

EXPERIENCE OF PATIENTS UNDERGOING LIVER TRANSPLANTATION DURING THE COVID-19 PANDEMIC

Neide da Silva Knihs¹ 
Rafaela Maria Rosa¹ 
Aline Lima Pestana Magalhães¹ 
Ariadne Matzembacher da Silva¹ 
Sibele Maria Schuantes Paim² 
Ana Paula Valim Agostinho¹ 
João Luís Erbs Pessoa³ 

¹Universidade Federal de Santa Catarina, Departamento de Enfermagem. Florianópolis, Santa Catarina, Brasil.

²Universidade Federal de São Paulo, Escola Paulista de Enfermagem. São Paulo, São Paulo, Brasil.

³Central de Transplantes de São Paulo. São Paulo, São Paulo, Brasil.

ABSTRACT

Objective: to understand the experience of patients undergoing liver transplantation during the COVID-19 pandemic.

Method: exploratory and qualitative research, developed in a reference hospital in liver transplantation, in the city of Florianópolis, Brazil. Participants were liver transplant patients between the years 2011 and 2021. Data collection conducted through a semi-structured script and data analysis performed according to content analysis.

Results: from the participation of 23 patients, two categories of analysis emerged: “Perceptions about social isolation”, with results related to coping and feelings related to social isolation; and “Actions and information: patients, support network and health services”, revealing the meanings of strategies and changes developed in life activities of daily living as well as challenges faced with information and health services during the pandemic period.

Conclusion: the study was able to understand liver transplant patients’ experience in the face of the challenges they face during the pandemic. It allowed to visualize coping strategies, feelings and meanings based on recipients’ perspective. As a contribution, it presents possibilities for achieving improvements in services and attention to weaknesses in health services, providing opportunities for reflections to improve this care and considering the specificities and complexities of the postoperative period of liver transplantation.

DESCRIPTORS: Liver Transplantation. Nursing Care. Delivery of Health Care. Continuity of Patient Care. COVID-19. Health Services Accessibility.

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VIVÊNCIA DO PACIENTE SUBMETIDO AO TRANSPLANTE HEPÁTICO DURANTE A PANDEMIA DA COVID-19

RESUMO

Objetivo: compreender a vivência do paciente submetido ao transplante hepático na pandemia da COVID-19.

Método: pesquisa exploratória, de abordagem qualitativa desenvolvida em hospital de referência em transplante hepático, na cidade de Florianópolis, Brasil; os participantes foram pacientes transplantados hepáticos entre os anos de 2011 e 2021. Coleta de dados conduzida por meio de roteiro semiestruturado e análise dos dados realizada conforme análise de conteúdo.

Resultados: da participação dos 23 pacientes, duas categorias de análise emergiram: “percepções acerca do isolamento social” com resultados relacionados aos enfrentamentos e sentimentos referentes ao isolamento social e “ações e informações: paciente, rede de apoio e serviços de saúde” desvelando os significados das estratégias e mudanças desenvolvidas nas atividades de vida diária bem como os desafios em face das informações e dos serviços de saúde durante o período da pandemia.

Conclusão: o estudo foi capaz de compreender a vivência dos pacientes transplantados hepáticos ante os desafios enfrentados por eles durante a pandemia. Permitiu visualizar estratégias de enfrentamento, sentimentos e significados com base na perspectiva do próprio receptor. Como contribuição, apresenta possibilidades de alcance de melhorias nos serviços e de atenção às fragilidades dos serviços de saúde, oportunizando reflexões para a melhoria desse cuidado, considerando as especificidades e complexidades do pós-operatório do transplante hepático.

DESCRITORES: Transplante de fígado. Cuidados de enfermagem. Atenção à saúde. Continuidade da assistência ao paciente. COVID-19. Acesso aos serviços de saúde.

EXPERIENCIA DEL PATIENTS SOMETIDO A TRASPLANTE HEPÁTICO DURANTE LA PANDEMIA DE COVID-19

RESUMEN

Objetivo: comprender la experiencia de los pacientes sometidos a trasplante hepático en la pandemia de COVID-19.

Método: investigación exploratoria, con abordaje cualitativo, desarrollada en un hospital de referencia para trasplante hepático, en la ciudad de Florianópolis, Brasil. Los participantes fueron pacientes trasplantados de hígado entre los años 2011 y 2021. La recolección de datos se realizó a través de un guión semiestructurado y el análisis de datos se realizó de acuerdo con el análisis de contenido.

Resultados: de la participación de 23 pacientes surgieron dos categorías de análisis: “Percepciones sobre el aislamiento social”, con resultados relacionados al afrontamiento y sentimientos relacionados al aislamiento social; y “Acciones e información: paciente, red de apoyo y servicios de salud”, revelando los significados de las estrategias y cambios desarrollados en las actividades de la vida diaria, así como los desafíos enfrentados con la información y los servicios de salud durante el período de la pandemia.

Conclusión: el estudio logró comprender la experiencia de los pacientes trasplantados de hígado frente a los desafíos que enfrentan durante la pandemia. Permitido visualizar estrategias de afrontamiento, sentimientos y significados basados en la propia perspectiva del receptor. Como aporte, presenta posibilidades para lograr mejoras en los servicios y atención a las debilidades de los servicios de salud, brindando espacios de reflexión para mejorar esa atención, considerando las especificidades y complejidades del postoperatorio del trasplante hepático.

DESCRITORES: Trasplante de Hígado. Atención de Enfermería. Atención a la Salud. Continuidad de la Atención al Paciente. COVID-19. Accesibilidad a los Servicios de Salud.

INTRODUCTION

Patients undergoing liver transplantation aim to improve their quality of life, combined with graft survival. Considering that this is a highly complex procedure due to liver functions, the postoperative period is marked by specific care to minimize the occurrence of hemodynamic instability, risk of rejection, liver failure and opportunistic infections caused by low immunity caused by the use of immunosuppressants¹⁻³.

Carrying out specific care became more challenging in 2020 with the arrival of the pandemic caused by the SARS-CoV-2 virus, which causes COVID-19. The multidisciplinary team had to adjust the care given that transplanted patients were more vulnerable to developing the severe form of the disease⁴⁻⁵.

Some of the factors that increase the risk of these patients are related to the greater susceptibility to virus contamination due to underlying immunosuppression, frequent contact with health professionals and environments, and high prevalence of comorbidities⁶⁻⁷. Furthermore, when SARS-CoV-2 contamination occurs in transplanted patients, the primary outcome may be death, and the secondary outcomes are serious illness with prolonged hospitalization⁷⁻⁸. However, even in the face of this reality, it was necessary to continue carrying out transplants, which are the only therapeutic alternative for patients with liver failure¹. As a way to manage the health crisis, health authorities have recommended that liver transplants be performed only in situations where patients are in serious clinical condition^{5,9}. Even so, the team was concerned about the exposure of this patient to contamination by donors as well as by the other team that provides care during this procedure^{5,10-11}.

Thus, all care processes involving donation and transplantation needed to be reviewed and adapted considering the reality imposed by the pandemic. The risk of contamination is present in all stages of the donation-transplantation process, and not only in hospital environments. Continuity of this care at home was largely impacted, challenges arose related to internal family organization with financial impacts and permanence of many people at home. This generated questions, insecurity and anguish in these patients, family and teams about the maintenance and quality of post-transplant home care¹².

In addition to the aforementioned challenges, the COVID-19 pandemic's reality highlighted the problem of misinformation. The quality of health information and even "fake news" presented themselves as problems for home care management as well as emotional factors and social isolation, which led to serious psychological problems in chronic patients¹³⁻¹⁴.

It is also worth mentioning that another confrontation experienced by these patients was related to the logistical aspects of some health services due to limited hours, difficult access and other changes that impacted the population's daily life¹⁴⁻¹⁵.

Faced with this context, patients and family members sought coping strategies. Studies developed with a sample of this population described some of these strategies, such as social isolation, family reorganization, use of preventive measures such as alcohol gel and mask. These strategies are in line with those advocated as a way to prevent disease contamination in the general population^{12,16-17}.

Considering the specificities and the degree of complexity related to the profile of patients who undergo liver transplantation, it is necessary to deepen the knowledge of how these individuals face the necessary changes during the pandemic, whose purpose is to optimize specialized care for this population based on the experience of the phenomenon by the patients themselves.

Therefore, the guiding question of this study was identified: what is the experience of patients undergoing liver transplantation during the COVID-19 pandemic? The objective was to understand the experience of patients undergoing liver transplantation during the COVID-19 pandemic.

METHOD

This is exploratory and qualitative, cross-sectional, theoretical and empirical research, with a time frame, which followed the COnsolidated criteria for REporting Qualitative research (COREQ) recommendations¹⁸.

The study was developed at a public health institution located southern Brazil, which only assists users Brazilian Health System (SUS – *Sistema Único de Saúde*) users, a reference for liver transplantation in the region. The choice of institution was justified by the scope of care for patients undergoing transplantation, in addition to the fact that it is a teaching hospital.

Patients over 18 years of age who underwent liver transplantation between December 2011 and June 2021 were included. The cut is related to the year in which transplants began at the institution, considering the time of the pandemic the focus of this study. Patients who underwent transplantation in other institutions and only follow outpatient care at the research site were excluded.

Patients were recruited from the transplant clinic. Upon arrival, for routine post-transplant follow-up consultations, the invitation to participate in the research was made, at which time the objective, risks and benefits were explained in detail. Upon acceptance to participate, two copies of the Informed Consent Form (ICF) were signed. Then, the interview was scheduled according to participants' availability. The place of data collection was one of the rooms of the institution's transplant clinic.

Data collection was carried out through semi-structured interviews, guided by a script composed of the following profile variables: initials of patient's name; gender; age; color (determined by the classification used by the Brazilian Institute of Geography and Statistics (IBGE – *Instituto Brasileiro de Geografia e Estatística*)); marital status; religion; transplant date; transplant indication; classification on the Model for End-Stage Liver Disease (MELD) scale; and presence or absence of a support network. Other questions related to the profile were included, especially in relation to contact with COVID-19, namely: has any family member in your household been infected with COVID-19? Did you perform vaccines against COVID-19?

As for the questions that explored the path that led to the objective of this study, the following stand out: what were the strategies/care you developed at home to prevent SARS-CoV-2 infection? Could you describe the challenges you faced in the process of hospital discharge, arrival at home and adaptation to a new reality due to the COVID-19 pandemic? What guidelines and precautions were taken to support you during the COVID-19 pandemic scenario?

The interviews were conducted by the researchers themselves in a reserved space with an average duration of twenty-five minutes. Initially, participants were informed again about audio recordings. Then, the interviews were transcribed with subsequent validation by patients who had their identity preserved. Identification was established using the letter P (Patients), following the order of interviews P1, P2, P3, and so on. Data collection was terminated as soon as data saturation occurred.

For data analysis, the content analysis framework was used. The choice for this method of data analysis is related to the potential of each of the steps to provide an understanding and at the same time evaluative look in the sense of giving meaning to the information obtained. Initially, transcripts were organized into tables, in order to allow pre-analysis. Readings and systematization of information and initial ideas were carried out, allowing the elaboration of first impressions about the addressed content. Subsequently, data exploration was carried out, in which the interviews' emerging contents were coded. Finally, for the treatment and interpretation of results, an analysis was carried out based on the thematic presence of participants' enunciations¹⁹.

The research followed all ethical precepts, as established by Resolution 466 of 2012 of the Brazilian National Health Council, Ministry of Health, which regulates research involving human beings, providing guidelines and regulatory standards for carrying out.

RESULTS

A total of 23 patients with a mean age of 62 years participated in the study. Overall, 14 (61%) were men, 18 (78.3%) self-declared white, 11 (47.8%) were Catholic and 9 (39.1%) were married. The mean MELD score of research participants obtained was 20. As for the support network, 21 (91.3%) described that their family members made up this network for continuity of home care.

Regarding contamination with the SARS-CoV-2 virus, 16 (69.5%) reported not having been contaminated as well as any family member who lives in the same house. As for the vaccine, 16 (69.5%) received three to four doses.

The data obtained from the interviews were analyzed and categorized. Two categories emerged: "Perceptions about social isolation"; and "Actions and information: patients, support network and health services".

Perceptions about social isolation

This category represents the experience of patients in the postoperative period of liver transplantation based on the need for isolation. In the interviews, it was possible to see that patients recognized the need for social isolation as an effective way to avoid contamination by the virus and disease development. However, experiences were revealed that included dependence to perform basic activities of daily living, such as going to the market and picking up medication at the health unit.

Feelings such as fragility and grief at the imposition of separation from family and friends emerged in this category, in addition to insecurity, sadness and frustration at being confined and isolated. Still, feelings arose in relation to the fact that they were missing important moments in the lives of their family members.

Figure 1 demonstrates the logic for determining the category and the consequences of analysis based on the interviews.

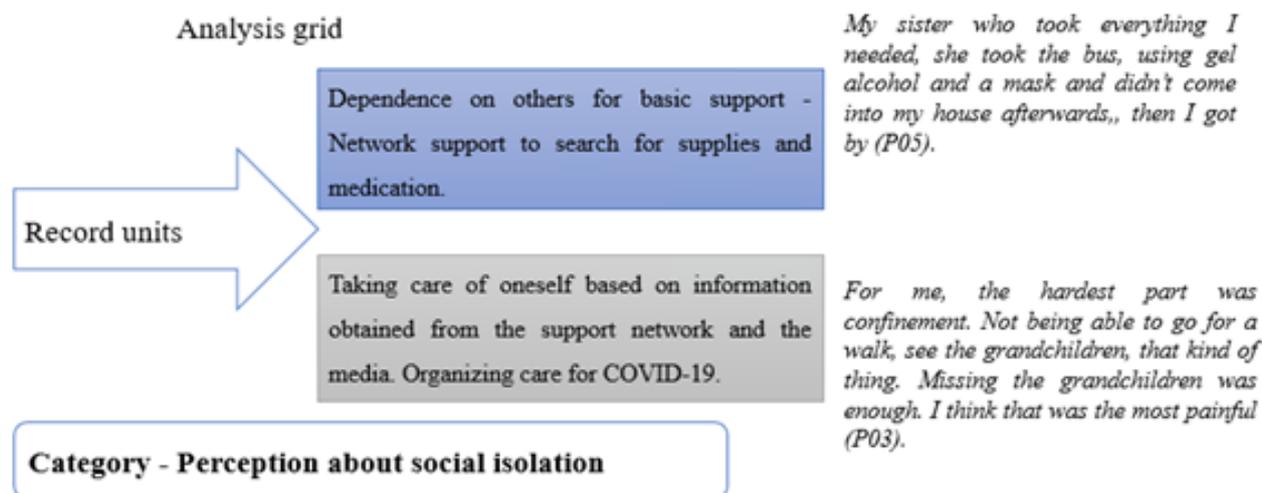


Figure 1 – Representation of the first category analysis grid – perceptions about social isolation.

Other speeches are presented below:

[...] *My sister helped me, she was the one who picked up the medications and materials for me, she always collected them during this period. Now that this greater risk of contamination has passed, I am starting to remove it. In these pandemic years, it has always been her (P15).*

[...] *I have a sister who took everything we needed (food, medication, everything). She left it at the door of the house. She didn't go in. Then, when she left, I took it. When she left things, she had already rubbed alcohol on everything and washed the fruit. (P19).*

[...] I went away; I have a place and it was just me and my wife. I felt a little frustrated, being further away from the family, I didn't want them to visit me too, just by phone. (P22).

[...] The most challenging thing was the lack of contact with people, because I couldn't get in touch with just anyone, I avoided contact precisely because of this and even more so because of being transplanted. I missed going out, being with other people (P07).

[...] Look, most of the time during the pandemic I went to the place, me, my brother and my sister-in-law and it was just us there. There were no visitors, no one else was coming. It was total isolation. I stayed away from all my family (P12).

[...] In fact, that's how we didn't go out. Nothing, I stayed a year that I only came to the consultations, to take the exam. I spent a year without going to the market, without actually leaving home. Ah, I almost went crazy, right, but we have to take care of ourselves (P03).

[...] My daughter used to do it, she would go, do it at the market, do the shopping, then she would arrive and leave it like this at a back door that we have, then she would leave the purchases there (P16).

Actions and information: patients, support network and health services

In this category, descriptions of prevention actions adopted by patients and their families, access to information and health service organization perceived by transplanted patients emerged.

The identified prevention actions reinforced the recommendations already known and described in this study, such as the use of a mask and gel alcohol, in addition to greater attention to the hygiene of products and clothing. However, weaknesses were revealed that impacted these patients' experience, especially in relation to information security and health teams' attention. It was seen that recipients of liver transplants did not feel secure about home care, due to the lack of standardization of information disseminated by multidisciplinary team members.

Another aspect experienced by transplanted patients was health service reorganization. It was possible to identify in the interviews that patients perceived and were impacted by the change in the way of procedures and health care. Still, from the teams' perspective, speeches point to team reorganization regarding continuity of consultations and examinations. They report that there was concern to ensure the rescheduling of returns and exams only when there was a need to assess a certain clinical situation in patients.

Regarding the second category, "Actions and information: patients, support network and health services", Figure 2 presents the logic of analysis and obtaining interpretations based on the interviews' content.

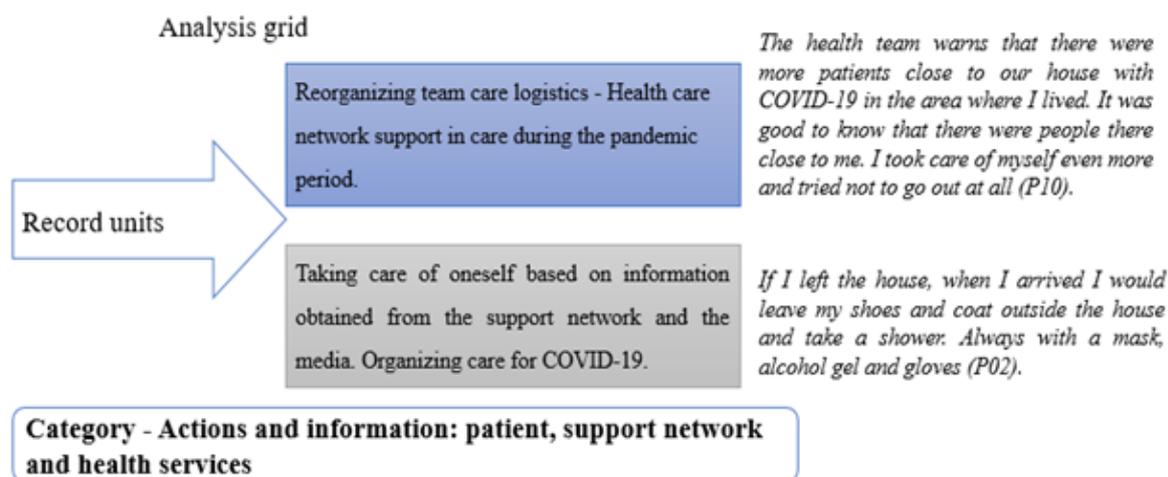


Figure 2 – Representation of the second category analysis grid – actions and information: patients, support network and health services.

However, in relation to the primary care team, they report a series of neglect regarding continuity of care. The speeches show the difficulty of facing the moment, enhanced by changes in health environments and the absence or difficulty in obtaining reliable information.

[...] There at the health center, they only gave us the medication. They were more distant. I just went to the health center with care, wearing a normal mask, I got home and changed clothes, took a shower. From them, I didn't get much help or guidance (P04).

[...] All the teams I deal with took care to reduce the number of consultations necessary, due to the pandemic, so as not to expose myself. It was totally different, I went in using gel alcohol, I use the mask I still have today, the distancing too. I didn't feel safe because there were people around, you ran the risk of catching the virus, calmer because of the care they took (P17).

[...] The only thing they told me, that was the doctor, is that we should stay without physical contact, that is, try to stay away from other people as much as possible. This is what I got from guidance (P05).

[...] We always use alcohol gel and mask and even frequent hygiene in the places of the house. We always cleaned everything. Even for those who worked at home, we maintained care. My daughter worked and studied from home. Who could do like this did it. My stepdaughter changed her job and had to go out every day (she went to the course and worked). She got COVID-19. Then she was isolated in a room for a while, away from the others. Even so, we all got the disease. It was very stressful (P13).

[...] We always used alcohol, and whenever someone arrived from the street, they always went to the bathroom. So, everything I was told to do I did. I learned a lot on the internet. At the time of COVID-19, I lived with my sister, grandson and daughter. I didn't let my grandson go out much because I was afraid he might get contaminated. I tried to take all possible care that I saw and was told to do. Here, no one got the disease. (P23).

[...] I am no longer a person like any other, my immunity is low, so I have to control myself, take care of myself more than a normal person. I always thought that I had to do my best not to get this disease. (P11).

[...] At home, whenever everyone went out, they had to be wearing a mask and passing alcohol. And when I got home, we usually took off those clothes and put them in the wash, until today, I still do that, it kind of makes us neurotic. My son-in-law always used to wipe the house with bleach (P07).

DISCUSSION

The profile data of study participants allow contextualizing the information revealed in relation to these patients' experience. However, one of the important data to be discussed is in relation to vaccination. The majority (69.5%) of respondents claimed to have the complete vaccination system. It should be noted that vaccination is currently the most effective way to prevent severe forms of COVID-19, especially for populations at risk, such as transplant patients undergoing immunosuppression. Vaccination coverage rates must be maintained and extended in order to guarantee the survival of these patients.

From this study, it was possible to reflect on the impacts caused in the lives of patients undergoing liver transplantation based on their experiences in the context of the pandemic. Understanding the experiences and challenges from this perspective allows for better and more effective strategies to be developed in the care of this population, especially in crisis scenarios.

The first category presented liver transplant recipients' experience regarding social isolation. Isolation was considered an effective strategy to prevent COVID-19 before the development of vaccines. Therefore, a series of changes and adaptations were necessary in how the population lives. The postoperative period of transplants, in general, and more especially liver transplantation,

naturally demands that behaviors, habits and lifestyle be transformed. This results in a search for better conditions that guarantee greater graft and patient survival. With the pandemic, these changes were more severe and in a shorter time, in order to avoid the mortality caused by the infection^{7-8,20-21}.

In this regard, what the study data show in relation to the subject is the experience and perception of transplanted patients in the face of an urgent need for confinement due to the global health crisis and added to the feelings perceived by them. Since transplanted patients attend health environments, either for outpatient follow-up, or for examinations, and also to withdraw medications for continuous use. Therefore, social isolation aroused a greater sense of dependence on family, friends and even neighbors.

Studies involving the population, in general, during the period of social isolation, show that there was a higher incidence of diseases such as anxiety, depression and conditions of emotional fragility derived from insecurity, uncertainty and constant feelings of sadness and loneliness. Moreover, maintaining this state of mental health can potentiate the development of sleep and stress problems that, over time, can generate or aggravate immunological disorders or other comorbidities²²⁻²⁵.

By understanding the reality experienced by these patients after liver transplantation, the need to develop support strategies capable of reaching this population is seen. Not only care is offered in relation to the postoperative demand, but also mechanisms for resolving doubts and insecurities regarding care in general, which is reflected in the second category presented by the study.

In the second category, participants point out weaknesses in the health system, especially regarding standardization of language and information about care, and also change in service flows. These changes were inevitable, since, in addition to services' common demands, it was necessary to meet the high demand for patient care due to COVID-19²⁶⁻²⁷.

It was necessary to quickly rethink how to maintain care and protect high-risk patients, as in the case of transplant recipients, which had an even greater impact on maintaining their isolation. This sequence of events during the pandemic generated insecurity in accessing information. Patients suffered from the lack of information from reliable sources, becoming susceptible to "fake news". It is noteworthy that misinformation was a problem that aggravated coping with the global crisis, delaying the development of more appropriate conduct, confusing patients, family members and the general population and generating more feelings related to insecurity and fear²⁸.

Considering other studies carried out in countries that created effective strategies to work with these patients, methods of virtual care in real time, availability and creation of mobile applications to facilitate assistance and supply of medications at home stand out. Also, the provision of online consultations and services via telephone call and e-mail with prioritization of care for more recent transplanted patients were considered as strategies²⁹⁻³⁰.

CONCLUSION

In this study, the experience of patients undergoing transplantation during the COVID-19 pandemic was revealed. Thus, it was possible to understand the diversity of feelings pointed out by them, involving fear, insecurity, anguish, especially the concern with contamination. Allied to this, a feeling of sadness and frustration was manifested for being confined and isolated, imposed on the distancing from family and friends.

Furthermore, the study reveals that patients sought to follow all the guidelines proposed by a multidisciplinary transplant team, in order to minimize the risk of contamination by SARS-CoV-2. However, it is worth noting that they point out the neglect, difficulties in contact, support and assistance provided by the primary care network when transitioning between hospital and home care during this pandemic period.

Thus, it is understood that the results of this research point to the need for strategies aimed at strengthening care for the transplanted population, considering the specificities and complexities of the postoperative period of liver transplantation. Whether during periods of crisis or not, there is an opportunity to rethink the logistics of care provided by health services, in order to guarantee care and reception with greater quality and security of information.

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NOTES

ORIGIN OF THE ARTICLE

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CONTRIBUTION OF AUTHORITY

Study design: Knihs NS, Rosa RM.

Data collection: Knihs NS, Rosa RM, Silva AM.

Data analysis and interpretation: Knihs NS, Rosa RM, Magalhães ALP.

Discussion of results: Knihs NS, Silva AM, Pessoa JLE, Agostinho APV, Paim SMS.

Writing and/or critical review of content: Knihs NS, Silva AM, Paim SMS, Rosa RM.

Review and final approval of the final version: Knihs NS, Magalhães ALP.

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There is no conflict of interest.

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CORRESPONDING AUTHOR

Neide da Silva Knihs

neide.knihs@ufsc.br

