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END OF LIFE CARE DECISIONS AND THE HOSPICE MOVEMENT

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ABSTRACT

In spite of spectacular technological advances made in the recent years, modern medicine has not been able to deny the inevitability of death. Slowly but surely, the approach towards death is changing with increasing emphasis on various end of life care decisions. Many of these decisions are being actively discussed, debated and practised all over the world. Palliative care in hospice has become an accepted mode of management of terminally ill patients, for whom the prognosis is limited. Increase in life expectancy of the Indian people and a strong movement to authorise ex-servicemen for treatment of malignant and other chronic diseases in service hospitals, requires the Armed Forces to consider these end of life care decisions and plan for terminal care in hospice.

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Introduction

'It is not death, but dying which is terrible' wrote Henry Fielding in his famous novel *Amelia*. In spite of spectacular technological advances made in recent years, modern medicine has not been able to deny the inevitability of death. The physicians, trained in the science of support and prolongation of life, attempt the same when the patient may even decide to forego life sustaining treatment or the physicians realise that their heroic efforts in sustaining life will result in a futile exercise of needless prolongation of the patient's life for a few hours or days. Modern medicine finds it difficult to accept that peaceful death may become a legitimate objective of medicine. Slowly but surely, the approach towards death has changed with increasing emphasis on various end-of-life care decisions and hospice care where the concern is on care rather than cure, on quality of life of the dying patient rather than putting him to more pain by life-sustaining therapeutics and on giving strong emotional support both to the patient and the family.

Medical Paternalism and Autonomy

Traditional medicine has imposed a form of medical paternalism on the patients. In an effort to counteract the effects of this paternalism, medical ethicists have proposed a model of patient autonomy. This dramatic shift towards patient self-determination received much of its momentum from the society's backlash to the paternalism imposed upon it by the physicians [1].

End of Life Care Decisions

In recent times, various end-of life care decisions are being hotly discussed, debated and practised all over the world. The leading concepts will be outlined below, all of which echo the concern of the society about modern medicine's tendency to view dying and death as disease related events and not as a natural process with both positive and negative dimensions a view that rejects the personal and spiritual dimensions of a milestone event of human existence.

Futile Care Policy

Futile care policy has been defined as 'any clinical circumstance in which physicians and their consultants, consistent with the available medical literature and practice, conclude that further treatment (except comfort care) cannot, within a reasonable possibility, cure, ameliorate, improve or restore a quality of life that will be satisfactory to the patient [2]. There are several arguments against futility judgement. Many physicians argue that futile care policy, places reliance on probability but not on absolute certainty and imposes the physician's value on that of the patient. Perhaps the solution lies in application of the basic principles of informed consent and shared decision making to all decisions to terminate futile care, giving importance to the informed patient's or surrogate's assessment of the benefit and burden of the intended treatment. It will be pertinent here to note that the American Medical Association on ethical and judicial affairs has circulated detailed guidelines regarding applica-

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tion of futile care policies in American hospitals [3].

Advanced Directives or Living Will

An Advanced Directive is a statement made by a mentally competent adult stating how they wish to get treated should they, at some stage in the future, lose mental capacity. Advanced Directives are seen as a way of extending autonomy by allowing patients to be involved in decisions from which they would otherwise be excluded because of their incapacity [4]. Advanced Directives are usually expressed in two forms as shown below :

a) Living Will (Instructional directive) - allows a competent adult to give directions for future care in the event that he becomes incapacitated due to terminal illness or impending death.

b) Medical power of attorney (Health Care Proxy)-names a trusted person to act as an agent or proxy in making health care decisions in the event of incapacity.

The Patient Self Determination Act 1991 in USA requires all health care institutions to recognize the living will and durable power of attorney of health care as advanced directives and require them to ask all patients about advanced directives and provide educational material advising patients of their rights.

Do-Not Resuscitate Orders

Several studies have indicated the futility of heroic cardio-pulmonary resuscitation in many cases, the probability of survival from in house cardiac arrest being observed to be less than 20% [5]. The Do-not-Resuscitate (DNR) orders instruct caregivers to refrain from initiating CPR for a patient who suffers an anticipated cardiac arrest. Any DNR order is made only after a thorough consultation with the competent patient or surrogates and clearly documented in the medical records.

Physician - Assisted Suicide

Physician assisted suicide is not a recent phenomenon in medicine. The prescription of Hemlock dates back to ancient Greek times. The concept was probably generated by very rational fears either of uncontrollable suffering at the end of life or of unwanted and undignified prolongation of a very poor quality of life. The opponents of physicians-assisted suicide cite the Hippocratic tradition of *primum non nocere* (first do no harm) while the proponents hold that if the terminally ill patient wishes control over the time and means of his or her death, there is an implied duty of a physician to be of assistance [6].

The Dutch were the first to legally recognize the

concept of physician assisted suicide by amending its **Burial Act** in 1991 while the Australians have legalized voluntary euthanasia by passing "**Rights of the Terminally ill Act**" in 1996. In 1997, the state of Oregon in USA passed the "Death with Dignity Act" which has legalised the concept of physician-assisted suicide in that state. These legal provisions in various advanced countries probably point to the public awareness that alternatives to institutional dying are needed for terminally ill competent patients and that careful consideration of physician assisted suicide is both ethical and appropriate [7].

Palliative Care

Slowly but surely, the worldview is veering towards a more rational end-of-life care decision of terminally ill patients by providing palliative care. The world is slowly rejecting the narrow biomedical view of dying and relearn some of the palliative and healing skills prevalent before the birth of scientific medicine and avoid the impersonal and fragmented care and unnecessary hospitalization that results from medicalisation of dying. Palliative medicine has been defined as "the study and management of patients with active progressive, far advanced disease for whom the prognosis is limited and the focus of care is the quality of life [8].

The essential features of palliative care are :

- a) Affirms life and regards dying as a normal process
- b) Neither hastens nor postpones death
- c) Offers a support system that helps patients live as actively as possible until death
- d) Offers a support system to help those close to the patients cope better during patient's illness and in their own bereavement.

Palliative care is being delivered by active hospice care programs which intend to manage a patient's total being by a multi-disciplinary team, the management ranging from pain and symptom management to emotional and spiritual counselling.

Hospice

The hospice movement is of relatively recent origin and has come out as an obvious alternative to hospitalization of a patient of terminal illness. The hospice is a philosophy rather than a facility. The concept was pioneered by the work of Dame Cecily Saunders, who was instrumental in the foundation of St Christopher's hospice in South London in 1967. The concept started with the care of dying and teaching and research into the control of pain of terminal illness. Subsequently, care of the terminally ill at their home and bereavement service for the family of the patient was brought

in. The different components of hospice care are as follows:

- a) Home Care - Professional team of nurses and paramedical workers, expert in the management of pain and other symptoms of the terminally ill, advising and supporting the family or community health service to care for the terminally ill patient at his home.
- b) Day Care - A multidisciplinary team providing palliative care to the patient on a day care basis.
- c) Inpatient Care - A specially trained multidisciplinary team providing palliative care to acutely ill terminal patients, the aim being to adequately control the acute symptoms of the patient and then return him to his own home.

Hospice in the Armed Forces

Along with the increase in the life expectancy of the Indian people, the number of elderly people and thus terminally ill patients will be increasing in the future and the Armed Forces population, particularly ex-servicemen, will be no exception. Though the ex-servicemen are not authorized treatment for malignant or many other chronic diseases, a very strong movement is gathering momentum for extending these facilities to the ex-servicemen by contributory health schemes on the line of CGHS scheme. Hence, the Armed Forces will have to prepare itself to provide terminal care to an increasing number of ex-servicemen, who have given the best years of their life to the Defence Forces. Then again the recent explosion in the number of AIDS cases cannot be ignored any more. To be ready to meet this future contingency of caring for terminally ill patients, following alternative solutions may be considered:

- a) Initiation of palliative care and hospice movement in the Indian Armed Forces.
- b) Training of medical officers, preferably physicians and nursing officers in various aspects of geriatric and palliative care.

- c) The hospices can come up as part of each regimental center as a part of their welfare programme for the ex-servicemen.
- d) Alternatively, hospices may come up in those areas having high concentration of ex-servicemen like states of Haryana, Rajasthan, Uttarakhand and Punjab, the funding coming from the welfare fund of AG's branch.
- e) Various formation HQs can also take initiative in setting up hospices in their area of command with suitable collaboration with well meaning NGOs.

Encouragement, support, fidelity and realism will remain the cornerstone of good patient care and informed participation of patients in decisions concerning their medical care will become prominent in the future. Death is inevitable but the question remains as to when to fight it and when to accept it. As long as we have choices, the question will not be easily answered.

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