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SURVIVING THE DEATH AND DYING PROCESS OF CHILDREN AND ADOLESCENTS: EXPERIENCES OF NURSING PROFESSIONALS

Sobrevivendo ao processo de morte e morrer de crianças e adolescentes: vivências de profissionais de enfermagem

Sobrevivir al proceso de morir en niños y adolescentes: experiencias de los profesionales de enfermería

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ABSTRACT

Objective: to understand how nursing professionals in a Pediatric Intensive Care Unit experience the grieving process resulting from the death of children/adolescents. **Method:** qualitative research carried out in a public hospital in the state of São Paulo, with twelve nursing professionals, using an open-ended interview with the guiding question "Tell me, in detail, how you have coped with grief after the death of a child and/or adolescent in the Pediatric Intensive Care Unit". **Results:** six categories emerged and were organized into two thematic axes. **Conclusion:** Nursing professionals revealed various facilitating beliefs and strategies for coping with the process of death and dying. It is recommended that health institutions offer mental health care to health professionals.

DESCRIPTORS: Bereavement; Nursing professionals; Pediatric intensive care unit; Pediatric nursing;

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RESUMO

Objetivo: compreender como os profissionais de enfermagem de uma Unidade de Terapia Intensiva Pediátrica vivenciam o processo de luto decorrente da morte de crianças/adolescentes. **Método:** pesquisa qualitativa, realizada em hospital público, do estado de São Paulo, com doze profissionais de enfermagem, por meio de entrevista aberta com a questão norteadora "Conte-me, em detalhes, como você tem enfrentado o luto após a morte de uma criança e/ou adolescente na Unidade de Terapia Intensiva Pediátrica". **Resultados:** emergiram seis categorias que foram organizadas em dois eixos temáticos. **Conclusão:** Os profissionais de enfermagem revelaram diversas crenças facilitadoras e estratégias de enfrentamento do processo de morte e morrer. Recomenda-se que as instituições de saúde ofereçam atendimento de saúde mental para os profissionais de saúde.

DESCRITORES: Luto; Profissionais de enfermagem; Unidade de terapia intensiva pediátrica; Enfermagem pediátrica;

RESUMEN

Objetivos: comprender cómo los profesionales de enfermería de una Unidad de Cuidados Intensivos Pediátricos viven el proceso de duelo resultante de la muerte de niños/adolescentes. **Método:** investigación cualitativa realizada en un hospital público del estado de São Paulo, con doce profesionales de enfermería, utilizando una entrevista abierta con la pregunta orientadora "Cuénteme, detalladamente, cómo ha enfrentado el duelo tras la muerte de un niño y/o adolescente en la Unidad de Cuidados Intensivos Pediátricos". **Resultados:** surgieron seis categorías que se organizaron en dos ejes temáticos. **Conclusión:** Los profesionales de enfermería revelaron diversas creencias y estrategias facilitadoras para afrontar el proceso de morir y morir. Se recomienda que las instituciones sanitarias ofrezcan atención de salud mental a los profesionales de la salud.

DESCRIPTORES: Duelo; Profesionales de enfermería; Unidad de cuidados intensivos pediátricos; Enfermería pediátrica.

INTRODUCTION

Pediatric Intensive Care Units (PICUs) are characterized as permanent medical and nursing care environments for children/adolescents with an imbalance in one or more physiological systems, who require technological support for diagnosis and treatment.[1]

Due to the severity of the health conditions faced by children in the PICU, nursing professionals are more exposed to the process of death and dying. This exposure can contribute to the development of high levels of traumatic stress and burnout.[2]

Even though they live with death in their daily lives, nursing professionals say that, with children/adolescents, dying is generally considered an unnatural occurrence,[3] because death at this stage interrupts the natural cycle of life, leading to questions about the care provided and also about the child and the family.[4]

Nursing professionals' grief can go beyond traditional conceptions, which involve emotional responses such as crying and sadness, as well as not accepting the loss of the child. It can be accompanied by moral distress, caused by a sense of failure and guilt.[5]

Taking into account the uniqueness of individual reactions, professionals describe mourning and distress through four themes: sequence of emotional responses, emotional stimuli of aggravation or relief, coping strategies and resilience. Other professionals, over time, choose to develop greater emotional resilience.[6]

Therefore, the feelings arising from bereavement must be recognized because, if they are not addressed, they can become chronic and cumulative. Thus, when there is recognition and support for the grieving process, nursing professionals are able to deal with the meaning of loss.[7]

Thus, the aim of this study was to understand how nursing professionals in a PICU experience the grieving process resulting from the death of children/adolescents.

METHOD

This is a qualitative study, inspired by Phenomenology as a philosophical school, which seeks to understand human phenomena in themselves, considering that only the individual who experiences that phenomenon is capable of unveiling it through their discourse.[8]

The setting was the PICU of a public hospital located in the state of São Paulo. Participants were recruited through a non-probabilistic sample, using the snowball technique, which employs reference chains built from people who share characteristics of interest.[9]

The participants were 12 female nursing professionals, nine of whom were nursing technicians and four nurses, aged between 24 and 62, with between one and 30 years' experience in the unit, according to the following inclusion criteria: being a nurse or nursing technician, working in the unit for at least one year.

Data collection took place on a date/time previously agreed with the participants, in a reserved space in the unit itself, with the guiding question: "Tell me in detail how you have coped with grief after the death of a child and/or adolescent in the PICU". The interviews were conducted between September 2022 and March 2023, recorded on digital audio and transcribed in full by the first author, totaling 139.43 minutes. All participants signed the Informed Consent Form (ICF) and kept a copy.

In order to analyze the interviews, we used Martins and Bicudo's8 steps for analyzing the structure of situated phenomena: global reading of the total content of the discourse; re-reading in order to identify significant statements; searching for convergences and divergences; building thematic axes with the respective categories; drawing up a descriptive summary.

In order to guarantee the anonymity of the participants, the nursing professionals were given symbolic names that evoke the idea of change, renewal and transformation, thus reflecting the profound transitions that the experience of working in the pediatric intensive care unit can cause in their lives.

The interviews ended when the discourses proved sufficient to help the researcher unveil the phenomenon in question, i.e. they reached theoretical saturation.[10] The research was approved by the Research Ethics Committee (CEP) - UNICAMP, Opinion No. 5.595.718, in accordance with Resolution 466/2012.[11]

RESULTS

The analysis of the discourses of nursing professionals who work in the Pediatric Intensive Care Unit and who have experienced the grieving process of children/adolescents made it possible for two thematic axes to emerge - 1. Beliefs Facilitating the Acceptance of Grief and 2. Strategies for Coping with Bereavement, which were organized into six categories: Believing that the child's death is divine permission; Perceiving death as a relief for the child; Considering that the death of children makes bereavement more difficult; Denying death in order not to suffer; Needing support to experience the process of death and dying and Looking for ways to accept death.

AXIS 1 - Beliefs that facilitate acceptance of bereavement
Believing that the child's death is divine permission

Nursing professionals seek comfort in the belief that death is part of a divine plan. They try to convince themselves that death is part of the cycle of life, but that when it happens in childhood, it transcends human understanding. In this way, they feel supported when they believe that the child has left after fulfilling their earthly mission.

> *What I try to get through my head is this: it was God's will, because he came, this child had a mission to fulfill. It could be days, it could be months, it could be years. He fulfilled his mission. I understand that it was God's permission, that she only had to survive until then.* (Cyrus)

> *I try to think about it, that he's already done what he had to do here.* (Orin)

In addition to the belief in death as divine permission, the nursing professionals understand the end of life as a relief for the child.

Perceiving death as a relief for the child

In order to end suffering, nursing professionals understand death as a relief for the child, ending the cycle of pain and anguish resulting from serious clinical conditions.

> *We have the case of a child who has everything and more. He has a giant abdomen, a very suffering child, so we understand that for him it's already close and that it will also be a relief. So I often see death as a relief for the child too.* (Neo)

> *I see that ending life is sometimes necessary at certain times, because it becomes painful. You no longer live as you should, you're not living.* (Selene)

One of the nursing professionals, as well as understanding death as a relief, wants death to be painless.

> *Sometimes it's better to offer a dignified death, without the child feeling pain or suffering.* (Rene)

Faced with all the challenges that the death-dying process imposes on those involved, nursing professionals report greater difficulties because they consider the death of children to be unnatural in the life cycle.

Considering that the death of children makes mourning more difficult

Although the death of children is sometimes perceived as a relief, as it puts an end to suffering, on the other hand, the loss of children makes mourning more complicated for nursing professionals, as the idea that life is just beginning makes it difficult to accept death.

> *Because it's a child, and we have a vision that the child has a whole life ahead of them, acceptance is much more difficult.* (Fatiha)

> *An adult is difficult, but a child? You can't compare.* (Tadesse)

In addition to the idea that the child will reach adulthood, witnessing the death of children in the same age group as loved ones can intensify the professional's emotional burden.

> *That was a death that affected me. I think I'd been here for a year. Because she looked like my niece and she was the same age, so these things affect me.* (Kia)

Professionals therefore need to develop coping strategies.

AXIS 2 - Strategies for coping with bereavement
Denying death so as not to suffer

The nursing professionals who work in the PICU, although immersed in the process of death and dying of children/adolescents, see themselves facing this problem through denial, in other words, they deny reality in an attempt to avoid suffering. One of their actions is to separate what is personal from what is professional.

> *Leave what I live here, here. I try to get out of here and not think about it too much.* (Íris)

In the end, however, the professional himself realizes that this attempt doesn't have the expected effect.

I have to know how to separate, but there are times when we really can't. (Navika)

So, as it is not possible to separate these two aspects - personal and professional, we move on to a second action, which is to avoid being present at the moment of death, in other words, the idea is 'if I don't see it, consequently, I don't feel it'.

I don't like being present at this moment [of death]. (Ishtar)

However, as it is impossible to be absent at every death, nursing professionals distance themselves from the child and the family during care, so as not to become attached, especially after some time working in this unit.

When I first came here, I was very attached to the children, I had a lot of bonds with the mothers, with the children. Over time, due to all the losses we've suffered, I've started to lose that bond. I take care of them as much as I can, with all the affection in the world, but I don't get so attached, because when you lose a child, I suffer a lot, a lot, because I can't come to terms with it either. (Cyrus)

The pain of the loss is so intense that, for some, in order to minimize the suffering, they start to think about giving up the profession.

I'm studying something else, because in the future I'm going to have to leave nursing, because today I understand that not everything we love is good for us, and that's fine. So, as much as I love nursing, I understand that it affects me a lot. I'm going to look for other ways. (Fatiha)

Although nursing professionals try to deny the process of death and dying through various actions, they also realize at some point that this strategy is not effective and, based on this perception, they understand that there is a need for support.

Needing support to experience the process of death and dying

When nursing professionals experience the process of death and dying, they realize that they need support to cope with the loss. Thus, they seek comfort in a support network, often made up of team members and family members, as sharing anguish about death can serve as a strategy for dealing with suffering.

I think it's talking, talking to each other, talking about it. At home I have a good support network, so I've always talked to my mother, who understands a little. I think it's important to talk about it, to get it out in the open, because if we keep it to ourselves, it could get worse. That's what helps me. (Rene)

Even with the support of team members and family members, in certain situations it is necessary to be accompanied by a mental health professional.

I've been in therapy for a while, so therapy helped me. (Rene)

In the workplace, bereavement support could come from the staff themselves, who are also part of the bereaved professionals' support network. Professionals show an interest in and need for moments of interaction and exchange during the process of death and dying.

Inside the ICU, it's very hectic, but whenever possible, the people who are closest to that bed would have a meeting, talk about that moment: 'What are the anxieties you experienced at that moment? This part of mourning isn't easy, it's very difficult for professionals. I think that if we had support on how to deal, what to do at these times [...]. (Cyrus)

In addition to mutual support, the professionals emphasize the need for formal preparation, i.e. training in the process of death and dying.

I would really like to have some preparation, to be prepared before and after. There could be something to help us deal with this situation, training, a conversation about how to deal with the situation before, during and after, I think that would be very interesting. (Cyrus)

I've never taken part in a course, but I'm interested. (Selene)

Another strategy pointed out by nursing professionals is the help of a mental health professional for the team itself and for families, especially in the aftermath of death.

I think there should be a post-mortem for the mothers and for us too, who are going to stay. There should be a conversation, preparation afterwards, support, even multidisciplinary support, with psychologists and everything to see: 'Guys, how are you now? I know it's hard for everyone...', no one is going to be fine at the moment, but maybe if we got together and talked, it would improve things, even for us to keep going and give comfort to the mothers. (Cyrus)

All of these possibilities of support for nursing professionals follow a very significant path, which is to look for ways of accepting death, even if this acceptance involves various feelings.

Looking for ways to accept death

When experiencing the process of death and dying, nursing professionals, in addition to the need for support, look for ways to accept death. One strategy is to understand death as a natural phenomenon.

You start to treat death in a more natural way, because it is natural, it will come. (Kia)

However, it's not easy to accept the death of a child naturally, as a child is synonymous with life. Therefore, another form of support is to take part in the children's funeral rituals, in order to support the families in their final moments.

I've even been to the wake of a child who died here, something I never thought I would do either. You need to go to a wake, see a funeral, so that it's in your head too. (Kia)

As well as taking part in saying goodbye to the child/adolescent, finding the family reorganizing after the loss of their child facilitates the process of acceptance on the part of the professional themselves.

> *I hugged her and everything got better. Because she was doing very well and when we see that they are beginning to experience their grief in the best way, it seems that our grief also diminishes. Seeing that she had accepted the process was the best strategy for me. So, the best strategy for experiencing grief is to know that the family has moved on, that the family has managed to understand the process.* (Akira)

In this way, it can be seen that, gradually, nursing professionals tend to find ways for mourning to be experienced in an uncomplicated or normal way.

DISCUSSION

For nursing professionals, death is a constant presence, since the health-disease process is the object of their work. Although death is less frequent in some areas of care, it cannot be permanently avoided, especially in intensive care units.

Nursing professionals therefore seek to draw on beliefs, such as spirituality/religiosity, in order to give new meaning to suffering over the death of children, making healthcare spiritually sensitive and transforming death into a moment of transition to a higher spiritual existence.[12]

In addition to spirituality/religiosity, which can help nursing professionals to accept death, there is a sense of relief at the end of this period of pain and anguish, as well as the desire for death to be painless.

In this context, the concept of a dignified death arises, which can be considered when professionals are concerned with avoiding physical and emotional suffering, as well as respecting the wishes of the patient and family, allowing death to occur in a respectful manner, free from unnecessary interventions or repeated attempts at cardiopulmonary resuscitation.[13]

The nursing team's involvement in ensuring a dignified end of life involves respecting human rights, providing emotional support and promoting dignity, not only in the physical dimension, but also in the spiritual and psychosocial dimensions, offering spiritual peace to patients and their families.[14]

Although the process of death and dying is part of professional practice, health professionals face significant emotional challenges when dealing with the loss of children, which can be perceived as a tragedy, impacting on emotional well-being. The complexity of infant death interrupts expectations of healing, reinforcing fears and anxieties in professionals who are parents about the safety of their own children.[15]

Therefore, it is recommended that these professionals seek balance, allowing them to distance themselves when necessary, while ensuring continuity in the provision of healthcare to children and families, in order to guarantee compassionate and quality care.[16]

Corroborating the findings of this study, nurses at a children's hospital tried to overcome the impact of the death of children by detaching the personal relationship from the professional one. However, most of the time, the attempt was frustrated.[17]

Painful experiences can drive professionals to remain indifferent to the child and family in order to deny the death.[18] One of the strategies described by nursing professionals is to distance themselves from the child and family during care, in order to avoid establishing a bond.

The longer you live with the sick child and the family, the more difficult it is to accept the child's death, as bonds are established and the loss of the child inevitably results in suffering.[18,19]

Death is a painful topic in itself, but in the first years of life it is incomprehensible and unacceptable, causing a negative impact on the quality of life of professionals[18]. This impact causes negative feelings, such as frustration and sadness, which is why it is necessary to understand the implications it can have on professionals' lives.[17] One of the possibilities reported was giving up the profession.

However, in order to cope with the loss, the professionals stressed the importance of support from the team, their families and a mental health professional. In order to reduce the risk of suffering from the loss of a child, it is suggested that professionals be encouraged to set up a bereavement monitoring system, made up of a multi-professional team, as there may be limitations in dealing with the problem in isolation.[20]

In addition to the support of mental health professionals by choice, professionals can establish social ties in the intensive care unit, creating the habit of being and at the same time having a source of support during work, as a way of easing the grief of bereavement,[21] which is also pointed out in this study.

Other ways of dealing with death in highly complex sectors are contact with the subject during academic training and the use of empathetic and humanized practices in care, as well as professional training, which must be qualified and continuous, about the particularities associated with the complexity of the unit.[22] The availability of a mental health professional in the unit also appears to be a strategy for managing grief.[23]

Although it is difficult to accept death during childhood as natural,[24] understanding death as a phenomenon intrinsic to life can help to understand death as a relief from suffering.

However, establishing a personal relationship with the children and family intensifies the feeling of bonding and attachment and can exacerbate personal feelings of bereavement.[21] Therefore, maintaining boundaries helps to balance personal and professional life.

An uncommon but important action was the participation of nursing professionals in funeral rituals, identified as part of the acceptance process, as the ceremony can serve as a means of bringing closure to life, helping to manage grief.

For many family members, the presence and support of health professionals, even after the child's death, is greatly appreciated, for example, their attendance at funeral ceremonies. The absence of the individuals who cared for the child at these moments of farewell is noticed and regretted by the family.[25]

Professionals' feelings when experiencing bereavement during and after the child's death are proportional to the feelings of the family members, i.e. when they encounter calmer reactions, they feel calmer and when they witness feelings of anguish and despair, the feeling of grief intensifies, making it more difficult to manage the loss.[26]

As found in this study, the nursing professionals felt relieved when they met the families after the child's death and realized that there had been progress in the grieving process, which is important for the closure of the professional-family-child relationship.

FINAL CONSIDERATIONS

The aim of this study was to understand how nursing professionals in a Pediatric Intensive Care Unit experience the grieving process resulting from the death of children/adolescents.

In addition to the facilitating beliefs, the professionals revealed coping strategies, from denying the death by physically and emotionally distancing themselves from the child and family, not only during care but also at the time of death, to looking for ways to accept the death.

Between denial and acceptance, professionals describe the need for a support network, from work colleagues and family members to professional help, and also consider the importance of training on the subject.

It is recommended that health institutions offer mental health care, on a free schedule, for health professionals who need specialized support, including individual and group interventions, such as post-mortem support and conversation circles between health professionals who share experiences. There is also a need to systematically include the theme of death in technical and undergraduate health courses.

The limitations of this study include the lower number of nurse participants interviewed compared to the number of nursing technicians, which is justified by the lack of availability of the former, as it was during working hours, although the work schedule of this unit is made up of 76.4% nursing technicians, as well as the fact that all the participants were female.

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