Significations of being the caregiver of the companion with cancer: an existential look

Significações de ser cuidadora do companheiro com câncer: um olhar existencial
Las significaciones de ser cuidadoras de sus compañeros con cáncer: una mirada existencial

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ABSTRACT

Objective: to unveil the significances of women who experience being the caregiver of their companion with cancer. Method: a Heidegger’s phenomenological research, performed with ten women who are caregivers of their companions with cancer in a town in the northwest of the state of Paraná, Brazil, from December 2013 to February 2014. The following guiding question was used: “How has it been for you to care for your companion with cancer?”. Results: from the analysis of the speeches the following ontological themes emerged: “Taking responsibility of caring for the companion with cancer”, “Learning to live with the intimacy changes” and “Learning to live with the feelings related to care”. The data revealed the wives’ sense of responsibilities for caring and the influence of feelings in the act of caring, including the impact on the couple’s intimacy. Conclusion: in the midst of difficulties, the feelings of affection are the driving force behind these women to continue their actions as wife-caregivers.

Key words: Neoplasia; Caregivers; Women; Nursing; Nursing Care.

RESUMO


Descritores: Neoplasia; Cuidadores; Mulheres; Enfermagem; Cuidados de Enfermagem.

RESUMEN

Objetivo: dar a conocer las significaciones de las mujeres que son cuidadoras de compañeros con cáncer. Método: estudio fenomenológico heideggeriano llevado a cabo con diez mujeres cuidadoras de compañeros con cáncer, en un municipio de la región noreste de Paraná, entre diciembre de 2013 hasta febrero de 2014. Se empleó la siguiente pregunta orientadora: “Para ti, ¿cómo está siendo el cuidado de un compañero con cáncer? Resultados: del análisis de los discursos surgieron los temas ontológicos: “Asumir la responsabilidad del cuidado del compañero con cáncer”, “Experimentar cambios en la intimidad con el compañero” y “Aprender a convivir con los sentimientos que involucran el cuidado”. Se desvelaron la toma de responsabilidades del cuidado por la esposa y la influencia de los sentimientos en el cuidado, afectando incluso en la intimidad.
INTRODUCTION

The increase in life expectancy in general has been reflecting in a higher incidence of chronic diseases, which contributes substantially to the intensification of care in the home environment. Among the diseases that bring greater physical and psychological repercussions, cancer stands out being a disease dreaded both by patients themselves and by their families, causing mixed feelings and meanings, reflecting in an existential redefinition of those who experience it.

The role of women as caregivers present itself with remarkable significance, since a woman, in addition to the care exercised in the home and with the family, is the main reference caregiver of sick people. In the same context, women are the majority of caregivers of patients with cancer, being the wives of these patients in most cases.

In this cancer experience, caregivers are faced with feelings of sadness, despair, fear and hopelessness, resulting even in depressive symptoms. We can also add the lack of preparation on the part of these caregivers, which goes beyond the psychological aspects, including insufficient knowledge about the disease, as well as caring for manifest symptoms and the difficulty in communication skills, factors that influence the act of caring.

The importance of such care repercussions on family and social contexts is enhanced to the extent that women themselves make reference to how much their lives changed after their involvement as caregivers to their companions. Thus, knowledge of the interactions between patients and their family caregiver, in this case their companion, is a necessity for the nursing staff so they are able to assess, plan and intervene, providing actions to improve the conditions of life and strengthen the relationships of care. Faced with this reality, the following restlessness arises: What is the significance attributed by the woman when faced with the care of her companion with cancer?

From this juncture, it is of fundamental importance to deepen the knowledge about this subject. Through understanding the meanings attributed by the female caregiver of their companion with cancer, regarding their function, it may be feasible to plan a nursing assistance care, to contribute to the care focused on those women who dedicate their lives to please others. Moreover, by offering assistance to those who exercise care, the patient facing cancer will benefit from this. Given the importance of this context, the interest of this study emerged, aiming to unveil the significances of a woman who experiences being the caregiver of a companion with cancer.

METHOD

This study can be characterized by being Heidegger’s existential phenomenologic in nature. From this phenomenological side, it is not limited to the pursuit of “what”, but rather the “how” of the object of research, paying attention to the possibility of their movements of veiling and/or disclosure.

In line with this thinking, the survey region, or the ontic-ontological region of the study, consisted in the significances of women when caring for their companion with cancer. Therefore, inclusion criteria elected women who cared for their companion for at least six months, having this level of dependency less than or equal to 40%, according to the Palliative Performance Scale (PPS), considering that, at this level of dependence, there is need of constant care, requiring more of the caregiver companion. Moreover, being registered in a philanthropic institution that provides support to cancer patients and their families, located in the northwest of the state of Paraná, Brazil. Exclusion criteria: being a caregiver of a patient with cancer, but not residing in the city where the institution is located or in a nearby metropolitan city.

This institution is a Non-Governmental Organization (NGO) that provides support to cancer patients and their families. It assists patients residing in the city of the institution, in the northwest region of the state of Paraná, registered to receive support through visits of volunteers, socio-educational group, psychological care, food basket, medicines not provided by the Brazilian Unified Health System (SUS), adult diapers, utensils and furniture donations. Moreover, it helps patients from other cities within the 15th Health Regional by offering lodging, food, transportation and other resources while they are undergoing treatment in the city of the NGOs. The choice is justified for ease of access to participants and also the receptivity they offer the institution, leaving them more comfortable to participate in the study.

The interaction moments with the participants took place between December 2013 and February 2014. The first contacts were developed through search entries in the database of the philanthropic institution, performed by random, and telephone contact with women that met the pre-established criteria, since such information was made available by the data of the register checked. After, approach visits were scheduled and they were invited to participate in the study. Subsequent meetings with the participants consisted of two to three visits to each woman, according to necessity. These had the objective of increasing the bond, knowing their life realities and realizing the apprehension of the phenomenon.

Therefore, to unveil the significances of the women who experience the researched phenomenon, we used the following guiding question: “How has it been, for you, to be the caregiver of your companion with cancer?” The interviews were conducted individually, in the home of these caregiver women, by an interviewer, in a private atmosphere without the presence of others, thereby minimizing any discomfort to the interviewee.
There were no refusals to participate and all interviews were recorded and stored by a digital recorder for later analysis.

The end of data collection took into account the sufficiency of significances, which is a determining factor in the closure of new additions and collections\(^9\), noting also that most of the research that are phenomenological in nature have about 10 to 20 participants\(^{11}\).

To understand the information in its fullness, expressed by the participants, two methodical moments were observed: in the first, vague understanding and median, when assumptions are eliminated, and, after listening and attentive reading of the statements, their meanings stand out, with a later time for analysis, seeking the essential structures that emerge and enable the understanding of the object of study; in the second methodical moment, the interpretive understanding, we sought to unveil the phenomenon, the sense of being, culminating in Heidegger’s hermeneutics\(^9\). Hence came the ontological themes, which were interpreted in the light of some Heideggerian ideas and authors that reference the philosopher, as well as researchers that deal with the theme of this study.

Since this is a research involving human beings, all ethical and legal precepts regulated by Resolution No. 466/2012 of the CNS – MS were followed. The institution consented and the study had the approval of the Standing Committee on Ethics in Research Involving Human Beings – COPEP – of the State University of Maringá. To ensure anonymity, the women were characterized according to names of biblical characters, who relate to some of their features and emphasized the faith unveiled by them in their experience as caregivers.

**RESULTS**

The results of this study presented the speeches of ten women who live the experience of being caregivers to their companion with cancer. The participants have insufficient family income to meet all the needs that come with the disease, requiring the need of aid, among other things, of basic food, medications and diet, from the nonprofit institution that is part of this study and in which they are registered. Among the caregivers, five were retired, two worked to help paying the home expanses and three quit their jobs to be able to provide care. All have children, but these are not directly involved with the care. As for the time dedicated to taking care of their husband, the period ranged from six months to one year and eight months. The age range of these caregivers varied between 24 to 71 years, six of which being over 55 years old.

Understanding the language of these wives showed the same responsibility they assume as primary caregivers, the change in the couple’s intimacy and feelings they need to face in the everyday care, presented through three ontological issues, as follows.

**Taking responsibility of being-with-the-other in cancer**

As the wife, the woman ends up being the primary caregiver and responsible person, almost exclusively, for monitoring all the coping trajectory of her companion’s disease, as demonstrated in the following speeches:

> [...] Because the one who helped more was me. For he has his own children, but they live separately. They only come from time to time. But who is living here with it all is me. I mean it is me [...] I always followed it closely. (Elisabeth)

> [...] There was an acquaintance of ours that was in the room with a broken leg and I’d say: I’m going to stop by home, can you check on my husband? I left the cell on his side, and if anything happened, he called me. I came and rested at home, when it hit six in the morning I came back, and stayed there all day. His sister, stayed only twice. The rest was me. Nobody stayed. I got very tired, but there was nothing to be done. (Sarah)

> [...] My daughter helped me in the hospital. But the rest was all me. At home, it’s me. I’m the one who take him to the doctor, go out to buy medicine, try to make the best food for him. [...] I even bought the equipment to make inhalation, pressure, thermometer, everything here, it was very complicated. At home, I took care and sometimes the girls from the clinic came. I was doing the dressing change, all the time, it had to be changed all the time because it didn’t stop. It was me. I put the towel, bed linen, but never won in the change. (Shunamite)

Also, the caregivers could not count with the constant support of the rest of the family members, due to appointments and daily tasks they have.

> [...] For me it was very difficult, my children all worked and I had no one to help me, only God. I had to do it all. I don’t even like to remember that time, you know. Because it was a very difficult thing, and me alone. There were days when the girls came here, but they did nothing, came and all was ready. Because all my girls worked and came after work. Sometimes a niece of his came, who is a nurse. She came here and sometimes when she arrived I had already done the dressings. Sometimes, she came and I didn’t have the time, and then she did it. (Jochebed)

> [...] Here is me and him practically alone. Because my daughter has her family. I can’t say no one came to rest with him in the room. My daughter came with me once. So I could sleep at home, because I have back problems and I was not holding on well, sleeping there. But she kept watch one night and I came to sleep at home. (Naomi)

In addition, the wife recognizes her role and understands that the companion prefers that she is the one to care for him, especially in those circumstances where privacy needs to be invaded.

> [...] Because as much as the kids take care is not like us. He is very ashamed, you know. When his nieces came to bandage him, he died of shame. He said: ‘No, I want my wife to do it’ he didn’t want his nieces to do it [...] He didn’t want to be with anyone. My daughter-in-law and my sister wanted to stay with him, but he didn’t want it. Since he didn’t want anyone to stay, I stayed. So I slept on the floor, I slept. Then when it was day, I left him here with the girls doing the things and I would say; now you stay here that I’m going home to wash some clothes. (Jochebed)
Learning to live with intimacy changes

Cancer brings with it emotional, behavioral, and physical changes that end up affecting the relationship between the couple. Changes in intimacy are highlighted by the wife, who even makes use of comparisons, when describing the distance as a couple, living with the disease.

[...] To summarize for you our relationship, I say that we are siblings. (Esther)

[...] Look, girl, he is very weak in sex, you know, we don’t have it, I’m not ashamed to say it, there isn’t that between us. I told him: I don’t know if I am your wife, your sister, or if I’m your friend, because I sleep here, right beside him, every day, every night, and the way I sleep, I wake. This got worse with the disease. We live for the sake of living. (Naomi)

This detachment also occurs through the very reactions that the companion has when she comes across instruments involving care, such as the colostomy bag and the tracheostomy of their companions.

[...] During the time he was really bad, I put a little mattress next to his bed. He was on the other bed and I had another little room. I put him here and I slept in the other bed. He sleeps in his bed and I sleep in mine, because I’m afraid of breaking that little bag of his and escape and get me dirty and it is a bad smell, you know, so I don’t like to sleep with him. So I sleep in my bed and he in his. (Jochebed)

[...] Sex? No way. There are times he even tries, but I reject it. [...] It’s not the same. I need nervous sometimes, I get tired, really tired. I lie down, I’m tired, and when I lay he puts his hand, then I shake it off. [...] I don’t think I’m a wife anymore. Because I don’t do anything anymore. Because there’s that hole there (tracheostomy), it has a lot of secretion, it’s disgusting. Forgiveness Lord! But it’s not that I want, not that I want! I ask God’s forgiveness all the time. (Hannah)

Beyond the situations when sexual intimacy is impaired, to the point that it almost does not exist, there is still the possibility of the couple meeting in dialogue to overcome the difficulties of the relationship.

[...] It was the most difficult period for me, he wanted to have relations with me, he couldn’t move or anything, we had to be helping. [...] It is difficult this issue of wife, he wanted every day, but that doesn’t work. Because the man doesn’t understand the woman’s part. One day it is in trouble, the other day it’s not. Because of the illness, one day there is pain, the other day there’s no pain. This has affected the relationship as a couple, affected it hard. He thought he was going to dump it all on me, you know? He thought that having relations every day, he would solve the case. So there are days when I talk to him, and it is fine. It didn’t work, we sit down to talk, to clarify. (Rebekah)

Even amid adjustments regarding intimacy, some wives manage to keep the feeling of closeness and affection.

[...] In the relationship, we even got more united, closer. But the sex business is over. We are like siblings. But it’s good. I think patience and coexistence help the couple a lot. I think so, especially respect. (Elisabeth)

The relationship as couple changed, the attention and bond remains the same, we had a good relationship, now, only the relationship is not having that [...] because he doesn’t have the conditions. What changed the most was just the sexual part, because the affective part remains the same. (Shunamite)

[...] For me not much has changed, no, sometimes we got like this, now he gets more nervous. But as a wife, is just like that, the more it’s the same. I think not much has changed, no. I could, yes, lead the situation at the same time, after he got problems there, we understand. You understand that the couple ends like that, one here, the other there. They have each other but, ah. (Dorcas)

Learning to be strong when facing the other’s frailty

In this care context emerge feelings that the caregiver has to deal with, when faced with situations of irritation and lack of control from her companion, when she tries to maintain emotional balance, patience and strength.

[...] He got nervous. He got very nervous and every little thing irritated him. In those times when he came back from the hospital, every little thing irritated him. It was too much for him. Anything that we said, wow. But I was patient, always had patience. There were times when I despaired, but I held myself back. But we always had, I think so, a lot of patience. If we don’t have patience, who will? You have to take care. (Dorcas)

[...] But you have to have a lot of faith because there are days when you think you won’t stand it! No way! Because he (husband), with this disease, also got really angry, nervous. You talk things, seems that they offend, you know? But you have to be patient. (Elisabeth)

[...] He said something to me and I didn’t understand then he got nervous. He got nervous about anything. He was going to do something and it didn’t work then he threw things. Punched, broke things. I said: no use you doing that, you won’t heal like that, and it will come out of your pocket to fix it. I started talking to him until he straightened out. I had a lot of patience, even I admire myself, I never had so much patience, I learned. (Ruth)

Faced with such situations, the wife often controls herself before the unpleasantness not to cause or aggravate the health status of her companion, even if this attitude impacts her emotionally.

[...] Our relationship is hard like that, because many things happen today in my marriage that I allow, I have to let it go. [...] Sometimes I feel the duty not to blame, not to judge, not to demand. Because of this situation he is in, you know. To avoid a fight, something he’ll be nervous about. During this period he has this disease should not be so, if he had
something, we should sit down and talk, but I feel trapped, you know, I can't express and I'm afraid of his reaction. I let a lot of it go. It's hurting me, you know, I'll continue to spare him, but it's still hurting me. (Esther)

[...] I drop what I’m doing and go there to help. He’s surly, pretty cranky, there are times that he says things that hurt the soul. But then I think: he’s old, he’s sick, I have to put up with it. Sometimes he starts to argue, to fight, and I avoided making him nervous. Maybe that ulcer bursts, right? I tried to appease the situation. So he’s my partner and I will fight for him until the end, may God give me strength to fight for him. (Naomi)

Beyond facing the feelings of the other, the women also experience situations that bring out their own feelings, and among them, there is a sense of acceptance of their reality.

[...] Between the couple, between husband, wife, all this, there’s complications, taking care of the husband and the children. So, life is not all roses, it has its thorns. Between me and him, its being so. One day he’s in a good mood, another day he’s not. We are living our life, it’s been two years like this. (Rebekah)

[...] Sometimes I get to thinking like this: wow, I’m so good and the person is like that. How can I speak, there’s no way to explain it. Unfair, it’s something like that. But as time passes by, you learn to live with it and see that is not all that, you get by. (Hannah)

DISCUSSION

The be-released is how the human being constitutes itself in the world through its opening process and, by constituting itself as a being opened to their own possibilities, the same projects to the ones around them[12]. In the presence of cancer in the family and living the reality of being the caregiver of her companion, the woman as a wife finds herself thrown to the need of taking this responsibility for herself.

This means that the being who falls ill is not isolated, living without others, because they are co-presences of being in the world[13]. The being-with-the-other in sickness can turn into a significant participation, when concern is expressed, i.e., caring for the other, being considerate and patient with him.

Thus, despite being overloaded and without the constant help of family members, the woman caregiver remains firm in her function, showing strength even amidst intense moments of wear. This reality is common, since, in about 60% of disease situations, the caregiver does not get help from her family to alleviate the burdens of care[10].

Despite such mishaps, by assuming responsibility for another’s care, the woman develops concern modes, in other words, authentically expresses the way of being-with, characteristic of Dasein[12]. The concern, however, can manifest itself in different ways: in a first expression, the one that cares withdraws the care of the other, replacing it, thus called dominating replacement. In this concern mode, the one who takes care takes the place of the other, the one being cared for may become dependent. On the other mode, the liberating fronting, the caregiver puts itself before the care, to return it as such, so that allows, in its existential possibility, the freedom for care[14]. This care provides room for the solicitude with the other, with it being the zeal expression of many of the women who care for their spouses with cancer.

Given this condition, where she was launched existentially, the wife also recognizes her importance, reinforcing her essential presence during the care, when often she comes to be irreplaceable. In this everyday with cancer, both must refrain from their own prejudices and values, aiming to strengthen the existing bonds and to find refuge that is conducive to coping with the disease[15]. Therefore, when the care is exercised by the wife, this assures the companion the opportunity to feel more comfortable in that it authentically demonstrates her desire to care.

Moreover, experiencing the care and the feelings that arise after the illness, the woman realizes such influence in the relationship with her companion, including the repercussions in the intimacy of the couple. Thus, some wives allude to a distancing, when they use the phrase “we are like brothers”. These changes may result from difficulties in accepting the disease, the intensity in the relationship between the roles of caregiver and the sick companion and even the fatigue caused by the moments of care[16].

Another aggravating factor in this distancing is the significance given by the wife regarding the innerworldly loved ones that invaded the space of the couple after the illness, limiting its proximity. This means that the use of a colostomy bag or a tracheostomy is permeated with meaning, in the sense that normality is ever present, thus changing the way of life with it, with others and with the world. Meanwhile, sexuality is a common limitation, since feelings of helplessness occur, as well as reduced self-esteem and concerns about the elimination of odor or feces during intimate moment of the couple[16].

Following Heidegger’s line of thinking, in its worldliness of the world, the human being can unfold in different ways and this disposition is presented through mood or emotional tone. This disposition, or humor, enables the loved ones to appear in different ways, both positive and useless or even threatening[17]. Given this thinking, we can observe in the words of Jochebed and Hannah an unveiling based on feelings of fear and disgust regarding the devices used by their companions, demonstrating how difficult it is for them to maintain close relationships with their companions in this moment of their lives. These dispositions are ontological characteristics to be launched into the world, where the being is at the mercy of possibilities, without being able to control them[12].

Regarding this issue, the emotional state is of great significance for the caregivers, since the act of taking care can lead them to most often develop anxiety and depressive disorders[18]. However, you can see how women, in spite of feeling “burdened” with “aggressive” behavior from their companion, can overcome this condition with a lot of dialogue and patience.

Philosophically, in its existence, the being exists already always ahead of himself, passing itself up, in other words, transcending. Thus, man anticipates himself, ensuring he overtakes the being itself[19]. In this context, we can distinguished also in the speeches that some women seek to anticipate their own possibilities, trying to cling to their situation, not with dismay, or

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sorrow, but with understanding of their existential conditions. This way, they overcome their own fears, manifesting their power of transcendence over the world and over themselves.

And, in this transcendence, some caregivers reveal in their speeches that, even without the close proximity, they overlap to such circumstances and the feelings of affection one for the other are valued by them, which minimizes the sexuality issues. Following this line of thinking, we can relate or translate them in the love, with this referred to as an expression of care: “Love [...] is the possibility of a relationship of the being-with, [...] as a possibility of the possibility of the relationship is the foundation of care” (18). We also know that, by becoming a caregiver, given the need to adapt and the insight on this new existential condition, women can overcome barriers and demonstrate dedication, sensitivity and willingness to help their sick companion (19). By understanding their role as caregiver as a holistic manifestation of the welfare of the other, the woman controls herself and lets their feelings be minimized so the care can be accomplished.

Through this tangle of feelings, women develop a patience unimaginable for many, by controlling their actions to avoid arguments or any situation that may worsen in some way, the well-being of their loved ones. This attitude of “avoiding” is adopted when faced with their companion’s reaction to the disease, when he decreases chances of conversations and negotiations (15) with his companion. However, the woman reveals herself to be impaired emotionally and, even so, takes care of the other in deference to herself. She shows herself once again as a being-with in the way she relates to, with her arranging her life to the available to care for her loved one (14).

Therefore, being the caregiver of the companion with cancer, the woman enters into a new existential reality that does not have easiness, specially so since the man’s care is differentiated by its own existential possibilities, permeated of masculinity, which ultimately influence their experience of the disease and also reflect in the care provided by the wife (19). Faced with this reality, she considers that the companion is like a being-in-the-world with cancer, seeing himself released in an unknown world, subject to expressing different feelings, which may be related to depression, isolation and anxiety (16).

This way, the caregiver can see the disease as an entity that affects the couple’s relationship or as the possibility of taking her power-being and transcending the factuality imposed by the disease. Considering such feelings and the effects thereof, beyond the severity of the cancer and its entrenched stigmas, one can see how this disease can influence the bonds, with two common situations, such as follows: their weakening or strengthening (19), as was presented in this study.

Because the situation experienced by these women, faced with numerous difficulties caused by caring for their companions, it is noteworthy still, that due to the physical and emotional burdens, they often require new significances in life, and, to this end, the support of the health team is crucial in this process, particularly from the nursing team, as a facilitator, who will provide knowledge and support for the caregiver (20).

This research allowed for an unveiling of the significances of women that care for their companions with cancer and considers it necessary to point out its limitations, which are related to the specificities of the participants, because they are the companions of the patient, and of its realities, with a focus on life experience and the home care. Thus, the results found should not be generalized, however, we believe that the data should be analyzed in order to support the assistance actions to this portion of the population, which also contributes to the care. So, we hope this research will encourage new questions that advance the knowledge of the themes presented here.

CONCLUSION

Through existential phenomenology, it was possible to glimpse the mishaps experienced by the women who are released before their existentiality, while caregivers of their companions with cancer, when experiencing this condition, in a deep and impactful way.

By embracing the care of a companion and experiencing cancer in their home, women find themselves in the face of changes in their dispositions, with the compromise of the intimacy of the couple and the need to deal with the feelings of their companion, as well as their own. However, in accepting their new existence status in the world, they transcend the vicissitudes and maintain feelings of affection for each other, thus, being driven to continue the condition of being-with the sick companion during his journey through the disease.

As health professionals, we can also be put before the need to monitor women in such circumstances of caregivers, so it is essential to understand the difficulties they face. Therefore, to the extent that actions are established based on such knowledge, it will be contributing to the minimization of impacts suffered throughout her role as a caregiver.

Faced with this reality, in which the woman is the protagonist caregiver, a critical reflection of the attention dedicated to this being falls to the nursing staff, as well as her importance in the context presented, not only to offer support for the continuity of the companion care, but also so she can maintain, even in the midst of difficulties, her own well-being.

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