

Perception of nurses about ethical dilemmas related to terminal patients in intensive care units

PERCEPÇÃO DE ENFERMEIROS SOBRE DILEMAS ÉTICOS RELACIONADOS A PACIENTES TERMINAIS EM UNIDADES DE TERAPIA INTENSIVA

PERCEPCIÓN DE ENFERMEROS SOBRE DILEMAS ÉTICOS RELACIONADOS A PACIENTES TERMINALES EN UNIDADES DE TERAPIA INTENSIVA

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ABSTRACT

The purpose of this study was to learn about nurses' perception about ethical dilemmas in nursing care for terminal patients in the context of a general hospital ICU in the city of São Paulo, and what they take into account when making decisions. The study was performed through interviews with ten nurses working at the ICU, using a qualitative approach based on content analysis. Ethical dilemmas were found to be linked to: diversity of values; presence of terminal patients at the ICU; uncertainties about terminality and the limits of intervention to prolong the patients' lives; disagreements in decision-making; non-acceptance of the process of dying by the patients' families and the lack of clarifications for the patient and the family. In addition, the nurses consider their values, the professional ethics, empathy and dialogue with co-workers to make decisions in view of such ethical dilemmas.

KEY WORDS

Intensive Care Units.
Ethics.
Terminally ill.
Nursing.

RESUMO

O presente estudo teve por objetivos conhecer a percepção de enfermeiros sobre dilemas éticos existentes na assistência de enfermagem a pacientes terminais, no contexto da UTI de um hospital geral do município de São Paulo e o que é considerado para a tomada de decisão. O estudo foi realizado através de entrevistas com dez enfermeiros atuantes na UTI, utilizando uma abordagem qualitativa, conforme a análise de conteúdo. Foram encontrados dilemas éticos ligados a: diversidade de valores; presença dos pacientes terminais na UTI; incertezas sobre a terminalidade e limites de intervenção para prolongar a vida dos pacientes; discordância de tomadas de decisão; não aceitação do processo de morte pela família do paciente e a falta de esclarecimento da família e do paciente. Além disso, para tomar decisão frente aos dilemas éticos, ele considera os seus valores, a ética profissional, a empatia e o diálogo com os colegas.

DESCRITORES

Unidades de Terapia Intensiva.
Ética.
Doente terminal.
Enfermagem.

RESUMEN

El presente estudio tuvo como objetivos conocer la percepción de enfermeros sobre dilemas éticos existentes en la asistencia de enfermería a pacientes terminales en el contexto de la UTI de un hospital de São Paulo y lo que se considera como la toma de decisiones. El estudio fue realizado desde una perspectiva cualitativa, utilizando el análisis de contenidos. Fueron entrevistados diez enfermeros actuantes en la UTI. El estudio mostró que los enfermeros encuentran dilemas éticos generados por diversos factores: diversidad de valores; presencia de los pacientes terminales en la UTI; incertidumbre generada a raíz de la condición terminal; los límites de intervención para prolongar la vida; discordancia en la toma de decisiones; resistencia para aceptar el proceso de muerte por parte de la familia y la falta de esclarecimiento de la familia y de los pacientes. Además, sus valores, la ética profesional, la empatía y el diálogo son tenidos en cuenta para tomar decisiones.

DESCRIPTORES

Unidades de Terapia Intensiva.
Ética.
Enfermo terminal.
Enfermería

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INTRODUCTION

The end of life is something inherent to all human beings, and, currently, the care for terminal life has become significant in our society, in the health area, and especially, in medicine⁽¹⁾. These issues are founded on the curative tendency of treatments, population aging, market trends, cultural stress, *medicine-oriented* life, human improvement, and the scientific and technological progress that sets the context of the origin of the factors composing this discussion⁽²⁾.

The causes include the scientific and technological progress that contributes for the growing improvements regarding the use of life support resources. In many countries, these technologies and their availability have shown new forms of treatment and hope for dealing with many problems and making it possible to extend life limits.

Therefore, hospitals have become privileged sites for the development of these technologies and, as of the 1950's, have gone through a qualitative leap, following the progress of human kind. In order to facilitate diagnosis and treatments, there has been an increase in the number of admittances to hospitals and among admitted patients, there were those who required more specific care, due to their critical condition and the life support measures employed. These life support measures (technologies) have constantly required more qualified labor and have originated the Intensive Care Units (ICUs). According to the Department of Health, ICUs:

Are hospital units aimed at caring for critical or risk patients, providing continuous medical and nursing care, with specific equipment, specialized human resources, and holding access to other technologies aimed at diagnosis and therapy⁽³⁾.

This definition shows that the features of this unit include the complexity of the services provided and the use of technologies that may, in cases, evidence intervention and curative features within their environment. These models hold the adoption of measures that often do not permit to provide care under all its aspects.

It is necessary to rescue, under a broader format, the value of the care that is provided, since it was set as secondary against the search for the cure of diseases⁽²⁾, and, under a broader sense, covers human, spiritual and social aspects. This attention is necessary to patient's rehabilitation, so that they may live with their limitations, in other words, even when there is no therapeutic possibilities of clinical cure, they may hold their human condition and be socially active, not only biologically.

Dignified and humanized care, apart from mastering the technology used with ICU patients, holds other features⁽⁴⁾:

[...] taking care is more than an action or moment of attention, warmth and zeal. It is an attitude. And attitude, in this situation, refers to the source that generates many actions

that express concern, responsibility and the attachment with the other. Taking care, therefore, features an attitude that may bring sensitivity to a human experience, recognizing the other as a person and individual [...]

This acknowledgment and sensitivity with the other should permeate the actions of every health care professional toward ICU patients, since they hold a fragile physical condition and are usually emotionally and spiritually sensitized. Among ICU patients, there is a distinctive group of patients characterized by the use of many technological resources, however holding discouraging results, since at some point of their disease evolution, saving them is no longer a possibility, and death is inevitable⁽⁵⁾ - a feature of terminal patients, who are afflicted by a difficultly treated disease, by a compound of situations where therapeutic possibilities of achieving cure or prolonging life with dignity is exhausted and, when there is irreversible disorders of the central nervous system⁽⁶⁾. In addition, it is the compound of conditions and situations that lead physicians to consider patients as terminal. It is also considered that defining a terminal patient is no easy task, and that even the expression *terminal* is complex since it is not precise. The difficulty lays on determining when patients present two features: incurability and therapeutic failure of medical resources⁽⁵⁾.

Part of this difficulty is due to the scientific advances that improved the knowledge on disease and cure mechanisms, however, the technological apparatus found in ICUs reveal ethical dilemmas that may be related to the limits of therapeutic actions and the value plurality of the people involved. Ethical dilemmas exist everywhere health professionals work and are situations that involve two alternatives regarding the treatment or conduction of a case, technically justified, however liable to moral and social questionings⁽⁷⁾. This questioning happens due to a combination of behaviors, habits, values, culture and beliefs expressed by human beings in the society⁽⁴⁾.

When these issues involve life relationships, they can be qualified as pertaining to Bioethics⁽⁸⁾.

[...] the systematic study of moral dimensions, including the vision, decision, conduct, and norms of health and life sciences, using a variety of ethical methodologies under an interdisciplinary context⁽⁹⁾.

One of the main bioethics issues within ICUs is related to life support and the care for terminal patients. People who are dying need to be treated with dignity and integrity, in other words, they must be assured the right to a dignified death, receiving continuous care and their autonomy must be respected. In order for this to occur, it is necessary for professionals to respect principles such as justice, beneficence, non-maleficance and autonomy in providing care⁽²⁾.

These principles are found by many authors that have mentioned the Hospice philosophy, aiming at providing dig-

nified care to terminal patients. *Hospices* originate from the 4th century of the Christian era with the care for the needy; where *hospitium* was the place where those actions were provided. The first *hospice* was founded in 1842 in Lyon, France and it served *dying men*. Later, other *hospices* were founded in Ireland (1846) and England (1885). Finally, in 1967, through Cecily Saunders, the *St. Christopher Hospice* was opened in South London, which brought the main characteristics of palliative care: pain management, the acceptance of death as a natural process of life, care to the patients' psychological, social and spiritual needs, and controlling the individual's organic disorder symptoms⁽¹⁰⁾.

Palliative care is part of nursing care, and terminal patients require specific knowledge from the nurse concerning the following: dealing with pain, analgesic administration, common clinical symptoms of the final phase of many diseases, patient communication, and also the ability to work as a team, reading and studying articles and books on the subject and also the reflection on the meaning of death and terminality⁽¹¹⁾. Therefore, the specific nursing care to terminal patients within ICUs is a competence of the nurse, including making care-related decisions and participating in the interventions performed on these patients.

These decision-making actions are filled [...] with situations that require a detailed analysis of the socio-cultural context [...], with a view to the complex process of technical or ethical decision-making⁽¹²⁾ and based on abilities, in addition to theoretical knowledge (associated to previous experiences), professionalism, autonomy, personal values, information processing, trust, self-esteem, beliefs, and susceptibility to take risks⁽¹³⁾.

Nurses consider values such as honesty, self-control, responsibility, tolerance, understanding, solidarity, and condescension when making decisions; which shows the influence of the historical foundations of the profession, the predominance of female values and the need for social, personal and professional acknowledgment⁽¹⁴⁾.

Not only nurses but every professional needs the knowledge of the decision-making process elements, its discussion with the involved parties, the evaluation of circumstances, values, risks and probable results, since they are directly involved in the care provided to terminal patients⁽¹⁵⁾ and connected to all dilemmas generated by these factors.

OBJECTIVES

Learn about nurses' perception on existing ethical dilemmas concerning nursing care to terminal ICU patients at a general hospital in the city of São Paulo and the elements nurses take into consideration when making decisions in view of ethical dilemmas.

METHOD

Study Location

The study was performed with nurses of a general adult ICU in a large private hospital in the city of São Paulo, type II, according to the Department of Health regulation No. 3432, of August 12th 1998⁽³⁾. The unit has 24 beds, receives chronic and acute, multiple-trauma, small or large post-operative clinical patients, including those that been submitted to transplantation, which characterizes it as a specialized ICU unit containing every equipment and conditions established by the regulation.

Study Subjects

The study subjects were nurses working in an ICU setting for at least one year. This time period was established so that the professionals taking part in this study would have experienced situations that might have generated ethical dilemmas. The number of nurses was not pre-established according to the method applied. Ten interviews were performed considering the occurrence of content repetition.

Nurses consider values such as honesty, self-control, responsibility, tolerance, understanding, solidarity, and condescension when making decisions.

Data collection

Data collection was performed after the project received the institution's authorization and approval by the Ethics Committee of the hospital (File #08.05). Data were collected through a previously booked interview with the written permission from the subjects in the Free and Informed Consent Form (including the use of data and of an electronic device to record their statements).

A pilot test was performed with ICU nurses from other institutions, who voluntarily cooperated with the study, with a view to adequate the interview questions and to adjust the parameters of the device.

After completing the pilot test, the first part of the guide for performing the interviews was designed, consisting of characterization questions regarding the subjects, with information pertaining to: gender, education, time in the job, position or function in the ICU, and another part consisting of three guiding questions related to the experience with terminal patients and about what they took into consideration when making decisions involving dilemmas. It is important to state that the interviews performed in the pilot test were not used in the study.

DATA PRESENTATION AND ANALYSIS

In order to achieve the study objectives, the qualitative approach was chosen, since it allows for a better understanding of the guiding questions exposed in the introduction. Content⁽¹⁶⁾ analysis was used with this purpose.

The option was chosen through a method that would enable the unfolding of experiences, beliefs, values and thoughts of the nurses that work with terminal ICU patients, using a methodical technique, composed of sequential steps that, through the study subject's discourse language, hold the prime material to enable its operation.

Thematic analysis was used as a way to find the themes present in the subject's discourses, the register units and the categorization. In order to select the record units, an exhaustive reading was made on the interview discourses, and the units that represented a real meaning responding the proposed objectives for this work were selected. In the categorization, the word semantics criterion was used, with a view to come up with the real meaning of the register units.

The results were treated using content inference and interpretation. Interpretation resumes the theoretical framework to found and justify the study, and supports it for the correct analysis⁽¹⁶⁾.

Through the study of the data obtained in the first part of the questionnaire, it was observed that all study subjects were women, with professional experience of over 4 years in the ICU, perform care functions, and, of all ten nurses, nine hold a postgraduate degree. This shows the studied nurses have specific education and significant experience. This characterization represents an important aspect in terminal patient care, since great preparation is needed for these professionals in terms of adopting comfort measures and controlling clinical and human nature complications⁽¹¹⁾.

In the second part of the questionnaire, the guiding answers permitted to observe that nurses carry many experiences that hold, in their opinion, a dilemmatic sense in terminal patient care.

In order to better understand the results, the meaning units were grouped under two categories: *Ethical dilemmas and other ICU terminal patient care factors and Decision-making facing ethical dilemmas*.

The first category was divided into the following sub-categories: *Dilemma-generating factors, Nursing care interferences over the terminal patient, Considerations about terminality, Feelings related to the terminal patient, and Verification of the therapeutic obstinacy*.

In the first sub-category, *Dilemma-generating factors*, nurses show that their *values and beliefs* conflict with the actions performed on terminal patients. The values of their professional class, their religious principles, the certainty that terminal patients should die in a room surrounded by the family and not in the ICU, the determination itself about when patients become terminal, and the doubt about how much should be invested generate deep personal conflicts and bring out the dilemmatic sense to the situation.

[...] we have our values, our beliefs, it's like, it all causes conflicts and generates dilemmas[...]

These conflicts experienced by nurses, related to beliefs and values, may be associated with personal and social processes currently experienced by human kind, originated from the plurality of values⁽⁴⁾ and the great cultural mix present in our everyday lives.

For the nurses, their *professional responsibility* also brings a dilemmatic sense related to direct terminal patient care, opposing their values. Their professional activity results in dilemmas, since it performs opposing actions to their opinion, however inherent to the profession.

[...] because sometimes there are some patients that arrive at the ICU and you say: *why?* But you also are committed, hold an ethical-legal responsibility to this patient, you say, I can't deny him the care.

Professional ethics appears to be a very strong guiding factor on performing terminal patient care. However, it is a deep personal conflict, since it makes nurses reflect about their conducts, responsibilities and values⁽¹⁷⁾.

The relationships with the terminal patient's family also presents dilemmatic situations, generated by the lack of knowledge on conducts and treatment conditions of a terminal patient and the lack of acceptance of the family on the patient's dying process.

[...] we end up in a dilemma of telling the family or not, since the medical team hasn't closed the prognostic yet, hasn't told the family that there is nothing else that can be done, how can I turn to the family and tell them about it [...]

When there is effective communication among the family, health professionals and patients, it presents important factors for a more humanized care, reducing the risks of a misguided interpretation that would generate conflicts⁽¹⁸⁾.

Nursing care interferences over terminal patients appear to be present in some perspectives. The first is related to the organization of the service, where ICU dynamics not always enables a more specific care, with a deeper interaction among nurses, patients and their families; this occurs because the physical structure of the ICU does not enable a continuous accommodation of the family members.

[...] because we have no accommodation to have a companion for 24 hrs there [...]

In order to maintain good care to these patients, there is scale organization, which covers procedures for pain management, and the improvement of comfort and hygiene. However, isolation is inevitable in the ICU, due to accommodations and pre-established visiting hours, and it also seems that some nurses find it difficult to recognize the patients' conscious response, which may affect care evaluation and management.

[...] you are able to do some things that will benefit the patient, you can add some comfort, sometimes you can even improve analgesia, control the patient's pain a little better, sometimes sedation, [...]

It's complicated, and sometimes, considering the reality of intensive care, you have a patient that does not respond, who is sedated or intubated, presenting multiple disorders and then...you can't really tell if you are really getting where you wanted, what you think would be best for this patient [...]

There is a reference to the difficulty on working with terminality and that it would be important to have a more adequate preparation of the team to deal with patients under this situation, since care will be delivered until the moment the patient dies.

[...] besides the nursing care, there is nothing else that can be done for the patient, the medical care is over, nursing care continues until he dies [...]

Terminal patients require care that goes beyond technical care. It involves cultural, ethical, human, social, spiritual issues and etc. It requires nursing professionals to have much greater preparation related to a care philosophy that will contemplate all these areas, the *Hospice* care⁽¹⁰⁾.

Some *considerations about terminality and feelings related to terminal patients* were pointed out by the nurses, such as the difficulty to work with the death process, dealing with terminal patients, helplessness facing death, the wish for the patient being cured, the family stress, and empathy toward the condition of dying.

[...] there are those patients that you will always remember, you don't forget, even when you want to forget, you don't [...]

[...] because for the family, it is too difficult, to accept that there is nothing else that can be done [...]

Some factors help to accept terminality, such as the patient's old age of patients and giving the best possible care.

[...] when it's an aged person, it seems that it is easier to accept the terminal phase [...]

[...] I stop, think and try to do the best within my power; I always like to do what it is within my power, and what is out of it too [...]

Proximity with the patient's pain and suffering seem to cause an important empathy on nurses for the therapeutic attachment, which provides better nursing care, however, at the same time, there is an emotional stress deeply connected with the difficulty on dealing with terminality.

The nurses' discourses revealed that sometimes physicians perform measures that may prolong suffering and do not bring any benefits to the patient's clinical condition, thus, verifying the *therapeutic obstinacy*.

[...] you are not improving or bringing any relief, no comfort, you are not providing any expectation, no comfort for the patient or for the family, and you still have to keep on doing things [...]

[...] the biggest problem is that sometimes, you see that you are doing something that is completely pointless [...]

The fact that nurses have to perform actions that, according to their judgment, bring no benefits to the patients also generates ethical conflicts. This happens due to the disagreement with the conducts taken by the medical team, which commonly imply on procedures performed by nursing professionals. The evaluation of the patients' clinical condition and the change in their health status may also difficult making decisions regarding the conducts to be performed and increase the occurrence of *dysthanasia*⁽¹⁾.

The second category, *Decision-making facing ethical dilemmas*, is divided into two sub-categories: *factors that influence decision-making and the Decision-making process*.

In the first sub-category, four important factors were identified: *clarifying the family and the patient, nurses and physicians' professional attitude, the referred difficulties, and nurses' principles and values*.

Clarifying patients and their families, according to the nurses, is important for decision-making, which makes it much more legitimate for facing the dilemma.

[...] So, raising their consciousness so that we can talk without trespassing the physician's area, clarifying the family about the patient's condition, in a calm way, not causing too much stress...

The humanization of patient care becomes more successful as more respect is given to the patient's autonomy and the family's participation in discussing the evolution of the clinical status and prognostic conducts.

According to the nurses, their *professional attitude and that of the physicians* should share their dilemmas with a multi professional team with a view to minimize conflicts generated by isolated decisions or by communication problems. The dialog among physicians, family, patients and other professionals should be more frequent, respecting the patients' decision, avoiding the withdrawal resulting from the lack of preparation on dealing with death, assuming an attitude of acceptance and empathy toward patients.

It's like the opinion of each person, there is no such thing as a guidebook telling you which conduct you should take about this. Something like, questioning, discussing the issue, would be one of the ways, [...]

Nurses also refer to some *difficulties* regarding making decisions. They are related to the conflict of opinions among the multi-professional teams, the lack of case discussion with the nurses, the attachment with terminal patients and the fact that they have to deal with the family.

[...] I think that one of these dilemmas would be, therefore, the divergent cases conduction, according to each team's thoughts. So, I believe that for the nursing team, it is a situation that causes some of the dilemmas.

The values and principles are used as factors in the decision-making process, which have been identified as logical thinking, principles, reflexive process, and religious faith.

[...] I search a lot... I'm religious, so I always turn to my faith, I think there is a God for sure, every path is His and it is that moment for that person and you have to accept it.

These values, may, sometimes, help or make things difficult for nurses in the decision-making process due to the internal conflicts generated by cultural and social differences, among which family members, patients and other professionals stand⁽¹⁴⁾.

In the second sub-category, the *decision-making process*, four agents were found: *the patient, the family, the medical team, and the nurses*.

Through nurses' discourse, we observed that the family participation is important and may be successful in the decision process.

[...] the patient may be considered a terminal patient, but he does not see himself as one, so he first needs to see himself that way and see what he wants, also what the family wants in this sense and then what would be desirable, the ideal thing, one thing that is always not well developed, patient, family, care team [...]

But the process is made difficult due to the attachment feeling and the difficulty to deal with death.

Well, I've seen cases when the family... respected, they didn't want him to suffer more, so they let go, but I also saw cases that they didn't accept it. The family decided they wanted the team to do everything that could be done, this, this, this, even if it meant extending life for one month or two, but they required the team to do it [...]

The patient's wish must be fundamentally respected, however his autonomy may be ceased by invasive measures of clinical support, by his own family or by physicians.

[...] Because we see that the family ends up deciding a lot, they say they want the patient to be intubated, they want everything to be done, they want his life to be prolonged, and this is just what the family wants; most of the times, the patient doesn't say much about it [...]

Preserving the patient's autonomy is fundamental to maintain the basic principles of bioethics that support the discussions generated by human life conditions throughout the life cycle, mainly through the death process⁽⁸⁾.

The nurses mentioned that most of the times the physicians' decisions disregard those of other professionals and they are not always linked to the family and the patient.

[...] decision-making usually comes from the physicians and the assistant medical team.

[...] so when the physician sees that there is no therapeutic possibility, he sits with the family, discuss it with the family, talks about the whole severity of the case and explains the paths that would be taken. And they decide together, as a group, therefore the nursing team has no active participation, [...]

And the participation of nurses in the decision-making process is not effective, however they are directly impacted by it and use, among other factors, empathy and informal dialog with other nurses to make their decisions when facing dilemmas.

[...] I think that, in my opinion, you have to make this decision yourself, you have to be aware that you cannot have this type of dilemma, you have to be, I think, that way, that you always have to put yourself in this persons shoes, how would it be.[...]

[...] we discuss among ourselves. But there is no such a thing as another professional, someone that will lead [...]

FINAL CONSIDERATIONS

Through the results it was possible to verify that there are ethical dilemmas related to terminal ICU patients, however these dilemmas present a deep personal and individualized conflicting character rather than a collective character related to the possibilities dualism on conducts with patients⁽⁷⁾. These dilemmas involve factors related to personal experiences and values, relationships with other professionals, with the family and the terminal patient, and the dynamics of terminal ICU patient care. Thus, searching to enhance the reflection and the discussion over the subject is important for the nurses, with a view to find ways to improve ethical attitudes in each action or interpersonal relation with the ones involved in the dilemmatic issue.

Nurses do not actively participate on the decision-making process related to the actions with terminal patients, but they consider that the family and other professionals' participation and the respect for the patients' wish are important in the decision-making process. When dilemmatic situations involve their actions, the nurses consider their values, professional ethics, empathy, and the dialog with other colleagues on decision-making.

It is important that nurses have a greater theoretical support of ethical principles that compose the necessary base for the delicate process of decision-making. And their participation is fundamental, where it is their responsibility to reflect on how to implement actions in their assisting practice, along with the other members of the multi professional team⁽¹⁹⁾ and involving not only the related terminal patients' dilemma, but also the ICU care humanization.

Ethical dilemmas related to ICU terminal patients will keep on existing, since new situations will appear every day and will require an even larger effort from all professionals to understand it, and the nurse, as a member of the multi professional team, must be present at this moment in order to collaborate for the development of an even more ethical and human assistance.

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