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Feasibility study and

Original research

BMJ Open Feasibility study and determination of prerequisites of telecare programme to enhance patient management in lung transplantation: a qualitative study from the perspective of Iranian healthcare providers

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ABSTRACT

Background Non-adherence to treatment plans, follow-up visits and healthcare advice is a common obstacle in the management of lung transplant patients. This study aims to investigate experts' views on the needs and main aspects of telecare programmes for lung transplantation.

Design A qualitative study incorporating an inductive thematic analysis.

Setting Lung transplant clinic and thoracic research centre.

Participants Clinicians: four pulmonologists, two cardiothoracic surgeons, two general physicians, two pharmacotherapists, one cardiologist, one nurse and one medical informatician.

Method This study adopted a focus group discussion technique to gather experts' opinions on the prerequisites and features of a telecare programme in lung transplantation. All interviews were coded and combined into main categories and themes. Thematic analysis was performed to extract the key concepts using ATLAS.Ti. Ultimately, all extracted themes were integrated to devise

a conceptual model. Results Ten focus groups with 13 participants were conducted. Forty-six themes and subthemes were extracted through the thematic analysis. The main features of the final programme were extracted from expert opinions through thematic analysis, such as continuous monitoring of symptoms, drug management, providing a specific care plan for each patient, educating patients module, creating an electronic medical record to collect patient information, equipping the system with decision support tools, smart electronic prescription and the ability to send messages to the care team. The prerequisites of the system were summarised in selfcare activities, clinician's tasks and required technologies. In addition, the barriers and benefits of using a telecare system to enhance the quality of care were determined.

Conclusion Our investigation recognised the main factors that must be considered to design a telecare programme to provide ideal continuous care for lung transplant patients. Users should further explore the proposed model to support the development of telecare interventions at the point of care.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- \Rightarrow The study investigates technology implementation in lung transplantation.
- \Rightarrow The qualitative design and use of focus group discussions provide flexible discussions to capture the participants' thoughts and opinions.
- \Rightarrow The thematic analysis was employed to gather experts' opinions on the prerequisites and requirements to enhance patient care through a telecare programme.
- \Rightarrow This study examines the prerequisites and characteristics of a telemedicine programme from the perspective of clinical experts.
- \Rightarrow Challenges and perceived benefits of telecare in lung transplantation in the viewpoints of patients and their caregivers have not been studied.

INTRODUCTION

data mining, Al training Lung transplantation (LTx) is the last treatment option for patients suffering from endstage lung diseases to prolong their life.^{1 2} ھ pu The ultimate goal of LTx is to give patients a chance to live more healthily and increase survival rates in end-stage lung diseases. A continuous and long-term follow-up care programme should be planned to ensure that patients receive comprehensive medical care for the rest of their lives after transplantation.

According to the literature, non-adherence to medication, healthcare advice follow-up, lifestyle recommendations and follow-up care programmes among lung transplant recipients ranged from 3.1% to 10.6%.3 ⁴ Despite various solutions, from paper-based plans to digital health solutions used by lung transplant centres to improve patient care quality, telemedicine-based programmes showed their effectiveness in facilitating continuous

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patient care for patients and clinicians using remote patient care technologies.⁵

Generally, telecare or telehealth programmes refer to any tailored and up-to-date care from a distance that enhances specialised care through coordination of involving multidisciplinary healthcare providers and providing rapid response to changes in patient health status.⁶ E-health refers to any digital health solution to promote care delivery, while telehealth could be as one component of e-health and relates solely to providing care from a distance.

Evidence showed that supporting transplant patients with additional technology-based support care programmes alongside traditional care could provide real-time patient access to the transplant team and emergency medical services.⁸ ⁹ The adoption of telemedicine services in other solid organ transplant care has shown the great potential of telehealth technology to improve the healthcare delivery model by providing increased patient-to-healthcare team interactions and accessibility.⁸⁻¹³ Such programmes engage transplant patients in their self-management activities and enhance the doctorpatient relationship.

Telehealth technology allows transmitting real-time patient health data with healthcare providers, shared decision-making, early identification of organ rejection symptoms and enhancement of patient-physician relationships. Despite all benefits, its implementation necessitates significant healthcare service and delivery changes. Accepting healthcare staff is crucial for a successful transition to telecare programmes¹⁴; it can be difficult to progress and achieve successful outcomes without their support.

In the first phase, our study aimed to investigate experts' opinions on the necessity and requirements of a telecare support programme for lung transplant patients to improve long-term care follow-up and quality of care in the first phase. Examining the patient's point of view will be done in the next step after ensuring the agreement of specialists to develop a remote patient programme in lung transplantation. Therefore, this study's main objective is to investigate clinical professionals' viewpoints about the features, prerequisites and characteristics of a telecare programme to increase the quality of care in lung transplant patients.

METHOD

Our results and methodology are reported according to Consolidated Criteria for Reporting Qualitative Health Research checklist.

Data collection procedure

A focus group (FG) discussion was used to gather the opinions and viewpoints of experts with LTx experience. The FG discussions aimed to gather experts' views on a telecare programme's needs and its central aspects to improve the quality of care in lung transplant patients ð

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by means of the telemedicine concept. The purposive sampling technique was employed to recruit experts involved in FG discussions. All experts were invited to participate in these sessions by mail/phone or short messages from lung transplant centres in Iran.

The sessions were moderated by a researcher with experience in performing qualitative studies (MG). The main objective of our project was explained to the participants at the beginning of each session. The meetings were held in meeting rooms at the Thoracic Research Center, Tehran University of Medical Sciences. Verbal informed consent was obtained from all participants. The experts were allowed to discuss issues freely. In the first session, 9 participants completed an anonymous questionnaire including demographic information, responsibility in the transplantation team and years of experience in LTx. FG discussions continued until data saturation was reached when no new themes arose from additional sessions. The average time of each session was between 45 min and 1 hour. All FG sessions were transcripted by the moderluding for uses relat ator verbatim.

Data analysis

All interviews were transcribed verbatim, coded and combined into main categories and themes. Subsequently, all transcripts were reviewed by two of the authors. Then, all statements were coded line by line. Based on the assigned codes, the topics were divided into main themes and subthemes. These themes were named and grouped by all the authors. The coding process was repeated iteratively to achieve the final themes. The thematic analysis was employed to analyse the results of FG discussions and extract the main concepts using ATLAS.Ti software.

The preliminary analysis of viewpoints was conducted after the meetings were held. The two final sessions presented the new concepts and the conceptual model extracted from the discussions to get the experts' opinions. All extracted themes were merged with an inductive reasoning approach to elucidate critical features and characteristics of a continuous remote patient care programme for lung transplant patients using telehealth technologies. Ultimately, a conceptual framework was similar technologies formulated. All specialists took part in the two final meetings.

Patient and public involvement

Patients and/or the public were not involved in this survey.

RESULTS

Ten focus groups with 13 participants were conducted through this survey. The FG size ranged from 7 to 13 specialists. All experts participated in nine FG discussions. The demographic characteristics of the expert panel are represented in table 1. Of the 13 experts, 8 were female (61.5%). The mean age of experts was 51±13.36 years. Table 1

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	Data	Frequency	Percentage	
Specialist	Pulmonologist	4	28.6	
	Cardiothoracic surgeon	2	14.3	
	General physician	2	14.3	
	Pharmacotherapist	2	14.3	
	Medical informatician	1	14.3	
	Cardiologist	1	7.1	
	Nurse	1	7.1	
Age	30–45	5	38.5	
	45–60	4	30.8	
	>60	4	30.8	
Experience	Lower than 5 years	3	23.1	
	5–10 years	2	15.4	
	10-20 years	4	30.8	
	More than 20 years	4	30.8	

The demographic characteristics of the expert

The years of experience in transplantation ranged from 1 to 25 years, with an average of 13.384±8.45 years.

Main themes and subthemes

All staff involved in the transplant expressed their opinion about telemedicine technology usage and its requirements. Overall, telehealth technology was perceived by staff as a suitable strategy to improve the quality of care and coordination of care. Forty-six themes and subthemes were extracted through the thematic analysis.

The themes reflected the viewpoints and experiences of experts regarding the main characteristics of a comprehensive care programme for lung transplant patients.

The nine key themes include: (1) improving accessibility of LTx team members to patients' medical records to retrieve and record information alongside providing collaborative care, (2) the possibility of reporting abnormal symptoms to transplant team members, (3) comprehensive prescription and medication therapy management, (4) enhancing continuous follow-up and improving patient adherence to regular visits, (5) refining communication and collaboration of patients with the transplant team members, (6) developing patient-specific care plan, (7) educating patient, (8) equipping patient and clinicians with decision aid tools, and (9) benefits, 8 pyright, including challenges and barriers of telehealth technology. The treemap structure of themes and subthemes is represented in figure 1.

Theme I: improve accessibility of LTx team members to patients' medical records to retrieve and record information alongside providing collaborative care

The variety and high volume of patient information in each patient visit are one of the main concerns of healthcare providers in transplantation. Specialists should make decisions based on diverse patient medical information, including all clinical tests, laboratory results, comorbidities, signs, symptoms and medical history. But considering all these findings at the same time is so complicated.

One of the topics raised in the meetings was the need to create a personalised electronic health record for each patient as a prerequisite for the telecare programme.



The treemap of themes and subthemes based on experts' opinions. LTx, lung transplantation. Figure 1

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Determining the components of electronic health records and the data sets that should be recorded in the form of information items will be one of the main stages of designing this system in a way to cover all the information needs of the transplantation team. It is clear that the electronic record, as a part of the telemedicine programme, must include the patient's medical history, patient demographic information, referral history, diagnoses, medications, treatment plans, immunisation dates, allergies, radiology images, laboratory results and any data from ECGs, CT scans and so on. It can be integrated into the symptom monitoring module to recommend the best treatment plan.

By creating an electronic health record for each patient, the physician can get an overview of the patient's condition and monitor the treatment plan.

The electronic health record helps the team members easily track the specific and non-specific complications of the transplantation. They can even prescribe the best treatment plan based on the response to medication.

Theme II: the possibility of reporting abnormal symptoms to transplant team members

Usually, patients with high adherence to self-care activities were selected for transplantation. Globally, the selfmeasurement ability of symptoms is recognised as one of the main aspects of eligibility for transplantation candidate.^{15–17} In our panel, all experts stated that continuous monitoring of signs and symptoms using telecare technology is one of the best solutions to prevent acute rejection and track the patient's status after transplantation.

Post-transplant lung recipients will be exposed to many risks and complications, such as severe infections and acute rejection. Being able to report unusual symptoms as soon as possible and providing access to the transplant team can lead to early diagnosis and timely treatment to overcome post-transplant complications. Following, there are some quotations that experts stated:

I think that daily symptom reporting tool aid clinicians in tracking the status of lung recipients more easily. So, if an immense change occurred, the clinician can easily do interventions.

The patients should be familiar with abnormal symptoms. So, if any abnormal symptoms occur, they can report to the care team member or coordinator for early intervention.

Experts felt that enabling the patient to report abnormal symptoms to the transplant team members could save the patient's life and prevent acute rejection. Thus, if the telecare programme is designed, it should have a symptom tracker or symptom management section.

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Theme IV: enhancing continuous follow-up and improving patient adherence to regular visits

Patients should go to the transplant clinic regularly so that physicians can perform necessary interventions in case problems arise. Nine out of 13 participants pointed out that patients adhere to regular visits more frequently in the first months after the transplant surgery. Therefore, it is necessary to define a standard programme to determine the appropriate time to refer patients in the months and years after transplantation. Equipping the remote monitoring system with a visit reminder can help patients attend outpatient clinics on the scheduled date. In addition, the physician could determine the next visit date and inform the patient by sending alerts to his/her smartphone.

In considerable cases, patients have to travel long distances to reach the clinic. More often, these are also possible through a remote visit or via a telephone connection.

Seven professionals believed that the presence of a coordinator to support patients could increase patients' adherence to regular visits. Patients can express their problems to the coordinator and refer for an in-person visit at his/her discretion. This concept has been implemented in the form of previsit programmes to promote regular visits in other domains.²⁴ Others suggested that visit reminders and alerts could enhance visit adherence among patients.

Theme V: refining communication and collaboration of patients with the transplant team members

The experience of LTx team members showed that if communication between patients and LTx team members is improved, the quality of patient care could be improved. In a friendly and interactive relationship between staff and patients, transplant patients can rely on LTx team members and comfortably accept their advice. They stated that the coordinator's presence at the middle level of care is crucial to enhance the clinician–patient relationships.

Transplant care team members provide special care for transplant patients, and they educate the patient's companions as health care provider's assistants.

The patient is considered an active member of the transplant care team. Without the direct cooperation of the patient with the care team, all the efforts of the specialists will be in vain. Therefore, the direct communication between the patient and the transplant team should be maintained.

Developing new means of communication, such as social networks, can be used to enhance this communication and even improve interprofessional collaboration. Nevertheless, a means of communication could be established through a web-based messaging system. This type of tool connects patients to share their experiences with other patients and connects physicians and all transplant team members to communicate closely with patients to make shared decisions based on treatment feedback and various aspects of the patient's condition.

Theme VI: develop a patient-specific care plan

All experts emphasised that patients in the lung transplant system should follow a comprehensive care plan and healthy lifestyle after the transplantation surgery and even while on the waiting list. According to experts, a patient-specific care plan includes different dimensions to consider as a comprehensive self-care management programme. These factors include giving up smoking, keeping active, drinking daily fluids, following a healthy diet and avoiding alcohol. Since the patient must be involved, physical rehabilitation must also be part of the lung recipient's lifestyle and treatment plan.²⁵

Maintaining a healthy weight through a healthy diet and regular exercise can support patients avoid complications such as diabetes, heart disease, and high blood pressure.

A patient care plan should be defined separately for each patient individually. This plan should be developed by multidisciplinary transplant team members with different approaches. Any changes in this treatment plan will be notified to the patient immediately through the telecare system.

Theme VII: educating patients

Experts believe that patient education is a crucial part of LTx. Patient education was discussed in various fields, including symptoms management, side effects of drugs and changing the dosage, how to take medications correctly, healthy lifestyle, and symptoms of rejection or infection. Five experts specified that patient education in more general fields, such as self-monitoring, hygiene, social relationship precautions and vaccination, must not be overseen.

Another issue discussed in this context was applying new technologies to educate patients, such as e-learning or distance learning. To provide electronic-based education, the e-health literacy level of patients must be estimated.

Compliance with the medication plans is important to improve patient survival rates. Thus, the patient should be educated to familiar with the side effects of drugs, accurate usage, benefits, and how to change the dosage.

Majority of patients eager to educate to cope with their new lifestyle before and post-transplantation. If they are educated properly, they could be part of LTx team members.

Therefore, all electronic training will be done along with traditional methods, such as designing paper pamphlets or paper-based symptom tracking sheets. Hence, all patients can benefit from the patient education.

Table 2 Benefits, challenges and barriers of telehealth technology in lung transplantation				
Main theme	Subtheme	For transplant team members/clinicians/ healthcare providers	Patients	
Benefits	Accessibility	 Providing 24-hour access to patient data Direct communication with patients Timely detection and action for specific conditions which require quick attention Provides near real-time patient supervision 	 Real-time access to the transplant team Preventing the unnecessary transfer Reduction of waiting time for access to care Reduced exposure to diseases Timely detection and action for specific conditions which require quick attention Reduces unnecessary visits Possibility of direct communication with patients 	
	Reducing costs and time	 Better utilisation of medical resources such as equipment, medical staff and others 	 Saving transfer costs Saving time for travelling and reporting abnormal symptoms 	
	Shared decision- making and team collaboration	 Simplifying the workflow Increasing the participation of nurses Ability to provide a standard of care Less healthcare resource utilisation 	 Benefit from different opinions of experts 	
Barriers and challenges	Technology	 Need high-speed internet Familiarity with technology Interoperability problems Information confidentiality Data transfer network problems Data security problems 		
		 High cost of developing and programming Technological hurdles 	 No access to computers or mobile phones No secure internet connection 	
	Human	 Resistance of healthcare providers to 	Resistance of patients to accepting and using	

accepting and using telecardiology

Concerns about patient mismanagement Increase the workload of clinicians

Concerns about shared delivery of care with

The need for a full-time nurse to manage the system and communicate with patients

Reimbursement

patients

Theme VIII: equipping patients and clinicians with decision aid tools There may be a problem that needs to be resolved by the patient before coming to the clinic. In this regard, four experts declared that it is possible to support patients in making the best decision by designing decision aid tools. The telecare programme could be equipped with such devices to guide patients when desired. These tools can be created based on the expert's knowledge and standard protocols for patients and clinicians.²⁶

resources and

health system

problems

It is essential for clinicians to know about improving a patient's condition in time. Therefore, sending alerts to the coordinator based on the patient's condition is so useful.

These types of tools can guide patients when they should have an emergency visit.

Theme IX: benefits, challenges and barriers of telehealth technology

The obstacles and benefits of implementing telecare services in LTx, which were discussed in group discussions, are shown in table 2. These cases are listed separately according to their benefits and advantages for patients and staff.

Protected by copyright, including for uses related to text and data mining One of the experts' critical concerns was the . ح programme's lack of use. Their experience showed that only a few e-health programmes had made their way into routine care. End users' acceptance is one of the preliminary issues that should be considered before implementa-J, and tion. Experts specified that considering a coordinator in remote patient care programmes is a kind of solution to similar technologies. reduce the workload of the transplant team.

Preference for a face-to-face visit

telecardiology

User-centered design and ongoing user training encourage patients and physicians to utilize the system in their routine care.

Since the foremost users in e-health programs are physicians, they should be developed in such a way that the workload of healthcare providers does not increase compared to traditional care.

A conceptual framework and prerequisites of a telecare programme in LTx

The main features of the final programme were extracted from expert opinions through thematic analysis, such as continuous monitoring of symptoms, drug management, providing a specific care plan for each patient, educating patients module, creating an electronic medical record



Figure 2 Conceptual framework of characteristics of a telecare programme in lung transplantation (LTx) based on extracted themes.

to collect patient information, equipping the system with decision support tools, smart electronic prescription and the ability to send messages to the care team. All themes and subthemes are integrated to generate a conceptual framework. We defined our conceptual framework in three main areas from the extracted themes-self-care activities, healthcare providers' tasks and required technologies-in a matrix shown in figure 2, exemplified by El-Osta et al.²⁷

In our model, self-care activities refer to all activities completed by patients or his/her supportive persons to improve their general health. According to experts' consensus, self-care tasks in LTx can be divided into five main categories, including regular symptom management, medication adherence, adherence to regular visits, following a healthy lifestyle and self-awareness. The second layer is related to the transplant team members' monitoring and patient follow-up activities.

Each electronic care platform should be designed to enhance interactions between healthcare providers and patients.²⁸ Thus, personal health records (PHRs) are considered a part of this programme in addition to electronic health records to provide the possibility of recording and collecting health data on the patient's side.²⁹ It enables patients to have more responsibility to empower their health status and improve the interaction between physicians and patients through clinical decision-making.

Remote monitoring can also be equipped with wearable sensors, internet of things devices, and biosensors to monitor a patient's symptoms and daily activities. However, wearable sensor usage is low due to high costs

and the need for equipment for both physicians and patients. Also, equipping a telecare system with decision aid tools could be so beneficial for both clinicians and patients.

Defining the key process in the suggested telecare programme

Ē By developing a telecare system, transplant specialists could deliver the highest level of care in person alongõ side remote patient care. Thus, the conceptual model to define the principal processes in a telecare system **>** based on the extracted themes is illustrated in figure 3. These kinds of models would be helpful in the next steps in designing the telecare system. Accordingly, a second , and level of care can be provided to patients by the transplant coordinator.

coordinator.
DISCUSSION
By summarising the viewpoints of experts, some significant aspects of the telecare programme emerged through our survey. Consequently, all the points raised by the & experts indicated the main requirements and features of **\$** the telecare system for lung transplant patients, which led to the devising of the conceptual model. The proposed care model is designed based on the remote patient care concept, which improves the relationship between the patient and the healthcare providers through continuous care.

Remote patient monitoring programmes have shown their advantages in improving the care of organ transplant patients.^{30–32} Since lung transplant patients are so





ⁱ6MWT:6-minute walk test ; DLCO: Diffusing capacity of the lungs for carbon monoxide (DLCO or TLCO is the extent to which oxygen passes from the air sacs of the lungs into the blood. Commonly,)

vulnerable, they must be in continuous communication with the transplant care team members, which is not practicable in traditional care. The suggested care model can support patients in a continuum of care by providing a platform to communicate with the transplant team. In epidemic emergence, such a care model could lead to a reduced risk of infection that may occur during in-person clinic visits and subsequently lead to a reduction in hospital readmissions. Poor adherence to a treatment plan, continuous care plan and clinicians' advice not only compromises the effectiveness of the remedy but also lessens the quality of life of the patients.³³ This challenge can endanger the lives of patients in organ transplantation. Evidence showed that various techniques, from paper-based sheets to electronic self-care forms, have been used to promote continuous care in organ transplantation, but electronic remote patient monitoring systems were known as the most effective solution.^{15 31 34}

Due to the possibility of provision of constant monitoring of the patient's symptoms in the care model, the LTx team can be notified of any abnormal symptoms as soon as possible and perform the necessary interventions to prevent rejection. In addition, this type of care model organises patient information in a structured way and creates a PHR for each patient. By creating an electronic medical record based on the daily monitoring of patients, developing a patient-centred care plan for each patient will be possible.^{35 36} In addition, the possibility of communicating with the transplant team in an emergency situation without visiting in person not only saves patients' time and money but also increases their sense of safety and self-confidence.

Despite all these advantages, some experts have raised the concern that the elderly and people unfamiliar with digital technology are examples who require traditional visits. Therefore, moving toward implementing digital health systems will not be done all at once. It will be provided to patients alongside traditional care so that no patient is deprived of medical services. Although this study is designed specifically for the lung transplant system, the requirements determined for implementing a remote care system can be considered a model for developing a system in other organ transplant systems.

Limitation

There were several limitations to this project. First, the sampling method was not randomly selected due to the low number of clinicians with expertise in LTx. In addition, our study is only limited to LTx. Second, though the generalisability of qualitative research is problematic, it could be done in a broader context in the future. Moreover, the feasibility of the proposed models will be investigated by developing a telecare system based on the suggested framework. The third was related to not including patients in group discussions and requirement analysis. Our survey investigated various aspects of physicians' and nurses' perspectives regarding patient telecare in LTx. There is a need to investigate patients and their caregiver's perspectives to understand the challenges and perceived benefits of telemedicine in their viewpoints. To address these limitations, further research could include more extensive and diverse samples of clinicians and patients to explore a broader range of pros and cons of telemedicine and LTx.

CONCLUSION

Our survey demonstrated the main factors that must be considered to design a telecare programme to provide ideal continuous care for lung transplant patients. We concluded that establishing such a support programme using telecare technology effectively solves poor adherence in lung transplant patients. All stakeholders should further explore the proposed model to support the development of telecare interventions at the point of care.

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Patient consent for publication Not required.

Ethics approval This study protocol was in accordance with the Declaration of Helsinki, and ethical approval was obtained from the Ethics Committee of the Tehran University of Medical Sciences (approval no. IR.TUMS.SPH.REC.1400.340). Informed consent was obtained from all participants.

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