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Concept development: new directions for research in thanatology and nursing

DESENVOLVIMENTO DE CONCEITOS: NOVAS DIREÇÕES PARA A PESQUISA EM TANATOLOGIA E ENFERMAGEM

DESARROLLO DE CONCEPTO: NUEVA DIRECCIÓN PARA LA INVESTIGACIÓN EN TANATOLOGÍA Y ENFERMERÍA

Regina Szylit Bousso¹, Kátia Poles², Lisabelle Mariano Rossato³

ABSTRACT

The article aims to present the importance of concept development for the construction of the body of knowledge in thanatology and nursing. Discusses the steps of the Hybrid Model of Concept Development and its application in a study that seeks to develop the concept of good death in a pediatric ICU. The elucidation of the antecedents, attributes and consequences of the concept of good death in a pediatric ICU during the field allowed moving the concept of a vacant field theory to a clinical phenomenon more concrete. This provides benefits for both child care and family, and for the advancement of teaching and research on the care of end of life care in pediatrics.

KEY WORDS

Thanatology.
Nursing.
Concept formation.
Nursing methodology research.

RESUMO

O artigo tem como objetivo apresentar a importância do desenvolvimento de conceitos para a construção do corpo de conhecimentos em Tanatologia e Enfermagem. Aborda as etapas do Modelo Híbrido de Desenvolvimento de Conceitos e sua aplicação em uma pesquisa que busca desenvolver o conceito de morte digna na UTI pediátrica. A elucidação dos antecedentes, atributos e consequências do conceito de morte digna na UTI pediátrica na fase de campo permitiu mover o conceito de um vago domínio teórico para um fenômeno clínico mais concreto. Isso possibilita subsídios tanto para assistência à criança e à família, quanto para o avanço do ensino e da pesquisa sobre os cuidados de final de vida em pediatria.

DESCRIPTORES

Tanatologia.
Enfermagem.
Formação de conceito.
Pesquisa metodológica em enfermagem.

RESUMEN

El artículo tiene como objetivo presentar la importancia del desarrollo de conceptos para la construcción del cuerpo de conocimientos en Tanatología y Enfermería. Aborda las etapas del Modelo Híbrido del Desarrollo de Conceptos y su aplicación en una investigación que busca desarrollar el concepto de muerte digna en la UCI pediátrica. La explicación de los antecedentes, atributos y consecuencias del concepto de muerte digna en la UCI pediátrica en la fase de campo, permitió mover el concepto de un vago dominio teórico para un fenómeno clínico más concreto. Eso posibilitó subsidios para la asistencia del niño y la familia, así como el avance de la educación y la investigación sobre los cuidados en el fin de la vida en pediatría.

DESCRIPTORES

Tanatología.
Enfermería.
Formación de concepto.
Investigación metodológica en enfermería.

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INTRODUCTION

Thanatology is an interdisciplinary science born in the United States whose focus is studying death and dying. Knowledge and a holistic practice are the basis of the interdisciplinary care provided in this area⁽¹⁾. For the last few years the models to provide care to a person during the dying process have changed drastically. The theoretical understanding of the mourning process has brought advances and fundamental changes to the paradigm of providing care to those people⁽²⁾. The advances in the Thanatology area in such a short period of time demands that the gap existing between theory and practice is filled up, particularly within our context.

The theoretical framework of the nursing science is built through a dynamic process that tends to start in the practice and be reproduced in the research, particularly by analyzing and developing concepts and theories. When we consider that science is built by a movement that goes from common sense to critical conscience of concepts, which often seem badly defined or improperly used, the clarification of a certain concept may contribute to build up the body of knowledge in that area. Therefore, the lack of clarity of some concepts results in a science less consistent than what would be desirable. Searching for clarification and setting names for facts in the practice in order to ease reflection and to act on it have been the motivation to develop nursing concepts⁽³⁾.

A concept is defined as *an idea or mental construction prepared about a phenomenon and it is essential to conduct researches and to build theories*⁽⁴⁾. Concepts include abstract attributes of the reality and, consequently, they represent more than words or mental images, once these do not capture concepts' complex nature⁽⁵⁾. So, concepts are cognitive and abstract representations of the perceptible reality formed by direct or indirect experiences⁽⁶⁾. Therefore, a concept should be inserted in a context so that meaning and application are possible, thus contributing with the advance of knowledge in a certain area.

When researchers intend to develop a concept, they should firstly select a conceptual problem and, based on that, to identify the nature of the problem to be dealt with in the research. At a practical level, it can refer to different situations, among which we could mention⁽⁵⁾:

- Using confusing expressions or ambivalent words to characterize certain events or phenomena.
- Problems that define concepts important for the development of a research, theory or practice.
- Potential conflicts between the concepts established and the current situation found in the clinical practice.

- Need of new or more effective concepts to characterize clinical experiences.

The Interdisciplinary Nucleus of Research on Losses and Grieving (NIPPEL) of the Nursing School of the University of São Paulo (EEUSP) has contributed to the body of knowledge in the area of Thanatology within the most varied contexts of healthcare: decision-making process at the end of life⁽⁷⁻⁸⁾, organ transplants⁽⁹⁾, experience of healthcare providers at the end of life⁽¹⁰⁻¹¹⁾. Helping dignifying and humanizing the last phase of life and death in Brazil has become a challenge for the Nucleus.

Knowing the meanings attributed by the team to the experiences allows defining concepts, strengthening theories, improving research methods, thus helping healthcare providers to intervene effectively by respecting the subjectivity of the families facing situations of loss, grieving and decision-making processes.

Therefore, this article intends to present the importance of developing concepts to build the body of knowledge in Thanatology and Nursing and to show its applicability in research by presenting an investigation using this methodology. The concept chosen was that of a dignified death once although researchers have dedicated themselves to understand how care is provided to a child during the dying process at a pediatric ICU⁽¹²⁻¹³⁾, there are no records in the Brazilian and international literature on the development of a concept of dignified death at pediatric ICUs.

We believe that without understanding the concept of a dignified death clearly, hardly anything can be done to promote dignity in the dying process. Learning more about how the team's decision-making processes take place, how interactions happen during this process and which meanings pediatric ICU's doctors and nurses attribute to the expression dignified death, can strengthen the basic concepts used in different theories about working with children and families at the end of life.

HYBRID MODEL OF CONCEPT DEVELOPMENT

The Hybrid Model of Concept Development is a research method that combines the theoretical analysis of a concept with field research, the final product being the presentation of a definition of a concept and the identification of conceptual gaps guiding the development of future researches. While concept analysis usually has been deemed a theoretical work based on the literature, the Hybrid Model proposes a combination of theoretical analysis and field work able to provide a deeper understanding of a concept⁽¹⁴⁾.

This Model considers three phases in the development of a concept, to-wit⁽¹⁵⁾:

The advances in the Thanatology area in such a short period of time demands that the gap existing between theory and practice is filled up.

- Phase 1 – Theoretical;
- Phase 2 – Field;
- Phase 3 – Final Analysis.

It is important to notice that the phases of the process are not separate, but interconnected, as presented next in the diagram below.

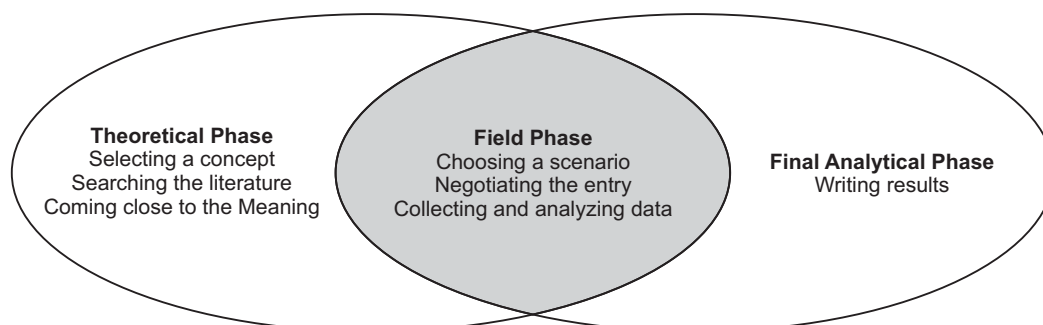


Figure 1 - Components of the Hybrid Model of Concept Development⁽¹⁵⁾

In Phase 1 – Theoretical, a definition is outlined through a search in the literature where the existing definitions are compared and contrasted against each other. In Phase 2 – Field, which overlaps the first phase, the empiric component of the process is emphasized by using qualitative methods to collect and analyze data. It is important to highlight that critical analysis of the literature starts in Phase 1 and goes up to Phase 2, which serves, among other things, as basis for a comparison with the data collected in the field research. Phase 3 – Final Analytical, includes an interface between the theoretical phase and the data collected in the field, and writing the results, i.e., integrating the two previous phases⁽¹⁵⁾.

Even if those phases are divided for didactical purposes, at a practical level they are interrelated, particularly in the theoretical and field phases. The authors argue that this guarantees that a concept has all of its dimensions explored bit by bit⁽¹⁵⁾.

EXPLORING ANTECEDENTS, ATTRIBUTES AND CONSEQUENCES

Developing concepts implies exploring attributes, antecedents and consequences⁽¹⁵⁾. The clearer a concept is, i.e., the expression of its *essential attributes*, the better its users' understanding will be. Attributes are words and/or expressions authors frequently use to describe the characteristics of a concept⁽¹⁶⁾.

Antecedents stands for situations, events of the phenomena preceding the concept of interest. The antecedents help understanding the social context where the concept is generally used, and they ease refining it⁽¹⁶⁾.

The consequences of a concept are related to events or situations arising from its use⁽¹⁶⁾. The precise definition of the consequences will be actually seen after exploring the concept in its practical manifestations.

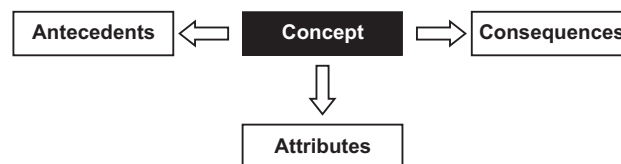


Figure 2 - Relation among antecedents, attributes and consequences

DEVELOPING THE CONCEPT OF DIGNIFIED DEATH AT PEDIATRIC ICU: AN EXAMPLE OF THE APPLICATION OF THE METHOD

Many children die at pediatric ICUs as a result of a decision of limiting or suspending life support or non-resuscitation⁽¹⁷⁻¹⁸⁾. It is well known that said decision is justified by the choice of a dignified death. These aspects mirror the broad discussion started in the 90's about the ethical dilemmas involving the end of life, challenging the *life at any cost* paradigm. Respect for patients started to be valued with an increasing concern about maintaining dignity at the end of life⁽¹⁹⁾.

Next we will present a research whose objective was to develop the concept of dignified death of children at pediatric Intensive Care Units. An important aspect of the analysis and development of a concept refers to the relevance of the proposal as to its importance for the practice. In the case of this study, the relevance exists considering the need of providing effective care targeting on a child's dignified death and its family.

The Hybrid Model of Concept Development was applied in its three phases: Theoretical, Field and Final Analytical. In the Theoretical Phase 49 articles were analyzed in the Medical and Nursing areas which studied and focused on a child's dignified death. The Field Phase was conducted through semi-structured interviews with nine nurses and

seven doctors who work at a pediatric ICU (Chart 1). The data of the Field Phase were analyzed by using the results of the Theoretical Phase with theoretical axle and Content Analysis⁽²⁰⁾ as methodological reference. In the Analytical Phase the results of the Theoretical Phase and Field Phase were compared, analyzed and integrated⁽¹¹⁾. We should stress that the project was submitted to the Committee of Ethics in Research of the three hosting institutions and was approved by all of them (Institution 1 – Protocol 091/06; Institution 2 – Protocol 06/396; Institution 3 – Protocol 534/12/2006).

The questions guiding the exploration of the material during the Theoretical Phase were similar to those guiding the interviews in the Field Phase, as shown in Chart 2. Equivalent questions were used in both phases in order to identify antecedents, attributes and consequences both in the data from literature and those from the interviews.

Next, the Chart of Results of the Analytical Phase is presented (Chart 3), where the results of the Theoretical Phase and Field Phase are compared, analyzed and integrated, thus allowing defining the concept.

Chart 1 - Data Collection and Analysis. São Paulo (SP) - 2009

Theoretical Phase	Field Phase
<ul style="list-style-type: none"> • 49 articles in the Medical and Nursing areas. • Period: from 1990 to 2008. • Databases: Medline, Lilacs, Cinahl, Pubmed and SciELO. • Languages: Portuguese, English and Spanish. 	<ul style="list-style-type: none"> • Three hospital institution in São Paulo with pediatric ICU: one mixed (public and private), one private and one public. • 16 healthcare providers: 9 nurses and 7 doctors. • Approval of the Committee of Ethics in Research of said institutions. • Data analysis – Theme Analysis⁽²⁰⁾.

Table 2 - Guiding questions: São Paulo (SP) - 2009

	Theoretical Phase	Field Phase
Antecedents	How has dignified death been described – papers, skills and context?	How can a child die in a dignified way? What should be done? How can we enable a child to have a dignified death? Which family's decisions enable a child to have a dignified death? What makes a dignified death possible?
Attributes	Which are the words or expressions used to describe dignified death?	Describe a situation where the death of a child was dignified. What do you understand as dignified death? Which words or expressions you think describe a dignified death? How would you describe an undignified death?
Consequences	What are the accomplishments intended with a dignified death?	Which were the consequences of the experience of watching a dignified death?

Chart 3 - Diagram of Results of the Final Analytical Phase. São Paulo (SP) - 2009

Theoretical Phase	Field Phase
Antecedents <ul style="list-style-type: none"> • Determining an irreversible or incurable disease. • Clear and effective communication among team, child and family. • Trusting relationship among team, family and child. • Bioethical principles in the decision-making process. • Consensus in the medical team about end-of-life conducts. 	Antecedents <ul style="list-style-type: none"> • Identifying a child beyond possibility of cure. • Communication skills. • Working close to the family. • Using bioethical and professional ethical principles. • Agreeing with a prudent practice.
Attributes <ul style="list-style-type: none"> • Limiting life support in situations of irreversible clinical situation. • Respecting the child and family's values and beliefs. • The family participates in the decisions. • Evaluation and treatment of pain and discomfort symptoms. • Meeting emotional, spiritual and social needs of the child. 	Attributes <ul style="list-style-type: none"> • Acknowledging the benefits of the natural evolution of the disease. • Respecting socio-cultural aspects. • Setting a partnership between team and family. • Providing physical comfort. • Promoting wellbeing.
Consequences <ul style="list-style-type: none"> • Minimizing/ Relieving pain and suffering of child and family. • Family's satisfaction with the care at the end of life. 	Consequences <ul style="list-style-type: none"> • Minimized suffering. • Safe team and family.

Once the data of the Theoretical Phase and Field Phase were integrated, it was possible to produce a definition of the concept of dignified death of a child at a pediatric ICU: DIGNIFIED DEATH at a pediatric ICU is to receive excellent clinical treatment at the end of life, honoring the benefits of the natural evolution of a disease, respecting socio-cultural aspects, physical comfort and wellbeing. Dignified death happens within a context of veracity and partnership between family and team, where it is possible to express expectations and concerns. The result of a dignified death is relief of suffering both of the child and family.

APPLICABILITY OF CONCEPT DEVELOPMENT IN RESEARCH ON THANATOLOGY AND NURSING

The Hybrid Model of Concept Development is an advance in the exploration of concepts when investigating their manifestation in the clinical practice, which enables broadening the antecedents, attributes and consequences evidenced in the literature considering the dynamism and variations of a concept according to the context where it manifests itself.

Identifying empirical aspects of an abstract concept is a complex process. However, empirical data offer more clarity to healthcare providers based on observable phenomena, allowing them to *diagnose* a concept as it is, which should be convincingly applied⁽²¹⁾.

Analyzing and developing concepts are intimately related to the evolution and expansion of knowledge in nursing⁽⁶⁾. As a result of the continuous reformulation and refining of concepts, nursing has been anchoring itself on solid bases of knowledge. Therefore, one of the important

points in nursing, as much as in other disciplines, is to deal with concepts.

In the Field Phase we could identify the experiential component that is behind healthcare providers' conducts towards a child at the end of its life. Thus, we could understand how the manifestation of the concept is expressed in the clinical practice, which enabled us to broaden the data identified in the Theoretical Phase. So, elucidating antecedents, attributes and consequences of a dignified death at pediatric ICUs in the Field Phase allowed us to move the concept from a vague theoretical domain to a more concrete clinical phenomenon. It subsidizes both assistance to child and family and advances in teaching and researching on the care provided at the end of life in pediatrics.

The field research increases the understanding of the values and beliefs behind protocol situations and conducts identified in the Theoretical Phase. It enables a reflection on healthcare providers' attitudes which are not exclusively motivated by conduct protocols, but also by the meaning they attribute to the situation experienced by child and family. These meanings are built during their life and professional practice as healthcare providers get in contact with varied situations and go on defining and redefining their conducts towards a child at the end of its life and its family.

Considering the potential theoretical researches may have for the advance of the science, the article concludes that the choice of adequate models to develop concepts hardly ever explored in the literature is very important. Additionally, the research showed the viability of an integrated use of the data gotten from a review of the literature and data from the field, as much as the importance of this procedure to understand the concepts relevant not only for the Thanatology area, but also for the Nursing science.

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