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ORIGINAL ARTICLE

# Perception of the health team on the application of palliative care to the person undergoing heart transplantation

*Percepção da equipe de saúde sobre aplicação dos cuidados paliativos à pessoa submetida a transplante cardíaco*

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## ABSTRACT

**Objective:** to elucidate the relationship between palliative care and heart transplantation in the view of the transplant team, and to develop a mind map that helps to rethink the palliative approach to the person after heart transplantation. **Methods:** a descriptive study with a qualitative approach was carried out through a semi-structured interview with 17 health professionals. The constituted corpus was processed by the IRaMuTeQ software. Minayo's content analysis and mind map were used. **Results:** the narratives revealed difficulty in establishing criteria to indicate a person after heart transplantation for palliative care. Fear, prejudice and lack of knowledge delay the palliative approach. The mind map shows conditions that can be considered for the indication of palliative care for people after heart transplantation. **Conclusion:** the palliative approach in the context of heart transplantation, in the view of professionals, is permeated by negative feelings and lack of information on the part of the teams. The proposed mind map brought elements that can guide professionals for the insertion of the person after heart transplantation in the palliative approach.

**Descriptors:** Palliative Care; Heart Transplantation; Comprehensive Health Care; Patient Care Team.

## RESUMO

**Objetivo:** elucidar a relação entre cuidados paliativos e transplante cardíaco na visão da equipe de transplante e desenvolver um mapa mental que ajude a repensar a abordagem paliativa à pessoa pós transplante cardíaco. **Métodos:** estudo descritivo, com abordagem qualitativa, foi realizado por meio de entrevista semiestruturada, com 17 profissionais de saúde. O *corpus* constituído foi processado pelo *software* IRaMuTeQ. Utilizou-se análise de conteúdo de Minayo, e elaboração de mapa mental. **Resultados:** as narrativas revelaram dificuldade em estabelecer critérios para indicar uma pessoa pós transplante cardíaco para o cuidado paliativo. Medo, preconceito e falta de conhecimento retardam a abordagem paliativa. O mapa mental evidencia condições que podem ser consideradas para a indicação de cuidados paliativos para pessoas em pós transplante cardíaco. **Conclusão:** a abordagem paliativa no contexto do transplante cardíaco, na visão dos profissionais, é permeada por sentimentos negativos e déficit de informações por parte das equipes. O mapa mental proposto elucidou elementos que podem orientar os profissionais para a inserção da pessoa pós transplante cardíaco na abordagem paliativa.

**Descritores:** Cuidados Paliativos; Transplante de Coração; Assistência Integral à Saúde; Equipe de Assistência ao Paciente.

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# INTRODUCTION

Despite the improvement in life expectancy resulting from clinical therapy, heart transplantation is still the main alternative for refractory heart failure[1]. According to the records of the Global Observatory on Donation and Transplantation (GODT), 5,981 heart transplants were performed worldwide, in 2020[2]. According to data provided by the Brazilian Association of Organ Transplantation (Portuguese acronym: ABTO), between 2009 and 2019, 3,269 heart transplants were performed in Brazil.

The survival of a person submitted to heart transplantation is around a decade, however, there is a survival of more than 20 years in many Brazilian groups. After surgery, there is an undeniable improvement in the quality of life of these people; however, there is a need for follow-up, because the risk of complications and even death remains high[3]. Faced with complications, it is inevitable to consider the probability of the death and suffering of these patients, resulting in the need for palliative care aimed at comfort, considering that there is no prospect of cure.

According to the World Health Organization (WHO)[4], palliative care is an approach that improves the quality of life of patients who are facing the problems associated with life-threatening illness, as well as their families. This approach can occur through the prevention and relief of suffering through early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. For the expansion of palliative care in the Brazilian context, it is necessary to promote educational support and professional training, and to disseminate and expand the perception of the possibilities of palliative care and care at the end of life for the whole of society[5].

Palliative care is still very much focused on cancer patients, and although this component is no longer present in its most recent definitions, there is still a vision of palliation associated with abandonment and lack of alternative[6]. In turn, transplantation is associated with rebirth[7].

An exploratory search was carried out in the literature to discover publications on these topics (palliative care and heart transplantation), from which a gap in knowledge was evidenced, with studies in oncology predominating.

The particularities inherent to the context of heart transplantation require care from professionals, which makes it possible to restore damage and limitations, and that go beyond the merely technical aspects, considering that an evolution that implies palliative care may occur. Thus, it is necessary to know the perceptions of the team on the subject to build a new way of behaving towards patients and families receiving palliative care. Only in this way will be possible to perceive the transplanted being in its entirety.

In this sense, the objective was to elucidate the relationship between palliative care and heart transplantation in the view of the transplant team and to develop a mind map that helps to rethink the palliative approach to the person after heart transplantation.

# METHODS

## Type of study

Descriptive study with a qualitative approach, carried out between March and June, 2018. It followed the guidelines of the Consolidated criteria for reporting qualitative research (COREQ)[8].

## Study scenario

The study setting was the Heart Failure and Transplant Unit (ICU) of a tertiary public hospital, which is a reference in care for people with cardiopulmonary diseases, heart transplantation for adults and children and serves patients in the 184 municipalities of Ceará and the North and Northeast regions of Brazil.

## Population

Professionals from the multiprofessional health team were included, who worked in the care of transplanted patients for at least one year. Those who were away from their professional activities during the collection period were excluded. Thus, 17 professionals were interviewed, among which 10 nurses, two doctors, two social workers, a nutritionist, a physiotherapist and a psychologist.

## Data collection

To know the perception of the heart transplant team about palliative care and the indication of this approach to the transplanted patient, a semi-structured interview was used as a data collection instrument. The interview had as a starting point the following question: What is your perception about the applicability of palliative care to patients after heart transplantation?

The interviews were individual and conducted in environments outside the office. To make the interviewee feel free to discuss the subject, a smartphone with a voice recorder application was used. Then, two researchers checked and transcribed the speeches in full.

Subsequently, based on the results, a mind map was developed to help rethink the palliative approach among heart transplant patients.

## Data analysis and processing

After being transcribed, the interviews were read and organized with the support of the software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ). This tool has a qualitative and quantitative

approach, and allows for different processing and statistical analysis of textual corpus[9].

A comparison of the answers was carried out for the analysis of the interviews. Initially, classical textual statistics were explored, using basic lexicography and searching for specifics by word groups. Soon after, for the multivariate analyses, the method of Descending Hierarchical Classification (DHC), Analysis of Similitude or Similarities and Word Cloud was chosen. In the DHC, textual segments or elementary context units (ECU) are classified according to their respective words and highest chi-square values in the class, in view of the understanding that they were significant for the qualitative analysis of the data. All words selected to compose the dendrogram classes had $p<0.001$, indicating a statistically significant association[9].

Then, the analysis of similitude was carried out, which constitutes the ideal mathematical model for the study of the relationship between discrete objects of any type and makes it possible to identify the concurrence between words and their result. To identify the keywords in the patients' statements, the word cloud was used, because it enables the grouping of words and organizes them according to their frequency[10].

From the organization and processing of speeches, the vocabulary was identified and quantified concerning the frequency and position in the text, submitted to statistical calculations, to be analyzed and interpreted according to Minayo's content analysis[11].

## Mind map construction

The results were presented through a mind map to propose a rethinking of the palliative approach to the person after heart transplantation. For this, we opted for the construction of a Mind Map. The technique was developed by Buzan[12] to visually create the record of facts and ideas in a structured way, which would favor the meaning of the content, aiming at learning, instead of just memorization. To this end, the Lucidchart tool (https://www.lucidchart.com) was used, a visual workspace that mixes diagramming, data visualization and collaboration to accelerate understanding and promote innovation, based on the results obtained[12].

## Ethical aspects

To preserve the anonymity of respondents, the descriptions of the statements are presented using the letter P, of professionals, followed by the Arabic numerals from 1 – 17, corresponding to the order in which the interviews were carried out. The Research Ethics Committee of the research locus institution approved the present study, under the number 2,051,518. All the norms for research with human beings present in Resolution No. 466/12 of the National Health Council of Brazil[13] were complied with. All participants signed the Free and Informed Consent Form (FICF).

# RESULTS

The resulting corpus consisted of 17 texts divided into 372 segments, of which 329 were analyzed by the software, which is equivalent to an 88.44% use. Initially, the software generated six classes (Figure 1).

After reading the words that make up the classes, their contents were clarified for naming and understanding the themes, linking lexical analysis to content analysis.

It was observed that the dendrogram (Figure 1) starts with class 5, called "Clinical dimension" due to the representative lexical content of this group of words (13.7% of the text segments processed by the software). Then, class 4, called "Palliative care", makes a strong mention of palliative care and terms that, in the interviewees' view, are associated with palliation, such as prejudice and dying (21.3% of the corpus segments). Classes 5 and 4 are linked, and both are connected to class 1 named "Personal and family acceptance" (21.6% of the corpus), which has words that are associated with the condition of receiving palliative care, family and social involvement, as well as the intrinsic pain of the process.

These three classes are interconnected with classes 3 and 2. In class 3, called "Care and spirituality", there is a predominance of words such as Life and God, class that corresponds to 14.3% of the analyzed segments. Class 2 corresponds to 16.1% and expresses the perception of the needs of these patients in the view of the participants. In this class, there is a predominance of verbs such as accompany, perceive and provide; that is, actions that need to be developed to satisfy the needs of these patients.

There is a last connection linking all classes, Class 6, named "Difficulties and certainties in the face of finitude", in which the words express the understanding of a close finitude, which highlights the need for an approach that prepares the patient for death.

It is possible to infer that the first five classes function as steps to be taken, so that the finitude represented in Class 6 can be comfortably experienced.

The similitude analysis shows (Figure 3) three interconnected cores, patient, palliative care and family, from which important concepts are derived for understanding the corpus. From the "patient" core, emerge words such as finitude, transplant, God, professional, life, prognosis, quality of life, conscience, comfort, intervention, dying, among others. From the "palliative care" core, emerge the words cure, believe, chronic diseases, prejudice, relationship and fear. It is noted that this core has a smaller number of words, which denotes difficulty on the part of the team in discussing the topic of palliation, same as the "family" core, from which only

**Figure 1.** Dendrogram of the classes referring to palliative care for a person undergoing heart transplantation, Fortaleza, Ceará, Brazil, 2018

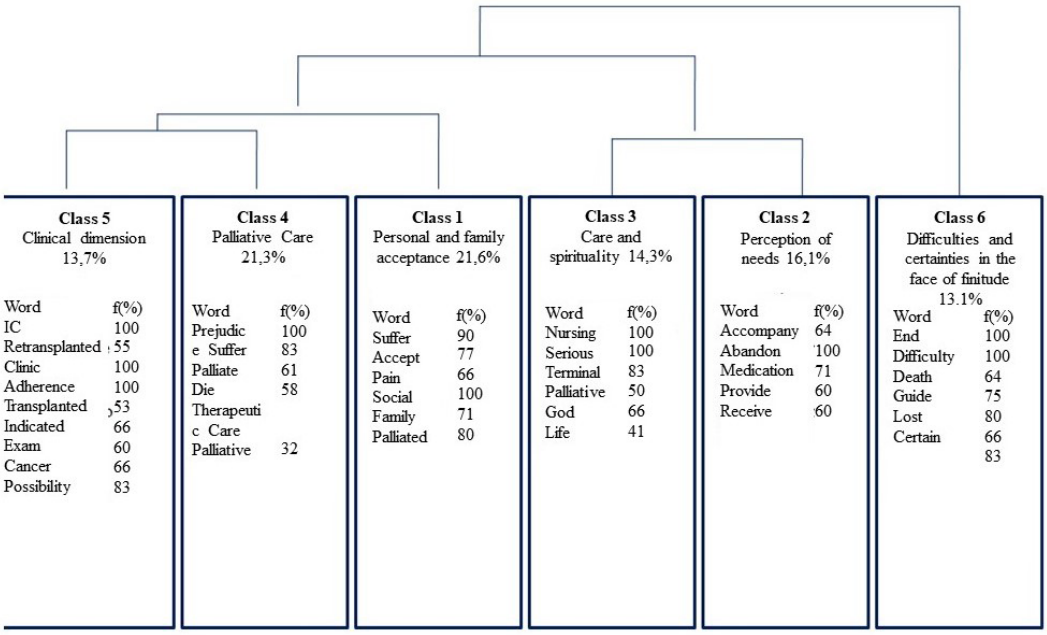



**Figure 2.** Tree of Similarity, Fortaleza, Ceará, Brazil, 2018

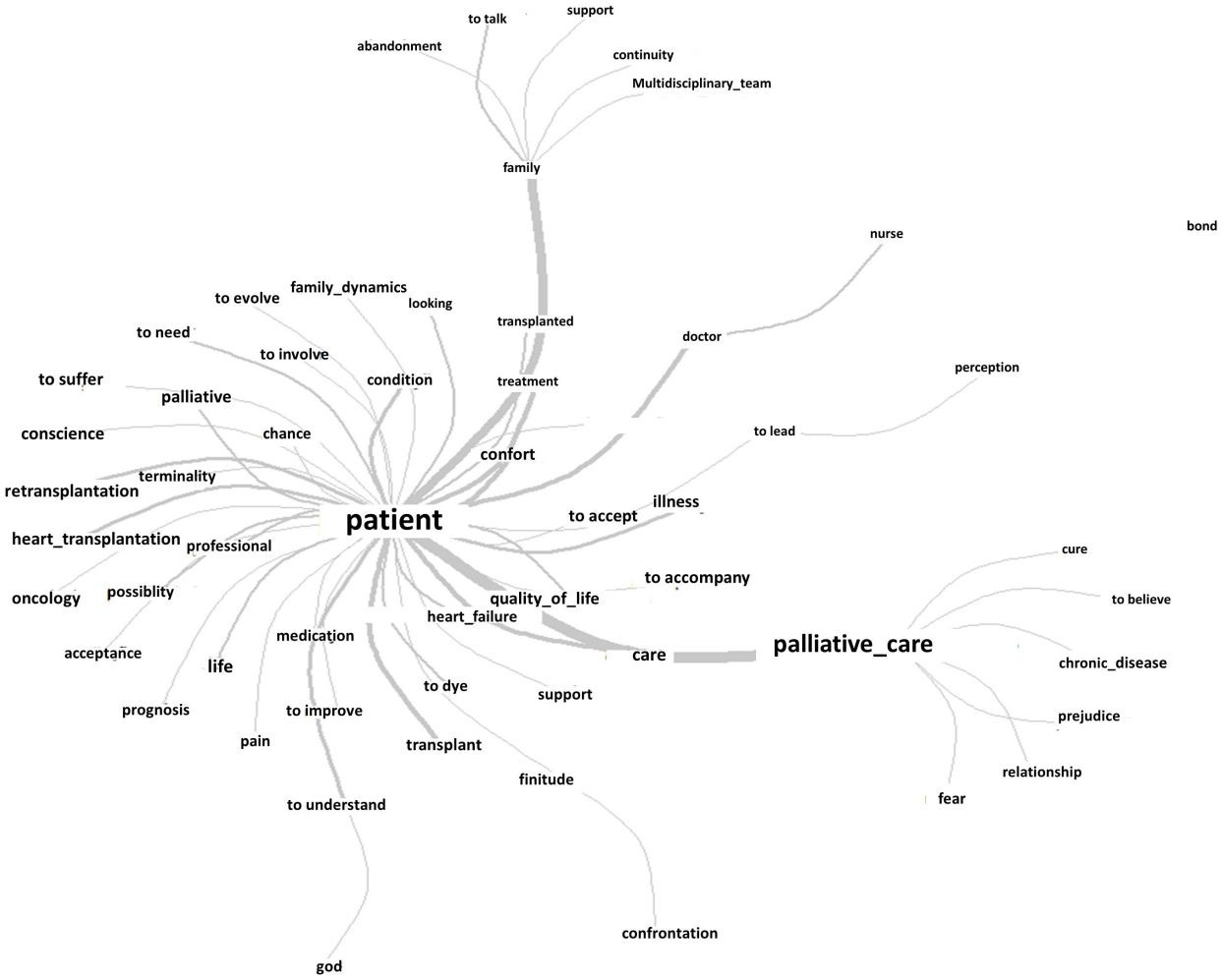


**Figure 3.** Word Cloud, Fortaleza, Ceará, Brazil, 2018


the concepts abandonment, talk, support, continuity and multidisciplinary team emerge.

In the representation visualized by the word cloud (Figure 3), which groups the words and organizes them graphically according to the frequency that they appear in the text, we observed that patient was the term most cited by professionals, soon followed by palliative care. Words also highlighted are: family, doctor, retransplantation, heart transplantation, care, comfort, quality of life, life, suffering, nursing, understanding, death. The position of the words in the cloud also allows us to understand that the term palliative care presents itself in a transversal way to the other terms.

Based on the professionals' statements, the elements related to palliative care in heart transplantation were represented in a mind map for better visualization, providing reflection on the topic and helping to refer patients to this approach (Figure 4).

It is notable that it is essential that the team analyze all dimensions and their formative aspects (Figure 5). However, it is not necessary for the patient to have all the items to opt for palliative care, considering that it is a tool to promote reflection and help for a potential indication for palliative care, and not a restrictive instrument of indication.

**Figure 4.** Mind map to rethink palliative care for transplant patients, Fortaleza, Ceará, Brazil, 2018

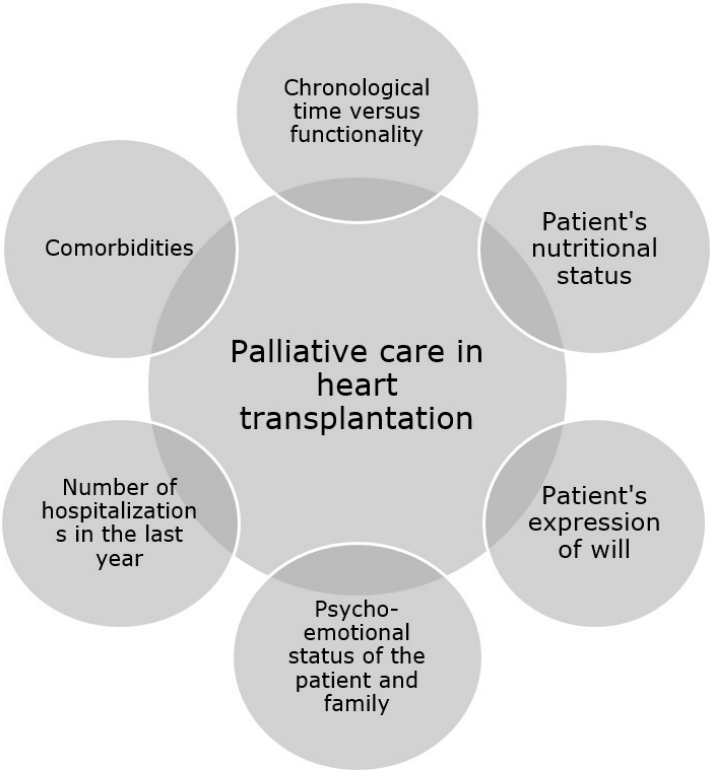
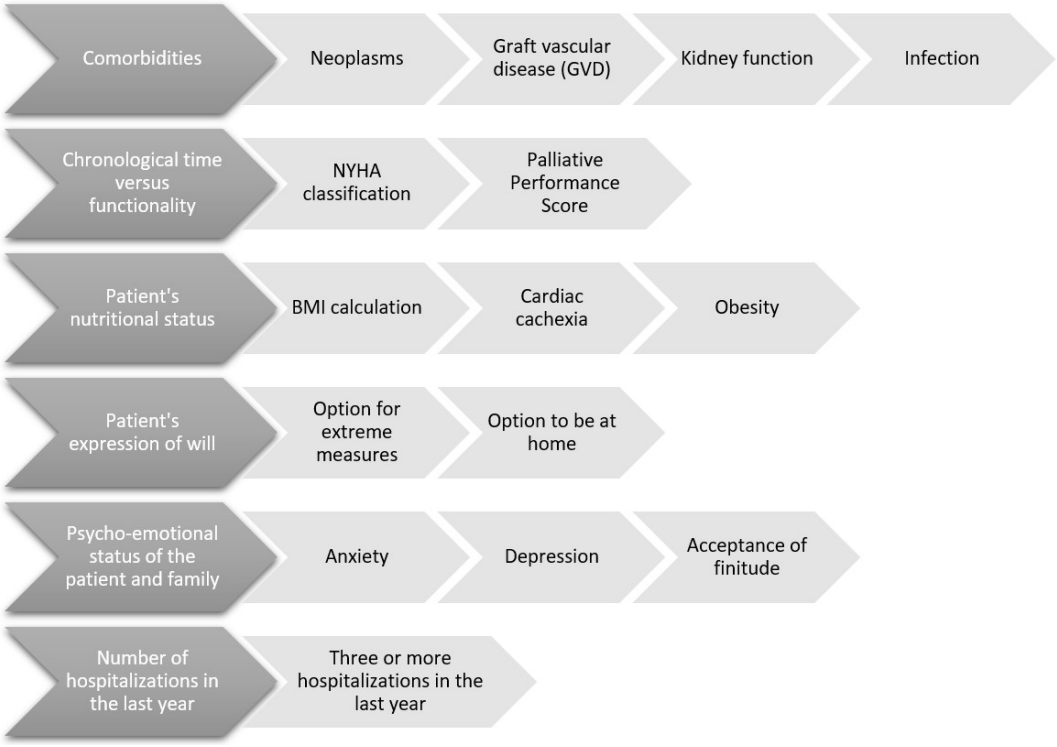


**Figure 5.** Forming aspects of each mind map dimension, Fortaleza, Ceará, Brazil, 2018




## DISCUSSION

The use of the textual corpus was satisfactory[9] and provided relevant information. In the dendrogram, the word "family" appears most frequently. However, despite a significant percentage, it is not an in-depth concept. In similarity analysis, family is a core with scarce content and distant from the patient core. The difficulties experienced by the patient, such as fear of death, pain and uncertainty about the future, are extended to the family. Caregivers face many difficulties due to interference in their personal life, which is a reflection of the function of caring for the sick person[14]. Considering the reality of these families and especially the emotional and physical burden of those who play the role of caregivers, it is also necessary to work with this family member to accept, not only the finitude of being cared for, but also the situation in which they find themselves. It is reiterated that the palliative approach also seeks the well-being of the family.

Suffering was another term with good representation, which demonstrates the professionals' difficulty in dissociating palliative care from suffering. Suffering with finitude begins with the possibility of diagnosing a life-threatening disease and extends to death itself. This suffering is unique in each individual, as diseases are repeated, but suffering is unique[15]. Heart transplantation confers greater survival and a good quality of life to patients; however, these benefits are maintained through restrictions and the use of immunosuppressive drugs, which have long-term consequences, such as diabetes and others.

The emergence of these complications, restrictions, and the risk of death in heart transplant patients legitimize the use of palliative care. However, there are factors that make it difficult to introduce this approach, such as prejudice related to the theme[16]. It can be noticed from the class dendrogram that "prejudice" is an expressive word, as it is one of the branches of the palliative care core of the similarity tree.

There is prejudice in relation to the practice of palliative care. This is because people believe that it should be used at a time when there is nothing more to do for the patient, a situation feared by the family and the doctor who is caring for the patient[6]. The palliative approach does not exclude the use of different technologies and therapies, but seeks to make rational use of such resources through a careful assessment of the cost-benefit of the intervention in the patient's life. It is necessary to question the extent to which a given procedure will be effective or harmful to the well-being of human being[15].

It was identified that terms such as "God" and "Life" had significant representation in the professionals' statements. Religiosity/spirituality can dampen sympathetic nervous system activity and increase parasympathetic activation. In addition, it is related to lower levels of circulating cortisol or cortisol responsiveness, therefore, it can contribute to the reduction of somatic complaints, especially in the improvement of depression and anxiety parameters[17]. For people who are in palliative care, spirituality gives a sense of continuity when they express that life does not end

with physical death. Including emphasizing that, with the weakening of the body, they feel the strengthening of the spirit and see death as a passage to another place[18-19].

In addition to spirituality, the clinical dimension of palliative care was also reported in the interviews, referring to the clinical and therapeutic conditions of these patients. After some time of transplantation, the patient may have symptoms of heart failure (HF) again. Similar to other chronic conditions, HF causes severe suffering to patients. Furthermore, patients with this syndrome have minimal understanding of their condition and less involvement in the decision-making process related to their care, in addition to being the ones who receive less palliative care[20].

At the end of the analysis, it is understood that the phenomenon of death, as well as birth, needs to be carried out by the individuals who live this experience. It is an essentially human event and existing technologies must be at the service of this human being and not the opposite, because it is not a sick body, but a person who should not be the object of unnecessary interventions.

Among the items recommended for a reflection on the palliative approach and therapeutic decision-making, it is necessary to pay attention to other elements in addition to the patient's chronological age, because, as an isolated factor, it does not indicate the need for palliation. The functional ability of this patient should be evaluated, considering that, according to the WHO[21-22], there is no longer a typical elderly person and the changes in the senescence process come not only from genetic factors, but mainly from the interaction with the physical and social environment. Thus, younger people may experience more significant physical and mental decline than older people may.

In addition to age, it is pertinent to consider the time of transplantation. At least one year after the procedure, graft vascular disease (GVD) can arise, being the main complication developed by transplant patients and most responsible for late graft dysfunction, in addition to being the second most common cause of long-term death[23]. Thus, the item in question needs to consider not only the number of years elapsed after the procedure, but how much the evolution of GVD was deleterious to this heart, that is, what this time represents in the patient's cardiac function. The decline in the patient's cardiovascular capacity causes symptoms of HF, which makes it useful to also assess the NYHA functional class, as patients in class III and IV have many limitations in daily activities.

Complications may also arise in newly transplanted patients. Sometimes the patient does not return from the surgery with a good prognosis, and there may be rejection, infection or other factors resulting from the procedure itself[3]. In this case, it is necessary to review the situation and what procedures are feasible to maintain the comfort of this patient, warning that, depending on the severity, extreme measures are not recommended[3]. In addition to GVD and complications that may occur after the surgical procedure, other comorbidities should be considered, such as the presence of kidney problems, neoplasms, diabetes, hypertension, infections[3].

It is relevant to examine the nutritional condition of the patient, as both malnutrition and obesity can be impeding factors for a retransplantation surgery, for example, as well as for the recovery of the person's general condition[23]. Nutritional assessment is of paramount importance throughout the course of heart disease, including post-transplant follow-up, whether conventional approaches are followed or palliative measures are chosen[23].

The comorbidities in question and the need for constant examinations and procedures result in successive hospitalizations to stabilize the patient's condition[24]. Thus, another component that deserves to be evaluated is the number of hospitalizations in the last year; the patient's cardiac function deteriorates with each decompensation of the disease. That is, even if there is a stabilization of the condition, it will occur at a lower level than the state before hospitalization, so a high number of hospitalizations in a short period represents a bad prognosis[24].

Furthermore, the psycho-emotional state of the patient and the family also deteriorates with each hospitalization and is essential to decide on the conduct of the treatment[24]. These are days of suffering, distance from family members, changes in the routine of these people, which makes it expected and even justified that, at some point in the process, there is a desire to stop or at least reduce so many hospitalizations and procedures.

With this proposal, the original principle is resumed, in which the action of palliating patients and families should not be restricted to those commonly expected clinical situations[25], such as oncological conditions. Therefore, the expectation is that, by bringing together the particular aspects related to different dimensions, professionals who care for and assist patients undergoing heart transplantation and their families will feel encouraged to rethink palliative care. Not as a sentence, but as a quality of life when the end is near.

This study brings the possibility of reassessing palliative care for transplanted patients, as many of them are in conditions likely to receive such care, but do not receive formal guidance, which compromises the quality of care and the patient's well-being. However, the study has limitations because it was performed in a single transplant center.

It is proposed to carry out further studies on the subject to apply and disseminate scientific knowledge about it, considering that other transplant centers may experience different and/or complementary realities, which need to be explored.

## CONCLUSION

Rethinking palliative care in heart transplantation is challenging due to the association made between transplantation and rebirth. The speeches revealed that there is a long way to go before heart transplant patients benefit from the palliative approach, considering that this approach, in the view of professionals, is permeated by negative feelings and lack of information on the part of the teams. The development of the mind map showed a complex process, as it involved the need to balance the specifics of heart transplantation with palliative principles. The mind map is useful as it contains elements of palliative care in heart transplantation and can guide the insertion of this care to the transplanted patient; however, its use does not exempt the team from analyzing each case in search of better decision-making.

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