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Health Care Professionals´ Perspectives on the Uses of Patient-Generated Health Data

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Abstract. Integration of digital self-management solutions into health care processes requires the involvement of health care professionals in the adoption and use of the solutions as part of the care pathway. We conducted 23 interviews with diverse profiles of health care professionals participating in the treatment of chronic patients in three different countries. Our results indicate that health care professionals appeared relatively motivated at the prospect of having access to patient-generated data. Nevertheless, they appeared less confident in weighing what types of data could be collected efficiently through mobile devices and how it could be presented in ways that would provide value to the care process. Our results identify four broad categories for how patient-generated health data could be useful: monitoring, prevention, research, and transparency of condition parameters.

Keywords. Self-management mHealth, Patient-generated health data

1. Introduction

As mobile technologies improve rapidly to provide more accurate measurements of physical status and physiologic parameters, they are starting to influence different aspects of health care practices [1] around the world. The use of mobile solutions for self-management is a growing trend and has been deemed as one of the main success factors in mHealth interventions [2]. This trend, combined with the appropriate use of patient-generated health data (PGHD), could become particularly useful in clinical activities such as monitoring, treatment, and follow-up, especially in the case of patients living with chronic conditions.

PGHD is the data created, recorded, or gathered by and from patients, often through the use of mobile technologies [3]. In patient-centered management models, this type of data can be useful for disease management and prevention[1], and related activities such as motivating patients to adhere to treatment or guiding them into healthier lifestyles [4]. However, several challenges arise as massive amounts of mHealth PGHD from wearable and mobile devices come into the scene, requiring efficient analysis methods and approaches to process and evaluate the collected data, to design actual solutions that could assist HCP and patients in shared decision-making is required. Previous research

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has shown that for HCP, involving medical experts in the design and development of digital health technologies is a determinant aspect for their endorsement and support [5]. Similarly, for most HCP, a solid scientific foundation and theory backing digital solutions is a prerequisite for their validation [5].

In this paper, we explore HCP's perspectives on self-management mHealth solutions and PGHD as means to support chronic patients' wellbeing, and how these new means are perceived as bringing value to standard care practices in monitoring and treatment.

2. Methods

The study was performed in a context of a larger design research process examining a mHealth solution for self-management of Multiple Sclerosis (MS) [6] called More Stamina. As a part of the solution's development process, a qualitative research approach was taken to conduct structured interviews with HCP from 3 different OECD[2] countries with overall good health care quality indicators: Finland, Spain, and Switzerland. Purposive sampling was used to invite HCP from the Neurology department of the Oulu University Hospital, the Multiple Sclerosis Unit at the Vithas Nisa Sevilla Hospital, and the neurological rehabilitation clinic Kliniken Valens. The main inclusion criterion was that participants should have direct experience working with MS care.

The goal of the More Stamina project is to explore how digital health solutions can survive beyond "laboratory" conditions and be integrated into healthcare systems. The mHealth solution is a gamified task organization tool, designed to help persons with MS manage the impact fatigue has on their daily life. The tool acts as a to-do list where users can input tasks they want to accomplish daily. Besides registering, analyzing, and creating trends for patients´ regular activities, the app tracks activity levels through the in-built sensors, counting steps, walking pace, distances, and GPS positioning. Users control what information to disclose and with whom.

Interviews in Finland and Spain were conducted by native speakers while interviews in Switzerland were conducted in English, with the assistance of a support person that could translate to Swiss German. The HCP were shown a short video featuring the More Stamina solution and later interviewed. Interviews were digitally recorded and translated into English for their analysis. The complete interview guide included questions regarding the overall care pathway of MS; for this paper, we focus only on the responses towards mHealth as means for coping with MS and how mHealth and PGHD could be used to assist HCP in improving care and follow up.

A preliminary analysis of the interviews from Finnish and Spanish HCP was carried out using an Affinity Diagram [7]. The Affinity Diagram is a method for summarizing and structuring large amounts of disorganized verbal data into manageable groups based on natural relationships. This analysis process was carried out by 4 researchers with health and computer science backgrounds. The analysis was performed in 3 workshops sessions. In the first 2 sessions, each interview was reviewed, with main observations and topics raised by the interviewees being extracted; categories were created through emerging topics resulting in an initial categorization. On a third session, topics and categories went through a final revision.

The interviews of the Swiss HCP were conducted on a second stage and were reviewed to identify whether new topics or categories had emerged. It was verified that

[2] Organisation for Economic Co-operation and Development

the observations from the new interviews could be integrated smoothly into the existing categories. The final Affinity Diagram was validated by the whole research team.

3. Results

A total of 23 HCP were interviewed (8 from Finland, 7 from Spain, and 8 from Switzerland). The professions of the interviewees included nurses, physiotherapists, neurologists, neuropsychologists, psychologists to occupational therapists. Clinical researchers and social workers were also included, due to their experience with MS care.

After the analysis, we found that the overwhelming majority of HCP (91.3%) considered that self-management mHealth solutions like More Stamina would be a useful tool to improve their patients' self-awareness, motivation, and overall wellbeing.

More than two-thirds (69.6%) felt that PGHD could assist HCP, whether themselves or other medical profiles, in the role in caring for MS patients (Figure 1).

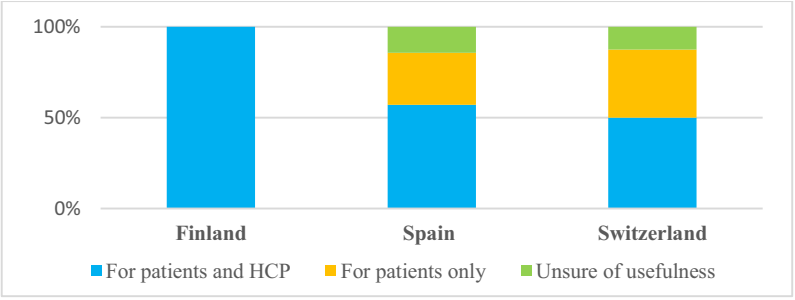

Figure 1. HCP´s views of usefulness of self-management mHealth by country

More than half of HCP (52.2%) showed a personal interest in the possibility of integrating PGHD into care. This group had diverse perceptions of possible uses for PGHD (Figure 2). In general, HCP appeared relatively motivated at the prospect of having access to PGHD that could potentially give them insights into their patients' behaviors or activities. Nevertheless, they appeared less confident in weighing what types of data could be collected through digital solutions, or even how that data could efficiently be presented for easy decision-making. Some of them though did have clearer expectations of the types of information they would like to get from PGHD. Their emphasis laid on:

- Significant changes to the patient's baseline indicators
- Summary of the change in energy levels in a given period
- Fatigue inducing or triggering activities
- Reports on sleep quality, heart rate, and physical activity amount

An 8.7% of HCP reported to be already using PGHD, to some extent, to monitor their patients' health behaviors, as some patients with MS had resorted to their mHealth apps reports to show how much they have walked or slept when asked at consultations

The HCP´s observations on PGHD produced the following subthemes:

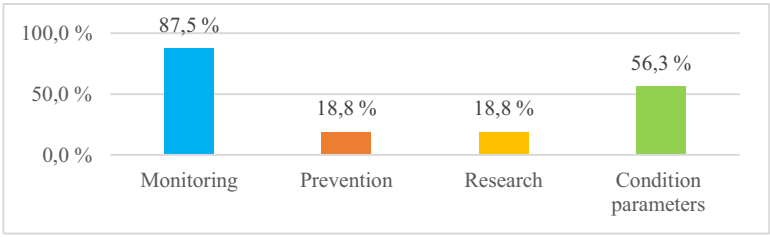

Figure 2. HCP´s Perspective on possible uses for PGHD

3.1 Monitoring and follow-up purposes

Most HCP considered that summaries from PGHD related to physical activity, sleep quality, heart rate variations, medication intake, and other metrics could give them a better understanding of factors affecting their patients in between appointments, especially when there are changes in treatment and medication.

3.2 Prevention of patient deterioration

Some HCP believed that mHealth can provide data that could assist them in the early identification of patterns that sign decline or imminent flare-ups. Prompting patients and HCP with alerts to take action was deemed very appropriate.

3.3 Collection of data for condition research and decision-making

Secondary usage of PGHD was relevant to some HCP for further research on chronic conditions evolution and decision-making in health care workflows and practices.

3.4 Increased transparency of specific condition-specific parameters

Most HCP considered that mHealth solutions as More Stamina could be a useful tool to assess condition-specific parameters, such as fatigue for individual patients with MS. It was suggested that PGHD could be used to help define more measurable indicators of fatigue levels and support in inferring whether patients' fatigue was physical or cognitive.

4. Discussion

The findings in the present study seem to be in line with previous research that confirms HCP views on mHealth solutions as additional support tools for remote management [5] and believe that data provided by digital technologies creates opportunities to better understand factors affecting patients' health outside of the clinical settings, by supporting remote monitoring, expanding care for individuals who have limited access and to improve care for those with acute or chronic conditions [3]. However, an increased use of digital tools seems to evoke concerns in HCP as they feel it might create additional demands and higher workloads in their jobs [8]. Despite those concerns, our findings suggest that HCP in countries with good quality health care indicators appear to have high expectations about the prospect of using digital technologies for patients' self-management in care practices and they seem to be interested in being able to analyze

data that might give them insights into their patient behaviors outside of the clinic. Nonetheless, the big majority of them are not yet using PGHD or do not have precise ideas on how they could use it practice. At least half of HCP appear to view value in the use of PGHD, however, most of them also see a challenge in making it easily understandable and usable.

5. Conclusions

Although perceptions by country varied, on average more than half of HCP considered that self-management mHealth solutions, and the data derived from them, could benefit patients and HCP. They considered that the advantages of using PGHD lay in knowing more about outpatient behaviors and activities, which could help HCP better understand factor affecting patients' health and how treatment could be adapted accordingly. There seems to be positive expectations from HCP about the use of self-management mHealth and PGHD and its possibilities for care. Further research is required to clarify how chronic patients´ PGHD could be better interpreted modeled and presented, using scientific-based approaches, to be efficiently integrated into health care practices in ways that it can make sense to HCP and can bring value to the patient-professional relationship in aspects as monitoring, treatment, and shared decision making.

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