


Meanings of life and death: reflections of patients in palliative care

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Abstract: Palliative care seeks to alleviate the suffering of patients with chronic and life-threatening diseases in the physical, social, psychological and spiritual dimensions. In the spiritual dimension, it seeks to imbue transcendental aspects, such as life and death, with meaning. Knowing these senses is the objective of this study, which is a qualitative research of exploratory character, and uses semi-structured interviews for data collection and discourse analysis. Four patients were interviewed and three categories of meaning were identified: finitude coping resources; sufferings related to finitude; meanings attributed to life and death. We noticed the greater suffering was not the finitude itself, but what arises from it, such as functional loss, concern for the family and threat of values. The difficulty in talking about death is not necessarily in itself, but in identifying the meaning it has for the person and the underlying sufferings.

Keywords: palliative care, spirituality, psychology, palliative care in the terminality of life.

Introduction

The worldwide phenomenon of population aging is well established by studies such as one by the United Nations, which demonstrates a trend of steady increase in the number of older people, particularly in developing countries, as a result of significant improvements in nutrition, sanitation, education, and major advances in medicine, among other factors (United Nations Population Fund & HelpAge International, 2012). In contrast, the increase in life expectancy has led to a higher prevalence of cancer and other chronic diseases that have advanced age as a risk factor. Concomitantly, the development of medicine has been turning previously acute and deadly diseases into chronic ones, thus promoting relative longevity for people who bear them (Kovács, 2014; Matsumoto, 2012).

In recent decades, there has been the emergence of specialized care for the suffering arising from these chronic, life-threatening and disabling diseases, as well as a rescue to the more natural experience of the process of dying, whose icon is Dame Cicely Saunders, founder of the modern palliative care movement and hospice philosophy (Matsumoto, 2012). As guided by the World Health Organization (WHO),

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. . . Palliative care is the prevention and relief of suffering of any

kind – physical, psychological, social, or spiritual – experienced by adults and children living with life-limiting health problems. (World Health Organization, 2016, p. 5)

Some of the principles of palliative care are: to provide relief from pain and other symptoms; to affirm life and perceive death as a natural process; not seeking to postpone or anticipate death; to integrate social, psychological and spiritual aspects in patient care; to offer help so that the family can cope with the process of illness and future mourning (Carvalho, 2018).

When the disease is called terminal, it evolves over time, threatens life and has no possibility of disease-modifying therapy with a curative end. There are poor prognosis criteria for the different diseases, as outlined by Nicodemus and Torres (2018). These diseases and their symptoms imply suffering in all human dimensions: physical, psychological, social and spiritual; not only to the patient, but also to its family. Thus, the practice of palliative care is necessarily interprofessional, in order to access and intervene in the different domains of human suffering, therefore including the spiritual one.

Spirituality is sometimes confused with religiosity, but in truth it is neither limited nor dependent on religion (Best, Butow, & Olver, 2015; Bovero, Leombruni, Miniotti, Rocca, & Torta, 2016; Churchill, 2015). The word “religion” descends from the Latin *religare*, which means “to bind” to an absolute or essential; another etymology is *religere*, “to reread”, in the intention of revealing the meaning of an event (Hennezel & Leloup, 1999). Religion can be considered

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a system of shared beliefs and dogmas that shape the conduct, to be either experienced spiritually or not (Safra, 2005), including doctrines, morals and rituals within a community (Pessini & Bertachini, 2011).

One of the dimensions of human life is spiritual (Carvalho et al., 2012; Churchill, 2015; Hennezel & Leloup, 1999; Puchalski, Vitillo, Hull, & Reller, 2014), being, thus, a potential demand of every patient, although it is an individual experience (Best et al., 2015). Spirituality concerns the transcendental meaning that a person attributes to their life, the values and purposes attached to it (Best et al., 2015; Puchalski & Romer, 2000; Puchalski et al., 2014). By “transcendental” we understand that which is beyond the practical, material and immanent, which is realized by a personal value and not by an objective end. Meaning, therefore, turns to elements that do not have an immediate, concrete representativeness. Thus, abstract aspects that are part of life are included, such as suffering, anguish, life itself and death (Bovero et al., 2016; Churchill, 2015; Fang, Sixsmith, Sinclair, & Horst, 2016; Pessini & Bertachini, 2011). Therefore, the sense is precisely subjective, although it occurs over time in relation to the external world. According to Victor Frankl (2016), the meaning of life differs not only from person to person, but from moment to moment, which makes terminality a special occasion since it enables the discovery of the meaning of life precisely at its end. However, to the extent that these senses are questioned or emptied, suffering is generated (Frankl, 2016).

Several authors pointed out the importance of spirituality in the quality of life and in coping with terminal diseases (Best et al., 2015; Bovero et al., 2016; Broadhurst & Harrington, 2015; Piderman et al., 2015; Puchalski, King, & Ferrel, 2018). Promoting an adequate space for listening and for reflection on the issue of death and life provides an emotional elaboration of re-signification, which can make less difficult the process of illness and approach to the final phase of life, considering that this space is often denied in society, in the family and even in a hospital environment. With denial, spiritual suffering can be understood as a suffering of another nature, leading to inappropriate interventions (Balducci, 2010). Thus, obtaining greater clarification on the way patients deal with the meaning of life and death can improve the resources of health professionals to accommodate and meet the demands related to these issues (Proserpio et al., 2016), being a common disability in vocational training (Best et al., 2015).

Objectives

To know the meanings attributed to life itself and death by patients with terminal disease. The specific objectives are:

- To identify the main aspects involved in the relationship with the idea of death;

- To identify psychological and/or spiritual sufferings related to finitude;
- To identify coping resources of psychological and/or spiritual dimension related to finitude.

Method

This study is qualitative and exploratory in nature, using semi-structured interviews for data collection. According to Balducci (2010), the best way to investigate spiritual and existential suffering is through qualitative studies with open questions and content analysis, since this suffering is still being understood and should not be evaluated exclusively as physical, social or emotional suffering, as it involves a complex sense of transcendence, even though these forms of pain are related.

The study was approved by the Research Ethics Committee under CAAE number: 65149717.3.0000.0068. The participants were not identified and fictitious names were used for reference.

Research participants

The participants of the research were elderly people who had been treated by a palliative care team of a public tertiary hospital for at least 3 months, who were informed about the diagnosis, prognosis and evolution of the disease and who agreed to participate in the study. The criterion of a minimum of 3 months of follow-up was stipulated by the hospital organization at the time of the discussion on the research. In their understanding, it would be sufficient time for patients to have minimally elaborated the issue of illness, thus reducing the risks for psychological suffering arising from the interviews.

The participants were selected among patients admitted to the hospital's palliative care ward, which has nine beds and specialized staff. This is intended for patients with end-stage disease who require control of symptoms, are in a period of exacerbation of the disease or are in the final stage of life. Among other criteria, hospitalization in this ward is carried out by discussion and agreement of the family members and the patient — when lucid and conscious — on the limitation of invasive measures and artificial maintenance of life, such as the use of vasoactive drugs, cardiopulmonary resuscitation, hemodialysis and intubation.

Considering the qualitative nature of the study, which aims to explore the individual experience, sampling was defined by saturation in qualitative research. As explained by Fontanella et al. (2011), saturation occurs when new data collections fail to aggregate significantly in the reflection and deepening of the study. Saturation can be empirical, from the moment the researcher finds that they have collected enough data to answer the questions and, thus, comply with the objective of the study. Saturation can also be theoretical, when new interviews do not add new

themes or new categories of meaning regarding the scope of the research (Fontanella et al., 2011; Fontanella, Ricas, & Turato, 2008). This is the saturation that was targeted. Therefore, the analysis was initiated during the collection period in order to identify saturation. If it is not possible to verify it, closure may be due to exhaustion, addressing all eligible participants within the time reserved for data collection (Fontanella et al., 2008).

Regarding the selection of research participants, the inclusion criteria were::

- To be in treatment with the palliative care team for at least 3 months;
- To bear an advanced terminal disease;
- To have been informed about diagnosis and prognosis;
- To show preserved cognition and communication;
- - To present symptoms under control at the time of the interview;
- To be aged 60 years or over;
- To authorize the use of the content of the interview for educational purposes, by filling in the informed consent form;
- To participate in the interview alone;
- To be under psychological treatment in the instance in which they are.

The exclusion criteria were:

- To be under psychological treatment with interviewer;
- To be in an acute episode of mental disorder.

Data collection instrument

A semi-structured interview script was used for data collection. This type of Interview allows and encourages the interviewee to speak freely about issues arising from the main theme, from a script of questions that enable this exploration (Gerhardt & Silveira, 2009). It is not necessary to ask all the questions, nor to follow the order in which they are arranged in the script, and there is the possibility of including questions not foreseen throughout the interview, as long as they are consistent with the purposes of the research. This flexibility is important when considering the delicacy of the subject, allowing the instrument to be adapted to the emotional response of each interviewee.

The script had two parts: sociodemographic questionnaire and open questions. The questionnaire included gender; age; main diagnosis; place of birth; education; marital status; time in marital status; number of children; race; religion and family income. The open questions were based on four axes:

- a. psychological/spiritual coping:
 - Throughout your life what most helped you to go through difficult moments and situations?
 - What gives you the most strength to face the current situation?

- How would you most like to live from here on out, respecting the limitations of the disease?
- b. psychological/spiritual suffering:
 - What would you like to have done differently in your life?
 - What would you do differently if you regained your health?
 - What could have been different in your life for you to pass away in peace?
- c. meaning of life:
 - What do you consider to have been the most important thing throughout your life?
 - What do you worry most about currently?
 - What gives meaning and purpose to your life?
- d. meaning of death:
 - Since you learned about the disease and what it means, have you come to think more about death?
 - Have you ever thought about death before getting sick?

Data collection procedure

For data collection, medical records were first analyzed in order to select patients who met the participation criteria. Then, the corresponding patients were contacted to explain the objectives of the research and to invite them to participate. If they accepted, the interview was scheduled and the Informed Consent Form was signed. If necessary, the interviews could be continued at a later time, according to the conditions and availability of the participant.

Data analysis

Discourse analysis was conducted, seeking to identify and understand the meanings manifested by the subjects, through guidelines established by Gill (2002). These are, in short:

- Literal and detailed transcript of interviews;
- Skeptical and abstract reading of the search for an essence underlying the text, performing it objectively and without the pretense of apprehending an intention behind the words;
- Coding by broad and inclusive categories based on research interest;
- Identification of speech patterns and functions, including nuances and silences;
- Analysis examining regularities and variability in the data.

Results and discussion

Interviews were conducted with four participants throughout the data collection period, to whom fictitious names were assigned. Two other interviews were scheduled, however, at the scheduled time, the patients were with disabling symptoms or were not in cognitive

condition to respond satisfactorily to the questions, and there was no new opportunity. The sampling was closed by exhaustion, since all the participants available in the given period were interviewed and closure was not possible by saturation.

It shows a reflection on each participant, based on their data and central themes of the discourse. Then, the discussion of categories of meaning identified in the process of data analysis is carried out. Throughout the text, there are excerpts from the participants' speeches, marked in italics, in order to illustrate and facilitate the proposed reflections.

Adriano

Adriano is 76 years old and has been married for 34 years. He has four children, is Catholic and Spiritist. His main diagnosis is chronic heart failure. Adriano's speech is marked by oscillations between the pole of significant self-demand and blame and the pole of self-contempt. This can be understood as an ambivalence, that is, there are contrary feelings manifested simultaneously or in the same situation (Mesquita & Duarte, 1996), as shown in the speech:

"Let's say, you've always thought you were a Superman, 'Oh, that doesn't happen to me, I'm always fine and so on.' And when it happens, you say 'I'm not what I imagined, I'm like others, or less even', I don't know". The emphases signal the aforementioned poles. This seems to be the way in which Adriano established his relations: he was the head of the family, responsible financially and for the well-being of everyone. He blamed himself for this and considered himself a failure when he was unable to maintain this role within the family with illness.

This dynamic was manifested in his coping with finitude: faced with the impotence caused by the disease, Adriano came to see himself only as a burden and cause of suffering to the family, with the feeling of having lost his function as patriarch and provider. He seems not to have realized the role that cannot be taken from him: that of reference figure and emotional support for everyone in the family.

Bruna

Bruna is 74 years old and lost her husband three years ago, with whom she had a marriage of 56 years and four children. She follows the Spiritist religion and has as her main diagnosis chronic obstructive pulmonary disease.

As Brunas's speech develops, she reveals a change in the way she speaks of herself, showing seemingly antagonistic points of view. We noticed that the first part of her speech is loaded with concepts that she has of herself; as her speech proceeds, contents arise opposite to these concepts.

At first: *"I've always been very talkative, I never held grudges for anything, no spite . . . I've never been a person of great grudges . . . , I always spoke, never hid."* And at a later time: *"I always hid my feelings. Maybe it [the marriage that worked out] would take away some of that hurt that I have. It's just, I can't say anything else."*

Bruna seemed to perceive herself differently than she had throughout her life, being part of the experience of a crisis situation, which invites self-reflection. This can demonstrate an important change in attitude towards life that, in some way, the participant herself recognizes.

Carmen

This 60-year-old patient has been married for 38 years, has two children and is evangelical. The underlying disease is acute myeloid leukemia. Carmen was the only participant who answered affirmatively about thinking of death before illness. She tells to have lost very close people and to have lived with death, so that she already routinely thought about her own death, even when she was healthy. She witnessed the unexpected death of young people, coming to see the phenomenon as something that can happen at any time, not only in old age or in illness.

Similarly, she was the only one who maintained the same coping resource to deal with difficulties throughout life and currently, in illness *"Faith in God. . . The same faith I've always had is the one I have today."* In this sense, Carmen does not notice, faced with finitude, any reason to change her faith or her perspective of death.

Throughout the talks about how she deals with the prospect of death, she stated not to be worried *"because it won't do anything."* She explains that there is no point in being anxious: *"One day at a time, living every day. . . There's no point in wanting to abbreviate anything . . . , you have to wait."* Carmen was also the only one who said she already felt at peace to die, not needing something for this. These answers gain validity to the extent that all of her discourse shows internal coherence, with no indicative elements of denial or contradiction.

We cannot deduce that her acceptance of death stems from living with this idea and naturalizing it throughout life, although this is possible. It serves as a counterexample, however, to the usual belief that talking or thinking about death outside of this context compromises coping.

Denise

Patient Denise is 67 years old, has been widowed for ten years and has seven children. She is evangelical and has as main diagnosis gastric neoplasia. She was

the only participant who answered negatively to the question about thinking more about death after getting sick: *“I don’t think about death, no. If my time is coming, it will come, if I’m to get better, I will.”*

This does not mean, however, that she is in the process of denial. After all, Denise demonstrates recognizing terminality in lines such as: *“If my time is coming, it will come. If [God] wants to take me, He’ll take me. The most important thing in my life was to have my health, if I have no health I have nothing.”*

She puts her health in the past and states that this was the most important thing for her, therefore, today she recognizes her weakness and some loss of what gave her meaning to live. She demonstrates, therefore, an attitude of resignation, understood as submission and passivity in the face of an unwanted and inevitable fate.

Denise did not even think about death before falling ill: *“Not me, I think about living!”* Nonverbal language, in this case, indicated a surprise with the question, as if asking “why would anyone think of death without being sick?”, perhaps with a belief that thinking about death is contrary to life. In fact, when relating health to resolution capacity, an important value for it, thinking about death is thinking about illness, and thinking about illness is going against these values.

Meaning categories

We initially discussed the main coping resources related to finitude: internal resources and religious faith.

The following category addresses sufferings related to finitude, in particular dependence and sense of responsibility, fear of after death and social suffering, showing how suffering in this context can originate more from secondary issues than from terminality itself.

Finally, the meanings perceived in relation to life and death are discussed: self-realization, family and acceptance of death.

Finitude coping resources — internal resources

Some of these resources were identified in three participants, manifesting through references such as resoluteness, autonomy, initiative, courage, activity (as opposed to passivity), ability to resignify and to review values: *“Willpower and determination. This I think is the indispensable minimum for you to achieve things”* (Adriano); *“Now that I have only this little bit, I give a great value to it [life], small things give me joy, small joys make me happy”* (Bruna).

Some studies show the value patients give to independence and autonomy for their quality of life (Melin-Johansson, Ödling, Axelsson, & Danielson, 2008). In this sense, preserving the position of autonomy and responsibility for one’s own decisions is a good coping strategy for both patients and the team and family towards patients.

Finitude coping resources – religious faith

Religious faith appears to a lesser or greater extent in three participants, except Denise, who does not evoke religiosity as a means of confrontation. Bruna speaks clearly about how her religiosity helps her, finding peace in the certainty that she will live again and with new opportunities, among other positive elements: *“When I met Spiritism I was, . . . I think that’s the one I’m going with. . . I’m leaving with that. . . , I feel very good, I became much more human, . . . more calm”* (Bruna).

Religious faith is a resource for confronting the spiritual dimension, along with spiritual beliefs and values (Puchalski & Romer, 2000), in addition to hope (Broadhurst & Harrington, 2015). These features are distinguished from psychological ones, such as good capacity for emotional elaboration and self-perception, active posture in the face of the disease process and provision of functional defense mechanisms.

In addition, faith turns to the unknown and allows a bond with it, that is, with the transcendent (Safra, 2013), facilitating the approach with this inexplicable phenomenon that is death.

Sufferings related to finitude – dependence and sense of responsibility

The loss of autonomy and independence, the limitations imposed by diseases and the feeling of helplessness are part of a kind of suffering highlighted by three of the four participants. This appears to the extent that these have come to depend on third parties for self-care: *“I’ve never been dependent, always others have depended on me, and when this inversion happens, I don’t know, it hurts, it’s painful”* (Adriano).

These same three participants also emphatically expressed the suffering for the concern for the well-being of their loved ones after their departure, in the sense of taking responsibility for the happiness of the family members and, in this case, cause them sadness when they die: *“They [the two children who live with the participant] are very close to me. . . I have two [children] and I’m very sad for dying and leaving them”* (Denise); *“What I worry most about is how family members, friends etc. will miss me. . . The concern not to leave the family, let’s say, in bad state”* (Adriano), referring to the situation of the family after his death.

Carmen did not express this form of suffering, since she did not identify anyone depending on her, stating that she was calm precisely because she did not have dependents: *“I see myself like this, as if I had no . . . cause for concern. . . I have children, they all work, do their things, [have] their husbands, the grandchildren, so, I have no one who depends on me; in reality, it me who is depending on others”* (Carmen).

Considering this role of responsibility for others as a meaning to live, once the ability to perform it is lost, this meaning is also lost, which leads to suffering (Frankl, 2016).

In addition, we noticed that all those who suffer from the impotence brought by the disease and with the dependence of third parties also suffer with family members supposedly depending on them, in a necessarily reciprocal relationship. In other words, being responsible for causing suffering to the other due to their own death was related to suffering by relying on them for their care. This reflection reveals an unspoken difference of a hierarchical nature in the responsibilities and roles in the family entity. A vertical character is revealed in a relationship in which it hurts to depend on others for one's own well-being, at the same time that they are expected to be dependent for happiness.

Sufferings related to finitude – fear of the after death

This form of suffering was expressed by Bruna, being related to the fear of what the after death would be like, due to a belief in the possibility of maintaining consciousness, enclosed in the grave next to the physical body – which is why she wanted to be cremated:

The only thing I'm afraid of, in this case . . . , I'm afraid of the grave. Of that hole. I wanted to be cremated . . . I'm afraid to run out of air there. But I think that's silly, childish, right? . . . I hear so many cases, so many, I read many spiritist books, so many stories in which they say it's true, that people are struggling, but [the person] needs to be evil to be in such a situation. I don't think I'm going to get to that point, I'm not evil.

At first, one might think that Bruna refers to the grave itself or the possibility of waking up in it without having actually died. When she cites Spiritism (“*I read many spiritist books*”) and moral character (“*[the person] has to be evil to be in such a situation*”), it is clear that this fear is of a religious scope. Scholars of religiosity and spirituality recognize that there are negative copings and religious beliefs that do not fulfill adaptive function and generate stress (Koenig, 2012; Panzini & Bandeira, 2007); so that the patient could benefit from assistance of this nature. However, it is noticed that for Bruna the relationship with religion fulfills a more beneficial than harmful purpose in her coping, as occurs in religious/spiritual coping in general (Panzini & Bandeira, 2007).

Furthermore, as the participant questions the relevance of this (“*silly, childish*”), there is a risk that this suffering is underestimated by the team and manifested in another way, making the treatment more complex and less effective, as elucidated by Balducci (2010). After all, as Best et al. (2015) pointed out, patients in general speak of their spiritual values and concerns only after the doctor's invitation, and not spontaneously. At the same time, physicians who have incorporated spiritual assessment into their clinics report a higher level of intimacy in the doctor-patient relationship, improving

understanding of who is being treated and deepening health care (Puchalski & Romer, 2000).

Sufferings related to finitude – social suffering

At one point in her speech, Bruna brings up the issue of slimming: “*Gosh, I used to weigh 62 kilos, then I lost weight with the disease, I went on to 52. Even so, I must have lost 8 to 10 kilos, it's too much, too much.*”

Throughout clinical practice, it is common to notice patients worried about weight loss because they associate it with illness and death. However, as Bruna's speech continues, the participant's real concern with weight loss is revealed:

I don't even know what I do to gain weight because I sometimes have the desire to go out at my gate, we live in a nice street, stay there a little bit, looking, and I have no courage, I think I'm so thin, and the people will think that I have cancer, I'm very thin, look at my arms . . . I want to see if I gain a little fat, it's bad, right. The first thing people think is 'you have cancer' with this thinness.

In addition to the sufferings proper to physical weakness and terminality, we recognize in this speech a social suffering to the extent that Bruna identifies with a socially charged stereotype of pity and negative values. As explained by Werlang & Mendes (2013), social suffering is present from feelings of loss, humiliation and social isolation, resulting from the loss of a social object that allowed the bond and interaction with other members of the social group. At this time, therefore, the social representation of cancer can distress Bruna as much as the biological meaning of slimming: the advancement of a serious and incurable disease.

Meanings attributed to life and death – self-realization

As internal resources of coping, one of the predominant senses relating to one's own life is internal and concerns the feeling of self-realization. One can understand this feeling in terms of autonomy, personal fulfillment, feeling of work accomplished and of having been successful in life. This meaning was present in three of the participants.

Adriano states: “*the most important thing? It was to have achieved the goals that a person would like to achieve. Regarding the financial part, regarding the family, that kind of thing.*”

Denise highlights the value not of health itself, but of what it is possible to achieve with it: “*the most important thing in my life was to have my health, if I have no health I have nothing . . . With health you can do anything, win anything, go everywhere, solve everything.*”

Carmen expresses a sense of satisfaction with her own life: *"I never let opportunities pass me by, I did everything I could."*

Meanings attributed to life and death – family

Family appeared as an important element in the discourse of all participants. Three of these responded that it provides life with meaning and purpose:

What makes more sense is to have this family union . . . The meaning of having one, there has to be a union, something like that, to give you that courage, or something like that . . . I want to get better to be able to continue living with them, in a quieter, softer way (Adriano)

That's what I say, it's my home, my family, to see my family improve in life, to see them with health, family, sons-in-law, to see my daughters prosper with their husbands and to see them well with their husbands. The most important thing for me is my children, I have no doubt (Bruna)

Meaning? Oh, to continue to live together with my family until the final hour. Having my family around (Carmen)

The feeling of being in the midst of the family and being cared for by intimate and close people, such as family members, tends to promote independence and well-being, improving the quality of life even in the condition of terminality (Melin-Johansson et al., 2008).

When asked what would have happened in her life for her to pass away in peace, Denise replies: *"Taking care of my children. Give them a good education, give good things to them . . . All of them should have had a good education . . . I have seven children, but I have two who make me very sad of dying and leaving them."* In this case, the family promotes concern and a feeling of impatience and does not necessarily act as a provider of meaning to life.

Meanings attributed to life and death – acceptance of death

Acceptance is understood as a calm and active posture in the face of death, with an internal willingness to approach it; in this sense, it differs from apathy, repulsion and passivity (Kübler-Ross, 1996). Thus, acceptance was noticeable in two participants, who expressed a feeling of fullness in the life they had and feeling at peace to pass away.

There was a time when I was a little terrified, but I said, that's it, I'm not the only one, the president goes, the princess goes, the king goes, the artist goes,

and why not me? I have to go and that's it . . . I'm not going to tell you I'm ready to go, of course not, but I'm trying. (Bruna)

Carmen, when asked about what she needed to be able to die in peace, said "I feel at peace" and kept all her speech consistent with this statement, as it was possible to verify in the analysis of her discourse.

In contrast, Adriano demonstrated a sense that death shortened what he had planned for his life, stating that "there wasn't time." He made analogy to a period of vacation or retirement in which he could do what he saw fit without worrying about money or time, only this period did not come.

Finding a meaning for life, whatever it is, promotes better acceptance and adaptation to the context of terminality. A study with 253 patients with advanced cancer proposed to evaluate two forms of group psychotherapy: centered in meaning and supportive therapy. Breitbart et al. (2015) found in the first group a significant difference in the improvement of spiritual, psychological and existential issues. Although the research referred to oncological patients, the question of meaning tends to emerge in the face of a terminal disease in the various forms that it may take. Therefore, in the same line, investigating the desire for death in people diagnosed with amyotrophic lateral sclerosis, an Indian study proposes that noticing a meaning in this context promotes better coping and acceptance of the perspective of death (Gourie-Devi, Gupta, Sharma, Pardasani, & Maheshwari, 2017).

Thus, the meanings identified in this study contributed to the alleviation of suffering and coping with the situation, since they highlight significant and positive issues, rather than suffering and anguish.

Final considerations

Sickness and death have always been part of humanity and have been sources of suffering. This study contributed to the elucidation of the meaning of life and death, which refers to suffering of an existential and spiritual nature, among other elements related to this theme.

As a limitation found in this research, we point out the difficulty in finding eligible patients for interviews. The criterion of being accompanied by a palliative care team for a minimum of three months was the main impediment to eligibility. It was designed to preserve patients with recent diagnosis of terminality and, in this sense, fulfilled its purpose. However, it is possible that some patients with less than three months of treatment in palliative care were in clinical and emotional conditions to participate in the research. In addition, defining the number of participants according to availability in the data collection period seems more coherent than aiming

for saturation in qualitative research, considering the depth and incipiency of the topic. These aspects could therefore be rethought in a future study of this nature.

It was possible to realize that, in the condition of a patient with terminal illness and in contact with finitude itself, the main coping resources were internal, in the sense of valuing the life that was lived and the achievements, in addition to religious faith to a lesser or greater degree.

The greatest causes of suffering reported by the participants were fear of the condition after death, suffering from the social stigma as a sick person and the limitations imposed by the disease — loss of autonomy and independence and a feeling of helplessness — combined with concern for the well-being of the family as a caregiver and future bereaved.

In this sense, the relationship identified between the suffering of depending on third parties and the belief that they depend on the patient is considered important, being a double suffering. This seems to be linked to a strong appreciation of intrinsic qualities, namely the abilities of resoluteness, achievement, and active posture. Thus, faced with the impotence characteristic of illness, double suffering appears in the dependence of others and the feeling of causing them suffering.

The main meanings attributed to life and death were identified as self-realization, which promotes feelings of fullness and satisfaction with one's own life;

family, considered as purpose and motivation to continue living, and an acceptance of death naturally.

Somehow, meaning points to a relationship, whether with a value, with a belief, or with people. It is a direct relationship when a patient says that the family is the most important for them or when they say that they want to see their children and grandchildren grow up; it is direct, too, when they turn to God as a provider of strength and hope to deal with difficult situations. In addition, an indirect relationship appears when patients value their independence, after all, the participants wanted to be functional and resolute to provide and care for others and not cause them suffering by depending on their care or cause them the pain of mourning with their death.

In short, the core of spiritual suffering was not identified as finitude itself, but rather with what flows from it — what is peculiar to each individual due to the process of subjectivation of what death represents and what comes attached to it. Talking about death does not necessarily bring out suffering, since it is in the concern for family members, in the loss of functionality and in any value that is compromised by illness and the limits of finitude. Because it is so subtle and personal, spiritual care to patients in palliative care is even more important, so that these existential issues have a voice and are part of care as a whole. The difficulty in talking about death is not necessarily in itself, but in identifying the meaning it has for the person and the underlying sufferings.

Sentidos de vida e morte: reflexões de pacientes em cuidados paliativos

Resumo: Cuidados paliativos visam amenizar o sofrimento de pacientes com doenças crônicas e ameaçadoras da vida nas dimensões: física, social, psicológica e espiritual. Na dimensão espiritual, procura-se imbuir de sentido aspectos transcendentais, como vida e morte. Conhecer esses sentidos é o objetivo deste estudo, que se trata de pesquisa qualitativa de caráter exploratório e faz uso de entrevistas semiestruturadas para a coleta de dados e análise do discurso. Foram entrevistados quatro pacientes e identificadas três categorias de significado: recursos de enfrentamento relativos à finitude; sofrimentos relativos à finitude; sentidos atribuídos à vida e à morte. Percebeu-se como maior sofrimento não a finitude em si, mas o que decorre dela, como perda funcional, preocupação com a família e ameaça de valores. A dificuldade em se falar sobre a morte não necessariamente se encontra em si mesma, mas em identificar o sentido que ela tem para a pessoa e os sofrimentos subjacentes.

Palavras-chave: cuidados paliativos, espiritualidade, psicologia, cuidados paliativos na terminalidade da vida.

Sentidos de vida y muerte: reflexiones de pacientes en cuidados paliativos

Resumen: Los cuidados paliativos se proponen mitigar el sufrimiento de pacientes con enfermedades crónicas y amenazadoras de vida en cuatro dimensiones: física, social, psicológica y espiritual. En la dimensión espiritual se pretende llenar de sentido con aspectos trascendentales, como vida y muerte. Este estudio tiene como objetivo conocer estos sentidos. Para ello, se utilizó el método cualitativo de carácter exploratorio y aplicó entrevistas semiestruturadas para recopilar los datos y el análisis del discurso. Se entrevistaron a cuatro pacientes, y se identificó tres categorías de significado: recursos de afrontamiento relacionados con la finitud, sufrimientos relacionados con la finitud y sentidos atribuidos a la vida y la muerte. Se observó que el mayor sufrimiento no era la finitud en sí, sino lo que deriva de ella, como la pérdida funcional, la preocupación por la familia y la amenaza de valores. La dificultad de hablar acerca de la muerte no reside necesariamente en sí misma, sino en identificar el sentido que tiene para la persona y los sufrimientos subyacentes.

Palabras clave: cuidados paliativos, espiritualidad, psicología, cuidados paliativos al final de la vida.

Sens de la vie et de la mort: réflexions de patients en soins palliatifs

Résumé: Les soins palliatifs visent à soulager les souffrances des patients atteints de maladies chroniques et potentiellement mortelles dans quatre domaines: physique, social, psychologique et spirituel. Ce dernier renvoie au sens que l'on peut donner à des aspects transcendants tels que la vie et la mort. Explorer ces différentes facettes est l'objectif de cette étude. Il s'agit d'une recherche qualitative de nature exploratoire, menée à partir d'entretiens semi-directifs pour la collecte de données et l'analyse du discours. Quatre patients ont été interrogés et trois catégories de signification ont été identifiées: les ressources d'adaptation liées à la finitude, la souffrance associées à la finitude, et les sens attribués à la vie et à la mort. Il en ressort que la plus grande souffrance n'est pas l'idée de finitude en soi, mais ce qui en découle, comme la perte d'autonomie fonctionnelle, l'anxiété à l'égard de la famille et la remise en question des valeurs. La difficulté de parler de la mort ne réside cependant pas nécessairement dans le fait de parler de la mort elle-même, mais dans l'identification du sens qu'elle revêt pour la personne concernée et dans l'identification des souffrances sous-jacentes.

Mots-clés: soins palliatifs, spiritualité, psychologie, soins palliatifs en fin de vie.

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