Article

Psychological fantasies about the administration of palliative sedation to terminal cancer patients: a qualitative study of reports from Brazilian nurses in a specialized hospital

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Abstract: Knowing the symbolizations constructed in people's consciousness, based on lived experiences, is crucial to understanding how they structure their lives. Palliative Sedation (PS) integrates treatment in terminal palliative care, with the purpose of offering support and relief of refractory symptoms that may occur at the end of life. This study aimed at interpreting psychic fantasies that permeate thoughts, as reported by a sample of nurses when administering palliative sedation to patients in the final stage of life. This is a clinical-qualitative study conducted in a large hospital in the city of São Paulo (state of São Paulo, Brazil), a national reference in oncology. The study included 11 nurses working in the care of cancer patients. For data collection, we used the technique of SDIOQD – Semi-Directed Interview with Open-ended Questions In-Depth. The treatment by CQCA - Clinical-Qualitative Content Analysis is grounded on psychodynamic concepts. The interpretation of the meaning cores found in the interviews, complemented by observation of the para-verbal and nonverbal manifestations of the interviewees, led to the construction of three categories: (1) to symbolically serve death on a tray; (2) the act of sedation and its unfortunate coincidences; (3) palliative sedation as an agent of mercy death. This study suggests that nurses face dilemmatic situations, going through periods of self-questioning and moments of the ambivalence of feelings of beneficence and maleficence. When sedating a patient, the nurses envision to be offering dignity in death. Euthanasia fantasies in the process of administering sedation are latent in consciousness.

Keywords: palliative sedation; terminal care; nursing; palliative care; qualitative research

1. Introduction

Psychologically, fantasies are imaginations in which the informants are present in the reported content, even if they do not have a clear perception of this phenomenon. The scene represented in their consciousness has a rudimentary psychic elaboration, manifesting itself distorted by the action of necessary psychologic processes of ego defense. The report of imaginations about certain human experiences is an unveiling material in the interpretative treatment of meaningful fragments in each

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interview. Nursing care for terminal cancer patients is recognized as a specialized area, whose activity is endowed with sophisticated peculiarities in the care process, considering the terminal condition of human beings. The professional will face situations of suffering characteristics of cancer illness, especially in the process of end-of-life in which patients find themselves [1]. Nurses play key roles in caring for patients in the final stages of life and in coping with death, including controlling end-of-life symptoms. This includes controlling physical and behavioral reactions by offering relief from suffering and promoting comfort, with palliative sedation (PS) being a relevant part of this therapeutic control.

PS is a treatment modality that leads to the reduction of the neurological level of consciousness with sedative drugs. There are guidelines based on which this clinical practice of sedation in terminal care is performed, but it varies according to country, due to different values and cultures [1,2]. There is an induction to a state of decreased or loss of consciousness until possible death, by the monitored use of sedatives, as a last resort to relieve unbearable symptoms of suffering in cancer patients at the end of life [2,3]. This procedure has emotional implications for both the family and the professional team. The PS procedure can generate conflicts with considerable anguish, and significant differences of opinion, as well as the impact on the various stages of the care process, from decision-making to the beginning of sedation [4].

The density of emotional burden in the context of PS is present in several moments of palliative care. The oncology palliative care environment is immersed in taboos surrounding the phenomenon of death. Even though we understand death as part of the natural cycle of life, and it is present in the daily activities of nursing professionals, it can become a source of psychic suffering for nurses when administering PS. Due to the idea of death, which can be associated with the technical procedure, undertaking this activity can lead nursing professionals to develop feelings of personal and professional failure. [5, 6].

We observe that the work environment with cancer patients at the end-of-life stage is conducive to challenges, which require professionals to expend physical and mental energy. Such demands can lead professionals to a state of stress, dissatisfaction, weariness, and exhaustion. However, experiences in this environment can also provide moments of learning and professional growth. An established bond between terminally ill patients, family members, and the professional, there is a closer relationship between those involved, favoring the emergence of feelings of relaxation, satisfaction, and a certain pleasure on the part of nurses [2,4].

The nursing professional's work environment is marked by ambivalence. These feelings can lead to suffering at work, as it involves a dichotomy between well-being and psychological illness. Studies in this area have sought to understand the dynamics of established relationships as well as the strategies that professionals adopt to maintain psychic balance. Nurses are professionals who, while undertaking their work activities, experience this duality of feelings that cause both pleasure and suffering [7]. This qualitative study aimed to interpret reports of perceptions and fantasies that permeated the reports of a sample of nurses, considering their task of administering PS to patients with cancer at the end-of-life stage.

2. Participants and Methods

This is humanistic research using the Clinical-Qualitative Method (CQM) described by Turato, applied to clinical-assistance settings, seeking to interpret emotional meanings attributed by individuals to the process of illness, treatment, care, and prevention [8]. The method is developed on three pillars: (1) a Hippocratic clinical attitude of leaning to those who suffer, providing to person an active listening moved by the desire to care; (2) a Kierkegaardian existentialist attitude of valuing vital anguish inherent in the human condition; and (3) a Freudian psychodynamic attitude of valuing the interviewer-interviewee affective relationship, latent in personal interactions, as well as the use of psychodynamic concepts for interpretation of the reported meanings [8,9]. The study was approved by the Research Ethics Committee of the University of Campinas, Brazil.

The study was carried out in an inpatient unit of a large hospital in the city of São Paulo (state of São Paulo, Brazil). All nurses working in the oncology inpatient unit, who provide assistance to

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terminally ill patients using PS, were considered eligible subjects to participate in the research. The data collection technique was the Semi-Directed Interview with Open-ended Questions In-Depth (SDIOQD), conducted in person and individually. The interviews were conducted by the first author of this manuscript, a female nurse. The sample is intentional, with the participation of 11 professionals by the criterion of information saturation - a strategy detailed by Fontanella and colleagues [10].

To interpret the speech excerpts, seeking the unsaid under the discourse of the said, the Seven Steps of the CQCA technique by Faria-Schützer and colleagues [9] was used, taking free-floating readings. Such readings were done in a group - composed of the main researcher and members of the LCQR/UNICAMP - Laboratory of Clinical-Qualitative Research from the University of Campinas, Brazil. The discussion categories were increasingly refined through the steps of the CQCA: 1) Editing material for analysis; 2) Free-floating readings; 3) Construction of the units of analysis; 4) Construction of codes of meaning; 5) General refining of the codes and the Construction of the categories; 6) Interpretative discussion; 7) Validity by research academic peers. These are professionals from different healthcare areas with mastery of Michael Balint's theoretical framework [8, 11]. The strategy of peer validation of the findings has been implemented in meetings of the LCQR group, composed of health professionals with knowledge of British medical psychology [11]. In addition, for the final paper, the checklist of COREQ – Consolidated Criteria for Reporting Qualitative Research was used [12].

3. Results

The study had the participation of 11 nurses working in the care of cancer patients, aged between 29 and 43 years, and predominantly women. All interviewed professionals had experience working with terminal cancer patients, and 10 of the participants had specialization degrees in oncology or hematology. In Table 1 we show the participants' characteristics. Data collection took place between January 2020 and March 2020. The interviews lasted an average of 40 minutes and were recorded fully. After the interviews, observations and self-observations from the interviewer were registered as field notes, such as para-verbal and non-verbal languages.

Table 1. - Sociodemographic characteristics of the interviewees, São Paulo, January-March 2020.

N	Age	Sex	Religion	Undergraduate Degree (in years)	Experience with terminally-ill patients (in years)	Specialization degree
N1	34	W	Evangelical	12	11	Hospital management, Hematology Proficiency, Antineoplastic therapy
N2	43	W	Catholic	14	07	Oncology
N3	35	W	Catholic	11	06	Teaching degree, Pediatric Oncology
N4	26	W	Evangelical	5	05	Oncology
N5	33	W	Spiritist	9	09	Oncology
N6	37	W	None	12	12	Oncology, Psychiatry, Teaching Qualification, MBA in Management
N7	36	W	Catholic	8	08	Oncology
N8	23	M	Catholic	2	02	No specialization degree
N9	25	W	Catholic	4	04	Oncology
N10	38	W	Spiritist	8	08	Oncology, Hematology Proficiency
N11	29	W	Evangelical	15	11	Oncology, Hematology Proficiency, Management

The categories constructed through CQCA, validated by the research group, and selected for this manuscript are the following: (1) To symbolically serve death on a tray. Even if the objectives of sedation are clear, for the informants, the feeling of responsibility for the possible shortening of life remains; (2) The act of sedation and its unfortunate coincidences. Ambiguity seemed characteristically embedded in the interviewees' feelings, such as the feeling of providing quality at the end-of-

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life and possible questions about guilt when the patient dies, coinciding with the moment of administration of sedation; (3) Palliative Sedation as an agent of mercy death. There is certain comfort generated for oneself, a sense of well-being when professionals see themselves as providing a dignified and good death, through palliative sedation, reflected in the attitudes of family members and the very patients.

3.1. To symbolically serve death on a tray

Carrying a tray is a strong symbolic act. The nurse's tray comprises the concrete (the medication) and the abstract (the provision of care and dignity). We objectively see the tray as an auxiliary instrument used by nursing, which serves to support and transport materials, devices, and medications that allow for various procedures. When preparing a tray, nurses do it so with the purpose of transporting the necessary resources aimed to improve the current conditions of the patient. Detaching oneself from the object, the object, and the act symbolize the provision of human dignity.

"It's a responsibility. You're providing a denouement to that patient. Both for this and for the end-of-life process itself. That's the moment. Not that it's decisive, but it's the moment that will change the scenario." N7

[…] "so, when I entered [the room]… She was already aware of her fate, it was kind of traumatizing. And the moment I went to administer [the sedation], everyone started praying. The Lord's Prayer…". N2

[…] "but then you walk in and it's like you're getting there and… I can't explain it to you. They notice [it] and you… You realize the suffering, 'cause you're getting there with the Midazolam solution, morphine, you know… knowing that the patient will have their level of consciousness lowered, they will no longer respond to them, you know." N11

We found in the reports that the manifest act of bringing sedation to the terminal patient on a tray leads to ambivalence about the certainties of the ideas already pre-established by the professional. Thus, there can be conflicts between the fantasies of providing healing and comfort for life, and also for death with the purpose of anticipating it. Imaginations that run in the professionals' minds define their sensation in consciousness and the feelings that arouse at the moment of complying with the prescription. The respondents reported administering palliative sedation with a feeling of bringing comfort and did not mention providing death. But they mention that, in their mind, palliative sedation in the process of death would represent an offer of care. Death would then come as a contradiction, as well as a consequence of the disease, and not of PS. This scenario also encompassed reports with fantasies about the relationship between temporal proximity, administering the patient's sedation and death. They report with deep anguish the association between the act of administering sedation and the anticipation of the moment of death.

Little elaborated imaginations, with manifest anguish that arise at the time of the sedation procedure, accompanied by underlying doubts, are defensive mechanisms between the implicit and explicit psychic material, 'slipping' into the professional's thinking. Some elements emerge, such as observation of patients in their potential self-perception and the reality of the facts; the emotional and behavioral reaction of family members; the imagination of the decision-making conditions on the part of the physician in charge or the team. This great mental game fluctuates from events to symbols generated in consciousness. Psychoanalysis considers that symbols unclasped from phenomena return from the (unconscious) psyche to the (conscious) subjects, organizing them and structuring them in the thinking and the action of their lives.

3.2. The act of sedation and its unfortunate coincidences

The nursing professional takes the material and emotional burden during the PS administration process, even considering the procedure necessary for the clinical evolution of the cancer patient. Participants' reports suggested certain embedded preoccupations that PS could hasten death, to which they attributed a double meaning. Even if there was this — unintentional — outcome, the experienced suffering would justify death.

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[…] "he wanted to die and kept asking to increase the sedation. So, for me it was a very borderline situation, what was a palliative sedation and what was not… if it wasn't a loss of consciousness from euthanasia… it caused me a lot of discomfort." N10

[…] "he progressed badly and the procedure is to administer sedation. Then you go and do it. It's a feeling of anguish, you go there and finish the job, you help to finish it." N4

"Sometimes there's not enough time for the patient to go through the whole acceptance process; and when you get there the patient is very ill. You go and start administering sedation and the patient immediately dies." N6

"Family members often link the medications (sedation) with the end-of-life as if that's really going to kill the patient, so when I prepare it, I get ready to enter the room, answer the questions, and welcome the anguish." N9

[…] "sometimes you correlate it with a case of sedation in the family. I've had colleagues who had experienced sedation in the family and, in this case, [the professional] was paralyzed, unable to perform this function. But due to personal experiences, I think there's also the influence of this block…". N7

The suffering experienced by the patient would justify death from the PS method, as the objective of this intervention is to alleviate suffering with death, considering that it would happen anyway. Thus, the administration of PS would be justified to the extent that this procedure is conceived as the only way to manage the patient's refractory symptoms. The greater the need to justify the practice of sedation, the greater the risk of developing emotional distress. The nurses reported concerns about the optimal or appropriate depth and frequency of palliative sedation.

3.3. Palliative Sedation as an agent of mercy death

It is understandable that, from the perspective of the professional who administers the PS, there is a need for courage, compassion, communication, skill, and support. The perception and opinions of the nursing team about the administration and use of PS can affect the way they perform their functions in the care provided to patients.

"To take the pain away, the patient's pain. The suffering. To ease the suffering. 'Cause that's usually what happens when you see them with respiratory failure, you see them in discomfort and you put them under sedation and you realize there's a sense of help: I'm helping to alleviate their suffering at that moment." N1

"Well, I think of it more as a comfort measure. In fact, I feel relieved when I see a symptomatic patient and sedation is administered, 'cause I know it will be a comfort measure." N4

[…] "sedation decreases suffering, especially in patients in agony or even in respiratory failure that the patient is going through at that moment., " N5

The speeches highlight a point of view in which the nurse who administers the PS ends up becoming an agent of mercy death or dignified death. They feel that they have contributed to the well-being of patients, family members, and the very healthcare team. There are reports that palliative sedation met the purpose of care and was seen as the last resort to provide comfort for patients with refractory suffering, as it offered quality and dignity in the last days of life. The emotionally beneficial action of this procedure can be inferred, as it enabled a serene death, comforted family members, and provided a sense of a dignified ending after a long period of suffering.

4. Discussion

Nursing professionals are involved in administering PS because they are the ones who prepare sedative drugs and control the level of sedation. They spend more time with the patient and their family members than the medical team. They may have unique insights and attitudes regarding the practice of palliative sedation [14, 15]. With our interpretation, we understand strong ambiguous feelings while undergoing this activity, corroborating the literature. Palliative sedation is a peculiar moment; therefore, there are strict criteria for this procedure [16]. PS can generate ethical and interpersonal conflicts in the daily life of the healthcare team responsible for terminal care, in such a way

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that choosing to do so implies decision-making not only in terms of ethics but also of axiology [17, 18].

This study suggests a set of feelings that are aroused in different situations. We interpreted that the undergone experiences change the feelings and perceptions of professionals. This finding is in line with the theorizing of Turato [8] when mentioning that people in the process of the health-illness experience begin perceiving the phenomena, organizing their ways of life, and establishing relationships according to new meanings they attributed to their own experience. To symbolically serve death on a tray is that moment that precedes the administration of PS. It evokes thoughts that involve both explicit and implicit dimensions, that is, issues that range from the clinical decision-making attitude of the healthcare team to the conduct of patients and their families. As a continuous source of experiences, the PS administration leaves its traces on the experiences of nursing professionals. Death has different meanings within the healthcare team, given that perceptions of loss are idiosyncratic. Perceptions are differently modulated, according to the personal identities and circumstances of involvement with the patient [17].

At this time, personal questions about the process of dying and the phenomenon of death also intensify. Clinical death results from serious damage caused by the disease and not necessarily from the actual administration of PS. However, there are professionals who report this practice as offering death instead of care and comfort. The historically and socially established idea that nurses' practices are aimed at "serving life" contrasts with the reality of PS. This procedure would presuppose that the action is aimed at "serving death'. The PS moment raises peculiar emotional reactions in nurses, as it puts them in contact with an inevitable reality [18].

The terminal condition using PS comes associated with ambiguous feelings in nurses, especially feelings of guilt and responsibility. It is known that when the sick person's approaches death and the suffering intensifies, the anguish experienced by family members and close people, including members of the healthcare team, also intensifies [17,18,19]. The concern with the affective states of cancer patients at the end of life was contemplated in a study conducted by Baczewska et al. [20]. Their research analyzed in depth the mood-based hope for the healing of cancer patients aged 18 to 90 years in an active dying process. Respondents with a strong hope of remission demonstrated hoping for a miracle and denied their clinical status. The little or no hope of patients with a sad mood is naturally considered a risk factor for depression. Both psychological states are challenging for the healthcare team, especially in palliative care. The rational and objective explanation provided by the nurses themselves regarding the phenomenon investigated in the present study becomes a tool to tackle the anguish experienced during this professional practice [21].

5. Conclusions

Administering PS in patients with terminal cancer remains a complex issue, which requires careful consideration from the perspective of mental health, inherent in the oncology nurse's role. The reports here studied indicated that the nurses' perception of PS symbolized the process of dying as more comfortable for patients and family members. Professionals should not be afraid of their mental fantasies, even if they are negative and persecutory content. They can confront them with therapeutic demands, even if they do not have a clear perception of this mental phenomenon. The scenes represented in their consciousness, even if rudimentary, make sense as a comprehensible defense for the ego structure.

Openly talking with colleagues, supervisors, and mental health professionals can help to discriminate the limits of nurses' personal beliefs, their cultural and religious values, and the social and institutional context in which they work. We point out that nurses understand the importance of palliative sedation to relieve the suffering of terminal cancer patients and help them die with dignity, even if it is a rationalization mental mechanism. Education and training programs for healthcare professionals on ethical and practical issues related to the use of palliative sedation in patients with terminal cancer should include psychological support meetings. Open communication and collaboration between healthcare professionals, patients, and their families to ensure the use of palliative sedation remains a necessary means such as informed consent and shared decision-making. We suggest

further qualitative studies to deepen the symbolic training, in this context of PS, now with the medical team and family members.

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