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RESEARCH

KNOWLEDGE AND PERCEPTION OF NURSES DEALING WITH PALLIATIVE SEDATION IN ONCOLOGY

CONHECIMENTO E PERCEPÇÃO DE ENFERMEIROS FRENTE À SEDAÇÃO PALIATIVA NA ONCOLOGIA

CONOCIMIENTO Y PERCEPCIÓN DE LOS ENFERMEROS FRENTE A LA SEDACIÓN PALIATIVA EN ONCOLOGÍA

Mariele Silva de Candido[1]
Marcela Mondadori Avila[1]
Odair de Freitas Trindade[1]
Aléxia Cassol Zeni[1]
Graciela de Brum Palmeiras[2]

[1]Universidade de Passo Fundo - UPF, Programa de Residência Multiprofissional Integrada em Atenção ao Câncer. Passo Fundo, RS - Brazil.

[2]Universidade de Passo Fundo - UPF, Curso de Enfermagem e Programa de Residência Multiprofissional Integrada em Atenção ao Câncer e Saúde do Idoso. Passo Fundo, RS - Brazil.

Corresponding Author: Mariele Silva de Candido

E-mail: silvamarielecandido@gmail.com

Author´s Contributions:

Conceptualization: *Mariele S. Candido;* **Data Collection:** *Mariele S. Candido;* **Investigation:** *Mariele S. Candido;* **Methodology:** *Graciela B. Palmeiras;* **Project Management:** *Mariele S. Candido;* **Statistical Analysis:** *Graciela B. Palmeiras;* **Supervision:** *Graciela B. Palmeiras;* **Visualization***: Aléxia C. Zeni, Graciela B. Palmeiras, Marcela M. Avilar, Mariele S. Candido, Odair F. Trindade;* **Writing – Original Preparation:** *Aléxia C. Zeni, Graciela B. Palmeiras, Marcela M. Avilar, Mariele S. Candido, Odair F. Trindade;* **Writing - Review and Edition:** *Aléxia C. Zeni, Graciela B. Palmeiras, Marcela M. Avilar, Mariele S. Candido, Odair F. Trindade.*

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ABSTRACT

Objective: to understand the knowledge and perception of nurses dealing with palliative sedation in oncology. **Method:** this is a qualitative, exploratory, and descriptive study, with a cross-sectional design. The study included 16 nurses working in oncology at a reference hospital located in the north of Rio Grande do Sul. Data were collected through recorded interviews lasting approximately 10 minutes, with a script of closed questions being applied to characterize the nurses participating in the research, and open and specific questions, to contemplate the objective of the study. The method used for the diagnosis and verification of research data was Bardin's content analysis. Data were analyzed and coded using the NVivo 10 software, which generated categories of similarity and correlations. **Results:** five categories emerged: (i) Knowledge about palliative sedation; (ii) Perception of palliative sedation in oncology; (iii) Feelings regarding palliative sedation in cancer patients; (iv) Experience with palliative sedation in cancer patients; and (v) Participation of the nurse in the palliative sedation procedure. **Conclusion:** nurses act effectively and fundamentally in providing care and evaluating patients undergoing palliative sedation, but there are still several obstacles related to their participation in decision-making. The importance of new research on the subject is evident, as well as the implementation of protocols that support the indication of palliative sedation.

Keywords: Conscious Sedation; Deep Sedation; Oncology Nursing; Terminal Care; Neoplasms; Palliative Care.

RESUMO

Objetivo: *compreender o conhecimento e a percepção de enfermeiros quanto à sedação paliativa em oncologia.* ***Método:*** *estudo qualitativo, exploratório e descritivo, com delineamento transversal. Participaram do estudo 16 enfermeiros atuantes na oncologia de um hospital de referência localizado no norte do Rio Grande do Sul. A coleta de dados ocorreu por meio de entrevista gravada com duração de aproximadamente 10 minutos, sendo aplicado um roteiro de perguntas fechadas, a fim de caracterizar os enfermeiros participantes da pesquisa, e perguntas abertas e específicas, para contemplar o objetivo do estudo. O método utilizado para o diagnóstico e a verificação dos dados da pesquisa foi a análise de conteúdo de Bardin. Os dados foram analisados e codificados por meio do software NVivo 10, que gerou categorias de similaridade e correlações.* ***Resultados:*** *surgiram cinco categorias: (i) Conhecimento sobre sedação paliativa; (ii) Percepção sobre sedação paliativa na oncologia; (iii) Sentimentos em relação à sedação paliativa em pacientes oncológicos; (iv) Vivência em relação à sedação paliativa em pacientes oncológicos; e (v) Participação do enfermeiro no procedimento de sedação paliativa.* ***Conclusão:*** *o enfermeiro atua de forma efetiva e fundamental na prestação do cuidado e na avaliação do paciente em sedação paliativa, mas ainda existem diversos obstáculos relacionados à sua participação na tomada de decisões. Evidencia-se a importância de novas pesquisas sobre a temática, como também a implementação de protocolos que subsidiem a indicação da sedação paliativa.*

Palavras-chave*: Sedação Consciente; Sedação Profunda; Enfermagem Oncológica; Assistência Terminal; Neoplasias; Cuidados Paliativos.*

RESUMEN

Objetivo: *comprender el conocimiento y la percepción de los enfermeros sobre la sedación paliativa en oncología.* ***Método:*** *estudio cualitativo, exploratorio y descriptivo, con diseño transversal. El estudio abarcó 16 enfermeros que trabajaban en oncología en un hospital de referencia localizado en el norte de Rio Grande do Sul. La colecta de datos ocurrió por medio de entrevista grabada con duración aproximada de 10 minutos, siendo aplicado un guión de preguntas cerradas con la finalidad de caracterizar los enfermeros participantes de la investigación, y preguntas abiertas y específicas para contemplar el objetivo del estudio. El método utilizado para el diagnóstico y verificación de los datos de la investigación fue el análisis de contenido de Bardin. Los datos fueron analizados y codificados utilizando el software NVivo 10, que generó categorías de similitud y correlaciones.* ***Resultados:*** *surgieron cinco categorías tituladas "Conocimientos sobre sedación paliativa; Percepción de la sedación paliativa en oncología; Sentimientos con respecto a la sedación paliativa para pacientes con cáncer; Experiencia con sedación paliativa en pacientes oncológicos y participación de Enfermeros en el procedimiento de sedación paliativa".* ***Conclusión:*** *el enfermero actúa de forma eficaz y fundamental en la prestación del cuidado y en la evaluación del paciente en sedación paliativa, pero aún existen varios obstáculos relacionados con la participación en la toma de decisiones. Es evidente la importancia de seguir investigando sobre el tema, así como la implementación de protocolos que sustenten la indicación de la sedación paliativa.*

Palabras clave: *Sedación Consciente; Sedación Profunda; Enfermería Oncológica; Cuidado Terminal; Neoplasias; Cuidados Paliativos.*

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INTRODUCTION

Cancer is a public health problem and is among the four leading causes of death in most countries. In 2018, there were 18 million new cases of cancer and 9.6 million deaths from it in the world. In Brazil, the estimate for 2020 to 2022 was 625,000 new cases per year[1].

Many patients undergoing cancer treatment end up needing palliative care during the illness process. This practice aims to promote quality of life for adult and child patients and their families facing a disease that threatens the continuity of life, preventing and alleviating suffering, in addition to promoting relief of physical, social, psychological, and spiritual symptoms[2-4].

When a patient in palliative care is in the process of dying, many symptoms can appear that cause discomfort both to the patient and to their family caregivers. Among these symptoms, delirium, nausea, vomiting, and constipation stand out, in addition to excessive pain and dyspnea, which can lead the patient to go through intense suffering in the end-of-life process. These symptoms are considered refractory when all the usual measures have already been taken and there are no further responses to the conduct. Then, palliative sedation is indicated for the patient's comfort[5,6].

Palliative sedation is a medical procedure defined as the use of medications that reduce the level of consciousness of patients who have an advanced stage of the disease and are in an active process of death, aiming at relieving symptoms considered refractory. Refractory symptoms are those that cause discomfort even if all the resources usually used have been used up[7,8].

When it comes to palliative care and the use of palliative sedation, the participation of the multidisciplinary team is extremely important to ensure better management of physical and emotional symptoms, both for the patient and the family. Among the health professionals, the participation of the nurse and the Nursing team stands out, who frequently accompany the patients being by their side for hours every day and knowing their anxieties, their feelings, and their wishes[9].

Nurses play a key role in assisting patients in palliative care. They identify signs and symptoms, assess pain, suffering, treatment responses, and the particularities of each patient, and contribute to the conduct of the multidisciplinary team and to carrying out the palliative sedation process. However, there are still divergences regarding the knowledge of these professionals about palliative sedation, its objective, its indication, and its functioning[3,10].

We justify our research because palliative sedation in oncology is a subject that is little discussed and that generates several questions regarding its use. This study may provoke professionals to their knowledge and assistance with this procedure. In addition, professionals will be able to share their experiences, their feelings, and their perceptions about death and the relief of suffering, being able to generate reflections that will open doors for better conduct, positions, and decision-making that will bring benefits to the patient in their dying process. Therefore, this research has the following guiding question: What is the knowledge, perception, feeling, and experience of nurses about palliative sedation in oncology? To answer this question, the following objective was defined: to understand the knowledge and perception of nurses dealing with palliative sedation in oncology.

METHODOLOGY

This is a qualitative, exploratory, and descriptive study with a cross-sectional design. The sample was for convenience, composed of 16 nurses working in the oncology unit of a reference hospital located in the north of Rio Grande do Sul who monitor the routine of Nursing residents, not using the theoretical saturation technique.

The selection of participants took place according to the following inclusion criteria: being a nurse; to be working in oncology for a period equal to or greater than one year; and voluntarily accepting to participate in the research. The exclusion criteria were: nurses on leave during the collection period. At the time of data collection, the oncology unit was composed of 16 nurses who met the inclusion criteria. Therefore, all nurses in the unit agreed to participate voluntarily in the research, signing the Informed Consent Form (ICT).

Ethical aspects were respected following the recommendations of Resolution nº 466/12 of the National Health Council and the General Data Protection Law (LGPD) nº 13.709/2018[7,8]. The research project was submitted and approved by the teaching and research management of the hospital institution where the research took place and, subsequently, evaluated and approved by the Research Ethics Committee (CEP) of the University of Passo Fundo, Rio Grande do Sul, Brazil, under opinion N° 5,376,808 and CAAE 57417822.7.0000.5342[11,12].

Data collection took place in a meeting room at the hospital in July 2022, through an individual and face-to-face interview, lasting approximately 10 minutes. A field diary was used and a structured questionnaire was applied to characterize the participants in terms of age, gender, time since graduation, time working in oncology,

and specializations in the area. A semi-structured questionnaire with open and specific questions was also applied to contemplate the objective of the research regarding the perception, knowledge, feeling, experience, and participation of the nurse in the care of the patient in palliative sedation. The interview was recorded using a tape recorder and later transcribed and analyzed, keeping the identity confidential; then the interviews were deleted.

The research participants were coded by the letter "P" (participants) and numbered from 1 to 16 (P1, P2, P3… P16), to identify the statements and maintain the confidentiality and anonymity of the participants. The method used for diagnosing and verifying the research data was Bardin's Content Analysis, consisting of the following phases: (i) pre-analysis; (ii) exploration of the material; and (iii) treatment of results, inference, and interpretation[13].

The participants' speeches were evaluated and coded by two nurses who carry out research with a qualitative approach. The speeches were systematized and coded using the NVivo 10 software, which generated categories of similarity and correlations. The analyzes carried out using this software went through three stages: (i) data preparation; (ii) coding and analysis; (iii) and reporting on the results. In the description of each of the stages, fragments of the data analyzed in the research are presented. The categories are called nodes and represent a category or an abstract idea, being able to store its definition.

The nodes are presented through "word clouds" of greater frequency in the speeches of the study participants. The definition was stored and automatically generated by the software at the time of category creation. In addition to the word cloud, the software also brings exact numbers of how many times the words were cited. The similarities of the categories were analyzed using Pearson's linear correlation coefficient, defined as a measure of linear association between variables. This association happens from the distribution of frequencies or the sharing between two variables[14].

RESULTS

For the interpretation of the results, the characterization of the participants was initially performed through a structured questionnaire regarding age, gender, time since graduation, time working in oncology, and specializations in the area. The average age of the respondents was 25 to 41 years old, and about 90% were female. Thirteen of the 16 nurses working in the oncology unit of the reference hospital had specializations in the area and three were in the process of specializing. The minimum training time for professionals was one and a half years, and the maximum time was 16 years. The performance in the area ranged from one year and a half to 15 years. Participants also had different areas of expertise, bringing different views and experiences with palliative sedation during data collection; three participants shared their experiences in pediatric oncology hospitalization, four in the outpatient service, and nine in an adult oncology hospitalization service.

Among the analyzes performed using the NVivo 10 software, we have five categories: (i) Knowledge about palliative sedation; (ii) Perception of palliative sedation in oncology; (iii) Feelings regarding palliative sedation in cancer patients; (iv) Experience with palliative sedation in cancer patients; and (v) Participation of the nurse in the palliative sedation procedure. Figure 1 shows the most frequent cloud of words in the speeches of the study participants.

In addition to the word cloud, the software also brings exact numbers of how many times the words were cited. The most cited words were: sedation (238), patient (86), nurse (76), suffering (68), important (46), little (38), family (36), relief (34), death (34), time (34), doctor (32), treatment (32), participant (31), disease (30), best (30), final (28), oncology (28), experience (28), teams (26), palliative (26), process (26), symptoms (26), enough (24), knowledge (24) and multidisciplinary (24). Figure 2 shows clustered nodes by word similarity of the defined categories, using Pearson's linear correlation coefficient. That is, one category becomes similar to another according to the frequency of one or more words that were cited in them.

Figure 1 - Cloud of the most frequent words in the nurses' speeches. Source: The authors, 2022.

Knowledge about palliative sedation

In this category, some participants emphasized the relief of pain and suffering, comfort, tranquility, and a dignified end of life as the most important objectives of palliative sedation; that is, the participants demonstrated knowledge about the topic.

P.1 stated that "palliative sedation is the use of medications that aim to reduce the patient's consciousness and treat refractory symptoms of some disease [...] It is for patients who do not have a curative treatment, to control pain and symptoms".

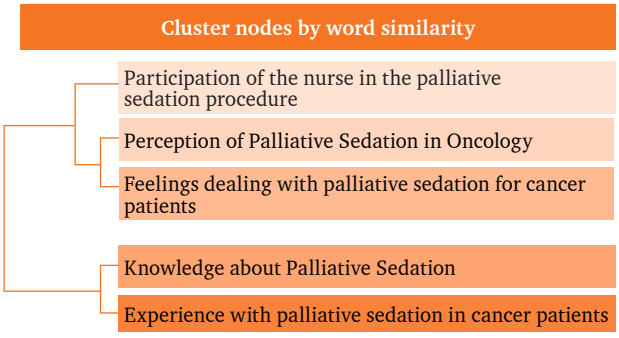

Figure 2 - Clustered nodes by word similarity of defined categories, using Pearson's linear correlation coefficient.
Source: The authors, 2022.

Next, we will show the five categories, followed by the speeches of the study participants.

> [...] *it is when the patient has exhausted the therapeutic possibilities, and there is no longer any possibility of cure, the disease arrived at a time when the patient is suffering, and the closest outcome is death, so sedation ends up being initiated so that the patient does not have to suffer very close to death.* (P.2)

> [...] *it is when the patient already has a palliative diagnosis, has already undergone chemotherapy, radiotherapy, surgical procedures, and is in a situation that the multidisciplinary team evaluates, who does not respond to treatments, is in a lot of pain, discomfort, does not resolve with medication, chemotherapy, so palliative sedation is chosen, so he does not feel pain.* (P.8)

> [...] *it is a means of treatment in a way that relieves the symptoms and promotes a dignified death for the patient, a death without pain, without suffering, which eases that period when we no longer have any therapeutic means of treatment.* (P.10)

Only one participant commented on the levels of palliative sedation and the medications used for this purpose. As a result, there is little knowledge by other professionals about the operation and performance of the procedure.

> *Sedation has several levels, a lighter sedation and a deeper one, so you can start with a lighter sedation* [...] *Studies and articles indicate the use of benzodiazepines, which would be midazolam and, for example, morphine in a lower dose to control the symptoms* [...]. (P.1)

Perception of palliative sedation in Oncology

The participants conveyed their perception of palliative sedation in the hospital environment. The lack of knowledge and understanding about the indications by the medical team was highlighted.

> [...] *We still have many difficulties related to the implementation of palliative sedation, we have resistance from the medical teams, [...] I think there is a little difficulty concerning understanding how palliative sedation works, and often this difficulty in the clinical management of the patient.* [...] *I think there is still a lack of knowledge, of studies on palliative sedation, what it is, how I can use it, even the issue of therapeutic doses, how much I can use, and there is this fear of use.* (P.10)

Some professionals pointed out the late onset of palliative sedation, which often postpones the patient's suffering. It follows the line that there is still a lack of understanding about the indications of palliative sedation.

> *I think there is a lack of knowledge, sometimes it is clear that this patient needs sedation, and he will receive it when he has already undergone a good portion of the entire treatment until someone will realize that he needs comfort, and a quality of life until death.* (P.16)

> *I think that the medical teams still have a certain fear, sometimes, in admitting that this patient is palliative, and starting with sedation, I think that many times we see that it ends up going until the last moment of the child, and when he no longer bear the pain, sedation begins.* (P.4)

In this category, they also highlighted the importance of communication between the team, patient, and family, emphasizing that, often, this communication is weak and does not happen effectively.

> *I think it's necessary, but it's done the "wrong" way, because there's no heart-to-heart conversation with the patient before that, you just talk to the family member, and sometimes you don't*

> *communicate with anyone, you just install the sedation, and tells the family that he is no longer conscious and that it is better for him. And the patient didn't have any time to express himself if he had something to say, or if he had someone to see, most cases that I see in adults are like that.* (P.2)

> *I think there are still many myths about sedation in oncology because the patient and family often don't know what's going on, and they think that sedation will cause the patient's death.* [...] *So we see that it is still very flawed, both in the medical area and in the nursing area, to explain to the patient, when he is still lucid and to the family, what it is if he is being sedated and what will happen to him from then on, for him to understand that he is not causing death* [...]. (P.5)

During the speeches, the decision to indicate and implement palliative sedation generates many conflicts. The delay in indicating the beginning of sedation in a patient at the end of life with constant suffering and the lack of communication between the team and the family has been a challenge for nurses, considering that there is still a lack of discussions and planning within hospital institutions to support this decision making.

Feelings dealing with palliative sedation in cancer patients

In this category, participants emphasized how they felt when caring for a patient in palliative sedation. They report feeling relieved to see a patient who suffered a lot receiving relief, but they also feel sad since they spend all their time with the patient, end up getting to know their entire trajectory of health and illness and, when they get to that point, they know that the final destination is death.

> *It's a mixture of feelings, it's sad because we know that the time they put the sedation on is because we really won't have that patient back, but it also brings comfort to the whole team, for not seeing that patient suffer anymore. It is very difficult to be there all the time and to see the patient complaining, crying in pain, it is very difficult for the whole team, so when we start with sedation, we are relieved to know that the patient is more comfortable, but we also feel sadness in knowing that it is irreversible. (P.4)*

> [...] *Relief, compassion* [...] (P.7)

The feeling of impotence was also mentioned and, once again, the issue of late indication of palliative sedation came up, generating anxiety in the Nursing team that accompanies the patient and perceives his suffering.

> *It's complicated, because many times I think I feel powerless because somehow, I would like it to be done correctly, but that's not part of us as nurses, so we feel powerless.* (P.2)

> *I am happy when I see that the attending physician understands the subject and encourages this for the family* [...] *at the same time it is also very frustrating because most teams do not encourage the patient to be sedated, it is very difficult to reach to the point of sedation, only when the patient is in the extreme, that he is very sick and that the family is there extremely distressed* [...]. (P.5)

The Nursing team goes through many moments together with the patients, thus creating a bond is inevitable. When the nurses assist them and realize that the pain and other symptoms are causing suffering, the team also ends up suffering from the situation.

The search for more knowledge is also addressed in this category.

> *It is a feeling that we need to know more, and study more about it, because the more knowledge we have about palliative sedation, the better we will be able to apply it to the patient.* (P.6)

The teams realize that there is still a lack of knowledge and understanding by all health professionals, and it is necessary to have discussions and plans for this procedure to be better carried out. Everyone wants to provide for the patient's well-being and manage to ease the suffering close to death. When they succeed in doing this, they feel fulfilled; when not, they feel frustrated.

Experience with palliative sedation in cancer patients

In this category, we observed that some have more experience with palliative sedation, while others are less so.

> *Minimal experience, I had the opportunity to see very few patients in palliative sedation, and when submitted, I believe it was not with the necessary humanization for that moment.* (P.3)

> *I had some experiences with adult patients, children, and adolescents, so I was able to evaluate this sedation in several patients, at different ages, and in different situations, and none of them are the same as the other.* (P.6)

The participants also reported cases that were remarkable for them, showing that, when the process is well-indicated and well-guided, it is better for everyone.

> *I followed a case not long ago at a health center where I worked, where a 32-year-old patient was sedated, and it was his choice, he made it very clear that if he reached a certain point in the disease, he would like to be sedated so as not to feel pain* [...] *we also experienced everything from the family members, who understood and were calmer, because the patient was opting for it, so we felt that it was a good moment, both for the patient and for the relatives, because they felt safe, and could stay with him, without seeing the suffering in the last moments of his life.* (P.8)

> [...] *One remarkable thing was a patient who used continuous medication, at a very high dose, mainly for analgesia, it was the solution for the patient who, at the end of her life, went through this phase, had some control, the dosage was reduced, until allowing her discharge, she went home, this patient is in palliative care, she is at home, so it is a reference that I have of this care* [...]. (P.7)

The experiences provide learning and understanding of the process. Some experiences are good and provide valuable knowledge, others not so much, causing many questions.

Professionals working in the oncology clinic end up not experiencing palliative sedation. Because it is a very rotating sector, patients undergo treatment and return to their homes; when their condition worsens or they need more specific procedures, they are hospitalized. It is during hospitalization that patients are submitted to sedation when indicated.

> [...] *in the outpatient clinic, our patient is daily, he rotates, we receive from time to time a patient who comes already in a bad state of health, is already very weak, needs to go quickly to hospitalization, but these interventions happen there in the hospitalization, they don't happen here, here we provide the first support, the first assistance, and then the patient goes to the hospital, so we end up not experiencing that in such a way here.* (P.9)

Participation of the nurse in the palliative sedation procedure

Nurses are involved in all stages of human life, and their role is of fundamental importance in all care, especially in the decision to initiate palliative sedation, in the monitoring and evaluation of this process.

> [...] *we see that the nurse has a fundamental role because they and the Nursing team are there evaluating the patient, checking signs, we see when this patient is in pain, there is a change, so we already have this opportunity to go to the medical team and say: look, he already has enough analgesia, would you indicate starting analgesic sedation for him? or not yet? so we can talk, as well as if we notice that the sedation has already started, but even so the patient is dying, he is suffering, the nurse can discuss, and can also adjust the issue of the volume to be infused, I believe that the nurse in this paper also has to be aware of what would be sedation, what is palliative care, or terminal care, what is a measure of comfort, so it is always up to us to also go after it, get informed and know what is happening with our patient, and what would be the best Nursing care at that moment.* (P.14)

In addition to providing care, procedures, and management, the nurse and the Nursing team are the professionals who spend the most time with the patient, listening to their feelings, wishes, and anxieties.

> *I think the nurse is very important, the multidisciplinary team is important, each one in their role, listening to the patient's wishes, but the nurse precisely at this point, listening to the wishes, or when the patient is not expressing himself, he is not being able to speak, listening to the family, promoting a better environment, comfort* [...] *I think the nurse does all this global care for the patient* [...]. (P.9)

The nurse must also participate in the decision-making and discussion process with the family members, have knowledge and arguments to explain the effects and benefits, and resolve doubts that the patient and family member will have.

> *I think the nurse needs to be prepared to talk to the family and the patient, to clear up all the doubts, which are often many, about what is happening and how this process will be.* (P.5)

> *I think it is very important for the nurse to be involved in the decision and the conversations between the medical team and the patient and the family member because we are the ones who are in contact with the patient practically 24 hours a day* [...]. (P.11)

In general, it is clear that most of the nurses participating in the study understand palliative sedation and are active in the process. They also seek to improve themselves more and more to be acting in the best way, even with some challenges. But some professionals find it difficult to participate in this procedure, perhaps due to a lack of knowledge or restrictions from medical teams.

> *I think the nurse's participation is minimal [...] Basically what the nurse does is install the medication, and increase it when*

> *necessary, so I think there is still a long way to go for Nursing participation within palliative sedation.* (P.3)

> *The professional nurse is often not active in the process of palliative sedation because it is a practically medical decision, they take the action of sedating the patient* [...]. (P.2)

DISCUSSION

Palliative sedation has been discussed since the 1990s and there are still many doubts about its definition, its indication, and its objectives. Following the knowledge of the participants regarding the research topic, the most debated concept in other studies is that palliative sedation is the monitored use of drugs that can decrease the level of consciousness to alleviate the suffering resulting from advanced and untreatable diseases[15,16].

As reported by one of the participants in this study, palliative sedation has classifications. Depending on the intensity, it is classified as superficial or deep. The superficial one starts with medications in low doses to alleviate symptoms, allowing the patient to remain awake; in the deep position, the patient remains unconscious. Sedation can also be classified according to duration, which can be intermittent or continuous. In the intermittent, the patient goes through periods of consciousness and alertness; on the other hand, in the continuous one, he will remain unconscious until the moment of death. The determination of which sedation will be indicated is based on the evaluation of the patient, his clinical condition, and the degree of his symptoms[16-18].

The most commonly used drug classes are benzodiazepines, neuroleptics, and barbiturates. Midazolam is part of the benzodiazepine class, being the most commonly used. It is considered the first choice and can be associated with other medications. In patients who present with delirium and agitation, neuroleptics such as chlorpromazine may be effective. Opioids such as morphine are also frequently used for pain relief, and may be enough to control moderate and severe pain and promote palliative sedation; however, it can cause delirium and agitation in high doses[15,17,18].

Most nurses interviewed brought the lack of communication between the team, patient, and family in the decision to start palliative sedation. Some studies highlight that talking about death and terminal illnesses is very complex, being considered taboo in society, which makes dialogue and early approach with the patient and their family difficult. They also describe that the decision to start palliative sedation should be discussed among all those involved, taking into account the sociocultural and family context and the patient's clinical status [16,19].

Other studies deal with the anticipated approach and argue that it is valuable, as it provides information and autonomy for the patient in choosing the procedures he wants to perform, which is his right. When the patient is not in a position to have this autonomy, it is acceptable for the family to decide for him, and he must know the patient's wishes[16,20,21].

Brazilian studies highlight that good communication between the multidisciplinary team and other people involved helps in decision-making, in the therapeutic bond, and in understanding the process. The multidisciplinary team can build a care plan for the patient individually, thinking exclusively about the patient and their family members. With this, it can provide a humanized end of life and cover all their needs, whether physiological, psychosocial, and/or spiritual[16,20,21].

The literature describes the implementation of institutionalized protocols to assist professionals in the indication of palliative sedation, as well as to optimize the prescription of the most used drugs. This would be the key point for making decisions and using this procedure clearly and effectively. The elaboration of a term of consent that would assure, to the patient and the relative, autonomy and knowledge about indications, risks, and benefits would also be a way to reduce the professionals' insecurity when indicating sedation[17,20].

Regarding the feelings of professionals in the face of palliative sedation, one nurse reported feeling powerless in the face of human suffering. Research shows that dealing with death and with patients in the final stages of life is not easy, much less taught in technical, undergraduate, or graduate courses. Studies explain that nurse enters the job market with a perception of care for the maintenance and recovery of health; however, when faced with human suffering and death, they often end up feeling guilty, helpless, angry, and frustrated because they are unable to help or avoid some action [3,21].

On the other hand, most of the nurses in this study demonstrated a feeling of relief and compassion when they saw comfort in the eyes of a patient who had suffered anguish in the face of refractory symptoms. This means that professionals understand the objectives of sedation, which provides tranquility and the final moments of life without pain and suffering. A survey carried out in Brazil showed that the confrontation of health professionals in the face of death can be interpreted as these professionals understanding and accepting death as a natural process of life[22].

Nurses' participation in carrying out the palliative sedation procedure is not much discussed in the literature, and publications related to this contribution are scarce. The nurses participating in this study reported their fundamental role in this process, which ranges from identifying the need for an indication, going through the discussion of the case with the physician and other members of the multidisciplinary team, participating in the dialogue with family members, to managing and monitoring of the effect of the medication, in addition to participating in listening and welcoming the patient.

The nurses highlighted that Nursing is present full-time with the patient, which corroborates studies that also mention the importance of this bond to identify and interpret complaints, symptoms, and expressions that cause suffering to the patient, as well as to evaluate the therapeutic efficacy to alleviate discomfort at the end of life[3,21,23]. An international study indicated that nurses should identify the need for palliative sedation and suggest it to the physician without fear. The administration and frequent monitoring of the patient during sedation is an essential practice of nurses, who may be observing the need to decrease or increase dosages, as well as changing the medication used, making this communication with doctors and other team members to prioritize patient comfort[24].

The bond between patient and nurse was also mentioned by participants in this study. Listening to wishes, anxieties, fears, and feelings and being willing to give attention, compassion and respect are valuable roles for Nursing and other professionals. According to studies, Nursing professionals plan different forms of care, including knowing how to dialogue and knowing how to listen to the patient and his family[23].

As limitations of this study, we highlight the low number of studies on palliative sedation and the role of nurses in this process, as well as their knowledge regarding the functioning of this procedure and their experiences and feelings regarding the process of palliative sedation and death.

CONCLUSION

From this study, it was possible to broadly verify the nurses' knowledge regarding palliative sedation, their feelings, their experiences, their perceptions, and their participation in the procedure. Professionals demonstrate an understanding of the purpose of palliative sedation but have little management knowledge. They also highlight medical resistance in the indication and effective communication between the team, patient, and family.

The nurse plays a fundamental role in providing care and evaluating the patient in palliative sedation, monitoring the entire process of health, illness, and end of life. It accompanies anguish, wishes, and thoughts, providing comfort to both the patient and their family members. However, it still has many obstacles related to participation in decision-making.

Sugere-se a realização de novas pesquisas sobre a temática, principalmente quanto à implementação de protocolos em instituições em que a sedação paliativa é indicada, a fim de subsidiar a atuação dos profissionais e respaldar a tomada de decisões, além de permitir mais segurança na indicação, na realização e na avaliação do procedimento.

We suggest that further research be carried out on the subject, mainly regarding the implementation of protocols in institutions where palliative sedation is indicated, to support the work of professionals and support decision-making, in addition to allowing more security in the indication. , in carrying out and evaluating the procedure.

REFERENCES

1. Instituto Nacional de Câncer. Estimativa. 2020[cited 2021 aug. 30]. Available from: https://www.inca.gov.br/estimativa/introducao

2. Instituto Nacional de Câncer. Cuidados Paliativos. 2020[cited 2021 Aug. 30]. Available from: https://www.inca.gov.br/controle-do-cancer-do-colo-do-utero/acoes-de-controle/cuidados-paliativos

3. Goi MG, Oliveira DR. Produção do Conhecimento de Enfermagem Acerca de Cuidados Paliativos: revisão narrativa. Rev Contex Saúde [Internet]. 2018[cited2021 aug. 30];18(34):20-6. Available from: file:///C:/Users/silva/Downloads/6585-Texto%20do%20artigo_-35533-1-10-20180628%20(1).pdf

4. Secretaria de Saúde do Distrito Federal. Atendimento em Cuidados Paliativos. 2023[cited2021 Aug. 30]. Available from: https://www.saude.df.gov.br/cuidados-paliativos-2#:~:text=Segundo%20a%20defini%C3%A7%C3%A3o%20da%20Organiza%C3%A7%C3%A3o,doen%C3%A7as%20que%20amea%C3%A7am%20a%20vida.

5. Ross H, Albert RH. End-of-Life Care: managing common symptoms. Am Fam Physician [Internet]. 2017[cited 2021 Aug. 30];95(6):356-61. Available from: https://www.aafp.org/dam/brand/aafp/pubs/afp/issues/2017/0315/p356.pdf

6. Santos RB, Gomes CM, Bonadio CB, Ferreira PS, Bertequine RB, Rodrigues LF. Estudo observacional retrospectivo sobre o perfil de pacientes que receberam terapia de sedação paliativa em unidade de cuidados paliativos de Hospital de Câncer no Brasil. Rev Bras Cancerol [Internet]. 2019[cited 2021 Aug. 30];65(1):e-09324. Available from: https://rbc.inca.gov.br/index.php/revista/article/view/324/217

7. Cherny NI. ESMO clinical practice guidelines for the management of refractory symptoms at the end of life and the use of palliative sedation. Annals Oncology [Internet]. 2014[cited 2021 Aug. 30];25(1):143-52. Available from: https://www.annalsofoncology.org/action/showPdf?pii=S0923-7534%2819%2934085-2

8. D'Alessandro MPS, Pires CT, Forte DN, Maiello APMV, Coelho FP, Schuls V. Manual de Cuidados Paliativos. São Paulo: Hospital Sírio-Libanês/Ministério da Saúde; 2020.

9. Couto DS, Rodrigues KSL. Desafios da assistência de Enfermagem em cuidados paliativos. Enferm Foco [Internet]. 2020[cited 2021 May 21];11(5):54-60. Available from: http://revista.cofen.gov.br/index.php/enfermagem/article/view/3370

10. Patel B, Bhat RG, Levine S, Shega JW. Nurses Attitudes and Experiences Surrounding Palliative Sedation: Components for Developing Policy for Nursing Professionals. J Palliative Med. [Internet]. 2012[cited 2021 Nov. 18];15(4):432-7. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3362321/pdf/jpm.2011.0336.pdf

11. Conselho Nacional de Saúde (BR). Resolução nº 466, de 12 de dezembro de 2012.[cited 2021 Nov. 18] Diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. Brasília: CNS; 2012. Available from: http://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf

12. Congresso Nacional (BR). Lei Geral de Proteção de Dados Pessoais. Brasília, DF: Congresso Nacional; 2018.

13. Bardin L. Análise de conteúdo. 3ª ed. Lisboa: Edições 70; 2016.

14. Figueiredo Filho DB, Silva Júnior JA. Desvendando os Mistérios do Coeficiente de Correlação de Pearson (r). Rev Polít Hoj [Internet]. 2009[cited 2022 Aug. 24];18(1):115-46. Available from: https://periodicos.ufpe.br/revistas/politicahoje/article/viewFile/3852/3156

15. Menezes MS, Figueiredo MGMCA. O papel da sedação no fim da vida: aspectos médicos e éticos - Revisão. Rev Bras Anestesiol [Internet]. 2019 [cited 2022 Sept. 14];69(1);72-7. Available from: https://www.scielo.br/j/rba/a/Q8NRspx3RYb7jCZmv56ND6z/?format=pdf&lang=pt

16. Eich M, Verdi MIM, Finkler M, Martins PPS. Princípios e valores implicados na prática da sedação paliativa e a eutanásia. Interface Comun Saúde Educ [Internet]. 2018[cited 2022 Sept. 14];22(66):733-44. Available from: https://www.scielo.br/j/icse/a/LJBHbyqmp7WKyXGhTbWFSyL/?format=pdf&lang=pt

17. Nogueira FL, Sakata, RK. Sedação Paliativa do Paciente Terminal. Rev Bras Anestesiol. [Internet]. 2012[cited 2022 Sept. 20];62(4):580-92. Available from: https://www.scielo.br/j/rba/a/6HWXszMptj6ZrVz7nHXWYTz/?format=pdf&lang=pt

18. Rehme BB, Galli NB. Sedação Paliativa do Paciente Terminal - revisão de literatura a propósito de um caso. Rev Med UFPR [Internet]. 2017[cited 2022 Sept. 22];4(1):31-4. Available from: https://revistas.ufpr.br/revmedicaufpr/article/view/52252/pdf

19. Eich M, Verdi MIM, Martins PPS. Deliberação moral em sedação paliativa para uma equipe de cuidados paliativos oncológicos. Rev Bioética [Internet]. 2015[cited 2022 Sept. 14];23(3):583-92. Available from: https://www.scielo.br/j/bioet/a/zzpv9FMFrN5CttRhyrKnKxp/?lang=pt&format=pdf

20. Soeiro A, Bastos TR, Vasconcelos VS. Sedação Paliativa, Bioética e Terminalidade da Vida: Implicações na Prática Médica. Rev Iberoamericana Bioét [Internet]. 2022[cited 2022 Sept. 15];18:01-14. Available from: https://revistas.comillas.edu/index.php/bioetica-revista-iberoamericana/article/view/15363/15764

21. Franco HCP, Stigar R, Souza SJP, Burci LM. Papel da Enfermagem na equipe de cuidados paliativos: a humanização no processo da morte e morrer. Rev Gestão Saúde. [Internet]. 2017[cited 2022 Sept. 18];17(2):48-61. Available from: https://www.herrero.com.br/files/revista/file56fb2faad065b8f7980ccdf2d0aa2da1.pdf

22. Souza MOLS, Troadio IFM, Sales AS, Costa REAR, Carvalho DNR, Holanda GSLS, et al. Reflexões de profissionais da Enfermagem sobre cuidados paliativos. Rev Bioét. [Internet]. 2022[cited 2022 Sept. 18]:30(1):162-71. Available from: https://www.scielo.br/j/bioet/a/M8PwcV7ZPSRcFVrKCRhnhYB/?format=pdf&lang=pt

23. Aquino ATT, Góes IMC, Malcher M. A percepção da equipe de Enfermagem sobre cuidados paliativos e o manejo da dor na unidade de terapia intensiva do Hospital Municipal de Santarém. Enferm Brasil [Internet]. 2016[cited 2022 Sept. 12]:15(6):295-300. Available from: https://portalatlanticaeditora.com.br/index.php/enfermagembrasil/article/view/717/1578

24. Heino L, Stolt M, Haavisto E. The practices of nurses about palliative sedation on palliative care wards: A qualitative study. J Adv Nurs [Internet]. 2022[cited 2022 Sept. 10]:78:3733-4. Available from: https://onlinelibrary.wiley.com/doi/epdf/10.1111/jan.15350