



# MEANINGS OF LIFE AND DEATH AMONG CARDIAC PATIENTS AND THEIR CAREGIVERS: AN INTEGRATIVE REVIEW

*SENTIDOS DE VIDA E MORTE ENTRE PACIENTES CARDIOPATAS E SEUS CUIDADORES: UMA REVISÃO INTEGRATIVA*

*SENTIDOS DE VIDA Y MUERTE ENTRE PACIENTES CARDÍACOS Y SUS CUIDADORES: UNA REVISIÓN INTEGRATIVA*

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## ABSTRACT

This article seeks to understand the meanings of life and death among individuals affected by heart diseases as well as among their caregivers. As a preliminary investigation procedure, an integrative review was conducted to understand the state of the art on the topic using the databases Virtual Health Library (VHL), Google Scholar, CAPES Journal Portal, and PubMed, focusing on open access works written in Portuguese. Out of the 4,178 publications found, 23 articles were selected after titles and abstracts were read. Out of these, a final sample of 18 manuscripts was obtained. The research findings highlight the fundamental role of emotions in coronary disease. In conclusion, the importance of the integrative review is emphasized for understanding Brazilian academic production on chronic diseases as well as an important tool for detecting possible gaps to be addressed in future research. It is believed that such reflections can bring a contribution not only to the field of health psychology, but also to the field of studies and research on chronicity and care practices.

**Keywords:** *Psychology; Heart disease; Meanings; Life; Death.*

## RESUMO

O presente artigo busca compreender quais os sentidos de vida e morte tanto entre sujeitos acometidos por cardiopatias quanto entre seus (suas) cuidadores (as). Como procedimento preliminar da investigação, a fim de compreender o estado da arte sobre o tema, realizou-se uma revisão integrativa nas bases de dados Biblioteca Virtual em Saúde, Google Acadêmico, Portal de Periódicos da Capes e PubMed, privilegiando-se trabalhos em língua portuguesa e de livre acesso (open access). Do total de 4.178 publicações encontradas, após a leitura dos títulos e dos resumos, foram selecionados 23 artigos. Desses, obteve-se uma amostra final de 18 manuscritos. Dentre os achados da pesquisa houve a constatação do papel fundamental das emoções no adoecimento coronariano. Como conclusão, destaca-se a importância da revisão integrativa tanto para uma compreensão da produção acadêmica brasileira sobre doenças crônicas quanto como importante ferramenta para detecção de possíveis lacunas a serem sanadas em futuras pesquisas. Acredita-se que tais reflexões podem contribuir não apenas com a área da psicologia da saúde, mas com o campo de estudos e pesquisas sobre cronicidade e práticas de cuidado.


**Descritores:** *Psicologia; Doença do coração; Sentidos; Vida; Morte.*

## RESUMEN

Este artículo tiene el objetivo de comprender los significados de vida y muerte tanto entre los individuos afectados por cardiopatías como entre sus cuidadores. Como procedimiento preliminar de la investigación, se realizó una revisión integradora en las bases de datos Biblioteca Virtual en Salud, Google Académico, Portal de Periódicos de CAPES y PubMed, enfocándose en trabajos en lengua portuguesa y de libre acceso. Del total de 4,178 publicaciones encontradas, después de leer los títulos y los resúmenes, se seleccionaron 23 artículos. De estos, se obtuvo una muestra final de 18 manuscritos. Los hallazgos de la investigación destacaron el papel fundamental de las emociones en las enfermedades coronarias. En conclusión, se enfatiza la importancia de la revisión integradora tanto para la comprensión de la producción académica brasileña sobre enfermedades crónicas como una herramienta importante para detectar posibles lagunas a ser abordadas en futuras investigaciones. Se cree que tales reflexiones pueden contribuir no solo al área de la psicología de la salud, sino también al campo de estudios e investigaciones sobre cronicidad y prácticas de cuidado.

**Descriptores:** *Psicología; Enfermedad del corazón; Sentidos; Vida; Muerte.*

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## INTRODUCTION

In the field of Human and Social Science, life and death are dimensions intrinsically linked to the human existence, interconnected and holders of multiple meanings that drive individuals to act in the world and to imprint marks in the shortness of a finite existence<sup>1</sup>. The relationship between life and death, especially in the interface with the health field, is complex and multifaceted, encompassing social perceptions, rituals, and cultural practices, processes of grief and confrontation, palliative care, access to health services and the ethics of care. Exploring this relationship is essential to reach a wider and humane understanding of the human experiences.

In this study, we have investigated the experiences cardiac patients have gone through and the meanings they and their caregivers have given to life and death. According to the World Health Organization<sup>2</sup>, cardiovascular diseases (CVD) are the illnesses that mostly affect the world population. In 2019, approximately 17.9 million people died as a result of such diseases, corresponding to 32% of all global deaths. CVDs represent a set of heart and vascular disorders, including coronary disease, cerebrovascular disease, peripheral artery disease, rheumatic cardiac disease, congenital heart conditions, deep vein thrombosis, and pulmonary embolism<sup>2</sup>.

Heart diseases can be sorted out as acute, chronic or terminal; all of them compromise the physical and functional condition of the heart. Terminal cardiac diseases, especially, significantly reduce life expectancy and do not react to maximum pharmacological therapy as well as to external hemodynamic support measures<sup>3</sup>. These diseases directly impact the quality of life of the individuals affected, leading to physical, psychological and social changes that are intensified as the illness progresses.

Aging is associated with increased risk of chronic diseases such as CVD, as longer longevity implies higher exposure to risk factors for non-transmissible diseases<sup>4</sup>. However, both aging and getting sick are not homogeneous processes; they are experienced in several ways, impacted by structural factors such as social class, gender and ethnicity, as well as conditions associated with health, education, and economic status<sup>5</sup>.

The presence of chronic diseases may affect cognition, memory, and the capacity of processing information, and also lead to significant social changes. The elderly often have to deal with retirement, loss of friends and family members, loneliness, and the reconfiguration of family roles. For this reason, Reis et al.<sup>6</sup> point out that this stage of life requires dealing with grief, either real or symbolic.

In this context, the emotional experiences play a fundamental role in thinking over life, in the search for meaning, and in facing finiteness. Mental health and emotional well-being are frequently affected, so that it becomes essential to value the desires and subjectivities of these individuals. Sublimation may come up as a mobilizing strategy allowing psychic energy to be directed beyond the self and one's very body, even in the face of losses<sup>6</sup>.

Moreover, aging and becoming ill does not affect only the concerned individuals, but also their caregivers. Oftentimes, these caregivers who have not yet aged or become sick face difficulties in handling issues associated with life and death. The imminent death

of a beloved person may cause distress, sadness and anxiety, feeling that are inherent to this complex moment<sup>7</sup>.

The emotional needs of caregivers are, therefore, a crucial aspect in the process of care, as it helps handle the overload, the access to moments of rest, the existence of a support network, and the availability of financial and structural support. Effective communication with health professionals also plays a key role, which directly affects the way caregivers deal with the proximity of the death of a beloved one. According to Fernandes and Angelo<sup>8</sup>, good communication may make this process easier and contribute to experience it in a less traumatic, more significant manner.

Given this scenario, it is paramount that the health teams devise strategies intended to strength self-care and the adoption of healthier habits. Health-enhancing activities are fundamental tools to improve the quality of life of patients and caregivers<sup>9</sup>. Additionally, the importance of communication between the health team and the Family must be emphasized when dealing with the proximity of death, which allows this moment to be understood and re-signified in the life trajectory of the caregiver.

Based on these reflections and drawing from a review of the literature, this paper seeks to comprehend the meanings of life and death given by both people living with heart diseases and their caregivers. The purpose is to encourage the academic, technical and scientific debate around the theme, in order to enhance the access of health education and education for dealing with death.

## METHODS

Whereas integrative review is a research method that allows for the synthesis and critical analysis of studies which have already been published about a given topic, whose main objective is to provide a comprehensive view of the knowledge available by identifying advancements, gaps and trends in the scientific literature<sup>10</sup>, a bibliographical review has been conducted on open-access databases. The databases consulted include the Virtual Health Library (VHL), Google Scholar, Capes's Journal Portal, and PubMed. In order to ensure greater accuracy in selecting the studies, search strategies were structured by combining the descriptors "Heart diseases" and "Psychology", with the use of Boolean operators to refine results.

Inclusion criteria were adopted to prioritize original articles, with full text available, published in Portuguese over the last 10 years (2014-2024) addressing the topics aligned with scope of the research. Duplicate works were excluded, publication in other languages, abstracts, editorials, clinical studies which, after reading the abstract, did not have a direct relationship with the theme being investigated.

As this is a bibliographical review, with no direct involvement with human beings, the study is exempt from being screened by the Ethics Committee, as set forth by Resolution No. 510, of 07 April, 2016, by the National Health Council<sup>11</sup>.

## RESULTS AND DISCUSSION

When searching the database, 4,178 publications were found and sorted out: 2,075 on the VHL; 2,089 on Google Academic; three on the Capes' Journal Portal; and 11 on PubMed. After reading the titles and abstracts, 23 texts were selected. Once this selection

was established, the articles were fully read, which resulted in a final sample of 18 studies. Table 1 presents a flowchart of the methodological path taken while choosing the studies.

**Table 1** - Distribution of the articles found, excluded and selected on the databases

Studies identified through searching the databases n = 4,178	VHL = 2,075 Google Academic = 2,089 Capes Journal = 3 PubMed = 11
Refinement of the search considering the last 10 years (2014-2024); language: Portuguese; full text = 1,163	Total studies excluded = 3,015
Studies selected after reading the titles = 38	Total studies excluded = 1,125
Studies selected after reading the abstract = 23	Total studies excluded = 15
Articles fully read for eligibility = 23	Article excluded after full text was read: 5 (Factors: do not match the topic)
Studies included in the review after reading the full text = 18 (3 – VHL; 12 – Google Academic; 2 – PubMed)	

**Source:** Prepared by the author.

To get started with the analysis of results, a table was set up to describe the publications selected, with the following items: authors, year of publication, database, and title. For best identification and use during the analysis, texts have been numbered according to their position in the table, as can be seen in Table 2. Afterwards, the contributions by each author will be explained.

One can realize how difficult it is to find materials associated with the concerned theme in the several databases, so that most texts were found through Google Scholar. In the table above, it is still possible to see the diversity of methodologies applied in the research, and this enhances the diversity of results obtained. It is also noted that most publications with contents associated with the theme had been released in 2020, in a total of seven out of the 18 papers selected.

Turning to the description of the studies, it is considered important to highlight the contribution of each study within their area of analysis.

**Table 2** - Characterization of data from the articles selected in the review

ID	Authors	Year	Methodological details	Title (translated from the original in Portuguese)	Results and conclusions
1	Dessote <i>et. al.</i>	2015	Data Analysis	Somatic and cognitive-affective depressive symptoms among patients with a heart condition: differences by sex and age	Patients with a heart condition have different expressions of depressive symptoms according to sex and age. Specific interventions may be required for risk groups.
2	Grisa and Monteiro	2015	Literature Review	Emotional aspects of the surgical cardiac patient in the pre-operative period	Emotional aspects such as anxiety and fear, prevail in the pre-operative period in surgical cardiac patients. Psychological support is fundamental to handle the situation.
3	Lemos, Moraes, and Pellanda	2016	Cross-sectional Study	Resilience in Patients with Ischemic Heart Disease	Patients with ischemic heart diseases show significant resilience, which helps them adapt to treatment and the illness, but psychological support may optimize such results.
4	Soares	2016	Cartography (Dissertation)	Nursing staff and the production of care to people who suffer with a heart condition: a cartography	The nursing staff plays a crucial role in producing care that involves not only physical aspects but also emotional and psychosocial aspects of patients with a heart disease.
5	Resende and Teixeira	2017	Quanti-Qualitative Study	Perception of heart disease and levels of stress among adult in-patients	Perception of the heart disease is tightly associated with levels of stress and patients with higher levels of stress tend to present a worse prognostic.
6	Silva	2018	Clinical Trial (Dissertation)	Clinical psychology and cardiac diseases: the reasons and un-reasons of the heart	Clinical psychology plays an important role in understanding the emotional factors that contribute to heart conditions. It also provides support for treatment and recovery.
7	Ventura and Rodrigues	2018	Literature Review	Traits of a sick heart: Psychology in dialog with Cardiology	Integration between psychology and cardiology may provide a more hollistic care to patients with a

					heart condition, considering the emotional and psychosocial aspects of the disease.
8	Barreto and Moreira	2020	Qualitative Study	Symbolisms of the heart: the relationship between oneiric content and the wait for a cardiac surgery	The oneiric content reveals profound meanings associated with the wait for the heart surgery, which indicated the importance of psychological approaches along the process.
9	Barros <i>et al.</i>	2020	Qualitative Study	Needs of comfort for patients of heart transplant	Patients of a heart transplant require specific comfort care, focusing both in the physical and emotional aspect during the post-transplant recovery.
10	Figueiredo <i>et al.</i>	2020	Quantitative Study	Synergic effect of the Disease's Severity, of Anxiety Symptoms and of Old Age on the Quality of Life in Outpatients with Heart Insufficiency	The disease's severity and the anxiety symptoms have a significant impact on the quality of life of patients with heart insufficiency, requiring that physical and emotional health be handled together.
11	Fraga and Faria	2020	Literature Review	Psychosocial aspects in an individual with a heart disease	Psychosocial aspects such as family support and emotional adaptation are essential for recovery of patients with a heart condition.
12	Menezes <i>et al.</i>	2020	Qualitative Study	The experience of mothers of child with an inborn heart disease that will undergo cardiovascular surgery	Mothers of children with inborn heart conditions show high levels of stress, so it is essential to provide them with emotional and psychological support before and after the surgery.
13	Oliveira and Benicá	2020	Intervention Research	Psycho-educative intervention with family caregivers of patients undergoing heart surgery	Psycho-education for caregivers of patients undergoing heart surgery has had a positive impact in reducing stress and improving how to handle the illness.
14	Souza and Staliano	2020	Qualitative Study	The heart as the center of life and emotions: a study of cardiac patients in hospitals general	Patients with a cardiac disease perceive the heart as the center of their lives and emotions, which reinforces the importance of whole care, including emotional and psychological aspects.

15	Roder and Vivian	2021	Qualitative Study	How heart insufficiency patients perceive their social support	Patients with heart insufficiency often report feelings of loneliness and lack of social support, it is essential to strengthen their support networks.
16	Wanderley, Mader and Bley	2021	Quanti-Qualitative Study	Caregivers of children and adolescents with inborn heart conditions: an empowering proposal	Empowering caregivers of children with inborn heart conditions may improve the quality of care, and also provide the families with increased well-being.
17	Coutinho <i>et al.</i>	2022	Cross-Sectional Study	Sense of consistency and quality of life in adolescents with a heart condition	The sense of consistency has a significant impact onto the quality of life among adolescents with heart diseases, with a highlight to how important strategies of psychological support are as they enhance the perception of understanding and being in control of the disease.
18	Vieira	2022	Qualitative Study	Production of meanings of heart post-heart transplant: articulations, flows and intensities	The period after heart transplant involves significant emotional and psychosocial changes; ongoing psychological support is essential to adapt patients to this new phase in their lives.

**Source:** Prepared by authors.



**Table 3** - Contributions of the studies (numbered according to Table 2)

ID	Contribution
1	Brings in greater prevalence of somatic symptoms in female cardiac patients in comparison to male counterparts. It is believed that depressive symptoms may be associated with biological aspects, such hormone oscillations during the reproductive period and menopause, as well as psychosocial aspects such as their social and family roles. Highlights the need of care in order to keep these symptoms under control as a way to avoid recurring decompensation of the cardiologic context.
2	Addresses how difficult it is to understand and accept the news/fact of having to go through a surgery; fear that the surgery will not be successful, of having pain, of becoming disabled for work or of dying. In post-surgery period, expectancies include improvement, change and greater dedication to the family. It also highlighted how important spirituality is as a factor of protection.
3	Establishes a relationship between resilience and the clinical outcome of patients over time, and points out the importance of developing strategies intended to improve resilience in individuals under adverse conditions.
4	Explores the production of expanded care patients with heart conditions are provided with, which introduces ambiguities and dualities of feelings that pervade professional caregivers (nursery staff).
5	This paper draws attention to the need of perceiving how patients with a heart disease understand their illness, since such understanding may affect as a whole the system of beliefs and emotions those patients experience/ this is a determiner in the quality of life along the path of the illness.
6	Investigated the involvement of emotional phenomena in the process of someone getting a heart disease, when conflicts are not symbolized and are unconsciously denied so that, as a result, they become somatic.
7	The study associates emotions, anxiety, stress and depression with the experiences of a patient with a heart condition, especially those who will have to go through surgery. It refers to the symbolism of the heart as an organ of the body and its functionality, and also the need to verbalize feelings and fantasies that mainly include the fear of death; it highlights the job of a psychologist as essential to reduce anguish.
8	By analyzing dreams, it investigated who cardiac patients waiting for surgery understand the possibility of finitude, in face of how fragile the body and the heart are. It mentions the suffering associated with the loss of autonomy and the impossibility of controlling the situations; this increases the fear of death and the wish to resume a safe, stable, fluid life by escaping from reality and the mechanism of denial.
9	Introduces Katharine Kolcaba's Theory of Comfort and how it is related to the physical, socio-cultural, environmental, and psycho-spiritual context in patients who had a heart transplant. Addresses the changes in the life of the individual with a transplant as well as the difficulties and suffering involving the adaptation and changes in personal relationships and the role of the nursing professional as a caregiver.
10	Demonstrates the correlation between symptoms of depression and anxiety and reduced quality of life in patients with heart insufficiency.
11	Presents two psychosocial factors affect the progress of a heart condition, and raises the question that the cardiovascular diseases are most prevailing among individuals of lower socioeconomic status, who, in turn, live in the poorest areas of the cities, with difficulty to access essential services such as education, health, and, and water and sewage facilities. Mentions the symbolic aspects involving the heart and points out the space for action the psychologist and health professionals have in such context of illness.
12	Addresses the fear of mothers who have children with an inborn heart at the moment they found out about the illness and its treatment – fear of the death of a child, the emotional suffering



	caused by hospitalization. On the other hand, presents the comprehension of the becoming ill, the feelings of hope, and the role of spirituality in this context.
13	Reports the experience of family caregivers and a potential overload resulting from care, considering that along hospitalization the entire family structure may change. Also brings in playful activities as a tool of binding and communication between the family caregiver and the health professional caregiver, in order to facilitate the psycho-educative intervention.
14	Presents the symbolic perspective of the heart as the center of life and emotions, and proposes reflections on the need to repair the organ and the meanings given by the patient. Points out the fantasy of disintegration of the heart, the body, and the very Self, as a result of its manipulation.
15	Reflects about the repercussions of becoming ill in the context of growing old and its connections with the social support perceived.
16	Investigates the potential physical and mental strain caused by the care of a child with a chronic disease to the caregivers, which seriously compromise several areas of the quality of life, since they require continuous complex forms of care. It also highlights the presence of the mother as the major caregiver.
17	This study demonstrates that the Sense of Consistency (SoC) is a protection factor for adolescents and helps improve the perception of Quality of Life (QL) and to successfully lead with daily adversities and the stress associated or not with a chronic illness.
18	Shows the presence of several actors and a variety of meanings of a heart transplant, meanings that are subjectively constructed, full of affectations and changes appearing in each context, creating singular realities.

**Source:** Prepared by the authors.

While looking for how meanings of life and death are produced by patients with a heart condition and their caregivers, as described by the contributions in Table 3, it is necessary to take a number of factors into consideration, since they are diverse in their significance. The existence of emotional dualities in these individuals can be observed as they strive for life and for quality of life and, at the same time, they face fears and concerns related to death and dying.

The fundamental role of emotions involved in coronary illness is noticeable, as well as the meanings the patient assigns the disease, which corroborates international studies that show how psychological factors such as stress, anxiety and depression are associated with coronary disease<sup>12</sup>. All of that leads to the importance of care in mental health, due to the ways emotions are handled affects the recovery of the sick person<sup>13</sup>.

Additionally, it is mentioned that the sick individual cannot be dissociated from his/her caregivers; that is because one cannot exist without the other, so that all articles highlight how important the care provided is, even if the articles do not discuss the meaning of the disease for such caregiver.

Thus, it is possible to conceive the discussion in three major topics: the description of the heart diseases and the production of meanings associated with the heart; who are the patients with a heart condition and their caregivers; and, finally, the meanings of life and death produced by these individuals.

#### **a) Severe heart diseases and the production of meanings related to the heart**

Severe heart conditions consist mainly of acute, chronic, and terminal heart diseases<sup>3</sup>. According to the Brazilian Society of Cardiology, the former are characterized

by the loss of the heart's physical and functional capacity, evolving quickly and becoming chronic, so that they fit in the second category in which, in addition to these limitations, drug treatment and/or surgery is necessary; finally, terminal heart diseases are those in which life expectancy is reduced, as generally they do not respond to maximum pharmacological therapy or to external hemodynamic support; in this case it is not possible to undergo surgery or a heart transplant, considering the severity of the clinical situation or other associated diseases.

Thus, it is possible to think that a severe heart disease is based on the individual's inability to perform labor functions and their relations, as a long-term prognostic, and the individual's survival, as there is implicitly a reduced life expectancy; it is responsible for the greater number of disabilities and, also, the chronic diseases with the highest number of deaths that could be avoided, either through activities of promotion and prevention, early diagnosis, or clinical and surgical treatments<sup>3</sup>.

One of the subjects mostly highlighted in the findings of this research was the functionality of the heart and its symbols. According to Teixeira<sup>14</sup>, the heart is the main organ in the cardiovascular system, it is located in the central area of rib cage, a little tilted to the left, and consists of a hollow chamber with four cavities, two of them are called atriums and the other two are called ventricles. Its job is basically to pump the blood and distribute it through the blood vessels such as arteries, arterioles, vein, capillaries and venules which make up the blood circulation system.

In spite of being a complex organ whose functioning is vital to all activities of the human body<sup>14</sup>, its functionality is not restricted to its anatomy and physiology; the damages caused when the heart becomes ill are not only physical because oftentimes the heart is symbolically associated with a variety of emotional and psychological meanings, although it is not an organ literally involved in the mental functions.

This condition is envisioned based on the studies by Ventura and Rodrigues<sup>15</sup>, who introduce the perspective that, socially speaking, the heart has been mystified as the seat of passions, feelings and affections, therefore, these attributes characterize the organ as the seat of emotions, fantasies, fears and the very defense mechanisms in patients suffering a heart disease at this may hinder the diagnosis, the treatment, and the rehabilitation of those patients.

Bearing this symbolic context in mind, the experiences lived by a patient with a heart disease are enhanced due to the dichotomy physical/emotional of the organ, since there is a great affective load associated with the heart, which may make it more prone to a somatic outbreak<sup>15</sup>. The authors highlight the idea that feeling emotions do not necessarily cause heart diseases, but the way those people experience these affections may change the rates of cholesterol, triglycerides, blood pressure and sugar level on a permanent basis, triggering some diseases.

The next section presents the studies focusing on the perspectives of patients with heart diseases and their caregiver(s).

## **b) Individuals with a heart disease and their caregivers**

Cardiac patients are those who suffer of cardiovascular diseases. The study by Silva<sup>16</sup> points out that, in the medical literature, cardiovascular diseases are sorted out and defined in their concept by several categories, the most usual disease being angina pectoris, myocardium infarction, arrhythmias, aneurisms, cardiac failure and valvular heart disease, in great variety and a wide range of symptoms. In addition, Resende and Teixeira<sup>17</sup>, in their study of the stress levels in patients with a heart disease, point out that such patients suffer from physical, social and emotional developments, together with the changes in their family dynamics and disabilities caused by the illness.

Wanderley, Mäder and Bley<sup>18</sup> also comment that the treatment of those individuals requires changes in their lifestyle, special diets, and frequent admissions to a hospital, which makes it difficult for them to strictly follow the treatment. Silva<sup>16</sup> adds that treating these illnesses varies from pharmacological, mechanical or hemodynamic therapies to surgeries in the context of the illness.

Therefore, living with a heart condition can be challenging and requires continued care as well as special attention, with the need for support and assistance in order to best manage one's health and quality of life. For Oliveira and Benincá<sup>19</sup>, becoming ill will entail consequences and changes in all the family's spheres:

[...] when a family member is stricken by a chronic or terminal disease, the whole family get directly or indirectly involved. Thus, the roles are redistributed and new functions arise, with an impact on the psychic structure of everyone involved.<sup>9:150</sup>

In this context, caregivers play a crucial role. That is because they provide emotional support, which is helpful in the daily chores and ensure that the treatments will be adequately complied with. Moreover, they foster a healthy environment and lifestyle are adopted so that the patient's cardiovascular condition is improved. However, taking care of a sick family member requires adaptation from the caregiver, configured as laborious and exhausting task which may cause some family unbalance leading to an overload when there is only one caregiver<sup>19</sup>.

It is possible to realize that the entire condition and exhaustion caused by the care is largely due to the physical and emotional stress, in addition to dealing with one's own concerns and responsibilities. Therefore, it is essential that caregivers are also given the necessary support, both in terms of practical resources and in terms of emotional assistance.

However, care is not restricted to family members. The study conducted by Soares<sup>20</sup> reminds that health professionals also have demands and feeling related to the aid they provide to patients, and they suffer with the ambiguities and dualities intertwined in this job – as, for example, the lack of recognition, work overload, low salaries and emotional suffering due to the constant loss of patients, in contrast with the pleasure in the work and the benefits it may bring about. Such elements become clear in the research in question, since in several occasions the authors point out the role a professional plays in the context of illness and in the practice of care.

Ultimately, according to Röder and Vivian<sup>21</sup>, the binding between patients with a heart condition and their caregivers is a vital part in the management of cardiovascular health. Generally, the studies that have been found show a correlation between the individual under care and the caregiver, and it is not possible to disconnect the former from the latter when considering the suffering and boosting the quality of life.

Therefore, as found in such literature, by turning to mutual support and a collaborative approach, it would be possible to tackle the challenges of a heart condition and seek a full healthy life by developing adequate ways of confronting both illness and death.

### c) Meanings of life and death

The third and last topic frequently found in the articles has to do with the meaning of life and death. According to Silva and Cardoso<sup>22</sup>, the search for meaning and understanding around life and death has been playing a key role in the artistic expression, in the religious practices and in the scientific investigations. It has become one of the most profound issues of the human existence. Therefore, one may think that, despite the fact that every human being is aware that she or he will die one day, talking about death is still denied, which is an unconscious desire of immortality and, no matter how painful it is for an individual to acknowledge his or her incompleteness and impossibility of being imperishable, it is necessary to admit one's mortality as well as the fact that life is transitory and that the human being is finite.

Thus, for these same authors, unconsciously, death is always the death of somebody else, a destruction or loss that was caused; the individual does not have, by him or herself, access to some kind of premonition of their own death; it is only through an ambivalent identification with a beloved one, in which their death is desired and, at the same time, feared<sup>22</sup>.

Consequently, it is undeniable that at this time of someone's life questions come up together with thoughts about death, since the topics of illness and losses become more frequent but not always well seen – this may strengthen that idea that these conceptions are shaped the individual's own experiences throughout their life, and it may also affect religious beliefs and cultural values as different religions and cultures have various interpretations regarding what happens after death and the purpose of life. Therefore, some people may accept death as an unavoidable part of life while others may fear the unknown and the loss of beloved ones.

Among the texts selected for this review, all of them address the real risk of death entailed by heart diseases, but most of them present the feelings and meanings the fact of dying has for these individuals. Feelings mainly described as fear of and anxiety towards death, or even the fear of losing. Fraga and Faria<sup>23</sup> explain that the lack of understanding in relation to death makes the human being feel submissive to something unknown, which generates suffering and hopelessness.

It is known that the disease has its progression and reduces the quality of life and the autonomy of the sick person and, in this context, the fear of death increases proportionally to the severity of the disease<sup>21</sup>. In his study, Soares<sup>20</sup> writes about the

production of care for people who suffer some heart condition and says that such fear and the expectancy of dealing with death may unleash a context where the disease and dying are denied, both by the patient and by family members and also the health professionals, so that this latter group experiences death on an everyday basis and cannot forget none of them whatsoever.

A chronic disease – which sometimes can be terminal – also changes the meanings and perspectives of life. The studies presented in this paper emphasize how important the support provided by the family and search for satisfaction in the interpersonal relationships for these patients. Moreover, the experience of a trauma of quasi-death and the possibility of carrying on with one's life makes it possible to produce new ways of playing an active role, aware that they will endure the treatment all life long <sup>24</sup>. Thus, in addition to being anxious about death, there are fears associated with the experience of becoming ill.

Drawing from such studies, it is possible to argue the importance of some kind of preparation for death, because this may affect the feeling of control over the process, and also the process of education in health and the follow-up of emotional issues – either of the individuals who are ill, or of those who are in charge of their care and who experience the whole process together, since the loss of beloved ones or even the daily experience of death in the health workplace may lead to illness.

## CLOSING REMARKS

The integrative review presented here has shown how complex the meanings of life and death are as experienced by patients with a heart condition and their caregivers. The findings highlight how important it is to comprehend not long the clinical aspects of heart diseases but also the existential and emotional meanings intrinsically involved in these experiences. By absorbing these dimensions, the debate is broadened beyond the conventional medical treatments, which underlines the need of more holistic, patient-centered practices of care.

The integration of different studies allowed for a comprehensive view of the topic, although such methodology has also limitations. The diversity of approaches, methodologies and contexts of the studies analyzed may cause heterogeneity making it difficult to conduct a direct comparison of results. Additionally, an integrative review relies on the quality and depth of the studies available, which may limit the comprehensiveness of the conclusions.

The findings of this review suggest several directions for future research in the field of chronic diseases and practices of care. In-depth qualitative studies may explore, with more details, the personal narratives of patients and caregivers, while longitudinal researches may examine how the meaning of life and death have evolved over time. Incrementally, investigations of specific interventions looking at the psychological and emotional well-being of those individuals may provide valuable insights for devising more integrated and effective practices of care.

All in all, by taking an in-depth view to best understand the meaning of life and

death among patients with a heart condition and their caregivers, this integrative review significantly contributes with the existing literature by encouraging more humane and comprehensive approaches to the treatment and care of chronic diseases.

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