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The resilience of nurses in caring for children who experience terminality

A resiliência do enfermeiro no cuidado à criança que vivencia a terminalidade

La resiliencia de las enfermeras en el cuidado de niños que experimentan terminalidad

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Abstract: **Objective:** to investigate the resilience of nurses in caring for children experiencing terminality in intensive care. **Method:** a qualitative study conducted with 12 Pediatric and Neonatal Intensive Care Unit nurses of two hospitals in the countryside of Bahia. Data collection occurred in April and May 2019, and semi-structured interview was used, analyzed through Collective Subject Discourse. **Results:** it was evidenced the difficulty of nurses in dealing with child terminality, referring to anguish and impotence, more intensely to those who are mothers. Empathy and spirituality proved to be important in caring for terminally ill children and in developing resilience. **Conclusion:** it is necessary that finitude be faced as a natural course of life. Thus, studies on the theme should be expanded and educational and labor institutions invest in discussions about terminality so that nurses develop coping mechanisms and build resilience in child care.
Descriptors: Nursing; Resilience, Psychological; Death; Child, Hospitalized; Child Care

Resumo: **Objetivo:** investigar a resiliência de enfermeiros no cuidado à criança que vivencia a terminalidade na terapia intensiva. **Método:** estudo qualitativo, com 12 enfermeiras das Unidades de Terapia Intensiva Pediátrica e Neonatal de dois hospitais no interior da Bahia. A coleta de dados ocorreu em abril e maio de 2019, utilizou-se a entrevista semiestruturada, analisada mediante Discurso do Sujeito Coletivo. **Resultados:** evidenciou-se a dificuldade das enfermeiras em lidar com a terminalidade infantil, referindo angústia e impotência, mais intensamente àquelas que são mães. A empatia e a espiritualidade se mostraram importantes no cuidado à criança terminal e no desenvolvimento da resiliência. **Conclusão:** faz-se necessário que a finitude seja enfrentada como curso natural da vida. Assim, deve-se ampliar estudos sobre a temática e que as instituições de ensino e laborais invistam em discussões sobre a terminalidade, para que as enfermeiras desenvolvam mecanismos de enfrentamento e de construção da resiliência no cuidado à criança.
Descritores: Enfermagem; Resiliência psicológica; Morte; Criança hospitalizada; Cuidado da Criança

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Resumen: **Objetivo:** investigar la resiliencia del enfermero en el cuidado de niños que experimentan terminalidad en cuidados intensivos. **Método:** estudio cualitativo, con 12 enfermeros de las Unidades de Cuidados Intensivos Pediátricos y Neonatales de dos hospitales del interior de Bahía. La recolección de datos se realizó en abril y mayo de 2019, se utilizó la entrevista semiestructurada, analizada a través del Discurso Colectivo del Sujeto. **Resultados:** se evidenció la dificultad de las enfermeras para afrontar la terminalidad infantil, referida a la angustia e impotencia, con mayor intensidad a las que son madres. La empatía y la espiritualidad demostraron ser importantes en el cuidado del niño terminal y en el desarrollo de la resiliencia. **Conclusión:** es necesario que la finitud se enfrente como un curso natural de la vida. Así, es necesario ampliar los estudios sobre el tema y que las instituciones educativas y laborales inviertan en discusiones sobre la terminalidad, para que las enfermeras desarrollen mecanismos de afrontamiento y construyan resiliencia en el cuidado infantil.
Descriptores: Enfermería; Resiliencia Psicológica; Muerte; Niño Hospitalizado; Cuidado del Niño

Introduction

Death is a complex phenomenon that arouses the fear of many people by revealing feelings such as sadness, loss and emptiness, including in health professionals, when it comes to caring for terminally ill patients. Terminality can cause health workers to come face to face with their weaknesses, by awakening feelings of failure and impotence related to assistance to those who face end of life.[1]

Sometimes it is not possible to predict the moment when death approaches; however, for some people, end of life can be announced, depending on the clinical conditions in which they are: they are the so-called terminally ill patients. Terminality can be characterized as a moment when curative therapeutic possibilities are exhausted and patients no longer respond to treatment, making death predictable and inevitable. Patients, health staff and family are limited and resistant to recognizing the finitude of life.[2]

When it comes to children, terminality permeates deeper fields, generating intense feelings and greater commotion due to the expectations employed by the infant and its projection for the future, considering the idealization of a life cycle. These cultural representations interfere in the care provided by nurses to terminally ill children.[3] Thus, the predominance of Western culture, with a tendency to rule out the idea of death, professional

preparation aimed at health restoration and a strong idealization of a future for children make it difficult for nursing staff to accept terminality.

Nurses working in child Intensive Care Units (ICU) are daily due to the uncertainty and fear of death in caring for terminally ill children. These experiences cause suffering in professionals, who even begin to question their skills, feeling sometimes frustrated and, therefore, tend to fight against this impending reality.[4-5] This reflects the process of curriculum training, permeated by gaps in teaching terminal care, given that training is focused on health repair, and during the performance there are hardly spaces to reflect and dialogue about child terminality and death. [1]

Coping concerns the efforts employed to deal with or sometimes change a circumstance. It should be noted that the way of looking at the process of death is based on individual values and meanings attributed. Thus, the standard of care received by children and their family also depends on nurses' coping capacity.[6]

Resilience is then presented as a tool for coping with terminality and enables developing strategies for professionals to assist child suffering. Although there is no absolute consensus on its concept, resilience can be defined as the ability to face, adapt and overcome adversities; it does not mean absence of anguish, but represents self-management, and the way of dealing with situations that can be traumatic.[3-4]

Considering the above, it is evident the importance of deepening studies on the subject, since issues related to terminality and its consequences, such as resilience of nurses who deal with infant death are not broadly addressed during professional training.[1] Moreover, the scientific literature review, performed in databases through the descriptors "Nursing", "Psychological Resilience", "Death", "Hospitalized Child", and "Child Care" demonstrated incipient research, when directed to the approach of child terminality with a focus on nurses, thus adding relevance to this study.

In the face of this, we sought to answer the following research question: how is resilience of nurses established in caring for children who experiences terminality in intensive care? In order to answer this question, the objective is to investigate the resilience of nurses in caring for children who experience terminality in intensive care.

Method

This is a descriptive, exploratory study with a qualitative approach, carried out at two public hospitals in a city in the countryside of Bahia, in Neonatal and Pediatric ICUs. One of them has a pediatric and neonatal ICU, 5 and 10 beds, respectively. The second has only neonatal ICU, with 10 beds. Nurses working in child or neonatal intensive care for at least six months, and at some point taking care of a terminally ill child were included. The choice of participants occurred in a non-probabilistic manner, for convenience, delimited by the criterion of data saturation, i.e., the final number of participants was determined at a point where there was no new information and redundancy was obtained.[7]

Thus, considering the total universe of 22 nurses (13 Neonatal ICU and 9 Pediatric ICU), initially 15 were invited to participate in this study, of which 14 accepted, but 2 professionals who did not fit the selection criteria were excluded, because they did not have a minimum time of six months of practice in Child Intensive Care. The other nurses were not invited because the objectives were achieved by data saturation, resulting in a total of 12 participants.

Data were collected during April and May 2019, consisting of applying a semi-structured interview containing questions in order to establish a sociodemographic profile of interviewees, in addition to the following questions: Why did you choose to work with children in need of intensive life support? How do you feel about caring for children who experience terminality? What challenges do you face at work when assisting children experiencing terminality? Have you ever faced a remarkable situation in which you were shaken when assisting a terminally ill

child? Did you turn to anyone? What support and/or strategies have you used to cope? What qualities do you deem necessary to work with critically ill children? Do you think you are resilient? Why?

Data collection took place in a private place, in order to guarantee privacy to participants, after signing the Informed Consent Form. The interviews were averaging 15 minutes, being recorded in a digital audio device, later transcribed and analyzed by Collective Subject Discourse (CSD).[8] To identify participants and guarantee anonymity, letter I (interviewee) was used, followed by the number corresponding to the sequence of interviews.

CSD was chosen because it is a proposal for organization and tabulation of qualitative data of a verbal nature, which seeks, from the central ideas or the anchors identified in the analysis process, to gather a maximum of expressions of subjects. This method uses as methodological figures: key expressions (KE), central ideas (CI), anchorage (CA) and the collective subject discourse (CSD).[8]

KE correspond to the exploration phase and highlights of excerpts from discourse that reveal the essence of the testimony. CI are removed from KE, which describe in a more synthetic and precise way the meaning of the discourse analyzed. CA is used to frame a specific situation, being a linguistic manifestation of an ideology or belief of the subject author of the discourse. Ci and CA are then categorized and grouped according to the direction they present. These elements contributed to building CSD, which is a unique and coherent discourse, conducted in the first person singular, with the purpose of the "I" speaking on behalf of a community.[8]

This research was approved by the Research Ethics Committee of *Fundação Pública de Saúde de Vitória da Conquista* on 03/26/2019, with Opinion 3,223,720 and CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 07992919.1.0000.8089, according to Resolution 466/2012 of the Brazilian National Health Council (*Conselho Nacional de Saúde*).

Results

Concerning sociodemographic analysis, all participants were female, aged between 31 and 41 years, with a mean age of 35.5 years, 41.7% (n=05) single, 33.3% (n=04) married, 16.7% (n=02) in stable union, 8.3% (n=01), divorced, 58.3% (n=07) have children and 83.3% (n=10) are Christian. Regarding ICU, 83.3% (n=10) of the interviewees work in the neonatal and 16.7% (n = 02) in the pediatric. Participants have an average of 10.5 years of academic training and six years of experience in child intensive care.

Analysis of the information collected through interviews allowed identifying three CI: (1) Challenges and feelings involved in caring for terminally ill children; (2) Empathy to assist children facing terminality; (3) Building resilience for caring for terminally ill children.

CI 1: Challenges and feelings involved in caring for terminally ill children

Caring for terminally ill children involves processes that challenge the practical performance of nurses and also their emotions, sometimes generating feelings of sadness, frustration, and impotence. This reflects the difficulty that these professionals present in accepting the terminality and the obligation to fight for healing, regardless patients' prognosis, as can be evidenced in the following discourse.

> *It is difficult to accept terminality, it is painful and we often work with a tight heart. Even after years, I haven't gotten used to it and I don't think I should get used to seeing a child die, I usually say that this couldn't happen to a child, they should be protected. We feel frustrated, sad and helpless to know that children will not leave that situation, it is as if we cannot offer treatment, it is out of our control and we do not know how to deal with it. Sometimes, even in palliative care, we are afraid of not carrying out certain behaviors because this "we cannot do anything" does not enter our minds, it does not make sense. Even more working at ICU, we are there to fight against that adverse situation, there is no way to*

> *think that you are doing good without interfering in anything. It's difficult. When you have children it gets worse; you end up having a different look. When I didn't have it, I was already sorry, then I believe it intensified the sensitivity.* (CSD 1)

CI 2: Empathy to assist children facing terminality

Nurses report that care for the minor who experiences terminality needs to be empathic, which is not only about the sensitive look at patients, but also at his/her family. The involvement with children's life history causes professionals to welcome the family members and assist them in the process of terminality. However, these factors can interfere with nurses' emotional, and finding a balance between technical routine of care and development of empathic attitudes is a challenge, as demonstrated in the CSD presented below.

> *We who work with children know that it is not just the patients, it has a context, a family involvement and a sharing happens. We feel and live that moment together with the family because we get attached to the parents' story and what they went through to have that child. That's why I always try to talk, get closer and help the family to work on this game, which is extremely difficult. From the moment I see a child dying, I realize parents' suffering and I'm fine, I'm no longer human. I try to be as human as possible, walking on their shoes and realize how much the other may be suffering. Not being melancholy or too hard, I try to find a middle ground. There are professionals who work at the mechanic and you need to be empathetic and think that that patient could be your child, because when you look like that, you are more attentive, caring and careful. You need to be sensitive, and in these terminal situations, sensitivity has an infinitely greater impact, and this is a challenge, not letting the loss issue become a routine*. (CSD 2)

CI 3: Building resilience for caring for terminally ill children

Based on professional experiences related to child terminality, many nurses develop strategies for coping with and building resilience, in order to obtain an emotional balance in the

face of children's death. They find support of co-workers and spirituality to support to develop resilience, which results in both personal and professional growth, as demonstrated by the CSD presented below.

> *The nursing staff is in direct treatment of patients, so they have to try to have an emotional balance to care for and alleviate suffering. Sometimes, we get a little unstructured, but we can't let our emotions overflow. If you fall, you can end up disrupting the group and even the family. Sometimes, people think we are cold, but there are moments that we cannot stop to regret, because there are other children, so as a protection we do it technically, because we have to be strong and have balance to cope. Of course, it is not possible to dissociate everything, it is not through gaps or boxes, because we are one. In some situations, it is difficult to hold on to emotion, mothers cry and we cry together, and so we get attached to what we believe. I believe and trust in God, I question, I ask Him for strength and explanation, I also tend to talk to people close to me, co-workers or at home. Soon after death, there is a great silence, but there is always a moment when we share the feeling to overcome fears, frustrations and everything we experience in ICU. These terminal situations also end up being a learning experience for the staff, it strengthens the way to act, see where it went wrong and grow as a professional. But, although we talk, when I go out I try to leave it here, at the beginning it was more difficult, it is always a feeling of anguish, but we learn to manage. Therefore, I believe that, in each situation we experience, we put a brick of resilience, build and get stronger.* (CSD 3)

Discussion

From CSD 1, it can be observed that accepting children's terminality is a complex challenge to the nursing staff, which finds itself facing situations considered unnatural, because there is an expectation of the future for children, raising distressing feelings and sensations. Such feelings are explained from a social expectation that these professionals are maintainers of life and the non-fulfillment of this responsibility causes such emotions to emerge. It is also

evident that the possibility of death of children, despite being a possible event to all living beings, is rejected and when reality becomes imminent suffering expands.[9-10]

The feeling of impotence is justified due to the inability to interrupt the terminal process and prevent death. This fact can lead professionals to challenge the therapeutic measures and even their action, leading to psychic repercussions that cause stress and increase the suffering generated by patients' death process.[5,10]

Other feelings are experienced, such as those reported in the study,[11] in which it is exposed that, at certain moments, the staff can also enjoy good feelings, such as gratification, valorization and achievement, when they see in some way their work recognized by patients and, especially, by the family. For the staff, the feeling of fulfilled duty works as a motivation for performance of care.

Palliative care can be understood as the moment when therapeutic possibilities are exhausted and patients no longer responds to curative treatment. However, Western society associates death at the end of life, not relating it to a natural physiological process, which causes sensations of strangeness, anguish, and sadness.[2] Thus, the interviewed nurses, as reported in CSD 1, demonstrated that they have limitations in accepting palliative care when it comes to terminality, and because they work in ICU and with children feel the responsibility to perform measures to maintain life, regardless prognosis.

A research[10.12] points out that, in the intensive care environment, faced with the technological device that helps in the maintenance of life, healing is sought incessantly, and for professionals, sometimes, it is difficult to understand and accept death. Thus, nurses who work in ICU is found between their professional technical responsibility and their beliefs, values and feelings, dilemmas that become intense when it comes to caring for terminally ill children.

It was observed in CSD 1 that nurses reported that the fact that they are mothers makes the process of acceptance of infant terminality painful, and this is justified due to the projection

of frailty in the other and an identification with patients, which causes finiteness of children to bring to light the possibility of children loss.[11] However, in the search for literature, it was noticed that there are still few studies that address health professionals' suffering who are mothers and work with child terminality.

Assisting a terminally ill child requires not only nurses to provide direct care to patients, but the social and family context to which a child is inserted also needs to be considered. However, all these aspects of care, depending on how they are configured, can interfere in professionals' emotions and in their coping with child terminality. Faced with this scenario, nurses begin to develop empathy, putting themselves on the family's shoes and providing them emotional support.

It can be observed in CSD 2 that nurses reported the importance of building bonds with the family of the terminally ill child, and this involvement is considered essential for the realization of humanized care. In this regard, studies show that caring for children in finite situations requires that professionals develop certain characteristics that contribute to the formation of bonding and trust with patients and the family, in order to promote comfort.[3-4,13]

As reported by the nurses interviewed, in CSD 2, the involvement with the life history of children and their family causes them to take an empathic attitude for care, seeking to understand how the process of terminality affects those involved. This attitude, according to them, makes them take a sensitive, welcoming and humanized attitude. In this context, the caregiver's empathy with being cared for is essential, because imagining in the other's place and experiencing their pain favors the realization of sensitive care, in which communication between nurse and patient is valued.[3-4]

When nurse practice empathic care, they consider the family as an inseparable part for patient care who experiences terminality. In this context, family is understood as a structure in which all its members are interconnected, and when one of them gets sick all the attention

turns to the sick, raising distressing feelings. Due to the closer proximity, nursing is the most accessible profession and, therefore, becomes a support for the family member by closely monitoring their concerns, concerns and anxieties.[4]

Dialogue, listening, understanding of priority needs, not only physical, but also subjective, through emotional support and support to cope with terminality, causes nurses to become emotionally involved with terminally ill children and with their family, thus approaching the suffering experienced by them. This care provides the exercise of sensitivity in care, but it is necessary to establish affective limits, in order to avoid further emotional problems to professionals, because it is perceived that, with the formation of bonds and involvement, the more difficult is the acceptance of terminality.[14]

When a humanized work is proposed, feelings need to be taken into account by both patients and professional who assist them.[4] Other studies dealing with death from the perspective of health professionals,[1,15] add that it is important to consider sadness or even the manifestation of crying in the face of a patient's death, thus recognizing the humanity that exists in professionals. However, it is reiterated that the expression of feelings must be measured, so that it does not harm the care provided and interpersonal relationships.

Humanized care makes the experience of finitude less traumatizing, both for professionals and for family members. The execution of sensitive care favors developing empathy, compassion and attachment to children and the family, and values the offer of comfort as a way to make this moment as smooth as possible.[16]

Even in the ICU environment, where there is a predominance of a technology-oriented care model, with the need to use a variety of equipment (monitors, mechanical ventilators, hemodialysis machines, among others), it is now recognized that humanization is a fundamental part of care, especially when it comes to terminality. Thus, to increase an expanded view of care

for terminally is children is not limited to stimulating dexterity and scientific knowledge, but, moreover, considering the psychosocial and spiritual aspects that involve care.[15]

By acting with empathy, nurses make their care practice more humanized and manages to approach end of life care goal, promoting comfort and well-being comprehensively. Implementing such care favors not only terminally ill children, but all those involved in the context of death.

Many professionals also see child terminality as an opportunity for personal and professional growth. To this end, it is necessary to develop strategies for coping with and building resilience. Among the strategies pointed out, faith and religion were evident, in addition to the emotional support provided by co-workers.

CSD 3 reports on the interviewees how they build resilience to deal with child terminality. This situation requires professional emotional balance, development of an ability to overcome and adapt to adversities. For this, building a resilient attitude is fundamental. Thus, nurses develop strategies to strengthen, face suffering and favor their development.[17]

Nurses spend most of their time in child care and their family group, so they need to develop skills to take care not only of the physical domain, but psychological and spiritual needs of children and their family.[18] Coping strategies can range from removal measures to a strong reception, so that each professional uses mechanisms based on his or her own experiences.[6]

Resilience can be learned, developed and shaped; it can be an individual characteristic, but also influenced by the collective, depending on how much that individual recognizes himself or herself as part of a group. This feeling of welcoming and belonging contributes to professionals finding support for building resilience.[17]

In general, hospital institutions require from their workers rationality and productivity,[5] characteristics that impose limitations on individuals, who have to separate their professional

side from the staff. This is corroborated in the interviewees' discourse, in CSD 3, in which they claim not to be able to complain, because they need to be well to assist the other children.

In order to minimize the impacts caused in coping with child terminality, through positive prayers and thoughts, many seek in the spiritual and faith spheres the necessary help to maintain hope, with the purpose of providing care and comfort to their patients. Others choose to individualize suffering; however, this usually causes an emotional overload. Understanding this process and talking about their anxieties makes professionals have a voice, be active and deal better with the bad environment at work. Thus, teamwork is essential not only for care, but also for providing support and emotional support among its members.[3,5]

As observed in CSD 3, experiencing terminal situations can also be productive for the staff, because it allows reflection on the care provided, which corroborates the findings of another study, which analyzed how pediatric ICU nursing staff deals with the death process.[19] This provides learning not only in relation to technical development, but also with regard to subjective issues, such as development of problem-solving skills, in addition to dealing with family members, and ethical aspects, in order to develop quality care.[16,20]

There is a need to create strategies, in the form of continuing education, so that professionals can express their feelings and face their dilemmas, especially those related to care and issues involving terminality.[9] Thus, it is necessary to reflect on the work process, recovering the understanding that death is a natural phenomenon that inevitably is part of life, so that psychic suffering is minimized and there is improvement in quality of life of professionals.[15]

A study[21] that evaluated the resilience of nursing workers working in hospitals in various sectors, including pediatrics, reiterates that resilience is not permanent but a state, since situations are changeable and the response to them is also dynamic. Therefore, resilience is improved with each circumstance experienced. The research also reveals the importance of

identifying and treating occupational stress, so that affliction is not harmful to professional performance.

In order to build resilience, nurses need to identify their sources of support, either in the spiritual sphere or through the support provided by co-workers or even professionals specialized in mental health. Proper support helps professionals to identify their limitations, develop self-care and self-manage their emotions, for caring for terminally ill children.

It was observed as limitations of the research the visualization of a single reality, because it is a local study in a municipality. Moreover, most interviews took place in Neonatal ICU, a fact that may not have explained the reality of pediatric units.

Conclusion

Infant terminality produces feelings of anguish, sadness and impotence in the study participants. It was also noticed that the nursing staff has insufficient emotional preparation to deal with the finitude of children's life, not accepting a terminally ill child's death. It was observed that nurses' suffering increases when they have children, but there is a need for further studies to be conducted to reinforce understanding how health professionals who are mothers deal with suffering generated by children's death in the workplace.

Analysis of results also demonstrated that empathy is essential for the care provided to terminally ill children to be humanized and that this is often due to emotional involvement with children and their family. It is clear that, despite the need for sensitive care, balance and affective limits should be established in order to minimize professional suffering.

Building resilience has been described as something that is constantly changing and is shaped by each situation experienced. As personal strategies for the production of resilience, the interviewees refer to the exercise of spirituality, in addition to dialogue to express their insecurity and anguish.

Therefore, it is necessary that finitude be faced as a natural course of life. To this end, educational and labor institutions should invest in discussions about terminality, so that nurses discover mechanisms for coping and building resilience in caring for children who are at the end of their lives.

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