THE MEANING OF BEING-A-CAREGIVER OF A DEPENDENT RELATIVE SUFFERING FROM CANCER: PALLIATIVE CONTRIBUTIONS

Joisy Aparecida Marchi, Cristiane Cardoso de Paula, Nara Marilene Oliveira Girardon-Perlín, Catarina Aparecida Sales

ABSTRACT: The goal with understanding the meaning of being-a-caregiver for a family member with cancer who is highly dependent for daily activities. Phenomenological analysis based on Martin Heidegger’s philosophy, undertaken at three health centers in a city in the Northwest of the state of Paraná, Brazil. Interviews were held between November 2012 and February 2013 with seventeen family caregivers. Two themes arose after the analysis: “Being-a-caregiver experiencing different modes of disposition” and “Being-with-a-relative: from daily occupation to liberating concern”. This meant that for the caregiver-being to get terrified by the diagnosis and horrified with the treatment, terrified by end-of-life care and being-with-the-other in the illness. Although occupied with daily things, caregivers were nevertheless concerned, showing solicitude in their actions. This basis for effective palliative care should pervade nurses’ work for this professional to be a true care-being.


SIGNIFICADO DE SER-CUIDADOR DE FAMILIAR CON CÁNCER Y DEPENDIENTE: CONTRIBUCIONES A LA PALIACIÓN

RESUMEN: Se tuvo como objetivo comprender el significado de ser-cuidador de un familiar con cáncer y con gran dependencia para las actividades diarias. Estudio fenomenológico fundamentado en Martín Heidegger, realizado junto a tres núcleos integrados de salud en un municipio del noroeste de Paraná. La entrevista sucedió entre noviembre de 2012 y febrero de 2013 con 17 cuidadores familiares. Del análisis propuesto surgieron dos temáticas: “El ser-cuidador vivenciando distintos modos de disposición” y “Siendo-con-el: de la ocupación cotidiana a la preocupación libertadora”. Significó para el ser-cuidador aterrarse con el diagnóstico, horrorizarse con el tratamiento, aterrorizarse con los cuidados paliativos y ser-con-el-otro en la enfermería. Se mostró ocupado con las cosas, pero también estuvo preocupado, evidenciando la solicitud en sus acciones. Esta base para un cuidado paliativo efectivo, debe permear la labor del enfermero visando que este profesional sea un verdadero ser-do-cuidado.

INTRODUCTION

Today, the public policies tend to transfer the care to patients with malign tumors to outpatient or home care, aiming to reduce unnecessary interventions, as well as the hospital costs for health institutions. In this system, the family can suffer from the diagnosis, treatment, post-treatment and everything permeating the experience of this disease.

In view of the trend towards home care for cancer patients, together with greater survival, the family needs to overcome the challenges that emerge all the time, including the need to elect a primary caregiver. This reference figure for effective care who is usually part of the family core assumes different functions. These tasks can cause a burden, whether due to the objective demand, which matches care-related tasks and the time involved in their delivery, as well as subjectively, related to the caregiver’s experience and the feelings about his role in this occupation.

To the extent that the disease progresses, and the patient under the caregiver’s care becomes increasingly dependent, the caregiver’s burden is aggravated. In this context, at the same time as the curative treatment, palliative care gains a special dimension, as a form of care that recommends individualized care for patients and families. This care permits understanding the people in their priority and specific needs in their life at home with the cancer. In this approach, the family’s involvement is fundamental, considering that it plays an important role in the recovery of health, as well as in the development of the disease and its consequences.

Although primary care is not commonly responsible for palliative care actions, it can be structured to incorporate this model. In addition, with the Family Health Strategy (FHS) team, its care can be strengthened, as the teams closely accompany the experiences of the subjects in their coverage area. Thus, weaknesses and gaps can be identified which patients and caregivers experience in view of the coping process with the disease, so as to offer elements to elaborate care planning according to the reality of each family.

Estimates appointed approximately 518,510 new cases of cancer in Brazil in 2013, a projection that demonstrates that the health professionals, especially the nursing professionals, increasingly have to include home care for family caregivers of people with cancer in their daily realities. In their care moments, the family experiences physical and emotional suffering and has to adapt to the situations the disease produces, a context that demands the FHS professionals’ reflection on the importance of palliative care in the planning of health actions and programs focused on the family group.

Thus, based on the premises that, for care, the caregiver-patient dyad and the caregiver also needs care, this study is focused on the following concerns: How do these beings feel when they deliver care to their highly dependent relative with cancer? How do these people experience this situation? In that sense, aiming to reduce the knowledge gap on this experience in the existential sphere, this study aimed to understand the meaning of being-a-caregiver for a family member with cancer who is highly dependent for daily activities.

METHOD

A qualitative study was developed, based on Martin Heidegger’s existential phenomenology. Heidegger’s phenomenology was chosen as his theoretical-philosophical-methodological framework is in line with the humanistic principles of nursing and its care focus, and because it challenges the researchers to look at the human beings’ subjective experiences.

The study was developed in a city in Northwestern Paraná, involving three Integrated Health Centers (IHC). The participating centers were chosen based on the number of teams registered in the National Register of Health Establishments (NRHE), selecting the centers with the highest number of FHS teams.

All caregivers were included who complied with the following criteria: age over 18 years; being physically able and in cognitive conditions to answer the questions; being the primary family caregiver of a cancer patient using the Palliative Performance Scale (PPS) equal or inferior to 40% and having taken care of the patient for at least three months. The PPS is a scale divided in 11 levels, from 0% till 100%, which assesses five functional dimensions: walking, activity and evidence level of the disease, self-care, oral intake and awareness level. It rapidly describes the person’s functional status and was used in this study to identify patients who are highly dependent for the activities of daily living.

After contact with the teams, the selected caregivers received the researcher’s first home visit.
together with the nurse and/or community health agent to present and observe the pre-established criteria. If they complied, they were invited to participate in the study and a second meeting was scheduled at the participants’ preferred time and place. Three meetings were held for direct contact with the participants, with a view to creating empathy and feelings of safety to talk about their experiences.

The phenomenological interview was held during an individual meeting between the researcher and the caregiver, which demanded ambience, empathy and intersubjectivity, made possible through the reduction of prejudices. The participants were asked the following guiding question: “What is it like for you to take care of (name of the family member with cancer)?” The interviews were held between November 2012 and February 2013.

The average duration of the testimonies was 40 minutes. To fully collect the statements, a recorder was used. As the fieldwork took place at the same time as the analysis, the number of participants was determined at 17, which demonstrated sufficient meaning to answer the research objectives. To capture the full range of the subjects’ expressions in their languages, the researchers chose to individually analyze each discourse. Thus, first, each testimony was read attentively, separating the excerpts or units of meaning that served as the fundamental structures of the interviewed participants’ existence. Then, the units of meaning of each testimony were analyzed, involving the phenomenological selection of each subject’s language, which gave origin to the ontological themes, analyzed in the light of some of Heidegger’s ideas, of experts on the theme, and of palliative care researchers.

The ethical premises of Resolution 196/96 were complied with, replaced by Resolution 466/2012. This study is linked with the project “Applicability of palliative care in primary health care promoting better quality of life to malign tumor patients, their relatives and health professionals”. Approval was obtained from the Permanent Ethics Committee for Research involving Human Beings at Universidade Estadual de Maringá, under opinion 435/2011. The request to participate in the study was accompanied by two copies of the Free and Informed Consent Form, when the collaborators were informed about the goals of the research, the type of participation they desired, the freedom to drop out and the probable length of the interview. To preserve the anonymity, the participants were presented using pseudonyms of angels and the choice was based on some reasons. The first, due to the frequent presence of beliefs in higher divinities among people with cancer and their relatives, which mean a coping strategy in the disease process of their loved one for them. In addition, it was observed that the nursing professionals are frequently caricatured as ‘angels’ in their ‘caregiving’ functions and verified that, during the meetings, the family caregivers are like angels who watch over, take care and attempt to attend to all of the sick relative’s needs.

RESULTS AND DISCUSSION

Seventeen participants took part in the study, including nine husbands/wives, five daughters, one mother, one aunt and one cousin, between 42 and 70 years of age, mostly married or having a fixed partner, only one single and another separated. Regarding the location of the disease in the relative, the following were obtained: five with initial intestinal cancer, four stomach cancer, two oropharyngeal, one brain stem, one lung, one bladder, one uterine, one prostate and one breast cancer, almost all with metastases. In total, six had 40% of PPS; six 30%; four 20% and one 10%. About the professions, most caregivers were housewives or retired, one massage therapist, one administrator, one auxiliary nurse and the remainder were on leave from work due to the new occupation.

Based on the analysis of the participants’ language, two ontological themes emerged, presented next.

The caregiver-being experiencing different modes of disposition

In Heidegger’s analysis, the sense of being is clarified based on the being because, in his thinking, it is through this thinking that the being is revealed to the world. “Being is everything we say in this or that way, being is also what is and how we are,” it is something concrete, determinate. “To be” is presence, it is the way of saying that the being alone is something due to the ways it is manifested, designated as Dasein, being-in-the-world, being-there. And, when looking at the world in its existence, the being-there find he is cast in a predetermined condition, independently of his will and choice, experiencing unplanned and unexpected
The babbling constitutes the way of understanding and the interpretation of being-in-the-daily-world. This babbling, which brings nothing new and even less invites the other towards sensitive listening, is satisfied to adopt what was said as correct and reproduce it, in a movement of repetition and certainty. This babbling, when repeated/transmitted, shows to be something familiar to the caregiver, who linked his relative’s disease with the “background knowledge”. Everything seems to be understood even without having appropriated himself of what is said.

When cancer was discovered at his home, the caregiver-being experienced the concreteness of being cast into the world of disease, shared peculiarities inherent in each disease phase, arousing different modes of disposition. Disposition is the mood or affective tone that does not represent a simple psychological phenomenon that colors things and people, but a constituent definition of the being.

In fear, one of the forms of disposition, what one is afraid of, called “fearsome”, is always something inside the world. Local, which can come from something or another Dasein. Being afraid can extend to others and, thus, the term used is being afraid instead. That is a mode of disposition together with the others, and what causes fear in this situation is the being with the other. Being afraid instead knows implicitly that it will not be hit although, in fact, it is affected by the co-presence one is afraid of. Hence, one does not lose the specific authenticity when one is not “actually” afraid.

During the reading of the testimonies, cancer was visualized as an intra-mundane being, in line with the co-adjuvants in this study (sick relatives) and, consequently, the protagonists (caregivers), unveiling the mastery of the fear in their median daily reality. The caregiver-being was terrified by the cancer diagnosis of his relative, revealing the awe, one of the variations of the fear. “The referent of the awe is, at first, something known, familiar […] and sudden”.8,202

[...]

The statements show how important the nursing professionals’ contribution can be in the deconstruction of this “colloquial knowledge” which, in most cases, arouses unnecessary anxieties for the caregivers. In addition, doubts can be clarified about the diagnosis and treatment, and the incurable nature of the cancer can be demystified, which provokes that much awe to the people entering its world.

When he starts the treatment phase, the caregiver-being reveals to be terrified by what he had to experience. He was apprehensive when, in his conception, the curative therapy, instead of helping, seemed to worsen his relative’s condition. In addition, he was afraid of the uncertainty of the treatment, unveiling the transition from awe to horror. In horror, the threat becomes the unfamiliar.

[...]

The statements assure that, when they recall the moment of the cancer diagnosis, the caregivers are terrified and do not know what to do. They are accustomed to the disease but do not expect this discovery at the heart of their family, shown in the way of being of their awe. It is common for this awe to be caused exactly by what the caregiver understands or heard about the disease, being disturbed by the babbling.
her eyes with tears and says: ‘that’s very painful, I don’t know what will happen’ (Antriel).

About the anti-cancer treatment, the different implications in the physical, emotional and social spheres are known, mainly of the chemotherapeutic and radiotherapy therapies, the patient and family’s general quality of life. Taking part in the world of treatments aroused the horror of the unknown, thus, the caregiver-being needs to be accompanied by health professionals capable of advising and sharing their doubts and experiences, reminding that the patient not only deserves attention, but also this family member who suffers for sharing each phase experienced.

To the extent that the threat appears as something unfamiliar, that is – the horror, which has a sudden nature at the same time – the fear, the awe turns into terror. That was unveiled when the caregiver-being externalized the unexpected and unknown threat: the oneness of the palliative treatment.

[...] since then, he has felt a lot of pain and the doctor said he had no resistance to have another surgery and that, now, it was taking care and waiting [cry]. He doubled the medicine to take away the pain, he’s getting a pit sedated (Manu).

[...] the doctors said his [family member] was just palliative, for him not to feel pain nor lack of air. That’s all! Nothing else… But I didn’t accept it at first. Then I went to a private doctor, I spent money, did a lot of things, you know that despair? [...] always thinking I would be able to save him (Moraël).

As shown, Moraël was terrified when he received the proposal to give end-of-life care to his relative. The terror the “palliative care” provoked can be linked exactly to the social stigma of this treatment, in which “it’s just waiting and there’s nothing else to do”.

The appropriate practice of palliative care recommends individual care to patients and their families, together with the health team, aiming for the biopsychosociospiritual improvement of all. For the caregiver-being to take care of his family member from this perspective, he needs to be equipped, he needs to know and understand the goal of palliative care, how fundamental and satisfactory a palliative care experience can be and that his presence and action are fundamental in this process.

It is likely that, in this phase of the disease, the care demand increases and the patient becomes increasingly dependent. The caregiver starts to perform activities related to basic needs, producing permanent and exhausting care. Throughout the cancer journey, the caregiver-being shares each moment with the patient; sadness, anguish, conquests and joy; this being becomes a legitimate being-with-the-other. The involvement of the caregiver-being who takes care of the dependent relative who has cancer unveils the mode of being-with.

**Being-with-the-relative: from the daily occupation to the liberating preoccupation**

Being-with is an essential element of being-there, it is an existential characteristic of being-in-the-world, signifying together with something or someone, not only being-with, and also has the sense of relating, engaging, living with, inferring and sharing. Nevertheless, the relationship between being-with and the “others” does not occur in an analogue manner when these are simply given beings or when they are other *Dasein*. When treating with daily thing, the being-with relates in the occupation mode, while with other *Dasein*, the being is involved in the preoccupation mode.

The being is occupied with performing the designated activities. In complying with these tasks, there is no true understanding, the being uses the tool that is fundamental to perform them, and then accomplishes them without reflecting on their process. In a first approach and, in most cases, the being-in-the-world focuses on the world of occupations. The caregiver-being is frequently occupied in the execution of basic tasks, such as hygiene, eating, dressings but, although they are no less important, it should be considered that, behind these activities, there are other as or more fundamental care demands.

*In the first place the bath, then I put his milk, about 250, 300 ml, I give water and, later, I make lunch, and that’s it. I do my things (Afriel).*

*Today, I’m still with him, I don’t even know why, because love is not, but we feel pity. I made his food, I put it by his bedside, I don’t know if he ate it (Jeremiel).*

Nevertheless, “the ontological nature of the occupation is not characteristic of being-with, although this mode of being is a being for the beings within the world of the occupation”.

In this context, being preoccupied is the ideal form of being-with-the-other of the *Dasein*, considering that it remits to being preoccupied, giving care or being accountable for something. As it has the nature of
the Dasein, the relation becomes correlation.\textsuperscript{20-21} It was verified, through the participants’ language, that some caregiver-beings remained in the occupation mode when performing their activities, while others motive to the possibilities of being and manifested being-with-the-other in the world of the preoccupation.

\text{[\ldots]} I'm doing what I can, despite all difficulties [\ldots] I try and spend as much time with her as possible, simply at her side, to give her good energy, friendly words, consolation. Although our family is a bit of a bottle rocket, I think I have been able to transmit something good (Miguel).

In Miguel’s statement, humanization is highlighted in his care, showing that some caregiver-beings support, help, take care and are concerned with the patients so that they do not feel alone. The intra-mundane things move to the background and what is worth it is to be-with, moving towards true and feasible palliative care.

What the preoccupation is concerned, there exist two possibilities to act in this way. The first, the dominating replacement, can withdraw the care from the other, assuming the occupation another person should accomplish. This form can entail the other person’s dependence, as well as domination, even if this domination is silent and remains hidden. The second, the liberating pre-fixation, does not succeed the other, but prefixes his possibility of being, respects the existence of the other and helps him to become free to take care of himself,\textsuperscript{8} that is, in the first form expressed, everything is done for the other while, in the second, it remits to the care that grants the other person conditions to grow and pursue his choices.

In the patient’s highly dependent condition, whether physical, cognitive or emotional, the patient’s autonomy can be compromised, with a greater demand for continuous care by the family caregiving group.\textsuperscript{22} In this interval, it is difficult for the caregiver-being not to perform almost all tasks for the other, presuming a dominating replacement. Nevertheless, even if the accomplishment of care as a whole is preponderant, by allowing the patient to decide on his life, and to expose his desires and anxieties, the caregiver-being can respect his relative’s existence and move towards authentic and liberating care.

\text{[\ldots]} he didn’t want to do chemotherapy, because he watched a man die next to him at the infirmary after he did chemo, and I let him! It wasn’t easy for me to respect this decision because it was a treatment [\ldots] he usually doesn’t complain, he stays there quietly but, one day, I caught him here on the couch crying a lot, I saw it was because he was in pain, I noticed he was suffering and did not want to show it, then he wanted to get back, so we worked for it! (Manu).

It is observed in Manu’s statement that attending less to the anxieties than what the relative says is fundamental and gratifying, just like denying them sounds like a gap in his existence as a caregiver-being. Thus, preoccupation reveals, in line with the premises of palliative care, that the disease is not his care focus, but his owner, understood as an autonomous being, with individual and priority needs, capable of deciding on his treatment.\textsuperscript{18}

The involving and expressive relationship with the other is called “solicitude”.\textsuperscript{23} Its primordial characteristics are: “being considerate with the other” and “being patient with the other”. Both are related to temporality; the consideration remits to the experience of the past, looks backward, and patience is seen frontwards, because of the hope of what can become.\textsuperscript{23} In some statements, these aspects could be devised in the caregiver-beings’ care performed.

\text{[\ldots]} with plenty of patience and love, that’s what I do, because it’s my part of fortysome years and, at difficult times, I also have to be with him, sometimes he has ups and sometimes he’s discouraged (Ariel).

\text{[\ldots]} we should never give up, I always try to do things with love, I don’t do it go get something, he says that, if it weren’t for me, he wouldn’t have managed and would already have given up [\ldots] it’s difficult, we really keep our fingers crossed for him to get cured soon (Gabriel).

When considering these characteristics, the being understands the other person’s difficulties and anxieties, opening up to the concern, in a movement of authenticity that emerges from daily reality. This form of preoccupation should permeate the care of family caregivers as well as health professionals in the “caregiving” function.

Being solicitous in care for the other is sensitive, as it permits rescuing the patient’s respect and dignity, that is, delivering palliative care. Guided by this philosophy, one should look at the human being as a whole, independently of the environment(s) he is inserted in, which can help the person in the coping process with the disease and death and guarantee humanized and high-quality care.\textsuperscript{18}
In view of the above, nursing can act to support the caregiver and help to identify the patient’s anguishing thoughts, such as the need to be considered as a person, to have one’s desires attended to, to reconcile with the others and oneself, to be released from guilt, besides other aspects that deserve attention in this phase of their life. Thus, the caregiver-being is preoccupied in the solution of the relative’s personal conflicts, through dialogue and listening and, at the same time, is solicitous.

It is highlighted that communication is imperative in care, a valuable resource in nursing practice which, if well applied, contributes to a true relationship, in which the nurse grants the patient support, comfort, information and feelings of confidence and self-esteem. Active listening and dialogue are the main work tools of palliative caregivers, as it is through their use that the needs are identified in the different dimensions of who experiences the end of life.\(^{25}\)

The professionals, guided by the palliative care premises, can help patients and their family in their death and dying process, in a solicitous and humane manner.\(^ {19}\) As the FHS monitors these families and establishes bonding and trust, it can contribute actively in the care process for the caregiver and the dependent relative, consolidating effective palliative care. Therefore, overcoming some obstacles is crucial, including the workers’ academic background, which hardly focuses on home care. It is fundamental to keep in mind that the success of this care is to look at the patients and their families in their context, with a view to praising the humanizing and autonomy of the people involved in care.\(^ {25}\)

FINAL CONSIDERATIONS

In view of the factual nature of the family member’s cancer, the caregiver-beings went through distinct moments in line with the disease, which provoked different disposition modes. The confirmation of the diagnosis was frightening and influenced by the babbling, they conceived the disease as incurable, mutilating and fearsome, reminding the social stigma of cancer. When coping with the treatment, they were horrified, afraid of the uncertainties the indicated therapies caused and because the unknown was turning into reality.

At first, the oneness of the palliative treatment meant terror. In this phase, as a result of the high dependence of the caregiver-beings, the caregivers revealed to be true-beings-with-the-other. This meant beings-with-a-relative who lived at home, who were co-present and shared each moment. Sometimes, they were occupied with the intramundane things and activities, while others moved around in an existential movement and turned into preoccupied caregiver-beings. Despite the family members’ range of dependences and difficulties faced, the caregivers can present liberating and authentic concerns.

The caregiver-beings were solicitous to their relatives, demystifying the impossibility of the correlation between solicitude and burden many caregivers alleged, whether they were the relatives in charge of this function or the other health professionals co-responsible for these patients. It is possible, despite the torment of setbacks the cancer journey entails, especially due to the high dependence, opening room for “caregiving” towards effective palliative care. This should be understood not as specific, unique and momentary care, but as daily action concomitantly with other therapeutics. These beings partially put in practice the palliative propositions, even if unknowingly. They lack appropriate care to allow them to increasingly offer authentic care at their home.

In view of this situation, nursing, particularly the FHS professionals, are responsible for guiding these family members, also assuming an identical conduct in their daily care, as disseminators of end-of-life therapeutics. Theoretical-practical knowledge is needed and an attitude that is coherent with the patient and family members’ demands, acting as facilitators in the implementation of care. Incorporating this interesting amalgamation of care in the professionals’ daily reality is feasible, even if cautious and progressive at first, within the possibilities the services offer, but always with the ideal that improvements can be implemented. Therefore, interest, competency and technical and communication skills are needed. These actions have always been fundamental in nursing knowledge but should be retrieved in daily care practice.

Some limitations of the study are highlighted, due to the qualitative nature of the research, being restricted to the time and space of the involved subjects’ experiences. Thus, its content cannot be generalized to other FHS teams from other cities. Nevertheless, the study permitted and aroused important reflections, contributing to the expansion of knowledge on the theme.
REFERENCES


