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Information requirements of a self-care application for patients with kidney stones undergoing extracorporeal shock wave lithotripsy

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A B S T R A C T

Introduction: Kidney stones and its treatment, control of possible complications after lithotripsy and prevention of kidney stones recurrence, are the most substantial concerns of patients and physicians. Nowadays, the high capabilities of mobile technologies have become especially important for the prevention and control of diseases and patients' self-care. Use of mobile technologies, applications and smart tools can be a good way to prevent and control kidney stones. The present study was designed to identify the data requirements to design a self-care application for patients with kidney stones undergoing extracorporeal lithotripsy.

Material and Methods: This paper is a descriptive study and was performed in Sabalan Hospital in Ardabil affiliated to the Social Security Organization of Iran. A needs assessment questionnaire was designed by reviewing the scientific sources, databases, guidelines and medical records of patients. Ten clinical and technical specialists surveyed the questionnaire.

Results: Four main characteristics of demographic data, clinical data, disease monitoring and application capabilities were identified. Familiarity with kidney stone disease, familiarity with treatment methods, familiarity with diet, reminders, interaction with the treating physician were the most important capabilities identified for the application.

Conclusion: The findings of the survey showed that all identified items and components scored above average. The identified components were approved by experts and considered necessary.

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INTRODUCTION

Kidney stones have become more common in recent decades. This has resulted in a decrease in the quality of life and increased medical expenses [1]. The prevalence of kidney stones varies in different countries due to climatic conditions, nutrition as well as economic and social status [2, 4]. Kidney stones are the third most common disease among urinary tract diseases [2]. Since there is a close association of kidney stone with other common diseases such as diabetes, metabolic syndrome and hypertension, kidney stones have been introduced as a systemic disease [3-5]. It is more common in people over 30 years old [6]. Studies in developed countries have reported an increasing trend in the last three decades. Approximately 5% of women and 12% of men in United States experience kidney stones at least once in their lifetime, and its prevalence has increased in both sexes [7, 8]. According to reports, with a prevalence of 5.7%, Iran has the highest percentage of kidney stones among West Asian countries after Saudi Arabia and Turkey [9].

Treatment methods for kidney stones vary according to the size, shape, type and location of the stone. Extracorporeal shock wave lithotripsy (ESWL), percutaneous nephrolithotomy (PCNL) and transurethral lithotomy (TUL) are some of the treatment methods for urinary stones [10]. In the ESWL method, depending on the type, size and location of the stone, ultrasound waves with a suitable level of energy are radiated from outside the body to the kidney containing the stone. By absorbing the energy contained in the ultrasound, the large stones are broken into smaller pieces and eventually

excreted from the urinary tract. Very large stones cannot be treated with this method. Stones smaller than 2.5 cm in diameter are the optimal size for ESWL treatment [11, 12].

The ESWL method can reduce the recovery time and discomfort of patients, but it has potential complications. These may include abdominal pain caused by the waves, damage to nearby tissues, blockage of the ureter, blood in the urine, infection, irregular heartbeats, and the need for dialysis [13]. Early detection of clinical signs is necessary to identify and control the above complications. Achieving this requires self-care counseling and training [6]. Educating patients with the goal of continuing care and improving their quality of life helps them to have enough knowledge to make decisions and be able to take on self-care activities. Therapeutic contents are improved by promoting healthy behaviors of patients and their greater involvement in health care and self-care activities [14].

Self-care generally refers to a person's ability to manage symptoms, treatment, physical and psychological complications with the aim of improving the quality of life [15, 16]. Self-care is a concept in which the patient voluntarily takes activities to ensure, maintain and promote his health [17]. According to research findings, patients' enjoyment of sufficient knowledge about their disease leads to better self-care by patients [18, 19]. The tendency of people to use mobile phones provides an increasing opportunity for the application of this technology in the field of health [20]. Mobile applications enable people to facilitate and improve people's self-care by providing capabilities such as collecting symptoms and clinical data for patients and service providers, managing and following medication and treatment processes, and lifestyle changes. The use of self-care software has reduced costs, facilitated remote care and for patient satisfaction, and provided access to information [20].

To the best of author's knowledge, no studies have been carried out and published to control the prevalence and recurrence of kidney stone by self-care applications Thus, the use of self-care in this context should be investigated. The first step in designing self-care application is to identify the information needs, components, and expectations of the application [21]. Therefore, this study was performed with the aim of identifying data requirements and effective components to design self-care application for patients with kidney stones undergoing extracorporeal lithotripsy.

MATERIAL AND METHODS

The present study is applied study with quantitative-descriptive method study that identifies the components and data requirements of a self-care application for patients with kidney stones undergoing extracorporeal shock wave lithotripsy referred to Sabalan Hospital in Ardabil city in 2021. In the first stage of this research, the components and data requirements of a self-care application were obtained by searching for information sources such as PubMed, Google Scholar, Scopus, Science direct and Web of Science. The review steps included set questions, search strategy and inclusion/exclusion criteria. Searches were developed in August and September 2020. The identified studies were added to an EndNote library, and duplicate items were eliminated.

The articles screened in three stages based on their title, abstract, and full text. After screening title and abstract full-text were reviewed. Then the articles screened in three stages based on their title, abstract, and full text. Articles were included if reported intervention and its effect. Review studies, non-English language papers, Letters to the Editor, opinions, protocols, and studies unrelated to the topic were excluded. Keywords used to search the databases according mesh database included kidney stone AND nephrolithiasis AND urolithiasis AND stone disease AND ESWL AND extracorporeal shockwave lithotripsy AND (apps OR smartphone OR mHealth OR applications OR self-care application OR self-management application). Key words were selected based on the mesh database to achieve the purpose of the study to define the minimum data required for the research.

Only articles with minimum data on kidney stone self-care program were considered. Studies were searched without time limits. After displaying the title and the full text of the abstract, it was checked. Two independent investigators reviewed all papers separately to identify eligible studies. Then, the reports were removed if they did not meet the inclusion criteria. Document data is included in the data collection forms. Disagreements between judges were resolved by group discussions.

Two of the reviewers extracted the data from the full text and summarized and presented it in a tabular format. After reviewing the resources, a questionnaire was designed to assess the need for self-care application design. The beginning of the questionnaire states the subject and purpose of designing the questionnaire and then the personal characteristics of the respondents such as gender, age, work experience, specialty is recorded. The questionnaire consisted of 64 questions in four sections including demographic data, clinical data, disease monitoring and application capabilities with a 5-point Likert scale (strongly agree, agree, have no opinion, disagree and strongly disagree) [21]. At the end of each section, an open case was considered for

suggestion by experts.

In the second phase, a survey was done in the form of a researcher-made questionnaire from urologists, health information management and technical experts about the requirements of the application The experts participating in the study were selected purposefully and based on practical experiences in this field. According to the studies, these experts in the clinical, informational and technical fields had the ability to confirm minimum data. The questionnaire was given to the target group in person. These three groups of experts had experience in identifying and confirming the clinical and technical areas of the self-made questionnaire content.

The findings of the survey were analyzed using descriptive statistics (frequency and mean). Frequency distribution and data analysis were done in SPSS software. Based on the scores given by the participants in the study, the frequency and average scores for each data element were calculated. Then, considering that the highest possible score for each data element was 5, half of this number (for example 2.5), was considered as the average score for each data element.

As a result, each item of the questionnaire that scored at least 2.5 and more was considered as an essential elements. In this study, the validity of the questionnaire was measured based on content validity and review of texts from reliable databases. The reliability of the study was based on the agreement coefficient of experts and Cronbach's alpha calculation. Ten clinical specialists, information technology specialists and health information manager surveyed the questionnaire and confirmed its reliability with Cronbach's alpha coefficient of 0.94.

RESULTS

In this study, information requirements of Self-Care Application for patients with kidney stones undergoing extracorporeal shock wave lithotripsy were presented four following parts: - Demographic requirements

-Clinical elements

-Disease monitoring

-Data elements of application capabilities

As seen in Table 1, 6(60%) of the respondents were male and 4(40%) of them were female. 3(30%) of the respondents were urologists, 4(40%) were health information management experts and the remaining 3(30%) were IT experts. The highest number of respondents with 4(40%) was in the age group of 40 to 50 years and 3(30%) in the age group of 30 to 40 years. The highest number of respondents had 4(40%) of work experience in the period of 15 to 20 years and 30% had work experience in the period of one to five years.

Based on the findings of the first stage of the research, 15 data elements were obtained for demographic requirements (Table2), 22 items for clinical elements (Table3), 14 items for disease monitoring (Table4) and 13 features for application capabilities (Table5). The urologists and health information management experts on the identified data elements and application requirements are shown in Tables 2-5. Data elements with an average value of 2.5 and more were selected as the data element in the self-care application.

The results of a survey of experts showed that all identified components and data requirements have a high average value and are necessary. The reliability of this questionnaire was confirmed by Cronbach's alpha coefficient of 0.94.

Participants in the survey gave the highest score (4.9) to gender and age in demographic information; stone location, stone size, number of stones, type of stone, history of stone excretion, frequency of stone recurrence in clinical information; hematuria in disease monitoring; familiarity with kidney stone disease and application usage guide in application capabilities.

Table 1: Demographic characteristics of study participants

Profile		n	%
Gender	Men	6	60
	Woman	4	40
Age	20-30	2	20
	30-40	3	30
	40-50	4	40
	50-60	1	10
Specialty	Urologist	3	30
	Health Information management	4	40
	Information Technology	3	30
Years of experiences	1-5	3	30
	5-10	0	0
	10-15	1	10
	15-20	4	40
	20-25	2	20

Table 2: Demographic data elements

Data element	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Average	Selected
First & Last Name	9		1			4.8	✓
Father Name	7	2	1			4.6	✓
National Code	7	1	1			4.3	✓
Age	9	1				4.9	✓
Gender	9	1				4.9	✓
Weight	8	2				4.8	✓
Height	8	2				4.8	✓
BMI	6	4				4.6	✓
Education level	6	3	1			4.5	✓
Occupation	7	3				4.7	✓
Insurance	8	1		1		4.6	✓
Location	7	2	1			4.6	✓
Phone number	8	1		1		4.6	✓
Marital status	8	2				4.8	✓
Number of children	4	3		2	1	3.7	✓

Table 3: Clinical data elements

Data element	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Average	Selected
Stone location	10					5	✓
Stone size	10					5	✓
Number of stone	10					5	✓
Type of stone	10					5	✓
History of stone	10					5	✓
Stone recurrence	10					5	✓
Previous treatment method	9	1				4.9	✓
Stone family history	8	2				4.8	✓
Personal history of the disease	9	1				4.9	✓
Hypertension	9	1				4.9	✓
Diabetes	8	2				4.8	✓
Cardiovascular disease	8	2				4.8	✓
Gout	8	2				4.8	✓
Thyroid disease	7	3				4.7	✓
Smoking	7	3				4.7	✓
Alcohol consumption	8	2				4.8	✓
Current medication	8	2				4.8	✓
Apacity of stone	9	1				4.9	✓
Type of anaesthesia	8	2				4.8	✓
Number of shocks	7	1	2			4.5	✓
Shock intensity	7	1	2			4.5	✓
Frequency	6	2	2			4.4	✓

Table 4: Disease monitoring data elements

Data element	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Average	Selected
Fever	9		1			4.8	✓
Haematuria	9	1				4.9	✓
Bruising	8	2				4.8	✓
Hypertension	8	2				4.8	✓
Nausea and Vomiting	8	2				4.8	✓
Sweating	8	2				4.8	✓
Weakness	8	2				4.8	✓
Pain	8	2				4.8	✓
Cardiac arrhythmia	8	2				4.8	✓
Dysuria	8	2				4.8	✓
Urinary frequency	8	2				4.8	✓
Urinary stasis	8	2				4.8	✓
Volume of urine	8	2				4.8	✓
Track the success rate of stone removal	8	2				4.8	✓

Table 5: Application capability data elements

Data element	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Average	Selected
Introduction to kidney stone disease	10					5	✓
Introduction to treatment methods	9	1				4.9	✓
Appropriate diet	9	1				4.9	✓
Proper exercise	9	1				4.9	✓
Reminders of water consumption	9	1				4.9	✓
Visits reminders	8	1	1			4.7	✓
Contact with doctor	9	1				4.9	✓
Reporting	9	1				4.9	✓
Monitor adherence to treatment	8	2				4.8	✓
Use username and password	9	1				4.9	✓
Change the password	9	1				4.9	✓
Internet access	9			1		4.7	✓
User guide	10					5	✓

DISCUSSION

The aim of this study was to identify data requirements and effective parts to design a self-care application for patients with kidney stones undergoing extracorporeal shock wave lithotripsy. Self-care application requirements were categorized into four sections: demographic data, clinical data, disease monitoring, and application capabilities. These requirements were approved by clinical experts and health information management experts.

The present study is in accordance with the studies concluded in the field of self-care application design.

In research conducted with the aim of designing a self-care application to control tuberculosis [22], AIDS [23], type 2 diabetes [24], cancer [25] and heart failure [15], demographics data, clinical data, and application capabilities were identified in the first stage. Since the present study was designed specifically for patients treated with extracorporeal lithotripsy, the disease monitoring section was dedicated to identify possible complications after lithotripsy such as hematuria, fever, and hypertension. In these studies, a self-made questionnaire was used in the clinical, demographic and informational elements of the application program. Designers and developers of applications can use these information requirements of this questionnaire containing confirmed information elements to design a self-care program for affected people that can help manage and improve the health status of patients [24].

Akand et al. [26] presented a study to develop the RIRS information registry system for patients with kidney stones in Turkey in 2019. They extracted and categorized the information into three sections. The first section includes information collected in the preoperative assessment (sex, weight, height, history of stones, family history, comorbidities, location of the stone, method of identifying the location of the stone). The second section includes information collected in the evaluation during surgery (type of anesthesia, stone opacity). The third section contains information collected in postoperative evaluation (postoperative antibiotics, observed complications, stone removal, stone fragments, residual stone management) [26].

In agreement with the approach of Akand et al., in the present study, data elements were categorized into data before lithotripsy (sex, weight, height, history of kidney stones, previous treatment method, family history of kidney stones, comorbidities, identification method of stone location, exact location of stone), data related to during lithotripsy (stone apoptosis, type of anesthesia) and data related to postoperative lithotripsy (drugs being used, postoperative complications, follow-up of stone removal).

Chang et al. [27] in collaboration with academic and non-academic experts in the United States, Canada, Japan and China to design a registry of kidney and urinary tract stones (ReSKU) in the electronic patient record system, variables and data required for ReSKU registry design is considered in 4 main parts as follows:

- Variables for registering a new patient: gender, age, education, medical history, family history, etc.
- Variables related to the operation: type of surgery, surgeon's specifications, duration of surgery, urine culture, etc.
- Variables for postoperative follow-up: analysis of stones, length of hospital stay, complications, remaining stones after surgery, etc.

Follow-up variables: 24-hour urine parameters, stone recurrence prevention management strategies, follow-up images, etc. In this study, four questionnaires were considered for data collection. These instruments collect new patient, Surgery, Post-op, and Follow-up clinical encounters. In accordance with the design and needs assessment process of the ReSKU registry program, in this research, the following has been considered: data and variables related to the new patient and the operation performed; Identification and follow-up of signs and complications after lithotripsy; Familiarity with diets and tracking water consumption; Various reminders to prevent stone recurrence. Kidney stones were not mentioned in general in the present study. Rather, data elements ESWL were extracted according to local information needs to be used in the design and development of self-care program applications. One of the challenges of the present study was the limited number of participants due to the specialization of the subject and the lack of access to experts. In most studies like the present study, a standard questionnaire has been used to collect data.

In the present study, the needs assessment of the application capabilities showed that it is necessary to provide knowledge and awareness in the field of kidney stone disease, kidney stone treatment methods, proper nutrition and proper exercise. The literatures of various studies on the education of patients with kidney stones undergoing extracorporeal lithotripsy show insufficient knowledge of patients about kidney stone disease and the method of extracorporeal lithotripsy, and emphasized on appropriate training for patients [28-31]. Therefore, the necessity of the identified capabilities in this study is consistent with the results of those studies.

This present study show that participants believed that sending appropriate reminders for water consumption and medication, and face-to-face visits should be the capabilities of the self-care application. This result is consistent with a study by O'Leary et al. [32] as well as Kendall et al. [33], who considered electronic reminders important in chronic illness care and increasing adherence to treatment and management of daily activities.

Communication with the physician was identified as an essential feature of the application that enables the patient and physician to interact without face-to-face visits. According to a study conducted by Scales et al. [34] with the aim of investigating the effect of unscheduled visits after treatment of urinary stones, showed an exorbitant cost of unnecessary referrals that can be largely prevented by establishing communication between patient and physician. In Kaboutari-Zadeh et al. study titled “Developing the Minimum Data Set for Designing Kidney Transplant Personal Health Records (KTPHR) Applications “the study method was conducted in three phases. In the first step, a literature review was conducted to identify the information elements of the kidney transplant electronic record. In the second stage, the questionnaire and model were validated using content validity ratio (CVR) and content validity index (CVI) by medical informatics and health information technology specialists, clinical laboratory doctors and nephrology specialists. In the third stage, the minimum information requirements for the design of Shahzadi's kidney transplant file were confirmed [35]. In the present study, in the first stage, a comprehensive literature review was conducted to extract informational elements, and in

the next stage, reliability and validity were measured.

One of the important limitations of the present study is the limited access to experts to confirm the data elements.

CONCLUSION

Kidney stone disease has become one of the major problems in Iran and in the world. Using the capabilities of mobile technologies, applications and smart tools can be a good solution to prevent and control kidney stone disease. The results of this study and the high percentage of expert agreements show that the elements and capabilities of the application were properly selected and extracted. The findings showed the importance of self-care for patients with kidney stones undergoing extracorporeal lithotripsy, which was confirmed by clinical experts, IT specialists and health information management. For further studies, needs assessment is recommended from patients and specialists in diseases associated with kidney stones.

AUTHOR'S CONTRIBUTION

All authors contributed to the literature review, design, data collection and analysis, drafting the manuscript, read and approved the final manuscript.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest regarding the publication of this study.

FINANCIAL DISCLOSURE

No financial interests related to the material of this manuscript have been declared.

ETHICS APPROVAL

The study was approved by the ethics committee of Tabriz university of medical sciences (IR.TBZMED.REC.1398.1223. All participants of the study provided written informed consent after they were informed of the general aims of the study and their confidentiality and privacy ensured.

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