



ORIGINALES

Between pulse and dying: the experience of patients waiting for heart transplantation

Entre o pulsar e o morrer: a vivência de pacientes que esperam o transplante cardíaco
Entre el pulsar y el morir: la vivencia de pacientes que esperan el trasplante cardíaco

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ABSTRACT:

Introduction: Transplantation is the gold standard approach in the treatment of heart failure, resulting in longer survival and quality of life. However, high demand and donor shortage lead to long queues in which patients experience ambiguous feelings of hope and frustration between life and death.

Objective: To understand the experience in the heart transplant waiting list from the perspective of patients and their families.

Method: Descriptive and exploratory research with a qualitative approach, conducted with 12 participants: six patients who were waiting for heart transplantation and six family members. They answered a semi-structured interview script, which was evaluated by textual analysis using the Iramuteq software (Interface for R for Les Multesanalysis de Textes et de Questionnaires).

Results: It was evident that the discovery of the diagnosis and the need for transplantation was permeated by feelings of sadness and fear, requiring reorganization of the family structure and use of different coping strategies. The difficulties experienced in waiting for an organ include the emergence of clinical complications that can take the life of the patient or prevent surgery, and the constant refusal of possible donors on the part of the family.

Conclusion: The waiting list for heart transplantation is a moment of "race against time for life", permeated by anxiety, hope and frustration, in which family support is essential. It is also essential to invest in organ donation campaigns and training professionals to make a correct approach to families when it comes to talk about potential donors, embracing their grief and clarifying their doubts.

Keywords: Heart Transplantation; Organ and Tissue Procurement; Patients; Family; Professional training.

RESUMO:

Introdução: O transplante é a abordagem padrão-ouro no tratamento da insuficiência cardíaca, resultando em maior sobrevida e qualidade de vida. Entretanto, a alta demanda e escassez de doadores geram longas filas, nas quais pacientes vivenciam sentimentos ambíguos de esperança e frustração, em meio a díade vida e morte.

Objetivo: Compreender a vivência na fila de espera do transplante cardíaco a partir da perspectiva do paciente e sua família.

Método: Pesquisa descritiva e exploratória, de abordagem qualitativa, realizada com 12 participantes: seis pacientes que estão em fila de espera para transplante cardíaco e seis familiares. Eles responderam um roteiro de entrevista semiestruturado, que foi avaliado por meio de análise textual no software Iramuteq (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*).

Resultados: Evidenciou-se que a descoberta do diagnóstico e da necessidade de transplante é permeada por sentimentos de tristeza e medo, que demandam reorganização da estrutura familiar e uso de diferentes estratégias de enfrentamento. Entre as dificuldades vivenciadas na espera por um órgão contemplam-se o surgimento de intercorrências clínicas, que podem lhe tirar a vida ou impossibilitar a cirurgia, e a constante recusa da família de possíveis doadores.

Conclusão: A fila de espera para transplante cardíaco configura-se como um momento de "corrida contra o tempo pela vida", permeada por ansiedade, esperança e frustração, na qual o apoio familiar é fundamental. Faz-se fundamental também o investimento em campanhas de doação de órgãos e capacitação de profissionais para fazer uma abordagem correta aos familiares de possíveis doadores, acolhendo o seu luto e esclarecendo suas dúvidas.

Palavras-chave: Transplante de Coração; Obtenção de Tecidos e Órgãos; Pacientes; Família; Capacitação Profissional.

RESUMEN:

Introducción: El trasplante es el enfoque patrón-oro en el tratamiento de la insuficiencia cardíaca, resultando en una mayor sobrevida y calidad de vida. Sin embargo, la alta demanda y escasez de donantes generan largas filas, en las que los pacientes experimentan sentimientos ambiguos de esperanza y frustración, en medio de la vida y la muerte.

Objetivo: Comprender la vivencia en la cola de espera del trasplante cardíaco desde la perspectiva del paciente y su familia.

Método: Investigación descriptiva y exploratoria, de abordaje cualitativo, realizada con 12 participantes: 6 pacientes que están en fila de espera para trasplante cardíaco y 6 familiares. En el programa Iramuteq (Interfaz de R para los Analyses Multidimensionnelles de Textes et de Questionnaires), respondieron un guión de entrevista semiestruturado, que fue evaluado por medio de análisis textual en el software Iramuteq.

Resultados: Se evidenció que el descubrimiento del diagnóstico y de la necesidad de trasplante está impregnado por sentimientos de tristeza y miedo, que demandan reorganización de la estructura familiar y uso de diferentes estrategias de enfrentamiento. Entre las dificultades vivenciadas en la espera por un órgano se contempla el surgimiento de intercorrencias clínicas, que pueden quitarle la vida o imposibilitar la cirugía, y el constante rechazo de la familia de posibles donantes.

Conclusión: La cola de espera para trasplante cardíaco se configura como un momento de "carrera contra el tiempo por la vida", impregnada por ansiedad, esperanza y frustración, en la que el apoyo familiar es fundamental. Se hace fundamental también la inversión en campañas de donación de órganos y capacitación de profesionales para hacer un abordaje correcto a los familiares de posibles donantes, acogiendo su duelo y aclarando sus dudas.

Palabras clave: Trasplante de Corazón; Obtención de Tejidos y Órganos; Pacientes; Familia; Capacitación Profesional.

INTRODUCTION

A transplant is the transfer of living cells, tissues or organs from one person (the donor) to another (the recipient) for the purpose of restoring a lost function⁽¹⁾. More specifically, heart transplantation is currently the definitive gold standard surgical approach in the treatment of refractory heart failure, a situation in which the patient has severe functional limitation and high mortality^(2,3).

However, in many countries this procedure faces a similar difficulty: the number of organs available is insufficient to meet the demand of patients who need a new heart. Waiting lists grow worldwide, and the people who need donations is huge, and they suffer and die waiting for an organ to save their lives⁽⁴⁾. In this context, in common sense, doubts remain about the transplant process: Who should receive an organ? Who has priority? How long does it take to receive this organ? How does the waiting list work?

In response, waitlist inclusion rules and priority criteria^(5,6) have been created. In Brazil, it is established that people with serious health problems whose function of organs or tissues are impaired and out of possibility of restoration and who present a risk of death, such as people with heart disease, may receive the organ. For these people, the transplant represents a therapy that improves the quality of life⁽⁷⁾. Priority criteria include patients with refractory heart failure who need to use vasoactive drugs in the intensive care unit (ICU), with recommendation for acute retransplantation and maintenance accuracy by artificial heart. These criteria also obey aspects as donor and recipient blood group compatibility, recipient waiting time, donor and recipient age and weight, and patient severity^(5,7).

On the other hand, patients with some characteristics as absolutely contraindicated for heart transplantation: Acquired Immunodeficiency Syndrome; cancer in the last three years (except for the cervix and skin cancer); fixed pulmonary hypertension (pulmonary vascular resistance greater than 6-7 units; pulmonary arteriolar resistance not falling below 4 Wood units with vasodilator); mismatch in cross-test between donor and recipient; lack of adherence to treatment; insulin - dependent diabetes with significant target organ damage; disease causing life expectancy shorter than transplantation; severe vascular or peripheral brain disease; irreversible liver or kidney disease (considering associated transplantation); unfavorable psychological / psychiatric profile, active alcoholism and/or drug addiction; severe lung disease; and contraindication to immunosuppression. These risk factors and complications due to comorbidities can compromise the efficacy and progress of the procedure⁽⁸⁾.

The registration in the waiting list is made by reference teams accredited by the Ministry of Health, through the National Transplant System (NTS). As for the priority, it is clarified that, by admitting that a patient in extremely severe state has priority as a recipient, the principle of equality is not hurt, but the right to life is preserved⁽⁹⁾. For example, people under 18 have priority to receive donor organs in the same age group. This is due to the higher life expectancy of these patients⁽¹⁰⁾. Also, donors who have some communicable disease can also donate to patients who have the same virus. Thus, organs from a donor who has hepatitis C, for example, can be transplanted to people who also have this disease⁽¹¹⁾.

The waiting time to receive the organ varies among patients, as waiting in the queue does not follow exclusively a chronological order, where the first registrant is the first to receive the organ. The waiting time follows the established criteria and rules, and depends on the donated organ or tissue and the State where the recipient is. To facilitate the organization of this process and the speed of donation reception, the recipients are sorted by organ needed, blood type and other technical specifications while they are still in the queue. This single list has a chronological order of enrollment, with recipients selected in that order, but according to these specified criteria. To ensure the seriousness and transparency of the process, recipients can track their position on the list through the Portal of the Ministry of Health⁽¹²⁾.

This is a complex process, full of rules, that calls for constant decision-making by professionals who make up the interdisciplinary transplantation team⁽¹³⁾. Decisions are usually made immediately, supported by the abovementioned technical criteria, but also permeated by a subjectivity that directly reflects the psychic aspects of these professionals. It is worth keeping in mind, thus, that most patients who are in the transplantation queue are people who “run away from death” and who have the transplant as the single alternative to keep living. Professionals know, therefore, that when they decide to include or exclude a patient in the waiting list, their choice may mean the life or death of that person⁽¹⁴⁾.

At the other end of this process, patients unveil on the path taken to join the list and wait in this queue, amid different feelings. In the pre-transplant preparation, involving routine examinations and care of the interdisciplinary team, there is a support for everything to be resolved as fast as possible and also to avoid contraindications to transplantation⁽¹⁵⁾. Then, after entering the queue, the wait is marked by the idealization of a new reality, with the expectation of freedom and hope that at any time can be graced with a phone call stating that a compatible donor was found. On the other hand, over the months and years, disappointment arises because they do not receive the call with the news about a donor, making the waiting for a compatible organ to seem fruitless. In addition, while waiting in the queue, some patients receive the call to perform the transplant, and after a day of preparation and waiting, this cannot be done for diverse reasons - the patient's clinical condition, or incompatibility or denial of the donor's family to carry on the transplantation, generating feelings of disappointment, frustration or renewal of hope⁽¹⁶⁻¹⁷⁾. These moments challenge the patient, require a reorganization of the family structure and the use of different coping strategies⁽¹⁸⁾.

For these patients and their families, heart transplantation is not just a simple surgery aimed at the quality of life of people with heart failure (HF), but a procedure that is synonymous with life and that requires many adjustments, because the preparation for transplantation and the necessary postoperative care are complex and affect the lives of patients and their families^(20,21). The receiver has to face changes in his habits and lifestyle, in his daily activities, at work, and in his social and family life. This shows that transplantation is not an individual act, because any dysfunction that affects a family member, somehow will affect the whole family. The support and collaboration of family members before, during and after the transplantation process is extremely important, as the success of the transplantation is directly related to the appropriate environmental and emotional conditions in the family context. Thus, the transplantation process is represented by the triad transplanted person - family - multiprofessional team⁽²²⁻²³⁾, and involves two other non-evident but essential actors - the donor and his family, who decide on the donation^(24,25).

Given the above, this research aimed to understand the experience of patients and their families while in the waiting list of heart transplantation. It is recognized that knowledge of these experiences can help managers in monitoring the difficulties existing in the transplantation queue, and the interdisciplinary team in assisting the real needs of those waiting for a compatible organ.

MATERIAL AND METHOD

This is an exploratory and descriptive research with a qualitative approach. Based on a saturation criterion, 12 participants participated - six patients in the queue and six relatives (see Table 1):

Table 1: Characterization of participants (n = 12)

Nº	Category	Sex	Age	Time in the queue	Number of experiences with potential donors
P1	Relative (mother of child patient)	Female	26 years	1 year	2
P2	Patient	Male	35 years	3 months	7
P3	Relative (mother of adult patient)	Female	60 years	3 months	7
P4	Patient	Female	42 years	15 days	3
P5	Patient	Female	50 years	6 months	1
P6	Relative (daughter of adult patient)	Female	25 years	24 days	1
P7	Patient	Female	53 years	10 months	7
P8	Patient	Male	59 years	1 year	1
P9	Relative (son of adult patient)	Male	35 years	10 months	7
P10	Relative (mother of child patient)	Female	36 years	7 months	0
P11	Patient	Female	62 years	1 month	5
P12	Relative (husband of adult patient)	Male	64 years	1 month	5

A semi-structured interview script was used for data collection, containing the following categories: (1) experience of the patient on the waiting list for a heart transplant; and (2) repercussion of the disease on family members. Considering the ethical aspects related to research involving human subjects, the research was approved by the Research Ethics Committee through Opinion 1,666,751. Participants were previously contacted by the researcher, and new participants were indicated by them, using the snowball technique⁽²⁶⁾. The interviews were conducted in person, individually and with the aid of a tape recorder, in a place chosen by the participants, in accordance with the ethical standards established by Resolutions 466/12 and 510/16 of the National Health Council.

Data analysis took place in three stages, using the IRAMUTEQ software (*Interface de R pour les Analyses Multimensionnelles de Textes et de Questionnaires*). Classical

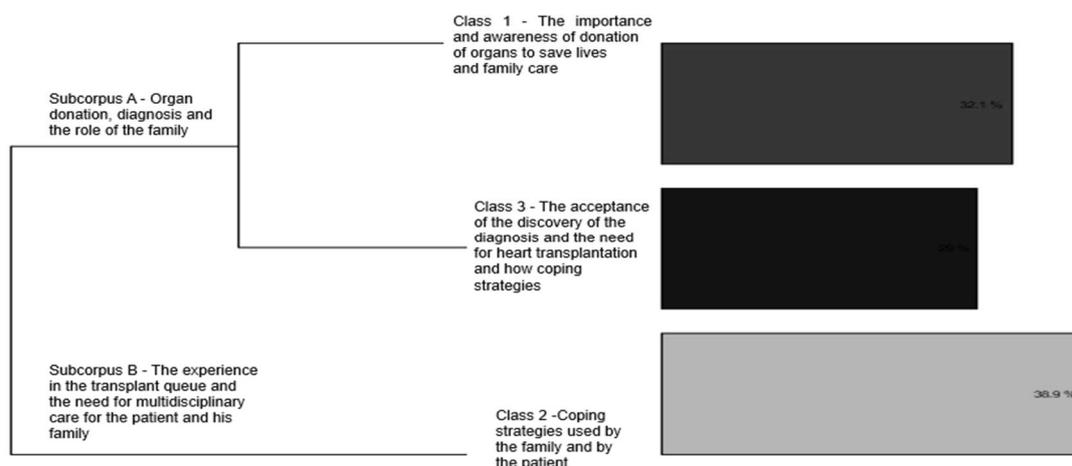
lexicographic analyses were performed to verify statistics of the amount of evocations and forms. Descending Hierarchical Classification (DHC) was obtained for recognition of the dendrogram with the classes that emerged. The word cloud was created in order to group the words according to their frequency⁽²⁷⁾.

RESULTS

The general *corpus* consisted of 596 text segments (TS), of which 442 TS were used (74.16%). There were 20,477 occurrences (words, forms or terms), 2,494 distinct words, and 1,674 with a single occurrence.

The total corpus under analysis was organized into three classes, divided into two branches (A and B). Subcorpus A, “Organ donation, diagnosis, and the role of the family,” consists of Class 1 - “The acceptance of discovering the diagnosis and the need for heart transplantation and coping strategies while waiting in the queue”, with 111 TS (28.98%); and Class 3 “The importance and awareness of organ donation to save lives and family care”, with 123 TS (32.11%). Subcorpus B, “Experiences in the transplantation queue and the need for multidisciplinary care for patients and their families”, contains speeches that correspond to the Class 2 - “Clinical complications and comprehensive patient care in the waiting list for heart transplantation”, with 149 TS (38.09%), as can be seen in Figure 1.

Figure 1: Descending hierarchical classification dendrogram



Class 1 - “The acceptance of discovering the diagnosis and the need for heart transplantation and coping strategies while waiting in the queue” consisted of 28.98% ($f = 111$ ST) of the total corpus analyzed. It presented words like “Strength” ($x^2 > 35.54$), “Faith” ($x^2 > 22.58$), “Trying” ($x^2 > 14.92$), “Crying” ($x^2 > 13.59$), “Helping” ($x^2 > 13.59$), “God” ($x^2 > 10.41$), “Accepting” ($x^2 > 9.91$) and “Hope” ($x^2 > 9.91$).

The discourses of the patients about the discovery of the diagnosis of the cardiac problem and how they reacted to the news about the need for heart transplantation and the coping strategies are presented below. The discourse is marked by sadness, fear, anxiety and spirituality.

When I learned about the transplant, I was very shocked at first. The day she told me, I swear to you, a hole like this was opened. Then I asked God for strength, I tried to

restructure myself, for her, because she had not given up. So I had to have the strength to be by her side. And then I was carrying on, and I started to accept better (P1).

It was found that patients and relatives use coping strategies to deal with the difficulties that arise while in the queue, which contribute to the maintenance of physical, psychological and social stability. The spirituality stood out in the speech of all participants. There was also the search for knowledge and information about the disease, the acceptance, family support to the patient, and the need for family members to avoid crying and showing suffering in front of the patient.

Oh my goodness, will it work today? I've been called 7 times, will it be today? But then I remember right away: 'It's in God's hands. God knows everything. I leave it with you. If it is to be so, we embrace it (P7).

There was a time when I would fall on the floor and say: Lord, how come that my son is in this situation? He doesn't get better, he doesn't get better. They took away his hopes, but it is God's miracle. If you don't have a base, a family structure that is there supporting you, giving you strength: "I'm here. We will make it together". Hope, faith, is also very important (P3).

Class 2 - "Clinical complications and comprehensive patient care in the waiting list for heart transplantation" represented 38.09% ($f = 149$ TS) of the total corpus analyzed. This class was composed of words such as "Examination" ($x^2 > 40.57$), "Consultation" ($x^2 > 19.46$), "Hospitalization" ($x^2 > 14.47$), "Follow Up" ($x^2 > 13.49$), "Hospital" ($x^2 > 11.71$), "Surgery" ($x^2 > 11.09$), and "Psychiatrist" ($x^2 > 9.57$).

In the analyses performed, there were aspects related to the clinical experiences of patients in the period before registration, and during the waiting time in the list for heart transplantation. Constant hospitalizations, medication, psychological/psychiatric treatment, and complications resulting from the disease and the need for a transplant were also highlighted. It was also reported that when these health problems occur they may interfere and delay the reception of a new heart, causing more pain, anguish and prolonging the wait.

The consultation was scheduled on Wednesday, when Wednesday came I was already in the last. Then the doctor hospitalized me, I was hospitalized from August 24 until September 19 (P5).

When I learned that I had to have a transplant, it was in my last hospitalization. There were nine hospitalizations. The last one was in October, when I left that hospital, then I was admitted to the heart hospital (P7).

To avoid these complications and mitigate the chances of the patient not being ready for the transplant when donors appear, it is necessary to provide comprehensive patient care through an interdisciplinary team of professionals - doctors, nurses, psychologists and nutritionists.

All I have to thank, thank the doctors, nurses, psychologists, therapists, all the staff, the consultations are all good. I just have to thank God and everyone. They give me strength too. The psychologists talk to me, they sit with me, and explain. I have to thank them (P5).

Class 3 - "The importance and awareness of organ donation to save lives and family care" represented 32.11% ($f = 123$ TS) of the total corpus analyzed. It was composed of words such as "Dying" ($x^2 > 24.89$), "Life" ($x^2 > 17.61$), "Heart" ($x^2 > 12.88$), "Willing" ($x^2 > 12.11$), "Depending" ($x^2 > 10.71$), "Caring" ($x^2 > 9.04$), "Donation" ($x^2 > 8.81$), and "Family" ($x^2 > 6.69$).

In this class, the participants reported on the importance of raising people's awareness about the relevance of organ donation to heart transplant patients. The need for authorization of the potential donor's family and the suffering of the recipient when the donation is denied and/or any alteration is found in the tests that prevents the transplantation is highlighted here.

It is important that people be aware of how important a donation is, not just those people who are standing in line at the hospital, because someday anyone may need it. There are seven lives that can be saved with a donation [...] It is the family that has to give the authorization, it doesn't matter if the person is a donor, if the family denies it, the organs are not donated. The important thing is to have this dialogue, to tell the family about the importance of donation (P2).

The refusal on the part of the family of the potential donor is a very impactful aspect in the life of recipients waiting for a heart transplant to live. They have high expectations, waiting to receive a call informing a generous donation action by family members who have lost a member. When the call occurs, they are called to the hospital to make a battery of examinations; there is a whole preparation all day long. There is a strong expectation as to whether or not the family will actually accept it; but the family often denies the donation. For example, of the twelve participants interviewed, 11 had the experience of receiving a call about a possible donor, going to the hospital, spending the day preparing for surgery, and eventually receiving the news that the family did not accept to donate the heart.

Run to the hospital, a potential donor appeared! Then, that affliction starts. You have to go through that moment of wait. Then in the end the family doesn't allow the donation. Then everything goes back to square one! This is all a lot of suffering! You go in that expectation, fear, anxiety! All this affects the person, the psychological aspect (P4).

The family did not authorize it, at the end of the day, after you spend the whole day waiting there! You shave the entire body! You cannot get a single hair... and then you go through all of that, then when it comes by the end of the day: 'Oh, the family did not authorize it'. It's a huge disappointment! (P2).

In this class, another aspect that emerged was the importance of the family, care measures, and adaptations in the structure of the house and in the family dynamics to receive this sick patient. In this sense, family structure, the presence of all family members (mother, father, grandmother and friends), a positive attitude, adaptations to the patient's routine, changes in family routine, research about the patient's disease, and collaboration for adhere to treatment indications - medications, hygiene and diet – stood out.

We have to adapt to the child's routine and not the other way around. The traditional thing is when the child fits the parents' routine, but we adapt to his routine. We had to buy air conditioning. It was a lot that we had to adapt, a whole change. Transportation,

These strategies also help deal with the clinical complications that may occur in patients waiting to undergo surgery, such as respiratory complications that end up imposing the need for intensive care, such as prolonged ventilatory support. These aspects, besides being painful, can generate hopelessness, because they prolong the patient's length of stay in the waiting line, because when a potential donor appears, the patient will be able to perform the transplant only if he is in healthy conditions^(16,18). In addition, prolonging queuing time can be a considerable factor in causes of mortality and morbidity⁽²⁰⁾.

These problems can be prevented through interdisciplinary team care^(16,18,20). Doctors and nurses have to follow the root cause of the problem; nutritionists advise on the restricted diet and feeding of patients waiting for transplantation; and psychologists may offer a space for speech and listening, assisting patients in adapting to this new condition and even as a means of sublimation of all these feelings that permeate the process of waiting in line for heart transplantation^(6,14).

The participants also portrayed the lack of programs aimed at facilitating the understanding of people about the importance of organ donation, strengthening myths, doubts and prejudices regarding the theme⁽²⁵⁾. It can be deduced that, due to this lack of information and dissemination, the number of donors is much smaller than the number of patients waiting for donation in the waiting list, and this generates a great load of feelings and emotions in those waiting to have life back⁽¹⁾.

Finally, the determining role of the family network is portrayed in the health care of patients on the waiting list for heart transplantation, through help in the various adaptive changes in the routine and daily habits of all involved. The literature says that the ideal is that in this phase of waiting for a transplantation, the family affects the patient in a beneficial and positive way. Aspects such as self-esteem, leisure activities that can be performed with family members to take the focus off waiting for the heart and health care are fundamental and bring benefits to the patient's health, as they stimulate the subject and prepare him to give continuity of life^(1,7,19,21,24).

CONCLUSION

It was seen that patients waiting for heart transplantation and their families are affected by changes in their habits, lifestyles, daily activities, and work and social life, leading to a great deal of emotional burden that permeates the entire waiting process. This process affects not only the patient, because any dysfunction that affects any family member will, in some respect, affect the entire family. Likewise, transplant success is also related to appropriate emotional conditions in the family context. To deal with these difficulties, those involved use different coping strategies: spirituality, faith, hope and strength to be able to wait and support their loved ones.

It can also be concluded that there is a need for campaigns that provide information and dialogue for the population about the importance of organ donation, as there are still myths, doubts and prejudices. Therefore, investing in information is encouraged. People need to know that organ waiting lists grow with a great number of people who need a donation and suffer, stay in hospitals, and die in the waiting list for an organ. People need to know about the suffering of a patient who receives a call about a possible donor, runs to the hospital, spends a whole day preparing for surgery, and at the end of the day is informed that the donor's family did not authorize the donation.

Likewise, there is a need to think about the way to approach families regarding the possible donor, to support the family concerning the acceptance of the patient's death, and only then, after this, assist the family in the decision making about organ donation, eliminating possible doubts.

As limitations of the present study, there was a cross-sectional collection of data where variations in the mood and clinical situation of the patients were not investigated through follow up. Another limitation was the number of subjects; a higher number would allow comparisons between different socio-demographic characteristics. It is stated, however, that, through a qualitative approach, the aim here deepen the understanding of the subject and of the experience of each reality, recognizing the experience of the subjects, their anxieties, hopes, grief and frustration. Further studies are suggested as a way of enriching the literature on the theme, with other methodological approaches, including longitudinal and large-scale ones, since the literary production on this subject is still scarce. It is argued, therefore, that by unveiling the reality experienced by these patients, it is possible to raise awareness and mitigate the problem of queues for heart transplantation.

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