

NURSES' EXPERIENCE IN CARING FOR A TERMINALLY ILL CHILD: STUDY IN THE LIGHT OF THE HUMANISTIC NURSING THEORY

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ABSTRACT

This study aims to investigate nurses' experience in caring for terminally ill children. This is a qualitative research, based on the Humanistic Nursing Theory, carried out between April and June 2010. We conducted interviews, recorded, with 10 clinical nurses from a public hospital specialized in oncology, in João Pessoa, Paraíba, Brazil. Data were qualitatively analyzed, by means of the content analysis technique, in the light of the Humanistic Nursing Theory. Two categories emerged: "nurses' experience in caring for a child with cancer in the terminal phase" and "coping strategies employed by nurses in caring for a child with cancer in the terminal phase". It was understood that nurses, when caring for a child with cancer in the terminal phase, deal with much suffering, but they seek a humanistic care, integrated to each child, expressing her/his feelings by establishing confidence, respect, and dialogue, and they are sensitive to human suffering, something which leads this experience to be enriching for them within their own life context. Thus, it is expected that this research can provide means for further approaches to the theme, since studies addressing the inter-relation between care and the Humanistic Nursing Theory are still incipient, focusing on the terminally ill child.

Keywords: Pediatric Nursing. Oncology Nursing. Child. End-of-Life.

INTRODUCTION

The act of caring for patients should be based on respect for the human being's dignity and, therefore, it is indispensable to consider the patient with regard to her/his uniqueness, something which distinguishes individual differences and the need for promoting an assistance aimed at each human being in a holistic way⁽¹⁾, either a child, an adult, or an elderly person who is terminally ill.

Regarding the care for a terminal ill patient, palliative care measures stand out, which constitute a unique caring approach, aimed at improving the quality of life of a patient with advanced disease, with no possibility of cure,

and that of her/his relatives, by means of evaluation and treatment suitable to relieve pain and symptoms. This is a psychosocial and spiritual support⁽²⁾.

It is worth stressing that, in all health care scenarios, there is an increasing number of children treated with diseases that have no therapeutic possibility of cure and threaten or limit their lives, leading them to a terminal condition, such as cancer⁽³⁾.

Regarding the provision of palliative care measures for children with cancer, the World Health Organization (WHO) emphasizes that we should offer a comprehensive active care for the body, mind, and spirit, as well as support for the family. It should be deployed when the disease is diagnosed and increased as the condition

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progresses, concurrently with curative treatment⁽⁴⁾. It is noteworthy that these care measures have been undergoing a construction process and, thus, their action strategies consist in an actual challenge for health care teams, especially for the nursing team, whose professionals stay beside the patient's bed, fulltime⁽²⁾.

This way, it is of crucial importance that the nurse adopts a Nursing theory to ground her/his assistance in palliative care measures in pediatric oncology, such as, for instance, the Humanistic Nursing Theory. This theory is regarded as a living dialogue that covers *the meeting*, in which there is someone's expectation to consent and another individual's expectation to be consented; *the presence*, involving the quality of being receptive and reciprocal to another individual; *the relationship*, through which one goes towards the other, providing an authentic presence and *a call and a response*, which show up in the form of verbal and nonverbal communication⁽⁵⁾. For this, the nurse should associate sensitivity to theoretical knowledge, in order to offer an assistance that encourages the expression of her/his feelings and leads her/him to face the terminal condition of a child who is under her/his care.

Therefore, palliative nursing care measures provided to a terminally ill child, guided by the Humanistic Nursing Theory, denote preserving her/his physical, moral, emotional, and spiritual integrity.

However, despite the relevance of this theme, we find out in the national literature, mainly that in the field of Nursing, that there is a reduced amount of publications about nursing care for a terminally ill child grounded in this theory. Hence, our interest in conducting a study that can collaborate to the dissemination of knowledge about the importance of nursing care, aimed at the terminally ill child, based on Nursing theories.

Based on this understanding, the proposed research has as its conducting wire the following question: "What is the nurse's experience in caring for terminally ill children based on the Humanistic Nursing Theory?". Given the above, this study aimed to obtain answer(s) to this guiding question.

METHODOLOGY

This is a field study, with a qualitative nature, which focuses on the Humanistic Nursing Theory proposed by Paterson and Zderad⁽⁵⁾. The research setting was the pediatric unit of a public hospital, in the city of João Pessoa, Paraíba, Brazil, regarded as a reference in the state for treating child and adult cancer.

The total number of participants has not been stipulated in advance. This was defined throughout the research process, according to the sufficiency criterion, which enables considering that the empirical material allows drawing a comprehensive picture of the question under investigation⁽⁶⁾. Thus, the total sample included in the study consisted in 10 nurses.

For eligibility purposes, the following inclusion criteria were adopted: to be working within the data collection period and have previous work experience in caring for a child with terminal cancer aged at least 1 year, so that she/he can talk properly about her/his care for the child concerned.

Data collection took place between April and June 2010 in schedules previously agreed with the institution and the professionals participating in the study. It is worth stressing that the research started only after the research project approval by the Research Ethics Committee of the Federal University of Paraíba, under the Protocol 062/10. It is also noteworthy that we took into account the ethical precepts of Resolution 196/96, from the National Health Council.

It must be mentioned that, to keep anonymity of nurses participating in the study, the testimonies derived from interviews were identified by using words related to the methodological foundation of humanistic nursing (humanization, authenticity, solicitude, care, share, dialogic relationship, singularity, presence, confidence, and embracement).

The empirical material was obtained through the semi-structured interview technique, using the recording system, by means of a script with questions related to the proposed objective: "What is your experience with a child with terminal cancer?"; "What strategies do you use when caring for a child with terminal cancer?". It is noteworthy that, just after conducting the

interview, the reports were transcribed, aiming to guarantee the reliability of data collection.

Empirical data, derived from the interviews, were qualitatively analyzed, through the content analysis technique, in the light of the Humanistic Nursing Theory. The categorical content analysis is a set of communication analysis techniques that aims to obtain systematic and objective procedures for describing the contents and indicators of messages⁽⁷⁾.

This technique has the following steps: pre-analysis, which consists in organizing collected data through the semi-structured interview technique; and exploration of material, through a full reading of descriptions, identifying the relevant points of each question, seeking to capture the meanings attributed by the subject the same way she/he has attributed them. Then, a new reading of descriptions was performed, in order to group them into categories, and processing of results, seeking to understand the meaning contained in them, time when inferences and interpretations are addressed, foretold in the theoretical framework of the proposed study, which resulted in new discoveries, seeking to reach the phenomenon's essence⁽⁷⁾.

RESULTS AND DISCUSSION

Through the analysis of empirical material, it was possible to view two categories that express the essence of the phenomenon under study, which are presented and discussed below.

Nurses' experience in caring for a child with terminal cancer

Experiencing the care for a child affected by a severe disease such as cancer and who is terminally ill is perceived, by some nurses participating in the study, as an experience permeated with suffering and a lot of struggle in order to provide her/him with better care. They report that, in their daily work in pediatric oncology, the experience is not good and it brings distress, leaving them aware and revealing their feelings and emotions, something which makes them increasingly try to strive harder in the care provided, as it is possible to evidence in the speeches:

My experience with a terminally ill patient is not a good experience. [...] essentially, the child, because we, professional, become distressed, not knowing how to deal with that situation. I am very sensitive, I try to give my best. (Authenticity)

My experience with a terminally ill child is not easy. And, then, we know it is a sarcoma. They are children who have mutilating diseases, they have already lost legs, arms, and lead a struggle. I suffer a lot, but I try to provide the best care. (Solicitude)

These testimonies emphatically demonstrate that these nurses have difficulties in dealing with a child with terminal cancer. However, they show to be aimed at promoting their *well-being* and the child's feeling better. A study⁽⁸⁾ with nurses from a pediatric oncology unit revealed they see the care for this child as complex and incomprehensible, because it involves a child, who is a synonymous of joy and future, but they understand the need to provide special attention and care, even when facing difficulties, something which ends up corroborating the results of this research.

Given the absence of a treatment that allows reversing the pathological condition of a person, in this case, a terminally ill child, the humanistic nursing enables the nurse to promote a genuine meeting, providing an environment for embracement, listening, and understanding of emotions, which may be differently present for each patient, allowing ourselves to be touched by human suffering⁽⁵⁾. This meeting provides the nurse with some strengthening in her/his relationship with the patient, since humanistic nursing drives her/his care, stimulating her/him to develop patient's *feeling better*, thus resuming the nurse's human potential, trying to *be more and better* in her/his care relationships⁽⁵⁾.

A research⁽⁹⁾ on the Humanistic Nursing Theory reveals that the focus of this theory is appreciating the human being's existential experience and the professional transactional relationship with the patient, by examining the values that underlie practice. This experience is wrapped by feelings that are interrelated, shared, strengthened, and experienced between professional and patient, especially when the latter is a child affected by a disease that drives her/him to a terminal situation.

Assisting a terminally ill patient is not a simple task. Furthermore, it does not depend on

experiences and the maturity degree every professional has, especially when she/he witnesses the situation of a child's imminent death. Given this event, she/he tends to suffer in face of the difficulties to deal with this moment, so full of meanings and emotions, permeated by the child's fragile situation, deriving from her/his physical and psychological symptoms⁽¹⁰⁾, such as pain, fatigue, dyspnea, nausea, and stress. This may be demonstrated in the following report:

[...] Working with a terminally ill patient, especially when this patient is a child, is very difficult. Especially when the child already feels pain, severe fatigue, and shortness of breath and, even suffering, we have to minimize these symptoms until the end. (Caring)

Human end-of-life is a phenomenon inherent to life. However, fear of it is significantly experienced in human existence⁽¹¹⁾. Caring for the terminally ill patient and providing her/him with comfort involve human acts, containing feelings and attitudes that lead the professional to aim all of her/his efforts to understand the patient, through the existence of an intersubjective relationship with her/him⁽⁵⁾.

A study⁽¹²⁾ with oncology nurses reveals that caring for pediatric patients with terminal cancer causes a series of reactions in the emotional status and the depersonalization of professionals who care for these children, such as emotional exhaustion, leading them to develop burnout syndrome, since they cannot adapt to the various mechanisms to cope with the imminent loss of a child or find out some meaning to their existence. This may be evidenced in the speech excerpt above, where the study participant reports that after years of treatment, suffering, all ends up in the loss of a child, emphasizing that she/he suffers a lot.

This care, evidenced in this study, is aimed at the concern to *be-with-the-other*, in the sense of *living along* with the child with terminal cancer, throughout the development of her/his care practice, which stimulates her/his willingness to explore and better understand her/his experiences, offering not a single way of what to do and how to do, since caring for the human being is dynamic and multidimensional (both for those who care for and those who are cared for).

According to this line of thought, in the daily practice experience and care for terminally ill children, there is always a new discovery, since when we face the situation of losing a child, we learn how to think through our own life. This fact is observed in the following testimony:

[...] the experience is this, every day is a new discovery. We learn how to live along, day by day, with these special human beings who experience the terminal condition, being truly present, and we actually see the reality of life and we see that there are no problems. (Singularity)

The respondent's account meets the assumptions of humanistic nursing⁽⁵⁾, which highlights that the nurse should promote care, by means of her/his life experience, through an inter-personal relationship, emphasizing that, as important as the act of caring for is being aware of the effects that this care produces in patients, being, indeed, present.

Humanistic nursing⁽⁵⁾ leads the nurse to view the extent of the others' suffering, by experiencing difficult situations, as uttered in the speech above, when the respondent said that we complain of life, small things, but when faced with a child's end-of-life situation, we actually discover the problem.

Even though it is difficult to face a child's end-of-life situation, this is an enriching experience, since it involves appreciating the life process as a whole and we have to envision the positive side, learning to work in a humanized way, through different behaviors with regard to each patient and being present in an authentic way, as we may evidence in this discourse:

It is an enriching experience for us, because we learn how to respect the life process as a whole. Although, at an age like this, children full of life, full of dreams, from the perspective of a wonderful life, and sometimes we deal with this patient in the terminal phase. (Presence)

A study with nurses in a pediatric oncology unit⁽¹³⁾ indicated that the methodology of humanistic nursing is grounded in the intersubjective relationship, something which leads the nurse who cares for a child with terminal cancer to find her/his own human potential. Hence, she/he works in a more humanized way, understanding the child according to her/his weaknesses and, for this, the nurse should be present in an authentic way.

Thus, it is believed that humanistic nursing plays a key role in nurse's assistance to the child with terminal cancer by assuming a more humanized care, based on respect for the child's uniqueness.

Coping strategies employed by nurses to care for a child with terminal cancer

Some study participants highlight as strategies, in their care for children with cancer, that they experience the end-of-life process, an assistance grounded in dialogue, physical comfort, emotional and spiritual support over the remaining days, as indicated in the following speeches:

I think you have to know how to talk, come and tell the problem the best way you can, so that the patient do not get more hurt. Dialogue is very important. (Sharing)

[...] for me, it is physical comfort, psychological and spiritual support, [...]. We have a lot to do, it is not because she/he is terminally ill that we do not care for. (Humanization)

During the child's terminal phase, we will provide a better care so that she/he has a dignified death. (Authenticity)

The communication referred to in these accounts alludes to the establishment of emotional involvement and a trust relationship with the child. Nurses realize that, this way, treatment and care provided to the child become more effective and less painful, by means of dialogue. They also emphasize the importance of providing physical comfort, psychological and spiritual support.

A research⁽¹⁰⁾ focusing on the care for a child with terminal cancer addressed the importance of palliative care measures, incorporated into the daily nursing care provided to this child, since the definition of diagnosis to the end of life, through the holistic attention to the child's physical, psychological, social, and spiritual aspects. Moreover, the care for a child with terminal cancer includes attention to her/his physical, psychological, and spiritual aspects and there is a need that nurses are included into this process, something which is evidenced in the speeches above.

The WHO has defined palliative care measures as an active care for the child's body, mind, and spirit, as well as for her/his family⁽¹⁴⁾. National and international documents are

important tools in this process, such as the Universal Declaration of Human Rights⁽¹⁵⁾, which emphasizes the right of all people to a dignified death, including care for the terminally ill patients, focusing on the importance of palliative care measures. From this perspective, the end-of-life process meets the palliative care philosophy, seeking to provide this child with a dignified death, by meeting the best choice for her/his treatment, complying with the laws indicated.

A study⁽¹⁶⁾ with oncology nurses, when caring for the child with cancer in the final stage of life, points out that these professionals, faced with the suffering experiences along with this child, undergo a unique impact that leads them to change their own philosophy of life. They also claim that, above their professional role, they are human beings, especially when they are able to express and recognize their emotions, enjoying them in the life context, allowing them to appreciate priorities and find a meaning in difficult daily life situations, such as in the imminent loss of a child, being more present in authentic care, providing this child with a dignified death.

Another study⁽¹⁷⁾ conducted in a pediatric oncology unit, on nurses' perception about the dignified death of a child with terminal cancer, showed that there is a need that the nurse is able to positively engage with those who suffer, being sensitive to human suffering and willing to dialogue, respecting and recognizing the human being's dignity under the most adverse circumstances, something which corroborates the research results.

It is noteworthy to point out that nursing is a living dialogue that occurs by means of an intersubjective relationship (*being and making along*), which includes *the meeting, the presence, the relationship, a call, and a response*⁽⁵⁾. This fact is claimed when one of the nurses participating in the study notices a child's call, responds to this call, listens to what the child has to say, dialogues, and provides attention.

In this sense, the humanistic nurse is in line with the dialogue pace and, "[...] noticing the opportunity for her/his development, fits the call's and response rhythm to the client's ability to call for a response at that time"^(5:65). This

harmony becomes clear in *being along* and in *doing along* with nurses, with children with terminal cancer, something which, in turn, provides means to a better care for the physical, psychic, emotional, and spiritual dimensions.

Considering the importance and need for a better care for this child, within her/his multidimensional sphere, some nurses expressed the importance of the multidisciplinary team, encompassing a global and active conception of assistance, including attention when caring for, so that there is a complementarity of their actions, by establishing trust, as evidenced by the testimonies below:

[...] what I think to be important in the relationship between the multidisciplinary team and a terminally ill patient is providing that patient with confidence. I think the main element is patient's trust in the team. It is very important. (Dialogical Relationship)

When there is something missing, I look for the physician, the psychologist. Anyway, I try to solve the most to alleviate that situation as much as I can, relying on the support of the multidisciplinary team [...]. This provides the patient with confidence. (Trust)

A research⁽¹⁸⁾ emphasizes that the challenges in pediatric oncology, when caring for the child who experiences the end-of-life process, should be coordinated by a multidisciplinary team that operates with regard to the interdisciplinarity of its health care actions, in order to customize it to each child, on a continued basis.

So, faced with the development of strategies to minimize the suffering of a terminally ill child, the nurse must notice it from a holistic perspective, providing, in a responsible manner, an individualized care that involves her/his own experience as a nurse, a participant in this process, so that the child can *be more* and *better* in the care relationship. In order to lead this inter-human relationship to take place (expressed as a living dialogue), there is a need that the nurse is willing, accessible to the lived, experienced with regard to care, and make the presence genuine.

The testimonies included into this thematic category reveal that nurses perceive the care for a terminally ill child as required by means of

attention to her/his physical, emotional, and spiritual dimensions.

FINAL REMARKS

The experience of nurses who care for the child with terminal cancer showed up surrounded by much suffering and sensitivity, leading them to express their feelings and emotions in face of their care measures aimed at the physical and psychological symptoms of this child. Nurses' discourses make clear that, in face of suffering, they seek the best care for the child, providing her/his with *well-being* and *feeling better* with regard to the drama experienced since the discovery of disease, addressing the various situations in a subjective manner, strengthening the nurse/patient relationship, by appreciating their existential experience in the provision of care, something which meets the assumptions of the Humanistic Nursing Theory.

Nurses emphasized that this experience leads them to think through their very existence, while they are present in the interrelationship of child care, and start understanding better the benefits of providing care, constituting an enriching experience. Thus, they envision the positive side of caring for in a more humanized and authentic way, by developing the dialogue, the promotion of physical, emotional, and spiritual comfort, derived from the establishment of a trust relationship with the child. This care leads the treatment to be less painful for the child before the end-of-life process, such as in palliative care measures, and there is also the multidisciplinary team participation and their care actions on an interdisciplinary and continued basis.

Given the considerations above, it is crucial that the promotion of care for the child who experiences the end-of-life process is grounded in the humanistic nursing care. Thus, this research provides a new look not only at the care for the child with terminal cancer, but also in the domain of Nursing teaching and research, so that further studies can be developed in order to trigger an increased knowledge on the theme addressed..

VIVÊNCIA DE ENFERMEIROS NO CUIDADO À CRIANÇA EM FASE TERMINAL: ESTUDO À LUZ DA TEORIA HUMANÍSTICA DE ENFERMAGEM

RESUMO

Este estudo objetiva investigar a vivência de enfermeiros no cuidar de crianças em fase terminal. Trata-se de uma pesquisa qualitativa, embasada na Teoria Humanística de Enfermagem, desenvolvida entre abril e junho de 2010. Foram realizadas entrevistas, gravadas, com 10 enfermeiros assistenciais de um hospital público especializado em oncologia, em João Pessoa (PB). Os dados foram analisados qualitativamente, mediante a técnica de análise de conteúdo, à luz da Teoria Humanística de Enfermagem. Emergiram duas categorias: "vivência de enfermeiros no cuidar da criança com câncer em fase terminal" e "estratégias de enfrentamento empregadas pelos enfermeiros no cuidar da criança com câncer em fase terminal". Apreendeu-se que os enfermeiros, ao assistir a criança com câncer em fase terminal, lidam com muito sofrimento, mas buscam um cuidado humanístico, integrado a cada criança, expressando seus sentimentos a partir do estabelecimento de confiança, respeito e diálogo, sendo sensíveis ao sofrimento humano, o que faz com que essa experiência seja enriquecedora para eles em seu próprio contexto de vida. Dessa forma, espera-se que esta pesquisa possa subsidiar novas abordagens sobre a temática, uma vez que ainda são incipientes os estudos que abordam a inter-relação do cuidar com a Teoria Humanística de Enfermagem, enfocando a criança em fase terminal.

Palavras-chave: Enfermagem Pediátrica. Enfermagem Oncológica. Criança. Terminalidade.

EXPERIENCIA DE ENFERMEROS EN EL CUIDADO AL NIÑO EN FASE TERMINAL: ESTUDIO A LA LUZ DE LA TEORÍA HUMANÍSTICA DE ENFERMERÍA

RESUMEN

Este estudio objetiva investigar la experiencia de enfermeros en el cuidado a los niños en fase terminal. Esta es una investigación cualitativa, basada en la Teoría Humanística de Enfermería, desarrollada entre abril y junio de 2010. Se realizaron entrevistas, grabadas, con 10 enfermeros clínicos de un hospital público especializado en oncología, en João Pessoa, Paraíba, Brasil. Los datos fueron analizados cualitativamente, mediante la técnica de análisis de contenido, a la luz de la Teoría Humanística de Enfermería. Emergieron dos categorías: "experiencia de enfermeros en el cuidado al niño con cáncer en fase terminal" y "estrategias de enfrentamiento empleadas por los enfermeros en el cuidado al niño con cáncer en fase terminal". Se apprehendió que los enfermeros, al asistir al niño con cáncer en fase terminal, lidian con mucho sufrimiento, pero buscan un cuidado humanístico, integrado a cada niño, expresando sus sentimientos desde el establecimiento de confianza, respeto y diálogo, siendo sensibles al sufrimiento humano, lo que hace que esa experiencia sea enriquecedora para ellos en su propio contexto de vida. Así, se espera que esta investigación pueda subsidiar nuevos abordajes acerca del tema, pues aún son incipientes los estudios que abordan la interrelación del cuidado con la Teoría Humanística de Enfermería, enfocando el niño en fase terminal.

Palabras clave: Enfermería Pediátrica. Enfermería Oncológica. Niño. Final de la Vida.

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