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## PSYCHOSOCIAL ASPECTS OF QUALITY OF LIFE OF HEPATIC TRANSPLANT RECEIVERS<sup>1</sup>

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### ABSTRACT

**Objective:** to assess the psychosocial dimension of patients' quality of life before and after a hepatic transplantation.

**Method:** descriptive, cross-sectional study of quantitative approach, with 150 patients submitted to a liver transplantation being monitored from the sixth month, in the outpatient clinic of a reference center in hepatic transplantation. The data collection was carried out through an instrument with sociodemographic/clinical data and the Liver Disease Quality of Life questionnaire. The descriptive statistical analysis, Student's t-test for comparison of domain means, and Games-Howell for multiple comparisons have been used.

**Results:** there was improvement in the post-transplant quality of life in the four domains evaluated (<0.0001), with higher scores for the domains: health distress (55.5 vs 87.9) and stigma of hepatic disease (58.6 vs 93.7).

**Conclusion:** the study has demonstrated that patients submitted to a liver transplantation had a significant improvement in the perception of quality of life regarding the psychosocial dimension, being more perceptive in the areas of health distress and stigma of hepatic disease.

**DESCRIPTORS:** Liver transplantation. Quality of life. Health assessment. Hepatic insufficiency. Psychosocial impact. Nursing.

## ASPECTOS PSICOSSOCIAIS DA QUALIDADE DE VIDA DE RECEPTORES DE TRANSPLANTE HEPÁTICO

### RESUMO

**Objetivo:** avaliar a dimensão psicossocial da qualidade de vida de pacientes antes e depois do transplante hepático.

**Método:** estudo descritivo, transversal, com abordagem quantitativa, com 150 pacientes submetidos ao transplante de fígado em seguimento a partir do sexto mês, no ambulatório de um centro de referência em transplante hepático. A coleta de dados foi realizada a partir da aplicação de um instrumento com dados sociodemográficos/clínicos e do questionário *Liver Disease Quality of Life*. Foi utilizada análise estatística descritiva, teste t de Student para comparação das médias dos domínios e Games-Howell para comparações múltiplas.

**Resultados:** houve melhoria nos níveis de qualidade de vida pós-transplante nos quatro domínios avaliados (<0,0001), com maior elevação de escores para os domínios: preocupação (55,5 vs 87,9) e estigma da doença hepática (58,6 vs 93,7).

**Conclusão:** o estudo demonstrou que os pacientes submetidos ao transplante hepático obtiveram uma melhoria significativa da percepção da qualidade de vida no que diz respeito à dimensão psicossocial, sendo mais perceptiva nos domínios preocupação e estigma da doença hepática.

**DESCRIPTORIOS:** Transplante de fígado. Qualidade de vida. Avaliação em saúde. Insuficiência hepática. Impacto psicossocial. Enfermagem.

## ASPECTOS PSICOSOCIALES DE LA CALIDAD DE VIDA DE LOS RECEPTORES DE TRASPLANTE HEPÁTICO

### RESUMEN

**Objetivo:** evaluar la dimensión psicosocial de la calidad de vida de los pacientes antes y después del trasplante hepático.

**Método:** estudio descriptivo, transversal y con un abordaje cuantitativo con 150 pacientes sometidos al trasplante de hígado y en seguimiento a partir del sexto mes, en el ambulatorio de un centro de referencia en trasplante hepático. La obtención de datos se realizó a partir de la aplicación de un instrumento con datos sociodemográficos/clínicos y del cuestionario *Liver Disease Quality of Life*. Se utilizó el análisis estadístico descriptivo, la prueba t de Student para la comparación de los promedios de los dominios y Games-Howell para las comparaciones múltiples.

**Resultados:** hubo mejoras en los niveles de calidad de vida post-trasplante en los cuatro dominios evaluados ( $<0,0001$ ), con una elevación mayor de resultados para los dominios preocupación (55,5 vs 87,9) y estigma de la enfermedad hepática (58,6 vs 93,7).

**Conclusión:** el estudio demostró que los pacientes sometidos al trasplante hepático consiguieron una significativa mejora de la percepción de la calidad de vida en relación a la dimensión psicosocial, siendo más perceptivo en los dominios de preocupación y estigma de la enfermedad hepática.

**DESCRIPTORES:** Trasplante de hígado. Calidad de vida. Evaluación en salud. Insuficiencia hepática. Impacto psicosocial. Enfermería.

### INTRODUCTION

The irreversible hepatic disease is associated with high morbidity and mortality, with the progressive decline of the quality of life when related to physical symptoms and psychological and social implications, leading to the indication of liver transplantation as the only alternative for survival.<sup>1</sup>

The transformations and limitations imposed by the chronic condition and the need to undergo a transplantation bring the necessity for these patients to adapt to a new reality. They have to adjust to changes in different areas of life, being fundamental the support of the multiprofessional team, especially of the nurse, who deals directly with this clientele in all the stages of the liver transplantation process.

Brazil has stood out in the area of transplants at the international level, and it occupies the second place in absolute number of kidney and liver transplants in the world. According to data from the Ministry of Health, 1,880 liver transplants were performed in 2016.<sup>2</sup>

In view of this reality, the liver transplantation currently represents a substitutive therapeutic modality, which brings the possibility of survival and improvement of the quality of life for the patients who are in the waiting list.

Changes in the quality of life and lifestyle caused by a chronic hepatopathy and the need for inclusion in a waiting list for transplantation favor the appearance of subjective difficulties, such as hopelessness, anxiety, low self-esteem, among others. It requires the reorganization of the personal, family, and social dynamics, requiring the understanding and support of those who deal directly with this patient, including their family, friends and health care professionals who assist them.

The role of nurses in the follow-up of patients undergoing a liver transplantation is of fundamental importance in helping them to cope with changes, providing them with individualized care and support, through which the needs of the family and the patient can be met. Therefore, it is of fundamental importance the nurse's role in the health education of these patients, providing support for self-care, and sufficient and adequate information so that the family can collaborate with the recovery of the patient and their reintegration into society.

Knowing the aspects that influence the quality of life of these people, and understanding how they experience this fact is an essential step in the search for a type of care that aims at meeting the needs of human beings through a holistic approach, offering a better quality of care.

Quality of life is defined as the individual's perception of their position in life, in the context of the culture and value system, in which a person lives according to their goals, expectations, standards, and concerns.<sup>3</sup> The term encompasses many meanings that reflect the knowledge, experiences and values of individuals and collectivities. These involve historical, cultural and social aspects that determine the standard of comfort and well-being for a society.

For this study, the Liver Disease Quality of Life (LDQOL) was chosen as instrument, due to the fact that it was translated and validated for the Brazilian population, allowing its application in patients with chronic hepatopathy of any etiology, in different degrees of severity of the disease, who were submitted to transplantation, in order to measure several aspects of patients' quality of life.<sup>4</sup>

Studies that assessed the quality of life in liver transplant recipients have demonstrated a positive impact of the transplantation on the quality of life.<sup>5-6</sup>

However, despite the expected repercussions of the liver disease and as a result of the treatments for these patients, there is still a shortage of studies to assess the quality of life among patients undergoing liver transplantation in Brazil. For this reason, it would be pertinent to carry out further studies to better understand the impact suffered and the effects of the surgical treatment in different dimensions, including the psychosocial aspects.

Thus, it is justified the use of instruments to assess the quality of life, working as a parameter to analyze the impact of the disease and the treatment on people's daily lives. It would consider the physical functioning, social aspects, emotional and mental state, and repercussion of symptoms and individual perception of well-being, serving as a criterion in the assessment of the transplant effectiveness. It is believed that the liver transplantation improves the psychosocial aspects of the quality of life of the recipients. Thus, the objective of this study was to assess the psychosocial dimension of the quality of life of patients before and after the hepatic transplantation.

## METHOD

Descriptive, cross-sectional study of quantitative approach, performed at the Center for Liver Transplantation of Ceará/Walter Cantídio University Hospital (HUWC - Hospital *Universitário Walter Cantídio*), national reference in liver transplantation.

The population size considered the number of patients who underwent a liver transplantation during the ten years of the unit operation, who are still alive, with the exception of those who are under 18 years old, totaling 425 patients. The calculation for the finite sample was performed, with a 95% confidence coefficient and a sample error of 4%, resulting in 138 patients. The following inclusion criteria were used: patients who underwent a liver transplantation at least six months before the study, who were aged at least 18 years old, and under a regular follow-up in the transplant service. In total, 150 patients participated in the study, surpassing the necessary sample.

The receivers transferred to other states, patients who underwent liver transplants due to fulminant hepatitis or double liver-kidney, with hearing and mental disorders that made it difficult for the understanding of the instrument were excluded.

The data collection was performed from July 2012 to January 2013, with the application of an instrument produced by the researchers, having sociodemographic aspects (gender, age, race, marital

status, educational level, occupation, and income), Clinical aspects (etiology, Model for End-stage Liver Disease - MELD, Child-Turcotte-Pugh-CTP, comorbidities, complications, waiting list time, and transplantation), and the Liver Disease Quality of Life (LDQOL) questionnaire, a specific instrument for assessing the quality of life of liver diseases, translated and validated for the Brazilian population,<sup>7</sup> in which questions are answered through the assessment of the the frequency, intensity, or agreement with statements on a Likert scale, with scores ranging from 0 to 6 points, which were converted into a scale from 0 to 100 for the calculation of the averages, in which higher values represent a higher quality of life. The complete questionnaire includes 12 domains that assess different aspects, however, to meet the objectives of this research the domains Quality of social interaction, Health distress, Loneliness, and Stigma of liver disease were used.

The LDQOL could be self-administered, however, due to patients' preference, it was applied by the researchers after the sixth month of transplantation, at the time the patients attended the postoperative follow-up visits, at the liver transplantation outpatient clinic. The questionnaire was applied twice for each patient: the first time, considering the pre-transplant period experienced by the patient, and then to assess the current quality of life (after transplantation).

For the analysis of sociodemographic and clinical data, the Statistical Package for the Social Sciences (SPSS), version 13.0 was used. The descriptive statistics were used, with absolute (n) and relative (%) frequencies, and the comparison of averages before and after the transplantation was performed by Student's t-test. The variance analysis (Anova) was used to compare the averages between groups of clinical variables, being complemented with the Games-Howell's multiple comparison test. The level of significance was set at 0.05.

This study in accordance with national and international ethical precepts involving human beings, with a favorable opinion of the Research Ethics Committee of the HUWC, under the Protocol No. 041.06.12.

## RESULTS

Regarding the sociodemographic aspects, among the patients who underwent a liver transplantation, the male predominance was observed (n=120; 80%), the age group between 40 and 59 years old, with

47.3% (n=71) of the participants, followed by 60 to 76 years old (n=51; 34%), with an average of 52.4 years old. Regarding the race, it was possible to observe a greater proportion of the mixed race (n=90; 60%) and White/Caucasian (n=45; 30%). Regarding the marital status, 68% (n=102) of the participants reported living with their partners, of whom 64% are married and 4% live in a consensual union.

The data referring to the educational level of the participants revealed that the majority (n=56, 37.3%) completed between ten and 12 years of study, followed by one to nine (n=48, 32%) and 13 to 18 (n=34, 22.7%), showing an intermediate level of instruction, considering that the average was 9.8 years.

Regarding their occupation, it was observed that 38.7% (n=58) were professionally active and 61.3% (n=92) were inactive, of whom 35.3% were retired, either by age or physical conditions, 16% were pensioners or were away by the National Social Security Institute (INSS - Instituto Nacional de Seguro Social), and 10% did not carry out any kind of activity outside the home.

Most participants (n=65; 43.3%) reported income of up to two minimum wages (MW), followed by three to four MW (n=38, 25.3%) and five to ten MW (n=20, 13.3%).

Regarding the clinical variables, the predominant etiology of hepatic disease was alcohol consumption (38.7%), followed by hepatitis C (28%), and cryptogenic cirrhosis (14.7%).

The majority presented the last MELD measurement before surgery equal to or greater than 15 (77.3%); however, the MELD value did not significantly interfere in the post-transplant quality of life outcomes. In the CTP scale, there was a predominance of level C (37.3%) and B (50.7%), besides A

(6%) and without registration (6%). Patients with CTP C had lower average values than patients with A and B, indicating a significant difference based on the multivariate comparison between the CTP groups C and A for the domains: social interaction (62.9 vs 80.5; p=0.023) and stigma of the disease (49.2 vs 77.4; p=0.043). And between the CTP groups C and B for: social interaction (62.9 vs 70.9; p=0.038) and stigma of the disease (49.2 vs 62.5; p=0.050).

It was verified that 53.3% of the study participants presented some type of comorbidity, with a high prevalence for diabetes mellitus (30.7%) and systemic arterial hypertension (22%), in addition to other diseases (16.7%). Significant differences were found between the groups with and without hypertension in the distress domains (82.4 vs 89.4; p=0.021) and loneliness (90.7 vs 97.4; p=0.006).

Postoperative complications were observed in 51.3%, with a higher incidence for infections (18.7%), vascular complications (14%), rejection (11.3%), and bile complications (7.3%). The rejection was associated with the reduction of the averages of patients in the domains: quality of social interaction (78.1 vs 84.5, p=0.023) and distress (77.0 vs 89.2); p=0.002).

The transplantation time ranged from 6 to 117 months, with an average of 36.9 months; and the waiting time on the transplant list ranged from one day to 67 months, with an average of 8.7 months. None of these items showed an influence on the quality of life (QoL) of individuals submitted to a liver transplantation.

The data regarding the aspects of each quality of life domain assessed in this study by the Liver Disease Quality of Life (LDQOL) instrument, before and after transplantation, are presented in tables 1 to 4.

**Table 1 - Distribution of the frequency of the domain Quality of the social interaction related to the quality of life of patients before and after liver transplantation. Fortaleza, CE, Brazil, 2013. (n=150)**

Aspects of the domain Quality of social interaction	%				
	All the time	Most of the time	Sometimes	Rarely	Never
<b>Before</b>					
Isolated yourself from people.	2,0	10,7	17,3	0,7	69,3
Was affectionate with people.	14,7	34,7	30,0	17,3	3,3
Was angry at people.	2,7	28,7	30,7	20,0	18,0
Asked unreasonable things to your friends or family members.	-	4,7	14,0	4,0	77,3
Was a very communicative person.	35,3	34,0	16,0	13,3	1,3
<b>After</b>					
Isolated yourself from people.	-	0,7	2,0	2,0	95,3
Was affectionate with people.	26,0	46,7	24,0	2,0	1,3

Aspects of the domain	%				
	All the time	Most of the time	Sometimes	Rarely	Never
Quality of social interaction					
Was angry at people.	-	2,0	26,7	39,3	32,0
Asked unreasonable things to your friends or family members.	-	0,7	0,7	0,7	98,0
Was a very communicative person.	48,7	40,7	5,3	4,0	1,3

The data regarding the Quality of social interaction domain showed that there was an increase in positive responses between participants before and after the liver transplantation, with a greater

emphasis on: never isolated themselves from people (69.3% vs 95.3%) and never asked for unreasonable things (77.3% vs 98%), besides the decrease in the frequency of irritation.

**Table 2 - Distribution of the frequency of the domain Health distress related to the quality of life of patients before and after liver transplantation. Fortaleza, CE, Brazil, 2013. (n=150)**

Aspects of the domain	%				
	All the time	Most of the time	Sometimes	Rarely	Never
<b>Before</b>					
Do you feel discouraged by your liver disease?	2.7	26.7	22.7	4.7	43.3
Do you feel frustrated because of your liver disease?	2.7	21.3	19.4	9.3	47.3
Do you worry about your liver disease?	19.3	36.0	22.7	10.7	11.3
Do you feel depreciated because of your liver disease?	8.0	24.0	12.7	8.0	47.3
<b>After</b>					
Do you feel discouraged by your liver disease?	1.3	-	6.7	3.3	88.7
Do you feel frustrated because of your liver disease?	1.3	-	4.0	1.3	93.3
Do you worry about your liver disease?	2.0	10.0	27.3	18	42.7
Do you feel depreciated because of your liver disease?	-	0.7	3.3	3.3	92.7

With regards to the domain Health distress, it was observed the reduction of the occurrence of most aspects between the moments before and after the transplantation, in which the patients stated they had never presented feelings of discouragement (43.3% vs 88.7%), frustration (47.3% vs 93.3%)

and depreciation due to the liver disease (47.3% vs 92.7%). In addition, there was also a change in the pattern of responses of the distress aspect, in which 45.3% previously stated that they used to worry all the time or most of the time, and then 42.7% have never worried about their liver disease.

**Table 3 - Distribution of the frequency of the domain Loneliness referring to the quality of life of patients before and after liver transplantation. Fortaleza, CE, Brazil, 2013. (n=150)**

Aspects of the domain	%				
	All the time	Most of the time	Sometimes	Rarely	Never
<b>Loneliness</b>					
<b>Before</b>					
Have you had company?	4,0	2,7	6,7	2,0	84,7
Have you had someone to count on?	2,0	2,7	5,3	0,7	89,3
Have you felt abandoned?	-	6,0	8,0	1,3	84,7
Have you felt isolated from the others?	0,7	9,3	9,3	2,7	78,0
Were you able to find company when you needed?	88,0	4,7	4,0	2,7	0,7
<b>After</b>					
Have you had company?	4,0	2,0	2,0	2,7	89,3
Have you had someone to count on?	1,3	0,7	2,7	3,3	92,0
Have you felt abandoned?	-	1,3	0,7	2,0	96,0
Have you felt isolated from the others?	-	1,3	1,3	2,0	95,3
Were you able to find company when you needed?	93,3	4,7	1,3	-	0,7

The Loneliness domain presented high levels of quality of life with similar values before and after transplantation, with a more evident increase in the frequency of the post-transplant period for the aspect of never feel abandoned (84.7% vs 96%) or isolated from the others (78% vs 95.3%).

**Tabela 4 - Distribuição da frequência do domínio Estigma da doença hepática referente à qualidade de vida de pacientes antes e depois do transplante de fígado. Fortaleza, CE, Brasil, 2013. (n=150)**

Aspects of the domain Stigma of hepatic disease	%				
	All the time	Most of the time	Sometimes	Rarely	Never
<b>Before</b>					
Some people avoid me because of my disease	26,7	8,7	0,7	3,3	60,7
I feel ashamed because of my appearance.	32,7	7,3	-	0,7	59,3
I avoid exposing myself because of my liver disease.	31,3	8,0	0,7	4,7	55,3
Some people feel uncomfortable in my presence because of my liver disease.	20,0	12,0	3,3	4,7	60,0
My illness makes me feel out of place in public.	22,7	11,3	1,3	2,0	62,7
I feel harmed and incomplete because of my liver disease.	54,7	14,0	0,7	2,0	28,7
<b>After</b>					
Some people avoid me because of my disease.	0,7	3,3	2,6	0,7	92,7
I feel ashamed because of my appearance.	0,7	1,3	-	1,3	96,7
I avoid exposing myself because of my liver disease.	1,3	2,7	-	3,3	92,7
Some people feel uncomfortable in my presence because of my liver disease.	1,3	2,7	1,3	2,0	92,7
My illness makes me feel out of place in public.	-	-	-	2,0	98,0
I feel harmed and incomplete because of my liver disease.	7,3	14,0	-	2,7	76,0

In the domain Stigma of hepatic disease, it was observed the reduction of the occurrence of most aspects assessed between the period before and after transplantation, with greater highlight to never feel ashamed because of the appearance (59.3% vs 96.7) and never avoid exposing yourself because of the

liver disease (55.3% vs 92.7%).

The averages of the domains involving the psychosocial aspects of quality of life assessed before and after the transplantation are presented in table 5.

**Tabela 5 - Análise dos domínios de qualidade de vida da escala LDQOL\* antes e depois do transplante de fígado. Fortaleza, CE, Brasil, 2013. (n=150)**

LDQOL Domains	Pre-transplantation	Post-transplantation	P
	Average ± D.P.		
Social interaction	69,0 ± 18,9	83,8 ± 11,0	<0,0001
Health distress	55,5 ± 28,8	87,9 ± 15,5	<0,0001
Loneliness	90,1 ± 18,7	95,9 ± 12,5	<0,0001
Stigma of hepatic disease	58,6 ± 33,0	93,7 ± 11,4	<0,0001

\*LDQOL= Liver Disease Quality of Life

The comparison analysis of the quality of life domains of patients in the pre- and post-transplantation period showed a significant improvement (p<0.05) in the levels reached in all the domains assessed by the LDQOL instrument.

Based on the data from before the transplantation, the domains that presented the lowest scores on the scale used were: health distress (55.5) and stigma of hepatic disease (58.6), indicating a higher

impairment of the quality of life of these subjects. The dimension with the best evaluation by the study participants in the pre-transplantation stage was loneliness (90.1).

The analysis of the differences between the averages of the pre and post-transplant answers showed that there was a statistically significant increase in the post-transplantation period for the domains: health distress (55.5 vs 87.9) and stigma

of hepatic disease (58.6 vs 93.7), with variation of scores greater than 30 points. In addition, other dimensions reached averages above 90 after the transplantation, including loneliness, indicating a high QoL satisfaction.

## DISCUSSION

### Quality of social interaction and loneliness

Regarding the Quality of social interaction domain, patients presented higher average QoL scores in the post-transplantation period (83.8) than in the waiting for the surgery period (69.0).

The results obtained in the pre-transplantation period were different from those found in validation studies of the Hispanic version of the LDQOL, applied to 200 patients waiting for a liver transplantation, in which the average score was 84.2.<sup>4</sup>

When comparing these data with studies involving the application of the SF-36 generic instrument, the social functioning domain achieved better scores after the surgery, with an average of 61.62 in the pre-transplantation and 76.69 in the post-transplantation.<sup>8</sup>

It is also worth highlighting that most of the patients in this study were classified as having high levels of severity of liver disease by the MELD and CTP criteria, and groups with more advanced stages on the CTP scale had a negative impact on social interaction before the transplantation, as demonstrated in a Brazilian study that analyzed the influence of liver disease severity on patients' quality of life.<sup>9</sup>

The results found in this study draw attention to the psychological and behavioral changes that occurred during the disease phase, such as irritability and loneliness, which interfere with family and friends, affecting family and the social dynamics, which can have repercussions after the transplantation.

During the application of the LDQOL, some patients reported difficulties in the family relationship due to the period of suffering they had, in which they experienced a routine of physical limitations, encephalopathy crises, periodic consultations and hospitalizations, which demanded the constant presence of a close relative. Many times, the companion, in addition to being overwhelmed with the demands of care, experienced the anguish of waiting and suffering with the beloved one.

On the other hand, in the Loneliness domain,

most of the patients presented high quality of life scores in comparison to the pre-transplantation period, with the score ranging from 90.1 to 95.9 post-transplantation.

These results were different from those found in a study with 221 patients with indication for liver transplantation, which found lower values, with an average of 75.84.<sup>10</sup>

The involvement in the family and social lives enables the improvement of the social dimension of quality of life, highlighting the important role of the family in the recovery and in facing the condition experienced.<sup>11</sup>

A qualitative study carried out in Iran with patients with critical liver cirrhosis showed that the patients presented a low quality of life and did not feel that they received family support, stating that they wanted to have a better relationship with family members to reduce distress and improve the coping with the disease.<sup>12</sup>

A study conducted in Tuscany, Italy, with 225 hepatic transplant recipients, found that only 5.3% of the participants presented social isolation, and 0.4% lack of psychological support. The study has also revealed that only 4.8% of the patients reported having insufficient family support, while 24% reported having no personal, social or family difficulties. Despite this, the study has found that 39.5% had depression after the transplantation, which may aggravate or contribute to social isolation.<sup>13</sup>

Although several authors report the importance of the family involvement in the quality of life of patients with liver disease, in a study carried out in France with eight liver transplant patients, some patients reported that the family treats them like any other healthy person after transplantation. However, they believe that the family members are not able to understand the whole process experienced by the patient, because they do not have the same experience and, therefore, many patients do not feel like sharing the subjects or activities related to liver transplantation with their relatives, which may negatively influence the patient's quality of life.<sup>14</sup>

It is important to highlight that the presence of the hypertension comorbidity resulted in a drop in the QoL scores after transplantation in the Loneliness and Health distress domains. Some authors have reported that the prevalence of hypertension, diabetes and hyperlipidemia increases continuously after the transplantation, and it may interfere with the survival and quality of life of individuals.<sup>15</sup>

## Health distress

In the domain Health distress, it was observed significantly lower scores in the pre-transplantation period, with high levels of quality of life after transplantation, with an average of 55.5 and 87.9, respectively.

The assessment of this domain involves the approach of negative feelings presented by patients, such as discouragement, frustration and depreciation, which may be related to the important psychological changes in the pre-transplantation period, affecting the quality of life.

Many are the reasons for distress that are part of the routine of a patient who needs the transplant, from the discovery of an incurable chronic disease, physical weakness, changes in family structure, waiting time for a compatible donor, uncertainty about the outcome of the surgery, and fear of the future.<sup>16</sup> For many, this all adds up to the need to look for a transplant center away from home.

During the waiting time, patients face many changes regarding their way of life, involving limitations of social life and leisure activities, inability to perform daily or professional activities, dietary restrictions, financial difficulties, and anxiety related to surgery; which may compromise their mental health and trigger psychic changes, being essential the psychological and psychiatric support in the transplant units.

The results of this research were similar to the results of a study with application of the LDQOL scale, which evaluated the quality of life of patients waiting for a liver transplantation and found average values of 56.1 in this domain.<sup>4</sup>

A study with 70 patients in the waiting list identified relevant depressive psychopathological symptoms in 47% of patients, with high frequency to "feel sad" (94%), followed by "not interested in things" (91%), "feeling useless or worthless" (82%), "feeling alone" (73%), and "feeling desperate about the future" (30%). The reported emotional changes were significantly associated with the characteristics of these patients, including partner absence and alcohol abuse. Among the patients with a depressive profile, 80% had a perception of family dysfunction and 79% considered the family/social support non-functional, demonstrating the relevance of family participation in the treatment.<sup>17</sup>

In a study carried out in Los Angeles, California, with 196 liver recipients, lower proportional averages were obtained (4.84) in the application of the Post-Liver Transplant Quality

of Life (pLTQ) instrument, which uses a scale ranging from 1 to 7 scores.<sup>18</sup>

In a study carried out in Taiwan with patients undergoing liver transplantation, the authors identified that expressive symptoms of depression ( $p=0.005$ ) were experienced after the surgery, being related to transplant distress and negatively affecting the social activities related to employment and leisure, which may contribute to the social well-being and improvement of the quality of life of transplant recipients. Among the patients, 20.8% presented depression, being 13.2% mild, 6.6% moderate, and 1.0% severe depression.<sup>19</sup>

On the other hand, in a study using the specific instrument Chronic Liver Disease Questionnaire (CLDQ), the post-transplantation group showed significant improvement in scores in all the domains assessed, involving physical aspects (fatigue, activity, abdominal symptoms, systemic symptoms), emotional function, and health distress.<sup>8</sup>

Despite this, it is relevant to consider that transplanted patients may suffer anxiety due to the concern about the side effects of the immunosuppressive treatment, difficulties in adapting to the post-transplantation conditions, and concern about the risk of death even after surgery due to fear of organ rejection.<sup>14</sup>

Rejection is a major cause of distress for patients and a challenge to be faced by the team that cares for transplant patients. Researchers from Sweden cross-checked the results of an instrument on the perceived risk of graft rejection with a questionnaire coping and SF-36 among 229 kidney, liver, heart and lung recipients, and they found a correlation with lower values of QoL in the mental health domain and relation with negative dimensions of coping: fatalism, renunciation, protest, social isolation, and intrusion.<sup>20</sup>

In this sense, the psychological assessment must be present throughout the perioperative period, in order to identify possible changes and offer appropriate interdisciplinary treatment to the demands that arise in each phase.

## Stigma of hepatic disease

The domain stigma of hepatic disease had a great variation, presenting an average considered very low, with 58.6 in the pre-transplantation period, rising to 93.7 in the post-transplantation period.

Due to the evolution of the severity of the liver disease, the clinical manifestations bring several physical changes that alter the body image of the



patients, which can imply in the self-perception and in the relationship with the others. Among the most common signs, it is possible to mention jaundice, dry skin, increased abdominal volume as a result of ascites, loss of muscle mass, edema, and the appearance of vascular spiders. In men, gynecomastia can also occur, which causes embarrassment because it is associated with the characteristics of femininity.

These physical manifestations, associated with social limitations, are extremely stigmatizing for patients, who tend to feel different, discriminated and excluded. In conversations with the study participants, some reported the absence of friends and relatives after the discovery and worsening of the disease, which caused emotional pain and rupture of affective bonds. Others reported feeling the looks of other people, which made them avoid leaving home and limiting the social interaction.

Similar values in post-transplantation were obtained in two studies that assessed the quality of life with the same scale, one performed in Portugal, in which the patients reached an average of 90.5, six months after the surgery, and another recent study conducted in Spain, which had average of 90.6.<sup>5-6</sup>

Associated with physical changes, the social imagery about hepatic cirrhosis in society also reinforces the stigma brought on by the disease. In a qualitative research about the social representations of people with alcoholic liver cirrhosis, there was the expression of a negative self-concept, anguish and dissatisfaction related to the changes in their image due to the clinical picture of the disease. As well as feelings of rejection and low self-esteem, which is associated with the inadequate moral conduct related to the alcohol use issue.<sup>21</sup>

The stigma of liver disease is often due to the misconception that all patients with cirrhosis have a history of alcohol abuse. A study conducted in the United States with 149 patients diagnosed with alcoholic cirrhosis, hepatic steatosis, among others, indicated that 89% of the participants perceived some type of stigma related to liver disease, mainly related to the alcohol use (82%) and culpability for contracting the disease (72%). Although 12.1% were not diagnosed with alcoholic cirrhosis and 52.5% stated that the diagnosis was not related to the behavior.<sup>22</sup>

The same study found that patients who felt more stigmatized were those who had less social support ( $p < 0.001$ ), were more depressed ( $p < 0.001$ ), had worse quality of life ( $p < 0.001$ ) and lower demand for medical care ( $p = 0.001$ ). Moreover, 22% of the respondents said they did not seek the service

for fear of being judged due to the stigma related to the liver disease.<sup>22</sup>

Many people associate the liver cirrhosis with the excessive consumption of alcoholic beverages, placing the patient as the main cause of the consequences of the disease, being considered less deserving of a complex treatment like the transplant. This fact was reinforced by a focal group of 13 patients with chronic liver disease in the United States, who reported that people generally assume that patients with liver disease were responsible for the condition, due to the fact that the disease is associated with alcohol and/or drug abuse, making them feel stigmatized and ashamed. It is for this reason, therefore, that they avoid sharing with others the diagnosis, to protect themselves from the discrimination of the population.<sup>23</sup>

On the other hand, there is also the prejudice regarding the hepatitis carriers, caused by the lack of knowledge of the population and fear of the transmissibility, which has also contributed to the removal of people connected with the sick person. "Fear of disease is a historical fact, just as the fear of becoming infected by something is an inherent condition of ignorance and the generation of stigmata, which compromises the social relations, family dynamics and the perception of oneself".<sup>21:674</sup>

The liver disease is not only a disease and the cause of cirrhosis, but also a psychological, familiar and social pathology. The stigma of the infected individual negatively interferes with their self-esteem and quality of life, affecting the course of the disease and treatment success.<sup>24</sup>

The social stigma of the liver disease is reflected in different areas of the individual's life, strongly interfering with their self-image and social relationships. However, with a successful transplantation and surgical recovery, the physical stigmas of the liver disease disappear and the person returns to a normal life. A study has observed an important improvement in patients' self-image and self-esteem after one year of liver transplantation, representing a significant improvement in the quality of life in this domain.<sup>16</sup>

The collection of data involving the pre and post-transplantation in the cross-sectional design was considered a limitation of the study. However, the average transplant time was low (three years), and the experience in the care of transplant patients and during the application of the instruments demonstrated how much the experience of the disease and of the transplant were remarkable in the life of the patients and that were able to be reported in

the period assessed. It should also be highlighted as a limitation of the study, the scarcity of studies involving the application of the LDQOL instrument to deepen the comparison and discussion of the variables studied.

## CONCLUSION

The study has made it possible to assess the psychosocial dimension of the quality of life of patients before and after a liver transplantation. It confirmed the hypothesis of the positive impact on the psychosocial aspects of the quality of life of the recipients, being more notable in the areas of health distress and stigma of hepatic disease, which were considered to be quite compromised in the pre-transplant period.

The recipients were able to envision several benefits of the liver transplantation, favoring a better family and social involvement, emotional aspects and suppression of stigma, representing an effective treatment for people with advanced liver disease.

The identification of factors that interfere in the quality of life amplifies the knowledge about the affected dimensions in the pre-transplantation period, which requires greater attention from the professionals involved in care, contributing to the planning of a better care, which should be directed to the needs and prevention of situations that may interfere in the results of the transplantation.

It is also pointed out the possibility of future qualitative research, in order to deepen the study of factors that interfere in the psychosocial dimension of liver transplant recipients.

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