

Editorial

Communicating Truth about Serious Illnesses in the Indian Context

Terminal illnesses come with limited choices. Malignancy and organ failure peak in the sixth and seventh decades, respectively, and are often compatible with a sentient individual largely in command of her last days. Frailty and dementia pick up pace in the eighth decade.¹ These and other disabling neurological illnesses have individuals surviving variable and often prolonged periods of time without the ability to decide and/or communicate. Advance care planning and living wills are not yet legally valid in India although there is now some movement on these issues, largely under the misleading rubric of passive euthanasia.² Even without a living will, an aware patient can make her wishes known to her family and her doctors. This is legally valid provided she has full information about her illness and prognosis at a stage when her cognition and ability to communicate are intact. From personal and anecdotal evidence, remarkably few Indian patients receive this information from their medical providers even if they seek it. Is this an acceptable situation? If not, what can we do about it?

Respect for patient autonomy is the cornerstone of biomedical ethics in the western tradition.³ An uninformed patient is considered a culpable act of omission and is usually blamed on paternalism of the medical establishment. In India and other Asian societies, the barrier is usually the family. It is said that the previous Japanese emperor, Hirohito died without knowing that he had metastatic malignancy.⁴ The reluctance to tell is usually attributed to solicitude, in an urge to protect the patient. The result is a severe compromise of the patient's autonomy. It takes little imagination to realize that in some situations this rationing of knowledge can impact family dynamics and power equations to the detriment of the patient. Indian doctors are often explicitly told by the family to hide the diagnosis and prognosis from the patient. In a similar situation, I refused to lie and was accused of 'unethical behaviour'. In this dilemma, what is the responsibility of a concerned doctor?

What we do not realize is that India is changing rapidly. Conversations that were unimaginable 20 years ago are now routine. Preformed assumptions about what is acceptable and what is not can and should be challenged. Rapid economic growth has brought both social and demographic changes. In East Asia, with education, marriage rates have dropped substantially among women. In Tokyo and Hong Kong, about 20% of women 35–39 years of age are single and expected to never marry. In China, it is projected that in two decades, 10% of men will never find brides!⁵ Single person households constitute 15% in China, 25% in South Korea and 35% in Norway, while in India currently only 5% live alone.⁶ Indian society is deeply uncomfortable with the 'landscape of the individual' and yet this will be the fastest expanding demographic. Filmmaker Anand Gandhi cogently argues: 'The individual is the sole owner of the self (and is) entirely responsible for the self. We have to accept and establish that the law has no moral right whatsoever to legally interfere with the lifestyle, sexual, reproductive or death choices of informed, consenting adults, even if they are beyond the understanding of presumably well-intentioned state representatives.'⁷ It is likely that advance care planning will soon be recognized as a constitutional right of every Indian citizen.

Indian physicians often deal with a very diverse population. Most of us are comfortable managing with our ethnic complexity, including occasional patients where you need an interpreter. Economic disparities add another layer of complexity and most patients will have limited healthcare budgets. To navigate these issues, one has to know one's patients and how the contexts of their lives affect their healthcare choices. Ignorance of these can lead to contextual errors which obstruct the conversion of medical decisions into delivered

care and are as important as medical errors.⁸ Obtaining an explicit and adequate social history is not a highly regarded clinical skill and is largely missing from Indian medical curricula. All too often this does not go beyond education, occupation, family status and the use of tobacco, ethanol or drugs. Behforouz *et al.*⁹ suggest a much wider list of topics in the social history to understand 'how patients' environments influence their attitudes and behaviors and how patients' agency—the ability to act in accordance with their free choice—is constrained'. But to obtain enough detail, clinicians need to 'be trained in basic and motivational interviewing techniques and challenged to examine their own biases, since unexplored prejudices influence our ability to obtain or act on important information'. Although not a realistic prospect for a currently practising Indian physician, this does tell us where clinical practice is heading.

On the other hand, most of us are comfortable dealing with the technological and scientific advances in our fields. The ethical dilemmas that arise from these advances are possibly most challenging in neurology. Like the social history, clinical ethics is not an important part of any Indian medical college curricula. Most of us 'learn on the job' and our responses are shaped as much by our own social culture as by our professional experience. Truth telling or serious illness communication is not easy though a teachable skill.¹⁰ It requires an empathetic doctor and a willing and empowered patient. And yet most physicians, who pride themselves on their clinical skills, either abdicate or fail the test. The palliative care encounter also requires more time than the standard clinical consult and this brings in the issue of monetary compensation. All these issues need to be discussed in our professional societies.

Perhaps the most fundamental challenge is the application of current medical ethics, which as enunciated by Beauchamp and Childress is based on principles.³ Respect for patient autonomy is the first and arguably the most important. It is also the least ambiguous from any perspective. The other three principles are beneficence, non-maleficence and justice and can change considerably when seen from perspectives other than that of the patient. These principles are a synthesis of Mills' consequentialism, Kant's deontology or the categorical imperative and virtue ethics. Together they constitute a system of rule-based principlism.¹¹ It has been argued that these precepts are part of a western value system, inappropriate to Asian cultures. Isn't this perspective analogous to the Asian values argument used to suppress democracy in East Asia? As Indians proud of our democratic traditions and our cultural heritage, can we reject obvious universal human values just because they were first enunciated in a western philosophical framework?

Delivering bad news is serious business and it often shows up these dilemmas in sharp relief. Palliative care specialists use the SPIKES protocol or some version of it.¹² This consists of **S**etting up the interview, assessing patient/**P**erception, obtaining the patient's **I**nvitation, giving **K**nowledge, addressing **E**motions, **S**trategy and **S**ummary. In the Beauchamp–Childress framework, the patient, if competent, is the essential interlocutor. This is usually unacceptable in our setting and a rigid insistence can lead to conflict. How then does a responsible physician, aware of her scientific training and her own usually liberal background, navigate these complexities? The answer probably lies in a structured process for resolving ethical dilemmas¹³ based on narrative ethics.¹¹ This posits that every moral situation is unique and any course of action must be justified in terms of its fit with the individual life story of the patient. What is essential is a dialogue which challenges received views and explores the patient's life as intertwined with her family and social setting. Unlike the Asian values argument, the patient remains the key player but the ensemble of her life has voice too. Inevitably this means that the social history is the first step in serious illness communication. The clinician then has to make an explicit decision of who to address next. This may well require a separate discussion with the family before speaking to the patient. This is an inversion of Beauchamp–Childress and can be regarded a substantial breach of the patient's primacy and privacy. Hence, we suggest that when the patient is competent, the first step of setting up the interview must be proposed jointly to the patient and the family. Also the encounter must be scheduled as a formal appointment. The clinician may well have to explicitly insist on the patient's presence in the main interview. If the patient chooses to opt out, this must be re-confirmed in the patient's presence and entered in the record. Although this seems a small detail, it is a major step and it will not happen unless we as clinicians understand and appreciate the importance of doing this.

I strongly affirm that empowering our patients to take charge at the end of their lives is morally and ethically an inescapable professional duty. Hopefully, it will soon become a legal responsibility as well.¹⁴

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