

# Terminally child life: perceptions and feelings of nurses

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## Abstract

**Objective:** To understand the perceptions and feelings of professional nurses towards death and the dying process of children. **Methodology:** qualitative and exploratory, based on thematic categories. The participants were seven nurses of the Neonatal and Pediatric Intensive Care Unit of a general hospital in the Northwest region of the Rio Grande do Sul (One of the Brazilian States). Data were collected through open questions in the period from February to March 2013 and were submitted to analysis by rating, sorting and final data analysis. **Results:** There has been difficulty for nurses to accept, confront and assimilate the finiteness of child life. It was also observed that nurse care is fundamental in those moments of end-of-life. **Conclusion:** The results show the lack of emotional preparedness of nurses and the lack of assistance, be it in the academic training or in continued education, as well as the lack of therapeutical support to deal with the situation in health care institutions.

**Keywords:** Death. Child. Family. Nursing. The intensive care unit.

## Resumo

### Terminalidade da vida infantil: percepções e sentimentos de enfermeiros

**Objetivo:** compreender as percepções e sentimentos do profissional enfermeiro diante do processo de morte e morrer infantil. **Metodologia:** qualitativa e exploratória, pautada por categorias temáticas. Participaram da pesquisa sete enfermeiros da unidade de terapia intensiva mista neonatal e pediátrica de um hospital geral da região noroeste do Rio Grande do Sul. Dados coletados por meio de pergunta aberta, no período de fevereiro a março de 2013, e submetidos a análise por classificação, ordenação e análise final. **Resultados:** além da difícil aceitação, enfrentamento e assimilação da finitude da vida infantil por parte dos enfermeiros, observou-se que o cuidado de enfermagem é fundamental nesse momento. **Conclusão:** os resultados evidenciam o despreparo emocional dos enfermeiros e a insuficiência de subsídio, seja em sua formação acadêmica, seja em sua educação continuada, bem como a falta de suporte terapêutico nas instituições de saúde para lidar com a situação.

**Palavras-chave:** Morte. Criança. Família. Enfermagem. Unidade de terapia intensiva.

## Resumen

### Terminalidad de la vida infantil: percepciones y sentimientos de los enfermeros

**Objetivo:** Comprender las percepciones y sentimientos del profesional enfermero ante el proceso de muerte y morir infantil. **Metodología:** cualitativa y exploratoria, basada en categorías temáticas. Participaron de la investigación siete enfermeros de la unidad de terapia intensiva mixta neonatal y pediátrica de un hospital general de la región noroeste de Rio Grande do Sul. Los datos fueron recogidos a través de preguntas abiertas en el período de febrero a marzo de 2013 y fueron sometidos a análisis por clasificación, ordenamiento y análisis final. **Resultados:** además de la difícil aceptación, afrontamiento y asimilación de la finitud de la vida infantil por parte de los enfermeros, se observó que el cuidado que proporciona la enfermería es fundamental en este momento. **Conclusión:** los resultados evidencian la falta de preparación emocional de los enfermeros y la insuficiencia de herramientas, tanto en su formación académica y en su formación continua, así como también la falta de apoyo terapéutico en las instituciones de salud para hacer frente a esta situación.

**Palabras-clave:** Muerte. Niño. Familia. Enfermería. La unidad de cuidados intensivos.

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Declaram não haver conflito de interesse.

The Intensive Care Units (ICU) are environments of differentiated care, due to the concentration of technology and meticulous routine of patient care in face of conditions of urgency and the need to sustain life<sup>1</sup>. The universe of infant hospitalisation encompasses the child, the professional who provides assistance and the family, in a coexistence that can last from days to months<sup>2</sup>.

Terminality of life in childhood in a neonatal intensive care unit (NICU) and / or paediatric intensive care unit (PICU) is considered more complex than the terminality of life of adults, since a child's death has - inevitably - a tragic connotation, before which survival is the first objective of the assistance team, given the high capacity of recuperation of paediatric patients<sup>3</sup>.

During the care given to the child, healthcare professionals create bonds of affection<sup>4</sup>, which establish a security base in the exercise of their work. However, when this sense of harmony is broken by the presence of death, professionals are thrown into suffering and sense of loss, which characterises mourning. An expected response in the face of the separation that the finitude causes<sup>5</sup>.

Continuous exposure to death and the dying process reveals the need to reflect and deal with fears and insecurities that create an obstacle to the performance of nursing professionals in face of the finitude of life. Technical and scientific knowledge, thanks to that need, are essential to the profession. The experience of an infant death with all the doubts, insecurities and uncertainties that permeate it causes nurses to review their concepts and feelings about the loss, which leads to the adoption of their own coping strategies, as well as to rethink their role as professionals in the intensive care unit<sup>6</sup>.

This study, through the use of field reports, seeks to bring assistance to nurses, in order that they can work through their feelings and understand the importance of integral and humanised care during the process of finitude of a child's life. By revealing the perceptions and coping mechanisms used by nurses working in NICU ( Neonatal Intensive Care Unit) and or PICU (Paediatric Intensive Care Unit) , facing the death and dying of a newborn or a child, this study contributes to nursing professionals, leading them to understand that they are not alone in their feelings and everybody needs support to live and overcome this sort of situation.

## Method

It is a qualitative, exploratory study, based on thematic categories and conducted with nurses from the Neonatal/Paediatric ICU of a general hospital in the northwestern region of Rio Grande do Sul (One of Brazil's federated states). Data collection occurred from February 2013 to March 2013, and the inclusion criteria was to be a nurse, to accept to take part in the survey and to be linked to the service as a collaborator of the institution for at least six months .

The initial population of the study consisted of 11 nurses, but the final sample comprised seven professionals, six of them female and one male. Of the remaining four, two did not deliver the questionnaire, one entered on maternity leave during the survey period and the other left the workforce during the data collection phase.

The survey was realised through a guiding question which required a written response: "What are the perceptions and coping mechanisms used by nurses who work in neonatal intensive care unit and / or paediatric intensive care unit before the death and the dying process of a newborn or a child?". March 11, 2013, was stipulated as the date to return the questionnaires so the participants of the survey had 20 days to fill out the questionnaire.

After the return of the questionnaires , we proceeded to the reading and rereading of the survey instrument as well as the organisation of the responses. At this stage, the data were subjected to methodological treatment, which consisted of ordering, classification and final analysis<sup>7</sup>.

Ethical principles were respected in their entirety: An informed consent (IC) form was used and the research was approved by the Ethics Committee of the Regional University of the Northwest of Rio Grande do Sul (abbreviated CEP Unijuí in Brazil), under the substantiated judgement number 182102 / 2013. The anonymity of the participants was assured through the use of the general name "Nurse", added by numbers 1 to 7.

## Results and discussion

The experience of nurses when facing the death and the dying process of newborns and infant

patients, revealed the perceptions of those professionals on the subject. Three analytical categories emerged from the study: 1) being a nurse who faces the death of children; 2) nurses in the care of the family during the process of finitude of a child life; 3) the need for professional qualifications and knowledge on the subject.

### **Being a nurse who faces the death and the dying process of a child**

The hospitalisation of children is perceived as a disturbing moment for anyone<sup>8</sup>, especially for those who maintain emotional bonds with the children. And when the possibility of death is evident, the role of the nurse is not limited to patient care as the care is also extended to the family<sup>9</sup>. Thus, in view of the finiteness of a child's life, nurses need to elaborate a care that provides less painful experiences to parents and other family members, trying to make the nearness of death less distressing<sup>10</sup>:

*"The nursing care, in a neonatal and/or paediatric intensive care unit . facing the death and the dying process of a newborn or a child consists of alleviating and helping to minimise the pain."* (Nurse 4)

*For me, at this moment, what we have to do is to try to give the maximum comfort to the parents ... to offer water, a hug, a shoulder to cry on and, if it is available at the institution, psychological support."* (Nurse 6)

Because of their training focused on the care and well-being of the patient, it is notoriously difficult for nurses to accept death and often even to provide adequate assistance when they verify the terminality of life<sup>9</sup>. Although common sense has as its premise the idea that health professionals are cold about a patient's death, many of them feel compelled to try to "save" the life; this way, if they assume a dispassionate air, it is above all to mask and deny the feelings of sadness and disturbing emotions when they witness the death process<sup>10</sup>:

*"Nurses must draw from within themselves enormous strength and they need, in these moments, to adopt a sense of coldness that often does not belong to them. To suppress the crying, to swallow a tear. It is not always possible to control emotions, but quite often it becomes essential!"* (Nurse 5)

*"It is important that all nurses know how to control their emotions in order not to impair or diminish their professional performance."* (Nurse 4)

Another aspect also due to the education of nurses is that they see in the terminality of life the opportunity to project onto the patient their desire to heal. For these professionals, the patient always has a chance of recovery, regardless of their clinical status. But when they can not prevent or delay the death, the nurses realise their limitations as human beings and professionals, which can cause feelings of powerlessness in the face of the finitude of life<sup>11</sup>:

*"There are moments of frustration when we don't achieve the desired success and the baby ends up dying; We ask ourselves: where did we go wrong? What we did not do to improve the health of this newborn [abbreviated as RN , in Brazil, for recém nascido ]?"* (Nurse 1)

*"The professional nurse is trained to work in the care of life, prevention of diseases and, undoubtedly, in the rehabilitation of individuals (...). Death, especially the death of newborns or children, triggers a sense of frustration, worthlessness and impotence in professionals committed to promote life."* (Nurse 2)

The feeling of helplessness expressed by nurses in the face of terminality of life reflects their unpreparedness to accompany this moment<sup>12</sup>. Daily, the nursing staff of the ICU face situations of assistance to patients who are in the process of dying. To answer these conditions effectively without causing undue suffering to the professional, a solid preparation of the intensive care unit nurse is essential. This preparation is essential not only for the nurse to act effectively in the technical, management and assistance care activities provided to patients but, above all, to ensure the physical and psychosocial health of those nurses<sup>13</sup> who, without it, could end up failing as professionals.

Death is still seen as taboo in our society. It is considered "morbid" to talk about it, even in the therapeutic areas in which it occurs with relative frequency, as in the ICU of hospitals. Such prohibition is explained by the psychological approach, according to which man seeks to defend itself in various ways of the increasing fear of death and the inability to foresee and prevent it<sup>14</sup>, as seen in the words of one of the nurses:

*"[Death] generates tension in the whole team, differentiated behaviours, ways of acting, thinking, expressing, insecurity, anger and fears before this undesirable situation, (...) that quite often we are not prepared to deal with (...) and we must be prepared to lead the team, for the work to continue. To*

*demand staff efficiency, professional ethics and the respect for children, religions and attitudes of each family.” (Nurse 3)*

Dealing with a social taboo is no easy task and it becomes even harder to deal with it when the taboo is directly related to the death of children and babies, who, according to our perception, would normally have a lifetime ahead of them. Besides all the pressure inherent in such circumstances it is important for nurses to provide motivation to their team, making the team harmonious and committed to improving the service provided, even if such assistance is directed only to provide relief to the little patient who dies<sup>15</sup>. Thus, the nursing professional should emphasise humanised care and the perception of the patient as a whole, in order to reduce the aggressivity of the treatment and to maintain the dignity and respect for the rights of the patients and their families<sup>16</sup>.

Acceptance of an infant death is difficult for nurses. In order to be able to maintain their role at times when they feel that they are beginning to falter, the nursing professional must keep in mind that the care given to the newborn or child, as well as the family, is essential to the welfare of these people, and the care should be based on comprehensiveness of the assistance provided, ensuring respect, ethics and human dignity.

### **The nurse in the care of the family during the process of finitude of child life**

In the process of death, the family needs assistance to understand and better experience the mourning<sup>17</sup>. By knowing things such as the story of life of the children, their relatives and the reason for the hospital admission, among others, the nurse ends up getting emotionally involved in the case. Often such involvement occurs simply because the patients are children. And, given the impossibility of healing, the professional suffers because of the child's loss, the pain of the parents or the nurses reflection on their own finitude<sup>18</sup>:

*“Death is hard to be accepted by most people who lose a family member or loved one, and also for nurses working with children because most of the time we end up creating a strong relationship of empathy with parents and children because of the time they remain hospitalised and because of the good relationship that is created with patient's families.” (Nurse 6)*

To sympathise and understand the whole situation and the experience of parents during the

hospitalisation of their child in an ICU, the nurse seeks to establish with them a clearer and more effective form of communication, which also extends to other family members. The professional understands that, even with the impossibility of cure, parents continue to believe that the child will survive. At such times, it is necessary that the professionals perceive the limitation of parents and relatives to deal with this circumstance, and thereby assist them to accept the finitude of life of their babies<sup>19</sup>. To carry out, effectively, this arduous task, the nurse must consider that each family interprets and experiences the death and dying process in different ways, according to their historical and sociocultural context<sup>20</sup>:

*“From the time to talk with the mother and father, the emotional aspect of the situation is so evident (...) This confrontation is always difficult (...) each moment is different, it is a special experience; families always react in different ways (...) The mother, when she enters the unit and finds her child among “thousands” of pipes, appliances, portholes, until she puts her hand on her baby, [keeps] the look of astonishment, the search for a gesture, a word of comfort that says: ‘Soon everything will be better, even in cases so complicated’” (Nurse 1).*

*“Let them go through this time reacting in their own way, because it's all part of the mourning, they need to get through this. There are parents who scream, cry, pray that the child will ‘come back’, and we should leave them to react that way as it is a hopeless suffering, and each one has his or her own ways of going through this phase.” (Nurse 6)*

*“(...) But no professional can accept, especially when asked by parents or family members who only wish the clinical improvement [of the patient].” (Nurse 2)*

It matters to nurses to realize the need of the child and the respective family to stay close as long as possible after exhausting all possibilities of healing. This proximity provides the relaxing of the strict rules of segregation in an ICU and values the presence of parents and family throughout the process, helping them to face death and at the same time allowing them to make it more dignified to the little ones<sup>21</sup>:

*“When I realise that the newborn or child might die, I usually try to provide the visit of the parents, I try to see which one of the parents is more likely to hear me talk a little about how their lives will be without their*

*baby or child (...) I provide time to allow parents to be alone with the child (...) When the child dies, we try to offer parents the chance to pick up the child in their arms (...) if they have a camera, I suggest the possibility of taking a picture to remember their child.” (Nurse 7)*

*“(…) Offering relief, asking if they want to stay with the child, after the child’s death, for a while.” (Nurse 6)*

Being a nurse faced with the impossibility of healing of a child, when trying to offer a dignified process of dying, means looking beyond these little patients, means to perceive the family as part of the care, as targets worthy of attention, understanding, respect and support for the experience of those moments that make the family so fragile.

### **Needs of professional training and knowledge on the subject**

The training of professionals in the health area provides them with technical and scientific knowledge aimed primarily to save lives and prevent death. Consequently, their unpreparedness to deal with terminality of life is clear <sup>22</sup>:

*“The lack of professional preparation to deal with death is well known (...) This confrontation is always difficult because they really are not prepared (...) although death is an event present every day or with frequency.” (Nurse 1)*

Silva et al <sup>23</sup> warn of the need to include this theme in continuing education programs for health institutions. Thus, according to the authors, it is possible to improve the quality of assistance offered and minimise the feelings generated on the team by the patients’ loss:

*“It would be very important for the institutions to work these matters concerning the support to teams, specific preparations, courses and debates.” (Nurse 1)*

*“I believe that a multidisciplinary team that works with the theme of feelings and attitudes of professionals, would alleviate sorrows, fears and would also give better emotional support to face or try to understand death (...) And, this way, we would be able to lead the team through these changes which would improve the spiritual, physical and emotional aspects of the nurses’ work . And we would also be better prepared to work with the family.” (Nurse 3)*

Feelings of fear and insecurity generated in nurses by death and the process of dying reveal possible gaps in undergraduate education, including the ineffectiveness of educational and psychological support to future professionals, in order that they can coexist with the suffering of patients and their families <sup>24</sup>:

*“It is important to note that this theme should be addressed over the course of graduation, as so often nursing professionals reveal an overlapping of professional feelings with personal feelings. Therefore, a suggestion to this work could be the development of teaching strategies in order to develop assistance for professionals to better cope, emotionally and professionally, with the idea of death.” (Nurse 2)*

*“Death of children or newborns often disturbs the peace in a hospital; however, it is known that this subject is little explained / clarified in the curricula of nursing courses.” (Nurse 4)*

It is recommended, as an important measure, to reformulate the academic curricula of nursing, by inserting disciplines and reflection spaces that focus on loss and grief, so that future professionals will be able to experience the reality of the finiteness of life and provide a participatory relationship, providing adequate and skilled attendance at such times <sup>25</sup>. Death completes the cycle of life; However, professionals are emotionally unprepared to face and to deal with the feelings aroused by death. They also face difficulty in the care to a patient who, slowly or gradually, is going to die <sup>24</sup>.

It is essential to create a different look for the assistance and the care given to the child who has no healing possibilities. Therefore, it is essential to offer assistance to nursing professionals who deal with these patients in order to guarantee to these patients a better quality of life through the comprehensiveness and humanisation of the care given, regardless of the time still left to those patients.

### **Final considerations**

The work of a nurse is permeated by a broader look, aimed at ensuring a humane and comprehensive care. But when the assistance needs to focus on the death and dying process of a child at any age, disturbing feelings emerge. They are difficult to accept by those responsible for the care of the child, especially the nurses. It is important that these



professionals understand that the care provided to patients at end-of-life stage delivers some quality to the life that remains and provides a dignified death, which implies redefinition of their role as nursing professionals.

The presence of parents and family during the hospitalisation period, be it of a newborn or a child in end-of-life stage, is essential for the parents in order to experience the most they can in the last moments of their child's life. Thus, the attention given by the nursing team should provide for the social, psychological and emotional aspects that are part of every family context, offering help and support, so that parents can face the loss of their child. To this end, it is recommended that nurses receive the necessary training to provide quality care in order to provide comfort and emotional support, facilitating the interaction between patients and their families.

The lack of academic training of nursing professionals in facing end-of-life illnesses and the process

surrounding it is clear. Such failure implies the need for hospitals to offer psychological support and continuing education on this subject, considering that the death of an infant, seen socially as complex and of specially difficult acceptance, requires an adequately trained professional. Thus, professional training will enable nurses to face their own taboos about the terminality of life without suffering too much or becoming ill whilst they try to exercise their professional tasks.

By revealing the perceptions of nurses that attend to children in newborn intensive care units and/or paediatric intensive care units, this study aims to contribute to the awareness of health institutions about the urgent need to improve the continuing education of professionals, especially regarding the issue of finiteness of a child's life. This measure will help nurses to better understand and experience their feelings and thereby will make them more qualified to provide adequate care for these young patients and their families.

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#### Participation of the authors

Gisele Elise Menin participated in the conception and design of the study, literature review, completion of the field work, data analysis, article writing. Marinez Koller Pettenon participated in the conception and design of the study, data analysis, article writing and critical review.

