

# Palliative care for the cancer patient: psychological impact on the caregiver family member

## Cuidados paliativos para o paciente oncológico: impacto psicológico no familiar cuidador

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### Resumo

**Introdução:** Os cuidados paliativos são uma abordagem ativa e integral de saúde prestados à pessoa com adoecimento grave, progressivo e que ameace a continuidade da vida. Este tratamento quando iniciado precocemente visa a melhor qualidade de vida do paciente, por meio do alívio da dor e sintomas da doença, beneficiando também seus familiares. **Objetivo:** O objetivo deste trabalho foi investigar os impactos psicológicos em familiar diante do diagnóstico e do tratamento em cuidados paliativos do paciente oncológico. **Material e Método:** Trata-se de uma pesquisa qualitativa com desenho de caso único, com uma participante de 50 anos, cuidadora do pai, durante o período de cuidados paliativos em sua residência. O instrumento utilizado foram duas entrevistas semiestruturadas com intervenção suportiva. **Resultados:** A partir da análise de resultados, observou-se que a participante decidiu se tornar cuidadora responsável pelo seu pai, demonstrando impacto emocional e físico intensos e questionamento sobre sua fé, sendo necessário adaptar-se e ressignificar sua vida diante desta experiência. **Conclusão:** Concluiu-se que, houve impacto psicológico na participante a partir da vivência das mudanças causadas pelo adoecimento do pai e a adaptação ao cuidado com ele, com sentimentos de medo e ansiedade diante da expectativa da morte, e após a falecimento, a entrevistada mostrou ambivalência afetiva relacionada à perda e à necessidade de readaptar sua rotina, sendo este um processo gradual do luto.

**Palavras-chave:** cuidados paliativos. câncer. morte. família)

### Abstract

**Introduction:** Palliative care is an active and comprehensive approach to health provided to people with severe, progressive illness that threatens the continuity of life. This treatment, when started early, aims to improve the quality of life of the patient by relieving pain and symptoms of the disease, also benefiting their families. **Objective:** The objective of this work was to investigate the psychological impacts on family members on the diagnosis and treatment in palliative care of cancer patients. This is a qualitative research with single case design, with a 50 year old participant, caregiver of her father, during the palliative care period at your home. **Methods:** The instrument used was two semi-structured interviews with supportive intervention if necessary. **Results:** From the results analysis, it was observed that the participant decided to become a responsible caregiver for her father, showing intense emotional and physical impact and questioning about her faith, being necessary to adapt and resignify her life before this experience. **Conclusions:** It was concluded that there was a psychological impact on the participant from the experience of changes caused by her father's illness and the adaptation to caring for him, with feelings of fear and anxiety at the expectation of death, and after the death, the interviewee showed affective ambivalence related to the loss and the need to readapt her routine, this being a gradual process of mourning.

**Keywords:** palliative care. cancer. death. family.

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## Introduction

According to National Cancer Institute, in Brazil, the cancer incidence in the world shows about 17 million people with the disease (excepting skin cancer no melanoma). The most frequent types of cancer are lung cancer, breast cancer, colon and rectum cancer with about 9,5 million deaths. In Brazil, the estimate for the biennium 2020-2022 was 450 thousand new cases, among them the most common types were breast cancer, prostate, colon and rectum, lung and stomach cancer. For every cancer type the early diagnosis is fundamental, because the metastasis is a risk whereas the velocity and cells multiplication have the capacity of invading other organs or other parts of the body, maintaining the primary tumor characteristics<sup>2,3</sup>.

When the discovery of the cancer illness occurs, all the family goes through moments of guilt and suffering and also through situations that influence family members' behavior: physical and emotional demands for the care, changes in daily routine, roles and responsibilities transformations, projects postponements, financial worries, beside other aspects the family has to deal with<sup>4,5</sup>.

Cancer diagnosis generally causes a destructive effect in family members who accompany the patient. The caregiver thinks about death and other possibilities which can initiate suffering, as mutilations, disfigurement, painful treatments and possible loss caused by the disease<sup>6</sup>.

Since its diagnosis, cancer is associated with death, even considering the advance of medicine. Death permeates all the treatment and passes through the after treatment. When the patient enters the state of remission or finitude, the blame for death of the other one and the lack of care

sensation are the family members' feelings. Many times, family members ask or demand for maintaining the patient alive, even when that includes a lot of suffering and excessive financial expenses<sup>7,8</sup>.

However, when the remission of the disease is impossible and the cancer patient's prognosis is not favorable, it is necessary to think about alternatives which can bring adequate comfort, total proper care taking palliative care. The patient's suitability process to the care depends on several factors like age, type of disease, previous individual and family experience relative to the disease and to death, the coping pattern of stress situations, patient's social and economical conditions and also a lot of cultural variables involved<sup>9</sup>.

[...] you should not confuse palliative care to second line treatment, rear or when you do not know what to do. Palliative care is a first line attendance since managed by specialized teams in that attendance. It is a contraposition to use the Intensive Care Unit, where the machines are more observed than the patients.<sup>10</sup>

Palliative care is linked to two health actions: to heal and to care. In the healing paradigm, the high-tech medicine has a very important role, letting more humanized practice in a second plane and generating losses in the quality of life. In the care paradigm, there is acceptance of death as a human condition, considering the individual who is sick, emphasizing multidimensional aspects of the disease and of the total pain. The quality of life in several dimensions is the professionals' main concern in this paradigm<sup>11</sup>.

In oncology, the practice of palliative care provides a total approach of the individual and when it is early initiated it may bring healthy prolongation actions, as palliative chemotherapy and

radiotherapy, as long as it is to care and to relieve suffering, decreasing clinical stressful situations and filling the lifetime with quality. It is about offering a dignified life to the chronic or terminal patients, thinking they are also parents, husbands or wives, sons or daughters or siblings with their life history<sup>12,13</sup>.

The caregiver's importance is unquestionable considering the health assistance to the cancer patient. The caregiver becomes the main auxiliary, being responsible for supplying the patient's physical and emotional necessities. But, in order to care the patient in a proper way, the caregiver also needs social assistance for daily emotional support, for eventual guidelines and for problems solving<sup>14,15</sup>.

Assuming the caregiver's role in the own residence, the family begins to perform many new functions never performed before, like administer medication, handle and clean probes and drains, bandage and also make the patient's personal hygiene. The caregiver needs to deal with the worsening of symptoms and the possibility of death. In the face of this reality, the act of caring the patient at his/her home in an advanced stage of the disease becomes an activity that causes physical, emotional, social and economical overload in the quality of family life. The fact demands a reorganization process, changes in everyday habits, professional and personal routines and also in psychological aspects<sup>16,17,18</sup>.

It is essential to understand that death should neither be anticipated nor delayed, but it has to occur in a natural process, and the caregiver's family should offer him or her a better quality of life in this stage that causes so much pain and suffering. It is necessary a natural disease recognition and the diagnosis must be objective and must have basis. It is important to have empathy between the

patient and the main caregiver in the family, because that will facilitate treatment and both will be more confident<sup>19</sup>.

Loved one's death, as a father, mother, sibling or a close friend belongs to an intimate patrimony, oneself's components. When the family bury a loved one, enjoyment and hope finish and there is no solace for that moment, because a person refuses to accept a replacement for the loved one<sup>20</sup>.

To live the fear of death everyday makes the patient and the family members transit among five stages before accepting their condition. The first stage is the "denial", when people deny the existence of the situation, trying to decrease or to soften the impact of the news; the second stage is "anger" that becomes a constant feeling when people admit the disease is real; after, "the bargain", when they try to negotiate with God; then, "the depression, loneliness and isolation", when a self-assessment process about what may be done begins; and finally, "the acceptance" that is the understanding of all the process<sup>21,22</sup>.

The last patient's moments are matched to a unique period, emotionally intense, when there are the possibilities of hits and goodbyes. It is required that patient and family are ready for future events with attention and proper management, punctually in that period, to not suffer unnecessarily and to not extend the death process in a painful way. The objective of those processes is to avoid the feelings of failure of caring or abandonment that may affect the family in that moment. There are people prepared to accompany a family member's death process and they have a different experience and no terrifying memories. The preparation helps to decrease anxiety and fear and increase confidence about the care given to the patient in the last days<sup>11</sup>.

It is requisite to say goodbye before death, because after that there are only memories and longing. Pardon must occur in life, because guilt may torment the caregiver for a long time and may harm the grieving process. In this way, family members are allowed to say what is not socially convenient including the desire that the patient may leave soon and in peace. The family is the caregiver, but the family needs care, too. Family is considered the “occult patient”, mainly when the patient needs lots of care, because the caregiver may succumb to sadness and to stress. Both will suffer less in farewell occasions if they can manifest their feelings: the patient gets respect and dignity in the end of his/her life and the family member gets the necessary care<sup>23, 10</sup>.

The idea of mourning is not only limited to death, but to the coping with recurrent losses that occur during human existence, which may be real or symbolic<sup>24</sup>. Mourning may be experienced through significant links with personal, professional, familiar and social aspects. Suffering in the mourning period is a feeling that takes time to be cured. The grief creates tasks which must be fulfilled, even they are sorrowful and difficult to people in their moment of experience. Psychological help facilitates the process giving greater hope that something can be done and showing that the way can be traveled by the bereaved in a lighter way<sup>25</sup>.

In another conception about mourning, Stroebe and Schut present the dual process. In that model, they do not consider phases or stages, but a dynamic oscillatory process in which now the bereaved confronts the mourning tasks, now the bereaved avoid them. The adaptive coping covers the confrontation of stressors related to mourning, avoidance and restoration<sup>26</sup>.

## Materials and Methods

This is a qualitative research describing a unique case. It addresses the possibility of describing how the phenomenon occurs in a unique individual, looking for evidences that contribute theoretically with the idiographic approach<sup>27</sup>.

The participant of the research was a 50 years old woman, a cancer patient's daughter. The patient was in palliative care.

Two semi structured an hour and a half long interviews were done with the participant. The interviews were related to the daughter's feelings, perceptions and behaviors since her father's diagnosis, the palliative care implementation and her role as main caregiver.

The interviews were performed via the internet, using the Google Meet platform, respecting the ethical norms of secrecy and privacy and with the signature of the Free and Clarified Consent Term. The interviews were recorded and transcribed in full. The recording was erased and the transcription is stored for five years.

The research was submitted to the Research Ethics Committee of the Institution under the number CAAE: 40585720.6. 0000.5510 with the judgement 4.446.875 on December 8th, 2020.

## Results and Discussion

The results and the discussion will be presented in this topic. The materials of the interviews will be presented with the analysis of the diagnosis meanings, of the representations of the illness, of the palliative care and the caregiver's experience with that family member. The first interview occurred when Mary (a fictitious name) took care of her father in her residence and the second interview occurred when her father had already died.

When she received a diagnosis of terminality, several sensations as incapacity, fear and uncertainty of how much time she could have with her father were awakened and she began an intense search for information and other medical opinions in order to finish the doubts about the severity of the diagnosis. Finally, she decided to reorganize her life to take care of her father.

*[...] I talked to many doctors, to more than three doctors when I've got the diagnosis and they said what will happen. When he was interned in the regional hospital here in the city, the oncologist talked to me, didn't she, telling how much it was aggressive and that it was already in metastasis and... kind of, not worth it, not worth it the suffering to investigate that metastasis, so much that he wasn't placed in the oncology group in the hospital.*

*Yeah. years ago when he had prostate cancer, I didn't know anything, in the family there were their relatives who died of that, but we didn't have contact, so we didn't know what they faced. And so, with the prostate cancer, I studied a lot about the theme and I saw that there was a great possibility of cure, wasn't there? Now with this one in the lung, we went to research, too, and we saw that the lung is the one that kills the most in Brazil, isn't it, and even more with his history.*

The confirmation of the second diagnosis generated the beginning of a new phase to Mary and her family members, an anxiety process was settled because of a palliative treatment which brought several

procedures with the objective of relieving her father's pain. It is known that the illness can change the family functioning, because depending on the degree and the cancer advance, the perception of finitude becomes present, making the family members go through a daily reorganization process. Cancer, being so full of stigmas, fear and uncertainties impacts on the diagnosed individual and on the family environment intensely, how shows Mary in her report.<sup>18</sup>

*[...]Now, when we discovered that cancer, I left my work and I made a deal, I said: I need to care him, beside this my mother is a wheelchair user, so it's impossible to let them alone, isn't it?! And to pay to someone, too, it didn't compensate, because I thought it was better that I'd stay with them, even because the salary I was receiving it wasn't worth it, so I wanted to care them for love.*

Mary decided to leave her work in order to be her father's caregiver full time. This is in accord with many authors who address the necessary changes in habits and experiences, when a family member gets sick. The caregiver has to give special care to the sick person, letting go of his/her personal and professional life to offer total care and attention to the family member.<sup>16,17,18</sup>

*[...] the first cancer I followed all the time, I was still working, wasn't I? I had full company support that time, because I went with him to the radiotherapies and so, radiotherapy is a lighter thing, isn't it? You don't vomit or anything, and so I was kind so calm.*

*[...] It's the three of us, I moved a time ago, they lived alone and I've been separated for a year and in that year we discovered the cancer and so I came back to live with them again.*

In the face of this report, it is clear that the participant changed her life to live together his father and to care him. In this way, she left her personal projects and dedicated herself to the illness situation exclusively. Other authors address the fusion of the patient's life with the caregiver's life, understanding that both become only one, because the caregiver leaves his/her necessities and obligations to supply the family member's need. The family and the patient become a single unit, doing a double role as caregivers and also as care receptors.<sup>15</sup>

It is common that the main caregiver's role is assumed by the closer person who has already done determined tasks. Sometimes the choice is made by the family members or it is made spontaneously. However, the role is performed by a female majority, daughters or patients' wives.<sup>18</sup>

*Yes, I'm strong. So, like today, he went to the Emergency Room, my mother cried a lot and before going to the Emergency Room, he's not speaking well, do you know? And I can understand the gesture he makes because I am all the time with him; he called me softly: "I am dying". And so he went to the Emergency Room, so it seems that penny is dropping because he told me that he was dying.*

The participant's report shows that there is an understanding of her father's

diagnosis gravity, but she hesitates to accept the loss that is approaching, with difficulty accepting the reality, suffering an advance regret as a reaction to the predicted loss. This fact is in accord with the family member's end of life process, being one of the most difficult to accept.<sup>11</sup>

During the treatment, several patient's and caregiver's feelings are expressed in many different ways, as anger, denial, tension. Such feelings can appear during the adaptation process to the new family condition.<sup>12,18,5</sup>

*[...] Sometimes I think that God doesn't exist, because He shouldn't make suffer the people we love, because if He was good, why does He do that? Then I am in this questioning with God.*

*[...] Then I have to take care of everything, I'm always very strong, but I'm going to collapse, I don't know, it's difficult.*

In her caregiver role, Mary begins to perform many functions that she has never performed before, and she had to deal with the worsening of symptoms and the possibility of death. With her father's finitude approaching, Mary begins to question her beliefs. Therefore, this report is not in accord with what several authors affirm, when they say that family members use faith as an important strategy to coping with both diagnosis and cancer treatment and that prayer and reflection are ways to bear the stages of the disease, when the family receives a loved one's cancer diagnosis. The participant in this research questions her Faith, when she looks for the necessary strength and perseverance to bear the disease and the consequences of treatment, feeling abandoned.<sup>16, 17,18</sup>

*In the past, I slept all night, now I don't sleep anymore, 'cause in the middle of the night he wakes up, he feels pain, and I make some tea to relieve his pain and I don't go out anymore, unless my sister comes and says: 'go out a little, I'll stay with him.' Then, in the meantime, I think I went out only once. I went to a friend's house to eat a pizza, but when it was ten o'clock, I said: 'I want to come back'. I'd rather be here than there.*

*[...] It also changed the fact of washing my hair everyday, 'cause before I washed everyday I made brush, I tidied myself up, now I enter in the bathroom, I take a bath quickly, I wash my hair twice or three times a week, 'cause it's very busy.*

*[...] I follow up with a psychiatrist, I'm a binge eating, so you can imagine how I am feeling in this period, I eat all night and I take care of him all night. Before I went hiking, I walked on the treadmill, but now it's finished, 'cause I'm not living for me anymore, I'm living for him.*

Mary begins to live for his father, showing a strong attachment to him, failing to do basic everyday activities in order to give him the necessary support. Some authors understand that family relationships begin to change with the advance of the disease and they are transformed in dependence and attachment between patient and caregiver.<sup>17</sup> But other authors affirm that caregivers not always demonstrate their suffering to the closest or complain about the care load, because they prefer to focus on the patient's condition, specially with the advance of the disease and treatments, fact that explains the participant's report.<sup>15</sup>

Facing the news of loss and when she witnessed the fact, Mary feels that she still needs to take care of him like she did in his life, as the following report demonstrates.

*[...] so when the door opened at noon, that scene, other horrible scene, too, that it's marked in my head, was that I wanted to enter soon to see how he was in the coffin, that instinct kind of: ouch! I need to take care of him, he needs me. But he didn't need me anymore.*

Mary begins to live her mourning with the awareness that her father was not there for her care. She initiates the elaboration of the loss and because of that memories and expectations related to the lost object begin to be switched off her mind in a slow and painful process.

Mourning is the loss of an important link between a subject and a love object considered as an expected phenomenon in human life cycle. Mourning is not only related to death, but it conceives the confrontation of successive real and symbolic losses during human development.<sup>24</sup>

*[...] So when he left, I already provided that they come to take the bad, 'cause it was rented. I changed the living room decoration, I changed the curtains, I put plants into the room, I lit incense and I did everything kind of that. I was relieved because I could do my little things, but with a heavy conscience for being thinking like that.*

Understanding that deal with grief is a dynamic process, the participant

confrontates the task of taking away the objects that reminded the father, things associated to his disease, although feeling guilt for that, demonstrating the possibility of oscillation which permeates all the process.<sup>26</sup>

*[...] The three granddaughters put a weathervane on the earth. I thought that was very beautiful (cry) and so after I went to see the meaning, the weathervane means that it is taking his soul to a good place, because of that it's spinning all the time, it's kind of a symbology.*

The rituals go beyond the action and are full of symbols. Those symbols may have many meanings and may describe what we cannot express by words. The weathervane meant to the bereaved a rite of passage, and those rites may be represented by successive acts restricted to the family and may be repeated as time goes by. Those actions and behaviors have the task of transmitting a value to each participant in each specific situation.<sup>23,26</sup>

*[...] My God! I'm not crying! I thought: 'am I so bad that I don't feel anything about my father's death? Because I'm not crying.*

*At the beginning I felt guilty because how I told you, gosh, I'm not crying, it seems I'm feeling good because he's gone, but it's not that, in anyway, but it's that most selfish human being's thing, that relief that now I can think more about me. I could sleep at night, thing that I wasn't doing anymore, but after all we put the thoughts in their right places and I'm intelligent and I could*

*separate them well and it's not that.*

*"Yes, it was. It was in this way, I'm going to be sincere with you and you're psychologists and you can understand. When my father's gone, I felt that feeling of relief, but relief with a heavy conscience, because I couldn't feel that relief, but I was really feeling that..."*

Mary presents ambivalence and guilt which appear during her mourning process. It is important to highlight that those main feelings experienced during the end of life care come from the family member's survival wishes and, at the same time, from the wishes of his/her death to relieve his/her suffering.<sup>8,26</sup>

*[...] the worst thing this feeling of catching[...] catching somebody's hand who has gone, it's an ice that freezes to the soul, do you know?! Then now, telling you, I can cry, can you see?*

Mary's report is in accord with the necessity of a mourning organization process for the acceptance of the definitive loss and the certification that a new life has to begin. During the acceptance phase may appear feelings like longing, sadness, cry, which are part of the gradual grieving process.<sup>26, 28</sup>

Every family member can have different behaviors and reactions facing death, therefore at that moment it is fundamental not make judgements about the feelings and emotions, because at that moment a family member can feel guilt for not feeling sadness. Accepting attitudes and feelings will avoid hostility and recriminations and it will provide



effectively solidarity. This is what Mary seems to ask to the researchers in her reports above, that they can understand and accept her feelings.<sup>29</sup>

*I had to ask my brother to stop with that silly and call my mother because she was missing him and he was sending me audios, crying, telling that he couldn't talk to my mother and the two siblings crying.*

*Wow, I've never cried like that after he's gone, I'm crying now, it's because I'm talking and reviving everything, isn't it? Then, many times my sister is always crying, but she's naturally dramatic, and so I'm blaming myself, I'm thinking, wow, why don't I cry?*

The caregiver's experience at the own residence seems to present a better answer relative to caregivers who lose their family members in hospitals or who could not take part in the patient's life in an active way. However, it seems that the participant continued as the family caregiver after her father's death. She was still looking for strength to deal with her mother's and sibling's pain and suffering, instead of thinking of herself. Being heard as a person who can suffer makes the participant express her own suffering.<sup>17</sup>

*[...] So, it was that the step I took for myself, I'm still with my psychiatric and my medication didn't change, it continues the same. I went back on a diet because I have binge eating, food, because of this I do that psychiatric treatment and all that thing with my father I ended up*

*making up for more and more food, so I forgot myself indeed.*

*[...] Now I have an online store, I'm an Individual Micro-entrepreneur and I'm doing some orders, but I do what I can do and I take care of the house, I take care of my mother.*

The adaptation to a new environment brought many different meanings to Mary, because she went back to do her craft work as a distraction. This fact is in accord with the approach about the coping with loss, that needs to be in such a way that reverses for the caregiver's benefit, giving meaning to the loss and finding earnings, in other words, there are two dimensions to the assigned meaning after a loss, therefore it is associated to the fact of finding benefits from death.<sup>25</sup>

## Conclusion

It is understood that impacts in Mary's caregiver life were real, bringing physical and mental changes, but they were also subjective impacts, because they came from the assigned meanings to the illness situation, to the changes she had to make in her life, to the importance of her role in that moment and to the relationship she established with her father.

Facing the suffering coming from the consciousness of the severity of diagnosis and from the understanding of death expectation, the participant realized that she had to change her daily routine. She began to learn about the illness to know it better in order to provide more well-being to her father in this palliative care process.

The experience of changes caused by her father's illness and the adaptation to

the care of him brought psychological impacts, because she began to live with frequent feelings as anxiety and fear. Those impacts reflected also in her body, with sudden changes, increased appetite and sleep disturbance, which became harmful to whom was in psychiatric treatment for a while.

In the face of her father's illness, religious representation was shaken, because with the approach of loss she began to put in doubt her beliefs, questioning God's protection in that moment she needed the most.

From the analysis of results it appears that the caregiver participant needed to give meaning to the care experience, for leaving her personal life in order to provide to her father a better quality of life in his finitude.

In the face of her father's death, the interviewee was impacted and she demonstrated affective ambivalence related to the loss and to the necessity of giving a new meaning to her routine, to her house, to her habits, parts of a gradual grieving process. The second interview had a welcoming aspect, being therapeutics to the participant, because it helped in the legitimation of her suffering for her father's death, fact that 'authorized' her cry during her report.

It is noticed the importance of doing new researches with critically ill patients' family members. The fact of being a single participant does not allow the generalization of knowledge and it is not possible to determine if there would be changes in results with a greater number of participants.

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