






ORIGINAL ARTICLE

PERCEPTION OF PALLIATIVE CARE BY FAMILY CAREGIVERS OF ELDERLY PATIENTS\*

PERCEPÇÃO DE CUIDADORES FAMILIARES DE PACIENTES IDOSOS SOBRE CUIDADOS  
PALIATIVOS\*

PERCEPCIÓN DE LOS CUIDADORES FAMILIARES DE PACIENTES MAYORES SOBRE  
CUIDADO PALIATIVO

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ABSTRACT

**Objective:** to understand the perception of palliative care by family caregivers of elderly patients.

**Method:** it is a qualitative, descriptive, exploratory study. The sample was composed by 11 family caregivers of patients assisted by the palliative care team. A semi-structured interview was carried out in which the participants answered three guiding questions, examined through Content Analysis. **Results:** three categories are detailed to have emerged: perception of family caregivers about palliative care; reasons for the relative to be cared for by the palliative care team; and 'Is it different to be cared for by the palliative care team?'. **Conclusion:** it is concluded that the family caregiver has an understanding about what palliative care is, about what the reasons are for his relative to be assisted by a palliative care team and recognizes that there is a difference between the care provided by the palliative care team and a non-palliative care team. An effective communication between the team and the family caregiver has been demonstrated.

**Descriptors:** Palliative Care; Caregivers; Knowledge; Elderly; Patient Care Team; Nursing.

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RESUMO

**Objetivo:** compreender o entendimento dos cuidadores familiares de pacientes idosos sobre cuidados paliativos. **Método:** trata-se de um estudo qualitativo, descritivo, exploratório. Compôs-se a amostra por 11 cuidadores familiares de pacientes assistidos pela equipe de cuidados paliativos. Realizou-se uma entrevista semiestruturada na qual os participantes responderam a três questões norteadoras, examinadas pela Análise de Conteúdo. **Resultados:** detalha-se que emergiram três categorias: percepção dos cuidadores familiares sobre cuidados paliativos; motivos de o ente estar sendo cuidado pela equipe de cuidados paliativos; e 'É diferente ser cuidado pela equipe de

cuidados paliativos’? **Conclusão:** conclui-se que o cuidador familiar tem entendimento sobre o que são cuidados paliativos, quais os motivos que levam o seu ente a ser acompanhado por uma equipe de cuidados paliativos e reconhece que há diferença entre o cuidado prestado pela equipe de cuidados paliativos e uma equipe não paliativista. Evidenciou-se uma comunicação efetiva entre equipe e cuidador familiar.

**Descritores:** Cuidados Paliativos; Cuidadores; Conhecimento; Idoso; Equipe de Assistência ao Paciente; Enfermagem.






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**RESUMEN**

**Objetivo:** comprender la comprensión de los cuidadores familiares de pacientes ancianos sobre los cuidados paliativos. **Método:** se trata de un estudio exploratorio, descriptivo y cualitativo. La muestra estuvo compuesta por 11 cuidadores familiares de pacientes asistidos por el equipo de cuidados paliativos. Se realizó una entrevista semiestructurada en la que los participantes respondieron a tres preguntas orientadoras, examinadas por Content Analysis. **Resultados:** se detalla que surgieron tres categorías: percepción de los cuidadores familiares sobre los cuidados paliativos; motivos para ser atendido por el equipo de cuidados paliativos; y "¿Es diferente ser atendido por el equipo de cuidados paliativos"? **Conclusión:** se concluye que el cuidador familiar tiene un entendimiento de lo que son los cuidados paliativos, cuáles son las razones que llevan a su ser querido a ser acompañado de un equipo de cuidados paliativos y reconoce que existe una diferencia entre los cuidados que brindan los cuidados paliativos equipo y un equipo no paliativo. Se evidenció una comunicación efectiva entre el equipo y el cuidador familiar.

**Descriptores:** Cuidados Paliativos; Cuidadores; Conocimiento; Anciano; Grupo de Atención al Paciente; Enfermería.

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## INTRODUCTION

With the transition of the epidemiological profile of the Brazilian population and the increase in morbidity and mortality due to chronic-degenerative diseases, the need for adequate care, such as patient-centered care, emerges. Within this perspective, there is an assistance modality which aims at humanized and holistic care: palliative care.<sup>1</sup>

Palliative care is explained as an approach, by means of a multidisciplinary team, that promotes quality of life through prevention and relief of suffering to patients who experience diseases that threaten the continuity of life and their families.<sup>2</sup>

It is pointed out that the scope of palliative care is to improve the quality of life of patients and their relatives, having as components the relief of symptoms and the offer of psychological, spiritual, emotional and social support during the assistance to the patient and his family even after death,<sup>3-4</sup> since suffering does not only involve the patient, but the family as well.<sup>5</sup>

The family caregiver, in the context of the palliative care team, can be any relative, friend and/or partner who has an important relationship and provides assistance, as well as physical, social and psychological support to the patient with a prognosis of a non-curable pathology.<sup>6</sup>

The family is presented as having a fundamental role in the person's life, representing the way in which he/she relates to the environment in which he/she lives.<sup>7</sup> The family is considered the institution that since ancient times and in most known societies has been the provider of the individual's primordial and basic needs, shaping him/her under the strong influence of the existing customs.<sup>8</sup>

In this way, some worries have emerged in face of the need and context in which the patient is in palliative care, considering that the care involves not only the professionals, but also the one who takes care of the person,<sup>9</sup> since he/she must be integrated to the care: “What is the family caregiver's understanding of palliative care?” and “Does the family caregiver believe that there is a difference for the patient when assisted by the palliative care team?”.

This survey was motivated by these questions and by the existence of a gap in the knowledge of studies that approach the theme of palliative care from the perspective of the family caregiver.

By understanding what the family caregiver perceives as palliative care, there will be a contribution to the reflection of best practices in the approach to this theme with the patient and with the family caregivers, aiming at improving the communication among the team-patient-family triad and at the understanding and partnership with all the palliative care team.

## OBJECTIVE

To understand the perception of palliative care by family caregivers of elderly patients.

## METHOD

This is a qualitative, descriptive, exploratory study, carried out at the Hospital das Clínicas of the Federal University of Minas Gerais (HC-UFMG), in Belo Horizonte, Minas Gerais.

It is reported that 11 family caregivers of elderly patients aged 60 years or more, assisted by the palliative care team at HC-UFMG, participated in the survey. Those who at the time of collection presented any emotional or clinical instability that prevented them from being interviewed were excluded. It is made clear that each participant of the survey received a fictitious name in order to preserve anonymity.

Data were collected between July and August 2019, in a private room at the hospital. For family caregivers who could not be absent from the ward, interviews were carried out in the ward itself, and partitions were used to preserve the privacy of the interviewees.

The data were collected by means of semi-structured interviews registered in a digital recorder, following a guide composed of sociodemographic data and by these guiding questions:

- a) Tell me, what is your understanding of palliative care?
- b) Do you understand why your family member is being assisted by the palliative care team?
- c) If by any chance your family member was not being assisted by the palliative care team, do you believe that the care of your family member would be different? In what way?

The interviews were stopped only when the concerns of the surveyor were answered, that is, when there was an understanding of the family caregivers' perception about palliative care.

The transcription of the talks was carried out immediately after each interview, respecting the sequence of ideas, language, pauses and repetitions. The data were organized and categorized for subsequent analysis by means of the Content Analysis.<sup>10</sup>

The survey followed the recommendations of Resolution No. 466/12 of the National Health Council, the project being approved by the Research Ethics Committee of the Federal University of Minas Gerais under opinion No. 3,388,074. The participants were informed about the survey, having signed the Term of Free and Informed Consent (TCLE).

## RESULTS AND DISCUSSION

Fourteen family caregivers were invited to participate in the survey, three of whom refused. In this sense, the sample was composed by 11 family caregivers, ten (90.9%) being female; seven (63.6%) with up to 40 years old, single and with complete High School level; five (54.6%) with work occupation; and as for the affective ties, eight (72.7%) declared to be the patients' children.

It can be noted that among the occupations, there was a driver, a teacher, a nutritionist, a saleswoman, two self-employed, the others being a retired person, two housewives, and two with no occupation at that moment.

It is observed, in relation to the elderly patients, that the most frequent medical diagnoses were cancer (five - 45.4%) and heart failure (four - 36.4%), with six (54%) being assisted by the PC team for less than 14 days during their current hospitalization.

Based on the talks by the family caregivers, three thematic categories emerged:

- a) Perception of palliative care by family caregivers.
- b) Reasons for the relative to be taken care of by the palliative care team.
- c) Is it different to be cared for by the palliative care team?

### ***Perception of palliative care by family caregivers***

This first category presents the perception of family caregivers about the term palliative care, this perception being the organization or the synthesis made by each individual's intelligence.<sup>11</sup>

*I understand that it is a clinic focused on caring where the patient does not have a cure. (Rosa)*

*There is no positive prognosis, right, unfortunately, we are waiting for the end really, see, of life. (Joana)*

It is reported that in palliative care the term terminality is no longer in use, but rather life-threatening disease; the expression impossibility of cure has also given place to possibility or not of a modifying treatment of the disease, in order to reduce the thought that there is nothing else to be done.<sup>5</sup>

Palliative care can be perceived as a differentiated assistance that transcends the traditional provided assistance and makes care more humanized, directed to the dignity of the patient, focusing on control of pain, on comfort and on the individual's needs.

*It is useful to give greater comfort to patients, [...] to help ease that pain and other things. (Angélica)*

*He (the doctor) is trying everything to make the patient improve, so there comes a certain time when he thinks about treating the patient to give him some comfort, so that he does not feel pain. (Camila)*

Palliative care is perceived by some family caregivers as a moment to provide quality of life to their loved ones, even in face of finiteness.

*My dad, he has cancer, see, he is going to have chemotherapy, only that this chemo, he has no more cure, but there are other things that can help him have a better life. (Daiana)*

*I think it's a way to give a better quality of life where there's no way to do something for the cure, right, then it'll be a way for her to have that, a better quality of life [...] I understood it to be a way to give her this quality of life. (Paula)*

It is inferred, when considering that quality of life is the individual's perception of his/her insertion in life, in the culture context and in the value system in which he/she lives, as well as in relation to his/her objectives, expectations and concerns,<sup>12</sup> that palliative care is an approach that aims at the quality of life of both the patient and the family member, with a view to also caring for the caregiver.<sup>2</sup>

*[...] it is to give some comfort both to the patient and to who is assisting the family, it is to clarify some doubts, it is to make the person understand better what the patient is going through and clarify it a lot better. (Carolina)*

Although most of the participants reported having an understanding of what palliative care is, the lack of such knowledge was expressed by some family caregivers.

*As for this palliative [...] I don't know how to explain palliative care to you. I don't understand much, but it's like this, I think that this palliative care is to observe how the person is, how he/she is reacting, to be always attentive. (Tatiana)*

In a recent survey, fragile knowledge about palliative care was identified among caregivers, some demonstrating not to know about the seriousness of their relative's current condition and, when questioned, they demonstrated noncontextualized knowledge of their clinical condition.<sup>13</sup>

Communication is considered an essential skill in the palliative approach, and especially in the communication of difficult news there should be an open and active dialogue, with the purpose of promoting trust and a bond with the patient and family, always considering making information available by means of slow, progressive and bearable truth.<sup>14</sup>

The verbalization of the lack of knowledge about palliative care by those two participants can be justified by the fact that their relatives had been recently integrated to the team, but it could also be for personal reasons, as a mechanism of protection, a way of confronting that new situation, the reality of the patient's current condition.

It is observed, in view of the participants' statements, that family caregivers understand care by means of the experience, observation, and instruction given by the team. However, there is still a need for greater dissemination of what palliative care is, how this care is offered and to whom it should be provided.

***Reasons for the family member to be taken care of by the palliative care team***

This second category describes the perception of family caregivers about the reason why the patient receives care from the palliative care team.

*From the diagnosis, you see, that this diagnosis was given in 2015 and the oncologist was quite clear when he said that there was no cure, that it would really be palliative care. (Rosa)*

*Because her case cannot be operated [...] there is no proposal for cure. (Paula)*

Confronting a diagnosis with no possibility of cure can have a great impact on the life of the patient and his/her relatives, leading to changes in the structure and dynamics of daily life.<sup>15</sup>

Through the multidisciplinary team, through the management of pain and other symptoms that generate suffering, asserting life and accepting death as a natural transition, neither delaying nor advancing it, but integrating psychosocial and spiritual components to patients and their families is what is sought.<sup>4</sup>

*As we opted for non-invasive treatment [...] they passed on to her [...] to help her with any ill-feeling or discomfort she might have. (Angélica)*

*They came, then they told me they could also extend it to another kind of treatment, if I would agree, I said no, you see, which is in this case to intubate, I do not agree [...] that the person may return, especially at the age of 93, it is more than risky [...] go to the ICU, a rough treatment, which might even have some effectiveness, but it could cause harm. (Camila)*

Acceptance is defined, in the final stage of life, as to when the patient welcomes his/her situation and the course of his/her illness, this being the stage when the family caregiver may need more assistance, understanding and support as the relative finds peace and the circle of interest is reduced.<sup>10</sup>

*It's because she's like this, and at any time the Lord may take her. (Carolina)*

*[...] this time it's been more complicated, see, this time he's bleeding [...] he had pneumonia, then, then I think they came, because then the psychologist came, everybody came to try to help. (Daiana)*

One participant was pointed out as reporting that she did not understand the reasons that made her relative be assisted by the palliative care team. Having demonstrated knowledge of the clinical condition throughout the interview, when asked about the reasons for this assistance, she hesitated.

*I don't understand, [...] the other time I came here, the lady told me about palliative care. (Tatiana)*

For one of the participants, it is specified that the reason would be a pressure injury, a new event in the clinical condition. This reason, justified by the family caregiver for palliative care, can express ignorance of the real motives or even a process of denial of the loved one's condition.

*It must be because of the injury he has. (Rodrigo)*

It is clarified that when one reaches the stage in which the disease points to the end of life, it is common to observe the incidence of mood swings, which can be reactive and preparatory. The reactive one is linked to the resolution of pendencies, whereas the preparatory one permeates sadness, silence, and when installed, tends to produce little or no need for words.<sup>16</sup>

Attention is drawn to the fact that the clinical condition of the individuals in this survey was complex and, to a large extent, their perspective of life was short. This can lead family caregivers to experience situations of constant changes, uncertainties about the future, which could justify the feeling of denial or silence towards the new condition of their relative.

In order to maintain a strong and reliable bond, the team must keep the family caregiver active in the caregiving process, considering their importance and knowledge in deciding upon their relative's care, being integrated in the whole process. The caregiver must also feel and be cared for by the team.

***Is it different to be cared for by the palliative care team?***

The perception of the family caregivers about the difference between the care provided by the palliative care team and the care provided by the non-palliative care team will be described in this category.

Care was differentiated in the following sections, due to the attention offered, the closeness of the team, the perception of a greater care by the Nursing team as a differential, maybe due to the everyday care, and to the evaluation centered on the need at the moment the patient is assisted.

*I think that if it were not... or it could be a little worse, because you are a little more caring. (Rodrigo)*

*Yes, because she wouldn't have this concern in well-being, right, at least do something for her to get better, you see. (Paula)*

*It would be quite different, because the patient who stays in hospital, no matter how well the nurses take care of them (palliative team). (Talita)*

The nurse participating in the multidisciplinary team plays an important role in the total care of the patient and his relatives through a systematic evaluation, contributing for the whole team to establish each patient's priorities, at the same time providing family interaction and demonstrating to the family member his/her important role in achieving the objectives set by the team. Thus, the nurse must provide sensitive and educative care, seeking a strong bond so that care and guidance can be put into practice.<sup>5</sup>

To some participants, the experience transcended to the care directed to their needs, providing active listening where the team seeks to understand the family caregiver, explains the situation



and worries about how he/she feels, that is, besides caring for the patient, they take care of the caregiver.

*I noticed a difference where there was more attention to us, to me, you see, and all the time they mentioned a concern with my mother's care [...] I had some support, I felt supported in the team, in the way I was treated. (Rosa)*

In addition, the palliative care team also acts in the recognition of psychosocial suffering, including care for family members or close ones, and in the relief of spiritual/existential suffering.<sup>5</sup>

*Palliative care also helps us, right, it mainly helps my mother, I think they advise her more. (Tatiana)*

*This work that you do here is excellent, it gives us great comfort. (Carolina)*

*At the same time, it treats not only the patient, it also treats the patient's companion [...] this thing, this affection, this coziness, I think it's cool in this sense, you understand [...] I really liked having them with me in this moment, you know, it was very important to me, it was very comforting. (Camila)*

Through the palliative care team, empathic communication between patient and the assisting team is pursued, always acting with respect and honesty towards them.<sup>5</sup>

*Definitely, because the palliative care gives that feeling, that he feels more at ease to be able to speak, to be able to communicate [...] with the palliative care, I think it's much better, you see, his routine here at the hospital. (Joana)*

*I don't know why, like, a medical meeting, you work together with everybody, right, here everybody works together [...] then the psychologist comes, you come, you see, there's the physiotherapist, she's a physiotherapist for the elderly [...] I think it's good to get everyone together, you know? (Daiana)*

By sharing the operation among professionals, patients and family members, safety and quality of care are enhanced, lowering the cost of this care and providing greater satisfaction among those involved. By centralizing the care on the patient, it helps to reduce the vulnerability generated by the disease.<sup>17</sup>

For one participant, the care was considered the same, and she stated that there was no difference.

*I honestly think it would be the same way, I haven't seen any difference [...] I don't know, sometimes, we expected a lot more [...] in reality, for her it didn't make much difference. (Angélica)*

The caregiver is an active character in the process of sickening, participating in all stages and assisting the patient, seeking alternatives for better care.<sup>13</sup>

It is observed that a foreign participant could not report if there was a difference in the care provided by the palliative care team, since in her country she was unaware of this approach.

*I don't know, because I haven't been here long, and I don't know how it was before, I don't know. At least, I imagine so, because of the care. (Luana)*

The palliative care aims to provide a change in the relationship among health professionals, patients and caregivers, having the expectation on the part of the team of a participation involving the caregiver in the course of the treatment.<sup>18</sup>

## CONCLUSION

It has become possible, when seeking to investigate about the perception of family caregivers of elderly patients about palliative care, to understand that family caregivers present some insight into what palliative care is, they know the reasons that took their relative to be assisted by the palliative care team and they understand that the monitoring provided by the team is distinguished because it is a humanized, patient-centered care, with appreciation of the family caregiver.

It has been demonstrated that effective communication and support to family caregivers give them an insight into what is offered to the patient and, consequently, to their companions. However, among those, 18.18% (two caregivers) still presented lack of knowledge about the theme. This situation may be due to weak communication, the patient's current condition or even a defense mechanism. It is believed that it is important to understand this process so that better practices can be carried out in the approach of the patient and the family caregiver by the palliative care team.

It is concluded that, because it is a qualitative survey, the results cannot be generalized, since they represent a phenomenon of the surveyed population, this being therefore a limitation of the study.

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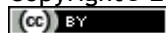
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