INFORMATION NEEDS OF LIVER TRANSPLANT CANDIDATES: THE FIRST STEP OF THE TEACHING-LEARNING PROCESS

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ABSTRACT

Information need' is defined as a deficiency of information or skill related to a domain of life that is relevant to the patient. This study's objective was to identify the information needs of candidates on the waiting list for a liver transplant. This is a descriptive study and was conducted at a transplant center in the State of São Paulo - Brazil. The sample consisted of 55 patients and data were collected from March to June 2009. The results showed higher average scores for information needs concerning the preoperative period. Identifying the information needs of liver transplant candidates is important to planning the teaching-learning process.

Descriptors: Nursing. Liver Transplantation. Teaching. Learning.

RESUMO

A necessidade de informação é definida como a deficiência de informação ou habilidade relacionada a um domínio de vida relevante para o paciente. O objetivo do presente estudo foi identificar as necessidades de informação de candidatos em fila de espera para o transplante de fígado. Trata-se de estudo descritivo, conduzido em centro transplantador brasileiro do interior paulista. A amostra foi constituída de 55 pacientes, e a coleta de dados foi realizada nos meses de março a junho de 2009. Os resultados evidenciaram que as necessidades de informação do período pré-operatório foram as que obtiveram pontuações médias maiores. O conhecimento de informações que o candidato ao transplante de fígado precisa é relevante para o planejamento do processo ensino-aprendizagem.

Descritores: Enfermagem. Transplante de fígado. Ensino. Aprendizagem.

Título: Necessidades de informação de candidatos ao transplante de figado: o primeiro passo do processo ensino-aprendizagem.

RESUMEN

La necesidad de información se define como la carencia de información o habilidades relacionadas con un dominio de la vida relevante para el paciente. El objetivo de este estudio fue identificar las necesidades de información de candidatos en lista de espera para el trasplante de hígado. El diseño del estudio es de una investigación descriptiva, llevado a cabo en un centro de trasplante en São Paulo - Brasil. La muestra abarcó a 55 pacientes y los datos fueron recolectados entre marzo y junio del 2009. Los resultados mostraron mayor puntuación promedio para las necesidades de información del periodo preoperatorio. El conocimiento de informaciones que el candidato a trasplante de hígado necesita es importante para planificar el proceso de enseñanza-aprendizaje.

Descriptores: Enfermería. Trasplante de hígado. Enseñanza. Aprendizaje.

Título: Necesidades de información de los candidatos a trasplante hepático: el primer paso del proceso de enseñanza-aprendizaje.

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INTRODUCTION

Liver transplantation (LT) is a therapeutic procedure that has been performed since the 1960s. It became possible due to the standardization of surgical techniques, the use of organ preservation solutions, and the emergence of immunosuppressive drugs. It is a procedure capable of reversing an individual's terminal condition due to advanced liver disease, which has no other alternative of treatment^(1, 2).

The Model for End-Stage Liver Disease (MELD) is a scoring system used to assess the severity of liver disease and a patient's condition; it predicts the probability of death in the next three months. It consists of a mathematical formula using the results of exams verifying the patient's levels of bilirubin, creatinine and the international normalized ratio (INR). This formula generates a score that ranges from six to 40 points; the higher the score, the more severe the patient's condition. Therefore, most patients scoring equal to or above 15, are included on transplant waiting lists, with the exception of special situations like the presence of primary liver tumor⁽¹⁾.

LT candidates need to be prepared for diagnostic exams, understand the treatment, and learn how to manage the self-care required for the rest of the patient's life. The nurse should help with lifestyle changes and provide ongoing support to candidates and families during the transplant-waiting period. Care delivery is focused on interventions that enable avoiding further damage to the liver, diet changes, restriction of fluids, and the discernment to recognize signs and symptoms requiring immediate assessment, among others⁽³⁾.

According to the results of an integrative review⁽⁴⁾, patient education is crucial to achieving a successful LT. There are, however, few studies addressing this subject.

The first stage in the teaching-learning process is to assess the patient's information needs, which is the basis of the entire educational process. What motivated this study is the fact that assessing the information needs of LT candidates, in terms of production of knowledge, is a subject little explored among nurses involved in transplant programs.

'Information need' is defined as lack of information or ability related to a given domain of life that is relevant for the patient⁽⁵⁾. Both verbal and written information, appropriate to the patient's

physical condition and level of education, should be provided. Family members or caregivers should also be included in the process, since they can help the patient to grasp and retain helpful information and also participate more effectively in care delivery⁽⁶⁾.

The learning-teaching process usually begins when the individual identifies the need to acquire knowledge or an ability to do something. Information needs are expected to be greater at the time the diagnosis is disclosed, and during and after the treatment proposed. The supply of information is considered a therapeutic intervention and part of the nursing care plan⁽⁷⁾.

Usually patients require information concerning their disease and related care, in addition to side effects, complications, and health-related problems. It is also important to obtain information concerning additional care, daily activities, practical solutions, and financial issues⁽⁸⁾.

Data collection and assessment concerning what the patient needs to know, as well as how prepared the patient is to receive teaching, help the perioperative nurse to determine realistic priorities. Information needs are not equal for all patients and not all patients need or desire to know everything related to the health-disease continuum. Most need to know what is sufficient to authorize the invasive procedure, ease intraoperative cooperation, perform self-care at home, and survive until more teaching sessions can be provided⁽⁹⁾.

Given the previous discussion and seeking to contribute to the improvement of care delivered to this population, this study's objective was to identify the information needs of LT candidates.

METHOD

This descriptive study was conducted in the liver transplant outpatient clinic at the *Hospital das Clínicas*, University of São Paulo at Ribeirão Preto, Medical School.

The individuals enrolled for LT composed this study's population. Inclusion criteria were: individuals 18 years old or older, LT candidates with a deceased donor, with a MELD score from six (lowest severity) to 25 (greatest severity)⁽¹⁾.

At the beginning of data collection, 77 candidates were enrolled in the Transplant Center of Ribeirão Preto, SP, Brazil, 55 of which composed this study's sample. The patients excluded from the

sample were candidates who reported or presented a liver disease progression that is unfavorable to filling out the data collection instrument or chronic hepatic encephalopathy at the time of data collection (n=22).

Data were collected after the facility's Ethics Research Committee approved the project (Process No. 12953/2008). A three-part instrument was used to collect data. The first addressed the patients' socio-demographic identification (i.e. age, gender, marital status, occupation, duration of sick leave, education). The second part addressed data concerning the chronic liver disease (i.e. duration of the chronic disease, medical diagnosis, how long the patients have been enrolled in the technical registration, knowledge concerning the definition of LT, cause of the hepatic disease, how the waiting list works, information received about the transplant, among other information).

Finally, the third part of the instrument addressed the patient's information needs. Among these items we note those concerning the identification of information needs. This item was based on theoretical concepts from the health education field⁽¹⁰⁾. A paper containing 17 suggestions concerning topics related to the LT process was developed to help the patients identify information needs, though its use was optional. The topics were based on the teaching-learning model from the transplant field⁽⁶⁾ for organ transplant candidates and on the informative booklet provided by the facility to LT candidates at the time they are added to the transplant waiting list.

Three experts performed the instrument's face and content validity: one physician and two nurses providing LT-related care. The experts analyzed the instrument considering how it was presented and its content, relating these elements to its ability to achieve the study's objective. Inter-rater agreement was above 80% and all the changes suggested were accepted. After validation, the instrument was applied to five patients waiting for an LT in order to detect comprehension issues on the part of the study's target population.

One of the researchers collected data from patients included on the waiting list in a private room and in the presence of a family member or caregiver. The patients' medical records and the transplant technical registration were also used for data collection. The instrument was applied over a period of four months (from March to June, 2009).

The study's participants responded to the instrument and were only helped by the researcher to record information. They were instructed to read the 17 items provided on the paper previously developed to answer the item pertaining information needs, and were encouraged to clarify any doubts concerning the content suggested. The patients were asked to rank, by degree of importance, ten topics they would like to learn about before their transplant. The answers were then classified from one to ten: the first answer was scored ten, the second was scored nine, and so on, up to the tenth answer, which was scored one. Therefore, the final score for each answer, obtained through the sum of each score obtained by the same answer, was computed, as well as its arithmetic average. The answers with the highest scores were considered the most important.

Data concerning quantitative variables were summarized in the form of arithmetic averages and standard deviation, while data from qualitative variables were summarized in the form of percentages. The Kolmogorov-Smirnov normality test was performed before comparing data from a given variable between two or among more groups.

Parametric statistics were used for the sample groups presenting normal distribution (p>0.05): (1) Student's t test to compare the means of two independent samples and (2) Pearson's coefficient of correlation (r) for simple linear correlations between two variables. The Mann-Whitney test was used in the event that at least one of the sample groups presented significant deviation from a normal distribution (p<0.05). Two-tailed versions of the tests were used in all analyses and the level of significance was established at 5% (a=0.05). The software GraphPad InStat 3.05 was employed to perform these tests.

RESULTS

In regard to the sample's socio-demographic characteristics, male individuals predominated (72.7%) and were aged 50.3 years old (SD=10.3) on average (minimum age was 19 years old and maximum age was 68 years old). The patients had attended school for 8.5 years on average (SD=4.3). In regard to marital status, 41 (74.6%) were either married or lived in a consensual union. As for occupation, 39 patients (70.9%) were on sick leave.

The length of sick leave for the individuals ranged from one to 204 months, with an average of 50.9 months (SD=45.4).

The average MELD score was 14.9 points (SD=3.4). The duration of the disease was estimated to be 101.2 months (SD=93.5) on average. According to the medical diagnoses, the chronic liver disease had a viral cause in 27.3% of the cases; was caused by alcohol consumption in 25.4%; alcohol associated with a virus occurred in 20% of the cases; and other causes accounted for the remaining 27.3%. The average waiting time for a transplant was 1,199.6 days (SD=742.3), while the minimum and maximum waiting time were 58 and 2,626 days, respectively.

The LT candidates' information needs are presented in Table 1. The first nine needs refer to the perioperative period; the 10th to the 12th needs refer to the intraoperative period, while the 13th to the 17th needs are related to the postoperative period.

The results indicate a positive correlation between the number of votes and the final average score of different suggestions (Person's coefficient of correlation: r=0.7873; p=0.0002). This means that, in general, the most selected suggestions also obtained the highest final averages, and vice-versa.

The suggestions that obtained the highest averages were: No. 4, concerning care required before the transplant (4.6), which was followed by No. 14, referring to complications after the transplant (4.3), and No. 16, related to care required after the transplant (4.1). Considering the number of votes, suggestions No. 16, No. 14 and No. 17 obtained 45 (81.8%), 43 (78.2%) and 40 (72.7%) votes, respectively, out of the 55 possible votes. These are suggestions concerning the postoperative period.

The suggestions that obtained the lowest scores were: No. 15 (2.0), which refers to the medication used after the transplant; No. 2 (2.1), concerning how the waiting list works; No. 9 (2.3), referring to transplant indications and counterindications; No. 13 (2.6), related to the mediate and immediate postoperative period; and No. 1 (2.7), concerning the system of organ distribution and MELD. It is worth noting that these are the sug-

Table 1 – Distribution of rankings for the instrument's item concerning the identification of information needs of liver transplant candidates. Ribeirão Preto, SP, Brazil 2009

Suggestions of information needs	ΣRating	No. of patients (votes)	Final average
01.Organ distribution system and MELD	149	28	2.7
02.How the waiting list works	118	20	2.1
03.History of liver transplant	195	31	3.5
04.Care required before the transplant	255	34	4.6
05.The work of the transplant staff	199	36	3.6
06.Anatomy and liver physiology	172	32	3.1
07.Liver disease complications	176	32	3.2
08.Complications before the transplant	185	30	3.4
09.Indications and counter-indications	128	27	2.3
10.Liver donors	193	35	3.5
11.The day of the transplant	213	33	3.9
12. Surgery and anesthetics	151	32	2.7
13.Immediate postoperative (ICU)	141	29	2.6
14.Complications after the transplant	239	43	4.3
15.Medication after the transplant	108	23	2.0
16. Care required before the transplant	224	45	4.1
17.Quality of life after the transplant	179	40	3.3

Source: LT outpatient clinic - HCFMRP, 2009.

gestions that also obtained the lowest number of votes: 23 (41.8%), 20 (36.4%), 27 (49.1%), 29 (52.7%) and 28 (50.9%), respectively.

In general, establishing the arithmetic average of the score obtained by each suggestion, according to the three phases that compose the perioperative period (i.e. pre-, intra-, and postoperative), the information related to the preoperative period was considered to be the most important for the patients (average of 3.3), followed by information pertaining to the intraoperative (average of 3.2), and the postoperative (average of 3.2) periods.

We compared, during data analysis, candidates with complete or incomplete k-8 education (group I) with candidates who attended high school, college or graduate studies (group II). The purpose of this comparison was to verify whether level of education influenced the studied sample (Table 2). In terms of age, group II was significantly younger than group I (p=0.0413, Student's t test). In terms of severity of disease, group I obtained a slightly higher MELD score than group II. The results concerning group II presented statistically significant differences in relation to group I in terms of knowledge concerning the definition of LT (p=0.0147, Fisher's exact test), and the feeling of being prepared, in terms of knowledge, for the surgery (p=0.0371, Fisher's exact test).

No statistically significant difference was found between groups I and II in relation to infor-

Table 2 – Distribution of candidates according to level of education, age, MELD score, knowledge concerning the liver transplant process, and information needs in the pre-, intra-, and postoperative periods. Ribeirão Preto, SP, Brazil 2009.

	Candidates (n=55)		
Variables	Group I (≤ K-8 education)	Group II (≥ High school)	P
Number of candidates	31	24	_
Years of education on average (Average \pm SD)	5.1 ± 1.9	12.8 ± 2.1	<0.0001°
Age (Average \pm SD)	52.9±6.8	46.8 ± 12.8	0.0413 ‡
Adjusted MELD (Average \pm SD)	15.0±3.0	14.8 ± 3.9	0.8225 ‡
Time on the waiting list in days (Average \pm SD)	1206.3±728.3	1190.9 ± 775.7	0.9398 ‡
Knowledge concerning the definition of LT*	24 (77.4%)	24 (100%)	0.0147 §
Knowledge concerning the cause of chronic liver disease	23 (74.2%)	19 (79.2%)	0.7561 §
Knowledge concerning time spent in the LT* technical registration	9 (29.0%)	10 (41.7%)	0.3973 §
Knowledge concerning how the waiting list works	18 (58.1%)	19 (79.2%)	0.1480 §
Information received concerning LT*	27 (87.1%)	23 (95.8%)	0.3728 §
How prepared one feels given knowledge acquired	19 (61.3%)	21 (87.5%)	0.0371 §
Read the informative booklet	20 (64.5%)	16 (66.7)	1.0000 §
Identification of Information needs (Average \pm SD) Score of suggestions concerning the preoperative Score of suggestions concerning the intraoperative		3.2±3.6 3.6±3.9	0.7196 0.5490
Score of suggestions concerning the postoperative	3.2±3.4	3.1±3.1	0.9442

^{*}LT = Liver Transplant; *Student t test; § Fisher's exact test; | Mann-Whitney U-test Source: LT outpatient clinic - HCFMRP, 2009.

mation needs. Group I, though, presented a greater need for information concerning the preoperative period (average score=3.4±3.7), and group II presented a greater need for information concerning the intraoperative period (average score=3.6±3.9).

Another comparison was performed to verify whether the situation "being on the waiting list" impacted knowledge concerning LT and on the candidates' information needs (Table 3). The patients who spent a longer time on the transplant waiting list (group II) felt more prepared for surgery due to the knowledge they already had (74.1%) compared to group I (71.4%). In turn, group I (78.6%) was significantly more active in reading the informative booklet provided at the time they were added to the waiting list (p=0.0496, Fisher's exact test). A statistically significant difference was found in relation to the level of severity of both groups.

Group I obtained a higher average MELD score (p=0.0483, Student's t test). In terms of information needs, no statistically significant differences were found between groups I and II. The patients in the group II showed a greater need for information concerning the preoperative period (average score=3.5±3.8), while group I showed a greater need for information concerning the postoperative period (average score=3.4±3.4).

DISCUSSION

There is limited literature addressing information needs in the context of LT. The only studies found were conducted in 1989 and 1990 and intended to identify the information needs concerning primary care provided to children undergoing LT^(11,12). Among other modalities

Table 3 – Distribution of candidates according to time on the waiting list, age, MELD score, knowledge concerning the liver transplant process, and information needs in the pre-, intra-, and postoperative periods. Ribeirão Preto, SP, Brazil 2009.

Variables	Candidates (n=55)		
Time (years) in the waiting list $ ightarrow$	Group I ≤ 3.5 years	Group II ≥ 3.5 years	P P
Number of candidates	28	27	-
Years of education, on average (Average \pm SD)	8.6 ± 4.4	8.2 ± 4.3	0.6552 ‡
Age (Average \pm SD)	49.0±9.9	51.6 ± 10.6	0.3468 ‡
MELD score (Average \pm SD)	15.8 ± 3.2	14.0±3.4	0.0483 ‡
Knowledge concerning the definition of LF*	26(92.9%)	22(81.5%)	0.2516 §
Knowledge concerning the cause of chronic liver disease	20(71.4%)	22(81.5%)	0.5279 §
Knowledge concerning time registered in the LT* technical registration	8(28.6%)	11(40.7%)	0.4032 §
Knowledge concerning how the waiting list works	19(67.9%)	18(66.7%)	1.0000 §
Information received concerning LT*	25(89.3%)	25(92.6%)	1.0000 §
How prepared one feels given knowledge acquired	20(71.4%)	20(74.1%)	1.0000 §
Read the informative booklet	22(78.6%)	14(51.9%)	0.0496 §
Identification of Information needs (Average \pm SD)			
Score of suggestions concerning the preoperative	3.1 ± 3.5	3.5 ± 3.8	$0.3693^{ }$
Score of suggestions concerning the intraoperative	3.3 ± 3.6	3.2 ± 3.5	0.9269 $^{ }$
Score of suggestions concerning the postoperative	3.4 ± 3.4	2.9 ± 3.1	0.1992

^{*}LT = Liver Transplant; *Student t test; \$ Fisher's exact test; || Mann-Whitney U-test Source: LT outpatient clinic - HCFMRP, 2009.

of transplantation, there are two other studies addressing information needs in the context of bone marrow transplants^(13,14), one study identifying information needs concerning lung transplants⁽¹⁵⁾, and another identifying the information needs of recipients of abdominal organs⁽¹⁶⁾. Note that there are also studies addressing general aspects concerning health education in the context of LT^(17, 18).

The instrument used to identify the information needs of LT candidates in this study enabled us to analyze the number of times each suggestion was selected and to present the final arithmetic average. The arithmetic average indicates that patients considered information concerning the preoperative period to be the most important.

The supply of knowledge concerning the preoperative period provides the surgical patient with information related to the surgical anesthetic procedure, enables him/her to anticipate expected feelings (i.e. anxiety, fear, depression) and potential outcomes. It is also useful to reassure the patient through therapeutic communication, which helps the patient to have their anxieties relieved and develop strategies to positively cope with their situation⁽¹⁹⁾.

The benefits reported in the literature of providing perioperative knowledge to patients include: shorter hospital stays, reduced use of analgesics, and greater satisfaction for patients and family members⁽¹⁹⁾. Especially in the case of LT, the supply of information to candidates means contributing to the transplant outcomes since nurses can provide information concerning the self-care that is required for the rest of the patient's life after the transplant.

Among the studies found on transplant information needs, we highlight one Canadian study conducted with the candidates, recipients, and family members and/or caregivers enrolled in a lung transplant program. The results indicate that most patients decided to undergo the surgery with the help of family members or caregivers, while the supply of statistical information concerning survival, level of physical ability after the transplant, and the side effects of immunosuppressive medication were crucial for decision-making. The patients also reported they received appropriate information, both written and verbal, at the time of their transplant decision-making.⁽¹⁵⁾

The Canadian study also identified different information needs, among which information concerning practical issues was highlighted (i.e. being near to a transplant center and sources of financial assistance), as was life after the transplant, and experiences of transplant recipients. It is noteworthy that all the patients who experience complications after the surgery reported the importance of receiving more detailed information about the post transplant period, namely: differences among patients in terms of period of recovery, type of potential complications, and lifestyle changes. Caregivers and family members reported difficulties dealing with the quantity of oral information provided during the process of transplant assessment; thus, the supply of written information concerning this process is extremely valuable (15).

One study was conducted in the United States of America to identify perceptions concerning gaps in knowledge and ways to improve the teaching provided to abdominal organ transplant recipients. The results showed that issues related to quality of life, use of medication, and follow-up after the transplant were the ones receiving the lower scores, meaning these were topics for which the patients presented the greatest gaps in knowledge. The study also reported that patients desire to acquire a greater quantity of information before undergoing the transplant⁽¹⁶⁾.

In contrast with the results reported by the study previously mentioned, this study's results revealed the patients have less interest in relation to medication used after the transplant. Additionally, the information concerning how the waiting list works, transplant indications and counterindications, the mediate and immediate postoperative periods, the system of organ distribution and MELD, were also considered by the candidates to be of lesser importance.

According to the results reported by another study, patients are not capable of becoming active partners in postoperative care if they do not receive adequate information⁽²⁰⁾. A lack of time, on the part of the health staff, to discuss issues of interest for each patient reinforces the relevance of obtaining knowledge concerning the information patients desire to acquire, while the use of strategies to identify the patients' information needs is extremely valuable.

The results show that patients with a higher level of education require more information concerning the intraoperative period, while patients with fewer years of education require more information concerning the preoperative period. Patients who were on the waiting list for shorter periods presented greater information needs concerning the postoperative period, while those waiting for longer periods presented a greater need to learn about the preoperative period.

CONCLUSION

The knowledge produced by this study supports the planning of the teaching-learning process in health services with LT programs. The results show that LT candidates require information, mainly concerning the phase they are experiencing, that is, the preoperative period.

In the literature, we highlight studies addressing the information needs of patients in general, however, there is a scarcity of studies focusing on LT candidates. How the information needs of patients are measured is also a subject that is poorly explored; no measurement tool, focused on the transplant process, was identified in the Brazilian literature.

The use of an instrument developed for this purpose is a way to identify the information needs of LT candidates. For future research, we recommend the use of this instrument in other studies to measure the information needs of patients in organ transplant programs.

In regard to this study's limitations we note that, even though a descriptive study enables the collection of a large quantity of data concerning the problem under study, it does not enable clarifying potential relationships among the studied variables.

In turn, due to a lack of Brazilian and international studies addressing the topic, this study demonstrates the importance of further studies focusing on the teaching-learning process of LT candidates, since patient education is a crucial strategy to achieving successful treatment.

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