CASE REPORT ARTICLE

NURSING CARE OF THE CHILD WITH A CHRONIC DISEASE: EXPERIENCE REPORT

CUIDADOS DE ENFERMAGEM À CRIANÇA COM DOENÇA CRÔNICA: RELATO DE EXPERIÊNCIA
CUIDADOS DE ENFERMERÍA AL NIÑO CON ENFERMEDAD CRÓNICA: RELATO DE EXPERIENCIA

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ABSTRACT

Objective: reporting the experience of nursing students about the teaching-learning process in caring for a hospitalized child affected by a chronic illness and its family. Method: A descriptive study developed from the experience of nursing students during activities of assistance in the discipline of health attention to children and adolescents II. These were held in November 2010 at the pediatric clinic of a teaching hospital in the city of João Pessoa, Paraíba. The research project was approved by the Research Ethics Committee, Protocol 222/09. Results: after describing the experiences four moments emerged: the approximation of the binomial to make the history, the focus of nursing care to the binomial, evaluation of care, the feeling of accomplishment. Conclusion: The care to children with chronic illnesses collaborated with the teaching-learning of the academic; therefore, required the deepening of scientific-technical and human skills to care actions. Descriptors: Nursing Care; Pediatric Nursing; Hospitalized Child.

RESUMEN

Objetivo: relatar la experiencia de académicas de enfermería sobre el proceso ensino-aprendizaje en el cuidado a un niño hospitalizado afectado por una enfermedad crónica y su familia. M étodo: estudio descriptivo desarrollado a partir de la vivencia de académicas de enfermería durante las actividades asistenciales en la disciplina de Atención a la salud de los niños y adolescentes II. Estas se realizaron en noviembre de 2010 en la clínica pediátrica de un hospital-escola de la ciudad de João Pessoa, Paraíba. El proyecto de investigación fue aprobado por el Comité de Ética en Pesquisa, Protocolo 222/09. Resultados: después de describir las vivencias emergieron cuatro momentos: aproximación al binomio para la construcción de la historia, el foco del cuidado de enfermería al binomio, avaleación de la asistencia, la sensación de misión cumplida. Conclusión: la asistencia a los niños con enfermedades crónicas colaboró con el proceso de ensino-aprendizaje del académico, pues, exigirá el aprofundamiento de habilidades técnico-científicas e humanas para las acciones de cuidado. Descritores: Cuidados de Enfermedad; Enfermería Pediátrica; Niño Hospitalizado.

RESUMEN

Objetivo: presentar la experiencia de los académicos de enfermería en el proceso de enseñanza-aprendizaje en el cuidado de un niño hospitalizado afectado por una enfermedad crónica y su familia. M étodo: estudio descriptivo desarrollado a partir de la experiencia de los estudiantes de enfermería durante las actividades de ayuda a la disciplina de la atención a la salud de los niños y adolescentes II. Estas se celebraron en noviembre de 2010 en la clínica pediátrica de un hospital-universitario de la ciudad de João Pessoa, Paraíba. El proyecto de investigación fue aprobado por el Protocolo de Ética de la Investigación 222/09. Resultados: después de describir las experiencias surgieron cuatro momentos: la aproximación binomio para la construcción de la historia, el foco de la atención de enfermería al binomio, la evaluación de la atención, la sensación de logro. Conclusión: la atención de los niños con enfermedades crónicas colaboró con el académico en el proceso de enseñanza-aprendizaje, por lo tanto requiere la profundización de conocimientos científico-técnicos y humanos para atender las acciones de atención. Descritores: Cuidados de Enfermería; Enfermería Pediátrica; Niño Hospitalizado.

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INTRODUCTION

The incidence of chronic diseases in children has increased significantly in recent decades, making hospitalization a recurring reality in the life of children and adolescents. This is defined as a condition that affects the functions of the individual in their daily activities for more than three months, causing hospitalization. Generally, leaving sequelae limit the functions of the individual possess curative treatment available but nevertheless may fail.

Children affected by chronic diseases usually require long and complex treatments; constant care in relation to therapy, in addition to being susceptible to determinants that may aggravate your health condition, can thus cause feelings of weakness in the family, associated constant concern, guilt and fear, followed by the overhead generated by the dependency continuing care.

During the theoretical-practical activities of nursing discipline in Care of the Child and Adolescent Health (DESCA - II), the undergraduate degree in nursing from a public institution, the student is inserted into the practical scenario in order to deepen their knowledge and co-responsible for assisting the binomial. Thus, discipline seeks to go beyond stimulate critical and reflective thinking nursing students. Corroborating some authors, it also stimulates their autonomy, decision making and initiative and responsibility to acquire providing assistance integrally in a real context of nursing practice.

It is during the theoretical-practical activities that the student is inserted in the healthcare universe to deal with the difficulties and challenges to nurses, especially with regard to the care of children and adolescents hospitalized, and thereby develop beyond technical skills to care, skills and attitudes to cope with the diversity of the world of work. In this context, provided nursing care to a child affected by myelodysplasia during lymphoid development of theoretical-practical activities of DESCA-II.

The Myelodysplastic Syndromes (MDS) are characterized as a heterogeneous group of hematologic malignancies that have in common a defect in hematopoietic progenitor cells and an increased risk of progression to acute myeloid leukemia. Its incidence is more common in the elderly, however, when children and young people they are usually secondary to congenital hematologic abnormalities.

MDS, as well as other chronic diseases are major generators of stress for the affected children and their families as well as for the professional who assists them. Given the immaturity of the student within the care process, this is a unique moment of learning, where the same is required to deal with psychological and emotional issues of the family who experiences this disease. In addition, you must learn to deal with the uncertainty of therapy, because this pathology, therapy is based on hemotherapeutic support and control of bleeding, however, the only curative treatment is by means of bone marrow transplantation, associated with intensive chemotherapy.

This study aims to report the experience of nursing students on the teaching-learning process in caring for a hospitalized child affected by a chronic illness and their families.

METHOD

This is a descriptive study of type reporting experience, developed from the care actions performed by the academic undergraduate degree in Nursing to a child affected by a chronic condition and its family. Considering it as a tool to discuss and reflect on the process of teaching and learning.

The assistance actions were experienced in the Pediatric Clinic of a University Hospital during the theoretical-practical activities carried out in November 2010 under the direction and guidance of teachers of nursing discipline in Care of the Child and Adolescent Health II, in addition to monitors discipline and collaboration of clinical nurses of that sector.

The institution is a referral center for the treatment of children with chronic diseases and is as rich in the process of vocational training field, since, enables the enhancement of skills, attitudes and skills necessary for professional practice, contributing to the process of teaching learning with respect to critical reflection of the situations experienced.

It is noteworthy that the report met the ethical principles of Resolution 466/12 of the National Health Council (CNS), which deals with the Guidelines and Standards Regulating Research Involving Human Beings, and the Code of Ethics for Professional Nursing, regulated through Resolution 311/2007. It is noted that it is the result of a research project developed with children and adolescents with chronic illnesses, approved.
DESCRIPTION OF LIVING

The process of hospitalization can generate dubious feelings on the family and child, because these can be related to suffering, but also represent the possibility of cure. In this perspective the proposed teaching/learning through direct assistance to the binomial nursing during hospitalization, provides students consider the health/disease process, and therefore the reactions of the child and family in the hospital for the purpose of promoting a holistic and humane care. Following this perspective, the construction of the experience occurred in a chronological, linear fashion, based on the process of care for the child and his family. However, for the description of this were considered four moments: 1st time: Approximation of the binomial for the construction of history, 2nd moment: The focus of nursing care to the child and his family. However, for the moment of the experience is based on the phases of the nursing process considering the assumptions of the theory of basic human needs of Horta, with care actions based from literature relevant to the topic.

Moment 1: Approximation of the binomial for construction of history

The process of approximation with the child was started by investigating the records in order to obtain a more comprehensive view of the general state of the same and better understand the history of their illness. As a result of clinical vulnerability due to anemia, thrombocytopenia and neutropenia characteristic pathology, as well as the presence of signs of infection, the child was in protective isolation contact. Because of this, besides the use of personal protective equipment and restrictions on visits, the child and its companions stopped frequenting places of socialization in existing service such as the cafeteria and playroom; what also contributed for the emergence of feelings of loneliness and fear often reported by the child's mother.

This is a fragile moment in which those who watch, in this case, the students also experienced a range of feelings, such as the fear of unknown situations and the technical and emotional insecurity marked the first contact with the binomial. However, the feeling of empathy for the child and family, and personal experiences of the students with their own losses facilitated understanding the suffering of others and the formation of a trust that has permeated all nursing care.

Despite the severity of the condition and show up less active the child remained cheerful and participatory recreational activities proposed in the bed. However, to formulate a plan of nursing care was needed to better understand the disease and the limitations imposed by the disease such as fatigue and the risk for bleeding. Considering that care was needed to direct the binomial was looking for a companion, because the whole process experienced by the child became exhausting for her. With the inclusion of the family in the hospital, the object of nursing care is extended to the family-child pair, triggering the need for new work tools to account for these new characteristics of the healthcare practice.

The time to meet with the mother was important to understand the social, economic and spiritual situation experienced by the binomial (child/parent). This allowed direct look at the needs of the family and create a bond of trust grounded in empathy with the aim of permeating the interpersonal relationships necessary care. In this context, the feelings, values and shared experiences facilitated the process of teaching-learning and adaptation related to child care in the hospitalization. The understanding of the socio-cultural context in which the binomial is inserted generated the desire to help and boosted demand and deepening of knowledge about chronic disease, the treatment, quality of care and the child and family spiritual support. Thus, the process of teaching and learning included the improvement of technical and theoretical skills, but also interpersonal skills with patients and their families, and health professionals.

This was a singular moment in which it was possible to see that actions to promote effective care is necessary to understand the universe in which the family is inserted, and the actors involved in it. Allowing understand that the process of teaching-learning builds all the time, and widens from the awareness of the student that he is part of this process and
extends to the assessment of their caring actions.

**Moment 2: The focus of nursing care to the binomial**

During the time of assistance the child's clinical status worsened and the hematological changes were intensified due to severe thrombocytopenia. It submitted gingival bleeding, melena, petechiae and diffuses bruising the body, as well as fatigue and fever. At this time we must understand that the physiological needs outweighed the other, because the child's life was in risk.

At this time the sense of impending loss arose in students and fear of human finitude and anguish of not knowing how to handle this situation were the predominant feelings. That was the first time during the academic training that those feelings were experienced. One study indicates that the intensity of these feelings varies according to the individual's psychological maturity, thus justifying the feeling of insecurity, powerlessness and guilt experienced by students.

Nursing care at this time is mainly directed therapy with blood products. The monitoring of the infusion of these components allows early identification of adverse reactions, especially in the first 15 minutes, because that's when the majority of reactions occur, thus became necessary to check the vital signs before and during this procedure.

Due to the fragility of the vessels, there were intermittent obstructions during infusion of the same, causing the child's sense of fear and anxiety and leaving her frightened and tearful; but, however, understands the need for cooperative procedure.

Care for the venous access also proved to be a stressor for children, mainly on account of obstructions during the infusion of blood product, which caused discomfort and pain in children and anguish in the mother. In this sense, the insertion of peripheral venous catheters is an invasive procedure that is for the nurse, and as such is subject to complications. Thus, the monitoring becomes an important nursing care.

Studies show that vessel obstruction, infiltration, phlebitis and inflammatory signs are the most frequent complications of intravenous therapy, resulting in the removal of the catheter and a second puncture and causing discomfort to the patient.

During the provision of care, the obstruction was the most frequent complication being held, therefore, several wash the catheter with saline in order to let it permeable. The washing of catheters is essential to prevent the formation of clots, avoid contact between incompatible drugs and still ensure complete infusion of all medication administered.

One study showed that the incidence of local or systemic infections associated with peripheral venous access is low in any patient; however, the presence of infections resulting from venous access in an immunocompromised child could worsen its condition. Importantly, in neutropenic patients the immune response is decreased and therefore cannot show up in conventional manner, requiring more attention than the other signs nurse and symptoms. Therefore, monitoring of this access in the presence of inflammatory signs became one of essential nursing care in the patient to prevent possible infections. In this context, we look at the care of venous access seeking to prevent complications that increase morbidity and length of stay of children in hospital.

On this occasion it was possible to understand that although didactically learn about the levels of theory Horta separately and the focus of care is guided by the physiological needs for care of these actions occur interlaced form, since that moment of care was also necessary to direct our gaze to the psychosocial needs in order to alleviate the suffering of the child. Because of the assistance is provided to the binomial was necessary to seek support in the mothers' faith to understand that time and with that also focus on the psycho-spiritual care needs.

The care directed to the emotional and spiritual comfort it is always necessary, since the nurse should focus beyond the biological body sick. The spirituality emerges in this sense, as an important coping mechanism, a haven that promotes comfort to the family and child during hospitalization.

It is clear, in this context, the complexity of care, in which technical knowledge is important, but is not sovereign. Therefore, it is necessary to share, support and respect the emotional and spiritual needs. However, this is an action that requires human involvement between patient and professional (academic) and consequently the need for a different look at the health-disease process.

**Moment 3: Evaluation of assistance**

The evaluation of care is an action of differentiated care, because it should provide improvement of the health of the child, but also a return to the learning process. It must be shared in order to visualize the potential
for learning in service show that beyond the possibilities of care to the binomial.

As a result, this moment was experienced in wheel conversation which was discussed critical-reflexive manner the clinical picture of the child care actions taken and those that could subsidize the service, to complement the care and provide more comfort to the binomial. This form of learning fosters the exchange of knowledge, in which the teacher and student relationship is surrounded by mutual teaching, where both learn and teach.18

Given the reflection discussion of care, assess the care provided in a positive way, where palliative care focused on the biological walked along with the emotional and spiritual comfort provided to the child-family ratio. In this perspective, the binomial care becomes peculiar and intense, which requires a lot of care and nurse in the emotional realm.19 And even during this process has arisen for us to insecurity and fear, we could understand while assisting the patient in all its uniqueness.

Moment 4: The feeling of accomplishment

The experience of the teaching and learning process through careful service enabled knowledge / observation of daily assistance to the binomial (hospitalized family-child), where he was being possible to understand the context in which it was inserted. Thus, it is possible to implement an assistance systematically establishing an appropriate and viable planning and implementing actions of care in a holistic and humane way able to meet the needs of the family.20

It was possible to describe the feeling of accomplishment, since the learning process was able to awaken in student perceptions of being a nurse, before starting the professional career. Daily practice made him realize that the emotional, social and cultural dimensions of care are as significant as the technical and scientific aspects.

CONCLUSION

To provide the student exercise its action/reflection/action the teacher provides the same experience the world of work and provides the opportunity to link theory to practice thus facilitating the process of teaching and learning, leading him to convert the abstract concepts of care in concrete experiences.

We believe it is appropriate and necessary to further reflections on the learning process through careful service, therefore this provides care to understand and reflect on the needs of the service and the uniqueness of each case. In addition, to develop the student's ability to learn to learn and perfect each time the search for technical and scientific knowledge and understanding necessary for insertion changing world of work.

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J Nurs UFPE on line., Recife, 8(2):464-70, Feb., 2014

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