Research Article
Artigo de Pesquisa
Artículo de Investigación

DOI: http://dx.doi.org/10.12957/reuerj.2019.45650

Cancer patients with advanced disease: concerns and expectations experienced in the end-of-life

Pacientes oncológicos com doença avançada: preocupações e expectativas vivenciadas na terminalidade da vida

Pacientes de cáncer con enfermedad avanzada: preocupaciones y expectativas experimentadas al final de la vida

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ABSTRACT

Objective: to highlight the concerns experienced by patients with advanced cancer. **Methodology:** qualitative study developed with 11 cancer patients in palliative care. The data were collected in Maringá - PR, from 2016 to 2017, through open interviews, addressing the experiences and confrontations experienced during the terminal life process, from which the speeches were extracted and submitted to content analysis after approval by the Committee Research Ethics. **Results:** the fear of becoming a nuisance and the uncertainties of how life will continue after his departure, were hegemonic issues of the patients, who found in the acceptance of death a moment of reflection on life, emerging as a positive probability of resilience and hope. **Conclusion:** the main concerns expressed were: to live better now, to get closer to those who do them well, worrying about the well-being of their families and how they will be after their departure, thus transcending their own suffering.

Descriptors: Attitude towards death; terminality; expression of concern; taboo.

RESUMO

Objetivo: evidenciar as preocupações vivenciadas por pacientes com câncer em estágio avançado. **Metodologia:** estudo qualitativo desenvolvido com 11 pacientes oncológicos em cuidados paliativos. Os dados foram coletados em Maringá – PR, no período de 2016 a 2017, mediante entrevistas abertas, abordando as experiências e enfrentamentos vivenciados durante o processo de terminalidade da vida, das quais foram extraídos os discursos e submetidos à análise de conteúdo após aprovação pelo Comitê de Ética em Pesquisa. **Resultados:** *o medo de tornar-se um incômodo e as incertezas de como a vida continuará após sua partida* foram questões hegemônicas dos pacientes, que encontraram na aceitação da morte um momento de reflexão sobre a vida, despontando como uma probabilidade positiva de resiliência e esperança. **Conclusão:** as principais preocupações manifestadas foram: viver melhor o agora, aproximar-se mais daqueles que lhes fazem bem, preocupando-se com o bem-estar de seus familiares e como eles ficarão após sua partida, transcendendo assim o seu próprio sofrimento.

Descritores: Atitude frente a morte; terminalidade; expressão de preocupação; tabu.

RESUMEN

Objetivo: resaltar las preocupaciones experimentadas por los pacientes con cáncer avanzado. **Metodología:** estudio cualitativo desarrollado con 11 pacientes con cáncer en cuidados paliativos. Los datos se recopilaron en Maringá - PR, de 2016 a 2017, a través de entrevistas abiertas, abordando las experiencias y confrontaciones experimentadas durante el proceso de vida terminal, de donde se extrajeron los discursos y se sometieron a análisis de contenido después de la aprobación del Comité Ética de Investigación. **Resultados:** el miedo a convertirse en una molestia y las incertidumbres de cómo continuará la vida después de su partida, fueron problemas hegemónicos de los pacientes, quienes encontraron en la aceptación de la muerte un momento de reflexión sobre la vida, emergiendo como una probabilidad positiva de resiliencia y Espero **Conclusión:** las principales preocupaciones expresadas fueron: vivir mejor ahora, acercarse a quienes son buenos para ellos, preocuparse por el bienestar de su familia y cómo estarán después de su partida, trascendiendo así su propio sufrimiento.

Descriptores: Actitud hacia la muerte; terminalidad; expresión de preocupación; tabú.

INTRODUCTION

Cancer is a complex and aggressive disease, whose prevalence has been increasing in recent decades. Despite scientific advances it may, at some point, progress to an incurable disease, and in this condition the patient begins to experience the process of end of life[1].

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[VIII] Thanks to the patients involved in the study for the opportunity to experience this very peculiar and intrepid life process.

Received: Sep 30th 2019 – Accepted: Dec 28th 2019

This stage of life is full of anguish and fears, which are accentuated by living with a chronic and limiting disease such as cancer, whose ingrained stigmas relate to suffering, pain and, above all, death. These factors can interfere in the search for health assistance and, consequently, in the detection of the disease, resulting in late diagnoses that compromise quality of life and prognosis[2].

Taboos make some patients believe that living with the certainty of an irreparable end is more painful than the diagnosis itself. In the terminal phase, it is important to address palliative care to ensure quality of life and an opportunity for the patients to expose their wishes, feelings and concerns, in fact assuming the power over their own lives[3].

The need for comfort and the availability for palliative care have been neglected worldwide. There is a strong attempt to extend life at any cost, with few implications for interventions that alleviate suffering or increase dignity at the end of life. However, giving space to address the concerns and needs of patients has already shown relevance and effectiveness in the terminal process of life[4], as it promotes well-being and autonomy in the face of this reality.

When facing the incurable state of the disease and the proximity of death, patients often lose their own meaning of life, questioning their existence and the care they receive. And much of what was valued before the disease becomes superfluous[5].

People who are not experiencing the end of life are able to think about the future even in adverse conditions, glimpsing desires and goals[6]; however, for those who live with a terminal illness, the future is threatened with concerns and uncertain expectations.

Thus, given the need to structure nursing care for patients with incurable diseases, the following question arises: What are the concerns that permeate the life of people with cancer at an advanced stage regarding their present and future? To this end, the aim was to highlight the concerns experienced by patients with advanced cancer.

THEORETICAL REFERENCE

The study was based on the conceptions presented by Elizabeth Kübler-Ross, a pioneer in describing attitudes and emotional reactions caused by the proximity of death and the process of dying in terminally ill patients[4]. When facing a loss or a serious diagnosis, the person tends to go through the five phases of death and the process of dying: denial, anger, bargaining, depression and acceptance.

When going through these phases, the patients accept the situation of life before death, assuming the awareness of being finite. Thus they can build from there a new understanding and way of living, with a different view of life, with new desires and concerns[6].

Reflecting on such concepts enables the understanding of strategies to envision biopsychosocial changes in the lives of people and their loved ones[4]. And so, to propose coping measures that can help them to reflect and better understand the situation they are experiencing. In this sense, palliative care presents itself as the main therapeutic measure to help and improve the quality of life of people living in the dying process[7].

METHODOLOGY

A descriptive research with a qualitative approach[8], carried out with people with cancer at an advanced stage, assisted by a non-governmental institution located in the city of Maringá, Northwest of the state of Paraná, which is a reference in the care of people with cancer and in social vulnerability.

The participants were pre-selected from medical records showing one of the following conditions: cancer at an advanced stage, under palliative care, advanced stage of the disease, presence of metastases, closed prognosis, or even by verbal information from the institution’s health care practitioners. The inclusion criteria adopted were the following: diagnosis of an incurable disease for more than 6 months, being aware of the clinical stage of the disease, being treated at the institution during data collection, and having their mental status preserved, as assessed by the mini mental status examination[9].

Fourteen patients were initially contacted, but two did not reach the minimum score in the mental status assessment and one passed away after the first contact, thus resulting in 11 study participants. The inclusion of new participants was interrupted when the concerns were answered and the objective of the study was achieved.

The interviews were carried out from November 2016 to March 2017, and the audio was recorded after the participants’ consent; they lasted 40 to 60 minutes on average. It took three to four meetings with each participant, which took place at the institution or at their home, without the presence of other people.

Considering the experience of the lead author as an oncology nurse with experience in the management of these patients, data collection was performed by him and began when he felt the interviewee was ready to expose his/her experiences before the death-dying process. The interviews followed this guiding question: What causes you the most concerns at this stage of the disease regarding your present and future? From this question, it was possible to understand the experience of each patient in living with the incurable status of the disease and imminence of death. Behaviors expressed as pauses, changes in the tone of voice, change of emotions, crying and interruptions were recorded in a field diary, so that, together with the statements, they made up the *corpus* of the analysis.

The interviews were transcribed in full and read carefully, so that no relevant information was disregarded; they were enriched with information contained in the field diary, referring to the events and impressions of the researcher, thus allowing for a better understanding of how the interviewees interpret, give meanings to, and understand this experience of finitude[10].

The data were analyzed concurrently with the interviews, following the methodological flow recommended by the content analysis technique[11]: Pre-analysis – performed by thorough readings of the statements, enabling the selection of the material to be explored according to its representativeness to the object of study. Exploration of the material, coding stage of the interviews, reducing the text to meaningful words and expressions and dividing them into categories. Organization of the results, final stage of the analysis, where the categorical interpretation and inferences were made, relating them to the theory that correlates to the object of this study.

The study was approved by the Ethics Committee for Research involving Human beings, Opinion No. 1,349,763. Due to the psychological changes that the approach could trigger, psychological support was made available to the participants; however, only one patient was referred for an appointment. To preserve anonymity, the statements are identified with names of characters from *The Little Prince*[12], followed by the age of the patients.

RESULTS AND DISCUSSION

The participants were between 40 and 82 years old, eight being female. The period of time with the progressing disease ranged between one and 21 years until the onset of the metastasis foci.

The discovery of the second focus of the disease (metastasis) was experienced by eight participants, and the time of living with this condition varied from 7 months to 4 years. The other three participants were diagnosed with the primary disease in an advanced stage. Regarding treatment, ten participants underwent at least one of the antineoplastic therapies (chemotherapy, radiation therapy and surgery) and for the other no treatment was prescribed, given the aggressiveness of the disease at the time of diagnosis.

The participants' statements about the concerns and expectations experienced in the process of dying were aligned in two categories, described below.

Acceptance: a moment of reflections on life and death

Understanding each of the five phases of the death and dying process systematized by Kübler-Ross helps health professionals, family members and, above all, patients themselves to face this process[4]. Such phases can happen in different contexts, periods and durations among the patients; they are not intentional behaviors, because at that moment they represent the only way in which the person is able to face the situation[13]. These characteristics were common in the protagonists of this study, and it is possible to evidence fragments of this process in their experiences.

However, going through these phases does not mean that they will follow a chronological order; there is even the possibility of not going through any of them or even experiencing more than one at the same time[14]. During the time spent with the patients in this study, it was possible to identify all these phases, each at its specific moment, especially the last one, regarding the acceptance of, or conformity with, the condition.

The *acceptance* phase is considered to be the last one experienced in this process, in which the person gradually accepts his/her reality and begins to more consciously understand the limits caused by the disease. In this last stage people have managed to get through the other phases. When this happens, they no longer feel angry at their destiny and are able to face it with serenity, being able to express and apprehend reality as it really presents itself. Thus, they express the issues related to the inevitability of their own death more naturally[15].

> *Now there's not much to do, there's nowhere to run [...] because when it comes to this [cancer], we know it's death, that's how we imagine it, that's how we should think. (The Businesswoman, 47 years old)*

DOI: http://dx.doi.org/10.12957/reuerj.2019.45650

> *A disease we can take medicine and get better, but death is different, sometimes you go to sleep and don't wake up anymore, it's something we have to wait for, we know it will be over and that's why we have to get used to it. (The Fox, 57 years old)*

It is noteworthy that the transition between these phases does not necessarily occur in a linear and progressive way, and not everyone will reach the last stage. Some will try to fight to the end, resisting and clinging to any remnants of hope, assuming a future with the possibility of prolonging their lives[16].

This flame of hope that some individuals insist on conserving provides setbacks and advances between the different phases. However, it is clear that in the acceptance phase, what predominates is the feeling of peace and not happiness[17].

In this context, the feeling of suffering was common and emerged in the form of small insights, as if in homeopathic doses, interposed with phrases, gestures or words. Some reports reveal static glances, a deep silence and small statements expressing regret for what they will leave behind, for what they have not yet experienced, for the unborn grandsons or for the sons who they will not be able to see grow up.

> *Today I'm not afraid of death, I'm just afraid of being away from my children, of not seeing them grow up and getting married, afraid of him [the husband] not wanting to be with me anymore, finding other women while I'm like this. (The Desert Flower, 57 years old).*
>
> *Sometimes I cried, out of pity for having to leave my children, my family, because I am a very loving husband, I am afraid to leave my life partner, it's been 57 years [...], we have a life together and we raised our children. (The King, 82 years old)*
>
> *Before we had our whole lives ahead of us, and suddenly, something like this appears. So, we just wanted to live a little longer, at least to see our grandchildren growing up. (The Fox, 57 years old)*

Living with the torment of no longer being able to share the moments they once planned portrays the lack of approaches on the death-dying process during treatment or even during life. In light of this, the importance of giving people a voice to inquire, speak, expose their doubts and needs is clarified, allowing those who are in the process of finitude not only to die without suffering, but also to express their feelings and needs in the face of death[18].

The phases of death and dying help both health professionals and family members to understand the feelings experienced by their loved ones: sadness, anger, losses, guilt, anxiety, loneliness, relief, among others – which may appear in this process[17].

Death is the only certainty in life, and essentially private to each person, no one can replace the other at that moment[19]. Likewise, the individuals in this study had unique ways of moving through the process of finitude. Some became attached to faith and hope, others held to the concept of time: time not lived, wasted time, time left behind or even running against that time, now limited, to get things in order in this world.

The desire to adjust everything that will remain here, after they leave, refers to the ideal death. Accepting reality also means that people begins, in their hearts, to adapt and plan how they would like the lives of their loved ones to continue after their death, according to their family and social expectations. People then begin to look into themselves through their cognitive processes to reach inner peace or, in their own words, the feeling of accomplishment[16].

> *I think mainly of my children, although they are grown up, they always depend on us for something, even if it is for advice. My concern is whether I will be able to teach them and whether they will be able to learn to survive without me. (The Vain Woman, 59 years old)*
>
> *All I've been doing lately is to make things better for the kids. It is the children and the family who stay, who continue, I am doing everything so that nothing bad happens to them. (The Geographer, 65 years old)*

It was also found that, in the acceptance phase, time emerged as the great support of life. So phrases like: *I would like to spend more time with my family*, *enjoy our time together* and *focus on living today* were more frequent and had a special meaning. Details that previously went unnoticed and considered irrelevant have taken on important dimensions in their lives.

> *Nowadays I don't do long-term planning anymore, before this I planned everything, I would like to have a house like this, I wanted to travel. After this [the disease] I don't plan anything anymore, at the most I make plans for a week. (The Rose, 40 years old)*
>
> *I see today that, in this world, it is not worth to get attached to anything, to possessions, it is not worth getting attached to anything [emphasis on anything], what is the point of having a lot of money or a beautiful house, and not having health, not having tomorrow, then it is useless. (The Businesswoman, 47 years old)*

The feeling of readjusting life in this terminal phase was widely apprehended and appears as a positive probability of resilience and hope. Thus, it should not be discouraged, as it contributes to the reduction of reactions of fear and anxiety, and benefits patients in adverse conditions, so that they can envision a future that fits within their new expectations[17].

It is noteworthy that, although there was sadness at certain times, many interviewees reported growth, attributing new values to this stage of life. This in turn increases in intensity and value when faced with death, demonstrating how important it is to provide opportunities for reflections and debates on the finitude of life. This gap must be filled by nursing, which should pay attention to the transformations of these individuals, so that the characteristics that seem to exhaust their hopes can be worked on continuously through listening and acceptance, so that humanized and dignified assistance to the terminal patient is promoted.

Understanding this moment and identifying signs of hope in the readjusted life can provide nurses with opportunities to plan care in order to stimulate a new way of looking at life and mitigate the impact that the possible approach of death causes on the daily lives of people with advanced cancer[20].

Perceiving the family/caregiver as a fragile unit

The diagnosis and treatment of cancer affects the patients, but also their families and, in particular, those who assume the role of caregivers, who are daily faced with physical and emotional challenges. Thus, the trauma that results from the diagnosis can sometimes be more expressive in a family member than in the patients themselves. This grief of the family member is noticed by the patient, who may express remorse for feeling they are responsible and the cause of this suffering[21].

The participants in this study, as identified in other studies, reported suffering from feeling powerless in the face of imminent death[22,23]. However, this feeling is enhanced by the possibility of being the cause of suffering for others, especially for their loved ones[24].

> *We suffer, but so do our children, because they are the ones who suffer from seeing the mother in this state and not being able to do anything. (The Fox, 57 years old)*
>
> *My fear is to be suffering on a bed, giving the children too much trouble and needing them all the time; I am afraid of causing this suffering to my family, I am not afraid of suffering, but of giving too much trouble. (The Geographer, 65 years old)*
>
> *I'm afraid of suffering, I don't want that, but I also don't want my children to see me like this, I don't want them to see me suffering. (The Desert Flower, 57 years old).*

It is perceived that, when going through the process of finitude, a vastness of feelings and concerns take over the patients, as they do not want to become a reason for suffering for their family. Thus, they start to daydream about the uncertainty of how their family members' lives will be like in their absence, and there is also the fear that they may also follow the same tortuous path.

In the meantime, care mediated by empathy and solicitude shows that concern for the loved ones is also an authentic form of care, expressed here inversely by those who need care.

> *[...] I am concerned about leaving my children, they will not be fine without me, I think about it a lot, and I thought a lot about my family, because I am everything in the house. (The Snake, 75 years old)*
>
> *My concern, when I leave [pass away], is how my children will be. As a mother, I don't like to see my children suffering, and I know they will suffer. I even joke with my husband: - You find another wife and you are fine, but my children will not find another mother. (The Businesswoman, 47 years old)*

Emotional problems and psychosocial suffering are common when individuals are confronted with an oncological disease and on the verge of death. The vulnerability to this suffering is specific to each person and depends, in addition to the circumstances in which it occurs, on the perception of the impact of the disease on their life plan[24].

From the interviewees' perspective, family members and caregivers share the same effects arising from their suffering. So they realize that many family members are affected by frustration and by a feeling of powerlessness because they have nothing else to do. They reported that some family members get closer in an exacerbated manner, while others leave because they do not believe they have the conditions to endure that situation[22].

> *I absolutely love my children and I am sure they feel the same way about me. We got much closer after this [disease]; we were closer, but now we are even more. (The Businesswoman, 47 years old)*

Experiencing the process of finitude leads the patient to understand death and the process of dying as inevitable. However, because they love them and do not want to see them go, some family members insist on denying death. At this moment, it is common to perceive behaviors such as those reported here, in which the loved ones keep distance from the patient[24].

> *[...] the one that I really miss is my daughter, we were very close, and lately, after I was like this, she disappeared. The others think this is weird, she was the closest to me, but today she doesn't care anymore, she doesn't call, she doesn't visit me, and we actually live in the same city. (The Vain Woman, 59 years old)*

Finally, considering the context of the terminal stage, the way patients and their families live changes and they begin to face several problems that are difficult to understand, requiring a slow and progressive adaptation to work on their feelings and emotions[23]. It is noteworthy that caregivers also need space to talk about their fears and, mainly, about their perceptions on death and the process of dying, so that they can express their feelings and rebuild the meaning of life and death.

In this perspective, several studies show that the burden and difficulties in caring for the person who experiences the end of life intensify in this phase of the disease, as the imminent reality of death increases the tension, insecurity and vulnerability of the caregiver, resulting in emotionaldistress[24].

CONCLUSION

The results show that the patients who experience the terminal state reflect on their values and meanings about life, starting to value the quality of life over its extension. In addition, they begin to show greater concern for the well-being of their family members after their death, to get closer to those who are important to them, or simply to experience the small pleasures of life, which, according to them, transcend the possessions and superfluous things of this world.

It is noteworthy that the taboo in addressing the death-dying process, especially death itself, associated with the fact that the interview was for some the only moment throughout the course of the disease when they were indirectly encouraged to reflect and express on this topic, limited the manifestations of feelings and concerns about their finitude. In this sense, it is expected that the results will contribute to a new assistance path of listening and paying attention to the terminal patient.

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