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THE MEANING OF CHILDHOOD CANCER: THE OCCUPATION OF DEATH WITH LIFE IN CHILDHOOD

Luana Maria de Souza Fernandes[1 2], Orcid: http://orcid.org/0000-0002-0989-0973
Airle Miranda de Souza[3], Orcid: http://orcid.org/0000-0001- 9478-6865

ABSTRACT. Childhood Cancer presents 70% chance of cure if diagnosed early, although it is a rare disease, it can result in death. The association between cancer and death becomes known to children, somehow, from the moment of diagnosis, this encounter is constant. This study sought to reveal if the subject of the death of itself or of other children with cancer are approached through the drawings stories. The research was developed in an association that provides psychosocial assistance, lodging, food and transportation to children and companions during cancer treatment. Collaborated with the research, five children who were on cancer treatment and hosted in the house, four girls and one boy, collaborated with the research. As a tool for data collection, a semi-structured interview was applied with those responsible for the children, aiming to identify general information about the child. Later, with the children, the drawing-and-story procedure was applied, by means of drawings and verbal associations, introduced by Walter Trinca, in 1972. For analysis and understanding of the information collected, we used the model of Amedeo Giorgi. Later, two thematic axes were constructed: the various losses when getting sick and the death of oneself and the ward mates. The results reveal that the child seeks to understand what happens to it and the environment, deals with uncertainty about the future, being able to feel the proximity of death and express its feelings and emotions.

Keywords: Childhood cancer; unveiling meanings; death.

SIGNIFICADOS DO CÂNCER INFANTIL: A MORTE SE OCUPANDO DA VIDA NA INFÂNCIA

RESUMO. O câncer infantil apresenta 70% de chance de cura se diagnosticado precocemente, embora seja uma doença rara, e pode resultar na morte. A associação entre o câncer e a morte passa a ser conhecida pelas crianças, de alguma forma, desde o momento do diagnóstico, esse encontro é constante. Nesta pesquisa buscou-se desvelar se o tema da morte de si mesma ou de outras crianças com câncer são abordados por meio dos desenhos-estórias. A pesquisa foi desenvolvida em uma associação que presta assistência psicossocial, hospedagem, alimentação e transporte às crianças e aos acompanhantes durante o tratamento oncológico. Colaboraram com a pesquisa cinco crianças que estavam em tratamento oncológico e hospedadas na casa, sendo quatro do sexo feminino e uma do sexo masculino. Como instrumento para coleta dos dados foi utilizado entrevista semiestruturada com os

[1] Instituto de filosofia e ciências humanas, Programa de Pós-Graduação em Psicologia, Universidade Federal do Pará (ufpa), Belém-PA, Brazil.
[2] E-mail: anaulfe@yahoo.com.br
[3] Universidade Federal do Pará (UFPA), Belém-PA, Brazil.

responsáveis, objetivando identificar informações gerais a respeito das crianças. Posteriormente, com as crianças, foi executado o procedimento de desenho-estória, por meio de desenhos e associações verbais, introduzido por Walter Trinca, em 1972. Para análise e compreensão dos dados coletados, utilizou-se o modelo de Amedeo Giorgi. Posteriormente foram construídos dois eixos temáticos: as diversas perdas no adoecer e a morte de si e de seus companheiros de enfermaria. Os resultados desvelam que a criança busca compressão do que ocorre consigo e com o ambiente onde se encontra, lidam com a incerteza em relação ao futuro, podendo sentir a proximidade da morte e expressar seus sentimentos e emoções.

Palavras-chave: Câncer infantil; desvelar significados; morte.

SIGNIFICADOS DEL CÁNCER INFANTIL: LA MUERTE OCUPANDO SE DE LA VIDA EM LA INFANCIA

RESUMEN. El cáncer infantil, presenta un 70% de probabilidad de curación si se diagnostica precozmente, aunque es una enfermedad rara, puede resultar en la muerte. La asociación entre el cáncer y la muerte pasa a ser conocida por los niños, de alguna forma, desde el momento del diagnóstico, ese encuentro es constante. En esta investigación se buscó desvelar si el tema de la muerte de sí misma o de otros niños con el cáncer son abordados por medios de los dibujos historias. Se desarrolló la investigación en una asociación que ayuda a la asistencia psicosocial, alojamiento, alimentación y transporte a los niños y acompañantes durante el tratamiento oncológico. Colaboraron con la investigación, cinco niños que estaban en tratamiento oncológico y hospedados en la casa, siendo cuatro del sexo femenino y una del sexo masculino. Como instrumento para la recolección de datos se utilizó una entrevista semiestructurada con los responsables, con el objetivo de identificar informaciones generales sobre el niño. Posteriormente con los niños, se ejecutó el procedimiento de dibujo historia, por medio de dibujos y asociaciones verbales, introducido por Walter Trinca, en 1972. Para el análisis y la comprensión de los datos recolectados, se utilizó el modelo de Amadeo Giorgi. Posteriormente se construyeron dos ejes temáticos: las diversas pérdidas en el enfermar y la muerte de sí y de sus compañeros de enfermería. Los resultados desvelan que el niño busca comprensión de lo que ocurre con él y con el ambiente en que se encuentra, se ocupa de la incertidumbre con respecto al futuro, pudiendo sentir la proximidad de la muerte y expresar sus sentimientos y emociones.

Palabras clave: Cáncer infantil; desvelar significados; muerte.

Introduction

Childhood Cancer, despite the optimistic reality with 70% chance of cure, if diagnosed early, is a rare disease and can result in the death of children and adolescents. In Brazil alone, there were 2,800 deaths in the age group from zero to nineteen in 2013. These expressive and alarming data place childhood neoplasms second only to deaths due to external causes (Instituto Nacional do Câncer no Brasil [INCA], 2015), reaffirming the significant presence of death.

Children with cancer are faced with impending death at all times. When they have the perception that something serious is happening due to changes in their own body or the death of other children, companions of treatment: some do not react as expected to the treatments available, those whose disease evolves independently of the prospects of existing cures. Others at a given time of treatment present problems arising from their own, not resisting the toxic effects of chemotherapeutic drugs. Some present relapses during the course of treatment, others present after their termination, where the disease returns and becomes more difficult to treat. Also, there are children whose prognosis is negative from the moment of diagnosis, given the type and/or extent of the cancer (Françoso, 2002).

Kovács (2008) mentions that in this trajectory, children begin to develop feelings and thoughts about death and when expressions are allowed on the subject, explicitly or not, the theme of death may arise in jokes, drawings, stories and questioning. Valle (2001) considers that the concept of death is integrated in the development of children being influenced by the knowledge, by the imaginary of the society in which they live and by the experience with the theme, similar to other constitutive concepts of the human psyche.

And in the midst of all these adversities, children are experiencing their deep and significant losses, such as: (change in life and in the family) where the new and unknown universe is represented not only by the absence of health, but also by the social and family distance and isolation (loss of school), due to the loss of autonomy, because the child is subjected to the schedules and interventions of the health team, restrictions on visits, dress, living with strangers, among many other situations (Schliemann, 2014).

It is generally thought that children are not emotionally prepared to deal with such a frightening subject as this, considering them immature to receive this kind of information, so everything associated with it becomes harmful. At the same time, we have a society that chooses to keep death in silence or talking through metaphors, believing that children will be protected (Kubler-Ross, 2003; Kovács, 2008).

From this conception, lies and/or fanciful ideas emerge for the protection and the adult end up harming the child, away from reality. And at the moment death is evident to the child, it can be seen as something truly terrifying, mysterious, traumatic (Aberastury, 1984; Kubler-Ross, 1998). For Kovács (2003), death should be approached from childhood, throughout life and not only at the end of life.

The investigations into the understanding of death by the child began in 1934 and continue throughout these years, differentiating between those who question the age at which children understand death, and those who seek to investigate whether the understanding of each component is related to the level of overall development. Torres (2008, p. 54) highlights four concepts that favor the understanding of the evolution of the concept of death for children:

> Irreversibility - refers to the understanding that a being with life, when it dies cannot live again. It is bound to the idea of death as something final, unalterable and permanent.
> Non-functionality - understanding that all the defining functions of life cease with death.
> Universality - everything that is alive dies, that is, death is an inevitable event.
> Causality - involves understanding why death occurred.

According to this author, studies show that the child who experiences a situation related to death, whether the possibility of its own death, or even the loss of the loved one, keeps records and emotions imprinted on the psyche. The way the child organizes and expresses its understanding and feelings is related to the cognitive development (Torres, 2008).

Death is also concerned with childhood, and it is necessary to recognize it, to demystify it, understanding that suffering and death are parts of existence and affect children and adults. Therefore, it is necessary to listen to what children have to say about death, especially when they are affected by diseases that represent risks to their lives. The present study sought to reveal if the theme of the death of itself or of other children is approached through the drawings stories produced by the children.

Method

This is a qualitative, exploratory, descriptive study, with emphasis on the meaning and the intentionality of human phenomena, considering the meanings attributed by children in oncological treatment. The research was carried out in a house-hostel, which provides psychosocial assistance, lodging, food and transportation to children and companions during the treatment, located in the northern region of Brazil.

Participants

Five (5) children participated, four girls and one boy, in cancer treatment, aged between six and eleven years. The inclusion of the participants in the study was made based on the inclusion criteria, first with those responsible for the children: being a parent, or another responsible for the child; greater than 18 years and accept to participate in the study. Subsequently, with the children: diagnosis of cancer already confirmed; being a guest of the house; aged 6 years or more and that the person responsible should freely agree to participate and sign the Free and Informed Consent Term - TCLE.

Instruments

Initially, a semi-structured interview was applied, with the participation of the mother, father or other responsible person. At this stage, general information about the child was identified, such as age, place of origin, schooling, diagnosis, time of treatment, among others, as well as the child's reactions to diagnosis, treatment and insertion at the house-hostel.

In relation to the child, the instrument chosen for data collection consisted of the drawing-and-story procedure, through drawings and verbal associations, introduced by Walter Trinca in 1972. These were developed in order to favor an expansion of knowledge to respect to the contents that are not accessible verbally.

Procedures

In order to carry out this study, the recommendations of Resolution 446 (Brasil, 2012) on research involving human beings in Brazil were followed. Collection started only after authorization of this project by the Ethics Committee in Research with Human Beings, under opinion number: 1622337.

Activities related to data collection with the mother or responsible, occurred from the interview with the mother, father or other responsible. Later, with the child with application of the drawing-and-story procedure in five phases, according to Trinca (1997): First, a sheet of paper is placed in the horizontal position and the child is asked to draw a free drawing, from the following statement: 'You have this blank sheet and you can make the drawing you

want and the way you want it'. The first drawing is awaited; At the end of each production the child is asked to tell a story about the drawing. 'Now, looking at the drawing, you can come up with a story telling what happens'; Subsequently, the 'inquiry' is carried out on any clarifications necessary for the understanding and interpretation of the material that has been produced, both in the drawing and in the story. And finally, still with the drawing before the examining, the title of the story is asked for.

For the analysis and understanding of the data collected, the Amedeo Giorgi model was used following four steps, (Andrade & Holanda, 2010): sense of the whole; discrimination of significant units; transformations of the everyday expressions of the subject into psychological language and synthesis of the structure of experience.

Results and discussion

Children and their stories

Sadness: Girl, nine years old. She had been in the hostel-house for two months. Born in the state of Pará, she lives in the municipality of Augusto Correa with her parents and seven siblings. She attended the third grade of elementary school when she entered the house. She is under the responsibility and care of her (maternal) aunt, because her father is the maintainer of the family as a farmer, and her mother is with the newborn baby. The aunt, in turn, for being a widow and having her adult children, volunteered to take care of Sadness. She has Ovarian Cancer (Figure 01).

Figure 1. Drawing by Sadness, first collaborator.

Wisdom: Girl, eight years old. Born in Maranhão, she studied in the third grade of elementary school, in the municipality of Palestina do Pará, where she lived with her family, composed of parents and three siblings. Her main caretaker is her mother, who came to accompany the child in her treatment, which has lasted three years, while her father, maintainer of the family as administrative assistant, takes care of the other children. Wisdom has Sarcoma (Figure 02).

Figure 2. Drawing by Wisdom, second collaborator.

Strength: Girl, six years old, single daughter. Born in the state of Pará, she attended the first grade of elementary school in the municipality of Ulianópolis, where she lives with her parents. The mother is the primary caregiver during her two years of treatment. The father is a farmer and maintainer of the family. Strength has Osteosarcoma (Figure 03).

Figura 3. Drawing by Strength, third collaborator.

Star: Girl, six years old. Born in the state of Pará, she attended pre-school in the municipality of Oeiras do Pará, a village in the Community of Nova América (rural area) where she lived with her parents and four sisters. Her mother came to accompany her on the treatment, which has lasted for two years and five months, while her father, who works as a farmer and maintains the family, takes care of the other daughters. Star has Acute Lymphoid Leukemia – ALL (Figure 04).

Figure 4. Drawing by Star, fourth collaborator.

Navigator: Boy, eleven years old, from the state of Pará, municipality of São Domingos do Capim, Community of Natal de Jesus (rural area), where he lives with his parents and his six siblings. His mother is his primary caregiver during a year and a half of treatment. His father serves as fisherman and farmer, stayed in the municipality taking care of the other children. Navigator has Acute Lymphoid Leukemia - ALL (Figure 05).

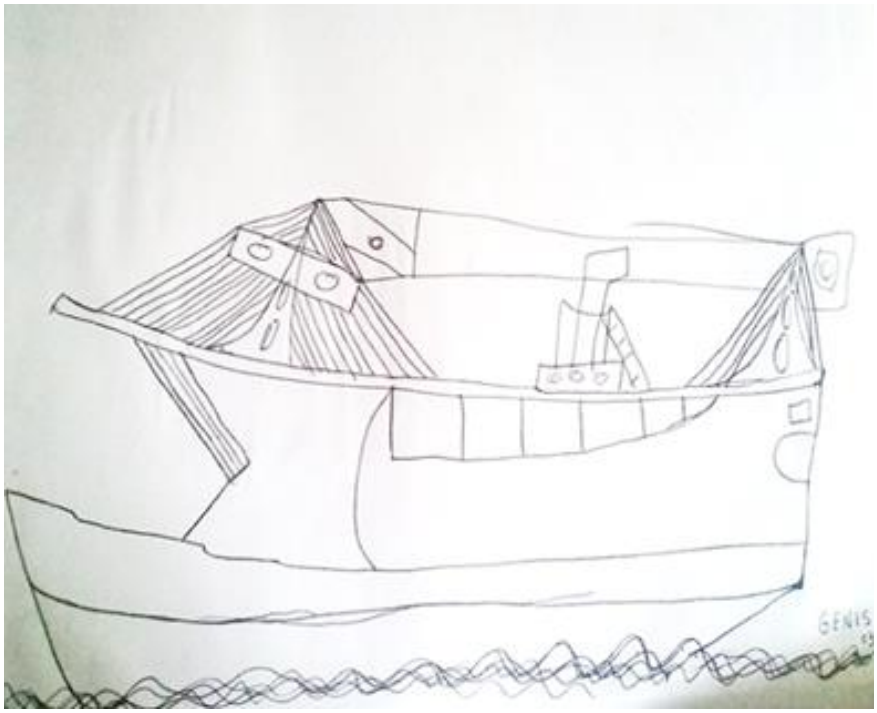

Figure 5. Design by Navigator, fifth participant.

The various losses when getting sick

All the children emphasized at some point in the construction of the drawing or in the elaboration of their stories, the losses and limitations that they experience or that they were perceiving during the treatment. These were related to various aspects of their lives, such as: daily activities (attending school), leisure activities (running, river bathing), changing habits, especially food (restrictions) and family isolation, as noted below:

> [...] a very beautiful field, where I went, my mother, my siblings, we were going to take a bath in a stream, play a lot, then go home, spend a few days, then go again [...] , I stopped going there, because I started my treatment, and I cannot take a river bath, I cannot do anything anymore, I miss those things and miss my siblings as well and my aunt also sold and bought another, which also has a stream, but I have not yet met, because I have not been there yet, but I know that I will be, we will return to play and have fun as before (Wisdom).

> I had the routine based on running, jumping, and playing house with my sisters. I was starting my school life, I wanted to learn to read and write, I started to write my name [...] I have a lot of friends at school and my teacher was cool (Star).

Children suffer because their bodies are objectified by interventions imposed by the disease, suffer from the physical pain felt, the loss of autonomy, by altering their body shape. In this sense, it is observed that each participant expresses their most significant losses, which go beyond the loss of health. They suffer from the loss of living with the rest of the family, from the sudden abandonment of their home, from not being able to attend school, from having restrictions on playing and eating, among others, but that does not prevent new ways of relating and rebuilding in relation to oneself and with others (Azevedo, 2011). This

can be corroborated by the speech of Navigator "[...] My greater pleasure was to go on a boat with my father, when they went fishing and tending the fields [...]".

The death of oneself and the ward mates

Throughout development, the child accompanies the actual deaths that surround them, trying to understand what happens, thereby forming conceptions about death (Chiattone, 2003). These experiences enable the child to face the suffering and frustration caused by the loss. The child seeks an understanding of what happens to oneself and the environment in which it is; deals with uncertainty about the future, being able to feel the proximity of death and express their feelings and emotions (Bifulco, 2014). This theme was evidenced by the children, and among these stands out the story of Star, who refers to a new place that she will reside, no longer in this existence:

> When I live in this house, I go alone, I cannot take my father, my mother and none of my sisters. They will need to stay here, that is, back home (referring to their municipality), taking care of each other. [...] I'll miss them, but I know I'll be better off being in this house (pointing to the drawing). [...] Because I will not have these things from here, having to go to the hospital, to get sick. Everything will be different there. I can play, run. It will be very cool (Star).

The speech of Star confirms that described in the literature, which states that children can sense death and express their feelings and emotions, when they are allowed to express themselves through words, gestures, games, drawings or stories (Baldini & Krebs, 1999). Star died in January 2017, approximately four months after this activity.

Another issue revealed and confirming other studies (Perina, 2005; Vendruscolo, 2005) refers to the child's perception of the death of treatment partners, as Navigator reports: "I think that death is a good thing, since after that, my colleagues went to a better place, where they do not feel any more pain and no longer need to undergo QT sessions, they are completely free". The proximity of death can be experienced as positive, as it can bring relief to pain and rest.

Cancer sickness, hospitalization, losses from chemotherapy side effects, such as hair loss and weight loss and death of ward mates, evoke the subject of death and dying, requiring the health professional to be open and skilled in order to respond to these demands. To postpone or refuse the meeting to hear what the child has to say about death is to deny total care, increasing suffering. It is necessary that the professional can understand his/her own mortal condition and thus open him/herself to the child who cries out to mean its life and its death.

Final considerations

Despite denial and the fear of death, unlike what is common to most people, children are able to perceive what happens to them and also to the environment around them, included here, the experiences of death that they can to come to experience, becoming essential the dialogue with the same on these themes and everything that relates to it.

This importance is justified by the need for the child to approach the subject in order to elaborate its grievances and the losses experienced during life. For this to occur, it is important to look for ways to approach the subject early, even in childhood (Kovács, 2008). For this, it is necessary that the adults, who are part of the groups (family and social) of the

children, also have a preparation, since the theme generates anguish. Thus, the theme of death with children will be addressed and the interdict minimized.

Not talking about it is commonly seen as a way to protect the child, but this does not hold up, since at any moment questions will arise, especially as they realize that something is occurring in their bodies and in their lives. In any case, it is usually the adult who defends him/herself from his/her fears and anguish, not the children, who are open to talk about death.

However, important aspects must be considered, among them: the child's cognitive ability, age, emotions, affections, social, family and cultural context in which he/she is inserted, as well as the experiences of losses that have already occurred (death in the family, a pet or something significant), talking openly about it, not needing ready answers.

It is also indispensable to use the children's language and recreational resources (drawings, stories, games, children's books, among others), and can approach the subject in environments in which children live, such as school for example, going beyond hospitals. Thus, it is possible that the subject is approached in an appropriate way, and it is essential that information not come alone, but accompanied by reflections and explanations, and when it comes to real death, the child may live its feelings, grievances and losses in a healthy way, being able to account for future losses and for its own death.

On the other hand, it is observed that most of the collaborators chose the drawing to talk about death and dying, not being receptive to constructing their stories, which makes us reflect that stories have a beginning and an end, but some of these children are still waiting the outcome of the treatment to know if they will overcome cancer or if its outcome will be life or death. So, it does not seem resistance or inability to produce their stories, but they explain and signify the moment when we contemplate life and prepare for that moment, waiting with acceptance for a future that may imply living or dying.

The results obtained evidenced the importance of the development of research in this area, in order to contribute to the health professional's openness and ability to respond to the demands of the themes of death and dying raised by children. To postpone or refuse the meeting to hear what the child has to say about death is to deny total care, increasing suffering. It is necessary that the professional can understand his/her own mortal condition and thus open him/herself to the child who cries out to mean its life and its death.

References

Aberastury, A. (1984). A percepção da morte nas crianças (M. N. Folberg, trad.). In Aberastury, A. (Org.), *A percepção da morte na criança e outros escritos* (p. 128-139). Porto Alegre, RS: Artes Médicas. Original publicado em 1978.

Andrade, C. C., & Holanda, A. F. (2010). Apontamentos sobre pesquisa qualitativa e pesquisa empírico-fenomenológica. *Estudo de Psicologia,* 259-268. Recuperado de: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-166X2010000200013

Azevedo, A.V.S. (2011). O brincar da criança com câncer no hospital: análise da percepção científica. *Estudos de Psicologia,* 565-572. Recuperado de: http://www.scielo.br/pdf/estpsi/v28n4/15.pdf

Baldini, S. M., & Krebs, V. L. J. (1999). A criança hospitalizada. *Pediatria, 3*(21), 182-190.

Bifulco, V. A. (2014). O luto do portador de doença crônica incurável: o modelo da psico-oncologia. In F.S. Santos (Org.), *Tratado brasileiro sobre perdas e luto* (p. 223-229). São Paulo, SP: Atheneu.

Brasil. Ministério da Saúde. Conselho Nacional de Saúde. (2013, 13 de junho). **Resolução nº 466 , de 12 de dezembro de 2012.** Aprova as diretrizes para análise ética de projetos de pesquisa que envolvam armazenamento de material biológico humano ou uso de material armazenado em pesquisas anteriores. *Diário Oficial da União*, p. 59.

Chiattone, H.B.C (2003). A criança e amorte. In Camon, V.A. (Org.), *E a psicologia entrou no hospital* (p. 69-133). São Paulo, SP: Pioneira Thompson Learning.

Françoso, L. P.C. (2002). Vivências de crianças com câncer no grupo de apoio psicológico: um estudo fenomenológico (Tese de Doutorado), Faculdade de Filosofia, Ciências e letras de Ribeirão Preto, Ribeirão Preto. Recuperado de: www.teses.usp.br/teses/disponiveis/59/59137/tde-03102005.../FRANCOSO_LPC.pdf

Instituto Nacional Do Câncer Brasil. (2015). *Estimativa 2016: incidência de câncer no Brasil*. Rio de Janeiro, RJ: INCA.

Kovács, M. J. (2003). Bioética nas questões da vida e da morte. *Psicologia USP, 2*(14), 115-167. Recuperado de:http://www.scielo.br/pdf/pusp/v14n2/a08v14n2.pdf

Kovács, M. J. (2008). Representações da morte. In M. J. Kovács (Coord.), *Morte e desenvolvimento humano* (5a ed.). São Paulo, SP: Casa do Psicólogo.

Kubler-Ross, E. (1998). *Sobre a morte e o morrer*. São Paulo, SP: Martins Fontes.

Kubler-Ross, E. (2003). *O túnel e a luz: reflexões essenciais sobre a vida e a morte*. Campinas, SP: Versus.

Perina, E. M. (2005). *Breve histórico da psicooncologia pediátrica no Brasil*. Campinas, SP: Livro Pleno.

Schliemann, A. L. (2014). A vivência do luto da infância e na adolescência. In Santos, F.S.(Org.), *Tratado brasileiro sobre perdas e luto* (p. 225-229). São Paulo, SP: Atheneu.

Torres, W. C. (2008). *A criança diante da morte: desafios*. São Paulo, SP: Casa do Psicólogo.

Trinca, W. (1997). *Formas de investigação clínica em Psicologia: procedimento de desenho-estórias e procedimento de desenhos de família com estórias*. São Paulo, SP: Vetor.

Valle, E. R. M. (2001). *Psico oncologia pediátrica*. São Paulo, SP: Casa do Psicólogo.

Vendruscolo, J. (2005). Visão da criança sobre a morte. *Simpósio: Morte: Valores e Dimensões, 38*(1): 26-33. Recuperado de: http://revista.fmrp.usp.br/2005/vol38n1/3_visao_crianca_sobre_morte.pdf

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Luana Maria de Souza Fernandes: Master in Psychology from UFPA, a specialist in Health and Hospital Psychology, and currently works at the Octávio Lobo Children's Oncology Hospital. Psychologist of the Palliative Care team. Member of the Laboratory of Mourning Studies in Health - LAELS/UFPA. Professor of the course of psychology of the Escola Superior da Amazônia – Esamaz.

Airle Miranda de Souza: Psychologist. Master in Mental Health. PhD in Medical Sciences. Full Professor, Universidade Federal do Pará (UFPA), Belém,Stateof Pará, Brazil.