



End of life care and family issues and their concerned at palliative care at bhaktapur cancer hospital

Chadani Vaidya and Roshan Prajapati

Abstract

Objectives: The objective of the study was to find out the family issues and their concerns about the end of life care planning at palliative care unit admitted the patient.

Method: A respective study was carried out among the family members of advanced-stage cancer patients who were admitted to the palliative care unit from 1st Jan to Dec 31st, 2017. 70 family counselling forms which include patient's demography, final diagnosis with stage, and patients knowledge about their own disease, present patients palliative performance status, relevant family issues from nearest family members and planning of end of life care.

Result: The study revealed the majority of patients were male. 70% have PPS <50% (80%) lies between 50 to 88 years with stage IV disease (80%). Most of them CA lung 80, Ca Stomach 30, Ca breast 36 Ca gallbladder 24, Ca head and neck 24, Ca ovary 16, Ca colon 24, Ca pancreas 18, sarcoma 24. 60% of family members prefer home for final hours of life and 60% want no active treatment and allow natural death. 62% patients did not know their disease as cancer due to family barriers, 70% of the family member thought to know their malignancy with increase their anxiety and hasten death.

Conclusion: Majority of the patients 62% did not know their disease due to the familial barrier, 2/3 of the families had many issues which need to be addressed financially, socially as well as emotionally, most of them want to take back to own home at last hour of life. As there are no good facilities to take care at the periphery, home hospices are the special need for patients care and bereavements.

Introduction

In 2002, the Nepal branch of INCTR (the Nepal Network for Cancer Treatment and Research) requested help in developing a collaborative program in palliative care. A team of palliative care experts drawn from the United States, Canada, and Saudi Arabia is working closely with the "Nepal Palliative Care Group," which was formed by some concerned and committed Nepali physicians and community leaders. During this process, it became apparent that addressing the three key WHO foundational measures (governmental policy, education and training, and opioid availability) were essential for ongoing progress.

Nursing Education

Recognizing that nursing education regarding knowledge, skills,

and attitudes is a critical aspect of effective palliative care initiatives, education for nurses is an integral component of INCTR's collaborative work in Nepal. Educational sessions for nurses in Nepal have been of two types: interdisciplinary sessions held jointly with physicians and other health care providers, and smaller groups organized solely for nursing staff, with the goal of fostering more open discussion and dialogue. Nepali nurses actively participate in these workshops, providing articulate feedback and contributing to discussions regarding the challenges and rewards of palliative care nursing. Many have given pertinent presentations to an interdisciplinary audience, both generating increased visibility for the important role of the nurse and enhancing physician-nurse collegial relationships. Additionally, select nurses have been chosen to attend advanced palliative care training at the Pain and Palliative Care Centre in Calicut, India. Nurses in Nepal struggle to provide care with limited resources, and efforts are underway within INCTR to address the specific need for nursing-related supplies, such as personal protective equipment to safely administer chemotherapy. Nurses at the sites described below must also cope with the frustrations that challenge nurses in all countries and institutions: staffing shortages, competing priorities within nursing administration, limited time for educational development, and the cumulative emotional stress of caring for terminally ill patients.

Bhaktapur Cancer Hospital

Bhaktapur Cancer Hospital in the Kathmandu Valley provides treatment to patients from all over Nepal. Presently it has 32 inpatient beds, five of which are designated for palliative care patients. Of 2,522 admissions in 2004/2005, 18% were admitted for palliative care (6% admitted specifically for pain management and 2.5% of patients for terminal care). There is also an outpatient palliative care clinic open two days per week. Of 13,178 outpatient visits to the hospital, 11% were for symptom management. There are also emergency services provided for palliative care patients. Similarly, there is a 24-hour phone advice service for those patients needing help but who cannot come to the hospital. Oral as well as parenteral morphine has been available for more than one year. The hospital also has counseling services, offered through its Cancer Support Program. Fifteen of these will be dedicated to palliative care patients. The hospital is developing a twinning relationship with Nanaimo Community Hospice, British Columbia, Canada.

The impetus for the development of palliative care in Nepal was based on the recognition by a group of Nepali oncologists and other health care providers of a profound and unmet public health need, that of the symptomatic care of people living with advanced disease. The collaboration between INCTR and the Nepal Palliative Care Group has been characterized by a systematic attempt to develop a secure basis for the growth and sustainability of palliative care by fulfilling the WHO foundational measures as well as implementing clinical programs at four facilities in the Kathmandu Valley and other identified regions. Planning is also under way to establish a Palliative Care Training Centre that will consolidate these advances, making the benefits of these services more widely available to greater numbers of people and communities.

*Corresponding author: Chadani Vaidya and Roshan Prajapati, Bhaktapur Cancer Hospital, Nepal