

Review Article

Palliative Care : Our Moral Obligation

Masud Ahmed¹. Md. Manowarul Islam². Nadeem Parvez Ali³. Azizun Nessa⁴. Kamal Krishna Karmakar⁵

¹Classified Specialist in Anaesthesiology, CMH Comilla. ² Associate Professor, Dept. of Anaesthesiology, Dhaka National Medical College.

³Graded Specialist in Anaesthesiology. BGB hospital. Dhaka. ⁴Graded Specialist in Medicine, CMH Dhaka. ⁵Junior Consultant, Dept of Anaesthesiology, NICVD, Dhaka.

Introduction

Palliative care (from Latin palliare - to cloak) is any form of medical care or treatment that concentrates on reducing severity of disease symptoms rather than striving to halt, delay or reverse progression of the disease itself or provide cure. The goal is to prevent and relieve suffering and to improve quality of life for people facing serious, complex, incurable illness. Non hospice palliative care is not dependent on prognosis and is offered in conjunction with curative and all other appropriate forms of medical treatment¹. There is often confusion between the terms palliative care and hospice. In United States of America (USA) two aspects of care share a similar philosophy but differ in their payment system and location of service. Unlike palliative care hospice service are usually provided by government fund or by charities outside traditional hospital. Elsewhere for example in United Kingdom (UK) this distinction is not operative. For all practical purpose it is better to use the broader term palliative care as hospice care is part of it¹.

World Health Organization (WHO) defines² palliative care as ‘an approach that improves quality of life of patients and their families facing the problems associated with life threatening illness.’ It -

- a. Affirms life and regards death as a normal process.
- b. Does not hasten or postpone death.
- c. Provide relief from pain and other distressing symptoms.
- d. Integrates the psychological and spiritual aspects of patient care.
- e. Offers a support system to help patient live as actively as possible until death.
- f. Offers a support system to help the family during the patient’s illness and in their own bereavement.

Historical Background and Development

Palliative care began in hospice movement. The word hospice derived from the Latin word ‘hospes’ meaning double duty in referring both to guests and hosts³. The first hospices are believed to have originated in the 11th century around 1065 AD when for the first time the incurably ill were permitted in

places dedicated to treatment by crusaders. In the early 14th century the order of Knights Hospitaller of St John of Jerusalem opened the first hospice in Rhodes meant to provide refuge for travelers and care for ill and dying persons³. After quite a few ups and downs in middle age hospice movement attracted attention of medical science in middle of 19th century when Lancet and British Medical Journal published articles pointing to the needs of impoverished terminally ill for good care and sanitary condition. But to gain momentum of this movement it took another century when an English registered nurse Dame Cicely Saunders⁴ a pioneer in this field disseminated her philosophy of palliative care internationally in a series of tours in USA that began in 1963. She founded first modern hospice in 1967 named ‘St Christopher’ working as charity. With time hospice care adopted more scientific approach and turned into ‘palliative medicine’ a branch of Royal College of Physicians since 1989. In USA there are more than 50 programme which provide 1-2 years of specialty training following a primary residency⁴.

In the last two decades palliative care service improved dramatically worldwide. The WHO (1990) and the Barcelona (1996) declarations both called for palliative care to be included in every country’s health service. A 2010 study

regarding the availability of palliative care in 120 US cancer centre reported only 23% have beds that are dedicated to palliative care, 37% offer inpatient hospice, 75% have a median time of referral to palliative care to the time of death 30 to 120 days⁵. In the UK in 2005 there were 1700 hospice services consisting of 220 inpatient units for adults with 3156 beds, 33 inpatient units for children with 255 beds¹. As of 2008 approximately nine hundred thousand people in USA were utilizing palliative care every year with more than one third dying American utilizing this service⁶.

Practice of Palliative Care

Palliative care originated because of the belief that terminally ill patients were not receiving optimal care and for a long time there was a mutual distrust between the practitioners of palliative care and orthodox medicine. Initially hospice or palliative care was practiced by very caring individuals who knew very little about medicine. But modern palliative care is integrated with mainstream medicine and provides active treatment of the underlying disease as well as holistic care which complements each other⁷. Successful palliative care requires attention to all aspects of a patient's sufferings whether it is physical, psychological, social, cultural or spiritual. So it demands input or assistance from a range of medical nursing and allied health personnel. Ideal multidisciplinary palliative care team includes medical staff, nursing staff, social worker, psychologist, occupational therapist, dietician, psychologist (or liaison psychiatrist), chaplain (religious personnel), volunteers, other personnel as required, family members and patient⁸. Regarding medical staff he/she should be expert on palliative medicine coming from any branch of clinical medicine. As in most dying cases pain in the centre point for all problems an anaesthesiologist skilled on analgesia and critical care can play a leading role in palliative care⁹. Palliative medicine specialist will ensure the scientific coordination of multidisciplinary approach of complex patient care, research in this field and organize training to develop expertise¹⁰.

In every year more than five million people die worldwide die, 80% of whom die from incurable diseases like malignancies, AIDS etc¹¹. Every patient with an active, progressive, far advanced illness has a right to get palliative care. Every doctor and nurse has an ethical responsibility to the principles of palliative care in managing these patients¹². Treatment of pain and other physical symptoms are addressed first because it is not possible to deal with the psychological aspects of care if

patient has unrelieved pain or other distressing physical symptoms¹³.

Woodruff R⁸ summarized palliative care as follows-

- a. Attitude to care - caring attitude, commitment.
- b. Treatment of underlying disease – e.g. radio or chemotherapy for cancer, antiretroviral therapy for AIDS.
- c. Active medical treatment of complications of primary disease or its treatment e.g. cancer- hypercalcaemia, fracture, gastrointestinal obstruction, AIDS – opportunistic infections, malignancies.
- d. Symptomatic and supportive care – pain and other physical symptoms like breathlessness, fatigue, loss of appetite, weight loss weakness, confusion, depression, anxiety, vomiting etc.
- e. Psychological, social, cultural, spiritual, existential problems.
- f. Diagnosis of other underlying, incurable diseases.
- g. Death.

Usually a palliative care patients concerns are pain, fears about the future, loss of independence, worries about their families and guilty feelings of being burden of the family. Most are also anxious about the life after death. All these concerns are better dealt by psychologist or religious personnel by open discussion with patient¹⁴.

No patient should ever be told there is nothing more that can be done – as it is never true and may be seen as abandonment of care. It may be permissible to say there is no treatment available to stop progression of the disease but it is always possible to provide care and good symptom control¹⁵. In the terminal days when all the treatment modalities fail patient and their family get frustrated and tend to accept any sort of alternative therapies like herbal, spiritual etc. These should be permitted unless it is injurious for patient. Some alternative and complementary therapies like massage, meditations can help to relieve tiredness, stress, anxiety, depression, frustration and loneliness. They can also be motivated by various recreational arrangements¹⁶.

In UK palliative care service offered as inpatient care, home care, day care and outpatient service, the cost of which is borne by National Health Service (NHS) or through charities working in partnership with local health service. In USA palliative care services are offered to any patient under hospice care benefit, however requires two physicians certificate that patient is unlikely to survive more than six months, of course they are not discharged from the hospital if survives more than that⁵. Such restriction does not exist in other countries.

Barriers of Palliative Care¹⁷

a. Physician:

Late referral due to poor prognostication, lacks communication skill to address end of life issues. Reluctant to refer – does not understand or believe in palliative care, loss of control on patient or income. Lack of institutional standard for end of life care. Lack of physician reimbursement.

b. Patient:

Believe prognosis better than they are told. Unrealistic expectation of disease response. Patient, family disagreement about treatment options Lack of advance care planning. Financial involvement specially for long term cases.

c. Social Factors:

Unawareness of the right to access. Poor, illiterate, ethnic minorities.

d. Access factors:

High cost of care if not subsidized by governments. Laws and regulations restricting production, use and purchase of drugs like morphine.

Our Perspective

In a poor socioeconomic condition like ours, it is very difficult to motivate our policy maker to divert more resources in palliative care when we cannot ensure curative care for most of our population. But a civilized society cannot ignore the importance and demand of palliative care for the hundreds of thousands of dying patients each year. At some point we have to start it as was done in 2008 when first palliative care unit of Bangladesh was established in Bangabandhu Sheikh Mujib Medical University (BSMMU) as branch of Anaesthesiology and Intensive Care Department with limited indoor and outdoor service. Now a days it is also practiced in intensive care unit (ICU) of various private hospitals where their admission is rather depriving actual ICU patient i.e. patients with serious but curable diseases¹⁸. To overcome all these obstacles following steps¹⁹ can be taken –

- a. Development of a national policy and thereby allocating yearly budget and establishing palliative care department in every government hospital.
- b. Extensive media campaign to motivate and recruit volunteers and involve charities to donate fund.
- c. Training of health workers and public education to develop expertise and create awareness amongst general population.

Conclusion

As a member of a civilized and humane society we must not consider palliative care is a useless charity. We should not forget that the dying person has given his/her everything for his/her family and society and we simply cannot leave them alone when they need us most. As healthy living person we should also remember that we may have to go through the same painful days at the end of our lives. So it is our not only ethical but also moral obligation to do whatever we can to reduce their sufferings at least partially with the help of medical science and a sympathetic touch.

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