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The process of getting sick of cancer patients in palliative care

ABSTRACT | Objective: To understand how the oncology patient in palliative care experiences or becomes ill. Method: The study is a qualitative assessment of the exploratory descriptive character, carried out at the Oncological Research Center, in Florianópolis, from October 2017 to February 2018. Participated 10 patients admitted to palliative care units. A Bardin content analysis was used and three thematic categories were constituted. The ethical precepts of the research were respected. Results: surveyed had a median of 57 years, complete elementary school, were widowed (40%) and married (30%). Cancer patients need to be fully understood. It was evidenced as the victims of a disease attack. Each individual expresses a different way to fight cancer. Conclusion: Effective communication with patients about their real health status is essential. Consider the following future research that addresses the theme addressed in this study, to improve knowledge on the topic.

Keywords: Nursing; Neoplasms; Palliative care.

RESUMEN | Objetivo: comprender cómo el paciente de oncología en cuidados paliativos experimenta el proceso de la enfermedad. Metodología: El estudio es una evaluación descriptiva cualitativa y exploratoria, realizada en el Centro de Investigación Oncológica, en Florianópolis, de octubre de 2017 a febrero de 2018. Participaron 10 pacientes ingresados en la unidad de cuidados paliativos. Se utiliza el análisis de contenido de Bardin. Se respetaron los preceptos de la investigación ética. Resultados: los pacientes con cáncer deben entenderse completamente. Se ha demostrado que las criaturas ayudan a enfrentar la enfermedad. Cada individuo expresa una forma diferente de tratar el cáncer. Conclusión: se cree que la comunicación efectiva con el paciente acerca de su estado de salud esencial real. La investigación futura se considera necesaria para abordar el tema abordado en este estudio, con el fin de mejorar el conocimiento sobre el tema.

Palavras claves: Neoplasia. Cuidados paliativos. Muerte y morir.

RESUMO | Objetivo: Compreender como o paciente oncológico em cuidado paliativo vivencia o processo de adoecimento. Método: O estudo é uma avaliação qualitativa de caráter exploratória descritiva, foi realizado no Centro de Pesquisas Oncológicas, em Florianópolis, de outubro de 2017 a fevereiro de 2018. Participaram 10 pacientes internados na unidade de cuidados paliativos. Foi utilizada a análise de conteúdo de Bardin e constituídas três categorias temáticas. Foram respeitados os preceitos éticos de pesquisa. Resultados: pesquisados tinham mediana de 57 anos, ensino fundamental completo, eram viúvos (40%) e casados (30%). Os pacientes oncológicos precisam ser compreendidos em sua integralidade. Foi evidenciado que as crenças ajudam a enfrentar a doença. Cada indivíduo expressou uma forma diferenciada de enfrentar o câncer. Conclusão: É fundamental a comunicação efetiva com o paciente sobre seu real estado de saúde. Considera-se necessárias pesquisas futuras que abordem a temática tratada neste estudo, afim de melhorar os conhecimentos sobre o tema.

Palavras-chaves: Enfermagem; Neoplasias; Cuidados paliativos.

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INTRODUCTION

The change in quality and lifestyle, as well as stress and the constant search for improvements in the professional career is making human beings susceptible to the appearance of chronic diseases to the point of approaching death. Among these pathologies, one that deserves to be highlighted are neoplasms for bringing aspects of finitude, which cause important emotional and important changes.¹

Based on the World Cancer Report document of the International Agency for Research on Cancer (IARC), of the World Health Organization (WHO), it is expected that, in the coming decades, the impact of cancer on the population will correspond to 80% of the more than 20

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million new cases estimated for 2025.²

Neoplasms can be understood as a disorderly formation of a set of cells, which invade other tissues and organs of the body beyond their point of origin¹. It is a chronic and progressive disease, generating physical pain, intense emotional and psychospiritual suffering.³

To support such a diagnosis, the cancer patient clings to spirituality and lives the hope of constant cure, these are defense mechanisms used to circumvent reality. Another important factor is fear when they project their permanent absence in the family environment, causing profound suffering in the individual and those who love them.¹

The hospital becomes the extension of your home, taking the cancer patient to abrupt separation from everything he loves and recognizes as his own, projecting it to a lonely and impersonal environment.⁴ Emotional support, especially related to spirituality, is extremely important, as it helps in accepting and preparing for death, which is seen in a less traumatic way for both the patient and their families, providing them with security in relation to events that are going to happen in his life.⁵

Palliative care is a philosophy that has the principle of facing death as something natural, does not postpone death or prolong it, but seeks to promote relief from pain and other symptoms, valuing the patient's life, supporting anguish and fears, providing support to continue your life more actively. In addition, palliative care includes looking at the family and the multidisciplinary team, so that they can go through the process of death and die strengthened.

It is assistance that is based on respect, humanization and welcoming, guided by communication, which is the effective element in the process of caring for the terminally ill and of paramount importance in the treatment.⁶ However, it is possible to highlight obstacles to the development of palliative care, either due to the lack of understanding of the worke-



In view of the above, this research seeks to understand how the patient with cancer in palliative care experiences the process of becoming ill, in order to answer the following guiding question: How does the patient with cancer in palliative care experience the process of becoming ill?



rs involved or the lack of physical or intellectual structure of health institutions.⁷

In view of the above, this research seeks to understand how the patient with cancer in palliative care experiences the process of becoming ill, in order to answer the following guiding question: How does the patient with cancer in palliative care experience the process of becoming ill?

METHOD

This is a qualitative, exploratory, descriptive research. Developed at the palliative care unit of the Oncological Research Center - CEPON, in Florianópolis, Santa Catarina. This comprises a public institution of reference in cancer treatment in Santa Catarina. Ten patients admitted to the palliative care unit participated in the study. Inclusion criteria were: over 18 years old, being aware of the cancer diagnosis, being conscious, communicative, being indicated by the multiprofessional team. Exclusion criteria: being under the effect of opioids, with some impediment of communication. Data collection was carried out from October 2017 to February 2018. The data collected were recorded in a field diary, in which the impressions, feelings, experiences lived through observation and interaction during the process of caring for and dying the hospitalized patient were described. In addition to the interview, participant observation was also developed with a view towards the health team during the care process, especially when approaching the end-of-life patient. The interviews with the patients were previously scheduled according to their possibility, and had an average duration of 30 minutes. The instrument is composed of open and semi-structured questions, in which the recorded data gave rise to the categories of analysis, based on the theoretical framework of Paterson and Zderad and updated scientific articles. Thema-

tic and categorical content analysis was used⁸. Bardin's analysis allowed to define three thematic categories that were developed from the saturation of the collected data. To illustrate them, speeches identified by human feelings and emotions will be used in order to preserve the identity and guarantee the confidentiality of the information shared by the participants. The study obeys the ethical precepts of research as per resolution, respondents who agreed to participate in the research signed a Free and Informed Consent Term in two copies. Project approved by the CAAE Ethics Committee: 71247317.0.0000.5369.

RESULTS

The participants had a median of 57 years old, there was a predominance of the disease at ages over 50 years old. With regard to education, only one of the participants completed higher education, six did not pass elementary school, and five of these did not even complete it. The low level of education may indicate an increase in the incidence of cancer, which stands out in the research results. As for marital status, the data show that most participants were widowed (40%), followed by married people (30%). Thematic categories are presented below.

CATEGORY 1. EXPERIENCING THE PROCESS OF SICKING: A PATH OF UNCERTAINTIES

When facing the process of falling ill, experienced by cancer patients without a prognosis for cure, it is possible to perceive not only the carnal effects of the disease, but mainly very significant emotional, mental and spiritual phenomena, since the disease sensitizes both the patient and his family in this new stage. After a longer time of treatment and knowledge of the prognosis, together with the pain and anguish, it is clear that the patient is more "tired", as suggested by the following statement:

... 6 years ago. 2010 ... 2011. Then I did the surgery, did the radio, did the "chemo", 5 years without anything! Then came the lung injury, but it's not metastasis to the other, it started with a little injury, then we did a biopsy, it was negative, but it progressed, right? Then we started the treatments. It's been ... last year ... this year ... 2 years! (Interviewee 1).

Given this moment, bonding and emotional involvement between the patient, family and the nursing team takes place.⁹ Asked about the follow-up of loved ones, most respondents reported the presence of family and friends, as can be seen in the following words:

Yes, my mother spent the days with me and my father and sister took turns during the night (Interviewee 2).

Regarding the understanding of the illness process, patients expressed doubts about the cause of the disease. The statements that express this doubt are clear:

Bah! This is a thought that I still ask myself today. I still haven't found an answer. "Because I? ", "Because with me? "And" Why, do I feel so much pain? "(Interviewee 3).

On the other hand, observing Perseverança's speech, he demonstrated to have a certain knowledge and awareness of the possible cause of the pathology:

I think there is no right explanation, there were several factors that led to this disease in my body (Interviewee 2).

With regard to emotions, it was evidenced that at this time of treatment the most diverse types of feelings can be expressed, such as fears, anguish, sadness

and failures, as shown by the following statements:

Confused, if that's what I can answer, if that's what you wanted to hear, [...] I don't know if that's what I'm going to say if it's right, there are times when I don't believe this is happening to me, but actually it is, right? (Interviewee 5).

In view of this, it was observed through the questions asked in the participants of this study that this variety of feelings and doubts regarding the disease, evidenced through the speeches, looks and body language, which sometimes showed implicit emotions. Each individual expresses a different way of facing the disease, from the reports it was possible to apprehend that each patient had a moment in the stage of the death and dying process:

I am facing it. I gave it to God, that God, if I am deserving, that puts a person in my path who can heal me, heal with his hand, that he has the power to heal me if I am deserving and I ask for it, and I thank him, because screaming, begging, it's no use, God knows, God knows that the three of us are here talking (Interviewee 6).

Within this context, it was observed in the interviewees' statements the search for something positive to explain the disease, which was sometimes seen as a life mission, as a duty or task to be faced in the name of a Higher Being, or even as a greater goal beyond the suffering caused by cancer.

CATEGORY 2. UNDERSTANDING PALLIATIVE CARE

In face of human terminality, palliative care becomes essential, as it seeks a better health condition in finitude, mitigating suffering, anxiety and depression in the facing death. When questioning the interviewees about the reaction to

the beginning of palliative care, it was observed that the understanding of the term “palliative” was not very clear by most patients. They understood the severity of the disease, however they did not understand the approach of its finitude. This misunderstanding is noticeable in the following statement:

If I say to you like that, that I reacted badly? No! But it was also a shock! Understand? But like this "look"! By the professional who is my doctor, Dr. X, he did not stay in the room to speak to me [...]. For the professional he is, he should have done this! He was in the next room, he didn't come and tell me that. He didn't come to fight with me! Understand? That's it (Interviewee 1).

However, some patients have shown knowledge of what palliative care is all about:

I was shaken right? Because the doctor said to me that there was no solution, only palliative. I could only give myself ... a better quality of life, but there was no cure (Interviewee 3).

It was observed, therefore, that the sensitivity to the patient's manifestations, consists of a differentiated and thorough ability to understand the imperceptible, the health professional, especially the nurse, using verbal and non-verbal communication, allows the prevention of injuries, pain relief and other symptoms present in this finitude process. In view of this, it is believed to be essential to communicate the patient about his real health condition, so that he collaborates with the treatment. In view of this reasoning, the interviewees were asked about the care they were receiving, making unanimous satisfaction and thanks clear, they valued the way the multidisciplinary team dealt with their pain and anguish, as well

as the management of other symptoms in a humanized way, which is noticeable in the following conversations:

“I think the care is good, I have been palliative for almost 10 years” (Interviewee 7).

“Very well, the care here is very good, they are taking care of me. I am treated well in the hospital, I am treated well at home, I have priority in the treatment, I have affection.” (Entrevistado 8)

In structuring patient care without a prognosis for cure, it was possible to understand that professionals achieve feelings of accomplishment, duty fulfilled and satisfaction when perceiving the results of their work through the recognition exposed by the patient and his family.

CATEGORY 3. FAITH AS A FOUNDATION IN ADDRESSING THE PROCESS OF SICKNESS

First, to talk about faith, it is necessary to pronounce “spirituality”, it is broader than religion, it is something personal, it relates to values, inner beliefs, it encompasses harmony and connection with people and with yourself. Spirituality gives meaning to life and is independent of religion, providing the ability to deal with the most diverse feelings, mobilizing positive energies and improving the quality of life. It is believed that the understanding of the beliefs reveals a professional attitude of concern towards the one who receives the care. This concern reflects the bio-ethical principles of respect for the patient's autonomy, in following the belief that he judges best, however different they may be and running away from general standards.¹⁰ When approaching the research participants about how their beliefs help to cope with the disease, most of the answers were positive, the belief in the existence of a superior being appeared many times, in others, they believed they were rewarded in the

post-mortem, as they were “paying” something in life:

I think that if it weren't for [...] care and faith, I wouldn't have faced it, because it was a very tortuous path, it is still being right !? (Interviewee 7).

It is interesting to note how some participants claimed to believe in God, but not to mention a religious institution, which characterizes spirituality. The hope of a cure was the most frequent answer, when the interviewees were asked about what they expect after the entire journey in search of treatment. On the other hand, some showed that they knew that the end of their life was near, however, they had the hope of not having more suffering.

Well, I'll start at the top... I hope, hence the call of God first... First. [...]. So, if he is going to give me this ticket, lighter you understand?! [It is possible to perceive a certain emotion in these words] May it not be difficult for relatives, for me, do you understand? That's right. And I am very grateful to be here until now, for him, for God, and for others, right? (Interviewee 9).

Hope is noticeable in the speeches, even if implied. The humanized care advocated by Paterson and Zderad makes it clear that “being with” fully is in a way nurturing this feeling so necessary for the patient to be able to endure his days.

Before, it was even normal for me, because nothing had happened. I went out, had fun, everything! But now, I saw that I have to be a little more careful with myself, with the disease. Because it is there, right? But I will not let it... it... overtake me! Understand? I won't go! Only God! As long as I have life to fight, I will fight! (Interviewee 1)

The experience of the terminality process allows patients to reflect on life, which is expressed through the hope of extending life, living with affective and family bonds.¹¹ Thus, faith, the relationship with family and friends, proved to be coping strategies that help the patient to deal with the stresses of illness, facilitating care, and providing relief from fears and insecurities present in the process.

DISCUSSION

The predominant age group pointed out in the literature is from 60 to over 85 years old, since with the aging of the population, neoplasms are concentrated in more advanced ages, not as a cause of morbidity and mortality, but as a growing element in the demand for hospital services.¹²

Age increases the time the individual is exposed to risk factors present in the environment, which results in the appearance of cancer.¹³ Due to doubts and anguish regarding the disease, the patient suffers, needing the support of children, relatives and friends, who sometimes have a better level of education, being of fundamental importance in the treatment and understanding of the pathology, since they can help the person with the cleansing of the neoplastic lesion, dressing changes, feeding and leisure activities.¹³

Thanks to the social support that married patients receive, treatment tends to be more appropriate in the face of a life-threatening illness, increasing the degree of resilience, with better coping.¹²

Cancer should not be treated as a family issue, but as a problem, as the family becomes the main source of support.¹⁴ It is inevitable that patients will think about a shortening of their life expectancy, re-mitting them to the urge to find out about the disease and how everything will affect their life from that moment on.¹⁵

Thus, during the long process of treatment, the patient begins to experience su-

ffering, causing innumerable limitations, anxieties and feelings of helplessness, requiring the patient to seek meaning in order to live in this new condition.¹⁶ The family receives information about the patient's condition, when the patient is unable to manifest.¹⁷

Such questions lead us to the second stage of the death and dying process, anger. This occurs when, for the patient, it is no longer possible to deny the facts, replacing the feelings with revolt, envy and resentment. Each individual interprets and reacts to the disease according to their own stigmas regarding their personal experience, in addition, cancer causes an extensive impact not only physiological, but also psychological and generates feelings of anxiety, anguish, fear, anger and doubts.¹⁸

Cancer presents itself due to multiple causes, thus being associated with lifestyle habits and genetic inheritance, in addition to environmental factors that predispose the patient to certain cancers.¹² The patient ends up suffering from the physical changes, turns away from leisure, excludes himself socially, which results in a feeling of worthlessness.

In this way, several emotional reactions arise, among them fear, sadness, anxiety and depression, both for the moment faced and for the direction it is going.¹⁹ These feelings can reduce quality of life, decrease adherence to treatment and mortality, can generate somatic symptoms such as loss of appetite and fatigue, which are also associated with the treatment itself.²⁰

In the process of becoming ill, depression is an important step in coping with the disease, which in turn can also be called acceptance.¹⁷ Most patients and their caregivers are not prepared to face the diagnosis of a potentially terminal disease and, at that moment, go through characteristic emotional stages, which do not necessarily occur in sequence, and may mix or be experienced in the same period.²¹

In the statements cited, stages such as bargaining, depression and accep-

tance are observed.²² It is possible to identify the bargain, where the individual seeks a postponement, a prize with the intention of prolonging life, therefore, this stage acts in a positive way, because faith reaches the function of building a commitment to life, of finding a partner in the fight it counts the disease.¹⁷

In the words of "serenity", depression is observed, at this stage when the individual cannot deny his illness, new symptoms begin to appear and the patient becomes more debilitated, feelings of great loss arise and it is difficult to hide the illness itself.¹⁹ Acceptance, on the other hand, is a way of letting go of illusions, which causes a noticeable change in the patient, due to the disposition that he starts to have in relation to pathology, going through a path of struggle and mourning.¹⁷

Communication becomes an essential agent for health care, especially when it comes to palliative care, so the positive interpersonal relationship with the patient enables the understanding of their experiences, so that humanized care is developed in its entirety.²³

In the context of terminality, communication is paramount, as it provides the patient with security, trust, transmits hope and strength.²⁴ The bond created between the health team, patient and family, through daily contact builds a relationship of trust, going beyond the usual care mechanisms, also involving psychosocial aspects.

This is of great value for the terminally ill, which is verified through the speeches of great satisfaction during all assistance.²⁵ When the professional is involved in palliative care for terminally ill patients, they are seen in their entirety, and the reward they receive is the thanks, perceived through the look, the affection for being on their side in this fight, in addition to all knowledge regarding the value of life.¹⁹

Spirituality allows the subject of death to be discussed between the

patient and the family, in a way that enables greater preparation for finitude and allows decision making in face of death. In addition, it provides moments between the sick and the professional to relieve suffering, perceive the naturalness of death and appreciate life.²⁶ The interaction between the patient, the family and the nurse is essential to moderate the emotional burden of those involved in this process, it allows security and identification of the care needs during the treatment.¹⁴

CONCLUSION

The elaboration of the study provided an awakening for sensitive humanized care focused not only on the physical needs, but also on the spiritual and emotional needs of the patient who falls ill with cancer. It is well known that the health professional, especially the nurse, needs verbal and non-verbal communication, sensitivity to the patient's manifestations, which consists of a different and thorough ability to understand the imperceptible. Effective communication with the patient

about his real health status is essential, so that he can experience the process in a more pleasant way. Faith, the affectionate relationship with family and friends, proved to be coping strategies that help the patient to deal with the stresses of illness, facilitating care, and providing relief from fears and insecurities present in the illness process. Finally, it is reiterated the need for permanent removal of the obscure veil, which falls not only on the theme of the process of death and dying, as well as the patient in its finitude, both deserve to be treated with respect and sensitivity. 🐦

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