

SELECTED SUMMARY

Death, dying and deciding: surrogate decision making in end-of-life care

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Most of us, if we were to imagine or wish our manner of dying, would take our cues from the way it has been portrayed in films. Death either occurs suddenly as part of a climax or as a more prolonged scene with a supporting cast of family and "significant others". In reality most deaths occur after variable periods of ill health in the later stages of life and this proportion will rise in India too, as poverty declines. A recent article in *The Economist* (1) estimates that by 2050, 80% of all deaths worldwide will occur after the age of 60 and the three main causes will be malignancy, chronic organ failure and overall frailty with or without dementia, each of which has a separate trajectory. In general, patients with malignancy retain control till the terminal decline sets in, and this usually has a predictable course. For people with organ (heart, kidney, lung, liver) failure, once identified, some degree of foreseeable decline is part of the remaining life span. Most can be expected to succumb during a severe episode of their basic illness. For those who survive the mid-70s without cancer and with functioning organs, the good night is neither short nor gentle nor predictable. The quality of life is usually poor but, above all, both dementia and strokes impair judgment and the ability to communicate so that the subject can neither make decisions nor express them. Thus it is quite possible for a senior adult previously capable of informed consent to gradually lapse into a state where all the decisions about his or her medical care have to be made by others.

Progressive improvement in intensive care over the past few decades has substantially improved survival in all critical illnesses. Neurologic disease is an apt example. Robin Cook's *Coma* had striking images of brain-dead bodies kept indefinitely in suspended animation for harvesting organs for transplant. It is no longer an unusual experience to see 80-year-old individuals maintained on life support for periods of weeks to months. This of course depends on available standards of ICU care that, in many Indian private hospitals, are arguably equal to the best in the world. Deciding the appropriate level of care at the end of life should be an individual decision and one which needs to be handled proactively. More often than not, patients land up in hospital in an emergency and there is little time for discussion. If a patient's decline is gradual, there is some likelihood that she would have indicated her wishes to

her family. Discussion of death is not easy and Indians often consider the mention of it an ill omen. Also when a doctor does not have any prior acquaintance with the patient or the family, establishing rapport and credentials does not go well with the process of conveying a poor prognosis. One way of conveying reality is by discussing the level of care that the patient is likely to require when discharged from hospital. Over a period of time, most physicians learn the skills required to communicate empathetically with patients' families. Most of us in practice use a framework that balances the patients' immediate needs with an active process of information and consent. Although the most important decision is about when to "let go", smaller decisions that significantly affect quality of life have to be tackled on a daily basis.

A recent paper by Berger, DeRenzo and Schwartz gives a perspective on surrogate decision making in adults who are cognitively impaired. This is based on current standards that are widely accepted both medically and legally in the West, especially the US. The decision making process follows a logical hierarchy: 1) Patients' known wishes, 2) substituted judgment (for the patient's wishes) and 3) patients' best interests as determined by the treating physicians. This sequence has evolved as part of a broader concept of human and consumer rights in medical care and is based on individual self-determination. It has been argued that this last concept is based on western notions of personhood which are absent in Asian societies. This may be true of more authoritarian societies but is unlikely to be wholly applicable in argumentative India. In any case decision making rarely follows a predictable sequence in a rapidly evolving clinical scenario. Even in the US, a rigid application of this normative framework is difficult because of the grey areas between the different levels of this hierarchy, and this article emphasises the need for flexibility.

The patient's wishes, if expressed when sentient and especially if recorded in a living will, obviously get first priority. Berger et al review the use of living wills and advance directives. These now have legal validity in many US states (not in India) and versions of the standard document are available off the net. These restrict the use of life-saving treatment if the subject is already terminally ill or permanently unconscious or brain damaged. Making such a wish explicit does definitely ease the decision making process. Unfortunately, it is impossible to foresee all possible interventions that may have been "life saving" once and are now routine procedures. For instance, in a home-

bound but otherwise independent patient with Alzheimer's and urinary infection, this would forbid the administration of an IV antibiotic. It would definitely preclude a short spell of artificial ventilation for any surgical procedure to prevent the urinary infection from recurring. Some living wills now include a choice of whether to make the document binding or not. As Berger et al specify, substituted judgment comes into the picture when advance directives have not been made. This may also be made part of the living will by giving a specific person power of attorney to take health-related decisions. In practice the spouse or the patient's adult offspring, who would be likely to share the patient's values and beliefs, are expected to take up this responsibility. Family dynamics vary substantially from case to case and it is always wise to confirm that all the immediate family members are involved in the decision making. These surrogates are expected to generate decisions which the patient would have made if not incapacitated. There is substantial evidence that substituted judgment is often inaccurate and may not correctly reflect the patient's wishes. This is partly because of the complex psychology of group decision making. Overtreatment is frequent because of a status quo bias. Nevertheless in practice, substituted judgment by formal or informal surrogates does take place and is largely accepted. In all systems determining the patients' best interests remains the domain of the treating physician or medical team. In practice this can trump advance directives and substituted judgment. However, in my experience the most complex end-of-life decisions usually evolve over time and as part of a consensus between surrogates and the medical team.

But in India above all, it is "he who pays the piper calls the tune". The scenario of hierarchical decision-making based on bioethical principles can be followed only if high standards of medical care do not clash with the daily reality check of a hospital bill. In a private hospital this is possible only for patients covered by insurance or paid for by an institutional provider such as a public or private sector company. Hospital expenses for patients on life support are usually in the range of Rs 5,000-10,000 per day and can often be twice or thrice this if newer antibiotics are used. Surgical procedures can cost many multiples of these figures. Personal financial planning rarely accounts for these substantial expenses and can rapidly exhaust the reserves of most middleclass families. Unfortunately this informal "pay-as-you-go" system has few checks on unscrupulous doctors with financial incentives for maximising expenses. It is not difficult to convince a grieving family that more is required to be done. At the other extreme the public health system is usually inexpensive or often totally free of charge. But with limited facilities and overburdened staff

it usually operates an informal, sometimes brutal triage where older individuals with a poor long-term prognosis rarely get decent care.

For Indian physicians, socio-cultural factors add another level of complexity. Religion does play a role, but this is a sensitive topic which may be difficult to document objectively. My impression is that followers of the monotheistic religions with clearly defined ideas of life span (eg the biblical three score and ten) and the afterlife tend to be more realistic when facing end-of-life issues. Hinduism, in contrast, does not have any rigid concepts, accepts reincarnation and allows for bargaining with the gods! Across religions, however, a sense of family duty and "what will people say" often restricts the ability of surrogate decision makers to reach closure. As a neurologist and physician dealing with end-of-life issues, I have often felt that families look for reassurance in the form of an explicit statement that the family has done its duty and that everything that is medically possible has been done.

As a practising Indian neurologist and physician (and a concerned citizen) I do have some prescriptions to offer:

1. Ideally the legal framework for living wills has to be created by legislation. In the absence of legislation our courts have a record of fairly creative and progressive interpretation of natural law. As individuals, we in the medical profession should take the lead in publicising this concept. A beginning can be made with ourselves and our families.
2. It is important for all of us to bring death into the discussion of the prognosis in all chronically ill individuals. Caregivers need to be made aware of the limitations of medical therapy and counselled to be able to accept the inevitable.
3. End-of-life care needs far more attention than it gets at present. As a society we are too comfortable with our mantra of family values. With societal change and mobility, the safety net of a large and accessible family is not going to be available for the majority of Indians in a few decades.
4. And as physicians, the last words are from the modern version of the Hippocratic oath (2): "I will apply for the benefit of the sick, all measures that are required, avoiding those twin traps of overtreatment and therapeutic nihilism."

References

1. Anonymous. Being Old: things to look forward to. *The Economist* 2008 Aug 2 [cited 2008 Aug 31]. Available from: www.economics.com/world/displaystory.cfm?story_ids11849226
2. Lasagna L. *Hippocratic Oath-Modern Version*. 1964. [cited 2008 Aug 31]. Available from: http://www.pbs.org/wgbh/nova/doctors/oath_modern.html.