ABSTRACT

Objective: to know the nurses’ experiences regarding the process of death / dying of the child admitted to the Neonatal Intensive Care Unit. Method: it is a descriptive study, with qualitative approach and content analysis. Data collection was performed by semi-structured interviews, which were conducted with six nurses of a Neonatal Intensive Care Unit from a university hospital in the Brazilian south, in accordance with the approval by the Ethics Research Committee from the Universidade Federal do Rio Grande/FURG, under CAEE nº. 23116003627/2008-86. Results: from the analysis of the interviews, three categories have emerged: The conflict between the idealized and the experienced; The living of negative feelings; The sharing of the death process with the family. Conclusion: it was possible to verify that this unit is a critical place which imposes to the professionals who work there the daily coexistence with the boundary between the life and the death. Descriptors: Death; Newborn; Intensive Care Units; Nursing.

RESUMO

Objetivo: conhecer as vivências de enfermeiras quanto ao processo de morte/morrer da criança internada na Unidade de Terapia Intensiva Neonatal. Método: estudo descritivo, de abordagem qualitativa, com análise de conteúdo. A coleta de dados foi realizada por meio de entrevistas semiestruturadas, as quais foram gravadas com seis enfermeiras de uma Unidade de Terapia Intensiva Neonatal, de um hospital do sul do Brasil, conforme aprovação do Comitê de Ética em Pesquisa da FURG, sob CAEE nº. 23116003627/2008-86. Resultados: a partir das análises das entrevistas, emergiram as três categorias: O conflito entre o idealizado e o vivido; A vivência de sentimentos negativos; O compartilhamento do processo de morte com a família. Conclusão: foi possível verificar que essa unidade é um lugar crítico que impõe aos profissionais que lá atuam a convivência diária com o limite entre a vida e a morte. Descritores: Morte; Recém-Nascido; Unidades de Terapia Intensiva; Enfermagem.

RESUMEN

Objetivo: conocer las vivencias de enfermeras cuanto al proceso de muerte/morir del niño hospitalizado en la Unidad de Terapia Intensiva Neonatal. Método: estudio descriptivo, de enfoque cualitativo, con análisis de contenido. La recolección de datos se realizó a través de entrevistas semiestructuradas, que fueron grabadas con seis enfermeras de una Unidad de Terapia Intensiva Neonatal, de un hospital en el sur del Brasil, según aprobación del Comité de Ética en Investigación de la FURG, bajo CAEE nº. 23116003627/2008-86. Resultados: tras el análisis de las entrevistas, emergieron las tres categorías: El conflicto entre el idealizado y el vivido; La vivencia de sentimientos negativos; El compartir del proceso de muerte con la familia. Conclusión: fue posible verificar que esa unidad es un lugar crítico que requiere a los profesionales que trabajan en ella la convivencia diaria con el límite entre la vida y la muerte. Descriptores: Muerte; Recién Nacidos; Unidades de Cuidados Intensivos; Enfermería.
INTRODUCTION

The life cycle is composed of born, grow, reproducing and die. Although natural, the contemporary man, perhaps by increased life expectancy, tries to delay as long as possible such a moment, by interpreting death as an opponent to be tackled. Such a fact, in spite of being inevitable, is not a simple matter to be discussed, since, in our culture, is not accepted.  

In hospitals, the death/die process is still little debated and questioned among nursing professionals, and those are the individuals who - perhaps - are more exposed and affected by it in their daily work.. 2,3 The Intensive Care Unit (ICU) is considered one of the most complex places in the health system, since the sickest patients are allocated in this sector, demanding the use of advanced technologies, requiring trained staff to quickly make decisions and take the necessary measures. Neonatal ICUs were created in order to save the lives of children at imminent life risk.

At this place, complex procedures are performed and, sometimes, invasive, coupled with the use of powerful technologies have been able to save and prolong the patients’ lives. However, death is present in this sector, as part of the daily lives of professionals who work in such a sector. Study on the psychological distress of nursing workers in care of hospitalized children found that they (healthcare professionals) consider more painful when death reaches a child, which causes anxiety and even impotence. 4

Despite the death is part of their everyday life, it should be observed that these professionals have difficulties to provide care to patients and interact with its family members before such a possibility, since it generates feelings and reactions that often cause suffering. 7,8 The death/die process is still little debated and questioned among healthcare professionals, by being a not widespread theme in the academic and professional scopes. In the Neonatal Intensive Care Unit (NICU), one of the great challenges of Nursing is to face everyday situations of care of people who are at imminent life risk.

It should be realized that professionals want to suppress the body illness, in order to overcome the death or, at least, postpone it when extolling the life as supreme value. 9 What is sought is the healing and there is little emphasis on questionings, conversations and reflections about the death/die process. Despite the death in the NICU be frequently experienced, this is not accepted and neither expected, since there is always the expectation that the infant will survive.

Professionals who deal with death in their practice, do it in a painful way, because caring for a patient in case of death/die process requires the understanding of the complexity of such a process and the factors that limit their care act. 10 Thus, in spite of the coexistence with death at the NICU, it should be checked that this matter is still a taboo for members of the Nursing Team, which avoid to talk about it.

Therefore, it becomes necessary that the intensive care unit worker finds a space where he/she can talk about these emotions, so that the interactions which take place in this environment are less conflictual. 5 Professionals should be helped in coping this process, through the humanization of the hospital environment, assisting them in their emotional preparation so that, before the process of death and dying of the child, execute care actions in an ethical and professional manner. 11

Thus, the guiding question of this study was << What are the feelings of NICU nurses before the child’s death in this sector? >> From this questioning, the study objective was to know the nurses’ feelings about the process of death and dying of the child admitted to the NICU from a university hospital in the Brazilian south.

It is believed that this study may assist NICU nursing professionals to reflect on their experiences of dealing with death, by seeking strategies for coping it.

METHOD

The current study was extracted from the Final Report of the Scientific Initiation Research Project/CNPq/FURG << The perception of members of the nursing staff about the process of death/dying of the child admitted to a neonatal ICU >>, in force from August 2008 to 2009. For this study, we have opted for a descriptive qualitative research. This type of research seeks to incorporate the meaning and intentionality regarding the acts, relationships and social structures, involving their transformations, as significant human buildings. It works with the meanings, reasons, aspirations, beliefs, values and attitudes, and it is not quantifiable, since it involves the meaning of relationships of processes and human actions. 12

It was developed in the second half of 2008, in a NICU from a university hospital in the Brazilian south, which is considered large
due to possessing more than 150 beds. The NICU is the hospital dependence in which the newborn is admitted to receive intensive care. The unit has nine beds and serves infants from zero to 28 days of life.

The study participants were six nurses who work in shifts morning, afternoon, night 1 and night 2 and met the inclusion criterion: working for more than six months in such a sector. We have excluded the nurses who were on vacation and leave in the period of data collection. After oriented about the study objectives and methodology, the participants signed the Free and Informed Consent Form. This agreement was signed in two copies, being that one copy was given to each participant.

Data collection was carried out by means of single semi-structured interviews with each participant. These interviews addressed issues with regard to the of nurses’ experiences before the death in the Neonatal Intensive Care Unit. Participants were invited to participate in the study at the prescription room of the aforementioned unit, during the work period of nurses, being that the interviews were previously scheduled. Next, they were recorded and, subsequently, transcribed.

The obtained data were analyzed using the Content Analysis Technique, which was operationalized through pre-analysis, material exploration and results processing, data interpretation and inference. At the pre-analysis, we held the transcription of the recordings, fluctuating reading of the data, constitution of the corpus and reformulation of the objectives. At the phase of material exploration, the data were read and subdivided into three categories. At the phase of inference and interpretation of the data, the emerged categories were discussed in the light of scholars who contemplate the issue at stake.

All ethical principles of the Resolution 196/96 of the National Health - Council Conselho Nacional de Saúde (CNS), which regulates researches involving human beings, were taken into account. The project was sent to the Ethics Research Committee and approved by the Certificate Presentation for Ethical Consideration - Certificado de Apresentação para Apreciação Ética (CAEE) nº 23116003627/2008-86, receiving a favorable assent to its publication under Protocol nº 96/2008. The nurses’ speeches were identified by the letter E, followed by the number of the interview, as a way of guaranteeing their anonymity.

RESULTS

Data analysis has generated three categories: The conflict between the idealized and the experienced; The living of negative feelings; The sharing of the death process with the family.

• The conflict between the idealized and the experienced

Before the death of a child that could have chances of recovering, the nursing professional may come into conflict due to feeling that she has failed in her mission and wonder what more could have been done, as if all that performed investment had been made in vain.

I always think in a hypothetical sense of what could have been different. That something could have been happened at some point and that would change the outcome in the end. That if the antibiotic had been another, or if we had made such an examination and did another, or if we had started feeding earlier or if we had not started feeding. It’s very conflicting. This brings about the feeling that we have failed in our mission. In general way, I see everybody feels itself really frustrated, failed (E4).

Another conflict experienced by the nursing professional before the death of a child at the NICU is a sense of professional failure. She feels powerless before the death of a child that could have chances of recovery and that progressed to death.

When it happens the death of a child that had all the conditions to be well succeed, without sequelae, and, suddenly, has a sudden worsening and dies. It awakes in me a sense of failure. Because all I did was not worthy. So it seems that I did not it right, that it should have done more and better (E3).

It should be evidenced that the professional may feel that was not completely competent. Therefore, it would emerge the feeling of failure, in relation to something that should have performed in another way, but had an unexpected outcome.

And there is something like this, we stop and think if, at some point, was it our fault? Will at some point we missed something? Did we see what should have seen? (E2)

But I think we always get involved as a healthcare professional. This is tricky to deal because beyond the death itself, it seems that you were not competent enough. We have a sense of failure, because we deal with human beings it seems that all thing that had to be right did not work, but this is not the truth (E5).
The death experience of a child can generate internal conflicts in a professional whose mission is to save lives. When the death prognosis clearly cannot be avoided, to perform invasive procedures and others seems to be contradictory and causing suffering and, therefore, unnecessary.

I know, as a nurse, I have to preserve the life, fight and use all available resources for sustaining the life, but it seems contradictory. In some situations, the prognosis is death and you stay questioning yourself: why so many invasive procedures? Make the baby suffer even more. But reason prevails and I keep to perform my duties (E1).

It was found that the time to stop trying to rekindle the child is very conflicting and causing intense suffering for all members of the involved team, mainly, the time to decide the exact moment when the death has occurred.

I see on the faces of the doctors, nurses, nursing technicians when serving the urgency and the resources end up. So, to know the time to stop is tricky for everyone. It is a responsibility that falls primarily upon doctors. And if we could try something else, in clinical terms? Thus, I think it is very conflicting. It’s even confusing. Everything happens. Wish of crying, screaming. It is a great suffering! (E4)

The nurses reported having hurt due to thinking that such a baby was born with no chance of survival. They feel hurt, because their work is done in a view of all admitted babies survive and, unfortunately, this decision is not up to them.

Furthermore, there are cases that I get pretty bored, even upset, by knowing that occurrence is the best for them, which are neurologically impaired babies or who actually do not have the chance of survival. What if they survived, they would be totally dependent. We are not here to decide who stays and who goes. We are here for that everyone is discharged and you cannot do it, sometimes (E1).

We are not here to decide who lives and who dies. We work to save all (E4).

• The living of negative feelings

The nurses reported that they felt more shocked by the occurrence of death when they started to work at the ICU. Over time, the feelings vary according to the clinical case. When a child is diagnosed as at risk of death, it appears that the team prepares itself for the occurrence of such a process, by considering it like natural.

Initially, I got quite shocked. Now I’m no longer, it depends on the cases. When babies are very small, premature. The one who arrives and that is extremely premature and that you know that the chances are extreme, very small, then I feel its death as a natural happening (E1).

Nonetheless, in spite of preparing themselves for the experience of death, nurses can demonstrate fear, both in relation to the unknown or what they have no control. It should be verified that the child’s death can remind the professional about its finiteness, and the fear of what comes after death can affect the worker, by generating feelings of fear.

I think it’s more the fear of the unknown. The word death is a word for which you have not the real meaning, about what will happen, even you having a religious background. It lets me afraid of what I do not know, what I do not control (E5).

What happens to a person who dies? We do not know, I do not know. Everyone will die one day, but working at the ICU and coexist with the child’s death reminds us that each time. It brings about fear, fear of what will happen to this child, to us in the future (E2).

The feeling of guilt can emerge when the nurse wonders if, somehow, contributed to this tragic outcome.

I feel guilty when, for some reason, I did not detect that the child had changes in its clinical status. I think I had not the perception and immediately did not notice, by taking appropriate measures to avoid the death (E1).

I feel very bad and with feeling of guilt. It’s very different when you immediately identify that there was a worsening of the clinical status and immediately intervene (E4).

There is a sense of sadness and emptiness when the deceased child remained hospitalized for a certain period, providing the team the building of a bond when taking care of it.

Look, not only under my care, but any patient who is here at the ICU, because we get unwell or well for everywhere and some children stay admitted for two, three, five, six months. We get attached to them and stay very sad. It is like our own children. It’s a great sadness, an empty that a so small child has left (E3).

It should be highlighted that nurses demonstrate anguish before the revelation of death to the child’s family.

That was horrible. I got very disturbed, especially when I had to give the diagnosis for the family (E2).

The worst anguish is informing the parents. In my opinion, the hardest is to call parents and tell it (E6).
Nurses’ experiences before the death…

Several times, when informing the child’s death to the family members, the nurse realizes the demonstration of gratitude from them. Such a gratitude comes from their attitudes towards the child, ie, for everything that was performed for her. The sharing of the death process of the child with its family members also generates the sharing of their suffering. This appears to be greater when, confronted with the news of the child’s death, the family still proves to be grateful to all healthcare workers due to everything that was well made by its infant.

Because the female doctor asked me to go until the door to give the news to the mother (that the baby was very sick) and did not say that he was dead. It’s even worse to see the father say like this: - Oh, I know you did everything you could do. Yep, we did everything, but the child has died. I felt completely powerless at that moment (E2).

**DISCUSSION**

The daily living with the suffering and the possibility of death occurrence does not relieve the professional from the living of conflicts and the expression of negative feelings. The nursing professional is in the midst of a scenario of diversity, a constant challenge, since he/she daily lives in strife, by fighting for the life and against the death.1,5

It should be evidenced that the conflict occurs, since the nurse takes upon itself the responsibility to heal, save and/or ease pain, always trying to preserve the life. The death is seen as a failure; therefore it is always steadily combated, thus avoiding the most the life expiration.1,13 Another reason of conflict, when the death prognosis is expected, is the conduction of invasive procedures, since they are considered unnecessary and a source of suffering.5,16

The therapeutic procedures to be instituted, usually, are medical criteria. Nevertheless, they reflect on the work of the healthcare team as a whole and, specifically, in Nursing, that, when performing therapy methods with which it does not agree, can intensely suffer, by questioning the values that underlie its practice. It should be verified that the therapeutic obstinacy, present in ICUs, is still little discussed, mainly by nursing professionals, who are responsible for implementing procedures with which, often, may disagree.16,17
In relation to the living of negative feelings, it should be verified that the death can leave in its place a feeling of emptiness and pain, since the preservation and extension of the life are their objectives, and may feel unable or frustrated when they do not get success in their striving.1,16 It should be observed that understand the death as the solution of the pain, the anguish and the entire process which surrounds the die fact is one way that nurses find to protect themselves against the psychological distress arising the loss of the patient.18,19

A study that aimed to describe and analyze the living of the nurse in the process of death and dying of oncological patients showed that nursing professionals demonstrate in their speeches a great anxiety and sense of emptiness in dealing with the death. They try to deny it, since this constitutes a painful phenomenon and hard to accept.17

It was found that they feel guilty before the the child’s death, perhaps because they are prepared to save lives, by denying, in some way, the conception of end, that is to say, the biological death. Their effort focuses on saving the child and not on understanding their finitude. They are prepared in the academic life to defeat the death, but when it wins, they feel guilty.18

They have feelings of loss, fear, pain and sadness when giving meaning to the word death, meaning that is determined by the socio-cultural context in which the professional is inserted, their daily experiences, inside and outside of the hospital scope, and in their religion.11

The end-of-life is inherent to every human being. A death within the NICU is first and foremost a great loss, provoking feelings of emptiness and anguish among those ones who deal with children in this environment.2,3 It is noticed that, no matter if you have done, as far as possible, to save the patient, the lethal outcome is not accepted, generating feelings of frustration, sadness, loss, powerlessness, stress, professional failure, and guilt in the healthcare workers who face the death at their workplace.15,20

The sadness is a feeling intrinsic to the human being; all people feel this way at some point in their lives. The professional who work at the ICU is close to critical situations and, therefore, becomes vulnerable to them.8,21 The pain and the grief due to the loss of the child make the death process sadder. The suffering is a normal and important answer, and it is necessary that the professional prepares its mourning to get going ahead strengthened.6

During the hospitalization of the child in the NICU, the professionals of the nursing staff share the death process with its family, by interacting with their members. At the time of the child’s death, they put themselves in the child’s place, by feeling sad and by living, partly, its mourning. Thus, the death constitutes a striking aspect in the trajectory of the nursing professional, since it highlights his/her ability to identify that the family needs of care to face such a moment.2

By keeping up all the time next to the child, when giving him a direct care, there is an emotional involvement with this being and its caregiver family member.1 Hence, it makes narrow the bond between the patient and the healthcare professional, and this last one is subjected to psychological distress when watching its death and the suffering of its family. It may seem that the guilt goes to the Nursing, which would not taken the proper care.8

It becomes, then, necessary to sensitize nurses and their team for not considering the death experience as something fragile, shameful, surrounded by negative feelings, but as an opportunity to extend the care, from the perspective of comfort, by providing effective and resolute support.22 To learn to deal with the death without losing the sensiveness can mean to transform the encounter with the child and its family in dialogic moments of true encounter, by giving meaning to the professional doing.23

CONCLUSION

Through this study, we have aimed to understand the of nurses’ experiences about the process of death / dying child of the admitted to the NICU from a university hospital in the Brazilian south. Concerning the conflicts between the idealized and the experienced, nurses reported feeling that failed in their mission to save lives; nursing workers suffer from the accomplishment of invasive procedures that they consider contradictory before the certainty of the child’s death; they believe to have failed as professionals and have difficulty to decide about the time to stop trying to rekindle the child and certify its death.

The data has highlighted that the death is causing negative feelings in these professionals who daily face it in their everyday work. These ones reported having fear, guilt, sadness, sense of emptiness, anxiety and frustration. When sharing the death process of the child with its family members, they experience the mourning and
have difficulty in giving them the news of the death, by feeling its sadness.

The understanding of the nurses’ experiences allows the seizure of their everyday experiences of care before the death process in the context of the NICU. We conclude that this unit is a critical place due to imposing to the professionals who work there a daily coexistence with the boundary between the life and the death, when being confronted with doubts about their performance, the conflicts and the suffering and the mourning living due to patients’ death to which they provide care, and the suffering of their families.

Study data show that this coexistence is not enough to prepare them to the death process. Each child, family and professional is exclusive, endowed with beliefs and values, and that, when interacting with each other, create bonds that are affected by the death, generating feelings and suffering.

It is believed that to live conflicts and to present negative feelings before the death is normal. However, these conflicts and feelings need to be worked in the sense that working in critical sectors, such as the ICU, does not become only a reason of suffering and illness to its workers, by interfering with their way of living the Nursing practice.

It is necessary to highlight the competence and the good care of these professionals, by giving them the certainty that to provide a dignified death and to give support and comfort to the family is something special and relevant. Caring in a compromised way, by sharing with them this process assures the sensitiveness of such a moment, by turning their world of work and highlighting the Nursing as an indispensable profession in this context.

The care for the caregiver becomes relevant to preserve its health, highlight of those who work in critical sectors, such as the NICU. It is necessary to create a space for discussion about the issue “death and dying”, by training the healthcare workers to deal with it. Thus, they may assist the patient in the process of death and dying and its family members in a more qualified, ethical and humane way, by understanding that this process is a part of the life cycle of every human being, and it can be postponed, but not avoided in many cases.

Before the child in process of death and dying, nurses can contribute to the maintenance of their life quality during this period, by minimizing its physical pain and suffering, avoiding useless procedures, and favoring family’s presence in the sector. Even if the healing is no longer possible, to care is necessary, by worrying about the patient, respecting its integrity, remembering that the care is the purpose, essence and basis of the professional exercise of the Nursing, which gives a meaning to this profession.

It is necessary to carry out further researches on the issue at stake, in the light of other benchmarks, that contribute to this area of knowledge, with regard to the conditions of professional from specialized areas which daily deal with the finiteness, as in the NICU setting.

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