

To be the caregiver of a family member with cancer and dependent: a glance to temporality***Ser-cuidador de familiar com câncer e dependente: um olhar para a temporalidade**Joisy Aparecida Marchi¹, Ligia Carreira², Catarina Aparecida Sales³

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ABSTRACT

We aimed to comprehend the meaning of being a caregiver, the responsibility to assist a dependent family member with cancer. A phenomenological heideggerian study conducted with 17 family caregivers through interviews. Ethical precepts were respected. The following theme emerged from the analysis: "Unveiling the temporality to live with cancer at home". The caregiver recalled his strength of being and maintaining himself stuck to this ecstasy and sometimes glimpsed a promising future and changed his reality. Professionals guiding families can turn the moment of realization less painful for the caregiver. It is needed to glimpse the temporality to reach the major goal of palliative care and nursing, that is, to assume the essential project to be a caregiver.

Descriptors: Caregivers; Primary Health Care; Oncology Nursing.

RESUMO

Objetivou-se compreender a significação, para o ser-cuidador, da responsabilidade de assistir um familiar com câncer e dependente. Estudo fenomenológico heideggeriano realizado junto a 17 cuidadores familiares por meio de entrevistas. Foram respeitados os preceitos éticos. Da análise emergiu a seguinte temática: "Desvelando a temporalidade de conviver com o câncer no lar". O cuidador, ora rememorou o seu vigor de ter sido e, se manteve preso a essa ek-stase, ora vislumbrou um porvir promissor e modificou o seu instante. Os profissionais que acompanham as famílias ao enaltecer o porvir podem tornar o instante realista e menos sofrido para o cuidador. Olhar para a temporalidade faz-se necessário para que se alcance o objetivo maior dos cuidados paliativos e da enfermagem, ou seja, assumir o seu projeto essencial de ser um ser-do-cuidado.

Descritores: Cuidadores; Atenção Primária à Saúde; Enfermagem Oncológica.

INTRODUCTION

In the last decades, families have been trying to assist the emerging demand of patients with chronic diseases, disabling and/or terminal. When a family member gets ill, it is within the family where care sources are and the needed attention is present to minimize difficulties caused by illness⁽¹⁾.

As the hospital admission time is commonly reduced and the cancer patient is monitored through ambulatory, family caregivers assume the physical and emotional care responsibility of the patient at home. In addition, the help in daily activities, transport, specific care with the illness, with the communication with health professionals and in general support⁽²⁾. Thus, caregivers can face stress due to changes, leading to health, financial, social and occupation worsening conditions⁽³⁾ with consequently reduction of their global wellbeing⁽⁴⁾.

As the illness progresses and death gets closer, the family member needs more assistance⁽⁴⁾. This care overload the caregiver, mainly on tasks related to care and the time involved in it, as well as in the subjective aspect regarding to the experience and feelings about this function⁽⁵⁾. Thus, the caregiver has to rethink his role throughout temporality, with the need of his own life resignification⁽⁶⁾.

It is fundamental for the caregiver to be informed about care at home in this scenario, because the lack of prepare to assist the family member is a complicating factor to assist emerging demands⁽⁷⁾. The continuous guiding process offered by the palliative care team is indispensable, as it offers a support system to patients and family⁽⁷⁾.

Adequate palliative care practice preconizes to look at the human being as a whole, independently of the environment where its inserted, guaranteeing a humanized and quality assistance⁽⁸⁾. In this perspective, palliative care should not be an alternative to treatment inefficacy, but a care philosophy that should permeate all disease phases⁽⁹⁾.

In this thinking, although Primary Health Care, represented by the Family Health Strategy (FHS), is not originally responsible and acting in the palliative care assistance, it can contribute, attending families who live with cancer, because they have the link, co-responsibility and integral attendance as guiding axis of its actions⁽¹⁰⁾. In these moments, the family can experience total pain, that is, beyond physical pain, the family has to face anguishing and acute pain; affecting them psychologically, existentially, and spiritually, making them fall in front of their situation⁽¹¹⁾.

Considering that it is in the family environment that cancer is experienced more each time, the need for the family to be responsible for the person in their homes, bringing new different feelings in the temporality of this role, the focus of this research tries to reflect: how does the caregiver of the dependent family member with cancer has experienced, throughout the time, the care for the other? Facing the exposed, this research aimed to understand the meaning of the responsibility to assist a family member with cancer and dependent.

Researches with this focus are justified considering the meaningful changes in the caregiver's life due to this new function. Besides, the necessity of the resignification should come from the caregiver, due to the temporality experience; but it should count with the health team support, not allowing to the caregiver to feel insecure, alone and sick from tiredness⁽⁶⁾. In addition, the caregiver experiences' comprehension while caring for a family member with cancer and with no possibilities of cure, can contribute to effective nursing assistance with a coherent and resolute planning⁽¹²⁾.

METHODS

This is a qualitative research with phenomenological approach, consolidated on heideggerian assumptions⁽¹³⁾. The inclusion criteria were: subjects should be the main family caregivers of cancer patients with Palliative Performance Scale PPS) lower or equal 40%; who were caring for their family member for at least three months;

were older than 18 years and had physical conditions and preserved cognitive state to answer the questions. The PPS is a scale that assess five functional dimensions⁽¹⁴⁾, and it was used to identify patients with high level of dependence for daily activities.

Participants were selected from the FHE of a city located in the Northwest of Paraná state, chosen from teams linked to the Health Integrated Centers (HIC) with higher number of FHE teams registered in the National Registry of Health Establishments (NRHS).

After contacting the teams, the researcher was introduced to caregivers by nurses and/or Community Health Agents, who took the researcher to families' houses. In cases when inclusion criteria were met, the researcher made the invitation for a next visit and participation in the study. For data collection, three appointments were set with participants so that empathy was created and they would feel secure to talk about their experiences.

On the beginning, participants received guidance regarding the study's objectives, as well as their rights. At this moment, they were asked to sign the Free and Informed Consent Term. For the interview, the guiding question was presented: **"How is it being for you to take care of (name of the family member with cancer)?"**. The phenomenological interview occurred in an individual appointment, with only the researcher and the caregiver, allowing the comprehension experienced by the human being, as it is presented in their daily routine. For that, they needed environment adaptation, empathy and inter-subjectivity, therefore reducing pre-concepts⁽¹⁵⁾.

Interviews had an average duration of 40 minutes, and a recorder was used as electronic resource to capture all sentences. When developing the field work concomitant with the analysis, we determined 17 subjects, once sufficiency of meanings capable to answer the objectives was shown⁽¹⁶⁾. With the intention to preserve participants' anonymity, they were presented by angels pseudonymous.

To capture full expressions from their languages, we opt for individual analysis of each speech. Thus, we read carefully each testimonial, separating the parts or meaning units (mu) shown as fundamental structures of the participant's existence⁽¹⁷⁾. After, we analyzed the meaning units of each testimonial, conducting phenomenological selection of each subject's language⁽¹⁷⁾, originating ontological themes, analyzed with some heideggerian ideas, as well as from experts about the theme, and researchers who teach about palliative care.

The field step occurred during November of 2012 and February of 2013, respecting the Brazilian norms to conduct research with human beings. The project gave origin to the research approved by the Permanent Ethics in Research Committee from the Universidade Estadual de Maringá, process nº 435/2011.

RESULTS

Seventeen people participated in this study, being 16 female, the majority was married/living together, only one single and one separated person. About actual profession, major part of caregivers stayed home and was retired, one was a massage therapist, one was an administrative professional, one was nursing assistant, and the others were away from work due to their new occupation. The main characteristics of participants can be seen at Chart 1.

Chart 1: Main characteristics of interviewed caregivers. Maringá, PR, Brazil, 2013.

Deponents	Age	Relationship	Time from diagnosis/Initial location	PPS (%)
Zadkiel	70	Wife	2 years / Oropharynx	40
Ariel	67	Wife	8 months / Intestine	30
Jeremiel	56	Wife	2 years / Prostate	40
Miguel	51	Aunt	1 year / Breast	40
Moraël	46	Daughter	2 years / Intestine	10
Shateiel	43	Cousin	4 months / Stomach	20
Rafael	59	Mother	3 months / Brain	30
Fanuel	44	Husband	6 months / Stomach	20
Jofiel	69	Wife	1 year / Intestine	40
Afriel	70	Wife	3 months / Oropharynx	30
Manu	60	Daughter	6 months / Intestine	20
Gabriel	49	Wife	5 months / Stomach	30
Antriel	50	Daughter	2 years / Lungs	40
Uzziel	70	Wife	7 months / Stomach	30
Caliel	55	Daughter	4 months / Blatter	20
Haniel	42	Daughter	1 year / Uterus	30
Camael	55	Wife	4 months / Intestine	40

From the language analysis, the following ontological theme emerged as presented:

Unveiling the temporality to live with cancer at home

In this theme, we present experiences of caregivers who care for dependent cancer patients, as temporal and historical beings, demonstrating that temporality is affected in the patient's life as well as in the whole family.

Remembering the vigor of the patient

[...] to see her suffering, wanting to eat and not being able to, to drink something and then spit it all out, before she used to eat with so much pleasure! It was nice to see her eat and now she can't anymore, I feel sad to see her like that, there are days when I can't sleep (Fanuel).

We feel agony, to see such a strong man, hardworking, on a bed, we suffer, it is too hard, it's not easy. He used to go out, worked a lot and came home, we lived few years away too, in Rondônia, he was so strong [...] (Camael).

Remembering the vigor of themselves

I think that I end up with myself, it's been a long time that I don't go anywhere, before I used to take walks, do arts and craft, I used to do everything, but now I don't do anything, there is no time, there was a time when I started

to do it again, but I would be worried about him and when I would get back he was complaining so then I stopped, on my free hours I sleep or do crochet (Jofiel).

We stopped in time, I don't go anymore to the city center to buy one piece of clothing, I used to get out of here to the center on Saturdays with the girls and I don't go anywhere anymore, I've stopped, stopped [sighs]. So then it's home, home, doctor, home, it is sad right?! There is no way, I would like to get out of this (Zadkiel).

[...] I used to stay a lot by the beach with my daughter hanging out, used to stay 15 or 20 days, she had a pool and I was always in the pool, used to go to birthday parties, weddings, I used to go out a lot, used to go to the city center, walk to Church and coming back, I used to be three years without going to the center, my life changed, I dedicate myself here, I stay two, three days without getting out of the gate, so my life changed, it changed a lot, but I feel happy because I take care of him with body and soul, sometimes I feel sad, but I don't cry (Uzziel).

Glimpsing in the future answers to their concerns

[...] it is hard, we are together in this path and all the sudden something like this happens, we hope a lot for him to be cured, I hope so much, every day I ask God because he is my companion, so many things together, when I

don't touch the subject I feel better, but when we have to talk about this I get really emotional, I even apologize to you [cry] (Gabriel).

[...] I used to be a person always fearing for tomorrow, and there was a point when I had to forget this fear and fight for today, only who goes through that knows [...] we have faith that he will be cured, we believe that God does the whole work [stops, look at nowhere] suffering makes you learn lots of things, learn to have patience and especially, to know how to wait (Rafael).

Temporality giving comprehension for the situation

One thing that I've learned is to search more for God, to trust Him, I've also learned to look more to ourselves, to have more love. It can also happen to me so I have to take better care of myself. I stopped smoking. Today it's completing three months, I took too long, tried and couldn't stop. So many people fighting to be with their health well and we are throwing life away?! (Anriël).

These days I was thinking that this is a learning process in our lives, I was so clean with the house, I was cocky right?! Everything stunk to me! I thought I would never go through this, I was so proud, and then I was thinking that we are nothing, everyone needs help, one day it can be me, then what? Proud doesn't bring nothing to anybody, we have to be always available to help [...] this made things change, I've started to act and think differently, to think that you can leave for later, you have to do it, everything changed in my life, I've learned to do things from my heart and I was happy to see that I could become another person (Haniel).

[...] I saw many people hospitalized, each one with a different disease, and this is really sad to see [cries], people dying on her side, I think this makes us think a lot [stops, reflects and say:] I've started to give more value in minimal details of life, no money pays your health! (Shateiel).

DISCUSSION

In the heideggerian analysis, the being is also denominated as Dasein, to be there or to be in the world, is how something becomes present, manifested, perceived, understood and, finally, known to the human being⁽¹⁸⁾. Its existence is inseparable from temporality, the man only exists because he is fundamentally linked to time, besides, discusses not only in addition of moments, but from a comprehension in the most profound meaning of the future, past and present⁽¹³⁾.

Temporality is not identified with things, it allows a manifestation of man and world, once the meaning of one is revealed by temporalization or the opening of time denominated temporality⁽¹³⁾. In the anticipated decision, that is, in the original and authentic way of caring, the person reveals all of its power-being, that is manifested in a temporal constitution⁽²⁰⁾.

In this temporality, one also becomes historical, but its historicity does not reside in the simple fact of him being the object or subject of the story, but if having a destiny. And what in fact makes part of its human existence can only be known in the history, in a sense that this is what predominates in his time in the world⁽¹⁸⁾. And in this existing path, it is possible to become temporal in three ecstasies, what is coming (future), the vigor of what had been (past) and the actual (present). Future refers to possibilities of being, the past refers to what was lived and the present, to the occupation⁽¹³⁾. These ecstasies are "mobilizations" that push the presence and do not succeed one another. The future does not come after the past and the past does not come before the present. At each instant, the presence is its future, its past and present⁽¹⁹⁾.

It was perceived in the deponent's language that living with cancer in this instant made the caregivers project and remember how healthy their family member were. "The past has sense only in the measure of this person seen as part of the present"⁽²¹⁾. It was also noted that in this reality, caregivers also expressed regret from have lost the life they had in themselves, that was taken

away from their family member disease. In this instant, they live with the emptiness in their souls.

The need of caring for a dependent family member exposes the caregiver to a series of circumstances that affect their senses, their daily lives and their lives in general⁽²²⁾. The caregiver starts to perform tasks related to the attention of basic needs, creating a permanent and wearing attention⁽²³⁾.

Thus, living with cancer in the house, the caregiver can return to his past and look at their trajectory of pain and suffering, as well as feel that their emotions are still alive in his present⁽¹¹⁾. "The human being can go back to his past because life gets compact; it crystallizes under meaningful ways, giving sense and value"⁽²¹⁾. Thus, its history shows memories from being the caregiver and from their ill family member, revealing the history of not only what happened, but also its origin and its meaning to the person, considering their everyday living experience.

Being one a temporal person, this temporality of existing in a world caring of a family member with cancer makes him always understand as this or that way. Also considering the caregiver perception of not feeling as himself/herself brings the positive possibility of becoming a whole in something. It was noted in some lines that the time of caring is at the same time to feel not like themselves when experiencing fear and sadness regarding the aggressiveness of the disease. In these moments, the time that brought some many sad truths and laughing lies comes as a lightning of hope in a pleasure to come.

The future takes precedence over other ecstasies, once it is in the future that there the caregivers will have the possibility to anticipate and properly come to themselves. However, it is not about holding the future as extension of the past and the present, but as what it is to come, from which emerges the possibility of a passage, that replaces the human in an original relationship with one. A possibility to be, to jump in freedom that, astonishing at nothing, he found another way of being for

humans, called presence for allowing the human being to be "there" of being⁽¹⁹⁾.

The future opens the can-be of Dasein, which is the crucial condition for projective self-comprehension⁽²⁰⁾. Thus, all can-be has conditions to come to himself, because his is already thrown in a reality, being necessary to reflect about his condition as being in the world, assuming or denying the different possibilities⁽²⁰⁾. So, some deponents found reasons to keep their hopes and, although all difficulties imposed by the high dependence, they keep themselves strong in the battle against the illness.

The comprehension of human existence is not something that happens immediately, it is constituted over time through articulations of meanings expressed to the world, because as a being, the man attributes meaning to things that are related in their existence horizon. The human being experience the everyday at each moment, and feelings of sadness and happiness that expose others surrounding them, in this existential horizon through their language⁽¹³⁾.

Therefore, some participants found themselves restrained to the present moment and past, not glimpsing an anticipative future neither their different possibilities. It was found that, sometimes they hide the disease in their families and feel afflicted with changes in their temporality. Regarding their experience as caregivers, they cannot see something positive and/or rebuild in their lives.

But, it was also interpreted from testimonials that to see the suffering of the other, it made them emerge in their everyday and search for strength to face their fears, letting their most proper power come to them. In summary, although the illness experience is not yours, by sharing every moment, some caregivers were able to reflect and project their future, rebuild their past and change their present.

Thus, temporality brings the capacity to anticipate themselves, when they comprehend their existing facticity. Thus, it is possible for the caregiver to find new

significance to this story away from the concreteness of a life fixed in frustration and in negative feelings⁽⁶⁾. This makes them feel their life restored and, especially, their ability of being themselves, that is, a caregiver.

Palliative care as a special assistance, can contribute to rethinking of caregivers' actions. When acting in agreement with palliative propositions, it becomes possible to be in a relationship with the other in a determined existing time and space. And, in this manner of being one with the others in this world, care is manifested as a worrying possibility of the person with himself, incentivizing him to also worry about others⁽²⁴⁾. Thus, caregivers maybe comprehend how imperative is to not deny the illness of their family members, reflecting that many things can still be done and that "existing" surpass cure.

In the elevated dependence condition, the care with the ill person becomes imperative considering that the end of cancer is a far possibility, thus, unveiling wishes and aspirations below of what is said by the patient; and his family can help them understand the temporality of the condition, therefore freeing them from the everyday world. When having conscience about what they can be and their freedom, the person produces initiative, spontaneity and creativity⁽²⁰⁾, allowing to find ways to meet their hidden desires.

Communication is a valuable instrument in implementing palliative care actions. If adequate, it is comprehensive for the patient and the family, valuing the experiences as a process that influences meanings attributed to the disease and its terminal stage and consequently, decisions that should be considered for treatment strategies⁽¹²⁾.

Nursing professionals from the FHS can establish a relationship of bond and trust through communication when accompanying families. This actively contributes in this care process between caregiver and dependent, consolidating an effective palliative assistance. Nursing assistance to the caregiver should privilege information, clarify doubts and help the caregiver to face difficulties

with the appropriate resources to their sociocultural needs⁽⁶⁾.

When knowing how to listen and promoting the growth of the other, it becomes a fact to incorporate palliative care science to the art of caring, propitiating improvements in the assistance provided. Thus, only through this effective communication it is possible to comprehend the temporality experienced by these people and, then support the cancer patient and family considering an integral, resolute and coherent assistance with its subjectivities.

CONCLUSION

Assuming the responsibility of assisting a dependent family member with cancer meant to the caregiver to have his routine and life changed by the other's disease. With that, it recalled the existence of his family member as well as his. Sometimes he was stuck to this ecstasy, closing himself to different possibilities; and sometimes he glimpsed a promising future and modified his instant.

To be inserted in the territory and to follow the families under his responsibility allow health workers, in special nursing professionals, to share the world of these caregivers, instigating health professionals to rethink their everyday actions trapped in the past that hides their possibility of being themselves. The future should be noticed within the ecstasies, so that the caregiver's thinking and actions prevail, because, to let the possibilities of being come to them makes the instant more real and less suffering.

Thus, it is necessary to look at temporality so that professionals comprehend the different nuances of this experience, as well as considering the desires from the patient-caregiver binomial, putting them in a therapeutic agent position and not only patients.

This authentic care is precisely present in palliative care, and it should be noted when present in the caregiver routine; presented and incentivized when absent, and strengthen when in disbelief. In addition, it should be developed, for example, by the nursing professional with

the intention to reach the major goal of palliative care and nursing, that is, to assume their essential project of being a caregiver.

It is noticed that it is not possible to generalize results from this study to other FHS teams from other cities,

considering that findings are linked to time and space of experiences lived by deponents and by the qualitative nature of the research. Even with those limitations, it is believed that this study allowed important reflections, contributing to expand the knowledge about this theme.

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