

CHALLENGES OF PALLIATIVE CARE

Shamima Parvin Lasker

Professor and Head of Anatomy, City Dental College, Dhaka, Bangladesh

General Secretary, Bangladesh Bioethics Society.

ABSTRACT: It has been moral duty of physicians to save and prolong patients' life for as long as possible. But the philosophy of treatment regime for terminally ill patients had been changed. To save and prolong human life if it is meaningful has got added value. Many criticize the modern way of death. Palliative sedation, euthanasia as a good death model is criticized for medicalization of management of death. Currently, end of life issues are one of the top 10 health care ethics challenges facing the public. There is a new ethical challenge that human life can be ended by a doctor, passively or actively or a doctor kills the patient. Withholding and withdrawing, refusal of treatments, physician-assisted suicide, do not resuscitate (DNR) orders, advance directives, consent and quality of end of life care and are the main debates in this field. There are many complex ethical issues that can affect patients and families in the health care setting. Good understanding of medical ethics will contribute to the health professional's decision-making and day-to-day practice of medicine for a terminally ill patient.

Key Words: challenges, palliative care

INTRODUCTION: Medicine or healthcare is not only to provide cure but also to offer comfort and empathy. Palliative care creates an environment where healthcare providers, patients, and patient's families can consider what treatments will or will not be used to treat a life threatening illness. The goal of palliative care is to improve the quality of life of patients and reduce the burden of illness by reducing the use of aggressive treatment measures at end stage disease and reduce suffering of long-term illness through managing symptoms providing nursing care and psycho-social and spiritual support. But the people are not aware about this mode of treatment. It is still an emerging field even in developed countries. Plan of palliative care is to make pain relief as a basic service only in most of the Asian countries. Unfortunately, care is merely limited to diseases like cancer. This policy is not translated into extensive service provision.

HISTORY OF DEATH SYSTEM: Traditionally a man who suffered from end stage disease called not the doctor but the religious person. Man was dying at home. He saw death as a spiritual passage. The authority of dying process was priest/ moulovi / purohit. Funeral and mourning adheres to the family.

Due to the improvement of nutrition and medical technology death rate reduced dramatically. Dying is no longer seen as spiritual but a medical condition. Key person is the doctor. Patient is hospitalized and dying

at hospital. Family and close relative keep their grief privately. Three quarter of British died in this modern system of death. Of 70% death in Britain is now followed by cremation.

Rising of individual and collapsing of community, dying person is the key person of the dying process. Patient has right to die without pain. Dying person can take decision when and how he /she wants to die (euthanasia, assisted suicide). Dying person can celebrate own funeral before death and get time to say goodbye to family members. Relative can express grief and talk how they feel to the dying person. Patients suffering from pain for long time with Cancer, HIV/AIDS, end stage cardiac or renal diseases, etc usually wish for postmodern system of dying. In USA, End-of-life care depletes 12% of total health care costs. Many criticize the postmodern way of death. End of life issues are one of the top 10 health care ethics challenges facing people.

CHALLENGES OF PALLIATIVE CARE:

Misconception: Palliative care is applicable early course of illness, in conjunction with other therapies such as chemotherapy or radiation therapy, intending to prolong life and enhance the quality of life. According to definition of World Health Organization (WHO), palliative care is an approach that improves the quality of life of patients and their family facing the problems associated with life threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical psychological and spiritual. But it is generally misconception that only people who are terminally ill and those whom doctors have given up hopes of any progress, need palliative care.

Information gap: Death and dying is not a failure but the most natural things and sure event in life. But there is a custom not to talk about imminent death to a terminal ill patient in many society and culture. Patients may not have discussed end-of-life decisions and wishes with their families while they were competent. Family members often do not want to be the ultimate decision maker when death is inevitable. Intensive care unit health care professionals may have challenged to support patients and families due to lack of information.

Pain: Pain is the dominant symptom in advanced stage diseases. Pain can make a patient anxious, discomfort and impatient. Due to continuous pain patients accompany unhappy death. Family members are repentant with sorrow due to miserable death of their love one. Pain relief can be successfully achieved by the scientific and holistic approach of analgesic administration in palliative care. Unfortunately, studies such as the large SUPPORT trial have shown that 50% of patients still die in pain and 33% of these people experienced severe pain in the last days of their lives. Lack of knowledge and skill in pain assessment, improper medication, unavailability of morphine and fear of opioid addiction are some of the complex hurdle of palliative care.

There is fear that drugs (sedatives and opioids) prescribed in the terminal stage hasten the death process. Research critic the Dutch end-of-life (EOL) policies and claimed that approximately 20.1% of all deaths were cases in which death occurred following an increase of medication to alleviate pain symptoms. Study revealed that one the patient died after an increase of morphine at the request of the family with alleviation

of suffering and intention to hasten death. This case criticized practice of the use of increased morphine, with the intention to alleviate suffering and at the same time also shorten life. Pain relieving medication has been administered in the end stage disease for its “double effect principle”. In one hand it mitigates unrevealing pain and on the other hand it shortens life. The Moral justification to provide analgesia at end stage disease for the noble intention of relieving distress provided that other conditions are satisfied. These conditions include, relevantly, that the physician must not intend to relieve distress by first killing the patient. The principle of double effect provides a basis for ensuring adequate symptom relief, even though this may hasten death, provided that this is not the physician’s intention. The legal justification of use of analgesia for palliative care practices is less clear.

Physician Value: The debate over influence of physician judgment on patient autonomy at end-of-life care has long been studied. Study suggests that decisions regarding terminal patient care may be altered by a physician point of view and subjective attitudes toward dying patients. Physician view on patient choice is more of an illusion than a reality. Physician’s anxiety towards death and their discomfort with dying patients reflect on their own past experiences, both personal and professional, impact on their feelings regarding the treatment options available to a given patient. Study also shown that of 25 percent reported difficulty honoring advance directives if these went against what the physician believed was best for the patient. Physicians picture the situation worse than it is in order to get the patient to decide what the physician feels to be in his/her best interests. Goal is to hope for the best course of illness or for best quality of life for the longest possible time. Physicians must be aware of their own values, beliefs and attitudes towards life-sustaining treatments as well as death and dying. Ethics education should be Intensify especially for physicians routinely involved in end-of-life care.

Do not Resuscitation (DNR): Some people believe that all attempts must be made to continue life since life is precious. Family want to feel that they have tried “everything” for the patients. If heart of a patient stops, family members want to restart it with cardiopulmonary resuscitation (CRP) using the paddles and electric shocks. This is not an easy or even very successful endeavour for the most of the cases. It may break some of ribs and bruise some of internal organs. If heart does not restart quickly, brain damage occurs. This may lead to loss of memory to paralysis. If heart restarts patient needs to be on life support afterwards. E. Ezekiel, a bioethicist of NIH, USA expressed concerns about the quality of care. Physicians provide different aggressive therapy to who are not responding. “Just to try something” is not only bad medicine, but also seriously unethical’.

In some cases, successful resuscitation is not possible as for example left ventricular dysfunction, advanced liver failure and metastatic cancer. In these cases physicians do not intent to offer CPR. In many countries of the world, patients and family members do not like to see the aggressive treatment at end stage disease on their love one and seek policy of do-not-resuscitate (DNR) in end-of-life care, even they may often seek to end his/her life quickly.

Decision making: Decision making in terminal care is a demanding and stressful duty for all involved and in any setting (hospitals, nursing homes, hospices or at home). It needs of truth telling and patient’s autonomy. Every patient has the right to know about his illness (patient autonomy). Physicians need to avoid giving

false hope of cure or of greater benefit than expected. Palliative care team should not be hiding the truth neither telling the diagnosis abruptly, but gently breaking the news on a need to know basis. Early and effective communications help both patient and family "digest" and accept the diagnosis and gives them a direction to move in. However, research has shown that patients and their families retain at best, 50% of the information they are provided.

A competent patient can refuse unwanted medical treatment only. Report says that nearly 60-70% of seriously ill patients are unable to speak. Capacity may change over time due to delirium, drugs, lack of sleep, depression, emotions and the underlying illness itself may render a person incapable. Therefore, capacity must be re-evaluated time to time. Unfortunately, capacity assessments have so far not been standardized. How capacity should be assessed, determinations of incapacity, who will give consent when patient is in incapable condition are challenged in palliative care.

Studies have shown that 62% of medical outpatients want to discuss their preferences in end-of-life care however only 10% of patients have completed an advance directive form in Canada. Decisions should be regularly reviewed in the light of changes in a person's condition or situation and review should always have as its aim the best interests of the patients.

Patient's beliefs and values should be respected in case of decisions making process in case of end of life issue even if these differ from the family or the health care professional's views. Decisions also need to respect cultural or religious beliefs, and the specific needs of groups such as people from culturally and linguistically diverse communities. Patients and their family will need time to think about their goals and expectations in light of diagnosis and expected disease course. They will need time to reflect on the treatment options, their risks and benefits in relation to their notion of quality of life, their life circumstances, past experiences, values, beliefs and in the context of their relationships with the patients.

Advance directives: The last period of life is much different from the rest of life, irreversible decay of bodily and mental capacities, pain and suffering, narrowing the consciousness and awareness, lack of time. May terminal palliative care patients like to avoid being subjected to unnecessary tests, hospitalization, and intensive monitoring and resuscitation procedure. Advance directive would be able to guide decisions in view of their previously expressed. Advance directives aim to honor individual autonomy and respect individual wishes, values and beliefs irrespective of their background, condition or culture, way of dying (euthanasia, and to avoid the ethical conflicts associated with withholding and withdrawing medical treatment or assisted suicide). Bioethics has placed a lot of emphasis on the principles of autonomy and self determination and value in decision-making. The patient, with the help of his/her health care providers, family members and loved ones, makes decisions about his/her diagnosis, prognosis, the expected course of the illness and the possible treatment alternatives, their risks

and benefits. However, confronted with dying patients may be seen as less important than relationships with loved ones and family and fears of burdening loved ones with their care. Moreover, a person cannot know in advance his or her ability to cope and adapt to living with a disease and disability in real life. Advance directives may improperly influence health care providers to limit the care. Moreover, in some culture and religion advance directive is forbidden. Palliative care is faced challenge to treat end stage diseased of these cultures as well.

Euthanasia: The practice of euthanasia is legalized in some countries (Netherlands, Belgium, some States of USA and Australia). Euthanasia poses an ethical dilemma in palliative care. Recent Dutch study, on 192 EOL cases, where 2/3 of patients were not capable of making an explicit request for euthanasia. Euthanasia predominantly the intention of the physician and not the patients wish. However, In some religion, terminating human life is unethical because it violates the moral belief that life should never be taken intentionally and the basic human right is not to be killed. How health services can go well beyond the biomedical model of health and treat the end stage patients with dignity is a great challenge.

CONCLUSION: Good understanding of medical ethics and good communication may contribute to face some of these challenges. Good communication can facilitate the development of a comprehensive treatment plan that is medically sound and concordant with the patient's wishes and values. Interdisciplinary seminar, conference and ethics training will provide valuable opportunities for participants to become involved in thoughtful, unique and creative dialogues with one another in terms of quality of care, professional and personal expectations, reluctance and resistance, institutional and individual. Continued efforts are needed to overcome the barriers to successful implementation of palliative care.

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