# ETHICS AND BASIC MEDICAL RESEARCH

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Medical ethics is a system of moral principles that apply values and judgments to the practice of medicine. The twentieth century saw major advances in the development of codes for medical ethics after various trials, most significant of which was the doctors trial or Nuremberg Trial after Second World War, leading to the famous "Nuremberg Code"1. Although biomedical ethics and principle of ethics are described since the time of Hippocrates, issues in medical ethics keep on arising and adding to or modifying already instated principles. The principles of biomedical ethics are enforced by a competent authority. These basic principles were developed by American bioethicist Tom L. Beauchamp and James F. Childress2. Their work advocate four basic principles that form the basis of moral reasoning in healthcare and research: respect for autonomy, non-maleficence, beneficence, and justice3-6. These prima facie principles were established after researching detailed case studies and real-life examples and scenarios and now can be expanded to apply to various conflicts and dilemmas in research and healthcare. These four principles provide a sound and useful way to deal with any situation that arises in research7. Medical ethics give the patient right of autonomy and self-determination. Family members, legal guardians, religion, state, patient's advance directives, the doctor; all affect the patient centered code of conduct. One way or the other, there is a disagreement in one of these wheels, that stops the smooth running process of patient treatment, all having the same aim; "the patient's relief".

The patient has been given full autonomy over his body to accept or reject participation in a trial or treatment offered by a doctor. Problems arise mostly when there is a question of life and death or something life threatening to the patient. For example, in case of Baby K, "a baby born to a mother with no brain but a viable brainstem, in 1992 USA.8 The mother insisted on keeping the infant on ventilator against the ad- vice of the hospital staff

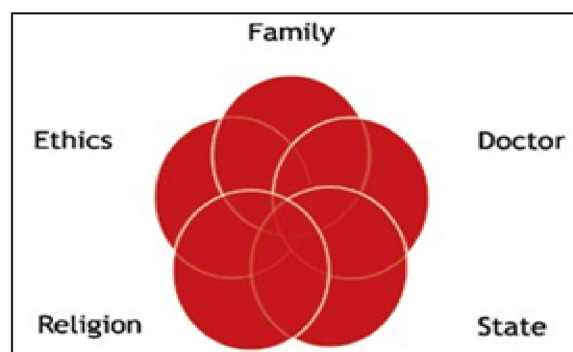


Figure 1. The complex wheel (patient is hidden behind the circles)

despite being repeatedly told about the prognosis of the child. She moved the case to court and finally got the decision in her favor until the baby died 3 years later while still on the ventilator. The continued treatment was considered futile by many. As they said, the same resources could have been used for creating awareness about the disease happening.

Decision becomes difficult at times when the patient or the patient's guardians want to withdraw the treatment and the doctor thinks the patient might benefit or if not, to prevent himself from an alleged assisted suicide or second degree murder. This happened in the case of Karen Quinlan in 19769. She went into a persistent vegetative state after an episode of unconscious- ness due to morphine, alcohol and dextropropoxyphene. After being on ventilator for few months, with no hope of improvement, her parents requested for withdrawal of support. The doctors were reluctant to do so due to the fear and threat of prosecution. The court allowed withdrawal of support and surprisingly she survived for another 9 years with spontaneous breathing but she died later on due to pneumonia.

When the patient has not made a will, neither expressed his/her wish ever before, the issue of stopping or continuing treatment becomes even more

complex. There is no clear cut boundary to define the point of starting or stopping treatment. The decision has to be judged keeping in view the principles, the law, the guardians and the patient chances of good quality survival. The guardians may insist on an expensive treatment like chemotherapy which the doctor would regard as useless. Under the principles, the doctors are not obliged to start a treatment at the patient's own choice which is not considered appropriate for the cure of dis- ease. Sometimes the patient says “you are a doctor; you know what is best to do”. Well, this “paternalism” is no more practiced. The patient has to be counseled about the benefits and risks of a procedure or treatment and he has to implicate what is best for him. He has to take full responsibility for taking any treatment after being counseled. He may make an unsafe decision, but this is at his end. There is no law against stupidity. The patient cannot use doctor as a means to his end.

A recent issue was the case of Terri Schiavo in 2005 in USA highlighting another aspect of difficulty in practicing medical ethics10. She was in vegetative state and on a continuous tube feeding as she could not eat and drink for many years. Her husband Michael wanted to remove tube feeding so that she could end her miseries with an early death. He also assumed Terri's will of discontinuing feeding. Her parents however, were not in his favor. The court ordered to remove the tubes as the first legal guardian was Michael. But the governor of the state at his end, ordered re insertion of tube few days after it was removed. The court decided again in favor of Michael upon request. Finally, she was deprived of feeding in March 2005 and died soon afterwards. This issue arose many public opinions on the role of doctors and the court allowing death of a patient by depriving her of food. The decision becomes difficult when the care is “futile” having no effect on patient's quality of life but relatives want to continue treatment and the law allows continuing treatment. Because resources are limited, the same facilities may be used for other needy patients in real need. The decision of court in Baby K case concluded that as long as the treatment can be afforded by the system, it should be continued. In a welfare health system like UK, there is rarely a limitation of resources when it comes to treatment, but, would this mean that every patient like this will be entertained till his/her last breath?

Pope John Paul II in 2005, said;

“Healthcare providers are morally bound to provide food and water to patients in persistent vegetative states.”

This statement is clearly opposite to the court orders in Terri's case. Infact this statement encouraged Terri's parents to reopen the case after her death but the decision remained unchanged.

In 1957 Pope Pius XII while addressing to a gathering of anesthesiologists said;

“The request of plaintiff for authority to terminate a medical procedure characterized as “an extraordinary means of treatment” would not involve euthanasia”.

This statement was based for the decision of Karen Quinlan case to withdraw ventilator support to let her die peacefully. Purpose of quoting standard religious personalities is that even the religious views vary for situation to situation. These statements depict patient and the guardian autonomy, each time resulting in a completely different decision. Islam does not allow assisted conception in case where the husband has died while it may be fairly legitimate in other religions. Jehovah witnesses may refuse blood transfusions as their belief but it is not prohibited in case of other believers of different ideologies.

Doctors cannot assist any terminally ill patient like cancer patient in dying. This would be considered as murder. A decision of not giving a treatment in a terminally ill cancer patient or withdrawing a treatment from a patient with persistent vegetative state is always with the will of the patient or guardian. Persuading the patient for death or persuading the relatives for with- drawing treatment when there is more than 1% chance of recovery is an assisted suicide and murder. This is called “euthanasia” i.e. killing by deliberate intervention to end life. Voluntary euthanasia is legalized in the Netherland but not in the UK. People in support of this EDITORIAL Concept, are of the opinion that doing no harm in this case is to help them in relieving their sufferings by helping them in dying. So doing nothing is causing harm by prolonging their miseries. An American consultant Jack Kevorkian was sentenced to 10 to 25 years jail for assisting 130 cases of terminally ill patients to death using his machines which were called as “thenatron” and “mercitron”. His philosophy is “dying is not a crime”.

Children under the age of 13 or at the age of 13 but with immature mind not capable of making decision have no right to decide or refute, under the law. Legal guardians (either parents or the first uncles) decide on their behalf. If a child refuses to get treated and the parents want the child treated, the decision to treat or not to treat becomes difficult. The child's basic

right is an exclamation mark. In emergency situation where the patient needs a procedure and neither the patient is in a condition to give consent nor there is a guardian, the doctor can proceed for the best possible treatment but later on involve officials in the case for a legal con- sent. But, what if a patient is a Jehovah witness believer brought in emergency with hypovolemia due to blood loss and the guardian wants the doctor to trans- fuse blood while it is prudent that the patient would not have given permission if he or she was in full senses? The doctor is in balance here. Either considering attendant as a legal guardian or considering the advance directives from a patient's perspective.

All these issues put the doctor in a tense situation. His duty is “the best interest of the patient” but he has to cope with multitude of varying scenarios challenging his power of decision. The best way is to be in constant consultation with the senior colleagues, lawyers and taking the relatives of the patient and the patient him/ herself on board.


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