

Assessing Information Needs for a Personal Multiple Sclerosis Application

Aleksander Nygård TONHEIM ^{a,1} and Ankica BABIC ^{a,b}

^a*Department of Information Science and Media Studies, University of Bergen, Norway*

^b*Department of Biomedical Engineering, Linköping University, Sweden*

Abstract. This paper presents a prototype of a mobile application for patient self-management within the field of Multiple Sclerosis (MS). Five study subjects provided information needs by suggesting functionalities and evaluating three existing MS applications. Prominent functionalities were to collect data about symptoms, physical activities, mood and goals in a form of a mobile diary. Collected data would be visually presented in a graph to support self-management and motivation. A low-fidelity prototype relies in first hand on four selected modules, two *Diary modules*, one *Visualisation module* and a *Physical activity module*. A high-fidelity prototype is being implemented and will be further evaluated by the experts.

Keywords. Application, Multiple Sclerosis, Information needs, Low-fidelity prototype, mHealth, Digital and Connected Health

1. Introduction

MS is a chronic inflammation in the central nervous system, and there are three types: relapsing-remitting, secondary progressive, and primary progressive MS [1]. Patient management of the disease has greatly improved symptoms. The quality of life could additionally be improved by patient self-management, and in later years with employing IT technology.

IT technology provides several possibilities to support patients with rehabilitation, such as telerehabilitation through a web application [2]. The technology was also used to improve by helping users set rules for defining short-term activity goals [3]. Furthermore, a visualisation framework was developed to monitor health indicators to facilitate users in understanding and exploring personal health data [4].

The main motivation to make an MS application is to meet user specific needs for persons living in Norway. We will contribute with a platform to collect data about the disease based on user input via a mobile diary. The application will use the collected data to suggest how the user should plan their day based on their personal historic data. Our goal is to provide self-management through functionalities, such as reporting symptoms, physical activity, as well as their mindset and mood.

The paper focuses on assessing information needs as a part of designing a prototype of a personal MS application.

¹ Corresponding Author: Aleksander Nygård Tonheim, e-mail: aleksander.tonheim@gmail.com



Figure 1. Publically available MS applications: A) *SymTrac*, B) *MS Self*, C) *My MS Manager*.

2. Method

Five study subjects were interviewed in a natural setting to collect initial requirements for a new mobile application. The semi-structured interview consisted of two parts; one part with questions, and the second part with evaluation of the publically available MS applications (Figure 1). These are *SymTrac*, *MS Self* and *My MS Manager*, all available through the iOS app store via free download.

The study subjects was selected through a Facebook group dedicated to MS during summer of 2017, and were interviewed at the University of Bergen, Norway. The group consisted of both persons with the disease and close family members. The range of the disease onset was from short to long term experience living with MS. The age was in range of 28 and 60 years; there were two males and three females.

The disease onset and disease type differed. The group had different experiences living with the disease, disease variation and use of IT technology.

The first part of the qualitative interview aimed to collect information about the subjects' experience and habits. For example, how to plan a day if the symptoms are present, what coping strategies they had and what IT habits they had.

The second part consisted of an evaluation of three selected applications for persons with MS. We conducted a case study with a person who had 12 years experience living with the disease. The purpose was to evaluate the three applications (Figure 1) which could be used as most representative of their type, and for which a qualitative interview could be carried out. These were selected due to the diversity of functionalities. To evaluate them, a Likert Scale [5] was used for the evaluation. There was enough of functionality variation to give the sense of what these applications offer.

3. Results

Results from the first part of the qualitative interview gave insights into the study group's use of technology to support, monitor and log disease-related events.

Three study subjects classified their IT habits as an average user. They said that an average user is a person who uses applications on their mobile device on a daily basis. Furthermore, two study subjects classified their IT habits as relatively experienced, and as advanced due to their education and current profession.

Persons with MS experience symptoms differently, both due to the way of coping and the intensity of symptoms. The study group reported non-motoric symptoms as most challenging symptoms. The group specifically mentioned fatigue, memory difficulties, and headache. One study subject reported motoric symptoms, especially spasms as a noticeable disease effect.

To manage motoric and non-motoric symptoms the study group reported everyday activities, outdoor activities and physical exercise. Additional coping activities included baking a bread, fishing and practical work around the house that were proven remedies for symptoms. Hiking outside was also mentioned. Two study subjects reported that even simple exercise was good enough to curb symptoms. In contrast, three other study subjects found such activities as too exhausting and could not experience them as beneficial.

The study group reported the need to have an application as means of communication with the environment, such as friends, family and colleagues. Moreover, the study group pointed out that there was also a need to communicate about social activities with other persons with the disease. Such activities could be sharing experience of the disease while hiking. Finally, the study group has not relied on IT based self-management in their everyday life.

The study group was also asked to identify the uppermost functionalities to include generally in an MS application. One study subject identified a list containing five most important activities to accomplish during one day. Three study subjects reported a function to track and register symptoms in the diary, and be presented a simple graph based on data entries as the most important feature. One mentioned the importance of being aware of changes in symptoms that could lead to a possible MS attack. However, one study subject said that the focus should not be on a diary, but *getting through the day*. Furthermore, the study subject noted the importance of removing stress, not adding it. Consequently, the subject would avoid additional stress related to data input.

The second part of the qualitative interview consisted of an evaluation of three selected applications, shown in the Figure 1. Feedback from users showed that *SymTrac* was reported as the application which was the most straightforward and easiest to use. That was followed by *MS Self* and *My MS Manager*. Furthermore, all applications offered a diary module where the user could add symptoms, mood, activity and general notes. Four study subjects rated *MS Self* as having the best diary module.

Based on user feedback, an initial low-fidelity prototype was developed. Figure 2 represents a selection of four wireframes of the low-fidelity prototype.

3.1. Low-fidelity prototype

The initial low-fidelity prototype had four modules. *Diary module 1* and *Diary module 2* in the Figure 2 represent an effortless registration process. *Diary module 1* prompts the user with *How are you feeling?* and records user input from gestures in form of a swipe on a colourful screen. *Diary module 2* shows a selection of motoric and non-motoric symptoms. Data stored from the diary module is then visualised in the *Visualisation module* presenting a simple graph to the user. Lastly, the *Physical activity module* is based on simple instructions to suggest exercise to the user.



Figure 2. A low-fidelity prototype based on feedback from the study group.

4. Discussion

The study subject reported different IT skills and experiences. The three could be seen as average users, and two of them as experienced users that utilized mobile applications daily. Surprisingly, none reported using MS applications as a part of their daily routine. The selected applications are representative of a wider group, offering different IT-support to potential users. The *SymTrac* application seemed to appeal most to the group which might be also explained by the usage of Norwegian language. Results indicated a need for an application to support their daily routines. For example, providing of registration of symptoms and presenting them in a simple graph to support the self-management. However, this was not fully utilized by the group.

One study subject raised the question *Why should I use my time to write a diary on my mobile device?*. The subject argued that the focus should be on removing stress rather than adding it by writing a diary. However, this was surprising as the same subject was aware of monitoring the condition and appearance of new symptoms, which is important to treat and prevent a possible MS attack. The rest of the group was positive towards an IT solution for the same reason, i.e. to control the symptoms and prevent attacks. Therefore, in the case of MS attack, the hospital must be alerted, which could be done using an application. Our focus is to design an efficient and uncomplicated mobile application that will support such functions and others in accordance with information needs. The modular build of the application should allow users to use and prioritise functionalities they find most useful.

Developing a mobile diary to register symptoms was perceived as useful by the majority of the study group. For other reasons, the mobile diary can also be used in interaction with medical personnel. For instance, if the doctor asks, *How have you been since last visit?*, then the patient can show the mobile diary containing symptoms, graphs, and other relevant information.

The initial low-fidelity prototype (Figure 2) has been used as a basis in the process of developing a high-fidelity prototype, which will be an interactive version allowing users to experience basic functionalities. The interactive version is helpful to identify

important issues, such as time to finish a task, user experience with functionalities as they will be running for real.

We facilitated the qualitative interviews to reduce bias by dividing the interview in two parts. This way we wanted to prevent the study subjects to use the three presented applications as reference points, but we rather gave them a chance to communicate their own needs.

5. Conclusions

Results from qualitative interviews led to the low-fidelity prototype of a self-management application for persons with MS. Two *Diary modules*, one *Visualisation module*, and *Physical activity module* (Figure 2) seem to address most of the information needs. A high-fidelity prototype is being developed to enable a full user experience. The future development will include implementation of the application and a comprehensive evaluation with clinical and IT experts.

Acknowledgements

The authors would like to thank the study group for their willingness to share information and to contribute to the study.

References

- [1] Bø L. Generelt om MS. Norsk MS veileder. [Available from: <https://helse-bergen.no/norsk-ms-veileder/>] Last access: 01.17.2018.
- [2] G. Eguiluz, B. Garcia-Zapirain, Telerehabilitation Web Application for Health Care Professionals and Adults With Multiple Sclerosis, *Proceedings of the 8th International Conference on Pervasive Computing Technologies for Healthcare* (2014), 286-289.
- [3] J. Lee, et al, Helping Users Set Rules for Defining Short-Term Activity Goals, *Proceedings of CHI Conference Extended Abstracts on Human Factors in Computing Systems* (2016), 2178-2184.
- [4] J. Szeto, et al., Visualization of Health Indicators: Utilizing Data Mining Techniques and Statistical Analysis for Effective Comparison of User Profiles, *Network Modeling Analysis in Health Informatics and Bioinformatics* **3(1)** (2014), 3-63.
- [5] M.C Kaptein, et al., Powerful and Consistent Analysis of Likert-type Ratingscales, *Proceedings of the 28th international conference on Human factors in computing systems* (2010), 2391-2394.