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View Point

In Search of a Good Death

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Abstract:

The ultimate desire of a person is a dignified death. To honour this desire the society, science, philosophy are always engaged in search of the appropriate definition of 'Good Death'. However with diversities of culture, over different time periods and across different countries, no universal definition has yet been accepted. Though 'Brain Death' is scientifically accepted to ascertain the very moment of death, some questions remain unanswered. Another issue has also become relevant at the point of dying: what will be the choice of patient, family and caregiver; euthanasia/physician assisted suicide or palliative care to uphold the best interests, autonomy and dignity of the patient. In case of euthanasia or physician assisted suicide the most striking question is who will determine the mode of death; patient, his/her family or the physician, whether it will be relevant in countries like India.. Palliative care may well be the best choice of patient care management at dying condition. Palliative care is the physical, psychosocial, and spiritual cares of the patients, whose diseases are not responsive to curative treatment.

Key Words: *Good Death, Brain Death, Euthanasia, Palliative care.*

Introduction:

According to the definition framed by the Institute of Medicine a good death is "one that is free from avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards."[1] But in reality it is very difficult, rather impossible to establish a standard with consensus. The perception of death is very much different from one man to another depending on their socio-cultural values, which are also changeable. It is very much necessary for patients, family and caregivers to give

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importance on determination of death, quality of life of the patient at dying condition, autonomy of the patient and at the same time honour the last wishes of the patient.

Determination of Death:

'Brain death' was accepted as the definition of death in medical science since 1959; which was expressed by the French word 'coma de'passe', the situation beyond coma instead of the past definition of irreversible cessation of respiration and heartbeat. In 1968, Harvard Medical School created the outline, how and when the determination of Brain death would be ascertained.[2.] In fact, introduction of 'Intensive care unit' and 'Ventilation' in terminal care management as also the issues like organ donation and transplantation made the 'Brain Death' definition more relevant. Besides United States of America, Australia and European countries, a number of Asian, African and Arabian countries have given the legal recognition of Brain Death. Although there is some variation of the tests in death determination in different countries, grossly it is confirmed by measuring the spontaneous normal breathing, all activities of brain, electrolyte balance, body temperature etc. at two hours interval by two different physicians. In India, Brain Death has received legal recognition under 'The Transplantation of Human Organ Act 1994'. In spite of that some questions are still unresolved. Scientifically, as the brain continues to produce neural stem cells throughout life, drugs and gene therapies may stimulate this self-repair capacity. It may not be impossible to engineer new neural tissue from patients' cells and transplant it into damaged areas. Progress in nanotechnology and the miniaturization of computing will also eventually allow brain damage to be repaired with implanted machines. Therefore in future 'Brain Death' definition will also be questionable scientifically.[3, 4.] It is impossible to define 'Death' only on the basis of medical science, the issues related to philosophy, ethics, law, religion and social values are also very important associated factors for making the definition of death holistically. For example, Japan has refused to adopt a brain-based definition of death in part because it would conflict with religious tenets that require the death of all major organs prior to a pronouncement of death**.**

Physicians' Responsibility in Death Determination:

A physician declares a person dead and issues a death certificate after a determination of death is made in accordance with accepted medical standards. It is not appropriate that the physicians restrict themselves only on the issuance of certificate. Physicians should inform and prepare the family regarding death and dying condition of the patient. It is difficult for the family members to accept the patient as 'dead' while the heart beat is still going on with the help of supportive devices even after 'Brain Death'. 'Truth telling' is very important in this situation from the ethical point of view. A systematic review of 46 studies on this issue showed that although the majority of health professionals believed that patients and caregivers should be told the 'truth' about the prognosis, in practice, many either avoid discussing the topic or withhold information. The reasons may include perceived lack of training, stress, lack of time to attend to the patient's emotional needs, fear of a negative impact on the patient, uncertainty about prognostication, requests from family members to withhold information and a feeling of inadequacy or hopelessness regarding the unavailability of further curative treatment.[5.] In this situation the physicians should discuss condition sensitively by which the patient/caregiver makes decision, reset goals and choose appropriate supportive treatment.

Furthermore if the family is being motivated for organ donation after 'Brain Death' they may wrongly misinterpret and raise question about physician's intention.

Information at Dying Condition:

There is no such practice in almost all the countries of maintaining the information regarding, how a terminally ill patient suffers with pain; whether 'life support' devices were used; or the willingness of the patient to give his consent of being experimented at the last stage. Without this evidence based information it is impossible to develop a universal outline of medical facilities at dying condition. It is impossible to build up the proper health care framework towards 'Good Death' depending upon death certificate information only. Dr. Steinhauser [6] made one study with the aim to formulate the definition of 'Good Death'. Six questions related to good death, e.g. pain and symptom management, clear decision making, preparation for death, the completion (the process of individual life review at the end of life), contributing for well-being of others, affirmation of the 'Whole Person' were asked to the patients, family members, physicians, nurses and social workers; all questions were based on different biomedical, psychological, social and spiritual aspects. There was a fundamental difference between the answers of the physicians and others. The answers made by the physicians were treatment oriented, whereas social, spiritual matters got priority in the answers of the others. Among the symptoms pain is the most important concern of suffering. Most participants voiced a need for greater preparation for the end of life. Almost all patients and families expressed that the spiritual considerations of the patient should be addressed at the dying condition. Every patient desires to spend his/her last days with family members and expect 'Good Goodbye' from them. When death is knocking at the door, the willingness to do something for everyone, and to share his/her life experiences etc. with others is common to every patient. Every patient possesses two identities, 'Self 'and 'Wholeness'. With the progression of the disease, due to aggravation of sufferings, helplessness, dependence on others, unresolved issues of life ,anxiety towards future; the 'Wholeness' of the patient has waned gradually. Every participant emphasized on acknowledgement of the patient as a 'whole person'. The family, the society as a whole plays a significant role to reestablish the bonding by alleviating these problems.

The Crisis at Dying Condition:

How a man dies; how he/ she accepts the death; whether he/she stays his/her last days in preferred place with dignity; whether he/she is prepared to accept the death: whether his/her last wishes are being upheld – there is no such system to maintain these data properly. 'Modern death' is nothing but a 'War' to control the suffering of the dying patient. A physician always thinks that it is his/her personal as well as professional failure if he fails to control the sufferings or is unable to cure the patient. The attitude of escapism of the family members from taking responsibility at dying condition also makes the situation complex. As a result the autonomy, willingness, opinion of the patient is undermined. The treatment and future planning are settled according to the opinion and wishes of the physician and family members. According to Glaser and Strauss the prognosis at dying condition influences the decision making and interrelationship amongst patient, caregivers and family members as well as shapes their experience differently either open, closed or no discussion made by physician.[7]

Euthanasia:

The fear of death; uncertainty, intolerable unnecessary sufferings at dying condition; failure or limitation of treatment at this stage, as well as patient's individuality and autonomy make the 'Euthanasia' issue relevant. The seventeenth century philosopher Francis Bacon coined this word, which comes from the Greek word 'Eu' means good, beautiful ; and 'Thanatos' means 'death' .Though in ancient era of Greece, the 'Hemlock Society' pleaded for the right of death, but in later period Socrates, Plato, Pythagoras as well as common Greeks were against that advocacy. As per medical definition, 'Euthanasia' is the act or practice of causing or permitting the death of hopelessly sick or injured individuals by a relatively painless way for reasons of mercy. In practical sense, it is the work performed by a self-motivated individual to help a patient with unbearable suffering to terminate his or her life at his or her request. It may be voluntary, involuntary or non-voluntary depending upon the decision making capacity, willingness and acknowledgement of the patient.

It is accepted generally that a physician should always take care for the beneficence of the patient and exert his best effort for the betterment of the patient; therefore 'Physician Assisted Suicide' may be considered as against the ethics of 'Doctor Patient Relationship'.

Euthanasia in Different Countries:

It was first introduced in Netherlands in 1984 for the patients, who were able to make decision. In later period, euthanasia, assisted suicide or mercy killing have received the legal validity in different countries e.g. Colombia, ,Switzerland, Japan, Germany, Belgium, Luxemburg, Estonia, Albania;

different states of U.S.A. as Washington, Oregon, Vermont, New Mexico and Quebec of Canada. On the basis of 'Aruna Shanbaug Case', March 2011 ,the Supreme Court of India has given the legal validity of conditional 'Passive Euthanasia', which can be applicable to coma patients with permanent vegetative state by withdrawing of different life supports and it should be permissible in the rarest of the rare circumstances.[8] Later on 25 February 2014, an NGO named 'Common Cause' filed a petition, in favor of the right to die with dignity. [9.] The Union Health Ministry, Government of India released a 'The Medical Treatment of Terminally Ill patients Draft Bill' in the public domain on May 2016 for consultation with stakeholders, about patient's right to take decision and express his/her desire to attending physician on this issue. Thereafter 'The Treatment of Terminally Ill Patients Bill, 2016' was tabled by MP Baijayant Panda in Parliament on 25th July, 2016.[10] The efforts have been made through this bill to recognize the right of terminally-ill patients to withhold and refuse medical treatment, and to express their desire to physician to assist them in committing suicide, though it does not directly permit 'Active Euthanasia'. Once the physician is satisfied that patient is competent and has taken informed decision, the decision will be confirmed by a panel of three independent physicians. This bill acts as a starting point; there is a need to debate how it would be ethically implemented. [11]

Different Aspects of Euthanasia:

A patient or his/her close associates think about Euthanasia for the following reasons:

- The unknown fear towards sufferings at last stage of dying condition
- Loss of all physical ability and self control
- Becoming fully dependent on others

On the other hand, some legal precautionary measures have been advised for Euthanasia, those are:

- Patients' written consent
- Physicians' report in every steps of treatment
- Always a physician will administer the injection, never a nurse at any situation
- In case of 'Physician Assisted Suicide', how it would be implemented should be written clearly and categorically in the prescription by the physician.

Euthanasia in countries, where the law already exists also needs some precautionary measures for implementation; and the relevant questions include:

- Whether the degree of suffering has been determined properly.

- Whether the caregivers try to create bond with the patient and his/her suffering empathetically.
- Whether doctors or family members pay sufficient attention to alleviate pain and sufferings.

Actually pain and sufferings are always measured by biomedical model; therefore the disease and curability of the disease have been emphasized primarily, but the patient as a ‘Whole Person’ is never considered.

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Most of the cases the discussion on Euthanasia was made by considering the view of physicians, family members and common people; the discretion of the dying patient discretion has received little prominence. As a result the discussion and research on the subject has remained inconclusive. Doctors should be careful, about this, because ultimately euthanasia would be implemented through them.

Good Death: Palliative Care:

Palliative care is becoming acceptable increasingly to ensure a good death. Palliative care is a term derived from Latin word ‘Palliare’ which means ‘to cloak ’i.e. cloaking the illness by relieving the pain. According to the definition of World Health Organization, “Palliative care is an approach that improves the quality of life of patients and their families 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, psychosocial and spiritual.”

The book ‘On Death and Dying’ written by Swiss psychiatrist Elisabeth Kubler-Ross and the five stages of grief (denial, anger, bargaining, depression and acceptance) model are the backbones of Palliative Care philosophy and movement. In 1967, Cicely Saunders took the pioneer initiative to introduce the effective team work in palliative care in the Christopher Hospice Centre at London. Thereafter, the palliative centres were built not only in the developed countries like France, Australia, Scotland, UK, USA etc.; but even developing and undeveloped countries like South Africa, Kenya, Tanzania etc, have also included palliative care as a part of their National Health Policy and take initiative to train the physicians to champion the issue . According to the study report of WHO, 40 million patients need palliative care, amongst them 78% patients from low or middle income countries; out of 234 participant countries only 20 countries are having integrated palliative care system, 42% of those countries have no palliative care facility and 32% countries are having some facilities.[11]

According to modern palliative care approach, the care should not be restricted for terminal conditions only; it should be delivered before that, from the very beginning to get the optimum effectiveness.[12, 13] Previously palliative care service was restricted to cancer and old age diseases, but now its scope has widened to include other incurable diseases.

The Palliative care aims to address the following problems:

- Physical problems (Pain, Nausea and Vomiting, Dry Mouth, Breathlessness, Pleural effusion, Loss of appetite, Ulceration etc.)
- Psychosocial problems (Change of relationship among family members, Communication problem, Financial problem, Dependency on others, Loneliness, Depression, Emotional isolation etc.)
- Spiritual problems (Self accusation for the disease e.g. Why me? ,What is the point of my being alive?, Loss of self confidence, Crisis on cultural and religious values)

Palliative care not only offers a support system to help patients, but also the family to cope during the patient’s illness and in their own bereavement. Palliative care also makes the family members courageous to end of life decision and educates them to accept death as a normal process. It is evidence based holistic approach.

Ethical Issues of Palliative Care:

The ethical and legal issues that should be addressed in palliative care plan and programme as recommended by WHO [14] include the following:

- Integration of Palliative care with curative care to ensure high-quality care.
- Autonomy of decision making, and valid informed consent of the patient and the family.
- Differing perceptions and attitudes in different cultural contexts e.g. quality of life vs. length of life goals, enduring or relieving pain, and the end of life.
- Societal, individual and professional obligations and responsibilities regarding the provision of care.

Conclusion:

In spite of medical and legal acceptance globally, the concept of ‘Brain Death’ is still unclear not only in common people but also medical practitioners. ’Brain death’ is not promptly declared due to lack of awareness and procedure of certification. Awareness about ‘Brain Death’ is extremely low in India also. Although guidelines are available in many countries for the diagnosis of brain-death, the variations and inconsistencies necessitate an international consensus and uniform guidelines considering the differences in clinical, practical, socio-cultural, ethical implications. Evidence based research should be directed towards these issues. Timely diagnosis and declaration of 'Brain Death' will be helpful for effective use of brain dead patients as potential organ donors, which in turn can meet up the problem of acute shortage of organs for transplantation.

In India,' Passive Euthanasia' has already been permitted by Supreme Court, whereas 'Active euthanasia' and 'Assisted Suicide' would constitute attempts to commit or abet suicide under Indian Penal Code 1860. However the court stated that 'Assisted Suicide' was only illegal in the absence of a proper law. Therefore, 'Assisted Suicide' could be legalized if legislation was passed by Parliament to that effect. Through the 'The Treatment of Terminally Ill Patients Bill, 2016' the efforts are being made in this direction. Debate over euthanasia, patient autonomy and best interest is currently going on in various forums, media etc. There is a need to debate how such a law could be operationalized to ensure the patient autonomy, to alleviate the suffering and to minimize the misuse the law.

'The Treatment of Terminally Ill Patients Bill, 2016' bill also emphasizes the need to account for palliative care when making end of life care decision. Palliative care is the choice of treatment for terminally ill patients in a low or middle income country like India. For effective palliative care there is a need to change some basic attitudes of physicians, patients as well as the society. The inclusion of family members in the care provider team comprise of physician, nurse, health worker etc., participation of community, trustworthiness of physician, standardization of treatment protocol based on evidence based knowledge; integration into public health system will make the palliative care effective, which in turn ensures the 'Good Death'.

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