

Existential and bioethical aspects of palliative care in cancer

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Abstract

Severe illness places individuals in direct confrontation with death, an element of the experience of living. A total of 12 interviews were conducted with adults undergoing palliative care in cancer, and investigated by phenomenological analysis, describing the axes of meaning produced in the narratives. Analysis of the ways individuals (re)organize their life projects based on illness and finitude identified three dimensions: spirituality/religiosity; life in the family; relationship with death. The meaning patients attribute to existential trajectories and the relationship established with their life project are essential for treatment adherence and coping with death. Resignifying life, illness and death can relieve suffering and help patients give meaning to the time left. Such questions help us reflect on the bioethical dimension of palliative care and enable planning in this modality of care.

Keywords: Attitude to death. Palliative care. Existentialism.

Resumo

Aspectos existenciais e bioéticos nos cuidados paliativos oncológicos

O adoecimento grave lança o sujeito à facticidade da morte, que faz parte da experiência do viver. Realizaram-se 12 entrevistas com adultos em cuidados paliativos oncológicos, as quais foram analisadas sob a perspectiva fenomenológica, com descrição dos eixos de significado produzidos nas narrativas. Verificaram-se três dimensões do modo como as pessoas (re)organizam seus projetos de ser a partir do adoecimento e da finitude: espiritualidade/religiosidade; ser em família; relação com a morte. O significado atribuído às trajetórias existenciais e à relação estabelecida com projeto de ser são fundamentais para o paciente aderir ao tratamento e enfrentamento da morte. Além disso, ressignificar vida, doença e morte oferece alívio ao sofrimento e auxilia o paciente a dar sentido ao tempo que ainda lhe resta. Tais questões são importantes para refletir sobre a dimensão bioética nos cuidados paliativos e auxiliam no planejamento desta modalidade de atenção.

Palavras-chave: Atitude frente a morte. Cuidados paliativos. Existencialismo.

Resumen

Aspectos existenciais y bioéticos en cuidados paliativos oncológicos

La enfermedad grave lleva al sujeto a la factibilidad de la muerte, una experiencia del vivir. Se realizaron 12 entrevistas con adultos en cuidados paliativos oncológicos; y para el análisis se aplicó la perspectiva fenomenológica, con una descripción de los ejes de sentido producidos en los relatos. Se encontraron tres dimensiones de cómo las personas (re)organizan sus proyectos de ser a partir de la enfermedad y la finitud: Espiritualidad/religiosidad; ser en familia; relación con la muerte. El sentido de las trayectorias existenciais y la relación con el proyecto de ser son fundamentales para la adherencia al tratamiento y el enfrentamiento de la muerte. Resignificar la vida, la enfermedad y la muerte alivia el sufrimiento del paciente y le ayuda a dar sentido al tiempo que aún le queda. Estos interrogantes permiten reflexionar sobre la dimensión bioética en los cuidados paliativos y auxilian en la planificación de ese tipo de asistencia.

Palabras-clave: Actitud frente a la muerte. Cuidados paliativos. Existencialismo.

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According to the World Health Organization (WHO)^{1,2}, patients facing advanced and potentially fatal diseases should be provided an approach to health care called palliative care (PC). By preventing and relieving suffering, this approach promotes quality of life for patients facing life-threatening illnesses and their families.

To work with palliative care is to address individuals who are alive, to care for people when they can recover what is most important to them: the meaning of existence. At this moment, there is an intense life being lived in all its aspects and (un)pleasantness, which marks the person's attitude towards treatments and death itself.

This ensures people their right to choose among available treatments since, according to Lima and Manchola-Castillo, *when a patient without possibility of cure is prevented from making choices, the principle of human dignity is violated (...). Thus, scientific-technological evolution requires a critical reflection involving the principles of bioethics. In each specific case, limits should be established based on respect for patient autonomy and self-determination*³.

For the authors, *the contributions of bioethics to palliative care have historically been based on the principles of dignity and autonomy*⁴, aiming to ensure that patients' choices are respected and that life and death happen according to their values, principles, and wishes. For this to happen, conditions for decision-making with the support of health care teams must be provided, respecting the biography of each subject. People's needs during the dying process are specific not only due to the proximity of this fact, but are also conditioned by the individual's life context in all aspects, whether family, material, professional, social, cultural, and individual.

In caring for end-of-life patients, one must emphasize the ill person's project of being, as this is a concrete individual, with history, dynamics and pains⁵. Illness and the need for care are thus part of the individual's trajectory—until death occurs, the patient does not cease to be a becoming⁶. Such existentialist approach dialogues directly with the bioethical concepts of dignity and autonomy, precisely because it is centered on the individual

and their freedom of choice as an ontological condition, even in the face of extreme situations, such as their own finitude.

Death, on the other hand, is a limit, a contingent fact, and constitutes the possibility of no longer being present in the world. According to Sartre, death is not what gives life its meaning, (...) *it is, on the contrary, that which eliminates all meaning from it. If we are to die, our life has no meaning, because its problems never receive any solution and because even the meaning of its problems remains indeterminate*⁷.

Given the above, this article seeks to understand the experiences of critically ill cancer patients facing the process of illness and death, regarding their project of being and its consequences for the care processes, in dialogue with the principles of bioethics.

Method

A qualitative, exploratory and descriptive research⁸ was conducted by means of narrative interviews with 12 people admitted to the palliative care unit of a public hospital, totaling seven women and five men between 39 and 57 years old. Participant selection used non-probabilistic sampling by accessibility or convenience, based on the following inclusion criteria established by the researcher: being between 18 and 60 years old, having already received a cancer diagnosis and prognosis of impossibility of cure from the health care team, being under palliative care, being conscious and in sufficient health conditions to participate in the interview.

Participants were selected assuming that they could somehow represent the researched universe. We also used saturation sampling, which (...) *implies suspending the inclusion of new participants when the data obtained presents, in the researcher's evaluation, a certain redundancy or repetition, and it is not considered relevant to persist in data collection*⁹.

One interviewee had tertiary education and the others, primary and secondary education. They experienced economic difficulties, being

off work and depending on social benefits for survival. Some had already been hospitalized a few times in the institution and most of them had been living with cancer for a few years, having undergone surgeries, chemotherapy and/or radiotherapy.

As Jovchelovitch and Bauer¹⁰ point out, narrative interviews, following the life history interview model¹¹, involves encouraging the interviewee to tell the story about some significant event in their life and social context. Such technique aims to reconstruct events from the informant's perspective, addressing aspects of their experience in depth.

To preserve the identity of the participants, all names used in the article are fictitious. A structured interview script was used, with questions aiming to know the trajectory of the individual's relationships and how they constituted themselves as a being in the world, as well as to retrieve their life history, experiences, concrete living experiences and family and social relationships, including their experience after receiving the diagnosis and a prognosis of impossibility of cure. The interviews were audio recorded, transcribed in full and analyzed in a phenomenological perspective.

According to Dutra¹², assuming a qualitative phenomenological research strategy implies unveiling the lived experience. Thus, phenomenology-based research achieves its objectives as the experience is described in relation to the world in which the person investigated lives.

Analysis of the interviews sought to reveal common aspects emerging from the patients' singular experiences by summarizing (albeit provisionally) the data produced. We then moved to a comprehensive understanding of the phenomenon, seeking to go beyond those individual situations from which the research originated¹³.

This approach indicates the possibility of elaborating collective trajectories based on stories and experiences of the interviewed subjects¹⁰. Such is the proposal of the progressive-regressive method¹⁴: to identify universal and singular aspects of a person within a concrete situation,

a psychosocial condition. In this article, we will evidence the universal aspects of this process to characterize the collective aspect of the trajectories studied.

Results and discussion

Three main aspects affected how participants (re)organized their projects of being based on the experience of severe illness and the perspective of death: their relationship with spirituality and/or religiosity; their project of being in the family; and their relationship with death, which implied a major revision of the existential trajectory, as the pains of life were mixed with the pains of death.

Relationship with spirituality

At the beginning of the interviews, when asked about the meaning they gave to life, some participants spoke of religious experiences and reflections related to transcendent aspects, confirming that religion and spirituality are distinct experiences. Religion can be understood as a set of institutionalized beliefs and practices—such as attending services and masses—, which involves a systemized doctrine shared with a group¹⁵. Spirituality, on the other hand, describes the search for meaning in life through concepts that transcend the tangible, being linked to the meanings each person produces about their experiences and life, and involves convictions of a non-material nature¹⁶.

Regarding religion, most participants declared themselves Catholic. As for the meaning of life, some mentioned never having thought about the issue, like Francisca, who said: “*I haven't found it yet, nobody has found the meaning yet.*” Or Pedro, who mentioned having “*left that part aside.*”

Others argued that the meaning of life was linked to religion, such as Adriana, a Jehovah's Witness who spoke about her understanding of death framed by her religion:

“The meaning of life is to do God's will. All of this is temporary; I'm going through a difficult time, but the hope that I have for the future helps me cope with problems” (Adriana).

In this statement, the future is seen as a moment “beyond life,” a possible experience afterwards and elsewhere, appearing, therefore, as a spiritual enabler of being. It is the belief in this afterlife that helps individuals cope with the pains, losses, changes generated by the illness, as well as the interruption of plans and life projects.

Mateus, a Catholic man, points to illness as a possible way to “*purge his sins*,” which could perhaps prepare him and make him worthy of the “*life beyond this world*” preached by religion. The illness would be something he needs to go through, perhaps programmed, foreseen for him and for each one who experiences it, as a way to make the person better and worthy of what is to come. For him, “*each person has his cross to bear or something that will happen in life, each one has his penance*” (Mateus).

Juliana, also Catholic, believes that the disease is something she “*has to go through*,” chosen or “*designed*” by God:

“I don’t know, sometimes it’s something [that] I have to go through, I think God sends things for us to face and I will face it in whatever way possible” (Juliana).

Spirituality, religious or otherwise, is portrayed as a resource that allows one to face experiences generated by severe illness, as well as the prospect of death. This reinforces findings according to which spirituality is, in most cases, linked to a positive coping with illness¹⁷. In this regard, the participants, regardless of their denomination, generally believed in a benevolent God who, despite suffering, reserved a better future for them.

According to Freitas, *religion was one of the first ways that society found to deal with death*¹⁸ because, in a way, it seeks to give meaning to what science has not been able to explain and what human beings still cannot define. In turn, Schmidt, Gabarra, and Gonçalves¹⁹ emphasize that the explanations offered by religious systems often come closer to the patients’ sociocultural context than those offered by medicine, which may seem reductionist to them.

Building or finding meaning for the suffering experienced can help individuals to organize their

experiences around an already constituted project of being, which, although altered, continues to make their identity viable. Not finding meaning or reason for suffering, on the other hand, can disorganize one’s self-identity and the future one can expect. As Saunders, Baines, and Dunlop²⁰ describe, it would generate relief and comfort to remember one’s own life history and believe that there is some meaning in it and that one may have achieved something greater, a truth to which one can commit oneself.

The above quotes demonstrates that the interviewees maintained hope that something could change in their present condition, despite being aware of the severity of the organic disease. Having hope does not mean that patients deny their situation, but that they do not limit their experience only to the disease. That is, knowing and understanding their physical condition and finitude did not prevent them from continuing to project themselves into the future, making choices and considering their desires, so that they continued to face and seek alternatives to suffering.

Spirituality and hope emerge as elements that allow them to continue living, because they point to a possible future, a projection beyond what is lived in the present. Maintaining hope and the meaning of life allows suffering to be faced with some perspective of the future, making the situation of coping with illness and death bearable, considering that what paralyzes the person is not suffering itself, but its lack of articulation with the subject’s life project.

Importantly, in palliative care, spiritual or religious care is part of the treatment and giving meaning to the illness can reduce the suffering associated with it. For Bertachin and Pessini²¹, transcendence is probably the most powerful way in which someone can have their integrity restored after suffering changes in their personality as a result of severe illness.

In the United States, 84 out of the 126 medical schools offer courses on the influence of spirituality on health, including Harvard, Johns Hopkins, and others²². Moreover, research shows that about 80% of end-of-life patients want to discuss issues related to

the spiritual dimension with their physician, but most patients said that their physicians have never addressed the topic²³.

Religious and spiritual beliefs are an important part of the culture, principles, and values used by individuals to form judgments and process information. As such, health care teams should understand that the confirming the beliefs and perceptual inclinations of end-of-life patients can provide order and understanding regarding painful, chaotic, and unpredictable events²⁴.

By favoring the spirituality and/or religiosity of those who already hold these beliefs, one can thus help patients to reflect on the role that these rationalities and attitudes play in their lives²⁴ and mediate the relationship with their own finitude. Moreover, if one intends to ensure patient autonomy during the treatment process and, in view of the impossibility of cure, in finitude, one must consider how their beliefs cross and compose their choices, aiming to enable what each one understands as worthy for their life and death.

Religiosity and spirituality can therefore be approached as a relationship of the subject with reality, and also as a rational horizon from which elements are drawn for understanding oneself and one's project of being. For existentialist psychology, religiosity or spirituality are ways for an individual to relate to the world, and this relationship also needs care and support, because, when it is meaningful to the subject, it can either enable or hinder one's being. In the latter case, based on their faith, the subject could deny treatment, believing, for example, in a miraculous cure.

Project of being in the family

The subject's relationship with their family and significant others helps them understand how their projects of being were elaborated and how they are crossed by the illness and (re)organized from the perspective of death and illness.

When asked about their family history and relationships, the participants stated they had lived their lives seeking to improve their material and personal conditions, especially with their

families. Most had little formal study, but with histories of dedication to work and the family group, with projects of being closely linked to significant people in their network.

All pointed out the essential character that being-with-the-Other acquires in the constitution of the being-in-itself, as well as the fact that they found strength and meaning to cope with the disease in the presence of family. When asked about what helped her cope with the disease and treatment, Ana says:

"(...) my family, who always supported me, my sister who is always by my side" (Ana).

Ana's sister, present at the interview, spoke about the decision to start palliative care having been made together by the family members. At the same time, Ana often talks about her family and the importance of the support she received, as well as how much she looked forward to returning home to be with her mother, over 80 years old, and also to cook for her siblings. She recognizes herself, therefore, as a person who has a role in the family and believes that, with and for them, it is worth fighting. For Sartre⁶, the other is indispensable both to existence and to knowing oneself, since one cannot know oneself if not through others.

About his family, João emphasizes how significant and fundamental these relationships were in moments of decision-making throughout his life:

"(...) I started to think, I can study, improve my life by studying, so I can help my mother, help my family" (João).

At the time of his illness, it was also with the family that he sought to find alternatives and ways to continue offering his loved ones what was necessary for a dignified life. In his account, João points to an experience of being-with-the-Other, as defined by Sartre, in which each subject can be a mediation for the Other realize their project. In Schneider's words, *being-with-the-Other is to share projects, to share situations, to make joint decisions. It is the establishment of a common transcendence directed to a single end—the project that we are as a group*²⁵.

Some research participants reported a desire to have more time to be with their families. Francisca, for example, who had, at the time of the interview, an eight-year-old daughter, mentioned she would like to have more time to pass on to her some kind of legacy:

“I’d like to pass on more to her. To have time to pass things on to her, to accompany her and for her to accompany me, for her to listen to my stories” (Francisca).

She regretted, thus, that she could not have more time to be with her daughter and participate in the constitution of her being as she had planned.

One of the interviewees, Antônia, spoke with great suffering about grieving for her son who died in a car accident two years earlier. Her mourning experience indicated the challenge she experienced *in living with the immediate disorganization of a world once shared, but still open to meaning*²⁶. Thus, the bereaved lives more than the loss of an “other,” but can experience the emptying of meaning of their existence¹⁹.

Antônia expressed a feeling of great sadness and anguish. She spoke little of herself, because she kept talking about her absent son and the difficulty she felt in continuing to live after the loss. When asked what was more difficult to cope with in the disease process, she said:

“Look, the hardest thing is the pain, it’s the suffering of the loss of the child, it’s everything. I can’t even explain what’s harder” (Antônia).

Later, when questioned how she felt about the lack of prospect of a cure for her illness, she said:

“I don’t know anything anymore, I’ll stay in bed a little longer, in a little while my son will sure come for me” (Antônia).

She then fell silent and cried. Then, when asked if there was anything that worried her, she said:

“No, he’s gone [son], the disease I already have, healing is difficult” (Antônia).

The pain caused by her son’s death was so intense that it was mixed with Antônia’s

physical pain, but also with the psychic pain due to illness and the possibility of death, recalling what Cicely Saunders²⁷ conceptualized as “total pain”: the pain felt in the process of getting sick and dying is multidimensional, involving physical, psychological, social, spiritual, financial, interpersonal, and family aspects.

Regarding the role played by the family in the development of individuals, according to Sartre, *the person lives and knows his condition more or less clearly through the groups he belongs to*²⁸. For the philosopher, the ideal is that the family relates from a group structure, organized according to its role as a mediator in structuring the subjects’ project of being¹⁴. Often, however, a family, due to the relationships established between its members, is corroded by an internal seriality, that is, its members cannot weave their individual projects around a collective project, remaining a plurality of loneliness⁵.

What Sartre¹⁴ stated was verified in the research participants’ statements: when there was family support, interaction among its members, and sharing of projects, suffering seemed more bearable. Mediated by the family group, the other becomes a means for the subject to be realized, as well as the subject to the group and, as its members assist in realizing their unique project, the common project of the family is preserved in their personal choices.

This point to the existence of a group structure, since, as Schneider describes, *(...) a family, when it manages to be a group, establishes a common project, and becomes one of the main mediations of the subjects’ project of being*²⁹. On the other hand, some participants spoke about loneliness and the pain of coping with the disease and treatment alone. Such is the case of Maria, who tells her story explaining the breaking of her family ties:

“My mother takes no interest in my illness; she is not a mother who does not abandon her children, so she did not come to see me here, nor did call me today, She’s like that, a very cold mother” (Maria).

Gabriel, in turn, spoke about the loss of his mother, who was his main familial bond,

and about how difficult it was for his siblings to support him. For this reason, he spends much of his hospitalization alone, in the company only of members of the health care team. For both Maria and Gabriel, the absence of family generates suffering beyond the physical illness, which could perhaps be split and supported if shared with a support network.

This demonstrates that receiving the diagnosis of a severe illness such as cancer causes important changes in the lives of patients and their families, with social, emotional and physical implications, besides aggravating difficulties related to the lack of resources and family ties, situations that potentially generate suffering. Thus, finitude should be understood not only in relation to the sick subject's subjectivity, but to the way their history and culture, as well as the society in which they live, allow them to understand and live such terminality³⁰.

The project of being in the family is thus part of the elements that outline the experience of illness, and may provide tools for coping with the disease, hospitalization, need for care, and changes in the individual project of being. It does not remove from the patients the suffering for saying goodbye to life and having to interrupt a common project with the Other, in the family, but it makes it more bearable the fact that, through death, they no longer have the openness and the possibility to update their relationships, coming into existence by the memories left behind and what others will make of their stories.

On the other hand, amidst feelings of loneliness, helplessness, and isolation, the suffering caused by the absence of significant people enhances the suffering generated by the change in the project of being based on the illness and the perspective of death.

If the other is *an indispensable mediator between me and myself*³¹, the absence of mediations that allow the being to realize itself, that enable it in its project, as well as the lack of confirmation of who they are in the world, can amplify and intensify suffering, since it leaves the subjects alone to face the absence of confirmations about who they are and what they can be. Moreover, it hinders the end-of-life

construction of what will be experienced by the family and the way the subject will remain with others after death.

Relationship with death

For some, being faced with the inevitability of death implies a review of their existence, accomplishments, achievements, and overcoming. For others, the pains of life are mixed with those of death—the losses experienced, the difficulties faced, and that which they would no longer have time to accomplish weigh heavily at this moment.

On this last aspect, Maria reported she started abusing drugs after 30, saying that she does not understand what happened and that she would like to have a new chance to live her life differently in the future:

"(...) I can't understand how I lost myself, my weakness was such that I chose to start doing drugs, to this day I don't understand. I pray to God to have another chance, to show that I have courage. I ask God, but whatever He sends me I accept" (Maria).

The pain of not understanding how she made choices that impacted her project to such an extent finds relief in the hope of resuming her living according to what she considers a dignified life. For those who feel they have lived a (somewhat) flawed life, who feel they have not lived intensely or that they have failed to realize important aspects of their being, this adds suffering at to their end of life, since it anticipates the end of a future and the possibility of reconciling with others and with themselves.

According to Sartre¹⁴, every human relationship is temporally demarcated, it is historical. On the other hand, the future is a peculiarity of humankind, related to our specific characteristic of questioning our own being⁶. Thus, *it is not the past that pushes the present; it is, in fact, the future that moves history, that imbues it with forces of fulfillment. (...) the strength of my being is given to me by the future and not by the past*³².

This is not about throwing oneself to death, since, ontologically, death removes from the being its possibilities. Rather, it means to

consider that death appears on the horizon as facticity and that, in psychological terms, understanding the being as an ongoing totalization can push individuals to make choices from a critical position, giving them the opportunity to finalize their project, at any time, with some sense of accomplishment.

Francisca spoke about some regrets and some sorrows about the life she led:

"I have regrets [regarding] married life, I think it could have been better. It's my sorrow. We were setting up a business, I feel guilty for not taking it more seriously" (Francisca).

Thus, when faced with the possibility of ceasing to exist, posed by death, some participants were made to think about their choices, evaluating them in relation to the time lived and the time they would no longer have to resume them, redo them, and realize them. Illness and death—as a concrete possibility—have therefore imposed limits and new conditions to the field of possibility of each patient.

When talking about death as part of life, some participants approached finitude as something "natural," but even so, it was evident the difficulty in thinking about death itself and facing the reality that they will die. As Dutra points out, *it is difficult for man to face his finitude, because in doing so, besides facing the certainty of death, he becomes aware that no one can ever live for him, thus revealing his power-to-be*³³. Such is the case with Ana:

"One day we will die. It's a normal thing for me, no one will remain as seed. You have to accept death and that's it. That's why I want a plain casket. Money, use it for something else, I don't want anything expensive. I am saying that I am ready when He comes for me" (Ana).

Ana speaks of death quite directly. She feels ready to die. Even so, she assesses how difficult it is to say goodbye to the family and the void her death will cause. She also worries about the situation in which her family will be left: if they will be able to deal with her absence, if they will be able to continue to meet their needs, if they will each continue with their project, previously shared and made possible by her. She anticipates, in a way, the impact that her

absence can have on her family members, on the family project, and on each child individually.

Pedro also speaks of death as something "natural," but describes its difficulties:

"While you're healthy, you only think from here on out, in the future. But when you start to have problems, you start to see things differently. You feel anguish, fear, like everyone. There is no point in saying that you are not afraid, because you are. Sometimes you don't even know what you're thinking, you're thinking about the past—I could have changed this, I could have changed that, would it be different" (Pedro).

Thinking about death and the possibility of no longer being in the world reveals the anguish that ceasing-to-be produces. As Peter says, what is known about life is the possibility of always existing in a future not yet determined. When revealing that the non-being imposed by death is only known when it happens as a fact, the interviewee points out that it is also difficult to conceptualize and describe it, for it is something not experienced and impossible to be appropriated by the being ontologically.

In psychological terms, however, it is possible to think that some participants were able, due to the project of being lived until then, to experience illness as an aspect of their being, which allowed them to continue living without the disease subsuming their project. Others, however, also due to the way their project of being had been produced until then and perhaps by the strength of the suffering imposed by the disease, at times felt reduced to it, and started living in the condition of being ill³⁴.

Experiencing extreme suffering, the reduction of the project of being to being ill, and the consequent closing of future possibilities during the illness process can lead some patients to idealize the possibility of anticipating death. Gabriel highlights moments when he thought about suicide:

"I've thought about doing a lot of stupid things, about suicide, about [committing] suicide, but then I ask God to help my heart not to do that, there is still life ahead of me" (Gabriel).

Suicidal thoughts or even requests for anticipation of death may be frequent in patients

facing severe illness. According to Kovács³⁵, these requests may denounce that an intolerable suffering is being experienced, not only at the organic level, but also existentially. Suicide, as a markedly human possibility, would be the choice that eliminates all others, because death make it impossible for the subject to choose⁶.

In this scenario, Kovács³⁵ highlights that the challenge of healthcare provides is transferred to caring for the dying process, rather than death itself. It is about offering care capable of expanding the subjects' possibilities of choice, even though they are in such a limiting situation and in a condition in which the field of possibilities is restricted.

At the same time, we seek to ensure that life will not be prolonged if there is no condition to maintain its uniqueness, choices, and wishes respected. In this regard, asking to die can sometimes configure a request not to prolong suffering or a life that one does not wish to live, rather than anticipating death.

One of the principles of palliative care proposes that health care teams seek to ensure the quality of life and death, allowing patients to live as actively as possible until death occurs^{1,2}. For this to happen, professionals must facilitate the understanding of patients and their families regarding the feelings that arise in the face of death, allowing the expression of grief, guilt and regrets, when they exist.

Likewise, one should consider the principles that govern bioethics when organizing care:

- **Autonomy:** involves respecting the personal and moral values of each patient;
- **Benefit:** determines the treatments to be applied considering the maximum benefit with the lowest incidence of harm, choosing those that cause no damage or cause the least possible damage;
- **Non-maleficence:** determines that healthcare providers must do their best not to cause intentional harm to patients, preventing them from having to deal with other pains or damages beyond those that already exist as consequences of their health condition; and
- **Justice:** implies fair access to health treatments, observing the patients' needs, besides ensuring that each subject receives care and attention

without distinction for social, cultural, ethnic, gender, or religious reasons³⁶.

The interviews allowed us to perform, albeit briefly, a retrieval of memories, helping the participants to realize what was accomplished, encouraging them to take care of their legacy. Moreover, we observed that whenever there was help to remain connected to what brings meaning to life, the emphasis was on realizing that there is still life to be lived—one continues to have desires and make choices.

Final considerations

One's relationship with death is still an act of life and its meanings are constructed based on patients' life trajectory, their project of being, and their network of significant mediations. Some participants described the feeling of not having enjoyed their lives as they would have like, which made the end-of-life experience more painful, expressing wishes to overcome their condition. They would then be able to resume their projects, reorganize and live them by making choices based on their desire.

Others felt like they have done what was possible, built a legacy, and accomplished much in their existence, which helped them face the possibility of death in the near future. These reports appeared mainly in participants who had the support of their families.

A certain paradox is established here, one which, however, can be understood: if, on the one hand, those who had family support were with their significant others, on the other hand, they suffered for having to leave them; those who experienced loneliness did not have their suffering eased regarding their departure—on the contrary, they were even sadder for not being able to share this final moment of life with their loved ones, for not being able to share these experiences and receive support for the parting.

In this regard, an important intervention by health care teams could be to bring patients closer to their significant relationships, whether in the field of religiosity/spirituality, or in the field of interpersonal relationships, helping them to rescue bonds, to forgive and be forgiven, to organize and support their network of relationships and

support, so that they receive affection, experience belonging, and avoid loneliness, which can increase anguish when they part with life.

For this to occur, as palliative care envisions, patients and families must be understood as a unit of care. Thus, teams need to strive to offer a support system to help family members not only during illness, but also after death, during the grieving process. In this respect, the concept of dignity allows us to think about palliative care in a broader sense, involving the patient's family.

Everyone hoped to be able to postpone death—they wished to live longer. Perhaps, for the lovers of life, we are always too young to die, there is always something one still wants to live, left unfulfilled or perhaps unresolved. Those for whom life had reserved intense pains—such as loss of important people, interrupted relationships, broken dreams—, these got mixed with the pain of death at the time of illness. Pain is, then, total: it strikes the subject in all its dimensions.

When palliative care recommends to maintain quality of life, besides controlling the symptoms

that cause physical suffering, it is also necessary to care for the psychosocial and spiritual dimension, seeking to maintain an existential meaning: reasons to continue living, reasons to be remembered, ways to remain through significant others. One can continue living in the memory of those who will remain and remember who this subject is, was and will continue to be. This can increase adherence to treatment and improve end-of-life quality of the, ensuring the autonomy of patients and their families.

Besides the evidence-based protocols and techniques, palliative care must recover the notion of the first-person clinic. This allows to exercise integrality in health, in which a systemic view prevails, with actions shared by integrated teams and attuned in thinking about human beings and their ills, with co-responsibility in the act of caring for patients and their families. Thus, it is up to palliative care providers to help the subject to expand a field of possibilities that narrows with the onset of the disease and the prospect of death, but that still includes choices.

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