

(Not) taking care of yourself as a woman while being a caregiver of a partner with cancer

O (des)cuidar-se como mulher ao ser cuidadora do companheiro com câncer

El (des)cuidarse como mujer al ser cuidadora del compañero con cáncer

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ABSTRACT

Objective: Unveiling the meaning of self-care as a caregiver of the partner suffering from cancer.

Method: Research based on Heidegger's phenomenology, performed with ten women caregivers of partners with cancer in a municipality in the northwestern region of Paraná, between December 2013 and February 2014.

Results: From the discourse analysis, the ontological themes emerged: "forgetting to be a woman to surrender to the care of the other and choosing the other to the detriment of themselves". It was evident that, when caring for their partners, they find it difficult to take care of themselves, both on women's issues that give them pleasure and also regarding their own health.

Conclusion: On this existential condition, the wives exercises care and spend a lot of time on it. They have to choose between the care of their partners and taking care of themselves. It should be underscored that nurses should develop specific activities with special reference to these women that dedicate so much to care-giving.

Keywords: Neoplasms. Caregivers. Self care. Nursing.

RESUMO

Objetivo: Desvelar o significado do cuidado de si frente à realidade de ser cuidadora do companheiro com câncer.

Método: Pesquisa fenomenológica heideggeriana, realizada com dez mulheres cuidadoras dos companheiros com câncer, em um município da região noroeste do Paraná, entre dezembro de 2013 a fevereiro de 2014.

Resultados: Da análise dos discursos, emergiram as temáticas ontológicas: esquecendo-se de ser mulher ao entregar-se ao cuidado do outro e escolhendo o outro em detrimento de si. Evidenciou-se que, ao cuidar do companheiro, apresentam dificuldades de cuidar de si, tanto nas questões femininas que lhe conferem prazer como na saúde.

Conclusão: Diante dessa condição existencial, a mulher exerce um cuidado que exige muito de seu tempo e, consequentemente necessita escolher entre o cuidado do companheiro ou de si. Assim, destaca-se a importância de se desenvolver ações específicas, atentando-se para as individualidades dessas mulheres que tanto se dedicam ao cuidado do outro.

Palavras-chave: Neoplasias. Cuidadores. Autocuidado. Enfermagem.

RESUMEN

Objetivo: Desvelar el significado del cuidado de sí misma frente a la realidad de ser cuidadora del compañero con cáncer.

Método: Investigación fenomenológica heideggeriana, realizada con diez mujeres cuidadoras del compañero con cáncer, en un municipio de la región noroeste de Paraná, entre diciembre de 2013 y febrero de 2014.

Resultados: Del análisis del discurso emergieron las temáticas ontológicas: "olvidarse de ser mujer al cuidar del otro" y "eligiendo al otro en detrimento de sí misma". Se evidenció que al cuidar al compañero presentan dificultades de cuidar de sí mismas, tanto en las cuestiones femeninas que le generan como en la salud.

Conclusión: Delante de esa condición existencial, la mujer ejerce un cuidado que exige mucho de su tiempo y, por ende, necesita elegir entre el cuidado del compañero o de sí misma. Así, se destaca la importancia de desarrollar acciones específicas, atentando a las individualidades de estas mujeres que tanto se dedican al cuidado.

Palabras clave: Neoplasias. Cuidadores. Autocuidado. Enfermería.

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■ INTRODUCTION

When experiencing cancer, relatives and the most direct caregiver face distinct moments that arise feelings and perceptions as the conception of the disease as incurable, dreaded, and all the uncertainties that are born since its diagnosis⁽¹⁾. Thus, having a beloved one affected by cancer brings repercussions to their relatives, and such changes reflect in the reorganization of life, especially, of the one who becomes the main caregiver⁽²⁾.

In this scenario in which the woman configures herself as a caregiver, especially when caring for the sick partner, the experiences of care can also be perceived as a possibility to re-significate her own life⁽³⁾. Thus, the woman caregiver (in most cases, the daughter or the wife) starts to use her time differently, dedicating an average of 18 hours daily to care, which may vary depending on the dependency of the person cared. It is worth mentioning that these women have their work and the care for their children as well⁽⁴⁾ and there are often the social weaknesses that affect their work, leisure and relationships⁽⁵⁾.

Given this, these caregivers also have a way of looking at their own distinctive health condition. According to a qualitative study, the caregivers classify their quality of life as average⁽⁴⁾. A study carried out in Chile corroborates this reality by showing that 63% of the caregivers present themselves ill and under medical treatment⁽⁶⁾.

Faced with the difficulties and restrictions experienced by caregivers, the need for professional support is justified so that such women can also take care of themselves. For this to be possible, it is fundamental that the nursing develop strategies that approximate and strengthen the caregiver-health team bond⁽⁷⁾.

But before, it is necessary to understand the realities experienced by these women, as well as how they perceive the care of themselves. Considering the context of taking care of the companion in cancer treatment, concerned us the following question: What is the woman's perception of taking care of herself when she experiences the care of her companion with cancer? In this sense, this study aims at unveiling the meaning of caring for oneself in the face of the reality of being a caregiver of a partner with cancer.

In our opinion, studies with this scope are justified by the scarcity of articles in the literature that specifically address the subjective issues regarding women's perception of caring for themselves as caregivers of the companion with cancer. Therefore, we believe that this study can broaden the horizons of knowledge on this theme, since the identification of the existential needs of these women should be valued and weighted in relation to the planning of health actions and programs aimed at this public.

■ METHOD

Study from a dissertation⁽⁸⁾, in which Heidegger's existential phenomenology was used, through which it is possible to understand the meanings and interpretations of experienced realities⁽⁹⁾ and thus respond to the question about the being. In this way, the ontological elements of their nature are determined, and these can contribute to the nursing care⁽¹⁰⁾.

The survey region of this study is in the significations of women about caring for themselves while caring for the companion with cancer. Therefore, as participants of the research, we have women caregivers of their companions, registered in a philanthropic institution of support to patients with cancer and their families, of a municipality in the northwest Paraná.

The following inclusion criteria were adopted: the woman should reside in the municipality of origin of the philanthropic institution or in a neighboring metropolitan municipality, for convenience of collection; and experience the care of the companion for at least six months, making it possible to experience the repercussions of caring, and her partner should score less than or equal to 40%, according to the Palliative Performance Scale (PPS)⁽¹¹⁾, being characterized as care dependent almost in its entirety.

In order to find these women, after the approval of the participating philanthropic institution, a search was carried out in the database of registered patients, and there was later telephone contact, in a random way, with the companions of such patients that met the pre-established criteria. It is reiterated that such criteria were seized through the cadastral information. Next, the approach visits were scheduled and the invitation to participate in the study was made.

After the acceptance, visits were scheduled for the interviews, with a total of two to three visits to each participating woman. The number of visits was established concomitantly, aiming to increase the bond and deepen the experiences, taking care not to damage the routine of the care. Thus, the period of encounter and search of the phenomenon directly with the participants happened between December of 2013 and February of 2014.

This path of approach, bonding and interviews enabled us to carry out the study with ten caregivers. This was the number of those who fit the mentioned inclusion criteria, and there was no refusal of any caregiver to participate.

To unveil the phenomenon sought, the following guiding question was used: "How is it for you to take care of yourself while caring for your partner with cancer?", besides questions of sociodemographic characterization. The interviews were carried out in the home of the caregiver

women, because it is the place where they experience the care. A digital recorder was used for storage, subsequent transcription and discourse analysis.

Aiming at the apprehension of the experiences in their fullness expressed by caregivers, two methodical moments were observed: in the first, vague and average understanding, when the assumptions are eliminated and, after careful listening and reading of the testimonies, their meanings are highlighted, with a later moment of analysis, searching for the essential structures that emerge, and make possible the understanding of the object of the study; in the second methodical moment, that is the interpretative understanding, the aim was to unveil the phenomenon, the sense of being, culminating in the Heideggerian hermeneutics⁽¹²⁾. This analysis made possible the encounter of the ontological themes, which were interpreted in the light of some Heideggerian ideas, of authors that refer to the philosopher, as well as of researchers who talk about the subject.

All the ethical and legal precepts regulated by the Resolution No. 466/2012 of the National Health Council - Ministry of Health⁽¹³⁾ were obeyed, and the research began after the approval of the project by the Permanent Committee on Ethics in Research Involving Human Beings - COPEP - of the Universidade Estadual de Maringá, under the Opinion No. 478.948/2013. Also, to ensure the anonymity of the participants, they were coded and named by women from the Bible, matching their characteristics and highlighting the faith demonstrated during the care of their partners with cancer.

■ RESULTS

The results of this study come from the experiences of ten women who care for the partner with cancer. Among these women, the ages ranged from 24 to 71 years old, and when they cared for their partner, five were already retired, two reconciled their work and care, and three stopped working to just stay with their companions.

Through the apprehension of the experienced realities, it is evident how the wives who care for the companion with cancer present difficulties to take care of themselves as women, both in the feminine issues that give them pleasure, as regarding their own health. Thus, two ontological themes emerged, as presented below.

Forgetting to be a woman by giving herself to the care of the other

By being a wife and caring for a partner with cancer, the woman engages in numerous caring activities that often end up by occupying her time and overwhelming her. In

this way, she fails to perform things that once were common to her, such as taking care of her own femininity, or doing things less often.

Of me? I totally forgot. It's incredible, we forget about ourselves. I'm realizing it now, because you asked. We do not even realize it. I did not even look, my hair needs some color. Wow! I need to dye my hair! [laughs] It's been days, and I've forgotten about myself again. I had not even stopped to think about it! I did not have time! (Ana)

If before I was vain, now I am much less, I settle for any clothes, with any shorts, with anything. I do not have that luxury vanity that every woman has. So sometimes my sister speaks like this: you have to go to the hairdresser, you have to do the nails, but I know I should do this, but I try. It's too busy, there's a lot for me to solve. (Rebeca)

Of me? [laughs] I totally neglected myself. To take care of myself, I did not have time, it was difficult. There were times when I said: I have to get my hair cut, but I do not have time, I'll leave it for next week! Leave it to the other week. (Isabel)

Among the women interviewed, only one reported being able to maintain self-care while caring for her companion:

We cannot give ourselves up; we cannot stop caring for ourselves due to his illness, it's not right. I always got some time for myself, too. I do not let myself down. We just do not go out like we used to. But I buy my things, I'm pretty vain. He encourages me too. I'll do my nails tomorrow. I go to my dressmakers, I order clothes. (Sunamita)

Choosing the other to the detriment of yourself

In addition to the care related to the woman's femininity, they are also faced with the reality of taking care of their own health. However, even though they may have some illness and need care for themselves, some women end up putting their partner's care needs as a priority.

When we found out he had cancer I was a little better, then I went to take care of him. The bandage was in his rectum. Mine was in the breast. I was in need of care too. I suffered a lot because it was for me to take care of myself and take care of him. I forgot myself, but God gave me strength and helped me, because nothing got inflamed or infected. Because we were in a very difficult time. Either one or the other, sick. (Joquebede)

So I said: I got to have strength for me and for him. I said: I'll leave myself aside, and I'll take care of him. After he's healed, I'll take care of myself. This is my life, you see that everything is stopped. I also have a health problem. It's stopped because of him. Because I'm fine, I'm walking. I think if I was in the same situation, he might be doing the same for me. (Noemi)

Often, routine exams and medical appointments are not performed because they are taking care of their partners.

The part of taking care of myself was left aside, because I always went to the doctor, did the exams and everything. Now, after he started to deal with it, after he started with these problems I started leaving it. I was leaving myself aside. Only the medicine I take, I take the prescription and I take it, there is always remedy. The exams I have to do. (Dorcas)

Doctor? I stayed three years without going. I did not do the preventive. Just looking after a job and taking care of him. You see, it's been all this time! And these days he [husband] said: you have to take care of yourself, you have to go because you're only after us, just taking care of me and you're not going to the doctor. You see, our time, only thinking of others and, it is the way it is. (Isabel)

So, now that he's a little better I started going after a check-up, because I have to be well to be able to take care of him too. (Sunamita)

I was supposed to operate both eyes, and on the day they called me to go do the surgery I was going with him to the doctor, now it has to wait, it takes almost a year. There was no one, it had to be me, I missed it, I was supposed to be good already. (Rute)

In addition, even some basic needs were put aside, facilitating the appearance or aggravation of diseases:

I was left with the thickness of a finger. I lost a lot, a lot of weight, I was not hungry. There were times when I felt that failure in my stomach, but I did not have time. There was a day that a niece came to visit him, and she said: Auntie for God's sake go eat! And I had put the food and left there, nor even remembered about the food. Everything was on the plate. I did not have time to eat and forgot it. My life was only for him. Take care of him in this period. (Joquebede)

I had no taste for anything else, nor to eat right, there was a time when I was getting depressed, I did not eat anymore, I

was tired, spots began to appear on my body, my diabetes was up there. (Rute)

■ DISCUSSION

In essence, man presents himself as caretaker of his own existence, and this responsibility cannot be denied to him⁽¹⁴⁾. In this context, we see that, in addition to caring for the companion with cancer, the woman has the existential responsibility to take care of herself.

It is worth emphasizing that self-care is characterized by the set of actions designed to keep and maintain one's own existence. It is the result of a socializing process in which one learns about customs, habits, attitudes, beliefs and values. It is also represented by self-worth, sensitivity and commitment to yourself⁽¹⁰⁾. In the experience of women in this study, it is possible to perceive how much self-care is neglected, reflecting on the personal issues of being a woman as well as on one's own health.

In the work "Being and Time", the interpretation of the authentically existing man, that is, the being-there in its totality, is exposed. For the author, the natural ontological foundations of the existentiality of being-there are temporality and historicity. Referring to temporality, he relates it to care, so that it constitutes the original ontological sense of presence, where it is always a possibility, thus, man is always constituted in a being. And in this authentic form of caring, the human being reveals all his power-being, which manifests itself in a temporal constitution. It is a primitive temporality that temporalizes according to three *ek-stases*: the upcoming (future), the vigor of having been (past) and the actuality (present)⁽¹⁵⁾.

From what has been mentioned, we visualize in the participant's languages that caring for their partners with cancer, in this moment of their lives, does not erase the memories of their power of being. In their speeches, they recall what was once part of their daily lives; such as caring for themselves by looking and beautifying themselves, and being deprived of what gives them pleasure. Such a situation refers to the past, when the disease of their companion was not yet present in their existence, that is, the power to have been. Thus, in caring for the other, the woman refers to the consciousness of her temporality, since she understands the reality of being cared for, her past and future. Through care relationships, she also finds the possibility of reflecting and understanding her own world⁽¹⁶⁾.

Still in this sense, it is essential to have empathy, that is, to project oneself into the existential situation of being ill, since care only occurs through solicitude⁽¹⁷⁾, characteristics

that are revealed in the experiences of the care presented.

In caring for the partner, the woman places him as a priority and often forgets herself while she is caring for her beloved one⁽¹⁸⁾, living for the other. Therefore, in addition to the ontological perspective, time can also be considered chronologically. Faced with such a situation is that women refer to time as an impediment, failing to separate it to the care with their own appearance. In addition, it is perceived that they are aware that self-care is delayed in the face of the many activities developed for the sake of the person being cared for. Sometimes they schedule themselves, but they end up delaying time again for themselves.

Thus, analyzed existentially in temporality, the understanding is grounded in the future, that is, by deducing its facticity, the being-there is projected in a power of her own, that is, ahead of herself, always attentive to what she cares about⁽¹⁴⁾. In this thinking, while feeling overwhelmed at this moment of her existence, the woman uses her power-being to bring time to her advantage and transcend her own anguish, since it reconciles self-care and caring for the other.

Heidegger's existential meditation has its primacy in the facticity of being in its being-in-the-world. The philosopher calls "factus," or facticity, the condition of man being cast into the world, living at the mercy of everyday events, and in this existential circumstance he discerns sickness as a distant possibility⁽¹⁴⁾. We realize that the reality of the care revealed here, in most circumstances, is as a restriction to the existential possibilities of women⁽¹⁸⁾. Still, these limitations are not restricted only to actions geared toward the well-being and personal satisfaction, but also extend to more fundamental issues such as health itself.

Following this thought, philosophically, the term care comes from the word cure, or "sorge," in the German language, and relates to "taking care of", of something or someone. It also gets involved with worry, concern and self-care⁽¹⁶⁾. In this sense, engaged in the care of their companions, such caregivers often give up on themselves and, thus, reveal their authentic way of being, proper of the human existence. According to the Heideggerian thought, through self-denial, they detach themselves from one another and throw themselves with their eyes centered on the other, by actions driven by their own existential characteristic⁽¹⁶⁾. Considering this, we find that they bring in their self-denial, to strengthen the other; seeking in those moments to forget their own needs of care.

It should be emphasized that the changes in the health context of caregivers also appear as a result of the care taken. In the face of illness, it is common to place the self-care and issues that bring personal satisfaction into the

background, and to prioritize the health of the person being cared of⁽³⁾. This reality was also revealed by the depo-nents, because they let their illness become worse, when they dedicate time only to the care of the other. They are faced with the need to choose between being totally devoted to their partner or taking care of themselves. In this conflict, some of them refer to losing consultations and medical exams that are difficult to access, choosing to care for their partners.

Faced with these choices, we emphasize renunciation, and in Heidegger's thinking, the "renunciation does not detract. The renunciation gives. It gives the inexhaustible strength of self-identity under the rule of self [...] It is growth and maturation of self from being"⁽¹⁵⁾. This is accomplished by the fact that, from the renunciation, these women assume for themselves an authentic possibility of their existence, guaranteeing their own power, their power-being in which they choose the other to the detriment of themselves.

The time that was spent on various activities, including health, is now spent on care tasks and they often perceive themselves as without free time. A study shows that more than half of the caregivers are almost unable to achieve what they planned for themselves because of their involvement in care⁽¹⁹⁾. So, often, time is not even separated for their basic needs like eating and resting. Given this, we realize that by being a caregiver and facing the intemperances of this experience, even if the woman "decides" not to take care of herself, she assumes a form of "careless" care, where she does not stop exercising a kind of caring. Thus, they can take care of themselves in the form of "carelessness"⁽¹⁷⁾. Such care as carelessness is an option the woman makes, given her possibilities of being, so that she can take care of the other and assume her own authenticity. It is noteworthy that the way in which the self perceives itself and is a protagonist in its own history, as well as being seen as fundamental in relieving the suffering of the other, is also related to its own self-esteem⁽¹⁹⁾.

Faced with this reality, we highlight the importance, as health professionals, specifically of the nursing team, to deepen our knowledge regarding these experiences in order to better understand the difficulties faced by the caregivers, and thus, to pay attention to their physical, emotional, spiritual and social characteristics. In such a way, to intervene through actions of health promotion and quality of life⁽¹⁸⁾. It is also reiterated that the example of renunciation of their own interests shown by such women in caring for their companions highlights an admirable conduct that can boost us and serve as a basis for a more authentic professional care.

■ CONCLUSION

The existential phenomenological analysis allowed us to understand that the time to exist, taking care of the companion with neoplasia, is surrounded by worries arising from the paradoxes that permeate the existentiality of caregivers. The women of this research experience a life that is apparently isolated in their own daily lives, that is, in an existential ontological sense, a spatialization, that is, to be close to their beloved ones and, at the same time, to feel distant from the world.

In this research, we learned that for these women, timing is the time to care for the other and to renounce oneself. And in this experience, this time experienced is the most immediate phenomenal aspect of this temporality. In this situation, the women expressed their ways of living with the disease, because, as intico-ontological entities, they revealed the needs that surpass their priorities.

Taking into account the feelings expressed by women in this temporality of caring, we distinguish the need for nurses to expand their focus of attention, considering that this profession has a relevant role in maintaining the health and quality of life of people in their care. Thus, it is necessary to implement and plan actions directed to the educational processes and psychosocial support of these people, sensitizing them not only to the physical care, but also to caring for themselves as women and thus being able to live their lives and take care of their companions in a full and healthy way.

Thus, we are encouraged to reflect on the care provided as nurses and other health professionals in order to improve care so as to address the needs of these beings in the world. In the course of this objective, it is imperative to look beyond the physical dimension, but to the totality of being. Thus, in order to improve the quality of care, nursing needs to devote more of its time and allow room for a broader look and a deeper listening. It should be considered that the temporality of caring for the companion with cancer enlivens in the caregiver a mixture of feelings, sharpened by not always having someone to share their existential condition. Thus, this condition reflects on their physical and mental discomfort, thus restricting their quality of life and fullness of being.

This study uncovered the meanings of self-care for women who care for their partner with cancer, and presented some limitations resulting from the fact that it was developed in a specific setting. Its results should not be generalized, but they may show a glimpse of the reality of many caregivers who experience the disease at home, not only in the context of cancer. The findings of this study are expected to stimulate other researchers and health professionals

to seek out, apprehend, and understand the vicissitudes of these people. Therefore, to recognize these women not only as "helpers" or caregivers, but rather as people who also need care.

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