation and engagement is the usage of virtual avatars. For children, this has already been proposed in health applications, e.g. to promote healthier food choice (Hswen et al., 2013). Based on a qualitative evaluation of the app developed within the MOND project, including a proposed avatar concept for epilepsy patients, this paper addresses the following questions: How can seizure documentation be supported by the app design? Do an avatar concept and dialogue-based interaction promote long-term usage?

METHODS

MOND App Conception and Design

The development of the MOND app followed a user-centered design approach. Therefore, users' perspectives and opinions were included throughout the iterative design process. Starting with a stakeholder workshop, which included patients' views on valuable factors when developing a system for epilepsy management, the concrete work on app-development was based on an app developed in the previous EPItect project (Houta et al., 2020). The basic functions were already evaluated but without focus on usability issues. To address these issues, we conducted a heuristic evaluation: Screenshots from the EPItect app were discussed and analyzed by a team of usability designers and usability experts. To promote the user-centered focus within the whole project consortium, the main results of the heuristic evaluation were collected and discussed with project members and representatives of various stakeholder and user groups. Additionally, storytelling was used to illustrate a patient's journey (including use of the app) from the first contact with the intended MOND system until daily use. With that work in mind, the concept of the EPItect app was further developed, and designs were changed to improve usability and motivation of use.

Evaluation

The developed app concept and design was presented to a sample of 4 epilepsy-patients (3 female, 1 male) in semistructured interviews that lastet between one to two hours. Interviews were conducted via video phone call between June and August 2021. The interviews started with an introduction of the MOND project and previous handling of epilepsy management. Then, the patients were shown wireframes of the app to get an overview and gather first general impressions. Subsequently, the used avatar concept was presented in detail, previous experiences were queried, and the possibility of enhancing long-term motivation through avatars was discussed. Emphasis in feedback was set on three aspects: 1) setup and entry into the app, including own definition and description of seizure classes. 2) quick import of seizures that were automatically detected and 3) detailed description of seizures. For this purpose, the corresponding wireframes were first shown in a realistic sequence, imitating a realistic use, before the participants gave feedback on the usability of the individual functions. Further parts of the interview covered the home screen arrangement, data visualization, gamification ideas and emergency situations.

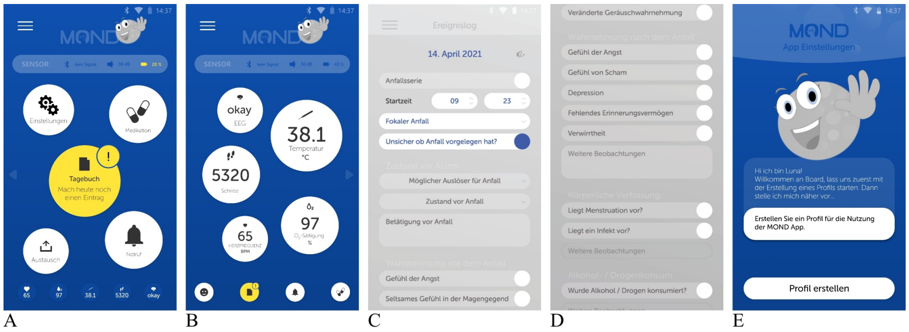
In addition to the extensive interviews, the app concept was presented in a stakeholder workshop attended not only by patients but also by healthcare providers and insurance companies, who were asked to provide feedback on the app concept and design.

RESULTS

MOND App Concept and Design

The developed app design comprises the following functions: 1) home screen (overview), 2) diary, 3) medication management, 4) display of sensor data, 5) seizure classification. The home screen is available in two different views, that can be freely chosen and changed by the user. It either displays the collected vital data of the connected sensor, or it displays a function overview of the app (Fig. 1 A, B).

From the home screen, the diary can be accessed to write entries. Furthermore, the medication management can also be accessed from the home screen (including reminders and a medication schedule). Sensor data collected via the MOND hardware can also be viewed in more detail. The design process of workshops, storytelling, and heuristic evaluation revealed the need to go



14. April 2021

Anfallsserie ○

Startzeit 09 23

Fokaler Anfall

Unsicher ob Anfall vorgelegen hat? ●

Gefühl der Angst ○

Seltsames Gefühl in der Magengegend ○

Veränderte Geräuschwahrnehmung ○

Gefühl der Angst ○

Gefühl von Scham ○

Depression ○

Fehlendes Erinnerungsvermögen ○

Verwirrtheit ○

Liegt Menstruation vor? ○

Liegt ein Infekt vor? ○

Wurde Alkohol / Drogen konsumiert? ○

Hi ich bin Luna!
Willkommen an Board, lass uns zuerst mit der Erstellung eines Profils starten. Dann stelle ich mich näher vor...

Erstellen Sie ein Profil für die Nutzung der MOND App.

Figure 1: (A, B) The two possible home screen views, which can be changed by swiping. (C, D) List for seizure documentation. (E) Luna – Avatar concept.

beyond standard descriptions in seizure classification and retrieval. Therefore, in addition to classifications such as tonic-clonic seizures or absences, the app provides the option to specify and describe individual seizure types. This is done when the app is initially set up and can be customized later. For day-to-day use and documentation of each seizure, a checklist is provided to speed up documentation and thus increase the willingness to record many details. This list can be seen in Fig. 1 C, D.

An avatar concept was developed to facilitate interaction with the app and, above all, to help users get started with it. Following the project name MOND (German for moon), a moon was chosen as the avatar and named Luna. The avatar has three main functions: the introduction to the app (Fig. 1 E), the first explanation of individual functions, and through reminders and short interactions the promotion of long-term usage. To further increase individual frequency of use, a gamification concept, including the unlocking of further content and appearances of Luna, was developed.

Evaluation

Avatar: The evaluation phase shows high acceptance of the avatar concept. The interaction is seen as more personal and Luna (or an Avatar in general) was seen as a “companion that provides assistance”. This was supported by other quotes on the interaction with the avatar: “I like it because it is funny and friendly”. Dialogue-like interaction was seen as superior to long texts, which were considered “dry” and compared to “a teacher with the pointing stick”. At the same time, there was skepticism about whether an avatar can really lead to increased motivation in the long term. The participants indicated high motivation of app usage just by giving suitable functionality and using notifications as reminders: “I also believe if you have the disease and have problems with it, everyone will use the app by themselves to help the therapy. It is an intrinsic incentive”. These expressions confirm that misses in epilepsy diaries are not simply due to motivational lack.

Desired (missing) content focus: Although the focus of the interview was on the usability concept, all interviewees addressed the topic of data protection. Questions such as “When will the data be deleted again?” or “For whom is the classification that I make actually intended?" indicate that transparency should also be created within the app as to how the data is handled, who has access to it at what time, and how settings can be changed.

When describing seizures and presenting symptoms or previous conditions, the role of other people was highlighted. When documenting seizures, respondents often rely on feedback and assessment from their relatives, beyond their own experience. It was perceived as important to distinguish between observation of symptoms by the patients themselves and observation by a third person. This was seen relevant for the exchange with the physicians and should therefore be considered in the documentation.

Furthermore, the documentation of auras was emphasized as particularly important. These physical, emotional or sensory changes sometimes occur without a coming seizure or are understood as a separate seizure type. Other respondents interpreted the aura as covered in the app, since the "perception before the seizure", which is queried in the event log of the app during a seizure, corresponds to the aura in their opinion. This means that there are also differences in personal nomenclature of different aspects of the epilepsy disorder which should be taken into account.

Customizability: In addition to the assessment of a perception or seizure as an aura, there are other areas of the app that require increased customizability. Dissatisfaction with other apps was reported because too few categories of classification are offered (e.g. minor vs. major seizure). One respondent, however, did not see the need for further classification due to currently having hardly any seizures. Overall, respondents reported two to four seizure types that they self-differentiated in their disorder. The concept of defining these seizure types themselves is perceived as new and welcomed: "It's easier to set your own title and description."; "The official seizure measures are way too complicated." To ensure efficient physician-patient communication, this classification can be defined together with the physician who can translate the individual definitions in official nomenclature.

When documenting a seizure, the app offers the possibility to enter the symptoms, previous perceptions and environmental factors in the form of a checklist and text fields for specification. The suggested checklist was accepted by the respondents. The input was thus assessed as very fast, it "makes it easier, the most common points are given". However, the given options in the design did not cover all necessary items. Patients identified further important symptoms, triggers and other factors in addition to those already presented. Therefore, in addition to the predefined checklist, it was desired to provide free text fields for further descriptions or even to integrate individual symptoms and aspects (in the long term) as items in the checklist and thus to customize it.

Contrary to the desired individualizable aspects, a customizable presentation of the home screen (personalized arrangement of functions, etc.) was not considered important and the proposed presentation is accepted. Desired customizability is directly connected to the description and documentation of the own disease and symptoms.

CONCLUSION

We described the applied usability engineering processes and the used methods to include user perspectives and feedbacks in the development of a medical app for epilepsy management including workshops, storytelling and heuristic evaluations that lead to a user-centered app concept. For a first evaluation, the concept and design were explored using a semistructured interview method with four patients. In this early stage of development, the feedback of a small sample already provides valuable insights for the ongoing development. The results of the interviews show a high willingness to use the app, as important functionalities supplemented by suitable input formats and dialogue-like interaction were positively evaluated. The avatar-based design was appreciated but questioned in the long-term effects on motivation to use the app. At the same time, customizability – mainly in the naming and description of symptoms and seizure types outside clinical classifications – is an important aspect in the development of an app for epilepsy management. Results show the importance of user integration in the process of technical development in the medical field. The long-term impact and use of such an app need to be assessed in follow-up studies after full development.

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