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# Dignified death for children: concept analysis

MORTE DIGNA DA CRIANÇA: ANÁLISE DE CONCEITO

LA MUERTE DIGNA DEL NIÑO: ANÁLISIS DE CONCEPTO

Kátia Poles<sup>1</sup>, Regina Szyllit Bousso<sup>2</sup>

## ABSTRACT

The purpose of this study was to describe the background, attributes and consequences of the concept of dignified death for children. The concept analysis strategy was used to evaluate the 40 articles found in journals in the medical and nursing areas, which studied or focused on the dignified death of children. The attributes of the dignified death concept include: quality of life, child- and family-centered care, specific knowledge about palliative care, shared decisions, relieving the child's suffering, clear communication, helpful relations and a welcoming environment. Few articles bring the definition of a dignified death for children, and, when they do, such definition is vague and often ambiguous among the many authors. This aspect indicates that the concept is not defined consistently, demanding studies about its manifestation in the clinical practice, contributing with the care at the end of life in Pediatrics.

## KEY WORDS

Thanatology.  
Concept formation.  
Pediatrics.

## RESUMO

O estudo teve por objetivo descrever os antecedentes, atributos e consequências do conceito de morte digna da criança. Utilizou-se a estratégia de análise de conceito para avaliar os 40 artigos, tendo como foco publicações nas áreas médica e de enfermagem, que estudaram ou focalizaram a morte digna da criança. Os atributos do conceito de morte digna da criança incluem: qualidade de vida, cuidado centrado na criança e na família, conhecimento específico sobre cuidados paliativos, decisão compartilhada, alívio do sofrimento da criança, comunicação clara, relacionamento de ajuda e ambiente acolhedor. Poucos artigos trazem a definição de morte digna da criança e, quando isso ocorre, essa definição é vaga e, muitas vezes, ambígua entre os vários autores. Esse aspecto indica que o conceito ainda não é consistentemente definido, demandando estudos de sua manifestação na prática clínica, contribuindo com os cuidados no final da vida em pediatria.

## DESCRIPTORES

Tanatologia.  
Formação de conceito.  
Pediatria.

## RESUMEN

El estudio tuvo por objetivo describir los antecedentes, atributos y consecuencias del concepto de muerte digna del niño. Se utilizó la estrategia de análisis de concepto para evaluar los 40 artículos, teniendo como foco las publicaciones en el área médica y de enfermería, que estudiaron o focalizaron la muerte digna del niño. Los atributos del concepto de muerte digna del niño incluyen: calidad de vida, cuidado centrado en el niño y en la familia, conocimiento específico sobre cuidados paliativos, decisión compartida, alivio del sufrimiento del niño, comunicación clara, relación de ayuda y ambiente acogedor. Pocos artículos contienen la definición de muerte digna del niño y, cuando eso ocurre, entre los varios autores, esa definición es vaga y, muchas veces, ambigua. Ese aspecto indica que el concepto todavía no está definido consistentemente, demandando estudios de su manifestación en la práctica clínica, contribuyendo con los cuidados en el final de la vida en pediatría.

## DESCRIPTORES

Tanatología.  
Formación de concepto.  
Pediatria.

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## INTRODUCTION

Advances in medicine have lengthened the survival of patients with terminal illnesses previously considered incurable. However, these advances have often led to a prolongation of the process of dying, resulting in additional suffering for the patients and their relatives<sup>(1,2)</sup>.

Nowadays, disease and death reside at the hospital, away from the comfort of home, as used to be the case. There is a characteristic to be noted in this point: In the middle of the last century, the modern intensive care units came into being, with the primary purposes of treatment aimed towards being able to qualify, quantify and control a wide range of biological phenomena. Such concerns lead one to forget that there is a human being at the receiving end of the tubes, cables and drains, behind alarms and restrained to the bed<sup>(2)</sup>.

In the world of Brazilian pediatrics, the first intensive care units were implanted in the 1970s<sup>(3)</sup>. Nowadays, several deaths of children occur in the hospital, especially in the Pediatric Intensive Care Unit (PICU). Therefore, in order to dignify and humanize the last stage of life and death, it becomes a challenge for the healthcare professionals who work there. The field of pediatric intensivism is a recent specialty, which has greatly benefited from technological advances in the past years. Such advances have created unimaginable situations, where prolonging life is balanced by prolonging death<sup>(4)</sup>.

Advances in supportive therapies have allowed for the ability to manage several organic failures, using advanced technology and knowledge in the form of mechanical ventilation, renal filtration, vasoactive drugs, and parenteral nutrition, among others. In addition, other modalities of treatment have expanded, such as heart surgery, neurosurgery and organ transplantation. As such, life expectancy is increased, with a consequent reduction in the mortality of children that were once considered irrecoverable. However, using these resources may lead to maintaining artificial life conditions<sup>(5)</sup>.

Nowadays, an increasing number of deaths in the ICUs are the result of the suspension or limitation of treatments considered futile or useless<sup>(6)</sup>, which shows the importance of effective communication between the patient, the family members and the healthcare team so that it is possible to reach a consensual, shared decision. Futile or useless treatment refers to medical treatments whose potential benefits for the patient are null or unlikely, not surpassing the potential setbacks<sup>(7)</sup>.

Several children die in pediatric ICUs as the result of a decision to limit or suspend life support measures, or even as a result of non-resuscitation<sup>(5,8)</sup>. We know that such a

decision is justified by the choice of a dignified or *good* death. These aspects reflect the broad discussion about the ethical dilemmas involving the end of life, which began in the 1990s. The discussions addressed the paradigm of *life at any cost*. Respect for the patient became valued, with increasing concerns towards the maintenance of dignity near the end of life<sup>(9)</sup>.

The determination of terminal status in an ICU is an extremely difficult situation, since it implies establishing, to a degree of certainty, that a patient is irrecoverable. In the case of children in PICUs, this issue is much more difficult, considering that children are highly capable of recovering, and the evolution of diseases in childhood is often surprising, regarding both prognosis and potential sequelae<sup>(10)</sup>.

Children with grave diseases and with bad prognostics trigger intense ethical dilemmas in the teams caring for these children. It is extremely difficult to establish boundaries between caring and relieving suffering, providing comfort and a dignified death, and using painful, invasive measures, resulting from technological advances, which only prolong suffering for some time.

Until the 1960s, healthcare professionals exerted paternalistic actions in end-of-life situations. The physicians made decisions about treatment and then informed their patients or, in some situations, the closest family members<sup>(11)</sup>.

The development of studies regarding this theme started with a belief of the necessity of clinical practice to offer more autonomy and guarantee that the care received by the patients was in accordance with their desires. Therefore, perhaps maybe due to this bioethical influence, the current studies focus on aspects of personal determination and the preservation of the individual's autonomy. These studies are related mainly to decision-making regarding life support, especially those referring to cardiopulmonary resuscitation and mechanical ventilation. The adult and elderly age ranges were studied more often<sup>(12)</sup>.

## OBJECTIVES

The purpose of the present study was to describe the background, the attributes and consequences of the concept of dignified death for children.

## METHOD

A concept is an idea or mental construct created about a given phenomenon, being essential in the development of research and the construction of theories. Concepts comprise abstract attributes of reality, and consequently represent more than words or mental images, since these are not sufficient to capture the complex nature of the concepts<sup>(13)</sup>.

The evolutionary method of concept analysis was used to guide the study<sup>(13)</sup>. This is an inductive technique, based on the idea that concepts are dynamic and dependent on context, instead of static or immutable, and aimed at clarifying concepts and reducing existing conceptual problems. We believe that the method was appropriate for the analysis of the concept of dignified death of children because the concept is not fixed – it is a dynamic concept through time, situation and perspective.

The steps of the methodology include: identifying the relevant sources for the study; identifying the related or substitutive concept and terms; verifying their use within different courses, identifying attributes, background, and consequences, and indicating future implications for the practice<sup>(13)</sup>.

This research covered journals in the areas of medicine and nursing, which studied or focused on dignified death. The search was also delineated by language, including studies in Portuguese, English and Spanish. The exclusion criteria were: studies whose abstracts were not available in the databases; studies outside the area of Pediatrics, since the focus of the study is the dignified death of the child; and studies that are difficult to access, such as theses and dissertations.

The selection of articles spanned journals published between 1996 and 2006. This period was selected because the term *dignified death* was introduced in literature in the 1990s, and there is no mention of it in Pediatrics journals before 1996.

The following databases were queried for articles: *Medline* (Literatur Internacional em Ciências da Saúde), *Lilacs* (Literatura Latino-Americana e do Caribe em Ciências de Saúde), *Cinahl* (Cumulative Index to Nursing and Allied Health Literature) and *Pubmed* (National Library of Medicine and National Institutes of Health). The keyword choices to access the journals were used in the following combinations: death, dignified, child; death, dignity, child; death, good, child; dying, dignity, child; death, child, intensive care unit. The search with the latter combination of words (death, child, intensive care unit) was performed with the purpose of accessing studies focusing the concept in this specific setting, because a large number of children's deaths occur in the PICU, as presented before.

These combinations of keywords were applied to all four databases, by selecting the possible languages available in each of them. For example, in *Lilacs* (Literatura Latino-Americana e do Caribe em Ciências de Saúde), the selected languages were Portuguese and Spanish, since this database is specific for countries of the southern hemisphere. The other databases were queried in English, Portuguese and Spanish, since they store journals from all over the world.

Each query yielded a number of articles and, from there, we began to select articles that were pertinent to the goals

of the study. In doing so, we initially excluded the articles that had no relation with the theme of this study by reading their titles – for example, articles dealing with physiological, biological or cellular issues were initially excluded. Next, the abstracts of the remaining articles were critically analyzed, which also eliminated articles that were not related to the theme we were focusing on. Abstracts raising questions about their relevance for this study were read wholly, so as to decide whether they would be included in the list of articles chosen for in-depth study.

Fifty-four articles were selected to be wholly read, but we only had access to 40 of those (74%). Of the 14 other articles, 6 of them (43%) had been published eight or more years before and the others were not available in either the electronic or the printed databases in our midst.

When the texts to be used were defined, we read them analytically, reading and re-reading the articles several times, so that it would be possible to select the parts that would be of real relevance to the research, and seeking to identify the constituent elements of the concept (attributes, background and consequences)<sup>(13)</sup>.

## RESULTS AND DISCUSSION

Initially, the 40 articles composing the body of this study were characterized, regarding the period and language of publishing. A significant increase of articles was observed for the period of 2001 to 2007 (75.0%), which shows an increasing interest in issues related to care for children at the end of life in the past six years. Regarding the type of article, 26 (65.0%) were research articles, four (10.0%) were literature reviews, three (7.5%) were expert's opinions, four (10.0%) were clinical guidelines and three (7.5%) were case reports.

Regarding the language of the articles, we noticed the concentration of articles in English (82.5%), followed by articles in Portuguese (12.5%) and Spanish (5.0%). Such data shows that a large share of research in the area has been developed or published in countries of the northern hemisphere.

### Definitions of a dignified death

The definitions found for the concept of dignified death of children were: *absence of interventions to prolong life*<sup>(9)</sup>; *absence of pain and physical discomfort*<sup>(9)</sup>; *absence of pain and symptoms of discomfort*<sup>(10)</sup>; *support for the child and the family*<sup>(14)</sup>; and *maximum comfort*<sup>(15)</sup>.

### Attributes of the concept of dignified death for children

The following questions were used to identify the essential attributes of the concept of dignified death for children in pediatric ICUs: *How did the authors define the concept? What are the characteristics/attributes that they note? Which ideas do the authors discuss regarding dignified death for children?*

Attributes are words and/or expressions used frequently by the authors to describe the characteristics of the concept<sup>(13)</sup>.

The following attributes of the concept of dignified death for children were found: *Quality of life*<sup>(5,10,14,16-28)</sup>; *Child and family centered care*<sup>(1,9-10,14-18,22,25-40)</sup>; *Palliative care*<sup>(9-10,14-15,17-20,27-29,33,41)</sup>; *Shared decision-making*<sup>(1,5,8-10,14-15,17-28,30-31,33,36,38-39,41-45)</sup>; *Analgesia*<sup>(1,9-10,14-18,21-22,25,27-33,35-36,41-42,44,46-47)</sup>; *Clear communication*<sup>(8-10,14-18,22,26-34,36-41,43-44,48)</sup>; *Helpful relations*<sup>(1,8-10,14-17,22,24-26,28-32,34-40,43)</sup>; and *Welcoming environment*<sup>(9,16-17,25-26,35)</sup>.

The attributes are made evident in the following excerpts, as mentioned by their authors:

- *Quality of life*

Quality of life is more and more valued, as well as the respect for patients' desires and their best interests. A dignified death is then sought, more than prolonging the patient's suffering and death needlessly<sup>(21)</sup>.

- *Child and family centered care*

[...] We seek to outline a favorable environment towards a dignified and humanized death, *in the perspective of the family and the patient*<sup>(9)</sup>.

- *Palliative care*

Children out of therapeutic possibilities of cure and their families can benefit from *palliative care* at the PICU<sup>(14)</sup>.

- *Shared decision-making*

[...] Support for the family occurs when there is understanding and acceptance of whatever *decision is made by the parents*<sup>(31)</sup>.

- *Analgesia*

[...] some form of sedation and analgesia must be used to relieve discomfort and pain during the process of dying<sup>(32)</sup>.

- *Clear communication*

*Clear and effective communication* is the most important attribute in the process of decision-making during the terminal stage<sup>(36)</sup>.

- *Helpful relations*

[...] establishing helpful relations is crucial for parents dealing with the process of dying of their child<sup>(36)</sup>.

- *Welcoming environment*

Whenever possible, the choice of removing the measures of life support in an *environment that is more familiar to the child* should be offered... One remedying solution devised in our PICU was to transform one of the isolation beds into a palliative care environment<sup>(9)</sup>.

### **Background of the concept of dignified death for the child**

The background of the concept consists of the situations, events or phenomena that precede the concept of

interest. The background aids in the comprehension of the social context, where the concept is usually utilized, and it also favors its refinement<sup>(13)</sup>. In the present study, the background was identified by answering the question: *How is the concept (roles, skills and context) described?*

The examined articles revealed the background of the concept of dignified death for children that emerge most frequently: *Acknowledgement of the irreversibility of the clinical situation*<sup>(1,5,8,10,14,20-21,23,26,28,30,33,43-45)</sup>; *Philosophy of palliative care*<sup>(9-10,14-15,17-20,26-28,30-32,36,44)</sup>; *Handling pain and the symptoms of discomfort*<sup>(1,9-10,14-18,20,22,25-33,35-36,39,41-42,44,46)</sup>; *Shared decision-making process*<sup>(1,5,8-10,14-15,17-20,22-28,30-33,36,38-39,41-45)</sup>; *Multidisciplinary teamwork*<sup>(9-10,14-16,18,21-25,28,30,32-33,35,40,45-46)</sup>; *Philosophy of child and family centered care*<sup>(1,9-10,14-18,21-22,25-44,46-47)</sup>; *Adequate communication among the team, child and family*<sup>(8-10,14-18,22,26-41,43-44,48)</sup>; *Respect for cultural diversity*<sup>(5,8-10,14-15,24-26,28,31,35-36,38)</sup>; *Favorable context at the pediatric ICU*<sup>(9,15-18,20,25-26,30,38,44)</sup>; and *Preservation of the bioethical principles*<sup>(5,8,21,23-25,36,38,44)</sup>.

- *Acknowledgement of the irreversibility of the clinical situation.*

Initially, in order to provide a dignified death, it is necessary to acknowledge the gravity of the disease and the prognostic, as well as therapeutic limitations, especially in cases of children with chronic illnesses or those who remained for some time in the pediatric ICU. On the other hand, in acute cases, it is necessary that the healthcare team be prepared to deal with the sudden and unexpected death of the child.

Care at the end of life starts when a grave disease is diagnosed in the child, or a life-threatening condition<sup>(14)</sup>.

- *Philosophy of palliative care*

The authors note the importance of consulting the palliative care team at the end of life, so that it may be possible to adequately meet the needs of the child outside therapeutic possibilities of cure, applying the principles of palliative care. As such, it is necessary that professionals qualified for child care at the end of life be available, especially in the context of a pediatric ICU.

Palliative care is essential in the pediatric intensive care units, given the frequency of deaths at the PICUs and the presence of life-threatening medical conditions in children admitted into these units<sup>(14)</sup>.

- *Handling pain and the symptoms of discomfort*

It is extremely important to acknowledge the presence of pain or physical discomfort (constipation, nausea or vomiting, dyspnea) so that analgesics can be used for effective pain control, as well as sedatives or other drugs necessary for controlling symptoms of discomfort, and including the application of non-pharmacological measures to relieve pain, such as: massages, application of sponges, musical therapy and relaxation.



Controlling pain and other symptoms of discomfort is considered evidence of adequate care towards the end of life<sup>(18)</sup>.

- *Shared decision-making process.*

In order to make the shared decision-making process feasible among the healthcare team, family and child, the following are necessary: including the family in the decisions towards the end of life, including the parents in the team discussions/meetings, as well as the involvement of the child in the decisions whenever possible, i.e., when the child is conscious and their cognitive development allows for their participation.

The time of reckoning inevitably comes when the team and the family need to make a decision, allowing the patient to die with dignity, without future interventions to prolong life, which in reality will only postpone death<sup>(9)</sup>.

- *Multidisciplinary teamwork.*

The importance of the work performed by a multidisciplinary team, which includes physicians, nurses, social workers, psychologists and spiritual consultants, where all members take part in the actions and decisions related to the child outside curative therapeutic possibilities, cannot be underestimated. In addition, the intervention of mental healthcare professionals to aid the patient and the family is noted, facilitating communication.

The ethical issues of each patient must be discussed among the whole team assisting the patient<sup>(22)</sup>.

- *Philosophy of child and family centered care*

This refers to the child's well-being at the final stages of life. As such, it is necessary to individualize healthcare, moving away from standardization and rigid protocols, seeing to the biological, psychological, social and spiritual dimensions of the child. Regarding the family, the following aspects are highlighted: participation of the parents in healthcare for the child; eased bureaucracy; respect for the family preferences; clarification about the infrastructure of the healthcare team; support to the family during the whole process of dying; sense of control over the situation by the family; constant presence of the family; providing time to the family so that it can come to terms with accepting the irreversible condition of the child; opportunity for saying goodbye; contact with the family after death (through cards, letters, phone calls, or by attending the child's funeral) and monitoring the family after the death of the child.

The central role of the team members is to provide optimal care at the end of life, applying the principles of care centered on the family and incorporating the patient's perspective in healthcare<sup>(33)</sup>.

- *Adequate communication among the team, child and family.*

This includes open communication with the child outside therapeutic possibilities of cure and with the family, through information that is true, honest and consensual

among the whole healthcare team. It is also extremely important to provide explanations about the details of the disease, treatment and care in a simple and accessible way. Moreover, the healthcare professionals need to develop skills for communicating with children at the end of life, according to their age and level of cognitive development, as well as skills to communicate any bad news to the family.

It is necessary that physicians and nurses be skilled to communicate bad news, improving the relations and communication with the families and the terminal patients<sup>(10)</sup>.

- *Respect for cultural diversity.*

This refers to respect for values, beliefs, religious and ethnical-cultural traditions of the child and their family, including religious support, when requested, through prayers or religious rituals.

Religious/spiritual beliefs are important for most parents during hospitalization and death of children<sup>(33)</sup>.

- *Favorable context at the pediatric ICU.*

Some of the aspects related to the context are relevant in order to provide a dignified death for the child, such as: free visitation within the pediatric ICU; welcoming environment; environment with privacy and opportunity for the child to die in another place instead of the pediatric ICU (at home, hospice, or infirmary).

The room has a different decorations, music, adjustable lighting, comfortable furniture and there is room for several people to sit down. We hide the technology with curtains [...] We monitor the child remotely from the central station of the PICU if the family decides to stay alone at the final hour, and we periodically enter the room in order to check if the child is comfortable<sup>(9)</sup>.

- *Preservation of the bioethical principles.*

This represents the application of the bioethical principles of beneficence, non-maleficence, autonomy and justice in decision-making, as well as the discussion of the ethical dilemmas with the hospital's Committee of Bioethics.

From an ethical perspective, the death of terminal patients is a natural and, sometimes, even desirable event, based on the bioethical principles of non-maleficence, beneficence, respect for autonomy and justice<sup>(9)</sup>.

### **Consequences of the concept**

The consequences of the concept refer to events or situations resulting from its utilization<sup>(13)</sup>. The following question was used to identify the consequences: *What is the purpose of a dignified death?*

The consequences of the concept of dignified death for children are: *Preservation of the autonomy of the patient and the family* (8-9,14,17,25-26,39,41,45); *Change in paternalistic attitudes and the philosophy of secrecy still permeate several PICUs* (9,23,32,38); *Minimized suffering* (1,9-10,14-15,17-19,21-22,25-33,35-37,40-

42,44,46-47); *Family feels safe and confident*<sup>(9-10,15-17,28-29,31,33,36-40,43)</sup>; *Inclusion of the theme of death in the curriculum of the healthcare professionals*<sup>(1,9-10,14,19,22,27,30,32,45)</sup>; and *New approach for pediatric healthcare at the end of life*<sup>(9-10,14-20,22,27,30-33,41,44)</sup>.

- *Preservation of the autonomy of the patient and the family.*

When a dignified death occurs, the preservation of the autonomy of the patient and the family is observed. They are the ones who hold the rights to deciding whether or not to accept a given therapeutic intervention, guaranteeing that the care received is in agreement with the preferences of the patient and/or the family.

Autonomy is important for the parents to adjust to the difficult situation of having a child at risk of dying<sup>(36)</sup>.

- *Change in paternalistic attitudes and the philosophy of secrecy still permeate several PICUs.*

It occurs when the family and/or the patient take active part in decision-making. As such, actions are not only based in the opinions of the team, favoring the expectations and desires of the patient and the family.

There is no more place for a paternalistic Medicine that excludes the family from the decisions in the ICU<sup>(9)</sup>.

- *Minimized suffering*

This refers to guaranteeing the relief of both pain and suffering experienced by the child. In order to be effective in this aspect, it is necessary to provide adequate analgesia and sedation, as well as the rational utilization of invasive measures.

Suffering in terminal stages must not be underestimated<sup>(10)</sup>.

- *Family feels safe and confident.*

This happens when the focus of care is not restricted to the patient alone, but also includes the family. Safety and trust of the family occur mainly due to the information received throughout the process of dying, which must be offered in adequate amounts and time, according to the demands of the family.

The healthcare team must encourage trust and communication, providing support to the families<sup>(14)</sup>.

- *Inclusion of the theme of death in the curriculum of the healthcare professionals.*

It is necessary that the curricula of the healthcare professionals be reformulated, so that discussion regarding dignified death can be broadened. Today, a greater focus on the curative aspects of care is observed to the detriment of healthcare during the process of dying.

Clinicians have reported that they are not sufficiently prepared to provide care at the end of life for children and their families. The healthcare professionals should be prepared to facilitate a good death for the child and their family<sup>(27)</sup>.

- *New approach for pediatric healthcare at the end of life.*

This regards a new attitude by the healthcare professionals at the end of life, contemplating the aforementioned backgrounds.

Although the quality of care at the end of life is widely studied in adults, there are still few studies about the death of children. Besides, the different perceptions of the healthcare professionals about the quality of care during the process of dying are not clear<sup>(28)</sup>.

- *Terms related to a dignified death*

With the literature analyzed, it was possible to identify some of the terms related to dignified death used by the authors, such as: dying well<sup>(16)</sup>, good death<sup>(9,15,27)</sup> and ideal death<sup>(9)</sup>.

Nowadays, many children die due to the purposeful limiting of life support. The focus of care changes, from an interventionist approach towards palliative care, and the healthcare professionals must constantly encourage parents to make decisions regarding the care of the child and the family<sup>(9-10,14,18)</sup>.

Care at the end of life, in Pediatrics, must meet the necessities of the child and their family, and the support of a multidisciplinary group is a real necessity. Open communication and healthcare planning with the participation of the family are aspects that facilitate the process. The capacity of negotiation of the healthcare professionals involved in care, in this sense, is fundamental<sup>(9-10,14,17,30,34,36,39)</sup>.

The participation of the family in the decisions and their presence during the process of dying is seen to be more and more a natural occurrence. However, several studies highlight the need for physicians and nurses to improve their communication skills towards the families, especially during the process of dying<sup>(14,22,27,30,32,34,38-39)</sup>.

Pediatric palliative care is an integral model of attention for the child in the last stages of life and also for the family, contemplating the physical, psychological, social and spiritual needs of the child and the family, including the treatment of physical symptoms and care during the process of dying, with the purpose of improving the child's quality of life and supporting the family. Multidisciplinary planning is required, having clear communication and shared decision-making as its basis<sup>(9,14)</sup>.

Caring for the child and their family during the last stages of life is a challenge and a privilege, because the care for the child and the family during the process of dying can have a strong impact on the experience of the family, as well as in the adjustment of the parents to life without the child.

## CONCLUSIONS

There are no significant chronological changes when we examine the concept of dignified death in literature, especially due to its emergence about 10 years ago, with the first bioethical discussions.

Several authors note the increasing interest for issues related to the end of life after the 1990s, with the emergence of discussions about maintenance of life at any cost and bioethics in an exponentially-increasing scientific context, where the use of technology results in conflicts with the therapeutic limitations<sup>(5,8,21)</sup>.

Most of the studies analyzed were published in the medical area, and only a few were published in the nursing area. This may have occurred because the physician is legally responsible for the patient, including responding directly to the bioethical dilemmas regarding artificial maintenance of life, for example.

On the other hand, regarding the development of concepts, nursing has built its theoretical foundations in a dy-

namic process, which tends to be born from practice and to focus on it, in a movement of searching for increasing levels of quality and complexity. The analysis and development of concepts are intimately related to the evolution and expansion of knowledge in nursing<sup>(13)</sup>. Because of the continuous reformulation and refining of concepts, Nursing finds support in solid knowledge bases. Therefore, one of the important points in nursing, as well as in other disciplines, is dealing with concepts.

Few articles include the definition of a dignified death for children and, when it occurs, this definition is vague and often ambiguous among several authors. This aspect indicates that the concept is not defined consistently, demanding an in-depth study regarding its manifestation in clinical practice, existing with care at the end of life in Pediatrics.

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