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Citation Details

A. S. Alhomod and S. Alzahrani, "Patient Empowerment via Mobile Personal Health Records and Mobile Health Applications: A Review of the Current Use," 2019 Portland International Conference on Management of Engineering and Technology (PICMET), Portland, OR, USA, 2019, pp. 1-4.

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Patient Empowerment via Mobile Personal Health Records and Mobile Health Applications

A Review of the Current Use

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Abstract—Consumer empowerment has gained a significant attention in the medical field recently, and despite the ambiguity of its definitions, elements and measurement tools, it is apparent that mobile and other communication technology can play a major role in keeping patients informed, involved and empowered. This paper aims to explore methods by which mobile applications contribute to consumer empowerment and allowed enhanced patient control over their health.

I. INTRODUCTION

Today, the use of smartphones is becoming a preferred method of communication, users across the world use smartphones to manage daily activities, such as task control, finance, social interactions & staying on top of health issue including patient portals and getting reminders about medications and due health maintenance. The numbers shows the growing market for the mobile health apps. The total market for mHealth apps is predicted to exceed \$50 billion in 2025 from around two billion dollars in 2016 [1]. The usage of health apps and smart health devices in the United States shows that in 2017 approximately 31% of the respondents stated that in the past 12 months they had used health apps that include: medication tracker, symptom checker, and nutrition apps [2].

Mobile Personal Health Records (PHR) and empowerment tools and applications have benefited from the technological advancements of the information and communication technology tools. At the fingertip of the patient, health information regarding certain health conditions can be obtained to aid health decision making. Mobile apps have brought significant contributions to patient health.

With the wild attention toward Mobile Personal Health Records (PHR) apps, the aim of this paper is to fill a gap in the current literature by examining the methods by which mobile Personal Health Records (PHR) applications contribute to consumer empowerment.

II. METHODOLOGY

A literature review is conducted to explore methods by which mobile Personal Health Records (PHR) applications contribute to consumer empowerment and allowed enhanced

patient control over their health. The goal is to review the existing literature on the mobile applications and their contribution to the patient empowerment. The sources used in this research are academic references; and high quality reports published by accredited institutions.

III. PATIENT EMPOWERMENT

A. Definiton and background

The patient empowerment concept is becoming a cornerstone in providing healthcare and planning outcomes. The WHO Health Promotion Glossary mentioned one of the earliest definitions for Empowerment for Health in 1998 as “a process through which people gain greater control over decisions and actions affecting their health.”[3] Since then, a large number of definitions and interpretations of the term have been discussed in the literature without a consensus. [4, 5] One of the most recent literature reviews by Eva Marie Castro, et. al. presented more than 20 different definitions and proposed the following as a result of comprehensive concept analysis research: “Individual patient empowerment is a process that enables patients to exert more influence over their individual health by increasing their capacities to gain more control over issues they themselves define as important.” [5].

B. Empowerment elements and measurement tools:

There are many tools for measuring patient empowerment, in addition to several elements and principles that constitute the concept of patient empowerment. As mentioned by Castro et. al., (3),patient empowerment is a boarder concept than patient participation and patient centeredness, and coming up with a comprehensive list of elements to cover patient empowerment can be extremely difficult. Without the presence of enough evidence on the appropriate elements of empowerment, researchers have used different sets of elements; some have used specific elements for patients with such specific diseases as rheumatology conditions; autoimmune diseases; diabetes; and mental health disorders, especially when the scope of the study is not to redefine the concept of empowerment. Still others have proposed a generic list that will fit all patients in all situations. (2, 3)

“People gain greater control over their health if they are informed, skilled, and motivated” said Alpay et. al., (4) as they described their view of the requirements for patient empowerment. It’s obvious how a wide range of elements can be extracted from just the terms informed, skilled or motivated.

On the other hand, a group of researchers at Cardiff University published a study recently (Date) aiming to accurately conceptualize patient empowerment; this study proposed categorizing the empowerment into three comprehensive elements: 1- Patient rights and responsibilities; 2- Healthcare professionals’ responsibilities; and 3- Healthcare system responsibilities. Each level includes a different set of activities (5).

For the purpose of this paper, we will review the potential for patient empowerment using the Personal Health Records (PHR) mobile portals and mHealth applications (app; apps) with respect to the top10 empowerment elements proposed by a recent literature review of more than 20 papers written about patient empowerment elements. (6) A List of the most common empowerment elements presented in the literature, from Cerezo et. al. (6)

TABLE I. LIST OF THE MOST COMMON EMPOWERMENT ELEMENTS PRESENTED IN THE LITERATURE, FROM CEREZO ET. AL. [6]

Participation in decision-making	Sense of meaning to patients’ experience
Gaining control	Motivation
Knowledge acquisition	Trust
Coping skills	Self-care
A positive attitude	Sharing and capacity building

It is not surprising that the measurement tools for patient empowerment are not the same across the board. Researchers and experts in the field have different approaches in building such tools. Some can be used only to assess the level of empowerment in specific patient populations, such as patients with Type 2 Diabetes Mellitus or patients with mental health issues. Other tools can be used with specific age groups, for example, geriatric patients, or in specific clinical settings such as inpatient or primary care settings. (6)

A systemic review by Barr et. al. provided a list of the most commonly referenced patient empowerment measurement tools, with some details, including the target population and the language of each tool (2)

IV. MOBILE PERSONAL HEALTH RECORDS AND EMPOWERMENT

A. Definitions and types:

Providing patients with access to their personal health records through an online portal is in itself a form of empowerment and the majority of patients agree with this statement despite the privacy concerns. [7] But the PHR role in empowerment is far more complex than just providing access. Before we review the potential empowerment through the implementation of a PHR system, we will present the definitions and types of PHR systems.

Like most unfolding concepts, the PHR definition is still under development; one of the common definitions to use is the one by the Mackle foundation, which states that a PHR is “an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it.”[8, 9] Different types of PHR systems are available for consumers; one of the most common types is the tethered PHR, which is usually provided to the patient by the patient’s insurance company or the healthcare system that is providing care, i.e. hospitals/clinics.

The second type is the standalone PHR, which is provided mostly by a third party without being controlled by the insurance company or the healthcare system. [9, 10] Another type of PHR is the interoperable PHR, where patients can retrieve their own health information from multiple integrated EHR systems and can control it and utilize it to monitor their health appropriately. This type is potentially could be or has the potential more helpful, despite the challenges in adequate interoperability. [9-11] All these types of PHR now offer mobile applications (hereafter mPHR).

B. Role in patient empowerment:

The question of how providing PHR systems empowers patients was answered thoroughly by the “Personal health records: Empowering consumers” article, that listed such aspects of empowerment, as helping patients managing chronic conditions, making informed shared decisions and increasing patient understanding of health issues and treatments provided. [12]

In addition to that, PHR that is connected to other health apps has the potential to promote healthy outcomes, as shown in the “empower” study, which developed an app to support self-management for patients with diabetes by providing a platform that has data from PHR in addition to data recorded by patients. According to that paper, this approach may potentially be helpful to physicians and to the physician-patient relationship. [13]

Mobile PHR apps can potentially provide benefits that may be added to the value of the traditional PHR. For example, they offer data sources at the point of care, which is important in case of emergencies as reported by some healthcare providers who participated in patient care during recent disasters (Hurricane Katrina). They also add value to such specific populations as pediatric and non-communicating patients when gathering data can be challenging. [14] In addition, they have value as a vault for data, especially in the case of interoperable and standalone mPHRs. In 2012, there were almost 20 standalone mPHRs. Some of these provide patients with the ability to store diagnoses, surgeries, and medication data. Others will also allow immunizations and lab results to be stored on the app. [15]

V. OTHER MOBILE HEALTH APPLICATIONS AS EMPOWERMENT TOOLS

A. Definitions and types:

“In 2016, Users Will Trust Health Apps More Than Their Doctors.” [16] This was the title for an article published at forbes.com recently and, despite the fact that this statement may not necessarily be true, it clearly shows the value of mobile apps in health care and their potential impact. A recent systemic review showed the effectiveness of and potential for outcome improvement by using tools provided by mobile apps to aid self-management of chronic illnesses.[17]

The concept of mHealth is defined by Istepanian et. al. as “emerging mobile communications and network technologies for healthcare.” [18] Major app stores have a vast number of mHealth applications, which increased the need to develop a method to categorize such applications. The types or categories of mHealth applications were discussed in publications in different ways; for example, a recent report published by the University of Tennessee based on prior work done at the University of Cambridge in conjunction with China Mobile categorized mHealth apps into multiple categories such as “Public Health Research, Primary Care, Emergency Care, Management of Long-Term Conditions, Information and Self-Help, Whole System Efficiency Improvement, Mobile-Enhanced Appointment Booking/Reminder System, Drug Authentication and Tracking, Well-Being, Sensors and/or Other Peripherals, Mobile Tele-care, Intelligent and Targeted Public Health Messaging, and Using Aggregated Private Data for the Public Good. [19] Another way of categorizing mHealth Apps is described by other authors as the following: [20].

TABLE II. A LIST OF MHEALTH APPS CATEGORIES [20]

Chronic Disease Management
Remote Monitoring
Diagnostic Tool
Personal Wellness and Healthy Living
Access to Health Information
Medication Adherence
Miscellaneous

B. Current status:

Many apps were developed to help the clinician make a decision, either by reviewing data from a current encounter and data available in the EHR, or by providing data that was stored to the patient’s personal mPHR. With regard to patient empowerment, some apps were developed to help patients participate in such decision making processes as:

My transplant couch: An app that was designed to help patients with renal transplant understand their medical condition. The multidisciplinary team who developed this app published a significant improvement in the patients’ ability to participate and a make an informed decision after using the app. [21]

MenoPro: Described in the app store as having been “designed to help clinicians and women/patients work together to personalize treatment decisions based on the patient’s personal preferences” this app has two modes, one for the clinician and the other for the patients. [22]

Chronic disease apps: Some app developers focused on chronic disease management, e.g., diabetes, asthma, COPD, and many other chronic diseases. [23] There are more than 30 apps to help patients with diabetes control their sugar.[24]

The Strong Heart App: mHealth can empower patients by facilitating knowledge acquisition as seen in this app, which was designed to provide patients with coronary artery disease (CAD) with evidence-based educational materials. This app successfully showed more than an 80% satisfaction rate by learners. [25]

The SmartQuit app: A mobile cessation app that was rated in the top 50 apps and was supported by high quality evidence according to a recent study. [26] Its method of empowerment: motivation.

Silva and his co-authors published a review on the current status of mHealth where they used the IMS Health App score to help identify significant mHealth applications. [27] Apps from this list were reviewed in the Apple app store and/or the Android app store, then evaluated for the possibility for fulfillment of elements needed for patient empowerment:

WebMd Pain Couch app: Designed to help patients monitor and cope with their chronic pain through providing tips, articles, goals, videos, slideshows and quizzes. Method of empowerment: coping skills.

Calorie counter app and chest training app: Such apps facilitate patient goals in monitoring lifestyle choices or developing healthy habits. [27] Method of empowerment: self-care.

Finally, it is important to emphasize the fact that most mobile health apps require further development and further evaluation in large, patient centered outcome studies to accurately assess the benefits of such apps.

VI. DISCUSSION

This paper showed the presence of different approaches to identify elements of patient empowerment and methods to measure the level of empowerment achieved by patients. Of the three types of mobile personal health record applications, the interoperable mPHR has a more significant potential to foster patient empowerment, but given the lack of universal interoperability until today, its maximum utilization is yet to be reached. A successful case seen by the use of an interoperable mPHR is allowing the interaction of patient-generated health data with the EHR data that is generated through a health care facility visit.

We showed that mPHR tools empower patients in many aspects such as providing secure access to data in critical situations such as during medical emergencies and for non-

communicating patients, and when patients cannot adequately describe their past medical and surgical histories. We also described how mobile health applications impact on patient empowerment goes beyond mPHR to other aspects of care such as chronic disease self-management aids, providing relevant and trusted information, and facilitate behavior changes as seen in smoking cessation, and weight loss tools.

There are many challenges in utilizing mobile health application in health care such as the lack of firm control over the content of mobile health applications. In addition to that, the digital divide and health literacy issues limit the value of such a tool to patients who can download apps and follow instructions required to use such tools appropriately. Another challenge is that the unsupervised used of such tools may lead to misinterpretation by the patient; it also could lead to inaccuracy of data entered manually by consumers.

VII. CONCLUSION

This paper aims to review the elements of patient empowerment and examine the methods by which mobile health applications can contribute to consumer empowerment. To achieve patient empowerment; patients, health-care providers and health care systems need to work hand by hand to set expectations, provide guidance and optimize measurement of patient empowerment, and mobile health app development. As mobile health Apps development, deployment and use by general population is growing, evaluating their use to promote empowerment is vital to ensure proper utilization. Today, mobile health Apps can be used to promote patient education, access to information, medication adherence and facilitate behavior changes. To facilitate proper utilization, mobile health Apps contents need to be frequently examined in a peer-reviewed process, patient must be educated to use the tools accurately and healthcare systems needs to facilitate interoperability and collaborate with health app development companies to target specific elements of patient empowerment.

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