

Lifestyle Intervention for Young Adults with MS: A Design Study

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Abstract. This paper presents a mid-fidelity prototype of a mobile application for self-management of the chronic disease Multiple Sclerosis (MS). The study focuses on newly diagnosed young Norwegians with MS and wants to deliver IT solutions for a healthier lifestyle. An analysis of a social media platform, interview with medical staff, a social media focus group interview and one case study were utilized to gather data alongside with design iterations. A high-fidelity prototype is being implemented with main functionalities: health, training, patient notes for next medical appointment, disease related life and work issues, and a reward point system.

Keywords. Multiple Sclerosis (MS), young adults, self-management, application.

1. Introduction

Multiple Sclerosis (MS) is a chronic disease that attacks the central nervous system. It can occur at any age, and at the early stages, it is common to have occasional attacks. A minority of patients will see a worsening of the disease after a few years [1]. There is no disease specific test, meaning MS can be hard to diagnose [2]. Medical attention mainly goes to those who suffered with MS for a longer time which in turn often leaves newly diagnosed with less attention and fewer follow-ups during asymptomatic periods. When creating a lifestyle application for young adults one should use technologies to promote wellbeing, connect people and guide them to best available help [3]. Another important issue is to assess the effectiveness of the intervention with measurable means [4]. The aim of this study is to design a prototype with highly relevant content for young adults with MS. Effectiveness could be realised through rewarding good lifestyle choices and collecting data for users' self-management and possibly for sharing with medical staff.

2. Method

The content analysis was carried out for a MS social media platform and thereafter the resulting data was evaluated by experts at the Norwegian Multiple Sclerosis Competence Centre at Haukeland University Hospital. A focus group with five young adults between 20-30 years of age was interviewed. Consequently, a mid-fidelity prototype was designed using the acquired data and evaluated in a case study with two participants.

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3. Results

3.1 Social Media Analyses

Displayed in Figure 1a-c are some of the data categories regarding the concerns and frequently asked questions at the MS social media platform [5] by the users during the last four years. Proving information are sought out at more places than the doctor's office. The results from the analysis were used to help establish user requirements.

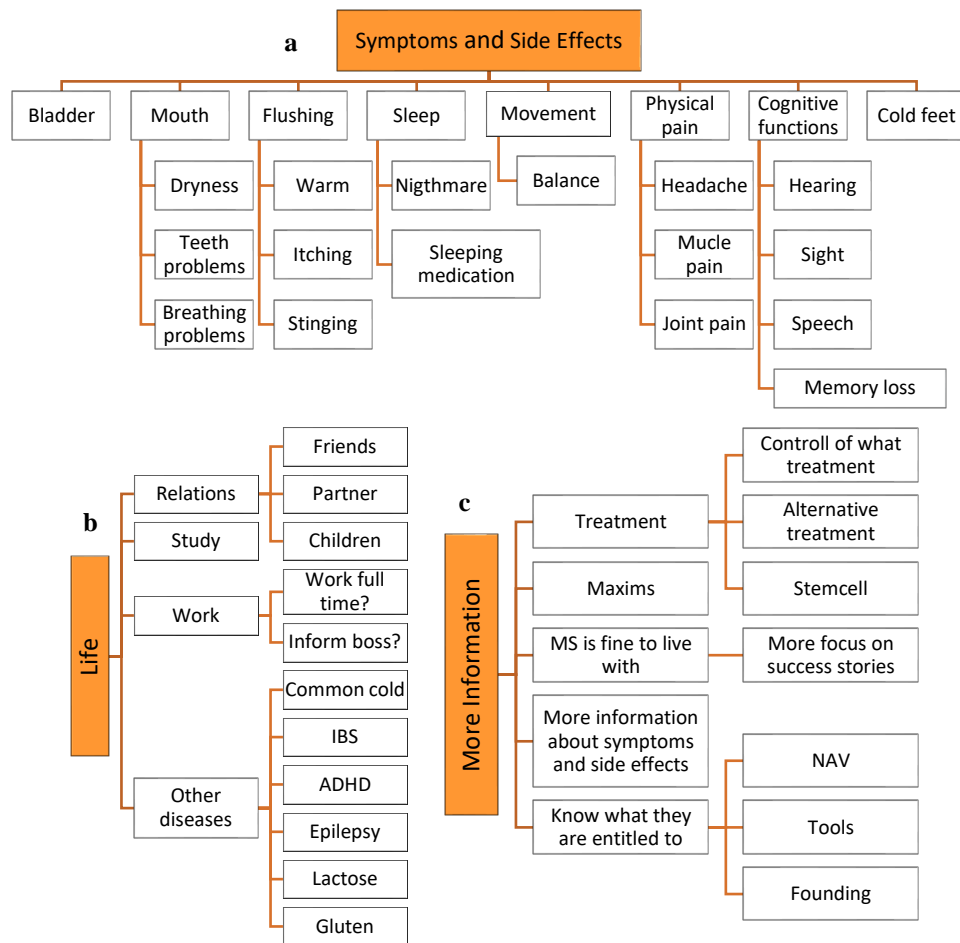


Figure 1a, b and c. Frequently asked questions concerning the MS diagnosis.

3.2 Expert Evaluation

The medical expert evaluation looked at the categories from the Figure 1, as well as some other figures not presented in this paper. After the evaluation, some categories were excluded from the requirements that were not specific for this group (e.g. food functions).

3.3 Interview with Social Media Focus Group

The focus group had a clear and mostly uniform opinion regarding their design and content preferences. All of them had struggled to find a Norwegian app for handling MS.

They did use apps with dark backgrounds such as Spotify, but they did not spend much time scrolling on it and agreed that a light background with dark text and a dash of colour was the best option. The group was presented with a list of functions (*calendar, work out, notes, health, frequently asked questions*) resulting from the analysis of the social media platform and expert evaluation. They wished for a list of available MS-nurses per geographic location. They suggested there should be a place with information on MS for family, friends, and work colleagues, especially bosses. They seek more information about treatment including medicine. One in the focus group would appreciate a calorie counter alongside with healthy recipes. A few would like to have a forum to discuss MS. The majority have found the calendar function redundant. All these results concerning design choices and content were used in the next design iteration.

3.4 Case Study

There were two participants in the case study who evaluated separately. Firstly, there was a 26-year-old female, finishing a master's degree, diagnosed in 2016. The second was a 29-year-old male, with a master's degree, working full time; his diagnosis was established in 2018.

Both liked the colour orange for the applications since it is the MS colour. The font size was good, but the font family was not satisfactory. One meant that there could never be enough content, whilst the other meant too much information could make it hard to navigate through. Suggested improvements were to change the position of the menu and adding a MS-dictionary. In addition, shorter workouts were requested. Information on the medical exams could be compressed when appropriate (e.g. "read more"-button). One felt food recipes were unnecessary whilst the other wanted easy and quick recipes due to fatigue. They both disliked push notifications. Figure 2 displays the landing page and not additional content; the first version of the prototype was created based on the focus group findings, and the second version was implemented after the case study.



Figure 2. The entry menu and the landing page before and after the case study.

4. Discussion

To really understand the needs of young adults, we have joined a Norwegian social media group for people with MS. In direct contacts we have identified main concerns and needs from which a dynamic picture appeared (Figure 1a-c). Important life and quality of life related questions that were discussed. Information often exchanged amongst peers is usually not addressed during regular medical visits, hence the information needs.

The medical experts from Haukeland University Hospital have also appreciated the data coming from this research (Figure 1a-c). Based on such positive feedback, we have designed a prototype to suit young adults and keep them interested in a healthy lifestyle instead of reminding them on the worrisome side of the MS. There are situations such as acute attacks that are demanding on patients and surroundings, but all other times the quality of life remains good. Ideally, they could manage their lives on their own and contact medical professionals when absolutely needed. An app would thus be helpful.

We have also used a case study to gain more information about the conditions of living with MS and to evaluate the prototype. The detailed feedback provided some reassurance that this kind of lifestyle tool would be a good addition to the already existing information [6]. Evaluation by the IT experts and the social media group will be important for refinement of the current design solutions.

5. Conclusion

The design for young adults with MS is the first in Norway, tested by a mini social media focus group and participants of a case study. Their suggestions have influenced the content and design. The results were satisfying but could be further improved regarding the medication, an MS dictionary, information on the medical exams, as well as suggestions for short, straightforward physical exercise and easy to make recipes. All these should help young adults with MS to maintain a conscious and healthy lifestyle.

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