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Umarani J Ms

Yenepoya Nursing College, Yenepoya University, Mangaluru, umasrmc1@gmail.com

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Case reflections on care of a child with palliative care needs

Umarani J

Email: umasrmc1@gmail.com

Abstract

Palliative care is a specialized medical care focused to provide treatment to the patients with life-threatening illness and to the families in order to fulfil the needs of physical, psychosocial and spiritual dimensions. The main aim of palliative care is to relieve the patients with terminal illness from sufferings. In paediatric palliative care, mostly parents are involved as care givers. The children and parents are expected to get health benefits from the palliative team. The palliative care team must identify the needs of patients and families for successful improvement in their quality of life. This article aims at reflecting the care and the issues on the care of a child with terminal illness.

Key Words: Reflections, Palliative care needs, Child

Introduction

World Health Organization (1998) defined that "Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family." Hamilton, et al., (2007), stated that the cause of death among children varies by age. Malignant neoplasm is the leading cause of mortality in preschool and school age children. Palliative care begins from the day of diagnosis of illness and it will be continued irrespective of the treatment received for the condition. It involves multidisciplinary team approach. Abdulrahman, (2011), highlighted that in 1995, Calman-Heine report recommended each cancer unit of the hospital must have non-surgical oncological services, lead clinician, nurses, physiotherapist, social worker, chaplain to ensure that the optimum care is received by the patient. Department of Health and Human Services (2013) reported that multidisciplinary care approach helps to improve the treatment protocol and to detect the psychological and psychosocial need of the patients suffering with cancer. Paediatric nurses are responsible to promote the quality of life of children when there is any health issues, educate the families,

and involve in bedside teaching for students in clinical setting. Their aim is to promote children to function at their maximum potential irrespective of their illnesses and making them as contributing members of their families and society. Buchan & Calman, (2004) reported that nurses have the responsibility to prevent illness, monitor the patient's progress, educate the patient and family, and coordinate the patient care.

Case summary

A 12 year old child was brought to the hospital with the complaints of high grade fever for one week and was feeling cold throughout the day, fatigue, not able to play actively for more than one week, pallor of the skin, conjunctiva, petechiae over the extremities, bone, joint pain and dyspnea upon even mild exertion for two days. The child's past history was uneventful. The child was admitted and the investigations were carried out and diagnosed to have acute lymphoblastic leukemia. Complete blood count with peripheral smear and coagulation studies were done to rule out the number of blood cells in each type. Prothrombin and partial thromboplastin time were done to rule out the clotting abnormality. In addition to that bone marrow aspiration, biopsy, blood cultures, chest radiography, and computed tomography scan were taken.

Umarani J

Professor, Department of Paediatric Nursing, Yenepoya Nursing College, Yenepoya University, Mangaluru

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Outcome of patient management

The management of the child involved a multidisciplinary team approach. The hematologist, radiation oncologist, counsellor, and nurses were involved in the care. Blood transfusion was done to correct anaemia. Induction chemotherapy was started for the patient after which he had nausea and vomiting. Antiemetic was given to reduce the nausea and vomiting. He was able to tolerate the chemotherapy administration to some extent and couldn't sleep well due to pain. Obtained opinion from radiation oncologist for radiation therapy. The family members were given diagnostic and therapeutic counselling by the counsellor. Medication was administered to reduce pain. The nurse encouraged the child to engage in diversional activities to minimize the negative impact of illness and hospitalization for children and their families.

Palliative care of a child with leukemia

a. Physical care: The child was feeling comfortable, but sometimes feeling fatigue. Regular exercise programme was taught by the physiotherapist to relieve the fatigue. Due to chemotherapy, he felt numbness in the fingers and legs. The nurse taught the exercises to strengthen the muscle and develop coordination.

b. Psychosocial care: The child was bit upset due to the separation of mother for some time of the days, as she had to go home to take care of two more children at home. The nurse counselled the child. As he was missing his school activity and friends, he was not much cooperative for the treatment and often asking for discharge from the hospital. This could have been rectified by starting some essential educative programme by the hospital for children to engage them in academic activities. Father stayed in the hospital when the mother went home to take care of other children. The father was the breadwinner of the family. As he couldn't go for his work regularly, he lost his daily wages. So the child's parents felt financial burden and upset.

c. Spiritual care: The mother was always crying that why God gave sufferings to her son in the young age. She felt that she had done some sin to others and due to that God punished her son. The nurse tried to console the mother whenever she was upset. The spiritual aspect was not given much important in the hospital. It

was observed that there were no activities conducted to involve the patients for spirituality.

Discussion

It was observed that the child and the parents faced certain issues related to communication, physical comfort, and spirituality. As the mother was not much educated, she could not understand the nature of disease and the prognosis of the treatment. Chaturvedi, Loiselle, & Chandra, (2009) stated that the Indian law stressed on autonomy, but when it comes to reality, patients are not aware of their diagnosis. The child and the mother can be taken on a trip or tour to patients who had undergone treatment for similar conditions and encourage rapport with the patient and their family members. This will help them to understand the situation well and reduce the communication barrier to clarify their doubts with the health care providers. King & Quill, (2006) said that worldwide the palliative care emphasized the importance of family. So both the parents must be given adequate information on the treatment progress according to their level of understanding. Most of the time the child was crying due to pain. He was not getting adequate management for pain. Sykes & Thorns, (2003) revealed that there was no reduction in the survival of patients who received appropriate doses of opiates. Hammes & Cain, (1994) said that many national guidelines reported the ethical issues related to pain management and the main problem is in the application of these standards into practice. The child's pain control can be achieved by means of initiating patient control analgesics concept and complementary therapy like play, guided imagery and music therapy an initiative to reduce the pain. Himmelstein, (2006) stated that Non-pharmacologic interventions help the patients to reduce pain. The child experienced numbness in the fingers and legs. The patients may develop peripheral neuropathy after chemotherapy. It was also found in a report by Bay, Yilmaz, Yilmaz, & Oner, (2006) that vincristine-induced neurotoxicity can cause some side effects including paresthesias. The signs and symptoms of numbness should not be neglected and it has to be consulted with the oncologist. Physical examination, electro myography, and nerve conduction test can be done to diagnose the peripheral neuropathy. Spiritual aspect was not given much importance in the hospital.

Balboni, et al., (2007) conducted a study to assess the importance of religion and spirituality in patients with advanced cancer. Among 230 patients, 68 % expressed that religion is very important, 20 % felt it's somewhat important and 12 % said it is not important. It was also found that the spiritual activities were increased from 47% before diagnosis to 61% after diagnosis of cancer among the patients. The spiritual issues can be reduced by arranging a clergy visit and a prayer hall for the patients and relatives. Palliative care has a great implication in the field nursing. Palliative care is meant to keep the person comfortable as far as possible. A centre for caring the patient with terminally ill at their home can be an initiative for them to feel comfortable. Health care providers must be encouraged to attend the workshop, conferences to get trained to care the patients better. In addition to that, they can take up some certificate course on essentials of palliative care. The concept of palliative care can be incorporated in nursing curriculum.

Conclusion

All the health care providers were actively involved as a team in treating the child with leukemia. In general, the hospital provided all possible care, but the palliative care aspect was very limited. Therefore, the nurses and other health professionals must understand the concept of palliative care well in order to provide better care to the dying children. This will promote the integration of palliative and supportive care and provide better quality of life for the needy.

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