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ORIGINAL RESEARCH

Feeling controlled or *being in control*? Apps for self-management among older people with neurological disability

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ABSTRACT

Purpose: The aim of this paper was to describe how people living with a neurological disability such as multiple sclerosis, Parkinson's disease and stroke reason regarding using apps to facilitate self-management in everyday life.

Material and methods: A qualitative research approach with a focus group methodology was used. The sample comprised 16 participants, 11 men and 5 women, with an average age of 64 years (ranging from 51–80 years). Six participants were diagnosed with multiple sclerosis, six with Parkinson's disease and four with stroke. Data were analyzed using thematic analysis, which is a method for identifying, analyzing and reporting patterns.

Results: The results formed two themes. The first theme "using apps to have control of my health" comprises two subthemes; "monitor and take responsibility for a healthy lifestyle" and "compensate to facilitate everyday life". The second theme "using the app as a tool and means for communication" also comprised two subthemes; "dare to trust the app" and "feeling safe when sharing information with health care professionals".

Conclusions: The use of apps put increased responsibility on the person and had the possibility to make them more involved in their own care. The use of an app can facilitate a healthy lifestyle and help to monitor disease-specific symptoms. In order to be able to use apps for communication with the health care sector legislation and safety issues need to be considered.

➤ **IMPLICATIONS FOR REHABILITATION**

- Apps can be used for self-management if they are safe and can be trusted.
- People with neurological disabilities want to be involved in their healthcare and needs to be addressed by health care professionals.
- The use of apps grasp over a wide variety of areas this is something that may be considered in health care and something that can be addressed by interdisciplinary approaches.
- Ordinary health-oriented apps and disease-specific apps were used differently and for different purposes.

Introduction

Traditionally, neurologic rehabilitation has mainly focused on recovery, that is, restoring function. During the last decade, the importance of rehabilitation intervention to also reinforce a positive view of self, promote participation in meaningful activities and thereby facilitate each individual's adaptation process, has been emphasized [1–3]. This is especially important since people today live longer, and the number of people living with a neurological disability is expected to increase. In turn, this can put greater demands on health care services [4], and at the same time, many are also interested in taking a larger responsibility for their health [5,6], and to make informed decisions regarding their health care.

In 2011, Huber et al. argued the current World Health Organisation's (WHO) health definition [7] focuses too much on complete wellness, that is, the absence of social, physical and emotional challenges [8]. People who live with chronic disabilities can seldom reach complete wellness. Thus, applying the WHO health definition with this group, health would not be possible for them to reach. Instead, the authors proposed the definition of health should focus more on peoples' ability to adapt and self-manage with social, physical and emotional challenges. Being able to self-manage means that people are able to take control over, and live a healthy life despite a disease or a disability. Self-management is also a method that is used within health care, building on cognitive psychology and social learning theory [9]. Learning problem-solving skills can enhance a person's self-efficacy to manage different roles in everyday life, taking a stand-point in life goals relevant for that person [10]. These interventions have also been shown to be more cost-effective than educational programmes or information only [10].

Even though self-management is a fairly new research area within neurologic rehabilitation, there is a growing interest in using this method in mobile health (mHealth) [11]. mHealth is defined as the use of mobile technology for transfer of health resources and health care [12]. Mobile technology includes mobile phones, smartphones and tablets, which are increasingly common. In the United States, 81% of adults own a smartphone and 53% of older adults (above 65 years of age) own a smartphone [13]. In Sweden, 92% of people above 12 years have access to a smartphone [14]. Among older people, mobile phones are more commonly used than computers; 73% of people aged 66–75 years use a mobile phone as opposed to 58% using a computer [14]. There is also an increasing development of apps related to health and more than 100,000 health apps have been developed [11]. Apps can monitor and manage symptoms, medication, activity, and participation and address lifestyle behaviour [15], as well as provide knowledge and advice on individual conditions [11]. The use of apps has the potential to improve health outcomes among people living with chronic diseases through enhanced symptom control [16]. For people with diabetes, cancer and for older adults with chronic diseases the use of apps has proven to facilitate self-management by improving symptom management, increased knowledge and facilitating informed decisions [15,17]. However, few studies on mHealth and self-management focus on people with neurological disabilities [18] even though a majority of people with neurological disabilities use modern communication technology on a regular basis [5,19]. In a previous study [20], we found that people with a neurological disability use apps for e-mail, finding information, social media and physical and mental exercises. Impairments and trustworthiness were perceived as barriers while the possibility to share data and connect with others were perceived as facilitators. Yet the knowledge of if and how apps can support people who live with neurological disabilities to self-manage in everyday life is scarce. Thus, the aim of this paper was to describe how people living with a neurological disability such as multiple sclerosis (MS), Parkinson's disease (PD) and stroke, reason regarding using apps to facilitate self-management in everyday life.

Method

Design

A qualitative research approach with focus group methodology [21] was used to capture the participants' experiences of using apps. Due to the study's interdisciplinary nature, perspectives from design/technology, law, occupational therapy, physiotherapy, and social science were utilized.

Participants

Participants were recruited from three user organizations for MS, PD and stroke in Sweden. In the first step, the first author mailed a contact person in each of the three user organizations. The contact persons received information of the study and were asked to help with the recruitment process. Each contact person also received an information email they could use to invite potential participants to the study. In a second step, the contact person forwarded the email to potential participants who matched two of the inclusion criteria. The inclusion criteria were age above 50 years of age and diagnosed with MS, PD or stroke at least five years ago. Those who matched the inclusion criteria and had experience in using smartphones or tablets, and were interested to participate contacted the first author for further written and verbal information. 22 persons matched the inclusion criteria. Four of them did not participate in the study due to practical issues and two declined to participate due to difficulties to participate in a group discussion. All participants gave their written informed consent prior to the study. The sample comprised 16 participants, 11 men, and 5 women, with an average age of 64 years (ranging from 51–80 years). Six participants were diagnosed with MS, six with PD and four with stroke. All participants had experience of using mobile technology; 14 used a smartphone, 14 used a tablet, and 12 participants used either a smartphone or a tablet daily. For details, see Table 1. The participants used apps for practical reasons such as to manage bank errands, health reasons, that is, to monitor food intake and physical activity and for leisure such as games. They had knowledge of apps targeting their neurological disease but had not used them.

Ethics

The Regional Ethical Review Board in Lund, Sweden, approved the study (2016/213).

Data collection

In order to stimulate participants' discussions, aspects of homogeneity and heterogeneity were taken into account when participants were included in the different focus groups [21]. We anticipated participants with the same neurological disability would share similar experiences. Thus, homogeneity was accounted for by placing those with the same disability in the same focus group; in total three focus groups. To further stimulate the discussions, the different focus groups were heterogeneous regarding age and type of mobile technology that was used, see Table 1.

To ensure the participants discussed issues related to the aim of the study an interview guide was used. The interview guide consisted of different themes such as; how apps can be used to stay healthy, facilitators and barriers when using apps and aspects of health. The interview guide was validated with a group of persons without any of the three neurological disabilities represented in the study. Minor changes were made to clarify the themes. Finally, the interview guide was approved by all seven authors.

Table 1. Characteristics of participants in three group discussions, including a total of 16 participants.

	Groups		
	1	2	3
Number of participants [n (ID)]	6 (P1–P6)	6 (P7–P12)	4 (P13–P16)
Age, range (years)	51–69	65–74	61–80
Sex (women/men)	3/3	1/5	1/3
Smartphone users	6	6	4
Frequency of smart phone use (daily/several times a week/less)	6/0/0	5/1/0	3/1/0
Tablet users	6	6	3
Frequency of tablet use (daily/several times a week/less)	6/0/0	5/1/0	3/0/0

Each focus group met twice with the same moderator and co-moderator in both sessions. The first author (CW) was a moderator in all focus group discussions while the second and the third authors, each, co-moderated one and two focus groups, respectively. In total, six focus group discussions were conducted, and all of them took place in a conference room at the University. Each discussion lasted about 60 min. All data were transcribed verbatim. Each group discussion started with a question to facilitate the discussion. During the first session the participants presented themselves and their experiences of using apps initially. In the second focus group the discussion started with a summary from the first session. In all the focus group discussions the participants brought their phones and tablets and used them for clarifications and for showing each other examples of apps when needed in the discussion.

Data analysis

The transcribed data were analyzed using thematic analysis, which is a method for identifying, analyzing and reporting patterns (themes) within data [22,23]. The main analysis was performed in several steps by CW, MK, CP and EML. Initially, the authors became familiar with the data by reading the transcripts several times. In the next step three authors (CW, MK and CP) generated initial codes, each focusing on one of the focus groups. The initial coded transcripts were discussed among the three authors in an iterative process to identify relevant findings. The codes were then collated into potential themes gathering all data relevant to each potential theme. A theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set [24]. After joint discussions, the three authors reviewed, defined and named the themes to represent the codes within each theme. As a validation, the last author (EML) read the themes and codes together with the interview data. Her comments were then discussed with the other three authors, until consensus was reached. Finally, the other co-authors, representing the disciplines of design/technology (POH), law (TM) and social sciences (TH) validated the results.

Results

The results of this study show that the participants in all three groups shared many experiences in the use of apps. The results formed two themes; using apps to have control of my health, and using the app as a tool and means for communication. The themes comprised two subthemes (Table 2).

Using apps to have control of my health

The first theme includes two subthemes; "monitor and take responsibility for a healthy lifestyle" and "compensate to facilitate everyday life".

Table 2. An overview of the two themes and their underlying subthemes based on the participants experiences.

Theme	Using apps to have control of my health	Using apps as a tool and means for communication
Subthemes	Monitor and take responsibility for a healthy lifestyle	Dare to trust the app
	Compensate to facilitate everyday life	Feeling safe when sharing information with health care professionals

Monitor and take responsibility for a healthy lifestyle

The participants described how apps enabled them to take increased responsibility for their health and well-being. They stressed the importance of being in control and to be able to adjust to a changing health situation, and how apps can be a mediator in this process. For instance, by taking notes and evaluating their well-being, apps could be used to monitor disease progression and deterioration of impairments. This increased their participants' awareness of how their symptoms changed overtime; information that was valuable when they planned and monitored, for example, how to use their energy efficiently.

> I acknowledge that I, myself, must take a greater responsibility for my health and my well-being in the future. I cannot hand it over to the healthcare professionals. I believe apps can contribute to this (my responsibility for my well-being). (P2)

> Yes, and the apps may increase the awareness and make me more aware of symptoms such as high blood pressure and make me reflect upon what I can do on my own about this. (P3)

> And they can be used to follow up the consequences of my actions and thus create a larger commitment. (P2)

They said they used apps to monitor physical activity and other lifestyle-related factors such as food and sleep habits, weight and blood pressure. Physical activity was considered important for a healthy lifestyle and hence they appreciated apps that motivated physical activity. Participants concluded apps could give clear evidence in terms of duration and intensity, and provided a credible image of activities in everyday life, which made them feel content. They set goals, for example for weight loss and the app gave them immediate feedback if they reached their goals. Feedback and sharing results were also recognized by the participants as a possibility when using apps. At the same time, apps could also create stress if the level of physical activity was not reached. Still, participants emphasized the importance to recognize and accept their limitations, instead of being affected by other peoples' performances. Overall they shared a positive attitude to app use as a way to obtain a healthy lifestyle, but at the same time they were aware that apps could not solve all problems related to their neurological disability.

Compensate to facilitate everyday life

The participants described how apps could be used to compensate for a lost ability, and facilitate everyday life. For instance, participants with MS described how the disease had affected their memory and how they used apps to make notes to remember different events. Another example was how participants, from all groups, who experienced problems with handwriting, said it was easier to take notes on a smartphone or a tablet than writing notes with a pen. Participants with MS and PD who took medicine regularly also used apps for notifications to remember medication.

Most of the participants said they used general apps instead of apps specifically targeting a specific disease. Few of them had knowledge of disease-specific apps but expressed the need for disease-specific apps. They thought that disease-specific apps could be used to gather information and contribute to increasing knowledge and understanding of the disease among users as well as among caregivers. Disease-specific apps could also contribute to sharing experiences among persons with the same disease. General apps and disease-specific apps had different areas of use and could complete each other. The participants speculated on apps based on individual needs:

A personal app where you can insert functions as your disease changes. (P2)

An app based on your needs, but as the needs are changing I will need more functions and help as my disease progress but I decide for myself which tools and functions I need (P4)

The app grows individually so to say (P2)

Exactly like a library of functions from which I can choose depending on my needs (P3)

Using apps as tools and means for communication

In the second theme two subthemes emerged; dare to trust the app and feeling safe when sharing information with health care professionals

Dare to trust the app

The participants presented themselves as empowered and critical subjects, capable of using technology to engage in self-monitoring. They considered it important to use data in a proper and safe way. For instance, they said they wanted to trust the apps measured aspects correctly, and stressed the importance of approved programmes. They also mentioned having apps that were updated on a regular basis.

Awareness regarding the commercial interests concerning apps were another aspect discussed. The participants were aware of how information in apps can be used for commercial interests and for targeted commercials. The information in an app needs to be relevant for the user and the developers need to find out the relevant needs before developing an app. Privacy issues were acknowledged, but considered easy to handle, for instance by not writing secrets in the digital diary.

I consider it a big risk, and people may make money from using this information. Make money on your misery. Security is extremely important (P7)

I do not write any secrets, only bullet points on what has happened during the day. (P9)

But there are disadvantages for instance regarding directed commercial. For instance, if you note certain days in the diary when you are not feeling well. Such information may be misused in directed commercial. (P12)

A too advanced app may make it difficult for the user, which in turn can impact the data and the reliability, and as a consequence also the information derived from the app. The participants also expressed the importance of secure systems for the apps and for the data reported.

Feeling safe when sharing information with health care professionals

Participants emphasized how apps could support the relation with health care professionals through digital meetings or as a means for communication. They expressed that a digital meeting using an app cannot replace a personal meeting but could be suitable for meetings that do not request physical contact. Communication via an app could contribute to continuity and increased quality. Information on medication and other treatments could be shared with health professionals. Participants agreed that health care professionals that read and used the information saved in an app, could contribute to a feeling of being acknowledged and monitored, in a positive and safe way.

They said the use of apps for digital meetings and for communication must be based on mutual interest and agreement to participate on equal terms. That is, patients need to provide health care professionals with information, and they need to read and use this information.

The participants, however, doubted that professionals would have the time to take care of health information saved on, for example, apps. There was an awareness of the lack of resources in the health care sector, which to some extent can be met by the use of apps. The participants had experienced that health care professionals do not have much knowledge on specific apps and that there was a lack of cooperation between health care professionals and app users in the development of apps.

The app must be useful not only for the patient but also for the doctor. (P7)

They tried it in X but the doctors did not use the information which made it all useless (P8)

I agree it seems like the doctors only trust information gathered in their own reception with methods that they are familiar to and that they are suspicious to all other forms of data collection (P9)

You visit the neurologist once or twice a year and you can't remember what has happened in the period since your last visit but if you have written it in your app the doctor can be better prepared for the visit (P7)

It ought to save time. (P10)

The apps were described as trustworthy in monitoring of the body, but less so in sharing information. Participants wanted to share their information not with the "entire world", but with the doctor, the person considered to possess the legitimate knowledge of their condition.

Discussion

This study focuses on how people with a neurological disability (MS, PD and stroke) reason regarding using apps to facilitate self-management in everyday life. The results show how monitoring their disability through apps could help them take control of health aspects in everyday life. At the same time, neglecting to follow the recommendations from the apps could cause stress and anxiety, and participants also raised concerns regarding safety aspects and trustworthiness when sharing information with others. Using apps for self-management can, therefore, be said to both empower and disempower people with neurological disabilities.

When persons use apps to monitor their disability, it will inevitably direct focus on individual choices and behaviours, not on social and medical support from society. This can be related to the strong norms about how to "age successfully" [25], that is, ageing with no disability is a result of an active and healthy lifestyle that each person needs to be responsible of. Minkler and Fadem [26] argued it can be difficult for people with a disability to "age successfully", and suggested taking on a broader ecological approach, focussing on social support, not individual action. Molton and Yorkston [27] added the importance to also focus on psychological support, healthcare resources and to live a life consistent with personal values in the context of disability. Having the opportunity to participate in and make informed decisions regarding one's care is another aspect they argue are important to autonomous successful ageing. This is in agreement with other literature, for instance described by Riggare [5] and

van der Eijk [6]. In the last decade, person-centred care [28] has influenced health care services in Sweden, involving the patient as a partner in all aspects of care. Person-centred care emphasizes a collaborative approach were patients and professionals mutually develop an individual health plan that includes goals and needs each patient identifies as important [28]. Still, a report from 2017 showed that people with chronic conditions in Sweden are less involved in their health care compared with peers in other countries [29]. Using apps to manage and monitor disease may be a helpful tool to better involve patients in decisions regarding their own health, in line with person-centred care. Still, the importance of having an individual approach in this process cannot be underestimated.

The use of apps for monitoring and controlling disability as well as for managing lifestyle behaviour was considered as an opportunity. A central feature was the individualization of assessment in order to control calorie intake and physical activity. The recommendations for a healthy lifestyle, including physical activity and diet, for persons with MS, PD and stroke are the same as for the general population [7] but it may be difficult to reach the recommended levels of physical activity due to the disability [30]. Thus the information gained from the apps could cause stress if the participants did not reach basic assumptions for a healthy lifestyle but on the other hand also decrease the stress of not being active enough since the apps told them that they were more active than they considered them to be. Apps can be seen as disciplinary and can also be described as surveillant tools used to gain knowledge and "medical gaze" that was once reserved for healthcare professionals [31].

Our participants strategically used the apps to compensate for lost function in order to handle everyday life and remember different events, which enabled them to participate in different activities in society. Compensatory strategies include adaptations that persons use to cope with detrimental changes in an effort to maintain activity and participation. These strategies may be obvious, like using a cane, or more subtle, like choosing an app to remember medication, or when to take pauses to save energy, etc. Our participants used apps as reminders, and to keep track of how physically and socially active they were. This is in line with results from previous studies [32]. Still, using apps as a compensatory strategy displayed a tension between mainstream and disease-specific apps. That is, our participants used a rather wide range of apps; ordinary health-oriented health apps readily available to all people as well as disease-specific apps. Ordinary health-oriented apps offered them the functionality they were looking for, in terms of tracking habits and physical activity, whereas disease-specific apps mainly were used to search for particular knowledge regarding their disease or to communicate with, and provide information to health care professionals. It has been suggested that using digitalization potentially can handle the upcoming challenges with an increasing population, especially the proportion of older persons [29]. However individual needs have to be considered during this process. For instance, by developing and adapting apps and other digital solutions to the target groups they are intended for [29].

When developing apps and other digital solutions, safety aspects need to be considered. The participants in our study raised safety concerns in relation to how information in the apps was used, and if they could be trusted when information was shared with healthcare professionals. The lack of laws and regulations between healthcare and the health apps system make use of such information by healthcare professionals totally up to the local department or even the single nurse or doctor [33]. Thus

the app user cannot demand that the health care professionals use information collected by the apps. The legislation does not offer individuals justiciable rights in this regard. The public healthcare sector in Sweden is founded on the goal-oriented framework legislation with the principle of good health for everyone [34]. This means that the implementation of new healthcare systems, such as the use of apps in a more organized way, must rely on other forces than rights-based claims from individual patients. It may lead to local solutions but with a lack of legal support [35]. This will most likely change as the recommendations from WHO recognize the potential of eHealth and recommend to strengthen health systems, safety and access to care need for standardized health data [7].

Strengths and limitations

This study included persons above the age of 50 who considered themselves experienced in using smartphones and tablets. The fact that this was a rather narrow group may have influenced our results but it was imperative in order to have informed focus groups. Our results may therefore not be generalized to all app users, but may still be transferable to participants with similar backgrounds. Still, it is important to acknowledge that we did not include people with no experience of using tablets or apps. This is, therefore, a group that needs to be included in future studies. The stroke focus group included fewer participants than the other groups. This could potentially be viewed as a limitation since the perspective of people with stroke may be less dominant than from the other groups. However, the discussions in the stroke group were vivid which deepened the discussions, and also confirm previous research reporting it as a strength rather than a limitation [21].

The moderators in the focus groups are all experienced in qualitative interviewing and have extended experience in meeting people with different neurological disabilities. To increase credibility and confirmability the analysis was initially conducted separately by the first three authors and the last author. The procedure and content of the analysis were then further discussed, in an iterative process, with the other co-authors. Another strength is the fact that the focus groups met twice with the intent to deepen the discussion, which gave the participants the opportunity to follow up on issues raised during the first focus group. Finally, this interdisciplinary study involved researchers with different professional backgrounds (medical science, law, social science and technical science) through the whole research process, and was considered a strength as the use of apps encompass many areas in a person's life.

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