RESUMO


Descritores: Doente Terminal; Bioética; Enfermagem.

ORIGINAL ARTICLE

TERMINAL ILL: THE ETHICS OF CARE IN THE LAST PROCESS OF LIFE DOENTE TERMINAL: A ÉTICA DO CUIDADO NO ÚLTIMO PROCESSO DA VIDA

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ABSTRACT

Objective: to identify the ethical-care conduct of nurses in the care of terminally ill. Method: exploratory-descriptive study, with qualitative approach, carried out at the Medical Clinic I, Medical Clinic Unit II and the Adult Intensive Care Unit of a teaching-hospital in Rio Grande do Sul/RS, with ten nurses. As an instrument of data collection, the vignette technique was used. For data analysis, Content Analysis was used. The research project got approval of the Research Ethics Committee, Opinion 0137.0.243.000-07. Results: the results show that some nurses would suspend and others would neither infuse the medication after the confirmation of the diagnosis, existing a difficulty in analyzing and considering the medical request in relation to that conduct. Conclusion: terminal patient care is a challenge to health professionals, especially doctors and nurses, because they are providing daily care.

Descritors: Terminal Ill; Bioethics; Nursing.
INTRODUCTION

Nursing professionals have an essential role in the care of human beings in different contexts and health, including the time of death. Thus, there must be a constant concern in assisting the terminally ill, as this phase can be terribly difficult for the patient and for family/caregivers, because it generates a range of sufferings and special needs that require technical, ethical and psychological preparation to promote care in order to provide an worthy life end, based on the principles of humane care and professional ethics.

In the care process, the nurse identifies customers as patients who are dying as well as their families and other significant people, however, some health professionals experience intense difficulty dealing with death, since it is seen as a depersonalized and unpleasant fact. It is perceived as an event that disturbs and challenges the human omnipotence, because health professionals are taught to take care of life but not death. Thus, there is an attempt to postpone death through excessive and incessant use of technologies.

Many patients are admitted in hospital institutions without improvement perspectives. Several of these, in terminal phase of a specific pathology, require specific care demands that inevitably, coexist with multiple issues related to death and personal, ethical, legal and professional implications that this situation causes. This fact raises the health team to seek knowledge about the subject and form their critical judgment about the factors involved in the situation of dying and death in the hospital environment.

Professionals should adopt respectful ethical attitudes and recognizers of its limits. Thus, discussing ethics in the end of life is especially important in conduct definitions, since bioethics clinic or decision, analyzes, in the real scope of medical practice and clinical case, what are the involved values, and among possible alternatives, which are appropriate paths to establish a conduit without changing these values. In these cases, to choose, or not, by a principle or to use pre-defined criteria for judging will determine the evaluation of the case and the possibilities of intervention.

There are three decision-making attitudes in terminal stage of life: euthanasia, which aims to accelerate the death to mitigate the suffering of the patient; dysthanasia, which, through multiple therapeutic interventions, prolongs the suffering in order to maintain the biological life of the terminally ill; and orthothanasia, enjoying life support with the use of only ordinary measures to relieve pain, provide family presence and spiritual care.

Arises the need of research, in order to assist in the discussions and the development of a body of own knowledge about the process of death and patient dying, to provide moments of reflection regarding the conduct and ethical dilemmas triggered by this process. Thus, we question << Which ethical-care conduct of nurses to perform the care to terminally ill? >>. In order to answer the question and in expectation of possible interactive and engaged views with the human being in the death and dying process, the objective is to identify the ethical-care conduct of nurses in the care for the terminally ill.

METHOD

Descriptive and exploratory study with a qualitative approach, it aims to provide an overview about a situation that can be considered as the first step of a broader research, since, due to its results, can be organized strategic action plans and thus, the search can contribute to change the investigated reality.

The survey was conducted in a teaching-hospital, located in the state of Rio Grande do Sul, in Clinical Medicine Unit I, Medical Clinic Unit II and Intensive Care Unit (ICU) Adult. The choice of these scenarios for the research occurred because these Units account for a considerable number of patients in the terminal stage.

The subjects of this investigation were ten nurses working in these scenarios, since they are responsible for the implementation of direct care to terminal patient. It is noteworthy that the choice of the sample was by raffle so that there was a representative of each local under consideration. As inclusion criteria were established: working in the units described by at least, two years, as it is believed to be a period of time required for nurses to acquire, from practical experience, a more comprehensive contact with the terminally ill.

Data were collected through the vignette technique in the period September-December 2007, after the authorization of the Research Ethics Committee of the Federal University of Rio Grande/UFRS, CAAE 0137.0.243.000-07. The vignette technique is characterized as a brief description of events or situations in which respondents are asked to respond. Descriptions can be fictional or real, but they are always structured to elucidate information about the perceptions, opinions or knowledge.
Silva KCO, Nietsche EA, Ilha S et al.

of the respondents about some studied phenomenon. The instrument for data collection included two questions that started from the explanation of the vignette, which asked the nurse if they could imagine the following situation: “A patient admitted into the unit in which you work, has indication not to be resuscitated in the event of cardiorespiratory arrest. He is receiving Noradrenaline intravenously in a continuous infusion pump to keep his blood pressure at levels compatible with life. Aware of the terminal situation, the attending physician requests to suspend the administration of this medication, even knowing this procedure will result in patient death”. Thus explained, we asked the nurses: what is your attitude towards the situation? How do you analyze ethically, the request of the doctor?

Data were collected individually, in the conference room of each Unit, from prior appointment with the nurses. The data were stored in digital recorder-type mp3 player and then transcribed in order to maintain the integrity of speech and privacy of individuals. The process of data analysis, along with discussion and interpretation of these, was guided by the technique of Content Analysis, which is composed of three parts: the first consists of a frequency with identification of the main participants’ perceptions; the second analyzes the content that identifies the categories that emerged from the collected data; and the third refers to the interpretation of the categories.

The ethical and legal issues involving research with human beings were considered, according to Resolution 196/96 of the National Health Council. Thus, it was previously distributed the Informed Consent Form (ICF) for the study participants, in two ways, one held by the participant and the other held by the researcher. The anonymity of the respondents was maintained and they were identified by the letter “N” (Nurse), followed by a numerical digit, according to the order of the interview (N1, N2, N3 ...).

RESULTS

Starting from the vignette that raised the performance of nurses before the request of disconnection of a medication to speed the death of a terminally ill patient, four categories emerged, namely: attitudes of nurses in relation to the act of disconnecting or not medication support after the diagnosis confirmation; nurses do not turn off the medication; ethical awareness in the care process is critical; discontinuation of medication is ethically correct.

- Attitudes of nurses in relation to the act of turning off or not medication support after confirmation of the diagnosis

After considering the issues contained in the hypothetical situation, some professionals mentioned that would suspend the infusion of the medicament since the diagnosis was correct. The following statements:

Knowing that the patient is no longer able, that is irreversible, and if has a more advanced age, something that we are watching on the day, we note it would not be back, I am not afraid to disconnect. (N4)

I suspend. The patient is terminal and I think it’s even a question of humanity. Staying with Norepinephrine prolonging the patient just to have an adequate blood pressure, just to have a little more life is incoherent. (N8)

I saw that the patient is in the final stage, the diagnosis has already done, already sure [...], I turn off. (N7)

In the reports, it is possible to observe that some nurses seek unambiguous information before performing the procedure. It was also commented about the decision to turn off the infusion of medication not to prolong the process of dying, even considering this act a matter of humanity.

- The nurses do not turn off the medication

Other nurses said they do not stop the medication or do not feel holders of “courage” to do it. There is even a wait for another colleague to turn off, as a way not to blame for anticipating the death of patients under their care. This is expressed in the statements below:

I end up wanting a little longer to see if it will actually be necessary. If the doctor would not being present there, I would wait till the end of my shift. And would say: is to suspend. But I would not suspend it. (N3)

I think I would not have courage to do. Because if you’re going there and turn off, in fact it’s you who is undergoing to it there. (N9)

In the speeches, it is clear that respondents nurses do not feel comfortable with the situation of turning off the medication. It is observed also, a sub alternate of nurses in relation to the medical profession, since one of the lines in the nurse says that in the doctor’s absence, he did not turn off the medication.

- Ethical awareness in the care process is critical

This category deals with the analysis of the application of the physician based on the
following question: “How do you ethically analyze the request of the doctor?” It is worth mentioning that before delivering the answer to the question, all the nurses said it is very complex considering the request of the physician, it is extremely difficult to take a position in these situations, thus expressed:

[...] It depends a lot on the point of view of each. I think anyone who asks you to remove, is seeing the situation for the colder side, is not involved. [...] It is very difficult to judge, to assess. (N1)
[...] It’s hard to argue ethics. Because you see so much ... Euthanasia, dysthanasia [...]. And ethics is both medical and nursing. I think you have to know why. (N6)
[...] I can not tell if it’s right or wrong. Because each situation is one. (N5)
[...] I do not know. [...] But I think it is unethical, should become ethical. (N8)

In the statements above, it is evident that there is a difficulty in analyzing and considering the medical request in relation to the conduct of turning off medication support, furthermore, it is difficult to address the ethical issue in this procedure due to the large number of values objective and subjective in matters of life and death.

- The discontinuation of medication is ethically correct

Some nurses consider to be prudent and/or ethically correct the suspension of the medication since it is determined from the evaluation of the case and a consensus among the staff as exemplify this concept:

[...] Since it is not a single person who thinks that the patient is terminal. [...] It is a consensus, I do not think is unethical. In up to certain episodes, I think even a very human attitude. (N4)
[...] I think ethically prudent. [...] It is not causing a cardiac arrest, is just taking a medication that is a supplement to maintain it. (N7)
[...] This case is not euthanasia [...]. It’s different. But these issues of keeping futile supportive measures to prolong life and suffering, I disagree. (N8)

At this point, the nurses agree with the interruption of medication that keeps the patient alive in order not to prolong his suffering, thus avoiding dysthanasia. It is important to emphasize the need for a consensus among professionals of the healthcare team to determine diagnosis. However, it should be noted that this consensus should extend to family members or legal guardians by the patient so that they can participate in decisions and behaviors involving the process dying of the loved one.

DISCUSSION

Terminal ill: the ethics of care in the...

From the moment in which the patient is considered terminal, staff should offer comfort and relief to their suffering observing ethical and moral commitment to maintain emotional support and procedures that seek not mischief, at the detriment of those who can go against such goal. That is, the team should be aware that the terminal patient needs only palliative therapy, it is not appropriate to adopt extraordinary measures to postpone the process of dying.

One of the premises of palliative care is to help people die with dignity, which demands a holistic care. However, it is important to remember and emphasize that the manipulation of the individual and the family with the knowledge of their disease state and possible prospects, in addition to their participatory role in decision-making, are fundamental attributes. The participation of patients and their families in decisions must be tempered by the interdisciplinary team considering advantages and disadvantages of treatment.

A survey called “Consensus report on the ethics of forgoing life-sustaining treatments in the critically ill”, held with doctors and nurses, such as Americans, found that the living wills of patients, the premorbid cognitive function, and the possibility of survival long-term reasons are very important in making medical decisions and family about the terminally of ill patient.

Addressing this issue, a survey is cited about conducts of the terminal patient, conducted between ICU professionals in the United States, which showed that about 90% of the professionals have employed non-adoption conducts and/or removal of life support measures during their professional activity. But these professionals, 26% felt more uncomfortable with the removal of the measures than the non-adoption of these.

At the same time, a study about the suppression of life support measures, also developed in the United States, showed that not administer or remove vasopressors drugs, is the first conduct to prevent unnecessary measures to the patient that is dying. This fact is justified because the team consider this medium as being more human and aim to take care of this type of patient. Therefore, the request from the doctor is clear.

In attempting to explain why the difficulty of analyzing the medical ethical attitudes, states that if a universal ethics existed, there would also be impossible difficulties to overcome, since there are a large number of objective and subjective values present in
matters of life and death. In other words, each case is designed, evaluated and discussed in a distinct manner.

It is worth addressing the Brazilian Code of Medical Ethics, dated 1998, which points out in Article 7 that, the physician must maintain absolute respect for human life, always working for the benefit of the patient. They will never use their knowledge to generate physical or moral suffering, to kill humans or allow or cover up the attacks to their dignity and integrity.

When there are doubts about the decision taken by the doctor, this, in any way, must be ethically grounded. However, there is an influence by previous factors, such as the life story of the doctor and the fear of the disease and its social consequences.

According to the nurses, the ethical analysis of the medical application to disconnect the infusion of medication that keep the patient alive, is extremely complex, especially when there is no proper knowledge about the professional Code of Ethics, whether doctors or nurses. It is worth to address the Nursing Code of Ethics of Rio Grande do Sul, which points out in its Article 29 as: prohibiting the act of promoting euthanasia or participate in practice designed to anticipate the death of the client.

Also agreeing with the words of nurses, as been diagnosed with the terminal condition, efforts should be directed to the comfort, reduction of suffering and not prolonging the patient's life. Therefore, this position is the opposite way to promote death, as in the case of euthanasia, cited by one of the nurses.

As to the participation of the staff to reach a consensus in decision making, this fact is relevant, since there are cases where there is a risk of medical unilaterality to the patient and their family with their own values, including injuring the ethical principle of beneficence, as hanging a vital measure in a still healthy patient. Thus, it is evident that an interdisciplinary approach to patient care and the quality of care is needed.

The interruption of measures considered futile [...] can only be considered after a consensus (not just a person or a segment of the team) that the patient is in the process of inevitable death. Even so, it is recommended to be suspended, initially, futile measures and that will not cause death by suspension.

It becomes relevant, both to hospitals institutions as class organs, encourage and/or create spaces for discussion and study, in which experiences can be shared as a way to minimize the consequences of dealing daily with the process of death/dying and have at the same time another human being as an object of study.

It should be emphasized that all the nurses said they had never experienced such a situation, i.e., no doctor requested to remove a support medication, explicitly or implicitly, to rash the patient's death. Such an attitude can be considered of immense ethical, moral and human value by the medical profession and the health care team in general.

CONCLUSION

After analyzing the results of this study, it was observed how complex is the context referring to terminally ill patients admitted to hospitals. The end of life involves personal issues, professional, practical, theoretical, social and bioethical that make it extremely wearing the care of who is dying.

In summary, the terminal patient care is a challenge for health professionals, especially doctors and nurses, as they are routinely providing care to this patient. The study about the impending death and all the implications that this event carries, requires of the healthcare professional to understand that, as a human being, is also finite. Therefore, as this research aimed at providing reflections about the care of terminally ill patients, proposes the elaboration of new studies concerning to the issue, since it is a complex and with difficult issues to be addressed.

Thus, there was the need to properly work the issues relating to terminally life since the beginning of undergraduate courses to prepare professionals to manage these situations, since research shows that professionals do not have or have in the graduation, little workload allocated to themes about death, dying patient and palliative care.

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Terminal ill: the ethics of care in the...