

Life Experiences of Hepatitis Patients Waiting for Liver Transplantation

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Abstract

Background: Since the number of hepatitis patients requiring liver transplantation is on the rise and the waiting list for such operation is long, the quality of life of these patients will be affected. Providing any care and health services requires an understanding of these patients' real experience and their specific needs.

Objectives: Therefore, this study aimed to explore the life experiences of hepatitis patients waiting for liver transplantation.

Methods: This was a qualitative study with content analysis approach. Participants in this study consisted of 10 hepatitis patients on the waiting list for liver transplantation, who were selected through purposive sampling. For data collection, semi-structured interviews were conducted and data were analyzed using Landman and Grantham and constant comparison methods.

Results: The participants included 10 hepatitis patients with a mean age of 41.4 years, and 34.8 months average time being on the waiting list. The main themes of "life turmoil (being troubled for the family and living with hardship)", "searching" (searching for information and search for a change in treatment approach), spirituality (trust and faith in God and relaying on Imams (Tavasol)), and "new concerns" (unhappiness in life and challenge and consequence of waiting) were extracted from the data.

Conclusions: Hepatitis patients' experiences included family economic problems, exacerbation of the disease and its complications, lack of adherence to treatment regimen, and physical and psychosocial problems. Knowing and understanding the issues and problems of these patients can create positive changes in their time when waiting for liver transplantation, and can empower them in this difficult time so they can have a more successful transplantation.

Keywords: Liver Transplantation, Waiting List, Hepatitis

1. Background

Nowadays, chronic liver disease and viral hepatitis are on the rise and considered as the most important causes of patients' death and mortality (1). For example, hepatitis B virus is the most common human-health threat and a worldwide health problem (2) that causes liver cirrhosis and liver cells carcinoma (3). About 1.5 million people are living with hepatitis B infection in Iran (4).

Liver transplantation is the only effective treatment for patients with end stage liver failure (5), and is a very successful method with 90% survival rate over one year period (6). In Iran, the number of transplantations due to brain death in 2009 and 2010 was 2.9 and 4.1, respectively, for every one million population. In addition, according to statistics, Iran is ranked third in terms of live donors in the world, which in the case of liver it is 0.6 for every one million population (7).

Although the number of organ transplants around the world has increased, the waiting time for the transplant candidates to receive organs is increasing day by day due to

small number of organ donors (8). Various statistics have been reported regarding patients waiting for liver transplantation. For instance, in Saudi Arabia and Turkey, 279 and 447 cases of liver transplantation take place, respectively, and despite this numbers, patients have to wait for a long time for organ transplant (9). Studies have reported that this period is associated with intense concern, doubt, stress (10), psychological and physical complications (11), high level of anxiety (12), and exacerbation of disease, and its complications that patients must cope with (13). Furthermore, these complications are expected to affect their quality of life (14). Increasing support to promote health-oriented care in order to increase health and life resources during the period of waiting for organ transplantation is of utmost importance (15).

It seems that waiting for liver transplant is associated with unpleasant experiences. For this reason, the waiting experience of people on the waiting list of liver transplantation can be a unique experience; different from the experience of other patients who are on waiting lists for other

surgeries and procedures (16).

Hepatitis patients face many challenges when waiting for organ transplantation. Providing any healthcare service as well as developing and designing holistic care for them require the understanding of these experiences according to their unique reality and needs. Healthcare workers can design a better care plan for these patients and their families if they understand better the problems and challenges that these patients are faced.

2. Objectives

Since there has not been so far a study on this subject among hepatitis patients in Iran and taking into account the unique complexities of the human being as an important phenomenon in the health field, and knowing that quantitative research is not capable of in-depth study of various aspects of human life, and also considering the differences in living conditions, beliefs, and culture of Iranian people, this study was conducted to explore the experiences of hepatitis patients waiting for liver transplantation.

3. Methods

This was a qualitative study with content analysis approach took place in Imam Khomeini liver transplant clinic (a public and referral hospital) affiliated to Tehran University of Medical Sciences in 2016. The participants consisted of 10 hepatitis patients on the liver transplantation waiting list who were selected by purposive and maximum variation sampling method. From these patients, 4 were women and 6 were men. Inclusion criteria were need for liver transplantation, ability to understand conversation in Farsi, and willingness to participate in this study. The selected participants were briefed about the objectives and methods of the study in person followed by obtaining written informed consent. Interviews' location was chosen to be at Tehran school of nursing and midwifery, University of Medical Sciences, because of the proximity to the liver transplant clinic and existence of private rooms for privacy and solitude. Semi-structured and face-to-face interview with the permission of the participants was used in this study and the interviews were recorded. The interviewer was a Ph.D. candidate in nursing. The interviews began with a completely open question: "What was your experience after you heard you need a liver transplantation?" Then, during the interview, the researcher in order to remain focused on the interview process, achieve the research objectives, and obtain richer data, asked follow-up questions from the participants. For example "How were

you placed in the waiting list?", "what is the concept of waiting for liver transplant for you?", "after being added to the organ transplantation waiting list, what changes occurred in your lifestyle?", "What sort of problems have you experienced since you have been placed on the waiting list?", "What changes have occurred in your diet and physical activity compared to past?". Interviews lasted for 30 to 55 minutes and continued to achieve the necessary richness and data saturation. At the end, interviews were recorded accurately and were fully implemented. Landman and Grantham's qualitative content analysis method was used for data analysis. First, the researcher listened to the taped interviews actively, and transcribed the recorded interviews sentence by sentence. Next, the interview transcripts were read several times in order to achieve a general understanding. Then, each section of the text that evoked key concept or idea was determined as semantic unit and was given a code. In this process, simultaneously with the progress of analysis, the titles of codes were determined directly from the text. At first, 1000 initial codes were formed. Then, the codes were classified in various themes based on their similarities and differences and the process continued to determine the experiences of hepatitis patients waiting for liver transplantation. Similar codes were classified in the same category and duplicate codes were removed.

3.1. The Trustworthiness and Rigor

There are four criteria of validity and reliability in a qualitative study, including credibility, transferability, dependability, and confirmability, which have been introduced by Guba and Lincoln (17). In order to determine the credibility of data by maximum variation sampling, the researcher maintained ongoing and long-term engagement with the study subject and data, persistent observation, effective interaction with the participants as well as member checking through verifying statements by the participants. Data dependability was achieved using the opinions of colleagues and re-examination of all data. For confirmability of the findings, measures such as the researcher's neutral opinion, presentation of reflective notes of all observations and interviews without any bias during the interview, agreement on codes and themes, and re-check of the transcripts, codes, and extracted themes by members of the faculty were taken. The transferability of data was obtained with detailed explanation of participants and their conditions.

3.2. Ethical Considerations

Concerning the ethical considerations, at first an introductory letter was obtained from Tehran University of

Medical Sciences to access the participants. All hepatitis patients participating in the study were informed about the objectives of the research and an informed written consent was obtained from them before the interviews. The participants were also assured about confidentiality of their information and the fact that, after the study, the audio file will be eliminated but if they want, they could receive the audio file of their interviews as well as the study's results. In addition, the participants were informed that they could leave the study whenever they wished to, but nobody withdrew from the study. The study proposal was approved by the ethic committee of Tehran University of Medical Science (research code: 9221199005).

4. Results

Participants consisted of 10 hepatitis patients (4 women and 6 men) with average age of 41.4 years. Their average time on the transplantation waiting list was 34.8 months. Demographic characteristics are presented in [Table 1](#).

In total, 4 main themes and 8 sub-themes were derived from the interviews, which are presented in [Table 2](#). The main themes and sub-themes included life turmoil (being troubled for the family and living with hardship), searching (search for information and search for a change in treatment approach), spirituality (trust and faith in God and relaying on Imams (Tavasol)), and new concerns (unhappiness in life and challenge and the consequence of waiting).

4.1. Life Turmoil

Life turmoil was the first theme derived from the participants' experiences that included two sub-themes: being troubled for the family and living with hardship.

4.1.1. Being Troubled for the Family

Being troubled for the family was one of the experiences expressed by all the participants. Engagement of all family members in the disease process and being responsible for the disease treatment, unwanted limitation for family members due to patient's care, and being economically pressured were also issues expressed by the participants. In this regard, one of the participants stated:

"My spouse is going to bear a heavy burden for a long time, and this bothers me. I am ashamed of him because how much money he makes he spends on me. I feel guilty because he has heart condition and cannot work a lot, but my disease has caused him a lot of trouble." (Participant No. 10)

4.1.2. Living with Hardship

According to the participants' experiences, going on the transplantation waiting list caused many economic, occupational, social, psychological, and living hardships for them and affected the path of their life. Other difficulties and hardships experienced by the participants were related to losing their job and financial difficulties. One of the participants in this regard said:

"I am undecided at the moment. I have not been working for a couple of months and I do not have full salary. My income has been cut to less than half. I told my employer to forget about me for the first 6 months of the year." (Participant No. 4)

Other experiences that the participants referred to were related to the challenges of dealing with the consequences and treatment of disease exacerbation, worsening of the symptoms caused by severity of illness, frequent hospitalizations, and suffering and enduring physical deterioration. A 51-year-old participant with a history of viral hepatitis who was also caring of his sick wife in this regard stated:

"I suffer from hepatic coma, it has caused me to have two accidents; when I was driving the car, I developed coma which was really bad. These issues annoy me very much." (Participant No. 1)

4.2. Searching

Most of the participants were searching for ways to control or cure their disease. Many of them were suffering from the lack of information and knowledge about their disease and its treatments. This theme included two sub-themes of searching for information and searching for health.

4.2.1. Searching for Information

Searching for information about the disease and treatment methods through different sources was one of the ways used by the majority of participants in this study. It seemed that, the main purpose of obtaining information for the participants was to find different ways of disease control and treatment and regain their health faster. In this context, the acquisition of knowledge about the disease and treatment from other hepatitis patients was considered a priority for the participants. A participant in this regard said:

"One of my friend's nephews had organ transplant surgery in this hospital. When I was very sad, I spoke to him and he said they transplanted the liver of a young donor to me and I soon became so well; my spirit lifted and I had more energy. I became so glad when I heard that, I said; so, transplant is not too hard." (Participant No. 3)

Table 1. Demographics of Participants in Content Analysis

Participant Code	Age	Sex	Marital Status	Education	Stay on Waiting List
P1	51	Male	Married	Diploma	7 years
P2	32	Male	Married	Bachelor	2 years
P3	49	Female	Married	Diploma	5 years
P4	36	Male	Married	Diploma	1 years
P5	29	Female	Married	Diploma	2 years
P6	47	Female	Married	Diploma	1 month
P7	27	Male	single	Bachelor	11 years
P8	52	Male	Married	Bachelor	3 years
P9	35	Male	Married	Bachelor	1 years
P10	46	Female	Married	Diploma	3 months

Table 2. Themes and Sub-Themes Derived from Data Analysis

Main Themes	Sub-Themes
Life turmoil	Being troubled for the family
	Living with hardship
Searching	searching for information
	Searching for a change in treatment approach
Spirituality	Trust and faith in God
	Relaying on Imams (Tavasol)
New concerns	Unhappiness in life
	Challenge and the consequence of waiting

Another participant referred to information acquisition through reading and searching websites as one of the ways to regain health and reduce disease complications, but this information may come from invalid sources. One of the participants in this regard said:

“When I get a new drug, I search it in Google to see its side effects, am I allergic to it or not. Of course, I was allergic to one and I developed skin rash, so I changed it.”

The same patient in response to the question “Did you inform the treatment and transplant teams that you have changed the medication?” said “No, because I must come here for visit every two months early in the morning.” (Participant No. 1).

4.2.2. Searching for a Change in Treatment Approach

The participants were always looking for ways to treat their disease and regain their health faster without needing organ transplantation. Non-surgical treatment methods such as traditional treatments and the use of herbal remedy as part of quest to cure the diseases were some of

the ways expressed by the participants. One of the participants in this regard stated:

“I use herbal remedies and spirits for myself and my family. I tell my children to drink chicory spirit because it is good for the liver” (Participant No. 2)

4.3. Spirituality

Most participants were spending their hard waiting time for organ transplantation and dealing with related challenges by asking God for help and relaying on him. This theme consisted of two sub-themes of trust and faith in God and relaying on him (Tavasol).

4.3.1. The Trust and Faith in God

Most participants referred to the religious and spiritual beliefs such as trust and faith in God, destiny and divine wisdom during their waiting period. Hepatitis patients, by relying on faith, endured the waiting period and were hopeful for their treatment and lives.

A 46-year-old woman who was recently being placed on the transplantation waiting list in this regard stated; “I pray to God, so I can stand the waiting period. Since I have put my trust in God, I know everything is going to be fine, and if something happens, it is the God’s will, and I am not afraid.” (Participant No. 10).

4.3.2. Relaying on Imams (Imams Are the Spiritual and Political Successors to the Islamic Prophet Muhammad) (Tavasol in Farsi)

Most participants referred to the importance of relaying on Imams and visiting holy shrine, and viewed them as effective and supportive factors in the path to treatment and overcoming difficulties. They believed that relaying on Imams could heal them when they were talking about their future and life. In this regard, a participant stated:

“God gives everything including treatment. Everything happens for a reason. Resorting to prayer, relying on Imams, and sacrificing for them affect my mood.” (Participant No. 2).

4.4. New Concerns

“New concerns” was one of the main themes extracted from the experiences of the participants, which included two sub-themes of unhappiness in life and struggle in life.

4.4.1. Unhappiness in Life

Despite the fact that majority of the participants were hopeful about most aspects of their lives, treatments, and future, some of them had concerns and occupied minds due to ineffective treatment and problems in life such as, financial status, family status, pity of people, mental and emotional dilemmas, surgery, and future concerns. Thus, such unpleasant feelings resulted in fear, anxiety, and grief in the participants.

One of the concerns of the participants was related to the transplantation and its results and complications. In this regard, one of them stated:

“When they first told me I need transplantation, I thought no, I cannot stand it, surgery hurts. I had a C-section and appendix surgeries, as well as few liver biopsy procedures. I said I cannot go under the knife again because I felt I do not have the ability to stand it.” (Participant No. 6)

Fear and anxiety were of the most unpleasant experiences expressed by the participants. For example, a participant said:

“I think this disease is going to turn into cancer. I fear that it becomes too late and physicians note it too late. This scares me a lot.” (Participant No. 7)

Furthermore, one of the experiences that most participants pointed at and complained about was the lack of information on the prognosis of their disease and treatment methods. For example, a female participant concerning her disease stated:

“I did not know what cirrhosis was, and I did not know what it meant. It is good to talk to people about their disease and explain about the disease prognosis, its progression, diet, sleep, and physical activity. I am a person who does not have medical training. If people have information, their condition may get much better.” (Participant No. 3)

4.4.2. Challenge and the Consequence of Waiting

A number of participants referred to difficulties of waiting period. Information obtained from the participants showed that, the life during waiting period was not

satisfactory for them. Dealing with life difficulties such as enforced limitations caused reactions such as lack of adherence to treatment and required follow-ups, and a kind of fighting in the patients. One of the participants concerning not adhering to the recommendations and instructions for the treatment team stated:

“They tell me not to eat salt, but I take it. I cannot eat food without salt ... I know that jam is bad for me but I eat it.” (Participant No. 3)

A 51-year-old man with a history of viral hepatitis, who was on the waiting list for 7 years, stated:

“I have a drug that I take often. Sometimes I forget to take it and some other times I do not take it deliberately as I do not like to become addicted and enter something into my body. It is useless.” (Participant No. 1).

Delayed follow-ups and waiting for physicians' visit followed by delayed transplantation surgery were among issues repeatedly mentioned by the participants. They stated that, they and their families feel uncertain and confused as their treatments are identified during visit follow-ups. A participant in this regard stated:

“I wanted to complete my file and register, when the doctor gave me an appointment in 3 month time, but I thought it's too late. I did not have a financial problem. They should have told me this hospital is inexpensive and you can go and find somewhere else to get your work done quicker.” (Participant No. 4).

5. Discussion

The results of this study showed that, majority of the participants' families were faced with unwanted limitations during waiting period caused by caring for their sick family member. These challenges can somehow create problems for the family members. The effect of the disease on the family can be compared with the expulsion of a hand grenade in the house where its fragments affect every family member. Study of Li et al. showed that, one of the main challenges of most participants was related to the engagement of families (18). Findings of Shariat's study also revealed that, majority of the participants were suffering in various degrees from the challenges of their illness for their families (16). Concerning factors affecting family challenges, we can refer to social, cultural, and religious beliefs of the participants. In addition, in Iranian community, family ties and accountability to each other are highly relevant.

Living with hardship, was one of the classes that emerged from the experiences of participants in this study. The waiting period for the participants was an unpleasant experience and a world full of pain and hardships. Exacerbation of the disease, its complications, diet limita-

tion, and difficult, costly, and long treatment processes affected their everyday life. Furthermore, majority of the patients belonged to low and middle income families and had to face many financial difficulties during their treatment process. The findings of Santos et al. study showed that, patients waiting for liver transplantation are affected by complications such as muscle weakness, and physical limitations, which increase the mortality rate significantly (19). Furthermore, results of numerous studies on patients waiting for heart, lungs, kidneys, and liver transplants showed that, patients experience multiple physical complications, including energy reduction, physical limitation, and exacerbation of disease and its complications (13, 20). In another study, more than half of the patients receiving organ had been experiencing financial difficulties (18). One of the extracted themes in the study of Lenzen et al. was the concept of living in purgatory, which referred to hardships and dilemmas of patients during their waiting period for heart and lung transplantation (21). Consequently, charities and insurance companies had an important role in supporting the patients financially.

The results of this study revealed that, one of the management requirements mentioned by majority of the participants during their waiting period was acquisition of information related to their disease and treatment methods as priority. Patients were seeking information from any sources to free themselves from their situation and disease. They were sharing information with their peers and were learning from their experiences. They were also using unreliable websites and social media to meet their educational needs. The results of qualitative studies on patients waiting for liver transplantation and management of their health and life showed that, acquisition of information to achieve new objectives during waiting period was one of the sources used by the patients (15). Thus, nurses and physicians can provide effective education and training for patients and their families taking into account their educational needs.

Searching for a change in treatment approach was another sub-theme extracted in this study. The findings from the experiences of participants indicated that, they were eager to restore their physical and psychological health, and considered it as a need. In addition, patients had undertaken every measure for recovery and getting rid of signs and symptoms of the disease. Hepatitis patients were using herbal and alternative medicines to take care of themselves and regain their health as much as possible, as they were afraid of heavy liver transplantation surgery and its potential complications. The result of a study showed that, patients were effectively using different ways to take care of themselves and maintain their health during their waiting period (22). The results of Shariat's study confirm

our findings (16). This issue highlights the importance of healthcare providers' role in increasing the knowledge of patients and their families about alternative medicines.

The results of this study showed that, religious and spiritual beliefs such as faith, trust in God, and divine destiny were among the methods that helped participants during their waiting period to cope with disease's difficulties and remain hopeful in life and treatment. In fact, spirituality and relying on God have helped patients during their waiting time. The experiences of participants indicated that, they were referring to their disease as God's will and they believed that God has ultimate power over their fate and he can heal them if he wants to. Similar studies also confirmed the effect of faith as a source of support (16, 23). The people of Iran mostly turn to religion in difficult situations and crisis due to their social and cultural conditions, and this could explain the results of this study. This should also be considered by healthcare team when caring for these patients.

Unhappiness in life was another sub-theme extracted in this study. Results showed that, participants in the waiting period were developing disorders and psychological stress, negative emotions, and various emotional responses. Waiting time for organ transplantation is a very stressful period and it is associated with the fear of imminent death, sorrow, and hopelessness that could have a negative effect on the quality of life of the patients. Results of Stewart's study revealed that, to spend waiting period, transplant patients needed the support of treatment team's members, and reduction of fear and anxiety had the highest effect on their quality of life (24). In another study, the participants in their statements referred to different levels of physical, psychological, social, and domestic problems that lead to desperation (25). Therefore, these patients require the support of treatment team during their waiting time.

Challenge and the consequence of waiting reflected the inner feelings and challenges of participants during the waiting period that had made life difficult for them. Long time wait for organ transplantation and the sense of uncertainty were among experiences of the hepatitis patients that exposed them to different stresses. Majority of patients were seeing their future uncertain, were confused and lost, which ultimately caused non-compliance with treatment regimen in them. They felt that, they are obliged to undertake some actions that are against their will, and this was causing defense mechanisms such as non-compliance with treatment regimen. The results of a qualitative study showed that, uncertainty regarding death and life as well as long waiting period were the most important issues identified by the study (26). In addition, another study revealed that longer waiting time is corre-

lated with lower quality of life as well as with stronger negative emotional reactions such as increased level of anxiety (14). According to the statements of the participants, perhaps the main reasons for difficult and longer waiting time were the high number of patients requiring organ transplantation and low number of organ donors, limited liver transplant centers, and exacerbation of the disease and its complications.

5.1. Conclusion

Results of this study showed that, hepatitis patients on liver transplantation waiting list are faced with economic difficulties, family problems, exacerbation of their disease and its complications, lack of adherence to treatment regimen, and physical and psychosocial problems. These challenges and painful experiences of this period reduce hepatitis patients' quality of life. The results of this study can help healthcare staff to understand the needs and concerns of patients, and to provide effective care programs, education, information, and appropriate support to address the challenges, concerns, and anxieties of patients and their families. The supportive role of the government and NGOs is critical in solving the economic problems of patients. For continuous monitoring of the patients, healthcare providers can provide follow-up care programs through telephone call. In addition, electronic methods such as email and telegram social media app can be used by healthcare professionals to provide patients with necessary information.

Considering the fact that patients with specific Meld score were included in the study, it is recommended to examine patients with other Meld scores. It is also recommended to study the patients who need transplantation but do not attend any transplant center.

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