

Decision-Making in End of Life Care

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Concepts about medical treatment have changed remarkably with the advent of artificial life support systems. Keeping a patient alive by sustaining his cardiac and respiratory activity is no longer the objective. The term used more and more frequently nowadays is to provide patients with a certain quality of life. This has given rise to the concept of palliative care; the ability to accept limitations of medical treatment and to shift efforts from blindly prolonging life to making whatever natural life remains of as high a quality as possible. Treatable or terminal, the doctor's actions should continue to be based on what is best for the patient as a complete human being and not a scientific challenge for his skills.

According to Socrates, "We should set the highest value, not on living, but on living well."¹ What constitutes a good life is a question not easily answered, but the answer involves far more than the simple physiological vital signs taught during first year of medical school. Food, clothing, shelter, health resources, employment, political participation, education, recreational and cultural opportunities are only a few of things generally considered necessary today for a sense of individual fulfilment.² Abraham Maslow attempted to objectify human needs for wellbeing by grouping these into five broad categories:³ physiological needs; safety or security needs; belongingness needs; esteem needs; and self-actualisation needs.

While this classification is far from being perfect, using it as a rough template, one can easily understand that different individuals would enjoy very different standards of quality of life, and there is no easy way of establishing a universal gold standard to measure against. One can also understand what some may consider a rather harsh (but unfortunately realistic) concept that while all human beings are equal, all lives are not. Sudden cardiac arrest in a man already under hospice care for vegetative state brought on by a CVA would have completely different implications from the same problem arising in a man of similar age who is active. While one would obviously be hoping for the second patient to return to his previous lifestyle, would it be ethical to restore the first to his

vegetative state again? More so, in a country with very limited medical resources to begin with. While these two examples are clearly extreme, we mostly find ourselves faced with situations which are not so black and white.

Whether or not a person's (or his next of kin, where the patient is unable to make the decision) right to choose should be extended to include his right to choose the mode of his death is a debate ongoing in many societies. There are complex philosophical discussions covering ethics of actively causing a death (euthanasia) versus passively assisting death by simply withdrawing support, and the deontological dictates of all killing being wrong (sanctity of all life) versus basic moral rights of individuals to do with themselves as they deem fit.⁴ However, there is an undeniable trend amongst Western societies to favour a terminally ill individual's right to choose his own treatment plan and death. The Netherlands has gone as far as to pass a law and formalise a procedure to monitor physician assisted deaths since 1991.⁵ In the United States, the people of Oregon passed its "Death with Dignity Act" in 1994 to legalise and regulate euthanasia.⁶

Polls in the UK, which is the most closely linked to the Pakistani medical education system, show a rise in favour of assisted dying from 69% in 1976 to 82% in 2004.⁷ While this concept was once very strongly opposed on all forums by the conservative British society, outlooks seem to be changing as the Royal Colleges of General Practitioners and Physicians withdrew their strong opposing stance in favour of a more neutral position in 2004.^{8,9} In June 2005, the British Medical Association followed suit, saying that this was an issue for the parliament and society to decide upon.¹⁰ In practice, however, every year sees a number of requests for euthanasia, made by terminally ill patients, turned down by the Courts in the UK.

While the healthcare system of Pakistan is still far from grappling with issues like assisted deaths, a lot of benefit can be reaped from improving doctor-patient communication and the introduction of guidelines to regulate a more rational handling of terminally ill patients. A doctor's primary objective remains preserving life in length and quality and the responsibility of appropriate decision-making in the patient's best interest is no less if the situation is irretrievable. Realistic assessments must be made about the possible benefits a hospital stay can yield and if these are not significant, the patient must be informed clearly and counselled about options of home-based palliation.

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Of course, simply refusing hospital admission is not the end of the road. Palliation clinics and better medical support for homes needs to be developed as a viable alternative to hospitals. The United States and Australia announced reforms to improve facilities for home care for the terminally ill in October 2004, while the UK has invested £12m in its “end of life care programme” between 2003 and 2006.¹¹

A systematic review of 58 studies with over 1.5 million patients from 13 countries conducted by King's College, London, described patient wishes and the presence of close family support as two of the major factors encouraging death at home for terminally ill patients.¹¹ Joint living and family support is very common in the Pakistani society and can be a major strength in this respect.

The onus is on us, as medical professionals, to use this strength to benefit patients for which hospital care is unlikely to provide a cure. Counselling, palliative care and home care need to be developed to the level where they can be offered as viable options. Perhaps, then will we be able to replace, to a small degree, the hopelessness and despair of a terminally ill patients with a sense of dignity, control and the love and comfort of home in his last days.

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