The real experience of patients after liver transplantation in intensive care unit

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Abstract
We aimed to explore the real experience of patients after liver transplantation in the intensive care unit (ICU).

Objective sampling method was used to select patients transferred to the ICU in 10 hospitals in Zhuhai from May 2018 to August 2020. Patients need liver transplantation due to advanced liver cancer and decompensated cirrhosis. The eligibility criteria of patients mainly included liver transplant patients who were clear-minded and willing to participate in the study and had stayed in ICU. Phenomenological research methods and in-depth interviews were used in this qualitative study.

The results showed that the true experience of patients after liver transplantation during ICU stay was summarized into four themes. The strengths of our qualitative research are that we can find the trend from a phenomenon through interviews and other methods to provide a directional foundation for future quantitative research. Its limitations are that it requires a lot of manpower and time, and its objectivity and universality are limited.

Hospitalization experience in the ICU may lead to many negative experiences for liver transplant patients. Nurses should fully understand and pay attention to the psychological changes in patients. Nurses should take effective targeted measures to reduce or eliminate patients’ fear of ICU stay and promote rehabilitation.

Abbreviation: ICU = intensive care unit.

Keywords: ICU, liver transplantation, psychological process, qualitative research

1. Introduction
The intensive care unit (ICU) is a comprehensive treatment room. Treatment, nursing, and rehabilitation can be performed simultaneously in the ICU. It provides isolation and equipment for patients with severe disease or coma, and provides the best care, comprehensive treatment, with combination of medical care, nursing care, early postoperative rehabilitation, joint nursing, exercise therapy, and other services.

Liver transplantation is the only treatment option for advanced cirrhosis.\(^1,2\) It is important for patients to stay in the ICU for postoperative monitoring for 2 to 3 days after liver transplantation surgery so that their normal vital signs can be observed and maintained.\(^2\) Adverse psychological changes may result in a loss of confidence in the treatment and, thus, slow recovery, further resulting in mental illness.\(^3\) Due to its special environment, the ICU is secluded, with reduced communication between doctors and patients, which causes great difficulties in disease recovery.\(^4\) In the past, most studies only focused on the success of liver transplantation, but only few studies focused on the physical and psychological changes of patients after liver transplantation. Therefore, it is particularly important to pay attention to the physical and psychological changes in patients after liver transplantation, especially the psychological changes. “As a group of nurses managing severely ill or comatose patients, how should we provide humanistic care?” is a question worth considering. We hypothesized that depending on changes in nurses’ humanistic care, patients’ real feelings and the speed of postoperative recovery vary. We explored the psychological experience of patients after liver transplantation in the ICU using phenomenological methods to find out the developing psychological problems of the patients, take targeted nursing measures to improve the basis, and improve the experience of the patients in the ICU.

2. Methods
2.1. Participants
A total of 320 participants were selected with objective sampling method from patients transferred to the ICU after liver transplantation.
transplantation in 10 hospitals in Zhuhai from May 2018 to August 2020. The following were used as inclusion criteria: advanced liver cancer, decompensated cirrhosis, and liver transplantation; being good at expressing ideas in clear language and logically; willingness to participate in this study; at least 2 to 3 days of ICU stay; and being provided with professional nursing service. The following were used as exclusion criteria: severe illness or coma and serious complications or inability to withstand long interview.

2.2. Design and interview

Phenomenological research methods and in-depth interviews were conducted in this single center study. Before the interview, the outline of the semistructured interview was drawn up to the following questions: “How does it feel to be transferred to the ICU after the operation?” “What are your discomfort symptoms after the operation?” “What kind of care did you receive after waking up?” “Was the tracheal intubation removed when you woke up?” “What are your psychosocial needs?” “What are you worried about?” and “What do you think we need to improve about your care?” The order of the questions in the outline was not fixed, and it was adjusted according to the specific situation of the interview.

The interviews were conducted in the ICU and general wards of the Hepatobiliary Surgery department. When the respondent’s condition was stable, the investigator started the interview after obtaining informed consent.

The interview was conducted in a quiet environment for 15 to 20 minutes, with 1 to 2 interviewers assigned per patient. The interview was conducted within the third and the seventh days after the operation, because the patient’s condition would have become stable and they could be interviewed at this time. The interview process was recorded, with the nonverbal materials recorded on the spot. During the interview, subjective opinions of the researchers were avoided so as not to induce the bias. The recorded data were transcribed within 24 hours of the interview.

During the interview, the researcher observed and recorded the daily treatment, nursing, and daily life of the interviewees so as to be able to understand the subtle changes in their psychology and emotions.[8]

2.3. Data analysis

Analysis of data was performed using seven steps of phenomenology with NVivo 12.0 software:[7] careful reading of all interview records; extraction of meaningful information; code recurring and meaningful ideas; pooling of the encoded opinions; writing of a detailed description; identification of similar points of view and sublimation of the theme; and returning to the interviewee for verification. Afterward, the researchers integrated the topics in a certain order and intersperse them according to their own understanding and reflection so that the resulting topics had a certain internal correlation. The same data were analyzed by 2 researchers, and the results were compared to summarize the themes (Fig. 1). The specific data analysis process includes the following aspects: the selection of analysis unit (overall interview); Use key words or phrases (code related to text) to determine the meaning unit and describe it; compress or shorten while retaining the core concept; abstraction, description and explanation at a higher logical level, and the creation of category.

The following approaches were used to improve the reliability and validity of the study:[8] before the formal interview, two ICU patients who met the inclusion criteria were selected for pre-interviews, and the interview outline was adjusted according to the interview effect to ensure that the outline could effectively be used to collect data; during the interview, the researcher avoided the use of inductive language and any intervention, listened wholeheartedly, and fully encouraged the interviewees to actively express their most authentic experiences and ideas around the interview outline; and to ensure the preciseness of data analysis, all the analysis processes were completed by the author and two nurses with rich experience in qualitative research. The theme is extracted by two people together, and the results with different opinions are discussed repeatedly to prevent the bias caused by one person’s thinking. Finally, the extracted topics were returned to the interviewees for verification to ensure the authenticity and precision of the research.

2.4. Ethical consideration

This study was approved by the ethics committee of the Fifth Affiliated Hospital of Sun Yat-Sen University, and the sample size was determined according to the principle of data saturation. All participants signed an informed consent form.

3. Results

3.1. General information

Following the interview of 320 participants, there were certain differences in gender, education level, income, occupation, and whether there was medical insurance. Among the interview
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3.2. Main results

The true experiences of patients after liver transplantation during ICU were summarized into 4 themes: Theme 1, the patient’s inner thoughts when staying in the ICU; Theme 2, discomfort after liver transplantation; Theme 3, longing for communication and care; and Theme 4, ICU treatment/accommodation (Fig. 2). We also summarize the content encoding of these four themes (Table 2).

3.3. Theme 1: The patient’s inner thoughts when staying in the ICU

During the patients’ stay in the ICU, their mood was complex and mainly manifested as optimism, gratitude, fear, loneliness, helplessness, confusion, worry, and other mood states (Fig. 3). Many patients believed that liver transplantation can improve their condition and bring hope for their lives: N: “I got a new life by acquiring a new liver” and N: “liver transplantation can cure my disease and provide a possibility for me to survive.”

Many patients thank their doctors for their treatment and their families for their help: “thanks to the doctor for my operation, treatment, and improvement” and N: “thanks to my family for taking care of me and encouraging me to overcome the disease.”

In the interview process, many patients have a sense of fear because of the lack of knowledge about liver transplantation: N: “I used to think about whether I could come out of the ICU alive,” N: “I used to think of a friend who died shortly after the operation. I wonder if it will be the same for me. I am really scared,” and N: “the doctor said that primary liver cancer is prone to recurrence, and that there are many people who relapse after organ transplantation. I am afraid I will have a relapse.” In addition to worrying about their condition, some patients also had great economic pressure: N: “I need a lot of money for the operation and more money for the later period. I cannot afford it,” N: “I borrowed a lot of money from others as well as my family for the surgery,” and N: “the cost of the operation is too expensive. I cannot afford it myself. I hope the relevant welfare department will support me.”

During the past ICU treatment, patients experienced loneliness and helplessness: N: “I am so miserable inside. I am alone from...
day to night. When my family and friends come, they say a few words and then leave,” N: “It is hard to be alone in the ICU every day. I am looking forward to my family and relatives coming, but they cannot stay for long,” and N: “in the period I spent in the ICU, I felt as if I was spending time in purgatory. I wanted to leave every day.”

3.4. Theme 2: Discomfort after liver transplantation

Pain, memory loss, and postoperative complications are the main symptoms of discomfort after liver transplantation. All patients interviewed denied having suffered a serious illness before. As a result, their tolerance to pain and discomfort is low (Fig. 4): N: “I have never been so miserable” and N: “I am afraid of the pain.” Patients cannot stay awake because of sedatives: N: “I do not know when I had the operation,” and N: “I have always been confused.” In addition, pulmonary infection, biliary obstruction, and other serious complications remain the main problems in liver transplantation patients: N: “I had a prolonged hospital stay because of lung infection and the use of ventilator, which is worse than the operation,” N: “the most uncomfortable thing is that when the lung is infected, sputum suction tube is inserted through the nostrils, which is very uncomfortable (painful facial expression). It is suffocating, just like the pouring of water into the nostrils,” and N: ‘I used to put a T tube because of biliary obstruction, and I carried a drainage bag at the waist, which was very uncomfortable.”

3.5. Theme 3: Longing for communication and care

During the interview, each patient mentioned that they wanted to get the care of the medical staff during the treatment and were eager to communicate with the medical staff about their recovery (Fig. 5): N: “I hope that doctors and nurses can tell me more about my illness to enable me have better understanding of it” and” N: “I know nothing about my illness. I am anxious staying here every day. I hope the doctor and the nurse can tell me about my illness.” In addition, the patients were interested in talking to the paramedics about life: N: “A nurse often praises me for my good skin. I was very happy when I heard it and felt very close to

Table 2
The content encoding of these 4 themes.

| Theme                                           | No. of interviewee | Source                                           | Description                                      |
|-------------------------------------------------|--------------------|--------------------------------------------------|--------------------------------------------------|
| Theme 1: The patient’s inner thoughts when staying in the ICU | 249                | Patient’s feelings                               | Patients’ inner thoughts in ICU                  |
| Theme 2: Discomfort after liver transplantation  | 262                | Patient’s feelings                               | The recovery of patients after liver transplantation |
| Theme 3: Longing for communication and care      | 284                | Patient’s feelings                               | The change of patients’ mental state              |
| Theme 4: ICU treatment/accommodation            | 299                | Patient’s feelings                               | The treatment process and living conditions of patients |

Figure 3. The patient’s inner thoughts when staying in the ICU. When the patients stay in ICU, their mood is complex, mainly manifested as optimism, gratitude, fear, loneliness, helplessness, confusion, worry, and other mood states.
Although I am physically weak, I have a clear mind. I often heard the nurses talking. I am eager for the nurses to also talk with me," and N: “When I was in the ICU, I wanted to ask the nurse about my relatives.”

Most patients tend to play a more important role in their families. They are children, parents, or partners: N: “I have not told my parents that I am in the ICU. After all, they are old, and I do not want them to worry. I think I will consider telling them after leaving the hospital,” N: “I did not think I was afraid of loneliness before, but now I am looking forward to the visit time every day, and I think the visit time is too short,” and N: “Every time my wife comes to visit me, she cries. I am also very sad. I hope my family can give me more encouragement.”

3.6. Theme 4: ICU treatment/accommodation

In a completely unfamiliar environment, most respondents said that they were not comfortable (Fig. 6): N: “During ICU stay, I woke up every morning and opened my eyes to see people I do not know. I felt very sad.” For some patients, especially female patients, the intrusion of their privacy leads to negative emotions: N: “When I was in the ICU, men and women were together, and people I did not know were all around. I felt very insecure.”

All the interviewees said that the decline in self-care ability was the most intolerable in the treatment process at the ICU: N: “I do not like to bother others, but during ICU stay, I had to bother nurses to go to the toilet and have a meal. I felt very embarrassed,” and N: “I am the pillar of my family, I took care of all family affairs. During my ICU stay, I needed a paramedic to wipe my urine.” Some patients were unable to move due to protective restraint measures: N: “I was trapped there. My hands and feet were tied, and I could not move. I felt like a prisoner,” and N: “When it was time, they would turn me over and pat me on the back. At that time, I wanted to change the side I was lying on. They did not let me try. They should have supported me.”

Patients who lose sensation due to sedatives are unable to stay awake: N: “they anesthetized me, and I kept sleeping,” N: “I do not know what medicine they gave me. I fell asleep in a daze,” and N: “my consciousness was very fuzzy. I knew they were moving me, but I felt as if was falling into a deep well, a dark one.”

Figure 4. The main symptoms of discomfort after liver transplantation were pain, memory loss and postoperative complications.

Figure 5. During the interview, each patient mentioned that they wanted to get the care of the medical staff and families during the treatment and were desiring to communicate with the medical staff and families.
4. Discussion

4.1. Key results

In this qualitative research analysis, we explored the true experience of patients after liver transplantation in the ICU. Production of scientific evidence needs to be evaluated, integrated, and reevaluated based on evidence-based nursing. In this study, interview records of the 320 patients were evaluated, understood, analyzed, summarized, and integrated into four themes (Theme 1: the patient’s inner thoughts when staying in the ICU; Theme 2: discomfort after liver transplantation; Theme 3: longing for communication and care; and Theme 4: ICU treatment/accommodation), hoping to further provide ideas of care experience by the patients after liver transplantation. Analyzing the interview records of participants, we found that the psychological performance of liver transplant patients was complex, and that positive and negative psychology existed simultaneously.

4.2. Interpretation

One study indicated that there are feelings of frustration and worry about complications after liver transplantation. A study shows that the negative psychological state of loneliness, depression, anxiety, and anger after liver transplantation is significantly higher than that of general inpatients, and the level of depression is higher than that of the general population. Related studies show that there are psychological symptoms such as worry and depression in patients before transplantation. After the operation, these symptoms can be improved to some extent, but they cannot be restored to the same level as that of other people who did not undergo the operation.

Another randomized clinical control study found that the wound of liver transplantation brought great pain and heavy psychological burden to the patients. A retrospective study of 46 patients with liver transplantation found that biliary obstruction and pulmonary infection were the main factors affecting the quality of life after liver transplantation. In a recent clinical study related to liver transplantation, complications of liver transplantation were found to bring additional pain to patients and affect the indicators of liver transplantation, and thus threaten life. At the same time, the authors point out that the occurrence of complications can easily cause patients to experience negative emotions such as worry and anxiety, increase medical expenses, and increase economic burden.

Patients are eager to receive the attention of, and communicate with, doctors, nurses, and their families in the process of ventilator-assisted therapy. In a clinical study of ICU-hospitalized patients, it was concluded that most of the patients wanted to get information about their condition and were eager to communicate with doctors. In related previous studies, some patients wanted to gossip with nurses. These results are consistent with the results of the present study. In a qualitative study of ICU patients, the results suggest that most patients want to see their families and receive encouragement. This is consistent with the results of the present study.

A related study shows that an unfamiliar and complex ICU environment aggravates the lack of physiological and safety needs of patients. A qualitative study of postoperative patient experience showed that the loss of control of the existing situation would cause these patients to experience negative emotions such as anxiety and fear when facing various stressful experiences.

Human needs are intrinsically complex, and in a specific state after liver transplantation, patients may have multiple psychological needs during hospitalization. The nurse actively listens to the patient’s demands and provides the patient with disease-related information to reduce their anxiety. In the nursing process, we must always put people’s needs first, emphasizing person-to-person communication and contact, rather than the disease itself. Nurses provide care according to individual differences to improve patient comfort. At the same time, more attention should be paid to protecting patients’ privacy.

Family members are considered an important source of support for patients. Nurses actively communicate with patients’ families to promote their support role in the process of rehabilitation and help patients face the disease with a positive attitude. Patients also need support from all sectors of society, in addition to the above. We are grateful to the government for providing support and reducing the economic pressure of transplant patients to ensure continuous treatment in the later stage of the transplantation.
4.3. Limitations

The limitations of this study include its single-center design, which may affect its generalizability. Because the prevalence of liver disease in men is much higher than that in women, most of the liver transplant patients were men, and the 320 patients in this study were only included from 10 hospitals in Zhuhai, so this study may have some limitations in that regard. However, we attempted to provide settings and certain details. The themes that appear in this study may not be unique to the included hospitals. Therefore, local and international readers can interpret the research results under the appropriate environment and background information and replicate them at their research centers. Therefore, this study also requires follow-up large-scale clinical randomized-controlled studies.

4.4. Generalizability

Through the above interview, we summarized the nursing measures for patients after liver transplantation. First is pain care, at ordinary times, nurses should try their best to divert the patients’ attention. Therefore, appropriate analgesics must be chosen. In addition, a more comfortable environment should be arranged. Nurses should also provide more comfort during the patients’ ICU stay. If the condition is serious, they should also choose to stay in bed. If the family can encourage the patient regularly, it will naturally keep the patient in a happy mood. Second is mental care, nurses must establish a good relationship with patients as far as possible to understand and meet all the needs of patients. In the process of psychological counseling, nurses need to address other medical problems of the patients. If they can effectively encourage patients, the patients would naturally be in a good mood for a long time, which can effectively extend the length and quality of life. Third is diet care, although patients may have poor appetite, nurses also need to strengthen diet care as far as possible to choose high vitamin and high protein intake. Fourth is life care, nurses also need to pay special attention to the management of life to determine whether the patient has a secondary infection or the occurrence of upper gastrointestinal bleeding in terms of whether it is accompanied by abnormalities or the patient needs to actively receive treatment.

In summary, this qualitative study analyzed the real feelings of patients in the ICU after liver transplantation and provided suggestions for further improvement of the nursing of patients after liver transplantation in the ICU. It can help medical staff to further understand the psychological state and needs of patients undergoing liver transplantation and provide reference for the training and support of medical staff. The hospitalization experience of the emergency ICU will bring a lot of negative experiences to these liver transplant patients, and nurses should fully understand and pay attention to the psychological changes of patients and take effective targeted measures to reduce or eliminate patients’ fear of ICU stay and promote rehabilitation.

Author contributions

Shi XR and Lian RL are responsible for the abstract and the introduction; Yang XY, Zhong J, Luo WX, and Yao JM are responsible for the methods; Shi XR are responsible for the results; Chen WQ is responsible for the discussion.

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