

# Formal caregivers and palliative care from the perspective of bioethics

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## Abstract

From the meanings attributed to palliative treatment by formal caregivers of Pouso Alegre, Minas Gerais, Brazil, this study aims to identify and understand possible gaps in the training of these professionals. The study is descriptive, exploratory and cross-sectional; sampling was intentional and followed the snowball technique. Two instruments were used to collect data: a personal and professional characterization questionnaire and a semi-structured interview. The collective subject discourse method was used to analyze the data. The social representations reported were: “care”; “Various meanings”; “Love, care, attention, dedication to the patient”; and “go beyond liking”.

**Keywords:** Palliative care. Bioethics. Caregivers.

## Resumo

### Cuidadores formais e assistência paliativa sob a ótica da bioética

A partir dos significados atribuídos ao tratamento paliativo por cuidadores formais de Pouso Alegre, Minas Gerais, Brasil, esta pesquisa pretende identificar e compreender possíveis hiatos na formação desses profissionais. O estudo é de caráter descritivo, exploratório e transversal; a amostragem foi intencional e seguiu a técnica bola de neve. Foram utilizados dois instrumentos para coletar os dados: questionário de caracterização pessoal e profissional e roteiro de entrevista semiestruturada. Para analisar os dados, utilizou-se o método do discurso do sujeito coletivo. As representações sociais relatadas foram: “cuidado”; “diversos significados”; “amor, carinho, atenção, dedicação ao paciente”; e “ir além de gostar”.

**Palavras-chave:** Cuidados paliativos. Bioética. Cuidadores.

## Resumen

### Cuidadores formales y asistencia paliativa desde la mirada de la bioética

A partir de los significados atribuidos al tratamiento paliativo por parte de cuidadores formales de Pouso Alegre, Minas Gerais, Brasil, esta investigación pretende identificar y comprender posibles hiatos en la formación de estos profesionales. El estudio es de carácter descriptivo, exploratorio y transversal; el muestreo fue intencional y siguió la técnica de bola de nieve. Se utilizaron dos instrumentos para recolectar los datos: cuestionario de caracterización personal y profesional y guion de entrevista semiestructurada. Para analizar los datos, se utilizó el método del discurso del sujeto colectivo. Las representaciones sociales relatadas fueron: “cuidado”; “diversos significados”; “amor, cariño, atención, dedicación al paciente”; e “ir más allá del gusto”.

**Palabras clave:** Cuidados paliativos. Bioética. Cuidadores.

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In the “Encyclopedia of Bioethics”, Reich<sup>1</sup> defines bioethics as a systematic and interdisciplinary study of moral dimensions that uses multiple methods. It includes the vision, decision and ethical conduct of life sciences and health norms, reconciling human and biological knowledge and values. The bioethics of protection - a reference adopted in the present study - is recent in this field of knowledge and was a response to the globalization process that made whole populations vulnerable, excluded from the ability to develop their potential and guarantee their dignity, a fundamental right of the human being.

Being one of the many topics to which bioethics pays attention, palliative care is an emerging model of end-of-life care, developed from a model of total care offered to patients with advanced and terminal disease and their families, based on the right to die with dignity<sup>2</sup>. This care is multi-professional and aims to control the bodily, mental, spiritual and social symptoms that afflict a person as death approaches since in this situation he needs protection given the fragility that can often hamper their autonomy<sup>3</sup>.

The etymology confirms this definition since the basis of the term “palliative” comes from the latin *pallium*, which means “mantle”, a symbol of protection in the process of dying<sup>4,6</sup>. Hence the idea of protecting, supporting, covering and wrapping when a cure for a particular disease is no longer possible. Moreover, in this context, the family is also welcomed by the multi-professional team, as it shares the patient’s suffering.

Palliative care emerged in London in 1967, with Cicely Saunders leading the Hospice movement and the founding of St. Christopher’s Hospice, which gained wide international repercussions<sup>1,4,6,7</sup>. Over time the concept has expanded, being linked to palliative medicine, which, in turn, refers to the practice of listening and understanding, proposing treatments that relieve the pain of terminally ill patients.

In 1990, the World Health Organization (WHO) defined palliative care as care focused on people whose illness no longer responds to appropriate treatments to control pain and other psychological, spiritual and social symptoms to improve quality of life of the patient and their families<sup>8</sup>. Only in the 1980s did palliative medicine come to Brazil, and two decades later, in February 2005, the creation of the Academia Nacional de Cuidados Paliativos - National Academy of Palliative Care (ANCP) was a milestone for the history of medicine in the country<sup>9</sup>.

Therefore, palliative care represents breaking paradigms, since it is not guided by protocols, but by moral principles; and the core of its attention and performance is not the disease but the well-being. This type of treatment seeks, for the first time in medicine, to integrate science with spirituality and psychology as a means of supporting the patient, encouraging them to live more actively until the moment of their death, as well as assisting and counseling his relatives in grief.

The five principles of palliative care are: 1) truthfulness, which constitutes the maturation of the relationship between the parties, enhancing the participation of patients and families in decision making; 2) prevention, which seeks clinical conduct that avoids complications and prizes proportional and appropriate treatment; 3) non-abandonment, which refers to the ethical posture in the face of professional challenges in terminal patient care; 4) double effect, which values ethical and legal conduct when deciding on actions that cause good and bad effects - for example, administering drugs that lead to loss of vigilance or consciousness; 5) therapeutic proportionality, which alludes to the balance of interventions regarding the means employed and the expected results<sup>10</sup>.

Other important principles are highlighted by Pessini, Bertachini and Barchifontaine<sup>11</sup> such as, for example, having the compassion to put oneself in the place of the sick and imagine what he would want for himself. Thus, palliative care demands professionals who remain with the patient constantly: the formal caregiver. However, often these professionals are not adequately trained to perform this function<sup>12</sup>, referring to themselves as “companions with nursing practice”, i.e. without any nursing course, whether technical or higher, which can endanger the patient’s quality of life<sup>13</sup>.

Today, palliative care is also provided in the home environment, including state-of-the-art technology such as artificial respirators. These situations require formal caregivers to replace informal caregivers, which drives the emergence of home care companies that provide professional palliative care.

It is common for formal caregivers to face overload because of professional practice due to the care provided and the bond they establish with the patient. Often, these professionals do not have time to take care of themselves, compromising their health (this occurs mainly when the caregiver is female, as it is common for women to also have tasks at home, performing an extra work shift).

It is essential that the patient be treated with humanity, concerning their autonomy and the principles of palliative care. Bioethics also reinforces the dimension of beneficence and non-maleficence, guiding aspects of the responsibility inherent to the performance of this professional.

Based on the definitions of palliative care, the objective of this paper is to identify the main gaps in the formal caregiver training for this type of treatment, seeking ways to fulfill them. To this end, we seek to define the skills and abilities needed by the professional, proposing criteria for their hiring to provide safety and tranquility to family members with loved ones and, in the future, to those who need such care.

## Method

This research, conducted from a qualitative, descriptive and exploratory approach, in cross-sectional, identifies and analyzes social representations through the collective subject discourse (CSD), proposing to know the meaning given by formal caregivers to palliative treatment, and identifying, in addition, personal, family and professional characteristics of the subjects to understand possible gaps in their formation. The study included 20 formal caregivers working at home, residents of the city of Pouso Alegre (MG). All respondents had their anonymity, privacy and confidentiality respected.

In the interviews, we sought to understand the social imaginary and identify aspects of formal caregivers' education from the semantic peculiarities of their discourse on palliative care. The sampling was intentional, and the selection of respondents followed the snowball technique.

The choice of participants was based on the following inclusion criteria: 1) contract or registration in the professional document attesting to work as a formal caregiver at home, working in palliative care; 2) have at least six months of experience; and 3) be at least 18 years old. Formal caregivers who did not work with palliative care or who had professional experience only in a hospital were not considered for the sample.

The interview with each of the caregivers was previously scheduled, and all were informed of the research objectives and about the audio recording of the conversation, which took place in a quiet, interference-free place, chosen by the interviewees to provide them with privacy and

safety. After transcribing the recording, the material with the participants' speech was duly archived in an appropriate place, where it will remain for five years, when it will be properly disposed of without harming the environment, according to current regulations.

Two data collection instruments were used: a closed questionnaire and a semi-structured one. The instrument with closed questions collected sociodemographic data, which were analyzed using the Statistical Package for the Social Sciences (SPSS), version 21. Of the categorical variables, the absolute and relative frequency were calculated; From continuous and numerical variables, the mean, median, and standard deviation were extracted. The semi-structured instrument posed an open question about the meaning of palliative care: *"If a friend asked you, 'What does palliative care mean to you?', What would your answer be?"*

Then, by the CSD method, a synthesis speech was formulated from the respondents' answers, inserted in the same organizational body or engaged in similar activities. The method is based on three methodological figures: key expressions (KEX), central ideas (CI) (signifiers that synthetically and precisely compile the meaning of the discourses collected), and the CSD itself.

Data processing and analysis followed five steps. In the first of these, the written answers were read several times to get a general idea and better understanding of the texts, and the audio material was literally transcribed. In the second step, all the answers were read carefully and, after that, each answer was read separately for patterns, i.e. the first question of all respondents, then the second and finally the third.

The third phase consisted of copying the answers of each caregiver to question 1 of the first instrument (Discourse Analysis Instrument 1), with the italicized representation of the KEX, from which it was possible to identify the CIs, which should describe the expressions key, and do not interpret them. This same procedure was performed with the other questions. Then, in the fourth step, the same or similar CIs were grouped. Finally, through the participants' speeches, the collective subject's speech was made, inserted in another instrument called "discourse analysis instrument 2" (DAI2).

## Results

Twenty formal caregivers were interviewed, with a mean age of 36.5 years ( $SD \pm 9.78$ ), being 85% female, 40% single, 70% self-declared Catholic

and with average children of 1.35 (SD±1.22). As for professional characteristics, 40% of respondents said they were nursing technicians, with an average training time of 2.5 years (SD±1.14), the time of experience with regard to years of professional practice as a nursing technician. corresponded to 2.45 years (SD±1.19). On the other hand, the average working time, which refers to the years of activity as a caregiver, was one year (SD±1.27).

Among the 20 participants, 95% had health care as their area of professional experience, all acted professionally and 90% referred to their role as “formal caregiver”.

The interviews allowed to articulate meanings for palliative care around four central ideas (CI): 1) “caring” 2) “various meanings”; 3) “love, affection and attention”; and 4) “to go beyond liking” (Frame 1).

It is important to clarify that the central idea “Caring” was represented by thirteen study participants. This means that the same central idea was extracted from the interviews of thirteen study participants.

**Frame 1.** Meanings of palliative care: central ideas, participants and frequency of the theme

Central Ideas	Participants	Frequency
Caring	1, 3, 5, 5, 5, 5, 6, 7, 8, 11, 15, 17	13
Several meanings	2, 4, 8, 9, 14, 16, 17, 20	8
Love, affection, attention and dedication to the patient	10, 11, 13, 14, 19, 20	6
To go beyond liking	18	1
Total	–	28

### Caring

*“Palliative care is an act of caring for the patient in the terminal phase, it is caring for the whole, providing care to avoid and relieve suffering as best as possible. With a dignified care always dialoguing and trying to bring peace to the patient and family.”*

### Several meanings

*“It is the action of the multi-professional team to the terminally ill patient, providing the best possible in all the areas he needs, meeting the need in what needs to be improved and making the family secure. Do your best by looking at the patient with other eyes so that they have and feel comfort.”*

### Love, affection, attention and dedication to the patient

*“Palliative care means love, affection, dedication, attention, dignity, comfort, and patience with the patient and family.”*

### To go beyond liking

*“Palliative care has to go beyond liking.”*

## Discussion

According to the CSD, the first CI, “caring”, indicates that palliative treatment *“is the act of caring for the terminally ill patient completely, avoiding and relieving suffering as best as possible, through decent care that dialogues and brings peace of mind to the patient and family”*. Thus, in contexts in which the well-being is compromised, care would have the purpose of relieving the physical pain and psychological distress that lead the individual to question, depreciatingly, their existence and potentialities. In these situations, the formal caregiver needs to bond with the patient and family through work that combines both technical and scientific knowledge to deal with the body and the disease as well as empathy and sensitivity with the human being.

Therefore, the social responsibility of formal caregiver is notorious, since their action protects the human dignity of the patient<sup>14</sup>. More than a moral obligation, the act of caring creates an intimacy that goes beyond techniques and training, stimulating the professional to extract from himself all creativity and lightness for the well-being and comfort of the patients and their families<sup>11</sup>.

In the second CI, “various meanings”, it is inferred from the CSD that palliative care is *“the action of the multi-professional team that provides the best care in the most diverse domains, addressing the disabilities of the terminally ill person and transmitting safety to family members. This action consists of giving the best of oneself while assisting the patient, ensuring due comfort”*. From this perspective, the focus is on the multi-professional team, as the demands are diverse and need a holistic and integrated look that brings dignity and tranquility to the terminally ill. This process respects the autonomy of the individual, supplying the possibility of dying at home, surrounded by family, friends and personal property<sup>7</sup>.

In a similar investigation, Fernandes and collaborators<sup>15</sup> also point out that professionals in the area consider palliative care as integral, humanized and multidisciplinary, emphasizing that the team must treat the patient individually and strive for excellence, in order to protect their dignity. Therefore, those who perform this function should broaden their theoretical, technical and ethical domain to prevent and alleviate the suffering of patients.

In the same perspective, the third CI encompasses a more humane understanding of formal caregivers: *“love, affection, dedication, attention, dignity, comfort, and patience with the patient and family.”* Thus, palliative treatment ends up creating greater involvement between the parties, since, as Figueiredo<sup>16</sup> indicates, the four dimensions of the human being are engaged: physical, mental, spiritual and social.

With care and patience, the formal caregiver should work the affection, in the sense of the word in this context, for the patient, who is fragile, offering their best to make them feel less powerless. For this, the professional has resources such as the therapeutic touch, active listening or the simple silent presence beside the patient. In palliative treatment, two conditions are essential for the professional: the human dimension and technical competence. Together, these two elements alleviate suffering and contribute to the quality of life of the patient<sup>17</sup>.

In the fourth and last CI, “to go beyond liking”, unlike the points linked to the bond with the patient, respondents stressed the importance of the relationship of the caregiver with their work. The professionals must take care of themselves since the care presupposes availability, solidarity, altruism, technical competence, and beneficence<sup>18</sup>. In addition to the technical and scientific skill, the exercise of the profession requires empathy and resilience in the face of the achievements, losses, and challenges of the professional day by day. Waldow<sup>19</sup>, in the same perspective, points out that the formal caregiver, when shifting the paradigm from cure to care, must combine theoretical knowledge with his intuition and sensitivity.

Finally, it is imperative to emphasize that formal caregivers should not assume paternalistic behaviors<sup>20</sup>, but encourage the treated person to do what their physical, mental and spiritual conditions allow them. It is necessary to respect the patient’s autonomy to want and be able to do something for themselves<sup>2,21</sup>, seeking to understand their memories and experiences to guarantee their independence. The caregiver, therefore, stands as

necessary support for the individual to enhance their abilities and make their choices consciously<sup>20</sup>.

## Final considerations

From the interviews, it appears that participants are aware of the responsibility of their work, even though they do not use academic terms such as “vulnerable”, “protection”, “ethics” and “moral”. This gap can be attributed to deficient training, which lacks reflection on the practice itself. Likewise, it is noted that respondents referred only to caring, without concern about making reflections on death.

The encouragement of multidisciplinary by scientific publications can help to reverse this scenario by articulating diverse pieces of knowledge and prioritizing new discussions, contributing to the dissemination of increasingly relevant knowledge. In turn, patients need both the attention to the body’s needs and subjective desires as well as the respect and comfort that their conditions demand.

The study results suggest four recommendations. The first is to stimulate scientific production, including works with larger samples and in different scenarios, to confirm or refute the results presented here. The second recommendation is that those responsible for home care services check the qualification of professionals and prepare them before starting terminal patient care, and then ensure constant training.

Research is also recommended to evaluate the quality of palliative care. Finally, it is recommended that multi-professional teams of basic units and the Family Health Strategy should be aware of terminal patients in their coverage area, since the provision of palliative care is a public health issue, and there is no doubt about the need to strengthen the Unified System in this regard.

The biggest challenge for the formal caregiver is to reconcile sensitivity and technical competence, which requires further training through bioethical reflection and, specifically, the bioethics of protection, which raises questions about human action and can guide the thinking and practice of health care professional. In conjunction with these reflections, an interdisciplinary and humanistic approach should be sought and the protection of those in need encouraged. The terminally ill individual demands assistance that should both avoid worsening their condition and look for ways to improve their quality of life.


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## Participation of the authors

Claudia Ferreira da Silva conceived and, with Mirelle de Paula Ribeiro, wrote the article, under the academic supervision of José Vitor da Silva.


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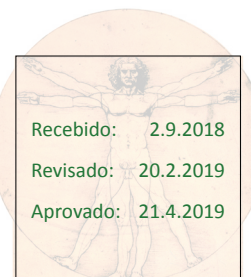
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**Annex**

**Personal and professional characterization of the formal caregiver**

**Instructions:** Read each question to the interviewee, mark the correct answer with an X or supplement the question where appropriate.

Application date: \_\_\_\_/\_\_\_\_/\_\_\_\_

1. Sex: ( ) Female ( ) Male

2. Age: \_\_\_\_\_ years

3. Marital status:

Single ( ) Married ( ) Widow(er) ( ) Divorced ( ) Other: \_\_\_\_\_

4. Religion

( ) Catholic ( ) Evangelical ( ) Other: \_\_\_\_\_

5. Schooling:

- ( ) Elementary school (complete) ( ) Elementary school (incomplete)
- ( ) High school (complete) ( ) High school (incomplete)
- ( ) Trade school ( ) College (complete)
- ( ) College (incomplete) ( ) Graduate / post-graduate / MBA

6. Children: ( ) Yes. How many: \_\_\_\_\_ ( ) No

7. Occupation:

( ) Nursing technician ( ) Nurse ( ) Other: \_\_\_\_\_

8. Time since professional training:

- ( ) Less than 1 year ( ) 1 to 5 years
- ( ) 6 to 10 years ( ) 10 to 15 years
- ( ) More than 15 years: \_\_\_\_\_

9. Professional experience:

- ( ) Less than 1 year ( ) 1 to 5 years
- ( ) 6 to 10 years ( ) 10 to 15 years
- ( ) More than 15 years: \_\_\_\_\_

10. Field of professional experience: \_\_\_\_\_

11. Professional update: ( ) Yes ( ) No

12. Field of professional update: \_\_\_\_\_ ( ) Does not apply

13. Time since professional update:

- ( ) Less than 1 year ( ) 1 to 5 years
- ( ) 6 to 10 years ( ) 10 to 15 years
- ( ) More than 15 years: \_\_\_\_\_
- ( ) Does not apply

**Script for semistructured interview**

1) If a friend asked you “What does palliative care mean to you?”, what would your answer be?

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