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# Benefit of a Mobile Application to Motivate People with Multiple Sclerosis to Practice Self-Rehabilitation at Home

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**ABSTRACT**

Rehabilitation is essential to Multiple Sclerosis (MS) treatment. Its efficacy can be maintained by self-rehabilitation but its execution often remains unpredictable. A mobile application could help people with MS (pwMS) practice these self-rehabilitation exercises at home. We are reporting the results of a study aiming to guide the design of a mobile application that would motivate pwMS to do so. With this aim in mind, a study has been conducted among the rehabilitation staff who work with these people. The results are steering the design of the application towards an occupation-centric application, in addition with some playful elements in order to provoke interest and commitment.

## 1. INTRODUCTION

Multiple Sclerosis (MS) is a degenerative chronic disease. One hundred thousand people are affected in France [1] and 2.3 million in the world [2]. MS is the first cause of non-traumatic handicap on young adults. It begins between 25 and 35 years old and 3 quarters of people affected are women [1]. There is no treatment to cure MS but some treatments enable the disease's evolution to slow down. MS symptoms are very different from a patient to another one. They can be motor, sensitive, cognitive or visual trouble. The disease evolves towards an irreversible disability [3].

One of the most common symptoms is fatigue [4]. It is an important cause of limitation in daily life and in work [5]. Moreover, the prevalence of depression and anxiety is high among pwMS [6]. It can be a natural reaction when faced with the difficulty of living with a chronic disease, but it can also be a predisposition linked to MS [7]. Thus, sensitive, visual, motor and cognitive trouble, but also fatigue and depression can lead to many incapacitating situations in pwMS daily lives. The loss of autonomy is very hard to live. PwMS's quality of life keep declining as the disease progresses. [8]. In order to avoid the loss of autonomy, self-rehabilitation and physical activity practice are highly recommended for pwMS [9, 10]. What we mean by "self-rehabilitation" consists of a program of exercises that are explained and advised by a rehabilitation professional. It is different from doing sport, which is freely practiced and without any explanation or advice from the rehabilitation professional [11]. It is acknowledged that without regular practice of physical exercises, pwMS progressively lose their functional capacity and thus their autonomy [12, 13]. Motivation and commitment in the practice of physical exercises by pwMS are very important factors for the rehabilitative care of this disease [14]. Fatigue, which is an important symptom of MS, highly limits the practice of physical exercises and restrains even more patients' motivation [15]. This brings the issue of upholding physical and rehabilitation exercises, and autonomy at home. During a preliminary study conducted among therapists and patients with MS from a rehabilitation center and a hospital neurology service (in Saint-Denis hospital) [16], we could define pwMS' needs: be led and be provided with a support to practice at home. Our hypothesis is that a mobile application that assists patients on their self-rehabilitation exercises will allow the loss of autonomy to be limited and the quality of life to be enhanced. Indeed, smartphones are part of the eHealth tools that are defined as communicating ways to strengthen the chance for a patient to benefit from quality healthcare and to be an informed stakeholder in their health management [17]. Thereby, our project involves designing a mobile application prototype that meets the pwMS' needs. The study that is presented in this article is going to give details on the survey conducted among therapists working with pwMS, in order to guide design choices for the mobile application prototype. It will be secondly completed with a study conducted among pwMS. The objective of these two studies is to determine what can motivate pwMS to practice their self-rehabilitation exercises by means of a mobile application.

## 2. RELATED WORK

Medical care of chronic diseases is constantly evolving. Indeed, the number of high-tech tools to do a follow-up of chronic pathologies keeps increasing. Lee et al. [18] highlighted some progress in communication between patients and their therapists in a literature review. This review deals with mHealth as a management tool for patients suffering from chronic disease; and in certain cases, it showed a better management of the chronic disease as well as a better medical care in its entirety. In addition, Giunti et al. 's team [19] conducted a study to analyze every mobile application that are available in American and Spanish market on Android and iOS for pwMS. The authors observed the absence of mobile

applications dedicated to pwMS for dealing with their fatigue and for motivating themselves to practice physical activities. In France, as far as we know, some applications are provided by pharmaceutical laboratories and only propose observance of medical treatments.

Furthermore, another study made by Giunti et al. [20] with 12 pwMS and 12 caregivers, has shown that pwMS need a 'professional endorsement' to practice physical activities. They don't practice exercises without advices about type of exercise, frequency or intensity, from physiotherapists or others caregivers. The fear of getting hurt or triggering a new relapse of MS block them to practice exercises alone without advices. It can be linked with motivation problem of pwMS. Indeed, if caregivers are involved in the use of a smartphone app to practice exercises, it can motivate pwMS to make physical activities. Moreover, the study of Thirumalai et al., about a test of a mobile app with programs of exercises has shown that it is necessary to propose specifics exercises to each pwMS and his capacities [21]. Simblett et al. [22] have defined the lack of motivation as a big obstacle to the use of mHealth for pwMS. Giunti et al. use gamification to help pwMS to manage their fatigue with a mobile app [23]. Gamification use elements and design specific to the games in another context [24]. Johnson et al. have studied this concept used in health in a literature review. It seems to have a positive impact on behavior and slef-management in health (improvement of alimentation, physical activities, stress management, …) [25]. Another literature review studying gamification in mHealth for people with chronic diseases has shown good reults. Indeed, it appears that adding gamification elements helps self-management of chronic diseases for patients [26]. Otherwise, taking into account of fatigue of pwMS in the mobile app's conception seems to be important. According to D'hooghe et al., the good mean to manage fatigue is to adapt activities to the fatigue of each user [27]. It allows participants to practice physical activities while managing their fatigue through the app. The mobile app of the study [28] propose to pwMS, exercises chosen by their physiotherapists who know them and their fatigue. So, finally, if fatigue is taken into account in the mobile app's conception, it is not an obstacle for making pwMS practice exercises. Geurts et al. have tested an app which motivate pwMS to walk frequently. They propose to fix goals about time and rhythm of walk, adapted to each pwMS' capacities at the beginning of the study. Although results show that participants walk more, they don't show an increase of fatigue [29]. Thus, to develop our prototype of mobile app to guide and motivate pwMS, it is important to interrogate users to design an app which respond to their needs. How can we motivate pwMS with a mobile app considering the chronic disease, the fatigue and also the depression?

## 3. METHODOLOGY OF THE STUDY

The study presented here is a qualitative survey. It is a step of the methology followed to develop a mobile app prototype presented below.

### 3.1 Context of the study

In order to develop a prototype of a mobile app and to test it, we use a centered users methodology presented in the figure 1. Users of this mobile app are on one side pwMS to motivate themselves and follow their exercises of self-rehabilitation, and on the other side, the therapists who program exercises on the app. About the methodology used for the mobile app conception, we firstly conducted a preliminary study with the 2 groups of users. It allowed us to determine the needs of the users [16]. Then, to direct the prototype conception, we elaborated a survey with focus groups of therapists. It is the survey presented in this article. It is focused on therapists, but a new survey focused on pwMS will be also conducted. Next, the prototype will be presented to the users, and it will be developed to be tested and improved according to the tests. This project is conducted by Paris 8 University Paris 8 associated with the Hospital Center of Saint-Denis (CHSD). CHSD allows therapists to participate to this project at work. This is a logistical advantage which helps to find participants. Also, all the studies of this project will be conducted with therapists and pwMS of CHSD.

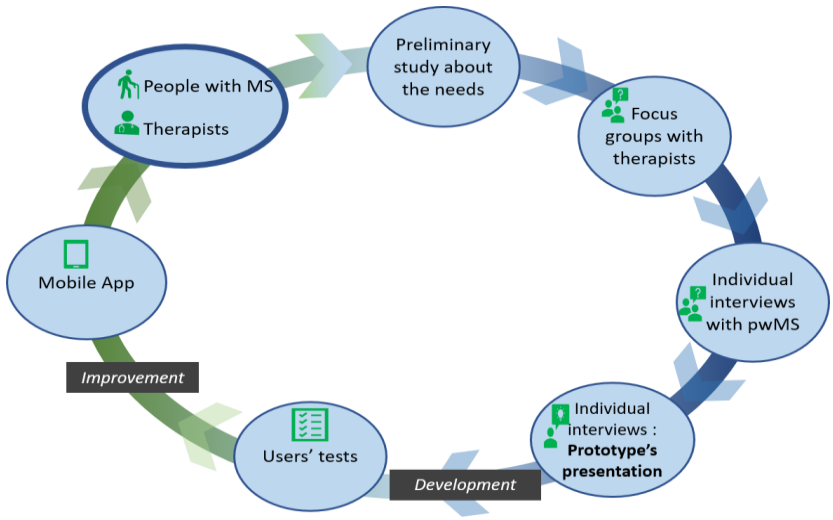


**Figure 1.** Design methodology

### 3.2 Survey participants

We conducted this survey with focus groups in CHSD. We asked for volunteers to participate to the project. 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 fixed these criteria to have people able to answer to questions according to their experience and knowledge about the subject. We built 3 groups of participants gathered by profession as they had different availabilities depending on their occupation. 3 groups have been built:

- 6 physiotherapists: 3 men et 3 women from 25 to 38 years old (average 29.8 standard deviation 4.5) from 3 to 8 years of experience with pwMS (average 4.8 standard deviation 1.9).
- 4 speech therapists and a neuropsychologist: 5 women from 26 to 52 years old (average 37 standard deviation 8.6) from 3 to 31 years of experience with pwMS (average 11.6 standard deviation 9.9).
- 7 occupational therapists: 7 women from 25 to 49 years old (average 32.8 standard deviation 7.2) from 3 to 23 years of experience with pwMS (average 7.4 standard deviation 6.4).

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

### 3.3 Focus group and discussion guide

We chose focus groups as survey's methodology to open a large discussion about motivation. Indeed, focus group is a method which stimulate reflection and discussion between participants [30]. We chose a discussion guide to open large questions and to close up on specific subject if needed. The moderator of the focus group had to welcome and introduce the subject by explaining the project: "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". The first topic of the discussion conducted by the moderator was a large question: "How can we motivate pwMS to practice 5 exercises with a mobile app?" This choice was to collect spontaneous answers of the therapists. The second topic to mention was gamification, the moderator defined the concept and interrogate about integrating it in the app. We wanted to discuss this concept to confront therapists' opinions with studies of literature. The third subject to talk about was about the daily life. The goal was to question about proposing exercises directly linked with pwMS occupations. It was also to confront the results with the literature. To finish, the moderator asked for others ideas to motivate pwMS to practice exercises of self-rehabilitation. We recorded each focus group with a voice recorder and transcribed each record.

## 4. RESULTS

We classified results of this study in 4 categories. Each one corresponds to one or more motivating elements. They are presented below, following the order in which they have been mentioned in focus groups.

### 4.1 Ludic aspects and chronic disease

The first idea spontaneous mentioned by all the groups is to add ludic elements and to win points or rewards when exercises are done. Indeed, a system of level or rewards could motivate pwMS to practice exercises as a speech therapist mentioned it. A physiotherapist added *"it is delicate to talk about improvement with pwMS, and it we should not base the rewards on it".* A system of level with exercises accomplished has also been evoked in speech therapists and occupation therapists groups. For these 2 groups, it should be qualified because *"there is a risk to be downgraded for pwMS whose disease evolves*" according to the neuropsychologist. An occupational therapist proposed to reward the time passed on the app, and not the number of exercises accomplished. According a speech therapist, the system of level can be used without talking about improvement. Indeed, although pwMS practice exercises, improvement is not automatic for them. System of level or rewards according time passed on the app is a concept to think about for the 3 groups. An occupational therapist said *"it is always difficult to approach games when we treat about a degenerative and chronic disease"*. According to a speech therapist, *"it is essential to not act with patients like he was a child".* So, about this subject, the 3 groups of therapists thought that games elements are interesting and motivating for patient but, they brought the light on a need of reflection on the choice of games elements.

### 4.2 Goals in daily life

The second idea mentioned by the moderator in the 3 groups is to propose goals in daily life with through the mobile app. The 3 groups defined this idea as an interesting solution to motivate pwMS. First of all, according occupational therapists and physiotherapists, it can allow to change pwMS' point of view on exercises. A physiotherapist explained that it could *"give a sense to analytic boring repetitive exercises".* An occupational therapist added *"if we direct pwMS to daily life activities that interest them, and we explain that analytic exercises will help them to reach their daily life goal, it can completely change the motivation".* The speech therapists' group highlighted that it can help to manage pwMS' fatigue because "*if pwMS use energy for a daily life activity which make sense for them and that they anyway have to do, it would be better received than repetitive exercises*". The 3 groups agreed that direct self-rehabiliation to daily life activities should make pwMS more actor in their rehabilitation. It would improve pwMS engagement and investment in exercises. Speech therapists talked about the daily life goals that could lower if the disease evolves and it can be hard for pwMS. Occupational therapists proposed to give the mobile app just before they leave rehabilitation center to go home. They proposed to choose daily life goals attainable with pwMS for the app. They saw that as a mean to guide pwMS to choose adapted goals. Speech therapists mentioned a problem about the time necessary to program exercises for each patient. Occupational therapists also 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.

### 4.3 Relationship with therapists

The 3 groups spontaneously mentioned in different ways the relationship with therapists through the mobile app. Physiotherapists explained pwMS could feel supported by their therapists to practice exercises through the app. Indeed, these exercises would be adapted according to their capacities because programed by their therapists. A speech therapist said that *"it is motivating to know that therapists have programed exercises for you and can check if you have made it or not".* One occupational therapist talked about a *"supervisory comforting"* towards the mobile app.

### 4.4 Others motivating aspects

Finally, others motivating aspects have been evoked. The 3 groups agreed that reminder can motivate pwMS to make exercises. A speech therapist added *"it is more motivating to receive small kind motivating sentence from the app"* A physiotherapist proposed challenges like *"tying shoelaces by timing and try to beat his record*". The speech therapists proposed notifications with information about MS to make pwMS want to open the app and give some information in an article like the example of the speech therapist: *"what is working memory and how does it function?".*

## 5. DISCUSSION

As a reminder, the goal of this survey is to know how a mobile app can motivate pwMS to practice exercises, we want to know how we can direct the conception of a mobile app to motivate them. It is important to remind that this survey talks about only one group of users (therapists) and it will be completed by the opinion of the second group of users (pwMS). First of all, by talking about games and ludic elements, therapists have mentioned gamification without naming it. It is a concept more and more studied and including in health. It can help patients to change life habits, to take medicines or practice physical activities through interfaces web or mobile app [31, 32]. Although, the subject has to be more developed, gamification seems to be efficient to motivate and engage people in their healthcare. About the survey presented here, the therapists made a reservation about games elements in a mobile app in a context of a chronic disease. The promising studies about gamification don't make a reserve and have good results [33, 34]. However, it seems important to take into account this element for the mobile app conception. Giunti et al. [23] has established a list of ludic elements for mHealth. Given the therapists' opinion about the subject, it could be interesting to add some elements in our mobile app like: the obtention of medal to reward some specific tasks; systms of levels and points to inform the user of his level of experience in the app; challenges and quests to give goals; social functionalities to make users interact and encourage themselves…

About centering the mobile app on the daily life activities goal, it is based on occupational therapy conceptual models. Indeed, on one side, the Model of Human Occupation (MOHO) is a occupation centered model. It encourages occupational therapist to focus on occupations and to propose a plan of rehabilitation with work activities, hobbies, and daily life in mind, in a temporal, physical and socio-cultural context [35]. On another side, the Canadian Model of Occupational Performance (CMOP) also focus on occupation in occupational therapists' interventions [36]. It defined occupation as one or several activities realized with regularity, bringing a structure in which people devote values and importance [37]. Thus, focus the intervention on occupation allows to give sense to this intervention for the patient. The patient is considered with his occupations, his entourage and his environment of life. This is why his engagement will be solicited since the activities arouse his interest. The 3 groups seem to be convinced of the importance of choosing concrete goals. According to them, it could arouse pwMS' motivation, and it joins literature about engagement and investment in patient's occupation [37]. Reserves are made about programing activities on the app because it could be time-consuming. Indeed, there is a need of personalization and adaptation for each patient since he has his own activities in his environment. It appears to be important to find a model as less time-consuming as possible. Furthermore, the 3 groups spontaneously evoked the relationship with therapists through the app as motivating for pwMS for different reasons: a support in the exercises, a reassuring effect for pwMS, a checkup made by the therapist. The relationship with therapist through the app has also emerged from literature. Giunti et al. [22] have shown that pwMS need a professional endorsement to feel reassured with exercises proposed by mobile apps. Moreover, make therapist choose exercises adapted to the capacities of each patient seems to work to make pwMS use the app [21]. Finally, several functions have been evoked by the 3 groups (daily reminder, motivating sentence, challenges…) to make users want to open the app. These functions are also used in tested app in literature [19-25].

## 6. CONCLUSION

To conclude, the study that we conducted allow us to direct the conception of a mobile app to motivate pwMS to practice physical activities. PwMS will be interviewed about this subject to confront the opinion of the groups of users. Next, we will develop a prototype of a mobile app. And then, the prototype will be tested by users (therapists and pwMS) to improve it and respond to the needs of users as well as possible, so by using a user centered methodology.

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