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Attitudes of cancer patients in palliative care towards death in the context of home care

Atitudes de pacientes oncológicos em cuidados paliativos frente à morte no contexto da internação domiciliar
Actitudes de pacientes oncológicos en cuidados paliativos ante la muerte en el contexto de la internación domiciliaria

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ABSTRACT

Objective: To know the attitude of cancer patients in palliative care towards death in the context of home care. **Methods**: This is a descriptive, qualitative study with six cancer patients undergoing palliative care in home care in southern Brazil. Data collection occurred from January to March 2018, through semi-structured interviews, which was recorded, transcribed, and then categorized by the Ethnography 6.0 software. For data analysis, Laurence Bardin's content analysis was used. **Results**: Five categories emerged: regret as a life experience; death as rupture and rest; life after illness; the experience of spirituality and religiosity; wishes at the end of life. **Conclusion**: Patients showed five attitudes towards death: regret, questioning of what death would be and where it would take them; the reflection on the present and the resignification of the current moment; manifestation and strengthening of faith, religion, and hope in a deity; and wishes.

Descriptors: Palliative care. Attitude to death. Nursing. Home care services. Hospice Care.

RESUMO

Objetivo: conhecer a atitude de pacientes oncológicos em cuidados paliativos frente a morte no contexto da internação domiciliar. **Métodos:** estudo descritivo, qualitativo, com seis pacientes oncológicos em cuidados paliativos em internação domiciliar no Sul do Brasil. A coleta de dados ocorreu, de janeiro a março de 2018, por meio de entrevistas semiestruturadas, gravadas e transcritas, e categorizadas pelo *software Ethnograph 6.0*. Para análise dos dados, se utilizou a análise de conteúdo de Laurence Bardin. **Resultados:** emergiram cinco categorias: o arrependimento como experiência de vida; a morte como ruptura e descanso; a vida após o adoecimento; a vivência da espiritualidade e da religiosidade; os desejos no final da vida. **Conclusão:** os pacientes apresentaram cinco atitudes frente a morte: o arrependimento, questionamento sobre o que seria a morte e aonde ela os levaria; a reflexão sobre o agora e à ressignificação do momento atual; manifestação e fortificação da fé, da religião e da esperança em uma divindade; e desejos.

Descritores: Cuidados paliativos. Atitude frente a morte. Enfermagem. Serviços de assistência domiciliar. Cuidados Paliativos na Terminalidade da Vida.

RESUMEN

Objetivo: conocer la actitud de pacientes oncológicos en cuidados paliativos ante la muerte en el contexto de la internación domiciliaria. **Métodos:** estudio descriptivo, cualitativo, con seis pacientes oncológicos en cuidados paliativos en internación domiciliaria en el sur de Brasil. La recolección de datos se realizó, de enero a marzo de 2018, a través de entrevistas semiestructuradas, grabadas y transcritas, y categorizadas por el software Ethnograph 6.0. Para el análisis de datos, se utilizó el análisis de contenido de Laurence Bardin. **Resultados:** surgieron cinco categorías: el arrepentimiento como experiencia de vida; la muerte como ruptura y reposo; vida después de la enfermedad; la experiencia de espiritualidad y religiosidad; deseos al final de la vida. **Conclusión:** los pacientes mostraron cinco actitudes ante la muerte: arrepentimiento, cuestionamiento sobre qué sería la muerte y hacia dónde los conduciría; reflexión sobre el ahora y resignificación del momento actual; manifestación y fortalecimiento de la fe, la religión y la esperanza en una deidad; y deseos.

Descriptores: Cuidados paliativos. Actitud frente a la muerte. Enfermería. Servicios de atención de salud a domicilio. Cuidados Paliativos al Final de la Vida.

INTRODUCTION

Palliative care is an approach that improves the quality of life of patients and their families who face problems associated with potentially fatal diseases, such as cancer,(1) dementias,(2) kidney and heart failure.(3) It also prevents and relieves suffering through early identification, the correct assessment, and treatment of pain and other physical, psychosocial, or spiritual problems.(4)

Home care is one of the contexts in which palliative care is inserted, which is regulated by Ordinance 825, of April 25, 2016, redefining Home Care within the scope of the Unified Health System (SUS), and updating qualified teams.(5) Home care is an integral part of home assistance, which is a complementary modality to hospitalization since the home team can provide humanized care and close to the family.(6) This type of care can offer comfort and safety for the patient and family by being at home and having the presence of family members, avoiding wear and tear, hospitalizations, costly budget, and hospital contamination.(7)

In the context of cancer patients, being aware of the process of illness and the worsening of the disease can trigger various attitudes towards death being a desolate moment, causing anxiety and fear in the face of what is to come.(8) In this way, the multi-professional health team needs to develop care to offer physical, emotional, and spiritual comfort, including family members and caregivers,(9) and dialoguing about the multidimensional aspects involved in the illness and end of life process.(10)

Thus, we justified the interest of the study in the perspective of knowing the attitudes of the cancer patient who is in palliative care in the face of death and, in this way, to offer a better quality of care during the illness process in the field of nursing.

Therefore, we defined a research question: what are the attitudes of cancer patients in palliative care towards death in the context of home care? Consequently, the article aimed to understand the attitudes of cancer patients in palliative care towards death in the context of home care.

METHODS

This is a descriptive study with a qualitative approach based on the script of the Consolidated criteria for reporting qualitative research (COREQ) of the Enhancing the Quality and Transparency of Health Research network (EQUATOR),(11) carried out with six cancer patients, in palliative care, accompanied by a home care service in southern Brazil.

We selected a sample of 28 participants by the interdisciplinary home care service team, based on the establishment of inclusion criteria: to be a cancer patient, with no therapeutic possibility of cure, to have the ability to understand and communicate, and be over 18 years old. We excluded patients who were admitted in the hospital environment and lived in the rural area of the city. Eleven of the 28 participants died during data collection, four were having difficulty communicating; five did not accept to participate; one was discharged, and the other could not be reached through the telephones given by the team.

Data collection took place in a meeting with each participant, from January to March 2018, through semi-structured interviews, at the participants' homes in a reserved environment, with only the main researcher and the participant. The collection took place by prior appointment by telephone, acceptance of participation in the research, and signature of the Informed Consent Term (ICF). We established a brief link before the recording started, in which the participant talked a little about himself, his history, and discovery of cancer, as well as the researcher, explained what the research was about, who was doing it, for what purpose, and read the ICF before signing it. The meetings lasted an average of 30 minutes.

After recorded on a digital device, we transcribed the interviews in a document in Microsoft Word 2013 and inserted them in the Ethnography 6.0 Software. We created codes from the answers, for example, belief, religion; desire; disease; death; health; miss; recovery; life; life before illness, and wishes.

We analyzed the information according to the content analysis of Laurence Bardin, which is configured as a set of communication and investigation techniques with systematic and objective procedures for describing the content of the messages. First, we organized the material by theme, which made up the corpus of the research, and then we chose the documents that responded to the objectives. We also used exclusivity, which argues that an element should not be classified in more than one category. (12)

The research was submitted and approved by the Research Ethics Committee of the *Faculdade de Medicina da Universidade Federal de Pelotas* (UFPel), under the number 2,456,889, and Certificate of Presentation of Ethical Appreciation (*CAAE*) 81381517.3.0000.5317, following all the ethical precepts of the Code of Ethics for Nursing Professionals and Resolution 466/12 of the Ministry of Health.(13)

We preserved the anonymity of the participants, respecting the aforementioned legislation, and as a substitute for their names, we used nouns that expressed their feelings during the researcher.

RESULTS

Regarding the personal characteristics of the participants, four were male and two were female with an average of 63 years old. Four were married, one was a widower and one was single, and all had family caregivers. From the reports, we elaborated five categories, which are mentioned and presented below:

Regret as a life experience

In the statements, the participants reported on regrets that surround their finitude of life, things, and attitudes that could be different, that they believe could have changed or even avoided their situation at the present moment.

> I put other things first, which I shouldn't have put, like overworking, making a lot of effort (physical). There is no point in working too hard. Working less, that's what I wanted to do [...]. I worked, cleaned, washed, tidied, built. [...]. And now I'm like this, "crazy" to get out of this (disease), to do something, [...] to get out. (Genuineness)

> It was my fault [...]. I should have stopped everything, there is nothing to be gained from it (working hard), and I should've taken care of my health. You can't wait until tomorrow. There is no money to pay for people's health. You always look back and you could have done it differently and you didn't. If I had consulted before… [...] I had the opportunity and I didn't. [...] Only the experience of life will tell you. (Strength)

The interviewees showed that the change in their attitudes could have contributed to health care, avoiding the illness of the physical body and their situation at the present moment. In the face of death, patients showed regret and, in a way, blame for past actions, which, according to them, could have been different and would avoid the health-disease situation they live in today.

Death as rupture and rest

In this category, we observed that participants interpreted death differently, which is the result of the beliefs, spirituality, and religiosity proclaimed during life.

> When someone's die? He/she is dead! [...] After he/she went through that door, nothing else happens! Reincarnation does not exist! [...] to hell or God [...]. I don't know. (Simplicity)

This line of Simplicity makes us reflect on a possible protection barrier that is established. In other words, if you decide not to believe in something, maybe it will make it non-existent, and you do not have to connect with the consequences or the feelings that what is going on brings.

In the same way, the testimonies of the participants called Credulity and Genuineness demonstrated that death is understood as ending, rupture and separation.

> Something sad, very sad! [...] the part of the separation, it is very difficult! [...] That's life! We live, then the end comes. [...]. (Credulity)

> I am scared! I don't want to "fade away" (cry)! I don't want to die! I want to stay here a little longer with my children, but it's not like that, I know it's not. It's in God's hands! [...] I cry, I feel sad, but at the same time I remember: I have them (children) [...] I think God "put" for us much better for us, I think it's better. (Genuineness)

For the participants, death can mean the end of everything or something sad, which comes to separate, breakdown, break the bonds with family members and dreams, peoples' wishes. Simplicity ended the speech by saying that he does not know what happens, in a tone of indifference, but sending a message of resentment in the face of the situation lived. The rest of the interviewees fear separation from family members, hoping for better days in God.

Despite this, Prosperity and Strength demonstrated that they believed that there is "something better" after death.

> It's about resting! [...] Spiritually, if we do good, we will rest! We will live well after death. That's what I think: that the spirit of the people rests in peace. (Prosperity)

> [...] it is very difficult! But I still believe in something better [...] It is a very complex thing! I believe it is better than this life, much better than now. Let's wait and see, this is the hope! (Strength)

In the same way, Prosperity and Strength declared to believe in something after death, in a spiritual plane, in resting in peace, in a better life. The belief in something greater seems to awaken comforting thoughts in the face of the inevitability of death. However, Prosperity believes in the idea that attitudes while on Earth condition the way of life that the person will have after death. In this way, we perceive how the religious discourse can influence the thoughts around mortality.

Life after illness

The illness affects human beings in several ways, especially in aspects of private life, such as body care, family and friendships, leisure, and work. Participants commented on some changes perceived during the illness process.

> Going out, meeting friends, I went out, I had fun, I used to hang out. [...] Stop walking complicated my situation. This led me to a "not very good" situation. (Gratitude)

> What I felt most about the disease was the lack of autonomy, independence. But, at the beginning of cancer, in the diagnosis, I didn't feel this loss of autonomy, I lost it now with the stroke. I used to do everything. Now I lost everything! (Credulity)

> It changed everything in life! [...] I can say, everything! I don't do anything else! I stay at home [...]. I can say that I am "worthless" because I cannot make a

> simple effort. It's complicated because I was used to doing everything and it simply stoped! There is nothing I can do. I feel that. I sure feel bad about it. For me, it is being very complicated! (Perseverance)

From the reports, we observed how the lives of patients change from the diagnosis of cancer and the worsening of the disease. Formerly autonomous, independent, today they suffer from the limitations imposed by the illness. Such factors and the dependence to accomplish what once seemed so simple, lead to feelings of sadness and anguish in the face of the inevitable. We also noted that there is an abandonment of leisure activities, which gave them pleasure in the past, directly affecting the emotional and spiritual health of patients.

The experience of spirituality and religiosity

Beliefs, religion, and faith in God were also reported, as present in the following statements:

> [...] I believe in God! But [...] there are people “doing nothing”, who do not do anything out of their lives at all and are cured! (Simplicity)
>
> God, our Lord Jesus Christ first! [...] This is my strength! (Gratitude)
>
> I give it to God. You can't complain too much. I am a Catholic, I have been praying. You have to accept it and let's move on. [...] We should not harm anyone. What sustains me is this! [...] Religion only makes you hold on a little bit [...] without hope it is difficult to move in this world. (Credulity)
>
> We give it to God. [...] I believe that He is wonderful and that only He can take us out of all barriers, to take us out of all this sadness that we have in life. I am a Catholic [...] I believe in God! [...] some people do not believe, I believe, it is the religion that I believe. He will do the best for us. (Genuineness)

The reports made us think that despite not knowing what happens after death, there are several beliefs, religions, doctrines, it brings comfort to imagine that something better exists “on the other side”. The thought that after suffering the illness there is something better, comforts, appeases and promotes hope that these events of emotional, physical, spiritual suffering will stop at some point.

Regardless of religion and belief, the spirituality that involves the most diverse religions and doctrines permeates the path of the person affected by some disease, even more out of the possibility of a cure. Whether to give meaning to their suffering, to the moment that is passing by, or to comfort a pain that is no longer of a physical but spiritual and emotional nature, or it can be a source of hope, healing, or that the best will be done.

Wishes at the end of life

Finally, patients in palliative care expressed some important wishes and desires at this point.

> [...] I miss it, especially after my *chimarrão* [...] to smoking a cigarette. [...] I would like to get well [...] and be able to work, heal myself. Better if I had nothing (disease)! [...] Get out of here tomorrow, have a cup of coffee, work, smoke a cigarette. (Simplicity)
>
> [...] what do I value most today? Health, my health. [...] Thank God, I have everything! My wish is not to be sick. (Genuineness)
>
> I feel the need for everything, to go out, to be able to move as I did, to do the things I did. That's what I feel the most! But life goes on, I believe I will get better, I will get over it. It is what I hope that someday I will stop taking this medicine (morphine), that it will no longer be necessary, and that I will not feel this pain so much anymore. (Perseverance)

Participants also reported on the importance of living more with the family, so that they can enjoy their days with them. For the interviewees, death represents separation, and for this reason, they will not be able to follow the growth and achievements of their children and grandchildren, live with their parents and enjoy the company and coexistence of their partner.

> [...] I want to see my son grow up, graduate, be someone. Living with my wife, with my father, I already feel fulfilled. (Perseverance)
>
> [...] I would like to see my grandchildren older. Having enjoyed life more, forming a family sooner, because then the grandchildren come too late […] it complicates it. Everyone would like to enjoy it more. I would like the family to always be more united. (Strength)

The testimonies steeped in emotion showing the intimacy of each individual be as their regrets, deepest feelings, with their desires and values appearing by the proximity of death.

DISCUSSION

The participants' expressions “I shouldn't have”, “this is what I wish I had”, “I should have stopped everything”, “I could have done it differently”, “if I had consulted before” and “I had the opportunity and I didn't do it” demonstrated that, when it is impossible to do something, the non-totality of the action means a pendency in the power to be, in what could be, mainly, if the individual had chosen differently[14]

We can consider that, when people are diagnosed with cancer, they rethink the illness process, how they lived their lives before the disease, the mistakes, successes, attitudes, and decisions.[15] As the human being recognizes himself as a mortal and finite human being, perceiving death as an inevitable event, he can manifest the attitude of reflecting on the several aspects of his life, which will influence his choices and postures in the face of illness and death.[14-16]

We also perceive the regret regarding some aspects, which can become impediments for them to have a fulfilled life in this period. This is because there is a difficulty in accepting finitude and understanding it as part of life, which at times hinders making decisions and behavior that provide the feeling of having had a satisfactory life and accordingly to their values and desires.

Another aspect found in the statements refers to the religious belief that after death people face heaven or hell. This can result in feelings of anger, sadness, and helplessness, which makes human beings reflect on the end of their existence, feelings brought by authors like Kubler-Ross when describing the phases of anger and depression.[17] These feelings characterize the first stage of death, also appearing in people who profess a belief or are devout and religious, including the sense of doubt about the existence of a divine being.[18]

There is also the perception that they are developing an attitude of "protection" when they say they do not believe in anything, this may cease to exist, so, they will not need to deal with the consequences and the feelings that emerge from this situation. In the meantime, authors bring that religiosity and spirituality can present a strategy of resilience in people's existence, contributing to coping with pathologies, loneliness, among other important demands. Resilience is a characteristic of the individual in dealing with and adapting to changes and overcoming obstacles, resisting adverse situations. [19-20]

Some participants considered death a sad experience, a moment of separation and distance from family members, the end of life. Together, there is the mystery, fear of the unknown, and insecurity, even believing in the divine, which brings comfort. At this time, feelings of fear, distress, and anxiety appeared.

We noticed in the interviewees that the act of dying and leaving their family members behind causes great regret. Upon being aware of this, a participant expresses the desire to obtain "more time", more opportunity to enjoy the moments with his family. In this way, the illness interrupts dreams, wishes, and desires, causing the feeling of inability to perform the activities that are important to them.[15]

For the interviewees, death appears to be predetermined and inevitable, but there is a belief that there may be "something more". The attitude of waiting for death is felt differently by each person. While some are curious to know what happens after this experience, others feel uncomfortable when they think about their finitude. [18]

Although the interviewees do not comment on their religiosity, they are comforted by imagining that something better awaits them "on the other side". There is the hope of a "better" life than the earth life, perhaps due to the possibility of not feeling the pain and suffering of the body and mind anymore. Consequently, it comforts, soothes, and brings hope in the sense that emotional, physical, and spiritual suffering will cease at some point.

Even if perceived differently, spirituality can be understood as a form of support, comfort, and connection with God and with faith, or as the essence of being, transcendence and self-knowledge.[21] We can think that these feelings can be also related to the attempt to attribute a meaning to what is done and give meaning to the suffering experienced. In the experience of people in palliative care who are in a situation of finitude, the presence of God is very strong and with the disease, it tends to intensify.[22]

However, death can still be seen as the abandonment of the physical body, a transition to a broader state of consciousness, in which we can continue to perceive, understand, smile, and develop. Due to the presence of feelings of fear, anxiety, and nervousness in the face of the "unknown", health professionals should assist patients in the process of the finitude of life to go through this stage feeling supported and comforted.[17]

The changes experienced by the participants when diagnosed with cancer followed by its complications limit the activities of daily living, feeling away from living with friends and family. There is a perception of loss of autonomy and inability to perform activities considered simple. We should emphasize that the patient becomes ill as a whole, needing to adapt to the organic and psychological manifestations that the disease promotes in his life, requiring the ability to adapt him and the people with whom he lives, who are not always prepared for these changes.[23] Thus, the most frequent changes are in the body image, difficulties in socializing, and sexuality.[24-25]

In addition to the limitations already felt by the physical body, the impossibility of healing causes suffering to the individual, who perceives facing the finitude of life and the lack of "control" over the disease.[26-27] Thus, comprehensive care promoted by palliative care needs to be carried out prioritizing emotional, spiritual, physical, and social aspects.

Regarding the death and the existence of God, several feelings arose such as anger, frustration, guilt, faith, hope, and the confidence that God will make the judgment, He will decide whether the individual will be healed or will died. These feelings are expected during the process of finitude, as the disease interrupts one's life and the plans drawn up, which is why the patient experiences a tangle of feelings, such as regret, guilt, and anger towards himself, others, and God.[17 -18]

However, there are times when faith, spirituality, and religiosity offer relief in difficult times, by providing courage and strength to overcome and accept situations. Spirituality assists in overcoming obstacles during the illness process, being a coping strategy for cancer patients without the possibility of a cure, as it contributes for the individual to assign meaning conducive to illness and suffering.(23-28)

The main desires and wishes reported by the interviewees were: to be healthy, to heal, to walk, to work, and not to feel pain, and the desire of one of them was the possibility of new birth to overcome the physical limitations imposed by the illness. In this sense, we perceived that the participants' wishes and desires can be understood as physical and psychological desires, which help them to hope for the reduction of symptoms and limitations, especially not to feel dependent on other people.(21)

However, the protection of the people is essential, as it allows goodbye and reduces the feeling of loneliness, guaranteeing dignity for those who are in the process of death. Thus, patients in palliative care need to be helped to make a dignified crossing, and for this, the assistance team needs to respect final wishes and relieve physical and spiritual pain. (29) In this way, comprehensive care needs to cover the physical, emotional, and spiritual aspects of patients and be extended to family and friends.

There is no single way to care for people at the end of their lives. This care will depend on the meaning that represents the final moment and death for each individual, both patient and professional. In addition to the physical pain of the patients, there is a subjective pain, “the pain of the soul”, “of the heart” and of the spirit, which is felt by each person differently and needs to be considered when aiming to provide comprehensive care in palliative care.(29)

In this context, the Peaceful End-of-Life Theory is one of the theories that guide nursing care, which consists of founding strategies to be used by nurses and direct the promotion of peace in the final moments of life. In the meantime, strategies that guarantee respect for the dignity of the person at the end of life are fundamental, and the fulfillment of their wishes and the solution of unresolved situations stand out.(30)

Recognizing the perception of the patient who experiences his process of the finitude of life can help health professionals to identify the aspects to be evaluated and assisted at this time, aiming to guide interventions and improve the quality of life and death. From this perspective, patients want to have control over complications, pain and have the energy to carry out their wishes and desires.

However, this study has some limitations because, generally, end-of-life patients have some level of weakness that prevents a more extensive interview. Some patients indicated by the team died before the interviews, which also limited the number of participants. We suggest carrying out further studies in this perspective in other locations and in different contexts to compare and obtain other perceptions of the individual.

CONCLUSION

We could know the attitudes of cancer patients in palliative care for death accompanied by a home care service. The patients showed five main attitudes towards death throughout this study, such as regret for past actions that led them to the moment of current health-illness; the attitude of asking themselves what death would be and where it would take them; reflecting on the now and reframing the current moment; manifesting and strengthening faith, religion, and hope in a deity, and leading them to manifest desires.

This study contributes to results that highlight the importance of health professionals performing care based on the philosophy of palliative care, considering attitudes towards death individually, especially when carrying out care planning in their daily care, considering what death represents for the patient and his perceptions of this moment. When reflecting on what death means for each individual, we can provide more dignified, human, and holistic care, entering and encompassing the patient and his family as a whole.

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