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Determining the Requirements for the Development and Implementation of Follow-up Software for Patients Discharged from intensive Care: A Qualitative Study

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Abstract

Background: Intensive care unit stays are associated with numerous complications. These complications can be reduced with timely and appropriate medical services. Mobile applications can provide these services without geographical limitations. Accordingly, the present study aimed to evaluate the statements by the intensive care staff and care team of intensive care survivors on the necessary functionality for designing a mobile-based system for monitoring and following up on patients discharged from intensive care.

Methods: This prospective study involved interviews with specialists that provided care to patients after discharge (including nurses, physicians, physiotherapists, speech therapists, psychologists, and nutritionists). The first interviewees were selected from the specialists in Kerman, Iran and then, the selection of the participants proceeded with the snowball sampling method. Interviews were transcribed and analyzed based on content analysis. Codes were extracted and categorized into three levels of abstraction using MAXQDA software.

Results: Four general categories emerged from the interview analysis: 1) Training, 2) Consultation, 3) Electronic health records (EHRs), and 4) Care team. The interviewees mentioned items such as nursing and physiotherapy training (training category), physician and psychological consultation (consultation category), nurses (care team category), and side reports (EHRs category).

Conclusion: This study presented healthcare professionals' opinions and statements regarding the requirements for developing a mobile-based intensive care follow-up system. User input is essential to design a scalable and efficient system. Provider input can create a system with all the necessary features. The results can be used to adjust insurance regulations, provide the necessary infrastructure, and train care teams.

Keywords: Intensive care units, Software, Care team, Consultation, Training

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Introduction

Every year, a great number of people are admitted to the intensive care units. For example, more than 5 million people in the United States (1), 1 500 000 in South Korea, and 235 000 in the United Kingdom are hospitalized each year (2). Over the past couple of decades, improvements in intensive care have decreased mortality (3). However, there have been reports of significant complications and illnesses following discharge from the intensive care unit, including long-term physical, cognitive, and neurological

diseases and mortality after discharge (4-6). Over the past few years, there have been efforts to improve post-discharge care in intensive care units to meet the needs of the patients and reduce complications and mortality (7,8). There are several approaches and methods available to assist people in recovering quickly and returning to their everyday lives.

In two systematic reviews of the interventions and services related to improving care following discharge from an intensive care unit in 2016 and 2018 (9,10),



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the interventions and services reported were frequent clinic visits, counseling, the patient's diary, calls to the patient or caregiver, a booklet on self-care and common complications, exercise, and group discussions (11-14).

While the evaluations of the interventions listed above showed positive results, most of them utilized traditional methods, such as telephone calls and written instructions. These methods require the patient or companion to memorize the information and record the resulting data. However, none of the interventions described used IT tools. Electronic methods have been shown to positively affect healthcare in several studies (15-17), and electronic methods can assist people in remembering what needs to be done. Electronic data storage offers the benefit of faster data access, the absence of geographical limitations, and the potential to replace in-person meetings in some instances. Only one study used an electronic questionnaire to monitor the recovery of patients discharged from intensive care units. More than 40% of the patients were excluded due to the use of email as a form of communication (18).

Health applications facilitate access to healthcare management assistance to improve clinical decision-making and patient outcomes (19). The prevalence of smartphone use (20), as well as the successful experience and use of health applications in areas such as caring for the elderly, providing assistance to psychiatric patients (15,16), and improving the care of Alzheimer's patients (17), shows that smartphone-based applications can be beneficial in enhancing care after intensive care unit discharge.

Several studies indicate that mobile software can be used to provide a variety of services to patients, including training and consultation (21,22). However, it is important to determine the exact services required for each type of patient. Accordingly, this study aims to evaluate the statements by intensive care staff and care team of intensive care survivors on the necessary functionality for designing a system for monitoring and following up patients discharged from intensive care units through smart electronic devices (tablets and smartphones).

Methods

This was an inductive qualitative study conducted using semi-structured interviews. The interview questions were developed using relevant studies (23) and expert opinions (a professor of anesthesiology critical care medicine, two nurses with master's degrees in critical care nursing, a professor of medical informatics, and a PhD candidate in medical informatics). The following interview questions were asked: 1) "What services can be provided via mobile applications to patients discharged from intensive care?" and 2) "What information is required from patients' caregivers to the treatment team?" Interviewees were

not interrupted unless they diverged from the topic. The interviews were stopped when it became clear that the new interviews did not provide further information.

Six initial interviewees were selected from the intensive care unit (ICU) wards of Shahid Bahaonar Hospital (a nutritionist, a critical care physician, a critical care nurse, and a psychologist) and the homecare facilities (a physiotherapist and a speech therapist) in Kerman, Iran. Based on the snowball sampling method, additional interviewees were selected according to the suggestions of the previous interviewees. A total of 25 experts and specialists were interviewed in this qualitative study. As there was no list of qualified participants available and given that there were a limited number of them who were willing to be interviewed, researchers specifically selected the snowball sampling method to acquire the most knowledgeable and experienced informants and to ensure that they were included based on the objectives of the study. The inclusion criterion was having at least three years of experience working with ICU patients. The interviews were conducted from August to November 2021. The participants were from Kerman, Tehran, and Mashhad cities. The interviews were recorded using a voice recorder. The results of this study were reported following the Standards for Reporting Qualitative Research (24).

Data were inductively analyzed using content analysis (25). The codes were extracted after reviewing the transcripts of the interviews twice. The original codes were compared, and similar codes were grouped together. MAXQDA 20 software was used for coding. Similar codes were combined into groups, and similar groups were combined into higher classifications. A hierarchy of codes was created by combining similar codes.

Two independent individuals (AA and YS) analyzed each of the six first interviews. At a team meeting, inconsistencies among coders were discussed, and the remaining interviews were coded by one of the researchers (AA).

This research project was approved by the ethics committee of Kerman University of Medical Sciences (ID: IR.KMU.REC.1401.122). All participants gave their written consent before the interviews. The interviewees were informed and voluntarily participated in the study. They were allowed to withdraw during or after the interview. The interview transcripts were also available upon request. The researchers were committed to maintaining the confidentiality of the identity of the interviewees.

Results

A total of 25 experts and specialists were interviewed in this qualitative study. The participants were ten ICU nurses, three critical care physicians, three speech therapists, three physiotherapists, three psychologists,

and three nutritionists. The interviews lasted from 11 to 37 minutes (Table 1).

The codes derived from the interviews were classified into four main categories: training, consultation, electronic health records (EHRs), and care team (Figure 1).

Most interviewees expressed the importance of training and consultation for patients and their families to ensure timely and appropriate treatment.

Training

In general, most participants viewed training as a necessary and valuable component of the ICU patient follow-up system. Nursing and physiotherapy professionals who were interviewed considered in-person training to be necessary for the first time. Despite finding the video tutorial very useful, these experts considered it a complement to in-person training rather than an alternative.

“Video clips can be great, but sometimes people follow the instructions incorrectly when we send them for training. We get better results if we do it in front of them so they can watch and record it” (Participant 21, a physiotherapist).

“Before patient discharge, we train their families for a few days. We train them gavage feeding, suctioning, or repositioning patients with bedsores. We let them do these with their own hands in different shifts” (Participant 5, a nurse).

The majority of the participants suggested that a training application that offers a broad range of training would be helpful. Specifically, nurses stated that in addition to routine care training such as suctioning and gavage feeding, patient caregivers need to receive training in warning signs, emergency management, and physical examination. To differentiate between the patient's normal condition and a potentially dangerous one, a caregiver must recognize the warning signs correctly to provide appropriate emergency management assistance. Furthermore, they must monitor and describe the patient's condition accurately while receiving treatment and consultation remotely.

“When they call, our first questions are: Is your patient breathing fast? Is he coughing or not? Is sputum coming out of his mouth or not? They need to write them down.

Patients’ families should do all of these as part of a physical examination and report to us. That would speed up the process. Sometimes my phone rings in the middle of the night when I’m asleep; I might miss something. Family members need to be taught how to do a physical examination and enter it into the software” (Participant 9, a nurse).

It was unanimously agreed that all required training should be provided. Some suggested that each patient should have a training checklist. Currently, all training is conducted in person, but in many cases, some of the training is not conducted due to the neglect of patient caregivers or caretakers.

Consultation

All interviewees agreed that professional consultation is beneficial. Physiotherapists and psychologists decided that an initial in-person evaluation is necessary. In most cases, physicians considered telemedicine a viable alternative to in-person physician visits. According to physicians and nurses, all care team activities should be conducted under the supervision of a physician.

“We should have an initial interview, and it should be in person. Then, we can come up with a plan for the patient or family” (Participant 23, a psychologist).

“We should be able to see patients in their current situation, and any action or treatment should be under a physician’s supervision” (Participant 11, a physician).

Most participants thought that consultation should be continuous. Psychologists believed that any future recommendations should be based on patients' feedback. According to physiotherapists, they should also receive regular feedback regarding how patients perform their exercises and progress. The patients' mistakes may need to be corrected or their exercises revised.

“For example, if a patient is doing an exercise and his leg becomes stiffer, then he can’t move it. He might be doing it wrong without understanding the video; he can be corrected” (Participant 20, a physiotherapist).

“If a person’s depression or mental illness is severe, there may be a need for medication, for which they have to see a psychiatrist” (Participant 24, a psychologist).

It is very critical to purchase the right equipment for the patients as they may suffer severe consequences if a wrong device is used. This would also incur considerable expenditures. Consequently, the interviewees stressed the importance of providing correct and timely advice on equipment purchases, considering the patients' condition and their accommodation and financial status.

“There are both excellent and lousy products on the market, even for an IV catheter. As a nurse, I know which devices are reliable. Patients in the ICU who want to go home have the same problem. Our job is to advise families on buying which equipment and device depending on the patient’s situation and budget. We also had to ensure we

Table 1. The participants' demographic information

Profession	Gender		Experience (y)	Participant codes
	Male	Female		
Nurse	1	9	4 to 27 (median 7)	1 to 10
Physician	1	2	4 to 17 (median 12)	11 to 13
Physiotherapist	3	0	3 to 7 (median 5)	20 to 22
Speech therapist	1	2	3 to 5 (median 3)	14 to 16
Psychologist	0	3	3 to 6 (median 4)	23 to 25
Nutritionist	0	3	4 to 7 (median 6)	17 to 19



Figure 1. Sunburst chart of extracted codes: inner ring (main categories), middle ring (subcategories), outer ring (most detailed codes)

gave appropriate advice” (Participant 10, A nurse).

Electronic health records

According to physicians and nurses, the patient follow-up system should include medical record summaries from patients' ICU stays. A patient's EHRs should contain information regarding the results of diagnostic tests, medical images, the reason for admission to the ICU, and the patient's condition upon discharge.

“It is essential to know the patient's admission conditions, why they were admitted to the ICU, their condition while in the ICU, and their condition when they are discharged” (Participant 11, a physician).

“Knowing past medical history is a must. What is

the patient's history of underlying conditions? Are they diabetic? Do they have cardiovascular diseases? Do they have hypertension? Do they have hyperlipidemia? Do they have hypothyroidism? What medication do they take?” (Participant 12, a physician).

Participants from all specialties agreed that recording patient care reports are helpful. It was noted that the following items must be reported: patient history, patient condition, feedback on prescribed care, patient tests, and vital signs.

Care team

According to the participants, intensive care physicians, infectious disease specialists, and cardiologists should all

be part of the care team. Intensive care nurses, speech therapists, physiotherapists, occupational therapists, and psychotherapists were other specialized groups that interviewees emphasized must be part of the care team. A physician should also oversee all stages of treatment. Having the rehabilitation team as part of the care team from the beginning ensures that rehabilitation activities will begin at the appropriate time.

“Physiotherapists, occupational therapists, and speech therapists need to be on the team. However, physiotherapists are the most important group” (Participant 8, a nurse).

“When patients are leaving the ICU, nurses should provide expert advice and services. Instead of one person, it should be a team under a physician’s supervision” (Participant 10, a nurse).

Discussion

The findings of this study contributed to understanding the complexity of patient follow-up and care after ICU discharge. There was a consensus among the experts that fundamental training and consultation are essential in care. However, they recommended different methods and modalities for various purposes.

The care team professionals as well as the minimum required patient data set for the system were identified. Moreover, expert opinions were collected on who should enter each data system and how. Intriguingly, most participants from different specialties believed they must make at least one in-person visit with the patient.

The participants emphasized the importance and necessity of training in patient care, psychology, physiotherapy, and speech therapy. This is consistent with the results of other studies (26-28). Among the methods used in ICUs (12,13,29), the care booklet and pre-discharge ICU training were mentioned. The participants also emphasized the videotape of these sessions should be provided to the patients as by watching themselves, they believe they will learn more effectively.

Currently, mobile health applications are used for the ongoing training of patients after discharge (30). Additionally, the participants sought feedback on doing activities at home to correct possible mistakes if necessary. Other studies also utilized patient feedback to adjust the services being provided to patients (31). In addition to the items mentioned in earlier studies, the participants in the present study pointed out several essential training, including speech therapy training and preventive training.

In the ICU follow-up clinics, counseling services are almost always provided to patients. In-person or telephone counseling has been reported in studies (13,32,33). Besides consultation using existing means like phone calls and in-person meetings, the interviewees indicated that mobile applications would also provide video calling or asynchronous voice, video, or text counseling. There is

evidence that video counseling benefits patients in various situations (34). Several physicians and nurses stated that all care services must be under physician supervision. Physicians can monitor the recovery process and each care professional’s services using an integrated system. In cardiac rehabilitation, physician supervision has been found to be beneficial (35). Therefore, rehabilitating under the supervision of a physician may be beneficial for ICU survivors. Several participants stated that continuous counseling in nursing care, physiotherapy, psychology, and nutrition is essential. The cases reported in previous studies received counseling by telephone or in person at intervals of several months (13,33,36). By utilizing mobile applications for patient follow-up, care teams would be able to provide continuous counseling to patients.

In the existing follow-up clinics, information needs usually include information about the patient’s condition at the time of discharge and the general process of the patient’s recovery following discharge via telephone or in person (37,38). Additionally, some ICU follow-up clinics collected data on the patient’s physical and mental conditions and their ability to return to work (39). In addition to the aforementioned required information, the interviewees in the present study indicated that more detailed information needs to be collected daily or periodically, like vital signs, patient status, test results, and the care team’s prescriptions. Using EHR could enable the care team to collect and store the required information effectively, and facilitate the relationship between care professionals and their patients (40). Using HER for home care could also benefit patients by providing timely and proper care (41).

Most of the reported ICU follow-up programs were nurse-led, and few of them were multidisciplinary (12,42-44). According to the interviewees in this study, a multidisciplinary care team is essential for a successful follow-up program, which is consistent with the recommendations of the National Institute for Health and Care Excellence (45). The interviewees stressed the importance of active participation by a multidisciplinary team at every stage and monitoring the patient’s condition and taking any necessary actions. A multidisciplinary team has also been shown to be effective in the provision of home care (46).

Interview-based qualitative research can provide insight into the requirements of a follow-up system for patients discharged from intensive care. However, because of the relatively small number of participants and the possibility of selection bias, it may not be easy to generalize the findings across hospitals or countries. A quantitative survey study based on the results of this study might be beneficial to bolster these findings.

As a result, it is not possible to determine whether a system designed based on the results of this study can improve the patients’ quality of life, patient satisfaction,

and staff satisfaction. System implementation and evaluation will address this.

Patients in the ICU could not be interviewed because they often had a low level of consciousness. For future studies, it is recommended that the views of recovered patients be considered.

Conclusion

The present study investigated the opinions and statements of healthcare professionals regarding the requirements for developing a mobile-based follow-up system. To develop and implement an effective system, healthcare stakeholders should utilize user-derived findings. By incorporating the opinions of the healthcare providers, a system equipped with all the necessary features can be designed.

Notably, constant patient training and monitoring via mobile applications may be used to adjust insurance regulations, provide the necessary infrastructure, and train employees in hospitals.

The findings of this study can be used to design and develop IT tools in other medical and health areas by conducting user-centered qualitative studies.

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Authors' Contribution

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Data curation: Ali Afraz.

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Competing Interests

At the time of conducting the interviews, one of the authors (MA) was the head of Shahid Bahonar Hospital, where several of the interviewees worked.

Ethical Approval

This study reports the results of a research project approved by the Student Research Committee of Kerman University of Medical Sciences (No:400001127, Ethics Committee code: IR.KMU.REC.1401.122).

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