A Dignified Exit

By Roop Gursahani, Raj K Mani, Srinagesh Simha

Last week, a five-judge division bench of the Supreme Court heard arguments for and against living wills. This follows the recent SC verdict on right to privacy, which also recognised individual autonomy and linked it to the right to liberty. All patients have the moral and legal right to take their own decisions about recommended treatment under the linked concepts of patient autonomy and informed consent. The living will or advance medical directive is an instrument by which an individual can control and influence decision-making regarding her own healthcare in situations in which she cannot make or communicate such decisions. They were devised by Luis Kutner, a human rights lawyer from Chicago with the Euthanasia Society of America in 1967. Medical advances, especially those related to intensive care and organ transplantation, evolved with patient education initiatives and consumer rights awareness in the 1960s to the 1980s in the US. States passed legislation making living wills and advance medical directives valid and in 1991, the US Congress passed the Patient Self Determination Act. This required government funded hospitals to provide patients with information about their rights regarding healthcare decisions especially, advance medical directives.

Who would want or need living wills and advance medical directives? Two examples make it clear. Mr RF is a wealthy 85-year-old, living with hired caretakers in a south Mumbai apartment. Last year, a serious illness led to a three-week ICU stay. He has no immediate family and is certain he does not want to "be tortured to death". He has read about living wills and advance medical directives but was told they are not valid in India. Ms DT is a middle class 90-year-old. She lived alone till a year ago, when two bouts of hospitalisation led to her moving in with her daughter and son-in-law. She too is clear about not wanting excessive treatment at the end of her life and has discussed this with her family. Both of them worry that if they lose consciousness towards the end, they may end up on ventilators. Ms DT has been assured by her daughter that her wishes will be followed but she would still prefer a legally valid document. Mr RF sees living wills or advance medical directives as protection from the tyranny of the default "do everything" mode of Indian medical care.

Living wills and advance medical directives can be a simple values document with broad philosophic statements only or it can include very specific directions of what may or may not be done. One of the most widely used living will/advance medical directives is the Five Wishes Instrument. It requires an individual to answer five questions: One, the person I want to make healthcare decisions for me when I cannot make them myself (the healthcare power-of-attorney or HCPoA); two, the kind of medical treatment I want or don't want; three, how comfortable I want to be when I am terminally ill; four, how do I want people (caregivers, family, friends) to treat me when I am terminally ill and five, how exactly will I communicate my decision to loved ones.

The HCPoA can list up to three persons as "alternate agents" to make decisions on behalf of the individual when a physician determines that she can no longer speak for herself. In the US, the advance medical directive comes into effect when a terminal illness (expected survival under six months) has been diagnosed and the patient cannot communicate her wishes or when the patient is permanently comatose. Some states insist on a POLST (Physician Order on Life Sustaining Treatment) form in which a doctor lists interventions (cardiopulmonary resuscitation, IV drips, tube feeding) that may or may not be carried out. No medico-legal liability applies if a valid advance medical directive is followed but there are penalties (generally minor) for disobeying it.

Can advance medical direvtives be misused? Like any other legal tool (contracts, estate wills) they can, but in the 40 years of its use in the US, there are probably only about 10 documented cases

of violation. It has been argued that we are a corrupt country and we require special safeguards but making living wills and advance medical directives foolproof is likely to make them unworkable.

Our group (ELICIT) has prepared a draft End of Life Care legislation which begins with the validation of advance medical directives since we believe that recognition of patient's autonomy is critical. A basic version will be compulsory for all hospitals and the patients - or their families - will have the option of filling this on admission (or refusing to do so) if they do not already have one.

Once the advance medical directives are legally valid, a public campaign to educate Indians about their use of the will be required. Their use will require conversations with families, doctors and communities and open discussion in the public sphere. But without legal validation of living wills, this dialogue will be meaningless. Let us also not forget that we are more than two decades behind most other democracies in this respect.

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