














# Profile and Social Assessment of Liver Transplant Candidates: A Retrospective Approach

Luzia Cristina de Almeida Serrano<sup>1</sup> , Vinícius Araújo Pereira<sup>1\*</sup> , Rafael Mangas Barbeiro<sup>2</sup> , William José Duca<sup>3</sup> ,  
Rita de Cássia Martins Alves da Silva<sup>3</sup> , Paulo César Arroyo Júnior<sup>3</sup> , Jemima Domingos Lemes<sup>3</sup> , Allana C.  
Fortunato<sup>3</sup> , Adriano Virches<sup>1</sup> , Eliane Tiemi Miyazaki<sup>3</sup> , Adília Maria Pires Sciarra<sup>1</sup> , Renato Ferreira da Silva<sup>1</sup> 

1. Faculdade de Medicina de São José do Rio Preto  – Programa de Pós-Graduação em Ciências da Saúde – São José do Rio Preto/SP, Brazil.

2. Anhanguera-Uniderp University  – Curso de Graduação em História – Nova Granada/SP, Brazil.

3. Fundação Faculdade Regional de Medicina de São José do Rio Preto  – Hospital de Base – Unidade de Transplantes – São José do Rio Preto/SP, Brazil.

\*Corresponding author: v.adm1997@hotmail.com

Section editor: Ilka de Fátima Santana F Boin 

Received: Nov. 14, 2023 | Accepted: Dez. 21, 2023

## ABSTRACT

**Introduction:** The complexity of liver transplantation requires a highly qualified team, in which the social worker plays a crucial role in analyzing and intervening in the social situation of candidates. **Objectives:** To investigate the social profile of liver transplant candidates and relate it to the interventions and reflections made during the social assessment at the Hospital de Base Liver Transplant Unit. **Methods:** Based on the records of the Social Work, the information of the candidates evaluated between January 2019 and December 2020 was analyzed. This quantitative-qualitative, retrospective, descriptive and documentary study, with participant observation, was conducted from a dialectical perspective. **Results:** During the data collection period, 174 evaluations were obtained. Social profile: Average age 55.8 years, predominantly male (N=116; 66.7%), with a partner (N=129; 74.1%), living in municipalities in the state of São Paulo (N=124; 71.3%), incomplete primary education (N=68; 39.1%), low level of education (N=65; 37.4%), inactive in the job market (N=151; 86.8%), accessing social security benefits (N=120; 69%), positive acceptance of the transplant (N=158; 90.8%), nuclear family (N=120; 69%), offer of care and family adherence (N=172; 98.9%), partial access to medication (N=122; 70.1%), ease of access to the transplant center (N=157; 90.2%), per person family income of 1\2 to 2 minimum wages (N=107; 61.5%) and satisfactory/conserved housing standard and state of repair (N=157; 90.3%). **Conclusion:** The social profile of greater social vulnerability required more interventions in most of the 25 variables assessed, providing important elements for identifying and meeting the social needs of each individual.

**Descriptors:** Situation analysis. Liver transplantation. Health profile. Social work.

## *Perfil e Avaliação Social de Candidatos a Transplante de Fígado: Uma Abordagem Retrospectiva*

## RESUMO

**Introdução:** A complexidade do transplante de fígado requer uma equipe altamente qualificada, no qual o assistente social desempenha papel crucial para analisar e intervir na situação social dos candidatos. **Objetivos:** Investigar o perfil social dos candidatos ao transplante de fígado e relacioná-lo com as intervenções e reflexões efetuadas durante a avaliação social na Unidade de Transplante de Fígado do Hospital de Base. **Métodos:** Com base nos registros do Serviço Social, foram analisadas as informações dos candidatos avaliados entre janeiro de 2019 e dezembro de 2020. Este estudo quantitativo-qualitativo, retrospectivo, descritivo e documental, com observação participante, foi conduzido a partir de um panorama dialético. **Resultados:** Durante o período de coleta de dados, obteve-se 174 avaliações. Perfil social: média etária de 55,8 anos, predominância masculina (N=116; 66,7%), com companheiro/a (N=129; 74,1%), residentes em municípios do estado de São Paulo (124; 71,3%), ensino fundamental incompleto (N=68, 39,1%), baixo nível de instrução (N=65; 37,4%), inatividade no mercado de trabalho (N=151; 86,8%), acessando benefício da previdência social (N=120; 69%), positiva aceitação do transplante (N=158; 90,8%), família nuclear (N=120; 69%), oferta de cuidados e aderência familiar (N= 172; 98,9%), acesso parcial a medicamentos (N=122; 70,1%), facilidade de acesso ao centro transplantador (N=157; 90,2%), renda per capita familiar de 1\2 a 2 salários mínimos (N=107; 61,5%) e padrão habitacional e estado de conservação satisfatório/conservado (N=157; 90,3%). **Conclusão:** O perfil social de maior vulnerabilidade social exigiu mais intervenções na maioria das 25 variáveis avaliadas, fornecendo elementos importantes para a identificação e atendimento das necessidades sociais de cada indivíduo.

**Descritores:** Análise de situação. Transplante de fígado. Perfil de saúde. Serviço social.

## INTRODUCTION

Brazil is among the countries with the highest absolute number of liver transplants, specifically occupying fourth position, having performed a total of 2,044 procedures in 2021, behind India (2,847), China (5,822) and the United States (9,236). However, despite its leading position, the country is still far from meeting the total demand for transplants. In 2022, 2,118 liver transplants were carried out, while the estimated need was 5,254. In other words, only 40.2% of the demand was met.<sup>1</sup>

Meeting this demand involves a central variable: organ donation. Despite the direct impact of the Covid-19 pandemic on donations,<sup>1,2</sup> rates have been increasing positively since the first half of 2023. For this increase to continue, attention needs to be paid to several important factors, such as the rate of medical contraindications for donation, an increase in family refusal of this process and adequate records of potential donors.<sup>2</sup> These figures from the Brazilian Organ Transplant Association (ABTO)<sup>1,2</sup> allow us to reiterate how complex and multifactorial this type of procedure is.

Still on the subject of the complexity of transplants, these procedures involve various health professionals. These agents assess and intervene in the risk factors that can impact on the success and adherence of candidates to treatment. With this in mind, as far as the Liver Transplant Unit team is concerned, the social worker has the role of identifying, analyzing and intervening in the social conditions that condition the candidate's life in relation to continued access to treatment. This professional directs actions that include the application of social assessments and interventions which,<sup>3,4</sup> in this context, relate to the issues of this research.

The social assessment consists of gathering information about the candidate's social profile. It includes sociodemographic variables, acceptability for transplantation, family dynamics, accessibility to the transplant center and socioeconomic conditions. This information is essential for formulating a social opinion, conducting and recording counseling sessions, talking to the transplant team and providing information tools to support the candidate.<sup>4</sup>

Together with the profile survey, the particular needs that condition the candidate are identified, a process that makes it possible to articulate social interventions. In addition, what has been learned by the candidate and his or her affective-family network is also measured, which is essential for joint actions between the Social Work and these agents. The intervention with families is guided by strengthening bonds and encouraging protagonism in the production of health,<sup>5</sup> a process which involves the co-responsibility of the applicant and family for the treatment.<sup>3</sup>

This study demonstrates its relevance by providing sociodemographic, social security and occupational data, as well as helping to gain an in-depth understanding of the social profile of transplant candidates, which is a fundamental process for future research and mapping. This research can also support health professionals, as it can serve as a basis for developing reflections and strategies to meet the social needs of the population waiting for a transplant.

The objective of this research was to demonstrate the interface between the results of the social assessment of liver transplant aspirants and the analyses, positions and interventions of the Social Work regarding facilitating access to treatment. To this end, it was necessary to survey the social profile (sociodemographic, social security, occupational and attitudinal in relation to treatment) of aspirants assessed by the Social Work at the Liver Transplant Unit of the Hospital de Base de São José do Rio Preto, from January 2019 to December 2020.

## METHOD

This study, which is quantitative-qualitative,<sup>6</sup> descriptive,<sup>7</sup> documental<sup>8</sup> and associated with participant observation,<sup>9</sup> analyzed the results using a dialectical approach.<sup>10</sup> In its retrospective approach, no human beings were directly involved since the data were obtained from the social assessment instruments in the files of the Social Work of the Liver Transplant Unit of the Hospital de Base de São José do Rio Preto.

The social evaluations that were analyzed in this study were carried out between January 2019 and December 2020, a total of 24 months.<sup>4</sup> The selection of evaluations included all the candidates evaluated by the Social Work in this time frame, in other words, 100% of the candidates who started treatment at the Unit in the period reported.

Regarding the classifications used in the social assessment tool:<sup>4</sup> the individual level of education was determined based on the level of schooling; the occupational level according to the quality of insertion in the job market; the family model based on the individuals or group of families that lived with the aspirant. Also within this scope, the family typology of adherence was determined because of resolution or evasive responses from family members regarding the candidate's transplant. Family education level was determined by the education level of the family in question.<sup>4</sup>

Microsoft Excel and Google Spreadsheets were used to record the information on the social profile and the care provided, as well as to calculate and process the results. The quantitative results were presented in tables and subjected to descriptive statistical analysis. On the other hand, the qualitative results, which include information about the care provided and which respect the ethical principles of National Health Council Resolution 466/2012, were categorized in a dialectical manner to facilitate their description and analysis.

The research project that precedes this article was approved by the Research Ethics Committee of the São José do Rio Preto Medical School (Opinion: 3.950.444; CAAE: 29383720.3.0000.5415). To develop the scientific discussions and reflections, a documentary and bibliographic survey was carried out in the Pubmed, Web of Science, Google Scholar and SciELO databases.

## RESULTS

From January 2019 to December 2020, the Liver Transplant Unit's Social Work assessed 174 candidates, including 100% of the patients who were admitted for the team's assessments during the period in question. The social profile (Table 1) of these individuals revealed that the majority were male (N=116; 66.7%), had a partner (N=129; 74.1%), came from the state of São Paulo (N=124; 71.3%), had incomplete primary education (N=68; 39.1%), had a bad level of education (N=65; 37.4%), were inactive in the labor market (N=151; 86.8%), had a social security record (N=120; 69%), accepted the transplant (N=158; 90.8%), had a resolution family adherence (N=172; 98.9%), had an intermediate level of family education (N=89; 51.2%), had partial access to medication (N=122; 70.1%), had a per-person family income of 1\2 to 2 minimum wages (N=107; 61.5%), had a bad occupational level (N=63; 43.7%) and had satisfactory housing standards (N=157; 90.23%). The social opinions issued indicated that 108 (62.1%) of the candidates had favorable social conditions for liver transplantation, while 66 (37.9%) had limited favorable conditions.

**Table 1.** Social assessments of liver transplant candidates from 2019 and 2020.

Ages: 15–76 years; average = 55.72(±)10.78	
Variables	N(%)
<b>Gender</b>	
Male	116 (66.7%)
Female	58 (33.3%)
<b>Marital status</b>	
With a partner	129 (74.1%)
Without a partner	45 (25.9%)
<b>Origin</b>	
Other municipalities in the state of São Paulo <sup>a</sup>	124 (71.3%)
Other states in the country <sup>b</sup>	31 (17.8%)
São José do Rio Preto <sup>c</sup>	19 (10.9%)
<b>Education level</b>	
No education	5 (2.9%)
Incomplete elementary school	68 (39.1%)
Complete elementary school	18 (10.3%)
High School Incomplete	9 (5.2%)
High School Completed	39 (22.4%)
Higher Education Incomplete	5 (2.9%)
Higher Education Complete	30 (17.2%)
<b>Level of education</b>	
Low	65 (37.4%)
Intermediate	46 (26.4%)
High	43 (24.7%)
Very high	20 (11.5%)
<b>Occupational level</b>	
Bad	43 (24.7%)
Fair	77 (44.3%)
Good	50 (28.7%)
Very good	4 (2.3%)
<b>Condition of occupational activity</b>	
Active	23 (13.2%)
Non-active	151 (86.8%)
<b>Religion</b>	
Religion	109 (62.6%)
Catholic	42 (24.1%)
Evangelical	17 (9.8%)
No religion <sup>d</sup>	6 (3.5%)

Continue...

**Tabela 1.** Continuation.

Ages: 15–76 years; average = 55.72(±)10.78	
Variables	N(%)
<b>Binding</b>	
Brazilian Unified Health System	162 (93.1%)
Health insurance	12 (6.9%)
<b>Nationality</b>	
Brazilian	173 (99.4%)
French	1 (0.6%)
<b>Social Security/ Welfare connection</b>	
Social security benefit <sup>e</sup>	120 (69%)
Social security benefit <sup>f</sup>	7 (4%)
Contributor	23 (13.2%)
No connection with social security	24 (13.8%)
<b>Residency</b>	
Fixed	146 (83.9%)
Temporary	28 (16.1%)
<b>Communication facilities</b>	
Mobile phone	164 (94.3%)
Fixed telephone	38 (21.8%)
<b>Acceptability for liver transplantation</b>	
Accepted	158 (90.8%)
Accepted with reservations	15 (8.6%)
Rejected	1 (0.6%)
<b>Family model</b>	
Nuclear	120 (69%)
Extensive	47 (27%)
Single-person	7 (4%)
<b>Caregiver</b>	
Family	166 (95.4%)
Third parties(outsiders)	9 (5.2%)
<b>Family adherence typology</b>	
Resolute	172 (98.9%)
Elaborative	2 (1.1%)
<b>Family education level</b>	
Low	24 (13.8%)
Intermediate	89 (51.2%)
High	61 (35%)
<b>Access to medicines through the public network</b>	
Full	45 (25.9%)
Partial	122 (70.1%)
No access	7 (4%)
<b>Access conditions for liver transplant treatment</b>	
Eased	17 (9.8%)
Difficult	157 (90.2%)
<b>Salary conditions</b>	
Up to 1/2 minimum wage	20 (11.5%)
From 1/2 to 2 minimum wages	107 (61.5%)
Above 2 minimum wages	47 (27%)
<b>Extra expenses</b>	
Medication	83 (47.7%)
Transportation	30 (17.2%)
Food	13 (7.5%)
Other <sup>g</sup>	13 (7.5%)
<b>Provider's occupational level</b>	
Bad	63 (43.7%)
Intermediate	56 (32.2%)
Good	42 (24.1%)

Continue...

**Tabela 1.** Continuation.

Ages: 15–76 years; average = 55.72(±)10.78	
Variables	N(%)
Housing standard and state of repair of the property	
Satisfactory/maintained	157 (90.3%)
Not satisfactory/needs improvement	17 (9.7%)
Social opinion	
Favorable	108 (62.1%)
Limited favorable	66 (37.9%)

Source: Own elaboration. a: Municipalities in the state of São Paulo except for the municipality of the transplant center. b: Municipalities in Brazil except for those located in the state of the transplant center. c: Municipality where the transplant center is located. d: Spiritist; Seicho-no-ie. e: Retirement due to length of service; Temporary incapacity benefit; Permanent incapacity benefit; Death pension; Unemployment insurance. f: Continuous benefit; Emergency aid. g: Covenants, housing, exams and consultations.

## DISCUSSION

Regarding the social profile of those aspiring to liver transplantation, the high percentage of males (N=116; 66.7) is similar to studies of the same type (male prevalence > 60%).<sup>11–19</sup> This incidence may be related to the fact that men are more affected by liver disease than women.<sup>20</sup> This may be due to men seeking medical care late, which is possibly linked to gender determinations that put pressure on men to assume the position of family provider as a priority, which may lead them to neglect seeking health services.<sup>21,22</sup>

Also within this scope, the social worker works with multidisciplinary strategies aimed at dealing with the anguish and suffering<sup>23</sup> of the candidate. With an educational focus, as well as reinforcing the idea of transplantation as a right, the social worker also works to reflect on changing preconceived notions about treatment and self-care. These educational actions seek to deconstruct conceptions of the search for treatment and health services as supposedly synonymous with fragility or deviation from gender roles, such as the social imposition of the male figure as the family's absolute provider.<sup>21,22</sup>

As for the findings of candidates with a partner (N=129; 74.1%), they are in line with other studies (most > 60%).<sup>12,14,15,19</sup> In addition to contributing to dialogue and communication between family and team, the presence of a partner is a positive and strategic factor both in terms of conveying information and in terms of family care and monitoring, which are fundamental dimensions of the treatment.<sup>12</sup> In this context, the transplant social worker carries out a humanized process<sup>5</sup> of listening, dialogue and planning with families and candidates<sup>23</sup> so that family care does not become an overload for the partner.

The predominance of individuals from municipalities in the state of São Paulo (N=24; 71.3%) is similar to the findings of previous studies carried out in this Unit.<sup>12,19</sup> This geographical emphasis is justified by the principles of regionalization and hierarchical distribution in the SUS, a structure that tends to absorb demands closer to the transplant centers due to the logistical factor. However, people from other states had access to the Unit (N=31, 17.8%) due to the principles of universality and comprehensiveness advocated in the Organic Health Law (LOA).<sup>24</sup> In contrast, it is important to note that access to health care is still far from being exercised by the entire population, as shown below.

In association with the positions of the Social Work, this information makes it possible not only to identify the most suitable means of transportation but also to ascertain the degree of knowledge that the applicants and their families have about access to the rights of locomotion.<sup>12</sup> With this, in addition to education about rights, the necessary transportation can also be articulated via Treatment Outside the Home (TFD, in Portuguese) and/or via assistance, both aimed at exercising the right to health.<sup>24</sup>

Regarding schooling, the findings on aspirants with incomplete primary education (N=68; 39.1%) show proximity not only to other studies<sup>12, 16, 19</sup> but also in relation to surveys by the Brazilian Institute of Geography and Statistics (IBGE). According to the Institute, incomplete primary education in 2019 reached 32.2%, characterized as the highest educational rate in the aforementioned survey.<sup>26</sup> The interface between education and health is fundamental, both in the context of the health conditioning factors and determinants emphasized by the LOA,<sup>24</sup> and in the field of conveying and assimilating strategic information that circumscribes the actions and guidelines of the transplant teams.

Individual education, in relation to the prominence of the low level (N=65; 37.4%), shows conformity with other studies<sup>12,16,19</sup> and with the data already mentioned the levels of education captured in Brazil by the National Household Sample Survey (PNAD). Considering that access to education influences the exercise of citizenship and social development,<sup>26</sup> the social worker is attentive to the individual's level of education, as this can indicate a greater or lesser need for educational actions or advice to convey rights.<sup>5</sup>

Still within this scope, the level of individual education allows for a pedagogically personalized service, enabling the process of listening<sup>18</sup> and dialogue that is efficient, didactic and in line with the social conditions of each applicant and/or family member and

directed towards access to rights in a conscious and empowered manner. For example, in social security guidance, in legal terms, the progress of processes and even the use of digital platforms, such as “My INSS”,<sup>27</sup> are subjected to a process of intelligibility based on the profile of the people served. The same is true of the TFD, as counter-referral reports, subsistence allowances,<sup>25</sup> the administration of appointments compatible with the family’s reality, and other procedures are “decoded”, applicants and their families access their rights and become active and aware<sup>5</sup> of the processes that condition them.

The quantitative prevalence of subjects in an inactive occupational condition (N=151; 86.8%), which is also similar in other studies,<sup>12,15-19</sup> can be contextualized by the problem of the huge transplant queues of people suffering from serious and/or chronic illnesses.<sup>2</sup> As a result of these illnesses, many people are affected by complications that lead to their absence from the job market. However, the candidate is also affected by national unemployment, which reached 8.7% in the third quarter of 2022, affecting a total of 9.5 million Brazilians.<sup>28</sup>

Because of its impact on income, inactivity in the labor market directly affects the livelihood of many families.<sup>12</sup> This situation is even worse when a family member has to restrict their professional activities to act as a caregiver and/or companion. Considering the various occupational structures and configurations, the social worker operates according to the specificities of the context involving the candidate and their family, with initiatives aimed at corroborating safe access to treatment.<sup>5</sup>

As for the predominance of regular occupational status (characterized by income and job stability) (N=77; 44.3%), this demonstrates a favorable character regarding transplant treatment, suggesting greater possibilities of access to social security benefits. However, despite being covered by social security,<sup>27</sup> it is clear that many candidates face obstacles such as a lack of information, excessive bureaucracy, and delays in analysis deadlines, among others, to gain access to these benefits.

The prominence of the Catholic religion (N=109; 62.64%) is in line with the Datafolha Institute survey, in which the largest portion of the Brazilian population was identified as Catholic (50%±2%).<sup>29</sup> This variable, as a phenomenon that articulates religiosities and spiritualities, can play a relevant role in the social context of treatment. Religiosity can have a beneficial effect on an individual’s mental and physical health, helping them to accept and adopt healthy habits,<sup>30</sup> which is important at all stages of transplant treatment.

In this sense, attention must also be paid to ethical and religious factors, as they may require the transplant to be replanned. For example, the procedure with Jehovah’s Witnesses (who do not adhere to blood transfusion) requires hematological preparation of the individual and, intraoperatively, technologies to reduce blood loss, which allows access to treatment without violating these ethical issues.<sup>31</sup> Therefore, through qualified listening, dialog,<sup>18</sup> and respect for the religious plurality of individuals, including those who choose not to start or continue with transplant treatment, the social work professional can understand the religious conceptions of the candidate and their family, articulating a positive interface between treatment and spirituality.<sup>30</sup>

The prominence of candidates with access to social security benefits (N=120; 69%) is in line with previous research.<sup>12,19</sup> In general, these benefits represent a crucial source of income for the subsistence of individuals and their families, especially in the context of the (already) mentioned transplant queues,<sup>1</sup> a scenario in which it is notable that many people are unable to work due to chronic illnesses.

Now, the role of the social worker is fundamental in providing strategic access to benefits and other appropriate rights, as well as the transplant treatment itself.<sup>5</sup> Also in this area, in the case of beneficiaries permanently incapacitated for work, when appropriate, the social worker advises the candidate and their family to request an increase of 25% in the value of the benefit, a feasible process if there is evidence that the beneficiary needs assistance from another person.<sup>27</sup>

The quantitative emphasis on fixed residence (N=146; 83.9%) at origin cannot be understood as synonymous with comfort for the candidates because as seen in other studies,<sup>12,19</sup> a considerable proportion of aspirants live in municipalities or states outside the municipality of the transplant center.

In this context, when there is a medical indication to stay around the transplant unit, it is not always possible for candidates and their families to bear the costs of a temporary stay. Faced with this demand, the social worker carries out a process of listening, dialog<sup>23</sup> and guidance to make it possible to articulate and then refer them to support homes that are in line with the particularities and preferences of the family-candidate group.<sup>12,19</sup>

The predominance of communication via mobile phone (N=164; 94.3%) is in line with data from the IBGE, which indicates that in 2021 alone, 155.2 million Brazilians over the age of 10 had a mobile phone for personal use, or 84.4% of the population.<sup>32</sup> In the context of the transplant service, the Social Work, candidates, their families and other team members establish communication networks that optimize time, facilitate the sending of documents, deliveries and information tools, and help register demands. As a result, the mobile phone is an allied tool in planning actions to prevent impacts, promote health, share experiences and strengthen bonds.<sup>33</sup>

The high percentage of acceptability for liver transplantation (N=158; 90.8%) shows that it is close to other studies in which acceptance rates are higher than 85%. This factor may be linked to the extensive guidance and information provided by the

transplant team,<sup>12,16,19</sup> which helps to improve the understanding of aspirants and their families so that they can make autonomous and informed decisions about adherence to treatment.<sup>12</sup>

It is also important to note that providing health information is not only the responsibility of the team, but also a fundamental right of the public health user.<sup>24</sup> When individuals and their family networks are properly informed, trained and empowered, their actions become even more positive in the context of treatment.

As for nuclear families (N=120; 69%), the findings are in line with other studies.<sup>12,19,34</sup> Finding out the type of family can facilitate the social worker's guidance, planning and interventions, as it shows how these groups are organized. By understanding the family structure, interventions and dialogues become more humanized and concrete, especially when it comes to the complex processes involved in transplantation, such as physical recovery, adaptation and experience with the new organ. In this sense, the social support of family and emotional networks is not only an ally but also fundamental.<sup>12,34</sup>

The predominance of family caregivers (N=166; 95.4%), consistent with other studies showing a presence of more than 90%, once again reinforces the crucial role of families in the context of care.<sup>12,19</sup> The fact that family caregivers are a potential decisive agent for a favorable social opinion is due to their contributions as disseminators of information about the treatment<sup>12</sup> and emotional support for the candidate due to the pre-existing emotional bond.

It is important to emphasize that in addition to articulating possible caregivers from the family network, the Social Work also provides guidance and conveys the rights of the caregiver<sup>5</sup> as a subject of law.<sup>24</sup> However, it is also essential that the social worker directs their qualified listening<sup>23</sup> to monitor how sustainable the act of caring and accompanying the candidate is, since family caregivers are potentially subject to intense and sometimes uninterrupted work, as well as stress and overload.

The predominance of a resolute family response (N=172; 98.9%) is also similar to the data mentioned previously (> 90%).<sup>12,19</sup> This high level of adherence can be explained by the fact that families understand that transplantation represents a possibility of treatment for a family member suffering from a serious and/or chronic illness, even if there are various risks.<sup>35,36</sup> To minimize insecurities and emphasize autonomous decision-making, the Social Work and the entire team provide guidance and information during treatment,<sup>5,24</sup> which also contributes to family and user adherence.

The prominence of the intermediate level of family education (N=89; 51.2%), observed in this Unit (<55%),<sup>12</sup> can be attributed to the predominant family configurations (nuclear and extended), in which the members have varying levels of education, a factor that can balance out the results for the middle. The higher the level of education, the easier it tends to be for the family to assimilate guidance.<sup>12</sup> In this context, the social worker pays attention to each consultation and dialogue, as well as listening to the family's needs,<sup>18</sup> with a focus on providing personalized, didactic guidance that conveys the democratization and universalization of health.<sup>24</sup>

As for the percentile of applicants with partial access to medicines (N=122; 70.11%) through the public network, similar to that found in another study (> 70%),<sup>12</sup> this can be attributed to a problem emphasized by the National Health Council, the structural insufficiency or lack of medicines.<sup>37</sup> This issue goes beyond an administrative problem, as it represents a violation of the fundamental right to comprehensive therapeutic care, including pharmaceutical care, as recognized in the Health LOA.<sup>24</sup>

In this context, the social worker dialogues with applicants, families and the medical team, reinforcing the importance of prescribing medicines on the National List of Essential Medicines. This is done to facilitate access and to avoid lawsuits<sup>38</sup> as well as delays in the legal release of the medication, which can have an impact on the individual's health. In this scenario, due to the lack of structural compliance with the right to health (in terms of comprehensive therapeutic care),<sup>24</sup> donations of medicines by solidarity networks of other individuals undergoing treatment often end up representing one of the few agile ways to remedy this situation.

Easy geographical access (N=157; 90.2%) to the transplant center, consistent with previous studies showing an access rate of over 85%,<sup>12,19</sup> is in line with the coverage offered by the SUS, especially regarding the TFD.<sup>24, 25</sup> The Social Work provides advice and guidance to candidates and their families to ensure compliance with the legal requirements for access to the TFD and other benefits, especially to avoid losing these benefits. This process helps to reduce the burden of legal bureaucracy and stress during treatment.

The prominent per-person family income of ½ to 2 minimum wages (N=107; 61.5%), which is in line with a previous survey that also shows a percentage higher than 60%,<sup>12</sup> is also in line with the average per-person household income of Brazilians in 2020 (R\$1,349.00). Meanwhile, per-person incomes above 2 minimum wages (N=47; 27%) and up to ½ minimum wages (N=20; 11.5%), which are also similar to those found in a previous study,<sup>12</sup> may reflect national income inequality by region, gender, and color, among others, as addressed by the IBGE through the Continuous PNAD.<sup>39</sup>

The emphasis in spending on medicines (N=83; 47.7%), which was also observed in a previous survey,<sup>12</sup> indicates that half of the applicants do not have full access to public healthcare, often leading them to use their own resources to buy medicines. In exceptional cases, the social worker investigates the availability of donations at the outpatient pharmacy. However, the social

worker's actions are aimed at conveying access to comprehensive treatment as a fundamental right,<sup>5,24</sup> in other words, charity does not replace the right and should not be understood in this way.

Regarding the occupational level of the family provider, the predominance of the bad indicator (N=63; 43.7%) may vary according to the current configuration of the socioeconomic field. Previous studies have shown the respective variation in percentages: 24.7%, 67.5%, and 12.3%.<sup>12,19</sup> This negative indicator may be linked to the inactivity factor, which may be linked to the fact that the provider is sometimes the candidate undergoing treatment and is thus impacted by chronic/serious illness and unemployment.

Still within this scope, high levels of unemployment, coupled with a highly demanding job market,<sup>3,28</sup> can considerably affect access to an active job position. With this in mind, the social worker articulates actions aimed at accessing and/or maintaining possible benefits, as well as reintegrating or securing ties in the labor market. These factors can contribute to a positive scenario in the field of autonomy and financial management for the family as a whole, helping not only to facilitate access but also to maintain treatment.<sup>12</sup>

The majority of people with satisfactory housing standards, in other words, properties in a good state of repair (N=157; 90.3%) is similar to previous findings (> 85%).<sup>12,19</sup> This reality is possibly justified by the influence of housing programs, in which there are dynamics of land regularization, housing improvement and even a reduction in interest rates for real estate loans.<sup>40</sup> Housing is a determining factor for health,<sup>24</sup> as well as being one of the spaces most frequented by families and aspirants. In this sense, well-maintained housing is essential for the care of individuals, especially those on immunosuppression, as it considerably reduces the risk of contamination by bacteria and fungi.<sup>19</sup>

Regarding the result of the social worker's assessment, the prominence of the favorable opinion (N=108; 62.1%), similar to previous studies (>60%),<sup>12,19</sup> characterizes the synthesis of the social study carried out in the assessment process. Even if the social opinion is defined as favorable for the transplant to go ahead, the social worker continues to work together with the families and candidates/transplant recipients.<sup>19</sup> These continuous actions seek constant access since the reality investigated changes according to the dynamics of support networks, family relationships and social policies.

## CONCLUSION

The analysis of the social profile of liver transplant candidates, based on twenty-four (24) social assessment variables, reveals a population with lower social vulnerability in ten (10) categories: marital status, religion, links with SUS, nationality, means of communication, acceptance of the transplant, family model, caregiver, family adherence and access conditions.

On the other hand, greater social vulnerability was observed in fourteen (14) categories: gender, origin, level of individual and family education, inactivity, occupational level in the labor market, social assistance or social security ties, partial access to medication, per person family income and extra expenses. This profile provides important elements for identifying and reflecting on the social needs/demands of each assisted individual.

The various social opinions, although favorable to the transplant, demonstrated demands on the Social Work. The other opinions (limited favorable) suggested the need for more attention, monitoring and care but did not constitute a contraindication to the transplant. In addition to the effectiveness of the professional actions of the Social Work being manifested in the evaluation process, this also occurs to the extent that the analysis is followed by personalized interventions and guidance. In general, these dynamics serve as a basis for decision-making by applicants and their families with a view to exercising their rights.

Thus, professional actions take place through a process of humanizing care and the dynamics of respect and consideration for pluralities and differences. By accessing health rights in accordance with the particularities that shape demand, it is possible to reduce financial impacts, which corroborates with family security and facilitates access to transplantation, in accordance with the fundamental principles of the SUS.

Considering the above, further research is recommended to identify the effectiveness of the work of social workers in accessing liver transplants, as well as make it possible to increase and improve their professional tools.

## CONFLICT OF INTEREST

Nothing to declare.

## AUTHOR'S CONTRIBUTION

**Substantive scientific and intellectual contributions to the study:** Serrano LCA, Pereira VA, Silva RF; **Conception and design:** Duca WJ, Silva RF, Pereira VA, Serrano LCA, Silva RCMA, Fortunato AC; **Data analysis and interpretation:** Serrano LCA, Pereira



VA, Arroyo Júnior PC, Lemes JD, Sciarra AMP, Miyazaki ET, Barbeiro RM, Fortunato AC; **Article writing:** Serrano LCA, Sciarra AMP, Pereira VA, Barbeiro RM, Virches A, Duca WJ; **Critical revision:** Serrano LCA, Pereira VA, Sciarra AMP, Silva RF, Virches A, Silva RCMA; **Final approval:** Pereira VA.

## DATA AVAILABILITY STATEMENT

Data will be available upon request.

## FUNDING

Not applicable.

## ACKNOWLEDGEMENT

Not applicable.

## REFERENCES

1. Associação Brasileira de Transplante de Órgãos (ABTO). Registro Brasileiro de Transplantes: Dimensionamento dos Transplantes no Brasil e em cada estado (2015-2022). Brasília: ABTO; 2022.
2. Associação Brasileira de Transplante de Órgãos (ABTO). Registro Brasileiro de Transplantes: Dados Numéricos da Doação de Órgãos e Transplantes Realizados por Estado e Instituição no Período: janeiro/junho - 2023. Brasília: ABTO; 2023.
3. Adeodato AI, Rolim GN, Andrade MD. Determinantes sociais da saúde como desdobramentos da questão social: análise da entrevista social no transplante hepático. *Research Gate*. 2020;20(2):157-79. <https://doi.org/10.18391/req.v20i2.5396>
4. Bustamante DA, Serrano LCA, Duca WJ, Silva RF, Silva RCMA. Adaptação do instrumental de avaliação social em transplante hepático. *Arch Health Sci*. 2019;26(2):99-106. <https://doi.org/10.17696/2318-3691.26.2.2019.1526>
5. Brasil. Conselho Federal de Serviço Social. Parâmetros para Atuação de Assistentes Sociais na Política de Saúde. Brasília: CFESS; 2010.
6. Souza KR, Kerbaury MTM. Abordagem quanti-qualitativa: superação da dicotomia quantitativa-qualitativa na pesquisa em educação. *Educ Filosofia*. 2017;31(61):21-44. <https://doi.org/10.14393/REVEDFIL.issn.0102-6801.v31n61a2017-p21a44>
7. Silveira DT, Córdova FP. Unidade 2 – a pesquisa científica. In: Gerhardt TE, Silveira DT, organizadores. *Métodos de pesquisa*. Porto Alegre: Editora da Universidade Federal do Rio Grande do Sul; 2009. p. 33-44.
8. Kripka RML, Scheller M, Bonotto DL. Pesquisa documental: considerações sobre conceitos e características na pesquisa qualitativa. *Revista de Investigaciones UNAD*. 2015;14(2):55-73.
9. Mónico LS, Alferes VR, Castro PA, Parreira PM. A observação participante enquanto metodologia de investigação qualitativa. *Atas CIAIQ*. 2017;3:724-33.
10. Masson G, Falch SE. O materialismo histórico-dialético nas pesquisas em Políticas Educacionais. *Rev Est Teóricos y Epistem Políti Educati*. 2018;3:1-15. <https://doi.org/10.5212/retepe.v.3.011>
11. Deutsch-Link S, Weinberg EM, Bittermann T, McDougal M, Dhariwal A, Jones LS, et al. The Stanford Integrated Psychosocial Assessment for Transplant Is Associated With Outcomes Before and After Liver Transplantation. *Liver Transpl*. 2021;27(5):652-67. <https://doi.org/10.1002/lt.25975>
12. Serrano LCA, Pereira VA, Jesus GA, Virches A, Silva RF, Duca WJ, et al. Application of the Validated Social Assessment Instrument for Liver Transplantation Candidates. *Trans Procced*. 2022;54(5):1290-4. <https://doi.org/10.1016/j.transproceed.2022.02.067>
13. Stine JG, Stukenborg GJ, Wang J, Adkins A, Niccum B, Zimmet A, et al. Liver transplant candidates have impaired quality of life across health domains as assessed by computerized testing. *Annals Hep*. 2020;19(1):62-8. <https://doi.org/10.1016/j.aohep.2019.06.018>
14. Garcia CS. Impacto psicossocial de pacientes candidatos a transplante de fígado. *Saúde e Pesquisa*. 2018;11(1):27-38. <https://doi.org/10.17765/1983-1870.2018v11n1p27-38>
15. López-Navas AI, Ríos A, Vargas Á, Pons JA, Martínez-Alarcón L, Ruiz-Manzanera JJ, et al. Psychological profile and disease-coping strategies of patients on the waiting list for liver Transplantation. *Cir Esp*. 2019;97(6):320-8. <https://doi.org/10.1016/j.cireng.2019.06.004>

16. Marques D. Fatores de risco para a mortalidade em candidatos ao transplante de fígado em lista de espera: estudo de coorte retrospectivo. Ribeirão Preto. Thesis [PhD ENFERMAGEM FUNDAMENTAL] – Universidade de São Paulo; 2022.
17. Swanson A, Geller J, DeMartini K, Fernandez A, Fehon D. Active Coping and Perceived Social Support Mediate the Relationship Between Physical Health and Resilience in Liver Transplant Candidates. *J Clin Psychol Med Settings*. 2018;25(4):485-96. <https://doi.org/10.1007/s10880-018-9559-6>
18. Berry KA, Kent D, Seetharaman S, Wong R, Mohamad Y, Yao F, et al. Loneliness in adults awaiting liver transplantation at 7 U.S. transplant centers. *Annals Hep*. 2022;27(5):100718. <https://doi.org/10.1016/j.aohep.2022.100718>
19. Serrano LCA, Duca WJ, Silva RF, Silva RCMA, Arroyo Júnior PC, Felício HCC, et al. Perfis sociais dos candidatos a transplante de fígado em um hospital-escola no interior paulista. *RCL*. 2019;4(2):1-12.
20. Buettner N, Thimme R. Sexual dimorphism in hepatitis B and C and hepatocellular carcinoma. *Semin Immunopathol*. 2019;41(2):203-11. <https://doi.org/10.1007/s00281-018-0727-4>
21. Batista GF, Drumond EF, Fonseca MC, Modena CM. Representações de gênero pelos gestores locais de saúde. *Saúde em Redes*. 2018;4(2):51-8. <https://doi.org/10.18310/2446-4813.2018v4n2p51-58>
22. Deus VAH, Silva RMCRA, Pereira ER, Silva RCF, Oliveira EF, Chicharo SCR, et al. Preceptoria in teaching about men's health from the perspective of the body in light of Merleau-Ponty: an integrative review. *Research Society Dev*. 2020;9(3):e108932500. <https://doi.org/10.33448/rsd-v9i3.2500>
23. Santos AB. Escuta qualificada como ferramenta de humanização do cuidado em saúde mental na Atenção Básica. *APS em Revista*. 2019;1(2):170-9. <https://doi.org/10.14295/aps.v1i2.23>
24. Brasil. Presidência da República. Lei nº 8.080, de 19 de setembro de 1990. Dispõe sobre as condições para a promoção, proteção e recuperação da saúde, a organização e o funcionamento dos serviços correspondentes e dá outras providências. Brasília: Diário Oficial da União; 1990 [Accessed on: 09 nov. 2023]. Available at : [http://www.planalto.gov.br/ccivil\\_03/leis/l8080.htm](http://www.planalto.gov.br/ccivil_03/leis/l8080.htm)
25. Brasil. Ministério da Saúde. Portaria nº 55, de 24 de fevereiro de 1999. Dispõe sobre o Tratamento Fora de Domicílio. Brasília: Diário Oficial da União; 1999. [Accessed on: 09 nov. 2023]. Available at: [https://bvsm.s.saude.gov.br/bvs/saudelegis/sas/1999/prt0055\\_24\\_02\\_1999.html](https://bvsm.s.saude.gov.br/bvs/saudelegis/sas/1999/prt0055_24_02_1999.html)
26. Instituto Brasileiro de Geografia e Estatística [IBGE]. Conheça o Brasil - População – Educação [Internet]. Brasília; 2023 [Accessed on: 09 nov. 2023]. Disponível em: <https://educa.ibge.gov.br/jovens/conheca-o-brasil/populacao/18317-educacao.html>
27. Brasil. Presidência da República. Lei nº 8.213, de 24 de julho de 1991. Dispõe sobre os Planos de Benefícios da Previdência Social e dá outras providências. Brasília: Diário Oficial da União; 1991 [Accessed on: 09 nov. 2023]. Available at: [https://www.planalto.gov.br/ccivil\\_03/leis/l8213cons.htm](https://www.planalto.gov.br/ccivil_03/leis/l8213cons.htm)
28. Instituto Brasileiro de Geografia e Estatística [IBGE]. Desemprego [Internet]. Brasília: IBGE; 2022. [Accessed on: 09 nov. 2023]. Available at: <https://www.ibge.gov.br/explica/desemprego.php>
29. G1. 50% dos brasileiros são católicos, 31%, evangélicos e 10% não têm religião, diz Datafolha. São Paulo: G1; 2020. [Accessed on: 09 nov. 2023]. Available at: <https://g1.globo.com/politica/noticia/2020/01/13/50percent-dos-brasileiros-sao-catolicos-31percent-evangelicos-e-10percent-nao-tem-religiao-diz-datafolha.ghtml>
30. Thiengo PCS, Gomes AMT, Mercês MC, Couto PLS, França LCM, Silva AN. Espiritualidade e religiosidade no cuidado em saúde: revisão integrativa. *Cogitare Enferm*. 2019;24:e58692. <https://doi.org/10.5380/ce.v24i0.58692>
31. Costa ACFGs, Fonseca Neto OCL. Alternativas às transfusões de sangue utilizadas no transplante hepático em pacientes Testemunhas de Jeová: uma revisão integrativa. *Rev Med* 2023;102(4):e-205575. <https://doi.org/10.11606/issn.1679-9836.v102i4e-205575>
32. Instituto Brasileiro de Geografia e Estatística [IBGE]. Acesso à Internet e à televisão e posse de telefone móvel celular para uso pessoal 2021 [Internet]. IBGE; 2021. [Accessed on: 09 nov. 2023]. Available at: [https://biblioteca.ibge.gov.br/visualizacao/livros/liv101963\\_informativo.pdf](https://biblioteca.ibge.gov.br/visualizacao/livros/liv101963_informativo.pdf)
33. Pimentel VRM, Sousa MF, Mendonça AVM. Comunicação em saúde e promoção da saúde: contribuições e desafios, sob o olhar dos profissionais da Estratégia Saúde da Família. *Physis*. 2022;32(3):e320316. <https://doi.org/10.1590/S0103-73312022320316>
34. Yıldız E, Demir B, Sarıtaş S. Perceived social support associated with posttraumatic growth in liver transplant recipients: A cross-sectional study. *Transpl Immunol*. 2022;72:101562. <https://doi.org/10.1016/j.trim.2022.101562>
35. Millson C, Considine A, Cramp ME, Holt A, Hubscher S, Hutchinson J, et al. Adult liver transplantation: UK clinical guideline – part 2: surgery and post-operation. *Frontline Gastroenterology*. 2020;11(5):385-96. <https://doi.org/10.1136/flgastro-2019-101216>
36. Raza F, Neuberger J. Consent in organ transplantation: putting legal obligations and guidelines into practice. *BMC Med Ethics*. 2022;23:69. <https://doi.org/10.1186/s12910-022-00791-y>

37. Brasil. Conselho Nacional de Saúde (BR). Recomendação nº 019, de 30 de junho de 2022. Recomenda orientações ao Ministério da Saúde e órgãos de controle, ações sobre a situação de desabastecimento de medicamentos no SUS. Conselho Nacional de Saúde; 2022. [Accessed on: 09 nov. 2023]. Available at: [http://conselho.saude.gov.br/images/Recomendacoes/2022/Reco019\\_-\\_Recomenda\\_medidas\\_relativas\\_ao\\_desabastecimento\\_de\\_medicamentos\\_no\\_Brasil.pdf](http://conselho.saude.gov.br/images/Recomendacoes/2022/Reco019_-_Recomenda_medidas_relativas_ao_desabastecimento_de_medicamentos_no_Brasil.pdf)
38. Oliveira CRV, Borges EMTM, Yarid SD. Management repercussions from the judicialization of medicines: an integrative review. *Res Soc Dev.* 2021;10(2):e32610212700. <https://doi.org/10.33448/rsd-v10i2.12700>
39. Agência IBGE de Notícias. Síntese de Indicadores Sociais: em 2020, sem programas sociais, 32,1% da população do país estariam em situação de pobreza [Internet]. IBGE; 2022. [Accessed on: 09 nov. 2023]. Available at: <https://agenciadenoticias.ibge.gov.br/agencia-sala-de-imprensa/2013-agencia-de-noticias/releases/32418-sintese-de-indicadores-sociais-em-2020-sem-programas-sociais-32-1-da-populacao-do-pais-estariam-em-situacao-de-pobreza>
40. Brasil. Ministério da Integração e do Desenvolvimento Regional. Dados revisados do déficit habitacional e inadequação de moradias nortearão políticas públicas [Internet]. Ministério da Integração e do Desenvolvimento Regional; 2021. [Accessed on: 09 nov. 2023]. Available at: <https://www.gov.br/mdr/pt-br/noticias/dados-revisados-do-deficit-habitacional-e-inadequacao-de-moradias-nortearao-politicas-publicas>