A User Study About Designing a Mobile App for Motivating Multiple Sclerosis Patients for Self-rehabilitation

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Abstract. Rehabilitation is essential to the treatment of Multiple Sclerosis (MS). Self-rehabilitation is rather a good way to keep it effective but its execution turns out to be often uncertain. A mobile application could help people suffering from MS practice those self-rehabilitation exercises at home. Indeed, therapists could manage and program exercises, and patients could follow therapists' programs through a mobile app. We are reporting the results of a study aimed at guiding the conception of a mobile application that would be attractive to people with MS. Therefore, a survey was carried out among users. We did one-on-one interviews with people with MS and focus groups to discuss with their therapists. The results are leading to an application that should be centered on people's occupation, and with playful components in order to provoke interest and investment.

Keywords: Multiple sclerosis · Motivation · Mobile app · Self-rehabilitation

1 Introduction

Multiple Sclerosis (MS) is a chronic degenerative neurological disease. 2.3 million people were affected in 2013 in the world [1]. This disease is the main non-traumatic cause of severe disability among young patients in many countries. MS begins between 25 and 35 years old and 2/3 of people affected are women [2]. There is no treatment to cure MS, but only actions to slow down its progression. Symptoms can be very different from a person to another. They can be visual, sensitive, motor or cognitive impairment, and the disease can progress to an irreversible disability [3]. The most common symptom reported by people with MS (pwMS) is fatigue [4]. Actually, it is one of the main reasons for inability to work for affected people [5]. Quality of life of pwMS decreases more and more while the disease progresses. Then self-rehabilitation and physical activities are widely recommended [6]. PwMS evolves into the loss of ability and thus of autonomy without appropriate regular physical exercises [7]. However, fatigue and depression are important symptoms linked to MS. As a

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consequence, pwMS may prove less motivated and invested in rehabilitating and physical activities, which has a direct impact on their daily autonomy and overall life quality [8].

In this way, our project aims at developing and testing a prototype of a mobile app to make pwMS practice exercises, that have been selected by their therapists. The goal of the research presented in this article, is to choose conception's directions of the app we want to develop by questioning users (pwMS and therapists). This study consists of an investigation on how the mobile app can motivate pwMS to practice exercises and to manage their fatigue. Therefore, our central research question is about the motivation of pwMS. In view of the risk of fatigue and depression, how can we motivate pwMS to practice physical exercises or their self-rehabilitation while they are at home? We hypothesized that a mobile app could solicit pwMS' motivation to follow self-rehabilitation. We previously conducted a preliminary study with pwMS and therapists, to establish the needs of pwMS to practice exercises [9]. It allowed us to confirm that a mobile app where therapists program exercises could be a good way to motivate pwMS. Consequently, we add hypothesis about how the mobile app would have to be developed. First, we suppose that the use of gamification-the concept which uses design and elements that are usually specific to games in another context [10] could be a mean to motivate pwMS to practice exercises. Furthermore, one of occupational therapy's theory used to motivate patients, considers that each person has an intrinsic motivation linked with performance and self-efficacy in occupation [11]. So, choosing a concrete goal of patients' daily life could enhance their motivation to practice exercises. Then, we also hypothesize that if exercises programed in the app are linked with pwMS' daily life activities or personal goal, it could make more sense and make them doing their self-rehabilitation and being motivated.

2 Related Works

Guinti et al. [12] studied all mobile applications made for pwMS, available in the American and Spanish Android and iOS markets. They found a lack of mobile applications dedicated to help pwMS manage fatigue and to motivate them to practice physical activities. In France for pwMS, to our knowledge, only some mobile apps exist to improve compliance of medicinal treatments, but nothing about physical exercises or self-rehabilitation. Furthermore, Thirumalai et al. [13] tried an app with generalized exercises programs with pwMS and showed that it is necessary to offer adapted and specific exercises for each person to have a better acceptance of the application, and to motivate pwMS to use it. The study conducted in [14] brings to light the fact that an official "professional endorsement" seems to be a necessary condition for pwMS to accept and to use mHealth solutions. For the pwMS' acceptance of the app, Giunti et al. [15] developed a mobile app for the fatigue self-management based on gamification. A literature review studying elements of gamification used in mHealth for chronic diseases showed that adding gamification elements facilitates self-management of disease for people with chronic conditions [16]. Moreover, Geurts et al. [17] tested a mobile app to encourage pwMS to walk more and showed that if the objectives are adapted to the person and if the fatigue is taken in account, pwMS can be

motivated and regular in the practice of exercises (walking, in this study). Lastly, the study described by Ehling et al. [18] aimed at trying to use a mobile app to decrease spasticity of pwMS by practicing exercises on their own at home, that were chosen by their physio therapist. This study showed good results. Indeed, the exercises were selected by physio therapists, therefore they are adapted to the individual capacity and the fatigue's level of each participant.

It appears that a mobile app might be a solution for making pwMS practice exercises, if their therapists are involved in the selection of exercises, if fatigue is taken into account for the choice of exercises, and if it uses gamification elements.

3 Method

One of the steps in the design methodology for developing the prototype has been to perform a qualitative study to investigate among future users the conditions that would make a mobile app to motivate patient. The user-centered methodology is presented on Fig. 1. There are two groups of users: the pwMS who use the mobile app and the therapists who establish the program of exercises in the app. First of all, we conducted a preliminary study to set out the needs of pwMS for the practice of their exercises [9]. Then we conducted focus groups with therapists to guide the conception of the mobile app and to build a second investigation with patients. This article presents the confrontation of these two surveys. Next, we will establish a prototype and present it to the users, and then we will develop and test it. All the qualitative studies of this project will be conducted with therapists and patients at the hospital of Saint-Denis. We have an agreement with the hospital so the local rehabilitation team takes part to this project.

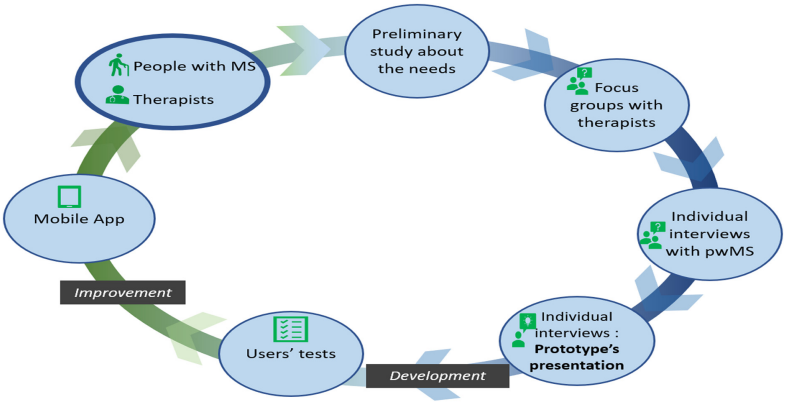

Fig. 1. Design methodology.

4 Participants

4.1 Therapists

Participants were volunteer therapists of the hospital of Saint-Denis. Inclusion criteria for each therapist were: (1) participant has been working with pwMS since more than 3 years; (2) participant is a mobile phone user. We built 3 groups of participants gathered by profession as they had different availabilities depending on their occupation. Our actual 3 groups are described in Table 1.

Table 1. Table of profiles of focus groups.

Therapists	Gender	Ages	Number of years of experience
6 physiotherapists	3 women 3 men	From 25 to 38 (average 29.8 standard deviation 4.5)	From 3 to 8 (average 4.8 standard deviation 1.9)
4 speech therapists 1 neuropsychologist	5 women	From 26 to 52 (average 37 standard deviation 8.6)	From 3 to 31 (average 11.6 standard deviation 9.9)
7 occupational therapists	7 women	From 25 to 49 (average 32.8 standard deviation 7.2)	From 3 to 23 (average 7.4 standard deviation 6.4)

All the participants have given their agreement to be recorded during the discussion.

4.2 PwMS

Participants were patients of Saint-Denis' hospital. Inclusion criteria required for each participant were: (1) to be diagnosed with MS; (2) to be affected by an evolved form of the disease and to need exercises in a rehabilitation center or physiotherapists; (3) to have a mobile phone and to self-declare having experience with mobile apps (4) have no physical disability that restrains the use of smartphone or means of adaptation to use their smartphone; (5) have no cognitive disability that restrains the use of smartphone. The evaluation of ability to use the smartphone was made by the patients' therapists. Four pwMS presented in Table 2 have participated.

Table 2. Table of profiles of pwMS interviewed.

PwMS	Age	Gender	Year of diagnose	Displacement
P1	38	Woman	2004	2 sticks for short way, electric wheeling chair for long way
P2	61	Woman	2016	Walking
P3	37	Woman	2018	Walking
P4	47	Man	1997	2 sticks

Each of them gave agreement to be recorded during the discussion.

5 Tools and Means

5.1 Investigation with Therapists

A methodology based on focus groups has been chosen for this investigation because it is a good way to open a large discussion about motivation, which seems relevant to have among professionals. The moderator had to begin with the explanation of the project to the therapists: *"Our project is to develop a prototype of a mobile app to make pwMS to practice their self-rehabilitation. The exercises in the app will be chosen by you: therapists",* and then the moderator opened the discussion. The first subject of the discussion was mentioned with a question: *"How can we motivate pwMS to practice exercises with a mobile app?"*. This large question has been chosen to collect therapists' spontaneous ideas. The second subject of the discussion was gamification, the moderator had to define the concept and investigate about the integration of this concept in the mobile app's prototype. It will enable to confront therapists' and pwMS' opinion with literature, and then to give elements to confirm or not our hypothesis about the use of gamification. The third subject to evoke concerned exercises directly linked with disabilities in daily life activities. It will also enable to compare therapists' and pwMS' opinion with literature, and to have elements to confirm or not our second hypothesis about exercises linked with pwMS' daily life activities. Finally, to conclude, the moderator had to ask if therapists have others ideas to motivate pwMS to practice exercises with a mobile app. Each focus group has been recorded and has lasted one hour.

5.2 Investigation with PwMS

We chose individual interviews because it was not possible to group the patients for logistical reasons. Our interview grid was based on the results of therapists' investigations. The interviewer had to begin with the explanation of the project to the patients: *"Our project is to develop a prototype of a mobile app to help you to practice your self-rehabilitation's exercises. The exercises in the app will be chosen by your therapists"*. The first part of the interview began with an open question to know the spontaneous ideas of pwMS: *"How could you be motivated to practice exercises with a mobile app?"*. The second part was about gamification, to know pwMS' opinion about adding game elements in the mobile app. It will enable to confront pwMS and therapists' opinion with literature and then to give elements for our hypothesis about the use of gamification. For the third part the interviewer evokes exercises' program directly linked with their disabilities in their daily life activities and if they think it can motivate them. It will also enable to compare pwMS and therapists' opinion with literature and to give elements for our second hypothesis about exercises linked with daily life activities. Then, the fourth part was based on spontaneous ideas of therapists to motivate pwMS. So, the interviewer asked about relationship with the therapist through the mobile app, daily notifications, and videos guiding exercises. It will enable to confront pwMS' and therapists' opinions with literature. To conclude pwMS were asked if they had others ideas to motivate themselves to practice exercises with a mobile app.

6 Results and Analysis

6.1 Gamification

The spontaneous first answer of the therapists about how to motivate pwMS with a mobile app that was spontaneously was to add some game to the app. They talked about gamification without naming it. They mentioned some gamification elements like giving some challenge to the patients or building a system using levels. Nevertheless, one physiotherapist drew attention on the difficulty to talk about progress with pwMS because of the likely course of this disease. For one of the occupational therapists, it is delicate to broach the subject of game while dealing with such a severe disease. They finally agreed that using a system of levels can be motivating but it must be linked with the number of executed exercises or time spent to work and not with progress. Moreover, P1, P3, and P4 described themselves as sensible to games and thought that gamification could motivate them. However, P2 said that she does not like games and thinks it will not help her practicing exercises at home. P4 stated that he is competitive, but he does not have too much time and it might be a problem. P3 was very enthusiastic and said that she loves challenges and she is very competitive. Added to that, literature showed very good results of gamification in m-Health to improve self-management of chronic disease or progress to a healthy life behavior [16]. Therefore, gamification can be a solution to motivate pwMS to practice exercises with a mobile app, but some elements have to be taken into account. Gamification will not be adapted to all people. Moreover, we have to be attentive to the fact that MS is a degenerative disease and we cannot use progress of the person to gamify the app like it is done in sports mobile app.

6.2 Occupational-Centered

The second topic discussed was the process of working on daily life goals through the mobile app. The therapists thought it could give a sense to the exercises and motivate patients to achieve a goal which means something for them. All patients answered that having a concrete goal would interest them. P1 told us that it would help motivating her because it would be something she wants to do, something that makes sense for her. One therapist also added that it could make patients more active on their exercises because they can make the link to a concrete goal. This is a theory of occupational therapy to motivate patients for their rehabilitation [11]. According to this theory, patients could have a better engagement and investment in their rehabilitation exercises at home. The Canadian Model of Occupational Performance and Engagement is a mean to work for occupational therapists based on this theory [19]. Moreover, P4 talked about a problem of time because he has a baby to carry on and does not find time and energy to practice exercises. He liked the idea to direct exercises towards exercises linked with his activities, like changing a diaper. Finally, occupational therapists brought the light on the need of adaptation of each objective and exercise for each patient. However, they feared that it would be too time-consuming for them to configure a different program for each patient. Therefore, the app will have to be built by considering this fact.

6.3 Relationship with Therapists

The three groups of therapists all agreed that choosing exercises according to the abilities of their patients is essential. Then, one speech therapist explained that, knowing the therapist can check what exercises patients have done or not, might be motivating. One occupational therapist talked about a "supervisory comforting" towards the mobile app. For pwMS, the maintenance of the relationship thanks to the app is motivating. P1 told us that she needs to be encouraged by her therapist to make her exercises. The 4 pwMS told that they are reassuring their exercises would be chosen by their therapist who would select exercises depending on their capacities. P2 mentioned she always feels alone when she has to practice exercises at home without any guideline. The literature confirms that if exercises are adapted and specific to each patient, the acceptance to the app is better [13, 18].

6.4 Others Aspects Motivating

Lastly, others feature emerged from the investigations to motivate pwMS to practice exercises. All the therapists mentioned daily notifications to remind to make exercises, and all pwMS answered that notifications can help to not forget the exercises. A speech therapist added that some supportive and friendly sentences could be even motivating to remind the exercises. Videos and photos to explain guidelines of the exercises also created unanimity with all participants to help and motivate pwMS. In several studies daily notifications and videos are also used and are well accepted by pwMS [13, 18].

7 Conclusion and Perspectives

To conclude, the results of this study show that m-health can be a good solution to motivate pwMS to practice exercises but also that the following points are very important and should be taken into account: (1) exercises have to be chosen and programmed for each pwMS by the therapists who work with them, and know their individual specificity and their abilities; (2) some specific aspects of gamification can be used, but in respect with the disease evolution to avoid discouraging patients; (3) the programs of exercises focused on pwMS' occupations seem to be an interesting approach to motivate them. As perspectives, we will design 2 interfaces: one web site for therapists to manage exercises, and one mobile app for patients to follow therapists' programs. The therapists' interface will be designed to be the minimum time-consuming possible, and as specific as possible for each patient. The prototype is in the developing phase. Next, we will test it beyond the hospital of Saint-Denis and then we will conduct a larger study.

References

1. Browne, P., Chandraratna, D., Angood, C., et al.: Atlas of multiple sclerosis 2013: a growing global problem with widespread inequity. Neurology **83**(11), 1022–1024 (2014). https://doi.org/10.1212/WNL.0000000000000768
2. France's government of health [page on the Internet]. Paris, [updated 30 May 2018, consulted 16 July 2019] (2018). https://solidarites-sante.gouv.fr/soins-et-maladies/maladies/maladies-neurodegeneratives/article/la-sclerose-en-plaques
3. Richard, N., Waqar, R.: Multiple sclerosis: clinical evidence handbook. Am. Fam. Phys. **87** (10), 712–714 (2013)
4. Langeskov-Christensen, M., Bisson, E.J., Finlayson, M.L., Dalgas, U.: Potential pathophysiological pathways that can explain the positive effects of exercise on fatigue in multiple sclerosis: a scoping review. J. Neurol. Sci. **373**, 307–320 (2017). https://doi.org/10.1016/j.jns.2017.01.002
5. Schiavolin, S., Leonardi, M., Giovannetti, A.M., Antozzi, C., Brambilla, L., Confalonieri, P., et al.: Factors related to difficulties with employment in patients with multiple sclerosis: a review of 2002–2011 literature. Int. J. Rehabil. Res. **36**(2), 105–111 (2013). https://doi.org/10.1097/MRR.0b013e32835c79ea
6. Latimer-Cheung, A.E., Martin, G.K., Hicks, A.L., Motl, R.W., Pilutti, L.A., Duggan, M., et al.: Development of evidence-informed physical activity guidelines for adults with multiple sclerosis. Arch. Phys. Med. Rehabil. **94**(9), 1829–1836 (2013). https://doi.org/10.1016/j.apmr.2013.05.015
7. Edwards, T., Pilutti, L.A.: The effect of exercise training in adults with multiple sclerosis with severe mobility disability: a systematic review and future research directions. Multiple Sclerosis Relat. Disord. **16**, 31–39 (2017). https://doi.org/10.1016/j.msard.2017.06.003
8. Alsaadi, T., et al.: Depression and anxiety as determinants of health-related quality of life in patients with multiple sclerosis. Neurol. Int. **9**(4), 7343 (2017). https://doi.org/10.4081/ni.2017.7343
9. Chassan, C., Sévène, M., Cras, O., Archambault, D.: Application smartphone, sclérose en plaques et auto-rééducation. In: Actes du Colloque JCJC'2019, pp. 7–12. IFRATH, Université Paris8, Saint-Denis (2019)
10. Deterding, S., Dixon, D., Khaled, R.: Gamification: toward a definition. In: 2011 The ACM CHI Conference on Human Factors in Computing Systems, pp. 12–15 (2011)
11. Sharrott, G.W., Cooper-Fraps, C.: Occupation theory motivation: theories of motivation in occupational therapy: an overview. Am. J. Occup. Ther. **40**, 249–257 (1986)
12. Giunti, G., Guisado Fernández, E., Dorronzoro Zubiete, E., Rivera, R.O.: Supply and demand in mHealth apps for persons with multiple sclerosis: systematic search in app stores and scoping literature review. JMIR Mhealth Uhealth **6**(5), e1051 (2018). https://doi.org/10.2196/10512
13. Thirumalai, M., et al.: TEAMS (Tele-Exercise and Multiple Sclerosis), a tailored telerehabilitation mHealth app: participant-centered development and usability study. JMIR Mhealth Uhealth **6**(5), e10181 (2018). https://doi.org/10.2196/10181
14. Giunti, G., Kool, J., Rivera Romero, O., Dorronzoro, Z.E.: Exploring the specific needs of persons with multiple sclerosis for mHealth solutions for physical activity: mixed-methods study. JMIR Mhealth Uhealth **6**(2), e37 (2018). https://doi.org/10.2196/mhealth.8996
15. Giunti, G., Mylonopoulou, V., Rivera, R.O.: More stamina, a gamified mHealth solution for persons with multiple sclerosis: research through design. JMIR Mhealth Uhealth **6**(3), e51 (2018). https://doi.org/10.2196/mhealth.9437

16. Miller, A.S., Cafazzo, J.A., Seto, E.: A game plan: gamification design principles in mHealth applications for chronic disease management. Health Inform. J. **22**(2), 184–193 (2016). https://doi.org/10.1177/1460458214537511. Medline: 24986104
17. Geurts, E., Van Geel, F., Feys, P., Coninx, K.: WalkWithMe: personalized goal setting and coaching for walking in people with multiple sclerosis. In: 27th Conference on User Modeling, Adaptation and Personalization (UMAP 2019), Larnaca, Cyprus, 9–12 June 2019, p. 10. ACM, New York (2019). https://doi.org/10.1145/3320435.3320459
18. Ehling, R., et al.: Successful long-term management of spasticity in patients with multiple sclerosis using a software application (APP): a pilot study. Multiple Sclerosis Relat. Disord. **17**, 15–21 (2017). https://doi.org/10.1016/j.msard.2017.06.013
19. Polatajko, H.J., Townsend, E.A., Craik, J.: Canadian model of occupational performance and engagement (CMOP-E). In: Townsend, E.A., Polatajko, H.J. (eds.) Enabling Occupation II: Advancing an Occupational Therapy Vision of Health, Well-Being, & Justice Through Occupation, pp. 22–23. CAOT Publications ACE, Ottawa (2007)