



# Patients' Experiences of Life Challenges After Liver Transplantation: A Qualitative Study

Journal of Patient Experience  
Volume 8: 1-7  
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DOI: 10.1177/2374373521996956  
journals.sagepub.com/home/jpx  


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## Abstract

Patients experience a new life with different challenges after liver transplantation (LT). Identifying these challenges can facilitate the improvement of their quality of life. This study aimed to explore patients' experiences of post-LT life challenges. This qualitative study was performed in 2019 through the content analysis approach. Participants were liver transplant recipients purposively recruited from a LT clinic. Semistructured interviews were conducted for data collection. Data were analyzed through Graneheim and Lundman's conventional content analysis approach. Meaning units were identified and coded, and the codes were grouped into subcategories and categories according to their similarities. In total, 18 transplant recipients were interviewed. Their age mean was 51 years and their transplant age ranged from 4 months to 12 years. Their post-LT life challenges were categorized into 4 main categories, that is, self-care deficit, the need for seeking information, fears and concerns, and hope–despair duality. Nurses and members of LT team are recommended to assess transplant recipients' life challenges and develop comprehensive plans for managing their challenges and problems and improving their quality of life.

## Keywords

liver transplantation, experiences, content analysis

## Introduction

Chronic hepatic failure and subsequent cirrhosis are among the major health concerns and the leading causes of death worldwide. Cirrhosis is the final stage of most hepatic disorders and happens when the liver loses its healthy tissue and function due to long-term injury (1,2). The prevalence of chronic hepatic failure and cirrhosis in the United States is 0.27%. Cirrhosis mostly affects men aged 20 to 59 years. It is the ninth leading cause of death in the United States and accounts for 3.5% of all deaths in the world. Saidi et al estimate that there are 3400 deaths due to nonalcoholic fatty liver disease, 2500 deaths due to hepatitis B virus cirrhosis, 1600 deaths due to hepatitis c virus cirrhosis, and 500 deaths due to cholestatic liver disease per year in Iran (3,4). The most common causes of cirrhosis are alcohol consumption and hepatitis B and C (5).

Cirrhosis is associated with many different physical, psychological, and financial consequences. Annually, it results in 150 000 cases of hospitalization in the United States. It is also associated with a high rate of 30-day rehospitalization which imposes heavy costs on patients, families, and health care systems (3,6,7).

Unlike patients with chronic renal failure which can survive through dialysis, patients with cirrhosis can survive only

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through liver transplantation (LT) (8). The first LTs were associated with 400-day survival. Advances in LT techniques and immunosuppressive medications have increased post-LT survival so that the 1-year and the 5-year survival rates of LT have increased by 90% and 70%, respectively (9–11).

Despite its many positive consequences, LT is associated with different challenges for patients (12). Although LT improves liver-related morbidity, because metabolic risk factors are still present, the recipients are at increased risk of recurrence after LT (13). Two former studies reported poor quality of life and poor treatment adherence as the main post-LT challenges (14,15). Evidence also suggests that ongoing patient awareness, structural psychological support systems, and caregiver engagement may help improve long-term health-related quality of life (16). Therefore, post-LT care mainly focuses on the improvement of patients' coping ability and quality of life, fulfillment of their needs, and management of their challenges (17). Moayed et al showed that "Self-regulation" among the recipients is required for life balance, as well as "self-care" efforts that can help maintain and improve patients' health (18). Liver recipients will need lifelong follow-up, which puts a huge burden on transplant team. Agreed protocols and good communication between recipients and all relevant health care providers are the keys to successful follow-up. This should be done in close collaboration between the liver transplant unit, the primary care team, and the hospital. Involvement of other health care practitioners, such as recipient coordinators, social workers, dermatologists, pharmacists, and addiction specialists, may enhance results (19). Yet, there is limited information about post-LT challenges. The present study was conducted to address this gap. The aim of the study was to explore patients' experiences of post-LT life challenges in which patients and their families undergo rapid changes after transplantation surgery.

## Methods

This qualitative study was performed in 2019 through the content analysis approach.

Study setting was an LT clinic, and study population consisted of adult liver transplant recipients referring to this clinic. The researcher (MT) attended the LT clinic multiple times and the study participants were recruited using a purposive sampling strategy with maximum variation respecting participants' demographic and socioeconomic characteristics. The inclusion criteria were adult post-transplant patients with history of LT at least 2 months before the study and agreement for participation. The Ethics Committee of our University approved this study. Participants were informed about the study aims and methods, and their verbal and written informed consents for participation were obtained. They were asked to participate in an interview and informed that conversations would be recorded. They were informed about the voluntary participation in study, knowing their right to withdraw at any time.

The time and the place of interviews were determined based on participants' preferences. In-depth semistructured interviews were held for data collection. All interviews were held by the first author in the counseling room of the study setting. An interview guide with open-ended and semistructured questions was developed by consensus of all authors, based on literatures. The following broad questions were used to start interviews, "What changes have happened into your life after LT?" "Which challenges did you face after LT?" Then, pointed questions were used. Examples of pointed questions were "Can you explain more about this?" "What do you mean by this?" Participants' verbal and non-verbal responses were used to develop questions for the next interviews. No new data were obtained from the interviews after the 15th interview. In other words, the data were saturated with 15 interviews. Yet, 3 more interviews were conducted to ensure saturation. The length of the interviews was 35 to 68 minutes. All interviews were audiorecorded using an MP3 recorder with participants' consent.

Data analysis was performed concurrently with data collection through constant comparison analysis and conventional content analysis approach suggested by Graneheim and Lundman (20). Immediately after each interview, we listened to it for several times and transcribed it verbatim. Meaning units were extracted and coded and similar codes were categorized into subcategories and main categories (16,17). As the analysis process progressed, the code titles were identified directly from within the text. The codes were then categorized based on similarities and differences in different classes, and this process was performed to explain the experiences and challenges of patients in the period after LT. Also, a peer debriefing process was applied in the coding development process, which ensures the credibility of the data through minimizing the bias of a single researcher. All the researchers reached a consensus through discussion and agreed on the code extraction, classification, and the obtained theme. Data were managed through the MAXQDA software (version 10.0).

Lincoln and Guba's criteria were used to establish trustworthiness (17). We attempted to establish close friendly relationships with participants, had prolonged engagement with the data, and asked participants to check the congruence between our findings and their experiences. Since participants were not English speaking, interviews were not conducted in English. Therefore, after completing the interviews and completing the qualitative analysis, the manuscript was translated into English.

## Findings

In total, 18 patients (10 males and 8 females) were interviewed. The mean of their age was 51 years (29–63 years) and the age of their LT ranged from 4 months to 12 years. All of them were married except 1 participant. The participants' demographic data are shown in Table 1. Post-LT life challenges were categorized into 4 main categories, namely self-

**Table 1.** Participants' Characteristics.

Characteristic	Value
Age (year)	51 (29-63)
Gender	
Male	10
Female	8
Occupation	
Self-employed	4
Housewife	7
Retired	2
Other	5
Marital status	
Single	1
Married	17
Educational level	
Primary	6
Bachelor's	3
Diploma	7
Illiterate	2
Transplantation time spent (year)	2.4 (4 month-12 years)
Residence	
Urban	16
Rural	2

**Table 2.** The Categories and Subcategories of Post-LT Life Challenges.

Categories	Main categories
<i>Limited self-care knowledge</i>	Self-care deficit
<i>Gradual decline of self-care</i>	
<i>Lack of a reliable source of information</i>	The need for seeking information
<i>Seeking strategies to change care-related approach</i>	
<i>Concerns over inability to afford care</i>	Fears and concerns
<i>Fear of death</i>	
<i>Hope</i>	Hope–despair duality
<i>Despair</i>	

Abbreviation: LT, liver transplantation.

care deficit, the need for seeking information, fears and concerns, and hope–despair duality (Table 2). These categories are explained in the following.

### Self-Care Deficit

Participants reported many problems in self-care. They not only had limited knowledge about post-LT self-care activities but also had experienced fluctuations in self-care.

*Limited self-care knowledge.* Liver transplant recipients need to make substantial changes to their lifestyle in order to have good quality of life and protect their transplant. A basic requirement for such changes is adequate self-care knowledge. However, despite knowing the importance of self-care, most participants had limited self-care knowledge in areas

such as nutrition, medications, personal hygiene, permitted level of physical activity, and transplant rejection symptoms. For instance, they knew that they should adhere to strict dietary and treatment regimens but had limited knowledge about the components of such regimens and hence provided different opinions about the best dietary regimen for post-LT life. Moreover, most of them did not know the primary symptoms of transplant rejection.

I take my medications after meal; but, I don't really know whether this is the right practice. (p 6)

“I was not taught about caring and things like that. There was only 1 patient next to my bed who was being discharged. I heard something happened while teaching and I learned something.” (p 8)

*Gradual decline of self-care.* After experiencing the positive physical consequences of LT, most participants had gradually lost their interest in self-care and poorly adhered to self-care activities. They were unaware that the stability of the positive physical consequences of LT depended on their close adherence to self-care activities.

When I felt better, I became indifferent to medications because I thought I had achieved complete recovery. (p 17)

Early after the transplant, I was very careful about myself. Now that I'm much better, the care has been reduced. For example, I eat all type of food. When I came to the doctor today, they said that my blood sugar had risen and I had to comply. (p 14)

### The Need for Seeking Information

Participants had limited knowledge about post-LT self-care and lifestyle modifications and hence, they attempted to seek information and improve their LT-related knowledge from different sources. They even relied on unreliable sources of information to improve their LT-related and self-care knowledge.

*Lack of a reliable source of information.* Most participants attempted to compensate their lack of knowledge about LT and self-care through searching internet websites or asking from other transplant recipients. Their limited access to reliable information sources was a major challenge of their post-LT life so that all of them felt bewildered at seeking information.

I frequently face questions about self-care and transplant; but, I don't know where I can find answer to my questions and what I should do. (p 9)

During the quarantine period, I had many questions in my mind when I came here, I asked other recipients with a history of what they were doing. (p 12)

*Seeking strategies to change care-related approach.* Bewilderment at seeking information caused participants to change their care-related approach. For instance, they sometimes

substituted herbal therapies for conventional therapies. For example, one of the participants had started a vegetarian diet and another used hydrotherapy.

I didn't know which foods I should eat and which food I shouldn't. Thus, I decided to start a vegetarian diet. (p 4)

I take my medicine and I follow my own food as far as I know. Of course, I do not know many things, for example, I know I should not eat oranges and grapefruit, but there is a series of herbal teas that are prepared from the village in Ilam. I eat, I feel better, now I do not know if it has an effect or not? (p 8)

### Fears and Concerns

Participants had many different fears and concerns due to their critical conditions and uncertain future. Despite improvements in their physical conditions after LT, they had fear over disease recurrence. They believed that their inability to adhere to their regimens may result in disease recurrence and hence had great fear over death.

**Concerns over inability to afford care.** Liver transplant recipients should receive immunosuppressive agents and perform strict self-care activities for life. Our participants were greatly concerned with their inability to afford medications and care services and also with receiving limited support for care from their family members. They also had fear over disease recurrence in case of their inability to afford medications and care services.

I should take transplant medications for life. If I cannot take them, only God knows what will happen to me. (p 9)

I have twins and my wife is unemployed. I had trouble getting medicine and we did not have money to go to the clinic. A charity came and helped me I have a lot of stress. What should I do if this person is not helping? (p. 11)

### Fear of Death

Most participants were uncertain about their future, had questions about their post-LT survival, and had fear over death. They considered transplant rejection likely and thought that it would be associated with death. Their fear over transplant rejection and death had considerably affected their lives.

My transplant may be rejected at any moment. If so, I will die. (p 17)

I had liver transplant 12 years ago and it has been a long time since my transplant, but I am still afraid of transplant rejection, and somehow I still see death following me. (p 6)

### Hope–Despair Duality

Liver transplant recipients undertake a difficult and long journey from disease onset to post-LT life, in which they may experience courses of hope and despair due to positive

or negative changes in their conditions, relationships, and activities.

**Hope.** Improvement in physical conditions helped participants follow a normal daily life, return to work or education, participate in social activities, think about their future, and even plan a pregnancy. Such activities brought them hope.

Today, I have come here to consult with my physician for pregnancy. (p 3)

I dropped out of school while I was in my second semester at university before the transplant. I stopped studying. After the transplantation, when I felt better, I continued my education and earned my degree, now I am working in a company. (p 2)

**Despair.** Negative post-LT experiences such as physical pain and discomfort together with the necessity to take different medications and take many health-related considerations into account had driven some participants to despair. They were also uncertain about their survival and hence considered any ailment as an imminent death.

When I think I need to receive certain care services for life, I get fed up with life. (p 6)

I have lost some of my activity after the transplant. When I walk a lot, my stomach aches so much that I can't work. I wish I never got sick to be like this. My life is no longer normal. (p 4)

### Discussion

This study revealed that liver transplant recipients experienced different life challenges, namely self-care deficit, the need for seeking information, fears and concerns, and hope–despair duality.

Self-care deficit was one of the major challenges of post-LT life. Findings showed that liver transplant recipients had limited knowledge, if any, about post-LT self-care, particularly in areas such as nutrition, physical activity, medications, and symptom management. In line with this finding, previous studies showed lack of self-care knowledge about medications among liver transplant recipients (21), about physical activity among bone marrow transplant recipients (22), and about nutrition and transplant rejection symptoms among kidney transplant recipients (23). Moreover, we found that recipients gradually lost their interest in self-care after LT due to experiencing improvements in their conditions. This finding denotes that the stability of post-LT conditions may move transplant recipients toward poor self-care. Therefore, health care providers, particularly the members of LT team, need to assess and determine transplant recipients' educational needs in the area of self-care and use effective strategies to fulfill these needs and improve their knowledge about LT and post-LT self-care. They also need to inform transplant recipients about the lifelong necessity of post-LT self-care. Contrary to our findings which showed gradual decline in self-care, a former study showed

that self-care deficit was mainly prevalent immediately after transplantation (24). Currently, self-care is trained and discharged from the hospital in clinical practice (3), but a large amount of education is done simultaneously and rapidly, which is a heavy burden for patients and their families in their fast changes after transplant surgery. Therefore, it is difficult to say that acquiring knowledge is enough (25).

The need for seeking information was the second main challenge of post-LT life. Participants attempted to fulfill their educational needs and improve their LT-related knowledge through seeking information from different sources. However, reliable sources of information, such as health care providers, were not easily accessible and hence participants resorted to unreliable sources such as peers and Internet websites. Information obtained from unreliable sources caused them bewilderment. In line with our findings, 2 earlier studies showed that transplant recipients sought transplantation-related information from unreliable sources (26,27). Seeking information from unreliable sources such as peers results in the dissemination of misconceptions among patients, negatively affects their approach to care and treatment, shifts them to other therapies, and thereby endangers their lives. Similarly, a former study showed that kidney transplant recipients had substituted complementary and herbal therapies for conventional therapies (28). These findings denote that in the center where this research has been done, the members of LT team mainly focus on the acute phase of LT including hospitalization and post-LT intensive care services and thereby fail to provide LT recipients with quality education about self-care. In this center, the recipients did not have prelisting formal and integrative discussion with health care workers and also did not receive complete and proper information when discharged. Although they are given a list of contacts at the transplant center for follow-up, but maybe they don't receive good feedback and support due to workload of the transplant center. The missing link in education for patients after LT started in the pretransplant period and was quite evident in the post-transplant period. Our liver transplant center mainly focuses on success in surgery and life preservation in the immediate post-transplant period and has neglected to educate patients to maintain and stabilize life expectancy. They need to provide patients with reliable sources of LT-related information in order to improve their self-care, reduce their bewilderment, prevent them from changing their approach to care and treatment, and thereby improve their health. Liver transplant centers around the world use the best international or national method to achieve this goal, and this can support the implementation of these systems and the allocation of appropriate staff, including nurses, social workers, and nutritionists. For instance, Yun et al in Seoul conducted a pre-discharge group education program for liver transplant patients such as emergency management, outpatient management, medication and nutrition management, complication and infection management, wound and drainage management, sex life, and also disability registration (25).

The third main category of post-LT life challenges was related to fears and concerns. Severe liver disorder had caused our participants to feel that their lives were at risk and hence they experienced fears and concerns. Their fears and concerns even existed after LT due to problems such as inability to afford medications and care services, possibility of transplant rejection, and death. A former study also showed that bone marrow transplant recipients had fear over infection and transplant rejection. Another study reported fear, particularly over death, as one of the most important post-LT experiences (29,30). Similarly, a study indicated that kidney transplant recipients always had fear over unpredictable post-transplantation complications (31). Moreover, a study noted that patients with myeloma had fear over an imminent death before and after bone marrow transplantation (29). All these findings highlight the importance of providing transplant recipients with assurance and reducing their fears and concerns. Facilitating their access to their medications and providing them with adequate support can also reduce their fears and concerns.

The last main category of post-LT life challenges was hope–despair duality. Hepatic failure and LT had affected participants' education, employment, income, and marital life. Some of them had lost employment and some of them had resorted to dangerous jobs in order to afford the costs of their medications. They also had considerable uncertainties over their future and survival. These problems had affected their morale and caused them a sense of despair. On the other hand, improvement in physical conditions after LT had brought them hope and caused them to plan for marriage or pregnancy. In agreement with these findings, a former study showed that patients perceived some levels of hope and despair before and after organ transplantation (32). Another study reported that heart transplant recipients showed an unpredictable pattern of hope and despair (27). Financial and occupational problems are among the main causes of despair among these patients (33). Therefore, identification and management of the main causes of despair among transplant recipients are of great importance.

## Conclusion

This study shows that after LT, recipients experience a wide range of challenges such as fears, concerns, financial problems, hope–despair duality, and uncertainty over future. Therefore, they need adequate support and quality care services in order to cope with their LT-related challenges. Health care providers, particularly nurses and the members of LT team, need to develop comprehensive care plans to manage these problems and challenges and thereby improve liver transplant recipients' quality of life.

## Limitations

The main research environment for access to patients in the transplant clinic was very crowded and obtaining initial

consent to participate in the research was inevitably done in this environment. Also the interview sections were impacted by coronavirus outbreak. Participants were not English speaking, therefore after completing the qualitative analysis, the manuscript was translated into English. One of the limitations of this study is that we were not able to explore all aspects of patients' challenges, because in qualitative studies, the results are limited to the study participants and the research setting.

### Authors' Note

MT& NDN contributed to study conception and design; MT contributed to data collection; all authors contributed to data analysis and interpretation; MT and NDN contributed to drafting of the article; and all authors involved in critical revision of the article. The Ethics Committee of Tehran University of medical sciences approved this study (code: IR.TUMS.FNM.REC.1397.200). Written informed consent was obtained from all participants included in the study.

### Acknowledgments

The authors would like to thank Tehran University of Medical Sciences that supported this research project. In addition, all the LT patients who participated in this study would be appreciated.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was funded by Tehran University of Medical Sciences.

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