

Hospitalized child and teenager with chronic diseases: feelings about death

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Objective. Analyze the feelings of hospitalized children and adolescents with chronic diseases towards death. **Methodology.** Qualitative research, with four children and one teenager with chronic diseases, aged between 11 and 13 years old, who were admitted at a teaching hospital in Brazil, in the period from January to March 2009. In-depth interviews were carried out using a ludic material for therapeutic purposes, named “As a guest in the hospital”. The empirical material was submitted to thematic analysis. **Results.** Two main meanings were obtained: Feelings of hospitalized children and adolescents with chronic diseases dealing with the death of the other; and children and adolescents with chronic diseases and the fear of their own deaths. Hospitalization makes children and adolescents come across the death of other sick people, arousing feelings of sadness, consternation, anxiety, making the fear of their own death become a threat. **Conclusion.** The health team needs to be attentive to the feelings of hospitalized children and adolescents facing death so that they can get the demands, minimizing fears and anguish.

Key words: child; death; chronic disease; hospitalization.

Niño y adolescente hospitalizados con enfermedad crónica: sentimientos acerca de la muerte

Objetivo. Analizar los sentimientos de niños y adolescentes hospitalizados con enfermedades crónicas en relación con la muerte. **Metodología.** Investigación cualitativa de cuatro niños y un adolescente con enfermedad crónica con edades de 11 a 13 años, ingresados en un hospital universitario en Brasil, de enero a marzo de 2009. Se realizaron entrevistas a profundidad mediante material del juego con propósitos terapéuticos llamado “Como huésped en el hospital.” La información fue sometida a análisis temático. **Resultados.** Se obtuvieron dos unidades de significado: Los sentimientos de los niños y adolescentes con enfermedades crónicas hospitalizados frente a la muerte del otro; y los niños y adolescentes con enfermedades crónicas y el miedo de la propia muerte. **Conclusión.** La hospitalización lleva a los niños y adolescentes a enfrentar la muerte de los demás

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enfermos, despertando sentimientos de tristeza, consternación, ansiedad, lo que hace que el miedo por la propia muerte se convierta en una amenaza. El equipo de salud tiene que estar atento a los sentimientos de los niños y adolescentes hospitalizados frente a la muerte para que pueda aceptar las demandas, lo que minimiza los temores y angustias.

Palabras clave: niño; muerte; enfermedad crónica; hospitalización.

Criança e adolescente com doença crônica hospitalizados: sentimentos sobre a morte

Objetivo. Analisar os sentimentos de crianças e adolescentes com doenças crônicas hospitalizados em relação à morte. **Metodologia.** Pesquisa qualitativa, com quatro crianças e um adolescente com doenças crônicas em idade entre 11 e 13 anos, internadas em um hospital escola no Brasil, no período de Janeiro a Março de 2009. Realizaram-se entrevistas em profundidade por meio do material lúdico com fins terapêuticos, denominado “Como hóspede no hospital”. O material empírico foi submetido à análise temática. **Resultados.** Foram obtidos dois núcleos de sentido: Sentimentos de crianças e adolescentes com doenças crônicas hospitalizados frente à morte do outro; e Crianças e adolescentes com doenças crônicas e o temor da própria morte. A internação hospitalar leva crianças e adolescentes a se depararem com a morte de outros enfermos, despertando sentimentos de tristeza, consternação, ansiedade, fazendo com que o medo da própria morte se torne uma ameaça. **Conclusões.** A equipe de saúde precisa estar atenta aos sentimentos das crianças e adolescentes hospitalizados diante da morte para que possa acolher as demandas, minimizando temores e angústias.

Palavras chave: criança; morte; doença crônica; hospitalização.

Introduction

The hospital is an environment planned to help people who have specific demands for health care and require some degree of confinement or temporary biological protection. In this perspective, the care in the form of various treatments can result in healing, maintenance of disease in more stable clinical conditions, or death. The whole situation exposes patients, families and health professionals to pleasant experiences when there are improvement of hospitalized individuals, or unpleasant, before repetitive episodes of suffering, pain and/or loss. For the child/adolescent, beyond the possibility of healing, the hospital means to be far from home and loved ones, which are natural sources of support and security, have changed their daily life and to undergo a new routine, often very different from their previous routine, live in an environment with situations and strangers people, be exposed to invasive and painful medical procedures, loss

of freedom and still having to live with different stress experiences.¹⁻³

Many hospital treatments cause stress and difficulties in adapting to typical hospital environment. Children and adolescents with chronic diseases, for example, require special attention as a result of repeated hospitalizations and the long period of time that they are hospitalized, whereas the situation requires greater risk to their development process. An important aspect to be considered in children's hospitalization, which has been rarely evidenced in literature and in care practice, are the feelings that children and adolescents have about death, since the hospital is a place where there is imminent risk for it due to the severity of some diseases. Even being death considered as a natural phenomenon, the reflection on the subject can bring up fears, concerns and afflictions⁴ and,

depending on cultural and age factors, each individual will have a unique understanding,⁵ awakening different feelings.

Study⁶ points out that the acquisition of the concept of death is correlated with the stages of cognitive development proposed by Piaget. Up to two years, sensorimotor period, death is perceived as absence and lack. From three to five years, the pre-operating period, the child understands death as reversible. From six to nine, operating period, the child has an understanding of death as irreversible. After twelve years, the period of formal operations, the concept of death becomes more abstract, and individuals come to understand it as inevitable, universal, irreversible and personal. The death of children and adolescents in hospitals has been discussed in some studies,⁷⁻⁹ highlighting the experiences and feelings of health professionals and family. The works that address the theme related to the death in the design of children and adolescents themselves, in general, have the perspective of participants affected by diseases with higher risk of death, such as cancer. But we must remember that even people with a favorable prognosis, can witness situations of death during hospitalization.

Thus, knowing how the child and the adolescent with chronic disease, although without imminent risk of death, feel about death and what are their fears, can instrumentalize nursing and other health professionals to offer comprehensive and humanized care, considering not only biological, but also psychosocial, which reflect in a direct way in their health. The main question of this study was: What are the feelings of children and adolescents with chronic diseases hospitalized about death? Therefore, the objective was to analyze the feelings of children and adolescents with chronic diseases hospitalized about death.

Methodology

Qualitative research conducted in the pediatric clinic of a teaching hospital in the state of Paraíba,

Brazil. Were randomly selected, children and adolescents with chronic diseases, hospitalized at this unit during the period from January to April 2009 that met the following criteria: a) be a child or adolescent; b) be literate; c) be able to write and draw; d) present stable clinical conditions; f) and demonstrate social interaction with the environment. The study included four children and a teenager, aged 11 to 13 years, diagnosed with nephrotic syndrome, scleroderma, sickle cell anemia, thalassemia and lupus. The time to diagnosis ranged from 4 months to 10 years. Although they could be of both genders, all study participants were female. The number of participants was defined by sufficient criteria.¹⁰ Was performed a pilot study and there was no refusal to participate in the study or by those responsible, nor by children/adolescents.

In view of Resolution No. 466/12 of the National Council of Health¹¹ the project was submitted to the Ethics Research Committee of the hospital, and was approved under protocol number No.136/08. The Informed Consent was signed by those responsible and the Consent Agreement signed by children/adolescents, after being informed of the objectives of the study. Data were collected by the first author, who is a psychologist and works with hospitalized children, during daily individual meetings, ranging between six and eight with each child/adolescent, lasting 40 to 60 minutes each, through in-depth interview. Were used the activities of a ludic material for therapeutic purposes, called "As a guest in the hospital", developed by the authors, which was the trigger of the interaction with the child/adolescent. The material consists of a collection of ludic activities that ask the child/adolescent draw or write about hospitalization, how are their feeling, what they like and do not like in the hospital, what they do when they're sad or afraid. Proposes coloring activities, filling sentence, create stories, hunting words. It aims to facilitate the child's and adolescent's expression of feelings in relation to illness and hospitalization, help in acquiring knowledge of hospital routines and to encourage the adoption of coping strategies.

Each activity, in addition to the ludic nature, approaches issues that potentially generate stress and suffering to children and adolescents in relation to illness and hospitalization experiences. These have been prepared by one of the authors of this article based on extensive literature in psychology, nursing and pediatrics, and her experience as a hospital psychologist. In general it is difficult for children and adolescents to express their feelings about the hospitalization and in a special way, death. So, ludic resources have been used in care¹² as in data collection of researches.¹³ All meetings were held in the recreation room, getting in this environment only the researcher and the child/adolescent. The speeches were recorded on digital media, after authorization for full registration of verbal behaviors, and use of field diary to the gestural and emotional behaviors.

The analysis of the empirical material followed the principles of thematic analysis, which seeks to reveal the meaning of a communication cores whose presence indicates any meaning to the objective to be achieved. The procedure was operationalized through the following steps: ordering, classification and final analysis of data.¹⁰ At first, were proceeded to the exhaustive and repeated reading of all material, starting a first classification. Subsequently, the themes are grouped and built the following units of meaning: Feelings of children and adolescents with chronic diseases hospitalized front of the death of the other; and Children and adolescents with chronic diseases and the fear of their death. In order to ensure the anonymity of the children/adolescents were used fictitious names for them.

Results

The material "As a guest in the hospital" has no activities that address directly the issue of death, however, many of these allow the emergence of the matter to allow talk about experiences related to hospitalization. So, the content was approached in different activities and will be presented in narrative form.

Feelings of children and adolescents with chronic diseases hospitalized front of the death of the other

Aurora was in her second hospitalization experience. The reason for her hospitalization, both the current and the previous one, was related to examinations as ultrasound, endoscopy and x-rays to control of the disease. She referred to death when she was doing an activity that prompts talk about what does not like the hospital: *I do not want the boys (ward-mates) die or become ill. [...] A little boy who died there in the room I was [...] but a long time ago, the last time I was admitted here. He didn't speak, nor walked, just listened. I do not want to do this not (referring to the activity). [...] They were very sick, nor get out of bed (Aurora, 11 years).* Aurora shows her feelings on death of a child in the previous hospitalization. But is explicit her difficulty in talking about death during hospitalization, leading her to avoid it.

Jasmine talked about death when performed activity that allows to write or draw what most caught her attention in the hospital: *I've got here (hospital) and had a girl who was taking medication for ... (cancer), her hair falls until ... she died. Also had "P" (another child), [...] he spent more than a year here. I went home and when I back he was here. I came three times and he was here, in the same room, he died. [...] I am sad because he was a person who wanted very well, resist disease, treat (Jasmine, 12 years).*

The child has a history of countless hospitalizations, therefore, heard or seen many death experiences in hospitals, so it was important to encourage them to talk about the experiences and feelings involved. Jasmine avoided pronouncing the words cancer, which carries the stigma of death and dying, which was replaced by "passed away", reflecting the strength to talk about death, as if it were a forbidden subject to be discussed. Jasmine also talked about death in the activity requesting write a comic story about "something sad that happened," reporting various situations: *Sometimes people come here with pain, too*

much pain, when have a person who is very sick. There is a little girl, a baby girl, [...] I left and she stays, in the next time that I back, she was here, but went to the ICU (Intensive Care Unit). It's a pain for the mother, is not it? Creates and then dies. [...] There was an also that I do not know what had happened, they put him in that stretchers there, called ... how? Which leads to another hospital? [...] There was one here that he was very ill, was one (who died) and the other, one that day and another in the next (Jasmine, 12 years).

The speech of Jasmine points clearly that, much more than you might realize right away, during hospitalization experiences not only their suffering but also that of other hospitalized children and adolescents. -The Theme of death proved to be so present in the imagination of children/adolescents that, in another situation, Ariel, who was experiencing her second hospitalization, did the association of the words “a day of life” as a death sentence, in relation a child had just been born: *It's because there are a lot of people that say so, that the person does not escape when she is very, very, very sick. “O” (another patient who was hospitalized) said that come a little baby that has only one day of life. I said no one knows, right? Only Jesus, giving ... that ..., only Jesus saves all, only he can say if the baby has only one day of life (Ariel, 12 years).* Children and adolescents experience during hospitalization death of comrades and the longer spend hospitalized more are exposed to these situations, which awakens the fear of death itself.

Children and adolescents with chronic diseases and the fear of their death

Ariel spoke about the fear of death itself when performed the activity that proposes complete sentences: *What else I'm afraid? I do not know anything. [...] I just put in there that I'm afraid of injection. You have fear of dying? [...] I do not know, because I do not have afraid. [...] Sometimes I think I'm scared to death, but whatever. I'm afraid to give something and I do not see the time I die, at night I sleeping. [...] A boy*

who had leukemia, his skin was all little purple, he yelled a lot of pain. Holly mother, I have a fear of dying that way, sleeping, happened a deal with me suddenly and I did not feel right, because there are people that when die, die suddenly! My grandfather gave that blood coming out of his mouth. [...] It was last year, my grandfather died and a month later my uncle's wife died of motorcycle crash. [...] I just want to die when I will be very old, my illness is not serious not, right? [...] I will put I'm afraid of suffering an accident. [...] My illness is not serious, so I will not be afraid (Ariel, 12 years).

The story of Ariel is full of meanings. Initially the child does not recognize, or does not allow the fear of dying, showing that her fear in the hospital refers only to the injection. However, after narrating the history of severity of the other child illness, she voices her fear of dying suddenly, whose concern is related to the unexpected loss of her grandfather and other experiences related to death present in your imagination. Sofia was on her first hospitalization and talked about death in the activity requesting write some known person who was hospitalized and what happened to that person: *My grandfather, but he died, [...] not returned. [...] He had high blood pressure, had a stroke and died. [...] There was a boy, son of my mother's friend, he had seems it was high blood pressure and also died. [...] I did not want to leave my home, I'm afraid of not returning! (crying) (Sofia, 12 years).*

For this child the hospital was a place of death and not treatment, which enables control of the disease or a possible cure, because she could not remember cases with successful outcome of hospitalization. So leave the safety of her home to enter this space, it posed a threat, which made its understandable anguish expressed by crying. Bela had countless hospitalizations and the reason for the current hospitalization was performing surgery for the removal of gallstones (cholelithiasis). The theme of death emerged in activity that asks the child know how she feels: *I'm just a little scared to do the surgery. [...] I am not afraid, it is not so, how will be the surgery, I'm afraid after the*

surgery, which can happen. I see people who do surgery and die, I wonder in my case, as I'll react? I get scared, you know? [...] The little boy who was here and went to do (surgery), died. I'm thinking after surgery, I'll be fine, I'll leave, but then the fear comes back all over again: my God and if I die, I keep thinking in this way. (Bela, 13 years).

From the report identifies a real fear, before the surgery, which was sparked by a recently lived experience, in which the participating witnessed, during hospitalization, death of another child due to complications from surgery. The fear of own death was also evidenced by Jasmine when, after narrating stories of child deaths during previous hospitalizations, the activity that requests to do a story in comic about "something sad that happened in the hospital," said about the fear before the surgery: *when I went to do the surgery, I also had a lot of fear (of death)* (Jasmine, 12 years).

One can show that during hospitalization, children and adolescents are faced with the death of other sick and that these situations provoke sadness, dismay and fear, causing death itself becomes a real threat, expressed by feelings that emerge in children's reports.

Discussion

The understanding and the form of expression may be different at various stages, but we must recognize that death is present since childhood, and did not accept this reality can harm the development of children and adolescents. The hospitalization puts them on the context of death and the fact of not talking about it does not protect them from fear facing the possibility of their own death and feelings of sadness, concern and dismay at the death of others. Study¹⁵ shows that children with cancer speak metaphorically of their experiences and the reality they face. In addition, those with more time of diagnosis and treatment, anguish over how much the uncertainty of their future, bringing in its unique narratives meanings about death and relentless daily struggle between

to live and to die.¹⁴ The results of this study corroborate with the results above, they points out that children/adolescents with strength time of diagnosis of chronic disease and higher frequency of hospitalizations reported more deaths stories occurred in the hospital.

Children and adolescents generally avoid talking about the topic of death due to the difficulty in drawing up this experience. In addition to the discomfort caused by the disease and hospitalization, witness the suffering, pain and even death of their hospital colleagues. These experiences are so striking that even with the passage of time, reappear in memory triggering sadness, causing them to avoid talking about it. Another revealing aspect is the hesitation in the pronunciation of the word death, replacing it by pass away. Even adults have difficulty in uttering the word death, the content and meaning it presents. Thus, the term becomes prohibited because the mere pronunciation could give it life.¹⁵ This adult behavior leads the child/adolescent to perceive the word as misuse, so replace it with one that seems more lightness.

It is also significant the avoidance of pronouncing the word cancer, which carries a stigma of death,¹⁶ and often is referred as "that disease" or just "CA". The adult attitude, to avoid talking about it, can create a taboo and hinder the expression of children/adolescents in the face of losses and generate feelings of anguish for not allowing the development of experiences.

When the topic death comes up, it can be seen initially by negation but, later, the admission of the fear of sudden death. At the same time, experience fear when relating death of another child with severity of disease. The conception of death is also explained as a divine determination, attributing to God the possibility of salvation in the face of illness. Therefore, religiosity is an important aspect in the dynamics of life of many families and cannot be neglected in the disease and cure process.¹⁷ Research with adolescents with cancer indicates that they did not address any clearly possibility of death, but it shows

as threat in front of relapse and worsening of diseases.¹⁸ The fear related to death was also confined to representations of children/adolescents over the hospital. This situation can cause insecurity during hospitalization, triggering great suffering and anguish, expressed by crying. Thus, health professionals need to be aware of the psychosocial aspects that are present in the process of illness and hospitalization, as it is often difficult for the child/adolescent verbalize their discomfort through verbal language.

The theme of death should be part of the training of these professionals, so that before the own experiences, develop their grief for the loss in their daily work and deal with the feelings of children/adolescents, facing the imminent risk of death, and family members who are also unsettled.¹⁹ The fear of death was expressed by children who would be undergoing surgery. In these situations it is necessary to listen their anxieties, fears and concerns in order to identify the meaning they attribute to the surgery so that fears and fantasies are demystified.²⁰ It is important the hospital encourage children and adolescents to talk about their fears, through the use of strategies appropriate to the age, minimizing trauma of hospitalization process.

Health professionals and family tend to show unpreparedness when facing the theme death. However, it is necessary perception of the relevance of an effective dialogue on the subject, which will enable better coping in the face of situations that are experienced. It is essential to have a unique look at the different meanings given about the disease and the imminent possibility of death at all stages of experience and treatment of chronic illness. The development of this action furthers our understanding of possible behaviors arising from this subjective constructions.¹⁴ The child and the adolescent with chronic disease need to have their valued experience, being necessary to give a voice so that they can express themselves²¹ and allow them to talk about their doubts, fears and experiences also related to death. In this context, it is important to have a cozy space where ludic resources are used, including toys,

games, children's or interactive books, video, among others, considering the value that they have for child and adolescent expression as a way to help in the intervention.

The fear of death is present in children/adolescents with chronic disease, even those not presenting an imminent risk of death. These findings highlight the need to create spaces for children and adolescents are encouraged to talk about a subject that, in most cases, is avoided, not only by the family but also by many health professionals. It is essential that the health care team, and in a special way, the nursing, stand next to the family and help the child and the adolescent, promoting the expression of feelings, fantasies and fears facing death. This may not be an easy task, for even part of the daily work of these professionals, there is still a great lack of preparation in dealing with death and their meanings. The team needs to direct his eyes and act proactively in the interaction with children and adolescents with chronic diseases, seeking a singular, comprehensive and effective attention.

Because of the shortage on the theme and the evidence presented in this study, highlights the importance of creating listening spaces and to promote ways for the child/adolescent develop content about death. It is essential that further research be conducted with children and adolescents in different age groups and with the use of other resources required to achieve the expression and forward intervention to the theme of death in hospitalized children and adolescents with chronic diseases. The study limits itself presenting the feelings of four children and one teenager.

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