Original Article

Patient Self-Management Of Cystic Fibrosis (CF) Using Mobile Health Applications: A Systematic Literature Review Of The Requirements

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DOI: 10.47750/pnr.2022.13.04.263

Abstract

Objective: The increasing growth of the creation and use of mobile health applications (mHealth apps) shows the importance of these applications for remote health control and self-management of people with chronic diseases such as cystic fibrosis (CF). To increase effectiveness, these programs should use requirements as the foundation of the applications. The purpose of this review was to extract requirements from research related to cystic fibrosis self-management based on mHealth.

Methods: Related keywords were searched in, PubMed, Web of Science, and Scopus. Then, articles have assessed and selected using the inclusion and exclusion criteria and finally, the requirements were extracted from this research.

Results: Finally, 11 articles were included in the study and CF self-management system requirements and their repetition in two categories of Core features and Non-functional were examined to determine the importance of each in different articles. Diary keeping, communication with HPs, and nutrition management were identified as the most common requirements for core features, and motivation and customization were identified as the most common non-functional requirements.

Conclusion: Patient Self-Management of CF Using Mobile Health Applications, have the necessary potential to facilitate self-care in patients, and attention to the important requirements for creating such systems should be a priority. Also, the importance of requirements can be changed according to which age group these systems are designed for.

Keywords: cystic fibrosis (CF), chronic diseases, patient self-care, mHealth

INTRODUCTION

Background:

Cystic fibrosis (CF) is a progressive genetic disease that affects the lungs, pancreas, and other organs and requires lifelong treatments. This disease can affect people of any race and ethnicity(1). The number of patients with CF is estimated to be 162,428 in 94 countries(2) and the average annual health care cost for the treatment of this disease is estimated to be 15,571 US dollars.(3)

People with cystic fibrosis face significant physical, psychological, and social challenges during adolescence and adulthood that affect their health-related quality of life(4, 5). Therapeutic advances in CF require increasing time and effort and pose ongoing challenges to patient self-management strategies, particularly in adults who attempt to achieve a balance family, work, education, and other responsibilities on the one hand and the management of this chronic disease on the other.(6, 7) The intensive, daily, and lifelong management of CF imposes a heavy burden on and several problems for patients and their families, one of which is frequent visits to the hospital for outpatient and inpatient care.(8, 9)

A multidisciplinary team approach has been the key to success in improving quality of life and other key outcomes for people with CF, but is financially costly to both the health care system and to the individual with CF. In

addition, there is concern about possible infections, especially in people who constantly visit health care centers. Therefore, some patients' reluctance to visit the hospital for routine appointments is understandable. In all health care systems, these events have led to greater attention and the use of telehealth in chronic diseases instead of face-to-face visits to health care professionals as much as possible.(10) With the growth in chronic diseases, patient empowerment (in which patients manage their health status) has been introduced as a tool to relieve strained health care systems.(11) Self-management can be defined as "a person's ability to manage symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic disease"(12), a process in which patients can benefit from the support of various health care professionals(13).

Self-management programs aim to achieve the best health possible and to fit treatment requirements based on a flexible management plan. Also, self-management educational interventions should equip patients and their families with the knowledge, confidence, and skills to take responsibility for their daily health decisions and have effective control over chronic disease management with flexible methods(14). New technologies have the potential to support self-monitoring and shared decision-making between the patient and the healthcare team.(5) One of the ways in which patient self-management can be strengthened is through personalized applications. However, to deliver high-quality applications, the development of these applications should be based on a thorough knowledge of user needs, derived from a user-participation approach. Several studies have reported the positive role of information and communication technology (ICT) in facilitating the self-management of chronic diseases. Therefore, there is a growing need to promote self-management in health care. Self-management is considered as a tool to better understand and cope with a disease and its treatment, for example by supporting behavior change and adherence to treatment.(11, 15, 16)

The technology acceptance model, introduced by Davis in 1986, shows that acceptance depends on the user's perception of the usefulness and ease of use of a system. Similarly, the innovation diffusion model emphasizes that a new technology must offer a "comparative advantage" over the status quo(17, 18). In a study that examined factors influencing patient acceptance of self-management technology, Grindrod et al., concluded that the first step in designing a system that would be accepted by patients is to focus on their needs.(16) Developers of these systems should also note that in situations where there is a significant treatment burden, patients should find these technologies acceptable and sustainable(19, 20). In order to design an efficient and usable system for users, it is necessary to have a proper understanding of the users' needs. Also, in the interactive design method, one of the methods to identify the goals of the users is to review the background of the research. Purposeful design helps designers create products that support users where they are weak and empower them where they are strong.(21) Therefore, this review study aims to extract the requirements and their frequencies from studies related to cystic fibrosis self-management systems based on mobile health so that researchers can use these requirements to create new systems.

Method:

Data Sources and Search Strategies

The electronic databases searched were Web of Science, PubMed, and Scopus. Also, unpublished studies including theses and the gray literature were searched in Google Scholar and Google, and the first 100 results were included in the review. A combination of MeSH terms and keywords related to cystic fibrosis and mHealth (e.g., mobile phone, smartphone, and apps) were used in the search strategy. The search language was English, and to identify potentially eligible studies published prior to 31 December 2022. The reference list of included studies and relevant reviews were also examined to identify additional studies.

Inclusion and Exclusion Criteria:

Studies were included if they met the following criteria:

1. Articles published in peer-reviewed journals and conferences
2. Articles published in English-language
3. Articles with available full text
4. Articles that discussed the requirements

Studies were excluded if they:

1. Publication type such as posters, abstract-only papers
2. Papers unrelated to self-management
3. Articles that did not have sufficient information regarding the requirements

Screening and Data Extraction

Titles, abstracts, and full texts were screened by two researchers independently (A.A. and H.F.). Full-text articles were retrieved from the searched databases and other available databases. Data were extracted from the included studies using a structured form. Any disagreement was resolved through discussions among all authors. Based on the classification of Vilarinho et al.'s study, system requirements can be classified into two categories (Core features and Non-functional).(22) In the present study, after reviewing the articles included in this study, these requirements were extract.

Data Extraction

For data extraction, researchers developed a data extraction form. The extracted data items for each paper included the author(s) name, year of publication, and Requirements categories (Core features and Non-functional requirements). Two authors independently extracted data for each study. Any disagreement between the two authors was resolved through discussion among all authors.

Results:

The search results and study selection process were summarized in the PRISMA flow diagram (Fig. 1). In total, 914 studies were found. After removal of duplicates and screening of titles and abstracts, 32 articles were eligible for full-text review. Finally, a total of 11 studies met all inclusion criteria.

The requirements of the CF self-care system were examined Based on the classification of Vilarinho et al.'s study(22) in the two main categories of Core features and Non-functional and their subcategories.

As indicated in Table 1, 11 articles were included in the study and CF self-management system requirements and their repetition in two categories of Core features and Non-functional were examined to determine the importance of each in different articles. Diary keeping, communication with HPs, and nutrition management were identified as the most common requirements for core features, and motivation and customization were identified as the most common non-functional requirements.

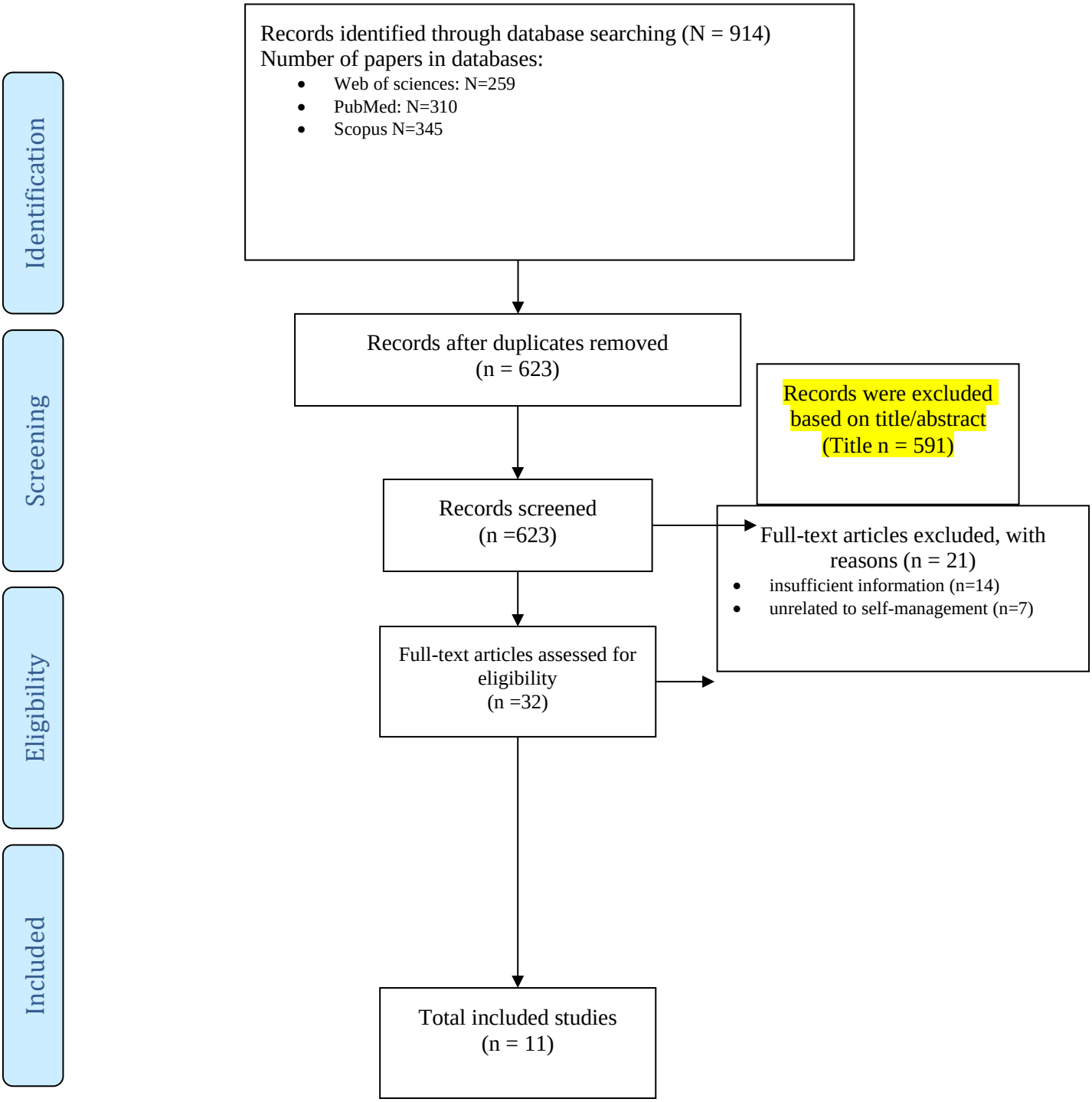

Fig. 1: Flow diagram of the literature search and study selection.

Table 1. Requirements for CF self-management of included studies

Author, year	*Core features*									*Non-functional requirements*				
	Enzyme management	Nutrition management	Recipes advice	Diary keeping	Treatment follow-up	Treatment organization	Education	Digital meeting place	Communication with HPs	Time saving	Motivation	Customization	Privacy	One App
Longacre et al, 2018(23)		*		*	*	*	*	*			*		*	
Calvo-Lerma et al,2017(24)	*	*	*	*		*	*		*					
Calvo-Lerma et al,2021(25)	*	*	*	*		*	*		*		*			
Martinez-Millana et al,2019(26)	*	*		*		*	*		*		*	*	*	
Rutland et al,2021(27)	*	*	*		*	*	*	*	*		*	*	*	
Rudolf et al,2019(28)		*		*		*			*		*	*	*	
Vagg et al,2018(29)				*	*			*	*					
Boon et al;2020(30)	*	*		*	*		*		*			*		
Floch et al,2018(11)	*	*	*	*		*	*		*		*	*		
Hilliard et al,2014(31)	*	*	*	*		*	*		*	*	*	*	*	
Floch al et, 2020(32)	*	*	*	*		*	*		*	*	*	*	*	

Discussion:

In the present study, we investigated the requirements related to CF self-management in several studies. A number of the studies included in the present study were examined the development, acceptance and effectiveness of self-care software(23, 24, 25, 26, 29), and some of them investigated the adjustment of applications to the needs of

users(11, 27, 28, 30, 31, 32). These studies have addressed requirements that were mentioned in the Findings section. According to the extracted requirements, it can be claimed that none of these studies have addressed all the requirements and that each of the studies had some shortcomings compared to the others.

All the studies reviewed in the present research mentioned the "nutrition management" feature that is supported by the self-management app and includes resources (nutritional education and practical recommendations) to empower patients to follow CF-specific nutrition guidelines. The results of the study by Calvo-Lerma showed that using this feature in self-care software can help health care professionals to accurately and completely evaluate the patient's diet.(25) In this regard, the results of Floch et al.'s study showed that support for enzyme dosage calculation and nutrition management is the most useful feature experienced by patients using this system.(32) Other studies reported that these features, along with education, increase awareness about food consumption and optimal dose of enzymes.(25, 30) Therefore, the requirements of nutrition management, enzyme management and education in CF can be considered as ideal goals of mHealth and self-management of patients.

The quality of health care depends largely on the successful communication between health professionals and patients.(33) The results of various studies showed that by using this program and the requirements of Communication with HPs and Digital meeting place, the patient can interact with each member of the health care team and other patients and gain a broad view of the self-care of the illness.(11, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32) In this regard, the Martinez-Millana study showed that, given the lack of care providers such as social workers, psychologists, endocrinologists in all units, the gap can be bridged by using the features of Communication with HPs and Digital meeting place for direct communication between patients and doctors beyond the classic mechanisms such as phone calls or e-mails.(26)

The results of various studies indicate that diary keeping supports the recording of health status, symptoms and other events related to disease management.(11, 23, 24, 25, 26, 28, 29, 30, 31, 32) The results of Floch's study showed that, with this feature, patients can remember past events and answer doctors' questions more accurately and receive better consultations.(11) However, Rudolph's study showed that the lower levels of diary keeping among adolescents could be due to the fact that adolescents did not consider these support measures important or that the program did not meet their needs.(28) Therefore, it is important to create programs that are not only initially engaging, but also maintain engagement over time.(31)

As for non-functional requirements, most studies mentioned motivation, privacy and customization.(11, 23, 25, 26, 27, 28, 30, 31, 32) None of the studies addressed the one app requirement. This feature helps to make a mobile app preferable to web or desktop and all the features be available in a single app instead of multiple apps.(22) Martinez-Millana mentioned concerns over privacy as the main obstacle to using self-management programs related to health on the part of the users.(26) Rutland et al. have suggested that the integration of patient-generated health data into clinical care through mHealth solutions should be done in a way that protects the privacy and integrity of patients.(27) Also, due to the non-uniformity of treatment routines and patients' knowledge about CF, such programs should be customizable, and depending on the health status and the patients' community, various functions be included in one program.(11)In addition to the requirements mentioned above, these studies have suggested using various technologies in these systems. Using barcode scanners of CF medications, adding gamification approaches, wearable sensors and tracking systems, and automatic data collection by CF-related programs are among the technologies that increase effectiveness, follow-up, increased adherence, and motivation to use the program.(26, 28) Therefore, designing automatic measurements will increase the motivation of patients to participate in health care programs and lead to positive health outcomes.

Limitations and future studies

The present study has some limitations. Firstly, only articles from the three main databases published in English were reviewed, and other potential articles were not included. To partially overcome this limitation, the reference list of the included articles and related review articles were searched. Secondly, as the aim of the present study was to identify the requirements of these systems, the quality of the included studies was not assessed and all the studies were included regardless of quality or design. Thirdly, articles not published in English were excluded. Therefore, some valuable articles in this area might have been missed. The final limitation is that, due to the emergence of mHealth applications, the results of unpublished and ongoing studies related to this field were not available. Consequently, the review does not reflect the experiences gained from non-English and unpublished studies. Future studies can use the requirements identified based on importance in the present study in the

successful implementation of mobile health self-management applications.

Conclusion:

This study showed that self-management systems of cystic fibrosis based on mobile health have the necessary potential to facilitate self-care in patients. The requirements of communication with HPs, diary keeping, and nutrition management are more important in creating such systems. However, the importance of the requirements changes depending on what age groups these systems are designed for.

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