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Experiences of cancer patients' family caregivers in palliative care

Juntos resistimos, separados caímos: vivências de familiares cuidadores de pacientes oncológicos em cuidados paliativos

Juntos resistimos, separados caemos: vivencias de familiares cuidadores de pacientes oncológicos en cuidados paliativos

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ABSTRACT

Objective: This study was aimed to describe the experience of family caregivers of cancer patients in palliative care and to analyze its implications for nursing care. **Methods:** It is a descriptive study with a qualitative approach that was carried out using open semi-structured interviews. The transcriptions were submitted to Content Analysis. **Results and discussion:** Three units appeared: "End of Life, Cancer and Palliative Care", addressing the impact of palliative care suggesting the need for providing assistance for end-of-life patients; "Challenges of family caregivers", regarding the caregivers' choices and difficulties, especially financial ones; and "Chocking Experiences of family caregivers", emphasizing the impact of diagnosis and cancer pain as more significant experiences. **Conclusion:** It is necessary to listen, give voice and know the life history of family caregivers for the satisfactory planning and promotion of nursing care and health education.

Descriptors: Oncology nursing, caregivers, palliative care.

RESUMO

Objetivo: Descrever a experiência de familiares cuidadores de pacientes oncológicos em cuidados paliativos e analisar as implicações para o cuidado de enfermagem. **Métodos**: Estudo descritivo de abordagem qualitativa, com coleta por meio de entrevista semiestruturada aberta e transcrições submetidas à análise de conteúdo. **Resultados**: Mediante análise construíram-se três unidades: "Adeus céu azul: a terminalidade da vida, o câncer e os cuidados paliativos", abordando o impacto e a migração para os cuidados paliativos sugerindo auxilio ao enfrentamento; "Respire fundo: desafios dos familiares cuidadores", tocante à escolha do cuidador, às privações e às dificuldades financeiras; "Maior que palavras: vivências que marcaram", enfatizando o impacto do diagnóstico e a dor oncológica como vivências mais significativas. **Considerações finais**: É necessário ouvir, dar voz e conhecer a história de vida dos familiares cuidadores para o

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planejamento e promoção satisfatórios da assistência de enfermagem e educação em saúde.

Descritores: Enfermagem oncológica, Cuidadores, Cuidados Paliativos.

RESUMEN

Objetivos: Describir la experiencia de familiares cuidadores de pacientes oncológicos en cuidados paliativos y analizar las implicaciones para el cuidado de enfermería. **Métodos:** Estudio descriptivo de abordaje cualitativo, con colecta a través de entrevista semiestructurada abierta y transcripciones sometidas a Análisis de Contenido. **Resultados:** Mediante análisis se construyeron tres unidades: "Adiós cielo azul: la terminalidad de la vida, el cáncer y los cuidados paliativos", abordando el impacto y la migración para los cuidados paliativos sugiriendo auxilio al enfrentamiento; "Respire fondo: desafíos de los familiares cuidadores", con respecto a la elección del cuidador, las privaciones y las dificultades financieras; "Mayor que palabras: vivencias que marcaron", enfatizando el impacto del diagnóstico y el dolor oncológico como vivencias más significativas. **Consideraciones finales:** Es necesario escuchar, dar voz y conocer la historia de vida de los familiares cuidadores para la planificación y promoción satisfactorias de la asistencia de enfermería y educación para la salud.

Descriptores: Enfermería Oncológica, Cuidadores, Cuidados paliativos.

INTRODUCTION

In 2016, there were more than 596,000 new cases of cancer in Brazil[1], and it is estimated that more than 20 million people need palliative care every year.[2] These circumstances required the implementation of national policies, such as the National Policy for Prevention and Control of Cancer in the Health Care Network of People with Chronic Diseases, from the *Sistema Único de Saúde (SUS)* [Unified Health System].[3]

Consequently, they demand multiprofessional action in a physical, mental, spiritual, social, and responsible way.[4] It is important to emphasize the nurses' dynamic work, especially regarding hospitalization, based on the triad that values the team, the medical institution, and the patient/family.[5] The caregiver accompanies the diagnosis, treatment, relapses and the follow-up for palliative care, carrying them out in an arduous and painful way, motivated by the hope of a cure, with disappointments, sufferings, heavy workload, and experiences that tend to be intensified with the evolution of the patient's disease.[6] The family often suffers from emotional, social, economic, and cultural embarrassments. Being an inseparable binomial, it is the responsibility of the nurse and team to establish partnerships and trust.[7]

Given the aforementioned, this research was guided by the following question: "What are the perceptions of family caregivers about caring for cancer patients in palliative care and what are the implications of these perceptions for nursing care?" In order to answer this question, the experiences of family caregivers about delivering care for cancer patients in palliative care were described, analyzing their implications for nursing care.

METHODS

This is a descriptive study with a qualitative approach conducted in a palliative care unit for oncology patients, which is part of the Center for High Complexity in Oncology (CHCO).

The study participants were 18 family caregivers being over 18 years old, who signed the Informed Consent Term. The number of interviewees was defined by means of saturation sampling. Continuously, data collection was defined through an open semi-structured interview - questions based on the discussions and theories of the study. The interviews were carried out between March and April 2016 in a private room, and recorded with prior authorization, ensuring respect for anonymity, autonomy and not maleficence.

The script of the interviews was: 1. "What do you mean by 'palliative care'"?; 2. "How have you been chosen to provide care?"; 3. "What has changed in your life since the diagnosis of your family member's cancer?"; 4. "What daily care do you deliver to your family member with cancer?"; 5. "Did anyone teach you how to deliver that care? Who?"; 6. "How do you feel about taking care of your family member?"; 7. "How is your relationship with the health team?"; 8. "Is there any impactful situation about the family member's cancer that you have experienced? How do you feel when you remember it?". Also, word association was employed: 1) "When I speak the word 'cancer' what comes to your mind?"; 2) "When I speak the word 'palliative care' what comes to your mind?" 3) "When I say 'taking care of a relative with cancer' what comes to your mind?".

Data were collected and submitted to Content Analysis using systematic procedures to describe the content of the messages, inferring knowledge about the conditions of their productions/receptions, and transforming them into thematic categories.[8] This study was approved under the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appraisal] No. 50318015.4.3001.5550.

RESULTS AND DISCUSSION

The participants' age range was from 18 to 48 years old (arithmetic mean of 23.7 years old). Out of 18 participants in the study, 13 (72.2%) were female and 5 (27.8%) were male. Fourteen out of 18 interviewees reported having children. Considering the family bond, 11 (61.1%) participants were grown-up children, two were siblings and 2 were spouses (22.1%), one was the mother, one was a grandchild and one was a nephew (16.5%) of the patient. All participants claimed to be Christian: 11 (61.1%) were Protestants and seven (38.8%) were Catholic. Ten (55.5%) participants had a paid job and eight (44.4%) were self-employed.

End of Life, Cancer and Palliative Care

Diagnoses are postponed for various reasons: lack of money for traveling, care site, delay, lack of specialists, belief in "no right for access", lack of a companion, lack of good feelings towards health care workers, strikes, among others.[9]

When asked about the word 'cancer', 12 participants (66.6%) reported the fear of death according to the following reports:

> *I think like one's life's not going to end, right, that his dreams are over. (E8)*

> *A horrible thing! You only know it when you have a relative and you go through a situation of this kind that we will know how serious it is. (E9)*

> *For me, death is coming. (E10)*

The image of cancer as an incurable disease were the second important aspect to be considered because of the reports of 6 (33.3%) participants:

> *It is a disease without a cure ... Loss is coming soon, too, because there is no cure. The family gets desperate because the loss is coming soon. It's certain pain! (E5).*

> *A disease that has no cure and leads people to death. So, for me, it's a very painful word. (E6).*

> *It is a difficult disease to cure, to treat. You see, it's a disease from this era, the doctors themselves don't know what to do. (E7).*

Regarding the health-disease process, cancer is stigmatizing due to its degenerative capacity. Denial and isolation are the phases of discovery, defense, and partial acceptance. Anger consists of impotence, which is caused by delayed treatment and self-punishment. After anger is gone, negotiation is the moment when the team needs to welcome both patient and family. Depression is evidenced by the visualization of the symptomatology and the changes in the activities causing the feeling of loss. Finally, there is acceptance, the loss of the will to fight.[10]

The main clinic is specific for patients with no prognosis of cure, justifying the discourses that make up the process of suffering characterized by the fear of death, shown as troublesome and difficult. By experiencing grief and its human realities, we return to the memories of those we have lost.[11] Because of this, the communication of the patient's admission to palliative care beforehand allows it to prepare for the patient's death.[12] The feeling of knowing about the death of someone still alive is called "anticipatory grief".[13]

A unique understanding makes up the philosophy of palliative care (the humanist focus), starting from the ethos of care and not from the ethos of cure.[14] Providing comfort and making the day less painful for the patient was evidenced by 12 family caregivers:

> *It's like giving an improvement, not only for the patient but for those who accompany it, giving better care, better support. (E1)*

> *Palliative Care... Giving the best comfort, giving assistance so that he has a quiet daily life. (E11)*

> *That's when you no longer have any possibility of having surgery, no procedure for the patient, then they send him here to be taken care of. Only God knows how long he'll be alive! (E9)*

On the other hand, 6 interviewees were unaware of the objectives of palliative care:

> *It's a disease that's spreading through the body. (E3)*

> *I don't know, we're getting by as it happens. (E7)*

> *I have no idea what it is. (E16)*

The word "comfort" originates from the Latin *confortare* which means "to fortify", "to certify", "to corroborate", "to grant", "to console", "to relieve", and "to help". Its meaning is the act of comforting oneself and others.[15] Palliative care was mostly linked to comfort, but only E1 related it to the support for the family caregiver. The speech of the participant E7 highlighted the importance of dialogue to induce resilience and confrontation.

Confrontation can be understood as the individual's ability to engage in behavioral and cognitive effort to deal with adverse situations.[16] Faith, trust, and belief in a Supreme Being help caregivers to deal with the short lifespan of the sick person.[17] Faith were evidenced in 13 (72.2%) out of the 18 family caregivers.

> *Science has that limit, but above that limit is God. And He can do anything. (E1)*

> *So, I already put it in Lord's hands because he was already abandoned by the doctors. (E17)*

> *I pray a lot to God to give strength to me, and to him. (E8)*

Spiritual belief is eventually the only source of relief for understanding death, life, and physical finitude in the face of misfortunes.[18] Family caregivers with strong religiosity and spirituality have a better general state of well-being, more confidence, and a lower incidence of anxiety and depression and.[19]

Despite scientific and technological progress, holistic assessment and the patient-professional relationship have become fragile: spirituality is a real proposal for the humanization of health services.[20] Effective spiritual care has obstacles: the spirituality term; lack of time and privacy; personal, cultural and institutional factors; discomfort in approaching; fear of impositions; thinking about irrelevance; high workload; and lack of professional training.[21]

Due to the lack of follow-up, the discovery may occur at an advanced stage or with no possibility of a cure. The health-disease process in the field of cancer produces innumerable feelings, high stress and affective memories that emerge into the desperate context, bringing great suffering. In palliative care, there is the intention of comforting and making the days of patients and relatives less painful. It is important to emphasize the relevance of spirituality as a mechanism of confrontation and anguish reduction, and also the academy's approach to spirituality.

Challenges of family caregivers

When asked about the adherence method, 12 family caregivers reported having been chosen by the family or felt that they had a duty:

> *It was by choice because I spent a lot of time without talking to my father, so I thought it was my duty. (E8)*
>
> *I'm an only child. I've always been more like a mother and her like a daughter. I always took care of her more, going after her, scolding her because she's a little disobedient, she liked to drink alcohol and I was scolding her. So, I was always responsible for everything at home, for her, my two children and my husband. (E9)*
>
> *I always lived with her, unfortunately, it was just me. (E12)*
>
> *I came because there was only me, nobody wanted to come! I live with her and said that I came to take care of her until the end of her life and I'm here. I had no choice, only I could come. (E16)*

On the other hand, informal agreements are observed for following up the patient in relays in order to reduce workload:

> *My three brothers and I talked with ourselves and decided. According to each one's needs, we take turns. (E1)*
>
> *It's because we do it: I, my mother and my sister. One day it's her, one day it's me, because it's just the three of us. (E2)*
>
> *We're eight brothers, but only four are taking turns, my brother said: "Let's do our part! Each one does his part and that's it. The one who doesn't want to come... He doesn't have to. 'That's when I made the decision to come. I'm self-employed, if I miss a day of work, nothing's is going to change. (E17)*

It is emphasized the affective proximity, gender issues, and filial and legal obligations because the majority of the family caregivers are daughters of the patients. Gender is constructed from social, political, and economic milieu.[22] In this study, the inequalities visualized by the gender perspective manifested themselves through symbolic violence as evidenced in the female participants' claims regarding being the only child and the follow-up relays being performed only by women, even with the existence of other brothers. Bourdieu[23] defined this as a "soft violence", which is unperceived and almost unrecognizable.

Filial obligation refers to the cultural responsibility and affective bond that justify the care of the adult children to elderly parents.[24] The Statute of the Elderly is considered a moral obligation because this law defines the rights and duties of children towards their parents, including the role of maintainers.[25] Thus, the affective bonds and motivations of this "acceptance" have repercussions on the execution of care:

> *It represents the affection I have for her and the certainty that she's here, because that's what she needs, the way she is, she needs affection, that we give her attention. (E6)*
>
> *Giving affection, giving love, affection, attention. (E1)*
>
> *Donation. It's about dedicating yourself to that person. (E15)*
>
> *I was the one who changed her dressings, I did it carefully in a very clean way. [...] I did it at home, every time, twice a day. I am happy to take care of her at the end of her life, mother is mother, right?! You have to take care! To this day I feel affection, I have nothing to complain about. (E16)*

Taking such responsibility also interfered with the quality of life. Thus, interviewees described it as a burden:

> *Well, that's pretty much what I do, I had to quit my job. Since there's not another person, I started to take care of everything: eating, dressing, cleaning up the house, everything. (E7)*
>
> *Much work. Concern. (E10)*
>
> *I feel constant suffering, because we suffer with him, with the patient. Every pain, every suffering, not to mention that sometimes they're feeling so good and we aren't. You have to try to be strong so you can give him strength. But sometimes it's difficult. (E12)*

With regard to changes in daily life, all participants reported changes, social isolation, and leisure deprivation. However, losing the job was the most drastic change:

> *My job ... I closed my bakery to take care of her! (E 11)*
>
> *I leave my work and come here. So, my workroom is closed and I'm here with him. (E18)*
>
> *I quit working, quit college. I can't even see my boyfriend regularly. (E15)*
>
> *I had to leave my job so I could stay here full-time. (E4)*

Maintaining paid jobs generates financial independence, good relationships and a sense of appreciation.[26] When they leave their jobs, they lose their autonomy, have debts and even lose social support. For example, the brothers of a woman interviewee felt no obligations to take turns as they paid for the hospitalization costs.

Caring for the relative as a means of showing thankfulness or "apologizing" for is an indicative of proximity. With the decision of who will take responsibility, challenges raised to alert other relatives about the relays. Gender, family and law obligations, and exhaustion are moral dilemmas and, in this perspective, the nurse has the choice of empowering themselves and alert the multiprofessional team in order for its members make contributions.

Chocking experiences of family caregivers

When asked about the most shocking experience:

> *When I was waiting for him to leave the surgery, they said that his organs were already lost. We thought he was going to be operated on and he was going to get well, that's what we thought, and it was shocking. We thought he would be happy after the surgery, but he was sad. (E2)*

> *When the pulmonologist told me that he's having metastasis and explained what it was, I came to understand what my father's real situation was and it was at that moment that I was feeling lost, knowing that it was irreversible. It's shocking! (E11)*

> *When they told me there was no way. "Oh, your mother will stay in the hospital taking medicine until her last days." That hurt me. I feel very sad, knowing that one day she may not be by my side. (E14)*

The second most significant experience was the disease's intercurrences:

> *When she went to stay at my sister's house. My sister was the one who took care of her. She screamed in pain, laid on the floor, rolled in pain. It is very sad to see a person suffering, even more being a relative. We feel sad... (E10)*

> *That was when I arrived with my wife at the ICU (Immediate Care Unit); and see so many people suffering from pain and even including two people near her who passed away after three days of hospitalization. Oh, if I could not remember. (E13)*

> *Waiting for the transport to bring him to the hospital and seeing him in pain and not being able to do anything. It is a slow drug process, slow transportation process, slow process of getting better care for the person there. (E5)*

Difficult news or bad news is negative and drastic information that negatively changes the expectations about the future and the response will depend on hope and psychosocial context.[27] Support activities include: assessing information needs, clarifying misunderstood information, acquiring and translating medical information into an accessible language and support.[28]

Another point is the understanding of pain beyond its physical manifestation and centered on the familiar caregiver because the multidimensionality of pain affects those who experience and who observes. Knowing the types of suffering, empathy must be strengthened: affective suffering (suffering, discomfort, fear, evasion, agitation, visceral sensations), vicarious pain (both painful and non-painful vicarious sensations) and empathic concern (compassion, desire to help, state of empathy).[29]

The relationship between professional and family caregiver was described as good and even aspects such as care, education, and attention were praised. Nonetheless, the perception of receiving a "good service" were highlighted. After recognizing the good relationship, the guidelines were rejected by the allegation of having no knowledge about them:

> *No. All that is the result of own observations. (E8)*

> *No. We learn at that very moment! (E9)*

> *Nobody taught me anything. Nobody told me anything. (E14)*

> *We learn how to bath as the time goes on, no one taught me. (E17)*

Likewise, support guidelines promoted by health education actions are recognized as essential for understanding the family caregiver:

> *Yes. The speech therapist taught me how to feed him. (E4)*

> *The nurses, yes, taught me to change the diaper, to bathe, they're teaching me slowly. (E18)*

> *I was just supporting the nurse. And then she told me where I had to help. (E1)*

Teams must pursue knowledge and answer questions with dialogue, provocation, reflection, questioning, and discussions.[30] Despite the idea of health education is focused on respect, participation, autonomy and gap filling, several times it is carried out as a transfer action and content repository without any connection with the subjects.[31] In order to dialogue, it is necessary to listen and give opportunity to speak, exposing the differences.[32]

Human interaction, stressful daily living, procedures and bad news are the challenges that technological advances and health professionals have not overcome. Faced with sociocultural characteristics and the subjects' worldview, there is no exact formula to deal with the emerging expectations about cancer. Considering the results regarding the absence of support guidelines, the interpretation of the Freirean conception can be a means to guide health education planning. We conclude that the impact of advanced diagnosis and pain were the most shocking experiences. It is emphasized that it is not possible to understand the depth of the chock in its entirety. However, empathy, active listening, welcoming and the construction of knowledge through the appreciation of the uniqueness and potential of every human being are inferred as medullary.

CONCLUSIOS

In the present investigation, we attempted to reach an understanding of the perceptions of family caregivers on the care of palliative cancer patients. In this way, it became possible to capture the experiences of suffering during the follow-ups and the understanding of the experience of finitude.

Confrontation, spirituality, and religion were emphasized as variables for minimizing the main concerns of the caregivers.

In addition, health education within the health care service should be an instrument for valuing knowledge, not focusing on transmitting information. Improving the nursing care for cancer patients demands the recognition of the family caregiver as care unit, enabling actions to their needs, planning and executing strategies and applying auxiliary strategies to decrease stressors.

We emphasize the relevance of this study for the assistance to family caregivers, the person in palliative care and the nursing science, given the discussions of social issues and health care practices, weaknesses in teaching, and paradigm shifts.

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