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Patient-Generated Health Data in the Clinic

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Abstract. Physician appraisal of Patient-Generated Health Data (PGHD) is unclear. It is not known how willing they are to consider self-registered measurements prior to treatment. In this research, a semi-structured interview was designed and administered to 10 physicians in Denmark. The study found that physicians are willing to work with unsolicited PGHD and integrate it as a part of the treatment if evidence proved the data to be valid and reliable. They request documented evidence for the use of each PGHD device and mobile application.

Keywords. Patient-generated health data, eHealth, Medical wearables

1. Introduction

The health care system is awaiting a revolutionizing paradigm shift, where it becomes more personalized and enable citizens to take more responsibility for their health and well-being. Digitalization in the health sector is increasing all of Europe as personalized medicine, digital innovations, the Internet of things, and artificial intelligence gains momentum [1]. This shift transfers the control of health care from hospitals and physicians into the hands of patients; more specifically, into their homes and mobile devices [2]. It is estimated that the global market for medical wearables will reach $19.5 billion in 2021 [3]. Patients are becoming more self-reliant in using digital opportunities to maintain their health [4]. Patient-Generated Health Data (PGHD) can be obtained digitally using various devices and mHealth applications. PGHD are health-related data created, recorded, or gathered by or from patients [5]. PGHD is often confused with patient-reported data (PRO-data). In Denmark, PRO-data is described as data about the patient's health, including physical and mental health, symptoms, health-related quality of life, level of functioning, as reported directly by the patient. The collection and reporting of data are requested by the health practitioners. In contrast, PGHD is initiated and driven by individuals, hence a patient-driven data collection modality [6].

It is assumed that PGHD can be instrumental in changing the health care system to focus on health care rather than sick care and to assist patients in being able to prevent many health problems before they become manifest [7]. Despite the growth in the use of PGHD, a literature search indicated a knowledge gap and a lack of evidence-based literature examining physicians' appraisal of PGHD in Denmark. However, the use of PGHD is more common in other countries, mostly in the US, where several health care professionals have worked with PGHD for clinical usage [8]. By accepting and utilizing PGHD, it is possible for physicians to gain greater insight into patients′overall health,

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from which the physicians can make more informed decisions [9]. Examples of PGHD can be physical activity, sleep, temperature, heart rate, electrocardiogram (ECG), blood pressure, blood glucose, and oxygen saturation. In addition to data captured by sensors, PGHD can be supplemented by patient entered information such as mood [10]. More active patients will result in an increasing number of appointments with self-recorded measurements [7]. The benefits of PGHD can be limited for patients if their physicians do not agree to utilize the collected data, and physicians' appraisal of PGHD is still unclear in many countries. It is not known how willing they will be to consider these measurements prior to treatment, hence the aim of this study is to examine physician's appraisals of unsolicited PGHD and investigate how these data can be applied in the clinic in collaboration with patients.

2. Methods and material

Since the aim of this research is to describe and understand clinicians' subjective appraisal of practical PGHD use, qualitative interviews were chosen as the method. An interview invitation was sent to 17 possible participants from the author's professional network in Denmark. Attention was paid to variation in age and field of specialization. In qualitative studies, it is not possible to determine the minimum sample size, but it was assumed that data saturation could be reached within the 17 respondents. An interview guide reflecting the research questions was developed for the semi-structured interviews. In order to test the set of interview questions, two pilot interviews were performed. Explanations for key terms for PGHD, PRO-data, mHealth, pHealth, and patient empowerment were prepared and used for unanimously describing the terms during the interviews. The need for this description indicates how known these terms were.

10 of the 17 invited agreed to participate, and interviews were conducted in the period from 21-03-2019 to 10-04-2019. The physicians decided the date and place for the interviews. All participants provided consent to the interview and audio recording. The interviews ranged in length from 7 to 36 minutes. The interviews were transcribed verbatim for later analysis.

A deductive analysis approach was applied to derive information on categories from the interview guide, priori concepts, and pre-existing knowledge. The themes and coding categories were: 1) current knowledge of PGHD, 2) Physicians´ perspective of PGHD, 3) Future use of PGHD.

To guide the questions and have a specific focus for the interviews, the ECG measurement facility on the Apple Watch, series 4, was demonstrated and used for reference during the interviews. Additionally, pictures of the ECG reading were shown, in the health application and in a PDF file.

3. Results

Generally, the physicians were open-minded about PGHD and the increasing use of mHealth and growing patient empowerment. Some of the perceived benefits mentioned are patients being more liberal, active in maintaining their health, can result in less overload for the physician and also be an assisting tool for the physician. One of the physicians mentions the following: *"I actually think there are some things that might be*

really great if the patients could monitor themselves because then they do not have to show up here to find out things and I also believe in that way it is the relevant patients which come to you, it is not just everyone that comes in, and then you think I am sorry, but I cannot really help you... Whereas you can be some kind of gatekeeper from the start and then the relevant patients come in, now I have this, you can see this is what I have, I want to come in and talk to you."

The results of the analysis of the interviews are presented in Table 1. Some of the concerns expressed were that it could create unnecessary worrying among patients and over-observations, concerns about an increase in the inequality in health and about the data validity. The majority of the physicians do not trust data validity for the Apple Watch´s ECG application and indicated that they would perform their ECG measurements.

Table 1. The different aspects investigated in the study

Item	Aspect/construct	Responses (n=10)	
1	Not familiar with PGHD	%	70
2	Confused PGHD with PRO	%	30
3	Familiar with the existence of PGHD	%	10
4	Experiences of patients seeking out to them with health-related data generated by themselves without prior being solicited from the physicians	%	40
5	Experienced the increasing use of mHealth and patient empowerment	%	70
6	Worried about patients over-diagnosing themselves and creating unnecessary	%	70
7	Worried about increase/creating an inequality in health	%	40
8	Feels it is a good idea that patients can register own data when symptoms occur	%	20
9	Concerned about data credibility and needs validation of data	%	80
10	Willing to work with PGHD in the future as a part of patient treatment if they find data	%	80

The physicians have different opinions about the future use of PGHD. Most of them are willing to use it but have different criteria and necessities. Additionally, physicians reported different ideas for future use where PGHD is included as part of treatment, as well as perspectives on how the data should be integrated as a part of the EHR.

4. Discussion

Overall the physicians were not familiar with the term PGHD. Those who said they were actually confused it with PRO-data, which some of them were familiar with to a certain extent. Although some of the physicians were not familiar with PGHD and the use of it, they already had experienced patients bringing their self-registered data without it being solicited by their physician. Most of the physicians had experienced increasing patient empowerment, except for two of them who work with elderly and mentally ill patients. Most of the physicians were familiar and experienced with the patients´ use of mobile health applications and patients looking up their symptoms and diagnosis on Google.

Generally, the physicians are open-minded about PGHD. Some of the benefits and concerns expressed in the interviews replicate results reported in the literature [6, 8], [11–13]. Benefits can be gained not only for the physicians but also for the patients, by

being more active and involved in the decision making for their treatment, thereby becoming more patient-centred. This can likewise help physicians to be diagnostic efficient and effective. The data validity and verification were one of the main concerns mentioned by the majority of the physicians, and it was decisive for their willingness to use PGHD. Concerns about over-diagnosing, patients becoming excessively worried, and making themselves feel more ill than they were, in reality were mentioned repeatedly. Even though the physicians felt that patients became more concerned from generating their data, some of the physicians still had an understanding of why they did so.

Another major concern was an increase of inequality in health among patients. The increasing inequality and deepening of the gap between the "haves" and "have-nots" are also one of the main apprehensions mentioned by Eysenbach as a considerable threat [14]. The concern of the availability of PGHD among low-income and elderly populations and those who often needed it the most was also shared among physicians' opinions found in the literature [11]. A cardiologist at University of California San Francisco states that the individuals who purchase Apple watches often are those who are already health-conscious and probably quite healthy, whereas those who would have the most benefit from the atrial fibrillation screening tend to be the elderly, who might be less tech-savvy and less concerned about their health [15]. In addition to worried patients, this situation can also induce a greater workload for the physicians.

Many of the physicians emphasize the importance of not only looking at measurements but also at the patients' symptoms. They would consider forwarding the patient to a cardiac specialist if the symptoms were significant and the ECG still showed a sinus rhythm. Generally, in this research, it was discovered that most of the physicians did not fully trust the ECG application on Apple Watch. Most of them were open to looking at the ECG reading brought by the patients but would then use their own verified device, e.g. a Holter. However, according to Cardiologist John P. Higgins, the updated capabilities of the Apple Watch Series 4 can broaden the monitoring capabilities of existing technologies. He states that it *is less invasive than Holter monitor, has great battery life and can be with the person 24/7* [16].

American physicians share the concerns of their Danish colleagues about the lack of evidence to justify the Apple Watch ECG against the risk of false positives. The latter would cause healthy/wealthy people to take up the time resources of both physicians and hospitals since there is no evidence that the benefits outweigh the harm. At the same time, another American physician states that for people with heart conditions or symptoms, the Apple Watch could serve as a good tool for detecting when something is wrong and when a visit at the physician is necessary [15]. This research shows that the physicians are willing to use PGHD as a part of treatment, as long as their individual criteria and needs are met. Some of the needs reported in the literature [13], such as making time to review PGHD, uncertainty of data quality and the need to distinguish between data measured by patients and by health care professionals.

Most physicians agreed with integrating PGHD into the EHR, as was already done according to [17]. Many of their future ideas for the use of PGHD is likewise based on importing the data into the EHR. However, it was important for physicians to be able to distinguish between the data collected by themselves and by the patients.

Despite the different opinions about PGHG and the benefits that can be gained by using it, and likewise the increased workload and burden for the physicians, it is clear that the first priority among the physicians is the safety of the patients. They do not wish to place all responsibility on the patients. They want to make sure that the devices and mobile applications can be trusted while avoiding unnecessary patients worry.

5. Conclusion

This qualitative study showed that Danish physicians sampled have an overall positive appraisal of PGHD for clinical usage. Despite the many clinical benefits to be gained, the physicians prioritize data from validated, and reliability checked sources before taking it into consideration for clinical decisions. The physicians appreciate increasing patient empowerment and are willing to use PGHD as a part of the treatment for those who have the resources and desire to do so. Additionally, the physicians welcome importing PGHD into the EHR, as long as they are clearly marked. The physicians request more studies and documented evidence for the use of each PGHD device and mobile application; therefore, further research is needed to achieve a general appraisal.

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