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DEATH AND DYING IN A PEDIATRIC ICU: CHALLENGES FOR NURSING CARE IN THE FINITUDE OF LIFE

Bruna Santos Ferreira Lima*
Roberto Carlos Lyra da Silva**

ABSTRACT
The objective of the study was to analyzing the relationship between the markedly technological environment of the Pediatric Intensive Care Unit (PICU) and the way they think and relate nursing professionals with the reality of death and dying in these units. The method was qualitative. The study was conducted with 24 nurses in a PICU of public health in Rio de Janeiro. The data were produced from semi-structured interview and subjected to thematic and lexical analysis. The results reveal that the nursing staff perceives the technology as capable of coming near the professional of children in critical condition; thus, not precluding the possibility of thinking the supersensible dimension of nursing care in situations where death can no longer be avoided given the natural course of the disease.

Keywords: Attitude to death. Nursing care. Pediatric Intensive Care Units.

INTRODUCTION

Over the years, many theorists and researchers have been trying to find explanations for human behavior in face of death and dying. From the twentieth century, the profile of the man maintains a distant relationship with death; unconsciously dodges the same and considers shameful a failure that should be hidden [(1)].

With the development of techniques and technologies related to advance support units, increasingly sophisticated intensive care, it has been possible life extension. With this, we have observed significant changes in the concept of death and dying in the contemporary world.

The establishment and use of artificial ventilator, for example, determined profound changes, both in the dying process, as in the concept of death, demanding of nurses of the twenty-first century, changes in behavior, attitudes and practices on patient who are in a situation of finitude, but which are still kept alive because of all this technological support available.

Through this perspective, and for being the intensive care units, units with higher hospital mortality rates, despite the fact that they are endowed with technologies to meet serious and retrievable patients[(2)], stereotyped and feared death picture, it seems that is no longer represented by the famous skeleton wielding a scythe, and shall be represented by the image of a dying man in a hospital intensive care unit, connected to machines, from a huge amount of wires and tubes.

That seems to be how the intensive care unit has been represented, marked by a discourse of humanization now gaining momentum in the late twentieth century, fundamentally based on the idea of depersonalization of the patient and the power of health professionals on the patient's body.

In the pediatric intensive care units, PICU, this idea is reinforced by the strangeness that is not infrequently caused by technologically rigged environment which is emotionally draining for both the newborn (NB), which seems to disappear before so many wires, tubes and machines, and for parents and family, who often are unaware of the true condition of their children [(3)].

In this movement, death came to be considered by health professionals as a synonym for not successful, causing sensations or feelings of failure as a reflection of their unpreparedness to face death as a natural process [(4)].

These feelings seem to be even deeper and more painful, in the pediatric context, because it seems more difficult and cruel for a PICU team,

*Nurse Master in Nursing. Pediatric Intensivist Pediatric Intensive Care Unit of the Fernandes Figueira Institute - FIOCRUZ. E-mail: enfebsan@ig.com.br
**PhD in nursing. Deputy Coordinator of the Doctoral Program in Nursing and Biosciences, Accredited as a permanent faculty of the Masters Program in Nursing and Doctorate Course in Nursing and Biosciences. Federal University of the State of Rio de Janeiro - UNRIO. E-mail: proflyra@gmail.com

for example, accept the fact that a being so small, so insecure, fragile and helpless, yet with a future all ahead, have your life cut short so early, even before all the possibilities offered by advanced life support units in these technologies, pointing to the following problem-question: "Is it possible to relate the technological apparatus available in the PICU to how professionals think nursing about the process of death and dying in these units?"

This article aims to analyzing the relationship between the markedly technological environment of pediatric intensive care - PICU and the way nurses think and relate to the process of death and dying in these units. The motivation for the study, the result of a Master's Dissertation defended in 2011[5], emerged from the experiences and professional experiences of the researcher, caring for pediatric clients in the process of death and dying in the use of advanced life support in intensive care units intensive pediatric, PICU, which had as its object of study, the confrontations of the nursing staff on the death and dying process of pediatric patients in the PICU.

METHODOLOGY

This is a descriptive study, which relied on the qualitative method, because we believe that it would be possible, from it, a proper understanding of confrontations experienced by nursing staff in the face of death and dying children in a markedly technological environment of Pediatric Intensive Care Unit - PICU.

The study was developed within a PICU called Graves Unit Patients (GUP) of a Public Health Institution belongs to the Federal Network reference in women's health, child and adolescent and located in Rio de Janeiro City.

The GPU has six beds and caters for children aged ranging from 29 days to 18 years old of incomplete life, which are elected for admission due to clinical worsening health condition that poses an imminent risk of death as severe respiratory disorders, with or generalized infection without other generalized infections and children in surgical postoperative. In general, children who are dependent mostly advanced life support because they are children at very seriously.

The nursing team consists of industry: Ten nurses being one head nurse, two routines-seven on duty; twenty-four practical nurses and two auxiliary hospital services, responsible for the provision of materials, attention to non-critical items, among other functions. Sometimes there are one or two nursing home residents during daytime as well as nurses in a specialization course in pediatric nursing practice to meet workload.

This study all professional nursing team, of both genders, who have worked for at least one (1) year providing direct care to pediatric clientele who wished GPU and willingly participate in this study by signing the consent form were included and informed. As a technique for generating data it was chosen interview.

The production data was after approval of the study protocol by the Ethics and Research Committee - CEP Institution. The number of the protocol approved by the IRB of Institution: 0076/10. It should be emphasized that the resolution of the National Health Council (CNS) 196/96 meets the Guidelines and Standards Regulating Research Involving Humans was respected.

The interviews took place in the hours and days of duty of each of the interviewees indicated that the most appropriate time to grant interviews, so that was not so possible to significantly alter the routine of these professionals in their daily work.

The instrument of production data contained closed questions in order to characterizing the subjects with regard to gender, professional category and the length of experience working in the PICU; and open-ended questions about what they think about death and dying process and how they act on the finitude of life of pediatric patients in the PICU.

The interviews were recorded in digital format MP4, using a portable recorder capable of 24 hours of audio recording. The recordings were transferred to the computer and heard for transcription through the Windows Media Player program that among other characteristics, allowed the researchers whenever necessary, both back recordings as putting them at a slower

speed in order to improving the understanding of the interviewees, thus facilitating the transcription of the interviews.

Data were analyzed following the steps proposed by the technique of thematic analysis, which defines three basic steps in content analysis: a comprehensive reading of the entire selected material; exploration of the material and the elaboration of categories / synthesis. During the thematic analysis during the development of the categories / synthesis, we used the lexical analysis in order to identify the subjects' statements, the most recurrent lexical able to make sense of themes / kernels, in order to guide the creation of the category analysis.

The Lexical Analysis is to assess or measure the size of the responses. It is the scientific study of vocabulary, with statistical methods for the description of the vocabulary methods applications [(6)]. Through lexical analysis there were identified in greater detail quotations from participants, using indicators that relate to aspects of the representations and quotes about death and dying in the GPU. The evolution took the overview text for the data in essence, be they words or phrases, which will later be reanalyzed with a view to the total universe of information.

For identification, description and lexicon from their comments, the study treatment Sphinx software, demo version 5.0 was used. First the word count was made if moving systematically toward identifying the size of the responses. Approximations or groups that allowed the presentation of the criteria most frequently cited by grouping related words, deleting words uninteresting, even result in a set of words that represented in essence the main descriptions cited in the text were made. Thus, identification of the frequencies of words possible to consolidate the application of a topic or phrase, enabling an analysis of the context in which the identified category is the essence of the ideas presented.

The Lexical Analysis enabled the presentation of words, groups, expressions in order to uncover paths and discover opinions, identify needs, obsessions of the study subjects, allowing mainly observe and discover these contents between the lines of the responses, indirectly or even options even obscure, discovering meanings and susceptible elements not identified a priori, thereby facilitating the emergence of a category of analysis called "paradox of sensations in lived experience of the finitude of life care in the PICU."

RESULTS AND DISCUSSION

Of the twenty-four professionals interviewed, seventeen were female and seven male. Sixteen nursing technicians were eight nurses. Regarding time of experience in pediatrics, it predominated in the studied sample eighteen professionals who said they had more than six years of experience.

With specific regard to length of experience of the study subjects, it is important to reflect how this aspect can affect how these professionals can think of nursing care.

The novice nurses, for example, may be much more worried about their professional practice, since it lacks the domain of characters that allow a safe act, or do not know completely what and how should be done in different and challenging situations daily care, such as those involving death and dying and the use of technologies.

The logic that guides you is that if you do not know, I, I cannot act. Therefore, the novice nurse contains in itself not able to design once again presents himself as a stranger to this business. This encounter with the new constitutes a circumstance that leaves nurses in shock with reality [(07)].

Among the more experienced, we expect a more accurate view of the situation, which could theoretically allow you to experience and solve problems in a different way from those less experienced. Thus, we must consider the possibility that there may be features, including behavioral, fear, insecurity, clearance / stoppage, for example, the typical lack of work experience, which become even more evident when considering the question which involves death and technology in health care. Thus, to unlink the death of embarrassment and guilt and failure, through planning, discussions and studies over training, which is possible only over the years, we can expand the care giving to the patient who is not curability the necessary attention to it in the process of coping [(08)].

This category was created to handle the sensations experienced by the respondents

before the process of death and dying on the UPG. Lexicons, pain, suffering, relief, emotional security and religion, which allowed the emergence of this category, seem to leave clear the mix of emotions experienced by these professionals, as well as the paradox of suffering and relief in the face of death and dying in these units and emotional burden on the finiteness of the pediatric patient.

Some lines may illustrate this difficulty experienced by all professionals when providing care to pediatric patients in situations of finitude of life, as described below:

> "Look, death in the pediatric intensive care ... First I think it is very painful, because death does not have to be painful in itself, but the pediatric intensive care she makes the painful death."

> "(...) You have to get stronger before that situation and try not to get involved, try not to let the sadness come regarding the process of dying, because we end up watching."

> "I think it means great suffering for every one of the team, for me particularly because it generates a feeling of incompetence, of people not being able to save that child. So for me it is a very painful process ..."

> "Death is a guess, means the loss of a patient, is a time where all the possibilities of life are exhausted, and you cannot, we as professionals, we can no longer maintain this life and I think that time has come in which we lost the patient."

Studies show that when the admission period is too long, the ties of affection between professional and the child may become more intense, as if they were family. The emotional bond is larger and is related proportionally to the time of admission of the child. However, there are professionals who, to avoid suffering and sense of loss, limited only to technical procedures, avoiding getting emotionally involved with the patient and it may harm care [(4)].

The nursing involvement with hospitalized children can occur naturally and the simple fact that they are children, or their life trajectory. But the involvement of this bond can cause immense pain and psychological consequences for bringing this professional when the child goes to death [(09)].

We can imagine, therefore, that the process of death and dying in the pediatric context events are generating greater feelings of discomfort among nursing professionals, by spending more time than the other professional team caring for these children, seem to create ties of affection stronger. So it is understandable that these professionals exhibit difficulties to cope with the death of a child, reinforcing the idea that being unacceptable for a human being who is starting to live event[(10)].

This behavior of pain and suffering is reiterated in other studies, which highlight that during patient care in the dying process, the professional nursing suffer much, because you feel helpless and unhappy with the presence of death, and its difficulty to accept it as a natural process, before the emotional and psychological unpreparedness to dealing with it [(11)].

The record of the interviewees and obtain the lexical components corroborate what is already well described in the above literature since it became possible to demonstrate through the meaning attributed to the words, what you think and feel the nursing staff in caring of children who experience the process of death and dying, in this UPG that served as the setting for this research.

Pain and suffering are common feelings among humans and may be related to the character of each being. This mixture of feelings may interfere with patient care, because, before technological advances, there were also increased expectation of death and dying, and increasingly, it is possible to intervene and postpone the end of life according to determinations and opportunities encountered by the team [(12)].

The way these professionals assume the reality of everyday life and to care for pediatric patients, with its joys and mishaps in a unit whose technological capabilities are able to postpone death, allows us to understand the paradoxical feelings of grief and relief gifts in his speech, and how emotional security is major factor in regards to overcoming difficulties emotional, for the provision of this care.

Some pros say experience a sense of relief when they come to call and take notice of the death of some patients who were in a situation of finitude, as we can see in the statements below.

> "(...) In a few moments for me this process of death and dying behind me both a distressing

> feeling like sometimes it's a relief, depending on the context." (E 01)
>
> "Then, when death is a sense of loss and failure in some cases, not in others, it's relief. When the child has no prospect of anything, a child who we know will not have future has a bad prognosis is relief."
>
> "Sometimes that happens, death and dying for us sometimes is like a relief, as I had spoken to, both for the suffering of a patient as a family."

In this sense, provide care to children who experience the process of death and dying seems even something very challenging, especially if we consider the "inefficiency" of the training schools of nursing professionals still are based on a biomedical, technical and scientific training in that only healing has notoriety and status of professional success. Thus, supported by therapeutic arsenal and technological support available to the PICU, these professionals are driven to believe that only the healing and restoration are characteristics of good care [13].

Health care professionals are prepared to act against the disease, but are not prepared to work with the sick patient, much less with the patient to death [14]. As a result, we launched on the market a significant number of professionals with little or no ability to assist and care for patients at death and dying, in particular, patients whose death appears to be accidental and unexpected, such as pediatric patients admitted to units intensive, especially care.

At college there is an urgent need to discuss the training of these professionals, from the proposition of training models that transcend the paradigm of healing, including the training of nurses, objectives and content aimed at enabling them to take full care to patient[15].

In this perspective, we believe that comprehensive care requires nurses training enabling you to think, and at certain times, prioritize the care inherent to nursing care and the human dimension, as the more subjective aspects of spirituality, for example, despite the fact already noted, usually of confusion between that and religion.

It must be noted, however, that the lack of studies that address the theme death and dying and how it is thought of in the context of today's world, marked by increasingly intense course of profound social, economic transformations and especially technological seems to hinder the beacon and the advancement in discussions of professional training of the future, considering that the idea of the future today, became very relative.

The fact is that yes there is a gap in knowledge regarding the experience of nurses in relation to the process of death of the child, especially when technologies are brought into the core of the research question, explaining, perhaps, a few studies that explore the experience of the professionals who care for children in these scenarios terminals [16]. So, it is undeniable that this has consequences in how we care in situations of finitude.

However, within this context unprepared some people assign this condition to personal barriers of professionals, ie, it is considered that these difficulties can be provided from the very meanings of death they created throughout his early life. If all health professionals to be able to admit the possibility of our own death, we could achieve many things, standing among the most important the welfare of our patients, families, and perhaps even our country [16].

The feelings expressed in the discourse of these nurses are challenging when it provides nursing care within the finitude of life, in an environment in which they have extraordinary technological resources available for the maintenance of life. The intensity and duration of the sensations of pain, suffering and distress experienced by professional assistance in the pediatric patient in the process of death and dying in the PICU, are only likely to be experienced because of the technological apparatus available which keeps the patient alive, even he faces extremely adverse situations. Paradoxically, the limitations of the technologies on the finitude of life and mortality of the human condition those allow those professionals to experience the feeling of relief when they reach the next shift and no longer find the patient who died.

This paradox makes us think that, in this study, the use of available technologies in the PICU to assist seriously ill patients was not as able to influence how nurses think and behave in the face of death and dying in the PICU, as initially thought, despite the fact that they believe that the more technical ownership in the

world for man to affirm the power of the latter, immortality is more rich and glorious[17].

So the idea that technologies available in the intensive care units are tools able to "protect it" against the reality of death, was not so evident in professional discourse, which to the authors, was a surprise, considering that technical progress may give rise to rational thinking, unable to criticize and dissolve the myth of immortality [17].

The behavior of these professionals on death and dying for their customers, expressed in his speeches, is very interesting and surprising in view of the considerable amount of studies currently available that address the use of technologies under negative aspect, especially in patients in the finiteness of life contributing to the practice of medical futility, compromising the quality of life, increasing the suffering and affecting the dignity of terminally ill people in their life [18].

About suffering and the sense of powerlessness in the face of death, it is believed that is related to possible illusion of professionals with technological advancement, causing them to lose critical thinking itself and consequently leading to greater job frustration due to the high level of expectations generated by his omnipotence [19].

Contrary to the aforementioned study, over half of the nurses from the PICU (fourteen) positioned themselves positively to the presence of technology in the drive, which is understood by them, as a facilitator of nursing care to children with critical care demand, a kind of tool complementary to skilled labor of nursing professionals, facilitating and improving the quality of care, providing benefit to the client, professional and family.

FINAL CONSIDERATIONS

Analyzing the scenario studied, it was realized that nursing professionals when dealing with the process of death and dying children think of death as a sense of loss, as something painful, like the end of a life cycle. These same professionals expressed that to take care of these children suffer during and with the outcome of the process, they often end up forming bond with the child and his family. Others mentioned also feel incompetent when the inevitable happens.

On the other hand, there are those professionals who choose not bonding with the child. This attitude was understood as a coping strategy used by some members of the nursing team in order to avoid pain and suffering. There was also, among nurses who confessed feel relief at the death of the child, they understand the event as the end of suffering for the child, her family and even the professional himself.

In this survey, more than half of respondents said they feel unprepared to care for children who experience the process of death and dying. They themselves attribute this gap to deficiencies in courses and training academies. Additionally, revealed the desire to receive support from specially trained professionals (psychiatrist, psychologist) to be offered by the health institution where they work. It was also suggested the creation of group meetings so that they can express and hear experiences on caring for patients at end of life, as a form of emotional relief.

On the question of preparation for dealing with the process of death and dying children and coping strategies, religiousness / spirituality was cited by nurses as an ally, because that way, they claim gather strength to face the situation in a less traumatic and relieve pain, distress and suffering senses.

With regard to technology and its possible influences on the process of death and dying, nursing professionals have surprisingly different position compared with that of nursing research that address the same subject. While these research reports noted that technology contributes to the therapeutic obstinacy and prolonging life at any cost, hurting the dignity of the patient, the nursing staff in this study perceives technology as a facilitator of care for children in need of critical care.

MORTE E MORRER NUMA UTI PEDIÁTRICA: DESAFIOS PARA CUIDAR EM ENFERMAGEM NA FINITUDE DA VIDA

RESUMO

O objetivo do estudo foi Analisar a relação entre o ambiente marcadamente tecnológico da Unidade de Terapia Intensiva Pediátrica - UTIP e o modo como pensam e se relacionam os profissionais de enfermagem com a realidade da morte e do morrer nessas unidades. O método foi qualitativo. O estudo foi realizado com 24

profissionais de enfermagem de uma UTIP da rede pública de saúde do Rio de Janeiro. Os dados foram produzidos a partir da entrevista semiestruturada e submetidos à análise temática e léxica. Os resultados revelam que a equipe de enfermagem percebe a tecnologia como capaz de aproximar o profissional das crianças em condições críticas, não inviabilizando, portanto, a possibilidade de se pensar na dimensão suprassensível do cuidado de enfermagem diante de situações nas quais a morte já não pode mais ser evitada, dada ao curso natural da doença.

Palavras-chave: Atitude frente à morte. Cuidados de enfermagem. UTI Pediátrica.

MUERTE Y MORIR EN UNA UCI PEDIÁTRICA: RETOS DE LA ATENCIÓN DE ENFERMERÍA EN LA FINITUD DE LA VIDA

RESUMEN

El objetivo del estudio fue analizar la relación entre el entorno marcadamente tecnológico de la Unidad de Cuidados Intensivos Pediátrica - UCIP y la forma cómo piensan y se relacionan los profesionales de enfermería con la realidad de la muerte y del morir en estas unidades. El método fue cualitativo. El estudio fue realizado con 24 profesionales de enfermería en una UCIP de la red pública de salud en Rio de Janeiro. Los datos fueron producidos a partir de la entrevista semiestructurada y sometidos al análisis temático y léxico. Los resultados revelan que el equipo de enfermería percibe la tecnología como capaz de aproximar el profesional al niño en condiciones críticas, no haciendo inviable, por lo tanto, la posibilidad de pensarse en la dimensión suprasensible de la atención de enfermería delante de situaciones en las que la muerte ya no se puede más evitar, teniendo en cuenta la evolución natural de la enfermedad.

Palabras clave: Actitud frente a la muerte. Atención de enfermeira. Unidades de Cuidado Intensivo Pediátrico.

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Corresponding author: Rua Luiz Beltrão, nº1.326, bl 1, apto 403. CEP: 21321-230. Praça Seca, Rio de Janeiro – RJ. E-mail: enfebsan@ig.com.br.

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