



An Indian Primer of Palliative Care

For medical students and doctors

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6. ETHICS BASED DECISION MAKING

Medical ethics is a system of moral principles that apply values and judgments to the practice of medicine.

Part of being a professional is to be concerned with ethical issues. It is necessary therefore to take time to learn about the concepts which are relevant and to be able to justify one's own position. The purpose of this section is to assist the professional to be able to analyse a clinical issue from an ethical point of view and to take decisions on how best to manage the complex problems related to patient care.

Clinical judgements need to be based on science; but the management must also be based on the patient's and family's values. In situations where there is "clear right" and "clear wrong" answers, decision making is easy. But in many clinical situations, more than one option may look right, leading to dilemmas and difficulties.

Codes of ethics

In some cases the perceived values have been codified and written down. The most famous of these is the Hippocratic Oath, which sets out some of the ethical principles which the doctor should follow.

There are many others, including the Helsinki Declaration and the Declaration of Human Rights.

These provide useful checks and prompts for those practising palliative medicine.

Some Key Ethical Concepts⁴⁰

The four fundamental principles of medical ethics must be balanced in each case:

1. **Autonomy:** This principle states that each individual has the right to make decisions about his/her own life. The patient is allowed to defer decisions to someone else. But even in the practice of this principle, there can be conflicts and limitations. For example:
 - Should we comply with the patient's wishes even if it would be harmful to him or others?
 - Can there be situations in which we should refuse to do what the patient wants?⁴¹ We must remember that an individual's autonomy is limited by what the society thinks is right.
 - What if an individual wants to commit suicide and asks for your help?

The key part of autonomy is the ability of the patient to consent to or refuse treatment or care. Their wishes should be respected. All ethical principles must be weighed to determine the right course of action.

⁴⁰ Kenneth Calman. Oxford Textbook of Palliative Medicine

⁴¹ E.g. A chronic renal failure patient might request that he be continuously dialysed to maintain renal parameters.

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body.” Justice Benjamin Cardozo (1914)

2. **Beneficence:** This principle states that we should choose the best action for our patients. One must ensure that the “best action” is also considered by the patient as a benefit⁴². In some cases, we must refer the patient to another health care provider to ensure the best care.
3. **Non-maleficence:** This principle states that we should not do anything that may cause a potential harm to the patient. All medicines and interventions can have some undesirable effects. We shall aim to do no harm, but there can be unexpected and unintentional adverse effects of our intervention (double-effect).
4. **Justice:** This principle states that we should ensure equity and equality of care for all. Clearly this is impossible to achieve in all instances, as there are conflicting pressures on how health care is reimbursed or allocated.

Practical application of principle of medical ethics in palliative care:

- **Informed consent:** If we respect autonomy, it automatically follows that we should never do anything on the patient without the person’s consent. For ordinary, everyday procedures and medications, consent is implied; that is, the very fact that the person comes to us for treatment is taken to mean that the person is willing to receive medicines or be subjected to usual injections. But for any significant intervention, such as a surgical procedure or the person being subjected to a medical research, written/informed consent is essential. In the context of illiteracy, written consent often becomes meaningless. With the imbalance of power between the medical system and the person, he/she may sign any document without understanding it. It is our responsibility to ensure, whether literate or illiterate, that every person understands the implications of the procedures that we perform on them.
- **Duty to alleviate suffering:** Beneficence is too often considered only in the context of disease and cure. This is not right. The physician has an obvious duty to alleviate suffering.
- **Respect:** Every human being needs to be treated with respect and courtesy and their dignity should be preserved.
- **Confidentiality:** We have the duty to preserve the person’s confidentiality and do not have the right to discuss matters related to his disease or psychological/social/spiritual issues with anyone other than the members of the treating team. In the context of today’s world of information-sharing and computerization, confidentiality can be easily breached. Respect for confidentiality requires our constant vigilance.
- **Human Rights:** It is important for health care personnel to understand current concepts of human rights –the right to be respected, the right for full disclosure of health information, the right to access to pain relief and the right to life and death with dignity.

⁴² Reduction in the size of a laryngeal tumor in a scan from 14 cm to 3 cms might be a beneficial effect from an oncologist’s point of view. But the patient might view cure or the ability to speak as a beneficial response to treatment.

⁴³ Suppose there is just one bed in a critical care unit and there are 2 patients waiting; one is a 25 year old man with multiple trauma and the other is a 72 year old delirious patient with unstable haemodynamics with reversible co-morbidities such as pyelonephritis. Who should be given this bed?

- **Ethics and the law:** It is possible that what is ethically correct may be legally wrong. As citizens of a country, we need to respect the law despite our feelings of moral distress/ conflict about the ethics of a situation.
 - **Euthanasia:** In India, euthanasia is illegal. While a nurse or doctor might find euthanasia morally or ethically permissible, it is not legally permissible to practice euthanasia in India. (It is interesting to note that patients' requests for euthanasia are frequently withdrawn once high quality palliative care is provided.)
- **Ethics committee:** There may be situations in which the ethical decision is not apparent. It is advised that the institution appoint an ethics committee to address serious ethical issues.

The aim of treatment is maximum longevity with the best possible quality of life; sacrificing one for the other can only be done with the patient's informed choice.

Benefit vs. Effect and Futile care

Effect is a response to an intervention limited to improvement in investigation parameter or function of an organ (e.g. serum creatinine decreasing from 6mg to 3.7 mg % OR urine output increasing from 100ml to 500ml/day)

Benefit is the response which the patient has the capacity to appreciate (e.g. an unconscious ventilated patient becoming oriented and ambulatory)

We as medical professionals are more often carried away by the 'effect' whereas we should be concerned more with 'benefit' that the patient values.

Futile Care: Goal of medical care is to achieve a benefit above a certain minimal threshold. Futile care is care that fails to achieve that benefit.

Let us look at another clinical scenario to understand the dilemmas and reason based on the four cardinal principles of medical ethics, namely autonomy, beneficence, non-maleficence and justice.

Lala is a 33 year old middle class man, running a small shop for his livelihood, diagnosed oesophageal carcinoma. He has had a recurrence of the disease six months after completing the surgery and radiotherapy. He now has progressive dysphagia. Lala knew about his prognosis. He has read about an expensive stent and asks you about it as he wishes to relieve his dysphagia.

ETHICS-BASED DECISION MAKING

Interaction with patient and family with honest and clear information sharing is the key to ethical decision making.

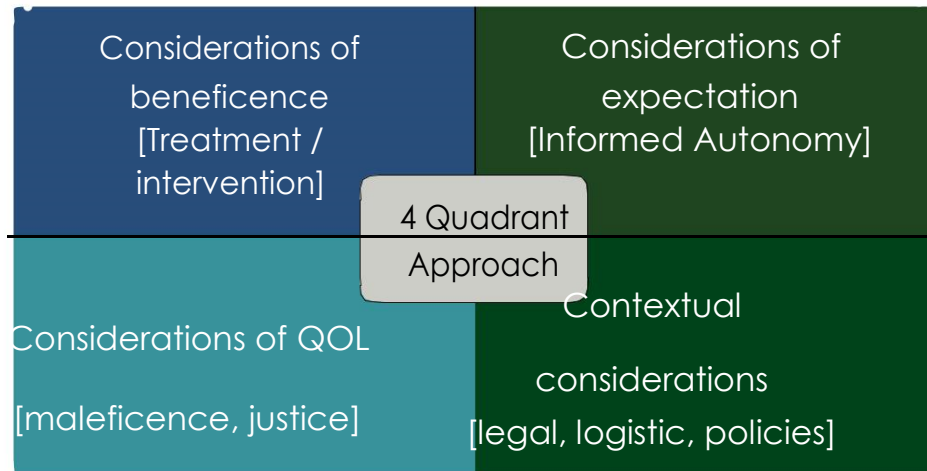


Fig 6.1 – Approach to Ethics based decisions⁴⁴

Conclusion

The framework adopted by any individual be it patient, family member, or professional; may vary on these factors-duties, right, and principles. From this brief discussion, certain conclusions can be drawn.

- There are many frameworks for ethical decision-making.
- Decisions may have to be taken at times in the face of uncertainty, and thus judgements will be required. So there is ample scope for disagreement on what to do.
- Often there is no right or wrong approach, just differences between different value bases held by individuals.

When one adds the differences in social, cultural, and spiritual aspects of life, then the possibilities become much more complex. It is critical to have a flexible and compassionate approach.

Suggested Reading

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7. [http://www.who.int/bulletin/archives/79\(4\)373.pdf](http://www.who.int/bulletin/archives/79(4)373.pdf)

⁴⁴ A. Jonsen, M. Siegler, and W. Winslade. J Leg Med. Clinical Ethics 1993 Jun;14(2):355-7.