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Coronary artery patient's empowerment through a user-centered design of an electronic personal health record: A qualitative study

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Abstract:

BACKGROUND: Coronary artery disease (CAD) is the most common cardiovascular disease. Electronic personal health record (e-PHR) enables patients with CAD to prevent or postpone complications. This study aimed to identify the requirements of e-PHR tailored for patients with CAD from the perspective of its potential users.

MATERIALS AND METHODS: This qualitative study was conducted in 2024. Data were collected through semi-structured interviews with 25 patients and cardiologists. The interviews were recorded digitally and transcribed verbatim. The data were analyzed using the framework analysis method and MAXQDA (version 10, VERBI Software GmbH).

RESULTS: Four themes, nine subthemes, and 25 categories emerged from data analysis. The main findings included necessary e-PHR contents, functional and nonfunctional requirements, and conditions for implementing it.

CONCLUSION: The developers should improve the performance of e-PHRs for long-term use by engaging patients and offering benefits for them to self-manage CAD disease trends. This would be better achieved by involving potential user groups in all phases of system development to ensure that e-PHRs match with users' requirements.

Keywords:

Coronary artery disease, health record, personal, qualitative research, user-centered design

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Introduction

Cardiovascular diseases are a leading cause of death in many countries and the primary reason for disability. They also place a significant financial burden on healthcare systems. The death and disability rates from these diseases remain alarmingly high despite major advancements in diagnostic and treatment services.[1]

Coronary artery disease (CAD) is the most frequent cardiovascular disease.[2] While the death rate from CAD is decreasing in developed countries, it has risen by 20%–45% in Iran.[3] Taking advantage of electronic health tools to empower individuals with CAD can effectively prevent or postpone complications.[4] The electronic personal health record (e-PHR) is an innovative health technology that is beneficial for individuals with chronic diseases, and has a higher acceptance rate among this patient population.[5] This technology enhances preventive care by fostering patient engagement and improving awareness of health status.[6] Additionally, enhancing patient-provider communication through e-PHR leads to greater patient engagement, thus improving self-care and resulting in higher patient

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satisfaction.[7] This technology helps healthcare providers better understand a patient's condition, improving decision-making and care coordination. This can also lead to better patient follow-up and fewer medical errors.[8]

For successful deployment of e-PHR, it is essential to focus on user-centric design approaches and consider the available infrastructure. The user-centered design is an approach for interactive systems development focusing on providing good user experience.[9] Specifically, there is a need to concentrate on developing a patient-centric e-PHR that reflects a patient's preferred form of accessing and using their data. Several studies have explored the development of e-PHRs, but there has been limited focus on understanding the requirements from the patient's perspective, especially using a user-centered design approach.[6,9]

Despite the increasing interest in the use of e-PHRs for managing chronic conditions, the implementation of e-PHRs in patients with CAD remains largely unexamined. Most existing literature has predominantly focused on other chronic illnesses,[6,7] leaving a significant gap in our understanding of e-PHRs about cardiovascular conditions, particularly CAD. Given the high morbidity, mortality, and long-term care needs associated with CAD,[1,2] it is crucial to explore how e-PHRs can support patients. This study is one of the first to specifically investigate the requirements of e-PHRs in the context of CAD, thereby addressing a notable deficiency in current research.

Study design and setting

This was a qualitative study conducted in 2024. Data were collected through semi-structured interviews with 25 patients and a cardiologist. The study setting involved cardiology inpatient wards and outpatient clinics.

Study participants and sampling

Purposive sampling method was used to select the potential participants of the study who were chosen according to the following inclusion criteria: maximum age of 50 years, familiarity with health information technologies, and holding at least a high-school diploma. We invited all cardiologists who worked in inpatient and outpatient settings of the cardiology ward to participate in our study. We stopped recruiting interviewees when data saturation was reached in the cardiologist and patient groups. In total, 25 interviews were held to reach data saturation.

Data collection tool and technique

The research data were collected using semi-structured interviews. Before holding the interviews, an interview guide was developed based on literature review.[6-13] The interview guide included five open-ended questions about the contents and requirements of personal health records (PHRs).

Ethical consideration

The interviews were digitally recorded with the authorization of the participants and transcribed verbatim. Informed consent was obtained from the study participants, and the identity of the participants was not disclosed. This study was approved by the National Committee for Ethics in Biomedical Research (IR.IUMS.REC.1399.047).

Statistical analysis

To analyze data, the framework analysis method and MAXQDA (version 10, VERBI Software GmbH) were used. The framework analysis method consists of five stages: familiarization, identification of a thematic framework, indexing, charting and mapping, and interpretation. The framework analysis method provides a systematic model for managing the data. Moreover, interviewees may have different viewpoints or experiences, and the framework analysis method is the most suitable technique for analyzing semi-structured interviews. It is desirable to generate themes by making comparisons within and between cases. Moreover, the summarized data contribute to understanding data patterns.[14,15]

The process of analyzing data was initiated after the first interview was completed. In this process, the main concepts of meaningful sentences were extracted as codes, which were subsequently categorized to show the themes, subthemes, and categories. All authors were involved in the process of data analysis, and the initial coding by the first author was reviewed by the second and third authors. The steps of the study are presented in Figure 1.

Results

We undertook 25 interviews, which lasted between 30 and 45 minutes. The characteristics of research participants are presented in Table 1.

As Table 1 shows, the majority of participants were women (n = 13, 52%) aged 40–50 years (n = 13, 52%). A summary of the results, including the main themes, subthemes, and categories that emerged from interviews, is presented in Table 2.

Theme one: e-PHR contents

According to the interviewees, necessary contents for e-PHRs in CAD included signs and symptoms, clinical information, patients' notes, and educational information. The participants declared that blood pressure data, heart rate, and clinical symptoms

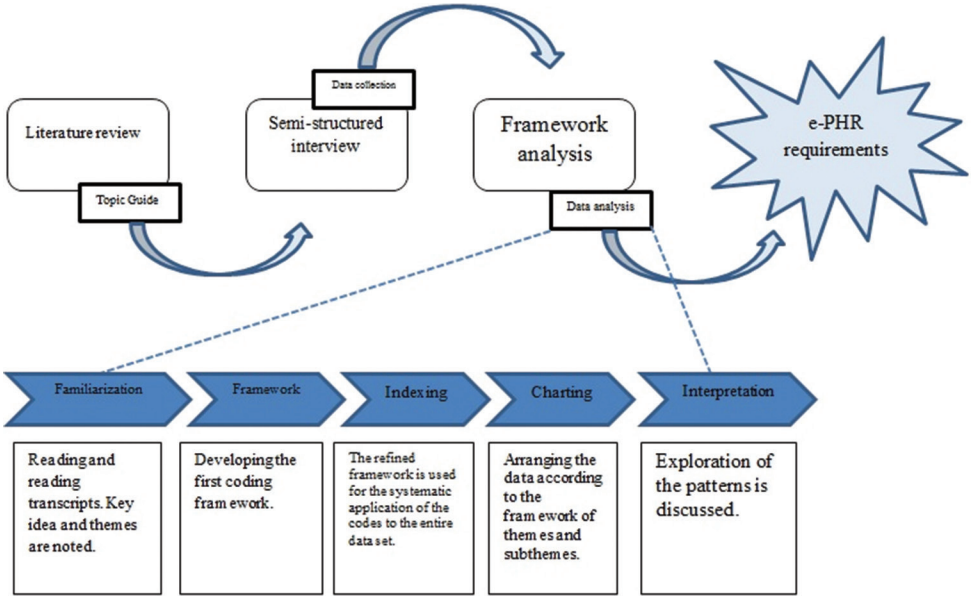


Figure 1: Theoretical framework of the steps of the study

Table 1: Research participants' characteristics

Variables	Patients (*n*=15)	Cardiologists (*n*=10)
Age group		
30–40	6 (40%)	4 (40%)
40–50	9 (60)	4 (40)
>50	0 (0)	2 (20)
Gender		
Female	7 (47)	6 (60)
Male	8 (53)	4 (40)
Education*		
Diploma	4 (27)	N/A
Associate	3 (20)	
Bachelor	5 (33)	
>Bachelor	3 (20)	
Years since diagnosis*		
<1	2 (13)	N/A
1–5	7 (47)	
5–10	3 (20)	
>10	3 (20)	
Years of professional experience		
<5	N/A	2 (20)
5–10		5 (50)
>10		3 (30)
Specialty		
General cardiologist	N/A	6 (60)
Cardiovascular imaging		1 (10)
Interventional cardiologist		2 (20)
Cardiac surgeons		1 (10)

*Only applicable for the patient participants; N/A: not applicable

after surgical procedures are important and can help cardiologists to create an effective clinical pathway. One of the interviewees said: "*I need to record my heart rate, blood pressure, and any symptoms like pain and swelling in my hands and feet for the doctor to check.*" (P14)

Most interviewees believed that the e-PHR should contain information about prescribed medications and their consumption instructions. This inclusion is essential for ensuring patient safety as well as effective medication management. Para-clinical information, medical history, summary sheets, and recommendations were other important clinical information cited by the interviewees. In this regard, one of the participants mentioned: "*The patient's clinical information, including medical images, summary sheets, and test results, must be accessible in the system for sharing with the doctor.*" (C8)

The interviewees considered recording information related to the type and intensity of pain as effective for the doctor to make accurate decisions. Moreover, some participants believed that documenting the severity of pain could assist people in accessing emergency services. As noted by one of the interviewees: "*The patient should be able to record his pain; for example, in what conditions the heart pain occurs to him, whether he is active or resting, which parts of his body the pain extends to, and how long it lasts.*" (C7)

Sexual activity, exercise, and self-care education were important from the interviewees' perspective. For example, some participants noted: "*Many CAD patients face a decline in sexual quality after illness, often due to irreparable issues or increased heart rate during intercourse. It is essential to provide them with educational information to effectively address these challenges.*" (C8)

"*It's crucial to prioritize our well-being by staying informed about self-care and the ways to enhance our quality of life.*" (P12)

Table 2: A summary of the themes and subthemes, and categories

Theme	Subtheme	Category
e-PHR contents	Signs and symptoms	BP* in different time intervals
		Heart rate
		Clinical symptoms after surgical procedures
	Clinical information	Medications
		Para clinical information
		Medical history
		Medical summaries
		Medical advice
	Patients' notes	Type and intensity of pain
	Educational information	Sexual activity
		Exercise
		Self-care
e-PHR functional requirements	Communication	Text chat, video, and voice call
		Information exchange with other systems
		Online appointment
	Reporting	Clinical laboratory parameters
		Treatment trend progress
e-PHR non-functional requirements	Usability	Easy to learn
		Understandability
		Optional data entry
	Reliability	security
		confidentiality
		Data accuracy
e-PHR implementation requirements	Patients trust	Not imposing legal responsibilities
		Practical use of data

*BP=blood pressure; e-PHR=electronic personal health record

Theme two: e-PHR functional requirements

According to the participants, communication methods such as text chat, video calls, voice calls, information exchange with other systems, online appointment booking, and reporting capability are necessary functional requirements of e-PHR for CAD management. These approaches were considered essential to streamline care, improve continuity, and reduce reliance on memory or manual data entry. In this regard, one of the participants indicated: "*Patients may not remember the details of their treatment or know what information to provide. Therefore, the results of tests and medical images, such as echocardiograms, should be automatically entered into the e-PHR.*" (C4)

Theme three: e-PHR non-functional requirements

Usability and reliability were key non-functional requirements raised by participants. From the participants' perspective, learning to work with the system should be straightforward for all patients. It should align with their general medical knowledge and avoid the use of specialized and complicated medical terminology. Furthermore, data entry in the system should be optional whenever possible, and incomplete steps should not block progress to the next steps. One of the interviewees said: "*Information presented to patients should be clear and understandable because their levels of knowledge and literacy are different.*" (C5)

The system must be reliable to ensure the security and confidentiality of patient information. In addition, the data entry methods should be designed to maximize the accuracy of input data. One of the participants highlighted: "*No one should access my electronic health record without my consent. It is essential to protect my personal information from misuse.*" (P1)

Theme four: e-PHR implementation requirements

The fourth theme was related to e-PHR implementation requirements, which included patients' trust. The components of patients' trust were no imposition of legal responsibilities and practical use of data.

Participants had concerns about citing PHRs in legal authorities. They believed that the PHR should only facilitate care services and cannot be a document for examining medical errors and imposing the responsibility of entering wrong data on the patients. One of them said: "*The information is recorded based on the patient's knowledge, so if the accuracy of the data cannot be proven for the therapists, it will certainly not be taken into account because the patient's health may be endangered.*" (C7)

Furthermore, the patients expected that the use of PHRs could be beneficial for them and that the doctors would pay attention to the data recorded in them. In this regard, one of the patients indicated: "*I trust my doctor's*

examination, but my previous information is also important. For example, if I write that I have a headache for several days, they should consider my notes and pay attention to them." (P8)

Discussion

According to the results, signs and symptoms, clinical information, patients' notes, and educational information were the necessary contents of e-PHRs.

Our results reveal that recording and monitoring data regarding vital signs in e-PHRs is necessary from the participants' perspective. For CAD patients, continuous monitoring of blood pressure and heart rate is critical for early detection of exacerbations as well as preventing complications such as myocardial infarction.[16] According to the findings, most participants emphasized the importance of recording medication information. The emphasis on tracking medications in e-PHRs is highly relevant given that CAD patients often require lifelong medication, namely antiplatelets, statins, and beta-blockers.[17] Additionally, results from other studies indicated that patients frequently review their medication lists, which helps them minimize medication errors.[10,11] Registration of para-clinical information, such as laboratory test results and medical summaries, was among other contents that were mentioned. Yang *et al*.[17] identified that integrating laboratory results and electrocardiography data into e-PHRs for CAD patients is crucial for assessing cardiac function, monitoring lipid profiles and inflammatory markers, and detecting arrhythmias or ischemic changes as soon as possible. Patient notes regarding the type and severity of pain can be helpful in providing better diagnoses and recommendations to patients. In one study, patients stated that providing narrative information can be beneficial, whereas the providers disagreed and believed that these data were highly subjective, which overwhelmed patients with a large amount of unstructured information.[12]

PHRs can facilitate access to health information, thereby enhancing patient awareness and well-being through health databases, prevention guidelines, and self-care management strategies. Providing educational information via e-PHRs helps CAD patients recognize early symptoms of worsening conditions (e.g. chest pain and dyspnea) and adopt preventive behaviors such as dietary changes, smoking cessation, and exercise. This aligns with evidence that patient training improves outcomes in CAD.[17-19] For example, Yang *et al*.[17] found that providing educational information through e-PHRs improves the recognition of signs of myocardial infarction or stroke.

Moreover, our participants also thought that online patient-provider communication would facilitate access to services and increase patient participation in care plans. The findings of the current study are supported by other similar studies in which the requirements of PHR have been highlighted. For example, Hajebrahimi *et al*.[20] noted that PHRs enable patients and doctors to communicate more effectively, leading to a better understanding of the patient's health and potentially improving health outcomes. Patients should be able to manage their appointments within PHRs. Online appointment reservation feature was reported to have a high adoption rate.[19]

Providing reports from the e-PHR helps patients realize the quality of outcomes and monitor them. This capability allows patients and clinicians to manage health problems and diagnose new conditions.[21,22] The ability to exchange information with other systems was found to be an important functional requirement of the PHR from the users' perspective. This feature minimizes the manual data entry required from users because information is automatically inserted into the PHR. Moreover, interoperability not only enhances the system's usability but also improves the accuracy of the data entered.[13] Standards should be established for connecting PHRs with each other and with various stakeholders, including care providers, insurance companies, government agencies, pharmacies, laboratories, and home monitoring devices.

Usability is one of the main issues in the adoption of health information systems, and developers need to take this into account.[12] For older CAD patients, often with limited tech literacy, the focus on ease of use and clarity in e-PHR design helps ensure that these systems are both inclusive and effective for all users.[21] The design of PHR should be straightforward, and medical terms must be clearly stated to suit people with different literacy levels.[9,23] Therefore, a developed e-PHR should accommodate the needs and requirements of entire patient groups based on their literacy levels. Optional data entry was another point raised by users. When patients do not have access to their information or forget certain details, they should not be forced to provide false information to complete the PHR forms. Experts believe that incomplete documentation is preferable to complete documentation that contains incorrect information.[24] The number of mandatory fields in PHR should be minimized to enhance usability and reduce cognitive load and error frustration.

Concomitant with the growth of eHealth initiatives, it is essential to pay closer attention to legal, privacy, and regulatory issues. Generally, security and privacy are among the top priorities for e-PHRs. Patients should have the ability to control who can access their information, as well as how, when, and which parts of their data are shared.[20] PHRs should allow emergency access to critical

information such as medication and allergy history. For CAD patients, this could be lifesaving during acute events such as a heart attack when rapid decision-making is vital.[17] Therefore, it is important to adopt an approach that allows qualified therapists to access this critical information in a read-only format.

Patients should be able to experience the usefulness of PHRs provided by supporting medical institutions while receiving customized health services, and hospitals should also receive corresponding compensation because there is no reward for providing patient information through PHRs.[19]

Limitation

In this study, a qualitative approach was used to gain a deeper understanding of end-users' perceptions about requirements of e-PHR for CAD patients. Lack of access to all cardiologists and reluctance of some cardiologists to cooperate were limitations of this study. Nevertheless, the participants had a relatively good knowledge, and data saturation was reached.

Conclusion

To support effective and sustainable implementation of e-PHRs, system developers should prioritize user engagement throughout all stages of system design and deployment. Integrating user-centered design principles not only enhances usability but also aligns with broader health policy goals such as improving system efficiency and patient-centered care. In spite of higher complexity, participatory development can lead to greater acceptance and satisfaction among patients, particularly those managing chronic conditions such as CAD. Health policymakers can strengthen the utility of e-PHRs as a strategic tool for self-management through customizing e-PHR capabilities to the digital literacy and cognitive capacities of intended users as well as ensuring compatibility with existing infrastructure, thereby advancing public health outcomes.

Suggestions for further research

The results of the current study can also be compared with future studies to notice the similarities and differences between the perspectives of specialists and patients regarding e-PHR requirements.

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Abbreviations

e-PHR: Electronic personal health record; CAD: Coronary artery disease; UCD: User-centered design; BP: Blood pressure.

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Conflicts of interest

There are no conflicts of interest.

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