

# Meanings attributed to death from the perspective of oncology healthcare professionals

Significados atribuídos à morte segundo a perspectiva de profissionais de saúde da área de oncologia Significados atribuidos a la muerte desde la perspectiva de profesionales de salud del área de oncología

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#### ABSTRACT

**Objective:** to understand the construction of meanings of death by healthcare professionals caring for people with cancer. **Method:** this qualitative study was carried out in an online environment through semi-structured interviews of 34 health professionals, which were interpreted using thematic analysis. **Results:** two analytical categories emerged from the data, indicating that the meanings attributed to death by the participants were: a process inherent in the human life cycle, a transition to the next life, and an end to the suffering of both patient and health professionals. The difficulties they pointed to in dealing with death related to lack of psychological support, lack of knowledge about death, palliative care, and communicating bad news. **Conclusion:** the professionals constructed different meanings to their patients' deaths: a natural process of life, the will of a higher being, a transition to a new existence, and an end to these people's suffering. **Descriptors:** Death; Neoplasms; Health Personnel; Attitude to Death; Professional Practice.

## RESUMO

**Objetivo:** compreender a construção dos significados da morte pelos profissionais de saúde frente ao cuidado à pessoa com câncer. **Método:** estudo qualitativo realizado em ambiente *online*, com a participação de 34 profissionais de saúde. Foram realizadas entrevistas semiestruturadas, interpretadas segundo análise temática. **Resultados:** duas categorias analíticas emergiram dos dados, indicando que os significados atribuídos à morte pelos participantes foram: como um processo inerente ao ciclo da vida humana, passagem para a outra vida, e fim do sofrimento tanto do paciente quanto dos profissionais de saúde. As dificuldades que apontaram em lidar com a morte se referem à falta de suporte psicológico, escassez de conhecimento sobre morte, cuidados paliativos e comunicação de más notícias. **Conclusão:** os profissionais construíram diferentes significados à morte de seus pacientes, tais como um processo natural da vida, vontade de um ser superior, passagem para uma nova existência e término do sofrimento dessas pessoas.

Descritores: Morte; Neoplasias; Pessoal de Saúde; Atitude Frente a Morte; Prática Profissional.

#### RESUMEN

**Objetivo**: **Objetivo**: comprender la construcción de los significados de la muerte desde el punto de vista de los profesionales de la salud ante el cuidado a la persona con cáncer. **Metodología**: estudio cualitativo realizado en un entorno online, con la participación de 34 profesionales de la salud. Se realizaron entrevistas semiestructuradas, interpretadas según análisis temático. **Resultados**: de los datos surgieron dos categorías analíticas que indicaron que los significados atribuidos a la muerte por los participantes fueron: como u proceso inherente al ciclo de vida humano, transición a otra vida y fin al sufrimiento tanto del paciente como de los profesionales de la salud. Las dificultades que señalaron para afrontar la muerte se refieren a la falta de apoyo psicológico, escasez de conocimiento sobre la muerte, cuidados paliativos y comunicación de malas noticias. **Conclusión**: los profesionales han construido diferentes significados para la muerte de sus pacientes: un proceso natural de la vida, la voluntad de un ser superior, un paso a una nueva existencia y el fin del sufrimiento de estas personas. **Descriptores:** Muerte; Neoplasias; Personal de Salud; Actitud Frente a la Muerte; Práctica Profesional.

#### **INTRODUCTION**

Cancer is an aggressive and complex disease, and deserves particular importance in the view of health policies and organizations at a global level, as it is one of the main causes of death from disease in all countries of the world<sup>1</sup>.

In relation to death, health professionals still face difficulties to overcome a strictly curative vision and recognize when the patient is out of therapeutic possibilities of being cured and with the possibility of dying due to their illness<sup>2</sup>. In their training, they are prepared to above all restore health and preserve life; and the death of their patients makes them reflect on their own finiteness and that of their families<sup>3</sup>.

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The difficulty in dealing with death can cause illness in health professionals who experience the death of their patients in their work activity<sup>2,4</sup>. Such difficulties can influence the care provided to people, especially those who are in palliative care, and there may be withdrawal and a strictly professional relationship with these individuals as a form of protection, as they are unable to deal with these loss experiences<sup>5,6</sup>.

The death process of a cancer patient can generate mourning in a health professional. Among the approaches aimed at understanding mourning, the theoretical perspective of the construction of meaning<sup>7</sup> is highlighted in this study. This theory is based on constructivism, in which the person is seen as an active constructor of meanings<sup>8</sup>. In this perspective, it is understood that human systems, from the individual to organizations and communities, constantly seek to define their place in the world and give meaning to their experiences. Therefore, it is possible to unveil the reality of death or loss for each person, instead of claiming that death has universal meaning for all individuals<sup>9</sup>.

The occurrence of death for health professionals is not a phenomenon experienced naturally, but accompanied by numerous difficulties, suggesting that the suffering resulting from routine contact with terminal situations is almost always veiled and silenced<sup>10</sup>. Despite the different categories of health professionals who care for people with cancer and experience the death of their patients on a daily basis, the senses and meanings they will build and attribute to this inevitable event in life will be different and unique. With the unveiling of these experiences, it will be possible to sensitize the management of cancer care services, and health services in general, in order to suggest ways to develop actions which aim to welcome and train them on issues that involve the finitude of life, so that they can deal with the death of their patients.

In view of the above, the following question was asked: what is the construction of the meanings of death for health professionals in relation to caring for people with cancer? This study aimed to understand the construction of the meanings of death for health professionals regarding the care for people with cancer.

#### **THEORETICAL REFERENCE**

The construction of meanings in facing mourning was adopted based on constructivism<sup>8</sup> as the theoretical reference in this study. This perspective defends the active role of people in the production of their human experiences and in attributing meaning in facing these experiences, using language to give meaning and express important dimensions of their experience in the world<sup>8</sup>. For Neimeyer<sup>11</sup>, the construction of meanings is an active process in coping with loss. The author also points out that the narrative chosen by the mourner to tell their story of loss and the meanings attributed to it are of vital importance to develop healthy mourning, because it is through it that the person organizes and gives meaning to the world.

#### METHOD

This is a descriptive and exploratory study using a qualitative approach<sup>12</sup> which was conducted in an online environment, which is a way of carrying out qualitative investigations in the context of internet research work which enables researchers to use communication tools (chats or videoconferences) as resources for contact and interaction with research participants<sup>13</sup>.

A total of 34 health professionals working in a hospital context providing care for people with cancer participated in this study. The inclusion criteria were: to be a health professional active in providing care to cancer patients, to have experienced the death of these people, and to have accepted to participate in the research based on the online interaction. Professionals who did not work in the area of oncology were excluded.

The snowball sampling<sup>14</sup> technique was used to select participants. First, health professionals who provide care to people with cancer in a hospital context were contacted through e-mail. These professionals helped the researcher to start their contacts online and to search for the group to be researched. The indicated people were asked to suggest new contacts with the desired characteristics for this research from their own personal/professional network. Next, theoretical saturation sampling<sup>15</sup> was used to define the number of participants.

Data collection took place from March to August 2017 using a semi-structured interview script consisting of sociodemographic questions and five guiding questions: 1. What reasons led you to choose to work with cancer patients? 2. In your perspective, what is the meaning that you attribute to cancer? 3. What feelings are produced in you when a cancer patient of yours dies? 4. For you, what difficulties do health professionals face when dealing with the death of cancer patients? 5. In your perspective, what is the meaning/sense that you attribute to the death of a person with cancer who is in your care?



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Each interview lasted approximately one hour at times scheduled by the participant according to their availability. The participants who wished to be interviewed via chat had their requests taken into account and the entire content of the interview was recorded in writing. For those who opted for videoconferencing, a portable digital recorder was used to record the interview with the participant's knowledge. Their speeches were transcribed in full, in addition to being verified twice by two researchers to guarantee their reliability.

The data were transcribed and analyzed using the thematic content analysis technique following the stages of: pre-analysis, material exploration, processing and interpreting the obtained results<sup>12</sup>. A floating reading of the material from the interviews was performed in the pre-analysis with the aim of absorbing this content by the researcher. In the material exploration, the themes were procedurally grouped according to their content from the units of meaning originated from the material until categories were formed. The processing and interpretation of the obtained results were articulated by the theoretical framework on the "Construction of Meanings" of mourning<sup>8</sup>.

The research was approved by the institution's Ethics Committee under opinion No. 1,781,468. Letters were used to represent the following professional categories to guarantee the anonymity of the participants: N (nurses), D (doctors), OT (occupational therapists), P (psychologists), PT (physiotherapists), NT (nutritionists), followed by the sequential number of interviews.

#### **RESULTS AND DISCUSSION**

There are the following professional categories regarding the sociodemographic profile of the 34 participants: nurses (n = 10), occupational therapists (n = 8), doctors (n = 6), nutritionists (n = 4), physiotherapists (n = 3) and psychologists (n = 3). Their ages ranged between 24 and 49 years with a mean age of 30.32 years, and 32 were female and two were male.

Regarding marital status, 21 professionals reported being single, 11 married, one divorced and the rest in a stable relationship. In addition, 17 declared themselves to be Catholics, eight Spiritists, three Evangelicals, one Buddhist and five said they did not have any religion.

Regarding the education level, all participants had higher education and reported that they had completed (n = 25) or were currently doing postgraduate studies in the modalities of residence, specialization, Master's or Doctorate degrees (n = 9). A large part of the interviewees (n = 19) had a specialization in the Oncology area. The average time of professional experience in this area was 4.01 years. A professional in Medicine and another in Occupational Therapy had a specialization in the area of Palliative Care, while one Nutritionist professional had trained in this area.

Next, two categories emerged from the data analysis: Death as a process inherent to life and end of suffering; Obstacles to be overcome in facing patient death in the oncology area.

#### Death as a process inherent to life and end of suffering

The construction of meanings in facing mourning of human life is a process which involves finding a meaning/explanation for the loss, which is based on a model of beliefs and worldview<sup>8,16</sup>. Although death is a universal phenomenon, each person can assign a different meaning to it, which in turn is related to the meaning found/constructed based on their lived experiences, in addition to being essential for adjusting between the bereaved person and the loss experienced<sup>8</sup>.

In this study, health professionals who experienced the death process of their cancer patients attributed different meanings to it, one of them being a process inherent to the human life cycle:

#### I try to see (death) as a natural process [...] (NT3).

It represents that their cycle has come to an end and that all therapeutic possibilities have been exhausted (N1).

It is evident in these reports that the death of the cancer patient was attributed the meaning of a natural life process. Some studies indicate that many professionals tend to naturalize the notion of death in an attempt to reduce discomfort in talking/thinking about it<sup>17,18</sup>. The sense of the cancer patient's death was also shown to be linked to the will of a superior being and of passage to a new existence:

When they are patients with a diagnosis which leads to palliative care, we always ask God to do his will [...] (N10).

[...] I believe in transcendental terms that our current life is a stage (P1).

I can think of it as moving to another place where he was prepared to be [...] (OT4).

The religious beliefs and values of these participants influenced the meanings of death and the process of accepting the loss of their patients<sup>19</sup>. It highlights the importance of valuing the spirituality of health professionals so



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that they can consider it in the care of terminally ill patients. This question corroborates a study which found that spirituality is an important dimension of palliative care for nursing professionals, considered a source of strength, comfort and faith, with significant impacts on improving the clinical condition of patients, contributing to coping with these individuals in their illness and terminal process<sup>20</sup>.

When the suffering of the cancer patient outside the therapeutic possibilities of cure is intense, death is commonly signified as pain relief by the health team. It is a way they find to not only resolve the pain experienced when all therapeutic possibilities have been exhausted, and consequently it was not possible to save the lives of these individuals, but also to protect them from the psychological suffering of the loss of the patient<sup>21</sup>:

In the finitude of life, the patient is usually suffering with pain, dyspnoea, and this also has an end with death (N1).

When they witness the death of their cancer patients, various feelings are awakened in health professionals: Sadness and helplessness. Impotence for not having succeeded in curing the patient (D2). There are several: sadness, compassion, impotence and frustration [...] (OT2).

In addition to these feelings, the literature evidences uncertainty, fear, despair and anxiety<sup>2,3,18</sup>. Death is configured as a loss in cases of greater bond between professional and patient, intensifying the feeling of sadness and affecting these professionals, especially in cases involving the death of young patients or children<sup>22</sup>:

I am more moved emotionally with a patient who has built a better bond with me [...] (P1). Some patients shock us more, the younger ones and the children [...] (N6).

In an attempt to protect themselves and not experience feelings which could cause them some suffering, some professionals created coping mechanisms during the death process of their patients, trying to keep their distance or to not get emotionally involved with them<sup>4,5,23</sup>, as can be observed in the following speech:

I was not upset in other cases of cancer patient deaths because of the distance, but with some patients I became more involved. The relationship with others was very professional (NT4).

It is perceived that academic training aimed at rehabilitation and health restoration with a view to prolonging life and healing generates a perception of professional failure/weakness in professionals in facing death<sup>3,23</sup>. It is necessary to offer professional training in order to prepare them to deal with death in their personal histories and in their work context<sup>2,3,24</sup>.

The importance of building institutional spaces for sharing experiences, discussion and professional training related to the finitude of life and valuing the meanings that health teams attribute to the death of their patients is noteworthy, which may be a way to reduce stress and situations of suffering<sup>5,25</sup>.

Regarding the construction of meanings after the loss of a loved one, the mourners have to not only seek meaning for the death which occurred, but also a new meaning for their own lives, making the search for meaning and significance a priority in the mourning process<sup>9</sup>. This movement is important, as losses which do not make sense and in which the grieving individual does not find meaning end up challenging the mourner to reexamine and reassess their previous meaning structures<sup>11,26</sup>.

The highlight among the senses/meanings attributed in response to the loss is encountering benefits and transforming identity<sup>26</sup>. It was observed that some participants were powerless and frustrated with the death of their patients. However, when the mourner can appropriate their growth with this experience of loss, they often feel more strengthened, which can contribute to their assimilation<sup>27</sup>. It is possible to notice a movement toward transforming identity, which will imply a process of reconstructing their own self; meaning that although pain and anguish are expected, it can enable an identity which seeks greater empathy for patients, as well as personal and spiritual growth<sup>26</sup>. Thus, it is clear that finding benefits in the experience of losing a loved one and growing with it can positively contribute to the adaptation process and elaboration of this loss by the mourner<sup>9,26,27</sup>.

According to studies<sup>9,11</sup>, exploring the meanings that people attribute to the death of a loved one and stimulating reflection on the meanings they construct in facing this loss, based on narratives and experiences, are therapeutic resources which help both in the mourning construction process as well as to relieve suffering. Understanding the meanings that professionals attribute to the death of their patients is of paramount importance in order to assist them in processing these losses and emotional strengthening.



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## Obstacles to be overcome in facing the death of patients in the oncology area

In this category, it was observed that one of the meanings attributed to the obstacles in facing the death of the cancer patient was the lack of monitoring and psychological support to the health professional for coping with personal mourning:

# There is no psychological support for professionals, we have psychological support for patients [...] (D3). [...] there is a lack of welcoming to this professional in the sense that routine, especially in the hospital, there are rare moments of listening to them (OT4).

Thus, it is relevant to offer psychological support to health professionals along with services, helping them to take care of their own mental health when dealing with the death of their patients<sup>28</sup>. A study highlighted that the support of psychologists to the health team was considered extremely important by professionals, helping them to face situations which cause suffering at work<sup>29</sup>. Another study pointed out that the offer of integrative complementary practices, such as Auriculotherapy and Reiki, can contribute to promoting the mental health of these professionals<sup>30</sup>.

It is possible to perceive the importance of an institutional culture which values the physical and mental health of these professionals through the provision of discussion channels, conversation circles, permanent education and psychology services, among other strategies, which can welcome and care for teams that deal with the suffering of cancer patients and their families on a daily basis. These actions will not only provide benefits to health professionals, but also better care to patients and their families<sup>5</sup>, thereby strengthening the care quality.

In addition to psychological support, it is crucial to prepare these professionals for communicating difficult news and for building actions aimed at offering support to patients and family members. Participants recognize the importance of a multidisciplinary team to support the bereaved family:

> Talk to the family both before death and after death to give the bad news [...] (D2). [...] a lack of multidisciplinary monitoring, I have no psychological preparation to welcome/guide a family member at that moment (death) [...] (D5).

It becomes necessary that the communication of bad news is included as a fundamental discipline during the training of health professionals<sup>31,32</sup>. A systematic review study found that mixed strategies involving practical and theoretical exercises on communicating bad news make it possible to improve the communicative capacity of students/health professionals<sup>33</sup>.

It highlights the importance of an interdisciplinary team to favor comprehensive care of the patient and their family. This articulation is essential, since no science/specialization can separately cover the complexity of human existence, and therefore there is a need for integrated teams to deal with all dimensions and forms of care, seeking to reduce suffering and pain, and consequently improve the quality of life of cancer patients and their families<sup>34</sup>.

Spirituality can be an important resource in the care of a family which experiences the terminality process of their loved one. One study<sup>35</sup> addressed a light technology of spiritual care called "departure permission". In it, it is suggested to the participants that they hold hands with the patient (conscious or not) with the development of some steps: affirm the patient as a human being worthy of respect; express feelings; forgiveness of faults committed; remember happy moments with the departing patient; each family member can positively verbalize something that has marked their existence with the person who is in the terminal process, as well as telling them that they can go in peace and that family members will take care of each other; and reading a message or saying a prayer with this person. This resource has shown itself to be promising, because in addition to enabling a favorable and trustworthy therapeutic relationship with the patient and their family members, it can also reduce the spiritual suffering of these individuals by facilitating free expression of their feelings, beliefs and religious or spiritual rituals in facing finitude.

It is noteworthy that despite the majority of the participants having a specialization in the oncology area, some of them attributed the lack of training as obstacles to the finiteness of life and palliative care as an obstacle in dealing with the death of their patients:

Lack of training, classes on how to deal with death (NT2). If we are not well, it is quite difficult to deal with the patient's death [...] mainly due to the lack of discussing palliative care (OT4).

Such facts demonstrate how important it is that institutions offer spaces for discussion and courses, since professionals who are sensitized and trained to assist patients in palliative care have better results, such as control of





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physical symptoms (pain), attention to psychosocial suffering, and development of specific skills and abilities related to care at the end of life<sup>36,37</sup>.

It was observed that the participants attributed different meanings to the death of their cancer patients, so understanding these meanings is essential to develop actions and coping strategies. In addition, a reflection on these senses may positively reflect on health care, providing the people provided care with a dignified and humanized death, which takes into account their desires and wishes.

Thus, the creation of spaces for mental healthcare at work by managers is essential. Psychological support strategies, inserting integrative practices, offering courses and/or discussion groups on the theme of death, palliative care and communication of bad news, both in theoretical and practical ways, can be effective in the human and professional training of these workers in facing death and the need for qualified support for the bereaved family. Furthermore, it is of utmost importance for educational institutions to place greater emphasis on the theme of death during the training process of health professionals through lectures, reflective readings and practical situations, in order to prepare them to deal with the finitude process of human life.

As a study limitation, the exclusive involvement of Brazilian health professionals working in the oncology area can be mentioned. Thus, the development of research with professionals of other nationalities is fundamental to broaden the understanding about the meaning construction of death in cultural diversity.

#### CONCLUSION

It was found that health professionals constructed different meanings of the death of their cancer patients, such as a natural process of human life, the desire for a superior being, in transition to a new existence, and an end to suffering, both for the patient and the health team. It is suggested to create strategies such as psychological support spaces and death education groups with the purpose of taking care of the health of these workers.

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