








The diverse faces of child death from the perspective of doctors and nurses

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ABSTRACT

Introduction: Sickness and death of children are little accepted events in society. **Objective:** To analyze the perception of intensive care doctors and nurses about the death of children. **Methods:** Qualitative approach study, with doctors and nurses from three Intensive Care Units (Pediatric ICU, Neonatal ICU and Cardiological ICU) of a teaching hospital. Recorded semi-structured interviews were carried out, transcribed and analyzed according to content analysis in the thematic modality. **Results:** 14 professionals were interviewed, aged 28-53 years, with a minimum of 2 years of intensive care experience time and an average of 43 hours of work per week. The feelings and attitudes towards death emerged from the speech analysis and were categorized in the following themes: perception of death in childhood, therapeutic obstinacy and suffering in meeting with families. Professionals recognized gaps in training during undergraduate and graduate studies to deal with the death of children. Suffering, anxiety, guilt, frustration, impotence and guilt were reported, demonstrating the complexity of child death situations. The clinical condition and the child's ability to interact influenced the attitudes and the professional's way of dealing with death. Spirituality was an important mechanism of confrontation. **Conclusion:** The death of children in ICU causes ambivalent feelings in doctors and nurses responsible for their care. Professionals suffer for the death of someone who has not yet enjoyed life, but accept it when they think about the end of a life marked by suffering and limitations imposed by the disease. Contact with the subject of death during professional training and in the regular discussions of services can help in the way to deal with this event. Spirituality was an important resource of coping.

Descriptors: Death, Attitude to death; Child, Critical Care, Qualitative research; Hospitals.

Descriptores: Muerte, Actitud Frente a la muerte, Niño, Cuidados críticos; Investigación cualitativa, Hospitales.

INTRODUCTION

Throughout the evolution of humanity, has presented different meanings that vary according to the role they play in the family at each historical moment [1]. Since the beginning of the 20th century, with pediatrics and childcare as specialties, children have been entitled to medical care. This context, added to the reduction in the number of children and changes in family dynamics, made death in childhood a little accepted event in society [2].

Many organizations around the world have worked to develop Health Policies capable of reducing child mortality. The emergence of Pediatric and Neonatal Intensive Care Units (ICUs) has contributed to increasing child survival. Over the years, there has been an increase in the number of these units and the specifics of the work developed in them [3]. These professionals deal daily with complex situations that involve, in addition to the expected death, as occurs in chronic cases of incurable diseases, the unexpected death

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of children hospitalized in ICU, affected by acute diseases or accident victims [1,2].

Death is part of the life and daily life of the health professional, becoming almost his work companion [4]. In spite of the attention focused on the development and technical-scientific capacitation of these professionals, there is still little investment in the way they deal with their emotions [4-5], just as there are still few publications related to the theme [6].

Professionals who care for critically ill patients at high risk of death are distressed by this daily proximity [2]. This feeling can be aggravated by the specificity of child care, which involves the personal anguish of the child itself and its family [5]. Seeking a better understanding of the theme, this research aimed at analyzing the perception of doctors and nurses regarding the death of children in the ICU.

METHOD

Qualitative research approach was performed in the Pediatric, Neonatal and Cardiological ICU of a university hospital in a capital city of the Brazilian Northeast.

The three units of the study have multi-professional teams composed of doctors, nurses, physical therapists, psychologists, social workers, nutritionists, nursing technicians, and other professionals. Inclusion criteria were to be doctor or nurse developing their professional activities in one of the units of interest for this study, for a minimum of six months. Specialists who responded to medical interconsultation or professionals from other units that eventually provided assistance in these units were not included. The decision to interview doctors and nurses took into consideration that they were the professionals most directly involved with the pre-death treatment decisions, with their confirmation, with the series of events that followed and with the communication of the news to the family.

In these units 53 doctors and 41 nurses worked. About 90% of the doctors and 30% of the nurses also worked in other neonatal and pediatric ICUs in the city.

The selection of the sample was intentional and sought to contemplate professionals from different services (neonatal, pediatric and cardiology ICU), the diversity of characteristics of the participants (men and women, older and younger, with more and less training time) as well as the different work regimes (on duty and day workers). In this way, professionals were invited so that the sample would reflect the totality of the multiple dimensions of the investigated subjects. The sample closing, 14 interviews, was made by the saturation criterion, understood as the moment of field work in which the data obtained are sufficient for the researcher to understand the internal logic of the researched group [7].

The data collection technique was a semi-structured interview conducted by the principal researcher. Two previously elaborated instruments were used for this research: questionnaire with closed questions for the identification and characterization of the interviewees and an interview script with open questions seeking to contemplate the contact of the interviewer with the theme death during graduation and post-graduation; experiences with the death of children in professional life and with the news of death; perception about the relationship with the critical patient and his family, besides cultural influences in the way of dealing with death. The interviews were conducted in a single meeting with an average duration of 40 minutes, recorded and later transcribed.

The data were analyzed using the thematic modality of content analysis, which searches for the manifest and latent meanings in the speech of the interviewed subjects [7].

The research was approved by the Research Ethics Committee, ruling nº 035/10. In order to preserve the identity of the interviewees, the names were replaced.

RESULTS AND DISCUSSION

Fourteen professionals were interviewed, seven of them doctors and seven nurses. The physicians were 28 to 42 years old, with graduation between 4 and 17 years and about 1 to 15 years in the ICU, five women and two men. Among the nurses,

age ranged from 30 to 53 years, time of graduation between 6 and 27 years, about 5 to 21 years of performance in the ICU, six women and one man. The Catholic religion was predominant among the interviewers. Regarding the average workload in the ICU, the doctors informed up to 47 hours per week and the nurses up to 33 hours in at least two different services.

The lines revealed contradictory feelings and postures, demonstrating the complexity of the situations experienced. These feelings were also mediated by the specificity of dying in childhood. According to the interviewed professionals, religious beliefs, lack of training, and previous personal experience influence the way of dealing with the death of children in the ICU.

For the interviewers, the expectation in front of a child admitted to the ICU, in general, is that he/she will recover and return home, however, this is not always the real outcome. The feelings and attitudes towards death emerged in three major themes: the perception of death in childhood, therapeutic obstinacy and suffering in meeting with families.

It has been found that the death of a child is considered a painful experience both emotionally and physically, especially when this death occurs unexpectedly.

The feelings of guilt and frustration were recurrent in the speech of the interviewers, who also revealed, impotence in the face of these situations. Even those experienced and technically capable, questioned their conduct.

We feel powerless. You've done so much and failed to save... You do everything... and it didn't work out and you lost the patient... If you feel guilty, you think you could have done more (Ella, 30 years old, nurse, 5 years in ICU).

We keep asking ourselves if we could have done more, if we could have prevented death. Did I do everything right? Was there anything missing? (Everton, 34 years old, doctor, 6 years in ICU).

The feelings of pain, sorrow, frustration, sadness, and self-judgement were also portrayed in other studies by professionals who assisted pa-

tients on the verge of death [6,8]. And although the manifestation of these feelings occurred in a generalized way among participants from different clinical areas, it was identified that professionals who assisted only children and adolescents gave more emphasis to their suffering [9,10].

Professionals are prepared to defeat death, but not to live with it, thus their feelings of guilt and powerlessness intensify when the patient is a child because life interrupted so early by the disease meets the cultural values about childhood [11-13].

Even for those professionals who manage to understand their limitations in the face of death, there is doubt as to whether, in fact, there was nothing more to be done in the face of that situation.

This is where the difference between the technical and the emotional comes in. You are technically aware that you couldn't have done anything else, but emotionally you think you could have. It's a kind of weird thing. (Elizabeth, 35 years old, doctor, 11 years in ICU).

A study on the perception of nursing professionals facing the death of newborns in ICU pointed out that each death must be seen as unique, where the professional must not assume a posture of non acceptance or non-conformism with its occurrence, but rather perceive this phenomenon as an intrinsic part of the life cycle[6]. Although death is an inherent condition to life, when it occurs in children it is more painful and a reason for non-conformism on the part of professionals: "admitting the death of a child or adolescent seems to take away hope, placing us before the premature end of an existence" [14,15].

For those interviewed, the death of adults and the elderly seems to be more easily assimilated, since they have already had the opportunity to live, differing from the child, who has a world of possibilities ahead of him.

This difference between adult and child is very clear in my head. From a child who hasn't lived at all, it's as if we've taken away the opportunity to live... (Elizabeth, 35 years old, doctor, 11 years in ICU).

Child... it seems that we feel that it is not the age to die. The elderly, we face [death] more easily (Elio, doctor, 34 years old, 2 years in ICU).

(...) Because it is not normal for the child to die before the parents (Emma, 40 years old, nurse, 10 years in ICU).

There are many reasons why death is not faced in a calm way and the main one is that to die, nowadays, is very sad, lonely, impersonal, mechanical and inhuman. It does bring suffering to not only the patient and his family, but also the professional, even if, consciously, he does not realize it. "The further we advance in science, the more we seem to fear and deny the possibility of death" [16].

The admission of a child to the ICU is usually due to a life-threatening condition that is often irreversible. In these situations, professionals recognize the seriousness of these patients and the imminent approach to death. The suffering of the child and the family, often prolonged, led professionals to understand death as the necessary end - the good death, which leads to the end of suffering - of the child, the family and, also, the team. For some professionals this death is acceptable.

Depending on the child's situation we suffer, but sometimes with more peace of mind because we know that her suffering would be much greater... (Elvira, nurse, 37 years old, 5 years in ICU).

Health professionals added another issue that needs to be discussed in their speeches. For them, the attitude of the professional changes before this situation.

I think: is it worth it? That child will suffer so much! Will the problem be solved? So we invest, but it is in a different way (Elio, doctor, 34 years, 2 years of ICU).

A child with severe congenital malformation, anencephaly, hydranencephaly or brain death, I do not reanimate. I think he may die. And if I die, I turn the device off,

register the death, and think that bed may serve to save another child... (Eden, 34, doctor, 2 years in ICU).

The inability to recover and the pain and physical limitation imposed on children, are factors that soften the feeling of impotence and failure of the professional related to death [13,17].

For nursing professionals, the ability to promote comfort and support to families during the process of death is a significant experience and they consider it essential to dedicate themselves to the context of the child and the situation of the family so that they have the opportunity to be honest and hopeful, but also to remain impartial to help in the final period of a peaceful life without suffering [18].

During ICU care, the decision not to use certain therapies, technologies and treatments when they are already useless for some patients does not mean abandoning them and interrupting the treatment, but rather, the contribution to fight suffering and pain, including palliative care [15,19].

Regarding therapeutic obstinacy, for some interviewers, even with the regulation of orthothanasia, individual practice often does not change because it is directly related to personal, ethical and moral values. Some interviewers expressed insecurity regarding the interruption of treatments, even when faced with the inevitability of death.

So... I stop vasoactive drugs, I switch off everything... except the mechanical ventilator, I don't have the courage. I imagine when we get to the stage that is determined like this: we have to turn it off. I'm the one who will be on shift and will tell my colleague: 'Honey, I don't have the structure for this! (Elena, 39 years old, doctor, 10 years in ICU).

You want a central venous line and go there and keep trying... trying... you can't do it anymore, but you want to! When the person is reanimating it's the same thing. They want to make it! (Elizabeth, 35 years old, doctor, 11 years in ICU).

This selfishness, in quotes, of the parents, I think is a pressure on us to want to stay resuscitating (Elena, 39, nurse, 10 years in ICU).

The lines contextualize the limitations and psychic suffering that accompany the chronic and/or irreversible pictures, leading to dysthanasia. The attempt to fight death at any cost, prolonging suffering, sometimes unnecessarily, is a form of dysthanasia [20], a reality still very present in the ICU, especially in pediatrics, where the prognostic evaluation is not always clear [21,22].

The attitudes and feelings of professionals towards the death of children are controversial. Orthothanasia, the non-performance of obstinate or even futile actions to postpone death, has been regulated, bringing the discussion of acceptance of death that interrupts suffering for which there is no therapeutic possibility, but it is still a point of discussion in the ICU, especially in pediatrics [23,24].

The moment of defining the irreversibility of disease is variable and depends a lot on evaluating the professionals involved in the care of each patient. In children, this definition is even more complex because, besides representing a tragic situation, the expectation of reversal of the acute condition is always present and becomes the main objective of the care team, taking into account the great capacity of recovery of pediatric patients [17,25,26]. In this scenario, palliative care contributes to fighting the suffering and pain present in children in ICU when technologies and certain therapies are useless [15,19].

Personal beliefs also seem to help in coping with the death of children. The doctors and nurses in this study used religion as a reason to justify therapeutic obstinacy.

(...) because from an emotional point of view it is more comfortable to believe in God... (Elio, doctor, 34 years old, 2 years in ICU).

(...) when I started to read about spiritism, I started to face death more naturally, because they try to explain the whys when a neuropathy is born, annoyed... (Elvira, nurse, 37 years old, 5 years in ICU).

I take religion a lot to my work, we trust in God and deliver what we do, that's what makes the wheel move (Eudora, 40 years old, nurse, 9 years in ICU).

Spirituality, religious belief or even personal convictions can guide one's conduct in both personal and professional life. Thus, having clarity of the influence of religion and doctrine allows the health professional to feel less guilt and failure before his work, accept death and even explain it [27-29].

Another aspect that also influences the handling of death is the contact with this subject during undergraduate or graduate studies, which many professionals in this study, have recognized as scarce.

If it was spoken, it was something without much emphasis, right? Without much concern even from our trainers in talking about it. About the question of death, about how... so to try even to guide, how to behave, how to act, how to talk to a relative who had that loss at that moment... (Eden, 34 years old, doctor, 2 years in ICU).

This aspect has been discussed as a generator factor of anguish and stress [30]. In the university, the vision of finitude, as a possibility, is not discussed. Patients are often reduced to the disease that must be fought, avoiding death. Even in palliative medicine classes, the time allocated for discussions about death, finitude and communication of difficult(bad) news is insignificant, generating a gap in knowledge and skills that can impact their attitude towards death [30].

Studies indicate that the inclusion of the topic "death" is still considered insufficient during graduation [31]. Medical schools should allow medical students to have contact with dying patients, since in their research the students and recent graduates attest that the lack of this contact left them "in the dark" and thus did not know what to offer patients at the end of their lives [31].

According to Avellar and Rocha [31], the difficulties of these professionals in the face of death could be reduced if they had the opportunity to talk about death and dying during their academic training as well as to express their feelings, that is, to have contact with death itself and receive

psychological support whenever emotional fragility manifested itself. In this way they could elaborate their difficulties of confrontation without having to camouflage or repress their feelings.

The speech below represents the suffering of the team in meeting with the families.

What makes me suffer is seeing the suffering of mothers and fathers! What makes me cry are the words that mothers speak (Elio, doctor, 34 years old, 2 years in ICU).

(...) is that the mother grabbed her lap when she died, understand? She grabbed her lap and that's always terrible. Traumatizing (Eliasa, 44 years old, doctor, 10 years in ICU).

From the perspective of the interviewers, it can also be understood that if on the one hand identifying with the patient can cause more suffering on the other hand, it can lead them to show empathy and thus strengthen the professional-patient relationship, leading to more humanized behaviors.

I think that getting closer, trying to be a little more truthful and less professional, I think you are more human (Everton, 34 years old, doctor, 6 years of ICU).

Family members seek to gain confidence in the health professional through technical procedures and differentiated attention[5]. However, for many professionals, emotional detachment is a way to protect themselves from suffering and pain [27,32,33], weakening the doctor-patient-family relationship.

In addition, personal experiences, such as the birth of children, modify the perception of professionals regarding the death of children and influence the way of confrontation.

Before I had my daughter I thought that child was like any other, any patient, but after I had my daughter... in the beginning, mainly, it was horrible! Because every time I saw a child here having a bad time, when

I got close, it was amazing! I looked at my daughter (Everton, 34 years old, doctor, 6 years in ICU).

When I remembered that the child had died, I spoke: my God could be my daughter (Eduardo, nurse, 44 years old, 21 years in ICU).

Studies on the emotional impact of the death of children in nursing professionals pointed out that a closer relationship with the hospitalized child or physical characteristics similar to those of the children themselves weakens them and leads to the idea of failure, leading to situations of anguish and stress in a greater proportion and making their recovery difficult [26,30].

Even though they experience intense feelings of pain, almost comparable to that of the family, health professionals who care for children in an end-of-life situation perceive vulnerability and identification with the family as an opportunity to mature and grow professionally and thus be able to assist in the recovery after the death of a child in their care [32].

CONCLUSIONS

The death of children in ICU causes ambivalent feelings in doctors and nurses responsible for their care. On the one hand, if professionals suffer the death of someone who has not yet enjoyed life, on the other hand, they accept it when they think about the end of a life marked by suffering and limitations often imposed by the disease.

The contact with the theme death during the professional formation and its inclusion in the regular discussions of the services can help deal with this event in the day-to-day assistance.

In addition, spirituality was an important resource for confrontation. Having a religion seemed to re-signify death as an inherent condition of human existence and, therefore, a more acceptable event reducing the pain and suffering of professionals in the face of the death of a child in ICU.

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