Original Article

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

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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%.[3,4] Inadequate care of CKD can lead to renal failure with severely impaired kidney function, and the patient needs dialysis

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or transplantation to sustain life, which imposes very high costs on patients.[5] 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.[1,6] 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.[3]

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.[3,5] 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.[7,8] 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.[9,10,11,12] MDS provides the same definitions for the data and allows the data to be compared nationally and internationally.[13,14]

Identifying the MDS can help appropriate data collection and is related to goals from a vast amount of data.[15] This standard method leads to comparing data and reports that can help manage kidney patients' conditions.[16] 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 most 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,[17] 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

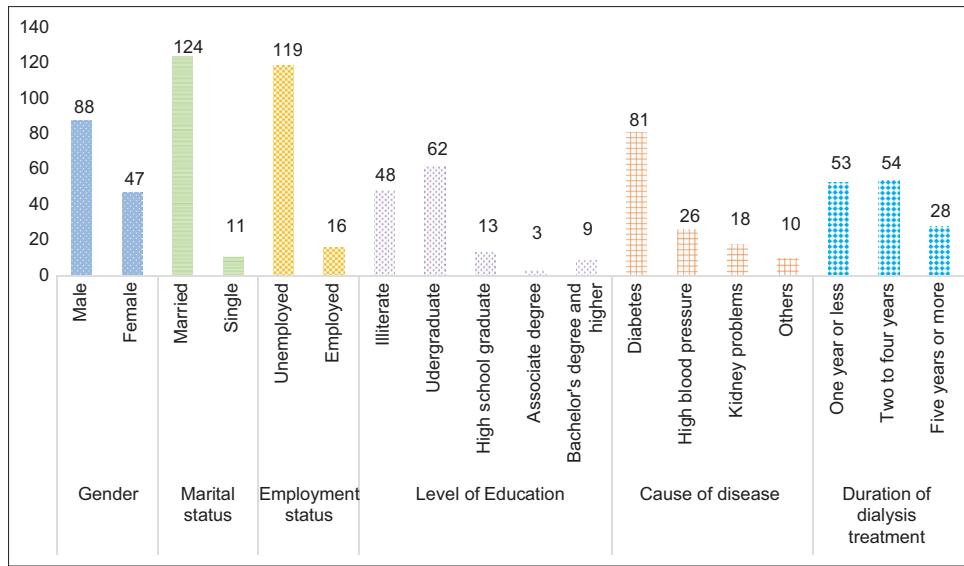| Personal health record	Data elements													
	Demographic information	Insurance information	Emergency contact information	Healthcare providers information	Appointment schedule	Family history	Vaccinations	Allergies	Home monitoring	Diseases	Procedures and surgeries	Lab results	Drugs	Diet plans
Health Companion	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-
My Doclopedia PHR	✓	✓	-	✓	✓	✓	-	✓	✓	✓	✓	-	✓	-
Remember It Now!	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	-
MyMedi Connect	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	-
My Health Folders	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Microsoft Health Vault	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓
Web MD Health Manager	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	-
Healthy Circles	✓	✓	✓	✓	-	-	✓	✓	-	✓	✓	✓	✓	✓
Juniper Health	✓	✓	-	✓	✓	✓	-	✓	-	✓	-	✓	✓	✓
Healthspek	✓	-	✓	✓	✓	✓	✓	-	-	-	-	-	✓	-
Mynetrecords	✓	✓	-	✓	-	✓	✓	✓	-	-	-	✓	✓	✓
Securamed	✓	✓	-	✓	✓	✓	✓	✓	-	-	-	-	✓	-
Google Health	✓	✓	-	-	-	✓	✓	✓	-	✓	✓	✓	✓	-

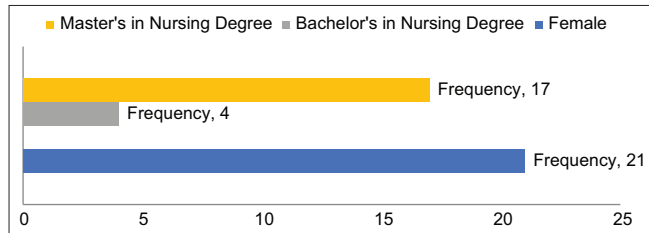**Figure 1:** Characteristics of participated patients

Figure 2: Characteristics of participated nurses

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.[18,19] 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.[20] Serum

Table 2: Frequency distribution of data items listed in web-based personal health records

Data elements	Frequency	Frequency percentage (%)
Demographic info	13	100
Allergies	13	100
Diseases	13	100
Insurance info	12	92
Healthcare providers info	12	92
Home monitoring	11	85
Family history	11	85
Procedures and surgeries	11	85
Drugs	12	92
Vaccinations	10	77
Lab results	9	69
Emergency contact information	8	62
Appointment scheduling	7	54
Diet plans	3	23

phosphorus and calcium/phosphorus product levels were significantly lower than the control group.[21] Patient education can positively affect improving treatment outcomes, reducing anxiety, and improved the timing to start dialysis.[14,22,23] 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.[19,21] Therefore, daily phosphate intake in these patients should be controlled.[24] 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.[25,26] 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 (56.3)	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)			
Value of the measurement	Date of the measurement	Time 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			
Name of vaccine	Date of injection	Reason for injection	
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...

Table 4: Contd...			
Minimum data set			
Laboratory tests			
Name of test	The measured value for each lab test	Date of completion	Recommendations
Results			
Diet			
Body mass index (BMI)	Required energy	Required nutritional supplements	Severity of malnutrition
Type of diet	The volume of required fluids	Dietary recommendations	Required protein
Food interactions with drugs			
Education materials for the patient			
Teaching how the kidneys work	The correct way to record the absorption and excretion by the patient	Familiarity of the patient with the signs and symptoms of the disease	How to control dialysis side effects?
Principles of care in peritoneal dialysis	How to observe oral health?	Treatment methods for patients with chronic renal failure	How to care for skin and fistulas?

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.

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.

Conflicts of interest

There are no conflicts of interest.

References

1. Keyfitz N, Flieger W. World Population Growth and Aging: Demographic Trends in the Late Twentieth Century: University of Chicago Press; 1990.

2. Bikbov B, Purcell CA, Levey AS, Smith M, Abdoli A, Abebe M, *et al.* Global, regional, and national burden of chronic kidney disease, 1990–2017: A systematic analysis for the Global Burden of Disease Study 2017. Lancet 2020;395:709-33.

3. Jeddi FR, Nabovati E, Amirazodi S. Features and effects of information technology-based interventions to improve self-management in chronic kidney disease patients: a systematic review of the literature. J Med Sys 2017;41:1-3.

4. Kalantar-Zadeh K, Jafar TH, Nitsch D, Neuen BL, Perkovic V. Chronic kidney disease. Lancet 2021;398:786-802.

5. Hughes JT, Freeman N, Beaton B, Puruntatemeri A-M, Hausin M, Tipiloura G, *et al.* My experiences with kidney care: A qualitative study of adults in the Northern Territory of Australia living with chronic kidney disease, dialysis and transplantation. PloS One 2019;14:e0225722. doi: 10.1371/journal.pone.0225722.

6. McMahon EJ, Bauer JD, Hawley CM, Isbel NM, Stowasser M, Johnson DW, *et al.* A randomized trial of dietary sodium restriction in CKD. J Am Soc Nephrol 2013;24:2096-103.

7. Tuot DS, Plantinga LC, Judd SE, Muntner P, Hsu C-Y, Warnock DG, *et al.* Healthy behaviors, risk factor control and awareness of chronic kidney disease. Am J Nephrol 2013;37:135-43.

8. Aminpour F, Sadoughi F, Ahamdi M. Utilization of open source electronic health record around the world: a systematic review. Journal of research in medical sciences: the official journal of Isfahan University of Medical Sciences. 2014;19:57.

9. Jeddi FR, Nabovati E, Amirazodi S. Features and effects of information technology-based interventions to improve self-management in chronic kidney disease patients: A Systematic review of the literature. J Med Syst 2017;41:170.

10. Uribarri J. Phosphorus homeostasis in normal health and in chronic kidney disease patients with special emphasis on dietary phosphorus intake. Semin Dial 2007;20:295-301.

11. Tomašev N, Glorot X, Rae JW, Zielinski M, Askham H, Saraiva A, Mottram A, Meyer C, Ravuri S, Protsyuk I, Connell A. A clinically applicable approach to continuous prediction of future acute kidney injury. Nature. 2019 Aug;572(7767):116-9.

12. Shahmoradi L, Izadi N, Shirbeigi L, Kandi MJ, Barzegari S, Rezayi S. Minimum data set as a necessity for designing a mobile-based self-care application for skin and hair diseases. Aust J Herbal Naturop Med 2021;33:72-80.

13. Archer N, Fevrier-Thomas U, Lokker C, McKibbon KA, Straus SE. Personal health records: A scoping review. J Am Med Inform Assoc 2011;18:515-22.

14. Aalipour E, Ghazisaeedi M, Moghadam MR, Shahmoradi L, Mousavi B, Beigy H. A minimum data set of user profile or electronic health record for chemical warfare victims' recommender system. J Family Med Prim Care 2020;9:2995-3004.

15. Mirbagheri E, Ahmadi M, Salmanian S. Common data elements of breast cancer for research databases: A systematic review. J Family Med Prim Care 2020;9:1296-1301.

16. Wells S, Rozenblum R, Park A, Dunn M, Bates D. Personal health records for patients with chronic disease: A major opportunity. Appl Clin Inform 2014;5:416-29.

17. Fernández-Alemán JL, Seva-Llor CL, Toval A, Ouhbi S, Fernández-Luque L. Free web-based personal health records: An analysis of functionality. J Med Syst 2013;37:9990.

18. Abbasi R, Khajouei R, Mirzaee M. Evaluating the demographic and clinical minimum data sets of Iranian national electronic health record. BMC Health Serv Res 2019;19:450.

19. Navaneethan SD, Jolly SE, Schold JD, Arrigain S, Saupe W, Sharp J, *et al.* Development and validation of an electronic health record–based chronic kidney disease registry. Clin J Am Soc Nephrol 2011;6:40-9.

20. Galassi A, Cupisti A, Santoro A, Cozzolino M. Phosphate balance in ESRD: Diet, dialysis and binders against the low evident masked pool. J Nephrol 2015;28:415-29.

21. Mehrotra R, Marsh D, Vonesh E, Peters V, Nissenson A. Patient education and access of ESRD patients to renal replacement therapies beyond in-center hemodialysis. Kidney Int 2005;68:378-90.

22. Zahmatkeshan M, Farjam M, Mohammadzadeh N, Noori T, Karbasi Z, Mahmoudvand Z, *et al.* Design of infertility monitoring system: Minimum data set approach. J Med Life 2019;12:56-64.

23. Elkheir H, Wagaella A, Badi S, Khalil A, Elzubair T, Khalil A, *et al.* Prevalence and risk factors of depressive symptoms among dialysis patients with end-stage renal disease (ESRD) in Khartoum, Sudan: A cross-sectional study. J Family Med Prim Care 2020;9:3639-43.

24. Ford JC, Pope JF, Hunt AE, Gerald B. The effect of diet education on the laboratory values and knowledge of hemodialysis patients with hyperphosphatemia. J Ren Nutr 2004;14:36-44.

25. Golper T. Patient education: Can it maximize the success of therapy? Nephrol Dial Transplant 2001;16(Suppl 7):20-4.

26. Bhatnagar M, Sirohi N, Dubey A. Prediction of hospital outcome in emergency medical admissions using modified early warning score (MEWS): Indian experience. J Family Med Prim Care 2021;10:192-8.