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Ethical and Economic Issues in terminal Health Care

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Abstract: Terminal care requires an active and compassionate approach that treats comforts and supports individuals, living with or dying with progressive life threatening conditions. Such care has to be sensitive to the personal, cultural and spiritual values, religious beliefs and practices of an individual and the community he/she belongs to. There is an urgent need to address ethical and economic issues and to bring appropriate legislation to better manage end-of-life care in our country. Ethical dilemma in terminal health care has been a matter of great debate in recent times. It has to be emphasized that withdrawing or withholding life prolonging treatment, has to be differentiated from euthanasia. Euthanasia implies ending life in certain terminal and often painful and distressing situations.

Keywords: Ethical, Economic, Terminal Health Care, Intensive care unit(ICU)

1. Introduction

Every soul shall have a taste of death (The Holy Quran - 3:185)

Death is the ultimate reality. Whereas medical care is all about prolonging life, death is an issue that always confronts the health care providers. Once it becomes apparent that death is imminent the concern changes from attempting a cure to providing comfort in terms of pain relief and ensuring a dignified end.

Everybody, under ideal circumstances would wish his/her death to be a peaceful affair in the presence of his loved ones. However this idea is not always achievable more so in these days of modern technology when death has come to be a rather artificial affair, away from the family members and surrounded by the gadgetry of modern critical care. This has come about as a result of the tremendous advances made in medicine and the increased expectations of people. Under such conditions death is all too often robbed of its dignity.

The decision about providing ventilator support to terminally ill patients as well as the decision to withdraw this support is a dilemma all too often faced by health care providers as well as patient attendants. Discontinuation of mechanical ventilation because of the recognition of futility of continued treatment or because of patient or family request is an increasingly frequent occurrence in critical care¹. This dilemma becomes even more pronounced in developing countries where in addition to the ethical issues and the cost factor, the limited resources are also a consideration.

Even as such terminally ill patients being usually unconscious and not able to take decisions, the issues related to terminal care are to be decided between doctors, counsellors and patient's attendants. Such decisions should be made in agreement and as early as possible so long as there are well-based reasons for the same². However, while

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the western world has clear directions and guidelines, for both patients and physicians, these are lacking in India. Most deaths in hospitals occur in the intensive care unit(ICU) as it is the end point of care in a hospital. Also, the majority of patients die after a prolonged stay in the ICU, draining resources and causing agony to family members.

For many people, life support interventions do not help to mitigate suffering, but have instead added to the agony and burden of a long drawn out dying process. Modern medical technology has the ability to prolong life using artificial supports like ventilators etc. These devices are useful in a limited number of patients, in sustaining order systems till natural death occurs. Unfortunately there is no way of predicting in whom the life support systems are likely to be a futile effort. Had there been a way to do so a lot of resources would be saved and the patient's as well as his attendants' agony would not be prolonged.

Although death is inevitable it would be deemed callous and unethical to simply allow the fatal disease to take its course and rightly so. It would indeed be a failure on the part of medical care providers if they are not able to effectively manage the terminal events of life. Thus palliative care is an important part of health and social care which can not be neglected. The aim, once it has been identified that a cure is not possible and death is inevitable, should be to make death as comfortable as possible

Terminal care requires an active compassionate approach that treats, comforts and supports individuals, living with or dying with progressive life threatening conditions. Such care has to be sensitive to the personal, cultural and spiritual values, religious beliefs and practices of an individual and the community he belongs to.

It is a fact that all diseases are not curable and hence it follows that all lives cannot be saved. Doctors are not magicians and they should know their limitations. The ability to make a distinction as to which patient can be saved

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with all the supports of ICU and in whom all these efforts and supports are likely to be futile is as much a part of clinical awareness and decision-making as arriving at a concrete diagnosis. This poses an ethical dilemma which has been a matter of great debate in recent times. It has to be emphasized that withdrawing or withholding life prolonging treatment, has to be differentiated from euthanasia. Euthanasia implies ending life in certain terminal and often painful and distressing situations.

Decisions about withdrawing or withholding life prolonging treatment in the form of ventilators and ICU care etc has another important aspect in context of the developing countries with limited resources. It is not only the emotions and economy of the patient and his attendants that is at stake here but the availability of the equipment which might be required in yet another patient with far better prospects of survival. It is not uncommon in our setting for the number of patients who need ICU care to be more than the available facilities. Hence, the ethics of resource allocation are increasingly becoming one of the most critical ethical problems faced by critical care decision makers.³

Against this background it becomes even more imperative to decide which patient really needs ICU care and which patient is likely to benefit with ICU care as against a patient who does not need such care or will not be benefited by it. Consideration must be given to limiting ventilator treatment in instances when benefit is highly unlikely or when the burdens of treatment outweigh benefits.⁴

It is vital that the family members and next of kin of the patient be taken into confidence. They should be given a clear picture of the patient's present condition, all the medical problems that the patient is facing or is likely to face in future, poor chances of a successful outcome etc. An estimate of the likely financial burden on the family should be explained. Proper counseling of the family members is important to assuage any feelings of unnecessary guilt that might arise in them if they mistakenly feel that they will be responsible for the death of the loved ones if they can not afford terminal life support. However, not only is it hard to recognize when these end-of-life conversations should occur, but also the important relationships needed to have a thoughtful and trusted discussion have to be developed so as to avoid adding to the emotional burden of the family members who are even such in the throes of agony because of sufferings and impending death of a loved one⁵.

There is a need to bring necessary legislation in this regard. At present, as per law a doctor cannot withhold or withdraw life support to a patient. On the other hand if the patient (if conscious) decides to leave the hospital or if unconscious, the family decides to take away the patient against medical advice, it is permitted as the law allows everyone a choice as to where they want themselves or their patient to be treated. In practical terms this aberration means that the blame shifts to the family as they have to take the decision to take their patient away or wean him off ICU support. This translates into a social burden because the family might be blamed for leaving their near and dear ones to die without medical treatment.

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There is an urgent need to address such factors and to bring appropriate legislation to better manage end-of-life care in our country.

In conclusion, while we as doctors should leave no stone unturned when it comes to prolonging the life of an individual and attempting a care for his/her disease and an alleviation of his/her suffering, we need to think twice about prolonging the death and consequently the suffering of an individual.

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