End-of-life care: Indian perspective

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ABSTRACT

According to Hinduism, the main religion of India, the end-of-life (EOL) deals with good and bad death. The WHO definition of palliative care stresses on improving not only the quality of life of patients facing incurable diseases but also their families by providing relief from the pain and suffering that includes the psychosocial and spiritual needs as well. The Indian Society of Palliative Care has been doing a commendable work and appreciable efforts are being done by the Kerala model of delivering the EOL care. The spiritual, ethical issues and ethical challenges raised when the patients are in terminal phase are also reviewed keeping in mind the socio-cultural norms. The Indian Penal Code (IPC) has lacunae, which hamper the physicians from taking proper decision in the EOL care. Some of the sections like IPC 309 are defunct and need to be changed. The Indian Society for Critical Care Medicine has developed a position statement on the patient management of the terminally ill patient in the Intensive Care Unit (ICU) which states that the society should move from the paternalistic model to the share based decision model of the West when deciding the fate of such patients. The literature review on the Indian research on palliative care shows very little emphatic results and the medical under graduates show illiteracy. To strengthen it Medical Council of India has included the palliative care in its curriculum by starting a PG course. Literature review revealed that more research from Indian perspective should be done in this area. This article studies the core issues of developing palliative care in Indian setting keeping in mind the ethical, spiritual and legal issues.

Key words: End-of-life, ethics, Indian research, legal issues, palliative care, spirituality

INTRODUCTION

Death is end-of-life (EOL) process and dying is the end process of the life. It can become stressful when one comes to know that he or she is going to die due to an incurable disease. We need to understand that to heal is more important than to cure. The World Health Organization definition of palliative care is set as “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”. Thus, palliative care should focus on comprehensive pain management as well as increasing the quality of life of the patients. Palliative care can also reduce the fear of dying and prepares the family for bereavement. It is now getting attention due to the increasing number of people with terminal illness. Therefore, this review has been done to understand the spiritual, ethical, legal and cultural aspects associated with it.

Dame Cicely Saunders in the United Kingdom drew the attention of the medical community and the public to the evolution of palliative care in the 1960s. From the 1980s, rapid progress was made in developing palliative care as a discipline in the health-care delivery continuum of medical care. The recognition of palliative care as an integral part of cancer control policy and the guidelines for morphine in cancer pain relief by the WHO were salutary efforts made...
in the 1990s. These two factors propelled the national policies of many countries to implement palliative care in the last 20 years. In India, the earliest facilities to deliver palliative care within cancer centers were established in some places like Ahmedabad, Bangalore, Mumbai, Trivandrum and Delhi in the late 1980s and the early 1990s. The Indian Association of Palliative Care (IAPC) was formed in 1994, at the venue of a conference on palliative care held at Varanasi.[4]

There are approximately 500 centers providing palliative care in India. The “Kerala Model” is very popular in the country with its own palliative policy.[5] The Neighborhood Network of Palliative Care and “Palliative care in Campus Groups” are part of initiative where there is an example of community participation.[6] The main functions would be to provide, first of all, clinical services, pain management, palliative nursing care, psychosocial support, counseling, spiritual care, access to physiotherapy or occupational therapy. EOL care varies enormously from country to country, and even within countries. For example, while India is ranked 37th on the quality of death index (a measurement of EOL care in 40 countries), there are areas within this country such as Kerala where, palliative care is well established.[7]

The IAPC is now 17 years old and though the Kerala State Government has declared a policy on Pain and Palliative Care[8] there is no Policy at a national level on Palliative and EOL Care. Palliative care is mentioned in the National Cancer Control Programme, but specific guidelines are lacking. Palliative Care is also needed in other incurable conditions such as AIDS and end stage chronic medical diseases, but these remain neglected. Previously published studies in palliative care journals were on reporting of moral problems (ethical issues),[9] euthanasia,[10] and community-based clergy[11,12] and religion and spirituality[12‑14] and cancer pain.[13]

Currently, there are about eight palliative care centers in Gujarat, including one at our institute. The experience of the EOL Care at our institution is heartwarming that the NABH policy statement on the palliative care has been prepared keeping in mind the spirit of the issue. This stands in with the core mission and vision of the organization.

**SPIRITUAL ASPECTS OF END-OF-LIFE CARE**

Spiritual pain has been defined as “pain caused by extinction of the being and meaning of the self.”[16] Palliative care patients use spiritual and religious coping methods naturally when other coping methods do not provide solace.[17]

Talking about various religions, Hinduism, which is the main religion of India sees death as transition to another life by reincarnation, life in heaven with god or absorption into Brahma (ultimate reality). There is a notion of good death, how to die and a bad death is greatly feared. Good karma leads to good birth and bad karma to bad rebirth. Suffering can be explained in terms of past karma. In the Sanyas ashram people detach themselves from material and emotional concerns and prepare for death through prayer, scripture reading and meditation. A dying person can refuse medications to die with a clear and unclouded mind and view pain as expurgating sin. There is a distinction between the willed death of a spiritually advanced person and someone in pain wishing to end an intolerable life. Suicide for a selfish reason is morally wrong and leads to hell. Hindu good death provides a model for how death can be approached positively without apprehension.[18]

Buddhism believes in after-life. The ultimate goal is to reach nirvana, freedom from the cycle of suffering and rebirth. Taking medications that may alter one’s state of mind like narcotics is discouraged as they believe it can affect one’s life transition and rebirth.[19]

Christianity believes that death is a consequence of sin and is temporary separation of body and soul. Christian patients may view their illness and death as punishment and may experience associated feelings of guilt. They believe that the soul of deceased goes on to the after-life, ultimately to heaven or hell after being judged by the Christ. Death anxiety is present as no one knows for sure whether he/she will go to heaven. The dying person is prayed over, and the body is anointed with holy oils, he confesses his/her sins and the priest absolves the person of any guilt. The dying person receives a holy water representing the body and blood of Christ. The ritual concludes with a prayer.[19]

The Islamic religion, considers submission to suffering as a submission to god. It affirms the use of narcotic analgesics for the management of severely pain in terminally ill patients. However, the religion does not allow use of narcotics to hasten death. Pain and symptom management has to be balanced against the patient’s ability to participate in prayers and rituals in the final moments of life.[19]

In Jainism, there is a concept of self willed death to obtain freedom by sacrificing self. Assessment of spiritual needs involves attention to three factors: Sense of meaning and purpose, means of forgiveness and source of love and relationship. There is a concept of Mahaprastrhana or Santhara seen as willful death.[20]

However, assumptions or conclusions about spiritual needs on the basis of patient’s religious status should be suspended.[21] Decisions about approach and treatment should be taken on the basis of the actual customs, opinions, values and attitudes of the individual patient, and not on the basis of a predetermined simplistic construction.[22]
ETHICAL ISSUES AND CHALLENGES

The four core values of medical ethics (1) Autonomy-patient has the right to choose or refuse the treatment, (2) Beneficence-a doctor should act in the best interest of the patient, (3) Non-maleficence-first, do no harm, (4) Justice- it concerns the distribution of health resources equitably.

Two more values of medical ethics are: (1) Dignity- the patient and the persons treating the patient have the right to dignity, (2) Truthfulness and honesty- the concept of informed consent and truth telling.[23] The Western model of palliative care which have evolved around these values of medical ethics may be at times difficult to adhere to looking at the current framework of palliative care available in India.

Modern methods of pain control are available, accessible and effective. It is estimated that less than 3% of India’s cancer patients have access to adequate pain relief.[24] Improper pain relief leads to violation of the principle of beneficence. In India, Narcotic Drugs and Psychotropic Substances Act regulates the medicinal use of opioids such as morphine. To dispense morphine to patients the hospitals must be registered with the government and adhere to a set procedure.[25] Thus, opioid accessibility continues to remain a constant problem for the providers of palliative care in India. The ethical dilemma faced when analgesics are used is that doses of analgesics sufficient to relieve some form of chronic pain might hasten death.[26] The doctor is protected against litigation if acting in the best interest of the patient. For the same purpose, the Indian Society of Critical Care Medicine has developed directives to deal with such issues in India. The document essentially deals with physician’s attitude towards the severely ill patients in ICU. It also refers to physician’s objective and subjective assessment, honest and accurate disclosure of prognosis, early option of palliative care in poor prognosis, ensure consistency among the care giver team, It also gives a checklist as when to put the patient on EOL care (i.e., withdrawal of life supports within the bounds of law.

The directives are not laws and only guidelines for proper behavior of the intensives/physician for severely ill-patients.[27]

Language differences between the healthcare professionals and the patients create considerable barriers in communication.[28] More than one relative is involved in the care of the patient and they would all like to know the clinical details. In situations where several family members are present, the health professional may need to identify who the patient thinks is the key relative or the ‘head’ of the family, who can then be involved in the disclosure and discussion process.[29]

Medical teams often collude with patients’ relatives to keep the former in the “dark” (e.g., please don’t tell him/her about the severity of the illness), or the physicians colluding with patients (e.g., please don’t tell my spouse or family about my disease), and not informing the family about the patient’s diagnosis or prognosis. In India, nearly one-half of patients seeking cancer treatment are unaware of their diagnosis or treatment.[30] However, it has been often noticed that patients are quite aware of the nature and severity of the illness and they regularly express their need for open communication.

It is known that timely institution of palliative care alleviates the distressing symptoms in terminal stages of diseases, avoids toxicities of questionable anti-cancer therapy. The treating palliative care team may face conflicts in terms of patient’s family carer refusing to stop the toxic anti-cancer therapy. Hence effective communication (and explanation of the disease process) is the key to ethical palliative care.[31]

Evidence based palliative care involves integrating effective research findings with clinical expertise and patient preferences towards a better individualized provision of palliative care.[32] Research that involves patients near the EOL creates numerous ethical challenges. Inclusion of patients for palliative care research involves unique situations: (1) Dying patients are especially vulnerable, (2) Adequate informed consent may be difficult to obtain, (3) Balancing research and clinical roles is particularly difficult, (4) Risks and benefits of palliative care research are difficult to assess.[33]

LEGAL ISSUES AND CHALLENGES

Most of the physicians believe that withdrawal of support would be considered as against the law and can either lead to cancellation of license or prosecution. This belief can be strengthened by the absence of any legal acts on this issue. Therefore, the decisions taken are such where the financial burden would come on the incurably ill patient and his family. The classical example has been the widespread use of LAMA (leaving against medical advice)[34] to allow discontinuation of therapy on the grounds that the patient requested it. LAMA is an easy way out of this situation where ethical principles are somewhat distorted and on the request of the patient or his family, the physician transfers his responsibility on to patients. This is known as the paternalistic approach where the physician acts as god deciding the fate of patient. We have to move to the pluralistic model, which is shared based decision model.

There exists, at present, discordance between the Fundamental Rights enshrined in Article 21 of the Indian
Constitution on the one hand, and the Supreme Court decisions and Indian Penal Code (IPC) sections related to suicide (IPC 309) and abatement of suicide (IPC 306), on the other.\[36\] However, the opinion expressed by the lawyers is that if a doctor who withdrew or withheld treatments in good faith was subject to criminal prosecution, there is ample room for his defense even under current laws.\[36\] Mr. S. Balakrishnan, the Supreme Court Lawyer, is emphatic that the best defense for the doctor in a civil suit related to this issue would be to prove that he “has acted in conformity with the standards prevailing in his profession”. In this context, he felt that a document such as the position statement would be a good example of the “professional standard” that the courts are seeking.\[36\] Justice Jagannadha Rao of the Law Commission reviewed the international consensus in favor of limiting life support in irreversibly ill patients\[27\] and felt that a similar law would ultimately come into existence in India as well. It has been stated that “the absence of guidelines for withdrawal and withholding of life support in Indian laws perceived to be the most important obstacle” to good EOL care.\[38\] Others have stated that withdrawal of life support is increasingly practiced.\[39\]

The legal requests for euthanasia brought forth in the Indian courts are turned down due to the IPC acts 309, 306. The courts even do not approve “dignified death”. The recent furor over the case of Aruna Shanbaug, where the plea was turned down by the High Court and Supreme Court. However, the Supreme Court laid down guidelines for such “vegetative cases” – “passive euthanasia” (where in all the food and water and the liquids should be willfully withheld to provide the person a natural death) could be done under exceptional cases if appealed by the significant others of the family. The Supreme Court also commented that the “the laws like 309 should be removed because they have become anachronistic.”\[40\] Recommendations have been made for the medical community to work to obtaining legislation that clarifies appropriate care.\[35\]

It has been argued that withdrawal of life support may be viewed differently by Hindus depending on the fulfilling of life ambitions\[18\] or “karmic thought” that may influence behaviors and perspectives on death and dying.\[41\] Outside India, Asian-Indian Hindu immigrants have a lower level of advance directives.\[42\] Culture and religion were not perceived to be barriers by a majority of survey participants. Religion ranked as the least important of the reasons given as a barrier. The above reviews of EOL beliefs in India suggest religion is a major consideration for patients and families.\[41,42\] Published information on rates of withdrawal of life support in ICUs in India is limited and only available from two sources. A review of practice at ICUs in four hospitals in Mumbai showed limitation of care in only 34% of deaths and a very low (8%) incidence of withdrawal of life support.\[43\]

Firth states; “In India, the patient can be taken home, which implicitly discloses to the patient that death is imminent”.\[19\] A position statement has been published by the Indian Society of Critical Care Medicine states “If the patient or family consistently desires that life support be withdrawn, in situations in which the physician considers aggressive treatment on beneficial, the treating team is ethically bound to consider withdrawal within the limits of existing law”.\[44\]

**PALLIATIVE CARE IN TEACHING**

Designing of the medical curriculum is a major challenge. Present health-care education is primarily focusing on the curative treatment neglecting the importance of end of care needs.

Medical textbooks fall short of providing relevant information for clinical management of terminal illnesses.\[45\] An analysis of palliative care education in the undergraduate medical curriculum found considerable evidence that current training is inadequate in dealing EOL issues, most strikingly in the clinical years.\[46\] Western studies among medical students, residents, fellows, and attending physicians have found lack of standardized training in dealing with terminally ill people,\[47\] inadequacy and unpreparedness in dealing with dying topics.\[48,49\]

EOL and palliative care education in medical school curricula stand at a crossroad. Despite consensus that these topics merit systematic instruction throughout medical school training, undergraduate medical education lacks standardized curricula for learning palliative care and humane care for the dying.\[50\] It is pertinent that health-care practitioners and allied staffs are made aware about the best practice and principles of palliative care.\[49\] Gearing towards this Palliative care has now been introduced as a course for Post graduate medical students by MCI.\[51\]

**FUTURE DIRECTIVES**

Future research should focus on community participation in delivery of the palliative care.\[51\] There is an ample scope of doing research on palliative care. It will help us in networking with other countries and the kind of researches done there. It has become clear that developments in palliative care are to be considered as efforts to address deficits in care, strive for further improvements and justly apportion the limited resources.\[52\] Health-care professionals need to become aware of the relatively lesser reporting of palliative care articles in the literature. Research from developing countries is needed to develop, implement and monitor the delivery of palliative care in ways that are feasible in resource-poor settings and acceptable to local populations.\[53\] Indian initiatives for research in palliative care have been largely done by individuals within medical institutions or, occasionally, by a group.\[54\]
CONCLUSION

This study focused on understanding palliative care and its philosophy, demonstrates the spiritual aspects of Indian culture towards death and dying. It focused on the various methods available in taking care of palliative care needs of a dying patient. Moreover, the cultural aspects are also touched. The ethical and legal issues involved were also reviewed to understand the policies made by the government about palliative life care needs. There is a need to integrate palliative care into health-care training and the national medical, nursing and allied health council should structure and implement palliative care education into basic health-care training.

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