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The Nursing Care And Education Plan For A Child With Epidermolysis Bullosa (A Case Report)

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ABSTRACT

Epidermolysis Bullosa (EB) is a chronic disease, some types of which may have morbidity and mortality. That is why the patients must receive multidisciplinary care in case any complications arise. Families must be informed about the disease, about home care and receive genetic counselling. The importance of genetic counselling cannot be stressed enough, since both M.C. and his younger brother were diagnosed with EB. If the family had received genetic counselling, this tragic situation could have been prevented. Home care education for the families of EB patients is also of great importance. Relatives of the patient must also be educated about wound care, infection control, patient nutrition and physical treatment. They must also be educated about how to use the medications and about bandaging, dressing, Vaseline bandages, antiseptics, bathing procedures, and the use of antibiotic cream ointment. It was obvious, therefore, that the nursing care given at home enhanced both the patient's and the family's quality of life.

Keywords:
Epidermolysis Bullosa, Education, Care, Nursing

1.Introduction

Epidermolysis Bullosa (EB) is a rare, chronic and heterogeneous disease which causes minimal trauma, bullas and erosions on the skin and mucous membranes (Fine et all, 2008). Its incidence is only 8 to 19 in one million (Fine, 2010). Although the disease, which can be diagnosed prenatally, has some symptoms in the neonatal period, clinical symptoms, some of which are normal during birth, may also appear in time. Since there is not a definite treatment for epidermolysis bullosa, supportive care is given. It has been reported that the caregivers of EB patients have much difficulty in caring for the patients due to the patients'9 physical limitations and their dependency on the caregiver (Greenwood, Mackenzie, Cloud and Wilson, 2008; Park, 2008). In our country, patient care is regarded as the family's responsibility. Therefore, caring not only has an effect on the patient but also on the caregiving family members, which in turn causes changes in the roles of the caregivers (Hinojasa, Rittman, Hinojosa and Rodriguez, 2009; Qiu and Li, 2008). In this sense, it is significant for the nurses, who are indispensable members of the health team, to make an effective plan and apply it so that the patient can adapt to his or her disease, so that the patient has continuity of care, and so that the patient's relatives can make informed decisions about the patient's care (Almborg et all, 2009; Yekta et all, 2011; Dinçer et all, 2009). A nursery designed for EB patients can contribute to the qualified sustainability of patient care and to the caregivers' well-being. A study to be carried out for this purpose should provide further data for other similar studies (Küçükgüçlü, Esen ve Yener, 2009; Mollooğlu et all, 2011).

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1.1. The Case Report:

In this paper, the case of 9-year-old M.C., a patient with epidermolysis bullosa registered in the *Şanlıurfa Social Assistance and Solidarity Foundation* (SYDV), is reported. The report will identify the problems related to M.C.'s disease, the planning and the practice of nursing care and the follow-up after the activity.

Epidermolysis bullosa treatment costs for M. C. resorted to grips with because they receive financial assistance from the Foundation and has been recorded. Based on these records it was made in the patient's home. official permission letter from the Social Assistance and Solidarity Foundation for the study were taken. approval of parents and children to work time and family were given information about the contents. Accordingly it was made between February 2014 to work in June. nurses during this time at least once a week, including home visits were performed.

Researchers made visits to the patient's home, the first being in February 2014. After the first visit, they made 20 visits in total at intervals of at least once a week. In June 2014, all of the visits concluded. During the first visit, they met the child and the family and got complete information about them and their child's situation. Moreover, they asked the family if they would accept regular visits to teach the child the principles of his own care, thereby ensuring the parents' participation. The home visits were made when the wound care was given to the child by the nurse and the mother. The visits lasted from 90 minutes to two hours.

1.2. The evaluation of M.C's Health Story, According to Gardon's Functional Health Patterns

1) **Detection of Health:** Because epıdermolysıs bullosa disease is known as an incurable, often fatal disease and will create a problem for the family, the child's--and the family's--quality of life has declined and the possibility of more complications related to the disease has increased. For the child, the concept of better health was defined as "passing a day less itchy and free from pain."
2) **Nutrition and Metabolic Situation:** There were wounds in M.C's mouth and tongue that caused him to be unable to take any nourishment. The child's weight was 10 (ten) kilograms., putting him well below the third percentile of the growth curve. The mother fed M.C. twice a day in the morning and in the evening with a glass of ready-made baby food. Difficulties were experienced while feeding him because he had a lot of pain during feeding. Clearly, the child had little appetite.
3) **Excretory System:** A diaper, changed once a day, was used for M.C. He usually produced faeces at this time. Even if he did not produce faeces, his mother changed his diaper before he went to sleep. Since a special diaper was not used, the diaper stuck to the wounds on his anal area. Each diaper changing, therefore, became a painful situation. Furthermore, M.C. suffered from constipation. He produced faeces only once in four days. Therefore, duphalac was given to him three times a day.
4) **Activity and Exercise:** M.C. had wounds on his fingers, toes and legs, beginning from his knees, which stick to each other. His limbs, too, were twisted and contracted. Therefore, the could not walk, nor could he use his hands and feet. The child was moved by his parents. He spent the entire day watching television or sleeping.
5) **Sleep and Resting:** M.C's sleep was broken up into short periods of time because the wounds were so itchy. When he scratched the wound, he created an even larger wound, it became infected or both. Due to this situation, both mother and child did not get an adequate amount of sleep.
6) **Cognitive Development, Self-perception, and Comprehension:** The child had never attended school or other institutions, such as day-care centers. Therefore, he could not use his hands properly or play with a toy that required manual skill or motion. He sat all day, cried continually, and did not have contact with anyone except his mother. He seldom smiled. He asked for his mother when he had pain or itching. When he soils his underclothes, he reacted by crying.
7) **Role and Relationship:** Since his illness was diagnosed at birth, he could not assume a normal childhood role as did his peers.

2. M.C.'S CARE PLAN

2.1. Descriptive Data: The ambient temperature increased the number of the wounds on M.C. and decreased the rate of healing.

2.1.1. Diagnosis and Objective: Making the ambient temperature suitable for wound healing and preventing wound formation.

2.1.2.Interventions: Since the child's home was very cold in winter and very hot in summer (38-39°C in the summer), air conditioners were installed by the foundation in the rooms where the child spends most of his time. The family was informed that the room temperature must be 24-27°C. The family was also educated to adjust the temperature using a thermometer in the rooms when stoves were used for heating.

2.1.3.Evaluation: It was seen that there were no wound formations due to the hot weather in May and June. When the temperature was above 28°C, the healing process picked up speed.

2.2. Descriptive Data: The infection in M.C's wounds was on his feet and around his stomach.

2.2.1.Diagnosis and Objective: M.C must be protected against trauma and infection. Erosion formation must be prevented with the use of topical agents; the skin must be moisturized, and the infection must be treated.

2.2.2. Interventions: The caregiving mother said that she did not know that the wounds on feet and around the stomach were infected and thought that they were normal, since she was not informed about the possibility of their being infected. The mother also said that she dressed M.C.'s wounds on alternate days, washing her hands before the procedure, removing the bandages with her bare hands, cleaning them with baticon, using fucidin cream and then binding up the wounds with non-sterile bandages. Furthermore, she reported that she had difficulty getting sterile gauze bandages. When she could not get sterile bandages, she covered his wounds with paper towels and removed the paper that was stuck onto the wounds by pouring tap water on it. On the second visit, M.C. was taken to a dermatologist with his mother to determine a how to treat his wounds. All of the equipment required for the treatment was supplied by the financial aid from the foundation. The topical agents were given both as a siccative for wounds and as a preventative against secondary infection.

After determining the treatment, the nurse applied it at home, and then showed the parents how to treat the child's wounds, thus correcting the misinformation. On the third visit, healing was observed, and the wound care was given to the child by both the nurse and the mother. During the fourth visit, the mother gave the wound care by herself under the nurse's supervision. M.C. had reacted by crying during the dressing hours before that visit. He did, however, stay calm during that wound care session. During the next visit (the fifth), it was observed that the infected wounds were desiccated and started to cicatrise. The mother reported that the child had slept longer for the first time during the previous night. When M.C. was asked about his pain, he made eye contact for the first time, and then nodded his head as a "yes" answer to the question about whether his pain was wearing off.

2.2.3. Evaluation: The wound care was given as taught every day in the first week and on alternate days afterwards. No infection symptoms occurred, and the preexisting infection was healed.
2.3. Descriptive Data: The contracture formation due to the coherence of M.C's wounds on his fingers, toes and knees kept M.C. from walking, and hence made him more dependent on his mother.

2.3.1. Diagnosis and Objective: Treating the complications caused by wrong or missing knowledge and care, preventing their reoccurrence and increasing the child's independence. **Interventions:** First, a plastic surgeon examined the child's wounds and said that it was possible to eradicate the joint contracture between the fingers and toes, but there was nothing to do for the knees because of the lasting contracture. It was told that it was a long-lasting treatment, and the family was asked to bring the child to the plastic surgery unit once a week to have a one-hour treatment. The nurse told the family that it would be effective for M.C.'s achieving more independence and feeling better if they would consent to the treatment. The family, who did not accept the process in the first week, said that they would approve it if nursery support was given. To see if M.C. would like to use his fingers, he was informed about the treatment and then asked if he wanted to receive the treatment. With a smile and eye movements, M.C. showed that he wanted it. On the first day of the treatment, the nurse accompanied the family, but in the following weeks, they went alone.

2.3.2. Evaluation: The treatment is continuing. The wounds between the fingers and toes were observed to be better. M.C. smiles more.

2.4. Descriptive Data: M.C's developmental progress was not enough for a nine-year-old child; his percentile curve is low; he was self-enclosed; he didn't not speak; he cried continually; he communicated only with his mother; he was fed with formula at two main meals; he had a poor appetite, and he was constipated. Therefore, he had the following issues:

1- Growth and Developmental Delay
2- Constipation
3- Inappetence
4- Psychological Breakdown

2.4.1.Growth and Developmental Delay

The family was educated about the significance of holistic care for healthy growth and development.

2.4.2. Inappetence and Constipation: For the wounds in M.C's mouth, he gargled three times a day as prescribed by the doctor. The mother was informed about the fact that the formula with which she fed the child was not effective and was increasing the constipation, so she gave up the formula. Instead, she started to feed the child with the soup she prepared at home. She first tried lentil soup. In the first week, M.C. refused to eat it. The mother was told not to give him any formula and to feed him with the soup when he got hungry. Two weeks later, M.C. started to eat soup. Although he only ate 4-5 spoons of soup in the first days, he started to eat more in time. Before eating soup, he only defecated every four days. After starting to eat it, he started to defecate every three days in the first week. The medication of osmoloc solution prescribed by the doctor was then stopped by the doctor. The mother was informed about the regular bowel habits. Until his bowel movements were regular, M.C's acquisition of toilet habits were delayed. The mother was educated to change the diaper properly and to be careful about cleaning the wounds in the anal region. Proper care, however, decreased the risk of wound reformation. The frequency of diaper changes was increased to once every 6 hours at the most.

2.4.3. Interventions: **Psychological Breakdown**:

At the beginning, M.C. started to cry when he saw the nurse. Two weeks later, he started to react to the nurse and to cry less. The nurse tried to speak to the child at the beginning of the home visit. He only nodded his head and made eye contact. He was still self-enclosed.

Evaluation: The practices were in progress. The inappetence of M.C. was decreased. The wounds in the anal region healed and no other wound formation was observed.

3. The Nurse's Diagnosis about the Mother:

3.1. Change in Emotional Mood: Caregiving may have an effect on the caregiver's health and well-being. The never-ending needs of the patient may cause physical problems, such as fatigue and exhaustion. Physical fatigue and health deterioration of the caregiver may increase depression and anxiety (Toseland et al., 2001). The mother had depression, exhaustion, and insomnia.

3.2. Role insufficiency and deficiency: The caregivers expressed that due to the caregiving role they must take, their roles in both their home and their work environments were negatively affected. The mother has three children: a 12-year-old girl, 9-year-old M.C. and another 4-year-old boy who suffered with EB. She described her difficulty in performing her caregiving role for two children with EB, as well as to care for her 12-year old daughter, who helped her mother with caregiving tasks and with housework. She also said that she felt bad because she could not perform her other roles at home.

3.3. Lack of knowledge: The mother felt that that having knowledge about child care alone was insufficient and it should be reinforced by practice, which was not possible in hospitals.
In the end of the four-month nursing care period, the mother said that she completed her missing knowledge and had less physical exhaustion, thanks to the nurse's support. She also told that she felt better herself, knowing that she was not alone.

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