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Understanding death in the eyes of hospitalized children

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Abstract

The aim of this article is to present how hospitalized children understand the concept of death and raise discussions on the theme of death in childhood. Semi-structured interviews were conducted with children aged 7 to 12 years, using story telling as a playful resource for data collection. The main results showed that children structure the concept of death in a multidimensional way, encompassing biological, spiritual, sociocultural and emotional factors. Inserted in the context of hospitalization, they approach the theme of death, sensitizing themselves. Thus, children demonstrate the need to be listened to and have their feelings welcomed when they face the loss of a loved one or even the possibility of the end of their own lives.

Keywords: Death. Pediatrics. Bereavement. Hospitalization.

Resumo

Compreensão da morte no olhar de crianças hospitalizadas

O objetivo deste artigo é apresentar como crianças hospitalizadas compreendem o conceito de morte, além de suscitar reflexões sobre o tema do óbito na infância. Realizaram-se entrevistas semiestruturadas com crianças de 7 a 12 anos, utilizando-se a contação de história como recurso lúdico para coleta de dados. Os principais resultados apontaram que as crianças estruturam o conceito da morte de forma multidimensional, englobando fatores biológicos, espirituais, socioculturais e emocionais. Inseridas no contexto de hospitalização, elas se aproximam da temática da morte, sensibilizando-se. Assim, demonstram a necessidade de escuta e acolhimento dos sentimentos que emergem quando enfrentam a perda de ente querido ou até mesmo a possibilidade do fim da própria vida.

Palavras-chave: Morte. Pediatria. Luto. Hospitalização.

Resumen

Comprensión de la muerte en la mirada de niños hospitalizados

El propósito de este artículo es presentar cómo los niños hospitalizados comprenden el concepto de muerte, además de suscitar reflexiones sobre el tema de la muerte en la infancia. Se realizaron entrevistas semiestructuradas con niños de 7 a 12 años, utilizando la narración como recurso lúdico para la recolección de datos. Los principales resultados mostraron que los niños estructuran el concepto de muerte de forma multidimensional, abarcando factores biológicos, espirituales, socioculturales y emocionales. Insertados en el contexto de la hospitalización, se acercan a la temática de la muerte, sensibilizándose. Por lo tanto, demuestran la necesidad de escuchar y acoger los sentimientos que surgen ante la pérdida de un ser querido o incluso ante la posibilidad del final de la propia vida.

Palabras clave: Muerte. Pediatría. Aflicción. Hospitalización.

The place of death in contemporary Western history was built over several years, undergoing numerous changes in how cultures and individuals conceived the end of life. Nowadays, there is the concept of interdicted death, in other words, that which has no space to be seen or experienced. Accordingly, discussing death and childhood is considered taboo. Adults refuse to talk about this subject with children, arguing that they are unable to have a dialogue about it, that they forget quickly, do not suffer enough with this process, or cannot understand the matter.

Childhood and adolescence are generally perceived as phases of human development in which vitality is at its peak. When they get sick and are hospitalized, these young people can undergo these processes as an interruption of the vital force, experiencing intense and complex emotions, which requires the mobilization of coping resources to adapt to this new condition¹. Given the need to remain in a hospital setting, children are faced with ruptures in their family and social milieu, including the possibility of their own life cycle ending – which is not expected by society at this stage of development since the loss of health and the possibility of death are understood as consequences of old age².

Children are often kept out of death experiences, and their participation in farewell rituals is denied. They may find themselves unable to express their feelings about the end of life and thus experience the loss of a loved one alone, deprived of proper explanations. Thus, it is possible to experience the grieving process without the emotional support of an adult and face feelings of distrust and insecurity when there is no adequate support that clarifies emotions resulting from a situation of loss³.

Children conceive death based on the understanding of some basic concepts: irreversibility, universality, and non-functionality. These characteristics will be assimilated as their cognitive processes mature, and children's reaction to death will also result from their current stage of development and from their relationship with the deceased person, in addition to individual experiences that involve their contact with the imminence of death⁴.

The possibility of having close contact with the subject of death in the hospital environment

can also be considered. There is evident need to promote healthy communication and cordial care for the feelings children express when facing the end of life, including families and health professionals in this debate. Thus, seeking to understand how hospitalized children understand the subject – the objective of this study – is one of the ways to start discussing death in childhood.

This study is relevant for both adults and children since data point to the importance of social support and authorization so children talk openly about their loss with surviving family members and other adults. Encouraging children to express their feelings concerning their experiences with death and allowing them to process their bereavement contributes to the prevention of childhood trauma⁵.

Method

This is a study with a qualitative approach which, when applied to health, is characterized as an attempt to understand the meaning of the phenomenon for people's lives, individually or collectively. It is not the phenomenon itself that interests the researcher, but its meaning for the subjects who experience it⁶.

In total, eight children were interviewed, aged between seven and 12 years, who were hospitalized in a process of diagnostic investigation in the ward, all with their respective companions. They were invited at their bedside in the ward and then the children and companions were taken to the reserved room. Informed consent form were read and accepted. The study was approved by the research ethics committee.

All participants and their guardians authorized the recording of the interview on a cell phone. Data were collected and recorded between August and October 2020, and interviews were carried out individually, respecting safety protocols against covid-19. To characterize the sociodemographic profile of the participants, a checklist was applied at the beginning of the conversation with the accompanying adult who was then asked to wait outside the room until the end of the interview with the child.

A semi-structured interview was carried out with the patient, reading a children's book called

A *grande roda*⁷ as a playful resource to facilitate interaction. The use of storytelling when working with children is characterized as a therapeutic method, as the plot often addresses issues that the child wants to discuss, such as what makes them scared, happy or terrified. Listening to the other tell stories leads the child to reflect on their own reality from another perspective⁸.

In the employed book, the life cycle is addressed, in the dialogues between a mother and her child, as a natural phenomenon in the course of child development until adulthood. The story introduces the subject of the death and mourning process in a sensitive manner, portraying the mother's death and, above all, the memories and love that remain even in her physical absence.

The interviews were transcribed, and the corpus was systematized according to the discourse analysis proposal presented by Michel Pêcheux⁹. This type of analysis works with the meaning of the text, produced at the intersection between ideology, history, and language. Ideology is understood as the positioning of the subject and their conception of the world inscribed in a certain culture; history represents their socio-historical context; and language is considered as the materialization of discourse¹⁰. Thus, it was possible to understand how children understand death through the observed productions of meaning. Throughout the text, participants' statements will be identified according to the sequence of the interviews, also indicating the age of the child in question (for example, "E1, 7 years old").

Results

Table 1 shows the sociodemographic profile of the interviewed children. Table 2, their companions'.

Table 1. Sociodemographic profile of the children

Variables	N	%
Sex		
Female	3	37.5
Male	5	62.5
Age		
7 to 9 years	2	25.0
10 to 12 years	6	75.0

continues...

Table 1. Continuation

Variables	N	%
Religion		
Catholic	7	87.5
No religion	1	12.5
Skin color		
White	3	37.5
Black	2	25.0
Brown	3	37.5
Education		
1st to 5th grade, elementary school	4	50.0
6th to 7th grade, elementary school	3	37.5
No education	1	12.5
Family income		
Up to 1 minimum wage	4	50.0
1 to 3 minimum wages	3	37.5
No fixed income	1	12.5
Parents' marital status		
Married	3	37.5
Divorced	2	25.0
Other	3	37.5

Table 2. Sociodemographic profile of the companions

Variables	N	%
Sex		
Female	7	87.5
Male	1	12.5
Age		
31 to 40 years	4	50.0
41 to 50 years	3	37.5
51 to 57 years	1	12.5

Discourse analysis enabled us to observe that the concept of death is constituted in a multidimensional way, encompassing biological, spiritual, sociocultural, and emotional factors. From the biological perspective, we found the notion of the universal, irreversible, and non-functional character of death, as well as its relation with human development, more specifically the stages of childhood and old age. From the spiritual perspective, conceptions about "heaven"

were presented as a way to explain the questions related to life and death. This is associated with the fact that most of the children interviewed consider themselves to be practicing Catholicism. The religious and spiritual discourse is present in the conception of death observed in the interviews, especially when respondents were asked where the boy's mother goes – in the story.

From the sociocultural perspective, the end of life is interrelated with the reality permeated by urban violence and the banalization of death, as conveyed by the media. The way children signify death also encompasses unpleasant feelings, such as fear of their own death and of the loss of a loved one, sadness, and confusion, reinforcing its negative character in the same way it is presented in their sociocultural context. Related to these feelings, reluctance to talk about death and the taboo around discussing the end of life also emerged, demarcating the social representation of something to be avoided.

The answers collected also show the need to listen when the topic arises, since we observed cases in which the children lost a loved one without being cared for by adults around them, emphasizing the notion that children need to be kept out of discussions about death for lacking psychological and intellectual resources to understand it. Such results show that, while adults try to keep children from having contact with death, they have contact with the subject in their routine but without proper support to help them apprehend the feelings involved in this experience.

Discussions

“Because everybody is going to leave, right?”

Death can be understood from different perspectives – biological, psychological, cultural, spiritual, anthropological –, that is, numerous dimensions contribute to the construction of the concept^{3,11,12}. The interviewed children are in two stages of development in which they apprehend the concept of death in its entirety. According to Paiva⁵, Piaget called these phases “operational” – from age 6 to 9 years –, when they already understand the duality between

life and death, which constitutes an irreversible and permanent process – and “formal operations” – from age 10 to adolescence, in which the concept of death becomes more abstract as a result of formal thinking, presenting explanations of a natural, organic, and theological order.

Wilma Torres¹³ presents the understanding of death in childhood based on three levels of cognitive development, in different periods, represented as a continuum. At level 1 children present characteristics of the pre-operational phase, not distinguishing between animate and inanimate beings, not yet being able to separate life from death and, thus, not understanding it as a definitive and irreversible process. Level 2 is characteristic of concrete operations, in which they distinguish between animate and inanimate beings, life and death, and do not attribute consciousness to the dead, recognizing the non-functionality of the body and its irreversibility. However, they are not yet capable of explaining death in its biological essence. Level 3, in turn, encompasses aspects of the period of formal operations, the current stage of development of the interviewed children, in which they can understand death as a universal, irreversible process in which the body ceases its functions, in addition to recognizing it as natural and part of life.

We could observe, in the analyzed answers, the presence of the biological character to signify death, described in a multiaxial way^{11,12}, showing, as already mentioned, the notions of irreversibility, universality, and non-functionality. As for universality, the children showed they understand that all living beings will face death at some point in life, as the life cycle eventually ends for everyone: *“Nobody is immortal, every day... every day, no, someone will die someday”* (E2, 10 years old); *“Yeah, everybody is going to die because, one at a time, they will”* (E6, 7 years old).

With regard to non-functionality, respondents associate death with deep sleep – sleeping and not waking up anymore – thus reiterating the notion of a body that is no longer in activity, a paralyzed, sleeping body, of those who no longer have the possibility of seeing: *“I think it’s that thing I said, going to sleep and you’re already dead, you can’t see anything”* (E6, 7 years old); *“After some days the body melts and only the bones are left”* (E7, 12 years old). Regarding irreversibility, they associate birth to a beginning and death

to an end, being possible to undo death: *"I think that when we die, we don't come back! Done, it's over! (...) The end of everything"* (E7, 12 years old).

When they structure the concept of death, the children present, in their perceptions, cultural aspects that are part of their context, as shown by the discursive segments obtained when they were asked about the reason why the child's mother dies in the story: *"Because she, in the end, was a little old"* (E1, 11 years old); *"Because she got old"* (E4, 12 years old); *"She got old, very old, and died"* (E8, 11 years old).

We could observe an association between death and old age, a stage of development in which the end of the life cycle is expected, as death approaches with the aging of the body^{11,12}. Discussing death is still taboo, associated with the thought of the incapacity of a body that no longer produces and the specific phase of development: old age.

The death of a child or an adolescent, on the other hand, is considered an interruption of the biological cycle, the impossibility of living a productive future in the social milieu, an unexpected tragedy that disorganizes what had been planned and expected. Dying in this age group is to leave without first being able to give meaning to life and to know what it has to offer. Such a conception shows the difficulty of adults to understand and accept the possibility of death in childhood and adolescence. Thus, we found a conception centered on the adult stage of human development, in which the apex of life would be found, without considering the relevance of the biographical dimension of childhood¹¹. The distance between human beings and death is even more evident when the end-of-life process is shifted to the hospital setting, as it isolates the person from their family context.

In the interviews, death is found at the stage of development in which the greatest power of living is expected, childhood: *"A friend of mine died because of COVID, so, she was only 9 years old, so everybody can die at some point. One day we will die, if we are old, even if we are not old, anyway"* (E4, 12 years old). From an early age, children experience situations that bring them closer to the end of life, which can occur at all stages of vital development. Trying to keep children from having contact with death and dying will

not spare them from experiencing bereavement through the death of a close person or even from facing their own finitude⁵.

"If I die, what happens? Will I go to heaven and live a new life there? Or will everything be dark?"

To structure the concept of death, children make use of different perspectives that help them give meaning to it, including the secular-biological conception, in which death is considered an end point, the irreversible and complete end of life, and a religious-metaphysical perspective, in which death is considered metamorphosis, life transition, the beginning, and not an end in itself¹⁴.

In the analyzed discourses, religious and metaphysical explanations also emerged to justify the meaning that children give to death, revealing the spiritual dimension that constitutes the subject, as well as the implications for the culture in which they are situated. Spirituality can be understood as the attempt to find meaning for issues related to the complexity of life and death. It is the pursuit of a meaning of life that transcends the concrete, elevating human feeling to experiences greater than existence itself. It may or may not be related to religious practice, and this factor is not an impediment to validating the spiritual dimension of people who do not profess formal religions¹⁵.

In the analyzed corpus, spirituality features as a part constituting the conception of death for children, as shown in the following excerpts: *"What happens when I die? Will I live a new life or will I be stuck in darkness or will I go to heaven, as they say?"* (E2, 10 years old); *"To heaven... I think she's up there, with God, taking care of him, even though she's far away"* (E3, 12 years old); *"I think it's something that will happen to everybody... but I wish there was life after death... like being there in heaven with my family"* (E3, 12 years old); *"That they go to heaven when they die!"* (E7, 12 years old); *"Went to heaven... because Jesus gave the time, that day!"* (E8, 11 years old).

Children fail to distinguish between spirituality and religion¹⁵ but they are situated in a Western cultural context consisting of philosophical ideas and beliefs from Christianity¹⁶. Death is a natural

and biological process, but it is also understood by means of cultural characteristics, including religious concepts. Christianity, as a religion, proposes salvation through belief in God and Jesus Christ, who came to earth to forgive the sins of mankind. According to Christians, heaven is the ultimate end, where man's deepest aspirations are fulfilled and where the state of supreme and definitive happiness is found, in addition to the possibility of rest and reunion with loved ones¹⁶.

At school age, children are able to present important ideas about spirituality, which they often use for support after traumatic events stemming from illness and hospitalization¹⁵. Their experiences with suffering favor an approach to spirituality, in which they also seek answers to questions related to death, as shown in the above excerpts.

"Yeah... I saw in the news... a guy who was 'deathed'"

Violence and the banalization of death are aspects associated with our subject when trying to understand the children's process of assimilating the concept, as shown in the following excerpts: *"I think she was buying fruit... I think the thug ran and killed her! (...) He took the gun and he killed her (...). The case of... the girl who was deathed, the young woman who was deathed, it was a 'cuckold'. I saw it on 'Triturando' [TV show]!"* (E5, 7 years old).

Here, death is also presented as a media spectacle to which the child has free access. The end of life invades everyone's daily life, including children, through violence, homicides, accidents, and natural disasters. Many of these events are reported in the media at any time, without restrictions, in such a way that anyone can watch them. The subject of death permeates the whole society and enters homes, without reflection on how it occurs, naturalizing pain and suffering and, consequently, favoring their banalization⁵.

The media, in general, whether television or social networks, has become one of the great informers of children about death, as it often displays scenes of violence¹⁷. The finitude of life becomes a social spectacle whose images everyone is prepared to record and contemplate. It is a death-spectacle, trivialized, transformed into a dry, appetizing image, in which people delight.

In this society of spectacle, everything becomes a reason for exhibitionism; the same happens with violence and death, which shifts from the family's intimacy and becomes a public show. It is about transforming the subject's pain and suffering into attraction¹⁸.

The scenes of violence and destruction overtly show distant death, a distant scene that represents the end of the other, and there is no taboo about this death. This censorship, instead, speaks of intimate death, that which permeates the subject's life story, which goes hand in hand with affections: the death of a family member, a friend, the death of oneself¹⁹. The taboo of discussing death represents the intimacy it reveals, it is the interiority that is presented when facing the much-feared end of life. This death brings the individual closer to their history, to their relationships with others, revealing their fears and anxieties. The intimate, the contact with the depths, is hidden, since society does not know how to respond to the need to get close to someone who is dying¹⁹.

"It scares me to death"

Some feelings also constitute the meaning of death for children and reiterate its negative character in current culture: *"When a person dies, they leave people with sadness"* (E1, 11 years old); *"I get sad for a moment and I also get confused..."* (E2, 10 years old); *"Very sad!"* (E4, 12 years old); *"Sign of sadness, other things out there that I don't know how to say"* (E6, 7 years old).

It is common for adults to feel sadness when they lose a loved one or when they are faced with the imminence of their own death. With children it would be no different. However, their emotional reactions to the loss are not equivalent to those of adults, given the different previous experiences related to death, their stage of cognitive development, and the sociocultural context that keeps children from having contact with the issue²⁰. However, feeling sad with death does not indicate an inability to cope with such events, but the need for support and care from people they trust and who can help in the processing of child mourning.

Fear and confusion are also highlighted when discussing death with children: *"I don't know, I get confused when I think about that..."* (E2, 10 years old);

"As much as I think every death has some kind of pain, something happens there, at that moment, and I'm afraid of that... so, I'm also afraid of not... like, I want to go before my mother, because if she goes before me I think I won't be able to live like this without her, so I always want to go, I think about going before her" (E3, 12 years old).

Fear of parents' death is common when talking about the subject with children, because, with that, they lose the world to which they were adapted, the one in which the father and mother left but returned. Their physical and emotional survival is jeopardized since the parents are often important figures for the maintenance of their development. The child is faced with a feeling of defenselessness and powerlessness before the situation, as the previous family configuration is also lost²¹.

Even with the attempt to keep them away from this process, death is part of children's history, as shown by the analyzed interview excerpts regarding previous experience of loss of a loved one: *"I know... my uncle, my grandfather too"* (E3, 12 years old); *"Yes, today a boy died, a man that my grandmother took care of"* (E2, 10 years old); *"I know... my great-grandmother"* (E1, 11 years old); *"I lost a friend of mine too because of covid. She also had a tumor in the brain"* (E4, 12 years old); *"Z.M., Z.A., and Aunt D. and Grandma... and that's all! Grandma M...."* (E6, 7 years old).

Many children feel confused when dealing with death and need adults who are part of their circle of trust to explain what happened, considering their cognitive and emotional aspects, in a clear and sensitive way. Caring for and promoting a listening space are essential to help children in processing the bereavement²¹.

Despite the positive benefits that are perceived when children are included in discussions about death, they also resist the subject: *"I wouldn't like [to talk about death] because I would start crying"* (E6, 7 years old). This difficulty reflects the place that children occupy in their cultural context, in which this is a forbidden, bad topic²¹.

Even with the denials about death and the attempt to dissociate childhood from this topic, some children show interest in discussing it: *"I think it's important [to talk about death], because it's a way of reflecting"* (E2, 10 years old); *"I think it*

would be interesting to see opinions of different people, you know... like, as I see it in one way and another person will see it in another, so I think it can be a nice combination, well... interesting, a debate" (E3, 12 years old).

These interview excerpts show the children's curiosity and desire to be included in discussions on the subject. This shows that not only sadness, fear, defenselessness, and pain permeate death but also the possibility of reflecting on life, knowing different perceptions and, thus, contributing to the process of building the concept of death and the particular meanings established in the course of the life of each person.

Final considerations

Talking about death is not always an easy task nor is it accepted when trying to include children. Even with society's refusal to deal with the issue in a natural manner, as part of the life cycle, it is present in all stages of human development, from birth to old age.

The way these children process the concept of death also shows the influence of illness and hospitalization at an early age. Experiencing childhood in the hospital setting leads the subject to face the imminence of the end of life, whether their own or that of other patients with whom they share the ward, thus sensitizing them to the issue.

Children structure the concept of death according to their sociocultural context, their cognitive and psychological capacity, previous experiences, and how they are cared for and listened to in situations of bereavement. The meaning they gave to death shows that their understanding of the subject is a process that shows biological, social, cultural, spiritual, and emotional dimensions. As the other people with whom they live, they also give a negative meaning to death but show that, even with the attempt to keep them from having contact with this issue, they are closer to it than expected.

They experience the death of grandparents, uncles and aunts, friends, children, adults, and seniors and in internet videos and urban violence. They face the possibility of going to heaven after death and meeting their family members again. They experience the fear of losing

their parents or close people, the fear of losing their own life, the loneliness before the sadness, and the anguish of perceiving themselves confused when the end comes. They also experience the desire and curiosity to discuss the issue and share their feelings, to be willing to rethink life considering the possibility of death.

Children experience death because dying is intertwined with living. So both can share the same space, it is necessary that adults are

prepared to care for and listen to children, showing respect for the feelings they express when dealing with death through sensitive and true language and with attentive eyes and ears to perceive how they behave and meet their needs. Thus, adults are expected to talk to children about the finitude of life, providing a caring atmosphere and promoting empathic relationships so they can experience a process of unconditional acceptance in relation to the feelings that emerge in the imminence of death.

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Participation of the authors

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