

End of Life Care in Pakistan; Some Ethical Issues

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End of life is a reality that all mortal beings have to face. However, the interplay between the patients, families, and health care providers at the end of life has changed dramatically over the last century. Medicine, about a century ago, was used to be an interaction between a patient and a doctor, dispensed out of a black bag, mostly harmless but at the same time, useless. Over this time span, health care has become highly technical, very effective and complex with interplay of multidisciplinary teams. All this has given rise to many ethical problems. In the words of Robert Walker, "The principal problem involves the appropriate use of technology at the end of life. While developments in technology have enhanced our ability to prolong life, issues have also arisen regarding the resulting quality of life, with sometimes marginal benefits to our patients, and the burdens that this technology imposes on patients, families, and society."¹ In Pakistan, where formal ethics education is lacking and a faulty health care system predominantly exists, some of these issues are magnified.

There is a general reluctance to breaking bad news, whether this is about a grave prognosis or impending death. To avoid breaking bad news, patients and sometimes families are kept in the dark unnecessarily. The reasons for this attitude are multifactorial. Physicians are not properly trained in the skill of breaking bad news as it is not being taught in formal curricula and try to avoid these discussions. Being a family centered society, lives of extended family members are entwined in a way that nothing is considered confidential. The concept of individual autonomy is overridden by family autonomy.² There is a huge pressure on health care providers of "not-to-tell" as telling will cause more harm to the patient. Diagnosis and prognosis of the terminal disease are shared with family members rather than the patient. These facts are usually hidden from the patient "to have a positive outlook." This lack of communication between the patients/families and health care providers leads to overtreatment at the end of life, and futile treatments are administered at times.

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Palliative care medicine is about looking after people with illnesses that cannot be cured, relieving their suffering and supporting them through difficult times with the shift of focus to 'care' from 'cure.' It extends far beyond physical symptoms' relief, seeking to integrate physical, psychological, social and spiritual aspects of care so that patients and families may come to terms with impending death as fully and constructively as they can. Palliative care is not a recognized field in medical curricula in Pakistan.³ There are no facilities for patients whose futility is realized leading to excessive burden on the families. Those lacking family support have nowhere to go at the end of life. Shift from 'cure' to 'care' is not taught and is considered a failure. Reasons are again many, ranging from pure greed to sheer inexperience but in any case, lead to unnecessary overtreatment and wastage of precious resources.

With advances in life support, the line between who is alive and who is dead has become blurred. The term futile refers to a situation in which patients who are irrecoverably dying have reached a point where further treatment provides no physiological benefit.⁴ In modern medicine, life has an absolute value and there is anxiety in accepting death in our lives. Physicians equate beneficence with saving life at any cost, even when patients' material resources have been exhausted. This commitment can lead to the patient being kept alive with little regard to the quality of living as well as dying. Those promoting the concept of death with dignity have questioned this 'medicalised dying', and have defined a 'good death' as one, which is quick, painless, and without suffering to the patient.⁵ Withdrawal and withholding of life-sustaining treatments in the management of patients at the end of life may be appropriate both medically and ethically. First, certain interventions may simply be medically futile, in which case there are no ethical, legal, or medical need for instituting them. Second, it is appropriate to withdraw and withhold treatment that is not wanted by the patient or the family.

Advance directive is a "medical will" where a person, while competent, either writes a directive for healthcare professionals, or select a surrogate to make decisions about life-sustaining treatments during periods of incompetence. Effective advance care planning can assure patient autonomy at the end of life even when the patient has lost decision-making capacity. Death in Pakistani culture is generally a taboo subject. Not many people like to discuss this eventuality while healthy hence there is no concept of advance directives.

Symptom control, especially relief of pain and suffering is an essential component of good care at the end of life. However, there are very few chronic pain relief expertise/setups in the country. Concept of analgesics leading to respiratory depression and death, makes the treating physicians fearful of pain relief medications with undertreatment of pain, hence a miserable death. There is a growing concern that biomedicine pays little attention to patients' subjective feelings and fails to acknowledge suffering, a more expansive concept. Prevention of suffering, as opposed to prevention of death, constitutes an important aspect of end-of-life care. The doctrine of double effect dictates that a single act having two foreseen effects, one good and one harmful is not always morally prohibited.⁶ Pain relief treatments, that can shorten life, but are administered to relieve physical pain and psychological distress and not to kill, are allowed, as long as the situation does not involve an intention to cause death.

Last but the most important issue is of priority setting when the resources are limited. Pakistan has a multi-tiered system of health care. Its public hospitals are meant to provide health care for all, while those who can afford, may receive care at private hospitals. In practice, however, the public sector provides only limited health services and even these are available at a cost. Health budget is less than 1% of GNP.⁷ Private sector provides more than 77 – 90% of health care hence most of the health care expenditure is 'out-of-patients'-pocket.' Pakistan has not been able to allocate sufficient resources to health sector to make a discernible change in the first six decades of its existence. Burden of terminal disease is huge, but the word palliation is alien in health system. Palliative care is a major, largely unmet public health need. Western style palliative care may not

be the answer to this problem as there is a huge resource constraint. In Pakistan, strong cultural, community, and family support systems can be utilized to help the professional health care system. Valid, simple, and relatively inexpensive methods that are acceptable and maintainable at the community level and that can ensure the relief of suffering can be explored. But for this to happen in practice, several things must be addressed. These include effective advocacy, and clear policies that support pain relief, education and training of health care professionals and volunteers, empowerment of family members, and easy provision of affordable drugs to health institutions, especially oral morphine. We cannot prevent death, but let's try to make it as dignified as possible by relieving suffering.

REFERENCES

1. Walker RM. Ethical issues in end-of-life care. *Cancer Control* 1999; **6**:162-7.
2. Moazam F. Families, patients, and physicians in medical decision-making: a Pakistani perspective. *Hastings Cent Rep* 2000; **30**:28-37.
3. Babar M, Haq SM. Self-esteem in a palliative care population. *Am J Hosp Palliat Care* 2000; **17**:327-32.
4. Schneiderman LJ, Jecker NS, Jonsen AR. Medical futility: its meaning and ethical implications. *Ann Intern Med* 1990; **112**: 949-54.
5. Chatterjee SC, Mohanty S. Socio-ethical issues in the deployment of life-extending technologies. *Indian J Med Ethics* 2005; **2**:81-2.
6. Beauchamp TL, Childress JF, editors. Principles of biomedical ethics. 5th ed. New York: *Oxford University Press*; 2001.
7. WHO. Health systems profile- Pakistan [Internet]. 2010. Available from: <http://gis.emro.who.int/HealthSystemObservatory/PDF/Pakistan/Health%20service%20delivery.pdf>

