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Towards a conceptual model to enhance treatment adherence in lung transplantation using telemedicine technology: a qualitative study from the perspective of caregivers

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Towards a conceptual model to enhance treatment adherence in lung transplantation using telemedicine technology: a qualitative study from the perspective of caregivers

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Abstract

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

Design: A qualitative study incorporating an inductive thematic analysis was employed to identify key themes from clinicians' viewpoints.

Setting: Lung transplant clinic and Thoracic research center.

Participants Clinicians, including 4 pulmonologists, 2 cardiothoracic surgeons, 2 General physicians, 2 Pharmacotherapist, 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 program in lung transplantation. All interviews were transcribed verbatim, coded, and combined into main categories and themes. Thematic analysis was employed to extract the key concepts using ATLAS.ti software. Ultimately, all of the extracted themes were integrated to devise a conceptual model.

Results: Ten focus groups with 13 participants were conducted. Forty-six themes and sub-themes were extracted through the thematic analysis. Main themes include 1) continuous symptoms monitoring, 2) medication adherence, 3) continuous follow-up, 4) refining communication with the transplant team, 5) suggesting a healthy lifestyle, 6) educating patients, 7) improved retrieving and recording patient information for LTx team members, 8) decision aid tools, and 9) user acceptance. The features were summarized in self-care activities, clinician's tasks, and required technologies. Ultimately, the three-level of care conceptual model was formulated.

Conclusion: Our investigation demonstrated the main factors that must be considered to design a telecare program to provide ideal continuous care for lung transplant patients. The proposed model

should be further explored by users to support the development of telecare interventions at the point of care.

Keywords: Lung transplantation, Long-term care, Telehealth, Remote care, Patient-centered care

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4 54 **Strengths and limitations of this study**

- 5 55 • The requirements for designing a continuous care program using digital health intervention
6 56 for lung recipients were investigated in this study.
7 56
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9 57 • The qualitative method was used to gather experts' opinions on the prerequisites and
10 58 requirements of the telecare program to enhance lung transplant patient care.
11 58
12 59 • The three-level of care conceptual model was formulated based on extracted themes by
13 59 thematic analysis.
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1-Introduction

Lung transplantation (LTx) is known as the last treatment option for patients suffering from end-stage lung diseases to prolong their life¹. According to the International Society of Heart and Lung Transplantation (ISHLT), more than 51,000 adult lung transplants have been conducted worldwide during the past ten years². The ultimate goal of LTx is to give patients a chance to live more healthily in addition to increasing survival rates in end-stage lung diseases. Planning continued medical care and long-term follow-up care program are essential parts of the lung transplantation process to make sure the patient fully recovers after transplantation. This program should be planned in a way to makes sure the patient receives comprehensive medical care for the rest of their lives.

It is so important the patient comprehends that transplantation is a chronic disease that requires adherence to complex medication regimens, a healthy lifestyle, and lifelong follow-up³. According to World Health Organization (WHO), only 50% of patients with chronic diseases adhere to their treatment plan and long-term medication regimens globally^{4,5}. According to the literature, non-adherence to medication among lung transplant recipients ranged from 3.1% to 10.6%⁶. Non-adherence is not limited to medication, it might occur in regular visits, healthcare advice follow-up, or lifestyle recommendations^{6,7}. Drawing patients to cooperate with transplant team members in the form of self-care activities is one of the solutions considered by transplant centers⁸. Abtahi et al. showed in their study that an effective healthcare follow-up and monitoring program should be defined based on a patient-centered care approach⁹.

Despite various solutions being utilized by lung transplant centers, implemented telemedicine-based programs showed their effectiveness in remote patient monitoring both for patients and

clinicians. Indeed, telecare programs have the potential to enhance the active role of patients in the continued care program and patient engagement in treatment plan adherence^{10, 11}. Supporting LTx patients with additional technology-based support care programs in addition to traditional care could facilitate life-long follow-up and engage lung transplant patients in their self-management activities. To our knowledge, investigating experts' opinions in the context of various aspects of a comprehensive telecare program using digital health technology specifically for lung transplant patients in practice has not been investigated. Comprehending the experts' point of view could be effective for moving towards patient-centeredness. Thus, our study sought to examine experts' opinions about the necessities and characteristics of a telecare support program for lung transplant patients to improve adherence to treatment plans, long-term care follow-up, and support self-management. The secondary objective is to devise a standard and applicable care model to improve the monitoring of lung transplant patients.

2-Method

Our results and methodology were reported according to Consolidated Criteria for Reporting Qualitative Health Research (COREQ) checklist.

2-1-Data collection procedure

A focus group (FG) discussion was utilized to gather the opinions and viewpoints of experts who have experience in lung transplantation. The focus group discussions aim to gather experts' opinions on the needs and main aspects of a telecare program for lung transplant patients by means of the telemedicine concept. The purposive sampling technique was employed to recruit experts that involve in FG discussions. All of the experts were invited to participate in these sessions by mail/phone or by short messages from lung transplant centers in Iran.

The sessions were moderated by one of the researchers who have 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 the issues freely. In the first session, participants completed an anonymous questionnaire including demographic information, responsibility in the transplantation team, and years of experience in lung transplantation. FG discussions continued until data saturation was reached, where no new themes arose from additional sessions. The average time of each session was between 45 and one hours. All FG sessions were transcribed by the moderator verbatim.

2-2-Data Analysis

The thematic analysis method was employed to analyze the results of FG discussions and extract the main concepts. All interviews were transcribed verbatim, coded, and combined into main categories and themes. Thematic analysis will be done using *ATLAS.ti* ® software, using an iterative and reflective approach. 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 sub-themes. These themes were named and grouped by all the authors. The coding process was repeated iteratively to achieve the final themes.

Finally, a comparative and relational analysis will be conducted to identify topics with which experts agreed on them. The preliminary analysis of viewpoints was done shortly after the meetings were held. The new concepts and the conceptual model extracted from the discussions were presented in the two final sessions to get the experts' opinions. All extracted themes were merged with an inductive reasoning approach to elucidate key features and characteristics of a

telecare program for lung transplant patients using telehealth technologies. Ultimately, a conceptual framework was formulated. All specialists took part in the two final meetings.

3-Results

Ten focus groups with a total of 13 participants were conducted through this survey. The FG size ranged from seven 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, eight were female (61.5%). The mean age of experts was 51 ± 13.36 . The years of experience in transplantation ranged from 1 to 25 years, with an average of 13.384 ± 8.45 years.

3-1-Main themes and sub-themes

Forty-six themes and sub-themes were extracted through the thematic analysis. The themes reflected the viewpoints and experiences of experts regarding the main characteristics of a comprehensive care program for lung transplant patients. The nine key themes include, 1) continuous recording of symptoms and monitoring by the clinician, 2) medication adherence improvement, 3) continuous follow-up and adherence to outpatient referrals, 4) refining communication and collaboration with the transplant team, 5) suggesting a healthy lifestyle and self-care plan, 6) educating patient, 7) improved access of LTx team members to patients' medical records to retrieve and record information, 8) equipping patient and clinicians with decision aid tools, and 9) increase user acceptance and ensure the program usage. The hereditary structure of themes and sub-themes is represented in Fig 1.

Theme I: Continuous recording of symptoms and monitoring by the clinician

All experts stated that continuous monitoring of symptoms is one of the best solutions to track the patient's status after transplantation. Since the patient will expose to many risks after transplantation such as high-risk infections and acute rejection, daily reporting of symptoms can

lead to early diagnosis and on-time treatment to overcome post-transplantation complications.

Following, there are some quotations that experts stated:

"I think that daily symptom reporting tool aid clinicians track 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 occurred, they can report to the care team member or coordinator for early intervention"

Overall, experts felt that enabling the patient to record and report abnormal symptoms to the transplant team could save the patient's life. Thus, if the telecare program is designed, it should be equipped with a symptom tracker or symptom management section. However, the patient should be trained on how to monitor their symptoms and where to report their abnormal symptoms.

One of the most important matters mentioned by four experts was the prevalence of mental problems among transplant patients. Due to the special circumstances that arise for patients after transplantation, they might experience courses of depression or some psychological disorders. Therefore, patients should also be evaluated psychologically in addition to the possibility of self-reporting physical problems. Consequently, the desired program should be equipped with a mental health assessment checklist or mental health monitoring questionnaire.

Theme II: Medication adherence improvement

There is a growing body of evidence that non-adherence to treatment has a significant relationship with graft failure and mortality. Hence, it was one of the main topics discussed in FG discussions.

The experts mentioned that adherence of patients to the treatment plan and accurate drug usage plays a significant role in transplant success rate. Ten experts declared that to improve adherence to the treatment, the patient must comprehend his disease and treatment plan to follow the healthcare provider's recommendations. Some related quotations are represented in the following.

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177 *“The patient must actively participate in the disease management program to adhere to treatment.*

178 *Therefore, it is necessary to help patients to learn about the correct way to take drugs and the side*

179 *effects of their drugs.”*

180 *“The individual characteristics of each patient, the social support the patient receives from family*

181 *and friends, and the cognitive ability to understand the disease can affect the rate of non-adherence*

182 *to treatment.”*

183 Another problem was related to forgetting to take medicine or *forgetfulness*. Usually, the

184 specialists encountered those patients who had worsened their condition due to forgetting at least

185 one dose of their medication during the course of treatment.

186 *“Most of the forgetfulness occurred unintentionally. A simple reminder can save the lives of*

187 *people who forget to take their medication due to preoccupation.”*

188 *“Sometimes the medication plan might change during follow-up, the patient needs to communicate*

189 *sufficiently with the LTx team. Moreover, a means of communication requires ongoing care.”*

190 ***Theme III: Continuous follow-up and adherence to outpatient referrals***

191 All experts agree on the necessity for establishing lifelong monitoring programs for lung

192 recipients. Patients should visit the transplant clinic regularly so that necessary interventions can

193 be performed by physicians in case of problems arise. Nine out of 13 participants pointed out that

194 patients adhere to regular visits more regularly in the first months after the transplant surgery. As

195 more time passes after transplantation, adhering to regular visits decreases. It usually occurs due

196 to the long distance from the clinic or the long time waiting.

197 *“In considerable cases, patients have to travel long distances to reach the clinic. More often, these*

198 *are also possible through a remote visit or via a telephone connection.”*

199 Seven professionals believed that the presence of a coordinator to support patients could increase

200 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 pre-visit programs to promote regular visits in other domains¹². Others suggested that visit reminders and alerts could enhance visit adherence among patients.

Theme IV: Refining communication and collaboration with the transplant team

The experience of LTx team members showed that if communication between patients and LTx team members is improved, patients' adherence to treatment can be improved. In a friendly relationship between staff and patients, transplant patients can rely on LTx team members and comfortably accept their advice. They stated that the presence of the coordinator at the middle level of care is crucial in this regard.

“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.”

Employing new platforms such as social networks can be used to enhance this communication and even improve inter-professional collaboration. Nevertheless, a means of communication could be established through a web-based messaging system.

Theme V: Suggesting a healthy lifestyle and self-care plan

All experts emphasized that patients in the lung transplant system should follow a healthy lifestyle not only after the transplantation surgery but even while they are on the waiting list. According to experts, a healthy lifestyle includes different dimensions that should be considered in a

comprehensive self-care management program. These factors include giving up smoking, keeping active, drinking daily fluids, following a healthy diet, and avoiding alcohol.

Since the patient needs to be active, physical rehabilitation is part of the lifestyle of lung recipients.

Eight experts noted that home rehabilitation programs could be developed for patients after face-to-face training. Some telerehabilitation programs for lung recipients are accomplished in other countries ¹³.

“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.”

Theme VI: Educating patients

Experts believe that patient education is a crucial part of lung transplantation that must never be neglected in transplant systems. Patient education was discussed in various fields including symptoms management, side effects of drugs and changing the dosage, educating the patient on how to take medications correctly, healthy lifestyle, and educating a patient about 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 not be overseen. Thus, all organ transplant systems usually provide programs to educate patients in form of booklets, video tutorials, portals, or educational applications.

Another issue discussed in this context was applying new technologies to educate patients, such as electronic learning or distance learning. To provide electronic-based education, the e-health literacy level of patients must be estimated. Accordingly, it is better to provide training in different modes so that patients can receive training according to their ability and level of knowledge.

Almost all experts agreed that the first step in patient education is improving patients' health literacy.

“Compliance with the medication plans is so 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.”

Theme VII: Improved access of LTx team members to patients' medical records to retrieve and record information

One of the concerns of LTx experts was the variety and high volume of patient information at each patient visit. Specialists should make decisions based on diverse patient medical information including all clinical tests and medical history. But considering all issues based on the traditional technique is very complicated.

One of the topics raised in the meetings was the need of creating a personalized electronic health record for each patient as a prerequisite for the telecare program. It can be integrated into the daily 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 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 make the best decision by designing decision-aid tools. The telecare program could be equipped with such tools to guide

patients when it is necessary. These tools can be designed based on the expert's knowledge and standard protocols both for patients and clinicians.

"It is very important for clinicians to know about the improvement of 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: End users' acceptance of technology-based care programs

One of the main concerns of the experts was the lack of use of the program. Their experience showed that only a few e-health programs had made their way into routine care. End users' acceptance is one of the preliminary issues that should be considered before implementing and designing an electronic healthcare system.

As a result of the group discussion, the experts concluded that the e-health literacy level of the users should be evaluated first before offering the telecare program to the patient. Experts specified that considering a coordinator in remote self-care programs is a kind of solution to reduce the workload of the transplant team.

"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."

3-2- A conceptual framework and prerequisites of a telecare care program in lung transplantation

All themes and sub-themes were integrated to generate a conceptual framework to formalize the prerequisites of a telecare program for lung transplant patients. We defined our conceptual framework in main three areas, self-care activities, healthcare providers' tasks, and required technologies in a matrix which is shown in Fig 2 exemplified by El-Osta ¹⁴.

297 In our model, self-care activities refer to all activities completed by patients or his/her supportive
298 persons to improve their general health. According to experts' consensus, self-care tasks in lung
299 transplantation can be divided into five main categories including regular symptom management,
300 medication adherence, adherence to regular visits, following a healthy lifestyle, and self-
301 awareness. The second layer is related to the monitoring and patient follow-up activities conducted
302 by the transplant team members. In our model, the patient is located at the center of care in telecare
303 programs.

304 Each electronic care platform should be designed in such a way that the interactions between
305 healthcare providers and patients enhanced patient-centered care ¹⁵. In our suggested framework
306 to enhance patient care, Personal Health Records (PHR) is considered a part of this program in
307 addition to electronic health record (EHR) to provide the possibility of recording and collecting
308 health data on the patient's side ¹⁶. It enables patients to have more responsibility to empower their
309 health status and improve the interaction between physicians and patients through clinical
310 decision-making.

312 Remote monitoring can also be done using sensors, IoT devices, and biosensors to monitor a
313 patient's symptoms and daily activities. Although wearable sensors usage is low due to high costs
314 and the need for equipment for both physicians and patients.

315 Due to the significant changes in the interaction between doctors and patients, decision-making
316 aid tools were created to improve patients' participation in the decision-making process and health
317 empowerment in recent decades. Besides, they could guide physicians to make evidence-based
318 decisions more accurately and safely. Hence, equipping a telecare system with decision-aid tools
319 could be so beneficial for both clinicians and patients.

3-3- A three-level care model of the suggested telecare program

Summarizing the experts' opinions showed that the most suitable solution to follow patients satisfactorily and encourage them to adhere to their treatment plan is to devise a three-level care model.

In this model, transplant specialists deliver the highest level of care in-person and remotely. The transplant team members cannot monitor the patient's symptoms permanently remotely and communicate with them due to the high workload. Accordingly, a second level of care can be provided to patients by the transplant coordinator. The third level covers all self-care tasks to be performed by the patient. At this level, patients perform tasks like entering their daily symptoms, receiving the necessary training, and receiving guidance and feedback from the coordinator. They can also communicate with the transplant team members and report their abnormal symptoms to the coordinator. In addition, they will be equipped with reminders and alerts through a web-based telecare program. This three-level of care model to design a telecare system based on the opinions of lung transplant experts is illustrated in Fig 3.

4-Discussion

Summarizing the viewpoints of experts showed that applying digital health solutions can be an appropriate solution for designing such a remote lung transplant patient monitoring system. Some significant aspects of the telecare program emerged through this survey by devising the conceptual model. Therefore, all the points raised by the experts led to indicating the main requirements and features of the telecare system for lung transplant patients.

One of the significant consequences of FG discussions was the necessity to use a three-level care model. The suggested care model is devised based on the remote patient care concept, which

343 enables patients to perform self-care tasks more conveniently. Remote patient monitoring
344 programs have shown their advantages in improving the care of organ transplant patients by
345 increasing access to health care providers, enabling real-time symptom monitoring, overcoming
346 long distances from the medical center, and providing patient education in previous studies.¹⁷⁻¹⁹.
347 In epidemic emergence, such a care model could lead to a reduced risk of infection that may occur
348 during in-person clinic visits and subsequently lead to a reduction in hospital readmissions.
349 Because lung transplant patients are so vulnerable, they must be in continuous communication
350 with the transplant care team members, which is not practicable in traditional care. The suggested
351 care model can support patients in a continuum of care by providing a platform to communicate
352 with the transplant team.
353 According to WHO, poor adherence to a treatment plan not only compromises the effectiveness
354 of the remedy but also lessens the quality of life of the patients²⁰. This challenge can endanger the
355 lives of patients in the organ transplantation. In similar studies, evidence showed that although
356 various techniques ranging from paper sheets to electronic self-care forms have been used to
357 promote continuous care in organ transplantation, electronic remote patient monitoring systems
358 were the most effective solution in this field^{18, 21, 22}.
359 Due to the possibility of provision of constant monitoring of the patient's symptoms in the care
360 model, the LTx transplant team can be notified of any abnormal symptoms as soon as possible and
361 perform the necessary interventions. In addition, this type of care model organizes patient
362 information in a structured way and creates a personal health record for each patient. By creating
363 an electronic medical record based on the daily monitoring of patients, developing a patient-
364 centered care plan for each patient will be possible^{23, 24}.

Our findings could be supportive of other lung transplant centers, but this study encounters some limitations. Since in the group discussion sessions, the participants may come up with new ideas by knowing the opinions of others, at the end of each session, the notes were returned to the participants to record feedback. This led to solving the problem of missing some ideas. Another limitation of our study was related to the sampling method and the number of participants. Though the number of participants is sufficient to extract the main themes, the sampling method was not randomly selected due to the low number of clinicians who have expertise in lung transplantation. Although the generalizability of qualitative research is difficult, we can do it in a wider context such as internationally in future studies. The feasibility of the proposed models will be investigated by developing a telecare system based on the suggested framework.

5-Conclusion

Our survey demonstrated the main factors that must be considered to design a self-management support program to provide ideal continuous care for lung transplant patients. We concluded that the establishment of such a support program is an effective strategy to solve poor adherence in lung transplant patients. The proposed model should be further explored by all stakeholders in lung transplantation to support the development of telecare interventions at the point of care.

Declaration

Ethical consideration

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.

Authors contributions

MG, HA, SA, and RS contributed to the conception and development of the study design, contribution to data analysis, and interpretation of data. MG, SA, and HA prepared focus group question guides, conducted the focus groups, analyzed the resulting transcripts, and coded data. MG, HA, SA, and RS validated coding structure and analysis. MG, HA, SA, and RS conducted the literature review and wrote a first draft of the manuscript. All three authors revised and approved the last version of the manuscript.

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Conflict of interest

The authors declare that they have no competing interests.

Availability of data and materials

The dataset analyzed for this study is not publicly available to protect participant anonymity. Additional information may be provided upon reasonable request to the corresponding author.

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Tables

Table 1. The demographic characteristics of the expert panel

	Data	Frequency	Percentage
Specialist	Pulmonologist	4	28.6
	Cardiothoracic Surgeon	2	14.3
	General Physician (GP)	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 5yrs	3	23.1
	5-10 yrs.	2	15.4
	10-20 yrs.	4	30.8
	More than 20 yrs.	4	30.8

Figure Legends:

Fig 1. The treemap of themes and sub-themes based on expert's opinions

Fig 2. A conceptual framework based on the extracted themes

Fig 3. The proposed three-level supportive care model in lung transplantation and desired features (All processes at the first level of care are represented with blue connectors. Green connectors indicate that all processes were performed by the coordinator at the second level of care. Ultimately, black connectors reveal that all processes have been completed by a patient at the third level of care.)

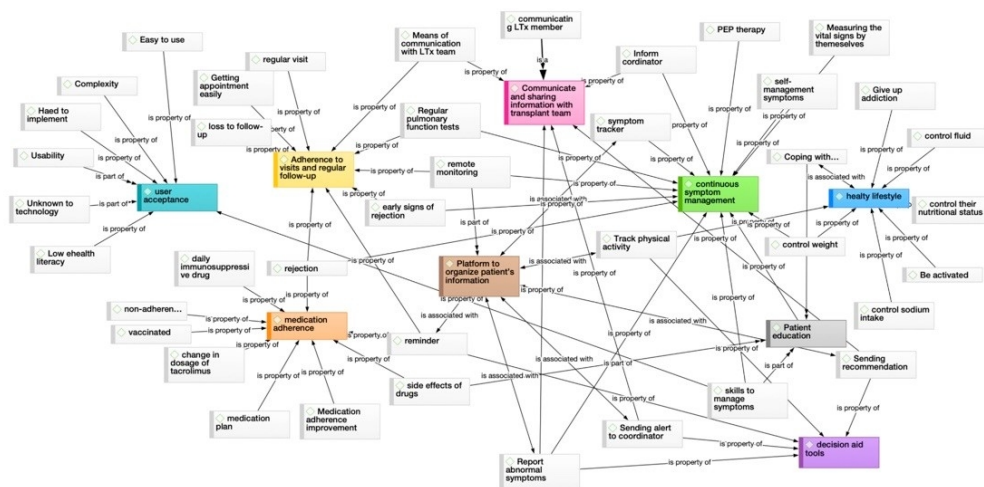


Fig 1. The treemap of themes and sub-themes based on expert's opinions

291x151mm (96 x 96 DPI)

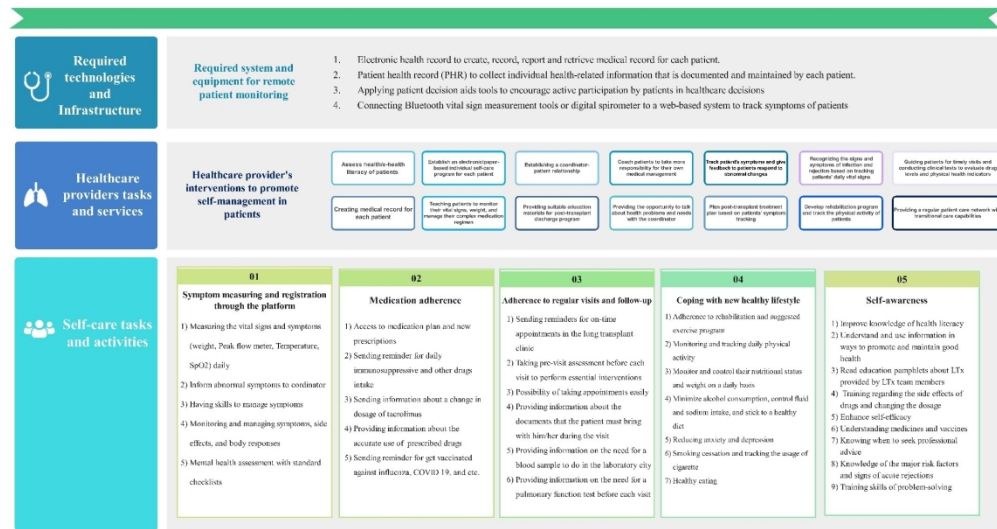


Fig 2. A conceptual framework based on the extracted themes

247x131mm (220 x 220 DPI)

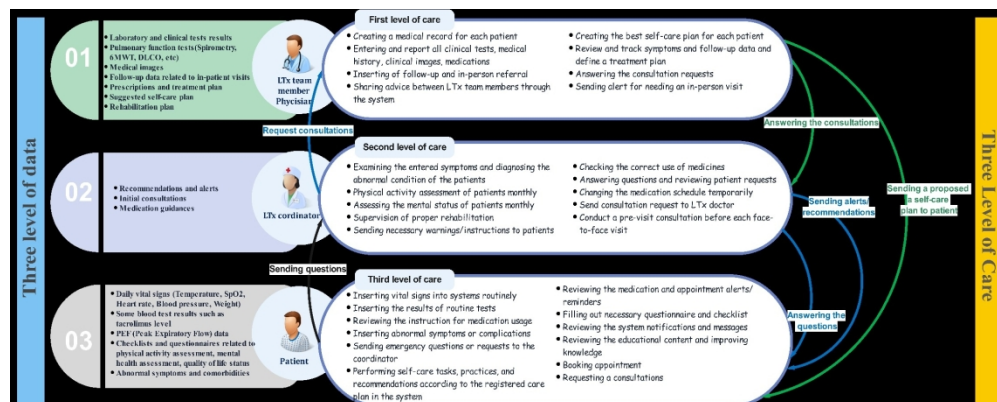


Fig 3. The proposed three-level supportive care model in lung transplantation and desired features (All processes at the first level of care are represented with blue connectors. Green connectors indicate that all processes were performed by the coordinator at the second level of care. Ultimately, black connectors reveal that all processes have been completed by a patient at the third level of care.)

260x103mm (220 x 220 DPI)

COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Feasibility study and determination of prerequisites of telecare program to enhance patient management in lung transplantation: A qualitative study from the perspective of Iranian caregivers

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Feasibility study and determination of prerequisites of telecare program to enhance patient management in lung transplantation: A qualitative study from the perspective of Iranian caregivers

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27 Abstract

28 **Background:** Non-adherence to treatment plans, follow-up visits, and healthcare advice are
29 common obstacles in the management of lung transplant patients. This study aims to investigate
30 experts' views on the needs and main aspects of telecare programs for lung transplantation.

31 **Design:** A qualitative study incorporating an inductive thematic analysis

32 **Setting:** Lung transplant clinic and Thoracic research center.

33 **Participants** Clinicians, including 4 pulmonologists, 2 cardiothoracic surgeons, 2 General
34 physicians, 2 Pharmacotherapist, one Cardiologist, one nurse, and one medical informatician.

35 **Method:** This study adopted a focus group discussion technique to gather experts' opinions on the
36 prerequisites and features of a telecare program in lung transplantation. All interviews were coded
37 and combined into main categories and themes. Thematic analysis was employed to extract the
38 key concepts using ATLAS.ti software. Ultimately, all of the extracted themes were integrated to
39 devise a conceptual model.

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

Conclusion: Our investigation recognized the main factors that must be considered to design a telecare program to provide ideal continuous care for lung transplant patients. The proposed model should be further explored by users to support the development of telecare interventions at the point of care.

Keywords: Lung transplantation, Long-term care, Telehealth, Remote care, Patient-centered care

Strengths and limitations of this study

- The study investigates technology implementation in lung transplantation.
- The qualitative design and use of focus group discussions provide flexible discussions to capture the participants' thoughts and opinions.
- The thematic analysis was employed to gather experts' opinions on the prerequisites and requirements to enhance patient care through a telecare program.
- This study examines the prerequisites and characteristics of a telemedicine program from the perspective of clinical experts

1-Introduction

Lung transplantation (LTx) is known as the last treatment option for patients suffering from end-stage lung diseases to prolong their life^{1,2}. The ultimate goal of LTx is to give patients a chance to live more healthily in addition to increasing survival rates in end-stage lung diseases. A continuous and long-term follow-up care program should be planned to ensure that patient receives 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 programs among lung transplant recipients ranged from 3.1% to 10.6%^{3, 4}. Despite various solutions from paper-based plans to digital health solutions being utilized by lung transplant centers to improve patient care quality, implemented telemedicine-based programs showed their effectiveness in facilitating continuous patient care both for patients and clinicians using remote patient care technologies⁵.

Generally, telecare or telehealth programs refer to any tailored and up-to-date care from a distance that enhances specialized care through coordination of involving multidisciplinary healthcare providers and providing rapid response to changes in patient health status⁶. E-health refers to any type of digital health solution to promote care delivery while telehealth could be as one component of e-health and solely refers to providing care from a distance⁷.

Evidence showed that supporting transplant patients with additional technology-based support care programs 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

accessibility⁸⁻¹³. Such programs not only engage transplant patients in their self-management activities but also enhance the doctor-patient relationship.

Telehealth technology allows the transmission of 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 of its benefits, its implementation necessitates significant changes to healthcare service and delivery. Hence, that the acceptance of healthcare staff is crucial for a successful transition to telecare programs¹⁴. Without their support, it can be difficult to make progress and achieve successful outcomes.

In the first phase, our study aimed to investigate experts' opinions on the necessity and requirements of a telecare support program 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 phase after ensuring the agreement of specialists to develop a remote patient program in lung transplantation. Therefore, the main objective of this study is to investigate the viewpoints of clinical professionals about the features, prerequisites, and characteristics of a telecare program to increase the quality of care in lung transplant patients.

2-Method

Our results and methodology were reported according to Consolidated Criteria for Reporting Qualitative Health Research (COREQ) checklist.

2-1-Data collection procedure

A focus group (FG) discussion was utilized to gather the opinions and viewpoints of experts who have experience in lung transplantation. The focus group discussions aimed to gather experts' opinions on the needs and main aspects of a telecare program to improve the quality of care in lung transplant patients by means of the telemedicine concept. The purposive sampling technique

was employed to recruit experts that involve in FG discussions. All of the experts were invited to participate in these sessions by mail/phone or by short messages from lung transplant centers in Iran.

The sessions were moderated by one of the researchers who have 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, participants completed an anonymous questionnaire including demographic information, responsibility in the transplantation team, and years of experience in lung transplantation. 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 and one hour. All FG sessions were transcribed by the moderator verbatim.

2-2-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 sub-themes. 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 analyze the results of FG discussions and extract the main concepts using *ATLAS. ti*® software.

The preliminary analysis of viewpoints was done shortly after the meetings were held. The new concepts and the conceptual model extracted from the discussions were presented in the two final sessions to get the experts' opinions. All extracted themes were merged with an inductive

reasoning approach to elucidate key features and characteristics of a continuous remote patient care program for lung transplant patients using telehealth technologies. Ultimately, a conceptual framework was formulated. All specialists took part in the two final meetings.

2-3-Patient and Public Involvement

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

3-Results

Ten focus groups with a total of 13 participants were conducted through this survey. The FG size ranged from seven 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, eight were female (61.5%). The mean age of experts was 51 ± 13.36 . The years of experience in transplantation ranged from 1 to 25 years, with an average of 13.384 ± 8.45 years.

3-1-Main themes and sub-themes

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 sub-themes were extracted through the thematic analysis. The themes reflected the viewpoints and experiences of experts regarding the main characteristics of a comprehensive care program 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, challenges, and barriers of telehealth technology. The hereditary structure of themes and sub-themes is represented in Fig 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 of creating a personalized electronic health record for each patient as a prerequisite for the telecare program. 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 program must be included the patient's medical history, patient demographics information, referral history, diagnoses, medications, treatment plans, immunization dates, allergies, radiology images, laboratory results, and any data from EKGs, 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.”

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

182 ***Theme II: The possibility of reporting abnormal symptoms to transplant team members***

183 Usually, patients with high adherence to self-care activities were selected for transplantation.
184 Globally, the self-measurement ability of symptoms is recognized as one of the main aspects of
185 eligibility for transplantation candidate¹⁵⁻¹⁷. In our panel, all experts stated that continuous
186 monitoring of symptoms using telecare technology is one of the best solutions to prevent acute
187 rejection and track the patient's status after transplantation.

188 Post-transplant lung recipients will be exposed to many risks and complications such as severe
189 infections and acute rejection. Being able to report unusual symptoms as soon as possible and
190 providing access to the transplant team can lead to early diagnosis and timely treatment to
191 overcome post-transplant complications. Following, there are some quotations that experts stated:
192 *“I think that daily symptom reporting tool aid clinicians track the status of lung recipients more*
193 *easily. So, if an immense change occurred, the clinician can easily do interventions.”*

194 *“The patients should be familiar with abnormal symptoms. So, if any abnormal symptoms*
195 *occurred, they can report to the care team member or coordinator for early intervention”*

196 Overall, experts felt that enabling the patient to report abnormal symptoms to the transplant team
197 members could save the patient's life and prevent acute rejection. Thus, if the telecare program is
198 designed, it should be equipped with a symptom tracker or symptom management section.

199 ***Theme III: Comprehensive prescription and medication therapy management***

200 There is a growing body of evidence that refers to the complexity of therapeutic management and
201 accurate prescription in lung transplant patients. Prescribing a high number of medications
202 increase the potential of adverse drug events and medication errors¹⁸. Prior studies showed that

203 drug-related errors and associated adverse drug events lead to hospitalization in two-thirds of solid
204 organ recipients¹⁹. Thus, equipping telecare programs with smart electronic prescription modules
205 to prevent medication errors is required. Such tools could be checked medications for their safety,
206 drug interaction, and appropriateness of dosing in patients and lessen the complexity of long-term
207 immunosuppressive therapy and other specific therapies^{20, 21}.

208 On the other hand, non-adherence to treatment has a significant relationship with graft failure and
209 mortality²². The experts mentioned that adherence of patients to the treatment plan and accurate
210 drug usage plays a significant role in transplant success rate. Ten experts declared the patient must
211 comprehend his disease and treatment plan to follow the healthcare provider's recommendations.
212 Some related quotations are represented in the following.

213 *“The patient must actively participate in the disease management program to adhere to treatment.*
214 *Therefore, it is necessary to help patients to learn about the correct way to take drugs and the side*
215 *effects of their drugs.”*

216 *“The individual characteristics of each patient, the social support the patient receives from family*
217 *and friends, and the cognitive ability to understand the disease can affect the rate of non-*
218 *adherence to treatment.”*

219 Another problem was related to forgetting to take medicine or *forgetfulness*. Usually, the
220 specialists encountered those patients who had worsened their condition due to forgetting at least
221 one dose of their medication during the course of treatment. Thus, using technology-based tools
222 such as alerts or reminders could be useful to enhance medication adherence in recipients²³. It is
223 crucial for transplant patients how to take drugs, follow the physician's orders, and be familiar
224 with medication side effects to address its complications. Medication alerts and reminders could
225 be integrated into patients' medical records to address forgetfulness challenges.

226 *“Most of the forgetfulness occurred unintentionally. A simple reminder can save the lives of*
227 *people who forget to take their medication due to preoccupation.”*

228 *“Sometimes the medication plan might change during follow-up, the patient needs to communicate*
229 *sufficiently with the LTx team. Moreover, a means of communication requires ongoing care.”*

230 ***Theme IV: Enhancing continuous follow-up and improving patient adherence to regular visits***

231 Patients should go to the transplant clinic regularly so that necessary interventions can be
232 performed by physicians in case of problems arise. Nine out of 13 participants pointed out that
233 patients adhere to regular visits more regularly in the first months after the transplant surgery.
234 Therefore, it is necessary to define a standard program to define the appropriate time to refer
235 patients in the months and years after transplantation. Equipping the remote monitoring system
236 with a visit reminder can help patients to go outpatient clinics on the scheduled date. In addition,
237 the next visit date could be determined by the physician and informing the patient by sending alerts
238 to his/her smartphone.

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

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

246 ***Theme V: Refining communication and collaboration of patients with the transplant team***
247 ***members***

248 The experience of LTx team members showed that if communication between patients and LTx
249 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 presence of the coordinator at the middle level of care is crucial in this regard 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 inter-professional collaboration. Nevertheless, a means of communication could be established through a web-based messaging system. This type of tool not only connects patients to share their experiences with other patients but can also connect 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 emphasized that patients in the lung transplant system should follow a comprehensive care plan and healthy lifestyle not only after the transplantation surgery but even while they are on the waiting list. According to experts, a patient-specific care plan includes different dimensions that should be considered as a comprehensive self-care management program. These factors include giving up smoking, keeping active, drinking daily fluids, following a healthy diet, and avoiding alcohol. Since the patient must be active, physical rehabilitation must also be part of the lung recipient's lifestyle and treatment plan²⁵.

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

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

278 ***Theme VII: Educating patients***

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

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

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

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

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

295 ***Theme VIII: Equipping patients and clinicians with decision-aid tools***

296 There may be a problem that needs to be resolved by the patient before coming to the clinic. In
297 this regard, four experts declared that it is possible to support patients make the best decision by

designing decision-aid tools. The telecare program could be equipped with such tools to guide patients when it is desired. These tools can be designed based on the expert's knowledge and standard protocols both for patients and clinicians²⁶.

"It is very important for clinicians to know about the improvement of 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 most barriers and benefits of implementing telecare services in lung transplantation, which were discussed in group discussions, are shown in Table 2. These cases are listed separately according to the benefits and advantages they have for patients and staff.

One of the key concerns of the experts was the lack of use of the program. Their experience showed that only a few e-health programs had made their way into routine care. End users' acceptance is one of the preliminary issues that should be considered before implementing. Experts specified that considering a coordinator in remote patient care programs is a kind of solution to reduce the workload of the transplant team.

"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."

3-2- A conceptual framework and prerequisites of a telecare care program in lung transplantation

The main features of the final program 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

1
2
3 323 prescription, and the ability to send messages to the care team. All themes and sub-themes were
4
5 324 integrated to generate a conceptual framework. We defined our conceptual framework in main
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8 325 three areas from the extracted themes, self-care activities, healthcare providers' tasks, and required
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10 326 technologies in a matrix which is shown in Fig 2 exemplified by El-Osta ²⁷.
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12 327 In our model, self-care activities refer to all activities completed by patients or his/her supportive
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14 328 persons to improve their general health. According to experts' consensus, self-care tasks in lung
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16 329 transplantation can be divided into five main categories including regular symptom management,
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18 330 medication adherence, adherence to regular visits, following a healthy lifestyle, and self-
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20 331 awareness. The second layer is related to the monitoring and patient follow-up activities conducted
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22 332 by the transplant team members.
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25 333 Each electronic care platform should be designed in such a way that the interactions between
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27 334 healthcare providers and patients enhanced ²⁸. Thus, Personal Health Records (PHR) is considered
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29 335 a part of this program in addition to electronic health record (EHR) to provide the possibility of
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31 336 recording and collecting health data on the patient's side ²⁹. It enables patients to have more
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33 337 responsibility to empower their health status and improve the interaction between physicians and
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35 338 patients through clinical decision-making.
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38 339 Remote monitoring can also be equipped with wearable sensors, IoT devices, and biosensors to
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40 340 monitor a patient's symptoms and daily activities. Although wearable sensors usage is low due to
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42 341 high costs and the need for equipment for both physicians and patients. Also, equipping a telecare
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44 342 system with decision-aid tools could be so beneficial for both clinicians and patients.
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47 343 **3-3- Defining the main process in the suggested telecare program**
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49 344 By developing a telecare system, transplant specialists could deliver the highest level of care in-
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51 345 person alongside remote patient care. Thus, the conceptual model to define the principal processes
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in a telecare system based on the extracted themes is illustrated in Fig 3. These kinds of models would be useful in the next steps to design the telecare system. Accordingly, a second level of care can be provided to patients by the transplant coordinator.

4-Discussion

By summarizing the viewpoints of experts, some significant aspects of the telecare program emerged through our survey. Consequently, all the points raised by the experts led to indicating the main requirements and features of the telecare system for lung transplant patients which led to devising the conceptual model. The proposed care model is devised based on the concept of remote patient care, which improves the relationship between the patient and the healthcare providers in the form of continuous care.

Remote patient monitoring programs have shown their advantages in improving the care of organ transplant patients³⁰⁻³². Since lung transplant patients are so 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 patients³³. This challenge can endanger the lives of patients in organ transplantation. Evidence showed that various techniques ranging 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^{31, 34, 35}.

Due to the possibility of provision of constant monitoring of the patient's symptoms in the care model, the LTx transplant 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 organizes patient information in a structured way and creates a personal health record for each patient. By creating an electronic medical record based on the daily monitoring of patients, developing a patient-centered care plan for each patient will be possible ^{36, 37}. 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 that require traditional visits. Therefore, the move towards the implementation of 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 the implementation of a remote care system can be considered as a model for designing a system in other organ transplant systems.

This study encounters some limitations. The sampling method was not randomly selected due to the low number of clinicians who have expertise in lung transplantation. Although the generalizability of qualitative research is difficult, we can do it in a wider context such as internationally in future studies. The feasibility of the proposed models will be investigated by developing a telecare system based on the suggested framework. Patients not participating in group discussions is another limitation of this study. Accordingly, the opinions of patients are supposed to be collected in the next phase after the feasibility of implementing the program.

5-Conclusion

Our survey demonstrated the main factors that must be considered to design a telecare program to provide ideal continuous care for lung transplant patients. We concluded that the establishment of such a support program is an effective strategy to solve poor adherence in lung transplant patients. The proposed model should be further explored by all stakeholders to support the development of telecare interventions at the point of care.

6-Declaration

Ethical consideration

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.

Authors contributions

MG, HA, SA, and RS contributed to the conception and development of the study design, contribution to data analysis, and interpretation of data. MG, SA, and HA prepared focus group question guides, conducted the focus groups, analyzed the resulting transcripts, and coded data. MG, HA, SA, and RS validated coding structure and analysis. MG, HA, SA, and RS conducted the literature review and wrote a first draft of the manuscript. All three authors revised and approved the last version of the manuscript.

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Conflict of interest

The authors declare that they have no competing interests.

415 **Availability of data and materials**

416 The dataset analyzed for this study is not publicly available to protect participant anonymity.
417 Additional information may be provided upon reasonable request to the corresponding author.

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527 Tables

528 Table 1. The demographic characteristics of the expert panel

529

	Data	Frequency	Percentage
Specialist	Pulmonologist	4	28.6
	Cardiothoracic Surgeon	2	14.3
	General Physician (GP)	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 5yrs	3	23.1
	5-10 yrs.	2	15.4
	10-20 yrs.	4	30.8
	More than 20 yrs.	4	30.8

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Table 2- Benefits, challenges, and barriers of telehealth technology in lung transplantation

Main Theme	Sub-theme	For transplant team members/ Clinicians/healthcare providers	Patients
Benefits	Accessibility	<ul style="list-style-type: none">• Providing 24h access to patient data• Direct communication with patients• Timely detection and action for specific conditions which require quick attention• Provide near real-time patient supervision	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• Better utilization of medical resources such as equipment, medical staff, and others	<ul style="list-style-type: none">• Saving transfer costs• Saving time for traveling and reporting abnormal symptoms
	Shared decision-making and team collaboration	<ul style="list-style-type: none">• Simplifying the workflow• Increasing the participation of nurses• Ability to provide a standard of care• Less healthcare resource utilization	<ul style="list-style-type: none">• 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	
		<ul style="list-style-type: none">• High cost of developing and programming• Technological hurdles	<ul style="list-style-type: none">• No access to computers or mobile Phones• No secure internet connection
Barriers and challenges	Human resources and health system problems	<ul style="list-style-type: none">• Resistance of healthcare providers to accepting and using telecardiology• Reimbursement• Concerns about patient mismanagement• Increase the workload of clinicians• Concerns about shared delivery of care with patients• The need for a full-time nurse to manage the system and communicate with patients	<ul style="list-style-type: none">• Resistance of patients to accepting and using telecardiology• Preference for a face-to-face visit

Figure Legends:

- Fig 1. The treemap of themes and sub-themes based on expert's opinions
- Fig 2. Conceptual framework of characteristics of a telecare program in lung transplantation based on extracted themes
- Fig 3. The proposed care model in lung transplantation and main processes

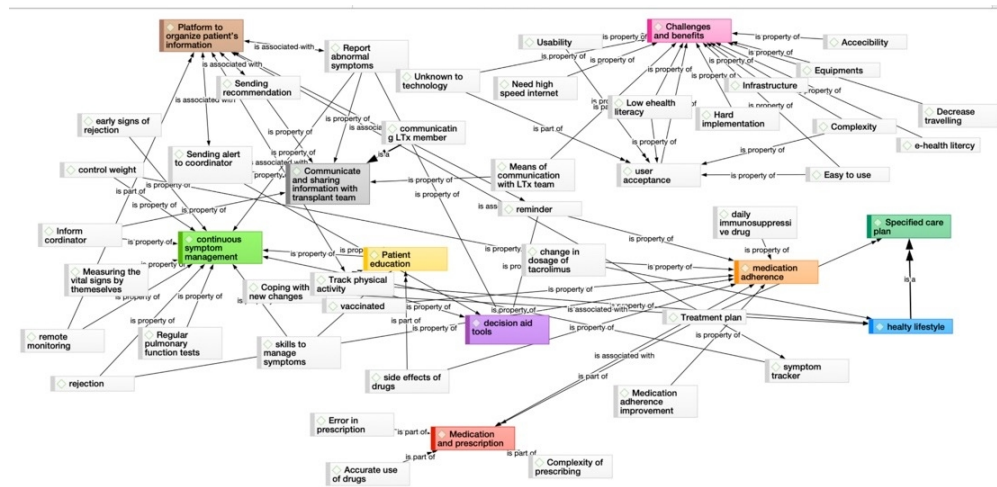


Fig 1. The treemap of themes and sub-themes based on expert's opinions

391x200mm (72 x 72 DPI)

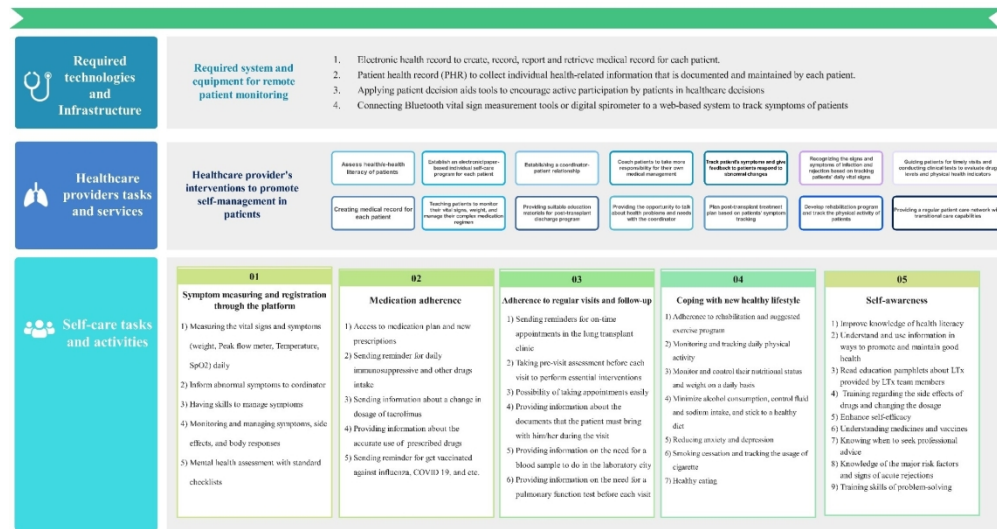


Fig 2. A conceptual framework based on the extracted themes

247x131mm (220 x 220 DPI)



Fig 3. The proposed care model in lung transplantation and main processes

186x205mm (300 x 300 DPI)

COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Feasibility study and determination of prerequisites of telecare program to enhance patient management in lung transplantation: A qualitative study from the perspective of Iranian healthcare providers

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Feasibility study and determination of prerequisites of telecare program to enhance patient management in lung transplantation: A qualitative study from the perspective of Iranian healthcare providers

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27 Abstract

28 **Background:** Non-adherence to treatment plans, follow-up visits, and healthcare advice are
29 common obstacles in the management of lung transplant patients. This study aims to investigate
30 experts' views on the needs and main aspects of telecare programs for lung transplantation.

31 **Design:** A qualitative study incorporating an inductive thematic analysis

32 **Setting:** Lung transplant clinic and Thoracic research center.

33 **Participants:** Clinicians, four pulmonologists, two cardiothoracic surgeons, 2 General physicians,
34 2 Pharmacotherapists, one Cardiologist, one nurse, and one medical informatician.

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

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

Conclusion: Our investigation recognized the main factors that must be considered to design a telecare program 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.

Keywords: Lung transplantation, Long-term care, Telehealth, Remote care, Patient-centered care

For peer review only

Strengths and limitations of this study

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

1-Introduction

Lung transplantation (LTx) is the last treatment option for patients suffering from end-stage lung diseases to prolong their life^{1,2}. 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 program should be planned to ensure that patient receives 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 programs among lung transplant recipients ranged from 3.1% to 10.6%^{3,4}. Despite various solutions, from paper-based plans to digital health solutions utilized by lung transplant centers to improve patient care quality, telemedicine-based programs showed their effectiveness in facilitating continuous patient care for patients and clinicians using remote patient care technologies⁵.

Generally, telecare or telehealth programs refer to any tailored and up-to-date care from a distance that enhances specialized care through coordination of involving multidisciplinary healthcare providers and providing rapid response to changes in patient health status⁶. 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 distance⁷.

Evidence showed that supporting transplant patients with additional technology-based support care programs 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

accessibility⁸⁻¹³. Such programs engage transplant patients in their self-management activities and enhance the doctor-patient 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 programs¹⁴; 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 program 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 program in lung transplantation. Therefore, this study's main objective is to investigate clinical professionals' viewpoints about the features, prerequisites, and characteristics of a telecare program to increase the quality of care in lung transplant patients.

2-Method

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

2-1-Data collection procedure

A focus group (FG) discussion was utilized to gather the opinions and viewpoints of experts with lung transplantation experience. The focus group discussions aimed to gather experts' views on a telecare program's needs and its central aspects to improve the quality of care in lung transplant patients 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 centers 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, participants completed an anonymous questionnaire including demographic information, responsibility in the transplantation team, and years of experience in lung transplantation. 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 and one hour. All FG sessions were transcribed by the moderator verbatim.

2-2-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 sub-themes. 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 analyze 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 program for

lung transplant patients using telehealth technologies. Ultimately, a conceptual framework was formulated. All specialists took part in the two final meetings.

2-3-Patient and Public Involvement

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

3-Results

Ten focus groups with 13 participants were conducted through this survey. The FG size ranged from seven 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, eight were female (61.5%). The mean age of experts was 51 ± 13.36 . The years of experience in transplantation ranged from 1 to 25 years, with an average of 13.384 ± 8.45 years.

3-1-Main themes and sub-themes

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 sub-themes were extracted through the thematic analysis. The themes reflected the viewpoints and experiences of experts regarding the main characteristics of a comprehensive care program 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

159 patient, 8) Equipping patient and clinicians with decision aid tools, and 9) Benefits, challenges,
160 and barriers of telehealth technology. The treemap structure of themes and sub-themes is
161 represented in Fig 1.

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

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

169 One of the topics raised in the meetings was the need to create a personalized electronic health
170 record for each patient as a prerequisite for the telecare program. Determining the components of
171 electronic health records and the data sets that should be recorded in the form of information items
172 will be one of the main stages of designing this system in a way to cover all the information needs
173 of the transplantation team. It is clear that the electronic record as a part of the telemedicine
174 program must be included the patient's medical history, patient demographics information, referral
175 history, diagnoses, medications, treatment plans, immunization dates, allergies, radiology images,
176 laboratory results, and any data from EKGs, CT scans, and so on. It can be integrated into the
177 symptom monitoring module to recommend the best treatment plan.

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

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

183 ***Theme II: The possibility of reporting abnormal symptoms to transplant team members***

184 Usually, patients with high adherence to self-care activities were selected for transplantation.
185 Globally, the self-measurement ability of symptoms is recognized as one of the main aspects of
186 eligibility for transplantation candidate¹⁵⁻¹⁷. In our panel, all experts stated that continuous
187 monitoring of signs and symptoms using telecare technology is one of the best solutions to prevent
188 acute rejection and track the patient's status after transplantation.

189 Post-transplant lung recipients will be exposed to many risks and complications, such as severe
190 infections and acute rejection. Being able to report unusual symptoms as soon as possible and
191 providing access to the transplant team can lead to early diagnosis and timely treatment to
192 overcome post-transplant complications. Following, there are some quotations that experts stated:
193 *"I think that daily symptom reporting tool aid clinicians in tracking the status of lung recipients*
194 *more easily. So, if an immense change occurred, the clinician can easily do interventions."*
195 *"The patients should be familiar with abnormal symptoms. So, if any abnormal symptoms occur,*
196 *they can report to the care team member or coordinator for early intervention."*

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

200 ***Theme III: Comprehensive prescription and medication therapy management***

201 A growing body of evidence refers to the complexity of therapeutic management and accurate
202 prescription in lung transplant patients. Prescribing many medications increases the potential for
203 adverse drug events and medication errors¹⁸. Prior studies showed that drug-related errors and
204 associated adverse drug events lead to hospitalization in two-thirds of solid organ recipients¹⁹.
205 Thus, equipping telecare programs with smart electronic prescription modules to prevent
206 medication errors is required. Such tools could be checked medications for their safety, drug

interaction, and appropriateness of dosing in patients and lessen the complexity of long-term immunosuppressive therapy and other specific therapies^{20, 21}.

On the other hand, non-adherence to treatment has a significant relationship with graft failure and mortality²². The experts mentioned that patients' adherence to the treatment plan and proper drug usage plays a vital role in transplant success rate. Ten experts declared the patient must comprehend his disease and treatment plan to follow the healthcare provider's recommendations. Some related quotations are represented in the following.

"The patient must actively participate in the disease management program to adhere to treatment. Therefore, it is necessary to help patients to learn about the correct way to take drugs and the side effects of their drugs."

"The individual characteristics of each patient, the social support the patient receives from family and friends, and the cognitive ability to understand the disease can affect the rate of non-adherence to treatment."

Another problem was related to forgetting to take medicine or *forgetfulness*. Usually, the specialists encountered those patients who had worsened their condition due to forgetting at least one dose of their medication during the course of treatment. Thus, using technology-based tools such as alerts or reminders could be helpful to enhance medication adherence in recipients²³. It is crucial for transplant patients how to take drugs, follow the physician's orders, and be familiar with medication side effects to address its complications. Medication alerts and reminders could be integrated into patients' medical records to address forgetfulness challenges.

"Most of the forgetfulness occurred unintentionally. A simple reminder can save the lives of people who forget to take their medication due to preoccupation."

229 *“Sometimes the medication plan might change during follow-up, the patient needs to communicate*
230 *sufficiently with the LTx team. Moreover, a means of communication requires ongoing care.”*

231 ***Theme IV: Enhancing continuous follow-up and improving patient adherence to regular visits***

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

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

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

247 ***Theme V: Refining communication and collaboration of patients with the transplant team***
248 ***members***

249 The experience of LTx team members showed that if communication between patients and LTx
250 team members is improved, the quality of patient care could be improved. In a friendly and
251 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 inter-professional 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 emphasized 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 program. 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.

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

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

279 ***Theme VII: Educating patients***

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

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

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

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

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

296 ***Theme VIII: Equipping patients and clinicians with decision-aid tools***

297 There may be a problem that needs to be resolved by the patient before coming to the clinic. In
298 this regard, four experts declared that it is possible to support patients in making the best decision

by designing decision-aid tools. The telecare program 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 clinicians²⁶.

"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 most obstacles and benefits of implementing telecare services in lung transplantation, 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.

One of the experts' critical concerns was the program's lack of use. Their experience showed that only a few e-health programs had made their way into routine care. End users' acceptance is one of the preliminary issues that should be considered before implementation. Experts specified that considering a coordinator in remote patient care programs is a kind of solution to reduce the workload of the transplant team.

"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."

3-2- A conceptual framework and prerequisites of a telecare care program in lung transplantation

The main features of the final program 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. All themes and sub-themes 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 Fig 2, exemplified by El-Osta 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 lung transplantation 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 (PHR) are considered a part of this program in addition to electronic health records (EHR) 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, IoT devices, and biosensors to monitor a patient's symptoms and daily activities. However, wearable sensors 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.

3-3- Defining the key process in the suggested telecare program

By developing a telecare system, transplant specialists could deliver the highest level of care in-person alongside remote patient care. Thus, the conceptual model to define the principal processes

in a telecare system based on the extracted themes is illustrated in Fig 3. These kinds of models would be helpful in the next steps in designing the telecare system. Accordingly, a second level of care can be provided to patients by the transplant coordinator.

4-Discussion

By summarizing the viewpoints of experts, some significant aspects of the telecare program 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 programs have shown their advantages in improving the care of organ transplant patients³⁰⁻³². Since lung transplant patients are so 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 patients³³.

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^{31, 34, 35}.

Due to the possibility of provision of constant monitoring of the patient's symptoms in the care model, the LTx transplant 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 organizes patient information in a structured way and creates a personal health record for each patient. By creating an electronic medical record based on the daily monitoring of patients, developing a patient-centered care plan for each patient will be possible^{36, 37}. 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 that 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 lung transplantation. In addition, our study is only limited to lung transplantation. Second, though the generalizability 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 participating patients in group discussions

and requirement analysis. Our survey investigated various aspects of physicians' and nurses' perspectives regarding patient telecare in lung transplantation. 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 lung transplantation.

5-Conclusion

Our survey demonstrated the main factors that must be considered to design a telecare program to provide ideal continuous care for lung transplant patients. We concluded that establishing such a support program 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.

6-Declaration

Ethical consideration

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.

Authors contributions

MG, HA, SA, and RS contributed to the conception and development of the study design, contribution to data analysis, and interpretation of data. MG, SA, and HA prepared focus group question guides, conducted the focus groups, analyzed the resulting transcripts, and coded data. MG, HA, SA, and RS validated coding structure and analysis. MG, HA, SA, and RS conducted

the literature review and wrote a first draft of the manuscript. All three authors revised and approved the last version of the manuscript.

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Conflict of interest

The authors declare that they have no competing interests.

Availability of data and materials

The dataset analyzed for this study is not publicly available to protect participant anonymity. Additional information may be provided upon reasonable request to the corresponding author.

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534 Tables

535 Table 1. The demographic characteristics of the expert panel

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	Data	Frequency	Percentage
Specialist	Pulmonologist	4	28.6
	Cardiothoracic Surgeon	2	14.3
	General Physician (GP)	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 5yrs	3	23.1
	5-10 yrs.	2	15.4
	10-20 yrs.	4	30.8
	More than 20 yrs.	4	30.8

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Table 2- Benefits, challenges, and barriers of telehealth technology in lung transplantation

Main Theme	Sub-theme	For transplant team members/ Clinicians/healthcare providers	Patients
Benefits	Accessibility	<ul style="list-style-type: none">• Providing 24h access to patient data• Direct communication with patients• Timely detection and action for specific conditions which require quick attention• Provide near real-time patient supervision	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• Better utilization of medical resources such as equipment, medical staff, and others	<ul style="list-style-type: none">• Saving transfer costs• Saving time for traveling and reporting abnormal symptoms
	Shared decision-making and team collaboration	<ul style="list-style-type: none">• Simplifying the workflow• Increasing the participation of nurses• Ability to provide a standard of care• Less healthcare resource utilization	<ul style="list-style-type: none">• Benefit from different opinions of experts
Barriers and challenges	Technology	<ul style="list-style-type: none">• Need high-speed internet• Familiarity with technology• Interoperability problems• Information Confidentiality• Data transfer network problems• Data security problems	
		<ul style="list-style-type: none">• High cost of developing and programming• Technological hurdles	<ul style="list-style-type: none">• No access to computers or mobile Phones• No secure internet connection
Barriers and challenges	Human resources and health system problems	<ul style="list-style-type: none">• Resistance of healthcare providers to accepting and using telecardiology• Reimbursement• Concerns about patient mismanagement• Increase the workload of clinicians• Concerns about shared delivery of care with patients• The need for a full-time nurse to manage the system and communicate with patients	<ul style="list-style-type: none">• Resistance of patients to accepting and using telecardiology• Preference for a face-to-face visit

Figure Legends:

Fig 1. The treemap of themes and sub-themes based on expert's opinions

Fig 2. Conceptual framework of characteristics of a telecare program in lung transplantation based on extracted themes

Fig 3. The proposed care model in lung transplantation and main processes

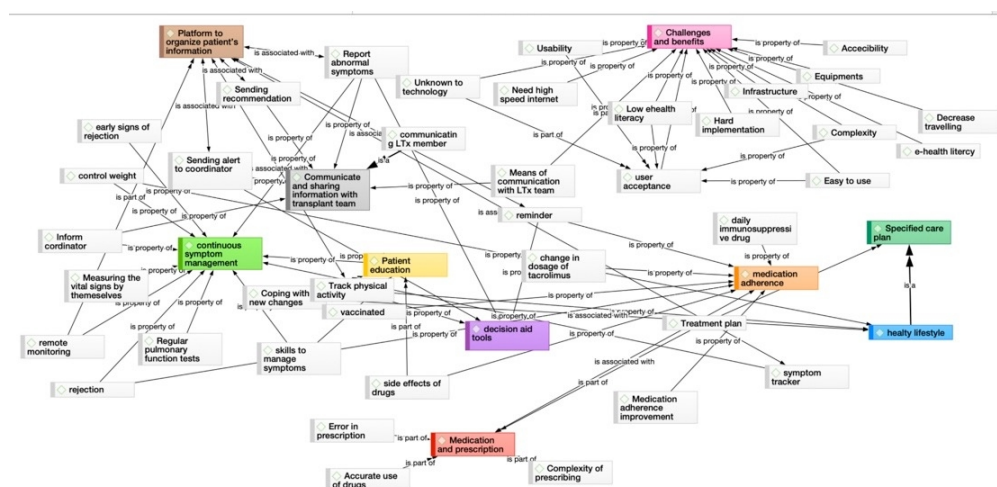


Fig 1. The treemap of themes and sub-themes based on expert's opinions

391x200mm (72 x 72 DPI)

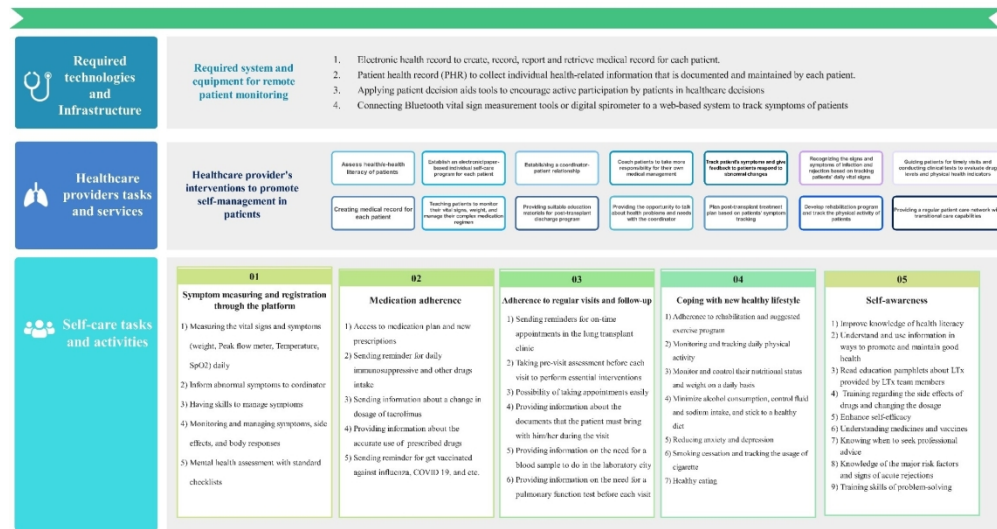


Fig 2. A conceptual framework based on the extracted themes

247x131mm (220 x 220 DPI)



Fig 3. The proposed care model in lung transplantation and main processes

186x205mm (600 x 600 DPI)

Interview guide

Thank you so much for taking the time to participate in focus group discussions conducted by the research team. I'm going to start by giving you an introduction and our goals for this interview.

As you know, in collaboration with the Thoracic research center at the Tehran University of Medical Sciences is studying care provider perspectives on lung transplant patient management. You are being invited to participate in this interview because we are interested in learning more about your experience, as a healthcare provider, with transplantation and your ideas on ways to make it easier to use using telemedicine technology.

Participation in this study is voluntary. You may discontinue your participation at any time. There won't be any identifying information linked to your responses. Only researchers on this project will have access to the data gathered.

Open-ended questions

- I will audiotape these sessions so that I can take fewer notes as we talk and review our conversation later to ensure that I don't miss any information. Please feel free to discuss at any time.
- In your opinion, what problems exist in the current traditional system for managing patients and accessing information?
- How to increase adherence to treatment through the implementation of a telecare system in patients?
- What are the characteristics of a suitable and practical telecare or remote patient monitoring system?
- What are the obstacles and benefits to implementing such telecare systems?
- Explain about workflow and shared decision-making process in the lung transplantation?
- What tasks can be assigned to the patient in the remote patient monitoring system?

COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher’s credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.