

# Moral deliberation in palliative sedation focusing on an oncology palliative care team

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## Abstract

The aim of this study was to understand how a palliative care team seeks solutions for ethical conflicts related to deep palliative sedation in everyday care and whether the discussions and the decisions that are made within the multidisciplinary team involve the sick person and his family. This is a descriptive exploratory qualitative study, based on dialectical hermeneutics. The research subjects were ten professionals on the health team of a hospital's Oncology Palliative Care department. The results indicate that a humanistic attitude assumes, among many things, the prudent use of palliative sedation as an available resource to minimize suffering during the process of dying. The practice of palliative sedation requires a thorough analysis of the clinical facts, ethical reflection by the multidisciplinary team, as well as respect for the values of the sick person and their family and their participation, which would result in a process of moral deliberation.

**Keywords:** Deep sedation. Palliative care. Bioethics. Decision making.

## Resumo

### Deliberação moral em sedação paliativa para uma equipe de cuidados paliativos oncológicos

O objetivo deste estudo foi compreender como uma equipe de cuidados paliativos busca soluções para os conflitos éticos relacionados à sedação paliativa, no cotidiano assistencial, e se as discussões e decisões são feitas e deliberadas em equipe multiprofissional, envolvendo também o sujeito doente e sua família. Trata-se de pesquisa exploratório-descritiva de abordagem qualitativa, com base analítica na hermenêutica dialética. Os participantes da pesquisa foram 10 profissionais que integram a equipe de saúde de um setor hospitalar de cuidados paliativos oncológicos. Os resultados indicam que uma assistência humanizada pressupõe, entre tantos aspectos, o uso prudente da sedação paliativa como recurso disponível para a minimização do sofrimento no processo de morrer. A prática da sedação paliativa requer análise minuciosa dos fatos clínicos, reflexão ética em equipe multiprofissional, assim como participação e respeito aos valores da pessoa doente e seus familiares, o que propiciaria um processo de deliberação moral.

**Palavras-chave:** Sedação profunda. Cuidados paliativos. Bioética. Tomada de decisões.

## Resumen

### Deliberación moral en sedación paliativa destinada a un equipo de cuidados paliativos oncológicos

El objetivo de este estudio fue comprender cómo un equipo de cuidados paliativos busca soluciones en la cotidianeidad de la asistencia para los conflictos éticos relacionados a la sedación paliativa y si las discusiones y decisiones son tomadas y deliberadas en el ámbito del equipo multiprofesional, englobando al sujeto enfermo y a su familia. Se trata de una investigación exploratoria-descriptiva de abordaje cualitativo, con base analítica en la hermenéutica dialéctica. Los sujetos de investigación fueron diez profesionales que integran el equipo de salud de un sector hospitalario de cuidados paliativos oncológicos. Los resultados indican que una asistencia humanizada presupone, entre muchos otros aspectos, el uso prudente de la sedación paliativa, como un recurso disponible para la minimización del sufrimiento en el proceso de morir. La práctica de la sedación paliativa requiere de un análisis minucioso de los factores clínicos, la reflexión ética en equipo multiprofesional, así como también de la participación y el respeto a los valores de la persona enferma y los de sus familiares; lo cual daría lugar a un proceso de deliberación moral.

**Palabras-clave:** Sedación profunda. Cuidados paliativos. Bioética. Toma de decisiones.

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The practice of *palliative sedation* to assist people in advanced stages of oncological disease and terminal stages of life, the essence of which is responsible care, should start from the assumption that the process of dying and death itself comprises the most *undeniable reality of humankind*. So, *to die with dignity, properly assisted, is as important as receiving the necessary care to maintain health and continue the always finite and temporary journey*<sup>1</sup>. In fact, palliative care is defined by the World Health Organization (WHO) as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual<sup>2</sup>.

The need to seek solutions to *cacothanasia*, and thereby prevent many diseases that lead to *the premature conclusion of the life cycle by nursing conditions, affectivity, and mental states that can inevitably cause a painful death and extreme anguish*<sup>3</sup>, requires due consideration by contemporary society. Furthermore, in the face of the difficulty in controlling the progress of diseases such as cancer, it is essential to transform the conditions of health assistance for people at the end of their lives, in order to minimize suffering before death. This assumes not only more equitable and universal palliative care as a human right, but also the development of a way of providing individualized care, based on ethical considerations that are able to raise the ethical and moral conscience of those who work in terminal care.

In addition to ethical reflection, it is necessary to see dialogue as a highly effective tool in the practice of palliative care when proposing palliative sedation as a resource available to the sick person, given its ability to integrate an act of caring intended for the whole community. Apropos, Camargo-Borges, Mishima and McNamee<sup>4</sup> understand that we are relational beings and that we should invest in this human condition, establishing interventions that are more sensitive to relational aspects, by emphasizing the similarities and interactions in a sensitization process geared towards more collaborative, contextual and responsible communication, thereby producing less polarized and hierarchical relationships.

Although palliative sedation is not an unusual procedure in this type of care, its use depends on several factors, which is why its prevalence varies widely. Several authors, such as Maltoni et al.<sup>5</sup> and Chiu et al.<sup>6</sup>, argue that palliative sedation, including continuous sedation until the time of death, does

not aim to shorten or prolong life, but to alleviate suffering. It consists of conduct that leads to *a reduction of consciousness, from mild to profound, temporary or permanent, but not deliberately causing the death of subjects affected by disease at an advanced stage, in the final phase of life and with specific refractory symptoms*<sup>7</sup>, palliative sedation is highly recommended in the practice of palliative care provided by multidisciplinary teams.

However, the use of palliative sedation generates ethical and interpersonal conflicts in the day-to-day life of the palliative care team, so that confronting these issues implies the need to make decisions based not only on ethics but also on the axiology, namely, the values of the people involved. This is what Diego Gracia proposed when drawing up his methodology for “moral deliberation”<sup>8</sup>. We believe that this method is very important in the practice of palliative sedation because, when the sick person’s death is imminent and suffering becomes more acute in all its dimensions, it also intensifies the anguish experienced by family members and other related persons, including members of the care team.

In this context, prudent and reasonable decision-making requires clarification and consideration of the values of the people involved in the process. That is because several factors, including poor communication or lack thereof, may create tensions and ethical conflicts. This results in a situation in which the sick person and their family are not sufficiently informed about the physical and psychological distress inherent in the final stage of life, as well as the resources that can be offered to minimize them, including palliative sedation. In the face of suffering and distress, it is necessary to take a responsible and committed decision regarding the process of dying with dignity. Effectively, we need to decide! In this sense, Diego Gracia says:

*Problems need to be tackled through a process of deliberation. And the intended objective is not to take decisions that are definitive or exclusive, but merely prudent. Different people can make different decisions based on the same facts and also be prudent (...). This is perhaps the great challenge ahead of us that will gain more and more importance in the coming years: the need to assume a kind of rationality that allows the participation of all those involved in the deliberation process regarding the practical problems - in our case, the moral problems. (...) Only then can we contribute to the great challenge for ethics and bioethics: the promotion of “responsibility”<sup>9</sup>.*

Therefore, moral deliberation is the method to find a solution to a problem, by seeking to overcome the ethical conflict with due care and responsibility, and considering the decision making as part of this process. This is a dynamic methodology, which needs, first of all, to take into account the socio-cultural and historical context of the person with advanced disease and without possibility of a cure, this also implies an understanding of the family context as a prerequisite to identify the ethical conflicts and values in question.

Elma Zoboli, referring to the method of moral deliberation in the work of Diego Gracia, sums up the deliberation process as an itinerary that includes: deliberation based on facts (presentation of the case and clarification of the facts); deliberation regarding the values (identification of the moral issues of the case, indication of the fundamental moral problem, and identification of conflicting values); deliberation regarding the duties (identification of extreme, intermediate and optimal courses of action); and deliberation regarding the responsibilities (submission of the optimal course of action to prove consistency regarding time, promotion and legality)<sup>10</sup>.

In light of this problem, this study sought to understand how health professionals deal with ethical conflicts related to palliative sedation, as well as to investigate whether the discussions and decisions are carried out and resolved within the multidisciplinary team and include the subject patient and their family, circumstances that favors the moral deliberation process, according to Gracia<sup>8</sup>.

## Method

To reflect on the deliberation process, namely, the discussions and decisions regarding the practice of palliative sedation within an oncology palliative care team, a descriptive exploratory qualitative study was developed based on the dialectic hermeneutical method. The research field was the palliative care unit of a hospital in southern Brazil.

Participants in the study were professionals within the health team: nurses, doctors, nursing technicians, social workers, psychologists, pharmacists, physiotherapists, and nutritionists, totalling 10 participants. The survey methodology took place through interviews with a team of health professionals with extensive experience in palliative care.

A semi-structured interview was used as the data collection instrument and adopted the content of the information presented by the research partic-

ipants as saturation criterion. That is, the repetition of information from one interview constituted an occurring parameter of saturation

In the process of analysis, the researchers employed a software program (Atlas.ti® 7.1.5) to organize and analyse qualitative data, by following these steps: 1) initial categorization; 2) reorganization of the data and a final analysis, as proposed by Minayo<sup>11</sup>. The analytical process of the reports of the experiences of the survey participants, which was done based on the guidelines for semi-structured interviews revealed the primary topic that is the subject of discussion in this article: the decision-making process.

The ethical aspects of this research – because it involves human beings - was treated according to the rules and guidelines of Resolution 466/2012 of the Brazilian National Health Council (Conselho Nacional de Saúde), which requires the submission of a project evaluation by an ethics committee on any research involving human subjects<sup>12</sup>.

Participants were informed about the purpose and procedures of the research, as well as the possibility to refuse participation at any time, and were then asked to confirm their consent by signing the free and informed consent form (ICF).

## Results and discussion

The interpretation of the topic, which emerged from the interview data analysis process, was divided into sub-categories or sub-themes related to the practice of palliative sedation, namely: understanding of ethical conflicts, process planning, and solutions to ethical conflicts. The sub-themes are discussed in the light of Diego Gracia's<sup>8,9</sup> contributions to bioethics applied in medical practice and of other scholars of the subject<sup>10</sup>, as well as of researchers whose works focus on the practice of palliative sedation in palliative care<sup>5-7</sup>.

To maintain the anonymity of respondents, the quotes that summarised responses to the problem have been referred to by code names: Daisy, Violet, Sunflower, Gardenia, Tulip, Hydrangea, Lily, Rosemary.

### *Understanding ethical conflicts and values*

In this analytical subcategory, it became clear that the decision-making process related to palliative sedation is considered complex, with tense moments and situations within the team and in its

relationship with the sick persons and their families, as can be seen in the following account of ethical conflicts experienced by one of these professionals: *“The main conflicts were experienced when the family did not accept sedation when there was a clear indication, for example, a refractory dyspnoea. There was also a family that wanted the patient to be sedated, and the patient did not want to be sedated. And there were cases in which the team did not reach consensus”* (Daisy).

For the healthcare professionals, when refractory symptoms are present, it indicates the sedation of the person in distress in the face of imminent death. This is where the issue of involving the family and the patient emerges, as highlighted in the testimony of another participant: *“When the symptoms are intolerable for patients, after we have made every possible effort to provide palliative care and we do not have satisfactory results controlling the patient’s suffering, the possibility of palliative sedation is addressed by the staff and then discussed with family members. We consider the family’s acceptance and, where possible, the patient’s. It sometimes happens that the patient wanted to be sedated and the family did not want to allow this; we have had situations like this”* (Violet).

In the meantime, conflicts of values between the sick person and the family also start to emerge. Furthermore, it is necessary to understand the “facts”, bearing in mind that the “values” of the professionals also interfere in the process. Between the healthcare team and the patients and their relatives, the main conflicts reported are associated with “values, beliefs and culture”: *“We acknowledge the values, beliefs and culture of the patient and the family. Certainly, one cannot help but notice that each patient reacts differently. Sometimes very differently from what I think, and in a way that clashes with my own values and the team values”* (Sunflower).

Indeed, between “facts” and “values”, there is fertile ground for the exercise of decision-making that takes into account the resolution of ethical conflicts and the values involved. In other words, it is an opportune field for the exercise of moral deliberation, which, according to Gracia <sup>9</sup>, seeks to analyze the problems in all their complexity. This means assessing the implied principles and values, as well as the circumstances and consequences of the case, allowing the identification of all, or at least most, potential courses of action, that is, the feasible decisions.

From this perspective, as reported by one respondent, *“the rationale is as follows: there is a*

*discussion amongst the multidisciplinary team. Afterwards, we have a conversation with the family and the patient, within the same timeframe. However, we will respect the wishes of the patient, because the patient is our primary concern. It is not uncommon that sometimes the family asks for the comfort that palliative sedation provides, and we really respect the autonomy of the patient when they can decide for themselves”* (Gardenia).

### **Planning of the decision-making process**

In this subcategory, the focus is on the planning of the deliberative process and decision-making, with the objective of considering how the actions are planned and carried out.

It was identified that the multidisciplinary team has been creating two occasions to discuss the palliative sedation cases: a weekly staff meeting, in which they seek to develop multidisciplinary work, and a family meeting, which is held in line with the needs of the patient and their family. According to a report from an interviewee, the professionals participating in the team meeting include: *“the doctor, nurse, psychologist, nutritionist, pharmacist, social worker, occupational therapist, nursing technicians from the ward and outpatients care (when their duties allow them to be available) and physiotherapist. Everyone involved in the care of the patient attend the meeting, and it is an important commitment”* (Tulip).

This statement also follows that the multidisciplinary meeting is considered an indispensable requirement for the development of multidisciplinary work that reflects the importance of the discussion process among the team members. The multidisciplinary meeting constitutes a legitimate forum to exercise bioethical reflection, since it is in these meetings that the team identifies and discusses the values involved in the practice of palliative sedation, whether they come from the inner circle of support (patient and family) or from the multidisciplinary team. This is because, according to Zoboli, *intuitive values may be clear to each of us individually, but we need to share them with others, as these values may differ between individuals* <sup>13</sup>.

To plan and make prudent and responsible decisions, respondents understand that it is necessary to identify the ethical and value conflicts, including those within the team: *“We try to resolve these in the team meeting. Of course, we have to remember that everyone who works here also have their beliefs, their own ethics and their own morals; based*



on their home and social environment and their own upbringing” (Daisy). The importance of the values of the professionals involved stands out in this report: “We all have our beliefs, and the multidisciplinary team is important to guide this decision. The team provides a foundation for this decision, this attitude. Without a doubt, my values (my ghosts, my beliefs, my knowledge) are imprinted there.” (Violet).

Resorting to moral deliberation as a method to reach a reasonable and prudent solution to the problem, with a focus on the conflicts to be solved, means to align the parties involved to the idea that the decision to be taken is just part of a dynamic process. In this process, it is also necessary to analyze the experiences of people who are in the advanced stages of an illness with no possibility of healing, together with the experiences of their families. Only from this perspective, can health professionals consider their values and discern them from those of the sick person and their friends and family.

From the reports of the participants, it became clear that the deliberation process is still under construction, given that, in addition to knowledge and skills, *deliberation implies attitudes, such as mutual respect, humility or intellectual modesty, and a desire to enrich understanding of the facts by listening to others*<sup>14</sup>. Without doubt, the planning of actions to be taken involves team discussions and decisions, as confirmed in the following statement: “I cannot take a complex decision like this by myself. It (team deliberation) is a very precious resource and so specific to a single moment, a unique experience” (Violet). In fact, when considering the importance of this practice for all those involved in the decision-making process regarding palliative sedation, it is evident how important shared understanding is, particularly for the professionals, as can be seen in the words of one respondent:

*“I do not know if it is because, every time something is not being done in the best way, I question it. Then, if we question, think about it, and talk to reach a particular conclusion, I think it is being done in the best possible way. I believe that it would not have been done in the best possible way, if I had left a doubt without questioning, without answering, without asking why. Therefore, every time I have doubts regarding the sedation, I try to listen to the opinion of the doctor and other professionals, because discussion is necessary. After all, I will be dealing closely with the family, and then they will bring these questions to me and I need to respond calmly” (Hydrangea).*

By analyzing the reports, it was found that the planning of the deliberative process and the professional conduct conducive to making prudent decisions are both factors associated not with only the professional experience, but also with the experiences related to the practice of palliative sedation:

*“I believe there was a great evolution over the time I experienced this. Even me, as a professional, wow, I changed a lot! It is a paradigm shift. It changes your life, the way you confront life. Then, I think there was a shift in improving the discussion of palliative sedation, because now people have more experience. They have experienced many cases and many situations, so they have a more holistic perspective than when we started this process. At first, it was very difficult, there was no consensus. Sometimes the decisions were very one-sided; it was more the doctor’s decision. With time, the decisions were more well-grounded. I think it is difficult for us to look at ourselves and appreciate this growth, but it happened. Because it is a very difficult issue for everyone, it is a difficult subject to broach. Therefore, I think we grew over time and I think we always have room for improvement” (Lily).*

There is a consensus, among the professionals, regarding the high relevance of discussing cases in teams, as well as the priority of identifying the values that are imbued in the family and the patient. Therefore, “the service will adapt to the increasing professional care surrounding patients” (Lily) – which means looking beyond the available facts: “Clinical facts are important, but, in palliative care, the person who will say what is important is the individual who is undergoing the experience and their family. Listening makes a difference because it guides the care towards their lives” (Violet).

Respondents believe that it is qualified listening that reveals the values of clinical facts. Thus, the understanding of this aspect by the multidisciplinary team allows an enriching dialogue that results in more reasonable and prudent decision making, which can be assimilated by all or most of the team members, in order to ensure the success of the endeavour. In this sense, the family meeting – seen as a time when the multi-professional team joins the family to talk about the healthcare needs of the patient – is extremely important for the correct understanding of the values, which, in turn, will be important in decision making, because, as stated by Zoboli, *clinical ethics begins with the clinical data, but the inclusion of values in decision-making increases the quality of care*<sup>15</sup>.

In addition to professionals, the family meeting is a time for interaction among a representative group of the multidisciplinary team, as shown in the two accompanying reports: *"We asked the social worker to contact all family members via phone for a meeting at the institution's premises. One of the team doctors, the social worker, the nurse and the psychologist participated in the meeting."* (Daisy) *"This meeting is attended by the doctor, the psychologist, the social worker, the nurse, and, sometimes, by the nutritionist and the occupational therapist, depending on the moment"* (Violet).

According to the needs of each family, the composition of the team that participates in these meetings can vary, and some take part with less or more frequency, depending on the concerns raised by the families: *"Each professional will demystify the situation regarding their expertise, but families ask questions. One of the families' areas of concerns is food. Their worry is the fact that the patient has not been eating and, when necessary, a family meeting is called to discuss the issue, as well as the benefits and risks of eating at this stage of the patient's life. The meeting includes: the nutritionist, the doctor, the nurse, the social worker and the psychologist"* (Hydrangea).

It was found, as can be seen in the following report, that the patient does not participate in the family meeting: *"Our family meeting includes the multidisciplinary team and the family, but the patient does not participate"* (Gardenia). The communication with the patient is held at a different time from the conversation with the family; so *"the patient does not participate in these meetings, only the family"* (Hydrangea).

Most likely, the reason for this procedure is due to the daily contact of the sick person with the health team, and the need to shield the patient from the discussions with family, or to the fact that the decision-making has often been delegated to the family. Generally, this occurs when the sick person presents evidence of refractory symptoms, when it is common to find the patient confused and disoriented due to the progression of the disease. In other words, although it is believed that palliative sedation should be proposed to the subject during the course of the progression of their disease, while they are still able to make decisions, this is not always possible.

In this case, as the patient cannot express their wishes regarding the process of dying, the sick person is dependent on the perceptions of family members and of the professionals in charge of

their everyday care regarding the "signs" of the patient's wishes. This becomes clear in the following statement: *"We, in our work, because we apply multidisciplinary care, make joint decisions. The team observes signs of distress and seeks to re-establish the patient's autonomy, or their possible autonomy. When the patient's autonomy is not present, we seek the family's opinion. We also try to recover anything through which the patient might have given a sign, any clue they might have given before they became unconscious"*. (Gardenia).

One of the reasons for the family meeting is to apprise the maximum number of family members about palliative sedation, in order to share the responsibility in making decisions: *"We call on everyone to acknowledge their responsibility, (...) and the psychologist (...) tactfully makes the family members realise their responsibilities. So that everyone has an understanding of the process and of their responsibilities to ensure everything goes smoothly."* (Tulip).

In addition, there is a concern regarding adequate preparation for grief. This measure is justified, since without a clear division of responsibilities in the decision-making process, grieving could end up causing additional suffering for the family. Therefore, according to Gracia, *it is irresponsible to make a decision while considering only the principles. Our responsibility always extends to the future and therefore it is necessary to consider the consequences as an integral part of moral judgment*<sup>16</sup>. It is in this sense that professionals assert the importance of the family meeting: *"We hold a meeting where we ask for more family members to be involved. It is not only the family member that is accompanying [the patient] who decides. We ask that the family be called, including those closest to the patient, so that we can sit, talk, and explain the disease from the diagnosis to the prognosis and everything else; to discuss expectations, to explain what sedation entails, and only then, a consensus is reached"* (Sunflower).

Therefore, an analysis of the interviews showed that for the patient, good communication based on a clear understanding of the information provided by the health team is essential for the family, to fulfill their responsibilities: *"If the family does not deal well with the question of sedation, it will be a family that will have problems in mourning. And they will begin to wonder: 'Why did I allow it? Why did I not stay? If I had not allowed it, would he/she not have survived more days?' While the family does not understand the whole question of sedation, they are not ready to*

accept sedation. So, we work things out. Sometimes it is necessary to talk with each family member separately, to understand why they do not want sedation, and it is very personal" (Hydrangea).

Close examination of the data showed that the work that is being developed by a multidisciplinary team is concerned with analyzing each situation to find a consensual solution, in other words, a group of professionals committed to finding the best solution for every difficult case, in order to improve the decision-making process and ensure, where possible, that these solutions are reasonable and prudent<sup>17</sup>. For the professionals, the team discussion, as well as the family involvement, is essential: "The decision to sedate is never simple. It is never a simple thing, but it must be taken, so we do everything to facilitate it" (Rosemary).

As seen, other problems arise as a result of the process of dying and the decision regarding palliative sedation.

### Sought solutions to ethical and values conflicts

By the analysis of the third sub-category, *solutions to conflicts*, it was found that the solutions to the problems were not present from the start, but - instead - they were sought by team debates. This search is exemplified by the decision to give enteral feeding to a patient, when the option was for an "intermediate" solution, seeking respect for the beliefs and values of the family and the principle of non-maleficence: "Not feeding is one of the issues that we face. Because, to the family, not eating, means the death of the patient. For the family, it is very sad to see their loved one unable to eat. So, often the enteral nutrition is left to a minimum, only to reduce the family anxiety, to make the family at ease. In the explanations about palliative sedation it is explained that the medications will be stopped, as they will no longer be necessary, with the reduction of nourishment, as patients remain with reduced feeding" (Hydrangea).

To make deliberations like this, in a consensual way and without accentuating conflicts between family members, it is necessary to identify what their values are in relation to food: "We try to show respect and try to talk, explaining the procedure, what will be best for the patient, while respecting the opinion of the family and the patient. For example, if we explain that the food could be removed and the family says no, we leave it. And I seek, within my expertise, to do everything that can make things easier, that can help to make the pa-

tient more relaxed and that can bring relief without causing harm. We value the knowledge of everyone, respecting their opinions and beliefs, and seek to understand" (Tulip).

In order to achieve prudent decision making and to respect the choice of the sick person and their family, the team relies on interpersonal dialogue in times of discussion, especially in cases where, for some reason, the family and / or the patient do not accept the use of palliative sedation. This dialogue is crucial in the deliberation process, given that the ultimate goal of a moral life is making prudent decisions. And these do not consist merely of the application of the principles, but in the intention to conform to the basic tenets of human decency<sup>18</sup>.

For the professionals, when the patient does not accept sedation, "the team remains very anxious (...) cannot handle the suffering; becomes very distressed and, once again, we have to talk, as it is not our decision, (...) if this suffering is distressing for us, it is even more so for the family, it is much greater. If it is difficult for me, it is much more difficult for the patient, and [I] respect them above all." (Hydrangea) Other respondents corroborated this point of view:

"We talked a lot, the team engages in dialogue to share experiences" (Sunflower);

"It's difficult and complicated to work with the decision of not applying palliative sedation when the patient has a refractory symptom. In general, the policy that we have among the professionals is that, when the family does not accept it, sedation is not applied. The autonomy of the patient and the family is respected as a justification for not performing the palliative sedation." (Daisy);

"We work with the team, recollecting our principles and remembering our respect for autonomy. Then the autonomy should be what the patient decides, rather than what the patient says that sounds like what we would do." (Gardenia)

It was possible to identify that mutual respect permeates the decision-making process in the multidisciplinary team. To Zoboli, moral deliberation in clinical practice requires a dialogue that enables the exchange of facts, emotions, feelings, beliefs, values, and not only information about signs, symptoms and test results. Recognising bonds and affections, and respecting differences and diversity, in an atmosphere of mutual respect, are essential to listening<sup>14</sup>.

However, one must consider that each professional is able to decide according to their expertise and their professional competence, so that, in the decision-making process, there is no guarantee that the solution reached by consensus shall be taken to effect, because we must not confuse the deliberative process with the ability to decide<sup>10</sup>. Therefore, in teamwork, one must take into account the specific competencies of the professions related to the act of caring: *“Most of the time, it is the attending physician or attending medical team [who decide]. And this is usually a decision taken after examination of the case, discussion of the case, and it is a decision that, obviously, must be shared.”* (Daisy).

The analysis of the reports led to the conclusion that the professionals consider fundamental the idea that, in order for the decision-making to be, effectively, made by the team, it needs to be based on the “arguments” of knowledge of the case, and not on the “authority” to argue. *“Sure, everyone can [argue]. But the decision will also have to be agreed by all, that’s what happens.”* (Lily)

The moral deliberation proposed by Gracia<sup>8</sup> is a method that can lead to a major improvement in the “way of thinking” in teams, particularly when it comes to the multidisciplinary palliative care team, in which health professionals, according to their expertise, can directly affect, positively and / or negatively, the patient’s quality of life and hence the quality of the patient’s death. Effects that depend on, among other factors, not only the theoretical basis and technical capability to provide care, but, above all, the moral justification of ethical systems that serve as ethical support for the work of these professionals. This means, that this refers to knowing whether they consider or not, or even, to what extent they reflect about the facts, duties and values involved in the whole process.

Each professional of the team has a good understanding of the clinical and personal history, that is, the “facts” and “values”, of the patient and their family. However, to facilitate decision-making, this knowledge should be shared with the team, as reported below by one interviewee:

*“You know this patient intimately, the whole family structure, in most cases, the profession of each of them, the inter-personal relationships. The problems experienced by the family are brought by the social service, the psychologist and also by us, through the daily contact that we share with them. And this becomes very easy for us to deal with, in the sense that we get to know the family structure and hierarchy.*

*Consequently, the decisions become less difficult with this perspective. When you make the decision simply based on isolated facts or specific symptoms, without the whole story to support it, it becomes more complicated.”* (Lily)

Besides favoring the deliberation process for prudent and responsible decision-making, sharing information helps to promote ethical reflection as a team. That is why the ethical deliberation regarding health is also a *permanent educational tool for professionals, through the mutual exchange of experiences and the dialogue on values, beliefs and principles*<sup>19</sup>.

Therefore, when it is stated that, in the field of research in question, you can create a process of moral deliberation, there is a conviction that this construction could be improved based on Gracia’s proposal<sup>8</sup>. This proposal suggests that, *a collective deliberation about common goals, with the exposure of different views and their rationale* can be, according to the author, *the appropriate method for the remoralization of the professions and the resurgence of professional ethics*<sup>17</sup>. Certainly, the same suggestion could be well received by any other palliative care service that has not yet created a deliberative and decision-making methodology, with the necessary bioethical foundation. Even for services that already have an established method it pays to become acquainted with the “moral deliberation” of Diego Gracia<sup>8</sup>.

## Final considerations

This study sought to investigate, through reflection and dialogue with health professionals involved in palliative care, in order to understand the deliberation process regarding some ethical conflicts related to palliative sedation. It was possible to identify that the reflections regarding this practice are done in multi-professional teams, demonstrating multidisciplinary work, and that the discussions held with family members regarding ethical problems and conflicts occur at different times and separately from those carried out with the patient. Even so, the research shows that the deliberation process still under construction, regardless of the team decision-making that is made based on the will and values of the patient, remains an unconsolidated procedure. However, the healthcare team understands and seeks solutions to ethical and value conflicts related to the practice of palliative sedation, even though, sometimes none of the solutions are entirely satisfactory.



Certain peculiar characteristics were verified not only regarding the professional culture but also regarding the culture of the users of palliative care (patients and family members) - cultures that are actually the source of the moral values of all involved.

According to the analytical framework used, for moral deliberation and its respective decision-making process regarding the practice of palliative sedation, a deep knowledge of the clinical facts (the physical and psycho-existential refractory symptoms), of the duties and of the values was identified as a necessity for the multidisciplinary team. In other words, to reach a prudent and responsible decision, it is necessary that the facts be clarified, that potential ethical conflicts are weighed within the multidisciplinary team, and that the values of the patient and their family are known and respected, as they are responsible for the final decision. This is the tripod of moral deliberation for the use (or not) of palliative sedation for sick people at the end of their lives.

It is in this sense that bioethics has become one of the conductors of the practices of health professionals, particularly in the context of palliative care, which, by its nature, routinely addresses the issues and problems concerning the boundaries between life and death, while always seeking to respect the sick patient and family values.

Therefore, the decision to use (or not) palliative sedation requires extensive team discussions ,

in which the role of the patient and of their families in decision making is respected above all - a condition considered essential for the characterization of this practice. It should also be noted that, in order to guarantee the right to information and respect for the autonomy of the patient, the use of palliative sedation should be proposed in advance, that is, during the progression of the disease, while the subject's capacity to make decisions has not yet been compromised.

Thus, the promotion of access to palliative sedation is of paramount importance in comprehensive care at end of life, given its ability to minimize suffering inherent in the process of dying from cancer, and to promote death with dignity. However, concurrent with the dissemination of this practice, it is recommended that palliative care professionals improve their ethical knowledge and axiology and that the grasping of such knowledge by them is encouraged, once the decision-making process is contextualised with the clinical facts, it requires the entire team to apply extensive ethical consideration and respect for the values involved.

In short, only in the context of the team's working relationship, is it possible to redirect the path to be followed in the practice of palliative sedation - a route taken with the consensus of all involved, with the objective of prudent and reasonable decision-making, that is, a moral decision.

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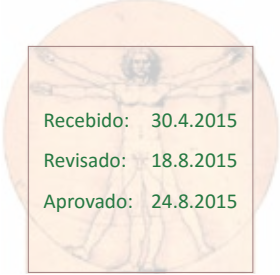
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#### Participation of the authors

Melisse Eich is responsible for the conception, bibliographic research, data collection, transcription of the interviews, analysis and interpretation of the results and writing of the article, under the academic supervision and revision of Marta Inex Machado Verdi. Pedro Paulo Scremin Martins collaborated in the bibliographic research, writing and formatting of the original text.



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