



## Addressing Physical and Psychosocial Needs of Patient Suffering from Ewing's Sarcoma

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### Abstract

Palliative care nursing addresses the physical, emotional, social, spiritual and sexual needs of the patients suffering from life threatening illnesses or those who require long-term care. Moreover, it facilitates patient's autonomy, access to information and choice as per their wish. Being a nurse, it is quite challenging to expedite the needs and the situation become even more challenging when the patient is young. This article will discuss the case study of the young patient suffering from Ewing's Sarcoma, the physical and psychological effects and will also recommend strategies for improvement.

### Introduction

Palliative nursing is an absolutely systematized philosophy of care that relieves sufferings and supports the best possible quality of life for patients and their families, irrespective of the stage of terminal illness by addressing physical, emotional, social, spiritual and sexual needs of the patients together with facilitating patient's autonomy, access to information and choice [1]. Therefore, the core of palliative nursing care is the protection and promotion of health by alleviation of sufferings of patients.

### Case Study

During palliative care clinical rotation, I encountered a 17 year's old, unmarried female patient who was diagnosed with Ewing's sarcoma of left leg. She was admitted for 4<sup>th</sup> cycle of chemotherapy. The patient verbalized that "I am having severe pain in my legs. Moreover, the side effects of chemotherapy had affected me holistically. I cannot visit my family due to treatment and procedures. I want to appear for my exams in April but I haven't studied due to frequent hospitalization for the management of disease process". Her detailed physical assessment revealed pain in left leg having score of four out of ten and mild edema in lower extremities that resulted difficulty in walking. As a result of pain and the side effects of treatment, her appetite had also decreased along with paling of eyes, dryness of skin and mouth ulcers. As a consequence of decreased appetite, she experienced weakness and fatigue and had lost significant weight in last six months. The pain in left leg did not let her sleep peacefully that resulted in frequent mood swings and irritability in personality. She also felt embarrassed in socializing and stayed at home due to her disturbed body image as a result of alopecia. Furthermore, she had left her family and friends and was staying with her mother's friend for treatment of the disease. Moreover, she was overwhelmed with the stress of her studies as she wanted to appear for HSc part I examinations that are scheduled in April 2015. The physical suffering and the psychosocial distress revealed by this scenario compelled me to address the physical and psychosocial needs of patient suffering from Ewing's sarcoma.

The moment this incident caught my attention, initially I felt the same pain and agony that was experienced by the patient. I was depressed on seeing the patient helplessly lying on the bed in devastating condition. I felt pity for the patient who was moaning as a pleading to God for curing her disease. Besides that, my emotions had suppressed my ability to think and work. Later, I prayed for this patient and thanked God for blessing me a healthy life.

### Recommendations

According to World Health Organization, cancer pain relief is a human right i.e. freedom from pain should be seen as a right of every cancer patient and access to pain therapy as a measure of respect for this right [2]. Referring to case scenario, pain management is the most evident need of physical aspect of palliative care. The appropriate physical symptom management is the most fundamental part of palliative care. This is also evident that the pain experience is closely related with

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Received Date: 27 Jun 2019

Accepted Date: 27 Jul 2019

Published Date: 30 Jul 2019

#### Citation:

Ali S, Muhammad Ali Allana HM.  
Addressing Physical and Psychosocial  
Needs of Patient Suffering from Ewing's  
Sarcoma. *Ann Palliat Care Med*. 2019;  
1(1): 1004.

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psychological and social issues that may adversely affect the quality of an individual's life [3]. This may include decreased endurance, poor appetite, interrupted sleep, diminished enjoyment, anxiety, fear, difficulty concentrating and diminished social relationships [4].

Accordingly, patient was prescribed opioid analgesic for relief of pain. I assisted patient by focusing care on the management of pain through non pharmacological techniques. I encouraged patient to perform active range of motion exercises according to the energy level. I placed the legs on the rolled towel to provide comfort to the affected leg. I also changed the positions of the patient every two hourly. I provided opportunities for rest during the day time and instructed for periods of uninterrupted sleep at night. I also discussed the non-invasive pain relief measures such as deep breathing exercises, warm bath, hot water compressions and massage. I also guided her distraction techniques to distract the person from pain experience such as talking or chatting with siblings and friends, reading story books, listening to music and playing games on mobile. Moreover, the importance of good nutrition was emphasized by encouraging the intake of small, frequent high energy and high protein diet to minimize weakness and fatigue. Furthermore, teaching was provided for the management of the side effects of chemotherapy.

## Model Integration

According to the Wellness Model, Wellness includes the mental, emotional, physical, occupational, intellectual, and spiritual wellbeing of a person's existence [5]. Each aspect of wellness affects the quality of life therefore it is important to consider different aspects of health. In the aforementioned case, patient was experiencing physical symptoms that were compromising the psychosocial aspect of patient's wellbeing. Moreover, the burden of serious illnesses causes newly diagnosed child and adolescent to experience responses, such as sadness on separation from family, anxiety about treatment and procedures, fear of death, stress about academic performance and loss of self-independency in response to the disease process that are classified as psychological and emotional distress [6]. Hence, there was a need to address the psychosocial distress for the maintaining patient's wellbeing.

Initially, I addressed psychosocial distress by encouraging her to ventilate and verbalize her feelings, thoughts and views about the disease process through therapeutic communication skills as therapeutic communication is the best tool to ventilate patient's feelings [7]. Moreover, information of disease process was presented in a simplified version through short and concise sentences. Frequent summarizations were done to assist patient in comprehending the conversation. Ample time was also provided for questions and queries. Furthermore, I guided her to study past papers of HSc I to pass the examinations. I advised her to collect notes of different subjects from classmates via cell-phone or email. I advised her to cover the head with the scarf to conceal alopecia. Family support was also reinforced by talking or chatting on mobile phones and also by promoting visits from friends and family to Karachi as convenient for family.

## Strategies for Improvement

Following strategies could be recommended to address the physical needs. At individual level, guided imagery could be performed to help patients divert their attention from the experience of pain through an imaginary scene, such as of a favorite holiday scene or a best day of life. Furthermore, diversional therapies such as card making, painting, puzzle solving could distract the patient

from experience of pain. At institutional level, counseling sessions can be arranged for the patient to reinforce the practice of non-pharmacological measures for the management of pain. At national level, research programs should be encouraged for effective palliative care. Besides that, the effective numerical, verbal and pictorial pain assessment tools could be used to assess the intensity and the severity of pain. In addition, Edmonton Symptom Assessment Scale (ESAS) and Memorial Symptom Assessment Scale (MSAS) are recently developed validated measures of cancer-specific quality of life [8]. They can be used to assess the severity of prevalent symptoms and evaluate the impacts on physical, psychological and social functioning of the patient.

Following strategies could be recommended to address the psychosocial needs. At individual level, a teaching activity regarding emotional coping skills can be practiced including stress managing exercises through music therapy. Moreover, meditation is another approach that requires the patient to practice quiet relaxation [9]. At institutional level; support groups can be formed by the patients who had been cure from serious illnesses to guide patients the ways to cope from illnesses. Furthermore, Cognitive and behavior therapies can be effective in enhancing positive self-concept by making patients realize the blessings of life [10]. Family therapy can be encouraged to elaborate the importance of family support in the management of disease process. Moreover, the family visits can be arranged to encourage socialization. At government level, training sessions and refresher courses for health care provider should be initiated to enhance patient's wellbeing. Nurses should be encouraged to join this specialty to enhance the quality of lives of patients suffering from terminal illnesses through media.

The face to face discussions and online virtual seminars helped me in understanding the concepts of palliative nursing care. Moreover, clinical rotation and guidance from faculty on ongoing basis helped me in understanding patient's disease process and assisted me in identifying the alternatives for the addressing the physical and psychosocial needs of the patient. By the end of my clinical, I realized the power we, nurses have to make a difference through our dedicated interventions. Despite of all the nursing efforts, holistic care was lacking in few aspects due to certain limitations like limited theoretical knowledge, time constraint and lack of resources at clinical settings.

## Conclusion

The journey of palliative care is the most challenging aspect of nursing profession. Yet, the essence of palliative nursing care is to relieve the suffering of mankind by all possible means.

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