

Caring for Patients on Palliative Care

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Abstract

Death and dying are undoubtedly expected destiny in human's life. Life becomes hard-hitting when assortments of life-limiting pathologies grasp human body. Every individual desires to spend a quality life but unfortunately those who are sufferers of terminal illness need special care to improve the quality of life. This special care is known as palliative care. As a nurse, it is one of the most intricate tasks to facilitate patients in peaceful and decorous death keeping patient's autonomy, access to information, and choice as the priorities.

Keywords: Palliative care; Dysphagia; Squamous cell carcinoma; Holistic care; Metastatic

Introduction

World Health Organization (WHO) defines palliative care as, "an approach that addresses physical, intellectual, emotional, social and spiritual needs of patients, advances the quality of life of patients and their families meeting problem associated with life-threatening illness" [1].

Case Study

During palliative care clinical rotation at Bait-ul-Sukun Cancer Hospital, I encountered a 50 years old female patient diagnosed with squamous cell carcinoma of esophagus. On investigation, histopathology and radiology reports (CT scan, MRI and biopsy) revealed metastatic deposit to sub-pleural membrane of lungs. She was presented with the complain of dysphagia, vomiting, coughing and moderate throbbing pain in left upper quadrant rating four out of ten. As a consequence of above mentioned symptoms and frequent hospitalizations, she had significant weight loss. In addition, patient appeared lethargic due to physical exertion caused by usual coughing. The difficulty in breathing and pain disturbed her sleep that caused recurrent mood swings and tetchiness in her personality. The patient verbalized "I am exhaust with this condition. I just want to have relief from these sufferings." Looking at the manifestations and investigations, she was advised symptomatic treatment as the disease had metastasized to lungs, suggestive of stage IV. To relieve her sufferings, esophageal stent was placed but unfortunately the insertion failed due to fistula formation.

According to Billings and Krakauer, the right to knowledge is derived from the principle of respect for patients as individuals [2]. Patient was communicated that she has infection of gastrointestinal tract that will soon recover by antibiotics. The point to ponder here is that the patient was unaware about the disease process, prognosis and its treatment options. The truth was concealed from patient by the family as they believed that revelation of the truth will make patient psychologically upset and her condition will deteriorate. Yet, the

patient doubted that she is suffering from life threatening illness as she asked multiple questions about her condition. In addition, she also felt embarrassed in socializing with other patients in the ward and preferred lying on bed with face turned. Telling the truth to palliative care patients is an important issue in our society that requires comprehensive efforts for its resolution. Therefore, this paper will focus on dealing with the physical and psychosocial needs of the patient on palliative care.

When I encountered this scenario, I began to feel the same suffering and anguish which my patient was going through at that time. My emotions had completely surpassed my capability to think. I felt disconsolate after seeing the helpless patient lying on the bed. I felt sympathy for her because of the devastating condition. Lastly, I thanked God for blessing me a healthy life.

Discussion

Referring to the scenario, symptom relief is the most noticeable need of physical domain of palliative care. It improves the quality of life and promotes patient's wellbeing. Downing and Radbruch, elucidate that the development of several chronic diseases bring number of symptoms that reasons severe impairment [3]. Therefore, appropriate physical symptom management is the most essential part of palliative care. In the above mentioned scenario, dysphagia is the most important symptom that needs to be looked. Consequently, malnutrition, weight loss, anorexia, aspiration pneumonia are the result of untreated dysphagia [4]. Initially, I planned my care focusing management of dysphagia. I encouraged the patient to eat semi solid food including blenderized low fat diet including chopped chicken, khichdi, mashed banana, pudding/jelly and porridge. Besides that, a teaching session was delivered to the patient and family members on importance of good nutrition and high energy, high protein diet with emphasis on taking small, frequent meals with two hour interval. It also minimized weight loss and fatigue by promoting repair of damaged tissues. Frequent water intake was also suggested to minimize dryness of mouth. Functional independency was enhanced by planning activities and rest periods to conserve energy. Assistance was given in self-care activities. Non techniques including guided imaginary, mind diversion activities were planned to relieve pain [5].

Painkillers were also administered as per the need. These interventions helped to overcome the physical symptoms.

The challenges faced by the families when encountered with a terminal illness of a loved one are complicated. Relating it with scenario, the family was in crises stage. According to Okun and Nowinski, a crisis is the first stage that disturbs the equilibrium within the family [6]. Anxiety prevails as initial reaction at this stage. The family is overwhelmed with number of questions and tries to conceal news from their loved one. Feelings of guilt and anger are very common. Dealing with these sensitive issues i.e. telling the truth or psychological distress etc. are the vast challenges and requires effective planning. Bad news leaves the patient frustrated and generates a variety of emotions in patients, family caregivers and healthcare professionals [7]. Panic, grief and sorrow at varying times in response to the disease process experienced by the patient are known as psychological distress [8]. Adjusting with losses and transformations are not easy as these changes demand flexibility and resilience. Furthermore, the patient kept herself isolated by avoiding interaction with other patients in the ward, maintaining silence, not participating in group activities and family gatherings.

I believe telling the truth and making someone cry is healthier than telling a lie and making someone smile. At individual level, I counseled the family to reveal the truth to decrease uneasiness of the patient. I explained family about the prognosis of disease (stage IV- metastatic stage) and guided treatment options with the help of pictorial explanation. Information was presented in a simplified version. Short and concise sentences were used. Sufficient time was provided for questions and queries. Moreover, frequent summarizations were done to remain on same wavelength as of the receiver's. According to Benkel, Wijk and Molander, receiving information is the first step towards coping with difficult news and regaining control over their own destiny [9]. I helped family in understanding the fact that quality of life matters rather than the quantity [10]. In addition, activities for emotional coping skills including anxiety management activities, muscle relaxation exercises, guided imagery were performed. Moreover, family support was also encouraged by endorsing visits from friends and family that ultimately helped to uplift the self-esteem of patient.

Recommendation

In future, it is recommended that hospice care settings should be extended in developing countries like Pakistan to heighten the significance of palliative care [11]. Home health care services, psychological support groups should be introduced. At individual level, nurses can adopt CARES model i.e. Comfort, Airway, Restlessness and delirium, Emotional and spiritual support, and Self-care to perform essential tasks that need to be accomplished during the last few days to hours of a patient's life [12]. At institutional level, trainings, seminars, workshops and conferences should be arranged to enhance the importance of quality care at end stage of life. At governmental level, there should be unbiased distribution of resources for patients on palliative care as every individual has the right to live. In addition, nurses must also be enrolled in this specialty to improve

the quality of lives of patients. Moreover, media should be utilized to create awareness among healthcare professionals and general population about the importance of palliative care. In addition, videos, panel discussions, power point presentations should be used to assist exchange of talk between patients, families and their physicians about various end-of-life interventions. Furthermore, research regarding palliative care should be encouraged to provide better holistic care in future.

During my palliative course, discussions, virtual seminars and clinical assignments helped me in learning the concepts of palliative care nursing. The clinical rotation provided me the opportunity to integrate the learned concepts into clinical practice. I learned to cure the disease with joy, empathy and comfort. As a nurse, I can commit to make a positive impact on the lives of the patients on end stage of life in future.

Conclusion

In conclusion, the expedition of palliative care is no doubt a challenge but I believe nurses have the power to transform lives of the patients through selfless enthusiastic efforts. Nurses working in palliative care settings should run with the motto of helping their patients to live each day to the fullest. As truly said by Maya Angelou, "as a nurse we have the opportunity to heal the heart, mind, soul and body of the patients, their families and ourselves".

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