

*Original Article***The lived experiences of liver transplant patients***Zahra Tayebi*, Heidar Ali Abedi*****Abstract**

Background: Today, liver transplantation is a routine procedure in the treatment of patients with end stage liver disease and its survival rate is high. In order to promote health, nurses and other health care professionals need to discover the meanings of lived experiences after liver transplantation. It is important for nurses to know what patients really experience; appropriate nursing intervention can be extracted from such understanding. This study aimed to describe the meaning of lived experiences of liver transplant patients after discharging from hospital.

Methods: A Phenomenological approach was chosen for the study. Unstructured and open-ended interviews were conducted with 9 liver transplant patients. The method of analysis described by Colaizzi (1978) was utilized.

Results: According to Colaizzi, seven categories emerged: support, gradual adaptation, transplant outcomes, concerns, follow up, gratitude and waiting for transplant. The patient's physical and mental problems prevented them to fulfill personal goals before transplant. Although they had some concerns such as fear of graft rejection, they were at the peace with the world after transplantation. Lifelong medications were identified insignificant for the participants. Social support was essential for recovery and meeting other recipients in the same situation as well as sharing health and life experiences is an important aspect among liver transplant patients. Health professionals were universally praised in the study however the follow up care they received from them was not desirable.

Conclusion: Health professional especially nurses should take a more active role in continuing care for such clients. Also, the support patients give each other should be encouraged and aided by health care team.

Key words: Lived experience; liver transplant patients, phenomenology

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In the past, nursing references mentioned that successful transplantation of organs had been a big dream for medical society, however in recent years by the help of scientific developments this dream is going to happen.¹

For many cirrhosis patients, liver transplantation is the only option of treatment. The survival rate of these patients without transplantation is less than 20% but with transplantation increased upto 60-80%.² Before 1980, one year survival after liver transplantation was 30% or less.³ Nowadays this extent is 85% after one year and 70% after the fifth year of transplantation.⁴ By increasing survival rate of these pa-

tients, quality of life and factors that can prolong their lives, become important.⁵

Many studies have been done in this way and their findings often showed a significant recovery in physical function after liver transplantation.⁶ As a whole, there are certain findings that the quality of life improves after liver transplantation, although not getting to the level of healthy people.⁷

The findings of one study that performed in Colorado University on patients before, 6 and 12 months after transplantation showed general recovery in all fields of life quality and to be pleased with it, although they had financial limits and personal worries.⁸

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Despite of the great number of prosperities of liver transplantation, there are many important and critical issues about it.⁹

From the liver recipients' point of view, pleasant quality of life in the long run is the main goal of transplantation; However post transplant adverse effects influence physical and psychological status of them.¹⁰

The main goal of all health care professionals in liver transplant teams is to help patients move from dependency phase toward independency phase and gain maximum quality of life.¹¹ Workman implies that caring for liver transplant patients require interdisciplinary approach.¹² Of course nurses play a very important role and the main responsibility of them is to ensure that the process of caring is continuous.⁹ To improve liver recipients' health, nurses need to know about their life experiences in order to present proper nursing functions.¹³

Liver transplant recipients often like to talk about their experiences and if their words become considered important by their relatives and medical team, they will have a better recovery and acceptance of post transplant problems.⁹

Being informed of patient's experiences would help nurses have a deep understanding of their health. In surveys which patients and nurses have answered similar questions, their answers have been quite different because both of these groups have had different understanding of the same problem. As a result, for nurses and all members of health team, it is important to know what patients really care about and how they experience that.¹⁴

Unfamiliar situation of liver transplantation and living with it among people and even medical society in our country and lack of sufficient research in this field (qualitative and quantitative) encouraged the researchers to do this qualitative study to describe the meaning of lived experiences of liver transplant patients after discharging from hospital. Knowledge and recognition that arises from this study can clarify those needs that have been waived and lead to present proper solutions for some problems.

Methods

This study was a qualitative one based on phenomenological approach. Purposeful sampling method was applied to select the participants. Data Saturation was reached after 9 interviews. Inclusion criteria were surviving for at least 6 months after transplantation, stable graft function, receiving orthotropic liver transplantation, being discharged from hospital at the time of interview and being eager to talk about the experiences.

The patients were all considered to be informants. Unstructured and open-ended interview had been used to gather data. Participants were chosen according to former familiarity with the researchers. The time and the place of the interview were decided by telephone and according to patients' preference. After explaining the purpose of the study, 2 participants in the conference room of the transplantation ward, 2 of them in transplantation clinic, 1 of them in researcher's home, 1 of them in her home, 1 of them in the university campus and 2 of them in their cars were interviewed.

Before the interview started, the patient received repeated information about the aim of the study and some greeting.

Interviews were started with a general question often such as "How is it going after transplantation?"

Although unstructured interviews had been used, the researcher has some senses about the issues which she wishes to clarify. For this reason interviews were often based on a form of topic guide that include key points and related topics.¹⁵

The interviews were audio taped and transcribed verbatim. The mean duration of the interviews was 35 minutes.

Analysis of the interviews was based on a modified version of phenomenological method developed by Colaizzi. The following protocol was used;

- 1) All the subjects' descriptions were read to acquire a feeling for them.
- 2) Return to each protocol and significant statement was extracted.

- 3) The meaning of each significant statement was spelled out, known as formulating meanings.
- 4) The formulated meanings were organized into clusters of themes;
 - a) Refer these clusters of themes were referred back to the original protocols to validate them.
 - b) At this point, discrepancies might be noted among and/or between the various clusters.
- 5) Results were integrated into an exhaustive description of the phenomenon under study.
- 6) The exhaustive description of the investigated phenomenon was formulated as unequivocal statement of identification as possible.
- 7) A final validating step could be achieved by returning to each subject and asking about the findings so far.¹⁶

About Rigour of research, as Longford (2001) said, accuracy of study is enough for research findings to express reality.¹⁷

In the present study, Member-Check method was used in order to confirm trustworthiness of data; in this method, results were given to the participants in order to add or remove any point that they mentioned in interviews.

Transferability of the results to the same place and time was provided by selecting the subjects with maximum variation of underlying disease, marital status, sex and age. Besides, many findings of this study are in line with previous studies which have been done in this field.

Informed oral consent was given. In qualitative studies, informed consent means that participants had sufficient information about the aim of study and a power of selection and participation in the study. All these points encouraged the patients to take part in the study voluntarily.¹⁸ In the present study, information confidentiality would be ensured to each participant and a code was given in place of each participant's name.

Results

Age range of participants was between 23-60 years. 4 of the participants were female and 5 of

them were male; 3 of them were single and 6 were married; all of them suffered from chronic liver failure before the transplantation; 3 patients were transplanted because of Wilson disease, 2 due to auto immune hepatitis, 2 patients because of hepatitis B, and 2 due to cryptogenic cirrhosis. 3 patients were working, 2 were students, 2 were house workers and the rest (2 cases) were retired.

By processing participants' interviews at the end of the third phase of Colaizzi's method, 191 formulated meanings were formed; from the total formulated meanings according to fourth phase of Colaizzi, seven main categories (cluster) were emerged that were shaped the structure of lived experiences of participants that come as following:

1. Waiting for transplantation:

Although the purpose of this study was taking out perceptions about post liver transplantation living, participants' experiences about waiting phase for transplantation were integrated with their lives. Participants have experienced different levels of physical, psychological, social and family problems during final phase of liver disease and called that a very tough and disappointing phase. Here some of their statements are mentioned:

"Before transplantation I felt awful, I had esophageal bleeding continuously, my feet were edematous, I was weak and ...; briefly I suffered a lot."

"My family fell a part because of my disease; even my condition had an effect on my children's education"

One of participants considered her previous situation (before transplantation) as "Bam earthquake" and believed that liver disease is like the destruction of sky on a person's head. Another patient said that doctors were disappointed about him and he was waiting for death.

Participants talked about opportunities on education and job that they had lost. On the other hand, participants talked about moments that they spent time with transplanted patients and this fact that visiting them revived hope in their hearts.

"Being transplanted was very difficult for me and I was very unhappy but an event happened and I got familiar with a transplanted patient. He revived hope in my heart. He said that my life has a cost and I should pay that cost. After that visit, I did all needed work up and got ready for transplantation."

2. Liver transplantation outcomes:

Participants discussed liver transplant outcomes from different points of view and mentioned their experiences about physical and psychological effects, getting back to work and improving their family relations. After the early postoperative phase, these recipients experienced a remarkable recovery in their physical and mental condition in comparison to their condition before transplantation.

The returning of the happiness to their families after transplantation was one of the significant points that were mentioned. Social rehabilitation also happened nearly after 6 months after transplantation.

"After discharging from hospital, I had some problems like tenderness in the site of operation but fortunately, I was getting better gradually; now that 30 months have passed from my transplantation, I'm 80 to 90% Ok."

"If my spiritual status before the operation had been 10, it would become 100 after the operation. Nobody believes that I am that previous weak person. These days I have a very nice life; I'm quite fresh and often travel and meet my friends."

"After 6 months, I started my job; I went to school and started teaching. I was quit fine; before transplantation I couldn't teach more than 2 hours and was always tired but these days I can teach for 8 consecutive hours."

3. Gradual adaptation:

Liver transplant recipients need a period of time to adapt to the complex nature of liver transplantation.

Participants of the present study pointed out this time for better adaptation. They talked about mechanisms by which they could adapt themselves to transplant's limitations.

One significant point among the participants of this study was their gradual and good adaptation to use lifelong immunosuppressive drugs.

"I didn't like Cellcept when I was in the transplant ward, even once or twice I threw it out to the dustbin. My nurse was informed and convinced me to use it. Since that time I tried to like it. I told myself that these pills are like pieces of chocolate and I should use them every day. Now I don't have any problem with my drugs. It's quite common for me to take them at university, in taxi or anywhere else."

Putting drugs in a life schedule like praying, positive thinking about the side effects of drugs and setting the time of taking pills with sleeping time were mechanisms that participants used for proper adaptation.

Participants also talked about transplanted liver and adaptation with that by passing of time.

One of the participants expressed the feeling about new liver like rooting a tree and another said that it was a unique experience.

"In the beginning, I could feel the new organ and could say where exactly it is located but now I don't consider it as a foreign organ and it has become mine."

4. Support:

One of the terms, which was extracted from the experiences of liver transplant patients was "support".

These patients said that the support they got from other transplanted patients has been quite pleasant.

"I always say that nobody can feel my status unless she or he has a liver problem. I had a good feeling when I was with other patients and I'd like to continue this relationship."

On the other hand, participants noticed the importance of family support in the recovery phase.

"At home my parents have expectancies exactly like a healthy person whereas I have been transplanted person and I need special care."

Participants had experienced lack of sufficient social support after discharging from hospital such as impossibility of consulting with people who were familiar with transplant matters, lack of existence of nongovernmental organization and lack of support by "Institute of special disease".

"Now kidney transplant recipients have communities and special identification card and even intel-

ligent card but when we confer everywhere, we find nothing."

Participants also talked about drug expenses.

"This is my main problem that my drugs are very expensive and there have been no change in this trend."

5. Gratitude:

Participants of the present study expressed deep sense of gratitude towards those who gave them the new life. Feeling of gratitude about donor and his family was common in participant's stories.

"I pray every night for the person who gave me the liver and I speak with this picture which is in my room."

"I think even the parents of the donor wouldn't remind their son after some years but I always and each moment after thanking god, pray for that person."

Participants praised attempts of transplant team members and expressed their gratitude to them.

"I praise and appreciate attempts of the doctors and the nurses of the transplantation department who cared me lovingly and gave me a new life. I am sure that this love would come back to their lives."

6. Follow up care:

One of the most important perceptions that were extracted from the experiences of participants was "follow up" care.

Participants of the present study experienced different points about inappropriate follow up care including no access to doctors in emergencies, lack of qualified local doctors for decision making about their problems, crowded transplantation clinics, lack of teaching about complication of post liver transplantation and reality of that.

"When a problem strikes, access to doctors is difficult and sometimes impossible. During the time of sickness and when we need to visit a doctor, access to them is very difficult. For example this fall, I had a sever sore throat and because all of the doctors were on vacation I couldn't access any of them and approximately my sickness period took about 20 days."

She continues: *"I feel it has been their main*

goal just to do transplantation but post operation cares are not important for them. For example, I used to take Aspirin and once accidentally one of the doctors was informed and prevented me to use that and it became known that it should have been stopped long time ago."

"When I went from Shiraz to Tehran, I couldn't find the doctor that had been introduced to me."

"In the transplant clinic, the results of the laboratory tests were just read and the doctors only listened, Of course if I express especial problem, they become curious and assessed me but on the whole, they didn't care much."

On the other hand, some of the participants experienced fewer problems because of being in touch with private gastroenterologist.

7. Concerns:

Although having a successful liver transplantation would cause a pleasant living afterwards, but liver transplanted patients and their families are facing with various concerns continuously.

Being worried about return to the previous situation was one of most important concerns of the patients.

"Although I was quite well, sometimes I used to get worried, when something even unimportant was happening, I was afraid of returning to the previous problems. When I caught a cold, I started using herbals and doing everything that I thought would be helpful except using pills."

Also, lack of well acceptance of liver recipients by the society has caused some limitations and problems for these recipients.

"My problem was lack of society acceptance and lack of the belief that I can live like a normal person and be active. Sometimes people had contradicted behaviors towards me. For example I'd like to marry like a normal person but acceptance of me is difficult for others because they consider me like a sick person."

Besides, some female participants were worried about possible pregnancies and parental complications.

"They told me to wait 3-5 years to become pregnant but now 3 years have passed and there is no firm permission for pregnancy. However my main concern is because of Wilson disease, I'm afraid it's hereditary."

Discussion

Seven themes (main categories) were taken out from findings of this research which was shaped the structure of lived experience of liver transplant patients. These themes were as following: Support, Follow Up, Concerns, Gradual Adaptation, Gratitude, Waiting for Transplantation and Transplant Outcomes.

Waiting for transplantation is a stressful and depressing condition. Participants had experienced a terrible condition disturbed their lives. This finding is in accordance with the previous work by Robertson (1999). The participants expressed that physical problems, before transplantation, had paralyzed their normal life.¹¹ In the Jonsen et al study (2000), some perceptions like weakness, pain, suffer and needing time to prepare for transplantation were noticed.¹⁹

Bucuvalas et al (2005) found out poor quality of life of these patients resulted half of them to be reluctant to accept 50% risk of death of the transplantation.⁶

After passing the early post operative phase, participants had celebrated a new life. They were happy and satisfied. Achievement of social rehabilitation in the minimum possible time and improving family relations were other positive outcomes of liver transplantation.

Positive aspects of quality of life after liver transplantation in Bean et al study (2005) included ability to work again, broadened spiritual perspective, restored or improved health and new perspective of enjoying life to the fullest. Although they have experienced some negative aspects like cognitive impairments, fear of organ rejection, financial stressors and drug side effects.²⁰

Present study findings showed that using drugs lifelong was not a significant point in participants' lives and they did not often think about side effects while participants of Lumby et al research (1997) stated that drugs were reminder of transplantation in the whole of their lives and they had little choice for taking them and also called them as limitation of transplantation.²¹

Fear of return to previous condition and organ rejection were concerns of our participants.

Participants of Forsberg et al study (2000) also were aware of rejection episode but the effect of this awareness was different on any of them; some of them considered transplant rejection as betraying Immune system or like an invisible threat that in the worst case was the same as facing the devil and some of them believed that rejection meant the end and facing death.¹³ However a few participants of Bean's research (2005) talked about the stress of living with the knowledge that they may reject their transplanted liver at any time, they stated this was not an overpowering fear but it was present in their mind and a part of their reality now.²⁰

Lack of desirable follow up care was one of the main and important findings of present study. In this direction, Kopp et al (2005) in a study on quality of life of Bone Marrow transplanted patients, emphasized that multidisciplinary care should not be ended after the critical phase of transplant.²²

Participants of our study considered support from other transplanted patients to be influential. This finding is compatible with finding of Wainwright's study (1995). Visiting other transplanted patients as a valuable experience was mentioned by her participants²⁴ while some participants of Robertson's study (1999) preferred not to be in touch with other patients.¹¹

The other significant point is lack of financial support of governmental and nongovernmental institutes for paying expense of Immunosuppressive drugs. Although significant attempts are done by health ministry recently and nowadays approximately this procedure (liver transplant operation) is free but expense of drugs are still remarkable for patients. One of the participants of Bean's study resembled the transplantation expense as hitting a ton of bricks.²⁰ In this direction, Bucuvalas et al (2003) showed that expense of Calcineurin inhibitors for each patient in U.S.A belongs to 3000-10000 \$.²³

Participants of present study experienced individualizing of transplanted liver in different forms however all of them were adapting this well. On the other hand findings of research that was done in Netherland (1990) showed that some participants had problems in accepting of

transplanted liver and they felt that this liver is strange or is an enemy while participants of Wainwright's study didn't have any concern about this.²⁴

Deep appreciation which is seen towards liver donors among participants of present study also is seen in Forsberg et al study (2000). They felt they owed the unknown giver a great deal of gratitude and they mentioned the regaining of life by the death of someone else.¹³ We found that participants are satisfied from living with transplanted liver. They also can play different roles well.

Family, peer and social support has been considered quite essential in recovery phase; nevertheless they mentioned some points related to lack of social support.

Happiness and satisfaction which were results of this new healthy condition, in addition to use adaptive mechanisms, caused them to adapt gradually to new situation.

Feeling of gratitude towards all who helped them to regain their life such as donor and his family and transplant team member was remarkable although they experienced some cases of unpleasant follow up such as crowded clinic, impossible access to doctors in emergencies and incompetent local doctors. Also matters like fear of graft rejection and lack of society acceptance worried them.

Suggestions for applying research findings

One of the responsibilities of community health nursing is to focus on continuous care; therefore it seems that the designing of continuous care

program (planning) according to participants' unmet needs may solve some problems of these recipients. Transplant nurse coordinator can play an important role in continuing care and be like a link between local doctor, transplant team and liver recipients.

Besides, nursing team should play a more active role in patient teaching. It seems that current teaching strategies are not sufficient so besides providing a traditional teaching leaflet, we can follow our instructions by electronic mail.

Attempt to form peer support groups for liver transplant recipients with leadership of trained nurse considered as a good step in direction of better adaptation. Using the mailing list group (list serve) also is a quite remarkable point for transferring information and experiences to them.

Eventually, although government has worked in order to reduce expenses but still expenses of Immunosuppressive drugs and other financial issues are quite a burden for them and their families. Surely joining liver transplanted patients to "Institute of especial disease" can help much in this field.

Since this research is the first of this kind, it would be suggested to perform further studies in the future.

Also, the authors declare that have no conflict of interest in this study and they have surveyed under the research ethics.

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