Liver recipient care transition: educational game content

Transição do cuidado do receptor de fígado: conteúdo para jogo educativo

Transición del cuidado al receptor de hígado: contenido de un juego educativo

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ABSTRACT: Objective: To explore, through the recipients' experiences, which information about postoperative care is perceived as crucial to include in an educational game aimed at strengthening home care. **Method:** A qualitative, descriptive, and exploratory study with an interpretative paradigm. Anchored in Dorothea Orem's self-care theory and conducted at a liver transplant reference hospital located in Southern Brazil, including patients who underwent liver transplants between 2019 and 2021. The information was gathered through a semi-structured interview guide containing two open-ended questions. The data were transcribed and submitted to Bardin's content analysis process. **Results:** Twelve recipients participated in the study. The indication for the transplant was related to the hepatitis C virus in four cases. The mean time on the waiting list was two months, and the average Model for End-Stage Liver Disease (MELD) score was 14.75. The results were organized into three categories: weaknesses in home care related to blood glucose monitoring, insecurity in the use of insulin therapy at home after the transplant, and difficulties accessing and using immunosuppressants. **Conclusion:** The main information suggested for the game are focused on the use of the glucose monitor, insulin, and medications. The data collected in the study provided information for developing the content of an educational game.

Keywords: Transitional care. Education in nursing. Health education. Educational technology. Liver transplant.

RESUMO: Objetivo: Explorar, por meio das experiências dos receptores, quais informações sobre cuidados no pós-operatório são percebidas como cruciais para serem incluídas em um jogo educativo, com o intuito de fortalecer os cuidados domiciliares. **Método:** Estudo qualitativo, descritivo e exploratório, com paradigma interpretativo. Ancorado na teoria do autocuidado de Dorothea Orem e realizado em hospital referência no transplante hepático, localizado no Sul do Brasil, com pacientes submetidos a transplante hepático entre 2019 e 2021. O levantamento das informações foi obtido por roteiro semiestruturado, contendo duas questões abertas. As informações foram transcritas e submetidas às etapas da análise de conteúdo de Bardin. **Resultados:** Participaram do estudo 12 receptores. A indicação do transplante estava relacionada ao vírus C em quatro casos. O tempo médio em lista foi de dois meses e o valor médio do *Model for End-stage Liver Disease* de 14,75. Os resultados foram organizados em três categorias: fragilidades nos cuidados domiciliares com a monitorização da glicemia, insegurança no uso da insulinoterapia no domicílio pós-transplante e dificuldades no acesso e no uso de imunossupressores. **Conclusão:** As principais necessidades de informações sugeridas para o jogo estão direcionadas ao uso do aparelho de glicemia, de insulina e dos medicamentos. Os dados coletados no estudo forneceram informações para desenvolver o conteúdo de um jogo educacional.

Palavras-chave: Cuidado transicional. Educação em enfermagem. Educação em saúde. Tecnologia educacional. Transplante de fígado.

RESUMEN: Objetivo: Explorar, a través de las experiencias de los receptores, qué información sobre los cuidados postoperatorios se percibe como crucial para ser incluida en un juego educativo, con el objetivo de fortalecer los cuidados en el hogar. **Método:** Estudio cualitativo, descriptivo y exploratorio, con un paradigma interpretativo. Anclado en la teoría del autocuidado de Dorothea Orem y realizado en un hospital de referencia en trasplante de hígado,

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ubicado en el sur de Brasil, con pacientes sometidos a trasplante de hígado entre 2019 y 2021. La información fue recolectada mediante un guión semiestructurado, con dos preguntas abiertas. La información fue transcrita y sometida a las etapas de análisis de contenido de Bardin. **Resultados:** Participaron en el estudio 12 destinatarios. La indicación par el trasplante estuvo relacionada con el virus C en cuatro casos. El tiempo promedio en la lista fue de dos meses, y el valor promedio del Modelo para la enfermedad hepática terminal fue de 14,75. Los resultados se organizaron en tres categorías: debilidades en la atención domiciliaria con el control de la glucemia, inseguridad en el uso de la terapia con insulina en el hogar después del trasplante y dificultades para acceder y utilizar inmunosupresores. **Conclusión:** Las principales necesidades de información sugeridas para el juego se centran en el uso del glucómetro, la insulina y los medicamentos. Los datos recopilados en el estudio proporcionaron información para desarrollar el contenido de un juego educativo.
Palabras clave: Cuidado de transición. Educación en enfermería. Educación en salud. Tecnología educacional. Trasplante de hígado.

INTRODUCTION

Liver transplantation (LT) is a complex surgical procedure that has shown continuous progress, especially regarding the use of new medications, equipment, and surgical techniques. Therefore, it is necessary to develop therapies using technologies and advancements to promote the quality of life of liver recipients and increase graft survival[1].

LT requires commitment and dedication from the multidisciplinary team, recipients, caregivers, and family members, who play a fundamental role in managing care and addressing the challenges posed by this new reality. After the procedure, home care is primarily carried out by the recipient and their support network, consisting of caregivers and family members. Therefore, it is necessary to integrate the support network into the health education of the recipient, ensuring that care is provided adequately and contributing to the maintenance of quality of life[2].

The transition of care, between hospital discharge and returning home, occurs amidst uncertainties and different types of care, representing a decisive moment in the recipient's life. The pre-transplant and immediate post-transplant phases are opportunities to adjust care to the new routine, during which recommendations are frequently communicated.

Some hospital care, previously performed by healthcare professionals, is now carried out by the family, caregivers, and the recipient at home, highlighting the need for support and assistance during this time[3].

The adult recipient undergoing a liver transplant experiences a new routine filled with care that involves the use of medications, including: immunosuppressants, monitoring of vital signs (blood pressure and temperature), blood glucose monitoring, insulin administration, measuring urine output, personal and environmental hygiene, restrictions on care related to infections, among other activities and responsibilities[4,5].

In this scenario, it is important that the recipient and those involved in their care be aware and trained to identify signs of complications and issues, such as diarrhea or constipation, anxiety, neurological variations (decreased level of consciousness, headache), emotional, respiratory, pulmonary, and hormonal changes, hypertension, hyperglycemia, rejections, and opportunistic infections. When complications and issues are identified early and treated in a timely manner, the risks of graft loss and death are reduced[4,6].

It is therefore necessary to develop strategies that provide security to liver transplant recipients and their support network in order to promote care management and self-care, considering the intense flow of information and details related to the specificities of the transplant modality.

Educational games emerge as a health educational technology to support self-management of home care, providing individuals with information for decision-making, promoting health education and quality of life, streamlining communication, and using accessible language[7].

Serious games are experiential learning activities with established and precise rules, defined objectives, multiple stages of activities, and challenges. The player, through their knowledge and skills, makes attempts to achieve the objectives of each stage. By stimulating factors as analysis, synthesis, and evaluation, educational games allow the learning process to be fun and engaging, reducing stress factors[8].

Thus, it is understood that such tools can support the multidisciplinary team in the health education of liver transplant recipients and their support network. Furthermore, for the nursing professional who works on the front lines of nursing education with recipients from the time they are placed on the transplant list, this educational technology can become a supportive strategy for the continuity of care in the home environment[9,10]. The use of this resource is aimed at health education, with an emphasis on information about symptoms

and treatment. Its benefits were measured in the improvement of self-care and adherence to treatment[11].

The contribution of this study is focused on addressing the real needs of liver transplant recipients and their support network regarding home care, so that they feel more confident in resolving doubts upon returning home. Therefore, the guiding question of the present study was, "What information about postoperative care is important to be included in the content of the educational game to strengthen home care?"

OBJECTIVE

To explore, through the recipients' experiences, which information about postoperative care is perceived as crucial to include in an educational game aimed at strengthening home care.

METHOD

Qualitative, descriptive, and exploratory research with an interpretive paradigm, characterized by a focus on the subjective experience and the context in which the participant was situated. Moreover, it is grounded in Dorothea Orem's self-care theory, considering the focus on the recipient's ability to efficiently perform home care with the support of the team during the transition of care[12,13]. Conducted from February to July 2022 at a large hospital located in the Southern Region of Brazil, a public institution that serves as a reference for liver transplantation and exclusively operates through the Brazilian public health system – Unified Health System (SUS).

Regarding the recipients' doubts during the care transition process, the study aimed to identify the main difficulties reported, even after follow-up and intervention by the support team, which consisted of faculty and scholarship students from the project titled 'Planning the hospital discharge of patients undergoing liver transplantation: the transition of care between hospital and home.

In two previous studies, other health needs and difficulties were identified[2,5]. The relationship between participants and researchers was established during the care transition process, with follow-up after liver transplantation and during the planning of hospital discharge. After discharge, the project monitored the recipients and their support network for up to three months at home.

Regarding the participants' home routine, temperature was checked twice a day (morning and evening); blood glucose was monitored three times (upon waking and 30 minutes before lunch and dinner); urine output was monitored over 24 hours; weight was measured once a day (in the morning); and blood pressure was taken twice (morning and evening). Insulin therapy depended on each individual case. As for immunosuppressive medications, they were obtained from the specialized drugstore in the municipality.

The teaching conducted by the project takes place in the period leading to hospital discharge, on alternate days, to provide the recipient with an understanding of home-care. Additionally, the support team creates a group using a digital messaging application (WhatsApp®) to monitor and assist the recipient with any questions they may have while at home.

The participants were adult recipients who underwent liver transplantation at the specified hospital between 2019 and 2021. The study was conducted during the pandemic, as various teaching strategies needed to be adapted to provide accessible and safe health education for the chosen population profile.

Recipients who only received outpatient care at this institution and had not undergone transplantation at this service were excluded. It is noteworthy that during the predetermined period, 19 transplants were performed, of which 12 recipients participated in the research. Due to factors as voluntary acceptance, availability for participation, and outpatient follow-up at other institutions, seven recipients were excluded from the sample.

The participants were selected by convenience. The first contact with the recipients for data collection was made through the transplant outpatient clinic, through the nurse. This process allowed for the identification of the participants responsible for post-transplant follow-up in the outpatient clinic. Initially, the objectives of the research were explained to the recipients. Those who wished to participate were provided with two copies of the Informed Consent Form (ICF) to sign; one copy was kept by the participant, and the other was returned to the researcher.

Shortly after, the interview was scheduled according to the participants' availability. The interview took place in a room at the outpatient clinic, following a semi-structured script that included demographic data of the participants and two open-ended questions related to the study topic: Could you tell us what you think you needed to learn or what you learned during your hospitalization about your home care,

but when you got home, you had questions and felt you needed to strengthen that information?" and "What were the main questions that arose at home?"

The interviews were recorded using a voice recorder, each lasting an average of 15 minutes. They were conducted and transcribed by the main researcher. Subsequently, the interviews were transcribed in full and reviewed for spelling without altering meanings. Data validation was carried out by sending the transcription to the participants, allowing each one to check and review the information provided during the interviews. Data collection concluded upon reaching data saturation.

The analysis and interpretation of the data were carried out through content analysis[14], divided into three phases: pre-analysis, involving reading the material, organizing, and systematizing the information and initial ideas, allowing for the development of preliminary impressions regarding the content addressed; data exploration, in which the emerging content from the interviews was coded; and treatment and interpretation of results, through analysis based on the thematic presence of the respondents' statements. As for the data, they were explored through the definition of categories, which were identified and organized logically to reflect the data structure and enable an in-depth analysis of emerging patterns. These categories emerged based on the frequency and relevance of themes identified in the interviews.

The research complied with Resolution No. 466/2012 of the Brazilian National Health Council, an agency of the Ministry of Health, and was approved by the Research Ethics Committee under the Certificate of Presentation for Ethical Consideration No. 5 4900716.8.0000.0121 and Opinion No. 1.575.457. To ensure confidentiality and anonymity of the participants, they were identified by the letter 'P' followed by a number corresponding to their order of inclusion in the study, such as P1, P2… and P12.

RESULTS

Twelve recipients participated in the study, ten of whom were males and two females, with mean age of 58 years. The indication for transplantation was related to hepatitis C virus in four cases (33.3%), followed by two cases (16.7%) due to alcohol-induced cirrhosis and hepatocellular carcinoma, two (16.7%) due to cryptogenic cirrhosis, and four (33.3%) due to other pathologies. The average time waiting for a transplant was two months, with a mean Model for End-stage Liver Disease (MELD) score of 14.75.

The focus of this study was to identify the difficulties that persist even after the follow-up and support provided by the support team. Thus, based on the information obtained from the interviews, three categories emerged: weaknesses in home care with blood glucose monitoring, insecurity in using insulin therapy at home post-transplant, and difficulties accessing and using immunosuppressive medications.

1st category: weaknesses in home care with blood glucose monitoring

In this category, the recipients' doubts and difficulties with blood glucose monitoring emerged. The most frequent topics were handling the blood glucose meter, understanding results and actions to take in case of glucose changes, pre-established times to monitor their levels, and steps of the procedure. The statements below illustrate some of these doubts:

> […] the main doubt regarded blood glucose level control, as we were completely unfamiliar with this type of fluctuation. We didn't know what to do when it was altered. (P10)
>
> […] The blood glucose meter didn't work, so we were also unsure about how to use it. We got home, and it wouldn't turn on. (P5)

The difficulties presented regarding the operation of the device and blood glucose control directly impacted the effective management of blood glucose levels. The challenges in correctly operating the device may have represented a failure to understand how to use the blood glucose meter and interpret the results, along with uncertainty about the appropriate actions to take in response to an unusual result, which relates to a lack of knowledge about what actions to take in the event of hyperglycemia or hypoglycemia.

2nd category: insecurity in the use of insulin therapy at home after transplantation

In the interviews with the participants, numerous factors of difficulty regarding insulin therapy were identified. Doubts and fears emerged concerning syringe handling, storage, necessary dosage, administration, and recognizing the signs of

hypoglycemia or hyperglycemia. Additionally, the difference in administration methods — vial and pen — was also a source of confusion. These details are described and illustrated in the statements below:

> [...] We think that the explanations about the restrictions on what he couldn't do, and the normal blood sugar levels could have been clearer. (P5)
> [...] We were worried at first about how much insulin to inject because we didn't understand the prescription. (P3)
> [...] We were unsure about where to store the insulin pen, specifically whether it needed to be kept in the refrigerator. (P2)
> [...] We were unsure about preparing the insulin, the dosages, and the amounts. It was really difficult for us. (P8)

3rd category: difficulties accessing and using immunosuppressants

The last category of analysis encompasses the difficulties faced by recipients regarding the use and acquisition of medications. They highlighted that they did not understand the flow within the healthcare system to access the medications to be used at home, as they needed to obtain them from the health center.

Additionally, the participants reported that in the first months post-transplant, due to the need for frequent adjustments in dosage and fasting time for tests, there was difficulty in reconciling the timing and dosage of medications. The following statements illustrate the analysis of this category:

> [...] We were unsure about picking up the document at the drugstore; we didn't know what time we could go and when we could collect the rest of the medications at the health center. (P12)
> [...] I was unsure about the medications—where we could get them and how to get there. We went around to various places until we finally managed to find them, especially with the pandemic. (P8)
> [...] We were unsure about the fasting time when he has tests to do. Sometimes he can't take that dose. So, I don't know if it could harm him. (P5).
> [...] The timing of the correct medications, which were many at first, was gradually reduced as some medications were discontinued. It's a lot of dose changes. (P2)

DISCUSSION

The results show that 83.3% of the participants are male, with an average age of 58 years. The pathology that represented the most significant indication for liver transplantation was cirrhosis resulting from hepatitis C virus infection, with an average MELD score of 14.75. These results are similar to those of other studies regarding sex, pathology, and average age[4,5,15,16].

Regarding the information obtained, the first category revealed the main difficulties related to blood glucose monitoring. The weaknesses involving this category encompassed the procedure of self-monitoring of blood glucose. The doubts were likely related to the new adjustment of the procedure to their routine, as these recipients generally had no prior experience with blood glucose monitoring.

Other factors that may have influenced this include low education levels and difficulty in understanding, exacerbated by the high volume of information during the post-LT hospital discharge process. Additionally, the types of blood glucose meters and lancets available in the healthcare system may have added to the complications[17].

Authors indicate that, in blood glucose self-monitoring, frequent questions are related to the need for hand hygiene before the procedure, reuse of sharps, technique for blood glucose testing, frequency and timing for monitoring, the importance of knowing blood glucose levels throughout the day, as well as the calibration and setup of the device[18].

The continued incorrect performance of blood glucose testing may lead to issues with glycemic control, improper use of insulin, and the development of unrecognized episodes of hyperglycemia or hypoglycemia. These problems are characterized as complications and incidents following liver transplantation and can pose risks of obesity, cardiovascular and renal issues, as well as dysfunction of the graft, decompensation in insulin production and release, and even the risk of mortality[19].

Regarding the second category, the revealed results demonstrated difficulty in preparing, storing, and drawing up the correct dose of insulin. All these factors typically cause tension and insecurity, making this care prone to administration errors.

The doubts are particularly related to insulin handling, the necessary dosage, preparation for administration, difficulty in identifying glycemic changes (hyperglycemia or

hypoglycemia), recognizing the different types of vials, and a lack of knowledge about the types of insulin and their storage.

Authors indicate that some difficulties and failures in the process of self-administering insulin involve understanding the need to rotate injection sites, as well as the supplies for insulin therapy. Health education, as a role of the nurse, is becoming increasingly prominent, as users report a lack of knowledge about the type of insulin being used and a misunderstanding of the syringe gradation scale and the steps of the application technique[20].

Regarding the complications arising from errors in insulin administration or dosing, one of the difficulties presented involves the visibility of the gradation on the syringe for those using the vial, a problem that is minimized when using the pen[21].

The third category emerges as a concern for these recipients in the continuity of care at home. The use of medications is a complex and challenging aspect of care, even though they were already using some medications in the preoperative period. In the postoperative phase, the number of medications increases significantly, while the doses are adjusted weekly in the first months until there is stability in the serum levels of the immunosuppressants. Factors such as doubt, fear, insecurity, and stress regarding the use of medications can lead to low adherence to the treatment regimen, especially due to a lack of understanding of the importance of continuous use.

Immunosuppressants in the post-transplant period are part of the essential therapeutic regimen; therefore, their use requires understanding, dedication, and competence from the recipients and caregivers to administer them at home, making it one of the main aspects of self-care. The daily process of organizing medications within the routine can create tension and be a stressor in the process, considering that the specificities of each medication and the importance of the medication therapy represent a foundation for maintaining the graft[4,15].

When adapting to the home setting, recipients sometimes alter the timing of the medications indicated in the pharmaceutical instructions. Authors point out that this behavior can compromise graft quality and increase the chances of rejection. Although the difficulties imposed by immunosuppressive therapy may encourage low adherence to treatment, recipients understand the importance of not skipping medications without medical prescription[22].

Games and other educational tools, as mobile apps, can provide monitoring resources, health education, ongoing education, nursing education, facilitated communication, and training in developing health care practices. They also raise awareness about safety measures and information for recipients as they adapt to their new reality. Health education, when delivered through technological strategies, allows both professionals and users to make unlimited use of the tools, encouraging greater user participation and enhancing self-care[23].

In this regard, the use of serious games can help recipients learn, internalize knowledge, and gain guidance and information about their care in a playful manner, providing distraction while using the educational game. Other studies emphasize these characteristics, demonstrating that educational games offer both educational and playful aspects and assist in cognitive, affective, and sociocultural dimensions[24].

Moreover, when games are developed based on the needs identified within a specific population profile, they can serve as a supportive tool for care. Therefore, this educational technology must address the real needs of users, making it essential to identify the demands and substantial information based on the experiences and realities of future users before their creation[24,25].

Regarding the limitations of the study, due to the pandemic context, difficulties were identified in data collection because of the restrictions imposed on the setting, requiring constant adjustments to logistics to comply with COVID-19 prevention guidelines.

Another limitation was the sample size of only 12 recipients, which may have limited the applicability of the tool. Additionally, the interviews did not address contextual factors, such as differences in recipients' perceptions based on their socioeconomic status or the support received from their support network, which may have influenced the application of home care.

With that in mind, it is important to conduct new research in different regions to capture perceptions across various geographical and cultural contexts, as well as to include contexts in a sample with a larger number of participants.

CONCLUSION

The study was able to identify the informational needs during the transition of care, which are important to be included in the content of the educational game with the aim of strengthening home care. In this study, the data indicated that the

main informational needs to be included in the game are focused on blood glucose monitoring, including the procedure (care development and results) and the use of insulin concerning storage, dosage, and technique. Another identified need was related to the use of medications, highlighting the importance of addressing changes in dosages, storage, and fasting times, among other factors.

The data obtained in the study provide information to compose the content of an educational game. The educational game, by addressing the demands identified by the recipients through their experiences in the post-operative phase of liver transplantation, can assist the nurse in their important role related to health education and empowerment for post-transplant self-care, including the recipient and their support network.

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CONFLICT OF INTERESTS

The authors declare there is no conflict of interest.

AUTHORS' CONTRIBUTIONS

AMS: Formal analysis, Concept, Data curatorship, Investigation, Methodology, Writing – original draft, Writing – review and editing, Validation, Visualization. NSK: Project administration, Formal analysis, Concept, Data curatorship, Investigation; Resources, Writing – original draft, Software, Supervision, Validation, Visualization. SMSP: Data curatorship, Investigation, Writing – original draft, Validation, Visualization. ALMP: Project administration, Formal analysis, Investigation, Methodology, Writing – review and editing, Supervision, Validation, Visualization. VCG: Methodology, Writing – review and editing, Software, Validation, Visualization. JT: Formal analysis, Writing – original draft, Software, Validation, Visualization.

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