

## EXPERIENCING THE SITUATION OF BEING WITH CANCER: SOME REVELATIONS<sup>1</sup>

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Siqueira KM, Barbosa MA, Boemer MR. Experiencing the situation of being with cancer: some revelations. Rev Latino-am Enfermagem 2007 julho-agosto; 15(4):605-11.

*This article aims to reveal the meaning of being-with-cancer to oncologic patient, trying to comprehend them in their living, discerning the discovery of new ways to deliver care. This study is based on the qualitative research methodology - phenomenological modality, realized with cancer patients who were aware of their diagnosis and were hospitalized at an institution specialized in oncology. Living a serious disease like cancer reverberates on the person's life in a significant way and affects his/her entire Being. The physical and psychical restrictions deriving from the disease imply significant changes, which may make the person become dependent or withdraw from social companionship. Moreover, the person suffers due to financial disarrangements and may come across the need to interrupt or give up of important life projects. The comprehension of what is lived by the person with cancer indicates the relevance of transformations in the philosophy of his/her care, including the need to discuss and share feelings.*

DESCRIPTORS: oncologic nursing; hospice care; care humanization

## EL VIVIR A SITUACIÓN DE SER CON CÁNCER: ALGUNAS ELUCIDACIONES

*Este estudio tuvo como propósito revelar el significado de estar con cáncer para pacientes oncológicos, buscando comprenderlos en esa vivencia y discerniendo nuevos caminos para el cuidado. Un estudio fundamentado en la metodología de la investigación cualitativa – modalidad fenomenológica, fue realizado junto a pacientes oncológicos, conscientes del diagnóstico de cáncer, internados en una institución especializada en oncología. El vivir de una situación de enfermedad grave como el cáncer repercute significativamente en la vida de la persona, afectando todo su Ser. Las restricciones físicas y psíquicas como consecuencia de la enfermedad implican en cambios significativos y pueden llevar a la persona a quedarse dependiente o apartarse de la convivencia social. Además, sufre con los desajustes financieros y se ve con la necesidad de interrumpir o desistir de proyectos importantes para su vida. La comprensión de lo vivido por la persona con cáncer señala para la relevancia de transformaciones en la filosofía de su cuidado, incluyendo la necesidad de discutir y compartir sentimientos.*

DESCRIPTORES: enfermería oncológica; cuidados paliativos; humanización de la atención

## O VIVENCIAR A SITUAÇÃO DE SER COM CÂNCER: ALGUNS DES-VELAMENTOS

*Este estudo teve como propósito desvelar o significado de ser-com-câncer para pacientes oncológicos, buscando compreendê-los nesse vivenciar, vislumbrando a descoberta de novos caminhos para o cuidar. Estudo fundamentado na metodologia da pesquisa qualitativa – modalidade fenomenológica, realizado junto a pacientes oncológicos, cientes do diagnóstico de câncer, internados em uma instituição especializada em oncologia. Compreende-se, aqui, que o vivenciar uma situação de doença grave como o câncer repercute significativamente na vida do Ser. As restrições físicas e psíquicas decorrentes da doença implicam em mudanças significativas e podem levar a pessoa a tornar-se dependente ou afastar-se do convívio social. Além disso, sofre com os desajustes financeiros e se depara com a necessidade de interromper ou desistir de projetos importantes para sua vida. A compreensão do vivido pela pessoa com câncer sinaliza para a relevância de transformações na filosofia de seu cuidado, incluindo a necessidade de discutir e compartilhar sentimentos.*

DESCRIPTORES: enfermagem oncológica; cuidados paliativos; humanização da assistência

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## INTRODUCTION

Cancer has affected an expressive part of the world population and has become one of the main causes of death. According to the World Health Organization, over 10 million people are diagnosed with cancer each year. Approximately six million of them die, which represents 12% of deaths in the world<sup>(1)</sup>.

In Brazil, estimates for 2006 showed that there would be 472,000 new cancer cases, 234,000 among Brazilian men and 238,000 among women<sup>(2)</sup>. Although several technological advancements in modern oncology have provided a better cure rate for malign tumors, incidence and mortality rates call the attention of public health authorities.

The fact that such an expressive number of people seek health institutions to treat malign tumors should make researchers reflecting on the quality of health care offered to those people. Despite conceptually aiming at human dignity and integrality, the reality of health institutions reveals that, over time, the health care process has acquired merely technical and reductionist characteristics. Health care professionals often assume an authoritarian and defensive posture. Moreover, health care actions seem to lose their originally interactive character, in which patients are co-responsible for making decisions on their health.

Health care should recover its essential meaning, and should be performed multidimensionally and involve the ability to recognize patients as integral beings. Health care should be characterized as an attitude, a way of being, and not only a task that takes place at a certain moment. As a way of being, health care becomes a basic ontological-existential phenomenon and, as a part of the human nature and constitution, it reveals its concrete way of being-in-the-world-with-others<sup>(3-4)</sup>.

Cancer is a disease that has historically been associated to experiences permeated with suffering and pain, followed by death. Due to the death stigma involving the disease, when people see themselves in the world with cancer, they move from their everyday existence to a life in another world dimension, in which the possibility of death seems to be inevitable. Hence, they yearn not only for health care regarding the disease and its physical manifestations, but also for actions that express solicitude and understanding toward their ill existence<sup>(5)</sup>.

Social perception usually reflects the association of cancer to a shameful fatal illness, commonly considered a synonym of death, which isolates patients and cultivates pessimist feelings toward the disease. Considering the health care offered to cancer patients and the interest that nurses working at a specialized oncology service have in offering health care that takes their patients' needs into consideration, the present study proposal was developed: to reveal the meaning of being-with-cancer for oncological patients, aiming to understand their experience and to find new pathways for the health care they are offered.

## THEORETICAL-METHODOLOGICAL FRAMEWORK

This study is founded on the qualitative research method - phenomenological mode, and was performed at an institution specialized in cancer treatment, located in Goiania, a city in the state of Goias.

The experience of becoming ill with cancer is a phenomenon with different particularities. Only people who live through this situation are capable of attributing the meaning of being-with-cancer and, thus, revealing their experience. Taking these facts into consideration, this study was performed with eleven oncological patients, aware of their cancer diagnosis, who were hospitalized at the health institution selected for the research during the data collection period. Patients were interviewed by one of the study authors.

The number of study participants was determined by the data saturation criterion<sup>(6)</sup>, adopted in qualitative research, in which information convergences and divergences indicate when data collection is finished. These convergences are referred to as *invariants* and express the essence of the study phenomenon<sup>(7)</sup>.

The research was developed in accordance with the recommendations of the National Health Council, Resolution 196/96<sup>(8)</sup>. The project was approved by the Institutional Review Board on Human and Animal Medical Research - Clinics Hospital at Goias Federal University (protocol CEPMHA/HC/UFG number 0129/2005).

Data collection took place between June and August 2005, through recorded interviews held after receiving patient authorization, and guided by the

following question: *To you, what does it mean to exist with cancer?* Interviews were performed in line with the phenomenological approach, which presupposes a sense of exchanging experiences, in which care and respect for people should always exist<sup>(9)</sup>.

Data analysis was based on the "Qualitative Analysis Method of the Situated Phenomenon"<sup>(10)</sup>, in which four moments are proposed to analyze statements<sup>(6,10)</sup>. These were strictly followed in the present study.

First, a comprehensive reading of the statements was performed in order to obtain an overall meaning, seeking to capture the meanings that subjects attributed as well as how they attributed those meanings. Next, a new reading of the statements was performed, slower and more carefully, and meaning units were identified. After identifying the meaning units in the statements, they were read once again with the aim of catching the meaning they contained. Finally, the meaning units were summarized or categorized according to the theme, attempting to reach the structure or essence of the phenomenon. This synthesis or categorization phase is also understood as thematization, which means to study a subject seriously and systematically<sup>(10)</sup>.

At each analysis moment, efforts were made to incessantly question the descriptions obtained in the statements regarding existing with cancer, aiming to understand the phenomenon. The comprehensive analysis of the statements made it possible to discover some aspects of being-with-cancer, according to the meanings attributed by oncological patients, which appointed the essence of experiencing this situation.

Phenomenology, as the theoretical-methodological framework, made it possible to obtain experiences of the Beings with cancer. It was possible to understand them in their existential sense of being-in-the-world-with-others, in order to apprehend the essence of their existence with cancer, with their own experiences, meaning attributions and world perspectives as starting points.

As a philosophical movement, phenomenology is one of the main thought lines in the 20<sup>th</sup> century, which appeared from the conceptions of Edmund Husserl (1859-1938) and was developed mainly in France and Germany, by his followers<sup>(11)</sup>. Husserl proposed, through phenomenology, the "return to the same things", the analysis of essences, understood as ideal units of meaning, elements that constitute the meaning of their experience<sup>(11)</sup>.

In the present study, the statements clearly pointed to the issue of human existence, to further perspectives or life projects, redimensioning existence, and, especially, to the finitude issue. These dimensions recall the philosophical thought of Martin Heidegger, since they incessantly question the issue of the Being and deal, fundamentally, with the issue of human finitude.

Heidegger considers man as being-there or *Dasein*, which means a being in the world, being with oneself and with others, who search for their own truth through self-interrogation. According to this framework, a Being can only be determined based on its own meaning, that is, it is only possible to understand the Being in the context of its own world, its own experiences<sup>(12)</sup>.

Besides the characteristic of being-in-the-world, the being-there is a being-toward-death. Existence is not given to man as a well arranged pathway in which death is at the end. Rather, death, as a possibility, can run across man's existence at any moment. Death is understood as an inalienable possibility of no longer being able to be present, an ontological possibility that *Dasein* has to assume; with death, the being-there completes its course. Hence, dying is not an event; it is a phenomenon to be understood existentially<sup>(12)</sup>.

These considerations, understood as Heidegger's main thoughts, permeated the thought lines followed during the analysis of this study. With phenomenology as the theoretical-methodological framework, the analysis was organized in thematic categories. Some of the revelations identified in this study are presented below, using fictitious names.

## COMPREHENSIVE ANALYSIS

### Changes due to existing with cancer

Changes in life habits and the need to stop doing pleasant things are highlighted as difficulties in existing with cancer. Patients report that their activities are now restricted to home or hospital, expressing their exclusion from social life: *You feel sad because you can't share, go out with friends, you can't play soccer. You can't go to the movies because of the commotion, and when you go to the mall, you wear a mask or your hair is falling out. (Rodrigo); It is hard to answer this question, there are lots of things that happen to us after the disease appears and changes everything, you know?*

*My life changed a lot, I had to quit school [...] I feel I miss my former life, I don't feel this is me, it is like I started another life after cancer, a more difficult, more painful life. (Roberta)*

These changes make the situation lived by Beings with cancer more difficult, and intensify feelings of anguish and uncertainty regarding their possibilities as Beings. These feelings are associated with the human condition of "being-cast" in the world, a form of being that refers to their own existential possibilities<sup>(12)</sup>.

Changes in body image are reported as one of the major difficulties faced by people with cancer. Patients report embarrassing situations, saying it is difficult to live with the changes experienced during treatment: *Now, living with this disease is very difficult [...] I had a colostomy and had to start using a bag. I was embarrassed, I'd never thought, I had suffered so much already and now I had to use this bag. But then, slowly, you start adjusting. It isn't easy, we can tell the truth, right? It isn't easy. (Luís)*

Another highlighted aspect was the discrimination due to people's lack of information regarding cancer etiology, its common clinical manifestations and side effects of treatment. Some patients report psychological and social sufferings due to prejudice and indifference: *I feel that people look at me with indifference, like at school there was a rumor that I had AIDS. My hair was falling out and I had lost a lot of weight. [...] People look at you differently; they think it's a contagious disease. Once I went to the mall and sat at a table, in the food court, near two girls. My hair was short and I was wearing a mask, so I was sitting there and they started staring at me, then they changed tables. (Rodrigo); Now, one thing we question a lot is discrimination, you arrive at places and people move away, you wear your mask, so they think you've had your teeth removed. When you don't have hair and you wear a handkerchief, many friends move away, so it gets really complicated. Usually, this discrimination still happens, until today. (Cristiana)*

Cancer has always been perceived as something embarrassing, contagious and incurable; an illness traditionally relegated by society<sup>(13)</sup>. Cancer can significantly affect one's self-perception, behavior and social relationships. In most cases, people start being treated differently after their diagnosis.

Social life is important for human beings. This evokes the Heideggerian comprehension that the being-there is a being-with, so it is impossible to separate Beings from those with whom they keep social relationships. The being-with is an existential characteristic of the being-there, since it is impossible for man to exist alone in the world and not establish relationships with others<sup>(4)</sup>. Patients report that

situations like suffering due to illness, self-care deficit and depending on others to perform daily activities cause feelings of insufficiency and inferiority: *I have faith that one day I will get cured and get back to my activities, be a real man again because now I don't feel like a complete man. Sometimes, there are days I get so sick that I need my wife's help to turn in bed. The disease makes us more and more debilitated, but I'll soon recover (Carlos); But for me it has been very complicated to deal with this disease, you know? It's hard to have cancer, you feel inferior, like life is really ending (Marta).*

Among the changes experienced by cancer patients, the impossibility to work was reported as something that intimidates and excludes. Work is one of the ways in which humans express and identify themselves and become fulfilled as a being-in-the-world. Physical incapacity to perform daily work activities causes feelings that reduce the quality of their existence: *But I pray to God that soon He will cure me and I can go back to doing what I did before, because I had a dangerous job, but I liked it. (Carlos); My life changed a lot after this disease. Now, even if I get better I won't be able to work with the cattle like I did before. I'm recovering step by step, but I can't go back to working with the cattle like I did before. I'll have to change my life radically, I'll have to move to the city [...] and totally change the rhythm, right? I'll have to, I don't know, buy and sell clothes, because I don't have much education, right? I'll have to try to live some other way. (Eduardo)*

Besides the lack of personal fulfillment through work, financial difficulties due to being away from work worry people, especially during treatment, mainly those whose families financially depend on them: *It is really hard not to work knowing that your children need your support. It's a good thing my wife also helps at home, she works in the clothing industry, the wage is low, but it helps. (Paulo); I'm not working and at home nobody works, nobody is employed, we live with a very low income. Actually, if I found someone to help me get retired it would be really nice. What makes it difficult is that I need to work and I can't [...] There's no way I can work, I lost my appetite, I feel weak, even pain sometimes. (Luís)*

In a capitalist society, the inability to work, provide for one's own needs and keep one's family in good financial conditions makes humans feel disposable, a dependant-being with no autonomy, a body that no longer meets the productive demands of a consumerist society<sup>(14)</sup>.

Existing with cancer: experiencing fear and suffering

Patients' statements regarding their existence with the disease show the suffering it causes. Becoming

closer with these people permitted understanding that the disease causes repercussions in Beings' lives as a whole, and not only regarding their being-ill. Experiencing fear and suffering becomes part of their human existence, and impairments due to the disease become, over time, more often and disabling.

One of the major fears and difficulties cancer patients face is the experience of physical pain. Beings with cancer recall pain as something that causes much physical suffering and that can cause situations of extreme psychological imbalance, which could even lead to suicide: *In the beginning my leg hurt too much, and I took medication and it wouldn't help. So I would just stay in bed, come to the hospital and go back, used a wheel chair [...] It was when my knee hurt so much that I jumped (attempted suicide) because the knee hurt just too much, you know? I would bang my head on the floor, bang hard, because of my knee pain, it really hurt, you could see my knee swelling, as if it would explode inside me (Gabriela).*

Suicide attempts reveal the inability of Beings to bear the overload of living with such a serious and disabling health problem. Suicide is one of the main causes of death among young adults, and though it is studied all over the world, it still remains a major enigma for sciences that study human behavior. However, from the Heideggerian perspective, it is *Dasein's* wish to no longer be there-in-the-world, and this understanding can be a way of rebuilding and redimensioning their existential perspectives<sup>(15)</sup>.

In several cases, the proposed cancer treatment procedures become aggressive and cause organic side effects. Patients recall chemotherapy as a difficult treatment, due to the side effects caused by chemotherapeutic agents: *Because before chemotherapy, I felt OK, I only had joint pain. After I started chemotherapy, I started feeling really sick, I felt pain, fatigue, tiredness, I felt a little rejected because I couldn't have visitors because the doctor did not allow me to have visitors at home (Rodrigo); Now the hardest thing is chemotherapy, in the beginning, the first times, fourth session I think, I thought of giving up. I thought I wouldn't handle it, that I would die if I continued (Marta).*

While they acknowledge and suffer due to the side effects of treatment, patients emphasize the importance of chemotherapy in their quest to become again a Being without the disease<sup>(16)</sup>. The following statements express patients' awareness regarding the need for chemotherapy: *[...] In this final session I'm feeling a little better, I took some medication for stomach sickness and I didn't vomit so much. My appetite is still bad and I don't like to*

*eat anything, I have lost all the pleasure regarding food. I used to eat well, but chemotherapy really wears you out. But you have to do it, right, there is no other resource (Roberta); Sometimes I worry about these reactions, afraid I might have to quit the treatment, so I try hard not to be sick. Because I know that, if I stop, it can mean I'll die because of this disease and I really don't want to die (Luis).*

Many chemotherapeutic agents cause a cytotoxic effect on hair bulb cells, which affects their rapid proliferation and partially or totally inhibits their metabolism and mitotic activity, which weakens and causes hair loss<sup>(17)</sup>.

Hair loss was reported as one of the most relevant side effects in terms of the impact of treatment in patients' lives. Their self-perception is that of an ugly person, different from the one that existed before the disease, and one that does not meet social beauty standards, causing significant psychological and social repercussions in the life of beings-with cancer going through chemotherapy: *The hardest part is the hair because you feel embarrassed around other people, I had really long hair, it was beautiful and now it is short and thin. I sometimes stop chemotherapy and it starts growing, but soon I go back and it falls out again. I know it isn't important considering the seriousness of the disease, but it's something that troubles me, makes me feel ugly, embarrassed, upset (Roberta).*

Though it is not a clinically significant side effect, some patients consider chemotherapy-induced hair loss as one of the most devastating side effects of treatment. Alopecia can have negative effects on one's body image, causing much suffering and changing interpersonal relationships and social life as a whole<sup>(16-17)</sup>.

The feeling of fear toward death is experienced at the moment of diagnosis and accompanies beings-with-cancer throughout their coping with the disease. Death is the most frightening fact in life, which no one can control or predict<sup>(12)</sup>. In the present study, the fear of death was reported by people who were unable to make life projects like seeing their children grow, meeting their grandchildren and enjoying their retirement. Some statements explicitly presented the fear of death: *I had depression before, but it got worse after I was diagnosed with cancer... because then you feel the threat of dying, so it worsens. You think that cancer and death are the same, I thought that way, even some health professionals think that way (Gabriela); But I'm still afraid, I'm afraid of the transplant, because I've been through it and it was the worst part of the treatment.*

[...] *At the moment of bone marrow infusion, I kept thinking: my God, am I dying today? (Cristiana); But I knew that I needed to operate, so I thought: either I loose a part of me or I loose my life, because cancer really kills you if you don't treat it [...] I'm not ready for death, you know? I'm afraid of dying because I don't think it's time. I don't have any grandchildren yet and I really want to meet my grandchildren (Lúcia).*

From the fundamental constitution of *Dasein*, the death phenomenon is revealed as a being-towards-the-end. It is an ontological possibility that *Dasein* has to assume, configuring it as a possibility of no longer being able to be present<sup>(12)</sup>. In this sense, the death phenomenon is no longer seen as a mere end or disappearance; it assumes its human existential characteristics.

Despite the advancements in cancer treatment, patients report that the fear of recurrence is something that worries and causes suffering. Anguish is associated with the fear of the disease returning and causing death, and is characterized by not knowing what is feared or causes that anguish. With anguish, what threatens the *Dasein* or the Being's existence is something that is nowhere, is unfamiliar with their everyday life, and is unexpected<sup>(12)</sup>.

The fragility due to the possibility of relapses causes moments of much anxiety. Some statements show those feelings: *But what can I do? I know I have to go on or I'll die, this disease will take me. That's why I continue. [...] I really wish to see them married, with children, but I'm afraid that won't happen. I know that even treating it, the disease can return, so I'm scared (Marta); The most difficult thing of this disease is not knowing when you'll get rid of it or if it will return. This fear of returning is difficult, It worries us a lot (Paulo).*

Important thoughts regarding Being-ill recall that the disease causes an aggression, a solution of continuity between the former and the present living, making the future uncertain<sup>(18)</sup>. This uncertainty is part of everyday life and worries especially those who are ill with a serious disease like cancer. There is a present fear of no longer living like they used to or of not overcoming this moment, which causes feelings that reduce the existential quality of Being of people with cancer.

When health professionals live with these people and come closer to these feelings, they should recover the original meaning of health care, a way-of-being with solicitude, which permits sharing experiences and clarifying patients' doubts and uncertainties, when possible.

## FINAL CONSIDERATIONS

According to the Heideggerian framework, man is the only being capable of reflecting on and questioning his Being. Men manifest themselves through speech; it is through their own statements that men reveal the meaning of human being and existing.

Though a difficult task, people who took part in this study agreed to describe the meanings they attribute to their disease situation. Hence, through their statements and non-verbal communication, they co-participated and allowed for a better understanding of the phenomenon *existing with cancer*.

As soon as Beings face the reality of existing with a serious disease, several existential projects tend to be annulled or changed by the experienced situation. Everyday activities become compromised and physical impediments cause significant changes, which can lead to dependence in several aspects. The present study showed that, from a new perspective, Being ill with cancer promotes a new direction to one's life; however, those changes are not easy or wanted by the Being.

The present study permitted to better understand the life-world of cancer patients. A fact that called special attention was that, during the study, patients reported being discriminated against. It was observed that cancer, as a reality, can affect one's self-perception and behavior regarding one's social relationships.

Besides the numerous sufferings caused by the disease, the stigma that still involves cancer is responsible for the continuing prejudice that increases suffering and intensively exhausts humans.

Despite the advancements in cancer treatment, it was observed that the fear of death accompanies patients when coping with the disease. Moreover, the possibility of recurrences was highlighted in the statements as something that worries and causes suffering. Anguish is associated with the fear of the disease returning and causing death.

Considering the presuppositions regarding human complexity and subjectivity of the disease-health process, it is believed that this study made it possible to reveal some aspects of the Beings with cancer, including their fears and existential perspectives. This permitted the development of a reflexive posture in health care professionals. Moreover, it collaborates with the integrality of care

offered to oncological patients, by recovering the authentic meaning of health care actions.

The comprehension of what cancer patients experience indicates the need to discuss feelings, share pains, sorrows and preoccupations, relieve tensions caused by a situation filled with uncertainty and fear. Caring for people with cancer implies developing the sensitivity to perceive patients and consider their fragility as people aware of their

situation and who need specific care in terms of their existential domain, and not only their physical body.

Health care professionals need to take responsibility for care with solicitude, guided by consideration and patience, and founded on these two words' sense of temporality. Consideration refers to the solicit experience looking at the past, at former experiences, and patience is the solicit experience looking towards the future, to what is yet to come.

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