THERAPEUTIC FUTILITY AS AN ETHICAL ISSUE: INTENSIVE CARE UNIT NURSES[1]

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Therapeutic futility in intensive care units (ICUs) is still little discussed among nursing professionals responsible for implementing prescribed procedures, which they might disagree on. Therefore, interviews were carried out with ICU nurses to understand how they are coping with the implementation of futile treatments. Based on the analysis of collected data, the following categories emerged: Therapeutic futility: what is it?; Therapeutic futility extends suffering; Therapeutic futility with healing as a priority; Coping with therapeutic futility: humanized care? The study indicates the need to evaluate therapeutic measures provided to terminal patients with a view to improving their quality of life in this final phase. When healing is no longer possible, care is necessary with a view to respecting the sick person's integrity because care is the essence of the nursing profession.

DESCRIPTORS: therapeutics; health; death; ethics; nursing

LA OBSTINACIÓN TERAPÉUTICA COMO UNA CUESTIÓN ÉTICA: ENFERMERAS DE UNIDADES DE TERAPIA INTENSIVA

La obstinación terapéutica, presente en las Unidades de Terapia Intensiva (UTIS), aún es poco discutida entre los profesionales de enfermería que son responsables por la implementación de las terapéuticas y con las cuales pueden discordar. Así, para comprender, como las enfermeras de UTIs, vienen enfrentando los tratamientos fútiles fueron realizadas entrevistas con estas profesionales. A partir del análisis de contenido de los datos, fueron construidas categorías: Obstinación terapéutica: ¿Qué es eso?; La obstinación terapéutica como la continuidad del sufrimiento; la obstinación terapéutica como la preferencia de la cura; el enfrentamiento de la obstinación terapéutica: ¿Es un cuidado humanizado? La evaluación de medidas terapéuticas que necesitan ser utilizadas en pacientes en proceso de morir y de muerte, de modo que puedan vivir su vida con calidad es fundamental. Cuando no existen posibilidades de curar, es necesario efectuar el cuidado respetando la integridad de la persona enferma. El cuidado es la base del ejercicio profesional de la enfermería.

DESCRIPTORES: terapéutica; salud; muerte; ética; enfermería

OBSTINAÇÃO TERAPÊUTICA COMO QUESTÃO ÉTICA: ENFERMEIRAS DE UNIDADES DE TERAPIA INTENSIVA

A obstinação terapêutica, presente nas unidades de terapia intensiva (UTIs), ainda é pouco discutida especialmente por enfermeiras, responsáveis por implementar procedimentos, dos quais, muitas vezes, podem discordar. Para compreender como enfermeiras de UTIs vêm enfrentando a aplicação de medidas terapêuticas que reconhecem como fúteis, foram realizadas entrevistas com essas profissionais e análise de conteúdo dos dados, construindo-se categorias: - "Obstinação terapêutica: o que é isso?"; - "A obstinação terapêutica como o prolongamento do sofrimento"; - "A obstinação terapêutica como a priorização da cura"; - "Enfrentamento da obstinação terapêutica: cuidado humanizado?". O trabalho demonstra a necessidade de avaliar as medidas terapêuticas a serem utilizadas com pacientes em processo de morrer e de morte, de modo que possam viver a fase final de sua vida com qualidade. Quando a cura não é mais possível, é necessário cuidar, respeitando a integridade da pessoa doente, pois o cuidado é a base do exercício profissional da enfermagem.

DESCRITORES: terapêutica; saúde; morte; ética; enfermagem

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INTRODUCTION

There are multiple ethical issues involved in care provided to people who are experiencing the dying process and death in the environment of an intensive care unit (ICU). Much has been discussed on this theme by several professionals from the health area and other areas, specifically the patient's right to die with dignity and therapeutic futility. Therapeutic futility is also employed as a synonym of futile and useless treatment, which leads to a slow and prolonged death accompanied by suffering. It is a medical attitude that, aiming to save the lives of terminal patients, submits them to great suffering. By this attitude, one only extends the dying process, but not life *per se*(1).

Along the text, the following terms have the same meaning: futile medical act, dysthanasia, therapeutic futility and therapeutic tenacity.

Nursing is beginning to discuss the issue and articles on the dying process and death appoint to the possibility of extending the life of patients without consideration of their quality of life and real chances of survival, as well as nurses' difficulties and suffering in these situations(2-3). The theme is considered of great relevance for nursing because this profession performs many of the prescribed therapies. Thus, health professionals need to discuss these practices so as to define what is currently expected as a model of health and life.

Issues related to therapeutic futility are possibly present in the routine of ICUs where different decisions are taken regarding the treatment of patients in the terminal phase of the disease without previous discussion with the patients themselves, their families and the health team and are usually restricted to one person's consideration, generally the physician on duty(4-5). Therapeutic procedures depend on medical criteria, but affect health teamwork as a whole, specifically nursing which, when complying with therapeutics they do not agree with, can suffer intensely and question the values underlying this practice(1,6).

Therefore, we sought to understand how nurses are facing the implementation of therapeutic measures they consider futile.

METHODOLOGICAL TRAJECTORY

This qualitative, exploratory and descriptive study was developed according to Resolution 196/96(7), approved by the Research Ethics Committee of only one of the studied hospitals because the committee at the other institution was being established. All participants signed the free and informed consent term.

Data collection was carried out in two hospitals in a city in Rio Grande do Sul, Brazil: Hospital A – large private institution, with nuns working in the nursing team, in command positions and in service coordination; Hospital B – private teaching institution with undergraduate and graduate students. ICUs of each of the two hospitals have ten beds and one responsible nurse, one nursing technician for each two beds and one physician on duty for each work shift, in addition to one physiotherapist. The nursing professionals' weekly workload is 44 hours.

The study participants were nurses working at the ICUs of these hospitals for more than a year and who agreed to participate: four nurses from Hospital A and two nurses from Hospital B, identified by letter E followed by Arabic numbers from one to six. Semi-structured interviews were carried out with the following questions: What do you understand by therapeutic futility? Do you believe it exists at the ICU you work at? If yes, how do you feel when you have to implement therapeutic measures you consider futile? What feelings do you experience in the implementation of these treatments? How do you cope with these situations? What strategies do you believe could be used?

Categories of analysis were elaborated after successive reading of the interviews, which were arranged and classified by similarities and differences according to the described essences and codification of collected data(8) . This permanent relation with the study's theoretical framework aimed to understand how professionals identify situations of therapeutic futility, how they experience it and what factors influence the decision making process, with a view to appointing the feelings experienced and potential strategies to cope with these situations. Four categories of analysis were constructed and are presented herein.

RESULTS AND DISCUSSION

Therapeutic futility: What is this?

To understand how nurses are coping with the implementation of therapeutic measures they consider futile, first, they had to acknowledge the existence of these treatments in the ICUs they work at. The majority was not familiar with the meaning of therapeutic futility (E1, E4, E5, E6) at the moment they were questioned about their understanding and whether these treatments were prescribed in the ICU they worked at. Thus, we opted to read the definition of therapeutic futility(9) after the first question and its respective answer.

The larger part of nurses, despite not being familiar with the term, affirmed after its clarification that they experienced the problem at the ICU they worked at and considered it very frequent, as this report shows: *Well, I didn't know what the term meant, so I had to ask you about it 'cause I had no idea, but after you told me what it is, I know we experience it a lot here at the ICU* (E1).

The reported lack of knowledge on the term reflects the prevalence, even nowadays, of a predominantly technicist model in the hospital context in which practice and technique are overvalued in detriment of a more humanist one(10). Thus, the nurses' work seems standardized and preserving order in the unit and seeing to the patient's biological needs are the priority. Still, perhaps even these needs are not being met because they are analyzed and defined mostly by health professionals, ignoring the patient's will. Changes in many practices still considered adequate and acceptable in ICUs may be possible through the exercising of thinking.

Although therapeutic futility is a problem routinely faced in ICUs, its perception and questioning by professionals may require further theoretical knowledge. Lack of knowledge on the issue leads to the perception that dysthanasia is normal and necessary in patients' treatment.

Therapeutic futility extends suffering

Some nurses explained that they understand therapeutic futility as a way to extend the life of terminal patients, extending their suffering as well. *It means to extend the time of a patient whom you know is going to die, you know it's useless to use any possible resource. It won't revert his condition. I feel sorry for these people, not because they're going to die, but because they go through all this suffering and you know it's useless* (E5).

Some nurses, possibly due to lack of understanding and consideration about what can, or better yet, what needs to be done for each patient who experiences a situation of terminal illness(11), reported feeling that they are implementing futile therapeutics that cause suffering to patients, which leads to antagonistic feelings. *[...] sometimes you get angry, 'cause you're doing some futile thing and you're not changing that patient's situation, but then you create bonds and think that it's better and think that deep, deep down, who knows, there's hope* (E3).

In the therapeutic futility perspective, unspecified investment in the patients' healing treatment, coupled with feelings of hope in patients' improvement, seems to be motivated by nurses' difficulties in dealing with death and the dying process and not by the acknowledgment of powerlessness in preventing them. Thus, therapies are needed that maintain the illusion that cure will be achieved even if one does not see its real possibility.

The implementation of dysthanasia also seems to be based on nurses' *religious conception* that disease and consequent suffering can be redemption for debt caused by mistakes committed during the patient's life. *I keep thinking, gosh, sometimes I think that we have to pay for a lot of things here on earth, it takes so long to die, it gets even longer with them working so hard like this, it extends it even more* (E6). This way, extending life as much as possible without considering the quality of life that is being extended, as well as patients' suffering in the process, not questioning their wishes and options regarding what they are putting up with, seems to be justified [...] *I have very religious people working here at the ICU who believe we have to keep trying as long as there's life* (E3).

Quality of life, in terms of therapeutic futility, even if subjective, can be understood as a process of dying without pain and suffering, respecting patients' wishes and allowing them and their family members to share their experiences(10).

Therapeutic futility with healing as the priority

Other nurses appointed that therapeutic futility means to implement therapy they consider futile, however, necessary because healing patients is a priority, as this report shows: *[...] here at the ICU we have the habit of investing in the patient, many times we know it's about a terminal patient and there's no return. The investment is considerable in terms of expensive antibiotics, ventilation, better respirators; we only don't work on patients with cerebral death. On the others we invest as much as we can. There're cases the patient will not survive and the physician keeps trying. We know that that a patient will not recover, only that, at least me, I talk for myself, I'll go if I have to administer some medication, I go. Nursing care is complete for me. I never doubt, never get* *angry, it is right for me. I go with the certainty that that is what I have to do* (E1).

Many of the measures adopted by these professionals might be based on the beneficence principle and they believe that, through maintenance of life, they are favoring the patient and minimizing harm, death, apparently in the faith that "while there's life, there's hope". Expressions like this are frequently heard in the hospital context and show the health professionals' need to deal with conditions of certainty, without time for doubts or questions. Thus, decisions about life and death should be made under these parameters and it is necessary to keep fighting for life until one is certain about death(1). This way, professionals might be implementing care based on the attempt to avoid the patients' death.

Because the patient is dis-identified during this process, his(er) real potential to recover cannot be disregarded, because there is no time to lose with questioning. When health is only absence of disease and medicine is only technoscientific and curative, the health team' attention tends to restrict itself to the pathology under treatment. However, one has to question if beneficence can be reduced to the simple achievement of cure, regardless of its real possibility and associated suffering. In the perspective of health as global wellbeing, involving physical, mental and social aspects, one has to attend the patient considering beneficence as a set of values that lead to wellbeing(12).

Oftentimes, health professionals may not realize or can even deny they are deciding the patients' fate. However, different actions like the physician's decision of hospitalizing or not hospitalizing someone at the ICU, opting for one treatment or the other, verbal orders to perform cardiopulmonary resuscitation or not and the implementation of routine nursing care are decisions made on the living and also dying processes of people and on how their families will experience the patient's dying process, that is, only the patient's physical removal due to hospitalization in a closed environment of difficult access is considered.

The nurses themselves sometimes initiate cardiopulmonary resuscitation based on previous verbal orientation. It is common for these professionals to start the procedure in case of night shifts until the physician is present. Other times, the physician on duty performs this procedure, however, making this decision without previous consideration of the patient's chances of recovery, nor his(er) will and/or that of family members. This decision is solely based on the attempt to avoid death. There are extreme cases when the family spontaneously interferes, like in the following report. *I had a 15-year girl hospitalized here because of respiratory failure for a very long time, we never found out about the diagnosis. She went back to the room, stopped breathing two times and came back to us, and we always reverted the situation, always. And the last time she was hospitalized here, I think that it was her fourth hospitalization in the ICU, she came with cardio respiratory arrest and we'd try to revert the situation; all beds were occupied, we set up an extra bed in the ICU and got an eleventh bed. When we started to work with the patient, she was already intubated, her mother knocked on the door and asked me not to try to resuscitate the girl. At the time it was shocking and I didn't even think about it, it seemed I had not heard that, I denied it. I went back, talked to the physician who was also taken aback, everybody was taken aback, the physician went to the door, talked to the mother. She said: "my daughter is suffering, it has been an year I'm suffering with this, my daughter is suffering, and I don't see she's coming back, I don't see any recovery and I don't want you to resuscitate my daughter." The physician came back and said: "Let's stop". When she said that, I got paralyzed. Like, to try to understand that mother, because it's difficult for a mother to come to you and say: "don't resuscitate my child anymore." We really didn't, we stopped everything, who was with the ambu bag took it out. That afternoon was totally silent, everyone taking caring of their patients, you could have heard a pin drop* (E1).

This way, therapeutic resources can be abusively used, valuing life regardless of its conditions, creating situations in which therapeutic futility can be observed, and there is no clear definition of what is the best for the patient, as can also be perceived in this report: *[...] you see the patient is there only because of the medication. You know that effect will stop and he's going to stop again. The patient stops and they keep resuscitating him. I've even heard: "...we've got to keep him up to eight o'clock which is when my shift ends*" (E5).

Resuscitation maneuvers can be implemented due to health professionals' fear of being legally charged with not providing therapeutic care to patients. However, in other situations, there is the option not to perform cardiopulmonary resuscitation and there is no record whatsoever in the patient's file. Even when these maneuvers are performed, the family is not previously consulted. Health professionals seem somewhat afraid and uncertain, and there even seems to be some lack of knowledge on the extent to which one should invest in the patient's cure.

The choice not to resuscitate the patient does not exclude other nursing and medical care because it does not imply in abandoning basic necessary care. As the patient is considered incurable, therapeutic resources destined to care should overcome those destined to cure. Thus, basic nursing care like oral hygiene, skin care, changing the patient's position, among others, should be maintained(13).

Coping with therapeutic futility: humanized care?

For issues related to therapeutic futility, some nurses appointed the adoption of *humanized care* as a coping strategy, though they did not indicate how to put it in practice. We consider that the implementation of humanized care mainly implies personalizing the patient hospitalized in the ICU.

The report of E1, when she refers to a quadriplegic patient who was hospitalized in the unit for many months and presented several complications, including respiratory failure and tracheotomy with consequent difficulty for weaning from the respirator, weight loss, among others, shows nurses' difficulty to communicate with patients, hindering knowledge about what they wish for themselves, which can favor therapeutic futility. *He doesn't talk, so we know nothing, and of course, we don't have the guts to ask if he knows he can't move. It's such a situation... We already told him he couldn't move, that he has to take exams, we're not sure. Every time we talk to him, we end up giving him some hope because we're never sure. In nursing, nobody is sure, we're trying, will take exams "let's see if you'll manage to recover, there's physiotherapy", we always give him some hope. We never say to the patient what he really has. Things not well resolved are very difficult to cope with* (E1).

Many professionals face difficulties to listen to patients. Before they try to express themselves, they already give them apparently convenient explanations, as a protection not to address issues regarding the diagnosis and prognosis of the disease, death and dying. Possibly due to difficulties in addressing this issue, opportunities for dialoguing are not created, which may restrict patients' potential doubts and questions.

It seems to be necessary to listen more to patients, talk about their values related to the dying process and death, life perspective, how the disease symptoms and treatment affect them. It is important that more than one professional talks to the patient, obtains information and discusses it in periodical multiprofessional meetings on the best way to move ahead. Although nurses usually occupy great part of their scarce time with several tasks, which are usually too many, dialog is necessary, due to its essential importance to establish criteria for patients' treatment(14).

It is also important to clarify options of care and their potential consequences during a *dialog* between nurse and patient. For patients to have options, they need to know these options. In the palliative care model, which is characterized by the control of patients with active and progressive diseases in an advanced phase, for which the prognostic is limited and care is focused on quality of life, spending time clarifying options to patients and their family members is essential(15).

Therefore, dialog can be established before procedures and therapies are implemented, asking for the patient's consent, acknowledging the individual and preserving the human nature of relations between individuals who experience radical situations of extreme vulnerability. Asking for consent is a minimum and mandatory procedure that shows responsibility for the patient and protects him(er) from potential abuse, assuring and promoting an ethical relationship between people who do not know each other(16).

In addition to dialoging with the patient, nurses should also talk to the nursing team, physicians and other professionals who might provide care and also establish co-responsibility and construct teamwork as a way to produce greater commitment of everyone in the patient's benefit, jointly establishing the best actions to be adopted. In this complexity of relations, the set of professionals is responsible for getting involved with patients and family members, including them in the care delivered as a way to make them active and capable of assuming their own care.

We believe that exercising thinking is an important strategy to provide tools for the care of patients in the terminal phase of disease, and also permits reflection on the best actions to be adopted with a view to avoiding dysthanasia.

Ethical issues like therapeutic futility should be included in the education process of nursing professionals, ideally in situations of practice and supervised training, aiming to educate professionals capable of allying technical competence with human sensitivity.

CONCLUSION

Therapeutic futility is a current problem and is very present in ICUs where several high technology equipments can preserve life, even in cases where vital organs and other structures are severely affected.

Reflecting on the meanings of experienced practices and values considered in the evaluation for choosing therapies is important as it permits changing practice. Not implementing healing treatments does not mean letting the patient die, but it actually means to accept the death process that cannot be avoided. Nurses can contribute to maintain quality of life, performing care that diminishes physical pain and psychic suffering and attending to patients' will, as well as favoring closeness to family members.

A ethical relation where patients' autonomy is respected can be established through small attitudes like deciding together with patients on the most convenient moment for their bed-bath, accepting their refusal to take some medication, making their privacy a priority when performing procedures that expose their body, calling them by their name, showing concern if any procedure causes pain. Other coping strategies can be discussed by health teams who work at the ICU, and other studies and discussions on the topic are needed.

The study reveals the need and importance of assuming this considerable ethical challenge to evaluate therapeutic measures that should be included in patients' treatment in the dying process and death, so as to assure that they live the final phase of their lives with quality. Considering that, when cure is no longer possible, care is necessary, and concern with the patient and respect for his(er) integrity are essential, keeping in mind that care is inherent to exercise the nursing profession.

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