Patient Empowerment Through a User-Centered Design of an Electronic Personal Health Record: A Qualitative Study of user Requirements in Chronic Kidney Disease

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Research Article

Abstract

Background

To improve chronic disease outcomes, self-management is an effective strategy. An electronic Personal Health Record (ePHR) is a promising tool with the potential to support chronic patient's education, counseling, and self-management. Fitting ePHRs within the daily practices of chronic care providers and chronic patients requires user-centered design approaches. We aimed to understand users' needs and requirements in Chronic Kidney Disease (CKD) care to consider in the design of an ePHR to facilitate its implementation, adoption, and use.

Methods

A qualitative study was conducted in a major Iranian nephrology center including inpatient and outpatient settings in 2019. We conducted 28 semi-structured interviews with CKD patients, nurses, and adult nephrologists. To confirm or modify the requirements extracted from the interviews, a focus group was also held. Data were analyzed to extract those requirements that can facilitate implementation, adoption, and sustained use based on the PHR adoption model and the Unified Theory of Acceptance and Use of Technology.

Results

Participants requested an ePHR that provides access to up to date patient information, facilitates patient-provider communication, and increases awareness about patient individualized conditions. Participants expected a system that is able to cater to low patient e-health literacy and high provider workload. They requested the ePHR to include purposeful documentation of medical history, diagnostic and therapeutic procedures, tailored educational content, and scheduled care reminders. Messaging function, tailored educational content to individual patients' conditions, and controlled access to information were highly valued in order to facilitate its implementation, adoption, and use.

Conclusions

We focused on the ePHR's content and functionalities in the face of facilitators and/or barriers envisioned for the implementation and adoption of an ePHR in nephrology care. Different users' requirements should inform the design and implementation of ePHR system especially in the context of CKD care. The insights gained can help ePHR designers and implementers to better support CKD patients in self-management.

Contributions To The Literature

- Fitting ePHRs within the daily practices of care providers and patients, especially in chronic kidney disease care requires user-centric design.

- To do so, understanding users' needs and requirements regarding the content, and functions of an ePHR is a prerequisite.
- Fully understanding users' needs and requirements can help to design an ePHR system that better supports users in the context of chronic kidney disease care and enable empowering chronic kidney patients in self-management.

1. Background

Self-management is an effective strategy to improve chronic disease patient's clinical outcomes and quality of life (1). As information technologies facilitate access to health information, their use can increase patient's health knowledge and enable patient-centered approaches to the delivery of care (2). Electronic Personal Health Records (ePHRs) are seen as one of the most promising tools to support patient's self-management (3–5). Studies acknowledge that ePHRs improve patient-provider communication and empower patients to self-manage their diseases, effectively (3, 6).

ePHRs have successfully been deployed in developed countries such as the United States (US), the United Kingdom (UK), South Korea, Australia, and Germany (7–11). In some countries, ePHRs allow patients to access their health data in Electronic Health Records (EHRs) or Electronic Medical Records (EMRs) (11–16). However, this is not the case in all settings for reasons such as the lack of interoperability between information systems (17). This can generally limit access to patient's health records available in healthcare settings and reduce ePHR adoption (18). Addressing this barrier requires a high investment in information infrastructure (19). Therefore, implementing an ePHR is not an easy task even in the developed countries due to various barriers (20). For example, the experience of implementing an ePHR in the UK showed that poor attention to user expectations and weak system usability led to the system's low adoption (9). In order to be widely used, ePHRs should meet different users' expectations regarding patients' conditions and fit in the existing health and technology infrastructures (21). Therefore, paying attention to the user-centric design approaches of ePHRs while having an eye on the available infrastructure seems a prerequisite for their successful deployment (22).

Given the positive impact of ePHRs on patient outcomes, many researchers have aimed to develop ePHRs to empower patients with chronic kidney disease (CKD) by supporting self-management (23–26). With ePHRs, patients are able to share their health-related information with care providers and self-manage their diseases, as shown in other chronic diseases (4, 6, 27). To this end, ePHRs need to satisfy chronic disease patient's needs and requirements and fit in with the daily practice of care providers and the healthcare context and infrastructure (28–30). Therefore, as a first step to develop an ePHR for CKD, we aimed to have a better understanding of users' needs and requirements with regards to its contents and functions. We were interested in getting this insight in the face of an ePHR's likely adoption facilitators and/or barriers and consider them in its design and implementation in a developing country.

2. Methods

This was a qualitative study conducted in a major nephrology care center in an academic hospital of Urmia University of Medical Sciences (UUMS), in Iran. The study setting included nephrology inpatient wards, outpatient clinics, and dialysis centers (i.e. hemodialysis and peritoneal dialysis units). All units use a hospital information system (HIS). Recently, a CKD disease registry has been implemented in nephrology care. The study was approved by the Ethical and Research Committee of the UUMS.

In this setting, we conducted a qualitative study and collected data through in-depth, face-to-face, semi-structured, and one-on-one interviews as well as a focus group performed between February to August 2019. In the first phase of this study, we interviewed CKD patients, nurses, and adult nephrologists. Participants were selected through "purposive" sampling (31) to identify the requirements for an ePHR for CKD patients. All nephrologists involved in nephrology care at the time of this study were invited to participate, and all participated, except one. We recruited patients with consideration to their gender, age, social status, educational level, stages of the disease, and hospital settings. Some of the patients were proposed by our participating nephrologists as informant patients. Patient participants were selected to include those aged 18 years or above and all CKD stages (Stages 1 to 5) with different disease conditions (i.e., before or after starting the dialysis, having various underlying diseases and comorbidities, etc.). Nurses were recruited from among those who worked in the dialysis units and nephrology inpatient and outpatient settings, again mostly recommended by our nephrologists as nurse informants. We stopped recruiting interviewees when the saturation of data in each group of nurse and patient participants was reached.

The interview questions were designed according to the knowledge and roles of the three participant groups. Appendix 1 provides the details of questions in our study. Formal consent was sought from the participants. They either completed a written consent form or gave verbal consent to participate in the interviews. The interviews (lasting on average 25 minutes) were audio-recorded after assuring participants that their confidentiality would be respected by the researchers. The interviews were transcribed verbatim. To ensure the validity of data, "member checking" was performed with the clinicians to confirm or correct their statements.

Afterward, we held a focus group with clinicians to discuss, confirm, or modify the information extracted from the analysis of the interviews. Like interviewees, the participants were purposefully selected. Some of them had previously participated in our interviews, as well. The focus group lasted for one hour forty-five minutes. During the focus group, a moderator (the corresponding author) and a note keeper (the first author) managed and facilitated the discussions among participants based on our questions (Appendix 1). This session helped to reach a consensus on the scope of the PHR and its functionalities (based on the requirements extracted from interviews) that would work in our context. Complemented by the written notes taken by the note keeper, the discussions were recorded and transcribed verbatim.

We used the "Personal Health Record Adoption Model" (PHRAM) to analyze the ePHR requirements mentioned by CKD Patients (32). This model integrates five factors that interact to affect the intent to adopt, and ultimately use, PHRs. These factors are personal (including demographics, e-health literacy,

self-efficacy, knowledge, and skills), environmental (including facilitating conditions and incentive motivation), technology (including cost, perceived usefulness, perception of external control, relative advantage, and complexity), and chronic disease factors (including self-management, preferences for self-regulation, perceived complexity of condition and treatment, access to care, and multiplicity of settings, healthcare providers and chronic illnesses) that affect the behavioral outcome (i.e., in our study intention to adopt a given ePHR). For the analysis of the requirements requested by our care providers, the "Unified Theory of Acceptance and Use of Technology" (UTAUT) was applied (33). The UTAUT comprises of four main factors of performance expectancy, social influence, effort expectancy, and facilitating conditions, which have prominent roles as direct determinants of user acceptance of a technology and usage behavior. The transcribed data were imported into the AtlasTi (ATLAS.ti 8, Berlin, Germany). The first author systematically coded the data to identify and categorize key themes. The corresponding author closely supervised this process and double-checked the extraction of themes based on the two aforementioned frameworks as well as the whole analysis. The inter-coder reliability was 0.84% between these two coders. Any disagreement was solved by discussion during multiple meetings. An audit log of decisions was kept along with the codes.

3. Results

3.1. Study participants

We undertook 28 interviews with 15 CKD patients, 10 nephrology nurses, and three adult nephrologists. Patients' age ranged 21 to 79 years; six patient participants were at the early CKD stages, and almost equally recruited from inpatients, outpatients, hemodialysis and peritoneal dialysis settings. Five nurses from the nephrology and the dialysis units and one senior nephrologist participated in our focus group meeting. The results are provided here based on the factors in the PHRAM and UTAUT models.

3.2. Factors that influence ePHR adoption by CKD patients

3.2.1. Personal factors

Our participants had positive attitudes towards the availability of an ePHR. They thought that it can increase their awareness of their disease and the care they needed. By removing temporal and geographical barriers, it can also facilitate access to care providers and educational materials and health information, helping to alleviate patient stress and expenses. Using such systems, patients expected to have access to a complete report of their condition anytime/anywhere. The following quote highlights such expected benefits from an ePHR:

"... very good, then I can control my health [condition]. For example, how much is my creatinine and what can I do to decrease it? It gives me all of my personal information, I can improve my care performance... my life performance will be improved [, too]...". (A CKD patient – 17th February 2019)

Yet, many concerned that the advancing age, lack of interest, and low e-health literacy would represent the main barriers to adopt the system. Similar barriers were also echoed during provider interviews. They mentioned that most of their patients have lower e-health literacy and therefore may not be able to understand or use these types of systems. A nurse told us:

"... not all of them [patients] are educated. Also, some of our patients might not be able to use [an ePHR] ... patients can't record everything [in the system by themselves], for example, patients can't record their CT-scan [result that]: "hydronephrosis was observed in my left kidney", our patients can't record these types of information ...". (A nurse – 22nd of February 2019)

3.2.2. Environmental factors

Several patients reported their inability to use or access the technical equipment to use the ePHR (e.g., the Internet or smartphones). They, however, believed that having supporters such as caregivers and their family members would assist them to bypass such barriers.

"...I'm an educated person, but, really, I don't know how to work with the internet. I think it is difficult to learn. If my daughter works with an ePHR instead of me, that will be fine because she knows how to work with it...". (A CKD patient-5th February 2019)

3.2.3. Technological factors

There was an agreement that the information in the ePHR should be displayed according to an individual patient's condition in a simple and easy to understand language and format. Thus, the use of complex medical terms and jargon should be avoided, because patients might misunderstand their disease condition or misinterpret information available within an ePHR. Participants believed that the availability of multimedia educational materials such as movies or even voice messages would facilitate ePHR's acceptance and use, especially by patients with low e-health literacy levels. The next point was the importance of preserving patient privacy and information confidentiality and preventing unauthorized access to the ePHR. They recommended establishing mechanisms to strictly define the levels of access to protect privacy and information confidentiality.

Using such technology entails costs. Besides the cost of acquiring the technical equipment, patients were concerned that care providers might not support using the ePHR because it wasn't clear how they would receive a fee for the service given through it. Therefore, some patients were willing to pay for this service rather than travel long distances and wait a long time to consult specialists.

"In all cases, the cost of counseling through this [ePHR] is less than the cost of face-to-face counseling. I come here from another town and one day of my life and also money is spent ..." (A CKD patient-3rd February 2019)

3.2.4. Chronic disease factors

One of the main supporting functions for self-management, which all patients emphasized, was the need for education and training through an ePHR on the subjects inflicting chronic patients. Specialized, individualized, and purposeful information and educational materials for different CKD stages and varying comorbidities would increase patient awareness and reduce provider time and efforts spent on the education of subjects such as lifestyle, medication use, diet, and care in hemodialysis or peritoneal dialysis. However, they were cautious that simply making the information available within the system without any reasonable explanation might sometimes increase patient anxiety about their disease. They also requested a reminder system due to the chronicity of their disease and frequency of events and preventive measures, for example, to remind the time of medication use, upcoming follow-up visits, vaccinations, laboratory tests checkups, and notification of result availability. Table 1 provides examples of data categories requested by patients.

Table 1
The data categories (and items) required for support of CKD patients by an ePHR

Category (number of information requested by participants)			Data items (number of information requested by participants)
Demographic information (8)	Patient demographic (5)		First and last names (5), gender (3), national identification number (1), date of birth (4), marital status (2), job (5), contact numbers (2), address (1), postal code (1)
	Patients' accompaniment demographic (6)		First and last names (3), gender (2), relation with patient (3), emergency phone number (6), address (2), postal code (1)
	Patients' care provider demographic (5)		First and last names (5), type of care provider (such as nephrologist, nurse, internal specialist, general practitioner, clinic secretary, intern or resident)(4), work address (1), contact number (2)
History of patient's CKD (28)	Specific clinical history of CKD (10)		The main cause of CKD (6), stage of the disease (9), first time CKD diagnosis (5), history of kidney biopsy (3)
	RRT history (19)	General RRT information (18)	Kidney transplant status (6), dialysis status (17), method of dialysis (12)
		Clinical history of hemodialysis patients (13)	Type of vascular access (including graft, fistula, temporary catheter or permacath) (13), vascular access insertion date (10), start date of hemodialysis (6), frequency of hemodialysis per week (7), hemodialysis section address (3)
		Clinical history of peritoneal dialysis patients (8)	Peritoneal catheter insertion date (5), start date of peritoneal dialysis (4), frequency of hemodialysis per day (7), exit site status (4), exit site infection (6), peritonitis history (3), frequency of peritonitis (2)
		Clinical history of diabetic patients (18)	Diabetes status (18), diabetic retinopathy status (9), diabetic ulcer status (8), place of diabetic ulcer (6)
	General medical history (23)	Life style (15)	Height (3), weight (15), history of alcohol use (6), history of smoking (4), the result of the last echocardiography (5), other comorbid disease (11)

Abbreviations: Chronic Kidney Disease (CKD), Renal Replacement Therapy (RRT), Complete Blood Count (CBC), Blood Urea Nitrogen (BUN), Fasting Blood Sugar (FBS), Hemoglobin A1c (HbA1c), Alanine Aminotransferase (ALT), Aspartate Aminotransferase (AST), Alkaline Phosphatase (ALP), Bilirubin Total (Bili-T), Bilirubin direct (Bili-D), Thyroglobulin (TG), Low Density Lipoprotein (LDL), High Density Lipoprotein (HDL), Intact Parathyroid Hormone (iPTH), vitamin D (Vat D), Total Iron Binding Capacity (TIBC), Hepatitis B surface antigen (HBsAg), Hepatitis C Virus Antibody (HCV Ab), Tuberculosis (TB), Prostate Specific Antigen (PSA), Erythrocyte Sedimentation Rate (ESR), Kidney, Ureter, and Bladder (KUB), Chest X-Ray (CXR), Computed Tomography-Scan (CT-Scan), Magnetic Resonance Imaging (MRI)

Category (number of information requested by participants)			Data items (number of information requested by participants)
		Allergies (21)	Medication allergies (19), food allergies (6), other allergies (2)
	Hospital admission history (15)	Internal sections admission history (9)	Admission date (3), record summary (7)
		Medical procedures history (12)	Admission date (4), record summary (9)
	Family history (11)		First and last names (3), relation with patient (5), type of disease (5)
Laboratory results (28)	Biochemical tests (26)		CBC (7), Creatinine (26), BUN (16), FBS (11), HbA1c (8), ALT (5), AST (5), ALP (3), Bili-T (4), Bili-D (4), TG (8), Chol (11), LDL (11), HDL (12), Calcium (8), Phosphate (4), iPTH (3), Vit D (4), Sodium (2), Potassium (6), Ferritin (1), TIBC (1), Iron (5), HBsAg (5), HCV Ab (6), TB (2), PSA (4), ESR (3)
	Radiological test (12)		KUB (5), CXR (1), CT-Scan (8), MRI (5), sonography (11)
Medication (28)			Medication name (25), medication form (6), medication dosage (12), time of medication intake (26), start time of medication intake (15), cessation of medication intake (12)
Training information (17)			System user instruction (3), training of important medication (9), training of nutrition (16), training of lifestyle (15), training of hemodialysis and peritoneal dialysis (8), training for providing patients recommendation for introducing family members in screening (1), frequently asked questions (1)
Daily reports (16)	Information of liquid consumption limitation (4)		Consumption date (1), consumption volume (3), volume of repulsed liquid of urine (3), volume of repulsed lateral liquid (3)
	Daily clinical symptoms (15)	Hypertension information (16)	Date (3), hypertension ratio (14)

Abbreviations: Chronic Kidney Disease (CKD), Renal Replacement Therapy (RRT), Complete Blood Count (CBC), Blood Urea Nitrogen (BUN), Fasting Blood Sugar (FBS), Hemoglobin A1c (HbA1c), Alanine Aminotransferase (ALT), Aspartate Aminotransferase (AST), Alkaline Phosphatase (ALP), Bilirubin Total (Bili-T), Bilirubin direct (Bili-D), Thyroglobulin (TG), Low Density Lipoprotein (LDL), High Density Lipoprotein (HDL), Intact Parathyroid Hormone (iPTH), vitamin D (Vat D), Total Iron Binding Capacity (TIBC), Hepatitis B surface antigen (HBsAg), Hepatitis C Virus Antibody (HCV Ab), Tuberculosis (TB), Prostate Specific Antigen (PSA), Erythrocyte Sedimentation Rate (ESR), Kidney, Ureter, and Bladder (KUB), Chest X-Ray (CXR), Computed Tomography-Scan (CT-Scan), Magnetic Resonance Imaging (MRI)

Category (number of information requested by participants)		Data items (number of information requested by participants)
	Glucose information for diabetics patients (11)	Date (5), glucose value (10)
Scheduled information (9)		Follow-up date (3), date of medical laboratory (6), date of receive laboratory result (8), date of vaccination (1)
Abbreviations: Chronic Kidney Disease (CKD), Renal Replacement Therapy (RRT), Complete Blood Count (CBC), Blood Urea Nitrogen (BUN), Fasting Blood Sugar (FBS), Hemoglobin A1c (HbA1c), Alanine Aminotransferase (ALT), Aspartate Aminotransferase (AST), Alkaline Phosphatase (ALP), Bilirubin Total (Bili-T), Bilirubin direct (Bili-D), Thyroglobulin (TG), Low Density Lipoprotein (LDL), High Density Lipoprotein (HDL), Intact Parathyroid Hormone (iPTH), vitamin D (Vat D), Total Iron Binding Capacity (TIBC), Hepatitis B surface antigen (HBsAg), Hepatitis C Virus Antibody (HCV Ab), Tuberculosis (TB), Prostate Specific Antigen (PSA), Erythrocyte Sedimentation Rate (ESR), Kidney, Ureter, and Bladder (KUB), Chest X-Ray (CXR), Computed Tomography-Scan (CT-Scan), Magnetic Resonance Imaging (MRI)		

While patients see an e-PHR as an opportunity for greater communication with their care providers, care providers highlighted that synchronous communication through such a system should be minimal. Therefore, they recommended that patients should be educated to use the system only for their chronic conditions without the expectation of a prompt response from care providers, especially for acute conditions and emergency situations.

"... if a patient has a problem in an emergency and this feature is in the system [messaging feature], first of all, it will lead to higher patient expectation, and we cannot respond to them all the time. Secondly, it also increases the responsibility of the system; the patients may not be able to correctly tell us their problems [through ePHR], and we may give them incorrect recommendations, or patients may not correctly understand our recommendations [given through the ePHR], and [this] may cause problems for them." (Focus group meeting – A senior nephrologist – 7th of August 2019)

3.3. Factors that influence ePHR adoption by CKD care providers

3.3.1. Performance expectancy

Our clinicians envisioned that easy access to patient latest medical information such as radiology and laboratory results (and their trends over time) and the ability to share them with other providers would save them time and prevent requesting extra tests. They also valued accessing such data all the time. This would save them going back and forth to find necessary information across voluminous, but generally incomplete and illegible, paper-based records. To assess the reliability of data, they recommended displaying the source or an individual who entered different pieces of information. Clinicians believed that available education on the ePHR would reduce the amount of time they spend on

patient education and training during regular visits, allowing them to spend more time on direct patient care:

"... Some of our [CKD] patients are not usually alert about their problems, also about their medications. They can't give us much information about their ongoing treatment. These patients usually get hospitalized several times and then go under the diagnostic procedures again; [for example] the patient doesn't know that has CT [CT-Scan results] ... the patient doesn't know what medication he is currently getting, and the patient is unaware of his/her drug allergies. If all of these are recorded in such a system [ePHR], we can easily reduce the amount of patient workload, reduce their lengths of hospital stay, reduce their costs, and maybe make our healthcare system more relaxed than what it is now." (A nurse – 20th of February, 2019)

3.3.2. Effort expectancy

A majority of clinicians envisioned that working with ePHR would be an easy task because of their prior experience with the HIS. They believed that the integration of the system to the HIS or the CKD disease registry would enable retrieving some basic patient information and test results, which would, in turn, reduce the amount of data entry time while increasing the accuracy of the information and facilitating ePHR adoption by different user groups. They also suggested considering a section for frequent questions and answers through the system to reduce the load of bidirectional communication.

3.3.3. Facilitating conditions

Our clinicians suggested considering two main user groups of patients and their family members, and care providers. They recommended full access to enter, view, and revise information for nephrologists and nephrology nurses but only permission to view information for other clinicians (e.g., internal medicine specialists, family physicians, residents, and interns in academic medical centers). Meanwhile, to protect patient privacy and information confidentiality, an authentication mechanism was overemphasized through predefined levels of access according to each user's role in CKD care. Some of our care providers have concerned that the accuracy and reliability of the information provided by patients and/or other care providers through an ePHR should be given much attention, because, for instance, if patients enter incorrect information into an ePHR, it can lead to serious patient health risks.

4. Discussion

In this study, we identified the requirements for an ePHR for CKD patients from users' perspectives, and its content and structure needed to help support those requirements. These characteristics were analyzed in the face of ePHR's likely facilitators and/or barriers to its implementation and adoption. If this knowledge is applied for ePHR design, it can most probably contribute to a smooth ePHR implementation/adoption. Overall, our participants expressed positive attitudes towards ePHRs and envisaged that the given ePHR will increase access to credible health information and individualized education, and thereby, empower patients to self-manage their disease more effectively. They also emphasized that such a system should be designed to fit the e-health literacy level of patients and only display CKD specific information

depending on patient different conditions. To put it in other words, it should tailor information in ways that protect patients from being overwhelmed with extra, unnecessary information.

Studies have reported that one of the many benefits of ePHRs is easier access to patients' past and present medical data and information breaking through the time and space barrier, and the ability to exchange and share them with whoever is involved in patient care (3, 34–37). According to our participants, ePHR can be a powerful tool to resolve problems with paper-based medical records such as their incompleteness, illegibility, and inaccessibility. It can also bypass time and space barriers to access care providers, for example, in cases when they do not remember the details of care recommendations or are puzzled about their roles and responsibilities in care plans. Such expectations from an ePHR are in line with the results of previous studies in which researchers reported improved patient-provider communication or where patients are reminded about what they will do for upcoming check-ups or vaccinations (7, 38). Besides these, our participants also thought that the ePHR would save them time on patient education and information access that they would be able to spend that saved time on direct patient care, as reported previously (39). Moreover, information access can potentially reduce unnecessary patient referrals for diagnostic or therapeutic procedures, and lead to more timely decision making (27). However, the findings on time saved via ePHR should be interpreted cautiously and the expectations kept modest because its use might also be perceived as a time-consuming task. This is because some studies reported that using ePHRs by providers required their duplicate time and efforts to handle issues related to the ePHR use parallel to the other tasks of patient visits in the office time (39, 40).

Several reviews have so far studied the barriers to ePHR adoption (37, 41–44). These studies have reported providers' concerns about legal issues to respond to patient inquiries through ePHRs (e.g., who from the members of a care team seeing a patient' inquiry would respond to an emergent situation) and also concerns over the privacy and security of information. Other barriers were also discussed in the literature such as patients' individual factors (e.g., patient age and gender, health and computer literacy, and access to computers and the Internet), technical factors (e.g., lack of interoperability with other Health Information Technology (HIT) systems such as electronic health records, and lack of customized features for chronic conditions) (45–47). Many of these issues were also raised by our participants as concerns that needed to be considered before any ePHR adoption. For example, they discussed the feasibility of automatically retrieving information stored in a CKD registry or HIS in order to reduce workload associated with data entry, as previously reported as a critical point especially in untethered ePHRs (39, 40, 48). Therefore, easy, intuitive, and preferably automatic data entry for some data should be taken into account when designing such systems. Our participants also emphasized the need to preserve the privacy and confidentiality of data. Similar concerns have also been reported in other studies, for example, patients had been concerned about the confidentiality of a stigmatized or sensitive condition such as having depression or infection with Human Immunodeficiency Virus, or others were worried that their information could be accessed and might be misused by insurance companies to deny coverage (49–51). This was also the case for *caregivers'* access to some sensitive information (50, 52, 53). Participants also highlighted the cost of services delivered through ePHR. Besides the necessity for

tangible incentives in order to adopt PHR, it has been shown that clarity is needed for how PHR-related services would be paid for, who would pay (patients or payers) and under what circumstances (48, 54–56). Such findings show that the successful application and use of ePHRs should address likely barriers before any implementation, or otherwise, these may threaten its deployment.

Parallel to barriers, we also considered likely facilitators, which might contribute to the ePHR's smooth implementation; and compared the findings with the others (41–44, 57, 58). A review found that patient encouragement by providers to use ePHR, their perception of control over health information, and also their perception of ePHR's greater potential to improve patient-provider communication are facilitators that can help expedite ePHR adoption (42). Similarly, our participants valued ePHR features such as facilitated communication with providers and easier access to data. Designing a system to satisfy these expectations would likely promote its adoption. Another review reported that besides the availability of secure messaging and eVisits with care providers, online appointment scheduling and reminders, and online access to patient laboratory and radiology results also promote patients to use ePHRs (43). Participants also requested the availability of care reminders (e.g., about the time to take medications or to receive a vaccination shot) and online availability of laboratory results and their trends because they believed that these features would promote self-management. Our findings also accord with those of others in which tailored system interfaces to the educational and e-health literacy level of patients are recommended for ease of use (57). Moreover, it also became evident in our study that caregivers should be considered as users and involved in the PHR application as surrogates to patients in order to overcome some of the predicted barriers such as health and computer literacy by elderly, as recommended in the literature (58).

In the deployment of HIT systems, their data elements and design structure can influence what advantages they would be able to deliver. In a CKD study in Canada, data elements were classified into four main categories of demographics, educational, behavioral and activity monitoring, and laboratory results (24). Researchers in Thailand reported a knowledge-based ePHR system, especially designed for CKD patients, which had electronic forms for recording personal information, medications, laboratory tests, dietary patterns, and exercise activity (23). In our study, besides the above data categories, participants requested the following categories to be included in the system as well: a comprehensive, purposefully documented medical history, patient' scheduled reminders, individualized educational contents, and information on record access by caregivers and care providers. When compared with the results of two previous CKD studies, data items associated with the recording of behavioral and activity monitoring, diet, and exercise were not included in our final list, mainly because they were not approved for the early implementation phase. Participants believed that the system to start with should be much simpler with the most important items individualized based on each patient's health conditions in order to be manageable. Extra functions can be added step-by-step later on when patients get acquainted with the system. It was also decided that the message exchange function between patients and care providers should be only for non-emergency situations; and in emergencies, patients should be trained to contact care centers to get the required care, promptly. This was because of concerns that messaging through the system may induce the perception that somebody is available all the time to respond even to an

emergency condition. This finding and other chronic disease factors have rarely given full attention in the literature (59). Our findings that the intended ePHR should include functions and structures such as messaging, reminders, disease-specific individualized educational information, and medical record summary, have also been similarly reported elsewhere (23–26). Meanwhile, ePHR is an evolving technology and it should be borne in mind that access to personalized, disease-specific information through a robust architecture controlling secure access to patient information should be at the center stage of the design efforts (60, 61).

4.1. Strengths and limitations

In the present study, we used nephrology care as exemplary chronic disease care with all its corresponding characteristics such as CKD patient's multiple comorbidities and underlying diseases and disease stages with various information/educational needs along the way, multiple patient hospital admissions/patient referrals, and the involvement of different kinds of care providers in different types of wards/units/settings, to get a deeper insight into what requirements/need an ePHR should cover in order to provide value for both chronic disease patients and their care providers involved in this complex chronic disease care. Therefore, the approach used in this study is fairly applicable for the analysis of requirements in other chronic diseases. However, it has limitations that deserve to mention here. Although our results provide a thorough overview of CKD care involving different stakeholders with an ePHR, its specific care requirements may not be generalizable to other nephrology settings. For example, our nephrology center was the pioneer in the design and implementation of a CKD registry in the country based on its care context (62). Several universities have just started negotiations for this registry's implementation. Hence, it is possible that the emphasis to integrate an ePHR with the available HIT systems would not be immediately feasible in other nephrology settings. Next, this study was conducted in adult nephrology care; therefore, its findings may not be applicable in pediatric nephrology care in which a patient' parents commonly deal with ePHRs.

5. Conclusions

This study is one of a few CKD-ePHR studies that specifically focused on the system requirements of chronic patients and their care providers with a bird's eye view of CKD care. According to our participants, an ePHR was perceived as a useful tool in improving the self-management of CKD patients by providing better patient information and improved patient-provider communication. If in use, patient lower health and technology literacy and the high workload of care providers will represent some of the main barriers to ePHR adoption, which should be mindfully considered beforehand. Drawing upon the facilitators identified in this study and others as well may help to overcome some of the barriers and to increase users' acceptance.

To conclude, according to the findings in the current study, we need to develop a patient-centered ePHR that is tailored to the needs of all its users in daily, short- and long-term use, especially in the context of chronic care. Meantime, chronic care has unique requirements that should be considered. Given the

multiplicity of users having varying roles and located in different units, it would be helpful and more productive if all are involved in the early stages of system development, and implementation in order to inform the design regarding each one's requirements. We hope that the insights gained from this study can be helpful for designers, implementers, and researchers of such systems in supporting patients in self-management in an orchestrated effort with their care providers.

Abbreviations

ePHR
electronic Personal Health Records
CKD
Chronic Kidney Patients
EHR
Electronic Health Records
EMR
Electronic Medical Records
UK
United Kingdom
US
United States
HIS
Hospital Information System
PHRAM
Personal Health Record Adoption Model
UTAUT
Unified Theory of Acceptance and Use of Technology
CT
Computer Tomography

Declarations

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study was approved by the research ethics committee of UUMS (ethics code number: IR.UMSU.REC.1397.375). Participation in the study was voluntary. Data were reported anonymously. Patient participants gave written informed consent for participation in the study. All care provider participants gave verbal informed consent, which was approved by the institutional research ethics committee.

CONSENT FOR PUBLICATION

This study does not include any confidential information. Then consent for publication is not applicable.

AUTHORS' INFORMATION

ZN, HP and ET designed the study. ET collected data. ET and ZN analyzed data. ET, HP, KhM, AM, and ZN contributed in the analysis and interpretation of data. ET and ZN drafted the article and revised it according to the other authors' comments. All authors approved the final version.

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- Appendix1.docx