

# Palliative care: narratives of suffering in listening to the other

Maria Emídia de Melo Coelho <sup>1</sup>, Amauri Carlos Ferreira <sup>2</sup>

## Abstract

This article is aimed at understanding the suffering of the caregiver facing the extreme situation of the end of existence. The study is qualitative – the methodological discipline of oral history in its thematic side – and it was carried out in the Paulo de Tarso Hospital, in Belo Horizonte/MG, Brazil. The participants of the study are caregivers, consisting of relatives of hospitalized patients and health professionals who accompany them. The narratives, collected through semi-structured interviews, were transcribed and broken down into analytical categories, by philosophical perspective of palliative care. The relevance of this study is found in the comprehension of the dimension of care that requires subtleties, sometimes only perceived through one look, one gesture, one conversation or silence. It was found that listening is essential for the human being to think, telling about his story, his choices and decisions, and, facing this subjectivity, trying to give sense and meaning to living, as a form of alleviating his pain and suffering.

**Keywords:** Palliative care. Personal narratives. Stress, psychological. Caregivers. Hospice care.

## Resumo

### Cuidados paliativos: narrativas do sofrimento na escuta do outro

Este artigo tem como objetivo compreender o sofrimento do cuidador diante da situação-limite da terminalidade da existência. O estudo é de natureza qualitativa – modalidade metodológica de história oral em sua vertente temática – e foi realizado no Hospital Paulo de Tarso, em Belo Horizonte/MG, Brasil. Os participantes da pesquisa são cuidadores, compreendendo familiares de pacientes hospitalizados e profissionais de saúde que os acompanhavam. As narrativas, colhidas por meio de entrevistas semiestruturadas, foram transcritas e desdobradas em categorias analíticas, na perspectiva da filosofia de cuidados paliativos. A relevância deste estudo encontra-se na compreensão da dimensão do cuidado que requer sutilezas, às vezes só percebidas mediante um olhar, um gesto, uma conversa ou o silêncio. Verificou-se que a escuta é fundamental para pensar o ser humano, dizendo sobre sua história, suas escolhas e decisões, e, diante dessa subjetividade, tentar dar sentido e significado ao viver, como forma de aliviar sua dor e sofrimento.

**Palavras-chave:** Cuidados paliativos. Narrativas pessoais. Estresse psicológico. Cuidadores. Cuidados paliativos na terminalidade da vida.

## Resumen

### Cuidados paliativos: narrativas del sufrimiento en la escucha del otro

Este artículo tiene como objetivo comprender el sufrimiento del cuidador frente a la situación límite del fin de la existencia. El estudio tiene una naturaleza cualitativa – modalidad metodológica de historia oral en su vertiente temática – y fue realizado en el Hospital Paulo de Tarso, en Belo Horizonte/MG, Brasil. Los participantes de la investigación son cuidadores, incluyendo familiares de pacientes hospitalizados y profesionales de la salud que los acompañaban. Las narrativas recogidas por medio de entrevistas semi-estructuradas, fueron transcritas y desdobradas en categorías analíticas, en la perspectiva de la filosofía de cuidados paliativos. La relevancia de este estudio se encuentra en la comprensión de la dimensión del cuidado que requiere sutilezas, muchas veces percibidas sólo por una mirada, un gesto, una conversación o un silencio. Se verificó que la escucha es fundamental para pensar al ser humano, pensando en su historia, sus elecciones y decisiones y, frente a esta subjetividad, intentar dar sentido y significado al vivir, como forma de aliviar su dolor y sufrimiento.

**Palabras-clave:** Cuidados paliativos. Narrativas personales. Estrés psicológico. Cuidadores. Cuidados paliativos al final de la vida.

Aprovação CEP CAAE PUC-Minas 4504.0.000.213-09

1. **Mestra** mariaemidia.coelho@gmail.com – Sociedade de Tanatologia e Cuidado Paliativo de Minas Gerais, Belo Horizonte/MG, Brasil
2. **Pós-doutor** mitolog@pucminas.br – Pontifícia Universidade Católica de Minas Gerais, Belo Horizonte/MG, Brasil.

## Correspondência

Maria Emídia de Melo Coelho – Rua Bolívia 499, ap. 302, São Pedro CEP 30330-360. Belo Horizonte/MG, Brasil.

Declararam não haver conflito de interesse.

In an attempt to decode narratives of individuals about their experiences with patients whose diagnosis indicates the impossibility of cure, we sought from the sensitive and respectful listening, to compose scenarios in which the language in its broad expression - gestures, silences, words -, was present and triggered narrative flows, allowing access to the human suffering in the face of illness and death. Therefore, we used the interviews with carers of people in extreme situation of pain and suffering. Reaching out to caregivers is to realize that caring, far beyond the cure, is inscribed in the subjective dimension, marked by the need to endure the pain of existing.

This perspective goes back to palliative care, the assistance and intervention mode targeting the diseased person, with emphasis in relieving their physical suffering and attending to their psychosocial and spiritual needs. It is the active response to problems arising from the prolonged, incurable and progressive disease, seeking to prevent discomfort and provide the best quality of life possible for patients and their relatives <sup>1</sup>. In this sense, it asked: in what ways does caring for the other leads to realize the drama of existence? In what sense does to speak of the other dates back to think of oneself? How does suffering collate subjectivity to bring out a story? How can palliative care relieve suffering?

In this attempt to find elements to understand the subjectivity of the caregiver who suffers from the pain of the other, the narratives of suffering were analyzed in this article. From the idea of palliative care to the patient, we sought to settle accounts of the one who takes care at a given moment, trying to understand, to the extent possible, how such individuals face pain and suffering.

## Methods

This qualitative study uses two data collection techniques: The first consists of semi-structured interviews or narratives, recommended by the methodology of oral history. The other concerns the participant observation and its related: field notebook and informal conversations.

We chose to work with thematic oral history, focused on activities involving issues related to the topic of the developed project. From interviews, we used the method of oral history in its thematic aspect, in which it elects a specific research topic: The thematic oral history is the closest to common and

traditional solutions of presentation of analytical work in different areas of academic knowledge <sup>2</sup>.

Field research was developed at Hospital Paulo de Tarso, in Belo Horizonte, Minas Gerais, Brazil, which implemented the philosophy of palliative care in the second half of 2009, in partnership with Unimed-BH, with twenty interviews and a home visit after the death of a patient, between January and April 2010. This research focuses not only on caregivers - be them health professionals, family or peers - which widen their approach to the difficulties involved in the care process. Thus, their narratives make up this mosaic about the suffering and the dimension of care. There were nine family caregivers, among daughters, wife and mother. Of the professional caregivers, there were eleven respondents, including physicians, nurses, psychologists, social workers, nursing technicians to carers for the elderly. The story of the family members is emotionally charged, while that of the professional is more technical, although humanized. The mother's narrative was the most heavily anguished, perhaps for the early loss of a child. Other relevant reports came from daughters who were losing their father. They were very keen to tell their life story and the legacy left by him. In this case, as this was a prolonged hospitalization, around eight months, the entire professional staff was very involved with these families. The research project was approved by the Ethics Committee of the Pontifical Catholic University of Minas Gerais ("Pontifícia Universidade Católica de Minas Gerais", PUC-MG).

## Result – narratives of suffering

Hearing the narrative of subject subjects who accompanied a family member in the extreme situation of illness and the diagnosis of pressing death, it was observed that conversation provides relief, conveys the feeling of warmth and has beneficial or therapeutic effect: *As love is the emotion that founded the origin of the human being and the pleasure of talking being our characteristic, it follows that both our well-being as our suffering rely on our conversation* <sup>3</sup>. Was so that careful listening to stories that express suffering: at the end of the interview, the subjects claimed that they felt much better after "our conversation".

This is how the methodology of oral history will compose the other's emotion puzzle, opening ground for the narrator to trust the interviewer and to be willing to talk about themselves. This is what

enables the construction of dialogue and access to subjectivity. It is the choice of listening: *The decision for listening to subjects, choosing from the multitude of those who will tell life stories or themes, dates back to the inscription of beings who narrate their itineraries. These only remain in time when there is a record, a testimony, a voice that can sometimes wonder about the trouble of entering the world to later leave*<sup>4</sup>.

The suffering of the soul can be expressed by a look or a gesture; but to be perceived, it takes attention and subtlety. Listening to the other, expressed in the narrative of suffering, records the memory of fear and anguish; these are inscriptions referring to the time of tearing, the (im) possibility of non-existence<sup>5</sup>.

The suffering of the soul can be expressed by a look or a gesture; but to be perceived, it takes attention and subtlety. Listening to the other, expressed in the narrative of suffering, records the memory of fear and anguish; these are inscriptions referring to the time of tearing, the (im) possibility of non-existence<sup>5</sup>. Listening to these people who want to be heard, with sensitivity to ascertain feelings, shows that conversation has therapeutic effects:

*The conversation is human mechanism par excellence, a simple means of promoting subjectivity. (...) The conversation relieves pain as it breaks the loneliness and helplessness and thus is a powerful instrument for health promotion. (...) Restoring the health and well: living is to be able to talk about oneself, to share pains and fears, weaknesses and strengths, take those turns along the way, tell stories and affections, finally, com-versare*<sup>6</sup>.

Diseases without possibility of cure cause, from diagnosis, malaise, suspicions, increasing symptoms; the treatment comes with fear, shame, isolation, dependency, fatigue and sometimes false hopes. All of this is an overwhelming threat, involving the person in a chain of losses that goes beyond the human capacity for confrontation. At that time, any one of us is faced with the limitations of existence, or impotence to prevent the destruction, namely the unbearable weight of reality<sup>7</sup>.

In the book "On death and dying"<sup>8</sup>, Swiss psychiatrist Elizabeth Kübler-Ross shows that, from the moment of the knowledge of the diagnosis of a fatal disease to the terminal stage, the person usually goes through five dynamic phases, marked by negative attitudes, anger, bargaining, depression and acceptance. This work, based on reactions of

her own patients, was considered a landmark for the understanding of care to the terminal patient. However, this survey found that it is possible to establish a parallel between the terminal patient's emotions and those experienced by their caregivers, especially in cases where there is a strong emotional bond between them. Kübler-Ross also states that family members experience different stages of adaptation, similar to those described with reference to patients.

Although death is the only certainty of any living being, to closely accompany one who follows this path may be difficult for those who are responsible for care. Standing by the patient can lead caregivers to remember their own finitude; it can awaken their anguish of existing - to be suffering in a world where the choices may seem inevitably tragic, especially when one considers that the desire to stay is inherent in life. But, although it is difficult to share the emotions at that moment, this may be the only condition able to give meaning to existence.

Kübler-Ross points out that in the first stage it is common to observe the denial and isolation of the person who expresses with responses like, "No! Not me..."; "It cannot be true"; "It is not fair!". This rejection of the initial diagnosis often leads to search for other opinions and predictions. Denial is a temporary defense and, in a sense, can be considered healthy for allowing the person to cope with this painful and unpleasant situation, inconceivable in psychoanalytic terms, which will require several adjustments. It is, in a sense, a natural reaction to the shock, which, over time, the subject will tend to absorb and cope with, recognizing the lack of alternative.

When one thinks of the relatives, *at first, many of them cannot believe it's true. It may be that they deny the fact that there is such a family illness or "start walking" from doctor to doctor in the vain hope of hearing that there was error in diagnosis. They can seek help and try to make sure, next to palm readers and healers, that is not true. They can plan expensive trips to famous and renowned medical clinics, only gradually facing the reality that can dramatically change the course of their lives. Therefore, the family suffers certain changes, depending largely on the patient's attitude, knowledge and skill with which the fact is communicated*<sup>9</sup>.

Family members interviewed expressed this denial with phrases such as: "We do not believe in the diagnosis"; "This can not be happening to my father"; "My son cannot be dying." Denial can be fo-

llowed by feelings of anger, rebellion, jealousy and / or resentment. The question arises: "Why me?". It's a difficult position because anger tends to propagate in all directions, turning mainly to health staff and the surrounding environment.

At this point, it is essential that the caregiver understands the patient's response, not to consider it personally, since, in its origin, such irascible attitude has little or nothing to do with the people who are victims of it. A clear example of this phase for the caregiver was the mother who, at the height of their revolt, started to attack the entire nursing team, as if they were responsible for her child's condition. And also the daughter who was said to be angry with God for letting her father be in that state (in this case, vegetative state):

*At the moment in which the patient is undergoing a stage of anger, close relatives feel the same emotional reaction. First, they show anger toward the doctor that examined the patient and did not presented the diagnosis immediately; later, toward the doctor who informed the sad reality. They can direct their fury against the hospital staff that never shows enough care, no matter how efficient the care is. (...) The more we can help the relatives to vent these emotions before the death of a loved one, the more comforted they will feel*<sup>10</sup>.

Another phase, less visible, is the bargain, in which one tries to negotiate possible improvement and be rewarded for their good behavior. The bargain is the attempt to delay the end. Most of the time, proposals are made to God and kept secret. They are generally promises made in exchange for an extension, however small, of life time. This attempt to bargain with God was observed in the caring mother when she said: "My son is very young, very good and hardworking. He deserves to live longer. I ask God every day to listen to me."

At the stage where the consequences of the disease point to the end of existence, it is common to observe the presence of depression, which can manifest in the following forms: reactive and preparatory. Reactive depression is more closely linked to specific problems that need to be solved, for example, who will take care of the children after death. The preparatory depression is permeated with sadness and silence, and when it is set, it tends to generate little or no need for words. It is time for a caring touch, a cuddle, or simply "stand alongside", preparing for the final stage: accepting the departure.

Once again we resort to the example of the caregiving mother, who at the time of worsening of her son's health condition turned out silent, resigned and prepared for death, despite the pain stamped on her features. *When anger, resentment and guilt arise, the family enters a phase of preparatory grief, the same as dying. The more they can vent this grief before the death, the better they will support it later*<sup>11</sup>.

Acceptance is characterized by a gradual shutdown period from issues and events from the outside world. The interest in everything and everyone decreases. The presence of the caregiver takes place through the shared, companion and welcoming silence, in which the look or touch can say much more than words. However, not all people pass or go through all stages. They may come and go, and even get to the end without accepting the process of dying.

*If family members can share these emotions together they will gradually face the reality of the impending separation, coming together to accept it. The period of the final stage, when the patient gradually gives off its world, including family, is perhaps the deepest sadness. They do not realize that the dying person, who found peace and acceptance of death, has to part, step by step, from their environment, including the most beloved people. How might one be prepared to die if one continued maintaining relationships full of meaning, and there are so many in one's life? When the patient asks to be visited only by a few friends, then only by their children and finally only by his wife, one should understand that this is the way he let go gradually. Often, the closest relatives misinterpret this fact, as rejection, and we have found many husbands and wives who responded dramatically to this normal and healthy detachment. (...) During this period, it is the family that needs more support, not so much the patient. (...) If the meaning of this shutdown is not explained to the family, problems can arise*<sup>12</sup>.

The caregiving mother felt very uncomfortable when the son entered this shutdown phase. She as only able to accept the fact after being guided by care team. This case of the caregiving mother is very illustrative. Her narrative is the story of her son, a 28-year-old, head trauma victim, as a result of a serious motorcycle accident. When he reached the hospital, it would be possible to begin rehabilitation, even with sequels. However, his status was changed by the progressive aggravation of neurological symptoms, with many seizures and brain damage, which eventually led to the prognosis of imminent death.

This account is what it is. It is the fact, the event. The possibility of the end, the inability to continue to exist in time. Given this imperative, what is left to the one who cares for and accompanies? What sensitive listening is possible, but the one of care? It is expected from the one who cares, an attitude of willingness to listen and narratives and, from the patient, only the relief of pain. Of the patient, just his story told by the memory of the other. So, it is that memory that gives access to the subjectivity that we are ready to listen to.

At first, the caring mother showed emotional fragility, with defensiveness and avoiding greater proximity to the team. She also showed to be very angry, which was, of course, understandable. She denied the severity of the son's health status and said all the time: "He's too young." This repeated assertion evokes the idea of premature death, referring to the notion of "inconclusiveness" and "unfulfillment" given the youth of the patient and his son condition.

Generally, the pain of the parents for the loss of their children seems to be particularly intense, be it because the death of a descendant looks unnatural, since it is expected that older people die before the younger, or because it highlights the feeling that the life of one who approaches death was not enjoyed in its fullness, and there was still much to live. In these circumstances, such a consideration is perfectly understandable, although it shows that, given the pain of losing a loved one, it is difficult not to forget the fact that no life can realize all its possibilities<sup>7</sup>.

Another phase described by Kübler-Ross is the revolt in the face of the illness or accident, which leads to questions about the existence of God as well as to the loss of hope and to the well known reflection: "Why is this happening to me or my family?" . In this research, the revolt phase before death can be seen in the following testimonials from caregivers, "I have no more hope that he will be fine. What can I think? Every day I think it's the last day of his life. There is no longer any meaning to life" (1 subject); "Yes... there are times that I get angry, very angry with God" (subject 2). Once the disease is revealed in a family member, we need to consider what kind of expectations the family and the patient himself nourish regarding the diagnosis. This facilitates the necessary adjustments, while improving the listening to the pain of others.

When it comes to illness and caregivers one must be alert to the uniqueness of action of each of them in this new context. To understand the interac-

tion between caregiver and the one under care, it should be noted that the *family plays an important role in the whole process of sick patient's relationship with their illness, treatment and hospitalization. Considering it a powerful ally in the difficult task of monitoring a chronic patient is very important for the health team*<sup>13</sup>. When the family is affected by any adverse fact, the entire environment changes. Caring for someone sick, dependent or dying requires not only physical and emotional effort, but also the sharing of tasks, decisions and adjustments, not at all easy.

Often, the role of caregiver is a contingency imposed by an unexpected situation: it is not a choice or an option. It demands assistance and guidance to make bearable what sometimes is unbearable. The following stories demonstrate the effort to make these adjustments:

*"The family has disrupted itself, too, it has even lost harmony somewhat. There is a lot of charging each other, who comes more, who is doing more" (subject 3);*

*"Life changes, people's lives change completely. You get turned on in the disease, your head is in the disease, hospital, hospital, Dad, illness, what will happen? (...). Many things you can no longer do, like traveling, because suddenly something could happen" (subject 4);*

*"It changes people's lives completely. I did not live here, I lived in Espírito Santo. While my father needs at least my affection, the warmth of my hand, I will stay with him" (subject 5).*

Such changes in family structure show the need for attention and care to the family, which is recommended by the philosophy of palliative care, which seeks to understand extreme situations. Jaspers<sup>7</sup> identifies death, guilt, fate and chance with so-called philosophical extreme situations, that is, those that put humans on major issues, since when living these experiences, discovering that you can not escape reality and elucidate its mysteries by thought. These are situations in which man realizes his dependence not on something specific or on one's own limitations, but simply on the fact of existing<sup>14</sup>.

When death does not happen abruptly, unexpectedly, the process of dying is permeated with introspection, reflection on the meaning of life and



death. It is when the patient sees several questions arise about whether there may still be future, when one tries to put in order all his affairs as demonstrates more intense affection for their friends and family, when one tries to forgive, communicate and say goodbye to relatives and friends. If the patient is welcomed and worked on his anticipatory grief, anxiety and fear present in it - and previously very acute - give way to acceptance of their condition, so that suffering is transformed. Dying is therefore a hard inner work can be performed more or less conscious. It's kind of giving birth to yourself:

*Understanding the limits of the self on your existing decline is to understand the ephemeral nature of things in the world. Thus, there is an impossibility in alleviating suffering before death, but you can listen to such suffering from the host. This procedure is the listening, whether of ordinary people, religious leaders or the actual respect for the silence on the other, seeking to take a break at this impulse to want to live beyond the limits. (...) Suffering is non-permanence in time, it's a pain in the spirit. (...) When other hosts that you can only comfort, but there is no way to give hope in this world, when the seeds of decay already initiated. Learning to accept the limits of the other and impotence in the face of death is to understand the being<sup>15</sup>.*

When the disease worsens and the body increasingly degenerates, fantasies of death push reflection to the emptiness inside, producing a sense of abyssal depths<sup>16</sup>.

Severe pain and discomfort can be relieved with appropriate medications, but the multiple sufferings of the soul are not amenable to these procedures. Therefore, the relatives often see death as a solution to problems and relieve the patient's suffering, but at the same time feel guilty for wishing it: *"Then I started to hope that God would have compassion and take him to stop suffering. (...) I tell my mother that, however bad it is, the improvement of my father is to go to heaven. Now, I have no expectation of improvement. The best for him at the moment is God to accept him, because there is no cure, there is no solution "* (subject 6); *"I talked to the priest and asked God's forgiveness for asking for my father to rest. It is much suffering. At this time I ask God to give rest to him"* (subject 7).

At such times, the serene and satisfying communication between staff, patient and family is essential for the good outcome of the process, and especially for accommodating suffering. Thus, the

transmission of safety and peace, in a way, leads to legitimizing of the treatment provided, as can be seen in this statement: *"The hospital is excellent. Not even at home, with all the love that we can offer, it will be the same as the hospital is doing for him. There is no money in the world to pay the treatment that my father is having. He is very well looked after, with affection, that neither the children would be able to give. Professionals, beyond the affection and love, listen and help the family, because they know that we are suffering. He does not lack any assistance, yet we keep wanting guess what goes on in his head"* (subject 8).

The testimony of the professionals also showed the importance of good communication in the face of the existence of limits: *"When we cannot cure a patient, we can do a lot for him/her and do everything to have a peaceful passing, with dignity. From a therapeutic point of view, we reach our limit and we have to acknowledge human finitude, the inexorability of death. We seek to discuss, talk to them, asking them to help us and asking: what we should do? Obviously we put the technical point of view, it has limitations, but we try to assess what may or may not be beneficial for the patient. We make this decision along with them. This approach has been very productive and interesting "* (subject 9).

The narratives of suffering open the possibility of sensitive listening, giving access to the subjectivity of the narrator: *There is a polysemy of senses that the oral document engenders: facial expressions, gestures, timbre and voice tone, breathing ways, regularity of pauses<sup>17</sup>.* In this listening it is impossible to remain indifferent to human suffering. Palliative care comes in and shows why its action is in the field of ethics of care, in which the other demands an attitude of respect and attention.

The issue of care ethics has its place in the field of applied ethics. The term "applied ethics" refers to the normative ethics issues in an attempt to resolve conflicts of everyday life. Its search takes place from micro-relationships in order to establish rational justification bases for acts of individuals. Thus, it creates the relationship between means and ends, arising from judgments based on parameters that are associated with the ideal of a fair and happy life. It is hoped that the discussion would encourage the commitment of the person with their actions, which is affecting the level of duty and thus would extend to all mankind.

## Discussion – the dimension of care

Care determines the human condition to the transience of time. Therefore, man must take care of themselves to prolong their existence in the world. The constant and permanent threat of death at any time confers life immense fragility. Therefore, man must care for life, since death is always ready. The attitude of taking care of ourselves and each other, of someone who is frail, establishes responsibility for the other through care:

*Care represents an attitude of concern, responsibility and involvement with the other; it enters the nature and constitution of the human being. The way of being cared shows concretely what the human being is. Without care, he/she ceases to be human. If they do not receive care from birth to death, human beings are disrupted, wither, lose meaning and die. If along life, they are not careful in everything they undertake, they will eventually harm themselves for destroying what is around them. So care should be understood in line with the human essence<sup>18</sup>.*

The term “care” refers to the word *coera* Latin, meaning “that which promotes healing,” which, in a way, presupposes the “art” of healing. Knowing this art implies the willingness to give in to a relationship in which there is a being who is available to take care of another, for their healing, relieving their pain, calming their suffering. It is this action of care, and of perfecting this art, that allows care to be understood as an attitude: (...) *even before being an action, the action of taking care characterizes an attitude. In the absence of this attitude - which expresses the consideration for each other and for their needs - the actions of caring lose their ethical motivation, lose value and deteriorate<sup>19</sup>.*

*It is with attitude that the human being perceives the dimension of care and the transience of existence, opening to another in the ethical perspective. Hence, the ethics of care takes its place in health care. Health care ethics brings the notion that, to take care of another, one needs exposure to the other. Acceptance of the other as he/she is, but also provision of care to what in him/her asks for passage (becoming, experimentation)<sup>20</sup>.*

The dimension of care searches to achieve the sense of being. It combines the very truth of the subject / individual, establishing relationships of complicity in an attempt to understand the history and the memory of the speaking being, bringing their marks and risking to enter the game

of the world. How to understand the world game in the health field? How does the truth of subject who speaks about him/herself assume the limit of existing? Such questions lead to the health-disease binomial, in which the ethics of care bases its *ethos*, circumscribed in the philosophy of palliative care..

Palliative care was originally designed as a strategy to meet the needs of patients with terminal cancer. Today, however, this concept has expanded, being increasingly applied to the care of a range of diseases without therapeutic possibilities, including those of long duration, such as dementia and other neurological diseases<sup>1</sup>. Such an approach has been recognized as the best for the care of these patients, whose needs differ from those of patients with cancer.

Such patients have many symptoms of discomfort related to their neurological condition. Many have behavioral or communication cognitive dysfunction, and physical deficits. Because of cognitive impairment, there are cases where the symptoms can only be assessed indirectly, through the observation of family members and caregivers. The evolution of this type of disease is usually long, its manifestation and severity of symptoms vary widely, and it is also difficult to verify clearly when its final phase starts.

The precursor of this care modality was the physician, nurse and English social worker Cicely Saunders, who in 1967 founded St Christopher's Hospice, whose structure has allowed not only to care for the sick, as well as the development of teaching and research in the area, receiving fellows from several countries. Dissatisfied with the hardships of patients and the care that was given to them, Saunders took upon herself the task of caring for these patients, treating their sufferings in full, i.e. the body, mind and spirit. Dedicated to pain studies and control of disabling symptoms, she was also responsible for the concept of “total pain”. Her intention was to make the life remaining dignified and comfortable<sup>1</sup>.

In Brazil, palliative care took its first steps in the 1980s, with significant growth since 2000, with the consolidation of existing services and the promotion of new initiatives. Currently, the prospect of expansion of services reveals a promising framework which allows to imagine that, in the near future, everyone will benefit equally from this practice, receiving full care and in a dignified manner, since *the goal of palliative care is to prevent and relieve suffering as well as providing the best possible*

quality of life for patients and their families, regardless of the stage of the disease or the need for other treatments<sup>21</sup>.

To accompany a human being who is suffering or dying is one of the biggest challenges that caregivers may face. This is a process permeated by fear and insecurity crises. There is no income or correct way to monitor these patients, because the death of each is as unique as their live. Hence the importance of palliative care, which teaches to promote quality of life in terminal patients with comprehensive care to the patients and their families.

The existence of human beings demands care. Care aims to rescue and give a new meaning to life, rebuilding its meaning. Care is related to the respect for the other's desire, with the acceptance of the other as is, with the host of their needs and the share of their troubles. Care is to give continuous presence, demanding attention and willingness to have communion with each other. The perception of their needs involves a degree of sensitivity, consideration of values, meanings and relationships. It takes time, internalization, openness and the exercise of respect for otherness.

### Final considerations

Combining the dimension of care to ethics and to palliative care involves thinking the human being, that is, listening to them, giving them the chance to say. Say about others, about their history, about their choices and decisions. Say about their truth, or rather weave narratives about the meaning and the significance of life. It was seeking to understand the marks of time mended the other body that the hearing of suffering was present. Some categories - such as spirituality and care - were identified in this research as a palliative, which refers to the Latin word *pallium*, meaning "cloak", "cover", "protec-

tion", providing symptom and pain control, that is, the comfort of the person.

Addressing this issue requires great responsibility, as it mobilizes difficult emotions to be translated, such is the fragility and pain of everyone involved - fact that the observation made clear throughout this study. The intensity of the pain varies according to the culture, values, emotional and social world, feelings of belonging, ideas and choices of the subject itself in his/her intimacy and their relationship with the ultimate mystery of reality. So, what is expected of family caregivers and professionals is the perception of this uniqueness and complexity, so that care is made integral.

Often, what we see when the patient is in the terminal phase of life is their submission to medical conduct, which tries to preserve their survival at any cost. The person loses the tutelage of his own body, becomes almost a non-person because their existence depends entirely on the care and respect. In these circumstances, it is only the medical discourse that determines what will be done. The patient can not express their feelings because they are numb from the impact of impending death.

Disease and death are still taboo subjects, and ultimately lead to so-called "conspiracy of silence" in which one avoids talking about the needs and troubles involving such experiences. In this context, in which - with few exceptions - there is no availability for open conversation about death that is approaching, the malaise settles because of the "game of make-believe," you want to keep the illusion that it is "all right". This behavior is detrimental not only to patients and their families, but also to any professional team. However, when the silence is broken by dialogue and attentive and sensitive listening, everyone involved is relieved. Both for the patient and family members, effective, respectful and ethical communication is fundamental in this inevitable moment - a fact demonstrated during this work.

### Referências

1. Matsumoto DY. Cuidados paliativos: conceito, fundamentos e princípios. In: Carvalho RT, Parsons HA, organizadores. Manual de cuidados paliativos. Rio de Janeiro: Diagraphic; 2009.
2. Meihy JCSB, Holanda F. História oral: como fazer, como pensar. São Paulo: Contexto; 2007.
3. Merquior M. Converso, logo existo: reflexões sobre a conversa como instrumento de humanização da saúde. In: Maia MS, organizadora. Por uma ética do cuidado. Rio de Janeiro: Garamond; 2009.
4. Ferreira AC, Grossi Y. Razão narrativa: significado e memória. História Oral. 2001;4:25-38.
5. Caldas AL. A noção de cápsula narrativa: a entrevista, o texto e o outro na hermenêutica do presente. [Internet]. 1999 [acesso 12 abr 2012]. Disponível: <http://www.albertolins.caldas.unir.br/capsula.html>
6. Merquior M. Op. cit. p. 296.
7. Jaspers K. Psicopatologia geral. São Paulo: Atheneu; 2000. v. 2. p. 905.



8. Kübler-Ross E. Sobre a morte e o morrer. 8ª ed. São Paulo: Martins Fontes; 1998. p. 174.
9. Kübler-Ross E. Op. cit. p. 174.
10. Kübler-Ross E. Op. cit. p. 174-5.
11. Kübler-Ross E. Op. cit. p. 175
12. Kübler-Ross E. Op. cit. p. 175-6.
13. Queiroz A. Atendimento à família. In: Mello Filho J, organizador. Psicossomática hoje. Porto Alegre: Artes Médicas Sul; 1992. p. 315.
14. Arendt H. Compreender: formação, exílio e totalitarismo. São Paulo/Belo Horizonte: Companhia das Letras/Editora UFMG; 2008. p. 253.
15. Oliveira JR. Silêncio. Belo Horizonte: O lutador; 2009. p. 13.
16. Verdade MM. Ecologia mental da morte: a troca simbólica da alma com a morte. São Paulo: Casa do Psicólogo; 2006. p. 86.
17. Ferreira AC, Grossi YS. A narrativa na trama da subjetividade: perspectivas e desafios. História Oral. 2004;7:41-59. p. 46.
18. Boff L. Espiritualidade: um caminho de transformação. Rio de Janeiro: Sextante; 2001. p. 32.
19. Plastino CA. A dimensão constitutiva do cuidar. In: Maia MS, organizadora. Por uma ética do cuidado. Rio de Janeiro: Garamond; 2009. p. 53.
20. Ceccim RB, Palombini AL. Imagens da infância, devir-criança e uma formulação à educação do cuidado. In: Maia MS, organizadora. Por uma ética do cuidado. Rio de Janeiro: Garamond; 2009. p. 155.
21. Campbell ML. Cuidados paliativos em enfermagem. Porto Alegre: Artmed; 2011. p. 23.

#### Participation of the authors

Maria Emidia de Melo Coelho is responsible for the conception of the research, under supervision of Amauri Carlos Ferreira. Both participated in the final writing of the article.

Recebido: 5.6.2014

Revisado: 25.1.2015

Aprovado: 9.3.2015

