Knowing nursing team care practices in relation to newborns in end-of-life situations

Conhecendo as práticas de cuidado da equipe de enfermagem em relação ao cuidado na situação de final de vida de recém-nascidos

Conociendo las prácticas de atención de enfermería ante final de la vida en recién nacidos

Abstract

Objective: Understand the care practices experiences of nursing staff in relation to providing end-of-life care to newborns and their families in neonatal intensive care units (NICU). Method: Descriptive study with a qualitative approach, involving eight nursing professionals from an NICU. Results: Through the data analysis, it was possible to identify three central themes: the “obscurity of death in neonatal ICUs”: coping with death at the onset of a human life; palliative care and end-of-life decisions: the challenges faced by nursing staff in neonatal ICUs; and types of nursing care in the daily activities of neonatal ICUs. Conclusion: It is essential to understand the experiences and needs of nursing staff, so that proposals can be formulated for seeking improvements in the care relationships that take place in this context.

Keywords: infant palliative care; neonatology; nursing.

Resumo

Objetivo: Conhecer as experiências de práticas de cuidado da equipe de enfermagem, em relação ao cuidado dos recém-nascidos e suas famílias, na situação de final de vida, vivenciadas na UTI Neonatal. Método: Estudo de abordagem qualitativa-descritiva, com a participação de oito profissionais da equipe de enfermagem que atuam em UTI Neonatal. Resultados: Através da análise temática dos dados, foi possível encontrar três temas centrais: A “obscuridade da morte na Neo”: lidando com morte no início da vida; Os cuidados paliativos e as decisões no final de vida: os desafios da equipe de enfermagem na UTI Neonatal; e As formas de cuidado da equipe de enfermagem no cotidiano da UTI Neonatal. Conclusão: Torna-se essencial compreender as vivências e as necessidades da equipe para que propostas sejam elaboradas, buscando melhorias nas relações de cuidado que ocorrem nesse contexto.

Palavras-chave: recém-nascido; cuidados paliativos; neonatologia; enfermagem.

Resumen

Objetivo: Conocer las experiencias de prácticas de atención del equipo de enfermería respecto del cuidado de recién nacidos y sus familias ante la circunstancia de fin de la vida, vivenciadas en la UTI Neonatal. Método: Estudio de abordaje cualitativo-descriptivo, con participación de ocho profesionales del equipo de enfermería actuante en UTI Neonatal. Resultados: A partir del análisis temático de los datos fue posible encontrar tres temas centrales: La “oscuridad de la muerte en la Neo”: afrontando muerte al inicio de la vida; Los cuidados paliativos y las decisiones en el final de la vida: desafíos del equipo de enfermería en la UTI Neonatal; y Las formas de atención del equipo de enfermería en el día a día de la UTI Neonatal. Conclusión: Resulta esencial comprender las experiencias y necesidades del equipo para elaborar propuestas en busca de mejoras en las relaciones de cuidado que ocurren en este contexto.

Palabras clave: Recién Nacido; Cuidados Paliativos; Neonatología; Enfermería.
INTRODUCTION

Death is an inevitable occurrence, permeated with feelings of powerlessness, fragility and sadness. It is a difficult experience that is potentially exacerbated when it occurs in the first moments of life: the loss of a child alters what is perceived as the natural course of life and, consequently, makes the search for reasons and meanings in relation to this change more difficult and intense.

This context affects the family structure and the relationships that are in some way connected to this situation; thus, each party experiences the process of loss and bereavement in a different way. In terms of these two aspects, attempts can be made to understand the influence and position of health professionals, specifically nursing staff that works with end-of-life newborns.

Although death is a relatively common occurrence in nursing, it was noted that professionals have difficulties, not only accepting, but also properly managing such situations, especially when it involves infants and their families.1

In general, the issue of death and bereavement tends to be denied by individuals - including those not undergoing the process, but who have to deal with it in some way. This denial is heightened when it involves children.

This aspect complicates the work of health professionals who, apart from dealing with the family's experience of loss, must also cope with lack of dialogue within the team and their own personal values. The following was observed among nurses: fear of provoking reactions in colleagues, patients and family members; the desire to protect family members from further suffering; and uncertainty about their own feelings regarding death.2

It was seen that the context of neonatal intensive care units (NICU) has various implications for the parties involved in the hospitalization process - newborns, families and multiprofessional and interdisciplinary teams - where the work process should enable the provision of care that meets the specific needs of the neonatal group.3,4

Newborns in ICUs are in a state of dependency, fragility and instability, which requires specific care and training, perspicacity and sensitivity on the part of health teams to provide safe and comprehensive care.5 Therefore, NICUs are environments where care must go beyond technical and scientific activities, and requires viewing all the parties involved in the experience of caring for seriously ill infants.

Health teams, therefore, play a fundamental role in the experience of families in these situations. A literature review on nursing and the relationship with mothers of sick newborns shows that they need emotional support, good communication, access to information with the appropriate type of language and involvement in the care of their babies. Health teams in turn, must understand these needs.6

Studies show that the attitudes of teams have a direct effect on the memories of those whose children were hospitalized in an NICU: when the team is sensitive to the questions, pain and needs of mothers during situations of anguish and stress, the experience is remembered in a positive way.7 During an infant's stay in an NICU, the relationship between caregivers and the family should be built on good communication and trust - so that the relationship is strengthened throughout the process.8,9

An integrative literature review on the involvement of parents in end-of-life care and decisions in neonatal ICUs found that training nurses in how to provide end-of-life care was reflected in better support for parents during this difficult experience.10 It considered end-of-life care as part of the macro context of palliative care. This type of care is defined by the WHO as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.11 For this reason, it is essential to address palliative care in the context of neonatal ICUs.

In Brazil, worth noting is the palliative care proposed by CAISM (Center for the Comprehensive Care of Women's Health).12 In 2002, CAISM's neonatology team started meeting weekly for theoretical updates, discussion of cases and incorporation of protocols and meetings with family members whose infants were hospitalized. As a result of these meetings, the team presented the first major guidelines for neonatal palliative care. This proposal was integrated into work routines in order to improve the lines of care of and coordinate the involvement of multiprofessional teams.

Nursing staff, which represents a significant proportion within multidisciplinary health teams, in the context of ICUs, is responsible for a wide range of actions where the core of the work process is nursing care. Therefore, it is necessary to listen to these professionals to understand how care is given in the NICU context, which requires the development of knowledge and skills to care for newborns, families and themselves. The objective of this study was to understand the care practice experiences of nursing staff in relation to providing end-of-life care to newborns and their families in NICUs.

METHOD

To achieve the objectives of this study, a descriptive qualitative approach was used with thematic content analysis,13 which sought to identify the core meanings in the interviews, whose presence or frequency was relevant and corresponds to the study objectives. Qualitative methods are the best and perhaps the only ones for providing responses for studies whose purpose is to understand the participants, the meanings attributed to experiences and how they interpret their experiences in specific processes and contexts.14 Qualitative research permits understanding results from the perspective of study participants. In the field of qualitative research, researchers establish relationships with participants; this permits social interaction. This interaction,
in turn, results in the building of knowledge through the comprehensive process of exchange between the subjects involved in the research.15

The present study was conducted with nursing staff professionals - nurses and nursing technicians - who worked in neonatal intensive care units. The inclusion criteria were: 1) be a nurse or nursing technician, with at least one year of experience in an NICU; this length of time was established so that participants would most likely have experienced providing care in an end-of-life situation; 2) have undergone an end-of-life care experience.

The snow ball sampling technique16 was used for recruiting participants. With this method, interviewees suggest the names of others who, in turn, recommend others, and so on, until the set goal is achieved (saturation point). The first participant, who was contacted by phone, was a nurse whom the researcher already knew; she was the starting point for the technique described above.

Eight nursing professionals participated in the study; five were nurses and three were nursing technicians. The participants were assigned fictitious names in order to remain anonymous.

The data was collected through semi-structured interviews. Interviews, as a dialogical practice, permit interaction and exchange among participants. They are an important tool that enables researchers to know interviewees and their values and experiences, based on the understanding that one experience is not truer than another.17 A script was used with personal information to characterize the participants, as well as guiding questions: "What is your daily life like in the neonatal intensive care unit?", "What is it like for you to take care of newborns and their families in end-of-life situations? Tell me about an experience you’ve had." and "What needs have you identified while caring for newborns and their families in end-of-life situations?"

The interviews took place between January and June 2016, according to the professionals’ availability and the place, time and date established by the participants. The interviews were digitally recorded and lasted an average of 30 to 45 minutes. The interviews were then transcribed and carefully read.

The data collection started after the study was approved by the Research Ethics Committee, in Opinion No. 1433734, and complied with the ethical recommendations regarding research with human beings of the National Health Council. The following ethical principles were upheld throughout the study: 1) autonomy, i.e., the person’s right to decide whether to participate, through signing a free and informed consent form; 2) beneficence, i.e., is useful, has social relevance and respects the well-being of those who participate in the study; 3) non-maleficence, i.e., ensures that foreseeable risks are avoided, and provides assistance, in the event of any harm; and justice, i.e., where everyone has access to the benefits of the results.

The data analysis was performed through a thematic content analysis,13 and it was decided to follow the data proposed by Bardin (2006). Since this type of analysis is characterized by a set of methodological instruments that is applied to extremely diversified discourses, there are three stages: pre-analysis; exploration of the material; and treatment of the results and interpretation. Pre-analysis consists of selecting the material that will be analyzed, reexamining the initial objectives of the study, and creating the indicators that will guide the final interpretation. Exploration of the material is for codification, where the raw data is transformed in an organized manner and divided into units. The data is classified and divided, and the categories that will govern specification of the themes are selected. Categorization makes it possible to gather a larger amount of information through schematization and, thereby, correlate classes of events for the purpose of organizing them. Last, treatment of results and interpretation entails organizing the raw data in order to determine the themes, which can be defined as cores of meaning that emerge naturally from the narratives analyzed.

RESULTS AND DISCUSSION

Five nurses and three nursing technicians who worked in an NICU were part of the study, as characterized in the table 1 below.

Through the analysis of the interviews, it was possible to identify three central themes related to the nursing staff’s experience in the neonatal ICU: 1. “Obscurity of death in neonatal ICUs”: coping with death at the onset of a human life; 2. Palliative care and final end-of-life decisions: the challenges faced by nursing staff in neonatal ICUs; 3. Types of nursing care in the daily activities of neonatal ICUs.

1. The “obscurity of death in neonatal ICUs”: coping with death at the onset of a human life

Experiencing the illness and death of a newborn is a complex process for nursing staff. This type of situation involves cultural issues related to the nebulous way in which death is handled, in addition to the subjectivities of nurses, interlinked with their beliefs, life experiences and lack of discussion about death in university studies.

The participants said that the death of a neonate is an obscure, confusing and incomprehensible time, since they view early death as a modification of the natural course of life, in which children die after their parents. Although health professionals know that death is often inevitable, acceptance of this fact in the first years of life of a child is a difficult and problematic process.

Neonatology is the start, not the end of life. Therefore, times like this are very disturbing and sad [...] preparing the body, the mother arriving with the clothing for us to dress the infant. That part is very sad. (Lúcia, nursing technician).

Death in neonatal ICUs is a very obscure area. (Carmem, nurse)
Feelings of suffering and frustration are directly linked to the experience of being nurses in neonatal ICUs. Length of experience and having already dealt with many losses of this kind is reflected in the way in which this involvement occurs - with both infants and families. The need for “distancing” and dividing oneself into two - professional and personal - is a form of protection and survival in a context where professionals must constantly face death. The availability and personal sensitivity of health teams undergo changes and adjustments according to the wear and tear caused by working in an ICU, which is reflected in how care relationships occur.

After a while, you start learning to separate [...] As soon as you leave, you have to separate things; if not, you’ll suffer. (Rosa, nurse)

There was a case where a baby died and I was also suffering. My heart was hardened, but we have to be professional [...] you have to separate personal from professional. (Carmem, nurse)

It’s a very difficult experience, [...] you have to learn to control yourself, especially in front of the parents, because if you cry the parents will realize that their child is dying. (Cláudia, nursing technician)

The extent of involvement is a dilemma that nursing teams face. Lack of understanding and the ability to deal with one’s own feelings generates suffering and an attitude of wanting to flee from the situation: when it is seen that an infant is dying, professionals ask to be switched to another team. Health professionals have difficulties dealing with their own limits and use defense mechanisms to negate a natural and inevitable occurrence in life, which is death.²⁻⁹,¹⁸

I have colleagues who freeze up. They see a child dying and they're unable to do anything. They're unable to provide comfort; it's as though it were their own child, or worse, you know [...] the situation is as painful for them as it is for the family. (Ana, nursing technician)

There are children that you know are going to die and you ask not to go to your shift, because you don’t know how you’ll react. It’s very complicated. (Júlia, nurse)

A friend asked me to switch with her and I asked her why. She said that a baby was going to die and she didn’t know what to do. She didn't know what to say to the mother. (Ana, nursing technician)

The participants reported difficulties coping with death due to lack of preparation and dialogue in relation to this issue. One of the reasons for lack of preparation of professionals is the scant training they receive on the subject, in both their university studies and in the workplace.

Working with children in end-of-life situations is difficult because we don’t have any academic training that prepares us for this... it’s necessary to provide support for nurses, including nursing technicians and assistants, because no one receives any training in this regard. (Carmem, nurse)

I think that end-of-life care is a very empirical thing. Everyone does what they feel would be best if they themselves were in the other person’s situation, because we aren’t taught about this at university. When we go to the job market, we don’t have any support or instruction in this area. (Júlia, nurse)

A study conducted in a neonatal oncology unit showed that the nursing staff did not feel prepared to work with children or families in end-of-life situations. Lack of theoretical knowledge and lack of preparation on how to handle death are the main factors that cause insecurity in teams.¹⁹

The healing model taught in universities, where health professionals are responsible to reverse patients’ diseases, acts as a barrier for dealing with end-of-life situations. This was also

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Table 1. Characterization of the interviewees

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age (years)</th>
<th>Type of service</th>
<th>Length of time in the NICU</th>
<th>Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rosa</td>
<td>33</td>
<td>Public</td>
<td>7 years</td>
<td>Catholic</td>
</tr>
<tr>
<td>Maria</td>
<td>29</td>
<td>Public</td>
<td>1 year</td>
<td>Catholic</td>
</tr>
<tr>
<td>Estela</td>
<td>34</td>
<td>Public</td>
<td>8 years</td>
<td>Catholic</td>
</tr>
<tr>
<td>Júlia</td>
<td>29</td>
<td>Private</td>
<td>8 years</td>
<td>Spiritist</td>
</tr>
<tr>
<td>Carmem</td>
<td>45</td>
<td>Public</td>
<td>19 years</td>
<td>Evangelical</td>
</tr>
<tr>
<td>Nursing Technicians</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ana</td>
<td>29</td>
<td>Public</td>
<td>7 years</td>
<td>Spiritist</td>
</tr>
<tr>
<td>Lúcia</td>
<td>39</td>
<td>Private</td>
<td>16 years</td>
<td>Catholic</td>
</tr>
<tr>
<td>Cláudia</td>
<td>41</td>
<td>Private</td>
<td>15 years</td>
<td>Spiritist</td>
</tr>
</tbody>
</table>

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²⁻⁹,¹⁸
When teams are able to apply palliative care among different professionals on the health team, participants commented on the absence of discussion about palliative care among different professionals on the health team, which reduces their feelings of impotence and frustration. The concept of palliative care was not clear to nursing staff, even though it is difficult to determine the right time in neonatal ICUs. The same study said that it is difficult to determine the right time in neonatal ICUs. The implementation of palliative care in neonatal ICUs appears not to be discussed much or clearly defined. The participants commented on the absence of discussion about palliative care among different professionals on the health team, the lack of preparing care plans for infants in end-of-life, and lack of communication in the decision-making process among team members. This process appears to be centralized in the medical team - which leaves little room for dialogue.

The concept of palliative care was not clear to nursing staff, since they still view this as a practice that is applied when nothing more can be done for the patient.

It's painful for the team too, it's draining, but you can't just go in and say you're not going to do anything, or waste material or waste your time. So, you go and do whatever you can. (Rosa, nurse)

There are also dilemmas in terms of deciding what is best for the infant; this involves the health team's decisions and the opinions, decisions and needs of the family, which should have a central role in the decision-making process. One participant said that in her department there are palliative care meetings; she explained how this process works, emphasizing the involvement of the multiprofessional team.

When we see there is no chance of survival, we talk first with the mother to explain that there is no hope for the child, and ask her whether she really wants to put the baby on ventilatory support. We involve the family - father and mother - in this discussion. Afterwards, there are parents who accept the situation, and we then start the process with the psychologist, social worker, obstetrics staff and nursery team. It is a meeting in which the whole team participates. (Maria, nurse).

In a study conducted with ICU nurses, it was shown that paradigm shifts to implement palliative care is a slow process and depends, in large part, on the initiative of the nursing staff. The same study said that it is difficult to determine the right moment for a change in approach - which was also noted in the present study.

You get there and everything has changed. You start seeing that investments are being made in the child as though it were not a case for palliative care. Many interventions are made that we feel are unnecessary for palliative care patients: it's a palliative care situation, but multivitamins were given, then antibiotics, then this and that, and much more will come [...] In neonatal, what I see is that the palliative care staff is afraid of making a mistake. (Ana, nursing technician)

Few families are offered end-of-life care, which is a one reason why palliative care is not administered or is given at the wrong time in neonatal ICUs. When teams are able to apply
palliative care action plans, there are fewer interventions and more attention is given to psychosocial needs, chaplaincy services and social services support for families. In their daily work, health professionals run up against obstacles when administering palliative care and have difficulties in relation to decision-making, unexpected death and the impossibility of alleviating the pain. They also reported conflicts with patients’ families.

A hierarchy was noted among health professionals who work in NICUs, with no room for dialogue or participation in decision-making, which is directly related to communication barriers between medical and nursing teams and to a paternalistic and verticalized care model where physicians are the final authority, responsible for end-of-life decisions.

They (physicians) are the ones who make the decision. There is no discussion between teams. (Julia, nurse)

Paternalism is another barrier, where “the physician needs to decide” and no one takes a stand while waiting for the physician to arrive, and if we give any opinion it’s not well-received. (Ana, nursing technician)

At the critical moment, physicians hardly ever listen to what we say. They do what they have to do, confirm the death and we - the nursing technicians and nurses - prepare the baby so that the parents can come in. (Lúcia, nursing technician)

It is important to bear in mind that palliative care, as a medical specialty, results from a collective production, inserted within a historical and social context. It is intensified in response to decisions by medical teams, indicating the need for the development of new competencies and knowledge. A hierarchy was noted among health professionals who work in NICUs, with no room for dialogue or participation in decision-making, which is directly related to communication barriers between medical and nursing teams and to a paternalistic and verticalized care model where physicians are the final authority, responsible for end-of-life decisions.

Communication, as a light technology, can produce relationships, where one result is the building of a welcoming environments and bonds. The involvement of the family in the infant's care was reported as an important practice and one that should be encouraged. The participants linked the importance of this practice with how much time the baby has left, and is more strongly encouraged when palliative care starts being administered.

The care of newborns and families in end-of-life situations requires a lot of sensitivity. Even though you may know that nothing more can be done, that father, or that mother always has a hope deep down that something might change, and you don’t have the right to strip them of that hope. (Rosa, nurse)

The participants emphasized that communication is an important instrument in the relationship between professionals and parents. Explaining all the procedures and using simple language were considered essential. A study conducted in Sweden revealed that parents feel secure in the team when there is regular communication. Conversation in this context creates possibilities for interaction: when there is no conversation and lack of information, parents feel lack of trust, and waiting for information becomes distressing. The same study indicated the need for teams to provide opportunities for parents to interact with their infant and assume a role that only they can play.

It is important that you explain what's being done, who you are, what you are planning. (Estela, nurse)

You have to explain, perhaps speak in a simpler way, be tactful when explaining, but you to have talk and provide guidance. (Cláudia, nursing technician)

The participants pointed out that the way the service of the neonatal ICU is organized hinders the care practices considered important by the nursing team. The large number of demands...
and the need to deal with bureaucratic issues of the institution are an impediment to providing care in a sensitive manner, corresponding to the needs and particularities of each party involved.

It would be good if they [the parents] could experience the process (end-of-life of the newborn, their final moments), but you are bound by a routine. When you work in a private hospital, you are very restricted. You don't have the autonomy you would like to have. (Julia, nurse)

I notice that a lot of times professionals don't have time to listen to patients. The demands are so great that you don't listen to complaints. (Cláudia, nursing technician)

Dealing with the rules established by institutions is considered a challenge for providing care to newborns in end-of-life situations and their families; these obstacles stand in the way of giving comprehensive care. Professionals try to find a balance between what they would like to do and what is possible to do. In this situation, health professionals say they need to “break the rules” in order to administer the care they feel is appropriate.

I understand what the rules are, but if it’s a child that’s dying, why not let the family get to know the baby? (Ana, nursing technician)

You have a whole unit to care for and there are many other procedures you must perform, other children... it’s difficult to manage. You think: I’m going to stay with the mother. I want to be there to provide her with support, but what about all the rest... I need to take care of the rest. (Julia, nurse)

Neonatal care based only on technical aspects needs to be reviewed, in terms of all the practices and relationships - involving infants, professionals and families - so that the care will take into consideration the various branches of knowledge and be sensitive to the individualities, subjectivities and needs of all the parties involved.

CONCLUSIONS

The results of this study highlight the experiences and challenges of nursing staff in the context of neonatal ICUs, in which there appears to be little room for discussion in end-of-life situations. This experience is difficult and may be exacerbated in NICU environments - due to the difficulty of coping with death at the onset of a human life.

Barriers - such as lack of dialogue between medical and nursing teams, the impossibility of expressing opinions in end-of-life decisions, and lack of preparation for dealing with these situations - appear to be obstacles that are reflected in care relationships. Nursing teams face challenges and have needs in terms of full sharing of care, having more autonomy and being able to share what they know. There are also other fundamental needs, such as training in end-of-life situations and providing room for professionals to share their anguish.

The experiences of the nursing technicians and nurses revealed that palliative care in NICUs is not addressed or discussed much, demonstrating the need to explore the concept further and establish principles that integrate the whole team in end-of-life situations. Informational lectures and specific courses on palliative care to train health professionals who deal with these situations are very important, representing strategies that institutions should take into consideration to improve the services they provide.

Nursing teams that work in NICUs play an essential role, in that they view families as being included in newborn care and perceive their needs. Care practices in this context can be directly reflected by how families experience the process of having a child in an end-of-life situation. The ways in which this care is given involves various factors, ranging from the personal beliefs to the training of nursing professionals who work in NICUs and deal with end-of-life situations.

In view of the difficulties and developments in the work of NICU nurses and nursing technicians, it can be seen that the work of nursing teams is not done in isolation: it is directly related to factors that make up NICUs (providers, customers, procedures and protocols, among others) and does not occur without the personal perception of the individuals who carry it out.

It is imperative to listen to the voice of NICU nursing teams in order to understand the experiences and needs of these teams and so that significant proposals can be formulated. These include creating venues where professionals can share their distress when dealing with death and the death process, and providing courses that address end-of-life circumstances and cultivate the necessary skills for providing care in these situations. Such investments will be reflected in improved care and in the relationships that take place within this environment.

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