Ethical Viewpoint Paper

Should Healthcare Providers in Intensive Care Medicine be governed by the Principle of Beneficence and Non Maleficence more than Autonomy for a Terminally Ill Case, or Should They allow the Caregivers and Patient to take the call ?

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Introduction

Ethics is an integral part of clinical medicine with the physician having an obligation towards the patient to ensure benefit, avoid or reduce harm, and respect the patient's preferences. The principles of beneficence and non-maleficence can be traced back to the 4th and 5th century BC to the time of Hippocrates which led to the Latin dictum "primum non nocere". Autonomy and justice subsequently gained importance as biomedical ethical principles. Beauchamp and Childress, in their book Principles of Biomedical Ethics, outlines four pillars of biomedical ethics, that till today form the basis for taking ethical decisions in the hospital [1]. However, these principles can tend to be conflicting with each other in certain circumstances.

Autonomy

The principle of autonomy states that all individuals have the right to make their own rational and moral choices. In medical practice, it is described as the right of competent adults to make informed decisions about their own medical care. Autonomy forms the basis of "informed consent", a necessity before any procedure or intervention, except in life-saving emergencies. The significance of this principle is seen in the landmark case of Mary E. Schloendorff in 1914, who alleged that the surgery done on her to remove a tumour was performed without her knowledge, leading to the incrimination of the Society of the New York Hospital [2].

Informed Consent

Obtaining an informed consent from patients or relatives is a routine practice in the hospital and requires three fundamental criteria to be fulfilled - the patient must be in full mental capacity, receive a full detailed disclosure which he/she clearly understands, and the freedom to take a decision without any external pressure or coercion.

1. Mental capacity to make important decisions, as in an intensive care setting, would be dependent on various factors such as age, medical disease, psychological stressors, and medication. Appelbaum, in his article on informed consent, describes the legally relevant criteria for decision-making capacity as the ability of the patient to understand the relevant information, appreciate the situation and its consequences, reason about treatment options, and communicate a choice which may be verbal or non-verbal [3]. In case of a patient who was previously autonomous but presently incompetent, his/her previously expressed preferences, if any, are to be respected. If there are no known directives, then a surrogate decision-maker would be needed. This may usually be a spouse, family member

or close relative depending on the family support and dynamics. In case of uncertainty in the decision-making process, the surrogate may either use a substituted judgment standard (what the patient would desire in this situation) or a best interests standard (what would be the most beneficial to the patient by weighing risks and benefits).

2. Full disclosure requires the treating physician to inform the patient about all details of his condition, treatment options with risks and benefits of each, and the prognosis, in a language well understood by the patient. This is aimed at enabling the patient to take a decision after receiving all the necessary information.
3. Freedom to take decision without external pressure: Various religious and social customs play a crucial role in the decision-making process. In our culture, senior family members, particularly in joint families, play an important role in the decision-making process. A study in 1990 by Deimling et al revealed that elders in the family (40%) and nuclear family members (53%) were the key decision-makers [4]. Religious beliefs of the patient also influence decisions taken in the hospital. Patients belonging to Jehovah Witness group refuse blood transfusion even in intensive care units.

An extreme form of patient autonomy is described as consumerism where the role of the physician is limited to sharing of information of the medical condition with details of the treatment options, leaving the fully informed patient to choose the treatment ahead. In this model however, the physician is unable to fully use his knowledge and skills to benefit his patient, a gross contradiction to the principle of beneficence.

Beneficence and Non-Maleficence

This principle of beneficence outlines the responsibility of the physician to act for the benefit of his patient, while non-maleficence ensures that the interventions by the physician do not cause the patient any further harm. The physician has a responsibility to advocate the most useful intervention that is available for the given patient.

The situation where beneficence takes preference over autonomy is described as paternalism, where the doctor is believed to know what is best for the patient. Joel Feinberg, a renowned philosopher, describes two types of paternalism in criminal law – soft and hard paternalism [5]. Applying this to a medical setting, in soft paternalism, the physician acts in circumstances where the patient is unable to make his/her own decisions. However, determining whether the patient is autonomous or not, particularly in an intensive care setting, requires a great deal of skill and experience. An extreme form of beneficence is hard paternalism, where the physician acts to benefit the patient, even though it is against the desire of a patient who is fully able to comprehend the situation and make his/her own decision.

Both, hard paternalism, and consumerism, though strongly supporting one extreme of a single principle, cannot be ethically justified. Faced with contrasting views of beneficence and autonomy, there is an urgent need to find a middle path between the two. At no point in the spectrum of ethical decision-making is the conflict as marked as when beneficence and autonomy collide. These controversial situations are most seen in the intensive care unit when dealing with a terminally ill patient, where difficult decisions need to be made with limited patient information, high uncertainty about prognosis, and extreme pressure to make these decisions in limited time.

Clinical Application

Common situations in the care of a terminally ill patient in which ethical conflicts between patient autonomy and beneficence appear are described below:

(a) **Admission:** Admission of a terminally ill patient to an intensive care unit is an extremely difficult and emotion-driven decision. This choice is usually urgent and required to be made in a stressful casualty ward. The information given by the treating physician is vital in making this decision and many patients choose to leave the decision to the discretion of the physician. While physicians aspire to make patient-centred decisions, they face multiple challenges such as being overworked, under-staffed, and limitations to resources and equipment at their disposal. Patients and their relatives, on the other hand, are stressed, unsure, inadequately informed and under duress to decide. Therefore, admission to intensive care should be implemented after shared discussion with the physician, the patient, and the family. The same should also be done if non-implementation of these therapies is being considered. A qualitative study by van de Kluit done by open interviews of 21 older hospitalized patients revealed that for all the participants, the decision for admission was taken acutely, even if the problems evoking admission were not acute. Admission to hospital was usually associated with positive expectations of hospital care – therefore prognosis and outcome must be adequately explained at admission, especially in a terminally-ill patient. The study also identified that advance care planning and shared decision making were not commonly encountered in the interviews [6].

(b) Diagnosis Disclosure: Complete diagnosis disclosure involves complete unrestricted information of the patient's medical condition, treatment options and prognosis to be shared with the patient and/or family members. There are various socio-cultural factors that play an important role in determining the choices of both physicians and patients. A significant shift has been noted in the attitudes of physicians between 1961 and 1979, where 88% of the physicians preferred to avoid disclosing a diagnosis in the former, but subsequently 98% of physicians favoured it [7-8]. A survey of 250 cancer patients' caregivers revealed that caregivers felt that patients knowing a diagnosis and prognosis may negatively affect the future course of illness and cause stress, depression, and loss of hope and confidence in the patient [9]. These evolving trends could be due to a paradigm shift from the age-old combination of paternalistic physician and patriarchal extended family, to a society with a clearer emphasis, both legally and ethically, on the issue of patient autonomy and informed consent. A recent survey of 304 cancer patients and 277 family members on complete disclosure of diagnosis revealed that patients preferred complete disclosure of related information as against their families who were more inclined toward scarce disclosure. Family members appeared to experience fear as the predominant emotion, compared with acceptance being the predominant attitude anticipated by the patient group [10].

(c) Ventilation: At the grey zone between intensive care and palliative medicine, many patients develop respiratory failure. While modern mechanical ventilation may improve ventilation, they may interfere with the patient's right to a dignified death, particularly at the end of a long-lasting chronic illness. Withholding and withdrawing of life support are considered ethically equivalent. However, issues in this aspect continue to exist as there is inadequate legal backing for withdrawal of life support. Keeping the above in mind, terminally ill patients should be carefully screened to determine the beneficial role of ventilation against the ill-effects of prolonging of life and suffering. Counselling of the patient and relatives plays an important role in taking this vital decision. Patient autonomy should be considered superior in these decision-making processes and should ideally be made early, during advanced care planning (ACP).

(d) Artificial Nutrition and Hydration (ANH): ANH describes feeding of a patient in the form of enteral tube feeds or parenteral nutrition. While many medical groups consider nutrition and hydration to be part of basic human care, others consider them to be life-sustaining interventions. A landmark judgement in the case of Margaret Anne Bentley, an 82 year old lady with severe Alzheimer disease living in a long-term care facility in British Colombia, clearly stated that feeds and fluids were considered to be part of basic care, and withholding of the same amounts to neglect on the part of the caregiver [11]. While ANH may improve the quality of life and prevent discomfort from hunger and dehydration, it also poses the risk of diarrhoea, aspiration pneumonia, infection and gastrointestinal discomfort. A randomized trial by Bruera et al studied the effect of parenteral hydration on 129 cancer patients in hospice care and found no difference in symptoms, quality of life, or survival [12].

(e) Terminal Sedation: Terminal sedation refers to the use of sedative drugs in the end-of-life care to make the patient unconscious until death occurs from the underlying illness, primarily as a means to alleviate severe pain and suffering. While the aim is not to cause or hasten death, the same may be seen as a side effect of these drugs –doctrine of double effect. Strict criteria must be enforced to ensure that terminal sedation is used in the best interests of the patient and not as an active intervention to end life.

(f) **Resuscitation:** Do not attempt resuscitation (DNAR), also known as Allow Natural Death (AND) is a directive to withhold futile cardiopulmonary resuscitation (CPR) in specific conditions where CPR does not change the outcome of the patient. The Indian Council of Medical Research recognizes DNAR as a valid medical directive in these conditions, as CPR would be nonbeneficial, inappropriate and only serves to prolong the suffering of the patient [13]. The guideline also describes an algorithm to facilitate the decision-making process and ensure the best interests of the patient. In cases of non-competence of the patient, the family and surrogate decision-makers would then need to be counselled to make the decision. A decision to give DNAR consent would depend on personal patient preferences, the estimated success of CPR, the risks involved, and the perceived benefit. Age of the patient was also found to be a major factor in deciding about resuscitation. A systematic review showed that DNAR orders were more common in older patients ≥75 years but was surprisingly independent of other contributing factors such as severity of illness and likely outcome [14].

(g) **Palliative Care and Advanced Care Directives:** A more acceptable alternative to hospitalization and intensive care of a terminally ill patients is palliative care at home or hospice. This option amalgamates quality of care with dignity of life to ensure that the patient shares their last few moments with their loved ones and enjoy a peaceful end. End-of-life care at home requires a medical support system to set up a home-based care and train the caregivers to provide the necessary care to the patient.

Advanced care directives (ACD) are oral or written instructions about medical care choices of a patient in case he/she becomes unable to communicate his/her preferences and loses his/her decision-making ability for any reason. ACDs include living wills, health-care proxies, and DNAR orders. However, despite the clear benefit of ACDs, a study showed that patients receiving home care have a lower rate of ACDs compared with long-term care users in nursing homes and hospice [15]. This increases the burden on the family members and other relatives to identify a care plan among themselves keeping the patient's best interests in mind. A study by Deterring et al on the impact of advanced care planning on end-of-life care in elderly patients demonstrated a significant benefit of ACDs by improving end-of-life care and patient and family satisfaction, and in reducing stress, anxiety, and depression in surviving relatives [16].

In conclusion, care of the terminally ill patient is filled with ethical dilemmas that leave the physicians and family members with very difficult decisions to be made. While the best interest of the patient is to be always kept in mind, aggressive management with interventions that prolong suffering must be avoided. While patient autonomy needs to be weighed against competing moral principles, autonomy usually overrules beneficence in most dilemmas provided the patients or decision-makers have been explained the risks and consequences of the decisions made. However, the role of the treating physician in guiding the patient and family in the decision-making process cannot be over-emphasized. Another important aspect that needs to be considered when making these decisions is quality of life. Treating physicians can best respect the patient's autonomy by allowing the patient and decision-makers to identify relevant health care preferences in advance, and by abiding by the choices that their patients have made. Incorporation of hospice and palliative care in the continuum of terminally ill patient care can improve the use of ACDs, assist in decision-making, enhance the end-of-life care, and support family members through the harrowing process of caring for their loved ones with a terminal illness.

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