2011

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NURSING ETHICS, v.18, n.5, p.694-709, 2011
http://producao.usp.br/handle/BDPI/17274

Nursing Ethics
http://nej.sagepub.com/

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Nurs Ethics 2011 18: 694
DOI: 10.1177/0969733011408043

Published by:
SAGE
http://www.sagepublications.com

Article

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18(5) 694–709

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nej.sagepub.com
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Dignified death: Concept development involving nurses and doctors in Pediatric Intensive Care Units

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Abstract

The aim of this study was to develop the concept of the dignified death of children in Brazilian pediatric intensive care units (PICUs). The Hybrid Model for Concept Development was used to develop a conceptual structure of dignified death in PICUs in an attempt to define the concept. The fieldwork study was carried out by means of in-depth interviews with nine nurses and seven physicians working in PICUs. Not unexpectedly, the concept of dignified death was found to be a complex phenomenon involving aspects related to decisions made by the multidisciplinary team as well as those related to care of the child and the family. Knowledge of the concept's dimensions can promote reflection on the part of healthcare professionals regarding the values and beliefs underlying their conduct in end-of-life situations. Our hope is that this study may contribute to theoretic and methodological development in the area of end-of-life care.

Keywords

concept development, dignified death, end-of-life decisions, hybrid model, nursing, pediatric intensive care, pediatrics

Introduction

Advances in medicine have increased the survival time for patients with illnesses previously considered to be irrecoverable. However, in many cases, such advances have led to prolonging dying at the price of additional suffering for patients and their families.[1]

Pediatric intensive care is a relatively new specialty, one that has gained significant technological advances in recent years. Such advances have created previously unimaginable situations and given rise to a painful juxtaposition of life prolongation and death prolongation.[2]

Studies have shown how, in the context of the pediatric intensive care unit (PICU), children can be violated because healthcare professionals lack knowledge of ethics and understanding about end-of-life decisions.[1] However, some studies show that changes in the conduct toward children in end of life can occur if healthcare professionals trained and acquired an increased understanding of dignified death.[3]

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Within the context of Brazilian pediatrics, the first intensive care units were inaugurated in the 1970s. In Brazil, at present, most children die in hospitals, above all in PICUs.[4] There are no palliative care units in Brazil. Therefore, children presenting illnesses with no possibility of a cure are admitted to the PICU when their clinical condition worsens even though they may be conscious and communicating. Thus, dignifying and humanizing the end-of-life stage and death constitutes a challenge for healthcare professionals working in PICUs.

Children with serious illnesses and poor prognoses engender extremely distressful ethical dilemmas in members of healthcare teams. It is very difficult to establish distinctions between what constitutes care-giving and relieving suffering – providing comfort and a dignified death – and using invasive and painful measures originating from technological advances that merely prolong suffering.

Several studies reveal that currently, most deaths in PICUs occur following a decision to limit or suspend vital life support measures, or from ‘do not resuscitate’ orders.[2,4–7] Such decisions are known to be justified in cases of opting for dignified death. Discussions originating in the 1990s regarding ethical dilemmas involving the end of life aroused awareness and critique of the ‘life at any cost’ paradigm. Death as a right and a dignity began to be located in ethical decision making in healthcare practices.[8]

Dignified death is a commonly used term both in health sciences literature[3,9] and colloquially by professionals active in end-of-life care. In addition, dignified death is a term recently used in theoretic models of care in end-of-life situations.[10–11]

The global relevance of this article lies in the fact that despite researchers’ devotion to attempts at understanding the workings of caring for children during the process of dying in a PICU,[12–13] literature on the subject, Brazilian and international, lacks references to development of the concept of dignified death in high-tech environments.

Emphasis on concept development in nursing has grown over the last decade since researchers have endeavored to elucidate problems previously relegated to common-sense decisions. This occurred because some concepts – concepts that may even seem obvious – feature vague terminology, ambiguous definitions, and a lack of coherence among theories.[14] According to Hopkinson and Hallet,[15] dignified death is a dynamic concept in that it changes according to the social context in which it appears. Clarifying concepts that to date had remained obscure makes it possible to strengthen theories about end-of-life care for children and their families, as well as allowing general practice healthcare professionals to reflect on the motivations that engender attitudes and decisions in regard to children for whom there is no hope of a cure.

To conceptualize the phenomenon of dignified death of children in Brazilian PICUs, we sought to answer the following questions: What is dignified death of children in Brazilian PICUs? Within this concept, what is necessary to make the death of a child in a PICU dignified? What actions or situations are needed to make it possible to provide dignified death for children in PICUs? What consequences can be expected when we provide for the dignified death of a child?

Our object in this article is to develop the concept of dignified death for children in the context of Brazilian PICUs. However, taking into consideration the cultural aspects of this research, it is our opinion that experiences involving death in PICUs transcend geographic or physical space. We thus deem the results to be applicable to other contexts and/or cultures.

Design and method

The method of concept development provides a vehicle to identify the meaning of the term in a logical dimension, cognitive and emotional. This implies that this case is not only useful in finding definitions and meanings, but also in the clarification of why such meanings are developed.[14]

The method used was the Hybrid Model for Concept Development proposed by Schwartz-Barcott and Kim.[16] This model calls for three phases in the development of a concept:

Theoretical Phase – samples for this analysis were obtained from literature on nursing and medicine published in English, Portuguese, or Spanish between 1990 and 2008. The articles were obtained using an electronic database search of abstracts available from CINAHL, PubMed, Medline and Lilacs. Thirty-one studies[5,12,17–45] were found and these constituted the study universe in the theoretical phase.

Field Phase

- Sample: Empirical data were obtained by means of interviews with nine nurses and seven physicians working in PICUs.
- Data collection: Over an 18-month period, June 2007 to December 2008, data were collected using research interviews. Participants were asked to respond to open-ended questions and to specify 'what they understood to be the meanings and characteristics of dignified death in PICUs'.
- Ethical considerations: Data collection was begun following project approval by the Research Ethics Committees of the institutions involved in the study. Oral and written descriptions of the study were given to participants before the interviews, and written consent was obtained. Participation was voluntary and confidentiality was assured.
- Data analysis: The analysis was developed using data from the Theoretical Phase as theoretical perspective, and thematic analysis as the methodological referential.

Final Analytical Phase – this phase is the interface between the Theoretical Phase, data collected during the Field Phase, and writing up of the findings. In this stage, all manifestations of the concept must be verified, making comparisons and seeking variations of data obtained from participants' experiences. The object is to synthesize the empiric and theoretical data with a view to finalizing the definition of the concept and its indicators.

As the actual investigation was conducted in three stages, data analysis was also carried out in three phases. Consistent with this approach, Rodgers[46] suggests that the literature review (theoretical phase) should result in identification of antecedents, attributes and consequences that contribute to clarification of the concept. The second phase analysis (Field Phase) was carried out in an inductive, thematic manner similar to thematic analysis. In other words, all date recorded were analyzed to identify the attributes of the concept of dignified death; this same procedure was followed for the antecedents and consequences. Data were organized and reorganized until a coherent system of categories emerged for each aspect of the concept. Finally, in the third phase (Final Analytical Phase) results of the analysis were combined to reveal a working definition of the concept.

The results of the analysis were then presented to a group of highly qualified and experienced physicians and nurses from the PICU of the institution where data was collected (not including persons who took part in the interviews) to validate the analysis. This group consisted of two physicians and two coordinating nurses of the PICU team. In this type of research, it is generally accepted that validation of analysis is located within a community of agreement among knowledgeable experts. When results are seen as credible, believable, trustworthy, and grounded in data, legitimacy of the findings is ensured.[47]

Findings

Definitions of the dignified death of children: Theoretical Phase

Definitions found for the concept of dignified death of children were: *preserving the child's autonomy*;[17] *absence of life-prolonging interventions*;[18] *absence of pain and physical discomfort*;[18] *absence of pain and symptoms of discomfort*;[12] *compliance with the basic principles of palliative care*.[19]

Antecedents

Concept antecedents are situations, events, or phenomena that precede the concept of interest.[46] The following guiding question was used to identify the antecedents: *What is needed to achieve dignified death?*

The antecedents found in the Theoretical Phase show standard situations or conduct when faced with the possibility of death of a child. For example, the first antecedent shown in the Theoretical Phase refers to establishment of an irreversible or incurable disease. However, the process used to define the condition of irreversibility of the clinical condition is not clear in the theoretic data. To this end, data of the Field Phase, presented below, show the experiential component of the decisions and conduct when faced with the possibility of death of a child.

In Brazil, doctors and nurses consider the following conditions essential if they are to provide dignified death for children in PICUs: *excellence in clinical practice*; *identification of children with no possibility of a cure*; *acceptance of irreversibility of the clinical condition*; *agreement on prudent practice*; *communication skills*; and *confidence to achieve inclusion of the family*.

Excellence in clinical practice represents a condition in which it is possible for healthcare professionals to use all available scientific evidence, technological and human resources to assess and cater to a child's current physical, emotional, social, and spiritual needs:

> although the child does die in the end, all available resources were tried and we can feel confident that this was a dignified death. (Nurse 6)

When healthcare professionals are able to provide excellent clinical practice and the treatment proves ineffective in providing a cure (i.e. the child shows no sign of any possible recovery), the attending physician initiates the *identification of children with no possibility of a cure*, a child that would die if not for life-sustaining measures. For this to take place, physicians must be confident that evolution of the disease will not undergo any alteration over time despite all available therapeutic resources employed to restore the child's health. They must also merge reason and emotion to assess the child's situation and admit that medicine has its limits:

> There comes a time when medicine has its limitations and we will be unable to save the child. (Physician 7)

Once the attending physician has identified the child as having no hope of a cure, he/she must accept the irreversibility of the child's disease, i.e. accept the fact that the child will die regardless of any efforts at recovery. *Acceptance of the irreversibility of the illness* only occurs when the attending physician has sufficient maturity to deal with death:

> For a doctor, it is difficult to accept death, and I think that the younger the doctor is, the harder it is to face death. But as you grow older you're able to see death as something more natural. (Physician 4)

Although this participant associated the ability to accept death with development that comes with age, maturity is a complex phenomenon that involves more than just age. There is professional maturity that comes with experience, where time, situations, and history breed discernment and judgment, but regardless of age, not all professionals are capable of dealing with death.

To make it possible to provide dignified death, physicians believe that a consensus must be reached among all the healthcare professionals involved in the child's care regarding the change from a curative focus, to one of relief from suffering. *Agreement on prudent practice* must be reached not only among the PICU staff, but among the specialty staff as well when such is the case:

Table 1. Antecedents of the Theoretical Phase

Antecedents	Authors
Establishment of an irreversible or incurable disease/irrecoverable situation/ irreversibility of the clinical condition.[5,12,18–38]	Kipper et al., 2005; Casanueva Mateos et al., 2005; Garros, 2003; Salas Arrambide et al., 2005; Vernon et al., 1993; Anderson et al., 1994; Levetown et al., 1994; Althabe, 1999; Carvalho et al., 2001; Meyer et al., 2002; Garros et al., 2003; Torreão et al., 2004; Zawistowski, DeVita, 2004; Lago et al., 2005; Rotta, 2005; Sharman et al., 2005; Tonelli et al., 2005; Robinson et al., 2006; Lago et al., 2007; Longden, Mayer, 2007; Martino Alba et al., 2007; Inwald, 2008; Tagarro García et al., 2008
Clear and effective communication between medical team, child, and family.[5,12,18,19,25,26,33–35,39–44]	Kipper et al., 2005; Casanueva Mateos et al., 2005; Garros, 2003; Salas Arrambide et al., 2005; Meyer et al., 2002; Garros et al., 2003; Robinson et al., 2006; Lago et al., 2007; Longden, Mayer, 2007; Burns et al., 2000; Meert et al., 2000; Meert et al., 2001; Meert et al., 2005; Matthews et al., 2006; Meert et al., 2007
Precise, honest, and consistent information to enable the family to make decisions.[18,21,25,29,35,38,40–42,44,45]	Garros, 2003; Anderson et al., 1994; Meyer et al., 2002; Zawistowski, DeVita, 2004; Longden, Mayer, 2007; Tagarro García et al., 2008; Meert et al., 2000; Meert et al., 2001; Meert et al., 2005; Meert et al., 2007; Althabe et al., 2003
Discuss and re-discuss end-of-life conduct with the family as often as necessary.[12,18,20,22,26,34,39]	Casanueva Mateos et al., 2005; Garros, 2003; Vernon et al., 1993; Levetown et al., 1994; Garros et al., 2003; Lago et al., 2007; Burns et al., 2000
Relationship of trust between the medical team, family, and child.[5,17–19,33,40–42]	Kipper et al., 2005; Bracegirdle, 1994; Garros, 2003; Salas Arrambide et al., 2005; Robinson et al., 2006; Meert et al., 2000; Meert et al., 2001; Meert et al., 2005
Decision-making guided by bioethical principles (beneficence, non-maleficence, autonomy, and justice).[5,17–19,23,24,26,27,30,31,40,45]	Kipper et al., 2005; Bracegirdle, 1994; Garros, 2003; Salas Arrambide et al., 2005; Althabe, 1999; Carvalho et al., 2001; Garros et al., 2003; Torreão et al., 2004; Rotta, 2005; Sharman et al., 2005; Meert et al., 2000; Althabe et al., 2003
Consultation with the hospital's Bioethics Commission in dilemmatic situations.[5,12,18,20,22,23,26,29,45]	Kipper et al., 2005; Casanueva Mateos et al., 2005; Garros, 2003; Vernon et al., 1993; Levetown et al., 1994; Althabe, 1999; Garros et al., 2003; Lago et al., 2005; Althabe et al., 2003
Consensus among the healthcare team regarding end-of-life conduct (specialty/ attending team with the PICU team).[12,21,23,25,32,34,42]	Casanueva Mateos et al., 2005; Anderson et al., 1994; Althabe, 1999; Meyer et al., 2002; Tonelli et al., 2005; Lago et al., 2007; Meert et al., 2005
Participation of the multidisciplinary team in decisions until consensus is reached among team members regarding the conduct of end-of-life care.[17–22,24,26,32,34]	Bracegirdle, 1994; Garros, 2003; Salas Arrambide et al., 2005; Vernon et al., 1993; Anderson et al., 1994; Levetown et al., 1994; Carvalho et al., 2001; Garros et al., 2003; Tonelli et al., 2005; Lago et al., 2007
Time for parents to accept the child's irreversible condition and make decisions.[18,21,26,31,40,42]	Garros, 2003; Anderson et al., 1994; Garros et al., 2003; Sharman et al., 2005; Meert et al., 2000; Meert et al., 2005
Preparation of the healthcare staff to work with child and family at the end of life.[12,18,19,26,29,36,38,43,45]	Casanueva Mateos et al., 2005; Garros, 2003; Salas Arrambide et al., 2005; Garros et al., 2003; Lago et al., 2005; Martino Alba et al., 2007; Tagarro García et al., 2008; Matthews et al., 2006; Althabe et al., 2003
Multidisciplinary team work – physicians, nurses, psychologists, social and spiritual assistants.[19,31,33,35,43,44]	Salas Arrambide et al., 2005; Sharman et al., 2005; Robinson et al., 2006; Longden, Mayer, 2007; Matthews et al., 2006; Meert et al., 2007

> Reaching a consensus is very good for everyone, especially for the child, because we often only prolong something that is not going to change. (Physician 3)

The idea of consensus is important and it differs from agreement. Agreement can imply consenting passively to team decisions, whereas consensus in this context implies that the entire team believed this to be the best decision, and thus it is a prudent decision.

Including the family in the decision-making process makes it essential for the healthcare staff to have *communication skills* that allow them to interact with the family in end-of-life situations. In the case of healthcare professionals, communication skills consist of an aptitude to speak openly with the family, voicing ideas in a sensitive, empathetic and honest manner to develop a feeling of fellowship with the family. In situations in which healthcare professionals have no time to establish a relationship with the family, they perceive that the possibility of effective communication is diminished because they realize that this competency is largely dependent on their history of interaction with and knowledge of the family. For healthcare professionals to establish an open dialogue with a patient's family, they need time to become acquainted with the family and for the family to become acquainted with them:

> Establishing a relationship is not something that you can achieve overnight. Only time that allows us to show our position, how we do things, how we solve problems, our concern regarding the situation, our involvement . . . (Nurse 9)

For dignified death to occur, healthcare professionals are always prepared to talk with the family, allowing family members to express their anxieties, ask questions, and voice doubts. This task is easier when healthcare professionals have developed a close relationship with the family that makes it possible for them to express their own perception regarding the child's condition and *feel confident about including the family*:

> It's very important to do this, to position oneself, to be honest, because I think that by doing so we manage to share the burden. (Physician 2)

Attributes

Attributes are words and/or expressions frequently used by authors to describe the characteristics of the concept.[46] The following guiding question was used to identify the attributes: *What are the expressions used to describe dignified death?*

The main attribute found in the Theoretical Phase refers to limitation of life support in situations of irreversible clinical condition, i.e. for the child to be able to die with dignity, curative treatment must be interrupted. In the Field Phase it was possible to discern the experiential component of healthcare professionals in actions that promote dignified death.

The following are attributes found in the Field Phase that make up dignified death in PICUs: *recognizing the benefits of the natural evolution of the illness*; *respecting social-cultural aspects*; *establishing a partnership between team and family*; *providing physical comfort*; and *promoting wellbeing*.

To recognize the benefits of the natural evolution of the illness refers to the healthcare professionals acknowledging the advantage or benefit of allowing the occurrence of natural evolution of the illness that will lead to death. Actions of the healthcare staff to this end consist of: not reviving a child whose situation is known to be irreversible; not introducing treatment that will not reverse the situation; and also, limiting the treatment the child is receiving – for example, diminishing infusion of vasoactive drugs or parameters of mechanical ventilation. In such situations, healthcare professionals find that the suffering of both child and family can be minimized by not prolonging a situation that is known to be irreversible and that, without life sustaining measures, will imminently result in death:

Table 2. Attributes of the Theoretical Phase

Attributes	Authors
Limitation of life support in situations of irreversible clinical condition.[5,12,17–23,25–32,34–38,45]	Kipper et al., 2005; Casanueva Mateos et al., 2005; Bracegirdle, 1994; Garros, 2003; Salas Arrambide et al., 2005; Vernon et al., 1993; Anderson et al., 1994; Levetown et al., 1994; Althabe, 1999; Meyer et al., 2002; Garros et al., 2003; Torreão et al., 2004; Zawistowski, DeVita, 2004; Lago et al., 2005; Rotta, 2005; Sharman et al., 2005; Tonelli et al., 2005; Lago et al., 2007; Longden, Mayer, 2007; Martino Alba et al., 2007; Inwald, 2008; Tagarro García et al., 2008; Althabe et al., 2003
Respect for the values and beliefs of the child and the family.[12,17–19,23–27,33,35,40,42]	Casanueva Mateos et al., 2005; Bracegirdle, 1994; Garros, 2003; Salas Arrambide et al., 2005; Althabe, 1999; Carvalho et al., 2001; Meyer et al., 2002; Garros et al., 2003; Torreão et al., 2004; Robinson et al., 2006; Longden, Mayer, 2007; Meert et al., 2000; Meert et al., 2005
Catering to the religious/spiritual needs of child and family.[12,18,21,25,33,35,38–43]	Casanueva Mateos et al., 2005; Garros, 2003; Anderson et al., 1994; Meyer et al., 2002; Robinson et al., 2006; Longden, Mayer, 2007; Tagarro García et al., 2008; Meert et al., 2000; Meert et al., 2001; Meert et al., 2005; Matthews et al., 2006
Parents' participation in the child's health care.[17,35,42,43]	Bracegirdle, 1994; Longden, Mayer, 2007; Meert et al., 2005; Matthews et al., 2006
Family's participation in decision-making.[5,12,17–32,34,35,37,38,40,45]	Kipper et al., 2005; Casanueva Mateos et al., 2005; Bracegirdle, 1994; Garros, 2003; Salas Arrambide et al., 2005; Vernon et al., 1993; Anderson et al., 1994; Levetown et al., 1994; Althabe, 1999; Carvalho et al., 2001; Meyer et al., 2002; Garros et al., 2003; Torreão et al., 2004; Zawistowski, DeVita, 2004; Lago et al., 2005; Rotta, 2005; Sharman et al., 2005; Tonelli et al., 2005; Lago et al., 2007; Longden, Mayer, 2007; Inwald, 2008; Tagarro García et al., 2008; Meert et al., 2000; Althabe et al., 2003
Child's participation in decision-making.[17–19,31,36,37]	Bracegirdle, 1994; Garros, 2003; Sharman et al., 2005;Martino Alba et al., 2007; Inwald, 2008
Transition of focus from curative to palliative care.[12,18,19,21,23,25,33,35,43,45]	Casanueva Mateos et al., 2005; Garros, 2003; Salas Arrambide et al., 2005; Anderson et al., 1994; Althabe, 1999; Meyer et al., 2002; Robinson et al., 2006; Longden, Mayer, 2007; Matthews et al., 2006; Althabe et al., 2003

(continued)

Table 2 (continued)

Attributes	Authors
Pain assessment and treatment.[12,18,19,21,25,26,28,33,34,39,40,42,43]	Casanueva Mateos et al., 2005; Garros, 2003; Salas Arrambide et al., 2005; Anderson et al., 1994; Meyer et al., 2002; Garros et al., 2003; Zawistowski, DeVita, 2004; Robinson et al., 2006; Lago et al., 2007; Longden, Mayer, 2007; Burns et al., 2000; Meert et al., 2000; Meert et al., 2005; Matthews et al., 2006
Assessment and treatment of the symptoms of discomfort.[12,18,19,21,26,28,34,35,39,40,42,43]	Casanueva Mateos et al., 2005; Garros, 2003; Salas Arrambide et al., 2005; Anderson et al., 1994; Garros et al., 2003; Zawistowski, DeVita, 2004; Lago et al., 2007; Longden, Mayer, 2007; Burns et al., 2000; Meert et al., 2000; Meert et al., 2005; Matthews et al., 2006
Catering to the child's emotional and social needs.[12,18,35,36,40,43,44]	Casanueva Mateos et al., 2005; Garros, 2003; Longden, Mayer, 2007; Martino Alba et al., 2007; Meert et al., 2000; Matthews et al., 2006; Meert et al., 2007
Catering to the family's needs.[12,19–21,23,27,37,40,42–46]	Casanueva Mateos et al., 2005; Bracegirdle, 1994; Garros, 2003; Salas Arrambide et al., 2005; Anderson et al., 1994; Meyer et al., 2002; Longden, Mayer, 2007; Tagarro García et al., 2008; Meert et al., 2000; Meert et al., 2001; Meert et al., 2005; Matthews et al., 2006; Meert et al., 2007
Constant presence of the family.[12,17,18,21,26,28–30,33–36,40–42]	Casanueva Mateos et al., 2005; Salas Arrambide et al., 2005; Garros, 2003; Anderson et al., 1994; Garros et al., 2003; Zawistowski, DeVita, 2004; Lago et al., 2005; Rotta, 2005; Robinson et al., 2006; Lago et al., 2007; Longden, Mayer, 2007; Martino Alba et al., 2007; Meert et al., 2000; Meert et al., 2001; Meert et al., 2005
Preparing the family for the child's death.[28,33,36,42–44]	Zawistowski, DeVita, 2004; Robinson et al., 2006; Martino Alba et al., 2007; Meert et al., 2005; Matthews et al., 2006; Meert et al., 2007
Opportunity for saying goodbye.[12,18,19,21,26,28,30,31,35,36,39,40,42]	Casanueva Mateos et al., 2005; Garros, 2003; Salas Arrambide et al., 2005; Anderson et al., 1994; Garros et al., 2003; Zawistowski, DeVita, 2004; Rotta, 2005; Sharman et al., 2005; Longden, Mayer, 2007; Martino Alba et al., 2007; Tagarro García et al., 2008; Burns et al., 2000; Meert et al., 2000; Meert et al., 2005
Appropriate environment and featuring privacy.[18,21,23,28,35,36,38,42]	Garros, 2003; Anderson et al., 1994; Althabe, 1999; Zawistowski, DeVita, 2004; Longden, Mayer, 2007; Martino Alba et al., 2007; Tagarro García et al., 2008; Meert et al., 2005
Flexible visiting policy.[18,21,30,35,36,38,40,42]	Garros, 2003; Anderson et al., 1994; Rotta, 2005; Longden, Mayer, 2007; Martino Alba et al., 2007; Tagarro García et al., 2008; Meert et al., 2000; Meert et al., 2005
Opportunity for the child to die somewhere other than in the PICU.[18,23,25,31,35,36]	Garros, 2003; Althabe, 1999; Meyer et al., 2002; Sharman et al., 2005; Longden, Mayer, 2007; Martino Alba et al., 2007

> This child ended up having a quite dignified death because when the time came, when the end was in view and we saw that there was no longer any hope, no one attempted to try any heroic measures. (Physician 1)

Healthcare professionals recognize that *respect for social-cultural aspects* – spiritual values, relationships, interests, behaviors – is essential in establishing a partnership with the family. They thus seek to become acquainted with, and respect, the family's perception in relation to hope of a cure for the child. These professionals consider that their role is to inform and orient the family regarding the child's condition to facilitate their participation in decision making. Another aspect pointed out by healthcare professionals has to do with the family's religious and spiritual practice. To these professionals, the family's religious and spiritual practice must be respected and receive all support necessary to face the child's death:

> We have to respect what the family says is significant and important to them. That is where dignity comes in – respect for what the family considers important. (Nurse 1)

Establishing a partnership between team and family relates to the healthcare team and the family reaching a consensus in regard to interruption of curative treatment, changing the focus of care from a curative approach to an approach that aims at physical comfort and promotes the child's wellbeing. As far as healthcare professionals are concerned, children may lack autonomy to make decisions regarding interruption of curative treatment due to the emotional and cognitive limitations inherent to their stage of development as well as their probable physical condition and cognitive awareness in this situation. Parents thus assume responsibility for end-of-life decisions, representing the child's best interests:

> When the patient is in a non-responsive condition, I call the family and come to an agreement. (Physician 2)

Providing physical comfort relates to the healthcare staff's actions aimed at relieving pain and symptoms of discomfort, especially respiratory discomfort, during the final phase of the illness. Healthcare professionals use pain killers and sedation because they feel that such medication can relieve or minimize symptoms of pain and discomfort:

> We initiate measures that make those final moments less painful for the child – pain killers, sedatives. (Nurse 2)

Allowing a child to die with dignity also implies *promoting the child's wellbeing*. Admission criteria for PICUs in Brazil is less rigorous than in other countries due to Brazil's lack of palliative care units, a lack that makes it necessary to admit terminal cases to PICUs, including patients who may still be conscious and coherent. In such cases, healthcare professionals seek to implement actions that provide wellbeing for the child at the end of life, such as having the family present, being able to do what they like, eat what they like, receive visits, or even be discharged from the hospital:

> Giving children comfort is allowing them to do all the things they really want to do and that won't cause them any harm. I think that we have to individualize care as far as possible. (Physician 5)

Healthcare professionals find that if they are to *provide comfort* and *promote wellbeing*, a favorable environment is necessary – an environment that makes it possible to cater to the needs of both child and family at the end of life, ensuring their privacy and comfort. Keeping a child in the ICU, a child for whom there is no hope of a cure, and whose death is imminent, is perceived as troublesome because it forces a change in customary ICU procedures aimed at recovery, such as constant monitoring, catheterization, dialysis, management of cardiorespiratory arrest, etc. The ICU is seen by professionals as an inappropriate place to keep a child and family at the end of life because they require a type of care unlike that which the ICU staff is trained to offer. These professionals point out the need for palliative care units, that is, units set up specifically to meet the needs of child and family at the end of life, needs such as comfort, wellbeing, and privacy. They hold that neither the ICU nor the infirmary are appropriate places for a child during the end-of-life phase because these units are planned for intensive treatment and cure of illnesses rather than for care aimed to provide comfort and wellbeing. In the opinion of these professionals, the ideal would be to have a specific palliative care unit where child and family could stay when there is no hope for a cure, because they believe that both the child and the family need care that differs from the care offered in an ICU or infirmary:

> If the child is terminal and it has been decided that nothing more is to be done, I think it's important to leave the child in a peaceful environment, not here in the middle of the ICU. (Physician 7)

Consequences

The consequences of the concept refer to events or situations resulting from its use.[46] The following guiding question was used to identify the consequences: *What do you intend to achieve by dignified death?*

Table 3. Consequences of the Theoretical Phase

Consequences	Authors
Minimize/relieve the child's pain and suffering.[12,18,19,21,23–26,28,29,31,32,34,35,37–39,42,43]	Casanueva Mateos et al., 2005; Garros, 2003; Salas Arrambide et al., 2005; Anderson et al., 1994; Althabe, 1999; Carvalho et al., 2001; Meyer et al., 2002; Garros et al., 2003; Zawistowski, DeVita, 2004; Lago et al., 2005; Sharman et al., 2005; Tonelli et al., 2005; Lago et al., 2007; Longden, Mayer, 2007; Inwald, 2008; Tagarro García et al., 2008; Burns et al., 2000; Meert et al., 2005; Matthews et al., 2006
Minimize/relieve the family's suffering.[17,19,21,23,31,35,36,38,39,41,42]	Bracegirdle, 1994; Salas Arrambide et al., 2005; Anderson et al., 1994; Althabe, 1999; Sharman et al., 2005; Longden, Mayer, 2007; Martino Alba et al., 2007; Tagarro García et al., 2008; Burns et al., 2000; Meert et al., 2001; Meert et al., 2005
Preserve the autonomy of child and family (consensual decisions).[5,12,17–32,34,35,37,40,45]	Kipper et al., 2005; Casanueva Mateos et al., 2005; Bracegirdle, 1994; Garros, 2003; Salas Arrambide et al., 2005; Vernon et al., 1993; Anderson et al., 1994; Levetown et al., 1994; Althabe, 1999; Carvalho et al., 2001; Meyer et al., 2002; Garros et al., 2003; Torreão et al., 2004; Zawistowski, DeVita, 2004; Lago et al., 2005; Rotta, 2005; Sharman et al., 2005; Tonelli et al., 2005; Lago et al., 2007; Longden, Mayer, 2007; Inwald, 2008; Meert et al., 2000; Althabe et al., 2003
Avoid disthanasia / futile treatment.[5,12,17,19,27,29,30,32,34,38]	Kipper et al., 2005; Casanueva Mateos et al., 2005; Bracegirdle, 1994; Salas Arrambide et al., 2005; Torreão et al., 2004; Lago et al., 2005; Rotta, 2005; Tonelli et al., 2005; Lago et al., 2007; Tagarro García et al., 2008
Family's satisfaction with end-of-life care (sure and confident family).[12,21,25,28,31,34,35,38,40,42,44]	Casanueva Mateos et al., 2005; Anderson et al., 1994; Meyer et al., 2002; Zawistowski, DeVita, 2004; Sharman et al., 2005; Lago et al., 2007; Longden, Mayer, 2007; Tagarro García et al., 2008; Meert et al., 2000; Meert et al., 2005; Meert et al., 2007

(continued)

Table 3 (continued)

Consequences	Authors
Ease family's grieving process/improve family's adjustment to the loss.[12,18,19,21,25,28,35,36,40–42,44]	Casanueva Mateos et al., 2005; Garros, 2003; Salas Arrambide et al., 2005; Anderson et al., 1994; Meyer et al., 2002; Zawistowski, DeVita, 2004; Longden, Mayer, 2007; Martino Alba et al., 2007; Meert et al., 2000; Meert et al., 2001; Meert et al., 2005; Meert et al., 2007
Broaden discussions regarding end-of-life care in pediatrics (in the course of professional training and at workplaces).[19,23,29,32,36,43]	Salas Arrambide et al., 2005; Althabe, 1999; Lago et al., 2005; Tonelli et al., 2005; Martino Alba et al., 2007; Matthews et al., 2006
Improve the quality of end-of-life care in pediatrics.[12,25,29,34,35,38,39,43–45]	Casanueva Mateos et al., 2005; Meyer et al., 2002; Lago et al., 2005; Lago et al., 2007; Longden, Mayer, 2007; Tagarro García et al., 2008; Burns et al., 2000; Matthews et al., 2006; Meert et al., 2007; Althabe et al., 2003

The main consequence of the concept of dignified death found in the Theoretical Phase was to minimize/relieve the child's pain and suffering. This shows that when healthcare professionals provide dignified death for a child, their main objective is to make the suffering experienced by the child and family less intense.

Consequences found in the Field Phase that make up the concept of dignified death in PICUs are: *minimized suffering*; *reciprocity in relationships*; *confidence of both professionals and family*; and *valorization of esthetic care*.

When healthcare professionals perceive *minimized suffering*, they feel that they have performed their role of caring for the child and family at the end of life and there is a sense of achievement from care well rendered:

> Although this moment is very painful and traumatic, it was a situation in which suffering was minimized. (Nurse 3)

Reciprocity in relationships reflects the ongoing exchange that occurs between the staff and the family due to having shared the experience of the child's end of life. This situation features the respect and trust that the family feels for the healthcare professionals, and vice versa. The family's trust in the healthcare team, developed and nurtured through interactions in which the professionals demonstrated reliability, integrity, and genuine concern regarding the child's wellbeing, leads the family to perceive that they and their child have been offered the best care possible. When the professionals are thus acknowledged by the family, they perceive that they have played their role of catering competently to the child's end-of-life needs:

> To my way of thinking, if we manage to give that child a dignified death with the family nearby, although it still involves suffering, I feel that I've done my job. When that happens, the family often comes and thanks us – they recognize all our efforts. (Physician 6)

Both healthcare team and family feel confident means that both healthcare professionals and the family feel that the child's best interests were preserved; although the child died, all necessary care was offered and received throughout the course of the illness. When both professionals and family are convinced that, given the situation, interrupting curative or life-sustaining treatment is the best decision, they feel calmer and devoid of any sense that they may have failed to do anything that might have changed the illness's natural course:

> The main thing is for everyone to feel sure that I'm not doing it just because it's not supposed to be done . . . (Physician 3)

Valorization of esthetic care is proof that healthcare professionals have relinquished the idea that sophisticated technology should be employed in all cases, valuing the art of care. Esthetic care occurs when healthcare professionals change focus from the surface of the experience, to understanding the meaning of that moment, which is unique for both patient and family.[48] Esthetic care is what makes it possible to know what to do and how to act in end-of-life situations without conscious deliberation. It arises from a direct perception of what is significant and meaningful in the care. By providing a dignified death for the child, healthcare professionals perceive that the priority in end-of-life situations is not to promote a cure, but to offer relief from suffering – inherent to extension of life when death is imminent – for both patient and family, while supporting them in this difficult process:

> I think it was dignified because the child spent the last few days in good condition, he/she did not die suffering, and not only the child, but the parents as well. Although they did suffer, it was not a case of nothing but suffering. (Physician 4)

Final Analytical Phase

The interface between the antecedents, attributes and consequences of both Phases is presented in the Final Analytical Phase diagram, which highlights the similarities found in both phases.

After integrating data from the Theoretical and Field Phases, we were able to produce a definition of dignified death of children in PICUs: *Dignified death in a PICU means providing excellent clinical treatment at the end of life, honoring the benefits of natural evolution of an illness, and respecting social-cultural aspects, physical comfort, and wellbeing. Dignified death occurs within a context of truthfulness and partnership between healthcare professionals and the patient's family, a context in which it is possible to express hopes and fears. The result of dignified death is relief, for both child and family, from the suffering associated with suspending death when life is no longer possible without life-sustaining measures.*

Diagram 1. Final Analytical Phase

Theoretical Phase	Field Phase
Antecedents	**Antecedents**
Establishment of an irreversible or incurable disease	Identification of children with no possibility of a cure
Consensus among the healthcare team regarding end-of-life conduct	Agreement on prudent practice
Clear and effective communication between medical team, child, and family	Communication skills
Relationship of trust between the medical team, family, and child	Confidence to achieve inclusion of the family
Attributes	**Attributes**
Limitation of life support in situations of irreversible clinical condition	Recognizing the benefits of natural evolution of the illness
Respect for the values and beliefs of the child and the family	Respecting social-cultural aspects
Family's participation in decision-making	Establishing a partnership between team and family
Transition of focus from curative to palliative care	Providing physical comfort and promoting wellbeing
Consequences	**Consequences**
Minimize/relieve the child's pain and suffering/Minimize/relieve the family's suffering	Minimized suffering
Family's satisfaction with end-of-life care	Of both professionals and family

Discussion

In the Theoretical Phase it was possible to identify the existing gaps in literature regarding the definition of the concept of dignified death in PICUs – gaps that lead to inconsistencies in proposals of end-of-life care for child and family due to lack of a common language among researchers and healthcare professionals active in clinical practice. None of the definitions we encountered include antecedents, attributes, and consequences of the concept. Lack of a common language leads to difficulty in the understanding and evolution of this important concept.

Clarifying the antecedents, attributes and consequences of the concept of dignified death in PICUs in the Field Phase made it possible to shift the concept from a vague theoretical domain to a domain of more concrete clinical phenomena. Such clarification provides subsidies for care of child and family, as well as for advances in teaching and research on end-of-life care in pediatrics.

For the concept of dignified death in PICUs to be applied in clinical practice, healthcare professionals must have a clear understanding of the antecedents, attributes, and consequences of the concept since, ideally, in this context such aspects should serve as a guide for child and family end-of-life care. We would point out that this study constitutes the first step toward exploring the concept of dignified death of children in PICUs in Brazil. Further research should be undertaken to apply, refine, and further broaden the concept investigated herein as well as to look at transferability to other cultures.

Methodological considerations

When considering the implications of the findings, it should be noted that only a small number of nurses and doctors in a limited geographic region in Brazil took part in this study. These findings cannot therefore be generalized, but it is important to the state of knowledge about care and decisions in end-of-life situations. The following remarks should be taken into consideration when conducting further research on the relationship between religion or world view and attitudes towards dysthanasia and palliative care.

Conclusion

A child is never expected to die, but children do die, and often under tragic circumstances where all attempts to rescue, cure, or sustain life have failed. Discernment and timing, knowing when to transition to death after fighting for life is not easy for families or healthcare professionals, but when it is acknowledged that death can arrive with dignity and exquisite care, healthcare professionals are obliged to work with families in allowing such a respectful privilege for both the child and themselves.

The Hybrid Model of Concept Development offers an advance in exploration of concepts by investigating their manifestation in clinical practice, making it possible to broaden the scope of antecedents, attributes, and consequences evidenced in literature, considering the dynamism and variations of concepts in accordance with the context in which they are manifested.

Identifying empirical aspects of abstract concepts is a complex process. However, empiric aspects based on observable phenomena provide the greatest clarity to health professionals. They allow for 'diagnosis' of the concept as it is and the application of which is convincing.

In the Field Phase it was possible to identify the experiential component underlying the conduct of health professionals faced with a child at the end of life. It is thus that we can comprehend how manifestation of the concept comes about in clinical practice and makes it possible to expand the data identified in the Theoretical Phase. Elucidating antecedents attributes, and consequences of the concept of dignified death in PICUs in the Field Phase allowed us to shift the concept from a vague theoretic realm to a more concrete clinical phenomenon. This provides subsidies for caring for the child and family, as well as for advances in teaching and research on end-of-life care in pediatrics.

Field research adds comprehension of values and beliefs that inform protocol situations or conducts identified in the Theoretical Phase. It allows reflection on attitudes of healthcare professionals not motivated exclusively by conduct protocols, but also by the meaning they attribute to the situation experienced by child and family. These meanings are constructed in the course of their life and professional practice insofar as healthcare professionals come into contact with various situations and proceed to define and redefine their conduct in the face of children at the end of life and their families.

Acknowledgement

The authors thank Nancy J Moules RN PhD, Associate Professor of University of Calgary, for her review and suggestions for improving the manuscript.

Funding

This study was supported by the National Council of Technological and Scientific Development (CNPq), Brazil.

Conflict of interest statement

The authors declare that there is no conflict of interest.

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