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ORIGINAL ARTICLE

Perception of health professionals about neonatal palliative care

Perceção dos profissionais de saúde sobre os cuidados paliativos neonatais
La percepción de los profesionales de la salud sobre los cuidados paliativos neonatales

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ABSTRACT

Objective: To identify the perception of health professionals about neonatal palliative care. **Method:** A phenomenological qualitative study, a non-probabilistic sample, of 15 health professionals from a neonatal intensive care unit in northern Portugal. Content analysis was performed. **Results:** Despite their lack of training in palliative care, the health professionals showed concern for the dignity, quality of life and comfort of the newborn and family. They expressed emotional and relational difficulties in following the trajectories of serious illness and death and in the ethical decisions regarding the end-of-life. **Conclusion:** It is emphasized that professionals are sensitive to pain and suffering and reveal dedicated and committed in the care of the newborn and family. They are available to train and embrace the current challenges posed by the constitution of pediatric palliative care teams and to help achieve an organizational culture that advances in such care.

Descriptors: Palliative Care; Intensive Care Units, Neonatal; Nurses; Death; Infant, Newborn.

RESUMO

Objetivo: Identificar a percepção dos profissionais da equipa de saúde sobre os cuidados paliativos neonatais. **Método:** Estudo qualitativo fenomenológico, amostra não probabilística de 15 profissionais da equipa de saúde de uma unidade de cuidados intensivos neonatal, do norte de Portugal. Realizou-se análise de conteúdo. **Resultados:** Apesar da falta de formação em cuidados paliativos, os profissionais revelaram preocupação com a dignidade, qualidade de vida e conforto do recém-nascido e família. Expressaram dificuldades emocionais e relacionais no acompanhar as trajetórias de doença grave e morte e a nível da decisão ética no final de vida. **Conclusão:** Salientamos que os profissionais estão sensíveis à dor e sofrimento e mostram-se dedicados e comprometidos no cuidar do recém-nascido e família. Mostram-se disponíveis para fazer formação e abraçar os desafios atuais que passam pela constituição de equipas de cuidados paliativos pediátricos e o alcançar de uma cultura organizacional que progrida nesses cuidados.

Descritores: Cuidados Paliativos; Unidades de Terapia Intensiva Neonatal; Enfermeiras e Enfermeiros; Morte; Recém-Nascido.

RESUMEN

Objetivo: Identificar la percepción de los profesionales del equipa de la salud sobre los cuidados paliativos neonatales. **Método:** Estudio cualitativo fenomenológico, muestra no probabilística de 15 profesionales de la salud de una unidad neonatal del norte de Portugal. Se realizó análisis de contenido. **Resultados:** A pesar de la falta de formación en cuidados paliativos, los profesionales revelaron preocupación por la dignidad, calidad de vida y confort del recién nacido y su familia. Expresaron dificultades emocionales y relacionales para acompañar las trayectorias de la enfermedad severa y de la muerte y para lidiar con la decisión ética. **Conclusión:** Debemos destacar que los profesionales son sensibles al dolor, sufrimiento y se muestran dedicados y comprometidos en el cuidado del recién nacido y la familia. Están disponibles para participar en formación y abrazar los desafíos actuales que pasan por la constitución de equipos de cuidados paliativos pediátricos y por lograr una cultura organizacional que permita el progreso de esos cuidados.

Descriptores: Cuidados Paliativos; Unidades de Cuidado Intensivo Neonatal; Enfermeros; Muerte; Recién Nacido.

INTRODUCTION

A neonatal intensive care unit (NICU) is a high-tech environment that usually assists newborn infants (NB) at the threshold of viability or critically ill. Threshold of viability is a term that refers to infants who are born prematurely at 25 weeks gestation and whose weight ranges between 600 and 700 grams, a gestational age and birth weight above which ≥ 50% of the NB survived without severe sequelae(1-2). Gestational age is an indicator of good or poor prognosis, yet a thorough and careful assessment of other factors is recommended to decide whether or not the provision of care should continue or should be limited(3). Parents should be involved in a decision-making process in which a culturally sensitive, empathic, repeated, coherent and unbiased information and discussion is indispensable to enable them to establish a trustworthy relationship with the healthcare team(1).

Despite advances in medical treatments, not all newborns survive: there is a 3.1‰ perinatal mortality rate and a 1.8‰ neonatal mortality rate(4) which corresponds to the death of 1 out of 476 children under one month of age. More than 90% of those deaths occur in NICU, after complex decisions and dilemmas to withdraw or to withhold life-sustaining treatments; this brings enormous challenges to highly differentiated teams(5-7). Neonatal mortality data put us on the list of countries with the lowest mortality rate among children who are less than 28 days of age. More precisely Portugal is ranked 17th in a list that includes 184 countries(8). Although there are relatively few NB deaths, truth is that some of them die and others suffer from complex chronic diseases that will limit their quality of life and their families' and that justify the implementation of a palliative care (PC) model in a neonatal context(9-10).

Neonatal palliative care (NPC) is provided by a range of technological improvements that will ensure the survival of newborns who are extremely premature and who were born with severe malformations. They are regarded as a holistic, multiprofessional, dynamic and integrative, family-centered kind of care. The families involved have to live with the diagnosis of a fetal disease that will cause the newborn/fetus to live a finite life or that can be potentially fatal. They have to struggle during the pregnancy, the child's birth, after his birth and during the mourning period. NPC will also provide the adequate support to the fetus/newborn and family, honouring them with due respect and dignity(5). They may, at an early stage, be applied in addition to curative care and be more evident when the curative objective is no longer appropriate and the intention is to prevent and relieve newborns' suffering and the pain endured by families and increase their quality of life while they are still alive and as they face imminent death(7-11). In the case of newborns who are close to death, the objective is to help them have a "good death", always maintaining a deep respect for human dignity(1,6,12). The NPC can be coupled with intensive care at any stage of the disease in order to provide care to newborns and their families in a constant, comprehensive and individualized way and will also have clear benefits for health professionals(12).

The NPC should be granted a growing relevance; however there are obstacles that hinder its implementation, namely the uncertainty of prognosis, technological and scientific imperatives, the difficulty families have in recognizing and accepting the fact that their child is affected by an incurable disease, conflicts between families and health professionals regarding the therapeutic objective to be achieved and health professionals' lack of specific training for the provision of NPC(13-14).

Health care should focus not only on the control of symptomatology, but also on the communicative and relational aspects that will have to exist between the team, the child and his family. This entails a change in the paradigm of care provision that will lead to the design of a therapeutic scheme and of another scheme that will contemplate the emotional, social and psychological consequences that will affect the patient and his family(5). However, most health professionals have little or no knowledge about the principles and practices of PC(10). Training in PC is necessary at three levels: firstly, basic training for all health professionals; secondly, intermediate training for those who often work with patients with life-limiting diseases; Thirdly, specialized training for those who deal with patients whose needs go beyond the mere control of symptomatology(10). Training aims at empowering health professionals who work with children with palliative needs and their families with the appropriate competencies and confidence that will enable them to provide high quality palliative care(15). The implementation of NPC guidelines also contributes to the improvement in the quality of health care provided and is associated with the increase in the use of medication to control pain and with communication strategies(6).

Some protocols/guidelines(16-18) suggest a multidisciplinary approach aimed at the NB, his family and at health professionals. As far as the NB is concerned, issues like symptom management (such as pain, respiratory distress and seizures), comfort, ethics, end-of-life decisions (ventilation, monitoring, feeding) and the relationship with parents/relatives are addressed. As far as parents are concerned, emphasize is placed on the need for psychological, emotional, spiritual and religious support, their involvement with the NB, their role in the care provided to the NB and the way they will be guided and supported during mourning period. With regard to health professionals, focus is given to the need for training in NPC (principles, communication, ethics and clinical aspects as well), the need for psychological and spiritual support and the holding of meetings that will take place after a neonatal death to have some joined-up reflection, conduct a constructive assessment of the therapeutic and palliative attitudes adopted and to express condolence. In the aforementioned protocols/guidelines, aspects related to conflict resolutions that might have been caused by some decision made were also addressed.

In Portugal, there has been a growing concern with children with palliative needs and some recommendations for the implementation of NPC have been defined. The recommendations are based on four pillars: training for all professionals involved in the provision of health care to children with palliative needs; the promotion of domiciliary care provision; the reorganization of existing pediatric facilities and the effective articulation among all health care providers to make the best use of the existing human resources(5).

Thus, this study came to be to answer the following research questions: What do health care professionals think of neonatal palliative care? What experiences do health professionals have in caring for newborns whose health condition will not improve and for their family? Our purpose is to raise health professionals' awareness and contribute to the implementation of neonatal palliative care and to the improvement of the humanization of health care provided to newborn babies who are facing a life-limiting condition.

OBJECTIVE

To identify the perception of health team professionals about neonatal palliative care.

METHOD

Ethical Aspects

The study was launched after approval by the Ethics Committee of a Hospital located in Oporto, in the northern region of Portugal. Informed consent was requested to the participants and data anonimization was ensured. The researcher travelled to the aforementioned medical unit to carry out the interviews that took place in a restrained location between June and July 2017.

Type of study

A qualitative phenomenological study, since it seeks to uncover reality from the viewpoint of the people who have lived it and which implies a detailed, dense and faithful description of the reported experience.

Sample and inclusion criteria

A non-probability accidental sampling, composed of 15 health professionals from a NICU in the northern region of Portugal was used. Inclusion criteria were the following: health care workers had to be part of the regular team of the neonatology service and to be present in that medical unit during the time the study was conducted. The number of participants was not determined beforehand and was established throughout the study according to data saturation criterion.

Data collection instrument

A semi-structured interview that uses a list of question whose topics addressed the concept of NPC, the kind of care that is valued when one deals with newborns experiencing a life-limiting condition, the existence of action protocols that will have to be implemented in palliative care situations and the professionals' experience in caring for the newborn who is being provided with end-of-life care and for his parents. The questions did not obey a specific predefined order, instead the interviewer let the conversation flow, always keeping the focus on the predefined objectives and always asking the questions to which the respondent did not answer on his own, at the right time and as naturally as possible[19]. The interviews were audio recorded and subsequently transcribed to a word document using the researcher's private computer. Content analysis method was used[20].

RESULTS

Socio-demographic Characterization

7 of the 15 health team professionals who have taken part in the study are nurses, 6 are neonatologists/pediatricians and 2 belong to the multidisciplinary team (social worker, psychologist and chaplain). They are between 31 and 59 years old (*M* = 47*)*. The length of their time of professional experience ranges between 9 and 30 years (*M* = 22.8) and their experience in neonatology ranges between 6 and 27 years (*M* = 16.8 years).

To organize the presentation of the results, we considered the categories that emerged from the content analysis performed and to illustrate those categories we used some excerpts from the participants' answers. In table 1, we can check the categories, their respective subcategories and the indicators related to the perception of the type of health care valued when caring/providing treatment to NB whose condition will not improve. Then we analyze each category *per se*.

Palliative Care

In this category we realized that health professionals valued the comfort care provided to the NB, the care provided to the parents and a set of ethical values. This categorization was based on expressions such as:

> *...comfort care… providing heating and a cozy atmosphere...* (E12)
>
> *...the pain... we can't let him suffer!... we want him to suffer as little as possible!* (E7)
>
> *...It is only fair to die without experiencing pain and surrounded by comfort, support and affection...* (E8)
>
> *... to keep the mother-child connection, the relationship with the parents...* (E2)

There were also references to "Family care... promoting the connection, the proximity... of parents "(E2, E1) and to the concern with "...keeping the baby's dignity... and to his quality of life" (E2).

Curative Care

Curative care is also valued as it reflects the difficulty to make decisions about whether or not to maintain intensive care and maintain life with ventilator support or letting death occur naturally:

> *...maintain life as much as possible, invest!... we are investing in life, until the end...* (E10)

Suggestions to improve care

We collected a wide range of suggestions that relate to the Amendments/optimization of the physical structure and of the operating regulation, Team and Protocols subcategories. The following expressions are good examples:

> *…amendments/optimization of the physical structure and the creation of a space intended for the most critical medical situations!* (E1)
>
> *...to include more people, relatives, important people, people who are meaningful to parents too, who would help them deal with their grief!* (E11)
>
> *...Those operating regulations that state, for instance, that grandparents can only pay one visit to their grandchild...* (E10)

Table 1 - Categories, subcategories and analysis indicators of the perception of the kind of care valued when caring/ providing treatment to newborn who is experiencing a life-limiting condition, Vila Nova de Gaia, Portugal, 2018

Category	Subcategories	Indicators (Enumeration Units)
Palliative Care	Comfort care provided to the NB	Comfort (9) Analgesia (7) Painless death (10) NB Hydration/feeding (3) Parents-children bond (2)
	Care provided to the parents	Presence/ parents-children bond/ contact (4) Support provided to parents (3)
	Ethical values	NB Dignity (1) Quality of life (6) Humanization of health care (2)
Curative Care	Intensive Care	Curative and invasive (4)
	Decision-making	Finding it difficult to stop the care provided (6) Decision-making shared with the parents (1)
Suggestions to improve health care	Amendments/optimization of the physical structure and of the operating regulations	Isolation and preserving NB and parents' privacy (6) Joint accommodation parents/NB (1) More people/increased contact with parents and siblings/ meaningful people (9)
	The team	Reorganizing and motivating the team (2) Training in palliative care (15) Multidisciplinarity (1) Support of the Ethics Commission in the decision-making process (3) Leadership (1) Changing attitudes to learn how to deal with failure (3) Creation of a team/work group (4) Team sharing and reflection (15)
	Protocols	Standardizing procedures (7) Make decision-making easier (7) Allow for the safety of the care provided (5)

Note: NB - newborn.

The Team subcategory was referred quite often with expressions focusing on the importance of training:

> *The need for training.* (E1, E4, E8)

> *Training in health care... food and comfort*. (E4, E11, E12)

> *Ventilation...* (E4, E14)

> *Development of personal and communicational skills...* (E11, E5)

> *Ethics!* (E9)

Multidisciplinarity was another topic that stood out:

> *...hiring a health professional belonging to the field of psychology!* (E1)

And the change of attitudes to learn how to cope with failure:

> *... It's hard for us to face failure...* (E1)

> *...it's hard to say no, there's no use in keeping it going.* (E3)

> *...people's inability to accept that we have to stop!* (E12)

In this subcategory (Team) there was also reference to the creation of a team/work group:

> *I think it would be important to have a team oriented to...* (E8)

> *Putting together a palliative care team...* (E2)

> *Getting a work group...* (E9)

And also to team sharing and reflection:

> *... We are working with different teams operating on their own! I think there should be more sharing and more joint meetings!* (E1, E7)

> *... Usually it starts in there, doesn't it?* [referring to the doctor's office] (E8)

> *... Experiences are not taken into consideration! And they should be, to improve...* (E4, E11)

The "Protocols" Subcategory stemmed from the participants' answers as they referred that there are no action protocols designed for neonatal palliative care in their unit:

> *There are no explicit or written protocol! There is a tacit attitude protocol...* (E8)

> *There are some guiding lines, but no action protocol and we could use one...* (E12)

> *Having a protocol that guides us, it is half the battle...* (E10)

Table 2 has to do with the categorization of experiences in caring for newborns who are experiencing a time-limiting condition. There are two categories that stemmed from the participants' answers: feelings and difficulties.

Feelings

The feelings experienced are related to the inability to save the NB and to the communication with the parents. In the subcategory referring to the inability to save the NB, there are repeated references to feelings such as:

> *...I feel a deep sadness...* (E3)

> *...I've already experienced situations that caused me great sorrow and where I thought it was so unfair and so pointless and that it should not have to be that way...* (E9)

> *...such pain...* (E4)

> *...distress...* (E14)
>
> *...a huge frustration...* (E4, E10)
>
> *...it's hard to accept...* (E1)
>
> *Sometimes it's a bit complicated to manage all these feelings...* (E3)
>
> *...there are situations where it happens suddenly, it's kind of a surprise and it's extremely sad...* (E11)

The feelings associated with the communication with the parents often involve notions like Empathy:

> *...support... trying to calm parents down and letting them knows that we are there...* (E1, E3, E5, E6, E11, E14)
>
> *...show them our sympathy, our solidarity...* (E14)

But involve also a defensive approach or an inability to give them the right support:

> *It's hard to put myself in their shoes.* (E9)
>
> *...I tend to shut down a bit... but I think it's just some sort of personal defense mechanism...* (E10)
>
> *I can't find the right words to tell them...* (E1)
>
> *...I don't feel well… it's not something I enjoy doing...* (E7, E8)

Dificulties

Health professional go through a wide range of experiences that involve caring for and treating newborns who are experiencing a life-limiting condition. These experiences have uncovered a set of key difficulties that were grouped into several subcategories. The first is related to the NB's severe clinical situation and the inability to:

> *...accept that they will not improve...* (E9)
>
> *...we have to deal with death…to deal with the end of life when it has barely begun...* (E10)

The difficulties related to communicating with parents refer to dilemmatic situations caused by the presence/ parents/children bond and, on the other hand, by a situation of early loss and mourning in which:

> *These issues have to be deeply discussed with the family!... sharing with the family what the options are, taking into account what they are going through, am I right?...* (E1)
>
> *The decision-making process we have to share with the family.* (E7)

The difficulties experienced by the team when they have to make ethical decisions stem from the fact that the therapeutic range has yet to be clarified:

> *...what is palliative and what is not palliative...* (E9, E12)
>
> *...the major difficulty is making decisions.* (E9)

But is also caused by the lack of consensus about when palliative care have to be assigned:

> *...it's trying to artificially prolong a hopeless situation… I find it unnecessary...* (E10)
>
> *...I have witnessed some conflicts between the members of the nursing team, between the elements of the medical team and between the two teams...* (E12)

Some difficulties have to do with the facilities, the physical conditions offered:

> *...lack of conditions to allow the child and his parents some privacy...* (E1)
>
> *Most of the time, we are not in any position to provide for that family...* (E6)

Table 2 - Categories, subcategories and analysis indicators of the experience in caring for newborns who are experiencing a life-limiting condition, Vila Nova de Gaia, Portugal, 2018

Category	Subcategories	Indicators (Enumeration Units)
Feeling	Related to the failure to save the newborn	Sadness, distress, pain, suffering (6) Frustration (8) Revolt (2) Non-accpetance (9) Feelings management (4)
	Related to the communication with the parents	Empathy with the parents (13) Defensive approach (2) Inability to provide support (4)
Difficulties	Related to the NB's serious clinical condition	Envisage the NB's death (8) Maintain hope while there is life (5) Changes in the quality of life (3) NB vulnerability (13)
	Related to the communication with the parents	Presence/parents-children bond (4) Dealing with the family (9) When providing emotional support (8)
	The team's ethical decison	The respect for the NB's dignity (1) Value his quality of life (1) Boundaries to therapeutic range (4) Lack of consensus regarding the application of palliative care (4)
	Facilities/physical conditions	Accommodations that allow for privacy (2) Comfort conditions for the parents (2)
	Relational	Conflicts among health professionals (5) Between health professionals and the parents (2) Between the couple (1)

Note: NB - newborn.

In the subcategory "Relational Difficulties", we found out that some health professionals have already experienced conflicts among fellow professionals:

> *Conflict among people, among the professionals… been there!* (E8)
>
> *...conflicts because there is no consensus between the team...* (E3)
>
> *But also between professionals and parents.* (E2)
>
> *...sometimes parents, blame us for everything...* (E7)

And even Between the couple.

DISCUSSION

The aim of this study was to identify the perception of health professionals of neonatal palliative care through the application of interviews.

During the analysis carried out on their perception of the NCP, we realized that palliative care is valued, but that most professionals have associated palliative care with end-of-life situations, with painless death, possibly because, for most, the word "palliative" is still greatly associated with end-of-life and death(21-22). Comfort care, analgesia, hydration/feeding were acknowledged as part of palliative care, as seen in other studies(6,16,23). The answers provided by some of the health professionals also show how much they value the use of curative care when caring for the NB who is experiencing a life-limiting condition. This may be due to the fact that it is difficult for them to accept they cannot save their patients' life(21). That's why it is so difficult for them to "give up" on them and why they use all the means they have at their disposal to try and save the NB's life. On the other hand, NPC own philosophy states that this kind of care should start in addition to curative care and should be increased when the curative objective is no longer appropriate(11-12,18). We found out that most health professionals recognize that NPC aims at preventing and soothing newborns' suffering and at increasing their quality of life while they are still alive and providing them with a painless death. Some of them also seem to value the care provided to the parents(11,24). In fact, communication with parents may be more stressful than the effective provision of care for newborn infants in a end-of-life situation(12), but parental care represents an ethical value included in the principle of patient autonomy in which any decision has to be discussed with parents, in accordance with their beliefs and culture, and includes the design of an individualized care plan(25). Other valued ethical values were the respect for the NB's dignity and for their quality of life, also found in another study(26).

Several suggestions were given to improve health care provided to newborns who are experiencing a life-limiting condition. One of the aspects covers the possible introduction of amendments/optimization of the physical structure and changes in the current operating regulations. Data collected is in accordance with another study accessed and showed that there are some obstacles that hinder the full implementation of NPC: the absence of facilities that would provide the child and his parents with the right isolation and privacy and some factors associated with the department's procedures and policies(27). The ideal situation would be to have the NB and his family transferred to a private room and make sure that relatives will be protected and will not be forgotten(6).

There is a wide range of suggestions for improving the team performance that focus mainly on the need for training(27-28). Another important aspect is team sharing and reflection. This particular aspect is also regarded as being an obstacle to the implementation of NPC and that comes not only from poor communication skills and conflicts between professionals, but also from existing discrepancies and the lack of administrative support and financial resources(12). The existence of protocols was suggested because this might facilitate decision-making, procedures standardization and is regarded as a factor that facilitates the provision of end-of-life care(6,12,28).

The experience in caring for newborns in an end-of-life situation is reflected in feelings and difficulties. The feelings related to the NB's severe clinical condition are associated with technological imperatives and with the yielding to the temptation of using any technology available, even when one knows that it will but hopelessly prolong the NB's life(27). The feelings related to the parents come from the empathy provided by health professionals but also from the awareness that dealing with the parents' expectations and desires is one of the most difficult areas in health care provision. Parents require direct and honest information from the team. This may represent a challenge for health professionals since they have to include them in the ethical decision-making process(29). We have also identified reports of dilemmas affecting the team's decision-making regarding the treatment or limitation of therapeutic effort because they are part of a long process that requires a team effort and has to be built in partnership with parents, under the guidance of the team and based on a relationship of mutual trust. These dilemmas can cause conflicts between professionals and between professionals and parents, a situation that is referred in other studies(16,29). All the members of the health team must be included in the decision-making process and will be encouraged to share their point of view. There will have to be a genuine openness between disciplines and professional groups(16). A good, open, clear and honest communication is considered one of the best ways to help resolve conflicts, but if this isn't enough the presence of an independent mediator may be useful. This person may be someone from the unit or an external element, a spiritual and religious guide, for instance. If no agreement is reached, the institution Ethics Committee may be asked to issue an official opinion(7,16,30). A second opinion may be essential if the team is unexperienced, if there are doubts regarding symptoms management or some treatment or at the request of the parents. The team should be open to any of these situations(16,30). The doctor responsible for the case must guide and monitor the decision-making process and must always take full responsibility for the treatment option taken(16,30). The entire decision-making process and the justification for the actions taken should be kept in the NB's file(3,7,30). Regular multidisciplinary meetings are recommended. They should involve the team members and a psychologist and will be used to discuss the cases, promote team cohesion and improve its performance as well as reduce potential conflict and potential therapeutic escalation(16). The role played by the different health professionals in the decision-making process has not yet been clarified, especially that of the nurses, who are the health professionals who spend most time with the NB and his family(29). Nurses play an important role in palliative care since they are responsible for the early assessment, identification and management of physical, social, psychological, spiritual and cultural needs(18). They are those who, due to the proximity of their relationship with the NB and his family, have to deal with hard emotional situations and who, in most cases, experience firsthand feelings like failure and defeat(31). We found out that caring for a NB facing an end-of-life condition is difficult for everyone involved, however health professionals understand that the suffering experienced by the parents is much greater than the one felt by anyone else and, despite the close relationship they have established with the parents/family, it is extremely difficult to find a way to deal with them in a time of so much pain and suffering(31).

Study Limitations

We weren't able to explore all the dimensions of palliative care, namely the kind of assistance that should be provided to the family during the mourning process, since there's no reference to this topic in the respondents' answers. Therefore, new studies are suggested in order to broaden knowledge about the perception of NPC. The results report to a specific experience and cannot be generalized.

Contributions to healthcare

It was important to study a specific unit and involve all professionals of the team, since it allowed us to raise people's awareness with regard to neonatal palliative care, but it was also an opportunity for health professionals to share their perception and reflect on their experiences and the contexts of their practice, in order to contribute to the implementation of neonatal palliative care and to the improvement of humanization of health care provided to newborns who are facing a life-limiting condition.

This study made it possible for health care professionals to come up with suggestions for improvement, namely: the implementation of training in PC, the creation of a NPC group, the establishment of protocols that will help standardize procedures and facilitate decision-making processes, the reorganization of the physical space with the creation of a suitable space where parents could be granted the privacy they deserve to be appropriately informed or to spend some time with their children. Through the answers provided, health professionals drew our attention to the need for new support approaches when we are dealing with NB who face a time-limiting condition and with their family: priority has to be given to end-of-life quality care, because science is able to prevent avoidable deaths, but will never be able to stop death...

CONCLUSION

It was evident that health professionals have a hard time talking about their personal experience in providing care to newborns facing an end-of-life situation and to their family. Evidence provided by their answers unveils their humanity as they share the feelings they have experienced: pain, sadness, suffering, frustration, but also the respect and the empathy they feel when they provide care for the NB and for his family.

Health professionals experience difficulties in making end-of-life decisions and claimed they had already experienced conflict situations due to differences of opinions and because of the inexistence of protocols that would surely have helped them deal with those situations. The physical structure of the NICU is regarded as another source of constraints since it cannot provide the parents with the right comfort and privacy conditions.

Despite their lack of training in PC, health professionals revealed deep sympathy for the newborns' needs and for their families' and showed that they are always willing to help implement NPC in their unit.

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