ORIGINAL ARTICLE

Dignified death for children: perceptions of nurses from an oncology unit*

MORTE DIGNA DA CRIANÇA: PERCEPÇÃO DE ENFERMEIROS DE UMA UNIDADE DE ONCOLOGIA

MUERTE DIGNA DEL NIÑO: PERCEPCIÓN DE ENFERMEROS DE UNA UNIDAD DE ONCOLOGÍA

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ABSTRACT
The objective of this study was to identify the meaning of dignified death and the interventions employed by nurses in pediatric oncology to promote dignified death for children. We used Symbolic Interaction Theory as the theoretical framework and narrative research methods. The data were collected from eight nurses in the pediatric oncology unit of a public hospital in Sao Paulo through semi-structured interviews. The data analysis revealed five categories: feeling no autonomy in decision-making, caring for the family, offering physical comfort, valuing humanized care and learning to deal with death and dying. This study helps to extend the understanding of this process of care and postulates a theoretical framework that integrates the knowledge and actions that constitute care that transcends clinical and biological needs.

DESCRIPTORS
Death
Child
Oncologic nursing
Pediatric nursing
Hospice care

RESUMO
O objetivo deste estudo foi identificar o significado e as intervenções de enfermeiros que atuam em oncologia pediátrica na promoção de morte digna da criança. Utilizaram-se como referencial teórico e metodológico o interacionismo simbólico e a pesquisa de narrativa. Os dados foram coletados junto a oito enfermeiros de uma unidade de oncologia pediátrica de um hospital público de São Paulo, por meio de entrevistas semiestruturadas. A análise dos dados permitiu a identificação de cinco categorias: sentir-se sem autonomia para a tomada de decisão; cuidar da família; oferecer conforto físico; valorizar o cuidado humanizado e aprender a lidar com a morte e o morrer. Este estudo contribui para ampliar a compreensão do processo de cuidar e permite avançar na postulação de um quadro teórico que contemple a integração de saberes e ações que constituem uma assistência integral, transcendendo o atendimento de necessidades apenas clínicas e biológicas.

DESCRITORES
Morte
Criança
Enfermagem oncológica
Enfermagem pediátrica
Cuidados paliativos

RESUMEN
Se objetivó identificar el significado y las intervenciones de enfermeros actuantes en oncología pediátrica en la promoción de la muerte digna del niño. Se utilizaron interaccionismo simbólico e investigación narrativa como referenciales teóricos y metodológicos. Datos obtenidos de ocho enfermeros de una unidad de oncología pediátrica de hospital público de São Paulo, mediante entrevistas semiestructuradas. El análisis permitió la identificación de cinco categorías: Sentirse sin autonomía para la toma de decisiones; Cuidado de la familia; Ofrecer bienestar físico; Valorizar el cuidado humanizado y Aprender a enfrentarse con la muerte y el morir. El estudio contribuye a ampliar la comprensión de éste proceso de cuidados y permite avanzar en la postulación de un cuadro teórico que contemple la integración de conocimientos y acciones que constituyan una atención integral, trascendiendo la atención de necesidades meramente clínicas y biológicas.

DESCRIPTORES
Muerte
Niño
Enfermería oncológica
Enfermería pediátrica
Cuidados paliativos

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INTRODUCTION

During the therapeutic process, nurses are health professionals who have the ability to stay in touch with clients for a longer time because their actions are not restricted to pure technical procedures; they also contemplate and seek to combine the various characteristics of human beings. Thus, nurses favor the socio-psycho-spiritual aspect of care[1].

In the area of childhood cancer, death disrupts daily care practices, and it is not possible to hide it. In this sense, to provide adequate nursing care to patients at the end of life, a high level of technical competence is not sufficient. Professionals must be sensitive to human suffering, be able to engage positively with those who suffer, be willing to engage in dialogue, and be respectful and appreciative of the freedom of human dignity in the most adverse circumstances. Although it is humanly impossible to conquer death, humans must find something to soften and give meaning to the experience of loss[2].

Thus, working with pediatric patients who face imminent death is not an easy task. To provide care that meets the needs of children and adolescents, professionals should understand what they must offer[2].

Professionals must be sensitive to human suffering, be able to engage positively with those who suffer, be willing to engage in dialogue, and be respectful and appreciative of the freedom of human dignity in the most adverse circumstances.

Advances in medicine have improved the survival of patients with serious diseases that were previously considered fatal. However, in many cases, these advances prolong the dying process at the expense of additional suffering for the patient and his or her family[3].

The Brazilian Code of Medical Ethics states that proper medical care for patients at end of life offers them therapeutic ways to prevent suffering in the dying process[4]. The medical obligation, legally and morally, is to act for the benefit of patients. In certain situations, this obligation means not intervening - letting patients die in peace and with dignity, respecting the autonomy of the person who is dying or his or her legal representative[5].

Although much has already been written about death with the focus on the individual, this study sought to explore the concept of dignified death as a phenomenon present in the decision-making of nurses in situations at the end of life.

Without a clear understanding about the concept of dignified death, little can be done to help a child dying in a pediatric oncology unit. Knowing more about the decision-making processes of the team, the succeeding interactions during this process, and the meaning that oncology nurses ascribe to the term dignified death can strengthen the basic concepts employed in various theories concerning working with children and families.

OBJECTIVE

To identify the meaning of dignified death and the interventions that nurses who work in pediatric oncology use to promote dignified death for children.

METHODS

This study is exploratory-descriptive research that used a qualitative approach. We adopted Symbolic Interaction Theory as our theoretical foundation and narrative research principles for our methodology, both of which allowed us to understand the perceptions of nurses regarding dignified death for children in pediatric oncology units.

Symbolic Interaction Theory, as a perspective, aims to understand the causes of human action, which includes human self-definition, self-direction and choices in diverse situations. Thus, this theory recognizes that choice and freedom play a role in human actions. The major premise of symbolic interactionism is that meaning emerges from interactions, which define the situation, the context, and all of its constituents. For interactionists, changes are linked to interactions because as interactions occur, they constantly change one's perspective. When interacting with others and with oneself, a human being receives stimuli that change the elements to consider in the context of a situation. Thus, perspectives are always actively defined in the present of every experience, and consequently, actions are triggered[6].

Thus, narratives should be used to examine the life experiences of an individual when there is material available and accessible and when the individual wants to report his or her experience[7]. Narrative research offers a way to generate understanding and to explain people's stories, and it also offers the possibility of exploring a singular experience[8]. Thus, narratives enable the understanding of life in time and the ways in which the actions of individuals form their histories.

Study location and the subjects of the research: The study was conducted in a pediatric oncology unit of a tertiary level public hospital in the city of São Paulo that participates in teaching and research. Before the study started, the project received approval from the Ethics Committee of the institution (process number 281/2002). Later, we began collecting the data. The participants were asked to participate, and if they agreed, they signed the consent form. The study included nurses in the admissions department and the outpatient chemotherapy department who agreed to participate, regardless of their qualifications and experience in the area, for a total of eight nurses.

Data collection: The data were collected between November 2008 and March 2009 through interviews consisting of two parts: the first part identified basic information regarding the research subjects (i.e., name, qualification level, working experience in the field of pediatric oncology, work experience in other areas and religion); the second part included semi-structured questions regarding the nurses' perceptions regarding dignified death for children with cancer. The interviews were recorded on cassette tapes with the consent of the interviewees and were fully transcribed.

For the first interviews, the following guiding questions were used: *Describe to me a situation in which a child's death was worthwhile. What do you understand dignified death to mean? What do you believe can be done to help a child to have a dignified death?* In subsequent interviews, as the categories were formed, new questions that could clarify the ideas raised by participants were added. The interviews were recorded and fully transcribed soon after their completion to avoid losing significant data.

Data analysis: The data analysis including preparing and organizing the data to reduce the data into categories and subcategories for the encoding process, condensing the data and, finally, presenting the data under discussion[9].

RESULTS

The nurses who participated in the study were identified by numbers in sequence according to the order of the interviews: *N1, N2, N3, N4, N5, N6, N7 and N8*. One of the participants was male, and seven were female, with ages ranging from 24 to 28 years old. The participants' lengths of experience ranged from one year and two months to four years, and the average length was two years and four months. The duration of work experience in the field of pediatric oncology ranged from two months to one year and six months. Three of the nurses declared themselves Catholics, four were evangelicals and one self-identified as spiritist.

From the analysis of the interviews, it was possible to identify categories (represented by lowercase letters in bold) and subcategories (represented by lowercase letters in italics) describing dignified death, as well as relevant interventions to provide more holistic care that culminated in dying with dignity. In the view of these professionals, dignified death in this context involves the concepts described below.

Lacking autonomy for decision making

Autonomy implies moral or intellectual freedom to act in certain situations and to participate in decisions about care and treatment without feeling threatened by legal issues. The nurses working in pediatric oncology feel deprived of freedom to make decisions or act autonomously in situations involving a child's death. There is evident concern concerning the legal and bioethical issues involved in discussions about end-of-life situations.

> I think that in nursing, we worry a lot about the credibility that we will have later, if we do not get involved with a child isn't it .... (N4).

Caring for Families

This category relates to the ability of a nurse to create bonds with a child and his or her family by providing emotional care to the children with cancer. The category also relates to the ability of a nurse to give the family and the child the opportunity to remain together as long as possible. This idea is further elaborated in the subcategories described below.

Creating Links

Emotional involvement and the creation of bonds enable a relationship of great trust between the child, the family and the nurse. The professionals notice that this relationship makes the treatment and care offered to children and their families more effective and less painful.

> ... often everybody cries together, this is very comforting to them. So to speak, 'Oh, we did not just pass through here, we really lived a story, and all those involved in this story lived it together... (N3).

Offering support and protection

A dignified death is possible only when the professional has the ability to offer support to help the child and family. Support is commonly associated with offering one's presence, listening and caring for family members.

> ... it is mainly to... assist the parents, because they often want to talk, want to open up... and it is to give them the opportunity to do that... (N2).

Supporting the child - family relationship

The discourses reveal the perceptions and opinions of the nurses regarding the need for the child and the family to have most contact possible during the process of disease and death. The nurses believe that the dignified death of the child requires the family to be present to participate in the whole process. Thus, the child goes through this situation in a more peaceful and comforting manner, ending in a dignified death.

> ... it was an irreversible clinical condition. It was not possible to resuscitate (...) so... the parents, the family... stayed together... it was very emotional, but it was... I think... it was comforting for the family... (N2).

Offering physical comfort

For nurses, it is not possible for a child to have a dignified death if the child is suffering physically. Thus, the nurses offer physical comfort to a child by attempting to reduce the symptoms that may be causing physical suffering for the child. This category includes several subcategories, which are described below.

Alleviating pain

To provide physical comfort to a child, a nurse seeks pharmacological or non-pharmacological strategies to eliminate or at least relieve the child's physical pain such that their suffering is minimized. In this sense, the professional can reference the principles used in palliative care.

> ... for me, it's a death... that is not dignified... if you feel pain until the end of your life... I think that I have to provide ... palliative care so that a child does not feel pain... (N6).

Providing comfort

Providing comfort means adopting strategies that improve welfare, give strength and reinvigorate a child who suffers because of the treatment or the consequences of cancer.

> We do what is needed to provide comfort to a child in that moment. If a child retains fluid, we need to pass a tube... (N4).

Valuing humanized care

Humanized care is health care that addresses the whole being, including its various aspects and peculiarities. Furthermore, encouraging and supporting the relationship between the patient and the family is an important aspect. The nurses value what is important to the child in that moment. This category includes the subcategories described below.

Opening the communication channel

Open communication between the nurse and the patient places importance on the doubts and the questions of the children, allowing them to talk, ask questions and clarify things that are confusing to them. It is also important to clarify and explain professional conduct and the procedures that will be followed. For a dignified death to occur, the nurses believe it is their obligation to communicate with the child; therefore, they should know how to approach children and identify what they mean in their words.

> ... I give them space to talk sometimes ... there are children who deal with it like... they make you understand what they want to say, but they never... never said to me, 'Auntie, I know I'm going to die'... They say, 'Oh, I'm scared'... (N5).

Being present

The phrase *to be present* appears in the discourse regarding humane care; it includes the demonstration of affection, respect and readiness to be next to a child when a child is willing, offering words of comfort or a shoulder to cry on.

> ... that day I went and told him, 'Look, Leo, Aunt loves you, you are important to Aunt,' then he replied, 'Aunt, you too, I love you' ... then I left ... (N5).

Teamwork

Teamwork was identified as a common concern among nurses, indicating that they seek to provide integrated care for families and children with cancer. The nurses recognize that teamwork makes child care more comprehensive and effective and can thus provide a dignified death.

> ... professionals, everyone involved in a child's treatment knows that the child is dying, and we all strive to offer more comfort... and then we can provide this support for a family, we can give more to them ... tranquility... (N6).

Providing holistic care

The attention given to the child should occur holistically, addressing issues that go beyond merely physical needs. In other words, a professional recognizes the importance of and seeks to provide care for the psychosocial, spiritual and emotional needs of the child and his or her family. For nurses, a dignified death is not possible without also caring for a child's family.

> ... I think for a dignified death you are able to give protection to an entire family, and for the patient, this shelter is a psychological, emotional shelter, knowing how to live with that and explain everything... (N1).

Allowing contact with family members

Another important point is represented by the flexibility and valorization of the professional, that is, to allow contact between the child and the family in the process of dying. Providing a convivial atmosphere for a child within the hospital setting is considered an important aspect for nurses.

> ... his mother was talking with him, then came the father, then the little sister came to talk to him. It was about three o'clock in the afternoon... then the doctor performed the procedure... he prescribed sedation. We gave it, and the child was breathing so slowly, was resting... for me it was worthwhile... (N5).

Respecting the autonomy of the family

Respect for the autonomy of the family should be shown when performing procedures, and the family's desires and views about the life and death of the child should be considered. Thus, the behavior of professionals is not based solely on the opinions of the team or the team's desires.

> … the mother chose it... the child stopped, but before that we already knew that the child was likely to stop (...) and the mother turned to the doctor, turned to me and said, 'I do not want intubation if he stops' ... (N5).

Learning to cope with death and dying

The difficulty in recognizing the care needs and providing care during the dying process is an important issue for nurses, as the child's death generates personal conflict about the quality of the care that is offered. Therefore, these professionals must deal with feelings of sadness, guilt and insecurity. The experiences of nurses are related to their professional abilities to exert a degree of power, to make decisions and to participate in the process of the child's death. The nurse is conflicted about the meaning he or she gives to the child's death. This category includes the subcategories described below.

The need for education

The nurses feel unprepared to work with children and families during the dying process. The nurses' lack of theoretical knowledge on the subject and their lack of preparation to help children and families cope with death make the professionals insecure. The professionals feel responsible for promoting a dignified death, but they not always able to provide it to the child.

> ... (a dignified death) often does not happen due to the lack of preparation, because the professional is thrown into oncology and cannot deal with death. Also, the professional receives no preparation for it, so people flee. Each one has a way of defending oneself.... (N6).

Recognizing death

This concept represents the capacity of the nurse to recognize the child's death as a stage of life, even though it has happened earlier. In this sense, the nurses acknowledge the care given to a child and no longer feel responsible for a child's death. The nurses perceive it from a positive angle, as a moment of relief and rest and the end of suffering for the child and all who were around him. For the professional, it is only possible to offer a dignified death when someone is able to see the child's death calmly.

> … there is nothing that describes the satisfaction that I have done all that I could ... not to save, but to care, because he received good care until the end, you know ... I know he did not suffer before dying ... he died because he had to die ... it was ... was ... it had to happen ... (N4).

However, the nurses are not always able to accept the child's death. The nurses may feel insecure about interrupting treatment. Consequently, to deal with the feelings that arise in the process of death, such as pain, suffering and insecurity, the nurse denies the proximity of the event, prolonging the dying process. In these situations, the nurse does not perceive that he or she is able to offer a dignified death.

Being able to mature with experience

A dignified death for a child is not referred to as the moment at which life ends or the heart stops beating but as a transition process that occurs during hospitalization. Nurses build caregiving protocols and strategies based on an analysis of their actions and the consequences of living with a dying child and his or her family.

> ... it is life experience you will know how to deal with, because you do not become cold, you will know how to deal with each situation... I went home trying to think about everything ... if you cannot handle it, you... it will really mess up your work... (N1).

In this process, empathy appears prominently in the discourses. The nurses refer to elements of their personal lives and reflect on what was important to them, how they reacted and how they would like to be treated and cared for by a professional.

> ... we get stressed... 'Oh, that father does not stop calling... I do not know what... ', but if we were, if it was someone close to us, like, our father, our mother, our sister, our son, we'd be just like that... (N2).

Being recognized for their efforts during the final stage of a child's life

Professionals need gratification for their work to find meaning in their profession. Realizing that, despite the death, the nurse's efforts to provide proper care and a dignified death were not in vain, the nurse is better able to handle the loss. The nurses find that the results of the nurses' care renew their energy to overcome situations involving death. A dignified death is a challenge, but when it is achieved, it makes the nurses feel accomplished and satisfied with the care provided.

> ... the salary that I get does not pay enough... and all that... pain that it brings me, but each child who says, 'Aunt, thank you,' or a child saying, 'Oh, you're my number one.' It is also priceless ... (N5).

Based on the narratives of nurses, we built a matrix to illustrate the descriptions of dignified death for children in the context of oncology and the interventions performed by the nurses.

Chart 1 - Dignified death for children in pediatric oncology: description and interventions - São Paulo – 2009

Categories	Description for a dignified death	Interventions
Feeling no autonomy for decision making	Have greater involvement of nurses about the care and treatment decisions, without feeling threatened by legal issues.	Perform actions (visits, caregivers) that are outside the stipulated and can refuse to perform procedures that prolong the patient's life, without bringing improved to their health.
Caring for families	The family is aware of everything that happens to the child. Actions and decision-making are accomplished together with the team.	Provide private time between the child and the family. Build a bond and a trusting relationship with the family.
Offering physical comfort	Pain and any other physical discomfort experienced by a child are relieved. Having comfort.	Use pharmacological and non-pharmacological measures for pain relief. Offer comfort.
Valuing humanized care	A relationship of generosity, kindness and respect exists between the child, the family and the nurse. Teamwork is used.	Open communication channels. Support the relationship between the patient and the family. Be present. Give support, care and psychosocial, spiritual and emotional treatment.
Learning to cope with death and dying	Nurses have the knowledge and training to deal with situations of death and dying. Death is seen as part of life.	Do not insist on procedures that prolong the child's suffering.

DISCUSSION

The analysis of the narratives allowed us to identify the meaning of dignified death and the interventions performed by nurses to promote dignified death in the context of pediatric oncology.

Many issues were highlighted in the discourses of the nursing professionals. The nurses presented ways to intervene in these areas in order to promote a dignified death to the child: offering social, psychological and emotional care to the family; relieving pain and promoting patient comfort; considering the many facets of treatment and not only the biological and physical aspects of the child's disease; recognizing the importance of the family for the child in the process of a dignified death; and providing affection and being present for the child.

During the illness and treatment of children/adolescents with cancer, the family lives completely within the world of the child/adolescent, incorporating the suffering and the struggles and sometimes putting aside their own selves[10]. The emergence of a serious illness that has no cure demands that the subject use psycho-social-spiritual methods to face it. This process triggers the mobilization of the family and/or others with whom the patient has meaningful relationships[11]. Many nurses raised this idea concerning the family, explaining the importance of taking care of the family and showing that the care for the family will be reflected in their later abilities to cope with illness, mourning and death and to lead their lives after the death of the child.

The results align with the findings of another study on the concept of dignified death in pediatric intensive care units, which also showed that to provide a dignified death, exceptional medical treatment is required at the end of life, but the treatment should be appropriate for the natural evolution of the disease and respect socio-cultural aspects, physical comfort and well-being. It is noteworthy to say that dignified death occurs in an environment characterized by complicity and truth between families and the professionals involved in the care, where is possible to express hopes and fears. In this context, the result is relief from suffering, both for the child and for the family[12].

We observed that pain extremely important to nurses. Pain takes on a special meaning when it happens to children, who are seen as innocent and free from sin and therefore should not suffer. It is extremely important to recognize pain or physical discomfort and make appropriate use of medications for effective pain control[12-13], as well as to implement non-pharmacological measures for pain relief, such as massage, the use of compresses, music therapy and relaxation[12].

The following issues were also highlighted in the discourses of the nurses: patient and family autonomy; preserving the patient's quality of life, which is reflected in the number of machines connected to the patient and his or her level of consciousness; communication as a method for clarification and a needs assessment tool and the role of the nurse in the opening channels of communication; the need for continuing education for nursing professionals about death and its processes and the need for better preparation of the nurses in this situation. Finally, the nurses noted the importance of liking what you do, which is an essential aspect of providing quality care and showing empathy.

In the United Kingdom, a qualitative study found that continuing education relating to end of life care in pediatrics is inconsistent because graduation in nursing and skill development for the job should not be restricted to the classroom. During the learning process, teachers should seek to address the concerns of the students in dealing with an event as significant as death, giving them the opportunity to reflect on their own experiences[14] such that they can become better prepared professionals.

Another relevant theme in the data is the acceptance of the child's death and its influence on the care provided.

The child's death forces professionals to face mortality, creating an internal conflict about death, doubts regarding the effectiveness, relevance and goals of their care and self-reflection concerning their own autonomy.

Nurses often experience situations of domination and subordination in relationships with other professionals within the hierarchical structure of the institution and under technical assistance models of health[15]; therefore, nursing professionals often set aside their own beliefs to focus on what is designated to them.

Decision-making is a process that is part of everyday nursing, and it is influenced by a number of factors, such as institutional culture and behavior models[16].

When dealing with death, for the nurses in this study, there are several interventions that can promote a dignified death and several definitions of a good death. The narratives do not describe strategies that result directly in care; they mainly describe how nurses deal with death and dying and what they consider necessary for nurses to be able to offer a dignified death.

Although in certain situations, it is not possible to prevent the child's death from happening, the nurse's role does not end when death occurs because the family needs care and attention to be able experience this time less traumatically. Moreover, although death is an event that is highly present in their daily lives, nurses have difficulty not only accepting death but also handling the situation properly, especially when it involves a child and a family[4].

Health professionals must be prepared to receive and care for children, adolescents and their families in situations that involve a severe prognosis and advanced disease, in which death is a constant concern. The nurses need to understand the reactions and behaviors families exhibit before death to assist them in their needs during the end of life process[17].

CONCLUSION

Offering a dignified death is a challenge because it involves balancing multiple perspectives and the needs of the child, the family and health care professionals.

There is also the personal conflict within professionals about resisting or accepting the death of a child as something natural. This conflict demonstrates the need for education regarding the subject of death and dying. In this sense, to widen the discussion concerning dignified death, it is necessary to reformulate the curriculum of health professionals, which, even today, seems to focus more on cures than on caregiving during the dying process.

The lack of legal support and professional autonomy can impede the promotion of a dignified death for a child. Nurses find themselves in a dilemma between what they believe is the best course of action and the legal response to these actions.

The nurses who participated in the study identified the characteristics of dignified death for children and described the interventions they use to promote dignified death, particularly emphasizing pain relief and care for the family.

These results identify not only intrinsic aspects that promote dignified death, such as professional maturity that gives meaning to death but also extrinsic factors, such as autonomy and comfort.

The concept of dignified death is used by various cultures in different parts of the world. The results of this research will improve understanding of the concept of dignified death for children, which has not been documented to date.

This study contributes to a broader understanding of the care process, enabling us to postulate a theoretical framework that integrates the knowledge and actions that provide vital assistance and transcend the clinical and biological care needed when caring for a child during the end of life process.

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