Identifying a minimum data set as a necessity to design a web-based personal health record for patients under chronic dialysis

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Abstract

Objective: Many people suffer from kidney disease, and self-management is essential in these patients. Personal health record (PHR) can be used as a tool to improve self-management in these patients. This study aimed to identify a minimum data set (MDS) of PHR in dialysis patients. Methods: This descriptive and cross-sectional study was conducted in 2019, and national and international scientific literature entitled "Personal Health Record," “Electronic Personal Health Record,” “Dialysis Patient Portal,” “Dialysis Health Record,” and “Dialysis Information Needs” by content analysis method was reviewed. A questionnaire with 14 items was designed to examine patients' problems and data needs based on the review of scientific literature and web-based PHRs. Based on the patients' survey and the review of scientific literature, a questionnaire with 114 questions was designed. Finally, with experts' opinions, data elements were determined. Results: An MDS for developing web-based PHR for patients under chronic dialysis was created with 17 data classes including demographic information, insurance information, contact information in case of emergency, information on dialysis sessions, physicians information, dialysis center information, information on individual measured values (blood pressure, blood sugar, and weight), disease history information, information on surgical procedures and operations, history of visits, allergies, vaccinations, family history, drugs, laboratory tests, diet, and education materials for the patient. Conclusion: In this study, an MDS was developed for a web-based PHR for dialysis patients. The use of standard data can help collect the data that is essential to improve the patient's health and track his medical condition.

Keywords: Chronic dialysis, Delphi technique, minimum data set, personal health record

Introduction

In recent years, with the population growth and aging, the trend of mortality has changed, and the mortality rate due to noncommunicable diseases has decreased. Vice versa, we have witnessed an increase in mortality in noncommunicable and chronic diseases.[1] In noncommunicable conditions, chronic kidney disease (CKD), a progressive disease, is one of the leading causes of morbidity and mortality.[2] According to the Global Burden of Disease study from 1990 to 2016, the incidence of CKD increased 89%, prevalence increased 87%, death due to CKD increased 98%, and disability-adjusted life years increased 62%.[2,3] Inadequate care of CKD can lead to renal failure with severely impaired kidney function, and the patient needs dialysis...
or transplantation to sustain life, which imposes very high costs on patients. The transition from predialysis CKD to end-stage renal disease is accompanied by the start of dialysis treatment, which leads to many problems for the patient. During this stage, mortality rate and cardiovascular events are ordinary, accounting for many deaths. Slowing down CKD progression requires the participation of patients in the treatment process and self-management in these patients is critical, and attention to systolic blood pressure and glycemic control, adherence to drug treatment, nutritional considerations, and attention to physical activity are very important. IT-based interventions can increase self-management in these patients. A systematic review study conducted by Rangraz Jeddi et al. showed that these interventions positively affected 75% of clinical outcomes and 86% of process-care results.

One of the IT-based interventions that can increase self-management in patients under chronic dialysis is the PHR. PHR allows patients to record personal health data, leading to early detection of critical situations and assisting in timely interventions. On the other hand, providing the necessary knowledge and education to the patient can improve self-management. PHR should collect data that can help the patient’s self-management and health promotion, so a minimum data set for these patients’ health records should be defined. Data collection plays a vital role in managing patients’ health information, and therefore identifying and creating a minimum data set (MDS) enables the management of patient data in a standard and integrated manner. MDS provides the same definitions for the data and allows the data to be compared nationally and internationally.

Identifying the MDS can help appropriate data collection and is related to goals from a vast amount of data. This standard method leads to comparing data and reports that can help manage kidney patients’ conditions. Providing the information needed by dialysis patients through a PHR can lead to self-care. Self-care is the most important form of primary care, both in developed countries with a healthier structure and higher literacy rates—or in developing countries where people are poor and have less access to specialist medical care. PHRs can meet the information needs of patients and physicians by providing the data they need and improve the interaction between patients and physicians. Therefore, this study aimed to determine an MDS for developing a personal health record (PHR) for patients under chronic dialysis.

**Methods**

**Study design**

An applied descriptive, cross-sectional study was performed in 2019. We efficiently utilized the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement for reporting this observational survey. Extraction of data elements and requirements for designing dialysis patients’ PHRs was done by investigating electronic databases and reviewing related sources. In this regard, to explore them, reputable articles were carefully reviewed through nonsystematic searches in Google Scholar, Scopus, Medline (through PubMed), and Science Direct databases with the following keywords up to December 2019: “Personal Health Record,” “Electronic Personal Health Record,” “Dialysis Patient Portal,” “Dialysis Health Record,” and “Dialysis Information Needs.” However, we investigated data elements of web-based PHRs also.

**Setting and participants**

In stage 2, after conducting a nonsystematic review of resources and web-based PHRs to determine the information needs and initial requirement assessment, a survey was performed of all dialysis patients in Kashan (135 patients). Initial information was collected through interviews and a researcher-made questionnaire based on the review of scientific literature. The questionnaire consisted of 14 multiple-choice questions (yes and no). These questions included various information that the lack of access to the appropriate mentioned materials will lead to difficulty following the patient’s treatments and care instructions. In the final stage of extracting the necessary data set for designing dialysis patients’ personal records, a survey was conducted from Akhavan Hospital nurses in Kashan. Due to the limited number of the research community (22 people), no sampling was performed regarding the nursing community, and all the nurses working in the dialysis department who met the inclusion criteria were invited to participate in this survey. Data collection was performed by applying a researcher-made questionnaire designed based on the review of scientific sources and PHR systems and need assessment of patients (stage 2). The questionnaire consisted of 114 multiple-choice questions (necessary, unnecessary) about the need for various data items in dialysis patients’ PHRs. There was also an open-ended question at the end of each section of the questionnaire to suggest necessary data elements.

**Statistical validations**

In stage 2, the patients’ questionnaire’s face and content validity were confirmed by three experts (Health Information Management Specialists and Nurses), and its reliability was assessed using the internal consistency method; the Cronbach’s α value was 0.78, which indicates the reliability of the research tool. To judge the acceptance or rejection of each item in questions, according to the expert’s view recruited, if each item in the questionnaire was identified as problematic by an average of at least 25% of patients, that item was considered an essential item for design. In stage 3, the questionnaire’s face and content validity for the nurses’ survey were acknowledged by three experts; Cronbach’s α value was 0.83. To judge the acceptance or rejection of each item in question, according to the expert’s opinion, if each of the data items in the questionnaire was deemed necessary by at least 60% of the respondents on average were entered as essential items. Furthermore, if new data were suggested by at least 40% of the participants in the questionnaire’s open question section, the offered data were determined as an essential item.
Results

In the first step, various data items were collected from web-based PHRs[5], which are given in Table 1 of data items along with the name of the PHR. The frequency distribution of data items considered in web-based PHRs is given in Table 2. At the patients’ survey stage, 135 patients have been recruited; Figure 1 shows individuals’ characteristics. Regarding the patients’ need for PHR information, the highest frequency was related to not knowing how to use the drug, with 74.8%. The lowest frequency was associated with forgetting the time of dialysis session with a frequency of 25.9%. Also, the highest percent related to self-care measures performed by the patient was related to blood pressure control with a frequency of 97%. The lowest percent was related to following the trend of test results with a frequency of 43%.

The needs of patients for the PHR information in the research community are detailed with their frequency percentage in Table 3. Hence, at the nurses’ survey stage, out of 22 members of the research community, 21 (95.4%) agreed to participate in the study. The characteristics of nurses participating in the study are given in Figure 2. It should also be noted that nurses’ average age was 38 years, and their average work experience was 10 years. Based on this stage’s findings, all 114 items of data surveyed by experts were necessary with an agreement of more than 60%.

Finally, the statistical analysis of the results obtained from the need’s assessment of patients and nurses was conducted by researchers; so a set of minimum essential elements for designing a personal record for dialysis patients was identified and approved by the research team. Table 4 provides the final data elements with their details.

Discussion

This descriptive, cross-sectional study aimed to develop the MDS for developing a web-based PHR for patients under chronic dialysis. Patients under dialysis and nurses were surveyed with a questionnaire to determine the MDS. The MDS that was proposed based on the results of this study to develop a PHR was classified into 17 main data classes, including demographic information, insurance information, contact information in case of emergency, information on dialysis sessions, physicians information, dialysis center information, information on individual measured values (blood pressure, blood sugar, and weight), disease history information, information on surgical procedures and operations, history of visits, allergies, vaccinations, family history, drugs, laboratory tests, diet, and education materials for the patient.

Self-care is the most important form of primary care and the first step in promoting people’s health in the community. Determining data elements to develop a PHR can improve the self-care of dialysis patients, provide the basic information, and reduce unnecessary referrals to primary care providers.

Based on the results of this survey, demographic information class includes first/last name, father’s name, gender, date of birth,

| Table 1: Data elements of web-based personal health records |
|---------------------------------|
| Data elements                  |
| ---------------------------------|
| Personal health record          |
| √ Health Companion             |
| √ My Diabetes PHR              |
| √ MyMedical Record             |
| √ MyMD Health Manager          |
| √ MyNotes Health Records        |
| √ MyHealth Vault               |
| √ MyHealth Folders             |
| √ MyHealth Records             |
| √ MyHealth Manager             |
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marital status, phone number, national code, e-mail address, type of blood group, type of dialysis, mobile number, job, education level, and home address. In a study conducted by Navaneethan et al. to develop a registry for CKD, the minimum required data set in the demographic information group included (1) patient identifier, (2) date of birth, (3) gender, (4) race/ethnicity, (5) zip code—socioeconomic status, (6) educational status, and (7) insurance details. One of the differences observed in the MDS of these two studies is race. In the present study, because we did not have different racial groups, these data were not identified as MDS at the survey time. Another difference is the insurance details, which in the Navaneethan study are included in the demographic information group. Our study is considered a separate category and includes the insurance organization name, insurance number, insurance type, and insurance booklet’s expiration date.

In the present study, one of the data element classes that, according to experts’ opinion, should be considered in the PHRs was the patient’s education. Experts believed that in this category, items such as kidney function, correct recording of absorption and excretion by the patient, control of dialysis side effects, skin and fistula care, patient treatment methods, and principles of care in peritoneal dialysis should be educated. A study investigating the effect of diet education on laboratory results in hemodialysis patients concluded that patients who received additional monthly education had positive laboratory value changes. Phosphorus and calcium/phosphorus product levels were significantly lower than the control group. Patient education can positively affect improving treatment outcomes, reducing anxiety, and improved the timing to start dialysis. One of the main identified categories was diet. Subcategories include body mass index (BMI), required energy, required nutritional supplements, the severity of malnutrition, diet type, the volume of required fluids, dietary recommendations, and required protein and food interactions with drugs. Diet consideration is crucial in patients under dialysis. One of the essential goals in renal disease is the control of phosphate levels. Therefore, daily phosphate intake in these patients should be controlled. Furthermore, one of the critical nutritional factors that should be considered in renal patients is the abnormal amounts of sodium level, leading to kidney disease progression and important cardiovascular events. Therefore, patients should pay enough attention to their diet, and PHRs can be considered a helpful tool to manage patients’ diet. We hope to enable and accelerate the
Table 3: The needs of patients to the personal health record

| Identified requirements                                      | Frequency percentage % |
|--------------------------------------------------------------|------------------------|
| Problems                                                     |                        |
| Lack of knowledge about how to take drugs (74.8)             | Lack of awareness of fluid consumption restrictions (72.6) |
| Improper food intake (66.7)                                  | Lack of knowledge on how to control the side effects of the disease (65.9) |
| Lack of knowledge about the signs and symptoms of the disease (64.4) | Lack of awareness of permitted physical activities and how to perform them (48.1) |
| Lack of knowledge about how to care for the skin (39.3)      | Forget about vaccinations (38.5) |
| Lack of access to contact information for dialysis centers (29.9) | Forgetting dialysis session time (25.9) |
| Self-care actions                                            |                        |
| Blood pressure control (97)                                 | Weight control (71.1)  |
| Blood sugar control (86.3)                                   | Track changes in test results (43)  |

Table 4: Minimum data elements of the personal health record

| Minimum data set                                           |
|------------------------------------------------------------|
| Demographic information                                    |
| First/last name                                            | Marital status       | Phone number | National code |
| Father's name                                              | Gender               | Date of birth | E-mail address |
| Type of blood group                                         | Type of dialysis     | Mobile number | Job           |
| Education level                                            | Home address         |               |               |
| Insurance information                                      |
| Insurance organization name                                | Insurance number     | Type of insurance | Expiration date of the insurance booklet |
| Contact information in case of emergency                   |
| First/last name                                            | Phone number         | Mobile number | Relationship |
| Address                                                    |                       |               |               |
| Information on dialysis sessions                           |
| Dialysis center name                                       | Date of dialysis     | Day of dialysis | Time of dialysis |
| Vital signs before dialysis                                | Vital signs after dialysis | Weight before dialysis | Weight after dialysis |
| Duration of dialysis                                       | Type of Vascular access |               |               |
| Physicians information                                     |
| First/last name                                            | Specialty            | Address       | Phone number  |
| Dialysis center information                                |
| City                                                       | Center name          | Address       | Phone number  |
| Website of center                                          |                       |               |               |
| Information on individual measured values                  |
| (blood pressure, blood sugar, and weight)                  | Date of the measurement | Time of the measurement |               |
| Value of the measurement                                   |                       |               |               |
| Disease history information                                |
| Diseases name                                              |                       |               |               |
| Information on surgical procedures and operations           |
| Name of procedures                                          | Date of surgical procedures | Side effects |               |
| Results                                                    | Body position         | Medical center name |               |
| History of visits                                          |
| Date of appointment                                        | Name of doctor       | Reasons to refer |               |
| Recommendations                                            |                       |               |               |
| Allergies                                                  |
| Type of allergy                                            | Date of first observed | Whether treatment has been given? |               |
| Allergens                                                  | Allergy symptoms      | Has treatment stopped the allergy? |               |
| Vaccinations                                               | Date of injection     | Reason for injection |               |
| Name of vaccine                                            |                       |               |               |
| Family history                                             |
| Relation of the person with the patient                    | The names of important diseases |               |               |
| Drugs                                                      |
| Name of drugs                                              | Dosage of drugs       | Date of discontinuation | Reason for prescribing |
| Name of prescriber                                         | Consumption time      | Date of initial use | Interaction with other drugs or foods |
| The number and frequency of drug use                        | Form of the drug      | Side effects   |               |

Contd...
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**Table 4: Contd...**

| Minimum data set |
|------------------|
| **Laboratory tests** | Name of test | The measured value for each lab test | Date of completion | Recommendations |
| **Diet** | Body mass index (BMI) | Required energy | | Severity of malnutrition |
| **Type of diet** | Type of diet | The volume of required fluids | | Required protein |
| **Food interactions with drugs** | Food interactions with drugs | Dietary recommendations | | |
| **Education materials for the patient** | Education materials for the patient | Familiarity of the patient with the signs and symptoms of the disease | | |
| **Teaching how the kidneys work** | Teaching how the kidneys work | Treatment methods for patients with chronic renal failure | | |
| **Principles of care in peritoneal dialysis** | Principles of care in peritoneal dialysis | How to control dialysis side effects? | | |

self-management process in dialysis patients by determining the standard data for developing PHR. By recording data in dialysis patients, abnormal trends can be detected, and appropriate intervention can be taken as soon as possible.

**Conclusion**

According to what was reviewed, dialysis patients need a personal record to have integrated access to their health information and to be able to follow their treatment trends. It is also worth noting that, based on other mentioned studies, the researchers carefully identified the minimum data set using two researcher-made questionnaires. However, in this study, researchers have developed main data elements for designing a web-based PHR by assessing the needs of dialysis patients and nurses; the designed PHR can improve patients’ access to their health information. In designing PHRs for dialysis patients, minimum data items related to personal information, insurance information, emergency contact information, dialysis session schedule, physician’s information, dialysis centers, elements measured by the individual (blood pressure, blood sugar, and weight), diseases, procedures and surgeries, visits, allergies, vaccinations, family history, medications, and tests are of paramount importance.

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**Key messages**

- This study aimed to identify an MDS of PHR in dialysis patients.
- Researchers have developed main data elements for designing a web-based personal health record by assessing the needs of dialysis patients and nurses.
- The use of standard data can help collect the data that is essential to improve the patient’s health and track his medical condition.

Availability of data and material: All data generated or analyzed during this study are included in this published article. The methodology for this study was approved by the Ethics committee of the Kashan University of Medical Sciences in 2017 (ID Number: 95,031)

**Code availability:** Not applicable.

**Ethical approval:** Not applicable.

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**Conflicts of interest**

There are no conflicts of interest.

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