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SYMPOSIUM

End of Life Care: A Curricular and Practice Need

SK Jindal

ABSTRACT

End of life (EOL) care is a subset of palliative care during the terminal phase of an illness. It primarily aims to provide psychosocial supports and symptomatic relief employing a step-ladder approach to management of physical pain, breathlessness and other distressing symptoms. Futile aggressive and invasive treatments are either withheld or withdrawn. The EOL care accepts the principles of stopping disease-modifying therapy after all possible reversible factors of the illness are excluded. It does not imply the non-use of curative treatment whenever it is considered useful. In case of the 'double-effect' of a drug, it gives preference to symptom-relieving over the harmful effects, which are accepted as of secondary importance.

EOL care is governed by well established moral principles and individual's freedom of choice. It allows the normal and natural process of death to happen for an incurable and end-stage disease.

Keywords: End of life care, Care of the elderly, Quality of life, Ethics, Religion and dying.

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INTRODUCTION

Palliative care defined as 'the active total care of patients whose disease is not responsive to curative treatment'.[1] Factually, end of life (EOL) or 'terminal' care is only a subset of palliative care toward the terminal phase of an illness and is an important issue in medical practice near the death (Fig. 1). It generally refers to the care of patients with end-stage cancers after exhaustion of all the options of curing cancer. The scope of EOL care has tremendously expanded in the past two decades to include several other nonmalignant, end-stage diseases of different organ systems. In the present context, the subject also includes the issues related to the terminal care in the elderly and to the withdrawal and/or withholding of life supports for patients with irreversible coma and other irretrievable critical conditions.[2-6] Incidentally, the subject has not yet drawn the attention it deserves in medical practice in India.

PALLIATIVE CARE

Palliative care is a broad interdisciplinary approach used to improve the quality of life (QOL) of patients and their families.[7,8] It essentially aims at providing relief not only from physical symptoms of the illness, but also from psychosocial, spiritual and financial burdens. It is this concept of 'total pain' which constitutes the primary focus of palliative care.[9-11]

Palliative care employs the step-ladder approach to symptom management for physical pain, breathlessness, gastrointestinal symptoms such as nausea, vomiting and diarrhea; neurological, psychological and other body systems.[10] It accepts the principle of stopping 'disease-modifying therapy' and adopting complete symptomatic therapy. In case of the 'double-effect' of a drug, it gives preference to symptom-relieving effects over the harmful effects which are accepted as of secondary importance.[4,12-14] This doctrine of 'double-effect' justifies the administration of symptom-relieving drugs even when they have the potential effect of hastening death, which however is not an intentional effect.[12-14] For example, multiple drugs including strong opioids, such as morphine are recommended for severe pain (Step 3 WHO analgesic ladder) in spite of their potential harmful effects.

CARE OF THE ELDERLY

Limitations of outcome of curative treatments for end-stage diseases in the elderly have posed several ethical questions with reference to curative *vs* palliative treatments. There exists a temporal relationship between age and disease. We know that there are age-related changes responsible for the occurrence of several fold increase in incidence of diseases in the elderly. Peto and others had undertaken interesting mathematical modeling with reference to cancers and reasoned that the separate cellular processes which tend to arise in the same part of the life span cannot be considered as good evidence of similar mechanisms.[15] Factually, both aging and disease are teleologically related not etiologically.[16] They both determine death near the end of a life span.

The principles of treatments for a chronic, progressive disease in the elderly are different than those for similar treatments in the younger individuals.[17-19] There are several difficulties and problems of diagnosis and treatment in geriatric practice of all medical and surgical specialties (Table 1). The problems get further aggravated in the advanced, terminal phase of the illness.

END OF LIFE CARE

What is EOL Care?

EOL care primarily refers to the care of the dying. It incorporates treatment for palliation of symptoms and

psychosocial supports. Aggressive and invasive treatments are either withheld or withdrawn (Fig. 1). It is therefore, critically important to define the parameters which determine the indication of resorting to EOL care (Table 2).[20,21] Most importantly, even the minimal chances of 'reversibility' of a disease complication or a treatable exacerbation (even if partially), must be excluded.[19-21] Essentially, curative and palliative treatments are not mutually exclusive (Fig. 1). Institution of EOL care does not imply the nonuse of a curative treatment, such as with antibiotic, incision drainage of a pus collection or debridement of a bedsore. It is the aggressive, life prolonging attempt which is generally withheld or withdrawn.

Moral Principles

EOL care is governed by the well established moral principles which have developed over centuries of medical care for the sick (Table 3).[20-24] There exist a few differences in the acceptance, application and implementation of these principles among different cultures and countries.[25-27] There is also a strong influence of religious, social and family traditions and beliefs on EOL care. Nonetheless, the basic principles are generally similar to what have been listed (Table 3).

There are, however, a few important aspects which need special mention:

Religious View Point

There is no controversy of basic principles in relation to the death of a living being and the end of the existing life in different religions. Almost all religions support the sanctity of the dying and of the death.[28] It is important to discuss than ignore the religious and spiritual issues.[29]

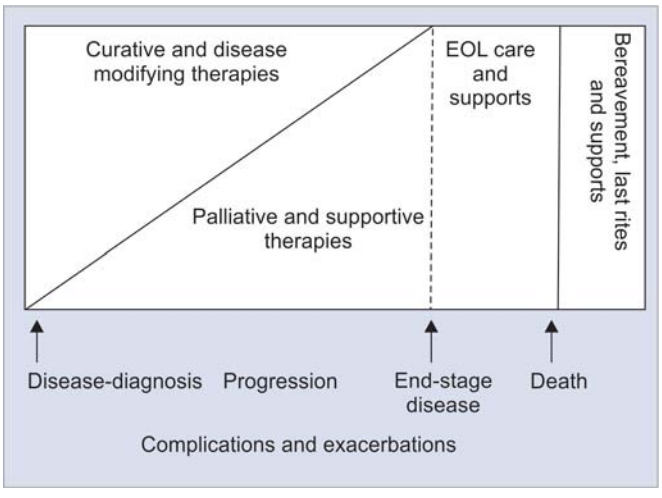

Fig. 1: Concept of total medical care for a patient with chronic progressive disease

Table 1: Difficulties and problems of medical care in the elderly

1. Presence of multiple illnesses and comorbidities.
2. Decreased body defences.
3. Poor tolerance to multiple drugs and other interventions.
4. Increased chances of side-effects of drug interactions and complications of various interventions.
5. Increased chances of risks of surgical procedures for diagnosis and treatments.
6. Poor response to drugs and treatments.
7. Attitudinal and behavioral difficulties of the elderly.
8. Psychosocial, fiscal and family issues related to continued care.

Table 2: Conditions before resorting to palliative EOL care

1. Documented presence of end-stage disease.
2. Absence of any reversible factor of disease-exacerbation or complication.
3. Failure of all available forms of curative treatments.
4. Documented consent of the patient and 'next of the kin' known to be primarily responsible for his/her care.
5. Provision of adequate time and explanation of issues of benefit and burden.

Table 3: Moral principles guiding EOL care

1. There is an important distinction between euthanasia and allowing a person to die a normal death: Assisted suicide and abutment to suicide are legally proscribed in India.
2. The patient (and his family) has a right to refuse aggressive, invasive and futile treatments.
3. Physicians have an obligation to make patient comfortable before and during dying.
4. Physicians are not obliged to continue with futile, and aggressive treatments which may also prove to be harmful.
5. A peaceful death is in conformity with religious and social values.
6. Withholding and withdrawing life supports are equivalent in terms of medical ethics.
7. Dignity of death is as important as dignity of living.

According to Hindus, it is significant to die an easy and peaceful death to attain 'nirvana' or 'mukti', i.e. liberation from the sufferings and miseries of the life and the death cycle.[28,30] The Sikh 'sloka' from Shri Guru Granth Sahib is self- explanatory: 'First accept death and then life; Even I and God incarnate die'.[28] The atmosphere of divinity and peace around the dying patient, recitation of holy verses and performance of last rites and rituals are highly valued in all faiths–Hinduism, Islam, Sikhism, Christianity and Jains.[28,31] Apparently, the values get somehow violated for those dying in the hospitals, particularly in the intensive care units.

The Law Governing EOL Care

EOL care involves difficult medical decisions as does the medical care for any other serious disease. It is only to avoid the dilemmas of a particular medical decision that a doctor may tend to look to the court for direction or guidance. There are several legal issues which influence

the conduct and practice of health personnel for prevention of criminal acts and other acts of misconduct.[32-36] The medical decisions however, lie in the sole domain of doctors, who obviously need to follow their professional ethics and guidelines. While the basic principles are similar, the management of conditions and cases has to be individualized every time.

Individual Freedom to Choose Care

Modern society including the existing laws lay great stress on the individual's consent and freedom to decide a form of treatment. It is rather an anathema that an informed consent is mandatory for institution of a treatment but not for withholding a treatment. As an example, an operation cannot be done without an explicit consent of the patient.[37-39] How can then endotracheal intubation and assisted ventilation be administered and continued in the absence of the consent?

Components of EOL Care

EOL care extends from the terminal palliative care and symptomatic management to guidance and supports through death and bereavement periods. Each individual symptom should be carefully attended to and treated. It is also important to discuss and provide appropriate advice on spiritual, psychosocial, marital, legal, insurance and economic issues related to the terminal care and death.

Withdrawal and Withholding of Aggressive Life Supports

Technology has made it possible to provide artificial supports to an organ after complete failure of its normal functioning. In the terminal phases, the support itself becomes a source of discomfort and misery without any significant benefit. This is particularly so in case of assisted mechanical ventilation for a patient with an end-stage disease when the weaning from ventilation becomes improbable or impossible. Essentially speaking, withdrawal of assisted ventilation and extubation is as much a medical decision as its continuation. There should be no medical or legal necessity to continue a futile effort.[32,33,40] As a simple example, the decision to discontinue failed cardiac massage after cardiac arrest is taken based on medical parameters. The same should apply to assisted respiration when it is medically proved as nonproductive. Guidelines to help the caregivers to take an appropriate decision on this issue have been drawn by all major medical associations worldwide.[3,4,35] Similar guidelines, recently framed by the Postgraduate Institute of Medical Education and Research, Chandigarh are also available for use in India.[41] Their use should, however, be governed in accordance with the decision of the Supreme Court of India, cited earlier.[42] The recent judgment of the Supreme Court of India in March 2011 on Aruna Shanbaug *vs* Union of India lays the procedure that applications for withdrawal of life supports to an incompetent person should be filed in a High Court.[42] It is important here to state that 'withdrawal of life supports' is sometimes considered as synonymous with a kind of 'euthanasia' especially in general terminology. On the other hand, withdrawal of treatment in terms of the limited context of EOL care is akin to 'allow the normal and natural process of death' to happen and is to prevent the 'prolongation of death'. It is in accordance with the principle of nonacceptance of a futile treatment to preserve the dignity of the dying and the death.[32,33,40]

Economic Issues

The subject of costs for continuation of aggressive treatments even when futile, is often neglected, or even avoided. It is considered as somewhat immoral and unreasonable to use the point in support of the withdrawal argument. I believe that this is a 'self-deceptive' attitude of the caregivers who tend to do their best. Conservation of fiscal resources for an average-income family with an end-stage disease patient is quite critical. In all probabilities, the patient himself/herself would not have desired and approved of the process in his/her competent state. Importantly, the continuation of treatment causes the aggravation of suffering of the patient. The costs for intensive care in this country may exceed an amount of ₹40 to 50,000 per day in a good hospital in India. This condition may continue for weeks to months, sometimes ruining the whole family resources. In the USA, the illness and medical bills contributed to 49.6% of bankruptcies in 2007.[43] Further, the odds that a bankruptcy had a medical cause was 2.38-fold higher in 2007 than in 2001.[43] The ethical issues of intensive care cannot be dismissed purely on the grounds of emotional justification.[44]

CONCLUSION

The EOL care is a sensitive but compassionate issue. There is enough evidence to support its role to improve the QOL, provide comfort and relief from troublesome symptoms, and avoid drug toxicities. It is less burdensome on the limited resources of the patients. Above all, it allows a natural death,

maintains the dignity and the values of the dying patient. The issue of withdrawal of aggressive life supports (such as the assisted ventilation in specific situations discussed earlier), is equally relevant. It is important to include the subject in routine clinical practice and medical curricula in India.

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ABOUT THE AUTHOR

SK Jindal

Professor and Head, Department of Pulmonary Medicine, Postgraduate Institute of Medical Education and Research, Chandigarh-160012, India
e-mail: skjindal@indiachest.org, dr.skjindal@gmail.com