






The experience of patients undergoing liver transplantation in the transition of care

Vivência do paciente submetido ao transplante hepático na transição do cuidado

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ABSTRACT

Objective: to understand the experience of patients undergoing liver transplantation in the transition of care between hospital and home. **Methods:** study with a qualitative approach, with 20 patients undergoing liver transplantation who were interviewed using a semi-structured script. Content analysis was the selected technique to identify aspects inherent to the transition of care. **Results:** based on the data obtained, four thematic categories were formed: Path marked by feelings and uncertainties; Path of comings and goings to the health network to acquire supplies; Learning path to develop home care and: Itinerary between social idealization and the reality experienced after transplantation. **Conclusion:** difficulties of recipients and family after liver transplantation were perceived, especially in the preparation for the transition of care and in coping and adapting to daily activities.

Descriptors: Nursing Care; Continuity of Patient Care; Transplant Recipients; Liver Transplantation; Transitional Care.

RESUMO

Objetivo: compreender a vivência do paciente submetido ao transplante hepático na transição do cuidado entre o hospital e o domicílio. **Métodos:** estudo com abordagem qualitativa, com 20 pacientes submetidos ao transplante hepático e que foram entrevistados por meio de roteiro semiestruturado. A análise de conteúdo foi a técnica selecionada para identificar aspectos inerentes à transição do cuidado. **Resultados:** com base nos dados obtidos, formaram-se quatro categorias temáticas: Percurso marcado por sentimentos e incertezas; Trajetória de idas e vindas à rede de saúde para adquirir insumos; Percurso de aprendizado para desenvolver cuidados domiciliares e: Itinerário entre idealização social e a realidade vivenciada após o transplante. **Conclusão:** perceberam-se as dificuldades de receptores e família após o transplante hepático, em especial, no preparo para a transição do cuidado e no enfrentamento e adaptação às atividades cotidianas.

Descritores: Cuidados de Enfermagem; Continuidade da Assistência ao Paciente; Transplantados; Transplante de Fígado; Cuidado Transicional.

Introduction

In recent years, studies have been developed with patients undergoing liver transplantation. Many of them to evaluate treatment compliance and quality of life of these patients⁽¹⁻²⁾. These results have scored a low compliance to treatment and, consequently, a worse quality of life due to the risk of opportunistic diseases, frequent readmissions, besides other comorbidities and complications⁽¹⁻²⁾.

Liver transplantation is considered a complex procedure that requires a long waiting time, with peculiarities that contribute to a certain potential for complications, such as: long surgical time, risk of bleeding, anepathic phase, risk of delayed reperfusion of the organ, among other situations. This complexity continues in the immediate and mediate postoperative period, when rejections, bleeding, hydroelectrolytic disorder, acid-base disturbance, hepatic artery thrombosis and graft malfunction may occur⁽³⁾. In addition, there are complications arising from the late postoperative period because of the repercussions of immunosuppressive therapy, such as rejection, risk of infections and development of tumors, due to the immunological alteration necessary for the maintenance of the transplanted patient's life.

The health/illness transition experienced by the patient after transplantation, as a transition from one condition to another, implies changes that affect the quality of life and can be associated with adverse factors after transplantation, such as the return to work, social support, concern with sexuality and body image⁽⁴⁻⁵⁾. It is essential that the multidisciplinary team knows the routine and the reality of the patient after transplantation, considered as determining factors for the success of the therapy, besides providing a dignified, safe and effective care^(4,6). With a central focus on autonomy, self-care, besides strengthening adherence to the proposed treatment, minimizes the occurrence of postoperative complications, favors the link with the institution and generates resolute and humanized care^(4,7).

It is believed that such information about the path taken can support the team in directing strategies and actions that have a direct impact on health promotion, quality of life and graft survival, in addition to ensuring greater support for transplant recipients and family members. Concomitantly, certainly, the data of this study can support the transplant team in the organization of the transition of care, logistics for hospital discharge, communication among the support network, besides proposing greater adjustments in the reference and counter-reference system in the transition of care during hospital discharge.

Given this scenario, the following guiding question was defined: What is the experience of patients undergoing liver transplantation in the transition from hospital care to adaptation to the new reality at home? As an objective, the study aimed at understand the experience of patients undergoing liver transplantation in the transition of care between hospital and home.

Methods

This is a qualitative study based on the theoretical framework of the Theory of Self-Care⁽⁸⁾, developed in a reference hospital in the south of the country, which has been performing liver transplantation procedures since 2011, and annually assists about 80 liver transplant candidates and recipients.

Participants were patients who underwent liver transplantation between January 2011 and June 2019 in a public and federal hospital unit in Santa Catarina. The year 2011 refers to the beginning of transplant activities in this institution, and 2019, to the period of data collection. All liver transplant recipients who underwent the procedure within this period and who underwent outpatient follow-up and post-transplant consultations with the multi-professional team of the same health institution were included. Exclusion: patients under 18 years of age, in addition to patients who did not perform outpatient care at this institution. Considering the study period (2011-2019), there

were 110 patients eligible to participate in the study. However, 20 patients participated in the data collection due to data saturation.

Data collection was performed between July and October 2019 by the researchers themselves. Upon arrival at the outpatient clinic, the patients were invited by the researchers to participate in the research, being informed about the project, the objectives of the study, as well as the risks and benefits. When they agreed to participate in the research, the informed consent form was presented and read with the patient and family present. After signing two copies, a date was scheduled for the development of the semi-structured interview. All participants opted to conduct the interview at the end of the multi-professional team. Some interviews were conducted on the same day, others were scheduled according to the date requested by some participants.

For the interviews, a semi-structured script was used with five questions related to socio-demographic identification data and transplantation, besides, four open questions involving the health needs of the recipient after liver transplantation: Tell me how was for you and your family the home organization to return home after transplantation? Tell me about the difficulties you faced in this trajectory between leaving the hospital and going home? How would you describe the support received by the health network team during the hospital discharge and the return home? How was for you the adaptation to the new reality at home after the transplantation?

All participants were informed that the interviews would be recorded in a PX240 4GB digital voice recorder and, later, these recordings would be transcribed in full, and only after their approval the data analysis would start. The interviews were performed according to the scheduled time, in a reserved space in the transplantation outpatient clinic by two researchers. The average interview time was 20 minutes. Each interview was marked by the letter P (patient), and the participant's name was not identified to ensure privacy.

The development of the data analysis was conducted by means of content analysis⁽⁹⁾, in three stages: pre-analysis, which happens from the floating reading and constitution of the corpus; exploration of the material, which constituted the codification phase of the emerging content of the interviews; and the last stage, the treatment of the results, which enabled the interpretation based on thematic presence, in the participants' statements, and emerging meanings. Four categories emerged from this analysis, entitled: Path marked by feelings and uncertainties; Path of coming and going to the health network to acquire supplies; Learning path to develop home care; and Itinerary between social idealization and the reality experienced after transplantation.

The present study is part of the macro project entitled: Liver transplantation in Santa Catarina: characterization and care management for process improvement, approved by the Research Ethics Committee of the Federal University of Santa Catarina as protocol No. 1,575,457/2016.

Results

Considering the qualitative nature of the study, information related to the sociodemographic and transplant identification data will be presented below, followed by the categories. Twenty patients participated in the research, whose mean age was 55.4 years, of which 75.0% were male, 70.0% were married, 50.0% had completed high school, and 25.0% were retired. Two patients underwent transplantation in 2012, six of them in 2016, four in 2017, four in 2018, and four in 2019. 40.0% of these had liver cirrhosis caused by the hepatitis C virus as an indication for liver transplantation. After the analysis of the information obtained, four categories emerged that represented the path taken by the patient and family in the transition of care between hospital and home after liver transplantation, which will be presented below.

The first category entitled, Journey marked by feelings and uncertainties, brings implicit doubts and

insecurities when returning home after liver transplantation. It expresses feelings of fear, anxiety and stress before the need to absorb, codify and put into practice the information received by the team. The speeches demonstrate the difficulties of understanding the amount of information provided in a short period of time during hospitalization: *On the last day, they came and went through all the orientations, one after the other. It was a lot of things, really a lot of things. I wanted to understand everything, I got nervous. They just handed out papers and papers talked and left (P4). I remember that the pharmacist came and talked about the medications, the schedules, how to store them. Then came the nutritionist, with the care with the food. After that I started to get confused, nervous and stressed. My wife became anxious. After that we started to feel afraid of going home and not being able to handle everything (P6). I was very anxious when they told me about discharge, it was as if I heard, but did not understand, I could not reason, I was very anxious and after that worried about getting home and not being able to handle it. When I got home, I was afraid to do it, because I could not remember much (P16).*

The second category, *Trajectory of comings and goings to the health network to acquire inputs*, represents the situations experienced by the patient and family to get materials and medications needed for the continuity of home care. By the speeches, it is observed flaws in the processes, in the communication, in the integration between the information systems, besides the lack of clarity related to the flow to be followed to acquire such inputs: *To get the medicines, my wife had to ask the doctor to fill out the papers three times, not even he knew what he had to put on the papers. She, poor thing, went three times to the pharmacy-school and there were always missing papers, there were always wrong things (P2). Who did everything for me was my mother, she is elderly, 82 years old. She had to walk a lot, I was in medical exams, I could not get paid, my card would not go. My mother went several times to the bank, and I could not do anything when I was hospitalized. Then she had to go after her medicine and so on. She would not stop (P8). I had many difficulties in getting the follow-up from the municipality's health team (P9).*

The third category, *Learning Path to develop home care*, represents the reality of the patient and family in the need to learn in a short time how to per-

form the care, how to control blood glucose, how to measure blood pressure, temperature, and urine volume control, in addition to the use of medicines and care related to hygiene and nutrition, as well as to identify warning signs of possible complications and complications. The statements make clear the moments of insecurity and apprehension before this learning trajectory and before the recognition of warning signs at home: *At home, we had to turn around and try to remember what was said about controlling diabetes. When it was altered, we did not know what to do. I was very afraid to do this exam in the beginning. I had never done it before (P9). Seven days after discharge I started to have fever, back pain, and each time I got worse. Then I became very tired and short of breath. My wife tried to reassure me, but each time I got worse and worse and had to come to the hospital, it was awfully bad. It was a serious pneumonia, I stayed several days in the intensive care unit, I almost died (P4). I left the hospital with the dressing a little open, I had to take care of it every day, in addition to checking the pressure, diabetes, temperature, take care of the urine. It was a lot of things. You get dizzy. I felt that I needed more time to learn so much (P18).*

The fourth category, *Itinerary between the social idealization and the reality experienced after transplantation*, represents the patient's struggle to adapt to social reintegration after liver transplantation, besides the need for follow-up with the health team at the liver transplant clinic. It is understood that there are many restrictions after liver transplantation, especially regarding contact with other people, return to socialization and work. Many patients reported that they stayed days alone with the caregiver, due to the request made by the team to comply with the measures of greater social isolation, due to the high dose of immunosuppressants and the risk of infections.

Besides these reports, they point out that there are times when the patient returns, in the same week, up to twice to the institution at different times. It is pondered that, so far, in many cases they still feel pain, difficulties to walk, among other limitations. They point out the necessity and the value of synchrony among the team members in the follow-up after transplantation: *I could not travel; I do nothing frequently anymore. In*

the beginning it was difficult because I could not receive visitors. I work all my life on the street and then I spoke to almost nobody. I had to stay straight at home. For me it was very difficult (P7). The first days I stayed directly in a room, well I mean, almost isolated, the room had a bathroom ...I stayed the first fifteen, twenty days at home, only with my wife. Far from the children, from everyone. It was very tiring (P16). It was very restrictive, I could not meet friends, go to a party, to go out I had to be very careful. I tried to go back to work twice, but I had an infection both times (P8). Every month I had a new hope when I went back to the consultations, I thought now yes it will work out. I will be able to go out again, eat what I want and try to go back to work. But there were several months in this hard and painful routine, especially for depending on others financially (P12). One week we went on Tuesday, then they called us to go on Friday, then on the weekend he had a fever, we had to go on Monday again and it had been a week since he had been discharged. Difficult! There are moments that are very tiring. There were times that we did not have a health car and did not even have money to pay for a cab (P16). It is consultation and more consultation, and more exams, and more consultations. Now I am a little better, more tranquil, but it is still a back and forth. I still have many consultations and many exams. Then you do the exam, then you go to show the exam and then another doctor wants to evaluate (P4).

Discussion

Given the experience of the authors, the main limitations of the study are related to the difficulty in developing the interviews with patients who are from other cities and depend on the logistics of transportation of the health network, besides the fear and concern of the patient in reporting facts and situations that may expose the team and thus bring feelings of embarrassment.

Considering the results of sociodemographic identification data and transplantation, it is observed in the literature that the indicators show an average mortality rate in males of 1.75 times higher than that of females, generally due to preventable causes⁽¹⁰⁾. The main cause for indication of liver transplantation was the C virus, which reinforces information from the Mi-

nistry of Health, which points out the notifications of cases of hepatitis⁽¹¹⁾.

Regarding the experience of the patient and family, the findings of the study made it possible to understand that they experience a real pilgrimage between the communication of discharge and the readaptation to their new reality. The trajectory they go through reveals doubts, fears, uncertainties, mismatched information, tiredness and even disrespect for the human being that, despite having undergone a complex procedure, is physically and emotionally shaken. Other studies corroborate these findings, when they point out that the patient submitted to liver transplantation experiences, in the home environment, the need to readapt to a new daily life routine. This routine, due to the complexity of the procedure, involves numerous home care procedures and frequent follow-ups with the health teams, demanding great effort and dedication from the patients and family members involved^(2,7,12-13).

In the first category, the participants pointed out the difficulty to grasp everything they were told since the hospital discharge forecast by the multi-professional team, which led them to fear, insecurity, anxiety, and stress. The team must plan carefully and attentively how each piece of information will be passed on, being prudent to evaluate the level of education, the learning style, the length of hospitalization, the receiver's clinical conditions, and the presence of the caregiver, besides having a careful look at each patient's individuality. Furthermore, it is suggested that the healthcare team provide written material for consultation, as well as videos and other resources that can help the transplanted patient to recall the information given at the time of hospital discharge⁽¹⁴⁾.

Based on these findings, it is understood that the transition of care needs to be discussed and prepared by the multi-professional team, from the moment that the patient can receive information at the hospitalization unit, and not only in the last days before discharge. Studies indicate that patients undergoing

liver transplantation need to be assisted by the multi-professional team to achieve complete functional recovery, aiming at psychosocial reintegration. The team needs to understand that the process should be gradual and that patients, in many cases, feel tired, discouraged and unmotivated with the continuity of treatment at home^(2,7).

Given this reality, in the Orem model, the goal of the health team is to help people identify their needs, requirements and therapeutic potentialities of self-care⁽⁸⁾. Thus, it is understood the importance of inserting the patient, as soon as possible, in the process of developing care. However, it is necessary to evaluate the various factors that involve each patient, such as: level of education, understanding of reality, clinical conditions, and other factors.

Still, it is reiterated the need for the team to strengthen the organization of information, especially through health promotion, which is an effective strategy in this process, since it promotes self-care, routine safety and creates greater freedom according to the patient's reality^(2,7,12,15-16). From the perspective of self-care, Orem points out that the practice of activities favors the improvement and promotes the maturation of people who initiate and develop them within specific spaces of time, whose goals are the preservation of life and personal well-being⁽⁸⁾.

Along with the organization of educational and care activities, the second category reinforces and reiterates how much counter-referral, protocol adjustments, and improvements in communication between the health network, still need evolution. In this perspective, it is prudent that the counter-reference be reinforced and ensured with previous contacts between nurse colleagues from tertiary and primary care. In general, the continuity of care between the tertiary care and primary health care teams is still permeated by weaknesses that impact its effectiveness⁽¹⁷⁾.

The lack of standardization in the transition of care also contributes to the forgetfulness of information and communication failures, which can cause errors and losses in patient care⁽¹⁸⁾. In this sense, the use

of standard operating protocols will be of great value to mitigate difficulties in this process. There are multidisciplinary teams that already use these care tools in the daily care transition⁽¹⁹⁾.

In the care transition scenario, communication should be considered a fundamental strategy, despite being ineffective, given the evidence of divergent information and lack of referrals to counter-referral services in an adequate manner. Authors point out that, even in the face of evidence about the importance of communication for an efficient transition of care, there are few tools available to help improve the health communication process^(1,20).

Considering the importance of communication in the transition of care, it is noteworthy that, in the third category, patients point out difficulties in assimilating and codifying everything that is informed by the team, so that they can implement self-care and identify the warning signs of complications. It is noteworthy that an effective learning requires that the information be given gradually, allowing the codification and retention of the information mentioned by the team, reinforcing the importance of health education. When supported by health education, the patient becomes safe, empowered and supported to adhere to treatment and minimize risks of adverse events, complications and intercurrents^(2,7,12,15).

Many transplant patients do not find the necessary support from the care team, which can lead to lack of commitment to treatment, difficulties with recovery and greater susceptibility to complications^(2,7). Such findings are in line with the fourth category, where patients point out the difficulties in the transition from care to social re-adaptation, in face of the new imposed reality, besides the comings and goings to the outpatient clinic with the healthcare team. This situation may be one of the factors linked to the lack of interest in continuing treatment, leading to low adherence. Considering that the patients' reports expose the dissatisfaction imposed by the restriction to home and by the social isolation, especially in the first months after transplantation.

It is pointed as factors that influence treatment adherence the individual characteristics of the patient, as well as the disease itself, the drug treatment, and the relationship between the patient and the health services⁽¹⁶⁾. Therefore, the care team needs to know the reality of each patient, directing its actions to create and structure the support network, even before the patient is discharged. Such strategies are fundamental and contribute to treatment compliance and the emotional state of the patient^(2,7,12-14).

The reports presented in this study described how challenging it has been to experience the isolation with the caregiver, the unsuccessful attempts to restart the work activities, among others. In this scenario, it is understood as necessary and fundamental that before hospital discharge, a support network of family members, friends, neighbors, and others who can help the patient and the caregiver in this new beginning is created by the team. Authors point out that it is necessary the active receptivity of health professionals, offering a more resolute, humanized and integral health care⁽¹⁹⁾.

The role of nurses in this context is crucial, since it is intricately linked to the process of transition of care, since the individualized nursing care provided in the hospital environment helps in the development of skills for the patient and family to face the changes in the home environment. The fundamental role of nursing professionals aims to develop strategies that seek to promote continuity of care between services, improving counter-referral and promotion of self-care, in addition to emotional support^(2,13).

Certainly, the support developed by these professionals at all levels of health care tends to minimize the dissatisfaction of patients, especially in the continuity of treatment, according to the details of the reports presented, especially in the last category, between the comings and goings in the follow-up with the team. It is important to emphasize that the study shows, in addition to physical and emotional limitations, limitations regarding the logistics of locomotion, since many depend on public health transportation. Such

facts can compromise the continuity of care and lead to complications, complications, rehospitalizations, loss of the graft or even death, especially in the first months after transplantation.

In this sense, the study shows the need for team communication, in addition to the review of operational procedures, with the inclusion of technological tools that can support the continuity of care. The literature demonstrates the usefulness and advantages for teams in the use of technological tools capable of supporting professionals, patients, and families alike. A study reveals the importance of using these tools, especially in the follow-up and support during the postoperative period of liver transplantation⁽¹⁶⁾. It is recommended the use of strategies, instruments and tools that, by standardizing and systematizing the care transition process, make it possible to guide, organize and increase health safety.

Conclusion

The present study sought to understand the path taken by the patient after liver transplantation. Certainly, this objective was achieved, since the data show the different moments experienced by these people between hospital discharge and adaptation to the new reality at home.

Throughout the analysis of the information obtained through the participants, it was possible to realize how difficult and painful this new beginning can be for this clientele, especially regarding the preparation for hospital discharge. Through the participants' experience it was possible to understand the difficulties in assimilating so much information from the health team, in addition to the difficulty in the trajectory in acquiring supplies, caused mainly by communication failures in the health network.

Collaborations

Knhis NS contributed to the conception and design, data analysis and interpretation, writing of

the article, relevant critical review of the intellectual content, and final approval of the version to be published. Wachholz LF, Sens S, Amante LN, and Mendes KDS contributed to the relevant critical review of the intellectual content and final approval of the version to be published.

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