

**The presence of the family in the existential outlook of cancer patients:  
understanding the phenomenon in the light of Heidegger**

**Presença familiar no olhar existencial da pessoa com câncer:  
compreendendo o fenômeno à luz heideggeriana**

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#### ABSTRACT

The objective of this study was to understand how people with cancer perceive the presence or absence of relatives while undergoing treatment away from home. A Heideggerian phenomenological research was conducted with 11 people undergoing antineoplastic treatment and lodged in a support house. Data were collected between June and September 2013, by means of in-depth interviews. The following ontological themes were originated: strengthening relationships with the family presence, recognizing the need for family presence and revealing the importance of treatment companions in the family absence. The study revealed that people with cancer recognize that the presence of relatives eases the situation experienced, since they authentically embrace and provide them with more intimate care. In conclusion, the family presence reduces the distance from home and improves the coping with the disease. In the absence of relatives, patients find support and comfort in companions from the support house.

**Descriptors:** Família; Caregivers; Neoplasms; Social Support; Nursing.

#### RESUMO

Objetivou-se compreender como a pessoa com câncer percebe a presença ou a ausência do familiar enquanto realiza tratamento longe do lar. Pesquisa fenomenológica heideggeriana, realizada com 11 pessoas em tratamento antineoplásico, hospedadas em uma casa de apoio. Os dados foram coletados no período de junho a setembro de 2013, por meio de entrevistas em profundidade. As temáticas ontológicas suscitadas foram: estreitando laços com a presença familiar, reconhecendo a necessidade da presença familiar e revelando a importância dos companheiros de tratamento na ausência familiar. O estudo desvelou que as pessoas com câncer reconhecem que a presença de seus familiares ameniza a situação vivenciada, pois estes, de maneira autêntica, as acolhem e lhes prestam os mais íntimos cuidados. Concluiu-se que a presença familiar diminui a distância do lar e melhora o enfrentamento da doença. Na ausência dos familiares, os pacientes encontram, nos companheiros da casa de apoio, amparo e conforto.

**Descritores:** Família; Cuidadores; Neoplasias; Apoio Social; Enfermagem.

## INTRODUCTION

Cancer represents an enormous challenge for health care, as it involves important changes in the lifestyle of affected individuals and in society at large, and imposes significant financial and other expenditures and emotional overload on patients and their family members<sup>(1)</sup>. These cause cancer patients to experience feelings of suffering and anguish that affect them in all dimensions as human beings<sup>(2)</sup>. In view of such evidence, attention is given to the psychosocial aspects of cancer and their effects on individuals, which are as important as treatment of the disease itself.

Progress with respect to antineoplastic therapies creates different perspectives for individuals with cancer, who currently have the possibility of being treated with new therapeutic options and systemic approaches to improve their survival<sup>(1,3)</sup>. However, this new situation does not eliminate the anxieties and fears experienced in different phases of the disease, especially during the search for treatment and care<sup>(4)</sup>. It is precisely at these times that families and healthcare teams start to play a determining role in the lives of those with cancer, as their support and help are, many times, the only resources available to these individuals in difficult times<sup>(5)</sup>.

In some cases, people suffering from cancer need to move to another town to undergo antineoplastic treatment and, often enough, they cannot count on the company of loved ones. In these situations, they go through subjective temporality, which is translated into vivid feelings of being away from their loved ones<sup>(6)</sup>. In addition, great distances from the locations of treatments can be a barrier to compliance of patients with antineoplastic therapies, which is why the creation and implementation of strategies to favor the continuity of treatment<sup>(7)</sup> are required. It is in this context that the preservation of support homes in reference areas for oncological treatment deserves attention and incentives. For this type of care, support homes may make it possible for countless people to be given continuity in their treatments and go through these difficult times more

smoothly, especially when family members are allowed to remain with their sick loved ones.

In view of the changes caused by cancer, nurses need to know the interactions and bonds that are formed between family members and patients in order to become increasingly effective in providing support to both and strengthen the possibilities of care, because most of the time, while away from their families, sick patients go through increased suffering and anxiety, which causes family members<sup>(8)</sup> to feel helpless. Thus, having cancer leads to a yearning for distinct and personalized care, with space for sharing feelings and emotional support<sup>(9)</sup>. In this sense, the importance of the presence of families to provide companionship and care for cancer patients needs to be emphasized, as family members can be allies in helping to keep positive feelings and improve the quality of assistance<sup>(10)</sup>.

Based on these facts and field observations of practice with cancer patients who are treated away from their homes, the question arises: What is the meaning for cancer patients of the presence or absence of family members during treatment away from their homes? This concern is justified by the need for healthcare professionals to acknowledge what people with cancer believe to be important during therapies; this way, they can provide assistance based on what they heard and understood about the actual demands of their patients<sup>(11)</sup>.

Thus, the purpose of this study was to understand how people with cancer perceive the presence or absence of family members while receiving treatment away from home.

## METHODOLOGY

This study is based on Martin Heidegger's existential phenomenology. This approach enables reflection and better quality in nursing assistance, because by means of phenomenological investigation, the needs of cancer patients may become widely known, and, therefore, open up new ways to provide care<sup>(12)</sup>.

The study was developed with individuals housed in a support home in the northwest region of the Brazilian state of Paraná who were undergoing antineoplastic treatment. The home is a not-for-profit charitable social entity that provides support to residents of other towns included in the 15<sup>th</sup> Regional Health Administration of the state of Paraná who are undergoing radiology or chemotherapy treatment in the town where the Regional Health Administration is located. The entity offers cancer patients housing, transportation, food and entertainment during the course of treatment in order to promote quality of life and prevent complications. The institution has a vehicle to transport patients to the treatment location.

For inclusion criteria, the subjects had to have completed at least half the treatment, which gave them a feeling for the presence or absence of family members on a routine basis while being treated away from home.

The interviews were conducted during visits to the support home on various days and at various times from June to September 2013. Two researchers visited, and one interviewed patients while the other interacted with family members and other people in the facility. The intent of this behavior was to ensure greater freedom for the subjects and greater honesty in their answers to the main question: How do you feel about the presence or absence of a family member while you are being treated away from home? They also used a semi-structured script with socio-demographic data to characterize the subjects of the study.

Data analysis was done in concert with the interviews. New participants stopped being added to the study when the phenomenon was revealed, the concerns of the researchers were answered, and the objectives of the study were attained. The interviews were transcribed in full, with later attentive readings in order to separate the parts or units of meaning that were shown to be essential to the meaning given by the subjects. Later, the units of meaning for each testimony were analyzed, and

phenomenological sorting of language for each subject<sup>(13)</sup> was performed.

As a result of this process, the following ontological themes came up: “narrowing bonds with the presence of the family,” “acknowledging the need for the presence of the family,” and “revealing the importance of other patients under treatment in the absence of family.” The discussion was based on Heidegger and other authors working on the theme.

As this was research with human beings, the ethical aspects outlined by Resolution 466/2012 of the National Health Council – Ministry of Health were observed, with the approval of the Permanent Ethics Committee on Research with Human Beings of the State University of Maringá in Legal Opinion No. 448.228/2013. Participation in the study only occurred after the signature of two copies of the Free and Informed Consent form, and the anonymity of the participants was ensured. Their names were replaced by a letter code followed by a number indicating the order of the interview, by the letters F or M indicating gender, and a last number indicating the age of the participants (E-1, gender, age; E-2, gender, age; E-3, gender, age...).

## RESULTS

The 11 participants in the study were between 40 and 96 years old; seven were female; seven were married, two were widowers and two were separated. All had children; however, two lived alone, three lived only with spouses, four lived with spouses and children, and two lived only with children. Regarding schooling, one was illiterate, eight completed basic primary education, one completed high school, and one had an incomplete college education.

During follow-up for antineoplastic treatment away from home, while staying in the support home, three had the company of their children, one had children and a daughter-in-law, three had a spouse, and four did not have family members there.

Below are the perceptions with regard to the presence or absence of family members when undergoing treatment away from home, based on the language of the 11 subjects.

### **Narrowing bonds with the presence of the family**

Among the subjects who had the presence of family members during antineoplastic treatment away from home, the pleasure of having someone from the family by their side during this process became clear, as it brought about positive feelings, and allowed the inference that affection and attention devoted to the patient contributed to their well-being.

*[...] You see the family members all there together with me, guarding me, taking care of me, taking good care, as if I were a newborn child there, pampered like this [...] when we receive care from the family it is the sweetest thing there is. [...] Very sweet. Real sweet. Very good. [...] In every little corner I have one there, listening to the old lady. This old lady here. It is my daughter, very good. I think the best thing in the world is the attention to the person. The person who receives the attention of others, he or she is a happy person. [...] I am a very happy person, thank God. [...] They all gather together, all my children, my grandchildren, my daughters-in-law, my great grandchildren, everyone, the whole family. It is the best thing there is. The very best. Oh my. It is too good, girl! Very good (E-1, F, 75).*

*It is very nice indeed, my niece takes good care, thank God. She is a daughter really, as I only have one, so, with her, I have two, the daughters that I have (E-2, F, 68).*

In even deeper bonds, the formation of relationships of complicity and intimacy was found, and it was established by care provided for the disease and the treatment, as well as closeness that was intensified by being away from home.

*[...] It is essential to me, there is no other way that I can explain, because to be with a stranger, I was never company for anyone, and I don't know how I would feel. It is me and my wife and that's it. Therefore, it is family, above all, to me it is family. So I have the company of my wife, 38 years married and I feel well, that is what gives me strength [...] it is essential, because I feel anchored, you understand. It is too much. I don't know if you want something else, another type of explanation, because how can I express myself, hum... We feel... We are already away from home, we are already with this little one... Because to me it is a problem, so we, both of us, I think we make one, me and my companion we are one, she already knows by heart what I need, and sometimes I don't even have to ask, she already knows the time for medication, all that, how I like to have my bath, how I behave, the clothes I like to wear, loose clothes, you understand? I think it would be difficult to find someone outside the family to perform this same role. It is quite hard. (E-3, M, 72)*

### **Acknowledging the need for family presence**

Cancer patients face many limitations caused by the disease. Family presence at this time is acknowledged by individuals to be necessary support when facing difficulties.

*[...] I think it is wonderful for us to have family here, we need everything, as we are sick we don't get to decide anything, right? I think it is good for me and it is good for my whole family, I feel calm, you know, I feel safe. I think it is right. For me, it's good, it's good good company, there is trust, I am glad. I hope everyone who is sick is happy, the same way, with family (E-4, F, 96).*

*[...] With someone from my family, who is my wife, I feel I am home. Because here is home to me. Here I have everything, and the people are very fond of me. Yes, I can't take anything from it, everything I have is theirs, and what is theirs is mine, they eat there, and I am not there at the table because of the hand, because with only one hand I*

*can't do it, the woman (wife) brings my food, eats here, brings water, leaves it there, gets the chair, and I like it here, and I feel calm, I get here, it's other air. Then it is family that we have. I feel accomplished, if that is the case, I have nobody unless I have her here. There are my children, the relatives, but a relative is never like family [...] it was hard for me to go to the bathroom and, here, my wife helps, then I go slowly, slowly, sit on the chair, take off the diaper there, put it in the basket, then I go to the bathroom and, when I'm done, she goes there, lifts me up from the chair, helps me put soap on, then she dries me, she leaves me all dried up, and then she changes me, and that's all. And the advantage is that I have her [...]* (E-5, M, 58)

There were also manifestations of gratitude and contentment about the presence of family members, for having support in the various limitations that patients start to experience, be they making decisions, routine aspects and basic daily treatment, or even staying in the support home to undergo treatment. Acknowledgement of the need for this presence can be even greater when sick patients associate family dependence with continuation of their lives:

*[...] Thank God, everything is very well, because if it weren't for her (daughter), alone, here, I could not stay, I might have "already travelled to Japan"... But thank God, I'm living yet another day because of her, and thank God, because if it were up to the others (his children), I would not still be here. [...] and thanks to the one who is with me, thank God, for what she is going through with me, I am feeling very well* (E-6, M, 71).

*[...] Thank God I feel very happy, [...] because I am away from my family and from my home, so there's my daughter here who is taking care of me, thank God. If it weren't for them, I would not be here. If it weren't for them, I would "have already gone below the ground". That is why I say that I feel happy, I feel glad, because my children are with me* (E-7, M, 63).

### **Revealing the importance of other patients under treatment in the absence of family**

In the absence of family members, the sick patients in the support home unite, helping each other, which creates friendships that minimize the fact that they are away from home.

*[...] Ah, to be away from home is bad, but we get used to everything in life, don't we? Now, to be like this alone, I am only alone when I am in my room, but not having someone from my family I think it is a bit bad, not to have anyone to talk to, but I'm glad that I have my friends who are in the other rooms. So, moving on! We get used to it, I'm already used to this battle* (E-8, F, 43).

Even those who said that they were used to the solitude, and claimed to have no problem with it, revealed that they liked the presence of their friends from the support home.

*[...] Here, to me, I feel like home. We have neighbors here and I feel very well, thank God. We are away from home, but what are you going to do? You have to conform, and we get along very well here. There are the girls here that are very sweet. And I was alone here, and then she said: 'no, turn off the TV here, and go watch it in the living room, there's a big TV there, come watch the TV here.' I was quiet here, I was alone. But I am used to being alone, but the ones who are not used to this miss it a lot; I don't. It is better to have someone, but if you don't... I have nothing to complain about, I am used to being alone, so. But there is one here who says that she misses home, her husband and her children, poor thing. Because she left a child, but I told her: think that we are together here to give you strength. But she likes it here* (E-9, F, 68).

*[...] No way, because back home I'm alone too, alone and with God. So, there's nobody. I come here and that's it, but here it is even better, I have friends here, then it is very good. You see, I was sleeping till now, just like at home. To me, there is no difference* (E-10, F, 60).

In another report, the subject revealed that, in addition to not having the presence of family during her stay in the support home, she also did not have a relationship with any other patient at the institution to help with the anguish of the time that she was going through, as there was no one else staying at the house at that time. However, she showed a desire to have someone to keep her company and provide her with moments of distraction.

*[...] To me, I miss it, I think it would mean a lot to have someone here with me, if I could have someone, if I could have someone to be with me, but, as I don't, we are alone, but I think it would help a lot. To have companionship, to have someone to talk to, at night, I wouldn't feel so alone, and then sometimes the little times that we have, to go out a bit, distract ourselves a bit. I think it would be very significant to have someone here too. If it is possible, who has it, I think it... would be good (E-11, F, 40).*

## DISCUSSION

*Dasein* (there being) is being-in-the-world by means of living-in-the-world, as individuals are not simply launched into a physical space<sup>(14)</sup>. Being-in-the-world is a condition closely related to being-with-others, because individuals are close to the beings with whom they share the world around them, and even if they are alone in their surroundings, being-in is an ontological characteristic of being-in-the-world<sup>(15)</sup>. Therefore, family members, as being-in-the-world of individuals with cancer, relate in a way as to being-in with sick family members.

In these circumstances, it is necessary to consider that, in Heidegger's analytic, being-in is manifested in two distinct ways, occupation and preoccupation. In occupation, individuals are guided by indifference and negligence when dealing with other beings around them; whereas, in preoccupation, they establish the mode of correlation and, by ontical/ontological privilege, it becomes being-with-others in an authentic way<sup>(16)</sup>. In this way of thinking, from the language used by the subjects,

it could be noted that family members, in their way of being, are revealed as authentic caregivers while they take over and share with loved beings the facticity of the cancer treatment in order to minimize suffering.

Regarding this issue, the attention given by family members by means of listening and being complicit with sick patients is understood as solicitude, which is an existential characteristic of humans in their being-in-the-world<sup>(14)</sup>. When family members perform the roles of caring for their sick loved beings, they do so as a means of retribution and, often, while providing for this care, they minimize their own anguish and suffering in view of the situation experienced by sick family members<sup>(17)</sup>. This concern is recognized in the speech of E-4, who noted that presence of family was something beneficial not only for him, but was also something that contributed to the well-being of all who were involved in the care.

By means of affection, human beings open up and let other beings come to them, which creates the possibility of being able to touch and be touched. Thus, when taking over feeding and dressing sick family members, a concern<sup>(14)</sup> is revealed. These aspects are revealed in the language of the subjects who were interviewed, as they explained the support and affection given by family members at such a difficult time in their lives.

It transmits safety and solidarity when families are able to accompany sick patients for medical appointments and office-based procedures, besides providing basic care with food and hygiene<sup>(8)</sup>. It is reiterated that, in view of the family presence, sick patients feel less uncomfortable when they receive the care of close, loved beings, and they express gratitude, especially when they are faced with the possibility of death, which is the case for most patients undergoing antineoplastic treatment<sup>(18)</sup>.

Humans are beings-in-the-world who always exist in relation to something or someone else; in this state, they understand their experiences, establish the meaning of objects and beings in their world, and give meaning to their existence<sup>(14)</sup>. In this sense, being-in-the world analysis must take into consideration the whole historical,

social and individual context experienced by individuals, which influences their way of interacting and relating to the world<sup>(19)</sup>.

When beings live the disease, but have someone close by whom they can trust and share their feelings with, they feel safe and are better able to face the difficulties of treatment<sup>(12)</sup>. On the other hand, if they have to face, alone and distant from their families, treatment riddled with vicissitudes, they feel lost in the world. In the excerpt from E-11, one can notice the feeling of solitude she expressed in view of the absence of a family member who could provide support, affection and, in particular, company in view of the facticity.

In this light, not only people, but also the structure of the house contribute to the well-being of cancer patients. Utensils and objects are do not merely exist, they are also available for certain uses, as something that human beings make use of to live in the world<sup>(14)</sup>. The manner in which beings-in-the-world discover and relate to utensils is given by occupation, mediated by their handling and use<sup>(20)</sup>. It is worth mentioning that, in the case of E-10, she felt like she was in her own house because she could sleep and feel comfortable. She occupied herself with a utensil that, just like at her home, contributed to her comfort.

In this sense, the provision of support homes in regions that are known for antineoplastic treatment deserves attention and incentives, because this type of care may allow countless people to continue their treatment and go through this time more smoothly, especially when they are able to be with family members.

In addition, cancer brings many transformations that affect family relationships; in addition to the suffering of family members who see that their loved ones are so fragile, patients themselves suffer an impact of the anguish of the ones close to them, which leads to a need to reorganize in order to meet new healthcare needs<sup>(17,21)</sup>. Therefore, interactions among family members must be considered in healthcare actions, as all parties influence the health and disease process<sup>(22)</sup>. The importance of this was clear in the language of the interviewed subjects who

were facing the challenge of fighting cancer, which was intensified by having to leave their homes in search of treatment. It was also found that the ability to be with their loved ones during their existential facticity, revealed the family members as authentic caregivers, passing on to sick patients shelter and the impression of not being-alone in their journey.

## FINAL CONSIDERATIONS

The study made it possible to understand that cancer patients who needed to move to get treatment away from their homes acknowledged the importance of having family at this time, and also expressed gratitude when they had loved ones with them during the difficulties of the disease and treatment. It became clear that attention received by family members allows reduction of the distance from home, which leads to less suffering when cancer patients face their journey. In addition, it was possible to acknowledge that, when family members cannot be present, the other patients in the support home, who are experiencing similar situations, are a source of support and comfort, showing solicitude in difficult times.

Therefore, by means of this study, it is possible to reiterate that support homes for cancer patients must shelter not only sick beings but also their families, who may contribute to the overall well-being of the subjects as a whole, and by having an extended outlook on the care, to being-in an authentic manner. Starting with this understanding by healthcare professionals, it is possible to promote more humanized assistance, based on solicitude and the needs of cancer patients who need to move from one place to another during their treatment.

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Received: 12/10/2013.

Accepted: 07/01/2014.

Published: 03/31/2015.