NURSING ACADEMIC PERFORMANCE IN THE CARE OF CHILD WITH EDWARDS SYNDROME: EXPERIENCE REPORT

ATUAÇÃO DE ACADÊMICOS DE ENFERMAGEM NO CUIDADO À CRIANÇA COM SÍNDROME DE EDWARDS: RELATO DE EXPERIÊNCIA

RESUMO

Objetivo: descrever o histórico de cuidados prestados a uma criança com prognóstico fechado e a vivência de alunos de enfermagem, das metodologias ativas de ensino-aprendizagem, neste processo. Método: relato de experiência com uma criança com a Síndrome de Edwards e sua mãe. Foi realizada busca no prontuário da criança e registro das percepções dos alunos em portfólios reflexivos. A análise das informações foi realizada de modo descritivo, subsidiada por discussão teórica. Este estudo foi aprovado pelo Comitê de Ética, protocolo nº 289/09. Resultados: as ações desenvolvidas pelos alunos durante a assistência a esta criança possibilitaram discussões com os profissionais da equipe sobre os aspectos relevantes ao cuidado, quando foi valorizada a importância da escuta ativa e do acolhimento ao binômio mãe-filha. Conclusão: discussões sobre a atuação dos profissionais são necessárias, a fim de proporcionar mais conforto para o paciente e os familiares, ajudando-os a lidar com o processo de morte com dignidade. Descriptores: Cuidados Paliativos; Humanização da Assistência; Enfermagem.

RESUMEN

Objetivo: describir la historia del cuidado de un niño con el pronóstico cerrado y la vivencia de los estudiantes de enfermería, de los métodos activos de enseñanza y aprendizaje en este proceso. Método: relato de experiencia con un niño con el síndrome de Edwards y su madre. Fue realizada una búsqueda en los registros del niño y registro de las percepciones de los estudiantes en carteras reflectivas. El análisis de la información fue presentado en un estudio descriptivo, con el apoyo de la discusión teórica. Este estudio fue aprobado por el Comité de Ética, número de protocolo 289/09. Resultados: las acciones tomadas por los estudiantes durante el cuidado de este niño permitieron discusiones con el personal profesional sobre aspectos relevantes al cuidado, cuando fue valorizada la importancia de la escucha activa y la acogida al binomio madre-hija. Conclusión: las discusiones sobre la actuación de los profesionales son necesarias, con el fin de proporcionar una mayor comodidad para el paciente y la familia, ayudando a lidiar con el proceso de la muerte con dignidad. Descriptores: Cuidados Paliativos; Humanización; Enfermería.

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ABSTRACT

Objective: to describe the history of care for a child with closed prognosis and the experience of nursing students, of the active methodologies on teaching and learning process. Method: report of experience with a child with Edwards Syndrome and its mother. Search was carried out on the child’s health record and a register of students’ perceptions in reflective portfolios. The analysis of the information was presented in a descriptive way, supported by theoretical discussion. This study was approved by the Ethics Committee, protocol nº 289/09. Results: the actions taken by students during the care of this child allowed discussions with professional staff about relevant aspects to care, when it was valued the importance of active listening and care to the binomial mother-daughter. Conclusion: discussions about the work of professionals are needed in order to provide more comfort for the patient and the family, helping them to deal with the process of death with dignity. Descriptors: Palliative Care; Humanization of the Assistance; Nursing.
INTRODUCTION

The Edwards Syndrome, Trisomy of chromosome 18, is characterized by developmental delay weight and height, muscular hypotony, mental hypotony and seizures, with changes in various systems, including the central nervous system and cardiovascular. It is one of the most frequent syndromes, only surpassed by Down Syndrome. Its prevalence in the general population is one in every 8000 live births, with a female predominance (77%).

Between 90-100% of Edwards Syndrome patients die within the first year of life. The low life expectancy allows the syndrome to be encompassed in the definition of prognosis closed. The Ministry of Health, which takes into consideration three main aspects: few therapeutic options, no chance of cure and no possibility of disease control.

Caring for children with closed prognosis is a difficult process, because his death is seen as an interruption of the natural flow of life. The nursing skills by humanistic and technical-scientific, plays an essential role in this process. Therefore, it is necessary that these aspects will be discussed throughout the formation of this professional category, so that nurses can assume their role conscientiously and responsibly seeking care strategies and total assets, helping the patient and family to experience the approaching end of life.

Considering the importance of preparing students for nursing care to patients with prognostic closed, this study came from the following questions: What is the care given to the child with prognosis closed? How nursing students, of active methodologies of teaching-learning experience this process?

In order to answer the questions, this study aimed to describe the history of caring for a child with prognosis and closed experience of undergraduate nursing students, active methods of teaching and learning in the process.

♦ Contextualization of teaching strategies - Methodologies active teaching-learning

The undergraduate degree in nursing from the College of Medicine of Marília was created in 1980. The traditional curriculum model adopted initially suffered from the 1990s, criticism from teachers who believed there was no appreciation of the student in the learning process, being based knowledge transmission (teacher-student) and centered on learning technical procedures.

From 2003, the Nursing Course adopted curriculum oriented skills, according to the National Curriculum Guidelines, not limited to learning technical and scientific profession, but valuing education as “a process of transformation facing for the construction of knowledge” (p. 15). The formation of the students started to occur so linked with the practices of health services, allowing the experience of real problems and interventions and training professionals critical-reflective, based on the principles of meaningful learning.

The methodology that supports learning practice is problematic, based on Paulo Freire. From the questioning, the student has direct contact with the reality of health services, building technical and scientific knowledge and human. In this methodology the learning process occurs in three steps: 1) experience of a certain reality and conducting inquiries (action), 2) the search for scientific knowledge, reflection of the reality experienced and small group discussion (reflection) and 3) new experiences the same reality with attribution of meaning (transformer action).7

METHOD

Experience report on the history of care for a child with prognosis and closed experience of nursing students, active methods of teaching and learning in the process.

The sample consisted of a child with closed prognosis carrier of Edwards Syndrome, and his mother. The choice of subjects occurred intentionally, from a curricular area of Child Health.

The experience was experienced in 2009, during the period of two months, over a traineeship performed in the pediatric ward of a public hospital, tertiary, in the state of São Paulo. That ward gets kids up to 14 years of age, has the operational capacity to 24 beds, an average of 18 patients/ day and six-day hospital stay.

It was realized a register of the perceptions of students in portfolios reflexive, being this activity part of the requirement the series. After signing two-way the Term of Consent Free and Clarified by child’s mother, occurred revision of the child’s records since its first attendance in the complex hospital until episode from the finding of death.

The analysis of the history of care and the experience of undergraduate nursing students were held in a descriptive, informed by theoretical discussion on the subject studied. To ensure anonymity, the child is presented as
R., letter chosen randomly, and the mother as the mother of R.

This study was approved by the Ethics Committee in Research of the Faculty of Medicine of Marilia - Famema (Case nº 289/09), in accordance with Resolution 196/96.

RESULTS AND DISCUSSION

The results are presented in two steps. First, it is presented the description of the subject and the historical care, in order to contextualize the experience of care. Then, we present the experience of undergraduate nursing, supported by theoretical discussion.

♦ Presentation of the subject and the historical care

R., one year old, female, white, born and raised in a city in the countryside of the state of São Paulo. Mother of R., 35, female, white, married, is dedicated to the care of children and the household.

The mother of R. became pregnant at age 33. Prenatal care was conducted throughout the gestational period; there were no complications during pregnancy. The delivery, cesarean type, occurred in the 39th week of pregnancy without complications. Born with 2520 grams and 45 cm, did not cry at birth.

R. lived with his mother, his father and his brother eight years in brick houses, with a monthly income of about twice the minimum wage. Parents maintained a stable relationship and supporters were Catholic religious practice.

R. had medical diagnoses of pulmonary complications secondary to Edwards Syndrome with severe cardiopulmonary, chronic non-progressive encephalopathy, epilepsy, recurrent aspiration pneumonia, pulmonary hypertension, ventricular septal and severe dysphagia.

The first contact with the hospital complex, site of this experience occurred through the Children's Clinic of Gastroenterology, in June 2008, five months of life, due to the need to exchange orogastric tube for enteral feeding. On this occasion, R. was referred to neurology, pediatric cardiology, speech therapy, physiotherapy and psychology to his mother.

The first hospital in the pediatric ward, lasting 35 days, occurred in September 2008, after eight months of life, due to aspiration pneumonia. Nutrition monitoring began collaborating with the diet plan, considering that R. had trouble gaining weight and had constipation.

In October 2008, R. underwent a hospital in Pediatric Intensive Care Unit, where there was a need for intubation. After being extubated, R. was dependent 2L/min. oxygen amount which varied along its monitoring. Social services helped in the acquisition of oxygen for home use.

The mother of R. obtained for all admissions support of health psychology and social work.

The last admission of R. happened in February 2009 due to tachydyssnea, lasting 48 days. On occasion, the case of R. was considered without prognosis and was talking with the family about comfort measures, without invasive procedures. Despite the gravity of the frame R. showed some stability when it was contemplated the possibility of a discharge plan for March 31th.

On April 2nd, 2009, R. was referred to the pediatric ICU and after successive desaturation (below 60%), followed by aspiration of large amounts of reddish secretion by tracheal cannula, R. did not improve, even with the increased supply of oxygen. At the moment, had ventilatory support and sedation for comfort. 5:30 am day three was found death, which was mainly caused by acute respiratory failure and pneumonia.

Nursing diagnoses made during the various admissions of R. were predominantly biological, being the most prevalent: delayed growth and development, impaired swallowing, ineffective airway clearance, hyperthermia, impaired skin integrity, impaired physical mobility, ineffective breathing pattern, ineffective tissue perfusion, aspiration hazard and risk of infection.

♦ Experiences of nursing students and theoretical discussion

The first contact of nursing students with R. (one year old) occurred during his last hospitalization in the pediatric ward (duration 48 days), when it was considered no prognosis.

Actions developed by academics at this child care possible discussions with professional staff on aspects relevant to care. It was felt that the care would not be limited to children, but extended to both mother and child.

When looking for the mother of the child, the students realized that at times she expressed anguish, anger and discontent over the state of the daughter and need to be strong for the whole family, corroborating the results found in other studies that analyzed...
similar situations. Given this, the stance taken by the students was the host of active listening and putting up always available, whether by performing nursing procedures or through constant visits to the bedside of the patient. According to authors, the decision to support the patient without the possibility of recovery on the knowledge of the family dynamics, analyzing for the patient prognosis is closed considering the importance of the quality of life of patients and their families, characterized by approach to improve the experience of care in cases of Edwards Syndrome, the prognosis closed, was deprecated because, although there is the possibility of recovery in biological terms, considering it as no therapeutic possibilities.

One of the precepts of the curriculum of the Faculty of Medicine of Marília is the change of the care, the disease to the person. When considering the child as the center of care, it is also important that attention be given to the family because of the family living with the child at the end of life is a complex and painful experience. In order to assist in the preservation of family dynamics, the students together with the nursing team, allowed visits Brother R., a minor, on the weekends, so he could see his mother, upon authorization institutional.

Studies discuss the importance of family participation in decision-making and delivery of care. In the experiment presented, knowledge of the child's mother about the daughter's illness, as well as its clinical course, allowed full participation in planning care, which provided greater security to cope with the process.

Insertion practices pediatric inpatient service, students were allowed to experience the care process in its entirety, with an appreciation of the ethical, respect, building relationships and addressing problems in an integral way, as recommended in the curriculum Faculty of Medicine of Marilia and the National Curriculum Guidelines.

During hospitalization R., she often was characterized as no therapeutic possibilities. In this study the use of this term is deprecated because, although there is the child without the possibility of recovery prognosis in biological terms, considering it would be therapeutic possibilities without disregarding other therapeutic resources inherent in the concept of comprehensive care. The assumption that there is nothing to be done for the patient prognosis is closed challenged in the scientific literature, the authors argue that "while there is life, there is a need of care."

Faced with this impasse, the need to consider palliative care for assistance to R. became imperative, and this type of care characterized by approach to improve the quality of life of patients and their families, through appropriate assessment and treatment for relief of pain and other symptoms, and provide psychosocial support and spiritual.

When considering the importance of palliative care, nursing students rigorously controlled oxygen saturation of R., by the oximeter, and evaluation of signs and symptoms of hypoxia, to ensure the child's breathing comfort. There was inserting the mother of R. this control, guiding them about the signs that should be attacks, causing had full participation in the delivery of care. There was also an attitude of respect for the religious beliefs of the mother of R., emphasizing the importance of spirituality then. Studies show that families who have a spiritual life more easily support the process of losing.

The welcoming posture assumed by the students and the creation of bonds allowed the approach was beyond the technical procedures and discussions about the syndrome, creating a relationship of trust with the exchange of experiences on the difficulties in dealing with the approaching end of life.

One of the biggest fears of mother of R. was to take the child home to “wait for death.” It is understood that the performance of the nursing staff is essential in this process, helping patients and their families to experience the process of death with dignity, in order to help the human being to seek quality of life when you can no longer prolong it.

The experience of caring for a child with Edwards Syndrome, the prognosis closed, was a valuable experience because it allowed the reflection from the process of action-reflection-action, the need for development of human competence, beyond the technical skills and theoretical. According to authors, the experience of care in cases of Edwards syndrome allows the emergence of important issues such as the value of life, personal values and limits of professional practice.

Authors believe that the lack of training nurses theoretical discussions about care in the dying process and practical experiences, arguing that when students are exposed to real situations near the end of life, there are building solid knowledge and preparation for providing this type care safely.

Some limitations to the practical experiences of care in the process of death, for the training of nursing students, are indicated in the literature as a lack of local training, curriculum excessive amount of disciplines, process of death not identified as need to study reluctance to allow nursing students to participate in the care of critically ill patients.
The curriculum of the Faculty of Medicine of Marília based on active methods of teaching and learning, overcomes these limitations by having the following characteristics: 1) education is directly linked to the health services, with different possibilities for local internships and 2) the process of learning occurs from practical experience, so the student can identify the care in the dying process as a learning need, 3) students are encouraged to act with autonomy and responsibility, supported by teachers and professionals services, so there is reluctance to allow them to participate in many different care experiences. 7

CONCLUSION

The care for children with closed prognosis was an important experience for graduate students in nursing, because from the practical experience was possible to reflect the actions of care in the dying process, building significant knowledge and developing human skills and technical-scientific.

Although this study has the limitation of being an experience report of a specific situation, it is worth considering the discussion of this experience by professionals and nursing students, since death is part of everyday life and the nurse's duty of this professional category help the patient and family to experience this process with dignity. Avoid discussions about care in terminally is limit opportunities for learning and performance.

REFERENCES


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