Original Article

Information needs of family caregivers regarding liver transplant candidates

Necessidades de informação do cuidador familiar de candidatos ao transplante de fígado

Necesidades de información de cuidador familiar de los candidatos a trasplante de hígado

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Amanda Silva Sá[a]
Luciana Costa Ziviani[b]
Orlando Castro-e-Silva[b]
Cristina Maria Galvão[a]
Karina Dal Sasso Mendes[a]

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ABSTRACT

Objective: To assess the information needs of family caregivers of candidates on the waiting list for a liver transplant.
Methods: It is a cross-sectional study conducted in a transplant center in São Paulo State in the period between April and October of 2012. For the assessment of information needed, an instrument submitted to face and content value was used. The caregivers put 10 subjects in order according to their importance and the amount of interest they had in learning about each, prior to the transplant their family member would be subjected to. Sociodemographic characteristics were also recorded. For data analysis, descriptive statistics were used.
Results: 42 families participated in the study. The information need about liver disease complications, complications after transplantation and care needed after surgery had higher averages.
Conclusions: Knowing the information needs of caregivers is important to plan teaching-learning strategies aimed at improving assistance to patients and families in transplant programs.
Keywords: Nursing. Liver transplant. Caregivers. Family. Teaching. Learning.

RESUMO

Objetivo: Avaliar as necessidades de informação do cuidador familiar de candidatos, que aguardam em fila de espera a realização do transplante de fígado.
Métodos: Trata-se de estudo transversal, realizado em centro transplantador do interior paulista, no período de abril a outubro de 2012. Para a avaliação das necessidades de informação foi utilizado instrumento submetido à validade de face e conteúdo, o cuidador ordenou por importância, 10 assuntos que gostaria de aprender antes da realização do transplante pelo seu ente familiar, além do registro das características sociodemográficas. Para análise dos dados, utilizou-se a estatística descritiva.
Resultados: Participaram do estudo 42 familiares. As necessidades de informação sobre complicações da doença do fígado, complicações após o transplante e cuidados necessários no pós-operatório obtiveram maiores médias.
Conclusões: Conhecer as necessidades de informação dos cuidadores é relevante para planejar estratégias de ensino-aprendizagem, visando a melhoria da assistência aos pacientes e familiares em programas de transplantes.
Palavras-chave: Enfermagem. Transplante de fígado. Cuidadores. Família. Ensino. Aprendizagem.

RESUMEN

Objetivo: Evaluar las necesidades de información de los cuidadores familiares de los candidatos en la lista de espera para trasplante hepático.
Método: Se trata de un estudio transversal realizado en el centro de trasplante en São Paulo, de abril a octubre de 2012. Para evaluar las necesidades de información, se aplicó un cuestionario sometido a la validación de apariencia y contenido, el cuidador ordenó por importancia, los 10 temas que le gustaría aprender antes de un trasplante de hígado por su ente familiar, así como el registro de las características socio-demográficas. Para el análisis de los datos, se utilizó la estadística descriptiva.
Resultados: Se recogieron datos de 42 familias. Las necesidades de información de las complicaciones de la enfermedad hepática, complicaciones después del trasplante y el cuidado necesario después de la cirugía fueron las que tuvieron el mayor promedio.
Conclusión: El conocimiento de las necesidades de información de los cuidadores es valioso para la planificación de estrategias para la enseñanza y el aprendizaje, con el fin de mejorar la atención al paciente y la familia en los programas de trasplantes de órganos.
Palabras clave: Enfermería. Trasplante de hígado. Cuidadores. Familia. Enseñanza. Aprendizaje.

[a] Universidade de São Paulo (USP), Escola de Enfermagem de Ribeirão Preto, Departamento de Enfermagem Geral e Especializada. Ribeirão Preto, São Paulo, Brasil.

[b] Universidade de São Paulo (USP), Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto, Centro de Transplantes de Órgãos Sólidos, Ribeirão Preto, São Paulo, Brasil.

INTRODUCTION

Liver transplantation is considered one of the most important advances in medicine(1). The first liver transplant was performed in 1963, in the United States of America (USA), by Earl Thomas Starzl and his team at the University of Colorado (Denver). Mortality at that time was around 70% of cases, due to the frequent complications and lack of safe and effective immunosuppressive therapies(1-2).

Only in early 1980's did the standardization of the extraction of multiple organs emerge, as did the new immunosuppressants and the development of the organ preservation solution, Belzer. This scientific-technological development lead to kidney, heart, lung and liver transplants achieving a survival rate of 80% in two years(3-4).

The most common indications for liver transplantation in the adult population are chronic hepatitis C, alcoholic liver disease, chronic hepatitis B, primary biliary cirrhosis, sclerosing cholangitis and autoimmune hepatitis(5). Absolute contraindications to surgery include multisystem organ failure, the presence of extrahepatic malignancies, advanced heart or lung disease, severe or uncontrolled extrahepatic infection and active use of substances such as drugs and alcohol(1,5).

Recent data from the Brazilian Association of Organ Transplantation show that in the last five years there have been 7,985 liver transplants in the country. In 2014, about 1,755 liver transplants were carried out by 64 teams distributed throughout the national territory. However, the need for this procedure is growing as the number of donors does not meet the demand of candidates on the transplant list, with the mortality rate of these procedures being around 20-30%. That same year, some 1,304 patients were waiting for a transplant(6).

In general, all patients should understand their treatment and learn to manage the care needed to perform the transplant. In addition, the participation of family members or caregivers is critical, as it can help in strengthening the information to patients and effectively help in the care giving process, contributing to treatment(7-8).

The information need, (NI) is defined as the information deficiency demonstrated by the individual in relation to a field of life, and the provision of information considered therapeutic intervention that is part of the nursing care plan(9). Usually, family caregivers need information about the disease and the necessary precautions with their family member, in addition to information about side effects, complications and health-related issues(10).

The family caregiver is defined as the most closely involved family member responsible for patient care. This person's main function is related to carrying out work considered primary or basic, such as housekeeping, hosting, support, maintenance, and providing personal and health care in the home environment(11). One of the conditions for the patient to be put on a liver transplant waiting list, is to have a caregiver who will accompany them most of the time, including for medical consultations in the pre-transplant phase.

The NI assessment constitutes the first step of the process of teaching and learning, forming the basis of all educational process. The well-structured data collection and evaluation of the content that the individual needs to clarify, contribute in defining priorities for the realistic way to nurse. The needs are not the same for everyone, and not all people need or would like to obtain information regarding all who understand the health-disease process of their family(12).

The literature on the NI of family caregivers of candidates awaiting liver transplants is scarce and little explored by nurses involved in organ transplant programs, which is the motivation for this research. The studies identified were conducted in 1980 (13)and 1990(14) decades and addressed the NI of the mothers of children undergoing liver transplants, and to date, no previous studies have investigated the needs of patient information from family members (adults / seniors) awaiting the completion of this operation. The objective of this study was to evaluate the NI of family caregivers of candidates on the transplant list waiting to perform the liver transplant.

MATERIALS AND METHODS

A cross-sectional study was completed, developed in the Integrated Liver Transplant Group of Hospital das Clinics at Ribeirão Preto Medical School, São Paulo, registered with the National Transplant System of the Ministry of Health. Data collection was performed by two authors of the study in a private environment. To do this, the physical space of the liver transplant clinic was used, which takes place on Tuesdays, in the afternoon, at which time candidates for liver transplants and their caregivers waited for multidisciplinary evaluation.

The family caregivers were identified by the researchers, according to the schedule of periodic consultations for transplant candidates. This schedule is guided by the classification of the patient regarding to the Model for

End-stage Liver Disease (MELD) and the occurrence of complications. This is the scoring system used to assess the severity of liver disease indicating the likelihood of death in the corresponding period of 90 days, considering the values of laboratory tests of bilirubin, international normalized ratio (INR) and creatinine of the patient(1). This formula generates scores ranging from 6 to 40 points, so that the frequency of candidate outpatient scheduling with MELD 11 to 18 was quarterly, with a MELD of 19 to 24 months and those with MELD scores greater than 25 were consulted weekly, once the chance of transplant and risk of death was greater due to the severity of the disease. The nurse responsible for the clinic's liver transplants assisted in the identification of candidates on the waiting list. The presence of family caregivers in treatment was ***sine qua non for*** the continuation of treatment.

Participants who included in the study were those 18 years and old; family caregivers of candidates for liver transplants from deceased donors with reading and writing abilities. Participants who were not family caregivers were excluded (eg, friend, neighbor). The convenience sample consisted of 42 family caregivers of liver transplant candidates in the period between April and October of 2012.

To identify the NI, an instrument submitted to face and content validity by its author was used(15). Authorization was requested for the use of this instrument. The instrument has three parts, however, as the assessment of chronic liver disease was not performed because the focus of the research was the family caregiver, only the parts of the instrument relating to sociodemographic data and evaluation of NI were used. Thus, the following data were recorded: age, date of birth, sex, place of birth (urban or rural), marital status, religion, full address, phone numbers, profession, occupation, number of children, time away from work, education (number of years), family income based on the minimum wage at the time (BRL 622.00), and health problems.

To evaluate NI, the ways information related to liver transplant was received, and the source of such information for the participant was identified. Then, it was asked if any leaflets had been delivered and were read upon the applicant's enrollment in the transplant list, ending with questions about teaching methods that most pleased the family caregivers in the search for new knowledge.

With regard to the information needs, all participants were required to perform the prior reading of a list (card) with 17 suggestions for issues related to the liver transplant process(15), and encouraged to ask any questions needed to clarify the suggested content. Next, the family caregiver was asked to list ten subjects by order of importance that he or she would like to learn prior to the liver transplant of their family member. The researcher only helped the participant in the data registration.

The responses of each participant were rated from one to ten points, with the first reply received a score equal to ten, the second response received a score equal to nine, and so on, until the tenth response with a score of one. Thus, the final score was calculated for each response, obtained by the sum of each score in the same response and the calculation of the arithmetic mean. The answer with the highest score were considered the most important. Sociodemographic and knowledge data and information source of family caregivers were tabulated and interpreted according to simple frequency, percentage, mean and standard deviation.

The study was approved by the Ethics Research Committee of the Ribeirão Preto School of Nursing of São Paulo University (CAAE: 0089.0.153.004-11).

RESULTS

Among the characteristics of the 42 participants, a female predominance was observed, with a mean age of 49.31 years (SD = 10.69), and the extreme age of 30 and 67 years. Most were married or in common-law marriages, and 29 (69.05%) lived in conjugal union with transplant candidates. The average number of children was 1.83 (SD = 1.12), and 14.29% were childless. Participants had a mean of 8.07 years of schooling (SD = 4.00), and the extremes were one and 15 years. Only one participant (2.38%) reported not having attended school, however, had reading skills and basic writing. The predominant family income was two to three minimum wages (Table 1).

In relation to information about the liver transplant received by participants, all said they had received some information on the subject, highlighting the information received through physicians and the transplant team of nurses and reading of liver transplant manuals delivered to the candidate at the time of the technical registration. Of the participants who had not read the leaflet, 19.05% did not receive it and 2.38% reported distress or anxiety related to the information contained in it (Table 2).

When asked about the preparation for the family member's surgery taking into account prior knowledge about the transplant, most reported that they felt prepared to undertake patient care. Regarding the preferred

Table 1 – Distribution of sociodemographic variables of family caregivers (n = 42) of liver transplant candidates, Ribeirão Preto, Brazil, in 2012

Variables	No.	%
Sex:		
Female	40	95.24
Male	2	4.76
Marital status:		
Married or common-law marriage	38	90.48
Single	2	4.76
Widower	2	4.76
Religion:		
Catholic	25	59.52
Evangelical	11	26.19
Spiritualist	6	14.29
Number of Children:		
Without children	6	14.29
1 child	6	14.29
2 children	24	57.14
3 children	2	4.76
4 children	3	7.14
5 children	1	2.38
Education (years of schooling):		
Did not attend school	1	2.38
Up to elementary school	22	52.38
Until high school	14	33.33
Higher education	5	11.91
Income (minimum wages):		
1	11	26.19
2 to 3	16	38.10
3 to 4	12	28.57
5 to 6	1	2.38
6 to 7	1	2.38
+ 8	1	2.38
Birthplace:		
Urban area	31	73.81
Countryside	11	26.19
Degree of kinship:		
Wife/Husband	29	69.05
Mom	5	11.91
Brother/Sister	5	11.91
Daughter	2	4.76
Daughter-in-law	1	2.38

Source: Data Research, 2012.

Table 2 – Description of knowledge and source of information related to the learning needs of family caregivers (n = 42) for liver transplant candidates, Ribeirão Preto, Brazil, 2012

Variables	No.	%
Receiving information about Liver Transplantation:		
Yes	42	100
No	0	-
Sources of information*:		
Doctor / Nurse	32	76.19
Leaflet	14	33.33
Internet	13	30.95
Other patients	5	11.91
Social worker	3	7.14
Relatives	2	4.76
Preparation for surgery in relation to knowledge:		
Yes	35	83.33
No	7	16.67
Read the manual:		
Yes	29	69.05
No	13	30.95
Teaching methods preferred in the acquisition of knowledge †:		
Readings	19	45.24
Group discussions	14	33.33
Class exhibition	8	19.05
Technical demonstration	5	11.91
Taking notes	8	19.05
Research and internet searches	11	26.19
Listening to explanations	27	64.28
Videos	10	23.81
Individual guidance	17	40.48
Material handling	7	16.66

Source: Data Research, 2012.

* Participants could choose up to three sources of information; † Participants could choose up to three teaching methods.

teaching methods for acquiring knowledge, participants were asked to choose three options, being the most prominent methods: listening to explanations, reading and individual guidance.

In the results on the information needs reported by participants, the issue about the signs, symptoms and

Table 3 – Distribution of the evaluation values of the information needs of family caregivers (n = 42) candidates for liver transplantation, Ribeirao Preto, Brazil, in 2012

Suggestions (IN)	$\Sigma^{\S}$ Rating by importance	No. of family members who responded (Votes)	Final average
01. Organs distribution system and MELD*	97	21	2.30
02. How the waiting list works	129	22	3.07
03. History of liver LT†	39	13	0.93
04. Care before the LT	135	22	3.21
05. LT team performance	120	22	2.86
06. Anatomy and physiology of the liver	54	11	1.28
07. Complications of liver disease	218	31	5.19
08. Complications before the LT	151	26	3.59
09. Indications and contraindications	78	17	1.86
10. The liver donor	134	19	3.19
11. The day of the LT	147	28	3.50
12. The surgery and anesthesia	107	22	2.55
13. The immediate postoperative period (ICU ‡)	188	37	4.48
14. Complications after LT	212	37	5.05
15. Medicines after LT	117	21	2.78
16. Necessary care after LT	193	32	4.59
17. Quality of life after LT	172	34	4.09

Source: Data Research, 2012.

*= MELD Model for End-stage Liver Disease; † LT = Liver Transplant; ‡ ICU = intensive care unit; $^{\S}\Sigma$ = mathematical symbol that indicates sum.

complications of liver disease (S.07) that was scored highest, followed by suggestions related to complications after the transplant (S.14), showing the greatest interest of family caregivers. The suggestion that got the lowest score was related to the history of liver transplant (S.03) (Table 3).

Performing the arithmetic average of the scores of each suggestion, according to the three periods of perioperative (preoperative, intraoperative and postoperative), the post-operative related information obtained the highest average (4.2 points), which shows greater interest of the participants. Next is the introperative information (average 3.08 points), followed by information about the preoperative period (average of 2.7 points).

DISCUSSION

The liver, one of the largest organs in the human body, plays different roles and interferes in various body systems. With the evolution of liver disease, liver transplant becomes the only therapeutic option able to prolong the lives of patients, because complications from portal hypertension and reduction of the hepatic parenchyma, such as gastrointestinal bleeding, refractory ascites, coagulopathy, jaundice, impaired metabolism due to drugs and encephalopathy, imposes extenuating circumstances and an impaired quality of life(1,16).

Given the complexity surrounding the transplant not only the patient experiences changes in his or her lifestyle, but also their family, therefore altering family dynamics. Considering that the family is a system, the behavior of its members are interdependent and the illness of one of them will compromise the whole family structure. Both the preparation for the transplant and the care needed after surgery are complex and require the recipient's and family's collaboration and understanding(7,17).

The necessary care for the person subjected to a transplantation require the commitment of those around them such as parents, partners and brothers. However, one of them will be responsible for direct care, being designated as a caregiver. The caregiver's responsibility to preserve the health of the transplanted person are different, such as: patient monitoring during the period of hospitalization and medical and outpatient visits; hygiene-related care; control of medication schedules, among other things (7,17) . The results of this research showed that the female spouse was the main caregiver of candidates for liver transplants.

In addition, the results showed that the main source of transplant information for participants about the transplant were the doctors and nurses of the transplant team, followed by written information (leaflets) provided to candidates, upon their registration on the waiting list. The number of participants who have not read the leaflet was an important finding. Considering the constant physical and emotional involvement of family caregivers in the care of candidates for liver transplants, the treatment decisions should also be made in the family context. Thus, caregivers have played a significant role in decision making and facilitating the course of the treatment proposed by the transplantation teams. Therefore, their needs should also be assessed, their contributions being useful to this study.

Among the preferred methods for acquiring knowledge reported by the participants, the highlights were the verbal information received, readings, the individualized instruction and group discussions. Depending on each of the learning styles, people identify different forms of learning. The learning style can be defined according to the preferences of the individuals in the way they engage in the learning process. Considering the influence of genetics, previous educational experiences, situational needs, age, among others, the learner understands and processes information differently(9-10). Therefore, knowing the preferences of family caregivers provides subsidies for nurses to plan educational interventions aimed at realistically teaching and that are in line with the preference of this clientele.

A study based on a questionnaire held with the mothers of children undergoing liver transplants showed that the largest NI corresponded to the laboratory values of tests related to liver functions, clinical signs of rejection episodes and infection and ways to support their children from the emotional point of view. The interviewees showed greater need for information in the stages of pre-transplant and surgery recovery(18). The data presented in this study indicates that the NI of higher interest refers to the postoperative period, which shows concern and insecurity of family caregivers with the progress of treatment after transplantation.

According to the results shown in a recent study on the NI candidates for liver transplants,(15) the most frequent needs were similar to those reported by family caregivers, and related to complications and care after transplantation. Another need mentioned in the relevant research has been on the care needed before transplantation, differing from the data presented. In contrast, the needs that showed less interest from candidates concerned the operation of the waiting list, indications and contraindications for surgery and medications after the transplant. In this study, only the suggestion about indications and contraindications for surgery was similar, and lower interest reported by family caregivers was about the history of liver transplantation and anatomy and physiology of the body concerned.

Another survey in which caregivers and patients awaiting lung transplants were interviewed, the results showed different learning needs. Many family members demonstrated the need for more information on life after the transplant and experiences of transplanted patients. Detailed information about the post-transplant period, specifically the variability in recovery time, the development of complications after the transplant and physical functions after transplantation(19). These data corroborate those found in this study, since the requirements related to the route after the transplant were those mentioned most often.

The literature on NI is reported in other populations. In oncology, eleven categories of information needs of family members of adult patients with cancer were identified and assessed: information related to treatment; diagnosis and prognosis; information on coping; self-care and home care; specific information about cancer; impact on the family; support information groups; information on the relationship with the partner; information on practical issues; hospital care and information on follow-ups and rehabilitation(20) In this sense, further investigations involving the NI of family members in other types of organ transplants are necessary to understand the differences in other therapeutic modalities.

The results of a study conducted with relatives of patients in intensive care and their NI demonstrated that educational actions by nurses can lessen the discomfort and anxiety of family members. This action should not be confined to informing the patient's family about the nature and causes of the disease, as well as risks related to therapy. The nurse must be prepared to establish relationships of trust with the family, communicating in order to encourage and motivate families to remedy their questions and satisfy their NI, thereby minimizing the anguish of everyone involved(12) Other studies to assess the family caregiver's NI at other stages of the transplant process is recommended, especially in the immediate discharge post-transplant, and throughout the evolution of the recipient after the transplant as there are crucial differences in care demands in different periods of postoperative outcome, whether immediate or late, especially in the early stages of immunosuppression.

There are few studies in the literature that address the NI of the family members of candidates awaiting solid organ transplants, being this a subject that is little investigated. Meeting those needs is critical, since the nurse, as a member of the multidisciplinary team, plays an important role in regard to the development of teaching and learning strategies to address deficiencies in knowledge, both patients and their family caregivers, which can contribute to better results for this complex therapy.

The study's limitations include the methodological approach, because it does not provide possible clarifications for relationships between variables, and the number of participants, making it difficult to generalize the results. It is suggested that further studies with larger sample sizes that encompass the family caregiver's NI not only in other modalities, but also in various stages of the course of treatment.

CONCLUSION

The results showed that family caregivers showed greater need for information related to the postoperative period, especially information about the complications and care required after transplantation.

The family remains the most important social context to consider in determining interventions to positively influence the outcomes of candidates for liver transplantation. Educational interventions that the nurse involved in organ transplantation programs should plan to begin the initial contact with family members from the time of inclusion of the patient on the transplant list, with the educational aspects of diagnosis, changes in life habits and outpatients. It is suggested that these interventions be based on the NI of those involved in the transplantation process, considering the various stages of treatment (before and after the transplant), and extends beyond hospital discharge, in order to prepare the family for the care and prevention of the receptor's complications at home. The importance of the transplant team, patients and families establishing a relationship of mutual respect, trust, empathy and collaboration is highlighted.

The knowledge of the information needs of caregivers is relevant to the planning of teaching and learning strategies. Future research in this area is needed in order to generate new knowledge that further strengthens the importance of assessing the NI of this population, aiming to improve care to patients and families in organ transplant programs. The study ends by recommending further research to evaluate other methods for the evaluation of NI in other modalities and realities of the Brazilian scenery.

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Corresponding author:
Amanda Silva Sá
E-mail: amanda.sa@usp.br

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