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Self-care application for rheumatoid arthritis: Identifying key data elements

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A B S T R A C T

Introduction: Rheumatoid arthritis is a systemic, chronic autoimmune disease that affects the joints, and limited mobility. The disease is progressive and can significantly impact a patient's quality of life. Today, mobile applications have the potential to address specific health needs and provide therapeutic interventions. The initial stage of constructing and advancing a healthcare information system involves the utilization of a minimum data set, which comprises essential and standardized data components aimed at capturing and overseeing patient care. This study aims to identify key components for a mobile-based self-care application for patients with rheumatoid arthritis.

Material and Methods: In this descriptive analytical study, two steps were undertaken. Firstly, a review of related articles and existing apps was conducted. Secondly, a researcher-developed questionnaire with a high reliability coefficient (Cronbach's alpha=0.97) was used to validate the identified information elements. Elements that scored at least an average of 3.2 (60%) on a 5 point Likert scale were deemed necessary data components for the design of an android-based mobile app catering to the self-care needs of rheumatoid arthritis patients.

Results: Based on the analysis findings, experts identified crucial technical requirements for a mobile-based self-management system. The system should include features for documenting drug side effects and providing educational content and physical exercise videos. Additionally, these requirements encompass reminders for medication, doctor appointments, and physical activities. Priorities also include clinical information, lifestyle management, and patient demographics.

Conclusion: Overall, the implementation of such a system has the potential to enhance patients' self-management skills, promote active involvement in self-care, and facilitate communication with healthcare providers.

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INTRODUCTION

Rheumatoid arthritis (RA) is a persistent autoimmune ailment that predominantly impacts the joints, resulting in discomfort, rigidity, and inflammation [1]. RA incidence varies globally, with higher rates in industrialized nations due to environmental and genetic factors. Over 30 years, RA severity has declined, but prevalence has increased. Risk factors include modifiable lifestyle factors and non-modifiable features like genetics and gender [2]. The disease can progress through different stages, resulting in joint damage, physical limitations, disability, and reduced quality of life, affecting aspects such as social function and mental health. These consequences can lead to considerable financial burdens, including hospitalization costs, treatment costs, and loss of income due to absence from work. The prevalence of RA varies globally, with reported rates ranging from 0.018% to 10.7% in different populations [3]. Unlike osteoarthritis, which is caused by wear and tear on the joints over time, RA is an autoimmune disorder where the body's immune system mistakenly attacks its own healthy tissues,

resulting in inflammation and damage to the joints. RA has the potential to impact any joint within the human body, however, it is predominantly observed to affect the smaller joints located in the hands and feet. In addition to joint symptoms, RA can also cause systemic symptoms such as fatigue, fever, and weight loss. RA has the potential to impact various other bodily systems, including but not limited to the respiratory, cardiovascular, and ocular systems [4]. RA is a progressive disease, and over time, it can lead to the destruction of cartilage and bone within the joints, resulting in permanent joint damage, deformity, and loss of function. This can have a substantial impact on an individual's quality of life, rendering it arduous to carry out routine tasks such as ambulating, donning attire, and even grasping objects [5].

In addition to physical symptoms, RA can also cause emotional and mental stress, as well as social isolation due to the limitations imposed by the disease. RA patients may also experience fatigue, sleep disturbances, and depression, further affecting their overall well-being [5, 6]. The impact of RA on a person's life can be significant, and it is important for patients to receive early and appropriate treatment to manage symptoms and prevent joint damage. RA is a condition for which no cure currently exists. However, symptom management and disease progression deceleration can be achieved through treatment. The available treatment options for rheumatoid arthritis (RA) may include the administration of medications, such as nonsteroidal anti-inflammatory drugs (NSAIDs), disease-modifying antirheumatic drugs (DMARDs), and biologic agents. Additionally, physical therapy and lifestyle modifications, such as regular exercise and a balanced diet, may prove beneficial in managing the symptoms of RA. In fact, a comprehensive approach that combines medication, physical therapy, and lifestyle changes can effectively alleviate the symptoms of RA and enhance the overall quality of life [7, 8].

Self-management of disease involves individuals taking active steps to manage their health, such as monitoring symptoms, managing medications, making lifestyle changes, and communicating effectively with healthcare providers. It's particularly important for those with chronic diseases. Key elements include patient education, symptom monitoring, medication management and lifestyle changes. Effective self-management can improve patient outcomes and quality of life, but requires ongoing education and support [9, 10].

mHealth refers to the use of mobile devices, such as smartphones and tablets, to improve healthcare delivery and health outcomes. It includes remote patient monitoring, health education and promotion, medication management, telemedicine, and health data tracking. Besides mHealth has the potential to improve access to healthcare and increase patient engagement. The utilization of mHealth possesses the capability to enhance the management of chronic ailments, such as diabetes, heart disease, and arthritis, by furnishing patients with convenient and easily accessible tools to monitor their symptoms, medication intake, and physical activity [11, 12]. It can also encourage healthy behaviors and provide real-time feedback. Besides it can be used for remote patient monitoring, medication management, and providing educational resources to patients. mHealth allows for the collection and analysis of large amounts of health data, which can be used to inform clinical decision-making and develop personalized treatment plans. For example, mHealth apps can help patients track their symptoms, medication use, and physical activity, allowing them to better manage their health and communicate more effectively with their healthcare providers [13].

mHealth can be beneficial in managing arthritis. Arthritis requires ongoing management and monitoring, and mHealth can provide patients with convenient and accessible tools to help them manage their condition [14]. Remote monitoring can identify joint swelling and range of motion, allowing for early intervention. In addition, mHealth provides patients with educational resources and helps them manage their medications. It also collects and analyzes health data for informed clinical decision-making. However, there are challenges, such as data privacy and security issues, regulatory concerns, and the need for proper training. Despite these challenges, mHealth has the potential to revolutionize arthritis management and lead to better patient outcomes [15, 16].

The use of mHealth apps in healthcare has been gaining popularity in recent years as a means of improving patient outcomes, particularly in areas where there is a shortage of healthcare providers. In the case of rheumatology departments in Iran, the limited number of physiotherapists presents a challenge in providing adequate care for patients with RA. The development of an mHealth app for exercise prescription and patient monitoring could therefore help to bridge this gap. The widespread use of smartphones and internet services in Iran makes it an ideal platform for developing such an app.

The acquisition of high-quality data and the establishment of an integrated health information system are essential objectives that can be achieved through the utilization of the Minimum Data Set (MDS). This tool serves as the initial phase in the development of a mobile-based self-care application [17]. Given the intricacies associated with RA, it is imperative to gather its data in a standardized

manner. Such data can be utilized in the pursuit of furthering research on the disease. So, this study aims to develop MDS for clinical purposes and use it to design a self-care mobile application for RA patients for patient management.

MATERIAL AND METHODS

In this study, a two-part approach was used, including (stage 1) a needs analysis study and (stage 2) a study of physicians' opinions on the features of the mobile phone application.

Stage 1: Needs analysis study

Initially, a survey study was conducted to determine the type of information and capabilities required for application development. In this stage, a literature search was conducted using keywords such as self-care, rheumatoid arthritis, mobile health, mobile application, self-management, and smartphone in various databases, including Google Scholar, ProQuest, Springer, Scopus, PubMed, and Iranian databases. Both printed and electronic sources such as texts, publications, authentic articles published in databases, and applications available in Google Play and App Store related to self-care for managing RA were extracted based on a combination of these keywords. The corresponding questionnaire was designed based on the results of these studies. In this stage, the study inclusion criteria consisted of the following:

- Articles published within the last 10 years
- Articles related to self- management of RA
- Fields related to E-Health technology
- A mobile application that is accessible through at least one app store
- The applications are intended for utilization by individuals who are 18 years of age or older and have been diagnosed RA
- Applications targeted the self- management of RA

The exclusion criteria were as follows:

- Articles that are not related to the topic
- Articles for which the text or full text cannot be accessed
- Applications that are not in English
- Applications that are unrelated to RA self-management
- Applications intended exclusively for utilization by healthcare professionals.
- Applications for clinics, conferences/conferences or products

A data extraction form was used to gather the following information for each eligible study: first author, year of publication, type of study and System Features. For each mobile application, the application name, country, language, price, platform and available features were also extracted. Then, following a thorough literature review and consultation with experts, we created an information Needs Assessment Questionnaire (INAQ). The questionnaire was designed with five sections, which included demographic information, lifestyle, clinical information, educational information, and system capabilities. To ensure content and face validity, the questionnaire was reviewed by five professors of health information technology and a rheumatologist. The reliability of the questionnaire was assessed by calculating Cronbach's alpha using SPSS 16.0 software.

Stage 2: Clinicians' perspectives about mobile application features

In this stage, a sample of eight rheumatology subspecialists from Kosar clinic of Ardebil, Iran was selected in a targeted and random manner to participate in the information needs assessment project. The specialists were required to meet the following entry criteria: expertise in rheumatology and a minimum of five years of service experience. The experts conducting the study were provided with a Likert scale consisting of five points, ranging from 1, indicating "very slightly important", to 5, indicating "highly important". They were instructed to assign scores to the tabulated data elements based on their level of significance. The data obtained from the survey study were analyzed in the following manner. To determine which data elements should be incorporated into the application, the researchers established a criterion. According to this criterion, any data element that was deemed "necessary" by at least 60% of the participants was considered important and therefore included in the application.

RESULTS

Stage 1: Needs analysis study

Characteristics of included studies/apps

A literature search yielded 420 articles and 43 apps, but after duplicates and articles that did not meet the criteria were eliminated, only 16 articles and 9 apps remained that fulfilled all the criteria for inclusion in the analysis. The process of selecting these articles is depicted in Fig 1 using a PRISMA chart.

The results of the included studies and applications were reviewed based on the relevant inclusion and exclusion criteria and finally classified in Tables 1 and 2.

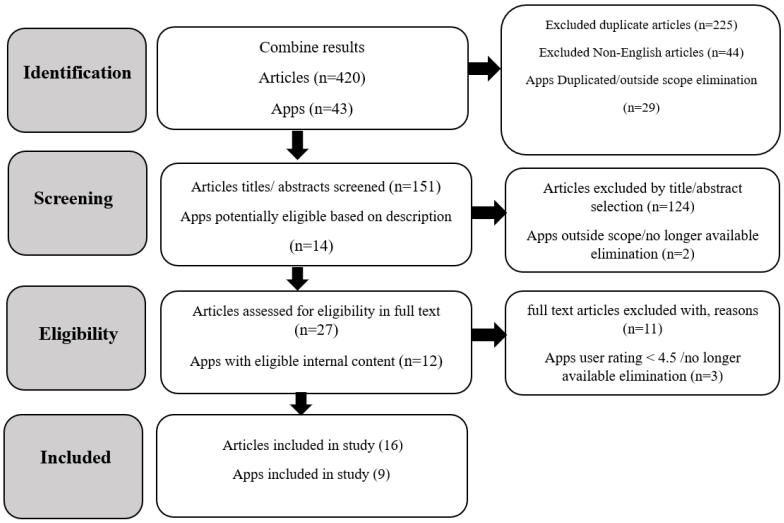

Fig 1: PRISMA chart for the study/app selection process

Table 1: Summary of characteristics of included studies

Year	Study	Type of Study	System Features								
			Reminders	Learning	Exercise	Disease Management	Life style	Communication	Medical record	Networking	Self-Assessment
2020	[18]	Review	*	*		*	*	*	*		
2019	[19]	Review		*		*			*		*
2021	[20]	Randomized Controlled Trial	*	*		*	*		*	*	*
2018	[21]	Pilot study	*	*		*			*		*
2017	[22]	Review	*	*		*	*	*	*		*
2015	[23]	Developmental study	*	*	*	*		*	*		*
2021	[24]	Research Article	*	*		*					*
2019	[25]	Review	*	*	*	*	*	*	*		*
2020	[26]	Pilot study	*	*	*	*	*		*		*
2018	[27]	Feasibility Study				*			*		
2021	[28]	Randomized Controlled Trial				*	*		*		*
2020	[28]	Systematic Quality Appraisal and Content Analysis		*	*	*		*			*
2016	[29]	Review	*	*	*	*		*	*		*
2015	[30]	Research		*		*			*		*
2020	[30]	Randomized Controlled Trial			*	*	*		*		*
2015	[3]	Research	*	*	*	*	*	*	*		*
2017	[31]	Research		*	*	*			*		*
2014	[32]	Research		*		*			*		*

Table 2: Summary of characteristics of included apps

Features \ Name		Rheuma Helper	My Arthritis	Arthritis Tracker	Arthritis Power	Bezzy RA	RA Monitor	Rheuma Buddy	Track + React	Joint fully Osteoarthritis
Country		Slovenia	UK	UK	UK	US	UK	Denmark	US	US
Language		English	English	English	English	English	English	English	English	English
Price		Free	Free	Free	Free	Free	Free	Free	Free	Free
Platform		Android	Android IOS	Android IOS	Android IOS	Android IOS	Android IOS	Android IOS	Android IOS	Android IOS
Learning	About Disease		*	*	*		*	*	*	*
	Symptoms	*	*	*	*	*	*	*	*	*
	Available Treatments				*	*	*	*	*	*
	Adverse effects of drugs			*			*			
	Personalized Note			*		*	*	*	*	*
Reminders	Medication reminder	*	*	*	*	*	*		*	*
	Exercise reminder		*			*				
	Medical appointment reminder	*	*	*				*	*	*
Exercise	Photos		*		*	*			*	*
	Movies								*	*
Disease management and life style	Stress management			*			*	*	*	*
	Diet planning	*	*	*	*	*			*	*
	Exercise planning	*	*	*	*	*			*	*
Communication	Notifications					*		*	*	*
	Social network	*			*			*		
	Online consultation			*	*			*	*	*
Medical record	Symptoms	*	*	*	*	*	*	*	*	*
	Underlying disorders		*			*				
	Previous records		*	*						
	The duration of the disease		*	*	*		*			
	Current medication	*	*		*		*	*	*	*
	Laboratory results		*				*			
	Radiology images		*				*			
	User status (Report)	*	*	*	*		*		*	*

During this stage, a questionnaire was developed to evaluate the information requirements for creating a self-care app for RA disease, using information collected from various sources. The questionnaire's reliability was assessed using SPSS software, and Cronbach's alpha was computed, resulting in a score of 91.3%. It consisted of seven categories: demographics, lifestyle factors, clinical information, laboratory findings, imaging, educational information, and system capabilities. The questionnaire was distributed to eight rheumatologists, all of whom responded. The mentioned rheumatologists were working in kowsar super specialty clinic in Ardabil province, the reason for this choice was the high prevalence of this disease in this city, the presence of a specialized clinic in this center and, consequently, the presence of a large number of patients in the respective center.

Stage 2: Clinicians' perspectives about mobile application features

Table 3 displays the frequency and percentage of personal attributes of the participating rheumatologists, such as age, gender, work experience, type of educational qualification, and job title.

Table 3: Baseline characteristics of participants

Variable		Frequency	%
Gender	Female	3	37.5
	Male	5	62.5
Age	<40	1	12.5
	40-50	5	62.5
	>50	2	25
Work Experience (Year)	<10	1	12.5
	10-20	4	50
	>20	3	37.5
Degree	Specialist	6	75
	Fellowship	2	25
Job Title	Faculty member	5	62.5
	Non-faculty	3	37.5

Table 4 presents the frequency distribution of responses provided by rheumatologists concerning the significance of data elements that are mandatory in the system. These data elements comprise demographic information, lifestyle, clinical information, educational information, and system capabilities.

DISCUSSION

The employment of mobile phone-based systems presents a multitude of benefits for both patients and healthcare providers. These systems have the capacity to aid patients in acquiring crucial education and disease management, while simultaneously enabling healthcare providers to gather data regarding their patients' health status and devise suitable care plans for them, without encountering logistical impediments such as distance and time. Additionally, such interventions can increase patient participation, thereby improving the quality of primary care. For chronic diseases like arthritis, organized care programs, education, and timely monitoring can prevent many of the problems that patients encounter. Mobile phone-based applications can serve as useful tools in monitoring patients' health status in real-time [33, 34].

In general, managing RA involves various individual, social, and clinical factors, and different individuals may face unique challenges in properly managing their care. Therefore, personalized interventions are necessary to cater to the diverse needs of individuals [35]. The MDS development process outlined herein can yield benefits in the standardization of data collection, management of patient care, and enhancement of care quality. Several studies have underscored the significance of standardized clinical literature, including patients with RA [36].

The initial phase of the study indicated that a majority of the data components suggested by extant literature and mobile applications were deemed indispensable by users and were advised to be incorporated into the system. Furthermore, the viewpoints of medical practitioners were found to be in close agreement with the requisite functionalities of the system.

Table 4: Required data elements and features for the mobile app

Required data elements and features			Necessary (%)
Demographic information	Age		92
	Gender		96
	Marital status		82
	Job		90
	Education		78
	Weight		94
	Height		86
	Body mass index		88
	Type of insurance		54
	Salary/ month		58
Life style	Physical activity		96
	Smoking		90
	Mental stress		78
Symptoms	Wrist pain		100
	Elbow pain		100
	Shoulder pain		100
	Knee pain		100
	Thigh pain		100
	Ankle pain		100
	Stiff joints in the morning		100
	Joint dryness		100
	Decreased performance		92
	Weakness and feeling tired		88
	Weight Loss		84
	Insomnia due to pain		42
	Duration of disease		90
Underlying diseases	Rheumatic disease other than RA		90
	Non-rheumatic diseases		92
Medications being taken			88
Allergy to certain medications			48
disease side-effects	Pulmonary involvement		90
	Cardiac involvement		92
	Eye contact		86
	Skin involvement		92
Previous records	Diabetes		86
	Blood pressure		84
	Blood fat		84
	Allergy		44
Laboratory findings	Calcium		100
	Phosphorus		86
	Ferritin		80
	ESR		86
	CPR		86
	Vitamin D		88
Imaging	MRI		88
	Radiography		86
System features	Information about the disease		96
	Symptoms		92
	Predisposing factors		90
	Types of diagnostic methods		88
	Drugs side effects		96
	Available treatments		92
	Reminders	Exercise	90
		Medication	94
		Appointment	96
	Registration of drug side effects		96
	Effective movements (educational pictures and videos)		94

The majority of experts considered all demographic information elements such as age, gender, marital

status, occupation, education, weight, height, and body mass index to be necessary with a high average. This is consistent with the study of Tian et al. [37], which highlighted the prevalence of osteoarthritis symptoms and the importance of age and gender factors, high BMI, smoking, and drinking alcohol on the disease and quality of life.

Bajraktari et al. [38] conducted a study on 951 patients with rheumatoid arthritis (RA) and discovered a significant correlation between demographic characteristics, such as gender, nationality, marital status, education, occupation, and the prevalence of the disease. This study underscores the importance of recording demographic information, including country code, age, gender, marital status, address, date of admission, and date of discharge. The study implemented RA registration at hospitals that receive RA patients. As a result, "Date of Admission" and "Date of Discharge," which are deemed crucial and validated, will be incorporated into the proposed MDS for inpatients with RA.

Besides, the most of physicians also considered all lifestyle information elements such as physical activity, smoking, and mental stress to be necessary with a high average. Physicians believed that the patients' awareness of the disease and knowledge of pain control methods was very effective in improving lifestyle and preventing further complications and exacerbation of the disease. Education and management of the disease were also considered very necessary [39, 40].

Mullard et al. [35] conducted a study on the self-management of RA disease through mobile phone applications, examining various factors that affect joint autoimmune disease. The basic features of programs designed for self-care included training for physical activities, lifestyle, the possibility of communicating with Physicians, recording side effects of drugs, and pain control. Lifestyle-related components such as controlling the level of anxiety and stress, and creating and increasing motivation to use and adhere to the interventions of self-management programs were emphasized.

Bendersky et al. [41] also studied the experience of patients with RA, emphasizing the importance of providing self-care education to patients to improve the quality of life and reduce symptoms of the disease. Also, he said that mental stress and pain from joint diseases are related. by lowering stress, joint pain can be lessened. Additionally, in his study, he suggests that practicing meditation and engaging in physical activities like walking, cycling, and swimming can help reduce stress.

In a study by Dahlberg et al. [42] a smartphone-based software program was used to decrease pain in patients with knee and hip osteoarthritis. The program consisted of eight videos and lectures on the effects of physical activity on pain improvement, as well as self-care and coping strategies. Participants were provided access to the program via email for six weeks. While the program was effective in increasing patients' awareness, access to web-based programs can be limited due to internet connectivity issues.

One study that can be compared to this is a similar project conducted by Ownby et al. [43] which developed a mobile application for self-management of multiple chronic conditions, including RA. The application included features such as medication reminders, symptom tracking, and goal setting. The study found that the application was effective in improving patients' self-management skills and reducing healthcare utilization. However, the study did not focus specifically on RA patients and did not involve healthcare professionals in the design and development process [43].

Overall, the mobile-based self-care application developed for people with RA in Iran represents an important step towards improving the management of this chronic disease. The study's focus on the specific needs of RA patients, involvement of healthcare professionals in the design and development process, and consideration of mental, cultural and linguistic factors makes it a valuable contribution to the field of mobile health.

One of the strengths of current study is its focus on the specific needs of RA patients. RA is a chronic disease that affects people from different cultural and socioeconomic backgrounds, and it is important to consider these factors when developing interventions for self-management.

Another important aspect of current study is its contribution to the field of mobile health. Mobile health, or mHealth, is a rapidly growing field that has the potential to transform healthcare by providing patients with access to personalized, convenient, and cost-effective interventions. The development of a mobile-based self-care application for RA patients is a promising approach to improving the management of this chronic disease and has the potential to be replicated in other countries and for other chronic conditions.

Debusche et al. [44] have observed that the provision of instruction to empower patients to self-manage their chronic illnesses remains a challenge in certain developing nations, particularly in the context of diabetes. Further field studies are necessary to address the ongoing needs and demands of individuals with chronic illnesses. Mobile health systems can be introduced in countries with affordable internet access. In developing nations, a scarcity of specialists and healthcare resources in various geographical regions results in patients having to endure prolonged waiting periods to consult with a physician. Such delays in receiving

treatment or medical advice can have a detrimental impact on the health of patients. However, the utilization of mobile phone-based systems can enable patients to access healthcare services promptly, when they are most required.

Collecting patient data in a standardized manner is critical to improving the quality and reliability of clinical amenities, promoting cooperative and successful work, evaluating clinical services against quality index as well as modifiers and treatment opportunities of clinical research. In current medicine, a lot of data is generated; However, there are gaps between data collection, understanding and interpretation. Furthermore, the data available is very large and complex. Thus, MDS is collected, which is a standardized approach to collecting the necessary data elements in order to facilitate their understanding and comparison.

The mobile-based self-care application developed for people with RA in Iran is an innovative approach to improving the management of this chronic disease. The application, which will design and develop based on the needs of RA patients and healthcare professionals, includes features such as self-monitoring of symptoms, educational information, medical records, disease management, reminders and reports.

CONCLUSION

In summary, the ability to make clinically and formally timely health care decisions depends on accurate and well-organized data and information. Therefore, the strategies used to enter and collect data will have a significant impact on the management and treatment of RA. MDS is a standard data collection tool that plays an important role in health information management. Developing a validated list of MDSs to assist with care management in RA provides an integrated and standardized approach to care planning, quality improvement, reporting, and delivery. The approach taken in this study was largely successful, involved the collaboration of eight rheumatologists, and could contribute to the development of a validated minimal data list for monitoring clinical care and outcomes in patients with RA. Rheumatologists have emphasized that capturing these factors through a well-coordinated data collection strategy is imperative and essential in the management of disease progression in patients with RA. It is recommended that future studies implement the proposed MDS with country linkage to assess its effectiveness. The MDS developed and validated in this study can be considered a significant step forward, advancing knowledge to have a profound impact on patient care.

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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

This study was approved by the researcher's institute review board at Tehran University of Medical Science (TUMS), Tehran, Iran, with code of ethics IR.TUMS.SPH.REC.1401.046.

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