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Intensivist nurses perception of intensive care unit dysthanasia

Percepção de enfermeiros intensivistas sobre distanásia em unidade de terapia intensiva

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Received from Hospital Universitário de Londrina – UEL – Londrina (PR), Brazil.

Submitted in April 6, 2009.
Accepted in June 4, 2009.

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ABSTRACT

Purpose: Identify and evaluate the perception of Intensivist Nurses in a University Hospital in Londrina, of dysthanasia in terminal patients at the Intensive Care Unit.

Methods: Qualitative study. Data were collected by semi-structured recorded interview involving nine nurses working in a university hospital intensive care units, during January 2009. A thematic analysis was used to evaluate subjects' speech and identify discussion categories.

Results: Five categories were identified, discussed based on the authors' experience and literature, namely: measures prolonging life of patients with no chance of cure in the intensive care unit; nurses' actions/reactions when facing dysthanasia; reasons leading to prolonging life of patients with no chance of cure; nurses' feelings about dysthanasia and life prolongation; care measures as opposed to dysthanasia.

Conclusion: Experiencing of nurses when facing dysthanasia actions was shown to be complex, a factor of suffering, frustration and discomfort for these professionals. In the nurses' view, lack of communication stands out as an important factor for dysthanasia, and measures to replace dysthanasia are those relieving suffering.

Keywords: Intensive care units; Terminal care; Bioethics; Nursing

INTRODUCTION

In the last decades, medicine has clearly benefited from technological advances. However, excessive use of new therapies in patients with no chance of cure has brought to light social, institutional, professional and particularly ethical and legal dilemmas.

In this new context, intensive care medicine paved new ways for cure and increased life expectancy for those treated.[1]

However, what should be done with a patient in an extreme situation, who even with all available therapeutic resources and after several consecutive days or sometimes weeks, shows no clinical improvement? Such cases are not unusual and may cause ethical doubts and dilemmas among professionals and family members.[2]

Measures that prolong the end-of-life but not life itself increase the suffering and impair death with dignity. In the United States, this is called "therapeutic futility", in Europe "therapeutic obstinacy" and in Brazil, "dysthanasia".[3]

Dysthanasia means extending excessively a patient's agony, suffering and death. This word may also be synonymous with futile and useless treatment, resulting in a slow end-of-life with suffering, thus prolonging not life but the dying process.[1]

It is very common in Intensive Care Units (ICUs) to find patients receiving many technological resources, but frequently with discouraging results. Sometimes during treatment it is no longer possible to save the patient and the end-of-life is unavoidable characterizing them as terminal patients or, patients with no chance of cure.

Stefanini, Rosenthal and Simon[4] classify terminal patients as those with a difficult to treat disease and set of situations where therapeutic possibilities for cure or prolongation of a dignified life are no longer available or when there is an irreversible central nervous system dysfunction.

Care is the essence of nursing and care of terminal patient requires from the nurse knowledge about management of pain and clinical symptoms common in the final stage of several diseases and communication with the patient as well as knowledge and reflection on death and terminality.[5]

Aware that intensivist nurses live daily with potentially curable critically ill patients, and also with those admitted with no chance of cure or those who become terminal during treatment, the authors decided to study this subject. We proposed to understand the perception of intensive care nurses regarding dysthanasia and life prolonging for patients with no chance of cure, as experienced in a university hospital.

METHODS

This is an exploratory, descriptive study, with a qualitative approach. This type of study allows finding what subjects think about their experiences on a given theme.[6]

The research was conducted at intensive care units I and II of Londrina's University Hospital. ICU I has ten beds, and attends mostly post-surgery and trauma patients or ward patients with worsening of the general condition. At ICU II, with seven beds, prevail patients colonized/infected by multi-resistant microorganisms, elderly, with chronic conditions.

The subjects were nine nurses who understood the dysthanasia concept and were working at intensive care units I and II. All nurses volunteered and signed an informed consent form with instructions on the study nature and purpose. To ensure anonymity we used the code E (E1 to E9), according to the interview sequence. Data collection was made by one of the investigators in January 2009 using a semi-structured recorded interview, following a script prepared by the study authors and later transcribed. This script was divided in two parts: nurse data (gender, age, religion, length of professional experience); report of personal experience with terminal patients and their actions and feeling regarding dysthanasia in their work. Interviews were conducted after approval by the Universidade Estadual de Londrina's Ethics Committee.

Data were qualitatively analyzed using thematic analysis.[7] Themes from the nurses' testimonies were analyzed with support from literature and the authors experience to achieve the purposes of this investigation.

RESULTS

Characterization of **i**nterviewed subjects was: of the nine nurses, six were female and three male; between 20 and 50 years of age; six had more than 10 years experience. Regarding religious beliefs, seven were Catholic and two Protestant and, eight said they were practicing. Six nurses reported that during their course they had classes and discussions on the themes of death and dysthanasia, subjects increasingly discussed in the media, however not so frequent in nursing courses. A study on death and end-of-life in a nurse graduation course at a Bahia university concluded that this issue is not being properly handled to comply with student needs. The training requires more focus on student emotional aspects to face their anxiety about the end-of-life.[8]

After analysis, data collected were organized into five categories: measures prolonging life of patients with no chance of cure in the ICU; nurses' actions/reactions to dysthanasia; reasons leading to prolonging life of patients with no chance of cure; nurses' feelings on dysthanasia and life prolongation; measures for care as opposed to dysthanasia.

DISCUSSION

Measures to prolong life of patients with no chance of cure in the ICU

High costs are increasingly relevant among the

aspects involved in several ICU treatments and such an investment in critically ill patient is justified only when recovery and discharge from the ICU are the goal. For nurses of this study most of the situations identified as dysthanasic involve last generation antibiotics and use of highly invasive catheters.

[...] they perform several invasive procedures, such as Swan-Ganz and other types of catheters, invest heavily in expensive antibiotics. E4

Hemodyalisis and cardiopulmonary bypass (CABG) were also recalled as dysthanasia measures/actions to which some patients are submitted.

[...] sometimes hemodyalisis [...] E7

One often sees a patient with cardiac arrest and being resuscitated for the sake of... "Oh, I did all I could to save this life." E8

CABG is associated to advanced age of some patients managed in the ICU, according to an interviewer:

I've seen patients with 99, 101 years of age. Critically ill, three months in the ICU and being resuscitated. E5

These measures frequently generate an objection and even upsets nurses, as can be perceived from the tone of their voice and emphasis. However, life prolonging efforts are observed even in professionals regarding their own life. This was seen in a study on the impact of information on the behavior of healthcare professionals facing death. Physicians and nurses, questioned about their wish to be or not resuscitated, if at the age of 85 had a cardiorespiratory arrest tended to accept CABG if they were healthy and did not want resuscitation if bearers of a severe disease.[9]

It is noteworthy that CABG is successful in only 40% of cases, and that in 25% of these, resuscitation merely prolongs the end-of-life process. However, in chronic disease patients, success does not exceed 10.5%.[10,11]

Evaluating refusal and withdrawal of treatments considered futile or useless in an ICU at a University Hospital in Santa Catarina, it was found that in 100% of patients with denial or withdrawal of treatment, futility was the reason in 100% of the cases.[12]

In addition to the suffering of patients or family members as an important factor to avoid prolonging life in case of no chance of cure, the high costs related to some treatments were also mentioned as dysthanasia attitudes because it was a public institution.

The excessively high investment in drugs, even if the family had already been informed on the prognosis and lack of therapeutic possibility. E1

[...] very high investment in these patients, with exorbitant costs [...] E2

There is no limit on cost. E4

Nurses actions/reactions facing dysthanasia

Facing dysthanasia situations in ICU patients, the nurses tried dialogue and questioning with the medical team, as an intervention in these situations.

[...] I try to interfere with the "weapons" I have, that is, talking to the on duty physician I am working with. E2

[...] I try to talk and find out the criteria and reasoning of the medical team, what was discussed, if tests really indicate nothing will be done, or if something is being done, why it is being done. E10

I try to negotiate case-by-case with the on duty physician, and normally I succeed. E2

In spite of the importance of involving a multiprofessional team and the family in decision making, about when to refuse or withdraw measures, it should be kept in mind that the final and legal responsibility for the treatment belongs to the physician.[9] However, it would be easier and less painful if decisions were discussed and shared, aiming to solve eventual conflicts on objectives and real possibilities of treatment.[2]

On the other hand, some nurses try to remain distant from these situations, sometimes consciously, perhaps because the emotional distress involved in these situations, is often not easy to live with.

I follow the protocol until it is officially stopped. E1

Distress and impossibility to interfere in the decision making process and ethical dilemmas may lead some nurses to seek their own solutions.

Considering the hypothesis that North American nurses practiced euthanasia or assisted suicide, research was conducted asking if the professional had administered a drug or used any procedure to cause or anticipate some patient's death. Interviews were carried out with 852 nurses working in ICUs, and, 129 said they had performed some kind of action to ease a patient's death at least once during their career. Reasons referred to abusive use of technology to extend life, a strong feeling of responsibility for the patient's welfare, intent to relieve discomfort and to overcome the physician's indifference about the patient's suffering.[13]

Reasons leading to prolonging life of patients with no chance of cure

Lack of communication within the medical team and different points of view, disclosed in several statements appear to be important factors for dysthanasia, from the stand point of the nurses, as stated below:

I won't say there is lack of knowledge, because that is not true. I think there is lack of communication. E2

Teams do not communicate with each other. They talk like that [...] let's solve this problem. This kidney. This kidney doesn't work. The heart doesn't work, then let's solve it. Resolving a couple of organs, but nobody talks about the patient as a whole. E6

Cessation of a futile or useless treatment is not always consensual among professionals and supported by the intensivists in a same institution. Thus, on occasion, in different shifts, another physician resumes a treatment previously discontinued because of personal beliefs, creating a vicious circle difficult to resolve that reflects lack of dialogue in the medical team.[14]

The medical posture is understandable, given the National Medical Council Resolution[15] allowing a physician to stop treatments and procedures prolonging the life of terminal and with no chance of cure patients after consent of the family members or patient, that was suspended by a legal procedure in 2007. Although the Resolution protected physicians from losing the professional license, it did not however avoid criminal responsibility.[16] Unfortunately the Resolution did not last long enough for ICU professionals to discuss the issue and implement it.

Different points of view between the responsible physicians for ICU patients were described in the interviewees' statements:

A disagreement between clinics. I think that mostly it is because of this. E10

[...] for this discrepancy of practices there is a continuity of treatment to attempt cure. One team thinks that there is a cure while the other does not. E10

There is no consensus among the medical team, and the patient suffers. E6

Divergences on how to conduct cases or clinical procedures for a patient are reasons not only to prolong life but also to trigger nurse dilemmas. Nurses reported that often there is no consensus on procedures to be used, causing difficulties for professionals in many cases where the physician is not present at visiting hours to communicate the decision to family members who then question the nurses.[17]

In many statements, another factor causing dysthanasia was that the hospital was a University Hospital.

[...] since this is a University Hospital, everybody also has to learn from the patients, and I think that this leads to dysthanasia, which may not be so frequent in other hospitals. I don't say it doesn't happen, but not so much. E5

Oh, as it is a University Hospital, they keep training, training, training and sometimes do not realize that the patient is beyond possibilities, and they don't stop the process. E7

[...] a student will always want to try something else, performing one more procedure. The surgery will not help, it is a metastasis, there is no reason for doing it, but this is a University Hospital, then let's take him to surgery. Yes, I think that there might be a difference. E10

Being a University Hospital does not justify dysthanasia, on the contrary, it should be a setting for graduate students and resident physicians to reflect on the limits of medicine/science as well as on death as part of the life cycle.

Nurses' feelings on dysthanasia and prolonging life of with no chance of cure patients.

Faced with terminality, suffering, impotence

and frustration were the main feelings described by nurses caring for patients subject to dysthanasia according to these statements:

It's complicated, I suffer too much. E6
Well, I feel sad and frustrated. E2
We (nurses) feel powerless. E1

We understand these feelings, since lack of preparation for death is still common among most healthcare professionals. Feeling frustrated and powerless is related to the cure-and-life-maintenance education. Nurses' impotence is also associated to a limitation of professional qualifications, because the physician decides when to stop life-supporting measures.

Chaves[17] emphasizes that the feelings of nurses in private ICU about terminal patient conditions were also of suffering when facing death and end-of-life, of being powerless in face of the unavoidable proximity of death; and of unpreparedness to deal with these emotions.

In the ICU end-of-life is an anguishing event for the nursing staffs, bringing on feelings of inadequacy, personal and professional failure. Intensity of suffering is directly related to the tie developed between the professional and patient during ICU stay.[18]

Suffering, failure and inadequacy are feelings common to nurses regarding death/terminality in ICU, regardless of dysthanasia.[17,18] Here shall be inferred, if to experience the indignity of prolonging life p in patients with no chance of cure using drugs and fundamentally curative resources does not contribute to the suffering of nurses.

Care Measures versus Dysthanasia

Questioned on how to manage treatment of with no chance of cure patients, only one nurse mentioned palliative care (PC) as an option.

The World Health Organization[19] defines PC as active and total care to a patient whose disease no longer responds to curative treatment, where management of pain and other symptoms is prioritized, in addition to psychosocial and spiritual issues.

The nurse, along with other PC team members should provide conditions for the patient to have a decent, serene death without suffering, close to the family members. Recalling that one of PC goals is orthothanasia that does not anticipate or postpone death.[1]

Curative medicine in ICUs still focuses on helping to lengthen life, disregarding quality at the end-of-life. To relieve the suffering of terminal patients has yet to be addressed.

Pain control, one of PC goals and a frequent aspect in ICU patients, was seen as a nursing concern and desire for with no chance of cure patients, as in these statements t:

[...] the patient doesn't have to feel pain. (E4)

[...] keeping up comfort, no pain. (E5)

A study involving 9105 adult patients in five American University Hospitals showed that one half of them presented with moderate to severe pain during the last three days of life. [20]

Relieving pain and other distressing symptoms should be viewed as a fundamental goal for patients with no chance of cure, because if physical pain is not relieved or controlled, spiritual, social and emotional needs will not be remedied. In this process, the nursing team plays a fundamental role, as they spend more time with the patients.[21]

For some nurses, that patients are with no chance of cure does not justify depriving them of nursing care, these should be provided to all patients, regardless of their clinical condition and prognosis.

[...] full nursing care, such as hygiene, change of decubitus or even feeding, I think should be continued. Water. A patient has to be clean and change clothes. E4

Such as, in terms of practical care, a normal bath. I don't know if this changes ... mattress. All the things (nursing care) we do for a patient with a chance must be kept up for those with none. E7

When the patient is at terminal stage, nursing still has still a lot to offer, to provide dignity we should always return to basic care, which the team should never deem to be futile or useless. It is essential to provide to the patient a dignified life until death.

[...] I believe that there is an issue of human dignity one should preserve. E10

Additionally, care by administering sedatives was mentioned to minimize pain-related suffering, distress and anxiety.

If there is no perspective, we should sedate him and let him rest. E3

[...] sedation. Deep sedation. E2

It should be stressed that, before introduction of "deep sedation", as a nurse stated attempts should be made to relieve a terminal patient from pain and anxiety, promoting comfort and the possibility of closer contact with family members and the external environment, instead of just deep sedation. This would ensure better contact with other professionals, as psychologists, welfare workers and spiritual support, which would help to seek the best quality of life and comfort at this end-of-life.

For these patients, the best indication is palliative or terminal sedation, consisting of drugs administered for an unreachable relief from physical or psychological suffering that cause major discomfort, by intentionally reducing the level of consciousness. This sedation may be continued or intermittent, superficial or deep, after consent of patients with incurable, progressive and terminal disease.[22] Symptoms which should be given priority are: pain, nausea and vomiting, apprehension, agitation, dyspnea, bleeding, existential suffering, severe fatigue and sleep disorders and others causing great distress.[23] The most often used drugs are: midazolamn, levomepromazine and propofol.[22]

For the interviewed nurses, company of family members is fundamental for terminal patient care.

I think that attention has to be paid to the family. E6

One has to see if the family wants to be there. If they can be close, if they want to be close. E7

Unfortunately, few ICUs have individualized boxes, better suited for the family staying 24 hours or longer than just during visiting hours. The healthcare services organization is mostly focused on service dynamics and professional priorities, at the expense of patients and family members.

In the context of managing a terminal patient, care to the family is very important, since most of the time the patient will not be awake. It will be necessary to deal with the family members and this care is the responsibility of the entire team. Unfortunately, attention to family members is still barely approached during healthcare graduation courses.[24]

CONCLUSION

The experience of nurses with dysthanasia and life prolonging has shown to be complex, as it involves bioethical aspects.

In the opinion of nurses, lack of communication stands out as an important factor for dysthanasia, and continues to be a problem. More effective communication, not only within the medical team, but also with nurses may contribute to prevent dysthanasia which was proven in this study to cause suffering, frustration and discomfort to nurses. Although it is not the nurse's responsibility to decide on stop or change the treatment procedures, they should be involved in the discussions, as the professional who spends more time with the patients and, with continued care, follows the course from admission in the ICU to discharge or death.

The nurse who is able to identify ways of providing better quality of life for terminal or dysthanasia patients, such as PC, pain relief, sedation (correctly used) and increased family members insertion in ICU should always try to act, preferably along with the health team, in favor of these patients and family members.

Another aspect explained in the study that interferes with professional conduct during the end-of-life is not to acknowledge death as a stage of existence. Therefore, it is fundamental that death be debated in healthcare courses, particularly the bioethical issues involving terminality and limits of technology and science about immortality of the human being.

RESUMO

Objetivo: Identificar e analisar a percepção de enfermeiros da unidade de terapia intensiva de um hospital escola em Londrina sobre distanásia em pacientes terminais na unidade de terapia intensiva.

Métodos: Estudo de natureza qualitativa. Os dados foram coletados por meio de entrevista semi-estruturada gravada, com nove enfermeiros das unidades de terapia intensiva de um hospital escola, no mês de janeiro de 2009. Foi utilizada a análise temática para analisar os discursos dos sujeitos e identificar as categorias de discussão.

Resultados: Foram identificadas cinco categorias que foram discutidas com base na experiência dos autores e na literatura, sendo elas: medidas que prolongam a vida

do paciente fora de possibilidade de cura na unidade de terapia intensiva; ações/reações dos enfermeiros diante da distanásia; motivos que levam ao prolongamento da vida de pacientes fora de possibilidade de cura; sentimentos dos enfermeiros sobre a distanásia e prolongamento da vida; medidas de cuidado em oposição à distanásia.

Conclusão: A vivência dos enfermeiros perante as ações de distanásia mostrou-se complexa, sendo um fator de sofrimento, frustração a inquietação para estes profissionais. A falta de comunicação destaca-se como fator importante na visão dos enfermeiros para a ocorrência de distanásia e a medida para substituir a distanásia são os cuidados que proporcionam alivio do sofrimento.

Descritores: Unidades de terapia intensiva; Assistência terminal; Bioética; Enfermagem

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