Meanings of Palliative Care for family members and its implications for anticipatory mourning

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This qualitative study aimed to understand the meanings attributed to Palliative Care and its implications for the anticipatory mourning process, from the perspective of family caregivers. Participants were 14 family members of patients in Palliative Care. Participant observation and semi-structured interviews were carried out. The data were analyzed and organized based on the Grounded Theory, using the Atlas.ti 7.5 software. The results showed the meanings attributed to Palliative Care marked by the impact of the treatment proposal, by the emergence of feelings and experiences, and traversed by the specific care requirements, the treatment, and the decision making, generating repercussions in the caregiver's life. Visualizing the set of meanings attributed during the process permits the support of actions in Palliative Care that recognize elements that constitute anticipatory mourning.
Keywords: Palliative care, caregivers, family caregivers, mourning, anticipatory mourning.

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Significados de los Cuidados Paliativos para miembros de la familia y sus implicaciones para el duelo anticipatorio

Este estudio cualitativo tuvo como objetivo comprender los significados atribuidos a los Cuidados Paliativos y sus implicaciones en el proceso de duelo anticipatorio, desde la perspectiva de los cuidadores familiares. Participaron 14 familiares de pacientes en Cuidados Paliativos. Se realizó observación participante y entrevistas semiestructuradas. Los datos fueron organizados y analizados teniendo como base la *Grounded Theory*. Los resultados mostraron los significados atribuidos a los Cuidados Paliativos marcados por el impacto de la propuesta de tratamiento, por la aparición de sentimientos, experiencias y atravesadas por las demandas específicas de cuidado, tratamiento, y toma de decisiones, generando repercusiones en la vida del cuidador. Visualizar el conjunto de significados atribuidos durante el proceso permite subsidiar las acciones en Cuidados Paliativos que reconozcan elementos constitutivos del duelo anticipatorio.

Palabras clave: Cuidados Paliativos, cuidadores, cuidadores familiares, luto, duelo anticipatorio.

Significados dos Cuidados Paliativos para familiares e suas implicações no luto antecipatório

Este estudo qualitativo objetivou compreender os significados atribuídos aos Cuidados Paliativos e suas implicações no processo de luto antecipatório, na perspectiva de familiares cuidadores. Participaram 14 familiares de pacientes em Cuidados Paliativos. Realizou-se observação participante e entrevista semiestruturada. Os dados foram analisados e organizados com base na *Grounded Theory*, com auxílio do *software* Atlas.ti 7.5. Os resultados evidenciaram os significados atribuídos aos Cuidados Paliativos marcados pelo impacto da proposta do tratamento, pela emergência de sentimentos e experiências, e atravessados pelas demandas específicas de cuidado, do tratamento, e de tomadas de decisão, gerando repercussões na vida do cuidador. Visibilizar o conjunto de significados atribuídos no decorrer do processo permite subsidiar ações em Cuidados Paliativos que reconheçam elementos constitutivos do luto antecipatório.

Palavras-chave: Cuidados Paliativos, cuidadores, cuidadores familiares, luto, luto antecipatório.

Signification des soins palliatifs pour les membres de la famille et ses implications pour le deuil anticipé

Cette étude qualitative visait à comprendre les significations attribuées aux Soins Palliatifs et leurs implications dans le processus de deuil anticipé, du point de vue des aidants naturels. Les participants étaient 14 parents de patients en soins palliatifs. L'observation des participants et les entrevues semi-structurées ont été réalisées. Les données ont été analysées et organisées en fonction de la théorie fondée. Les résultats ont montré les significations attribuées aux Soins Palliatifs par l'impact de la proposition de traitement, par l'émergence de sentiments, d'expériences et traversés par les exigences spécifiques des soins traitement et la prise de décision, générant des répercussions sur la vie de l'aidant. Visualiser significations assignées tout au long du processus il permet de subventionner les actions en Soins Palliatifs, qui reconnaissent des éléments constitutifs du deuil anticipé.

Mots-clés: Soins palliatifs, les soignants, les aidants naturels, deuil, deuil anticipé.

Palliative Care is treatment aimed at assisting the patient with serious illness and their family, in which the proposal consists of care from diagnosis to the support of mourning by a multidisciplinary team. This care values the early identification and prevention of physical, psychosocial, and spiritual symptoms, in addition to the relief of pain and suffering resulting from these, aiming to promote quality of life for the subjects involved (World Health Organization - WHO, 2002). Accordingly, Palliative Care can be considered an important care intervention proposal, taking into account the specialized knowledge regarding the end-of-life process (Breen et al., 2018).

The entry into Palliative Care can cause an impact on family members, including reactions and feelings of despair, anguish, and fragility (Cavalcante et al., 2018). In a study conducted by Bastos (2019), aiming to understand the experience of the primary caregiver of children and adolescents with cancer receiving Palliative Care, who entry into this treatment being showed the possibility of death, which is received with sadness and pain. Furthermore, the study highlighted that, even though the family members were informed about the Palliative Care, not everyone presented understanding about it, which led them to relate it to the impossibility of a cure. Another study, carried out with family caregivers, aimed to identify their perception of palliative care. The results revealed the lack of knowledge about what constituted palliative treatment and the health status of their sick relative, which indicates a lack of communication between the team and the caregivers, as well as possible assimilation difficulties of some family members (Cavalcante et al., 2018).

Regarding the relationship of the family with the health team, situated within the Palliative Care experiences, the study by Bastos (2019) highlighted that, with the exception of one mother, whose perception indicated the lack of adequate care and understanding with the family members, all the other participants said they trusted the work performed by the professionals, feeling calm and confident. The relationship with these professionals represented an important element for coping with the adversities arising from the illness process (Bastos, 2019). Similarly, in the study by Breen et al. (2018), which aimed to explore the family caregivers' preparation for the death, the participants were satisfied with the quality of communication and care provided by the professionals. In other services, the study's findings reported the physicians' harshness and lack of empathy, in addition to difficulties regarding access to relevant information.

The health team professionals compose the social support network, defined in this study as the service provision practices developed in formal institutions and organizations, with a view to preventing harm and promoting health. Individuals in this network can perform functions with both emotional and material perspectives, which collaborate to reduce stress and increase the subject's well-being (Ornelas, 2008). Regarding the social support system, there are perceptions about inadequate services that trigger stress in individuals due to their slow responses (Williams et al., 2011) and the feeling of being insufficient to fulfill the needs of the patients and family members. Furthermore, caregivers can feel that they are on the sidelines of the care, considering the focus on the patient (Nicholas et al., 2016), as well as being frustrated with the Palliative Care services when they feel that their expectations are not fulfilled due to receiving little practical assistance (Arber et al., 2013).

During the illness, family members are called upon to perform specific care, exclusively dedicated to the patient, and to adapt to the treatment routine, its requirements, and its developments. The repercussions can cause changes in the caregiver's life, including changes in daily activities and in their work (Bastos, 2019). Therefore, the task of looking after for the patient can represent demanding care, based on a routine that involves providing practical assistance, related to hygiene, food, and medication, as well as emotional support (Queiroz et al., 2013). This not only results in the disruption of their usual routines, but also impacts on the health of the caregiver, considering that the implications of the performance of care can be reflected in feelings of fatigue and physical and/or emotional exhaustion (Breen et al., 2018; Coelho et al., 2019; Nicholas et al., 2016). In addition, the financial costs associated with the care and the loss of profitable activity led to impacts on the family's financial situation (Bastos, 2019; Williams et al., 2011).

Corroborating these aspects, the study by Coelho et al. (2019), which aimed to explore the experiences of family caregivers of patients with terminal cancer in the context of end-of-life care, identified the feeling of interruption and suspension of their lives, given the abandonment of work and leisure activities due to a routine centered on the illness, considered tiring. The need for family members to make decisions related to the patient, such as whether or not they should invest in other treatments, or to ask for other medical opinions, was evidenced. These issues resonated at other times throughout the process (Coelho et al., 2019).

Family caregivers can also feel that their task effects their social relationships, which, in turn, can lead to the social isolation of the caregiver (Coelho et al., 2019; Collins et al., 2016; Nicholas et al., 2016). This can also be seen in changes in intra-family relationships, in which, for example, there is a decrease in intimacy among the caregivers (Nicholas et al., 2016), or avoidance behaviors by other family members and friends (Arber et al., 2013). Conversely, this experience can lead caregivers to constitute a new network of relationships, through being close to people that are going through similar situations, generating the feeling of reciprocity (Collins et al., 2016; Nicholas et al., 2016). The possibility of sharing with people who have issues in common provides reciprocal support relationships, which favors coping with the experience of the disease (Sluzki, 1997).

Sluzki (1997) highlighted that, when falling ill, there may be a negative impact on the individual's significant social networks, since there is a restriction of social contacts. The people that favor the recognition of the individual as such and that perform functions, helping in times of crisis are considered to compose these networks. It is, however, possible that other networks can be constituted based on experiences in health systems (Sluzki, 1997). In the context of Palliative Care, these networks can be thought of as the route through which the interactions of caregivers become centered on the illness scenario, due to the care and treatment requirements, causing limitations in their exchanges with people outside the situation.

In this process, caregivers can feel supported by the other family members, who help in the provision of care (Breen et al., 2018; Williams et al., 2011). Care requirements can be balanced when there is a network articulated and available around the caregiver, such as family members, friends, and the health team. However, these members may not be available to provide assistance, and the low availability of support can generate a burden on the primary caregiver, with feelings of anguish and an increase in stress levels (Arber et al., 2013; Bastos, 2019; Queiroz et al., 2013; Williams et al., 2011), as well as causing tension in the caregiver's relationships with family members and friends in general (Breen et al., 2018).

The performance of the care can assume representations, such as providing comfort and support for the patient, as well as a sense of duty and affective repayment. Furthermore, the task of caring for and accompanying the patient can be considered painful and difficult, requiring patience and sacrifices (Queiroz et al., 2013). In view of this, the impossibility of controlling the disease and containing the patient's suffering favors the emergence of feeling of helplessness (Bastos, 2019; Nicholas et al., 2016). The worsening of the disease tends to make these feelings more evident, leading some family members to hold the care providers accountable for failures and absences in social support (Coelho et al., 2019). In addition to the feeling of helplessness, it is common for family members to suffer when faced with the effects of the disease (Cavalcante et al., 2018).

In turn, it should be noted that the repercussions of severe illness, as well as the implications generated by the performance of patient assistance in Palliative Care, place family members in the position of facing the possibility of loss and death, configuring the experience of anticipatory mourning. This is understood as a process experienced by the patient and their family since the diagnosis of a serious illness, which involves reactions and feelings according to moments that resemble the stages of mourning after death, such as shock, denial, ambivalence, anger, bargaining, depression, assimilation, and acceptance. This experience affects both the unity of the family and each of its members, considering anticipatory mourning as a family, social and, also, individual and subjective process (Fonseca, 2004). From this perspective, entry into Palliative Care can produce the anticipatory mourning of family members (Bastos, 2019), considering the losses triggered by the progression of the disease and limitations in their personal lives (Collins et al., 2016).

Based on what has been presented, the aim of this study was to comprehend the meanings attributed to Palliative Care and its implications for the anticipatory mourning process, from the perspective of family caregivers. The relevance of this study is based on its contribution to the scientific production on the theme, which is still incipient in the Brazilian context, regarding the focus on family members. In addition, it highlights the importance of making the guiding thread of anticipatory mourning visible, in order to shed light on the experiences of family members. This information could also favor support for health promotion actions that consider family members as protagonists in Palliative Care, assisting in the management of this process and contributing to the elaboration of anticipatory mourning.

Method

Participants

This qualitative, exploratory, and cross-sectional study was carried out from October to November 2019 with 14 family members of patients receiving Palliative Care in a hospital context. The number of participants was based on the study by Guest et al. (2006), developed in the context of qualitative research with the use of in-depth interviews. This study indicated that 12 participants would be sufficient to achieve the theoretical saturation of information. Accordingly, family members over 18 years of age were included, who, at the time of the hospital admission, were accompanying a patient whose health status was considered stable by the hospital health team.

The participants, 9 women and 5 men, were between 25 and 72 years of age. Regarding the level of education, the participants presented: Incomplete Elementary School (3), Complete Elementary School (1), Complete High School (6), Incomplete Higher Education (2) and Postgraduate degrees (2). Regarding the occupational situation, the participants were: unemployed (3), retired (3), graphic designer (1), self-employed (2), physiotherapist (1), distance teacher (1), shop attendant (1), installer (1) and furniture assembler (1). Half of the participants were married or were in stable relationships, and 7 of the participants lived with the patient.

The time since the discovery of the family member's illness varied between 6 months and 18 years, and the length of Palliative Care hospitalization, between two days and five years, with all the patients suffering from cancer. Regarding the performance of care, 2 participants mentioned not sharing the task with any other person, and the other 12 counted on the help, even if in a casual way, of: siblings, aunts, father, mother, sister-in-law or godmother. The patients' ages ranged between 36 and 84 years, and the relationship between the family member and the patient were: spouses (2), children (9), granddaughter (1) and siblings (2).

Measurement and procedures

The first stage was constituted as a participant observation that lasted for 1 month and 3 weeks, with fieldnotes. The hospital, located in the South of Brazil, had an Oncology Support Unit for the provision of Palliative Care from a multidisciplinary team.

After this stage, semi-structured interviews were conducted with the accompanying family members, the script of which included questions covering socio-demographic data as well as: a) the meaning attributed to starting Palliative Care; b) the meaning of the patient's illness process considering the possibility of death; c) how the participant had faced the situation; d) decisions related to the illness process; e) the conversations developed between the family members about death; and f) additional auxiliary questions aimed at deepening the narratives. For this, healthcare providers from the Palliative Care team indicated which patients were in a stable health condition and then the researcher approached the possible participants, explained the aims of the study, and invited them to participate, with the best time to start agreed obtaining consent. Before starting the interviews, the Consent Terms (Appendix 1) were explained, and the participants signed the form. Due to unforeseen circumstances arising from a reform of the hospital structure, the interviews were conducted in different places in the institution. In all these places, efforts were made to preserve the participants' privacy. With the participant's authorization, all interviews were audio recorded and subsequently transcribed and analyzed.

Data analysis

The data that emerged from the study were analyzed and organized considering Grounded Theory, proposed by Strauss and Corbin (2008), using Atlas.ti 7.5 software. This method includes open, axial and selective coding steps. Considering this, the material was thoroughly examined, and elements were identified in the common and differential aspects among the data. Subsequently, these elements were grouped together, relating them to categories and subcategories. Subsequently, the data were refined and integrated, allowing the construction of interrelated categories, configured around the central phenomenon of this study. This process allowed the organization of 3 main categories: 1) Following the Palliative Care treatment trajectory; 2) Experiencing changes faced with the care requirements; and 3) Feeling the implications of the care process on the family caregiver.

Ethical considerations

In addition to the care related to privacy, preservation of the subjects' well-being and the procedures related to the consent terms, all other ethical aspects, as explained in Resolution No. 466/2012 of the National Health Council of the Ministry of Health, were respected. The research was only started after approval from the Ethics Committee of the University with which the study was linked, under CAAE number: 03196118.2.0000.0121, as well as approval from the Ethics Committee of the hospital where the data were collected. To explaining the results, the participants are identified with the letter "P" followed by a reference number.

Results

The results of this study were organized into categories and subcategories around the central phenomenon. The elements of analysis, highlighted in italics, lead to the presentation and articulation of these results, as well as further discussion.

Following the Palliative Care treatment trajectory

Based on reactions to the social support system. The participants' narrative brought elements of the history of the illness, that is, from the discovery of the advanced disease, the impact of the diagnosis, to the physical and emotional interventions and repercussions of the treatment trajectory, even those prior to starting Palliative Care. The trajectory through the health services showed reactions to the social support system, such as anger and the perception of this cruel thing, causing despair: "I arrived at the Health Center screaming for them to help me, to do something, because they had let it get to that point ... Hell, why did you do this! I had saved him... Now it's there, look, he's condemned" (P7).

From the impacts of the palliative treatment proposal. The proposal for palliative treatment caused *shock*, *questioning* and *discomfort*, as explained by P2:

> It was at shock when they said they were not going to do anything ..., I even questioned them a lot about doing exams, because I still think they left something to be desired in this matter (...), but what bothered me was the fact that she couldn't do the treatment.

This led the family members to seek information about Palliative Care on the internet, from scientific knowledge, as well as information obtained from the contact with other people: "From what I was told, hardly anyone leaves here alive" (P14). "She did not want to go up, because she heard that here, the 2nd floor, was already heaven's door" (P1). Faced with this, there were also reflections on how to tell the patient: "How am I going to talk to her about this, that there is nothing she can do, that she just has to wait for death to come" (P5). This, at times, caused the information about Palliative Care to be withheld from the patient, with the reasoning of not taking away their hope.

Based on the meanings attributed to Palliative Care. The treatment trajectory was also traversed by the meanings attributed to Palliative Care, which were constructed around the representation of giving up on life, when the patient opted for this treatment. Also included was the concept of "having nothing more that can be done", being synonymous with death. From another perspective, the family members understood palliative care as end-of-life comforts and essential given the patient's fragility, promoting pain control, assistance for the family and a sense of security.

From this, different perspectives in the family were glimpsed, regarding the understanding and positioning in relation to the palliative treatment, including the patient. This perspective generated conflicts among the family members: "We went through many conflicts before we could understand that she was not giving up ... we had several, various conflicts with her, with all the children. Nobody understood, not my brothers, nobody understood" (P3). In addition, some family members (4) mentioned not knowing what Palliative Care meant: "Palliative care, I don't know. They say Palliative. For those who don't know, it's the same thing as having a coffee" (P7) and others reported "not knowing that it existed" before the hospitalization.

From the feelings related to the Palliative Care process. Feelings emerged in this trajectory, related to the Palliative Care process, such as the *relief* that the treatment represented an alternative, given the impossibility of a cure. Hopelessness and frustration at "having nothing more that could be done" were revealed; grief, due to the sadness felt faced with the situation; as well as a mixture of feelings: "I had mixed feelings about it" (P3).

Based on the Palliative Care experiences. The experiences in Palliative Care were considered positive, as they provided the possibility of experiencing this end-of-life process together with the patient, as well as being able to "open the heart", and to develop bonds between the caregivers. Concomitant to this, witnessing other deaths was mentioned as an impacting moment for the family members and for the patient: "Two people have already died in the room we're in.... It was heavy! ... My wife looked at me, wide-eyed like 'help me, do something'". (P1), "Because the day I arrived my father's roommate died... Then, this morning, I went out in the hall, saw a father crying, probably his relative had died. So, it is difficult to think that... you get out of here alive" (P14).

The perceptions about the health team and the performance of the Palliative Care referred to: being humanized, providing the service with good treatment; with the healthcare providers being understanding, attentive, caring about the patient and offering comfort and welcoming the family members. The institution was considered to be a "reference": "Here you feel... in a way, comforted by everything you're experiencing" (P6). Communication with the team, at times, seemed rushed "because... it is not every day that the doctor is there to... let you know about things, which is a hell of a rush" (P4). These indications point to possible difficulties in communication, the provision of mismatched information, discomfort among family members, patients and the care providers, leading P1, for example, to consider Palliative Care as a "misleading advertisement" and, in the words of the same participant: "I will be very honest with you: it doesn't work" (P1), because, according to him, the quality of life valued by Palliative Care encompassed more than the treatment they received, in addition to mentioning that the "greatest" concern was always directed toward the patient.

Through the acceptance of the Palliative Care. The assimilation and acceptance encompassed the possibilities of conversations about Palliative Care with family members, the team, with the patient, and with people that had gone through a similar situation:

> When she arrived here, we talked to many people, many care providers, because then I wanted to understand 'is that so? Do you think so too?'... So, wow! The load came off our backs and... it was very good for her, because we had the opportunity to tell her 'mom, I'm sorry I didn't understand you before, but I understand you now' (P3).

These meanings, together with the experiences of the illness and care process, allowed the redefinition of the Palliative Care, gaining other forms, such as: providing quality of life, comfort, relief in seeing that the patient was no longer suffering, with it being seen as caring and humanized. Other family members indicated that their concept of Palliative Care remained the same. The acceptance process also represented a family journey, based on the length of time each member needed for preparation: "After we take the initial blow, we have to accept it in some way, some take more time, others take less, each one has their own way... you reflect and try to accept it in the best possible way" (P8).

Experiencing changes faced with the care requirements

From the requirements of the patient and the treatment and the implications for the caregiver's life. The requirements related to the patient and the treatment led the family caregivers to "assume the front line" in relation to the care of the patient, in addition to emphasizing that the focus of their lives became the patient, causing the feeling of having stopped living: "Now I'm living her life, I'm not living my life anymore... so my life doesn't exist anymore, I don't exist anymore... I go to the bathroom when I can, I brush my teeth when I can" (P5). The family members reported a routine of care, for example P1 said:

> If she needs to go to the toilet, something like that, that's another period of 2 hours, 3 hours to organize that... If she wants to take a shower, that's it, there goes my day, because I have to bathe her … Then she gets out of the shower. After she dries, there's the bandage on her back, where she has secretion…

These requirements permeated the personal and family routine and demanded the reorganization of activities, such as time and place of work, leisure, and household shopping, among other aspects. To assist the patient, the caregivers received support from family members with whom they could share care tasks, while, on the other hand, they also reported the absence of support from family members: "and my brothers, where are they? It is me who takes the entire responsibility" (P5), which sometimes caused conflicts in the family, due to refusals to help with the care of the patient. The care demands also generated financial expenses due to the need to buy medicines, diapers, hygiene products, and other items.

In the care process, relational changes were noticed between the patients and caregivers, such as, for example, one patient that started to call her daughter "mother". There were also changes among family members, such as one participant that mentioned having distanced herself from her brother because of his attitude against the palliative treatment. It was also observed that other people withdrew from social networks: "We don't receive visits from anyone, we don't have friendships, because we can't... we don't have a social life. In short, I spend most of my time... alone" (P1).

From the repercussions on the caregiver's commitments. The care requirements effected the caregiver's daily commitments, such as paying bills and having no one to stay with the patient or having to work and not being able to organize the time for this, as well as the need to perform domestic activities, such as cleaning the house and preparing meals. The following narratives exemplify this: "For you to have an idea, I already gave my mother medicine to sleep during the day, so that I could go out, I said, 'I have to pay the credit card and it has to be today, how am I going to do it?!' (P5) and "I found a job and would carry on working. It was just that, it was very complicated because… I am there at work, registered, I have to be on time, I have to leave, 'oh love, I need to go to the toilet', and she needs physical help" (P1). This, in turn, generated a financial impact for the family, given the difficulty in maintaining a stable and profitable activity.

Based on decision-making related to the care and treatment and its repercussions. The decision-making referred to assuming responsibility for the care of the patient: "First, it was to assume the responsibility, to take charge of everything and to assume responsibility… I said, 'guys, my mother needs me', you know? And so, no matter how much it hurts me, it is a decision that I had to take" (P5). The patient's home was also mentioned, which required the caregiver to consider the patient's desire in this regard, the availability of family members to care, and the feasibility for the caregiver to perform the care. In addition, there was a need to manage *bureaucratic aspects*, such as getting powers of attorney, doing financial transactions, and paying bills that were previously the patient's responsibility.

Accordingly, the decisions provoked questioning from the family member "my God, are we really giving up fighting for her, will I regret this?, several times I thought this" (P3). Disagreements and conflicts with other family members were also mentioned: "There is one more difficult decision, which is to set up this home team at my aunt's house against the wishes of my brother, who wants to take him to his house at all costs. And there is a type of war" (P3).

Feeling the implications of the care process on the family caregiver

From the impact on the caregiver's health. The implications generated by the care process were felt on the family caregiver because of the physical and emotional exhaustion due to the need to accompany the patient during hospitalizations and to be involved full time with the effects of the disease and the end of life: "I've lost about 5 or 6 kilos, I think... it consumes us a lot, you know?" (P4), or "I even said 'why did I bring her here?!'... look at that, for you to see how we get to this stage, like this, because I was exhausted" (P5). These implications, in turn, caused the feeling of stress, exhaustion and overload, especially for the family members who had little help.

From the meanings attributed to the patient care. The duty of care caused the concept of repayment to be present: "It is because he also took care of us, we have to take care of him. You have an obligation, right?" (P9), which was associated, for the family members, with the feeling of accomplishment: "I am sure that when my mother leaves, I will have a clear conscience, that I did what I could, that was within my power to make... you know, the rest of her life... the best possible" (P5). Performing the care also meant giving comfort to the patient, so that they would not feel alone. On the other hand, it meant sacrifice, given the "donation" of oneself and having to deal with the patient's stubborn and sexist ideas and behaviors, in addition to the repercussions of the disease, such as pain and hallucinations. These repercussions also led the care of the patient to be considered as something suffered.

From the feelings related to the patient and to the performance of the care. The feelings that permeated this process were related both to the performance of the care and to the patient, such as the feeling of anger of P5: "I was angry, because like I said, damn, it was her choice, she chose to smoke her whole life, you know, and now I'm living her life". Added to this, there were feelings of suffering and helplessness when witnessing the patient's pain: "I have seen myself, several times, lying next to my wife crying in pain, her holding my hand, saying 'help me, take this away from me', and the only thing I can do at that moment is to be by her side" (P1), "the patient and the person who is caring end up suffering, I think the family suffers even more, because… there is no medicine for the person who is there providing the care, to stop the anguish, the suffering…" (P6).

The set of results presented a constant interrelation of the main categories, subcategories, and elements of analysis, produced directly from the participants' narratives. This set intended to respond to the central phenomenon, which refers to the meanings attributed to Palliative Care and its implications in the anticipatory mourning process, with each component having a singularity and contribution to the comprehension of this process in the context of Palliative Care.

Discussion

Considering the results of this study, it was observed that the proposal for palliative treatment caused different reactions in family members, which passed through the feeling of shock, causing questions about whether this would be the appropriate treatment, generating discomfort and doubts about how to communicate the process to the patient. It is believed that these reactions, as well as the communication and omission of information for the patient, are related to the meanings attributed to Palliative Care and its possibility of assimilation, given the narratives associated with the departure of the patient, as if this treatment were approaching the end. This is in line with the studies by Cavalcante et al. (2018) and Bastos (2019), in which the entry into Palliative Care generated negative feelings, such as despair, anguish and sadness, due to the patient's health status and to highlighting the possibility of death. However, meanings related to comfort and essentiality were linked to the Palliative Care proposal, with the WHO (2002) proposing that this care be directed toward providing quality of life and assistance to patients and their families. The study by Breen et al. (2018) also demonstrated the possibility for family members to view palliative care from another angle, that is, from the perspective of providing care based on specialized knowledge at the end of life.

This breadth of perception led to divergent positionings in the family in relation to the palliative treatment and the generation of conflicts, with it believed that the different perspectives also refer to the possibility of assimilation of the loss on the part of each family member. According to Fonseca (2004), anticipatory mourning is considered to configure a singular and subjective, as well as family and social experience. Added to this is the idea that conflicts and disagreements are also elements that are part of the process and, therefore, need to be considered.

Studies such as those by Bastos (2019) and Cavalcante et al. (2018) also demonstrated the lack of understanding by some caregivers regarding the aims of Palliative Care, which was one of the findings of this study. It is understood that the difficulty in comprehending palliative treatment may be related both to gaps in communication with the team and to the difficulties for family members in assimilating the information, as found by Cavalcante et al. (2018). It can be reiterated that the feelings that emerged from the entry into Palliative Care may have led family members to defend themselves in a psychic dimension from the imminence of death, moving away from the reason why palliative treatment was being provided, that is, the worsening of the patient's health status. In this sense, it is possible to visualize, as highlighted by Fonseca (2004), the experience of a stage of denial, that is, detachment from what represents an inconceivable idea. This evidences once again the hallmark of the anticipatory mourning process.

Regarding communication with the team, there are indications in the literature that this communication may suffer difficulties in the transmission of important information regarding the care provided and the patient's condition (Breen et al., 2018; Cavalcante et al., 2018). Another factor that may have influenced the way family members signified this care was that they sought information from other sources and heard that the Unit where Palliative Care was performed in that institution was the place "where people died", which, in turn, affected them faced with the transfer to that Unit.

Furthermore, the arrival in Palliative Care was also influenced by the social support system, since reactions of despair and anger regarding the perception of “failures” in the service, both in technical and relational terms, were cited. Faced with this, health services can be considered poorly articulated and insufficient to fulfill the requirements of patients and family members, in view of a slow resolution time, which can generate helplessness and stress in caregivers (Nicholas et al., 2016; Williams et al., 2011). It is also considered that the responsibility of the healthcare providers regarding the patient’s health status may also be related to the feeling of helplessness faced with the progress of the disease (Coelho et al., 2019). It was found that the feelings that emerged from the process can also be seen as linked to the meanings attributed and to the patient’s health condition, since they varied between the concept of relief - when understanding that the treatment represented a care alternative - to hopelessness, frustration and grief, considering the association of Palliative Care with the imminence of death, and as equivalent to doing nothing more for the patient. The studies by Bastos (2019) and Breen et al. (2018) also highlighted feelings of sadness and anguish throughout the process on the part of family members.

With regard to the experiences in Palliative Care, these experiences were considered positive as they favored going through the process with the patient, as well as the development of bonds between the caregivers. This can be considered from the perspective of Sluzki (1997) regarding the configuration of new networks in health systems, such as professionals and other caregivers. Furthermore, there is a feeling of reciprocity when sharing experiences with people who are going through similar situations (Collins et al., 2016; Nicholas et al., 2016; Sluzki, 1997).

The experiences in Palliative Care also contemplated the relationship with the health team, with the perceptions of the participants moving between them being humanized, allowing the family members to feel comforted by what they were experiencing, to the indication that Palliative Care did not work, with the caregiver feeling little support from the service. This perception corroborates the findings mentioned in the study by Nicholas et al. (2016), in which the results indicated that the family members did not feel the focus of care, which was directed toward the patient, as well as in the study by Arber et al. (2013), in which the study participants mentioned that they had not received the assistance they expected from the Palliative Care service. Aspects of communication with the health team during the hospitalization were also considered in this relationship, having sometimes been perceived as being carried out in a hurry. In the context of Palliative Care, Bastos (2019) and Breen et al. (2018) also observed perceptions that fluctuated between a quality service, with reliable professionals and clear communication, and, from another perspective, insufficient care, lack of understanding with family members and difficulty of access to relevant information.

The set of meanings, experiences and conversation possibilities during the illness process made it possible to redefine palliative care, so that it started to gain other forms, such as comfort and quality of life. It is believed that this, in turn, favors the family's acceptance of the palliative treatment – whereby each member can assimilate in their own time and way - also adding positive concepts to the experience and making the process less painful. On the other hand, the experiences related to the death of other patients impacted the family members, highlighting difficulties in resignifying Palliative Care. This was visualized, for example, in the report of a participating family member that mentioned having difficulty changing their perception of "not leaving there alive", given the fact that they had witnessed two deaths since their arrival at the Unit.

The patient care and treatment requirements generated implications in the lives of the family caregivers, such as the need to have a care routine, as well as financial expenses, and, as a consequence, the reorganization of their personal and family routines, which also had repercussions, with the feeling of disruption in their own lives. These requirements intersect with the caregiver's commitments, among which the impossibility of working stands out, which, in turn, can trigger impacts on the family income (Bastos, 2019; Breen et al., 2018; Coelho et al., 2019; Williams et al., 2011), as observed in this study. This became even more evident in the absence of support from other family members, given the difficulty in reconciling their own daily commitments with the family's care requirements, highlighting the caregiver's burden.

Accordingly, in view of the performance of care, family members can either count on the support of other family members, or sometimes verify the absence of these family members, who start to adopt avoidance behaviors, generating conflicts between these people (Arber et al., 2013; Bastos, 2019; Breen et al., 2018; Queiroz et al., 2013). In this sense, studies indicate that family members are one of the main support networks during patient care, providing stress reduction, while their absence favors increased stress (Arber et al., 2013; Williams et al., 2011). It should be emphasized that, even though the majority (12) of the participants mentioned that they had some help, those family members who reported receiving such help on an occasional basis, or who considered themselves on the "front line" of the care, also reported feeling exhausted and overloaded.

In this process, there is also the need to make decisions related to the patient, as was seen in relation to housing and bureaucratic aspects that can generate long-term issues for the caregiver (Coelho et al., 2019), as well as questioning of the family members and conflicts between them. As an example, P3's questions about whether she would regret having accepted palliative treatment for her family member can be highlighted. Care tasks also place family caregivers in the face of relational changes between family members, with the patient, and among the other participants in their social networks. This is because, as noted, there may be changes in roles, considering, for example, the children who need to take care of their parents. In addition, withdrawal can happen due to differences among family members in relation to the process, the loss of intimacy between the caregivers or the difficulty for the caregivers to reconcile social interactions, leading to social isolation (Coelho et al., 2019; Collins et al., 2016; Nicholas et al., 2016). In this, the illness can lead to changes in the social networks, with the restriction of social contacts and the lack of activation of networks and of possibilities for interaction (Sluzki, 1997).

The implications of the care process also generated impacts on the physical and emotional health of the caregivers, with reports of fatigue, exhaustion, stress, and overload, which has also been found in other studies (Breen et al., 2018; Coelho et al., 2019; Nicholas et al., 2013; Williams et al., 2011). This indicates the repercussions caused in the caregiver's life, due to the performance of the care, with this assistance being considered a physically and emotionally demanding task.

In view of this, the meanings attributed to the care can be recognized, in which it gains the concept of duty, especially when it comes to children caring for their parents. This can be thought of in the sense of affective repayment. Family members can also signify this care as a way to provide comfort and support to the patient. It was also possible to perceive that performing this care, depending on the patient's position, was considered painful, difficult, and a sacrifice, as it represented a abandonment of their lives (Queiroz et al., 2013). Faced with this, following this process and not being able to transmute the patient's pain provoked feelings of helplessness and suffering in the family (Bastos, 2019; Cavalcante et al., 2018). These feelings can be recognized in the anticipatory mourning process due to the family members being faced with imminent loss and substantial changes in their lives (Collins et al., 2016).

Based on the results of this study, the family members' different reactions to the proposal for palliative treatment became evident, considering the meanings that the caregivers attributed to this treatment, meanings that were linked to the concepts of giving up investing in the patient and of imminent death. On the other hand, the promotion of comfort was also evident, representing essential care in the assistance for the patient. It was comprehended that the meanings could differ among the family members and, in some cases, trigger conflicts between family members and with the patient. In addition to the meanings attributed to the Palliative Care process, feelings emerged that were diverse and were signaled depending on the family member's understandings of palliative care and their expectations regarding the treatment.

The experiences in Palliative Care were considered positive by family members, providing the development of bonds between caregivers, which highlights the change of the social networks in this process. In another way, having witnessed the death of other patients represented a significant experience in the companions' narrative, given the impact generated by the magnitude of that moment. Passing through these experiences, the perceptions related to the health team and the performance of Palliative Care deserve to be highlighted, which were both positive and conflicting. Through this, it is understood that this set, over the course of the treatment trajectory, may or may not lead to the acceptance of Palliative Care through conversations and the resignification of this care, with the way in which this journey is experienced suffering from nuances within the family.

Throughout this trajectory, the experience of changes in the face of care requirements was permeated by the demands of the patient and the treatment, which implied transformations in the caregiver's personal and family life. These changes were influenced by the need to assume the position of primary caregiver, which required the organization of a patient care routine. Therefore, the caregiver that was in charge of patient care had the support of other family members to perform this task and, at times, felt overwhelmed in the absence of this support. Furthermore, the patients' demands generated costs that represented financial expenses for the family caregivers.

Based on these requirements, the caregiver's life was marked by the need to exercise full-time care, in such a way that they were forced to give up activities directed toward themselves and had to reorganize their personal and family routines, as well as deal with relational changes with the patient and with other family members, including family conflicts related to the organization of the care. The care process caused repercussions due to the need to perform other tasks and, at the same time, finding difficulties in completing them or reconciling them with the obligation to provide assistance to the patient.

The caregiver also had to deal with the need to make decisions, such as those that refer to taking care of the patient, relocating their home and bureaucratic aspects, with the decisions triggering questioning and conflicts with other members of the family. Fulfilling all these requirements related to the patient and the changes in the caregiver's life led the family member to feel the effects on their health, including physical and emotional impacts, in addition to the feelings that surfaced, such as anger, suffering and impotence.

Accordingly, the procedural character of the categories that allude to the journey of family members and the patient in Palliative Care reiterated the changes in personal life and the implications faced with the care requirements. Regarding this, it is possible to observe the implications in anticipatory mourning, in the set of meanings attributed to Palliative Care, linked to reactions and feelings throughout the trajectory, through reactions, feelings and possibilities of resignification.

Final Considerations

Based on what was constructed, from the objective of the study, the meanings attributed to Palliative Care and its implications in the anticipatory mourning process were visualized. This is because, the reactions caused by the palliative treatment proposal are located in the trajectory of the treatment followed by the patient and family caregiver and are related to the meanings attributed to the treatment. In this sense, this refers to the experiences of changes in the lives of family caregivers caused by the performance of the care with the patient faced with their requirements, those of the treatment, and the need to make decisions related to the patient. These requirements are intertwined with the caregiver's personal and family life, reflecting on the organization of their daily lives and affecting their physical and emotional health, with the feeling of overload having wide repercussions on the caregiver's life. The implications are mediated by the meanings attributed to the performance of care, in addition to provoking feelings about the care and the patient.

In this context, the set of meanings, experiences, conversations, and feelings have repercussions on the possibility of resignifying and accepting the treatment, which, in turn, highlights indications of the progression of the anticipatory mourning process. Based on what was discussed, the implications for their experience were evidenced, as the way the process is signified affects the way in which family members relate to the possibility of imminent loss. This, in turn, favors the visibility of elements of anticipatory mourning, which facilitate the health intervention. It is important to reiterate that, according to the definition used in this study, this process starts from the diagnosis of the disease, that is, prior to the specific hospitalization in the Palliative Care Unit, the latter possibly representing the realization of the fear of the family members. That said, it was justified to include family members whose time of entry into palliative treatment varied.

In addition, the importance is highlighted of these elements being recognized by the healthcare provider, to identify whether the difficulty in understanding Palliative Care is related to an emotional issue or to gaps in communication. In the case of gaps, the importance of communication that contemplates the other's alterity is emphasized when considering the experience, history and situation in which the family members find themselves. It is necessary, considering these precepts in the communication, to discuss the concept of Palliative Care and the patient's health status, since the lack of understanding can cause obstacles in the elaboration of anticipatory mourning due to the difficulty of assimilating the possibility of death.

It is understood that the opening to dialogue, in order to produce other meanings for this care, favors the family member's acceptance of the condition of the patient undergoing palliative treatment, allowing the progression of the grieving process. Therefore, it is suggested that the concept of Palliative Care can be debated at the level of the institution and the health system to demystify the concepts that surround it, so that entering the treatment does not provoke reactions that prevent the process from being resignified.

A limitation of the present study that can be mentioned is the setting in which it was developed, an oncology hospital in southern Brazil, in which palliative care already had a consolidated standard of functioning, that is, a specific support network marked by its own cultural characteristics. Considering that these are variable according to the regions of the country, the experience of Palliative Care acquires singular contours and different impacts. In view of regional differences and that, at the national level, this care proposal is still under development, it is relevant to understand the meanings of family members in other specific contexts, such as in the general hospital or at home, and in different regions. In addition, future research could explore the perception of healthcare providers working in Palliative Care, especially health technicians, given their close contact with the patients and family members, and their training that does not always include important aspects related to working with these people, with the aim of instrumentalizing them in their interventions, as they are considered privileged interlocutors. It is believed that this study will advance the area by making the guiding thread of anticipatory mourning visible, aiming to support health actions in which family members are also recognized as vital protagonists in Palliative Care.

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