

## Palliative Care: Caregiver's Reflective Praxis

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### Abstract

*Objectives:* Palliative patients need a caregiver, often a family member, to assist their daily activities. The relationship helps in the mourning process and brings better sharing of decision making, but it can bring the burden of care. Studies exploring the mixed view brought by caregiver's daily practice in palliative care are scarce. Therefore, that was the target of the research. *Methods:* Descriptive study with a qualitative approach through semi-structured interviews with family members-caregivers of palliative patients in a hospital in Brazil. *Results:* Most caregivers weren't familiar with the term "Palliative Care". The recurrent miscommunication and lack of tact between doctor and patient's family was highlighted. However, most caregivers were aware of the patient's condition. They described changes in routine after becoming caregivers, which generated financial difficulty and the feeling of living someone else's life. Many reported strengthening religious life to deal with the current situation. Amid physical and emotional overload, often reinforced by the need to mask their feelings and by personal exigency, caregivers reported feeling powerless and guilty, but also useful in their role and feeling both abandoned and supported by the community around them. *Conclusion:* Caregivers revealed antagonistic and dubious feelings regarding the act of caring, being present and preserving human dignity. Personal overload emerged frequently in the speeches and guilt was the determinant for them to move forward despite physical, mental and spiritual tiredness. That can be mitigated through dialogue between professional team, patient and family, when doubts regarding the palliative care process are clarified.

### Introduction

According to history, *pallium* was the cloak that protected the knights during the horseback riding in the ancient era. Protect! Simple word, which gave rise to what is now called "palliative". Thus, palliative care connotes providing care that aims to protect and accompany the individual.

The World Health Organization (WHO) defined palliative care in 2002:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.<sup>(1)(p.3)</sup>

Face to the impact generated by the communication of imminent death, studies show clear preferences brought by patients and these data are consistent with what palliative care has to offer: they, specifically, want to know what to expect; to feel prepared for the passing; to feel like they have control over the pain and symptoms, besides maintaining proximity with the family and achieving the "conclusion of life", the feeling of "mission accomplished".<sup>(2)</sup>

Therefore, it's safe to say that palliative care is not a practice based only and exclusively on a protocol, but rather on principles that aim to promote relief. In a WHO 2002 review on the principles of palliative care<sup>(1)</sup>, following its definition, it is listed as it follows:

1. Promoting relief of pain and other unpleasant symptoms;

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2. Affirming life and viewing death as a normal life process;
3. Never accelerating or postponing death;
4. Integrating the psychological and spiritual aspects in patient care;
5. Offering a support system which allows the patient to live as actively as possible until the moment of death;
6. Offering a support system to assist family members during the patient's illness and in coping with mourning;
7. Multi-professional approach to focus on patients and their families' needs, including grief monitoring;
8. Improving quality of life and positively influencing the course of the disease;
9. It should be initiated as soon as possible, along with other life-prolonging measures such as chemotherapy and radiation therapy, and include all necessary investigations to better understand and control stressful clinical situations.

In that context, it is possible to determine that euthanasia is not an accepted practice within palliative care. In addition, the use of pharmacological treatments is possible, as long as these do not negatively affect the quality of life of the terminally ill individual. Non-pharmacological treatment and psychosocial support for family members are also recommended, requiring other professionals besides the physician, such as nurses, physiotherapists, psychologists and even people related to the patient and family's spirituality.

Moreover, face to this multi-professional performance, the acceptance of the process of finitude and the view of death as something natural and inherent to the human being help to reduce suffering during the course of the disease and grief after its end, which facilitates joint decision-making and medical work, breaking the stigma of palliative care as the idea of "giving up treatment".

Development of palliative care aims, in addition to what is mentioned in its definition, to reduce the length of hospital stay, as well as the costs for this purpose, besides aiming a more humanized, private and attentive patient care. Thus, the term Home Care emerges in the health system, public or private, where health professionals act to implement the care of terminally ill individuals.

There is a need for family caregivers to assist the palliative patient in numerous daily activities. In addition to the proof that when the family engages in treatment, there is mourning mitigation and better sharing of the decisions to be made.

However, it must be taken into consideration that, without any help, these caregivers end up becoming hostages to their relatives: according to studies, two out of five of them report depressive symptoms.<sup>(3)</sup> Thus, the caregiver's suffering due to their relative's illness and process of finitude becomes evident, making multidisciplinary intervention necessary providing due training and psychological and social support.

The family caregiver's profile is generally an adult or elderly woman. The care-taking activities require high demand of time and energy, making some of them lose their jobs or even give up the main sources of income in search of resources for the time that is required of them; in addition to that, they tend to spend their financial reserves to invest in patient care.

Face to all tiredness, fear and doubts, it is common for the conspiracy of silence to emerge and, in some situations, conflict-generating misunderstandings appear, which tends to contribute to intra-familial relationships difficulties, that end up interfering in progress and evolution of patient's prognosis.<sup>(4)(p.2)</sup>

Nevertheless, palliative care is based on home care, aiming to reduce hospitalization costs and to provide the patient more privacy. Therefore, the figure of a caregiver, who may or may not be a member of the family, is essential to help with personal hygiene, medication administration and life habits in general.

A report<sup>(5)</sup> points out the importance of understanding the family context when discussing palliative care and the indication or choice of a family member who'll occupy the role of a caregiver. The contemporary heterogeneous family configuration is influenced by the emotional, social and financial framework of its members, emphasizing that not always the caregiver assumes this position willingly.

It is a role that demands time and responsibility, overloading the caregiver and giving the patient the feeling of dependence.

Nowadays, there is a considerable number of studies that have been identifying barriers in patient and caregiver integration to palliative care. In spite of that, most of these studies are focused on the perception of healthcare workers, exposing their fears and yearnings in destroying the patient's hopes. On the other hand, the scarcity of studies which explore palliative care from the perspective of who is the orbital point of this approach, the caregiver, is evident.

Considering this scenario, we aim to know about the daily *praxis* of the caregiver in context of care, moment of contemplation of life and death and dichotomy of feelings and actions.

## Method

A descriptive study was performed during 2019 using a qualitative approach. After Research Ethics Committee's approval under notion No. 11714419.0.0000.5580, semi-structured interviews were initiated with eleven family members who had taken on the role of caregivers of palliative patients in a large general hospital in Curitiba, PR (Brazil), who answered three guiding questions.

Bardin's precepts<sup>(6)</sup> were used as a theoretical framework for the treatment of the data, after extensive exploration and meticulous reflection on the interviews, when a review of the material was carried out through thorough reading to extract units of responses that led to categorization of the seized content, which will be presented by the acronym "FC" aiming the preservation of anonymity.

## Results

The participants of the interview included eleven family caregivers with an average age of 49 years old and ages between 25 and 77 years old; four of them were male and seven female; one of them was single, another was a widower and the rest of them were married. Their kinship degree to the palliative patients included: two children, a niece, a mother-in-law, a partner and the rest of them were husband or wife. Only three of the interviewed people were still working, two were retired and the others were unemployed since their relative's diagnosis. To facilitate the presentation of the participants speeches, the content will be presented in three categories, to know: Knowledge regarding palliative care, Life change and Revealed feelings

### 1. Knowledge regarding palliative care

The interviewees answers, when faced with the question "do you know what palliative care is?", gave rise to the category "Knowledge about Palliative Care", with four response units: "Unfamiliarity to the term", "Attempt to define the term", "Failure in communication" and "Understanding the family member's condition".

The first response unit, "Unfamiliarity to the term", is evidenced in the following speeches:

**FC4:** "No, I, I can't denominate the word 'palliative' now..."

**FC5:** "Palliative? I can't imagine."

**FC9:** "Palliative, well... I have no idea."

That determines that people are each time less familiar with the finitude stages and, thus, the reality of this process becomes more and more hidden. So, in an effort to make sense of the term and demystify it, it was possible to observe the second unit response, "Attempt to define the term", highlighted below:

**FC1:** "Oh, I had an impression that it extends the patient's life... if you don't do it, they die..."

**FC2:** "Does it mean cancer?"

**FC6:** "Oh, taking care is dedicating, dedicating everything, sometimes the doctors give, give the medicine and you give your support, family support, support at home, support all the time."

**FC11:** "Taking care of someone."

Another point that is analyzed through the reports concerns the signs of failed communication, or even misinterpretation, of the information transmitted by professionals to family members. This enabled the creation of the “Failure in communication” response unit:

**FC1:** *“Nobody told me anything so far, just... just that they’re going through with treatment.”*

**FC5:** *“... The doctor told me that she doesn’t have anything anymore, she just has to do that and it’ll be great.”* (referring to the cure of the disease)

**FC6:** *“... It’s been said that, since it’s cancer, she has a chance and, and, at the same time she can no longer have it, so she could be cured today or she could come back later...”*

However, it was possible to obtain reports in which the professional’s objective communication was clear:

**FC3:** *“It has been stagnant because there’s nothing else to do, it was very quick... he’s been worse... he’s already mentally confused, having delusions, so she said that it’s... hm... what... it’s normal, it happens more and in a worse way.”* (FC3)

**FC10:** *“The doctor doesn’t hide anything [from us]. He says what he has to say. (...) It’s this, it’s that”*

Despite the fact that all the interviewees refer unfamiliarity to the term “palliative care”, most of them know about their relative’s condition, which fits the fourth response unit “Understanding the family member’s condition”, illustrated by the speeches:

**FC8:** *“So, she takes the medicine (...) and it doesn’t cure her, it only helps her for awhile, like, it doesn’t... cure [her disease], it only helps with the pain...”*

**FC4:** *“... it’s malign, you know, they were trying [to improve] the survival I think... but like, to heal [the disease] like that, only a miracle...”*

On the other hand, many family members still believe that the patient is in the treatment process and some of them believe that the cure has been reached.

**FC5:** *“... The doctor told me that she doesn’t have anything anymore, she just has to do that and it’ll be great.”* (referring to the cure of the disease)

It is not known for sure whether this report is due to communication failure with professionals or if it is an anticipated grief process with denial signs. It is important to highlight the relationship between doctor and patient to seek a moment of acceptance of the end of life.

## 2. Life change

When questioned about what changed for them after referring their family member to palliative care, the interviewees pointed out routine changes that could be clustered in the category “Life change”, also with four response units: “Religious bargain”, “Routine change”, “Financial hardship” and “Living someone else’s life”.

Considering the situation in which caregivers are inserted, the need to have a place to seek support, refuge and hope leads to an increase in old beliefs or, when they are inexistent, it makes those come to light. This perception made it possible to compose the first response unit: “Religious bargain”.

**FC1:** *“I’m not very, very attached to religion, I’m not very attached to belief, I’m a non-believer, (...) but sometimes the pain, you know, it makes you get attached to something...”*

**FC3:** *“... because I’m a religious person, I’m conscious that we’re just a body and that everybody will die someday. (...) Unfortunately, human beings have to go through that phase.”*

**FC4:** *“We get really sad, you know, we wanna try to find an alternative somehow, to work around the situation, but I think there is no way, only God, only a miracle...”*

In another analysis, it is clear that the act of taking care of someone leads to changes in pattern and lifestyle of those involved, highlighting the important issues in response unit “Routine change”:

**FC3:** *“... I started a pasta company and everything was going well, but then my father had this relapse, he moved in with me, that was when I stopped working.” (...) “we had leisure time, now we don’t have it anymore... in the first month I got to miss my daughter inside my own home.”*

**FC4:** “... *my goals were different, I was supposed to take a course, go to work, then I said like wow, now I can't...*”

**FC8:** “*So I had to, I had to move to another house, because there were stairs, you know, so I moved, because she couldn't take the stairs and I couldn't help her with that. (...) Then my husband stayed in a house with my daughter and I was with her in another one.*”

It can be said that there is a certain disharmony in caregivers' daily lives. With home care obligations, adjustments to the routine end up being inevitable. The availability of leisure time, meal time, household chores, expenses and everything that involves former occupations of the family caregiver are changed. Thus, a feeling of burden arises, added to insecurity and isolation.

One cannot ignore the fact that, along with this change in routine, especially when it is necessary to give up work, the number of people dependent on income in relation to the number of people who get the money changes, leading to the response unit “Financial hardship”:

**FC1:** “*We had an income, every month, of more than eight thousand (R\$) and today we don't... we can't get a thousand (R\$) at home... to pay the bills and get food... to pay for fuel for the car... the things I could sell are for sale, but no one buys them...*”

**FC1:** “*... I was caught by surprise, with no financial conditions to pay for the private service... the little I had, I paid for it and I'm still paying, you know... I owe, but I'm paying...*”

Nevertheless, faced with the reality of a familiar's process of finitude, the management of pain becomes a part of everyday life. The family then begins an active search for emergency services, transferring the patient from one assistance center to another, increasing their expenses, often because they don't know what else to do.

In response unit “Living someone else's life”, it was observed that many family members, due to the terminality news' impact, are faced with the need to provide care for which they are not ready. As a result, feelings such as those reported below emerge:

**FC3:** “*... it's not easy, you know, to stop living your life to live someone else's... I don't know how to tell you what it feels like, because it's a mix [of feelings], you know, but it changed completely...*”

**FC4:** “*... it took my time, I wasted my time, like, you dedicate yourself to someone else, right...?*”

**FC5:** “*... there are some exams that I was supposed to do for about four months now, but I can't go (...) the doctor said I had a poor heart... but how could I leave her all alone?*”

**FC6:** “*I stopped doing my stuff to take care [of her] (...) I'm with her every day, you know, every time she needs me. I change my routine to be with her, I won't go out, I won't hold off, I won't... as long as she's here I'll take care of her. It all changed, I left my stuff to take the time to take care of her.*”

### **3. Revealed feelings**

When asking: “How do you feel now?”, according to caregivers' responses (who often feel relieved by the fact that they had someone to share it with), it was possible to organize the response unit in this category, “Revealed feelings”, with six response units: “Powerlessness, usefulness and guilt”, “Feeling of abandonment x support”, “Emotional and physical overload”, “Lack of tact and effective communication”, “Personal and third party exigency” and “Masked feelings”.

Over and over, phrases included in the first response unit, “Powerlessness, usefulness and guilt”, made it possible to interpret yearnings towards feelings of weakness and inability to resolve situations, guilt for not being able to do more, but, above all, feeling of usefulness in doing what is possible:

**FC1:** “*How do I feel? Right now?Powerless, but useful.*”

**FC3:** “*Very sad, you know, because there's nothing I can do.*”

**FC4:** “*... I think it's very useful, what I'm doing...*”

**FC7:** “*It's a situation that's out of our control (...) if I could, I'd take everything that she's feeling away... all the bad stuff, you know?*”

**FC9:** *“I feel guilty for, let’s say, leaving him... I mean, not leaving him, because I’m here with him now, but he isn’t home with me anymore... But it’s... I feel guilty.”*

**FC10:** *“I won’t give you up’... I told him that no matter what happens, I’ll take care of him until the end.”*

Powerlessness. It is how these caregivers describe what it feels like to have their hands tied and unable to change the situation in which their family members find themselves.

In “Feeling of abandonment x support” response unit, something notorious — not only in words, but also in sighs and in between lines, is the magnitude of the positive impact generated by the expression of support towards the situation in which interviewee and family are in and also the relevance of abandonment cited by them, sometimes through tears:

**FC1:** *“... the relationship with people, we end up finding out who people really are... from whom we least expect, it comes [the support]... from whom we most expect, it doesn’t.”*

**FC3:** *“It’s complicated for them, but not for me, I mean, in the beginning it was, but love is greater, when we realize, we’re already doing it.”*

**FC6:** *“... but when you need it, people walk away. (...) they stop visiting or they always find an excuse...”*

**FC7:** *“We were very close before, but now we’re even closer and it helps a lot. (...) They were always close because they lived next to us, you know. So, it helps.”*

**FC10:** *“We got home, he wanted to eat and we had no money, there was nothing. So some friends came by... We asked to borrow some money. After that, we heard that they said to someone: ‘if they don’t even have money for the bus, imagine for food’. (...) They put money for me inside our bible.”*

Physical, emotional, financial and even mental demands are tangible when it comes to having to dedicate yourself to someone. All that care requires time, which, whether it’s integral or not, must be taken from some other activity. Besides the need to shorten sleep and leisure hours, caregiver’s personal problems are added to this situation. Based on that, the response unit “Emotional and physical overload” was created. Sometimes, all that overflows through self-destructive thoughts.

**FC1:** *“... I got to the point where I offered my life to God over hers, but he didn’t listen to me... I wanted her to stay alive... to stay with her daughter and her granddaughter, who’s coming, and I... (crying)... I’d go, I’d die and she’d stay... more... fate is not like that...”*

**FC4:** *“... It was a very tough moment for me because it was right at the time when I was getting a divorce, I’m still getting divorced, right, so I said like ‘hey, it’s coming’, right, suffering for one thing and immediately there comes another on top of it, so it’s really difficult...”*

**FC6:** *“Sometimes our psychological state shakes, there are times when you start to think about things back there, sometimes we feel alone and we shouldn’t be alone, if we’re too alone, we start to think a lot and that... that’s it, it’s hard, it makes you wanna cry, sometimes it gives you the urge to... do something...”*

Given the above, it is possible to observe, among the tears, the difficulty generated by the interruption of the normal course of life. A study<sup>(4)</sup> states the need for family conferences in that context, since all this exhaustion, associated with fear and uncertainties, leads to friction among everyone involved and may even influence worsening in terminally ill patient’s prognosis.

All things considered, these caregivers feel obliged to take care of their family members, often not having another choice other than assuming such a role.

Still, in the response unit “Lack of tact and effective communication”, it is feasible to infer, given the following statements, that family caregivers feel distant from doctors. In their speeches, the difficulty, and even fear, of questioning is notable and they also see the situation with the emotion and sensitivity of those who are going through a difficult moment, if not the worst, in their lives.

**FC1:** *“So I went to talk to the doctor, (...) he said to me: ‘why did you bring her here?’. (...) it’s like my wife was treated like a bag of meat, you know, throwing her from side to side. (...) It was a profound lack of tact and communication, so... right? Some doctors would be better as mechanicals, you know?”*

**FC3:** *“The doctors, if only they were more affectionate when saying stuff... (...) I also understand that the bond between doctor and patient cannot be so strong... it’s just that I get a little worried, (...) because there are people who don’t... who think they really can’t ask the doctor any questions, (...) so they stay in that circle, you know? Where time runs, where the patient gets more and more sick and the family feels lost.”*

In view of what has been presented so far, it is perfectly possible to understand the existence of the response unit “Personal and third party exigency” since when faced with questioning, strangeness, abrupt or insidious changes in routine, insecurity, personal and financial difficulties, these caregivers find themselves in a situation in which there is no way out but to dedicate themselves to the other, either moved by the love they feel for their family member and/or by others, who do not understand the situation as they do.

**FC1:** *“They say... that people go there and abandon their family member with the doctor and go away... But there are the ones who take care of their family member... It’s love, I feel love, I don’t feel like they’re like an object.”*

**FC3:** *“Like my dad, he’s bedridden, I never imagined, both me and him, because for him it’s very embarrassing the fact that he wears diapers, that I have to bathe him... besides being the only daughter.”*

**FC4:** *“... there is a lot of demand there, like, it’s like, people say that I have to live my own life, that his wife has to take care of him. (...) It seems like they don’t understand that you’re dedicating yourself to it.”*

**FC5:** *“I gotta stay home all the time with her, so I’m... I’m going to see my mother this year, it’s been two years since I’ve seen her because I can’t go see my mother who’s ninety-six years old...”*

One of the greatest challenges in palliative care is to convince patients and their families to talk about finitude and their feelings in an open and clear way. That difficulty was identified in many moments during the interviews, making it possible to create the response unit “Masked feelings”:

**FC3:** *“... I’m super sad, upset. (...) and what I’m doing is to give love, care and comfort. (...) because the one who’s really suffering is him...”*

**FC6:** *“... sometimes I just wannacry in the corner...”*

**FC8:** *“So when we brought her here and she was diagnosed with cancer and... it was in a really advanced stage, you know? (...) And... it was complicated... We started to hide that from her.”*

The people closest to the patient constantly try to protect them from suffering, refusing to tell them about the true stage of the disease or its consequent limitations. What these people don’t understand is that the patient will, in one way or another, realize that their body no longer responds as it used to.

Besides that, the lack of due communication between patient and family increases the tension and the tiredness felt by both parts, accumulating the weight of fatality and, sometimes, culminating in the separation between the family and the sick individual.

## **Discussion**

Regarding the first category, called “Knowledge regarding palliative care”, it can be said that the lack of knowledge is referenced in a study,<sup>(7)</sup> which describes that many of the interviewed family members are also unable to attribute any meaning to the term. They also point out how the subject is not propagated enough.

In this sense, a recent report<sup>(8)</sup> mentions that palliative treatment is an extremely recent approach in Brazil, dating from 1980, and, in addition to that, it was recognized in the medical field only in 2011. Therefore, that would justify why that type of care is not free from prejudice and doubt yet.

In a report,<sup>(9)</sup> the author comments that contemporary medicine is based on the false illusion that it will always save its patients and, according to that, it interprets death as nothing more than a failure. It is almost irrefutable what needs to be done when the patient has a problem with an objective solution, but when faced with one that remains as an unanswered question regarding what to do, insensitivity and suffering are evident.<sup>(9)</sup> In a recent study,<sup>(7)</sup> authors assume that the caregivers’ difficulty in defining the term is due to the theme novelty — not only for them, but also for the professionals involved.

Thus, if there are no professionals fully capable of understanding what they are dealing with, how can they demand that their patients and family members do so?

It was also found that each individual describes palliative care according to their own experiences. Thus, the same authors mentioned above assume that the search for an explanation of the term follows the isolated definition of the word “caring”, an argument that is in agreement with the statements presented.

In addition, another report<sup>(10)</sup> suggests that caring goes beyond the limits of the practical act, reaching deep dimensions of human emotion, thus dealing with emotional care.

A report<sup>(11)</sup> by one of the pioneers of the hospice movement mentions the “contribution of cultural influence to the difficulty of communication and information transfer between professionals, patients and family”.<sup>(11[p.41])</sup> Because it is a critical life process, the difficulty in addressing the lack of a healing perspective and potential terminality makes the truth not be told clearly to the patient and their family.

In this regard, in another study,<sup>(12)</sup> it is noted that:

Effective, harmonious and patient centered communication helps to overcome physical discomfort, allows emotional and spiritual distress, minimizing suffering and helping the patient and family members to go through the process of disconnecting from each other and disconnecting the sick individual from life.<sup>(12[p.86])</sup>

In a relation to the negation signals, a report<sup>(13)</sup> assumed that this stage concerns the moment of revelation, in which the individual acknowledges his condition or the condition of a loved one. He then proceeds to tirelessly search for a mistake in diagnosis, a non-existent justification, and the only path that will take him to absorb the idea is time.

Under those circumstances, a study<sup>(14)</sup> points out that if a frank relationship between doctor and patient was established immediately after the recognition of terminality, both parties would deal with the situation in a much easier way.

The second category called “Life change”, also with four response units: “Religious bargain”, “Routine change”, “Financial hardship” and “Living someone else’s life”, is related to a report<sup>(13)</sup> recalls that, in the bargaining stage, the individual is faced with the desire for exchange, hoping to get the cure as a retribution for good behavior. In this context, the search for spirituality arises with the purpose of reducing suffering and facilitating the process of coping with the disease.

Another recent report<sup>(15)</sup> explains how this search for a greater force can lead to different results, working as an effective healing tool or leading the individual to deep damage. The author also argues that patients and their family members try to establish a power relationship. They want God to behave as expected, and when it doesn’t, a breach opens up for feelings of betrayal and abandonment. Therefore, the author is faced with the importance of the difference between belief and faith. Referring to the first, she states that, when we believe in divine healing, we are convinced that it is the best solution for the situation in which we find ourselves.

On the other hand, she mentions: “when we have faith, we put ourselves in a condition to be cared for, to be protected, to give ourselves the luck of having a God”.<sup>(15[p.123])</sup> Therefore, by having faith, we would be more susceptible to the acceptance of our destiny.

Still in that context, a recent study<sup>(16)</sup> points out that spirituality, face to difficult experiences, is an important resource for coping and that can work as a cloak that welcomes individuals in a state of suffering, highlighting the origin of the word palliative: *pallium*. In that sense, the authors reiterate the need for health professionals to be trained to identify and work with the spiritual demand of each person, helping in the mourning process.

The disharmony in caregivers' daily life was observed by a research<sup>(17)</sup> in which the authors refer to a great demand in the care process regarding lifestyle adaptations, mainly related to the limitations faced by caregivers and patients. As a perception, they describe that the caregiver "leaves their life aside".

Regarding a financial hardship, a study<sup>(18)</sup> concludes that a family, once inserted in palliative care, requires two types of social support: the emotional/instrumental and the one to help guide everyday problems. Other reports<sup>(19),(20)</sup> found that caregivers present high deficiencies regarding that support, as they need to focus not only on physical and emotional problems, but also on economic ones besides patient's specific care.

In a socioeconomic investigation research,<sup>(21)</sup> it was found that caregivers with lower economic status have more issues in providing proper care to terminally ill patients. That can be justified not only by limited resources, but also because there is an association between low economic income and lower education levels, culminating in incomprehension regarding high quality care demand.

A report<sup>(22)</sup> argues that the burden imposed by the situation, despite reaching the whole family, is usually heavier for the patient's primary caregiver, who's responsible for the greatest emotional, physical and financial impact.

Another research<sup>(23)</sup> concludes about "Living someone else's life" that the main complaint brought by interviewees was the lack of time for self-care and the need to reduce work dedication time or even to abandon work, which generates full time tiredness, neglect with their own body and health, in addition to marital argument and worsening in family relationships.

So, it's possible to resume the concept of family conference, described by a recent report,<sup>(4)</sup> in which the professional must elucidate the questions and get as close as possible to calming and welcoming these people. It is believed that the clear dialogue between staff, patient and family leads to better understanding of the patient's condition, relieves emotional overload and makes it possible to unmask and mitigate feelings, helping in family and patient support.

When talking about emotional and physical overload, a report<sup>(5)</sup> illustrates this situation as "islands of communication", in which some family members, and even the caregiver himself, act as stronger people and end up, in an attempt to perhaps not make the situation worse, absorbing all their feelings for themselves.

Considering the statements above, reiterated by a report,<sup>(4)</sup> in which caregivers must assume all commitments, in addition to their own and, with the disease's evolution, patients become more and more dependent, increasing the burden. An increasing and progressive anguish is then generated, through discomfort and sadness, which leads to mistaken thoughts and a feeling of despair.

An intriguing factor exposed in the speeches about "Feeling of abandonment x support", and illustrated by a research,<sup>(24)</sup> is the need these caregivers feel to be cared, to feel welcomed and supported while, at the same time, they go through a moment when they need to dedicate themselves to the third party. Many times, the feeling of being distanced from a partner, family and friends was quoted and linked to a feeling of abandonment and isolation. In a family context, in face of a disease, the act of caring is no longer optional, it becomes a necessity.<sup>(24)</sup> That's how it is inferred that caregivers, being family members, already place themselves in this position without questioning or analyzing the situation too much, as if this is their obligation within the context in which they find themselves, creating the ghost of charge in an attempt to fulfill their role.

When thinking of masked feelings, a report<sup>(15)</sup> states that encountering family members who plead for not telling the truth about the disease to their sick loved ones is extremely frequent.

This attitude, common in palliative care centers, is underpinned by the misconception that telling the truth to a person with a serious illness could kill them before time. "Families think they spare their loved ones when they lie, without knowing that their loved ones also lie to spare them".<sup>(15p.95)</sup>

## Conclusion

As we revisit the proposed objective in this study, of knowing the daily *praxis* of the family caregiver in context of care, we can affirm that caregivers revealed antagonistic and dubious feelings regarding the act of caring, of being present, of preserving human dignity.

Coping with care in this scenario is similar to coping with death and finitude. Everyone felt unstable face to the complexity of taking care of themselves and others, with ambiguous and uncertain feelings mixed between pain and love.

In addition, personal overload emerged frequently in the speeches and guilt was the emotional determinant that allowed them to develop the strength to move forward, despite physical, mental and even spiritual tiredness.

This burden can be mitigated through dialogue between the professional team, the patient and the family. That is when doubts, generated by the introduction to palliative care, information sharing and adherence to planning, are clarified. But it is not enough.

The caregiver who does not know the concept of palliative care, and yet knows about the condition of term inability of their family member, observes, most of the time, statically the change of his/her life, feeling the need to expose feelings, but keeping emotions in silence so as not to aggravate the condition of the terminally ill individual.

Nevertheless, it can be noted that the individual to be cared for does not only expect to control his/her pain, but to enjoy the time he/she has left by feeling useful and preserving as much independence as possible.

The apprehension of the caregivers' *praxis* revealed that there are no unique answers, but an intrinsic complexity to the act of giving in through the care for the other. The dying process brings elements with it, whose relations of dependency is somewhat incomprehensible and lead to the caregiver's inscrutable dedication.

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### **Ethics approval and consent to participate**

The study has Research Ethics Committee's approval under notion No. 11714419.0.0000.5580 and all interviewees received two copies of the consent form – one of which was signed by the respondent and collected by the authors.

### **Availability of data and material**

An audio-recorded interview was performed to obtain the data. Therefore, the data supporting the results described here is available on a password-protected pen drive to preserve confidentiality and anonymity, as indicated by the Research Ethics Committee. If necessary, the corresponding author may make it available, but we affirm that it is not publicly available so as not to compromise the privacy of the research participants.

### **Competing interests**

There are no conflicting interests.

### **Funding statement**

The research funding was personal to the researchers themselves.

### **Authors' contribution**

All of the authors participated sufficiently in the conception and the design of this study or in the analysis and interpretation of the data as well as in the writing of this text and in reviewing the final version of the article and approval for it to be sent for publication.

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